

# Guide for women with secondary breast cancer



Endorsed by:



**NATIONAL  
BREAST AND OVARIAN  
CANCER CENTRE**



# Guide for women with secondary breast cancer

Developed by National Breast and Ovarian Cancer Centre



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## Introduction

### Who this book is for

This book is for people who have been diagnosed with secondary breast cancer (also known as metastatic breast cancer or advanced breast cancer). It contains information to help you understand your diagnosis and your options for treatment and care. It may also be helpful for your family and friends. Everyone's situation and needs are different. Some of the information in this book may be helpful now and some may be more helpful later.

### Men with breast cancer

This book is written for women who have been diagnosed with secondary breast cancer. Men with breast cancer may also find the information helpful. National Breast and Ovarian Cancer Centre also has a website for men with breast cancer. Visit [www.nbocc.org.au/men](http://www.nbocc.org.au/men).

### Other types of breast cancer

National Breast and Ovarian Cancer Centre has a range of information about different types of breast cancer. Ask your doctor for the information most relevant for you or visit [www.nbocc.org.au/resources](http://www.nbocc.org.au/resources).

### How to use this book

This book is designed to be read at different points during your cancer journey. It is divided into sections and chapters to help you to find the information most relevant for you. **You can read the sections in any order. For example, you may find it useful to read the 'Finding support' section soon after your diagnosis.** At the beginning of each section, there is a summary of key points. There is also a glossary of terms at the end of the book.

## Guide to symbols



'Dictionary' boxes provide definitions of medical terms used in the book



'More information' boxes identify other relevant sections in the book and other sources of information



'Question' boxes provide suggested questions you may like to ask your healthcare team

There is space at the end of each section for you to make notes or write down questions for your healthcare team.

## Receiving a diagnosis of secondary breast cancer

If you have been diagnosed with secondary breast cancer, it is likely that you have had early or locally advanced breast cancer before. For some women, this may be your first diagnosis of cancer. Your diagnosis of secondary breast cancer will probably come after appointments for a number of different tests.

When your doctor first tells you that you have secondary breast cancer, it will probably be a shock for you and those close to you. You might feel overwhelmed, scared, anxious and upset. These are all natural feelings.

**Sharing your feelings with others, even painful feelings, can help you and those close to you to cope with your diagnosis of secondary breast cancer.**

Ask your healthcare team as many questions as you feel you need to. You might find it helpful to take a friend or family member with you when you go to appointments. Having someone with you can be a great support and can help you to remember what is said.



Breast Cancer Network Australia's (BCNA) *Hope & Hurdles* Pack is a free resource for women diagnosed with secondary breast cancer. The pack, which has been developed by women with secondary breast cancer, includes an information guide and personal record. BCNA's *Hope & Hurdles* Pack can be ordered online at [www.bcna.org.au](http://www.bcna.org.au) or by calling 1300 887 340.

National Breast and Ovarian Cancer Centre has an audio CD for the partners of women with secondary breast cancer. To order a copy of *When the woman you love has advanced breast cancer*, go to [www.nbocc.org.au/resources](http://www.nbocc.org.au/resources) or call 1800 624 873.

If you are of Aboriginal or Torres Strait Islander background, you can seek further support from your local Aboriginal Medical Service or GP. Some hospitals also provide Aboriginal or Indigenous Liaison Officers who can help you to access mainstream health services.



National Breast and Ovarian Cancer Centre has a DVD called *My Story*, which tells the stories of Aboriginal and Torres Strait Islander women diagnosed with breast cancer. To order a copy of this resource, call 1800 624 873 or go to [www.nbocc.org.au/resources](http://www.nbocc.org.au/resources).

Different types of services and support for people from culturally and linguistically diverse backgrounds are available in different communities. Contact your local community centre or Migrant Resource Centre to find out what is available for you.

## Using a professional interpreter

If you are reading this book for someone who does not speak English, you can ask a professional interpreter for help. Interpreters are available in public and private hospitals.

To arrange for an interpreter to come to an appointment:

- ask a member of your healthcare team about the hospital's interpreter services
- call the **Cancer Council Helpline** on **13 11 20** for information about interpreters in your area
- call the **Translating and Interpreting Service** on **13 14 50**.

## How this book was developed

The information in this book was developed by National Breast and Ovarian Cancer Centre with input from health professionals and women with secondary breast cancer. The book is based on National Breast and Ovarian Cancer Centre clinical practice guidelines. Copies of the clinical practice guidelines are available to view or download from the National Breast and Ovarian Cancer Centre website at [www.nbocc.org.au](http://www.nbocc.org.au).

**New treatments and technologies are continually being developed and may be introduced in the future. If you hear about treatments and technologies that are not included in this book, ask your healthcare team for more information.**

## Notes

# Understanding your diagnosis

This section explains what secondary breast cancer is, the symptoms of secondary breast cancer and what we know about survival following a diagnosis of secondary breast cancer. It also describes some of the common tests used to diagnose secondary breast cancer.

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## About secondary breast cancer

Date of development: November 2009

### Summary

- Secondary breast cancer is breast cancer that has spread from the breast to other parts of the body.
- The most common places that breast cancer spreads to are the bones, liver, lungs or brain.
- Symptoms of secondary breast cancer depend on which part of the body is affected.
- Secondary breast cancer cannot be cured, but treatments are available that can control the cancer and relieve symptoms.
- For some women, living with secondary breast cancer is like living with a chronic disease.

### What is secondary breast cancer?

Secondary breast cancer is breast cancer that has spread from the breast to other parts of the body.

Secondary breast cancer is also called **metastatic breast cancer** or **advanced breast cancer**. Many women diagnosed with secondary breast cancer have been diagnosed with breast cancer before. For some women, a diagnosis of secondary breast cancer may be their first diagnosis of cancer.

*"I've met a lot of women through 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."*

### How does secondary breast cancer develop?

In some women with breast cancer, cancer cells break away from the cancer in the breast. The cancer cells spread to other parts of the body via the blood vessels or lymphatic vessels and form a new cancer deposit. This can happen before or after treatment for breast cancer. The original cancer in the breast is called the **primary cancer**. If breast cancer develops in another part of the body, it is called a **secondary breast cancer** or a **metastasis**.

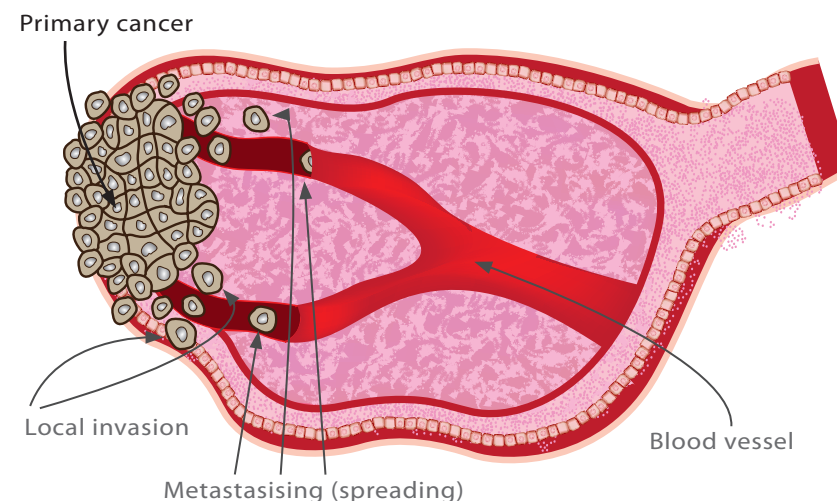


Diagram of how cancer spreads



**Lymphatic system:** tiny vessels next to blood vessels that collect fluid and waste products from the body's tissue. Lymphatic vessels are connected by glands called **lymph nodes**. Lymph nodes protect the body from infection by removing foreign substances from the body.

**Metastasis:** another name for cancer that spreads to another part of the body.

The most common places that breast cancer spreads to are the bones, liver, lungs and brain. **If you have secondary breast cancer, it does not mean that your cancer will spread to all of these places.**

## Finding secondary breast cancer

Secondary breast cancer may be found during a routine follow-up visit after treatment for early or locally advanced breast cancer, or after a woman sees her doctor about a new symptom. For some women, secondary breast cancer is the first diagnosis of breast cancer.

Some women who have had breast cancer before and are diagnosed with secondary breast cancer think that they should have been having different follow-up tests after their original treatment for breast cancer. **However, there is no evidence that having regular blood tests or scans after treatment for early breast cancer improves the length or quality of life for women who have no symptoms.**

*"My doctor said 'A lot of women are living with these cancers for quite a long time.'"*

*"You do all the right things and you try your hardest but you really have no control over it and six months down the track I have metastatic disease."*

## Symptoms of secondary breast cancer

Every woman's experience of secondary breast cancer is different. Symptoms depend on what part of the body is affected. They may develop over weeks or months. It is unlikely that you will have all of the symptoms listed in the following sections. Some of your symptoms may not be due to secondary breast cancer at all.

Symptoms of secondary breast cancer can be managed with medical care to make you more comfortable. It is important to tell your doctor about any new symptoms or if your symptoms do not go away or become worse.



For more information about symptoms of secondary breast cancer and how to manage them, see the 'Symptoms and side effects' section.

## Symptoms if cancer spreads to the bone

One of the first symptoms of cancer in the bone is usually a constant ache or pain in the bone. The pain can get worse when you move and can make it difficult to sleep at night.

**Not every new ache or pain means that breast cancer has spread to the bone. You may like to keep a note of how often your symptoms occur or how long they last. See your doctor if you have an ache or pain that does not go away.**

If breast cancer spreads to the bone, it can damage the bone and make it weaker. If the bone becomes very weak, it can fracture. When breast cancer damages the bone, it can also increase the level of calcium in the blood. This is called **hypercalcaemia**. Symptoms of hypercalcaemia can include feeling sick, thirsty, tired or confused. You may also become constipated or need to urinate more frequently. However, hypercalcaemia is often found using blood tests before symptoms develop.

Sometimes breast cancer can spread to the bones in the spine (vertebrae). Damage to bones in the spine or cancer around the spine can put pressure on the spinal cord. This can cause loss of movement, loss of feeling or power in the arms or legs, or loss of bowel or bladder control. This is called **neuropathy**.

See your doctor immediately if you:

- have back pain that does not go away or if back pain suddenly gets worse
- have a loss of feeling or power in your arms or legs
- suddenly lose bowel or bladder control.

*"I was thinking 'This isn't happening to me. I'm just an ordinary person who goes about an ordinary life. I don't get cancer.'"*

### Symptoms if breast cancer spreads to the liver

Symptoms of cancer in the liver include weight loss, tiredness and discomfort in the area of the liver (on the right side of the abdomen or tummy). Some women also feel sick or lose their appetite.

The liver produces **bile**, which helps the body digest food. If cancer cells block the vessels that carry bile out of the liver, bile can build up in the blood. This can cause **jaundice**. Jaundice can make the skin and the whites of the eyes turn yellow and can make the skin feel itchy. It can also make the urine darker and can make bowel waste (stools) paler in colour.

In some women, cancer can make the liver bigger or can cause fluid to build up in the abdomen (tummy). This fluid is called **ascites** and can make the abdomen swell up.

**See your doctor immediately if you have unusually severe discomfort and tenderness in the right upper part of your abdomen (tummy) or if discomfort in this area does not go away.**

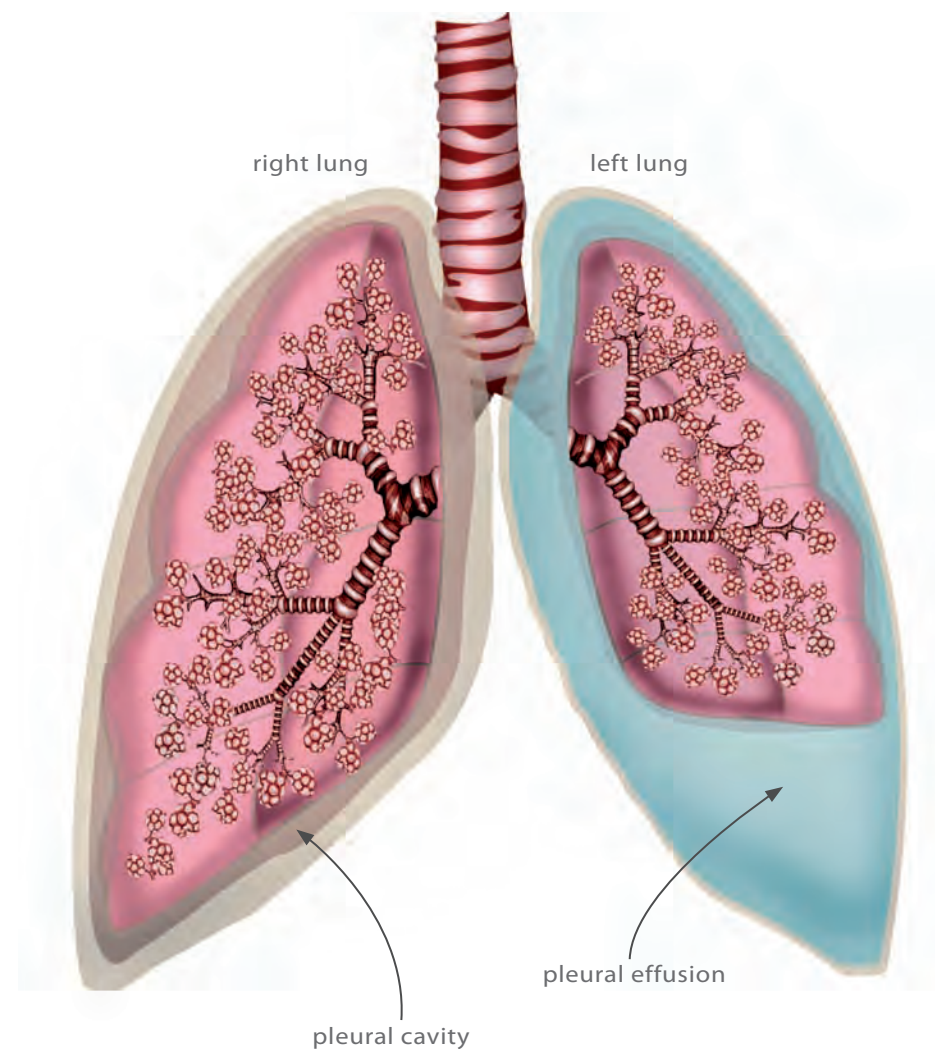
### Symptoms if breast cancer spreads to the lungs

The space between the lungs and the rib cage is lined with a membrane called the **pleura**. This space is called the **pleural cavity**. If cancer cells enter this space, they can cause fluid to build up and press on the lungs. This is called a **pleural effusion**.

