



A guide for | women with

Metastatic breast cancer

In memory of
Marcia O'Keefe
whose vision and determination
made this book possible

and

Denise Cole
who gave so much of her remaining life
to the development of this booklet

Every woman's situation and needs are different.
Not all the information in this booklet will be relevant
to you and your current situation.

It is recommended that this booklet be used as a resource,
rather than a booklet to be read from cover-to-cover.

The Contents pages can be used as a guide to the
information in each chapter.

Acknowledgments

Introduction

Key messages

Chapter 1	What is metastatic breast cancer?	10
	• How metastatic breast cancer develops	
Chapter 2	What does this diagnosis mean for me?	14
	• Your initial diagnosis of metastatic breast cancer	
	• How long will I live?	
Chapter 3	Treatment of metastatic breast cancer	19
Chapter 4	Deciding about treatment	24
	• Deciding about your treatment	
	• Your involvement in treatment decisions	
	• Your treatment team	
	• Feeling comfortable with your treatment team	
	• Obtaining a second opinion	
	• Obtaining information about cancer and treatment options	
	• Questions to help you decide about your treatment	
Chapter 5	The symptoms of metastatic breast cancer.....	33
	• What are the symptoms of cancer in the bone?	
	• What are the symptoms of cancer in the lungs or pleura?	
	• What are the symptoms of cancer in the liver?	
	• What are the symptoms of cancer in the brain?	
Chapter 6	Hormonal therapies.....	41
	• How do hormonal therapies work?	
	• Who can benefit from hormonal therapies?	
	• What is the evidence about the effectiveness of hormonal therapies?	
	• What are the different types of hormonal therapies?	
	• What hormonal therapy would be best for me?	
	• What are the side effects of hormonal therapies?	
	• Questions you may ask about hormonal therapies	

Chapter 7	Chemotherapy52
	<ul style="list-style-type: none"> • How does chemotherapy work? • What is the evidence about the effectiveness of chemotherapy? • Who manages chemotherapy treatment? • How are chemotherapy drugs given? • Where will I get chemotherapy? • How often will I need to have chemotherapy? • What are the side effects of chemotherapy?
Chapter 8	New anti-cancer treatments69
Chapter 9	Radiotherapy71
	<ul style="list-style-type: none"> • When is radiotherapy recommended? • Who will manage my radiotherapy treatment? • How many radiotherapy treatments will I need? • Where will I have radiotherapy? • What are the side effects of radiotherapy? • Questions you may ask about radiotherapy
Chapter 10	Surgery78
	<ul style="list-style-type: none"> • Surgery for cancer in the breast • Surgery for cancer that has spread to the bone • Surgery for cancer that has spread to the lungs • Surgery for cancer that has spread to the brain • Surgery for other reasons
Chapter 11	Complementary and alternative therapies83
	<ul style="list-style-type: none"> • What are complementary and alternative therapies? • Questions that you may ask an alternative health practitioner
Chapter 12	Clinical trials88
	<ul style="list-style-type: none"> • What is a clinical trial? • Why are there clinical trials? • What are the advantages and disadvantages of participating in a clinical trial? • How do I decide whether to participate in a clinical trial?

Chapter 13	Pain management91 <ul style="list-style-type: none"> • The main causes of pain • Key messages about cancer pain • Reporting your pain • Drug treatments for pain • Other medical treatments for pain • Non-medical pain relief methods
Chapter 14	Controlling any other symptoms106 <ul style="list-style-type: none"> • Hypercalcaemia • Tiredness • Nausea and vomiting • Loss of appetite • Poor sleep • Constipation • Mouth ulcers • Lymphoedema • Immobility • Distended or enlarged abdomen • Breathing difficulties • Headaches • Change in thinking ability • Pressure sores • Incontinence of the bowel or bladder
Chapter 15	Palliative care126
Chapter 16	Coping with your feelings and where to get more support and information129 <ul style="list-style-type: none"> • Your feelings • Treatment of anxiety and depression • Deciding about whether to continue, change or stop any paid work • The impact of your diagnosis and treatment on your sexuality • Lesbian women • Support for women diagnosed with metastatic breast cancer • Suggestions from women who are living with metastatic breast cancer about coping with the diagnosis

Chapter 17	Dealing with the impact of the cancer on your family and friends151 <ul style="list-style-type: none"> • Feelings your partner, family or close friends may have about your diagnosis • Ways to help your partner, family or close friends cope with your diagnosis • Support services for partners, families and friends of women diagnosed with metastatic breast cancer • Living alone or being isolated from others • Talking with any children/grandchildren about your diagnosis • Talking with any teenage children about your diagnosis
Chapter 18	Practical support161 <ul style="list-style-type: none"> • Accommodation while undergoing treatment • Care for you at home • Care for you outside your home
Chapter 19	Putting your affairs in order171 <ul style="list-style-type: none"> • Unfinished business • Spiritual or religious comfort • Coping with the ‘no more cancer treatment’ decision • Fears about dying • Practical aspects of preparing for death
Chapter 20	Financial support179 <ul style="list-style-type: none"> • Costs • Where to get information about financial assistance • List of places to contact for financial assistance
Appendix 1	Medical tests183

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This booklet provides information for women with metastatic breast cancer, their partners, families and friends. It is largely based on evidence in the *Clinical practice guidelines for the management of advanced breast cancer*, endorsed by the National Health and Medical Research Council.

The evidence concerning treatment and support has been highlighted in this booklet with a tint background.

For more information about the evidence in this booklet see the *Clinical practice guidelines for the management of advanced breast cancer*, distributed by the iSource National Breast Cancer Centre or available on the Centre's website at <http://www.nbcc.org.au>

This booklet aims to provide women with metastatic breast cancer, and their partners, family and friends with information and support to assist them with making decisions about their treatment and care.

Although the experience of being diagnosed with metastatic breast cancer is difficult, women can be hopeful that there are many treatments available to improve the quality of their life, as shown in this booklet.

A very small number of men are diagnosed with metastatic breast cancer each year. However, for ease of reading, this booklet refers to women diagnosed with metastatic breast cancer. We hope that this booklet will be useful to both men and women diagnosed with metastatic breast cancer.

New technologies and treatments are continually being developed. When new technologies and treatments have been approved they will be introduced into the management of women diagnosed with metastatic breast cancer.

This booklet includes the best currently available evidence, including research published up to early 2001. Please ask your doctor for more information about any other technologies and treatments that you may hear about that are not included in this booklet.

- Every woman's cancer is different, and the way the cancer develops will be different for each woman.
- For some women, living with a diagnosis of metastatic breast cancer is similar to living with a chronic illness.
- Although the present treatments for metastatic breast cancer cannot cure the cancer, they can improve the quality of your life and may increase the length of your life.
- There are many treatments available for women diagnosed with metastatic breast cancer. Treatment may include one or more of the following: hormonal therapies, chemotherapy, radiotherapy, surgery and other drug treatments to help relieve your symptoms. *See Chapter 3, page 19*
- Deciding about treatment is an ongoing process of weighing up the possible benefits and side effects of each treatment option. Only you can judge what matters most to you. *See Chapter 4, page 24*
- You may be eligible to participate in a clinical trial that tests new treatments. Ask your doctor about clinical trials that may be appropriate for you. *See Chapter 12, page 88*

- The symptoms you experience will depend on where the cancer is in your body and the type of treatment you have for the cancer. *See Chapter 5, page 33 to Chapter 10, page 78*
- Pain and other symptoms of metastatic breast cancer can be effectively controlled. *See Chapter 13, page 91*
- The experience of being diagnosed and treated for metastatic breast cancer is different for every woman. Each woman brings to her experience her past experiences, beliefs, strengths and strategies. Support is available to help you get through difficult times. *See Chapter 16, page 129*
- A diagnosis of metastatic breast cancer will greatly affect those close to you. Good communication between yourself and others is essential in adjusting to your changing circumstances and resolving any problems. Support is also available for family and friends. *See Chapter 17, page 151*
- Practical support and financial assistance are available. *See Chapter 18, page 161*
- For more information about treatment, support services and practical issues call the **Cancer Helpline** on 13 11 20.

What is metastatic breast cancer?

“I’m sure I was thinking this isn’t happening to me. I’m just an ordinary person who goes about an ordinary life. I do not get cancer.”

Metastatic breast cancer is the term used to describe cancer that has spread from the original site in the breast to other organs or tissues in the body.

Another name for metastatic cancer is **secondary cancer** or **advanced cancer**.

If you have previously been diagnosed with breast cancer and your breast cancer comes back in your breast or in another part of your body it may also be said you have a **recurrence** of your original cancer.

For some women, a diagnosis of metastatic breast cancer may be their first diagnosis of cancer.

How metastatic breast cancer develops

Cancer cells can break away from the original cancer in the breast. This may happen before treatment of the cancer in the breast or after treatment if some cancer cells are left. Cancer cells that break away can spread to other parts of the body via blood vessels or lymphatic vessels. *See Figure 1.* Lymphatic vessels are tiny vessels that usually run besides veins and collect fluid and dead cells.

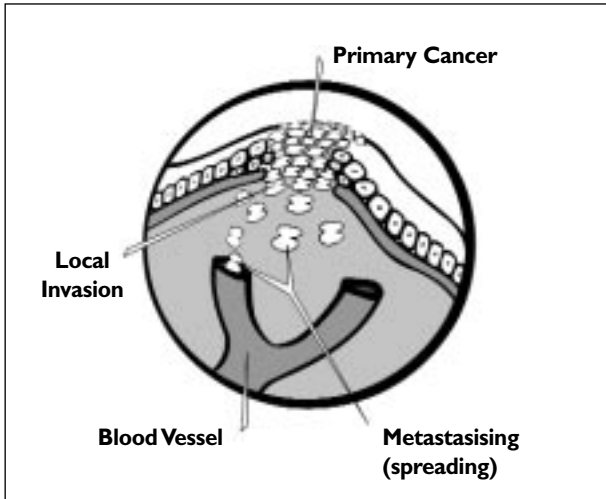


Figure 1 – How cancer spreads

The original site where the cancer cells came from is called the **primary cancer**. In metastatic breast cancer, the primary cancer is breast cancer.

When cancer cells travel from the breast around the body they can lodge themselves in various body organs or tissues. These cells can begin to form breast cancer in a new place. This new cancer is called a **secondary** or a **metastasis**. More than one secondary or metastasis are called **secondaries** or **metastases**.

Breast cancer most commonly spreads to one or more of the following sites:

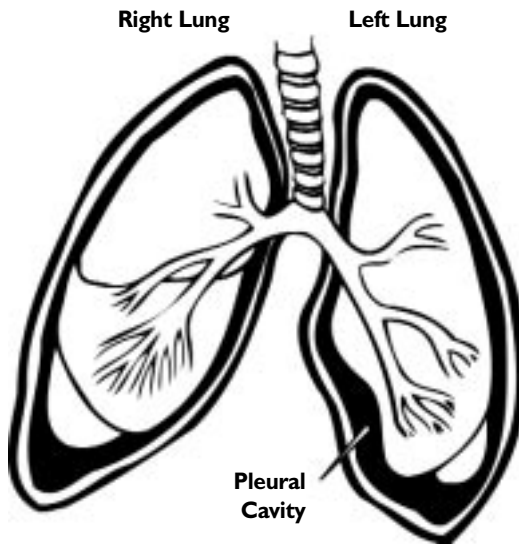
- *bones*

One bone or several bones may be affected by cancer.

“I’ve met a lot of women through the forums I’ve been to for breast cancer. They have the same cancer as me. They’ve been around for a while. So, I’m just taking each day as it comes.”

- *liver*
- *brain*
- *lungs* and/or the lining that covers the lungs, called the **pleura**. The **pleura** is composed of two thin layers. One layer covers the lungs and one lines the inside of the chest cavity. Between these two layers is the **pleural cavity**. This is the area that can fill with fluid when cancer spreads to the lungs. If this occurs it is called a **pleural effusion**. See *Figure 2*.

Figure 2 – The Lungs



These are the common sites that metastatic breast cancer spreads to. **This does not mean that if you are diagnosed with metastatic breast cancer then your cancer will spread to all these sites.**

In metastatic breast cancer, the cancer that develops in other parts of your body is made up of the same type of cancer cells that were in the breast. For example, if the cancer cells spread from the breast to the bone, the new cancer in the bone would be made up of breast cancer cells rather than bone cancer cells.

If the breast cancer spreads to places near the breast such as the skin, bones or muscles of the chest, but does not spread to any other place in the body, this is called **locally advanced breast cancer**.

This booklet does not contain information about locally advanced breast cancer. This booklet only contains information for women diagnosed with metastatic breast cancer.



What does this diagnosis mean for me?

“It certainly begins to rearrange your priorities. In some sense it’s your mortality coming to meet you, means that you have to think differently about what you’re doing, how you’re spending your life, who you’re spending it with maybe, what you’re choosing to spend your time on.”

Your initial diagnosis of metastatic breast cancer

Most women who are diagnosed with metastatic breast cancer have already been diagnosed with and treated for early or locally advanced breast cancer. For some women, this may be their first diagnosis of cancer.

Symptoms or signs develop over weeks or months. It may be difficult at first for you and your doctor to tell if your symptoms are from less serious problems such as muscle pain.

Current evidence suggests that being diagnosed with metastatic breast cancer a few weeks to months after your first symptoms develop does not make a difference to the length of your life or how you respond to treatment.

You may feel regret about the treatment you had for the original cancer. It may be important, depending on your situation, to reassure yourself that you and your doctors have made the best possible decision

during your previous treatment with the information available at the time.

You may want to talk to your doctor or a counsellor, breast nurse, psychologist or psychiatrist about these concerns. *See Chapter 16, page 145.*

You may be concerned that you did not receive appropriate follow-up after your initial diagnosis of breast cancer.

Appropriate follow-up after a diagnosis of early breast cancer involves regular examinations and mammograms. It does not involve chest X-rays, bone scans or blood tests unless a problem arises which indicates the need for these tests.

There is evidence to show that additional tests when there are no symptoms or problems do not improve the length or quality of life of women with breast cancer.

Being told you have metastatic breast cancer may make you feel overwhelmed, shocked, anxious, and feel a sense of injustice. Chapter 16, page 129 discusses some of the feelings you might have about your diagnosis.

Discuss with your doctor how much information you want to know about the cancer. You may feel more in control by receiving a lot of information,

“I don’t want to know about my prognosis. I don’t like something that could become a self-fulfilling prophecy. I think it’s better just taking each day as it comes. Everybody’s cancer is so individual that no-one can really say.”

*“My theme song is
‘I get knocked down
but I get up again,
you’re never gonna
keep me down.’”*

or you may not want to know very much at all. Your need for information may also change throughout the course of your illness.

How long will I live?

How long you live may depend on where in your body you have cancer, how extensive it is and your response to any treatment you may have. Every woman’s cancer is different and how the cancer develops and responds to treatment will vary for each woman.

Some women live for a number of years with metastatic breast cancer and have a good quality of life. For these women, living with a diagnosis of metastatic breast cancer is similar to living with a chronic illness.

Currently, treatment for metastatic breast cancer is unable to get rid of the cancer completely.

However, treatment can improve your quality of life by lessening your symptoms.

Some treatments may help decrease your symptoms by stopping the cancer from growing or by decreasing the size of the cancer for a period of time, even years. By stopping the cancer from growing or decreasing the size of the cancer for a period of time, this may also improve the length of your life, although this has not been proven in a clinical trial. See Chapter 12, page 88 for information about clinical trials.

Your doctor will monitor how well any treatment you have is working by whether your symptoms are reduced. If your symptoms are reduced or remain at a level acceptable to you and your doctor, it is said that your cancer is **well controlled**.

If your treatment is no longer controlling your cancer, this means your symptoms may be getting worse and your cancer may be growing or spreading. If your treatment is no longer controlling your cancer another treatment or treatments will be discussed with you.

Living with metastatic breast cancer frequently involves trying one treatment after another over an extended period of time, often over a number of years. In the later stages, the cancer may spread more widely and treatments such as chemotherapy and hormonal therapy may become less effective at controlling your cancer. **However, pain and symptom control and support will continue to be a priority to ensure that you are as comfortable as possible.**

It is difficult to decide when to stop cancer treatment. You need to get as much information as you can from your treatment team and weigh up the possible benefits and the side effects of each treatment. It is important to think about your quality of life. *See Chapter 4, page 24 for more information.*

Your doctor will not be able to predict exactly how long you will live.

“You can’t say, well cancer’s in and out of my life (this time) it’s here to stay, which is a bit different from the first time.”

“I was diagnosed about two years ago, with primaries and secondaries at the same time. They diagnosed the breast lump. Then they did further scans and they found liver lesions and spinal lesions. But look at me – I’m pretty healthy.”

Although your doctor will not be able to give you an exact time frame you **may** like to ask your doctor the following questions:

- *What is the best case scenario? In other words, what is the longest time women have lived who were in a similar situation to myself?*
- *What is the worst case scenario? In other words, what is the shortest time women have lived who were in a similar situation to myself?*

You may also like to know what sort of quality of life you can expect. Will you be able to do the things that you do now? How sick will you be and for how long? Your doctor may be able to give you some information about other women’s experiences of metastatic breast cancer but will not be able to tell you exactly how things may be for you. For more information you may like to talk to other women diagnosed with metastatic breast cancer. *See Chapter 16, page 145.*

When the future seems uncertain, living in the moment, living your life as fully as possible and setting short-term goals may be the best way to cope. Coming to terms with uncertainty and any fear, anxiety, anger and sadness you may feel can be extremely difficult. *See Chapter 16, page 129 for ways to cope with your feelings and get more support. See Chapter 13, page 91 to Chapter 14, page 106 for ways to improve your quality of life.*

Treatment of metastatic breast cancer

The main aim of treatment of metastatic breast cancer is to improve your quality of life by reducing any symptoms you may be experiencing.

Some treatments for metastatic breast cancer help lessen your symptoms by stopping the cancer from growing or by decreasing the size of the cancer for a period of time, even years. By doing this, treatment may also improve the length of your life, but this has not been proven in a clinical trial. *See Chapter 12, page 88 for information about clinical trials.*

Treatment of metastatic breast cancer

If you have been diagnosed with metastatic breast cancer you will usually be recommended to have one or more **general anti-cancer treatments**.

You may also be recommended to have one or more **specific treatments**. The specific treatments recommended to you will depend on where the cancer is in your body and the symptoms that you are experiencing.

“I have always asked if there was anything I didn’t understand, even if it sounded stupid. I make a note of things. They don’t mind explaining things.”

*“My doctor is always
honest with me.
I’d sooner know where
I’m at. Some people
apparently don’t want
to know, but I think
it’s better to.”*

A. General anti-cancer treatments

General anti-cancer treatments are treatments that work on the whole body to control the size and spread of the cancer. By doing this, they help relieve symptoms. They include:

1. Hormonal therapies

Hormonal therapies act on the female hormones in the body to stop the cancer from growing.

Hormonal therapies may be recommended if your cancer has estrogen receptors on it. *See Chapter 6, page 41 for more information about estrogen receptors and hormonal therapies.*

2. Chemotherapy

Chemotherapy includes drugs that destroy all rapidly dividing cells in the body, such as cancer cells.

Chemotherapy may be recommended if hormonal therapies are not appropriate for you or if hormonal therapies are no longer keeping your cancer under control. *See Chapter 7, page 52 for more information about chemotherapy.*

B. Specific treatments

You may also be recommended to have one or more **specific treatments**. The specific treatments recommended to you will depend on where the cancer is in your body and the symptoms that you are experiencing.

1. If you have been diagnosed with cancer in your bone, you may be recommended to have one or more of the following treatments:

- **Radiotherapy** involves X-rays directed at the cancer in your bone. It may be used to help relieve bone pain, treat cancer in the spine, and prevent and treat fractures. *See Chapter 9, page 71 for more information.*
- **Surgery** may be used to treat or prevent a bone fracture, to replace a joint affected by cancer or to treat or prevent compression of the spine affected by cancer. *See Chapter 10, page 78 for more information.*
- **Bisphosphonates** are drugs that may be used to slow down the growth of the cancer in the bone, and help reduce bone pain and other symptoms such as hypercalcaemia. *See Chapter 13, page 101 for more information.*
- **Pain relief** involves drug and non-drug treatments such as muscle relaxation and acupuncture. *See Chapter 13, page 91 for more information.*

2. If you have been diagnosed with cancer in your lungs, you may be recommended to have one or more of the following treatments:

- **Surgery** may be used to reduce any fluid in the pleural cavity, the space around the lungs. Surgery may also be used to remove cancer in the lungs (if there is **only one small cancer**).



However, this is uncommon. *See Chapter 10, page 79 for more information.*

- **Relaxation therapy** may be used for shortness of breath and pain relief. *See Chapter 13, page 104 for more information.*
- **Pain relief** involves drug and non-drug treatments. *See Chapter 13, page 91 for more information.*

3. If you have been diagnosed with cancer in your brain, you may be recommended to have one or more of the following treatments:

- **Radiotherapy** involves X-rays directed at the cancer in the brain. It can reduce the size of the cancer in the brain and relieve symptoms. *See Chapter 9, page 73 for more information.*
- **Surgery** may be used to remove cancer in the brain (if there is only one small cancer), or to drain any excess fluid in the brain. Surgery is uncommon for cancer in the brain. *See Chapter 10, page 81 for more information.*
- **Pain relief** involves drug and non-drug treatments such as muscle relaxation. *See Chapter 13, page 91 for more information.*
- **Drugs** for nausea. *See Chapter 14, page 111 for more information.*

4. If you have been diagnosed with cancer in your liver, you may be recommended to have one or more of the following treatments:

- **Surgery** may be used to remove cancer in the liver (if there is **only one small cancer**). However, this is uncommon.
- **Pain relief** involves drug and non-drug treatments such as muscle relaxation. *See Chapter 13, page 91 for more information.*
- **Drugs** for nausea. *See Chapter 14, page 111 for more information.*
- **Dietary** management and drugs for weight loss and lack of appetite. *See Chapter 14, page 114 for more information.*

C. Other new treatments

New treatments and technologies are continually emerging.

Before treatments can be recommended by your doctor they usually need to be studied in a clinical trial to prove their benefit to women with metastatic breast cancer.

For example, trastuzumab (Herceptin®) is a new treatment that has recently been shown to be of benefit for some women with metastatic breast cancer but is yet to be more fully researched.

See Chapter 8, page 69 for more information about trastuzumab.

Deciding about treatment

“I think it would be great to get some options, to have some choices and then you can go home and think about it and then you can discuss it.”

Deciding about your treatment is an ongoing process of weighing up the possible benefits and side effects of each treatment as you need it.

See Chapters 6-10 for information about treatment options.

This chapter discusses:

- deciding about your treatment
- your involvement in treatment decisions
- who is involved in your treatment team
- feeling comfortable with your treatment team
- obtaining a second opinion
- obtaining information about the cancer and its treatment
- a list of questions about deciding on your treatment

Deciding about your treatment

When you are told that the cancer has come back or spread, or that you have metastatic breast cancer, there is a temptation to rush in and make a decision about what to do next, or to want the doctor to decide for you.

Evidence shows that there is usually no need to make a decision about treatment straight away. Taking your time to make a decision will not affect the length of your life.

You need time to gather and digest information, and to receive support from family and friends. This can help you understand the disease and choose the most appropriate form of treatment, at the best time for you. This will be an ongoing process of weighing up the possible benefits and side effects of each treatment or drug as you need it. Your doctor should provide you with this information. If not, you can ask for it.

Deciding about which treatment or treatments is best for you will depend on:

- your preference
- your general state of health
- where the cancer is in your body
- your symptoms

Your involvement in treatment decisions

You are entitled to choose the treatment or drug that best suits you after discussion with your doctor and any others you may care to consult. You may want to be actively involved in deciding about your treatment, or you may wish to allow your doctor to make the decision for you. Either way you need to tell your doctor what you prefer. Your desire for

“My oncologist said ‘Look - anytime you can pull out of any treatment if you don’t like it, if there are some side effects you can’t stand.’”

“I liked him [the doctor] and he seemed to be a person who was very competent and I think in a specialist field... you feel you can trust the experts.”

involvement in deciding about your treatment may change, so it is best to keep your doctor informed about any change in your preferences.

After weighing up the possible benefits and side effects of each treatment *you may decide not to have a particular treatment*. It is within your rights to say so. Discuss this decision with your doctor and people close to you, so everyone is well informed about your situation. This does not mean that at a later stage you cannot have this treatment, although the recommended treatment may change if your situation changes.

Your treatment team

The treatment of the cancer will require you to meet a number of doctors and other health professionals from different fields of medicine. They may include some of the following:

- a *medical oncologist*, who specialises in chemotherapy and hormonal therapy, as well as management of pain and other symptoms
- a *radiation oncologist*, also known as a radiotherapist, who specialises in radiotherapy management
- a *radiation therapist*, who delivers radiotherapy
- a *surgeon*
- *breast care nurses*, who specialise in caring for women with breast cancer

- *oncology nurses*, who specialise in administering chemotherapy and assist with radiotherapy
- a *general practitioner*
- a *palliative care consultant, palliative care nurse* and *palliative care volunteers* who specialise in providing support and symptom relief
- a *counsellor, psychologist* or *psychiatrist*, who specialise in providing support. They are also trained in treating anxiety and depression, and helping cope with pain
- a *social worker*, who specialises in providing support and helping organise practical and financial assistance
- a *dietitian*, who specialises in providing information about diet
- an *occupational therapist*, who specialises in providing practical assistance
- a *physiotherapist*, who specialises in pain management and providing exercise programs
- a *pastoral care / religious representative*

Many women find the large range of specialists to whom they are referred confusing.

Ask the members of your treatment team about their role in your care.

You can also ensure that there is open communication between the members of your treatment team by asking them to send your medical

“They mentioned on more than two or three occasions that they, the oncologists and surgeon, would consult each other. They do work well as a team and you’ve got new blood and old blood in there and they consult, and that makes me feel supported and monitored.”

“My doctor’s quite hopeful, he always says to me don’t worry if this doesn’t work there’s other things, we can try something else.”

information to relevant clinicians in your treatment team, including your general practitioner.

At different times in the treatment of the cancer, different treatment team members may be the main co-ordinator of your care. This person may be your general practitioner, surgeon or oncologist or another member of your treatment team. This role will change over time, so it is important to ask, if you are unsure, about who to contact regarding any concerns.

If you live outside a major city, your general practitioner or surgeon may discuss your treatment on your behalf with a medical or radiation oncologist to avoid unnecessary travel. You may meet the oncologist if your region provides an outreach service. Travel to a major centre will be necessary for radiotherapy. Chemotherapy can usually be provided where you live.

Below are some questions that you can ask your treatment team in order to establish the role of each member in your care:

- Who shall I call if I have a problem?
- Who should I contact out of regular hours if needed?
- Who will regularly review my health and any symptoms I have, such as pain?
- When should I contact my general practitioner?

- Does information about tests results and treatment go to all treatment team members?
- Do my treatment team members regularly meet or discuss my progress via telephone calls or letters?
- Who can organise social support services should I need them?

Feeling comfortable with your treatment team

You need to feel comfortable with your treatment team and that you are getting the information and support you need. It may take some time to establish a good relationship with your treatment team members, and for them to understand your needs. It is important to let your treatment team know of any particular concerns and priorities. Looking after your emotional wellbeing should be part of your overall care.

If you were previously diagnosed with an early breast cancer, you may decide that you wish to stay with the same surgeon, medical oncologist or radiation oncologist, or you may wish to be referred to another specialist or specialists for your care.

Obtaining a second opinion

You have the right to get a second opinion at any time. Having a second opinion can help clear up any questions, can help you decide which doctor you prefer to manage your treatment, and help you decide which course of treatment to follow.

“I think sometimes it is a two-way street, that you have to find out the information also. If your heart’s in it you have to make that effort.”

If you are happy with the treatment recommended by your doctor and his/her manner, a second opinion may not be needed.

Should you wish to get a second opinion, you could ask either your initial doctor or your general practitioner to refer you to another doctor.

You may decide, after seeing another doctor, that you want your initial doctor to manage your treatment. Having seen another doctor will not affect how your initial doctor manages your treatment.

Obtaining information about the cancer and treatment options

In order to make decisions, you need good quality information. Ask your doctor as many questions as you need, and encourage your family to do the same.

“It is helpful to have my husband there with me when I go to the doctor. He listens more closely than I do.”

You may find it helps to:

- ask for more information at each visit to your doctor
- ask a relative or a friend to come with you
- read pamphlets, notes and booklets – your doctor will be able to help you get these
- if your doctor agrees, tape record all discussions so you or your family can go through what the doctor said later

- write down questions as they come to mind, so you can remember to ask your doctor at your next visit

If you are reading this booklet for a family member or friend who is not fluent in English, a **professional interpreter** is available. Interpreters are available free of charge in both the public and private hospitals, although they must be booked before any consultation. Only a qualified and appropriate interpreter can ensure that the person gets all the information that the doctor provides during the consultation. Talk to the doctor about arranging an interpreter to be with your family member or friend during their consultation.

Questions to help you decide about your treatment

Below is a list of questions that can provide a guide for deciding about the management of the cancer. You will want the answers to some of the questions straight away, while some will become important later on. Some will not matter at all to you. You can either ask these questions directly, or use them as a guide to formulate your own questions.

- Do you mind if I tape record this consultation?
- Do you mind if my friend/relative comes in with me?
- What treatment do you recommend? Why?
- What happens if I choose a different treatment?



“It’s really up to you to decide about treatment. Therefore you need a lot of information, and you need a lot of help.”

- For each of these treatments, what are the benefits? What are the risks? What are the side effects?
- How successful are these treatments for my type of cancer?
- Will this treatment make any difference to the length of my life?
- Will this treatment make any difference to the quality of my life?
- Will the treatment have any permanent damage?
- Will I experience menopause early?
- Will my sex life be affected?
- I would like a couple of weeks to make a decision – will that make any difference?
- Where do I go for treatment? What are the costs?
- Are there any complementary/alternative treatments that might help me?
- Can I undertake complementary/alternative and mainstream treatments at the same time?
- Can I decide against any further treatment?
- Do I need a special diet to help me fight the disease?
- Can I seek another medical opinion?
- What help can I get in explaining my cancer to my family, close friends, partners or children?

The symptoms of metastatic breast cancer

Every woman's experience of metastatic breast cancer is different. The type or severity of symptoms that one woman experiences will not be the same as those experienced by another woman. Some women with metastatic breast cancer experience few or no symptoms.

The symptoms you may experience will depend on:

1. **where the cancer is in your body, and the extent of the cancer**
2. **the type of treatment that you have, and how you respond to treatment. See Chapter 6-10 for the possible side effects of treatment.**

In the next pages the symptoms **caused by where the cancer is in your body** are discussed. *Symptoms caused by treatment are discussed in Chapter 6-10 under side effects of treatment.*

The symptoms discussed in this chapter can be lessened so that you are made as comfortable as

"The human spirit's a remarkable thing, I've realised."

"You have to decide whether banging your head against a brick wall about your career or whatever is really important, or whether life itself is important, and enjoying quality of life. That's the way I think now - that quality of life is number one."

possible. See Chapter 13, page 91 to Chapter 14, page 106 for how the symptoms discussed are managed.

If you experience any of the symptoms discussed in this chapter, see your doctor.

The symptoms discussed in this chapter may be due to other medical problems and not to cancer in the bones, lungs, brain or liver. See your doctor for the correct diagnosis of any symptoms.

“There are good things for this stage of cancer, there are good treatments. You know, if you’ve got breast cancer there are things that they can do.”

What are the symptoms of cancer in the bone?

If the cancer has spread to your bones you may experience some of the symptoms or conditions discussed below.

Some women with metastatic breast cancer in the bone experience few or no symptoms.

Symptoms of metastatic breast cancer in the bone can include:

- **bone pain**

Bone pain is a fairly constant, aching pain. It may increase with movement or activity. It is usually experienced in the day and may cause difficulty sleeping at night.

Bone pain is due to:

- *cancer pressing on the bone*
- *cancer in the bone pressing on nerves*

- *a fracture of the bone:*

Approximately 9% of women who have cancer in their bones will develop a bone fracture. Fractures are due to the cancer breaking down some of the bone tissue, causing the bone to become weaker.

However, fractures can be prevented and treated early by radiotherapy and surgery.

See Chapter 9, page 73 for treatment.

- *spinal cord compression:*

This can occur in women who have cancer in the **vertebrae** (the bones in the spine).

This can occur if the cancer causes the vertebrae to collapse and press on the spinal cord.

It may also be caused by cancer cells growing around the spinal cord.

Spinal cord compression can cause the loss of some movement or sensation in the legs, loss of bladder and/or bowel control and (in severe cases) paraplegia.

However, spinal cord compression can be prevented and treated early by radiotherapy and surgery. *See Chapter 9, page 72*

for treatment.

Seek medical attention immediately if you experience persistent back pain, a change in feeling or a decrease in power in your legs, or suddenly lose control over your bladder or bowel. Urgent treatment is required to prevent permanent damage.

“Live for today and make the most of it. I don’t think there are magic solutions. I think you certainly do stop and think about the priorities when something happens to you.”

“Booklets on radiotherapy and chemotherapy and how to cope are useful. I think it is better to know.”



- **hypercalcaemia**

Hypercalcaemia is an increase in the levels of calcium in the blood. This can occur from cancer in the bone or from metastatic breast cancer without any cancer in the bone. The symptoms can be mild or severe. Some of the symptoms include increased pain, increased urinating, excessive thirst, vomiting, constipation, muscle weakness, dehydration and confusion.

See Chapter 14, page 10407 for more information about hypercalcaemia and how to treat it.

What are the symptoms of cancer in the lungs or pleura?

If the cancer has spread to your lungs you may experience some of the symptoms discussed below.

Some women with metastatic breast cancer in the lungs experience few or no symptoms.

Symptoms of metastatic breast cancer in the lungs can include:

- **shortness of breath**

You may experience shortness of breath on mild exertion. Or you may suddenly become short of breath.

Seek medical attention immediately if you experience breathing difficulties or a change in the severity of your symptoms, or cough up blood.

Shortness of breath can occur due to the cancer cells entering the **pleural cavity** (the space around the lungs). *See Chapter 1, page 12.* The cancer cells increase the amount of fluid in the pleural cavity and stop some of the fluid from being absorbed. This will affect the ability of your lungs to expand and will make you feel breathless. Shortness of breath may also occur if cancer cells invade the lungs and take up space so there is less normal lung to absorb oxygen.

However, shortness of breath can be treated by general anti-cancer treatments such as hormonal therapy and chemotherapy, and sometimes by surgery, to make you as comfortable as possible.

- **dry cough**

A dry cough may occur due to the cancer irritating the passages in your lungs or due to fluid around your lungs, called a **pleural effusion**.

- **fatigue**

Fatigue or tiredness may occur due to the cancer itself or the effect of the cancer on your breathing.

- **chest pain**

Chest pain may occur if the pleura around your lungs is irritated by the increase in fluid. This is not a common symptom of cancer in the lungs.

- **a feeling of heaviness in the chest**

This may occur from cancer in or around your lungs.

Chest pain and a feeling of heaviness in the chest can also be due to heart disease. See your doctor about any chest pain or feeling of heaviness in the chest.

The symptoms discussed above can be treated so that you are made as comfortable as possible.

What are the symptoms of cancer in the liver?

If the cancer has spread to your liver you may experience some of the symptoms discussed below.

Some women with metastatic breast cancer in the liver experience few or no symptoms.

Symptoms of metastatic breast cancer in the liver can include:

- **weight loss**
- **lack of appetite**
- **fatigue**
- **discomfort or pain on the right side of the abdomen, where the liver is situated**

- **nausea**
- **jaundice (yellowing of the skin)**

The liver produces **bile**, which helps the intestine to digest food. If the vessels that carry bile are blocked by cancer in the liver, bile may build up in the blood and cause jaundice. This will make the skin and the whites of the eyes yellow and may make the skin feel itchy.

- **swelling of the abdomen**

Swelling of the abdomen may occur if the liver becomes enlarged due to the cancer, or if fluid builds up in the abdomen from the cancer blocking blood vessels in the liver.

The symptoms discussed above can be treated so that you are made as comfortable as possible.

See Chapter 14, page 106 for information about controlling these symptoms.

What are the symptoms of cancer in the brain?

If the cancer has spread to your brain you may experience some of the symptoms discussed below.

Some women with metastatic breast cancer in the brain experience few or no symptoms.

Symptoms of metastatic breast cancer in the brain can include:

- **headaches**

Unlike ordinary headaches, headaches from cancer that has spread to the brain do not go away, and they gradually get worse. The headache may also be worse in the morning.

- **nausea and vomiting**

Special drugs called anti-emetic drugs will help control nausea and vomiting.

- **weakness in an arm or leg, or unsteadiness in walking**

- **change in vision**

- **seizures**

Seizures can be controlled with treatment.

- **confusion or disorientation or personality changes**

This is rare.

The symptoms discussed above can be treated so that you are made as comfortable as possible.

Hormonal therapies

The main aim of hormonal therapies, also called endocrine therapies, is to improve the quality of your life by reducing your symptoms.

Hormonal therapies can help lessen your symptoms by stopping the cancer from getting bigger or spreading, and can even decrease the size of the cancer for a period of time, sometimes for years. By doing this, hormonal therapies may also improve the length of your life, although this has not been proven in a clinical trial. *See page 43.*

This chapter discusses:

- how hormonal therapies work
- who can benefit from hormonal therapies
- the evidence about the effectiveness of hormonal therapies
- the different types of hormonal therapies
- deciding about the type of hormonal therapy that is best for you

- the side effects of hormonal therapies
- questions you may ask about hormonal therapies

How do hormonal therapies work?

Some cancers grow in response to estrogen, one of the female hormones in the body.

Most hormonal therapies work by decreasing the amount of estrogen in the body or by stopping the cancer cells from getting estrogen. By doing this, hormonal therapies can help reduce the size of the cancer and slow down the spread of the cancer.

Who can benefit from hormonal therapies?

If you were first diagnosed with early breast cancer or locally advanced breast cancer, you would probably have had breast surgery. During your surgery, some breast tissue is sent to your pathologist. The breast tissue may have been tested to detect if the cancer had estrogen receptors. This information may have been included in your pathology report.

If your cancer had estrogen receptors on it this means that your cancer needs estrogen to grow. Because the cancer you have now has spread from the cancer in your breast, this cancer also needs estrogen to grow.

Hormonal therapies are used mainly in women who have estrogen receptors on their cancer.

If your cancer has estrogen receptors on it, hormonal therapies may be recommended *before* other anti-cancer treatments such as chemotherapy.

Hormonal therapies may also be recommended if your cancer *has not been tested* for estrogen receptors, to see if the treatment controls your symptoms and the spread of the cancer.

If you do not have estrogen receptors on the cancer, you may have little benefit from hormonal therapies and will usually be recommended to have chemotherapy. *See Chapter 7, page 52 for more information about chemotherapy.*

What is the evidence about the effectiveness of hormonal therapies?

No studies have been done that compare the survival of women with metastatic breast cancer who do not have hormonal therapy to women that have hormonal therapy, and none are likely to be done. This means that although doctors think that hormonal therapies probably increase the length of life in women with metastatic breast cancer, this has not been proven by a clinical trial. *See Chapter 12, page 88 for information about clinical trials.*

Systematic review of studies conducted about hormonal therapies has shown that:

- **Hormonal therapies or chemotherapy are equally as effective in controlling cancer, if given as the first treatment for women after their diagnosis of metastatic breast cancer (if the woman has estrogen receptors on her cancer).**
- **There is no evidence that any one particular hormonal therapy is more effective at controlling symptoms and the size or spread of the cancer than another hormonal therapy (although recent evidence has shown that aromatase inhibitors have less side effects than tamoxifen and progestins).**
- **Within the normal dose, high doses of hormonal therapy drugs are not more effective than low doses.**
- **Using two or more hormonal therapy drugs at the same time is not more effective than using one hormonal therapy drug.**
- **If a woman responds to one hormonal therapy, this often indicates that she will respond to other types of hormonal therapy.**

If you do not fully understand any of the above or want more information, ask your medical oncologist to explain.

What are the different types of hormonal therapies?

Hormonal therapies include:

- **Anti-estrogens**, for example, drugs such as tamoxifen, toremifene, and other drugs not fully researched.

Anti-estrogens work by stopping cancer cells from getting estrogen.

Anti-estrogens are usually used in women of **all ages** who have estrogen receptors on their cancer.

- **Aromatase inhibitors**, for example, drugs such as letrozole, anastrozole and arimidex.