One of the first symptoms of cancer in the lungs is shortness of breath or a dry cough. Some women also have chest pain or a feeling of heaviness in the chest.

Breathlessness can be frightening. However, treatments are available that can help to manage your symptoms and make you feel more comfortable.

**See your doctor immediately if you have difficulty breathing, if your symptoms become worse or if you cough up blood.**



Pleural effusion

## Symptoms if breast cancer spreads to the brain

The thought of cancer in the brain can be very frightening. However, symptoms can be managed to make you as comfortable as possible.

Symptoms of cancer in the brain can include a headache that does not go away, nausea (feeling sick) and vomiting. Headaches may be worse in the morning. Sometimes cancer in the brain causes changes in the part of the body controlled by that part of the brain. For example, an arm or leg might become weaker or your vision may become blurred. Cancer in the brain can also cause seizures (fits). In rare cases, cancer in the brain can cause confusion or a change in personality.

See your doctor immediately if you:

- have an unusually severe headache that does not go away, especially if it is accompanied by nausea or vomiting that cannot be explained
- develop blurred vision or weakness in an arm or leg
- have a seizure (fit)
- notice changes to your personality.

## What does this diagnosis mean for me?

Secondary breast cancer cannot be cured. However, treatments are available that can control or slow the growth of secondary breast cancer and relieve symptoms.

It is likely that you will have a number of different treatments tailored to meet your individual needs. Your doctors will monitor how well your treatment is working. If your symptoms become worse, your doctor may suggest that you try a different treatment. In later stages, treatments may become less effective at controlling your cancer and you may find that the side effects of treatment are becoming more difficult to manage. You and your doctor can decide when to stop having active treatment to control the cancer. **However, pain control and support will continue to be a priority to make you as comfortable as possible.**



For more information about treatments for secondary breast cancer, see the 'Treatment' section.

*"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."*

## How long will I live?

Everyone responds differently to treatment for secondary breast cancer. As treatments improve, more women are living for a long time with secondary breast cancer and are able to live a full and active life for many years. For these women, living with secondary breast cancer is similar to living with another chronic illness, such as heart disease.

It is unlikely that your doctor will be able to tell you exactly how long you will live after your diagnosis. However, you may like to talk to your doctor about how other women in similar situations have responded to treatment. You may also find it helpful to talk to your doctor or nurse about the possible impact of treatment and symptoms on your day-to-day activities.

It can be difficult to come to terms with the uncertainty of a diagnosis of secondary breast cancer. Talking to others can help. Tell your doctor if you are experiencing feelings of anxiety, sadness or anger that are overwhelming you.



For more information about your feelings and how to find support after a diagnosis of secondary breast cancer, see the 'Finding support' section.

*"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."*

*"The media portrays people as having cancer and either beating it or not beating it. It's very black and white. And that's not actually what it's about. It's an ongoing disease."*



## Questions to ask about secondary breast cancer

Listed below are some questions you might want to ask a member of your healthcare team about your secondary breast cancer.

- Which parts of my body are affected by secondary breast cancer?
- Is my cancer slow or fast growing?
- Can you explain what my test results mean?
- Can I bring a friend/family member with me to my appointments?
- Can you write down what you have told me so that I can read it again later?
- Can you tell me how other women in my situation have responded to treatment?
- Can you tell me how my diagnosis will affect my day-to-day life?
- Is there someone I can talk to about my diagnosis and the decisions I need to make?

You may like to write your own questions here:

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## Frequently asked questions

### Why did my breast cancer spread?

We do not know what causes breast cancer to spread in some women and not in others. If you have previously been diagnosed and treated for early breast cancer, it is important to remember that you and your doctors made the best decisions about your previous treatment with the information available at the time.

### Is secondary breast cancer painful?

Secondary breast cancer affects different women in different ways. The type and level of pain experienced by one woman may not be the same as that for another woman with cancer in the same parts of the body. Not everyone with secondary breast cancer finds it painful. Some women have no pain; others find that pain affects them at certain times of the day or night or while doing different activities. Pain caused by secondary breast cancer does not always get worse with time. Cancer pain can usually be controlled. It is very rare to have cancer pain that cannot be lessened or changed.

### If cancer spreads to the brain, will this cause changes to my personality or mental function?

Secondary breast cancer that spreads to the brain does not cause mental illness. Women may experience different symptoms depending on which part of the brain is affected by the cancer. The most common symptom is a headache that does not go away. Some women have difficulty concentrating or reading difficult text. A small number of women may experience changes in their mood or personality. It is important that this is assessed by a health professional to make sure the changes are not due to other things, such as depression.



## Tests and diagnosis

Date of development: November 2009

### Summary

- A number of tests can be used to find out which parts of the body are affected by secondary breast cancer.
- You may have several different tests to help your doctors confirm your diagnosis and decide what treatments are best for you.
- Waiting for test results can be a worrying time for you and those close to you.
- Ask your doctors as many questions as you need to about the tests and what they involve.

### Waiting for test results

If you have symptoms that might be due to secondary breast cancer, you will probably have a number of tests before your diagnosis is made. It can be difficult at first for you and your doctor to tell whether your symptoms are due to secondary breast cancer or other medical conditions. Waiting for test results can be a worrying time for you and those close to you. Ask your doctor as many questions as you need to. You and your partner or family may find it helpful to talk to your doctor or another health professional about your fears or concerns.

Some women worry about the time it takes to diagnose their secondary breast cancer. **Current evidence suggests that being diagnosed with secondary breast cancer a few weeks or months after your first symptoms develop will not make a difference to the length or quality of your life or how you respond to treatment.**

*"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."*

## Tests for secondary breast cancer

Different tests are used to look for cancer in different parts of the body. These tests involve **radiology** and **pathology**. You may have a number of tests so that your doctor can plan how best to manage your treatment and care. You may find it helpful to keep a record of your test results so that you can refer to it later.

Tests may include:

- X-rays or bone scans to look for cancer in the bones
- blood tests or an **ultrasound** scan to look for cancer in the liver
- a chest X-ray or **CT scan** to look for cancer in the lungs
- a CT scan or **MRI scan** of the head to look for cancer in the brain.

More information about each of these tests and some of the other tests you might have is given below.

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



**Radiology:** tests that involve taking pictures of different parts of the body.

**Pathology:** tests that involve examining blood, tissue or cells from the body.

**Ultrasound:** a way of examining parts of the body using high frequency sound waves instead of radiation.

**CT scan** (computerised tomography) — a special type of X-ray that provides a two-dimensional picture of the inside of the body.

**MRI scan** (magnetic resonance imaging) — a way of imaging parts of the body using magnetic fields instead of radiation.

## X-rays

You might have an X-ray of your bones or your chest to look for any changes due to cancer. X-rays are quick and easy to do but may not show early signs of cancer.

## Bone scan

During a bone scan, a small amount of radioactive substance is injected into a vein, usually in your arm. The radioactive substance travels around the body in the bloodstream to the bones. It will need to concentrate in the bones before scanning can start. This can take up to three hours. You may be allowed to walk around during this time. You will then be asked to lie still while the scanner moves over you and produces pictures of your bones. The scan may take up to an hour. Some women like to take a personal music player with them to help them to relax during the scan.

A bone scan can pick up small areas in the bones where cells are growing more quickly. These are called 'hot spots'. Hot spots may be due to cancer or another medical condition, such as arthritis, infection or an injury. If the scan shows hot spots, you might have other tests to confirm the diagnosis. A bone scan to detect secondary breast cancer is different from a bone density study used to assess your risk of **osteoporosis**.



**Osteoporosis:** thinning of the bones that usually develops as a result of ageing.

## CT scan

A CT (computerised tomography), also known as a CAT scan, may be used to look for cancer in different parts of your body. The test takes about 10 to 20 minutes. You will be asked to lie on your back on a table, which passes through a doughnut-shaped machine that takes pictures of the inside of your body. The scan is painless. Some people may feel claustrophobic inside the scanner, although this is less common than with MRI scans. You can ask to have a sedative to make you more comfortable during the scan.

Some women have a small amount of dye injected through a vein in the arm or hand before the scan. The dye makes it easier to see changes in the body that may be due to cancer. You may feel a warm flushing feeling when the dye is being injected.

You may be asked to drink an **oral contrast** before you have the scan. This makes it easier to tell the difference between the bowel and other organs nearby.

## Ultrasound

An ultrasound may be used to look for changes in the liver and elsewhere in the body. This only takes a few minutes and is painless. It is likely that you will be asked not to eat anything for at least four hours before an ultrasound of the abdomen.

## Blood tests

Blood tests can be used to check for different things, including how well your liver is working, how healthy your bone marrow is and whether you have higher than normal levels of calcium in the blood. High levels of calcium can be a sign of secondary breast cancer.

## MRI scan

An MRI (magnetic resonance imaging) scan may be used to check for signs of cancer in the brain, spinal cord, spine or liver. The scan takes about 30 minutes. You will be asked to lie inside a tunnel-like machine while it takes pictures of the inside of your body. Some women have a small amount of contrast agent injected through a vein in the arm or hand during the scan. This makes it easier to see changes in the body that may be due to cancer. The injection does not make you feel any different. The scan is painless but some people feel claustrophobic inside the machine, and the machine can be noisy. Talk to the health professionals at your hospital about what can be done to make you more comfortable while you are having the scan. This might include having a sedative.

*"I've 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."*

### PET scan

Occasionally, a PET (positron emission tomography) scan may be recommended to look for cancer in the body. A small amount of radioactive substance is injected into a vein, usually in your arm. You will then be asked to lie on your back on the scanning table. The table moves through a scanner 'ring', which takes pictures of the inside of your body. The scan can show any areas in the body where cells are more active than usual (for example, fast-growing cancer cells). The scan is painless and may take between 15 minutes and two hours, depending on the type of scan. PET scans are available in only a few centres in Australia, as they require specialised equipment. A combined PET and CT scan test is available in some centres.

### Pleural aspiration

If a chest X-ray shows that there is fluid around your lungs, doctors may aspirate (drain) the fluid to look for changes that may be due to cancer. You will be given a local anaesthetic before the fluid is drained. A small needle will then be inserted between your ribs into the space around your lungs. Fluid is drained and sent to a pathologist for examination.

### Bone biopsy

A bone biopsy is not a common test for secondary breast cancer. A bone biopsy may be done if an abnormal area is found on a bone scan to check whether it is due to cancer. You will be given a local anaesthetic before the biopsy to reduce the pain. A needle is then inserted into the bone and a sample of bone is removed for examination by a pathologist. The biopsy can be uncomfortable and the area may be sore for a few days afterwards. You can take a painkiller as needed after the anaesthetic has worn off — ask a member of your healthcare team for more information.



**Biopsy:** removal of cells or tissue from the body for examination under a microscope.

### Breast biopsy

If secondary breast cancer is your first diagnosis of cancer, you will usually have a **biopsy** of the cancer in your breast to confirm the diagnosis and find out what **receptors** are on your breast cancer cells. This information will help your doctor to work out which treatments are best for you.

If you have been diagnosed with breast cancer before, your doctor will be able to look in your records to find out what receptors are on your breast cancer cells. You may have a repeat biopsy to test for changes in receptors since your original cancer was found.



**Receptor:** a protein on or in a cell to which a substance such as a hormone or a drug can attach.

### New tests

Research is being done to look for new ways of finding cancer. You may hear or read about new tests or methods. Any new test or technology must be tested to check how effective it is before it can be used routinely. Ask your doctor if you have questions about any new tests or treatments you hear about.

*"My theme song is 'I get knocked down, but I get up again, you're never gonna keep me down'."*





## Questions to ask about tests for secondary breast cancer

Listed below are some questions you might want to ask a member of your healthcare team about tests for secondary breast cancer.

- Which test(s) do I need to have?
- What will the test(s) show?
- What are the risks of the test(s)?
- What will the test(s) involve?
- How much will the test(s) cost?
- How will I feel during/after the test(s)?
- Can I bring a friend/family member with me while I have the test(s)?
- What can be done to make me more comfortable during the test(s)?
- Can you write my test results down?
- Will the results of my test(s) make any difference to what treatments I can have?

You may like to write your own questions here:

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## Frequently asked questions

### Should I have been having regular scans or blood tests after my first breast cancer diagnosis?

Some women who have been diagnosed and treated for early breast cancer assume that they should have regular scans and blood tests after treatment. However, studies have shown that having more tests *does not* improve the length or quality of life for women who have been treated for breast cancer, unless they have symptoms which suggest that cancer has spread outside the breast or armpit area.

### How often should I be tested to see if the cancer is under control or continuing to grow?

The type and frequency of scans or other tests used to check whether your cancer is responding to treatment will depend on where the cancer is and the type of treatment(s) you receive. Tests might be less frequent if your cancer has been controlled for some time. Ask your doctor about what tests you might have and when these might be needed.

# Treatment

This section explains who is involved in managing your care, the different treatment options for secondary breast cancer, their possible side effects and information about clinical trials. It also includes information about complementary therapies.

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## Understanding your treatment options

Date of development: November 2009

This chapter provides a brief overview of treatment options for secondary breast cancer. More detail about each of the treatment options is provided in the following chapters.

### Summary

- The aim of treatment for secondary breast cancer is to control the growth and spread of the cancer, relieve symptoms and improve or maintain your quality of life.
- Your treatment options will depend on a number of things, including where your cancer is, your symptoms, whether your breast cancer cells have particular receptors on them, what treatments you have had before and how long ago, your general health and your preference.
- A range of health professionals will be involved in managing your treatment and care. This is called multidisciplinary care.
- You and your doctors can decide which treatments are best for you.
- It is OK to take some time to think about your treatment options before making decisions about treatment.
- If you are pregnant when you are diagnosed with secondary breast cancer, this will affect the types and timing of treatments recommended for you.
- It is recommended that you do not become pregnant during treatment for secondary breast cancer.

### Overview of treatment options

The aim of treatment for secondary breast cancer is to control the growth and spread of the cancer, relieve symptoms and improve or maintain your quality of life.

A range of different treatments for secondary breast cancer is available. Everyone is different. Treatments that may be suitable for one woman may not be suitable for another. In addition to treatments to control your cancer, you may also wish to consider **palliative care** to help to control symptoms and improve your quality of life. Palliative care is not just for people who are nearing the end of life. You can have palliative care at the same time as active treatment for secondary breast cancer.

*"I've met a lot of women through 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."*



**Palliative care:** specialised care for people who have a disease that cannot be cured. Palliative care focuses on helping to control physical symptoms such as pain, and on emotional wellbeing, relationships with others and spiritual needs. In later stages, palliative care can also help people to prepare for death.