Aromatase inhibitors work by stopping or ‘inhibiting’ estrogen from being produced.

Aromatase inhibitors are usually used in women who have estrogen receptors on their cancer and who have **already experienced menopause**.

Aromatase inhibitors may be used as an alternative to anti-estrogens in women who have experienced menopause.

- **Ovarian treatments** include the injection of certain drugs, radiotherapy to the ovaries and surgery to the ovaries.

Ovarian treatments work by stopping the ovaries from producing estrogen.

Ovarian treatments are usually used in women who have estrogen receptors on their cancer and in women who have **not yet reached menopause**.

- **Other hormonal therapies**, for example drugs such as progestins.

These therapies may be used in women who have estrogen receptors on their cancer and who have **already experienced menopause**.

These therapies are usually recommended if other hormonal therapies are not effective in controlling your cancer.

See Table 1 below

Table 1
How hormonal therapies are currently used in treatment of women with metastatic breast cancer

	Women who have estrogen receptors on their cancer and who have not yet reached menopause	Women who have estrogen receptors on their cancer and who have already experienced
First treatment that may be offered to you	controlling your cancer, or <i>in addition</i> to the first treatment	Ovarian treatments Anti-estrogens
Second treatment that may be offered to you if the first treatment is not effective in		

This table is a guide only and your doctor will recommend the hormonal therapy or therapies that are appropriate for your particular situation.

Hormonal therapies *may* be recommended if your cancer **has not been tested for estrogen receptors**, to see if the treatment controls your symptoms and the spread of the cancer.

What hormonal therapy would be best for me?

Your doctor will discuss with you whether hormonal therapies may benefit you and the type of hormonal therapy or therapies that may be most appropriate for you.

The decision about whether you would benefit from hormonal therapy and the type of hormonal therapy or therapies that may be best for you will depend on:

- whether you have estrogen receptors on your cancer
- whether you have reached menopause
- any previous hormonal therapy treatment you have had
- your general state of health *and*
- your preference

Your doctor will discuss with you the benefits and side effects of the hormonal therapy or therapies that he or she thinks are most appropriate for your current situation.

What are the side effects of hormonal therapies?

The different types of hormonal therapies have different side effects. Also, every woman is different in the way she responds to a particular hormonal therapy. The main side effects of hormonal therapies are discussed below.

- **Side effects of anti-estrogens**

Some women will have few or no side effects from taking anti-estrogens.

The possible side effects of anti-estrogens include:

- *menopausal symptoms*, such as:
 - hot flushes
 - vaginal dryness and/or discharge
 - irregular menstrual periods in women who have not yet reached menopause
 - a decrease in libido

Menopausal symptoms experienced while taking anti-estrogens usually stop if your treatment stops, unless you are experiencing a natural menopause.

Ask your doctor about controlling any menopausal symptoms you experience.

Even if your period stops while you are taking an anti-estrogen, you cannot be sure that you could not become pregnant if you are sexually active and have not yet reached menopause. It is important to use a non-hormonal contraception, since it is not known whether it is safe for women diagnosed with metastatic breast cancer to take the oral contraceptive pill.

- ***blood clots***

This is a **rare** side effect of anti-estrogens. Discuss with your doctor about how to help prevent blood clots.

- ***cancer of the uterus***

This is a **rare** side effect of anti-estrogens. The risk of cancer of the uterus is very small. **See your doctor immediately if you have any irregular vaginal bleeding.**

Anti-estrogens can also have benefits other than cancer treatment, such as:

- decreasing your chance of getting osteoporosis (frail bones usually experienced in older women)
- decreasing your cholesterol level and your chance of getting heart disease
- **Side effects of aromatase inhibitors**
Some women will have few or no side effects from taking aromatase inhibitors.



The possible side effects of aromatase inhibitors are similar to those of anti-estrogens. *See page 48.*

- **Side effects of ovarian treatments**

Surgical removal of the ovaries and radiotherapy to the ovaries will cause a **permanent menopause**.

If your menopause is permanent, you will be unable to have children after treatment.

It is important that you discuss this side effect with your doctor before you start any ovarian treatment. You may also like to discuss with your doctor or a counsellor, psychologist or psychiatrist any feelings of loss you may have about not having any more children. *Chapter 16, page 129 provides more information about your emotions and where to get support.*

In those women whose menopause is permanent, menopausal symptoms may last only a few months. *See page 48 for the symptoms of menopause.*

However, some women may experience symptoms for much longer.

If the menopause is permanent you may be at risk of developing osteoporosis (frail bones) or heart disease.

It is important to tell your doctor if you are experiencing any menopausal symptoms so that they can be controlled. You can also be monitored and treated for osteoporosis and heart disease if they develop.

- **The side effects of other hormone therapies**

The side effects of other hormone therapies depend upon the type of hormonal therapy used. The possible side effects of drugs such as **progestins** include:

- *weight gain*
- *fluid build-up / generalised swelling*
- *vaginal bleeding*
- *blood clots, though this is rare.*

Questions you may ask about hormonal therapies

Here is a list of questions that can provide a guide or starting point for deciding about hormonal therapies.

- **How can I benefit from hormonal therapies?**
- **What are the side effects and risks of the hormonal therapy that you recommend?**
- **What does surgery or radiotherapy to the ovaries involve?**
- **How will the hormonal therapies affect my fertility?**
- **Do I need to use contraception if I am having hormonal therapy?**

Chemotherapy

The main aim of chemotherapy is to improve the quality of your life by reducing your symptoms.

Chemotherapy can help lessen your symptoms by stopping the cancer from getting bigger or spreading, and can even decrease the size of the cancer for a period of time, sometimes for years. By doing this, chemotherapy may also improve the length of your life, although this has not been proven in a clinical trial. *See page 53.*

Chemotherapy is usually recommended for women diagnosed with metastatic breast cancer:

- **who do not have estrogen receptors on their cancer (and therefore may have little benefit from hormonal therapies)**
- **when hormonal therapies are no longer controlling symptoms**

This chapter discusses:

- how chemotherapy works
- the evidence for the effectiveness of chemotherapy
- who manages chemotherapy treatment
- how chemotherapy drugs are given
- where you will have chemotherapy treatment
- how often you will need chemotherapy
- the side effects of chemotherapy
- other anti-cancer treatments for metastatic breast cancer

How does chemotherapy work?

Chemotherapy kills cells in the body that are reproducing rapidly or 'rapidly dividing', such as cancer cells. This means that some normal cells that are also rapidly dividing can be damaged. The main areas in your body where normal cells are damaged are the mouth, stomach and bowel, skin, hair and bone marrow. The damage to normal cells causes the side effects of chemotherapy.

What is the evidence about the effectiveness of chemotherapy?

No studies have been done that compare the survival of women with metastatic breast cancer who do not have chemotherapy to women that have chemotherapy, and none are likely to be done. This means that although doctors think that

chemotherapy probably increases the length of life in women with metastatic breast cancer, this has not been proven by a clinical trial. *See Chapter 12, page 88 for information about clinical trials.*

However, currently doctors think that chemotherapy may prolong the life of women diagnosed with metastatic breast cancer, because:

- There is evidence to show that treatment with a greater number of cycles of chemotherapy is associated with longer survival and improvement of symptoms than treatment with a fewer number of cycles.
- There is evidence to show that standard doses of chemotherapy produce better survival time than half-doses of chemotherapy.

Other studies conducted about chemotherapy have shown that:

- Although chemotherapy may have significant side effects, it may improve or relieve the symptoms of metastatic breast cancer, so that on average the quality of life is improved.
- The use of more than one chemotherapy drug, called combination chemotherapy treatment, may increase survival time compared to the use of only one chemotherapy drug.

- Chemotherapy or hormonal therapies are equally as effective in controlling the symptoms and the size and spread of the cancer, if given as the first treatment for women after their diagnosis of metastatic breast cancer (if the woman has estrogen receptors on her cancer). *See Chapter 6, page 42.*
- In women who have metastatic breast cancer that is progressing rapidly or women who do not have estrogen receptors on their cancer, chemotherapy may be more effective than hormonal therapies.
- There is no evidence that having chemotherapy and hormonal therapy at the same time is of benefit to women with metastatic breast cancer.
- Current evidence does not support the use of very high doses of chemotherapy in metastatic breast cancer outside a clinical trial. This type of treatment is called high dose chemotherapy with stem cell rescue, or sometimes bone marrow transplantation.

If you do not fully understand any of the above or want more information, ask your medical oncologist to explain.

Who manages chemotherapy treatment?

Your medical oncologist will explain to you which

chemotherapy drugs are recommended for your situation and their side effects, how long you may need to take chemotherapy drugs and where you can have chemotherapy.

If you live in a rural area or in an area where there is not a medical oncologist, your general practitioner or surgeon will monitor and make any changes to your treatment by discussing regularly your situation with a medical oncologist. Alternatively, you may decide to travel to the city for treatment managed by a medical oncologist.

Your chemotherapy treatment will be adjusted according to your side effects and how well your cancer is being controlled.

How are chemotherapy drugs given?

Chemotherapy drugs can be given to you in different ways. The most common ways are:

- by **mouth** (orally) in pill, capsule or liquid form
- into a **vein** (intravenously or IV). A thin needle is inserted into a vein, usually on your hand or lower arm. The drugs are given via a ‘drip’ into your hand or arm.

The drugs are then absorbed into the blood and travel around the body so they can reach all the cancer cells.

Because different chemotherapy drugs kill the cancer cells in different ways, often more

“The first two chemotherapy drugs were fairly similar, and this one’s much better.”

than one drug is used to maximise the effect of the chemotherapy. This is called **combination chemotherapy**.

Where will I get chemotherapy?

If you are taking chemotherapy by mouth this can usually be taken by you at home. If you are receiving chemotherapy by injection into your vein, this may be done as an outpatient or day patient, or you may need to stay in hospital for a short while. In some centres a specialist oncology nurse can visit you and give chemotherapy at home.

How often will I need to have chemotherapy?

How often you need to have chemotherapy and for how long will depend on:

- the drugs that are used
- how effectively the chemotherapy controls your cancer
- the side effects you experience from chemotherapy
- your preference

Depending on your situation you may have chemotherapy treatment every day, every week or every month. Chemotherapy is usually given in cycles. This means that you have chemotherapy for a period of time ranging from a few days to a few weeks, followed by a rest period so that your body has a chance to build healthy cells again and regain its strength.

“I threw up twice at night and then they adjusted the anti-nausea drug. Then I was fine.”

What are the side effects of chemotherapy?

Research has also shown that more than 50% of cancer patients receiving chemotherapy experience:

- nausea
- tiredness
- hair loss
- concern about family members
- depression
- dread of treatment

Different drugs affect individual women differently. You may experience more side effects with one drug than another. Your cancer may be better controlled by one drug than another drug. There are many chemotherapy drugs available. Also, newer drugs are becoming available all the time. Ask your doctor to tell you what side effects are commonly experienced with the particular drug that you are being offered.

Tell your doctor about any side effects so that the chemotherapy drugs can be adjusted to your needs.

Most side effects of chemotherapy can be controlled by good medical care

The side effects include:

- *nausea and vomiting*

Nausea and vomiting are common side effects.

Nausea can last from a few hours to a few days.

Some chemotherapy drugs may make individual women feel more nauseated than other

chemotherapy drugs. You may need to try another drug that makes you feel less nauseated.

Nausea and vomiting are usually controlled with drugs called **anti-emetics**. These drugs are given routinely with chemotherapy.

See Chapter 14, page 110 for practical suggestions to help you alleviate nausea.

- ***fatigue***

Feeling tired is one of the main side effects of chemotherapy and can last three to six months after your treatment is finished. Fatigue may also be due to the chemotherapy drugs reducing the red blood cells in your blood. This is called anaemia. Your doctor will check your blood cell count, through blood tests, during chemotherapy treatment to detect if you have anaemia.

See Chapter 14, page 109 for practical suggestions to help you cope with tiredness.

- ***feeling vague or ‘in a fog’***

Some women may feel vague or even mildly confused or have memory problems while they are having chemotherapy. Ask your doctor about any symptoms that concern you.

- ***hair loss***

Hair loss from chemotherapy can range from mild thinning of the hair to total hair loss (including body hair).

“I’d just grown my hair to shoulder length and I really liked it. That was one of the hardest things.”



Not all chemotherapy drugs cause hair loss. Chemotherapy drugs such as anthracyclines and taxanes cause hair loss. However, less than half of all women taking CMF (a combination of cyclophosphamide, methotrexate and fluorouracil) lose enough hair to need to wear a wig. Ask your doctor to explain to you the risk of hair loss from the chemotherapy drug or drugs that are recommended to you.

If you do lose some of your hair, it will usually grow back within weeks or months of ending chemotherapy. You might want to wear a scarf, hat or wig to cover your head while your hair is growing back. When it does grow back it may be a different texture from before. Although losing your hair may not seem serious compared to coping with metastatic breast cancer, many women do find it distressing. It is important to discuss such concerns with your doctor.

If you are having treatment that will cause hair loss it may be best to obtain a wig, hat or turban before treatment. *For information about where to get a wig, hat or turban phone the Cancer Helpline on 13 11 20.*

- ***diarrhoea and constipation***

Some women experience diarrhoea during chemotherapy treatment. Ask your doctor to recommend medication to control any diarrhoea.

Alternatively, some women may experience constipation during chemotherapy. This may be due to the chemotherapy drugs or due to you being less active or because you are eating less, if you feel nausea. Some anti-emetics (anti-nausea drugs) can also cause constipation. Do not use any laxatives or medication for constipation without telling your doctor.

See Chapter 14, page 116 for suggestions about relieving constipation.

- ***weight gain or weight loss***

Some women having chemotherapy lose their appetite and lose weight, while other women gain weight.

See Chapter 14, page 112 for practical suggestions about maintaining your weight.

- ***anxiety***

Some women feel anxious, distressed and teary before, during and after treatment. Some anxiety is normal. If it is severe or is interrupting things at home or affecting your relationships, discuss this with your doctor as there are effective treatments available.

Chapter 16, page 137 provides more information about how you might feel and where to get support.

- *menopausal symptoms and permanent menopause*

Women who have not yet reached menopause may experience menopausal symptoms during chemotherapy. See Chapter 6, page 48 for the symptoms of menopause.

Not all chemotherapy drugs cause permanent menopause.

However, some chemotherapy drugs may cause permanent menopause. The closer you are to the age of natural menopause, the more likely it is that the chemotherapy drugs will cause the menopause to be permanent.

If your menopause is permanent, you will be unable to have children after treatment.

It is important that you discuss the possibility of infertility with your doctor before you start any chemotherapy treatment.

In those women whose menopause is permanent, menopausal symptoms may last only a few months. However, some women may experience symptoms for much longer.

If the menopause is permanent you may be at risk of developing osteoporosis (frail bones) or heart disease.

It is important to tell your doctor if you are experiencing any menopausal symptoms so that they can be controlled. You can also be monitored and treated for osteoporosis and heart disease if they develop.

It is unknown whether it is safe for women who have metastatic breast cancer to take hormonal replacement therapy (HRT) to reduce the symptoms of menopause.

- *mouth ulcers*

Some women taking chemotherapy drugs get mouth ulcers. Mouth ulcers usually occur about five to ten days after taking chemotherapy drugs and clear up within three to four weeks. If you develop mouth ulcers it is important that you brush your teeth and gums with a **very soft** brush after every meal to prevent infection.

For suggestions about treating mouth ulcers see Chapter 14, page 118.

- *nerve and muscle problems*

Some chemotherapy drugs can, uncommonly, cause **peripheral neuropathy** while you are taking them. This is a condition that makes you feel a tingling, burning or numbness in the hands or feet. Sometimes women may also experience other nerve problems such as a loss of balance, or

muscle problems such as the muscles feeling weak or sore.

Report any of the above symptoms to your doctor so that your chemotherapy can be adjusted if necessary or treatment can be given to improve your symptoms.

- *skin problems*

Some women may experience minor skin problems while taking chemotherapy drugs, such as redness, itching, peeling, dryness or acne. Some women's nails may also become darkened, brittle or cracked. Most skin and nail problems are not serious.

Get medical assistance immediately if you develop sudden or severe itching, a rash or you have difficulty breathing. You may be having a severe allergic reaction.

- *infection*

Chemotherapy can, rarely, make you more likely to get an infection. This happens because the chemotherapy drugs can affect the bone marrow and reduce the white blood cells being produced. The white blood cells are the cells that fight infections.

If the chemotherapy affects your white blood cells this will usually happen within 1-2 weeks after

treatment. Your doctor will regularly check your white blood cell count during chemotherapy treatment.

Report any signs or symptoms of infection to your doctor immediately.

If you have a fever (temperature greater than 38°C), chills, or severe sweats, seek medical attention urgently as this could be the first sign of a serious life-threatening infection. Immediate treatment with strong antibiotics may be required.

Other possible symptoms of infection may include loose bowels, a burning sensation when you urinate, a severe cough or sore throat, unusual vaginal discharge or itching, and redness, swelling or tenderness around a wound, sore, pimple, boil, or IV site.

Any infection you get during your chemotherapy treatment can be treated effectively with antibiotics.

- *'flu-like symptoms*

Some women report that they feel as if they have a 'flu a few hours to a few days after chemotherapy treatment. The symptoms include muscle aches, headache, tiredness, nausea, and poor appetite. These symptoms may last from 1 to 3 days.

These symptoms can also be caused by an infection, *see page 64*, so it is important that you report any 'flu-like symptoms to your doctor.

- *bleeding or bruising*

Chemotherapy can, rarely, make you more likely to bleed or bruise easily. This happens because the chemotherapy drugs can affect the bone marrow and reduce the platelets being produced. Platelets help stop bleeding by making the blood clot.

If the chemotherapy affects your platelets, this will usually happen within 1-2 weeks after treatment. Your doctor will check your platelet count during chemotherapy treatment.

Tell your doctor if you have any signs or symptoms of reduced platelets – such as easy bruising, bleeding from gums or nose, reddish urine, and black or bloody bowel movements.

Any unusual bruising or bleeding during your chemotherapy treatment can be treated by a platelet transfusion.

- *kidney and bladder problems*

Some chemotherapy drugs may irritate the bladder or cause temporary or (rarely) permanent damage to the kidneys. Ask your doctor about whether the drugs you are taking could have this effect.



Contact your doctor if you experience pain or burning when you urinate, frequent urination, a feeling that you must urinate right away, reddish or bloody urine, fever or chills.

Drink plenty of fluid to help prevent problems.

- *Other rare or uncommon side effects* include cardiac toxicity (especially with anthracyclines), allergic reactions (especially with taxanes) and hand-and-foot syndrome – abnormal sensation, swelling, redness, pain and blistering on hands and feet (especially with capecitabine).

If these side effects develop during treatment, the chemotherapy drugs will be changed or the dose decreased.

Questions you may ask about chemotherapy

Here is a list of questions that can provide a guide or starting point for deciding about chemotherapy.

- How will chemotherapy benefit me?
- If I do have chemotherapy, should I start it now? Or later?
- If I have chemotherapy, how will it be given? For how long and how many cycles?
- Will the drugs make me sick? Will it make my hair fall out?
- What are the other side effects? How can I deal with them? How long will I take to

recover from them? Are they permanent or temporary?

- Will chemotherapy make me go through menopause permanently?
- How will chemotherapy affect my fertility? Will I still be able to have children?
- Will I still be able to work?
- If chemotherapy doesn't work, are there any other treatments that might help?

New anti-cancer treatments

New treatments are continually being developed for metastatic breast cancer.

Before treatments can be recommended by your doctor they usually need to be studied in a clinical trial to prove their benefit to women with metastatic breast cancer.

What are the results of new research about trastuzumab (Herceptin®)?

A new form of treatment called trastuzumab has recently been shown to be of benefit to some women diagnosed with metastatic breast cancer. It is not a chemotherapy drug. It is an antibody which attacks cancer cells that have an excess of a special substance or **receptor** called HER2/neu (sometimes called c-erbB2). If your cancer does not have HER2/neu on its surface, trastuzumab will have no benefit at all.

If this is your first diagnosis of cancer you may be able to have a breast biopsy, in which a small

amount of breast tissue is removed, to test if you have these receptors on your cancer. If you have already had breast surgery, you will usually not need to have a biopsy because the breast tissue that was removed and stored with the pathologist can be tested.

Trastuzumab may be used alone or in combination with chemotherapy.

One large study has found that trastuzumab can, in **some women** diagnosed with metastatic breast cancer, improve the length and quality of life.

This is the result of **one study only**. Further studies are needed to assess the benefit of trastuzumab in women with metastatic breast cancer.

As with many new therapies, this drug may not be available everywhere. Discuss with your medical oncologist about whether trastuzumab is recommended in your situation and the side effects and benefits of taking trastuzumab.

Radiotherapy

Radiotherapy is the use of X-rays to destroy cancer cells. Radiotherapy can reduce the size of cancer in some areas of the body and relieve pain, especially in a bone.

You may have experienced radiotherapy in your initial treatment for breast cancer.

This chapter discusses:

- when radiotherapy is recommended
- who manages radiotherapy treatment
- how many treatments of radiotherapy are needed
- where radiotherapy is available
- the side effects of radiotherapy
- questions you may ask about radiotherapy

When is radiotherapy recommended?

Radiotherapy is used in women with metastatic breast cancer:

“I had radiotherapy to my spine. It really helped and I haven’t had a lot of lower back pain since.”

- to treat bone pain

Radiotherapy is the most effective single treatment for bone pain. 80% of women with bone pain experience some pain relief following radiotherapy. Two-thirds of women will experience *complete* pain relief.

- to prevent and treat spinal cord compression

Spinal cord compression can occur in women who have cancer in the bones in the spine, called **vertebrae**. This can occur if the cancer causes the vertebrae to collapse and press on the spinal cord. It may also be caused by cancer cells growing around the spinal cord.

Radiotherapy can reduce the size of the cancer in the spine, help heal the spine and decrease the symptoms of spinal cord compression.

There is evidence to show that treatment of spinal cord compression with radiotherapy is just as effective as surgery in relieving symptoms.

If surgery is needed for spinal cord compression, radiotherapy is recommended after surgery.

Your doctor will recommend radiotherapy or surgery or both, depending upon the extent of the collapse of your spine and your symptoms.

If your doctor thinks that you are at a high risk of spinal cord compression, radiotherapy or surgery or both may be recommended.

- **to prevent and treat fractures**

Radiotherapy is usually used **after surgery** to prevent or treat fractures of **weight bearing bones**, such as the long bone of the leg.

Radiotherapy can reduce the size of the cancer in the bone, help the bone heal after surgery, and help relieve pain.

Radiotherapy can be used **without surgery** to prevent or treat fractures of **non-weight bearing bones** such as the ribs, fibula (lower leg) and much of the pelvis. Radiotherapy can reduce the size of the cancer in the bone, help the bone heal and help relieve pain.

If your doctor thinks that you are at a high risk of a fracture, radiotherapy or surgery or both may be recommended.

See Chapter 10, page 79 for information about how to prevent and treat fractures with surgery.

- **to treat cancer in the brain**

There is evidence to show that radiotherapy leads to improvement of symptoms in women whose cancer has spread to their brain.

Radiotherapy can reduce most of the symptoms of cancer in the brain.

The main side effect of radiotherapy to the brain is complete loss of hair. However, **hair will usually regrow after 2-3 months** although it may be less dense than previously. Other side effects which occur in approximately 10% of people receiving radiotherapy to the brain include lethargy, nausea, vomiting, headaches, and lack of coordination of muscles. These side effects are usually prevented or treated with the use of medication called steroids.

Chemotherapy may be used as an alternative to radiotherapy to the brain, particularly in women with symptoms from cancer in other places in the body.

- **to relieve pain or swelling in other parts of the body**

Radiotherapy can be used for other problems such as to reduce the size of enlarged lymph nodes (glands).

Who will manage my radiotherapy treatment?

A **radiation oncologist** specialises in treating cancer with radiotherapy. He or she will:

- advise you when radiotherapy would be useful to you

- prescribe the appropriate dose and duration of your radiotherapy
- answer any questions you may have

The person who works the radiotherapy machines under the direction of your radiation oncologist is called a **radiation therapist**. An **oncology nurse** may help monitor your progress and any side effects you experience.

How many radiotherapy treatments will I need?

If your doctor recommends that you have radiotherapy, the number of treatments you may need will depend on:

- where the cancer is
- the symptoms you are experiencing
- how extensive the cancer is
- your general state of health
- if you have had radiotherapy before in the same area

For these reasons, treatment is planned for each woman individually.

Where will I have radiotherapy?

Radiotherapy is carried out in hospitals or specialised clinics in major centres only. Not all hospitals can provide radiotherapy. Your radiation oncologist, or perhaps your general practitioner if you live in a rural area, will inform you about which centres in your area offer radiotherapy. If you need

to travel long distances to a radiotherapy centre, travel rebates and accommodation are available. *See Chapter 20, page 181 for more information about travel rebates and accommodation.*

What are the side effects of radiotherapy?

The side effects of radiotherapy will depend on the part of your body receiving radiotherapy and the dose and duration of your treatment. In general, the main side effects of radiotherapy are:

- **tiredness**

See Chapter 14, page 109 for suggestions about coping with tiredness.

- **skin reaction**

Local reaction of the skin, similar to sunburn, may occur in some individuals after a number of radiotherapy treatments. However, skin problems are very unusual with the doses of radiotherapy needed to treat the conditions discussed in this chapter.

Your radiation oncologist will tell you how to manage any skin reactions. Skin reactions usually settle down two to four weeks after the radiotherapy has finished.

It is important that skin care begins from the first day of your radiotherapy. Your radiation oncologist will tell you how to look after your skin during your treatment.

- **loss of hair**

Complete but temporary hair loss is the main side effect of radiotherapy to the brain. *See Chapter 7, page 60 for more information.*

- **nausea and vomiting**

Nausea and vomiting can occur if part of the abdomen is treated. Anti-nausea drugs can be used to control nausea and vomiting.

Questions you may ask about radiotherapy

Here is a list of questions that can provide a guide or starting point for deciding about radiotherapy.

- How will radiotherapy benefit me?
- Where can I have radiotherapy?
- How long will I need to have it for?
- What are the side effects? How can I deal with them? How long will I take to recover from them?
- How can I look after my skin during radiotherapy?



Surgery

Surgery *is not commonly* used in the treatment of women with metastatic breast cancer.

However, surgery can sometimes be used to treat cancer in the bones, lungs or brain, or more rarely in the liver. Surgery may also be recommended if this is your first diagnosis of breast cancer.

This chapter explains the situations in which surgery is more commonly recommended, and some of the surgical procedures.

Surgery may be recommended for:

- **Cancer in the breast**

If this is your first diagnosis of breast cancer you will usually be recommended to have a biopsy of the cancer to confirm the diagnosis and test the cancer for estrogen receptors. A biopsy involves removing a small amount of breast tissue. It is not usually necessary that all of the breast cancer is removed. In fact, leaving the breast cancer can help your doctor assess whether your treatment is working by measuring the size of the cancer.

If you feel uncomfortable about leaving the breast cancer, talk to your doctor about taking out the lump. Radiotherapy and removal of the lymph nodes under the arm are not recommended.

- **Cancer that has spread to the bone**

Surgery can be used to:

- **prevent a fracture** if your surgeon considers that a bone is at high risk of a fracture
- **treat a bone fracture**
- **replace a joint** that has been severely affected by cancer
- **treat or prevent spinal cord compression**

Surgery to the bone is often followed by radiotherapy. *See Chapter 9, page 71.*

- **Cancer that has spread to the lungs**

Surgery can be used to:

- **reduce the fluid in the pleural cavity** if the cancer has spread to the pleura around the lung. Usually surgery is recommended if the cancer in the pleura is not being controlled by chemotherapy or hormonal therapies.

Some of the possible surgical procedures for cancer in the pleura are listed below.

Ask your doctor to explain whether any of these procedures are recommended in your situation.

Pleural drainage

This involves inserting a needle into the space around the lungs, the **pleural cavity**, and draining the fluid. This will relieve breathlessness, but usually the fluid builds up again within one month.

Tube thoracostomy

This involves inserting a tube into the pleural cavity and leaving it there to drain the fluid until the fluid falls to 50-100ml per day.

Drugs can then be inserted into the pleural space to harden the pleura and prevent fluid from leaking into the pleural cavity. The most widely used drugs are **bleomycin and doxycycline** (a tetracycline).

Thoracoscopy and talc insufflation

This procedure involves inserting a thoracoscope into the pleural cavity. With this instrument the surgeon can see any fluid in the pleural cavity and the condition of the pleura.

The fluid is drained and talc is sprayed into the pleural cavity. The talc causes the pleura to harden and prevent fluid leaking into the pleural cavity.

There is evidence that thoracoscopy and talc insufflation is more effective than using the drugs bleomycin and doxycycline.

Surgical pleurectomy

This procedure involves removal of part of the pleura. This procedure can result in pain and so is usually not considered unless there is no alternative.

Pleuro-peritoneal shunting

This procedure is rare and involves inserting a tube between the pleural cavity and the abdomen so that fluid can be drained. The disadvantage of this procedure is that cancer cells can be transferred into the abdomen.

- **Cancer that has spread to the brain**

Surgery can be used to:

- **remove the cancer** if there is only one area of cancer detected in the brain.

There is evidence to show that, if a woman has only one cancer in her brain, removal of the cancer by surgery followed by radiotherapy to the whole brain can be better than having radiotherapy alone.

If there is only one cancer detected in the brain, surgery plus radiotherapy can contain the cancer better and increase the time without any symptoms compared to having just radiotherapy to the whole brain.

An alternative to removal of the cancer in the brain by surgery is very focused radiotherapy called **stereotactic radiotherapy**, followed by radiotherapy to the whole brain.

- **drain fluid from the brain**, if the cancer increases fluid in the brain.

If this occurs a tube can be inserted into the brain to help drain the fluid from the brain.

- **Other reasons for surgery**

- cancer ulcerated through the skin
- bowel obstruction
- nerve compression and nerve pain
- upper abdominal pain

Complementary & alternative therapies

What are complementary and alternative therapies?

Complementary therapy is used to describe any treatment or therapy that is not part of the conventional treatment of a disease, which in the treatment of breast cancer includes hormonal therapies, chemotherapy, surgery and radiotherapy.

Some complementary therapies include:

- acupuncture
- relaxation therapy / meditation
- yoga
- tai chi
- positive imagery
- faith / spiritual healing
- laughter
- music
- art
- massage
- aromatherapy
- dietary therapies
- some support group programs

*“Surrounding yourself
with positive things.
Sometimes you have to
retrain your thinking.
And don’t dwell on
terrible things
happening to you.”*

“I do yoga, which I find wonderful.”

Most women who use complementary therapies also use conventional treatments.

Complementary therapies may increase your wellbeing or quality of life, although this is yet to be fully researched.

There is evidence to show that the following complementary therapies can improve the quality of life with women diagnosed with metastatic breast cancer:

- Relaxation therapy can ease cancer pain.
- Muscle relaxation and imagery can reduce distress in women with mild anxiety.
- Acupuncture can ease pain.

Healthy living – including a good diet, exercise within limits, enough sleep and relaxation, and effective management of stress – is important for everybody.

Alternative therapy is used to describe any treatment or therapy that may be used as an alternative to conventional treatments.

Some alternative therapies include:

- naturopathy
- immune therapy
- homeopathy
- Chinese herbs
- megavitamins

Although these therapies are called alternative therapies, research has shown that most women who use alternative therapies also use conventional treatments.

Alternative therapies may increase your wellbeing or quality of life, although this is yet to be fully researched.

At present, there is no evidence that alternative and complementary therapies, apart from supportive group counselling (see Chapter 16, page 146), can increase the length of life in women diagnosed with metastatic breast cancer.

Alternative therapies have not been tested for their interactions with conventional treatments and for their side effects.

It is important to inform your doctor about any complementary therapies or alternative therapies that you are undertaking, as some treatments may be harmful if taken at the same time as conventional treatments.

Some potentially dangerous treatments include:

- calcium supplements in women with cancer in their bones may increase the level of calcium in their blood, and this may be harmful

“In moments of stillness I have come to realise that I am already whole, already complete in my being, even if I have cancer or pain, even if I don’t know how long I will live or what will happen to me.”

"I have realised that I am not my cancer and I have made a commitment to living each moment of my life as fully as possible, and to use my cancer to help me rather than to shower blame on myself for having it."

- too much iron supplementation in women having blood transfusions may result in iron overload
- vitamin C supplements in women taking methotrexate, a chemotherapy drug, may increase the side effects of the drug
- some diets – such as the beetroot diet, the grape diet and the Gerson diet – may be nutritionally inadequate
- the frequent use of enemas such as coffee enemas or high colonic washouts may cause electrolyte imbalances
- manipulative therapies such as chiropractic, osteopathy, physiotherapy or rigorous massage may cause harm in women whose cancer has spread to their bone *if the affected area is treated.*

Questions that you may ask an alternative health practitioner

Before you decide on any treatment it is important to be well informed and feel confident in the training of any alternative health practitioner. A possible list of questions you should ask any practitioner include:

- **What is your training? Exactly what is the therapy you are proposing?**
- **What do you hope it will do?**
- **What are the chances of success? What is the evidence for success of this treatment?**

- What side effects may occur?
- How commonly do they occur?
- Will this therapy affect other treatments I am having?
- How much will it cost?

Most specialists or general practitioners will be happy to discuss these therapies with you. If not, you may need to seek out a doctor who is happy to do this. *Phone the Cancer Helpline on 13 11 20 for more information.*



Clinical trials

During the course of your treatment you may be asked if you would like to take part in a clinical trial.

This chapter discusses:

- what a clinical trial is
- why there are clinical trials
- the advantages and disadvantages of participating in a clinical trial
- deciding about whether or not to participate in a clinical trial

What is a clinical trial?

Clinical trials are studies involving patients, conducted in order to help find better ways to prevent, diagnose, or treat diseases.

Why are there clinical trials?

Studies involving cancer patients try to find out whether promising approaches to cancer prevention, diagnosis, and treatment are safe and effective.

The major advances that have been made in breast cancer treatment were first tested in carefully conducted clinical trials.

Each clinical trial must be approved by an ethics committee established by each hospital and health service.

What are the advantages and disadvantages of participating in a clinical trial?

The advantage of participating in a clinical trial is that you *may* receive newer treatments that are not yet available to the general public and may be more effective. By participating in a clinical trial you will also be helping other women who are diagnosed with cancer in the future.

The disadvantage of participating in a clinical trial is that the newer treatments may not be more effective than standard treatments and may have more side effects.

Also, many clinical trials have a control group which means that you may not receive the newer form of treatment during your participation in a trial. You will not be able to choose whether you are in the group that receives the newer treatment or in the control group. However, you will always receive the best proven care.

How do I decide whether to participate in a clinical trial?

If you are invited by your doctor to enter a clinical trial you need to weigh up the risks and benefits of this decision.

You should be assured that refusal to take part in a trial will not compromise your treatment in any way. You are also able to leave a clinical trial at any time without prejudice to your ongoing treatment. The consent form you sign ensures this.

If you are interested, ask your doctor about any clinical trials that are appropriate for you.

For more information about clinical trials:

- phone the NHMRC Clinical Trials Centre on (02) 9562 5000.
- email *enquiry@ctc.usyd.edu.au*
- visit the iSource National Breast Cancer Centre website at <http://www.nbcc.org.au>

Pain management

Not everyone with cancer will suffer pain. According to the World Health Organization, about 30% of people with metastatic cancer do not experience any pain at all. For those women who do experience pain, improvements in drugs and a better understanding of the causes of pain mean that there is rarely any need, at any stage, to continue to experience pain.

Cancer pain can be effectively controlled.

Pain management aims to relieve your pain during the night and the day, and both at rest and on movement. It can involve drug and non-drug treatments.

This chapter discusses:

- the main causes of pain in women with metastatic breast cancer
- the key messages about cancer pain
- reporting any pain to your doctor

“My belief is that you’re not dying until the last minute. That you’ve got to focus on living and getting the most out of life while you’re here.”

- drug treatments for pain
- other medical treatments for pain, such as radiotherapy
- non-drug treatments for pain, such as relaxation

The main causes of pain

Pain in women with metastatic breast cancer may occur for many reasons, including:

- cancer in any part of the body, including the bones, lungs, liver or brain if the cancer presses on nerves or soft tissue
- a side effect of treatments such as surgery or medical tests
- a bone fracture
- an infection
- a blood clot caused by cancer or its treatment
- obstruction of the bowel caused by cancer
- **any other illnesses or problems** you had before your diagnosis or developed after your diagnosis that have nothing to do with the cancer

Key messages about cancer pain

- *Every woman's experience of pain will be different.*

The amount or type of pain that one woman experiences may not be the same as that experienced by another woman who has the same cancer.

“The doctor talked a lot about pain medication, its effects and that you should take the next dose before the first dose wears off.”

- *Pain does not always gets worse.*

The level of pain experienced may remain unchanged, or may increase or decrease.

In any situation medication can be adjusted to ensure pain relief.

- *Pain is not related to the extent of the cancer.*

Experiencing pain does not necessarily mean that the cancer is more serious than if you had no pain.

- *Take action as soon as the pain starts.*

Take pain relief when you first start to feel uncomfortable. It is harder to ease pain once it has taken hold. Taking medication for pain relief when the pain is bearable will not make the medication less effective later. **The aim is to prevent pain.** If you wait until the pain comes back you will suffer from unnecessary pain.

- *When pain relief is taken regularly or 'by the clock' (such as every 4 hours), there is little danger that you will become addicted to these drugs.*

Addiction to pain killers is very rare in women with metastatic breast cancer. The dose can be tailored to your needs. Doses are increased or decreased according to the severity of your pain.

- *Drugs for pain do not usually make you feel drowsy after the first or second day.*

Drowsiness can occur with strong pain relief drugs like morphine. However, the drowsiness

usually passes in one or two days. People vary in how the medication affects them. You should ask your general practitioner about whether you can drive or work with machinery, and the effect of drinking alcohol with your medication.

- *If one drug does not effectively help your pain, many other drugs or combinations of drugs can be used to give you pain relief.*

There is a large range of effective drugs for pain of all types and severity. It may take time, in consultation with your doctor, to establish the drug or drug combination that is right for you.

- *Any pain can be difficult to cope with. However, pain is more difficult to cope with if you are also experiencing anxiety or depression.*

Also, being in pain can make you more likely to be depressed or anxious. If you are concerned by the feelings you are experiencing, it is important that you talk to your doctor as soon as possible. Help is available. *See Chapter 16, page 135 for more information about depression and anxiety.*

Reporting your pain

Many people think that telling others that they are in pain means that they are complaining or being a nuisance. However, **it is important that you do not put up with pain.** You should report any pain to your doctor even if it is minor, so that your doctor



can investigate the cause of your pain and recommend appropriate pain relief. There are various drugs to control different levels of pain.

Always consult your doctor about any new or worsening pain. Do not change or start any pain relief medication without consulting with your doctor.

Some questions your doctor might ask about your pain include:

- Where is the pain? Is it in one part of your body, or more? Does it start in one place and gradually spread during the day?
- What is it like? For example, is it dull and aching, burning, or sharp and stabbing?
- How bad is it? Try to rate your pain by comparing it with pain you have experienced before, such as headache, back or period pain, sports injury, childbirth. If you were to rate your pain on a scale of one to ten, how would you rate it, if one was no pain and ten the worst pain you can imagine?
- Does anything make the pain better or worse? For example, do you feel better standing, sitting or lying down? Does a hot-water bottle or ice-pack help? Or perhaps some pain-killers, such as paracetamol? Can you distract yourself with a good book, music, TV etc?

- Is the pain there all the time? Does it come and go? Is it worse at night? Does it keep you awake? Does it wake you up?

Drug treatments for pain

Choosing a drug or a combination of drugs for pain depends on the type and severity of pain. Every individual is different and therefore it may take time to establish the treatment that is right for you.

While most pain relief drugs have some side effects, they are generally not serious. Not everyone experiences side effects. They can be reduced by treatment or by changing to a different medication. Your doctor should advise you about any side effects that you should look for, and what to do if you experience them. You can also ask your pharmacist for a drug information printout.

There is evidence to show that drugs for chronic pain should be taken regularly, such as every 4 hours, rather than waiting until pain is experienced.

Drugs used to control pain include:

Aspirin and paracetamol

Aspirin and paracetamol are very effective drugs for mild to moderate pain. Aspirin or paracetamol may be used, for example, to treat pain caused by:

- mouth ulcers
- ulcers in the skin
- cancer in the bone

Paracetamol is generally considered to be a better choice than aspirin for mild to moderate pain because it has less effect on the stomach and on blood clotting.