For more information about treatments for secondary breast cancer, including palliative care, see the later chapters in this section.

The treatments recommended for you will depend on a number of things, including:

- where the cancer is in your body
- your symptoms
- what treatments you have had before and how long ago
- whether your breast cancer cells are positive or negative for **hormone receptors** or **HER2**
- your general health
- your preference.

Your doctor will recommend treatments that are most likely to control your breast cancer, with side effects that you can cope with. Your doctor may try several different treatments before finding one that your cancer responds to. If your cancer stops responding to a particular treatment, other options may be available. **Talk to your doctors about the possible benefits and risks of the treatments recommended for you.**



**Hormone receptors:** proteins in a cell that allow hormones to bind to the cell, causing it to grow and divide. Hormone receptors must be present for the cell growth to be influenced by hormones.



**HER2:** a protein on a cell that allows a growth factor to bind to the cell, causing the cell to grow and divide. HER2 is also called HER2-neu or c-erbB2.

*"I think sometimes it is a two-way street — that you have to find out the information also."*

## Systemic therapies

Systemic therapies are drugs that travel around the body in the bloodstream and treat cancer cells wherever they are in the body. Systemic therapies include **hormonal therapies**, **chemotherapy** and **targeted therapies**. Systemic therapies may be given as tablets or an intravenous infusion (drip) or injection, depending on which drug is used.

Treatment for secondary breast cancer usually involves one or more systemic therapies.

### Hormonal therapies

Hormonal therapies are drugs used to treat women who have **hormone receptors** on their breast cancer cells. Hormonal therapies are usually used as the first treatment for secondary breast cancer and may be used alone or with other treatments.

## Chemotherapy

Chemotherapy uses drugs to treat fast-growing cells like cancer cells. Chemotherapy may be used to treat women who do not have hormone receptors on their breast cancer cells. It may also be used after hormonal therapies, or to treat secondary breast cancer that is growing quickly, particularly if it is in the liver or lungs.

## Targeted therapies

Targeted therapies are drugs that stop the growth of particular types of cancer cells. Targeted therapies are only suitable for some women. They are usually used in combination with other treatments. The most common targeted therapy used in breast cancer is trastuzumab (Herceptin®).

## Radiotherapy

Radiotherapy uses X-rays to destroy cancer cells in one area of the body. Radiotherapy may be used to reduce the size of secondary breast cancers in some parts of the body and to relieve pain, especially in the bones.

## Surgery

Surgery is not often used in the treatment of secondary breast cancer. It may be used to treat cancer in the bones, lungs or brain, and more rarely the liver. Surgery may be used if secondary breast cancer is your first diagnosis of breast cancer.

## Palliative care

Palliative care is the name for care or treatments that help to reduce or control symptoms and improve quality of life for people with an incurable disease. Many people think that palliative care is only for people who are dying. However, anyone with secondary breast cancer can access palliative care services to help with physical and emotional symptoms and get practical support. There are benefits in making contact with a specialist palliative care service even when you are still feeling well.

## Clinical trials

Clinical trials are studies that compare new treatments with standard treatments. Some trials also look at new combinations of treatments or new ways of giving treatments.

*“My doctor always says to me ‘Don’t worry if this doesn’t work, there are other things we can try’.”*

## Complementary and alternative therapies

Complementary therapies are treatments or therapies that can be used alongside conventional treatments to enhance quality of life and improve overall wellbeing. Examples include relaxation therapy and meditation. Alternative therapies are treatments used instead of conventional treatments. There is no evidence to support the use of alternative therapies in the treatment of breast cancer. **It is important that you talk to your doctor about the safety of any complementary treatments or therapies you are considering.**

## Your multidisciplinary healthcare team

During your treatment and care for secondary breast cancer, you will meet a number of health professionals. Your healthcare team will provide support and help you to decide how best to manage your cancer. The people involved in your care may change at different points in your cancer journey. Meeting many different health professionals can be quite daunting. However, you will usually have one main contact person at each stage along the way. **Ask a member of your healthcare team if you are unsure who your main contact person is.**

It is likely that the health professionals managing your care will meet to discuss what treatments are best for you. This is called **multidisciplinary care**.

**Talk to your doctor or nurse about who will be involved in discussions about your treatment and care.**



**Multidisciplinary care:** a team approach to cancer treatment, planning and support.

The health professionals who may be involved in your care include:

- **medical oncologist:** specialises in cancer drugs such as hormonal therapies, chemotherapy and targeted therapies
- **radiation oncologist:** specialises in radiotherapy
- **radiation therapist:** assists in planning and giving radiotherapy
- **breast care nurse:** specialises in caring for people with breast cancer
- **oncology nurse:** specialises in caring for people with cancer
- **surgeon:** specialises in surgery, including biopsies
- **pathologist:** examines cells, tissue and blood from the body
- **palliative care specialist, palliative care nurse:** specialise in providing practical support and symptom relief
- **general practitioner (GP):** provides ongoing care and works with other members of the treatment team
- **community/district nurse:** provides care and support for you at home
- **community palliative care team:** provide practical support and symptom relief at home
- **psychologist, psychiatrist or counsellor:** specialise in providing emotional support and managing anxiety and depression
- **social worker:** specialises in providing emotional support, counselling and advice about some practical and legal matters
- **welfare worker:** provides practical support and advice
- **dietitian:** specialises in providing advice about what to eat
- **radiologist:** examines scans, X-rays and other imaging results

- **pharmacist:** specialises in supplying, dispensing and manufacturing drugs
- **physiotherapist, occupational therapist:** assist with exercise and pain management
- **research nurse:** assists in the planning and coordination of clinical research studies and clinical trials
- **pastoral care/religious representative:** provides spiritual support.



**Oncologist:** a doctor who specialises in treating cancer.



The names for different health professionals might vary depending on which State/Territory you live in. Ask a member of your treatment team if you have any questions.

It is important that you feel comfortable with the members of your treatment team. Talk to them about your questions and what is important to you. Ask for more information if you need it. If you have been diagnosed with breast cancer before, you may want to be treated by the same doctors or you may choose to see someone else. **You have the right to a second opinion at any time. If you would like to talk to someone else about your treatment options, ask your GP or specialist to refer you to another doctor.**

*“They mentioned on more than two or three occasions that they — the oncologists and the surgeon — would consult each other. They do work well as a team and they consult and that makes me feel supported and monitored.”*

## Travelling for treatment

If you live outside a major city, you may need to travel to see a medical oncologist, radiation oncologist or surgeon. Alternatively, your GP or surgeon may talk about your treatment on your behalf with a medical or radiation oncologist from another hospital. Once you and your doctor have decided on your treatment plan, you will probably be able to have chemotherapy at a hospital in your nearest regional town or at home. If you do need to travel, you may be able to get financial assistance, accommodation or other practical help while you are having treatment. Ask a member of your healthcare team for more information.



For information about practical and financial support during treatment, including government-funded patient transport schemes, see the ‘Finding support’ section.

To find out about the breast cancer services available in different hospitals throughout Australia, visit the National Breast and Ovarian Cancer Centre *Directory of Hospital Breast Cancer Services* at [www.nbocc.org.au/hsd](http://www.nbocc.org.au/hsd).

## Making decisions about treatment

You can be fully involved in all decisions about your treatment.

Some people like to be involved in deciding about their treatment. Others prefer to let their doctors make decisions for them. You are entitled to choose the treatment that best suits you. After weighing up the possible benefits and side effects of each treatment, you may decide not to have a particular treatment. Talk to your doctors and those close to you about your options and what is important to you.

When you are told about your diagnosis, you may feel that you have to make decisions quickly about what to do next. **There is usually no need to decide straight away. Taking time to make a decision will not usually affect the outcome of your treatment.**

*"It's helpful to have my husband there with me when I go to the doctor. He listens more closely than I do."*

### Tips for talking to your healthcare team

Some people find it overwhelming to receive a lot of information, while others want as much information as they can find. It may take a while for you to feel comfortable or confident to ask questions of your healthcare team. The following tips might be helpful for you.

- Tell your healthcare team how much you want to be involved with decisions about your treatment and care.
- Ask as many questions as you need to, and do not worry about asking the same question more than once.
- Ask a relative or friend to come to your appointments and ask them to write down what is said.
- Write down questions when they occur to you so you can remember them when you meet with members of your healthcare team.
- If your doctor agrees, tape-record your discussions so you and your family can listen to them again later.
- Ask a member of your healthcare team to write down what was said during your appointments.
- Ask to talk to a breast care nurse or oncology nurse to go through any other questions you might have.

*"It's really up to you to decide about treatment. Therefore you need a lot of information and you need a lot of help."*

### Treatment during pregnancy

Some treatments are not recommended if you are pregnant when diagnosed with secondary breast cancer.

If you are pregnant when you are diagnosed:

- **radiotherapy** is not recommended during pregnancy because it may harm the unborn baby; radiotherapy can be given after the baby is born
- **chemotherapy** is not recommended during the first trimester because it may harm the unborn baby; chemotherapy is often given during the second and third trimesters, when the risk of harm is lower
- **hormonal therapy** and **trastuzumab** are not recommended during pregnancy
- you can have **breast surgery** with only a slight risk of miscarriage; the risk of miscarriage is lower after the first trimester.

Talk to your doctors about what treatments are possible for you and the timing of treatments.

### Pregnancy during treatment

It is recommended that you do not become pregnant during treatment for secondary breast cancer.

Some treatments for breast cancer may cause your menstrual period to stop or become irregular (for example, some hormonal therapies and chemotherapy). It is recommended that you use contraception if it is possible that you could become pregnant during treatment. Treatments such as chemotherapy and radiotherapy can harm the unborn baby.



For more information about pregnancy and breast cancer, see the 'Breast cancer, menopause and fertility' chapter in the 'Symptoms and side effects' section.





- Who are the members of my healthcare team?
- Who is my main contact person?
- Who will be involved in discussions about my treatment and care?
- Whom can I call if I have questions about my treatment and care?
- Whom should I contact/what should I do in an emergency?
- Can I bring a friend/family member to my appointments?
- Do you mind if I tape-record our discussion?
- Can you write down what you have told me?
- Will I need to travel for treatment?
- Can you refer me for a second opinion?
- What impact will being pregnant have on the timing of my treatment?
- What will my treatments/tests cost? Can they be bulk billed?
- Are there any lifestyle changes I should make during treatment (for example, diet, alcohol, exercise)?

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## Frequently asked questions

### What if I can't remember what the doctor says?

A diagnosis of secondary breast cancer can be overwhelming. You will be given a lot of information and you may find it difficult to remember everything. You can ask your doctor to repeat things or write them down for you. You may find the tips on page 12 helpful.

### How will I know what treatment to choose?

Your doctor will explain your treatment options. Ask your doctor about the possible benefits and side effects of each treatment. You may need time to read about different treatments or to talk to family and friends. After weighing up the benefits and side effects, you may decide not to have a particular treatment. Discuss your decision with members of your healthcare team and those close to you.

### What should I do if I want a second opinion?

You have the right to have a second opinion at any time. If you want a second opinion, you can ask your specialist or your GP to refer you to someone else. You may decide after seeing another doctor that you would prefer the original doctor to manage your treatment. The fact that you have seen someone else should not affect how the first doctor manages your treatment.

### Can I decide not to have treatment?

You may decide after talking to members of your healthcare team that you do not want to have a particular treatment. Weigh up the possible benefits and side effects of the treatment and talk to your doctor about what might happen with or without treatment. If you decide not to have a particular treatment, discuss your decision with your doctor and with those close to you.

## What role will my GP play in my care?

Your GP can help to coordinate your care and provide you and your family with support and information to help you to make informed choices about treatment. When treatment is over, your GP can help you and those close to you to manage your physical and emotional health needs throughout the cancer journey, including palliative care.

In some regional and rural areas of Australia, your GP may also supervise the treatment programs that are prescribed by your oncologist.

## Hormonal therapies

Date of development: November 2009

### Summary

- Hormonal therapies are treatments for women with early and secondary breast cancer who have hormone receptors on their breast cancer cells.
- Hormonal therapies can stop secondary breast cancers from growing or spreading and can relieve symptoms of secondary breast cancer.
- Hormonal therapies are usually recommended as the first treatment for women with secondary breast cancer who have hormone receptor-positive breast cancer. If a woman has been treated previously with a hormonal therapy for early breast cancer, other hormonal therapies can be tried.
- The benefits of treatment with hormonal therapies can last for some time — sometimes for years.
- The type of hormonal therapy recommended depends on whether you have reached menopause.

### What are hormonal therapies?

**Hormonal therapies are treatments for women who have hormone receptors on their breast cancer cells.**

When breast cancer cells have hormone receptors on them, it means the growth of the cancer cells is affected by female hormones. Breast cancer cells with hormone receptors on them are said to be 'hormone receptor positive'. About two-thirds of women with breast cancer have hormone receptor-positive breast cancer. There are two types of hormone receptors — oestrogen receptors (ER) and progesterone receptors (PR).

Hormonal therapies can slow or stop the growth of secondary breast cancers and can relieve symptoms. For some people, hormonal therapies can make the cancer smaller. The benefits of treatment with hormonal

therapies can last for some time — sometimes for years. Hormonal therapies may increase the length of your life, although this has not been proven in a clinical trial.



**Hormone receptors:** proteins in a cell that allow hormones to bind to the cell, causing it to grow and divide. Hormone receptors must be present for the cell growth to be influenced by hormones.

**Endocrine therapies:** another name for hormonal therapies.

**Oestrogen:** a type of female hormone.

**Progesterone:** a type of female hormone.

**Hormonal therapies used to treat secondary breast cancer are not the same as hormone replacement therapy (HRT) used to manage symptoms of menopause.**

### When are hormonal therapies recommended?

Hormonal therapies are usually recommended as the first treatment for women with secondary breast cancer who have hormone receptor-positive breast cancer. Hormonal therapies are usually given before chemotherapy. If the cancer is growing quickly, especially if it is in the liver or lungs, chemotherapy may be given first. Clinical trials have shown that hormonal therapies are as effective as chemotherapy in controlling secondary breast cancer for women with hormone receptor-positive breast cancer.

If you have been diagnosed and treated for early breast cancer, and you have hormone receptor-positive breast cancer, it is likely you will have taken a hormonal therapy before. If you have taken a hormonal therapy before, or if the hormonal therapy you are taking stops working, there are others you can try. You will usually continue to take hormonal therapies for as long as you are benefiting from treatment and the side effects are manageable.

**Talk to your doctor about whether hormonal therapies are suitable for you.**

## Menopause and oestrogen production

All women produce the female hormone oestrogen; however, it is made differently before and after menopause.