Aspirin and paracetamol can also be used with stronger pain drugs such as morphine if you have moderate or severe pain.

If aspirin or paracetamol does not give complete pain relief, stronger pain drugs such as morphine or codeine will be required.

You should take **no more than 8 (eight) pain killers containing paracetamol per day** unless told to do so by your doctor.

Non-steroidal anti-inflammatory drugs (NSAIDs)

There is evidence to show that NSAIDs can be effective in treating:

- bone pain
- pain caused by inflammation (redness and swelling) eg ulcers in the skin, cancer in the liver causing pain, and compression of a nerve

NSAIDs may affect the stomach or cause bleeding in some individuals.

NSAIDs should *not* be taken with aspirin. NSAIDs should be used in consultation with your doctor.

Codeine-based drugs

Drugs containing codeine are effective for **moderate** pain. These drugs often also contain paracetamol. Drugs containing codeine may cause drowsiness in the first two days of treatment. Most people taking these drugs also experience constipation.



To prevent constipation from drugs containing codeine, laxatives should be taken with these drugs.

See Chapter 14, page 116 for suggestions about relieving constipation.

Some people may also experience a dry mouth and nausea from drugs containing codeine.

Morphine and other opioid drugs

There is evidence to show that morphine and other strong opioid drugs are safe and effective for moderate to severe pain.

The dose of morphine can be increased or reduced according to the severity of your pain. The dose is not limited. The correct dose is the dose that gives you pain relief.

Morphine can be taken in the following ways:

- *Tablets or liquids*

Taking tablets or liquids orally is considered the best way of taking pain medication. It is also easy to adjust the dose to your needs.

- *Suppositories*

Pain relief drugs can sometimes be given by the rectum if you are feeling sick or vomiting.

- *Injection into skin or muscle*

This method is used if you are feeling sick or vomiting. In some situations a small needle is inserted under the skin and connected to a small pump to administer morphine continuously. Once the needle is inserted, you can continue to use this in your home.

- *Injections into a vein*

Pain relief drugs can be injected into a vein through a small tube, called an intravenous (IV) catheter. The tip of the tube stays in the vein. Drugs can be given through the tube at set times, or continuously, depending on your type of pain. This method is rarely used to treat cancer pain.

Patient-control analgesia (PCA) pumps are sometimes used for severe pain **after surgery**. With PCA, you can adjust your pain medication to achieve your own level of comfort and tolerance of side effects. When you begin to feel uncomfortable, you can press a button and the

drug is injected, usually through the IV tube in your vein.

- *Other*

Fentanyl patches are another opioid alternative to morphine. They are applied to the skin as a patch for effective control of pain.

Morphine or other opioid drugs can be given for **acute pain that cannot be controlled by other means** by injecting it into:

- the spinal canal
This is called **epidural** or **intrathecal** pain relief.
- the brain
This is called **intracerebroventricular** pain relief.

Epidural, intrathecal and intracerebroventricular opioid are often effective in treating acute pain that is not controlled with other treatment.

Side effects of morphine or other opioid drugs

Possible side effects of morphine or other opioid drugs include:

- *drowsiness*

Drowsiness may occur when starting or increasing the dose of medication. This usually wears off as one gets used to the drug. If prolonged drowsiness occurs contact your doctor.

- *constipation*

Constipation occurs in most women taking morphine and fentanyl skin patches.

To prevent constipation from morphine and drugs containing opioids, laxatives should be taken with these drugs.

See Chapter 14, page 116 for suggestions about relieving constipation.

- *dry mouth*

A dry mouth is a common side effect of morphine or other opioid drugs.

- *nausea and vomiting*

Nausea usually is only experienced in the first three to five days of starting to take morphine or other opioid drugs. An **anti-emetic** drug can be taken to counteract this.

- *itchiness*

This is a less common side effect. If this occurs, inform your doctor.

Other drug treatments for pain

Other drug treatments for pain include:

- *Bisphosphonates*

Bisphosphonates stop the activity of special bone cells that break down bone. They are used to control cancer in the bone and bone pain.

“I’ve had some radiation therapy to my neck and to my pelvic area and it helped stop a lot of the pain.”

There is evidence to show that when given regularly to women with metastatic breast cancer with spread of their cancer to the bone, bisphosphonates can:

- reduce bone pain
- reduce the need for other pain relief medication
- slow down the rate of development of new bone cancers
- decrease hypercalcaemia (high calcium levels in the blood)
- reduce the need for radiotherapy and/or surgery to bones

Bisphosphonates are more commonly given by injection into a vein (IV). They can also be given by mouth.

- ***Steroids***

Steroids may be used to relieve pain caused by:

- cancer pressing on a nerve
- cancer in the brain
- cancer in the liver

Common steroids are dexamethasone and prednisolone.

Taking steroids in high doses and for prolonged periods can cause a number of side effects.

Discuss these side effects with your doctor.

- *Muscle relaxants*

Muscle relaxants such as benzodiazepines can help relax muscles if you have muscle spasm pain. They may also cause drowsiness.

- *Antidepressants*

Antidepressants can be used with morphine or other opioid drug for pain that involves the nerves to increase the effectiveness of the morphine or opioid drug.

Pain can also make you more likely to become depressed or anxious. So it is important that your pain is treated effectively. *See Chapter 16, page 135 for more information about depression and anxiety.*

Other medical treatments for pain

- *Radiotherapy*

Radiotherapy is the most effective method of controlling pain in the bones and is also useful for pain in other sites in the body. *See Chapter 9, page 71 for more details about radiotherapy.*

- *Antibiotics or anti-fungals*

Antibiotics or anti-fungal may be used to treat infection causing pain.

- *Surgery*

See Chapter 10, page 78.

*“When I’m feeling bad
I do a bit more
meditation to try and
relax, dream of
attacking the area
where the pain is and
sort of say go away, it
seems to help.”*

Non-medical pain relief methods

- *Relaxation*

There is evidence to show that relaxation therapy can ease cancer pain.

Relaxation techniques can be helpful for people coping with pain. Simple techniques include abdominal breathing, jaw relaxation, methods of self hypnosis and yoga.

- *Education programs about how to take pain medication*

There is evidence to show that education programs can ease cancer pain.

- *Acupuncture*

There is evidence to show that acupuncture can ease pain.

Acupuncture involves placing small needles in key areas of the body. Consult your doctor about the location of qualified practitioners.

- *Massage*

Some health professionals and other women diagnosed with cancer suggest that massage and aromatherapy (gentle massage using essential oils) may help with relaxation and coping with pain.

*“The massage therapy
is just wonderful.
You come away
floating.”*

Massage should not be used on acutely inflamed or swollen parts of the body. Massage should not be used during radiotherapy. Rigorous massage should not be applied to parts of the body where there is a known cancer.

- *Cold and hot packs*

Some health professionals and other women diagnosed with cancer suggest that cold packs may be useful where there is swelling or inflammation, and that hotpacks or hot-water bottles can help relieve back pain and joint pain.

Hot or cold packs should not be used during radiotherapy.

- *Support*

Support from friends, family, religious organisations, trained counsellors, psychologists or psychiatrists, or joining support groups with other women in a similar situation, may help you cope with your pain. *See Chapter 16, page 145.*

“It’s interesting to be with other people in the same situation [in the support group]. As we say to each other, we’re really the only ones who can understand what we’re going through.”

Controlling any other symptoms

*“I’m not cancer.
I’m me first and the
cancer just happens to
be one of the things
around me, like all the
other things that are
around me.”*

The symptoms you may experience may be caused by the cancer, or by the treatment for the cancer, or by any other illnesses you may have.

Not all the symptoms you experience will be due to cancer.

Some of the symptoms and conditions discussed in this chapter have been mentioned in previous chapters. This chapter will explain the treatment of these symptoms and conditions and provide practical suggestions to help you manage your symptoms.

This chapter discusses the following symptoms and conditions:

- hypercalcaemia
- tiredness
- nausea and vomiting
- loss of appetite
- poor sleep
- constipation
- mouth ulcers

- lymphoedema
- immobility
- distended or enlarged abdomen
- breathing difficulties
- headaches
- change in thinking ability
- pressure sores
- incontinence of the bowel or bladder

This is a comprehensive list of symptoms. **You will not experience all of these symptoms.** They are included as a reference because each woman will experience different symptoms.

Always report new symptoms or any change in the severity of your symptoms to your doctor.

When describing your symptoms to your doctor, be as specific as you can so that the appropriate treatment can be prescribed. You may find it helpful to keep a diary of how well your symptoms are being controlled to take with you when you see your doctor.

Your doctor should inform you about any side effects of drugs or other treatments that are recommended.

Hypercalcaemia

Hypercalcaemia is an increase in the levels of calcium in the blood. Hypercalcaemia can be detected by a blood test. The symptoms may be mild or severe and include:

“I am amazed that anybody can get something so destructive and yet be well, be coping with life and doing everything you do without any symptoms.”

- increased urination
- excessive thirst
- dehydration
- vomiting
- constipation
- muscle weakness
- drowsiness/confusion

Inform your doctor if you are experiencing any of these symptoms so that they can be evaluated and controlled.

The possible causes of hypercalcaemia include:

- cancer in the bone: *See Chapter 5.*
- metastatic breast cancer without any spread to the bone

Treatment of hypercalcaemia

Treatment of hypercalcaemia includes:

- fluids to treat the dehydration
- bisphosphonates: *See Chapter 13, page 101.*

There is evidence to show that when given regularly to women with metastatic breast cancer with at least one cancer in the bone, bisphosphonates reduces the number of episodes of hypercalcemia.

- change in chemotherapy or hormonal therapy: Usually the development of hypercalcaemia

“What I found difficult was the ray treatment, the exhaustion.”

indicates that the cancer in the bone is not well controlled and that a change in treatment is needed.

Tiredness

More than 50% of women diagnosed with metastatic breast cancer feel tired or fatigued.

The **possible causes** of tiredness include:

- the cancer itself
- anaemia (low amount of red blood cells in blood)
- the side effects of treatment such as chemotherapy, radiotherapy and surgery
- travelling for various treatments
- coping with pain or other symptoms
- the stress of living with cancer

Inform your doctor about any tiredness you experience so that it can be evaluated and controlled as best as possible.

Treatment of tiredness

Treatment of tiredness includes:

- treating the underlying cause of the tiredness
- gentle exercise
- steroids only if severe due to side effects such as weight gain, muscle weakness, insomnia, increased appetite, and stomach ulcers

Some **practical suggestions** to help you conserve your energy are listed. These suggestions are based



“My doctor said, don’t have the long overseas holiday which you might not be able to handle fitness-wise. She said, have two or three little ones and have something to look forward to.”

on the experience of health professionals working with women diagnosed with cancer, and from women themselves.

Practical suggestions to help you conserve your energy include:

- Make sure your symptoms such as pain are adequately treated.
- Conserve your energy for what you want to do, and for activities that give you pleasure.
- Ensure you have adequate sleep.
- Plan rest periods in the day during which you will not be disturbed.
- See a physiotherapist about a gentle exercise program appropriate to you.
- Encourage friends and family to have short, frequent visits rather than longer ones if you are feeling tired.
- Have a well-balanced diet.
- A wheelchair may be useful to allow you greater mobility than you could achieve on your own.

“Part of the chemotherapy treatment was anti-nausea drugs the day prior, day of and day after the chemotherapy. This completely controlled my nausea.”

Nausea and vomiting

More than 50% of cancer patients receiving chemotherapy experience nausea. You may also experience nausea or vomiting if you are not receiving chemotherapy.

The **possible causes** of nausea and vomiting include:

- chemotherapy
- radiotherapy
- drugs for pain or symptom relief
- hypercalcaemia: *See page 107.*
- cancer in the brain
- cancer in the liver
- bowel obstruction

Inform your doctor about any nausea or vomiting that you experience, so that it can be evaluated and controlled.

Treatment of nausea and vomiting

Treatment of nausea and vomiting includes:

- treating the underlying cause of the nausea and vomiting
- anti-nausea drugs, called anti-emetics
- steroids

There is evidence to show that steroids can be useful in controlling nausea and vomiting from chemotherapy treatment.

- bisphosphonates for hypercalcaemia:
See Chapter 13, page 101.

Some **practical suggestions** to help prevent nausea and vomiting are listed. These suggestions are based

"I dropped so much weight when I first got the cancer secondaries, but now I've put it all back on again."

“I have changed my eating habits, but you also have to be happy.

If you’re eating this really stringent diet that’s so good for you and you feel miserable about it, it’s no good for you overall.

So I mean I’ll go out and have my cappuccino and a nice piece of cream cake and enjoy it.

But not often.”

on the experience of health professionals working with women diagnosed with cancer, and from women themselves.

Practical suggestions to help prevent nausea and vomiting include:

- Take small meals at frequent intervals.
- Avoid fatty or fried foods.
- Rest before and after eating.
- Don’t lie flat during or after eating.
- Take anti-emetics before meals if nauseated.
- Ensure adequate liquid intake.
- See a dietitian or nurse about dietary advice.

Loss of appetite

26% of women with metastatic breast cancer experience loss of appetite.

The **possible causes** of loss of appetite include:

- the cancer itself
- treatment such as chemotherapy, radiotherapy, drugs for pain or symptom relief
- decreased physical activity

Inform your doctor about any loss of appetite that you experience so that it can be evaluated and controlled as best as possible.

Treatment of loss of appetite

Treatment of loss of appetite includes:

- dietary advice from a dietitian: *See below.*
- drugs such as progestational drugs or steroids

Some **practical suggestions** to help treat loss of appetite are listed. These suggestions are based on the experience of health professionals working with women diagnosed with cancer, and from women themselves.

Practical suggestions to help you eat more include:

- Eat small meals and snacks as often as you can during the day.
- Eat a variety of foods with the emphasis on high fibre if possible, with plenty of cereals, fruit and vegetables.
- Select foods that you think you will enjoy.
- Make the most of ready-prepared foods when you are too tired to cook.
- Use protein and carbohydrate drinks to give you energy, protein and vitamins if you are unable to eat a balanced diet or find it difficult to eat solid food.
- Do not force yourself to eat, but do take advantage of those times when you feel able to face food.



“This time I’ve needed antidepressants because I wasn’t sleeping. I was just lying in bed feeling afraid about what’s going to happen to me, what’s going to happen to my daughter, all that sort of thing.”

“I think if you can find someone to get your emotions out with that you have bottled up for so long. I think to be a whole person you have to get that out. You have to expect to come to terms with it.”

If you feel unsure about what you should eat, ask your doctor to refer you to a dietitian. Call the **Cancer Helpline** on **13 11 20** for more information.

Poor sleep

Women with metastatic breast cancer can experience some trouble sleeping at some time.

The **possible causes** of poor sleep include:

- the side effects of some drugs
- anxiety or depression: *See Chapter 16, page 135.*
- pain: *See Chapter 13.*

Inform your doctor about any poor sleep that you experience, so that it can be evaluated and controlled as best as possible.

Treatment of poor sleep

Treatment of poor sleep includes:

- treating the underlying cause of poor sleep
- drugs to help you sleep

Some **practical suggestions** to help you sleep better are listed. These suggestions are based on the experience of health professionals working with women diagnosed with cancer, and from women themselves.

Practical suggestions to help you sleep better include:

- Inform your doctor if pain or other symptoms are preventing you from sleeping.
- Gentle exercise each day, such as walking, can help you sleep at night. Your doctor, nurse or physiotherapist can show you simple exercises you can do even if you spend most of your time in a chair or in bed.
- If you find it hard to sleep at night because you are dozing during the day, try and develop a schedule of gentle activities or visits from friends so that you can maintain a normal daily rhythm.
- Avoid coffee, tea and caffeine drinks in the afternoon and evening.
- Drink a warm drink such as milk and honey or a cup of herbal tea before you go to sleep.
- Practise deep breathing and relaxation exercises or listen to relaxation tapes before you go to bed.
- A warm bath before you go to bed may help you sleep. Using essential oils such as lavender in your bath or on your pillow may help you sleep.
- Occasionally having a massage from a qualified massage therapist or a friend or partner may help you relax, sleep better and cope better with your symptoms.
- If you are unable to sleep at night, use the time to listen to music or read a book.

“Listen to happy songs, sing around the house, sing while you’re vacuum cleaning, instead of looking at the black side of everything.”

“My doctor sent me off to see a lady counsellor, who was very good. I only went once. I think that was the turning point, to get things out of my system by talking about it.”

- You may be unable to sleep because of fears and concerns you have about yourself and your family. You may need to discuss your concerns with your family or friends, or you may want to talk to other women who are in a similar situation to yourself or to a trained counsellor, psychologist or psychiatrist. *See Chapter 16, page 145 for how to get more support.*

Constipation

Constipation is very common among women with metastatic breast cancer, especially those taking pain relief drugs.

The **possible causes** of constipation include:

- the side effects of some drugs, especially pain relief drugs such as codeine or morphine
- a low-fibre diet
- not drinking enough fluids
- not eating enough food
- lack of movement due to immobility or weakness

Inform your doctor about any constipation that you experience, so that it can be evaluated and controlled.

Treatment of constipation

Treatment of constipation includes:

- encouraging increased fluid and fibre intake
- laxatives
- enemas if required

Some **practical suggestions** to help prevent and relieve constipation are listed. These suggestions are based on the experience of health professionals working with women diagnosed with cancer, and from women themselves.

Practical suggestions to help prevent and relieve constipation include:

- Follow a gentle exercise program that is appropriate for you.
- Increase the fibre in your diet as far as possible, for example by eating fresh fruits and vegetables and grains.
- Increase your water intake.
- Take laxatives to prevent constipation.
Talk to your doctor about the most appropriate laxative for you.

Mouth ulcers

Mouth ulcers can be very uncomfortable and can affect the amount and type of food you are able to eat.

Mouth ulcers may be caused by chemotherapy or may develop for reasons unknown.

Inform your doctor about any mouth ulcers that you experience, so that it can be evaluated and controlled.

Treatment of mouth ulcers

Treatment of mouth ulcers includes:

- pain relief such as aspirin, paracetamol or a topical or local anaesthetic
- treatment of any thrush or other infections of the mouth or throat

Some **practical suggestions** to help relieve mouth ulcers are listed. These suggestions are based on the experience of health professionals working with women diagnosed with cancer, and from women themselves.

Practical suggestions to help relieve mouth ulcers include:

- Use a solution of sodium bicarbonate as a mouth wash.
- Keeping your teeth clean may prevent infection from occurring. Use only a soft toothbrush to avoid aggravating your gums.
- An analgesic gel or mouth wash can help relieve the discomfort.
- See an oncology or community nurse for specific advice.

Lymphoedema

Lymphoedema is swelling in an area of the body due to the lymphatic vessels being blocked.

The lymphatic vessels are tiny vessels running from the limbs towards the heart, usually beside veins. They collect normal tissue fluid and dead cells.

Lymphoedema may be experienced, for example, in the arm if your lymph nodes in the armpit have been removed during breast surgery.

The **possible causes** of lymphoedema include:

- the cancer itself
- previous surgery or radiotherapy to the area

Lymphoedema may be permanent or temporary, and can range from very mild to severe.

Inform your doctor about any swelling that you experience, so that it can be evaluated and controlled.

Treatment of lymphoedema

Specially trained nurses, physiotherapists and occupational therapists are available to help women manage lymphoedema if it occurs.

Management of lymphoedema includes:

- wearing professionally fitted elastic garments
- massage by a trained therapist (and self-massage if the lymphoedema is mild)

- looking after your skin to prevent any infection
- drugs for pain relief if needed

If you develop an infection in the affected area, seek medical attention immediately to obtain antibiotics.

Obtain details about lymphoedema treatment facilities by telephoning the **Cancer Helpline** on 13 11 20.

Immobility or lack of ability to move normally

The possible causes of immobility include:

- muscle weakness (experienced by 57% of women with metastatic breast cancer)
- muscle wasting
- pain, especially bone pain
- problems in the nerves
- spinal cord compression: *See Chapter 9, page 72.*

Inform your doctor about any difficulty you have with movement, so that it can be assessed and controlled as best as possible.

Treatment of immobility

Treatment of immobility includes:

- treating the underlying cause, if appropriate
- physiotherapy to help strengthen muscle and increase mobility
- care to prevent pressure sores

- care for the bowel and bladder
- pain relief before any medical tests that involve movement

Distended (enlarged) abdomen

Some women with metastatic breast cancer may experience a distended abdomen.

The **possible causes** of a distended abdomen include:

- constipation
- cancer in the liver
- fluid in the abdominal cavity
- obstruction of the bowel from cancer
- inflammation of the bowel due to chemotherapy or radiotherapy

Inform your doctor if you experience a distended abdomen, so that it can be evaluated and controlled.

Treatment of distended abdomen

Treatment of distended abdomen includes:

- treating the underlying cause
- removal of any excess fluid in the abdomen
- treating constipation

Breathing difficulties

24% of women with metastatic breast cancer experience breathing difficulties. The symptoms may be very mild or may be severe.

The **possible causes** of breathing difficulties include:

- infection
- anaemia, low amount of red blood cells in the blood
- cancer in the lungs: *See Chapter 5, page 36.*
- fluid in the pleural cavity: *See Chapter 1, page 12.*
- fluid around the heart
- a rare side effect of radiotherapy
- a rare side effect of chemotherapy

Seek medical attention urgently if you suddenly experience breathing difficulties or a change in the severity of your symptoms.

Treatment of breathing difficulties

Treatment of breathing difficulties includes:

- treating the underlying cause
- treating any fluid you have on your lungs: *See Chapter 5, page 37.*
- oxygen is *usually not needed* in the treatment of breathing difficulties, but if it is it can be provided
- counselling or relaxation therapy for women who feel distressed by their breathing difficulty
- anti-depressant or anti-anxiety medication
- morphine or other opioid drugs

Headaches

Headaches may be mild or severe, experienced occasionally or more frequently.

The **possible causes** of headaches include:

- muscular tension
- exhaustion
- hypercalcaemia: *See page 107.*
- change in the acidity of the blood
- cancer in the brain

If the headache does not go away and gradually gets worse, see your doctor about investigating the cause of the headache.

Treatment of headache

Treatment of headache includes:

- treating the underlying cause
- pain relief: *See Chapter 13.*

A change in thinking ability

Confusion, disorientation, agitation, decreased concentration, change in behaviour and memory may occur in women with metastatic breast cancer, particularly in extensive disease.

The **possible causes** of a change in thinking ability include:

- anxiety and depression: *See Chapter 16, page 135.*
- infection

- medication
- cancer in the brain
- hypercalcaemia: *See page 36.*
- change in the acidity of the blood
- liver or kidney failure

Treatment of a change in thinking ability

Treatment of a change in thinking ability includes treating the underlying cause.

With the appropriate care, these symptoms are potentially reversible.

Seek medical attention if you or your family or friends notice changes in your memory or thinking ability.



Pressure sores

There is a risk of pressure sores developing if you are lying in bed or in any position for long periods. It is important to move around as much as possible. If you are bedridden your carers will need to move you frequently. Palliative care and community nurses can show your carers how to move you properly, if you are unable to do this yourself.

Incontinence

Some women may lose control over their bladder and bowels, although this is rare.

A community nurse can advise you on how to try to control incontinence, and how to make you feel more comfortable.

Seek medical attention urgently if you suddenly lose control over your bowel or bladder, as you may have compression of your spinal cord.

See Chapter 9, page 72.

Palliative care

“I thought that once you had palliative care you were going to die.

I didn’t realise that they could come in when you were in a crisis situation and then as you got better they went out.”

Palliative care includes care at home or in hospitals, hospices or palliative care units for people whose disease cannot be cured. Palliative care focuses not only on physical symptoms but on emotional well-being, relationships with others and spiritual needs.

Palliative care includes more than care for people who are dying. Any treatment that you have for metastatic breast cancer that helps reduce your symptoms and improves your quality of life, such as radiotherapy, chemotherapy and hormonal therapies, can also be called **palliative care**. See *Chapters 6-10*.

Also, **specialist palliative care services** are available for women with metastatic breast cancer in their home if they need extra support and information. **You do not have to be dying to access a specialist palliative care service.**

A specialist palliative care service can provide:

- information about drugs used for pain and symptom relief

- practical support about how to cope with your symptoms
- emotional support for yourself and your family/carers

A specialist palliative care service may involve a palliative care consultant, a palliative care nurse, a palliative care social worker/counsellor and palliative care volunteers. The team works with your specialist, general practitioner and community nurse to provide you with optimum care.

There are benefits in establishing contact with a specialist palliative care service, even while you are relatively well.

Establishing contact with a specialist palliative care service does not prohibit you from having treatments that your doctor recommends. Ask your general practitioner or specialist to refer you to a specialist palliative care service if you feel you would benefit by the extra support and information.

A member of the specialist palliative care team will visit you in your home, or if you are in a hospital, hospice or palliative care unit they can visit you there. They will assess your need for care by a specialist palliative care team.

There is evidence to show that specialist palliative care services improve:

- patient satisfaction with care
- patients being cared for in their place of choice
- family satisfaction and family anxiety
- control of pain and other symptoms

Palliative Care Australia is the national organisation for palliative care in Australia. For further information:

- visit their website at <http://www.pallcare.org.au>
- telephone the national office in the ACT on (02) 6232 4433.

For information about pain relief, see Chapter 13, page 91.

For information about controlling other symptoms, see Chapter 14, page 106.

For information about accommodation, hospice or respite care, see Chapter 18, page 161.

For information about death and dying, see Chapter 19, page 171.

Coping with your feelings & where to get more support information

The experience of being diagnosed with metastatic breast cancer is very personal. Each woman brings to her experience her past experiences, beliefs, strengths and own coping strategies.

Coping with your diagnosis is an ongoing adjustment process. It may be reassuring to know that other women are also experiencing some of the feelings you are experiencing.

There is evidence to show that expressing thoughts and feelings about a diagnosis of breast cancer and its meaning improves women's adjustment to the diagnosis and quality of life.

Throughout the difficult times you may also discover your strengths and weaknesses. You may deepen your relationships with others, or form new friendships and explore your spirituality. Although difficult, it may be a time of great learning.

"Anyway the test came back positive, it was definitely cancer in the liver, and of course I just burst into tears."

"I was fairly shocked, but then my belief is that you're not dying until the last minute. That you have to focus on living and getting the most out of life while you're here."

“In Greece, they never told you if you had the disease [cancer].”

“Although I have many friends and supporters, I am still the only one to go through this and to have the fears and the pain. I am the one who has to face each day with the knowledge that my days are numbered and keep on going.”

This chapter discusses:

- some of the feelings that you may experience
- the causes, symptoms and treatment of anxiety and depression
- deciding about whether to continue, change or stop working
- the impact of your diagnosis on your sexuality
- support services
- suggestions from women who have been diagnosed with metastatic breast cancer about how to cope with the diagnosis, treatment and illness

Your feelings

Many, if not most, women rate the diagnosis of a recurrence of breast cancer as more devastating than the original diagnosis.

Some of the feelings that you may experience include:

Shock

It is common to feel extremely shocked by a diagnosis of metastatic breast cancer. You may have a sense of disbelief or unreality, and an inability to experience what is really happening. You may feel like an outsider, looking at a scene. You may feel “this can’t be happening to me.”

Feeling a lack of control

When diagnosed with a cancer it is natural to feel that you are no longer in control of your body or your life.

Facing an uncertain future is extremely difficult to come to terms with.

Anger

It is natural at some stage for you to feel anger, rage, envy and resentment. You may feel “Why me? Why couldn’t it be her?” You may feel envy of all the ‘healthy’ people that you see and resent that you have to cope with this diagnosis. You may also feel angry with others, or angry with God. You may feel angry at the loss of control that you feel over your life.

You may also feel angry about your previous treatment for cancer and at your doctors involved in any previous treatment you may have had. You need to reassure yourself that you and your doctors made the best possible decision at the time. *See Chapter 2, page 14.*

You may also feel angry or frustrated about others in your life who you feel do not acknowledge the seriousness of your situation. You may also feel angry about the lack of support from a partner, family member or close friend.

“You just still feel it’s not fair. You feel cheated out of a few years of watching your grandchildren.”

“In the support group I could tell them what a bloody awful week it’s been, because for other people I have to be so positive.”

*“There are some things
I would rather be doing.
If my husband and I go
to the park I usually sit
on a seat while he
pushes the grandchildren
on the slide because
I get tired standing up.
But at least
I’m there, aren’t I.
At least I’m
still around.”*

*“It is important to do
the things that you
really want to do,
and leave the other
things to take care
of themselves.”*

Isolation and loneliness

At times you may feel alone or isolated. Although the intentions of others may be good, sometimes people may not know how to deal with the cancer and the emotions it may bring up for you. Your diagnosis may also be a reminder of their own mortality. This may be difficult for others to cope with.

You may feel people are avoiding you, or that they are pretending everything is fine and carrying on normally with their lives. At times you may feel pressure to act as though things are not serious, and people may tell you to ‘be positive’, which may make it hard for you to talk about the things that matter to you.

Bargaining

You may find yourself bargaining with God or the universe for an extension of your life or to allow you to fulfil a dream, if you ‘behave well’ or fulfil some other promise. You might promise, for example, ‘If I can live just to see my daughter married, I won’t ask for more’.

However, if you do live longer than you expect or are able to do what you have dreamed of doing you may feel guilty that you have not fulfilled your part in the bargain. If you find yourself feeling excessively guilty for a promise you have not kept, talk to your religious representative or a trained counselling specialist such as a trained counsellor, psychologist or psychiatrist.

Self-blame

Some women diagnosed with metastatic breast cancer feel that they have somehow caused their illness or are being punished for something they have done wrong. You may feel ‘Where did I go wrong?’ or ‘What have I done to deserve this?’

Some women may feel that they are a failure because they are having a recurrence of cancer.

This perception may be heightened by the media attention on women who have ‘beaten’ breast cancer.

However, developing primary or metastatic breast cancer is not within your control. There is nothing you have done to have caused this situation.

There is no evidence that stress can make your cancer come back.

Feeling like just a number

Some women diagnosed with metastatic breast cancer may feel that they are just another number in the clinic. The many medical tests and treatments may make you feel that you are seen as a cancer, rather than as a woman with a medical problem.

At times you may feel that your oncologist or surgeon is not really aware of you as a whole person, and is just focused on your physical cancer.

Although some doctors may pick up on your concerns, others will need you to tell them directly. If you do not feel that this sorts things out, you may

“OK, I know what the situation is. It’s not going to beat me. I’m going to beat it. And I’m going to enjoy myself in the process.”

“In our community cancer is taboo, no-one talks about cancer at all.”

“Within the next two years I’d like to do some more travel, and then I’ve begun seriously thinking about doing a psychology course or a counselling course. And maybe helping other people with cancer.”

“I think I felt for the whole of this year that I was living as though I was expecting to die. I wasn’t doing a lot of things. And I realised that’s ridiculous.”

consider whether you would like another doctor to treat you. See *Chapter 4, Page 29* for information about getting a second opinion.

Some women find that bringing a friend or family member to appointments helps.

Guilt

You may feel guilty if you have to depend on others to do practical things, such as help you with household chores, or care for you or your children. It may be difficult to ask for what you need, although asking for help can give you more energy for things that you want to do.

Search for meaning

A diagnosis of cancer often leads people to asking questions about meaning in life, such as ‘Am I living my life the way I want to?’, ‘What is the meaning of life?’, ‘Does God exist?’, ‘Is there life after death?’ and ‘Why should I and the people I love suffer?’ Some people who are religious may find their faith shaken by their diagnosis.

It may be helpful to talk about some of your concerns with a counsellor, psychologist or psychiatrist; or with a priest or other religious representative.

Depression, sadness and grief

It is common to experience sadness, grief or some level of depression. These are not signs of weakness but are common reactions to experiencing tremendous loss. Such loss could include losing part of your body such as your breast, being ill, experiencing financial hardship, changes in relationships and losses associated with your change in circumstances.

Working through loss is an ongoing process. Allow yourself the opportunity to experience your grief and sadness. This is an important part of the process of coping with the cancer. Over time, most women find the distress lessens. However for some women, the sadness is more severe and long-lasting, and *specific treatment may be needed, as discussed on page 139.*

Physical causes of depression

Besides the emotional response to a diagnosis of metastatic breast cancer, its treatment and the effects of illness, there are also physical causes of depression, including:

- cancer in the brain
- change in chemicals in the blood
- chemotherapy treatment
- steroids

“Quite often I go along to the support group feeling very sorry for myself, and I listen to someone else’s story and I think what have I got to be worried about? At least I am this and this.”

“Some people think that the doctor knows everything, and that they have no control over their illness. I think if you have an element of control you’ve got more of a chance of getting better. Or having a better quality of life for that time that you do live.”

Symptoms of depression

Below are some questions that you can answer that may be clues to depression:

- Have you lost interest and pleasure in activities or work?
- Do you often feel a sense of hopelessness?
- Do you often feel guilty?
- Do you often feel a sense of worthlessness?
- Are you often tearful?
- Is it harder for you to laugh and see the funny side of things?
- Do you often get upset?
- Do you have difficulty sleeping?
- Do you feel less interest in seeing family or friends?
- Do you feel less motivated to organise activities or to be involved in regular daily activities?
- Do you feel down a lot?
- Do you feel overwhelmed by your feelings and feel you are unable to control them?
- Sometimes when things seem hopeless it can feel too hard to keep going on. Do you ever feel like that? Would you describe any of these feelings as suicidal?

If you are experiencing any sadness, grief or depression that feels overwhelming, it is important that you talk to your doctor as soon as possible.

See page 139 for how depression is treated.

Fear and anxiety

Women with metastatic breast cancer face many fears as they try to come to terms with their diagnosis. Feeling anxious or fearful is not a sign of weakness but is a common reaction to a very distressing situation.

Anxiety may be due to fear about:

- the unknown
- any ache or pain you experience
- being dependent on others
- not being able to cope
- changes in your relationships with family and friends
- being abandoned by family and friends
- how family or friends will cope
- death and dying
- the future of a partner or children
- loss of a job
- financial strain
- medical tests such as CT scans or MRI scans
- waiting for test results
- specific fears or phobias which existed before the diagnosis, but which are increased by it

“I think in many ways it has been a kind disease, I have gained so much from it. I have met many friends.”

*“My doctor said that
‘a lot of women are
living with these cancers
for quite a long time.’”*

Physical causes of anxiety

Besides the emotional response to a diagnosis of metastatic breast cancer, its treatment and the effects of illness, be aware there are other physical causes of anxiety, including:

- uncontrolled pain
- drugs such as steroids
- any other illness you have, such as thyroid disease
- withdrawal from benzodiazepines (used to treat anxiety) and alcohol

Symptoms of anxiety

Here are some questions that you can answer that are clues to anxiety:

- Do you frequently have worrying thoughts?
- Do worrying thoughts interfere with your daily life or relationships?
- Do you often feel tense and find it difficult to relax?
- Do you often feel irritable?
- Do you have difficulty concentrating?
- Do you often feel angry?
- Do you have difficulty sleeping?
- Do you get sudden feelings of panic?
Or do you experience panic attacks accompanied by a feeling of dread, by difficulty breathing or by fear of dying?

*“That’s the way
I think now.
I think that quality
of life is
number one.”*

- Have you developed phobias – eg intense fear of needles, intense fear of closed spaces, intense fear of social situations – or have your phobias become worse?
- Do you often avoid distressing issues and situations?

If you are experiencing any anxiety or fear that feels overwhelming, it is important that you talk to your doctor as soon as possible. See below for how anxiety is treated.

Depression and anxiety are common in people with cancer.

Treatment of anxiety and depression

Treatment of anxiety and depression includes:

- **treating the underlying cause**
- **counselling, support and education**

This may involve discussions with a **counsellor, general practitioner, breast nurse, psychologist or psychiatrist** about your feelings and concerns. See page 145 for details about support services.

There is evidence to show that:

- **supportive group counselling increases the number of women who are alive 10 years after their diagnosis**

"I have three grandchildren and another on the way. I hope to have a few more of those and hope to live long enough to see them, that's my main aim at the moment."

"I don't always want people to be here all day, anyway. I'd rather be left alone some of the time."

- appropriate counselling should be offered to women experiencing anxiety and depression, as it reduces their symptoms
- group therapy can increase self-esteem and reduce anxiety, depression and anger
- education sessions can improve adjustment, knowledge, death awareness and self-concept for women newly diagnosed with metastatic breast cancer

- **muscle relaxation therapy and imagery**

Techniques for relaxing the whole body are taught in relaxation, meditation and yoga classes, and in some support groups. Audio-tapes are also available to help you relax. Ask your general practitioner or breast nurse about where classes and/or audio-tapes are available.

There is evidence to show that muscle relaxation and imagery can reduce stress in mild anxiety.

- **anti-depressants or anti-anxiety medication**

Medication can be extremely valuable and may help you get through difficult times. A lot of women diagnosed with metastatic breast cancer need to take anti-depressant or anti-anxiety medication for a period of time.

There is evidence to show that most people with cancer who are depressed and are given anti-depressants benefit from them without significant side effects.

Most women find that they are much better able to cope with their physical symptoms when their depression or anxiety is effectively treated.

Talk to your doctor about any side effects you may experience from taking anti-depressant or anti-anxiety medication.

Deciding about whether to continue, change or stop any paid work

Some women who are feeling well and are employed at the time of their diagnosis find that continuing to work after their diagnosis is helpful. For these women, continuing to work makes them feel valued and provides them with the comfort of being around people they are familiar with.

Other women who are employed at the time of their diagnosis want to make changes in their work life. They may stop work so that they can have more time to enjoy the things they have always wanted to do, they may change jobs, work part-time, work flexible hours or do volunteer work.

Deciding about whether to continue working will depend on your health, your financial situation and

“The oncology nurses are very good.

When I was in hospital they were very good, very thoughtful.

A few times I've got a bit upset and they'd all come in and sit with me, you know, they were great.”

{from partner}

*“To me it didn’t change
who Joanne was,
the fact that she only
had one breast.
It didn’t change the
woman I loved.”*

*“I have suffered a loss
of libido and have
vaginal dryness.
I am happily married
and there are always
practical ways around
any problem.”*

{from partner}

*“If your wife is sick,
if she’s not feeling well,
sex is the last thing on
your mind.”*

your priorities. If you feel you need more support, other than from your family and friends, in making decisions about work talk to your doctor or ask your doctor for a referral to a health professional who is experienced in counselling.

The impact of your diagnosis and treatment on your sexuality

The physical changes of having metastatic breast cancer and its treatments often have a profound impact on how women feel about themselves and their attractiveness, whether they have a partner or not.

The changes to your body, your level of energy and your mood will affect how you feel about yourself, your sexual desire and your ability to be sexual with others. Coping with these changes will involve an ongoing adjustment process as your situation changes.

The sexual difficulties that you may experience include:

- feeling less attractive because of hair loss, breast surgery, other treatments, and illness
- lower libido due to feeling unwell, worried, being in pain, having cancer treatment or taking medication such as tamoxifen
- vaginal dryness due to chemotherapy or medication such as tamoxifen
- difficulty being physically active due to pain or disability

Things you can do if you have a partner

The suggestions below are based on the experiences of health professionals working with women with metastatic breast cancer, and from women themselves.

- Although it may be difficult, it is important to communicate with your partner about your respective fears and needs. This may help you find creative ways to adapt to your situation and help you feel closer to one another.
- If sexual intercourse is difficult or not what you feel you want to do, explore being sexual in other ways.
- Use a water based lubricant for vaginal dryness.
- Increase the affection in your relationship, for example by holding hands, back rubs and cuddling.
- Seek help or advice from a counsellor, psychologist, psychiatrist, breast nurse or doctor. If your health professional is unable to help you arrange for a referral, the *Cancer Helpline* on **13 11 20** may be able to provide information about health professionals who specialise in this area.

{from partner}

"The sex thing, it comes down to between the couple, there's no real rules."

"Sometimes I'm happy here just at home pottering around, spending time with my family and doing my own thing."

"You've got to rely on your resources to a certain extent."

*“I’ve sort of reconciled
with it now I suppose,
but it’s funny – you
never really think it’s
going to be you.”*

*“Most of the time
I feel really positive
and happy,
but I’ll go through
big downers too.”*

Things you can do to improve your body image and feelings of well-being

The suggestions below are based on the experiences of health professionals working with women with metastatic breast cancer, and from women themselves.