- **Before menopause (pre-menopause)**, oestrogen is made mainly by the ovaries.
- **Around the time of menopause (peri-menopause)**, the ovaries stop making female hormones, including oestrogen. This usually happens when women are in their late 40s and early 50s. Symptoms of menopause include irregular menstrual cycles, hot flushes and sleep disturbances.
- **After menopause (post-menopause)**, monthly menstrual periods have stopped. The body still makes small amounts of oestrogen by changing hormones called androgens into oestrogen. Androgens are produced by the adrenal glands, which are above the kidneys. A hormone called aromatase changes androgens into oestrogen. Aromatase is produced mainly by fatty tissue.

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

## Types of hormonal therapies

There are several different types of hormonal therapies. If hormonal therapies are suitable for you, the therapies recommended will depend on whether you have reached menopause. If you are not sure whether you have reached menopause, talk to your doctor.

### Ovarian treatments

Ovarian treatments work by stopping the ovaries from making oestrogen. Drugs like goserelin (Zoladex®) temporarily stop the ovaries from making oestrogen. They only work while you are taking the drug. This is called **ovarian suppression**. Goserelin is given as an injection under the skin every month.

Oestrogen production can also be stopped permanently by removing the ovaries surgically (oophorectomy) or, rarely, by giving radiotherapy to the ovaries. **Ovarian treatments are only suitable for women who have not yet reached menopause.**

### Anti-oestrogens

Anti-oestrogens work by stopping breast cancer cells from getting oestrogen. The most common anti-oestrogen is tamoxifen. **Tamoxifen can be used to treat women of any age, regardless of whether they have reached menopause.** Tamoxifen is taken as a single tablet every day.

Fulvestrant (Faslodex®) is another anti-oestrogen that is given as a monthly injection into the muscle of the buttock. It may be recommended if other hormonal therapies have stopped working or if you cannot take tablets because you are feeling sick.

### Aromatase inhibitors

Aromatase inhibitors work by stopping androgens from being changed to oestrogen. Examples of aromatase inhibitors include anastrozole (Arimidex®), letrozole (Femara®) and exemestane (Aromasin®). **Aromatase inhibitors are only effective for women who have gone through menopause permanently.**

Aromatase inhibitors are not suitable for you if:

- you have not yet reached menopause
- you are in the middle of menopause
- your menstrual periods have stopped temporarily because of other treatments you are receiving.

Aromatase inhibitors are taken as a single tablet every day.

### Progestins

Progestins are artificial forms of the female hormone progesterone. The most common progestins are megestrol acetate (Megace®) and medroxyprogesterone (Provera®). Progestins are given as a tablet. Aromatase

inhibitors are more effective than progestins in women who have reached menopause. In general, progestins are only recommended if other hormonal therapies have stopped controlling the cancer.

## Side effects of hormonal therapies

Everyone is different in how they respond to treatment with hormonal therapies. Some side effects are common to all hormonal therapies, and some only happen with certain therapies. For some of the newer drugs, such as aromatase inhibitors, we do not yet know all the long-term side effects.

**Ask your doctor about the possible side effects of the hormonal therapy recommended for you.**

All hormonal therapies can cause menopausal symptoms. These include:

- hot flushes
- vaginal dryness
- reduced libido (sex drive).

There are treatments that can help with these problems — ask your doctor or nurse for more information. The severity of these symptoms varies between women and between treatments.

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

Treatment with hormonal therapies can sometimes cause permanent menopause. This means you will be unable to have children after treatment. If you have not yet reached menopause, talk to a specialist before starting treatment. **Infertility can be very hard to come to terms with, and not only for women who are planning to have children in the future. Talk to your doctor about your feelings and concerns.** Even if your periods stop while you are taking an anti-oestrogen, it is possible for you to become pregnant. It is important to use a non-hormonal form of contraception if you are sexually active while you are taking anti-oestrogens.



National Breast and Ovarian Cancer Centre has a booklet about menopause for younger women with breast cancer. To order a copy, go to [www.nbocc.org.au/resources](http://www.nbocc.org.au/resources) or call 1800 624 873.

## Additional side effects of ovarian treatments

Surgery to remove the ovaries or radiotherapy to the ovaries causes permanent menopause. Women who have these treatments can no longer have children. Drugs that stop the ovaries from working also cause menopause, but this usually only lasts while you are taking the drugs. However, the effects of these drugs may be permanent if you are close to your natural menopause when you start treatment.

**Talk to your doctor about whether your ovarian treatment will cause temporary or permanent menopause.**

## Additional side effects of tamoxifen

Rare side effects of tamoxifen include an increased risk of:

- blood clots
- stroke
- changes in vision.

Tamoxifen can also cause changes to the uterus (lining of the womb) and in rare cases has been associated with an increased risk of cancer of the uterus.

**See your doctor immediately if you have any new or unusual symptoms, in particular if you have:**

- irregular vaginal bleeding
- chest pain
- warmth, pain, swelling or tenderness in an arm or leg.

Irregular vaginal bleeding does not mean that you have cancer of the uterus but you will need to be examined by a doctor to be sure.

Tamoxifen may have some other benefits in addition to treating your cancer, including reducing your risk of osteoporosis and lowering your cholesterol level.



**Osteoporosis:** thinning of the bones that develops as a result of ageing.

**Uterus:** another name for the womb.

### Additional side effects of aromatase inhibitors

Some of the side effects of aromatase inhibitors are similar to those of tamoxifen. The risk of hot flushes, stroke and vaginal bleeding is lower with aromatase inhibitors than with tamoxifen.

Side effects of aromatase inhibitors include:

- pain in the bones or joints (arthralgia)
- an increased risk of fractures due to osteoporosis.

Your doctor may measure your bone density before prescribing an aromatase inhibitor if you are at increased risk of osteoporosis. If you are already at increased risk of osteoporosis, your doctor will consider this when recommending which hormonal therapy is suitable for you. Treatments are available that can improve bone strength. **Talk to your doctor about how to reduce the risk of fractures and maintain bone strength.**

### Additional side effects of progestins

Treatment with progestins may increase your appetite. This means that you may put on weight. Other possible side effects include muscle cramps and light vaginal bleeding (spotting).

***“Talk to your doctor, nurse and dietitian about weight loss and weight gain. I found my dietitian to be very helpful.”***

### Deciding about hormonal therapies

Your doctor will recommend the treatments that are best for you. Some general guidance to help you to decide about hormonal therapies is provided below.

### Before menopause

If you have not yet reached menopause and your cancer cells are hormone receptor positive, it is usually recommended that you start treatment with tamoxifen and an ovarian suppression drug. Your doctor may suggest that you start treatment with tamoxifen alone but may add an ovarian suppression drug if your cancer does not respond to the treatment as well as it could.

### After menopause

If you have reached menopause and your cancer cells have hormone receptors, it is usually recommended that you start treatment with an aromatase inhibitor. If you are already taking tamoxifen when your secondary breast cancer is diagnosed, it is recommended that you change to an aromatase inhibitor.

If your breast cancer stops responding to treatment with an aromatase inhibitor, or if you have side effects that are not manageable, your doctor may recommend that you change to a different type of hormonal therapy.

In general, fulvestrant and progestins are only recommended if other hormonal therapies have stopped controlling the cancer.

### Questions yet to be answered about hormonal therapies

As with many cancer treatments, there are important things we still do not know about some of the newer hormonal therapies. Clinical trials to answer these questions are ongoing and more information will become available in the future.

Some of these questions include:

- whether giving an aromatase inhibitor with an ovarian suppression drug or fulvestrant is helpful for women who have not reached menopause
- which hormonal therapies are best for women who develop secondary breast cancer while taking an aromatase inhibitor

- how the benefits and risks of different aromatase inhibitors compare with each other
- how the benefits and risks of fulvestrant compare with aromatase inhibitors
- what effects hormonal therapies have on the day-to-day life of women with secondary breast cancer
- the long-term side effects of hormonal therapies.



## Questions to ask about hormonal therapies

Listed below are some questions that might be useful when discussing hormonal therapies with your doctors.

- Can I benefit from hormonal therapy? How?
- Which hormonal therapies are suitable for me? Why?
- What does the hormonal therapy you are recommending involve?
- How much will the hormonal therapy you are recommending cost?
- What are the side effects of the hormonal therapy you are recommending?
- Is there anything I can do to reduce the risk or impact of these side effects?
- Whom should I contact if side effects develop?
- How can I manage side effects if they develop?
- Will hormonal therapy affect my ability to have children?
- Do I still need to use contraception if I am having hormonal therapy?

You may like to write your own questions here:

This image shows a full page of white paper with horizontal blue dashed lines. The lines are evenly spaced and run across the width of the page, providing a guide for handwriting practice. There are no margins, text, or other markings on the page.

## Frequently asked questions

### How do I know if I am hormone receptor-positive?

If secondary breast cancer is your first diagnosis of breast cancer, your surgeon will probably do a biopsy to see whether there are hormone receptors on your cancer cells. If you have been diagnosed with early or locally advanced breast cancer before, your pathology report may show whether your breast cancer was hormone receptor positive. However, your surgeon may decide to do another biopsy to see whether there has been any change in the receptors on your cancer cells.

### How do I choose which hormonal therapy to have?

The decision about whether to have hormonal therapies and which one is best for you will depend on your individual situation. This includes:

- whether there are hormone receptors on your breast cancer cells
- whether you have reached menopause
- whether you have taken a hormonal therapy in the past
- whether you have completed your family
- your preference.

When recommending which hormonal therapy is best for you, your doctor will consider the likely benefits and possible side effects of the different treatments.

### If I have side effects, can I lower my dose of hormonal therapy?

The recommended doses of hormonal therapies are the ones that have been shown to be beneficial in clinical trials. Taking lower doses or less frequent doses is not a good idea. If you have side effects that are concerning you, it is important that you discuss them with your oncologist, surgeon or GP.

### If I change GPs during treatment, what should I do?

If you change GPs while you are taking hormonal therapies, it is important to let your new GP know what you are taking.

### If I run out of my script, can my GP renew it?

Your GP can renew most hormonal therapy scripts. Ask your treatment team about the therapy you have been prescribed.

### If I am planning to have surgery (including dental surgery), can I continue to take my hormonal therapy?

Tamoxifen increases the risk of blood clots. If you are likely to be confined to bed or if your movement is likely to be limited for a period of time, your doctor may recommend that you stop taking your hormonal therapy before surgery. If your doctor suggests that you stop taking your hormonal therapy, you should not start taking it again until you are fully mobile after surgery. Talk to your doctor about what you should do if you are planning to have surgery.

### If I miss a dose of hormonal therapy, should I take a double dose?

No. Just take the next dose as normal. You can take the tablet with or without food at any time of the day. It is best to pick the most convenient time, for example in the morning when you take other tablets, and stick to that time.

### If I have side effects of treatment that worry me, can I change to another hormonal therapy?

This may be possible. Talk to your doctor about your options if you have side effects that you are finding difficult to manage.



## How long will hormonal therapy be of benefit for me?

There is no easy answer to this question. It depends on you as an individual. Some women use hormonal therapies for several years, for others treatment only works for a few months. Talk to your oncologist about your particular situation.

## What can I do to manage side effects?

The severity of side effects of hormonal therapies, such as hot flushes and vaginal dryness, vary for different women. For most women, side effects are mild and not troublesome, but for some women these side effects can be distressing. Talk to your GP or nurse about how to manage symptoms.



National Breast and Ovarian Cancer Centre has a booklet about menopause for younger women with breast cancer. To order a copy, go to [www.nbocc.org.au/resources](http://www.nbocc.org.au/resources) or call 1800 624 873.

## Chemotherapy

Date of development: November 2009

### Summary

- Chemotherapy involves using one or more drugs to stop cancer cells from growing or spreading, to relieve symptoms and improve quality of life.
- There are many different types of chemotherapy drugs, each with different side effects.
- The benefits of treatment with chemotherapy can last for some time — sometimes for years.
- If you have had chemotherapy before, it is unlikely that you will have the same drugs again, and the side effects may be different.
- Most side effects of chemotherapy can be managed with medical care.

### What is chemotherapy?

Chemotherapy is the name for drugs used to treat cancer. The aim of chemotherapy for secondary breast cancer is to stop the cancer from growing or spreading, to relieve symptoms and improve quality of life. For some people, chemotherapy can make the cancer smaller. The benefits of treatment with chemotherapy can last for some time — sometimes for years.

Chemotherapy works by killing cells that are dividing rapidly, such as cancer cells. As well as killing cancer cells, chemotherapy also kills normal cells that are dividing rapidly. However, unlike cancer cells, normal cells can repair the damage and can recover. The main areas of the body that are affected by chemotherapy are the mouth, stomach and bowel (gut), skin, hair and bone marrow. Damage to these normal cells causes the side effects of chemotherapy.

When deciding about treatment for secondary breast cancer, it is important to weigh up the possible benefits and side effects of treatment for your situation. Some women are prepared to deal with more side effects of treatment if there is an increased chance that the chemotherapy will work. For other women, it is more important to have time free of side effects. Talk to your treatment team about your preferences and what is important for you.



**Bone marrow:** a spongy material within some bones that makes different types of blood cells.

### When is chemotherapy recommended?

Chemotherapy is usually recommended for women with secondary breast cancer who:

- do not have hormone receptors on their breast cancer cells
- have hormone receptors on their breast cancer cells but have stopped responding to hormonal therapies
- have a fast-growing cancer, especially if it is in the liver or lungs.

Talk to your doctors about whether chemotherapy is recommended for you.

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

### Types of chemotherapy

Several different types of chemotherapy are used to treat secondary breast cancer. **Currently, the most effective chemotherapy treatments for secondary breast cancer involve more than one drug.** However, having more than one drug can also mean more side effects.

Chemotherapy drugs are grouped based on how they work. The main chemotherapy drugs used to treat secondary breast cancer are:

- **taxanes** such as paclitaxel (Taxol®), docetaxel (Taxotere®)
- **antimetabolites** such as capecitabine (Xeloda®), 5-fluorouracil (5-FU), gemcitabine (Gemzar®)
- **anthracyclines** such as doxorubicin (Adriamycin®), epirubicin (Pharmorubicin®)
- **alkylating agents** such as cyclophosphamide.

Combinations of chemotherapy are often talked about using the initials of the drugs being used. For example, **FEC chemotherapy** is a combination of 5-fluorouracil, epirubicin and cyclophosphamide.

You may also have the option of a newer chemotherapy drug not listed here, as part of a clinical trial.



For more information about clinical trials, see the ‘Clinical trials’ chapter later in this section.

### What does chemotherapy involve?

Before you start treatment, you will meet with a medical oncologist. He or she will talk to you about the types of chemotherapy recommended for you and their side effects. Not all hospitals have a medical oncologist. If you live in an area where there is no medical oncologist, your treatment may be managed by another doctor such as your GP. If this happens, the doctor will talk regularly about your treatment to a medical oncologist in another hospital. Alternatively, you may decide to travel to another hospital to meet a medical oncologist to talk about your options and receive your treatment.



For information about practical and financial support during treatment, including government-funded patient transport schemes, see the ‘Finding support’ section.



A woman receiving intravenous chemotherapy by drip



**Medical oncologist:** a doctor who specialises in prescribing and giving cancer drugs.

## Having chemotherapy

The most common way to give chemotherapy is by injection into a vein. This is called **intravenous chemotherapy**. The drugs are given using a 'drip', usually into the hand or arm. Some chemotherapy drugs are given as a tablet. You may have a combination of tablets and intravenous chemotherapy.

Sometimes it can be difficult to find a suitable vein through which to give chemotherapy. If this happens, your doctor may talk to you about having a long-term access device (infusaport or Portacath®) or a PICC line (peripherally inserted central catheter). This involves putting a thin soft plastic tube into a vein in your chest or arm that can be left in for weeks or months. The tube can be used to give chemotherapy into your vein. Sometimes, the tube connects to a disc (the 'port') under the skin of your chest. You will be able to see or feel a bump under your skin but there will not be anything visible on the outside of your body. A member of your healthcare team will talk to you about how to look after the infusaport/ Portacath® or PICC line.



Delivering intravenous chemotherapy into the blood stream

Once chemotherapy starts, you will usually have treatment in a clinic or hospital as an outpatient. This means you do not need to stay overnight. If you are having treatment through a drip, you will usually be able to choose the day of the week on which you have treatment. Your chemotherapy will usually be given by a chemotherapy nurse. You may have your chemotherapy in a room or ward with other people who are receiving chemotherapy. If you live in a rural area, it may be possible for a nurse to visit you at home to give you your treatment.

### Treatment cycles

Chemotherapy is usually given in 'cycles'. Each cycle involves a short period of treatment followed by a rest period in which you do not have treatment. This gives your body a chance to recover between treatments. Depending on your situation, you may have chemotherapy treatment every day, every week, every three weeks or every month. How often you have chemotherapy and how long treatment is continued will depend on:

- the drugs that are used
- how well the chemotherapy is controlling your cancer
- the side effects of treatment
- your preference.

Your doctors will do tests every 6–12 weeks while you are receiving chemotherapy to see how your breast cancer is responding to treatment. Your breast cancer is said to be responding well if the growth or spread of the cancer is slowed or stopped by treatment and the side effects of treatment are manageable. It is likely that treatment will be continued until the side effects are significant or until the cancer stops responding to the treatment. Treatment may be continued for longer than this, if your breast cancer is responding well and the side effects of treatment are manageable. In most instances, chemotherapy is stopped after about six months. Trials have shown that, on average, extending chemotherapy beyond the standard duration has little or no effect on overall survival.

If your breast cancer does not respond to treatment, your doctor may recommend changing drugs or stopping chemotherapy. Sometimes the dose of drugs might be changed or delayed to help to manage the side effects. If you are concerned about what effect a delay or change in dose will have, talk to your doctor.

### Side effects of chemotherapy

Chemotherapy drugs affect individual women in different ways. You may have fewer or more side effects than another woman receiving the same drugs. Or the side effects you experience may be more or less intense than for other women.

**Before you start treatment**, ask your doctor to tell you about the common side effects of the drugs recommended for you.

**After starting chemotherapy**, tell your doctor about any side effects you are experiencing. You might find it helpful to keep a diary of side effects. Write down what the symptoms are, when they happen and how long they last, so that you can discuss them with your doctor at your next appointment.

**Tell your doctor about any side effects you are experiencing — even if you do not think they are serious. Most side effects of chemotherapy can be managed with medical care. Ask for an out-of-hours contact number so you can get help if you develop any serious side effects.**

The following section lists some of the side effects of chemotherapy. The list may seem long and overwhelming. **It is unlikely that you will have many or all of these side effects.** It is possible to have chemotherapy with very few side effects. If this happens to you, it does not mean that the chemotherapy is not working.

**Most side effects of chemotherapy can be managed.**



For more information about managing symptoms and side effects, see the 'Symptoms and side effects' section.

## Common side effects of chemotherapy

### Nausea and vomiting

Nausea ('feeling sick') and vomiting are common side effects of chemotherapy. These symptoms are less common with chemotherapy treatments that involve taxanes.

Some women become nervous or worried before their next cycle of treatment and this can make them feel sick or vomit. This is called **anticipatory nausea**. Talk to your doctor if this happens to you, as treatments are available that can help.

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

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

### Fatigue (tiredness)

Fatigue (feeling tired) is a common side effect of chemotherapy and can last 3–6 months after treatment is over. Fatigue can also be due to **anaemia** caused by chemotherapy. You will have blood tests while you are having chemotherapy so that your doctor can check your blood cell count. If you develop significant anaemia with your treatment, your doctor may recommend a red blood cell transfusion.



**Anaemia:** a condition in which there are fewer red blood cells in the blood than normal.

### Hair loss

Not all chemotherapy drugs cause hair loss. Hair loss is more common with chemotherapy treatments that include anthracyclines and taxanes. If you do lose all or some of your hair, it will grow back within weeks or months of stopping chemotherapy.

Ask your doctor about the risk of hair loss from the chemotherapy treatment recommended for you.

Hair loss from chemotherapy can range from mild thinning of the hair to total hair loss (including body hair). When your hair grows back it might be a different texture and/or colour than before treatment. Although losing your hair may not seem serious compared with coping with breast cancer, many women find it upsetting. Losing your hair may affect how you feel about yourself and your sexuality. **Talk to your doctor or nurse about how you are feeling.**

*"I'd just grown my hair to shoulder length and I really liked it. That was one of the hardest things."*



For more information about your feelings, including your body image and sexuality, see the 'Finding support' section.

### Diarrhoea or constipation

Some women experience diarrhoea or constipation during chemotherapy. If you have diarrhoea during chemotherapy, your doctor can recommend medication to control this.

Constipation can be caused by chemotherapy and some anti-emetic drugs, or it can develop because you are less active or eat less during treatment.



**Anti-emetic drugs:** drugs used to control nausea and vomiting.

### Weight gain or weight loss

Some women lose their appetite during chemotherapy and lose weight. If you lose your appetite, try to eat small meals and snacks as often as you can throughout the day. Other women find that they put on weight during treatment because they become less active, and due to some of the drugs used to treat the nausea associated with chemotherapy. Doing gentle exercise can help to prevent weight gain during chemotherapy. Talk to your doctor or nurse about what exercises are suitable for you, or call the **Cancer Council Helpline** on **13 11 20** for information about diet and exercise.





For more information about your feelings including your body image and sexuality, see the 'Finding support' section.

### Mouth ulcers

Some women receiving chemotherapy get mouth ulcers. Mouth ulcers usually occur about 5–10 days after starting chemotherapy and clear up within 1–2 weeks. It is important that you keep your mouth clean while you are having chemotherapy. Talk to your medical oncologist or chemotherapy nurse about what you can do to help to reduce the risk of mouth ulcers.

Sometimes chemotherapy can cause other infections in your mouth, such as thrush or cold sores. **Talk to your doctor about any infections in your mouth, so they can be treated.**



**Thrush:** an infection caused by yeast that appears as white patches on the tongue or mouth.

### Hand-foot syndrome

If you have chemotherapy that includes capecitabine (Xeloda®) or liposomal doxorubicin (Caelyx®), you may develop a condition called hand-foot syndrome. The skin of the hands or feet can become red, swollen, cracked or painful. For many women, symptoms are mild and do not interfere with daily activities. However, for some women, the symptoms can be very painful and can make it difficult to walk or use their hands. Tell a member of your healthcare team if you notice skin changes on your hands and feet.

### Skin and nail problems

Some women have minor skin problems while they are having other types of chemotherapy. These include redness, itching, peeling, dryness or acne. Some women's nails become darker, brittle or cracked. Some chemotherapy drugs may make your skin more sensitive to the sun. If you are having these drugs, it is recommended that you avoid being in the sun for long periods, and use sunscreen when outdoors.

Most skin and nail problems are not serious. **However, if you develop a rash or sudden or severe itching, or if you have difficulty breathing, you should seek medical assistance immediately from your doctor or hospital emergency department.** These may be symptoms of a severe allergic reaction that requires treatment as soon as possible.

### Nerve and muscle problems

Some chemotherapy drugs can cause nerve and muscle problems during treatment. Severe problems are uncommon. Symptoms that are more common include tingling, burning or numbness in the hands or feet. Some women have problems with balance or have weak or sore muscles for a few days after chemotherapy.

**Tell your doctor about any nerve or muscle problems, so that your treatment can be adjusted.**

### Depression or anxiety

Some women feel depressed, sad or teary before, during and after chemotherapy. Others feel anxious, worried, nervous or upset. Some sadness, depression and anxiety is normal. If your feelings are severe, interrupting things at home, or affecting your relationships, talk to your healthcare team about how you are feeling. Treatments are available that can help.



For more information about your feelings, see the 'Finding support' section.

### Menopausal symptoms and permanent menopause

Younger women may experience menopausal symptoms during chemotherapy. For some women, this menopause may be permanent. The closer you are to the age of natural menopause, the more likely it is that menopause will be permanent. If your menopause is permanent, you will be unable to have children naturally after treatment.

If being able to have children is important for you, speak to your oncologist before starting treatment. Your oncologist may suggest that you see a fertility specialist to discuss your options.



National Breast and Ovarian Cancer Centre has a booklet about menopause for younger women with breast cancer. To order a copy, go to [www.nbocc.org.au/resources](http://www.nbocc.org.au/resources) or call 1800 624 873.

For more information about breast cancer and fertility, see the 'Symptoms and side effects' section.

## Sexual difficulties

Many women have some sexual difficulties during chemotherapy treatment. This can be because you feel unwell or because of how you feel about your body due to side effects of treatment. Some women experience these feelings for a while after treatment is over.



For more information about sexuality and your feelings, see the 'Finding support' section.

## Less common side effects

### Feeling vague or 'in a fog'

Some women feel 'vague' or mildly confused or have memory problems while having chemotherapy. This can last for some months after treatment is over. The causes of these effects are being studied. **Talk to your doctor about any symptoms that concern you.**

### Rare side effects

The following side effects of chemotherapy are *rare but can be quite serious*. **Talk to your medical oncologist, GP or nurse if you develop any of these side effects.** If these side effects develop during treatment, the chemotherapy drugs will be changed or the dose decreased.

## Heart problems

Some chemotherapy drugs called anthracyclines can affect the way your heart works. If your doctor thinks you may benefit from anthracycline chemotherapy, you may have some tests on your heart before and during treatment. Symptoms of heart problems include very low blood pressure, breathing difficulties, tightness in the chest, chest pains, shortness of breath or an irregular heartbeat. **Tell your doctor immediately (or go to your hospital emergency department if your doctor is not available) if you experience any of these symptoms.**

## Swelling in the arms or legs

Swelling or fluid retention, particularly in the arms and/or legs, is most commonly associated with the use of a taxanes. Swelling is most common in the feet and ankles due to the effects of gravity. The risk of arm or leg swelling can be reduced by giving another medication before chemotherapy. Symptoms will slowly improve once treatment is over. Arm and leg swelling associated with chemotherapy rarely requires any specific treatment. However, your medical oncologist may prescribe treatment if the swelling is severe.

## Infection

Chemotherapy drugs reduce the number of white blood cells your body produces. When this happens, you might be at increased risk of developing an infection. The risk of infection is highest for people who have chemotherapy containing taxanes and anthracyclines.

Your doctor will check your white blood cell count while you are having treatment. If your white blood cell count drops, this will usually happen 1–2 weeks after treatment. If this happens, your doctor will probably adjust the dose of your chemotherapy or suggest a different treatment.



**White blood cells:** blood cells produced by the bone marrow that help the body to fight infections.

Tell your doctor immediately (or go to your hospital emergency department if your doctor is not available) if you have:

- a fever (a temperature greater than 38°C)
- chills
- severe sweats.

This could be the first sign of a serious, life-threatening infection and you may need immediate treatment with strong antibiotics. If these signs develop during the night or on a weekend, call the out-of-hours number given to you by your doctor. If you see your GP, they should take your symptoms seriously, arrange for you to have a blood test and contact your oncologist.

Other symptoms of infection include:

- loose bowels
- a burning sensation when you urinate
- severe cough or sore throat
- unusual vaginal discharge or itching
- redness, swelling or tenderness around a wound, sore, pimple, boil, or the site where you have had a drip for your chemotherapy.

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

### Bleeding or bruising (rare)

In rare cases, chemotherapy can make you bleed or bruise easily. This is because chemotherapy can affect cells in your blood called platelets. Your doctor will check your platelet count while you are having chemotherapy. If chemotherapy affects your platelets, this will usually happen 1–2 weeks after treatment.



**Platelets:** blood cells produced by the bone marrow that help the blood to clot.

Tell your doctor as soon as possible if you experience any of the following symptoms:

- bruising easily
- bleeding from the gums or nose
- reddish urine
- black or bloody bowel motions (stools).

If these signs develop during the night or on a weekend, call the out-of-hours number given to you by your doctor. Unusual bruising or bleeding can be treated by a platelet transfusion. With some chemotherapy drugs, it is normal to have reddish urine for 24 hours after treatment. Your doctor will tell you if this is the case with the chemotherapy you are receiving. Reddish urine caused by an infection usually develops a few days or longer after treatment.



**Transfusion:** the transfer of blood or blood products from a donor to another person.

### Kidney and bladder problems (rare)

Some chemotherapy drugs can irritate the bladder or cause damage to the kidneys. In very rare cases, this damage can be permanent. Ask your doctor about whether the drugs you are taking could affect your bladder or kidneys.

Drinking plenty of fluid can help to prevent kidney and bladder problems. If you do develop kidney or bladder problems, this will usually happen a few days or longer after chemotherapy treatment.

Contact your doctor as soon as possible if you experience:

- pain or burning when you pass urine
- frequent urination
- a feeling that you must urinate right away
- reddish or bloody urine
- fever or chills.



If these signs develop during the night or on a weekend, call the out-of-hours number given to you by your doctor. With some chemotherapy drugs, it is normal to have reddish urine for 24 hours after treatment. Your doctor will tell you if this is the case with the chemotherapy you are receiving. Reddish urine caused by an infection in the bladder or kidneys usually develops a few days or longer after treatment.