- Gentle physical exercise such as swimming, yoga or walking may improve your well-being.
- A massage by a friend or professional massage therapist may help you to feel relaxed and nurtured.
- A hot bath with aromatherapy oils may help you feel relaxed.
- Eating well may improve your energy.
- Asking those close to you for a hug, if you feel that this is appropriate, may increase the physical contact in your life.

Lesbian women

Sometimes lesbian women who are diagnosed with metastatic breast cancer and their partners may feel that their needs are not being addressed by health professionals.

You may feel that a lot of attention is placed on heterosexual couples. Or you may feel that lesbian sexuality is not mentioned when talking about the effect of the diagnosis on sexuality. Some partners may also feel invisible, or even feel discriminated against.

You may decide that you would like another doctor or health professional to be involved in your treatment – someone that you feel more comfortable with.

You do not need to disclose your sexuality to your treatment team. However, if you feel comfortable with your treatment team, disclosure may help you feel more supported.

Contact your local women's health centre, which may be able to refer you to any appropriate support services.

Support for women diagnosed with metastatic breast cancer

Apart from support from a partner, your family and friends, church/religious community, social or sports clubs and your doctor, the following support is available:

- ***Cancer Helpline***

Contact the **Cancer Helpline** on **13 11 20**.

The Cancer Helpline provides telephone and written information about cancer and related issues. Each call is confidential and remains anonymous.

- ***Support groups***

Support groups are regular meetings for people to talk about their experiences and share their concerns and fears with other women in similar circumstances.

“In the support group they're just such wonderful women. At least I can cry – I didn't cry for thirty years of my life.”

“It's good to hear other women's stories, to have a variety of people's attitudes, because there could be one where you think, 'Yeah, that's how I feel, I can relate to that'.”

“The illness really is a message to slow down and do something for yourself.”

Support groups may be run by health professionals or by women diagnosed with cancer, called **self-help groups**.

Some support groups are for women with metastatic breast cancer, others are for women with early breast cancer, others are for people with any type of cancer and some are for family and friends of women with breast cancer.

There is evidence to show that:

- **Supportive group counselling increases the number of women who are alive 10 years after their diagnosis.**
- **Group support reduces distress in women with breast cancer.**
- **Group support is more effective in reducing distress if women are involved in the group for a long period of time and the group is run by a more highly trained therapist.**

To find out about support groups in your area contact:

- the Cancer Helpline on 13 11 20
- your doctor
- your local hospital
- your local community health centre
- your specialist palliative care team:

See Chapter 15, page 126.

You may also like to talk to other women who are in a similar situation via “chat” groups on the Internet. You can access the Internet via your local library.

- *The Breast Cancer Network Australia*

The Breast Cancer Network Australia (BCNA) produces a free quarterly newsletter, *The Beacon*, which often includes stories written by women with metastatic breast cancer. The BCNA telephone number is (03) 9805 2500 and its website address is: <http://www.bcna.org.au>

- *Professional counselling*

A counsellor, general practitioner, psychologist or psychiatrist can help clarify some of your feelings and help you cope with your diagnosis. Ask your doctor to refer you. The **Cancer Helpline** on **13 11 20** may also be able to give you information about health professionals who are experienced in counselling people with cancer.

There is evidence to show that counselling and social support decrease anxiety and depression, improve coping, and improve physical symptoms.

“Everyone is their own worst critic. Be kinder to yourself in every way. Nobody’s perfect.”

Suggestions from women who are living with metastatic breast cancer about coping with the diagnosis



There are no easy answers when it comes to facing a life threatening illness. Every person finds their own way to cope as best as they can.

Here are some suggestions from women who are living with metastatic breast cancer about coping with cancer. You may find some suggestions helpful. Some suggestions may not be appropriate for you, and some suggestions can be difficult in practice.

Some suggestions include:

- *Maintain hope. Some of your hopes may include that you will be cured, that a new effective treatment will be found, that you will live much longer than expected, that you will be made comfortable, that you will be supported by family, friends or your medical team, that you will be able to talk to someone about your innermost concerns and experiences, that you will always be involved in any major medical decisions, or that you may live to participate in a major event.*
- *Find what gives you greatest meaning and joy in your life - for example, time with friends or family, music, nature, seeing movies - and pursue these activities. Have something planned each week that you can look forward to.*

- *Continue to set small goals that you want to achieve in the next few weeks or months, such as attending a wedding or having a holiday with your children, and then when this is achieved set new goals that you can look forward to.*
- *Conserve your strength for the activities you want to pursue.*
- *Live in the present as much as possible. The past cannot be undone and the future is unknown, and many of our fears might not happen.*
- *Keep focusing on life rather than on the thought of dying. You are living until you die.*
- *See your illness as a challenge.*
- *Recognise that you have control over how you react to situations, even if you cannot control what happens to you.*
- *Find ways to be grateful for your past and present experiences.*
- *Use humour as much as possible to lighten your situation.*
- *Gentle exercise, appropriate to your situation, can reduce your stress levels and help your body be as healthy as possible.*
- *Learn to accept your negative feelings such as anger, sadness and resentment. This may help them to pass.*
- *Remind yourself that everything is changing and that any feeling or pain will change, too.*

“I’m probably happier than I’ve been in all my life, which is amazing really. I’m happier with myself. I’m learning to like myself more.”

“I think humour is very important.”

- *Seek a deeper contact with others to make you feel less alone and to add more meaning to your life.*
- *Seek a deeper spiritual connection. This may be with God, or it may be a connection to the natural world.*
- *Maintain a sense of control over the choices you have by being involved in decisions about your care and by seeking as much information as you need.*
- *During the bad times try to remember the good moments and remind yourself that there will be good times ahead.*
- *Express your needs with friends and family and your treatment team. Let others help you. Let others know what they can do for you and what you can do for yourself.*
- *Try not to isolate yourself from family and friends. Make appointments to see friends, particularly if you are feeling down or anxious.*
- *Learn to unwind and relax. Find a good relaxation tape.*
- *Keep a journal about your experiences to help you understand and express your feelings.*
- *Help someone else. This may take the focus away from your situation and give you and others fulfilment.*
- *Be involved in breast cancer support groups and newsletters. This may help you feel that through your experiences you are helping other women in a similar situation.*

Dealing with the impact of the cancer on your family and friends

A diagnosis of metastatic breast cancer will greatly affect others in your life such as a partner, your family, and close friends.

Every person is different and will have their own way of coping with this difficult situation.

Women often worry about the burden of their illness on their family and friends.

The diagnosis of metastatic breast cancer highlights the strengths and problems within your relationships with your family, a partner and close friends. It can be a time of great stress and change. Some relationships or friendships may break up, while others may grow and be deepened by the experience.

Many women and their partners, family and close friends report that being close to a woman diagnosed with metastatic breast cancer has increased the meaning, depth and mutual respect of their relationships.

"I appreciate my friends more. You realise how precious everything is."

"Everyone has been extremely helpful."

"My husband's not the easiest person to talk to. He doesn't show his emotions. I know he's upset."

“It [the cancer] has brought us together [as a family]. It has bound us as a family.”

“I’d like to be able to be fit as long as my mother is about. That worries me.”

For your family, partners or friends, coping with your diagnosis is an ongoing adjustment process.

This chapter discusses:

- some of the feelings your family, partners or close friends may have about your diagnosis of metastatic breast cancer
- ways to help you and your family, partner or close friends cope with your diagnosis
- living alone or being isolated from others
- if you have children, the affect of your diagnosis on them

This chapter is based on the experiences of women diagnosed with metastatic breast cancer, their partners, family and friends; and on the experiences of health professionals caring for women with metastatic breast cancer.

Feelings your partner, family or close friends may have about your diagnosis

Some of the feelings that a partner, your family and close friends may have after your diagnosis, as experienced by others in a similar situation, include:

- *shock*

People close to you may be extremely shocked by your diagnosis and unable to accept that you have a serious cancer.

- *feeling powerless*

People close to you may feel powerless because they are not able to change your circumstances. They may not know what to do or say.

- *sadness and depression*

People close to you may feel sad or depressed because of your distress and pain, your change in circumstances and the possibility of you dying. They may feel sad that some of the shared dreams and experiences may now not be possible.

- *fear and anxiety*

People close to you may feel fearful and anxious about the future, about how sick you may be and the possibility of you dying. They may feel anxious while waiting for your test results, feel worried about upsetting you by talking about the cancer, and feel anxious about financial strain.

- *anger and resentment*

People close to you may feel angry at the injustice of your situation. They may be angry at the possibility of you 'leaving them' and feel resentment because of the increased work, such as doing more household chores, or being involved in childcare, and the increased financial responsibility.

"My partner had been very concerned and very supportive. He comes from another culture, which is less into acknowledging the gravity of the situation to the patient. So he tends to be, sometimes annoyingly, positive."

"It has had very minimal impact on me and it has had quite a devastating impact on my husband. He actually saw a psychologist or psychiatrist."

“One of my daughters-in-law is pretty good but they’re so busy you know, they’ve got kids in day care and they’re all working.”

“I really don’t tell the children any gloom and doom things, I really try to keep it fairly up but they know I can’t do as much as I used to do.”

“I just think they [my family] aren’t coping well. They need help or to talk to a counsellor. They’re not good at saying what they feel or visiting hospitals or things like that.”

- **guilt**

People close to you may feel guilty that they are not doing enough, feel guilty when they are tired or irritable and not cheerful, and feel guilty about carrying on normal social or work activities rather than spending more time with you.

- **feeling closer to you**

People close to you may feel closer to you and appreciate that they can be of some comfort and support to you.

Ways to help you and your partner, family, or close friends cope with your diagnosis

Everyone is different in the way they cope with your diagnosis and the way they are able to give support. Some people may be better at giving emotional support, while other people are more comfortable giving practical support.

Adjusting to role changes can cause upheavals in the way family members interact. It can also affect your friendships. Being close to someone with a serious illness is a process of adjustment.

Good communication between yourself and others is essential in adjusting to your changing circumstances and resolving any problems.

Some suggestions from health professionals and other women diagnosed with metastatic breast

cancer, to help you and your partner, family and friends cope include:

- Think of your family, a partner if you have one and close friends as a **support team**. Try not to rely on just one or two members. The more people that share the support the better the support will be. Choose the individuals that are best able to meet your different needs.
- **Communicate** with a partner, family members and close friends about your respective needs and concerns.
- **Involve a family member, a close friend or a partner, who you feel is supportive, in discussions with your doctor** or other members of your treatment team.
- **Encourage your family, a partner or close friends to have time away from you**, involved in pleasurable activities with friends or family. They need to meet their own needs, otherwise they will have less energy to be supportive to you.
- **Talk with your doctor if you are concerned about any of your relationships**. Your doctor may be able to talk with a family member, partner or close friend during your next consultation, or a separate appointment can be made to discuss any issues of concern.
- **Prioritise enjoyable time together**, for example by going to the movies or by reading together, depending on your level of energy.

“Last year my husband was due to go to Japan with the Scouts and he said, ‘I’m not going,’ and I said ‘Don’t be ridiculous, of course you’re going’.”

“I know a lot of people say that they don’t see their friends again. They don’t visit as much, they drop off but everyone comes to start with.”

*“But I do find
with one friend,
that if you
mention cancer,
you don’t get
an answer.
There’s a
dead silence.”*

*“I don’t think people
realise what it’s like to
live by yourself and
have to do every single
thing yourself,
even though I’m
pretty capable.”*

*“Lacking a partner has
never worried me up
until this point,
but I suppose it would
be nice to have
someone to really
share with.”*

An audiotape is available from the iSource National Breast Cancer Centre, *When the woman you love has advanced breast cancer*. It includes interviews with the partners of women diagnosed with metastatic breast cancer.

Support services for partners, families and friends of women diagnosed with metastatic breast cancer

Some support services include:

- the *Cancer Helpline* on 13 11 20
- counselling from a counsellor, breast nurse, general practitioner, psychologist or psychiatrist: *See Chapter 16, page 145.*
- support groups for family and friends of people with cancer: *See Chapter 16, page 145.*
- practical and financial support: *See Chapter 18 and Chapter 20.*

Living alone or being isolated from others

Women who live alone, do not have family or friends close by or do not have a partner may find coping especially difficult.

If you are in this situation, try to develop a support network. Support may be obtained from your general practitioner, religious organisations, social clubs, support groups, or a trained counselling specialist such as a trained counsellor, psychologist or psychiatrist. This may make you feel less isolated and allow you to express your feelings and concerns.

For information about practical support, see Chapter 18, page 161.

Talking with young children/grandchildren about your diagnosis

Children will be affected by their mother being diagnosed with metastatic breast cancer.

They usually know that something is wrong without you even telling them.

It is important that you talk to your children about your situation.

Children need to understand what is going on. They may be more upset by what they imagine to be happening rather than the reality. If they are not told they may feel isolated or not important enough.

Children are often concerned about changes in the family and are worried that the well parent may get sick too. Children may also worry that they have caused your illness.

Children may have a range of responses to your diagnosis – such as, being angry at you for being sick, withdrawing from you, clinging to you, resenting that they need to help you, behaving badly to cover up real feelings, wanting to get sick to get attention, going through the stages of grief you are going through, and being afraid that they will get cancer too.

“It is really hard to say how my daughters are coping because you can’t always tell on the surface. I mean they can be lovely on the surface and in torment underneath.”

“I told the children one at a time. Our oldest boy didn’t know where to look or what to say. Our youngest boy said ‘Oh yeah, okay,’ because I wasn’t sick.”

Some suggestions from health professionals and women diagnosed with metastatic breast cancer to help children cope include:

- **Answer children's questions** as honestly as possible in words they can understand. Correct any misinformation and tell them when you 'don't know'.
- **Reassure them that they did not cause the cancer**, as children often think this way.
- **Don't make promises they you are not able to keep.**
- **Give them as much support as you can.** A relative, friend or teacher may be able to give them extra support.
- **Do special things with your children**, depending on your level of energy, such as watching TV, singing together or playing cards.
- **Keep a daily routine if possible.** Outside practical help is available. *See Chapter 18, page 161.*
- **Deal with each child individually.**
- **Help your children feel that they are part of what is happening** by encouraging them to take on extra responsibilities, such as bringing you your medicines or deciding what time to visit you if you are in hospital.
- **If you are worried about your children you can ask your doctor** to refer them to a trained counselling specialist such as a trained counsellor,

{from partner}

"A few of the younger fellows at the support group had kids and they were still working and they had careers. They had the problem of trying to do their job, come home and then make meals, and they had kids, mortgages to pay."

{from partner}

"Sometimes, strangely enough, newer friends have been there for me. Some older friends haven't coped so well."

psychologist or psychiatrist, or the whole family can see a family therapist.

- **The school counsellor** should be notified and can become an important support person for your children.
- You may also want to explain to the **school teachers** about what is happening.

Talking with teenage children about your diagnosis

Teenagers may feel particularly vulnerable as they try to cope with their own problems and with the situation of the cancer. Daughters may also worry whether they will also get breast cancer. It may be difficult for teenage sons to talk about these issues.

Teenage daughters and sons may need to take on more household chores or care for you. Disruption to their social outings or leisure activities can be issues for them. Sometimes this can make them feel that their needs are not being met.

Teenagers may have an intense desire for life to return to 'normal' and may feel resentful at the disruption to their lives and the change of roles within the family.

Teenagers find difficulty in coping with the cancer because they are trying to develop their own identity and become independent of their parents. Although teenagers may need to take on more household responsibilities, they also need to be encouraged in

{from partner}
"Some friends cope well, and others... they don't know what to say."

{from partner}
"Things change and you can't really go back to the way you were before. It's a little like a rollercoaster, it stops and you get off, you go for a walk in the woods, and then you have to get back on again."

"My daughter tends to ignore the fact that she's not going to have a mother sometime in the future, and she won't talk about it."

{from partner}

*“On that Tuesday night
we were both very
upset, and it was the
first time that Jo had
actually cried with me.
I’ve done a lot of crying
privately that she didn’t
know about. We cried
together and one of the
nurses brought in
a counsellor.”*

*“It is very difficult to
know with teenagers
how much they want
to talk about things
and how much
they don’t.*

*And boys particularly
tend not to be
great talkers.”*

*“I think it’s probably
more threatening to my
daughter, who wonders
whether all of this is in
store for her as well.”*

gaining a sense of independence apart from the family.

Some of the issues teenagers face at this time include wanting to be closer to you, dealing with unresolved issues with you that they may have, fear about whether your treatment will be effective, anxiety about the well parent, feeling isolated from friends, feeling stigmatised because their mother has breast cancer, worrying about the effect of the cancer on your marriage and the stability of the family, and concern about their relationship with the other parent.

Encourage them to communicate honestly about their needs and about their feelings. It is important that they are allowed to talk about death and their feelings of loss and resentment. If they cannot talk to you there may be a relative or friend with whom they can let out their feelings.

It can be a difficult experience dealing with the changes in family and marital relationships. As problems arise, open communication between family members can help in the adjustment and resolution of difficulties.

If you are worried about how your teenage children are coping you can ask your doctor to refer them to a counsellor, general practitioner, psychologist or psychiatrist, or the whole family can see a family therapist. *See Chapter 16, page 145.*

Practical support

If you are recovering from treatment, or the cancer progresses, you may no longer be able to do all the things you would usually do in your home.

It can be difficult to accept the loss of some of your independence and to have people look after you.

Family, friends, partners or neighbours may be able to give practical support. Although it is sometimes difficult to accept this support, remember that others may feel good if they can help.

Accepting help can allow you to conserve your energy for things that are really important to you.

As well as practical support from family, friends, partners or neighbours, **outside help is available.** Accepting outside help can put less strain on family and friends and allow you to spend more pleasurable time with those close to you.

“I’ve made changes such as the whole family doing the shopping together on Saturday morning, rather than me having to lug it in and out of the car.”

“I’m learning to accept help a bit. I was terribly terribly proud. And I think part of that is learning to know that you deserve help.”

This chapter discusses:

- the different forms of outside help that you may need, including accommodation while undergoing treatment
- home care services
- care for you outside your home, including day centres, nursing homes, hospitals and hospices

The **Cancer Helpline** on **13 11 20** can provide you with more details about the support services available to you.

Remember, the sooner you ask for help for whatever type of care, the easier and quicker it will be to organise and receive it.

Accommodation while undergoing treatment

If you need to have treatment such as surgery or radiotherapy in a centre or hospital that is far from where you live, accommodation is sometimes available for a minimal fee for patients and their families. To find out about accommodation while undergoing treatment, phone the **Cancer Helpline** on **13 11 20** or the hospital social worker.

Care for you at home

Help is available for you in your home from a number of different people and organisations. A variety of services are available, including:

- home help with cleaning, washing, cooking and shopping

- nursing care
- palliative care and pain management
- physiotherapy
- occupational therapy
- counselling

Listed below are some of the people and organisations that may be involved in your care at home, if you need it:

- **your general practitioner**

Your general practitioner may be responsible for your care. He or she will assess your need for nursing and medical care and arrange the necessary help such as domestic help, bringing meals to your home and other support services available in your area.

The support services available to you will depend on the State and the region or town in which you live.

- **social worker**

If you are in hospital having treatment, a social worker, discharge planner or community liaison nurse will assess your need for care at home. They can inform you about the support services available in your area. They can make the necessary arrangements for care for you at home.



- **community nurses**

Your general practitioner, social worker or hospital discharge planner may suggest that a community nurse visit you in your home and assess your need for nursing care. You can also arrange to see a community nurse by contacting your community health centre and your local council.

The community nurse works together with your general practitioner, palliative care nurse and you to give you optimum care.

Regular visits can be arranged according to your needs and will change as your needs do.

Visits may be daily, weekly or monthly, depending on your needs. The community nurse will assess your needs regularly.

Community nurses offer a variety of practical services, such as assistance with bathing, changing dressings, giving medication and providing support to you and your carers.

You may choose to contact the community nurses *before* any nursing help is needed. The community nurse can give emotional support to you and your family, help discuss treatment decisions with you, and inform you about services available in your area.

- **breast care nurse**

Breast care nurses are available in some hospitals. A breast care nurse can provide you with valuable information and support.

- **occupational therapist**

Your community nurse or general practitioner can arrange for an occupational therapist to see you in your home. The occupational therapist can assist in providing practical aids to assist you being self-caring.

After an initial assessment, she or he will be able to arrange for you to get aids such as walking frames, shower chairs or wheelchairs. They can also arrange for minor changes to your home, such as door widening or fixing of handrails in bathrooms. If you are having difficulty dressing they may be able to suggest and arrange alterations to clothing.