## Deciding about chemotherapy

The types of chemotherapy and the frequency and duration of treatment recommended for you will depend on a number of things, including:

- whether you have particular receptors on your cancer cells
- which parts of your body are affected by your breast cancer and how fast the cancer cells are growing
- what treatments you have received in the past (if you have had chemotherapy before, it is likely you will receive different drugs this time)
- whether you have other medical conditions
- the possible effects of treatment on your quality of life (for example, the likely side effects of treatment)
- practical considerations (for example, some treatments may require you to have more clinic visits than others)
- your preference.

## Questions yet to be answered about chemotherapy

There are still things we do not know about many cancer drugs. Clinical trials to answer these questions are ongoing and more information will become available in the future. Some of these questions include:

- the ideal length of time for which chemotherapy should be given
- whether there are other tests that can be used to decide how best to tailor chemotherapy to individual patients.



## Questions to ask about chemotherapy

Listed below are some questions that might be useful when discussing chemotherapy with your doctors.

- How will chemotherapy benefit me?
- Which chemotherapy drug(s) do you recommend for me? Why?
- If I have chemotherapy, when will it start?
- If I have chemotherapy, how will it be given and for how long?
- Will I need tests while I am having chemotherapy? When?
- How much will the chemotherapy cost?
- What are the side effects of the drugs you are recommending?
- How can I manage side effects if they develop?
- Are the side effects permanent or temporary?
- Whom should I contact if I have side effects or other problems?
- Is there an out-of-hours number I can call if I develop serious side effects during the night or on weekends?
- Will chemotherapy affect my ability to have children?
- Can I still work while I am having chemotherapy?
- If I am having complementary therapies, how will they affect the chemotherapy?
- What exercises do you recommend while I am having chemotherapy?
- What sort of food should I eat while I am having chemotherapy?

[illegible]

## How do I decide whether to have chemotherapy?

### How often will I have treatment?

## Will chemotherapy make me lose my hair?

## Will having a higher dose of chemotherapy increase the chance of it working?

The doses of chemotherapy recommended are the ones that have been shown in clinical trials to be most effective with manageable side effects. In general, higher than recommended doses do not improve the overall response to treatment and can cause increased side effects.

## Targeted therapies

Date of development: November 2009

### Summary

- Targeted therapies (sometimes called biological therapies) are drugs used to treat certain types of cancer cells.
- Targeted therapies are only suitable for some women with secondary breast cancer.
- Targeted therapies include trastuzumab (Herceptin®), lapatinib (Tykerb®) and bevacizumab (Avastin®).
- Other targeted therapies are being tested in clinical trials.

### What are targeted therapies?

**Targeted therapies are drugs used to treat certain types of cancer cells.**

Targeted therapies are only effective for people with particular types of cancer cells. Targeted therapies may be used in combination with chemotherapy. Targeted therapies available in Australia for secondary breast cancer include:

- trastuzumab (Herceptin®) — only effective for HER2-positive breast cancer
- lapatinib (Tykerb®) — only effective for HER2-positive breast cancer
- bevacizumab (Avastin®) — potentially effective for secondary breast cancer, irrespective of HER2 status



The area of targeted therapies is changing rapidly as researchers find out more about breast cancer and how to treat it. New drugs are in development. Ask your doctor for more information about targeted therapies that are not listed here.

### What is HER2-positive secondary breast cancer?

HER2 is a protein that helps cells to grow and divide. Some women with secondary breast cancer have higher than normal levels of the HER2 protein. This is called 'HER2-positive breast cancer'. About one in five women with breast cancer have HER2-positive breast cancer.

Your pathology report shows whether your breast cancer cells are HER2-positive.

If secondary breast cancer is your first diagnosis of breast cancer, your surgeon will probably do a biopsy to see whether there are HER2 receptors on your cancer cells. If you have been diagnosed with early or locally advanced breast cancer before, your pathology report may show your HER2 status. However, your surgeon may decide to do another biopsy to see whether there has been any change in the receptors on your cancer cells.



**HER2:** a protein on a cell that allows a growth factor to bind to the cell, causing the cell to grow and divide. HER2 is also called HER2-neu or c-erbB2.

### Trastuzumab (Herceptin®)

Trastuzumab (Herceptin®) is recommended for people with HER2-positive breast cancer. Clinical trials have shown that trastuzumab can decrease the size of secondary breast cancers and can increase survival for people with secondary breast cancer.

**If your breast cancer cells are not HER2-positive, trastuzumab will have no benefit for you.** Trastuzumab may be given on its own or with other treatments for secondary breast cancer:

- if you are taking an aromatase inhibitor for secondary breast cancer, it is recommended that you have trastuzumab at the same time
- if you have not already had chemotherapy for secondary breast cancer, it is recommended that you have trastuzumab at the same time as chemotherapy

- if you have already had chemotherapy for secondary breast cancer or if chemotherapy is not suitable for you, you can have trastuzumab on its own.

If you have been given trastuzumab previously for early breast cancer, you may be given it again to treat secondary breast cancer.

Trastuzumab can be given at the same time as radiotherapy. However, we do not yet know the long-term effects of giving trastuzumab at the same time as radiotherapy.

### What does treatment with Trastuzumab involve?

Trastuzumab is given by slow intravenous (IV) infusion. A healthcare professional gives the infusion once a week or once every three weeks. You and your doctor will decide for how long trastuzumab is given to you. The dose will depend on how much you weigh.



**Intravenous infusion:** a method of putting fluids, including drugs, into the bloodstream through a fine tube (cannula) or needle.

Treatment with trastuzumab will usually continue as long as you are benefiting from treatment, and as long as the benefits outweigh the risks and side effects.

**Talk to your oncologist about the expected length of treatment for you.**

### Side effects of Trastuzumab

The most significant side effect of trastuzumab is the risk of heart problems. This risk is increased if trastuzumab is given with certain types of chemotherapy called anthracyclines. **Trastuzumab should not be given at the same time as chemotherapy that contains an anthracycline (epirubicin, doxorubicin, adriamycin).**



For more information about chemotherapy drugs used to treat secondary breast cancer, see the 'Chemotherapy' chapter earlier in this section.

**Trastuzumab is generally not recommended for patients with pre-existing heart problems.** Before starting trastuzumab treatment, your doctor will check your heart using an **echocardiogram** or a **multi-gated acquisition (MUGA) scan**. Your doctor should also check your heart at intervals while you are receiving treatment. If you develop heart problems while you are receiving trastuzumab, you should have more frequent heart checks and you may need to see a **cardiologist**.

Symptoms of heart problems include very low blood pressure, breathing difficulties, tightness in the chest, chest pains, shortness of breath or an irregular heartbeat.



**Cardiologist:** a doctor who specialises in diagnosing and treating heart problems.

**Echocardiogram:** a type of ultrasound test that looks at the size, shape and function of the heart.

**Multi-gated acquisition (MUGA) scan:** a test that measures how well the heart pumps blood.

Other possible side effects of trastuzumab include allergic reactions, such as chills and fever. Tell your doctor about any new symptoms or if any of your symptoms become worse. **Talk to your doctor about possible side effects of trastuzumab and ways of managing these side effects if they develop.**

### Lapatinib (Tykerb®)

Another targeted therapy for women with HER2-positive secondary breast cancer is lapatinib (Tykerb®). Clinical trials have shown that when given in combination with a chemotherapy drug called capecitabine (Xeloda®), lapatinib slows the progression of advanced breast cancer.

Lapatinib may be offered to women whose secondary breast cancer has stopped responding to a combination of trastuzumab and chemotherapy.

**If your breast cancer cells are not HER2-positive, lapatinib will have no benefit for you.**

### What does treatment with Lapatinib involve?

Lapatinib is a tablet that is taken every day (usually 5–6 tablets a day). It is taken with a chemotherapy drug called capecitabine (Xeloda®).

### Side effects of Lapatinib

Common side effects of lapatinib include diarrhoea, hand–foot syndrome, anaemia and nausea. Other possible side effects include dyspepsia, liver dysfunction and rash.



**Hand–foot syndrome:** redness, tenderness, and peeling of the skin on the palms of the hands and soles of the feet, caused by certain chemotherapy drugs.

**Dyspepsia:** another name for indigestion.

### Bevacizumab (Avastin®)

Bevacizumab is another targeted therapy sometimes used to treat women with secondary breast cancer. Bevacizumab works by targeting blood vessels associated with the tumour deposits. Clinical trials have not shown long-term benefit and the routine addition of bevacizumab to chemotherapy for women with secondary breast cancer is not recommended because the benefits do not outweigh the additional adverse effects.

Bevacizumab is given as intravenous treatment, usually every three weeks. Because bevacizumab affects blood vessels, the side effects can include high blood pressure and some kidney problems, and these are generally monitored in women having this treatment.

### Questions yet to be answered about targeted therapies

As with many drugs for breast cancer, there are important things that we still do not know about targeted therapies. Clinical trials to answer these questions are ongoing and more information will become available in the future. Some of these questions include:

- the long-term effects of targeted therapies, including effects on the heart
- the ideal length of time for which targeted therapies should be taken
- the ideal combination of targeted therapies with other therapies like hormonal therapies, chemotherapy and radiotherapy
- the use of targeted therapies during pregnancy, and the impact of treatment on fertility and contraception
- whether to continue targeted therapies once the cancer has progressed in the original site or developed in other sites
- whether other targeted therapies, including bevacizumab, are beneficial in the treatment of secondary breast cancer.



### Questions to ask about targeted therapies

Listed below are some questions you may like to ask a member of your healthcare team about targeted therapies.

- Can I benefit from treatment with a targeted therapy? Which one is suitable for me?
- What are my other treatment options if targeted therapies are not of benefit to me?
- How much will treatment cost?
- When will I start treatment with targeted therapy if I am having other treatments?
- How will treatment be given?

- Will I need to go to hospital to receive my treatment?
- How often will I have treatment?
- Will I need any extra tests or follow-up if I am receiving a targeted therapy?
- What are the possible side effects of the targeted therapy you are recommending?
- When are side effects likely to occur?
- Whom should I contact if side effects happen?
- How can I manage side effects if they develop?
- Can I take part in any clinical trials?

You may like to write your own questions here:

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## Frequently asked questions

### How do I know if targeted therapies will be of benefit to me?

Targeted therapies will only be suitable for you if your breast cancer cells have particular characteristics. For example, trastuzumab and lapatinib are only suitable for women who have HER2-positive breast cancer. About one in five people with breast cancer have HER2-positive breast cancer.

### Am I at a disadvantage if my breast cancer cells are HER2-negative?

Some women who have HER2-negative breast cancer are concerned that they are not suitable for treatment with trastuzumab or another targeted therapy. However, it is important to realise that HER2-negative breast cancer is actually a less aggressive form of breast cancer than HER2-positive breast cancer and it often responds well to chemotherapy. Research into new targeted agents that could be used in HER2-negative cancers is ongoing.

### How long will targeted therapies be of benefit to me?

There is no easy answer to this question. It depends on you as an individual. Some women use targeted therapies for many years. For others, targeted therapies only work for a few months. Treatment will usually be given until the disease progresses.

### Will Trastuzumab or Lapatinib treatment make me lose my hair?

No, hair loss is not a common side effect of trastuzumab or lapatinib. If you are also receiving chemotherapy, you may lose your hair due to the chemotherapy.

# Radiotherapy

Date of development: November 2009

## Summary

- Radiotherapy uses X-rays to destroy cancer cells.
- Radiotherapy can reduce the size of secondary breast cancers in some parts of the body.
- Radiotherapy can relieve pain caused by secondary breast cancer, especially bone pain.

## What is radiotherapy?

Radiotherapy uses X-rays to destroy cancer cells in some parts of the body.

Radiotherapy is a localised treatment, which means it only treats the area of the body it is aimed at.

## When is radiotherapy recommended?

Radiotherapy may be used to treat different parts of the body that are affected by secondary breast cancer. **Talk to your doctor about whether radiotherapy is recommended for you.**

### If cancer is in the bones

If secondary breast cancer has spread to the bones, radiotherapy may be used:

- to relieve bone pain caused by secondary breast cancer
- after surgery to prevent or treat fractures of weight-bearing bones such as the bones in the legs
- without surgery to prevent or treat fractures in non-weight-bearing bones such as the ribs.

Radiotherapy to the bones in the spine (vertebrae) may be used to prevent and treat cancer in or around the spine that may be putting pressure on the spinal cord.

*"I had radiotherapy to my spine. It really helped and I have not had a lot of lower back pain since."*

### If cancer is in the brain

If secondary breast cancer has spread to the brain, radiotherapy may be used:

- after surgery to treat cancer in one area of the brain
- instead of surgery to relieve symptoms of cancer in the brain.

Some women who have cancer in one area of the brain may have targeted radiotherapy (called **stereotactic radiotherapy**) to the part of the brain affected by the cancer, followed by radiotherapy to the whole brain.

### If cancer is in other parts of the body

If secondary breast cancer has spread to other parts of the body, radiotherapy may be used to relieve pain or swelling or to reduce the size of enlarged lymph nodes.



**Lymph nodes:** glands in the armpit and other areas of the body that protect the body from infection.

## What does radiotherapy involve?

Before you start radiotherapy, you will meet with a radiation oncologist who will plan your treatment and talk to you about what is involved. The number of radiotherapy treatments will depend on:

- where the cancer is and how big it is
- your symptoms
- your general health
- whether you have had radiotherapy before in the same area.

Not all hospitals can provide radiotherapy. It is usually available in hospitals or specialised clinics in capital cities or major regional towns. If you need to travel long distances for radiotherapy, you may be able to get some help with the costs of your travel and accommodation.



For information about financial support for breast cancer treatment, including government-funded travel schemes, see the 'Finding support' section.

## Before treatment

Before you start radiotherapy, you will meet with a radiation oncologist who will plan your treatment and talk to you about what is involved. You will be asked to visit the hospital for a planning session, usually on a separate occasion to your treatment. During the planning session, you may have an imaging test or scan of the part of the body that will be treated. Marks may be put on your skin to show the radiation therapist where to direct the radiotherapy. These marks are small and may be temporary or permanent. If they are temporary, you need to be careful not to wash them off. The radiation oncologist may or may not be present during this session.

If you are having radiotherapy to the head or neck area, a mask (or mould) of your head will be made at the planning session. You will then wear the mask during radiotherapy treatment to make sure the radiotherapy is directed at exactly the right area. Your radiotherapist or another member of the team will explain what is involved in making the mask.

## Having radiotherapy

Radiotherapy will be given by a radiation therapist. Each radiotherapy session will be in a treatment room with a radiotherapy machine. The radiation therapist will leave the room while you are having treatment but he/she will still be able to see you and can speak to you through an intercom.

Each treatment usually takes only a few minutes. However, you will need time to change and you may need to wait for the machine to become available, so you could be at the hospital for up to an hour for each treatment.

**If you feel upset or anxious during treatment, the therapist can turn off the machine and come back into the room straight away.**

## Side effects of radiotherapy

Receiving radiotherapy is painless. However, depending on which part of the body is being treated, you may have to lie in an uncomfortable position while you are having treatment. If this happens, you may find it helpful to take a painkiller 30 minutes or so before treatment.

The side effects of radiotherapy will depend on which part of your body is treated and the dose and duration of your treatment. Some of the side effects of radiotherapy may appear several months after treatment. Your follow-up care after radiotherapy will include checking for these side effects so that they can be managed as required.

**Most side effects can be managed with medical care. Talk to your radiation oncologist, radiation therapist or nurse about any side effects you are worried about or think you are developing.**

Possible side effects of radiotherapy include:

- **tiredness** — you will probably feel more tired than usual during treatment and for a few weeks after treatment
- **skin changes** — the skin on and around the treated area may become red, dry, itchy or blistered; however, skin problems are very uncommon with the doses of radiotherapy used to treat the conditions listed in this chapter
- **hair loss** — if you have radiotherapy to the brain, you will probably lose your hair; your hair will usually grow back 2–3 months after treatment but it may be thinner than it was before
- **nausea and vomiting** — you may feel sick or vomit if you have radiotherapy to parts of the abdomen; your doctor can give you an anti-emetic drug before treatment to stop this happening
- **oesophagitis** — if you have radiotherapy to the upper back or chest, your oesophagus (gullet) may become sore.





**Anti-emetics:** drugs used to control nausea and vomiting.

About one in ten people who have radiotherapy to the brain have other side effects, including headaches, in addition to loss of energy (lethargy), nausea and vomiting. These side effects can often be prevented or treated using drugs called **steroids**.



For more information about managing the side effects of treatment, see the 'Symptoms and side effects' section.

### Skin care during radiotherapy

The following information may help you to care for your skin during and after radiotherapy. Talk to the nursing and radiotherapy staff at the treatment centre about how you can look after your skin and make yourself more comfortable. **Tell the nursing or radiotherapy staff if you develop a skin reaction or if your skin reaction gets worse.**

Things that can make the skin reactions worse include:

- having chemotherapy at the same time as radiotherapy
- being overweight
- other health problems, such as diabetes
- having sun-damaged skin
- smoking.

To reduce skin reactions caused by radiotherapy, wash with a mild soap or cleanser and use a light moisturising cream — ask your doctor or nursing staff about which moisturisers they recommend. Avoid using products that contain alcohol and do not use body talc. If you are having radiotherapy to the head, use gentle hair care products.

Other suggestions, based on the experience of women having radiotherapy for breast cancer, and doctors' and nurses' observations, include:

- **wear sun protective clothes or use sunscreen** over the treated area when you are in the sun
- **do not sunbathe** — if you are having radiotherapy to the head, wear a scarf or hat if you are in strong sunlight
- **avoid irritants** — protect the skin in the treated area by avoiding chemicals (for example, perfumes, deodorants, hair dyes or hair spray) and temperature extremes during your course of radiotherapy
- **avoid damaging the skin** — protect the skin in the treated area from damage by abrasion (for example, by shaving with a wet razor); if you are having radiotherapy to the head, pat your hair dry after washing and avoid rubbing
- **keep skin folds dry.**

As long as your skin is not broken, you should be able to exercise, including swimming in either the sea or chlorinated pools, without making the skin reaction worse.

When any symptoms have settled down you can go back to your normal skin care routine. However, it is suggested that you always protect the treated area from exposure to the sun.



### Questions to ask about radiotherapy

Listed below are some questions you might want to ask a member of your healthcare team about radiotherapy.

- Is radiotherapy recommended for me?
- Where will I need to go for radiotherapy?
- If I have to travel a long way for radiotherapy, can I get financial support for travel and accommodation costs?
- How often will I have radiotherapy? How long will treatment last?
- What side effects can I expect and when? How can I manage them?

- You may like to write your own questions here:

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## Surgery

Date of development: November 2009

### Summary

- Surgery is uncommon for secondary breast cancer.
- Surgery may be used to treat breast cancer that has spread to the bones, lungs or brain, or more rarely the liver.

### When is surgery recommended?

The aim of treatment for secondary breast cancer is to destroy cancer cells that are circulating in the body or that have spread to areas of the body outside the breast. Surgery is not routinely used in the treatment of secondary breast cancer but may have an important role for some women as a way of controlling the disease or reducing symptoms in particular parts of the body.

Some of the situations in which surgery may be recommended are listed below.

### If cancer is in the breast

If secondary breast cancer is your first diagnosis of breast cancer, you will usually have a biopsy of the cancer in your breast to confirm the diagnosis and find out what receptors are on the breast cancer cells. This biopsy can usually be done under local anaesthetic. It is often not necessary to remove all of the cancer from the breast. **If you feel uncomfortable about leaving the breast cancer in your breast, talk to your doctor about surgery to remove the cancer.**

In some situations, your doctor may recommend removing all of the cancer from the breast. This will be done under a general anaesthetic.



**Biopsy:** removal of cells or tissue from the body for examination under a microscope.

Radiotherapy to the breast after surgery and removal of lymph nodes from the armpit are not usually recommended for women with secondary breast cancer.

### If cancer is in the bone

If secondary breast cancer has spread to the bone, surgery can be used to:

- prevent or treat a fracture
- replace a joint that has been damaged by cancer
- remove cancer in or around the spine that is putting pressure on the spinal cord.

Surgery to the bone is often followed by radiotherapy.

### If cancer is in the lungs

If secondary breast cancer has spread to the lungs, surgery can be used to:

- remove fluid from the pleural cavity
- treat cancer in the pleura that is not being controlled by other cancer therapies.



**Pleura:** the membrane that lines the rib cage and covers the lungs.

**Pleural cavity:** the space between the membrane that lines the rib cage and covers the lungs.

There are different types of surgery to manage cancer in the pleura. These are listed below. Some techniques can be carried out under local anaesthetic while others will require a general anaesthetic. Ask your surgeon to explain whether any of these types of surgery are recommended for you and what will be involved.

- **Pleural drainage** — involves using a needle to drain fluid from around the lungs. This will relieve breathlessness but usually symptoms will come back if the fluid returns. This procedure can be repeated as needed.

- **Tube thoracotomy** — involves inserting a tube into the pleural cavity and leaving it there to drain the fluid. Once the fluid has drained, drugs can be used to harden the pleura and stop fluid from leaking into the pleural cavity.
- **Thoracoscopy and talc insufflations** — involve inserting an instrument called a thoroscope into the pleural cavity, which allows the surgeon to look into the cavity. The fluid is drained and talc is sprayed into the pleural cavity, which makes the pleura harder and stops fluid leaking into the pleural cavity.

### If cancer is in the brain

If secondary breast cancer has spread to the brain, surgery may be used to remove the cancer. This is usually only appropriate if the cancer is small and in one area of the brain. Surgery to remove cancer from one area of the brain is usually followed by radiotherapy.

Surgery may also be used to drain fluid from the brain.

### If cancer is in the liver

If secondary breast cancer has spread to the liver surgery is rarely performed. This is usually only appropriate if one isolated area of the liver is affected.

### Other reasons for surgery

Surgery may be used to treat other symptoms of secondary breast cancer. These include:

- cancer that has grown through the skin
- cancer that has blocked the bowel
- cancer that is pressing on nerves in the body causing nerve pain.

## What does surgery involve?

The length of your operation and your stay in hospital will depend on the type of surgery you have. If you live in a rural or regional area, you may have to travel for surgery. If you need to travel long distances for surgery, you may be able to get some help with the costs of your travel and accommodation.



For information about financial support for breast cancer treatment, see the 'Finding support' section.



## Questions to ask about surgery

Listed below are some questions you might want to ask a member of your healthcare team about surgery.

- Do I need to have surgery?
- What will surgery involve?
- What are the benefits to me of having surgery?
- Will I have scars after surgery? Where will they be and what will they look like?
- How long will I be in hospital?
- How long will I take to recover from surgery?
- What side effects can I expect?
- Whom should I contact if side effects happen?
- How much will the surgery cost?
- What difference will surgery make to the quality of my life?

[illegible]

**If secondary breast cancer is my first diagnosis of breast cancer, why is surgery to the breast usually not recommended?**

## Palliative care

Date of development: November 2009

### Summary

- Palliative care improves quality of life for people who have a disease that cannot be cured.
- Palliative care is not just for people who are dying, but can begin soon after a diagnosis of secondary breast cancer.
- Palliative care provides pain control and treatment of other symptoms.
- Palliative care also provides emotional, spiritual and social support to patients and their families.

### What is palliative care?

Palliative care is specialised care for people who have a disease that cannot be cured. It focuses not only on helping to control physical symptoms such as pain, but also on emotional wellbeing, relationships with others and spiritual needs. In later stages, palliative care can also help people to prepare for death.

Palliative care includes more than care for people who are dying. Any treatment you have for secondary breast cancer that helps to relieve your symptoms and improve your day-to-day life can be called palliative care.

**You can continue to have treatment from the rest of your healthcare team while you are receiving palliative care.**

***"I didn't like the idea about being referred to palliative care when I had only just been diagnosed with secondary disease but I found it really helped. They told me how to apply for financial assistance and they gave me helpful suggestions about how to control the pain under my shoulder."***

### Who provides palliative care?

Palliative care includes care at home or in hospitals, hospices or specialist palliative care units. The palliative care team works with the other health professionals involved in your care.

Palliative care might involve:

- a palliative care specialist
- a local general practitioner with skills in palliative care
- a palliative care nurse
- palliative care volunteers
- allied health professionals, such as a dietitian or occupational therapist
- social workers
- counsellors.

***"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."***

### What does palliative care involve?

Palliative care is available for anyone who has a progressive life-limiting disease. The care required is determined by an individual patient's needs. Services are available that are age and culturally appropriate. Your palliative care team will work with you to help to provide care that is most helpful for you and those close to you.

A specialist palliative care service can provide:

- pain and symptom relief by providing medication and information about drugs
- practical advice and support for you and your family/carers

- temporary respite care to give your carers some 'time out'
- counselling and support groups for you and those close to you
- support with spiritual issues through referral to appropriate resources
- support in helping you and those close to you prepare for the later stages of your disease, including understanding your preference for where you would like to die
- bereavement support for families and carers.

## When can I access palliative care?

You can ask your doctor to refer you to a specialist palliative care service at any point after your diagnosis of secondary breast cancer. Palliative care may be particularly helpful if you decide you no longer wish to have active treatment to control your cancer. However, there are benefits in making contact with a specialist palliative care service, even when you are relatively well. **Making contact with a palliative care service does not mean you cannot continue to have treatments recommended by your doctor.**

Your doctor may decide to consult a palliative care specialist to get advice about how to manage your symptoms even while you are having active treatment. This should occur if you have any symptoms that are difficult to control. **Ask your specialist or general practitioner to refer you to a specialist palliative care service if you feel you would benefit from the extra support and information.**

You may be able to consult a palliative care specialist at a hospital clinic. If you are not well enough, a member of the palliative care team may visit you at home. If you are in hospital or in a hospice, they may visit you there.

*"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 Australia has a directory of palliative care services in Australia as well as a list of organisations in each State and Territory who can provide more information about palliative care. For more information, visit the Palliative Care Australia website at [www.palliativecare.org.au](http://www.palliativecare.org.au).



## Questions to ask about palliative care

Listed below are some questions you might want to ask a member of your healthcare team about palliative care.

- Would palliative care be helpful for me and/or my family?
- Can you refer me to a palliative care service?
- What support can palliative care provide?

You may like to write your own questions here:

This image shows a full page of white paper with horizontal blue dashed lines. The lines are evenly spaced and run across the width of the page, providing a guide for handwriting practice. There are no margins, text, or other markings on the page.



## Frequently asked questions

### Do I have to be in a hospice or hospital to have palliative care?

No. Palliative care can be provided for you as an outpatient through a clinic, at home or in a hospital or hospice.

### Does palliative care mean I am dying?

No. Palliative care can be provided to anyone who has an illness that cannot be cured.

### If I have palliative care, does that mean that my other treatments will stop?

No. Palliative care can be provided at the same time as active treatment.

## Clinical trials

Date of development: November 2009

### Summary

- Clinical trials are studies used to find new ways to prevent, diagnose or treat diseases.
- You may or may not be eligible to take part in a clinical trial.
- If you are invited to join a clinical trial, you should weigh up the benefits and risks of taking part.

### What are clinical trials?

Clinical trials are studies carried out to help to find new ways to prevent, diagnose or treat diseases.

Clinical trials with cancer patients try to find out whether new approaches to cancer prevention, diagnosis and treatment are safe and effective. Many clinical trials about breast cancer involve people in Australia and overseas. Major improvements in breast cancer treatments are always first tested in carefully conducted clinical trials.

Every clinical trial must be approved by an **ethics committee**.



**Ethics committee:** a group of experts who review clinical trial protocols to make sure that the rights of the patients involved are protected.

In a clinical trial, there are usually two groups of patients:

- those who receive the newer treatment (**the intervention group**)
- those who receive the standard treatment (**the control group**).

Standard treatment is the currently recommended treatment. Two groups of patients are needed, to see whether the newer treatment is better than the standard treatment.

If you take part in a clinical trial, you will not be able to choose whether you have the newer treatment or the standard treatment.

### How do I decide whether to take part in a clinical trial?

To join a clinical trial, you must meet certain criteria. For example, a trial may be for women in a particular age group, or for women who have had certain treatments. If you meet the criteria, your doctors may invite you to join the trial.

**If you are invited to join a clinical trial, you need to weigh up the risks and benefits of this decision.**

You will not have to pay any additional costs to be in a clinical trial. Your treatment and care will not be affected should you decide not to take part.

Advantages of joining a clinical trial include:

- you may receive a newer treatment that is not yet available to the general public
- the newer treatment may be more effective than standard treatments
- the progress of your treatment will be monitored closely
- you will also be helping other women who are diagnosed with secondary breast cancer in the future.

Disadvantages of joining a clinical trial include:

- you cannot choose which treatment you have
- if you are in the control group, you will not receive the newer treatment
- the newer treatment might not be more effective than standard treatments
- the newer treatment might have more or different side effects to standard treatments
- you may need to have more tests during and after treatment than with standard treatments
- you may be asked to fill in more forms and surveys than with standard treatments.