- **physiotherapist**

Your community nurse or general practitioner can arrange a physiotherapist to see you in your home. She or he can help you keep mobile and help you with pain relief, specific treatments, massage and exercise programs.

- **palliative care team**

Your community nurse, general practitioner or cancer specialist can arrange for you to be assessed and have ongoing care by a palliative care team.

“They [the occupational therapist] arranged a bathroom stool for me and a few other things.”

“The palliative care team were very friendly and very helpful. They explained to me it wasn’t just for people who were dying. It was more pain relief.”

A palliative care team may involve a palliative care consultant, a palliative care nurse and palliative care volunteers. The team works with your specialist, general practitioner and community nurse to provide optimum care.

A palliative care team can help you with control of pain and other symptoms you may have, and give emotional support to you and your family or carers.

Your need for palliative care can be assessed in your home, hospital or palliative care unit.

See Chapter 15, page 126 for more information about palliative care.

- **private nursing agencies**

If you can afford private nursing it is available as a 24-hour service in some areas. Private nursing can be supplied immediately for one to 24 hours a day. They will cover all your nursing needs and may include meals, laundry, housework, shopping and transport. They can also offer any carer **respite care** (a break away from caring) either during the day or for longer periods. Private nurses can be used to provide extra support at night if required.

Like community nurses, private nurses will also work with your general practitioner and palliative care team to manage your treatment, pain relief and other aspects of your life.

It is possible to have a community nurse visit you during daytime hours and a private nurse visit you after hours.

- **home care service/domiciliary care services**

Home care or domiciliary care services can provide practical help in your home.

They can provide:

- basic domestic help, such as cleaning, laundry, shopping and cooking
- personal care, such as bathing, personal hygiene, eating and dressing
- respite care for your carers, involving hourly breaks or up to a week's break
- (sometimes) essential home and yard upkeep

Because of funding constraints, you may be placed on a waiting list. The greater your need, the sooner you will receive help.

The cost of the service is adjusted according to your ability to pay.

Staff who speak languages other than English are also available.

- **private home care services**

Private home care services are also available, providing assistance with shopping, washing and cleaning.

- **Meals-on-Wheels**

Meals-on-Wheels will deliver meals to housebound people for a minimal charge. You can contact them directly, but you need a referral from your general practitioner, social worker or community nurse. The meals are available Monday to Friday.

- **church or other religious groups**

Some church or other religious groups will offer support to their members, such as going shopping for you. Contact your local group, if you belong to one, to find out if any such help is available.

- **volunteer respite carers**

Volunteer carers can come and visit you for a set time each week or fortnight to give your carer a break. They may visit for between half an hour to a few hours to chat, help with letter-writing, phone calls, reading or just to be there.

To find out about volunteer respite carers, contact your local community or neighbourhood centre.

Care for you outside your home

If your illness progresses, you may feel that you need to be looked after outside your home, such as in a hospital, hospice or palliative care unit. Or you may go into care for a short period in order to give your carers a break. This is called **respite care**.

Below is a list of services available to give you care outside your home.

- **day centres**

Day centres, often attached to nursing homes, hospitals or hospices, are available to give your carers a break. These centres are open during the day and often have transport to pick you up and return you home. They offer specialist care in nursing, leisure activities, symptom control, counselling and an opportunity for social interaction. Ask your general practitioner or community nurse about these centres.

- **nursing homes**

Some nursing homes can offer short-term accommodation, and sometimes long stay care, to give your carers a break. Your general practitioner, community nurse or social worker can arrange this for you. Nursing homes will charge a fee.

- **hospitals**

Public hospitals and private hospitals have beds available for short- or long-term care. Access to public hospitals will depend on beds being available at the time and your level of need.

- **hospices/palliative care units**

Hospices or palliative care units are places that specialise in the care of people living and dying with cancer. They focus on controlling pain and other symptoms, and on improving each person's quality of life.

Not everyone goes into a hospice or palliative care unit to die. People often go into hospices for short periods in order to help their symptoms, or to give their carers a break.

Hospices are smaller than hospitals. Palliative care units may be wards in a local hospital. Some hospices also have accommodation available for relatives. They are usually attractive and comfortable, with staff that are qualified in giving emotional, medical and physical support to people with metastatic breast cancer.

Some hospices are public, some are funded by charities and some are attached to private hospitals. They do not generally have waiting lists.

You can be referred to a hospice or a palliative care unit by your palliative care team, social worker, community nurse or general practitioner.

Putting your affairs in order

Reading this chapter does not mean that you are dying. However, this chapter may be difficult for you to read. Please read this chapter when you feel you are able.

Facing the possibility of death is painful. Contemplating one's own death and dying may create anxiety, depression, fear or a deep sense of loss.

It is normal to feel that you do not want to think about your own death. However, thinking and talking to others about death and dying will not hasten your death or affect your fighting spirit. There is no evidence that being upset will worsen your prognosis. In fact, there is evidence that expressing your feelings can help you adjust to your diagnosis and improve your quality of life.

Planning for your death, whenever it may be, can bring a sense of relief and leave you free to focus on life. Awareness of the inevitability of death for us all can help focus us on living more fully in the present.

"I felt very privileged and pleased to be able to fulfil her last wish of looking after her at home and letting her die peacefully in our bed."

“I hope my family can accept it even if I die, you see I don’t believe that death is everything, and that’s been a great help.”

“I’ve got a prayer group praying for me, which is really nice.”

You may find that thinking about death and planning for your death can be overwhelming. **It is important that you do this when you feel the time is right for you.**

This chapter discusses:

- unfinished business with family and friends
- spiritual or religious comfort
- ways to cope with the ‘no more cancer treatment’ decision
- fears you may have about the process of dying
- the practical aspects of preparing for death

Unfinished business

When facing an uncertain future it is a good opportunity to think about the relationships or friendships that are important to you. You may not have been in contact with some of your friends for a while, or you may have had a ‘falling out’ with someone that you may now want to repair. You may want to spend more time with particular people, or you may want to say something to someone that you feel you have always wanted to say. This can be a time of healing and of strengthening the relationships and friendships that are important to you.

However, it is unrealistic to think that all the conflicts in your past or present relationships and friendships will be able to be resolved. It is a matter of **prioritising** who in your life is important to you,

who in your life, if any, you want to try to resolve any issues with, and who in your life you want to spend time with.

You may find yourself thinking about the past. You may want to visit the place where you were born, or go through your old photographs. This may be a good way to come to terms with the events in your life.

You may also want to write letters to people you are close to, or prepare a tape to be given to them after your death, or to be given to children or grandchildren at major events in their lives.

Whatever you do is a very personal experience, and you need to do what is right for you at the time that feels right.

Spiritual or religious comfort

Concerns about death, religious beliefs and the question of meaning become increasingly important to women with metastatic breast cancer. You may find that your diagnosis has deepened your faith or has made you question it. You may feel confused about what you believe and why this is happening to you.

It may be useful to talk to a priest or religious representative about questions you have, even if you feel that you have not attended any services for a while.

"I feel a bit cross with God I must admit, because I've been in the Church all my life. But I feel God's let me down a bit. Other people pray more, and I find I pray less."

"I don't know too much about the whole process of dying, how sick you've got to get before you die. Do you fade away to a shadow, or are you almost healthy one day and dead the next week?"

“I’m not worried about dying, I have firm beliefs about dying and spirituality and all, not religion but spirituality. I know that when the time comes it will be my time, this body will be worn out and my time will come and I’ll go on to something else.”

“My husband said ‘I’ve got no idea what sort of funeral you’d like or even whether you want to be buried or cremated, and we should update our wills’. So we discussed what sort of funeral I wanted, and we talked about those sort of things.”

Or perhaps your spirituality is related to your connection with nature. It can help to spend more time in nature, such as sitting quietly in your garden or in a park.

Coping with the ‘no more cancer treatment’ decision

Living with metastatic breast cancer frequently involves trying one treatment after another over an extended period of time, often over a number of years. In the later stages the cancer may spread more widely, and treatments such as chemotherapy and hormonal therapy may become less effective at controlling your cancer. However, pain and symptom control and support will continue to be adjusted so that you are as comfortable as possible.

It is difficult to decide when to stop cancer treatment. You need to get as much information as you can from your treatment team and weigh up the possible benefits and the side effects of each treatment. It is important to think about your quality of life. Remember, there is no evidence that any treatment can ‘cure’ metastatic breast cancer.

Talk about your decision with your doctor, your community nurse, your palliative care team, and your family and friends or a counsellor, psychologist or psychiatrist. *See Chapter 16, page 145.*

Ultimately, **the decision to stop cancer treatment is your decision.** You may feel that although you want

to stop treatment, your family or your partner does not want you to stop treatment. If this happens, you and your doctor or a counsellor or psychologist may need to talk to your family or your partner about their concerns.

Deciding to stop cancer treatment does not mean giving up hope. **You still need to preserve hopes** – such as, that you will be made as comfortable as possible, that you will not be alone when you are very sick, that there is an afterlife if that is what you believe, that you will have more time with family and friends, or that you can accomplish an important deed. Each person must find hope in his or her way.

Fears about dying

Many people fear dying. This is natural, particularly in the Western world where we do not have much contact with people who are dying. Dying can be a very peaceful process, and health professionals working with people who are dying report that there is often a sense of calm surrounding the person who is dying.

The process of dying for women with metastatic breast cancer usually occurs over a period of time; it does not occur in an instant. The body gets weaker over time, and this can help women to let go. Health professionals working with people who are dying say that most people know when they are dying.

“But I do know that the cancer is there and spreading. And I just hope that when it spreads, it doesn’t do so painfully. I hope that when it spreads, it makes up its mind to spread, it spreads quickly and gets it over with. But that doesn’t make me negative. I’m positive about the whole business.”

“I’m not a particularly religious person or spiritual. I have a girlfriend who’s very deeply into the Church but I haven’t felt the need for that yet, and I’m not sure whether I want to go down that road.”

You can be reassured that everything will be done when you are dying to keep you as pain free and comfortable as possible, and that you can have family and friends with you.

Coming to terms with dying is an ongoing process. Although difficult, it can be helpful to express with your doctor, family and friends your fears and concerns about dying. This can also help them to express their fears and grief about you dying, and bring you closer together.

Practical aspects of preparing for death

Although difficult, it is important to think about the practical aspects of preparing for death. This can ensure that your wishes are acted upon. It can also prevent any painful decisions that your partner or family may need to make if you do not express your wishes.

Legal considerations differ in each State.

However, some things to consider include:

- **preparing a living Will or an advanced care directive**

Discuss with your partner, family and/or a close friend and your doctor about whether or not you wish to be kept alive by artificial means or resuscitated if you stop breathing.

You can also write a living Will or an advanced care directive stating your wishes. Talk to your

doctor about what you want and how to write a living Will. A copy of your living Will should be given to your treatment team, to ensure that your wishes are carried out.

- **naming a power of attorney**

Discuss with your partner, family and/or a close friend about choosing someone who you trust to make decisions about your treatment if you are not able to decide for yourself, for example if you are in a coma. This person is called a *power of attorney*.

If you wish, a power of attorney can also manage your financial or practical arrangements, if you are not able to do this for yourself. Talk to a solicitor about how to nominate a power of attorney.

- **writing a Will**

A Will outlines who should receive your possessions and property after your death. If you do not write a Will, a government body will decide this for you and this may not be in accord with your wishes and can also be very costly.

A Will can also contain instructions for funeral and burial arrangements.

Talk to a solicitor about drawing up a Will or making changes to any existing Will. It is better to do this when you are feeling well.

- **you may also need to discuss with your partner, family and/or close friends:**
 - how any children you have under 18 years will be cared for
 - your wishes about your funeral and burial arrangements
 - your preference about dying at home or in a hospice, palliative care unit or hospital

Your thoughts may change over time, so it is good to keep others informed of any changes.

You should tell your partner, family and/or a close friend about where you have kept any legal documents and how to contact your solicitor.

Financial support

This chapter discusses some of the costs of living with metastatic breast cancer, and where you can get information about financial assistance.

Costs

Some of the costs and financial concerns you may have if you are living with metastatic breast cancer include:

- the difficulty of financial planning
- the cost of medications
- the gap between treatment costs and what the insurance funds pay for treatment
- the cost of some services, even in the public system
- the cost of services such as counselling
- the cost for rural women of travelling to regional centres to see doctors, or to capital cities for specific treatments
- the cost of travel if partners go to treatment with you

“This has given me a chance to re-evaluate everything. It’s really like coming to a crossroad and having to take a different direction instead of going straight ahead.”

- the cost of accommodation for you and your family while undergoing treatment
- taking time off work to have treatment
- stopping work
- your partner may stop work to care for you
- loss of pay if your partner comes with you to treatment
- childcare for children while you are having treatment, or if you are too unwell to look after them

Where to get information about financial assistance

To find out about financial assistance you should start by asking your hospital or community **social worker** or your **community nurse** about benefits for which you are eligible. He or she can also help you in claiming them.

You can also phone the **Cancer Helpline** on **13 11 20** for information about financial assistance.

Seek financial advice about **superannuation** or **life insurance** from your financial institution.

Financial counselling services are also available from charity organisations such as the Salvation Army or St Vincent de Paul.



List of places to contact for financial assistance

Below is a list of places that you can contact to see if you are eligible for financial assistance.

Most assistance schemes are means tested.

- **Centrelink / Department of Social Security**

You may be eligible for a benefit or pension such as:

- sickness allowance
- disability support pension
- family allowance
- age pension
- carer allowance

You may also be eligible for a health care card (which reduces the cost of your medication) and a pension transport card (which reduces the cost of public transport).

- **Department of Health and Aged Care**

A domiciliary nursing care benefit (DNCB) is available to those **caring for** and living with someone who is ill.

A patient's **travel assistance** scheme is available to provide financial assistance for women who have to travel over a certain distance for treatment.

- **Department of Veterans Affairs**

The Department of Veterans Affairs has a number of benefits and pensions available for veterans or partners of veterans.

- **Taxi Transport Subsidy Scheme**

A subsidy on taxi fares is available in some States for people with severe and permanent disabilities.

- **Charity organisations** such as the Salvation Army, Anglicare and the Walter and Eliza Trust Fund sometimes provide assistance for women with metastatic breast cancer.

- **Cancer Helpline or your treatment hospital**

Accommodation is available in some States for a minimal fee for patients undergoing treatment, and sometimes their families.

If you are a public patient, public hospitals may cover part or sometimes all of the cost of your first **prosthesis**.

If you lose your hair during treatment, you can borrow a **wig or turban** while it is growing back. You can buy a wig or turban for a small fee.

Some **private health funds** also cover the cost of a wig if you have a letter from your specialist.

- **Program of Aids for Disabled People (PADP)**

This program provides funding for equipment such as wheelchairs, crutches and sometimes wigs.

Your local hospital or community nurse will be able to tell you about other schemes that are available or places that you can get equipment cheaply.

Medical tests

You may need a number of medical tests to detect whether the cancer has spread, and the extent of any spread.

Which medical tests you will need will depend on your symptoms and the physical examination by your doctor. CT or MRI scanning of the whole body is rarely appropriate.

Waiting to have medical tests and waiting to hear the results is often an extremely worrying time. This is the time you need support from family or friends. *See Chapter 16, page 145 for further information about support.*

If your doctor recommends that you have a test, discuss:

- the purpose for this test
- any risks involved
- what the procedure involves
- how you may feel during the procedure

Most women diagnosed with metastatic breast cancer will not need all the medical tests discussed in this appendix.

Some of the medical tests that you may have in order to detect whether the cancer has spread and the extent of the spread include:

- **bone X-ray**

During an X-ray of the bones an image of the bones is taken so that any abnormalities can be detected. X-rays may not show early bone metastases.

- **chest X-ray**

During an X-ray of the chest an image of the chest is taken so that abnormalities in the lungs can be detected. A chest X-ray may not show very early spread of cancer to the lungs or chest.

- **bone scan**

During a bone scan a tiny amount of a mildly radioactive substance that is not harmful is injected into a vein, usually in the arm, and travels around the body in the bloodstream to the bones. A couple of hours later the body is scanned. The scan does not take long and is painless.

The bone scan can pick up small areas of increased activity in the bone. These are called 'hot spots'. 'Hot spots' may be due to cancer, arthritis, infection or an injury. This means that



not all 'hot spots' on a bone scan are cancer. Your doctor may suggest that you have some of the tests discussed below in order to make a correct diagnosis.

- **CT scan**

A CT or CAT scan may be used to detect whether the cancer has spread to your bones, lungs, brain, liver or other parts of your abdomen or pelvis.

For this test you may have to lie on your back for up to 30 minutes while the scanner takes the images. A CT scan usually provides a more detailed image of the area being scanned than an X-ray. This test is painless. However, some women feel a bit claustrophobic during this test. You can arrange, before your test, to have a sedative medication during the procedure to make the experience more comfortable.

Some patients having a CT scan will require an injection of a contrast dye to highlight certain tissues or blood vessels and make any abnormalities easier to see. A small needle connected to an intravenous line is placed in an arm or hand vein. Through this line, the contrast dye, usually containing iodine, will be injected. If a contrast dye is injected, you may feel a warm flushing sensation during the injection. You will be asked if you have any allergies to contrast dye before the injection.

- **liver ultrasound**

A liver ultrasound may be used to detect cancer in the liver. It uses sound waves to build up an image of the liver and can measure the size and position of any metastatic cancer in the organ. It only takes a few minutes and is painless.

- **blood tests**

A variety of blood tests may be taken.

Blood tests can be taken to check the functioning of the liver. These are called **liver function tests**.

Blood tests will also check how healthy your **bone marrow** is at producing red blood cells and cells to help the blood clot if you bleed.

Blood tests can also be taken to check the level of calcium in the blood. Sometimes, in women whose cancer has spread to their bone and in women who have other types of metastatic breast cancer, the calcium blood levels can be high. This is called **hypercalcaemia**. *See Chapter 14, page 107 for more information.*

- **MRI scan (magnetic resonance imaging)**

A MRI scan may be used to detect if the cancer has spread to the brain, spinal cord or other nerves. Occasionally it is used for other organs, such as the liver.

For this test you may have to lie on your back inside a tunnel for about 30 minutes while the scanner takes the images. This test is painless. However, some women find this test claustrophobic and noisy. You can arrange, before your test, to have a sedative medication during the procedure to make the experience more comfortable. Or you can bring a friend or partner into the room with you. This test can show a very accurate image of the area being scanned.

- **PET scan**

A PET scan may be used to detect cancer in organs such as the lungs, liver or brain. During a PET scan a tiny amount of a mildly radioactive substance that is not harmful is injected into a vein, usually in the arm, or injected through a urinary catheter. The radioactive substance travels around the body in the bloodstream to highlight areas in the body of increased activity. An image is then taken of the body by a scan. The scan does not take long and is painless.

The scan can pick up small areas of the body that have been affected by cancer, called ‘hot spots’.

- **Pleural drainage of the chest (pleural) cavity**

A **pleural drainage** may be performed if you have fluid around your lungs that has been detected by a chest X-ray. Doctors may refer to a pleural drainage as a **pleural tap** or **pleural aspiration**.

During a pleural drainage a needle is inserted above a rib into the pleural cavity around your lungs. *See Chapter 1, page 12 for more information about the pleural cavity.*

A local anaesthetic is injected into the skin before the needle is inserted. You may feel a slight stinging sensation when it is injected, and a sense of pressure when the needle is inserted into the pleural cavity.

Fluid is then drained and sent to the pathology laboratory for analysis. Cancer cells may be detected if cancer has spread to the pleura, the coating around your lungs.

- **bone biopsy**

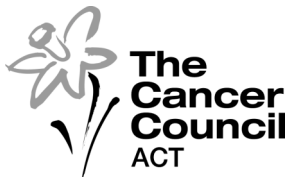
A bone biopsy is not commonly performed. It may be performed if *one* area of abnormality is detected on a bone scan and your doctor wants to confirm whether this is due to cancer.

During a bone biopsy, a needle is inserted into the bone and a sample of bone is obtained. You may feel moderate discomfort and pressure, even though a local anaesthetic is used. After the biopsy, the area may be sore or tender for several days.

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For further information about breast cancer, call your state/territory member
of The Cancer Council Australia by calling the **national Cancer Information Service**
(the cost of a local call anywhere in Australia)
on 13 11 20.



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