It is up to you whether you choose to join a clinical trial. If you decide to join a clinical trial, you will be asked to sign a consent form. You can withdraw from the trial at any time. If you decide not to join a clinical trial, or if you withdraw from one, you will receive the standard treatment and care available. **The quality of your care and treatment will not be affected should you decide not to take part in, or withdraw from a clinical trial.**

**If you are interested, ask your doctors about any clinical trials that are suitable for you.**



Several different organisations have information available on their websites about clinical trials for breast cancer in Australia. These include:

The Australian and New Zealand Clinical Trials Register  
[www.anzctr.org.au/](http://www.anzctr.org.au/)

The Australian and New Zealand Breast Cancer Trials Group  
[www.anzbctg.org/](http://www.anzbctg.org/)

The Trans-Tasman Radiation Oncology Group  
[www.trog.com.au/](http://www.trog.com.au/)



### Questions to ask about clinical trials

Listed below are some questions you might like to ask a member of your healthcare team about clinical trials.

- What is the purpose of the trial?
- What treatments or tests does the trial involve?
- What treatments or tests will I have if I do not join the trial?
- What are the advantages and disadvantages of joining the trial?
- What are the possible side effects of the treatment or tests being studied in the trial?
- What are the possible side effects of the treatments or tests I will have if I *do not* join the trial?

- What follow-up tests will I have if I join the trial?
- Have the treatments being tested been used before to treat other types of breast cancer?
- Have the treatments been used before to treat other cancers?
- Can I leave the trial at any time?
- Are there any costs involved if I join the trial?

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## Frequently asked questions

### How do I know what the clinical trial involves?

Your doctor will give you information about the trial. If the trial involves a new drug, it will have undergone some tests and checks before the trial started. Ask your doctor about what tests have already been done and how many other people are involved in the trial.

### Will I need extra tests if I agree to join a clinical trial?

If you agree to join a trial, you may need to have some extra tests during and after your treatment. This may involve blood tests or other checks so that your doctor can record what effect the treatment is having. Your doctor will explain what tests are involved before you decide whether to join the trial. You will not be charged for additional tests used as part of a clinical trial.

### If I agree to take part in a clinical trial, can I change my mind later?

Yes. You can change your mind at any time.

### Whom do I contact if I have a complaint about a clinical trial?

If you have a complaint about a clinical trial you have joined, you can contact your local ethics committee. Ask your doctor or nurse for more information. The details about whom you can contact should also be included in the information provided to you when you joined the clinical trial.

### Can I ask to see the results of the trial?

If you join a clinical trial, you have a right to access the results when they are published, although depending on the length of time that the trial runs for, it may be a number of years before the results are available. Ask your doctor or nurse for more information.

### What are the phases of clinical trials?

The 'phase' of a clinical trial refers to how much is known about the new treatment/test.

- A phase I trial is the first time a treatment is tested in humans. Phase I

trials usually involve a small number of healthy volunteers or patients and a range of doses to test how the body responds to the treatment and to look for side effects.

- A phase II trial tests the effects of a drug in people with a particular disease. These trials usually involve small numbers of patients and are used to work out the correct dose of the treatment and how effective it is in the short term.
- A phase III trial compares the effect of a new treatment with the current standard treatment and usually involves a large number of patients in several different countries.
- A phase IV trial is a trial or study of a drug that is already approved. Phase IV studies check how well a treatment works over a longer period of time and monitor long-term side effects.

## Complementary and alternative therapies

Date of development: November 2009

### Summary

- Complementary therapies are a range of approaches to care aimed at enhancing your quality of life and improving your wellbeing. Complementary therapies may be used alongside conventional treatments for cancer.
- Alternative therapies are approaches to care that are used instead of conventional treatments for cancer. There is no evidence to support the use of alternative therapies in the treatment of breast cancer.
- There is no evidence that complementary therapies can remove breast cancer, or stop it from growing or spreading.
- It is important to tell your doctor about any complementary therapies you are taking or are planning to take.

### What are complementary and alternative therapies?

Complementary therapies are a range of approaches to care aimed at enhancing quality of life and improving wellbeing. They may be used alongside conventional treatments such as hormonal therapies, chemotherapy or radiotherapy.

Complementary therapies may include acupuncture, relaxation therapy, meditation, gentle exercise, guided imagery, music or art therapy, massage, aromatherapy, vitamins, dietary therapies and some support group programs.

You may also hear people talk about alternative therapies. These are therapies that are taken instead of conventional approaches to treatment. When cancer has spread and you have been told that a cure is unlikely, you may feel that conventional medicine has failed you. However there is no evidence that the use of alternative therapies results in better outcomes than standard treatments.

*"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 do not know how long I will live or what will happen to me."*

### What is the evidence about complementary therapies?

There is evidence that some complementary therapies can improve the wellbeing of people with cancer. For example:

- relaxation techniques and guided imagery can reduce feelings of anxiety, stress or depression
- exercise can improve feelings of fatigue and distress
- relaxation techniques, guided imagery, massage and reflexology can relieve pain and some side effects caused by cancer and its treatments.

These therapies are encouraged by health professionals and are part of clinical practice guidelines.

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

*"I've 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 is no good for you overall. So I'll go out and have my cappuccino and a nice piece of cake and enjoy it...but not often."*

However, it is important to note that a number of complementary therapies have not been tested in clinical trials so we do not know how effective they are or what their long-term side effects might be. Some therapies can interact with conventional treatments and make them less effective. Others may actually be harmful if taken with conventional treatments. **It is important that you talk to your doctor before starting any complementary therapies to check that they will not interact with your treatments.**

There is no evidence that complementary therapies can remove breast cancer, prevent it from growing or from spreading to other parts of the body.

*"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 shower blame on myself for having it."*



The Cancer Council NSW has produced a booklet about complementary therapies and cancer. To download a copy of *Understanding Complementary Therapies*, go to [www.cancercouncil.com.au](http://www.cancercouncil.com.au), select 'Patients, family and friends' and then click on 'Booklet and online information' in the left hand menu.

Memorial Sloan Kettering Hospital in the USA has developed a website with information about complementary therapies. The website describes what is currently known about a range of herbal products and supplements. To access this information, go to [www.mskcc.org/mskcc/html/11570.cfm](http://www.mskcc.org/mskcc/html/11570.cfm). Please note that this is a USA website and not all of the products listed may be available in Australia.



### Questions to ask a complementary health practitioner

Before you decide on any course of treatment or activity, it is important to be well informed. You should also feel confident about the training of any complementary health practitioner. Questions you may want to ask include:

- What is your training?
- Exactly what is the therapy you are proposing?
- What do you hope it will do?
- What is the evidence for the success of this therapy?
- What side effects could there be?

- How common are the side effects?
- Will this therapy affect other treatments I am receiving?
- How much will this therapy cost?

It is also important to ask the doctor(s) who are providing your conventional treatment whether the complementary therapies you are considering could interact with the conventional treatments you are receiving.

You may like to write your own questions here:

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## Frequently asked questions

### Can I take complementary therapies at the same time as my conventional treatments?

Some complementary therapies are encouraged by health professionals. These include relaxation therapy, guided imagery, meditation and gentle exercise. Some complementary therapies may be harmful if taken at the same time as conventional treatments, such as some vitamins. It is important that you tell the health professionals managing your care about any treatments you are taking or involved in.

### What is the difference between complementary and alternative therapies?

Complementary therapies are therapies or treatments that are used *alongside* conventional medicine. Alternative therapies are therapies or treatments that are used *instead of* conventional medicine.

### Can complementary or alternative therapies be used to treat or prevent breast cancer?

There is no evidence that complementary or alternative therapies can remove breast cancer, stop it from coming back or stop it from spreading to other parts of the body.

# Symptoms and side effects

This section explains what you can do to help to control pain and other symptoms of secondary breast cancer. It also includes some information about side effects of treatment, including effects on fertility and menopause.

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## Managing pain

Date of development: November 2009

### Summary

- Not everyone with secondary breast cancer experiences pain, and pain does not always get worse with time.
- Cancer pain can usually be controlled using medical and non-medical treatments.
- The treatments recommended to manage your pain will depend on the type of pain, how severe it is and what other symptoms you have.
- If one type of pain relief stops working, there are others you can try.
- It is important to tell the people managing your care about any new pain or if pain gets worse.
- You may find it helpful to keep a diary to help you to describe your pain to your healthcare team.

### Will my secondary breast cancer be painful?

Secondary breast cancer affects different women in different ways. Some women have no pain, others find that pain affects them at certain times of the day or night or while doing different activities. Pain caused by secondary breast cancer does not always get worse with time.

The type and level of pain experienced by one woman may not be the same as that for another woman with cancer in the same parts of the body. Not everyone with secondary breast cancer finds it painful.

Cancer pain can usually be controlled. It is rare to have cancer pain that cannot be lessened or changed.

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

### What causes pain?

Understanding the reasons for cancer pain can help your healthcare team to work out the best way to manage the pain. There are a number of different reasons for cancer pain, including:

- cancer pressing on nerves or soft tissue in the body
- side effects of treatment, such as radiotherapy or surgery
- a bone fracture
- cancer in the bone
- infection
- a blood clot caused by cancer or its treatment
- a blockage in the bowel.

You might also have pain due to other medical conditions that have nothing to do with the cancer.

**If you have pain, it does not mean that the cancer is more serious than if you did not have pain.**

Any pain can be difficult to cope with. However, it can be harder to cope with pain if you are anxious or depressed. If you are feeling anxious, depressed or down on a regular basis, talk to a member of your healthcare team. Managing your emotional health can help you to manage your physical symptoms.



For more information about your feelings, see the 'Finding support' section.

*“The human spirit is a remarkable thing I’ve realised.”*

## How to report pain

Many people do not like to complain about pain. However, it is important that you tell the people managing your care about any pain you are experiencing — even if it is minor. Reporting your pain means that your doctor can find out what is causing it and recommend the best way of managing the pain.

**Always tell a member of your healthcare team about any new pain or if your pain gets worse. Cancer pain can usually be controlled.**

When you describe your pain, try to give as much information as possible. The table below lists some questions that will help you to describe your pain. You may find it helpful to keep a diary, noting the times of the day when your pain gets better or worse. This can help you to describe your pain to your healthcare team.

## Questions to help you to describe pain

Question	What to think about
Where is the pain?	Is it in one part of your body or more? Does it start in one place and spread during the day?
What is the pain like?	What words best describe the pain? Is it a dull ache or throb? Is it a sharp, stabbing pain? Is it more like a burning feeling or pins and needles?
How bad is the pain?	How does the pain compare with pain you have had before — for example, period pain, headache, a sports injury or childbirth?  How would you rate the pain on a scale of 1–10 (where 10 is the worst pain you can imagine)?  Does the pain keep you awake or wake you up at night?
Does anything make the pain better?	Do you feel more comfortable if you sit or lie in a particular position?  Does a hot water bottle or ice pack help?  Does the pain get better if you take a painkiller like paracetamol?  Can you distract yourself with music or a good book?
Does anything make the pain worse?	Does it hurt more if you are moving around or sitting in a particular position?
Is the pain there all the time?	Does the pain come and go? Is the pain worse at night?

## Treatments for pain

### Drug treatments

There are many drugs available to manage different types of pain. Everyone is different in how they respond to pain relief. It may take a while for your doctors to find the treatment or combination of treatments that are right for you.

If your pain comes and goes, you might only need to take painkillers from time to time. If you have pain all the time, you should take painkillers at regular intervals. Do not wait until the pain comes back before taking the next painkiller. The important thing to remember with pain relief is that it is best to take it when you first start to feel uncomfortable and to keep taking it at regular intervals. It is better to prevent pain rather than waiting until it comes back.

Listed below are some of the most common drugs used to control pain. More information about some of these drugs is provided later in this section. It is not possible to list all of the drugs used to control pain or to list all of the possible side effects. Talk to your doctor about the drugs most suitable for you and their side effects.

**Do not start or change any pain relief medication without consulting your doctor.**

Addiction to painkillers is very unlikely in women with secondary breast cancer. The dose of the drugs you take can be increased or decreased according to your needs.

Type of drug	Examples	Can be useful for:	Things to note
Paracetamol	Panadol®, Panamax®	Mild-to-moderate pain For example: mouth ulcers, ulcers in the skin, cancer in the bone	Take no more than eight painkillers containing paracetamol per day unless told to do so by your doctor  Can be used with stronger pain drugs for moderate or severe pain
Non-steroidal anti-inflammatory drugs (NSAIDs)	Aspirin	Mild-to-moderate pain For example: cancer in the bone	Can cause indigestion and can irritate the stomach lining and make it bleed  Do not take on an empty stomach  Can interact with other medications: always check with your doctor before using  Can be used with stronger pain drugs for moderate or severe pain

Type of drug	Examples	Can be useful for:	Things to note
Non-steroidal anti-inflammatory drugs (NSAIDs) (cont)	Ibuprofen e.g. Nurofen®, Brufen®  Naproxen e.g. Naprosyn®	Mild-to-moderate pain  For example: bone pain, pain caused by swelling or inflammation	Can cause indigestion and can irritate the stomach lining and make it bleed  Only use after advice from a doctor  Do not use in combination with aspirin
	COX-2 inhibitors e.g. Celebrex®	Mild-to-moderate pain  For example: bone pain, pain caused by swelling or inflammation	Can cause nausea and indigestion  Can cause abdominal pain, back pain or headache  Only use after advice from a doctor
Codeine-based drugs	Panadeine®, Panadeine Forte®	Moderate pain	May cause drowsiness for the first few days of treatment  May cause constipation (can be avoided by taking laxatives)  May cause a dry mouth and nausea initially

Type of drug	Examples	Can be useful for:	Things to note
Opioid drugs	Morphine e.g. Kapanol®, MS Contin®, Ordine®  Fentanyl e.g. Durogesic®, Actiq®  Oxycodone e.g. OxyContin®, OxyNorm®, Endone®  Hydromorphone e.g. Dilaudid®  Methadone e.g. Biodone forte®	Moderate-to-severe pain	Dose can be increased or reduced depending on how severe the pain is  <i>See below for side effects and how to manage them</i>
Bisphosphonates	Clodronate e.g. Bonefos®  Zoledronic acid e.g. Zometa®	Bone pain	Used to control cancer in the bone and reduce bone pain  Can cause dental problems with long-term use
Steroids	Dexamethasone Prednisolone	Pain caused by cancer pressing on a nerve, cancer in the brain, cancer in the liver, cancer in the bone	Can cause side effects if used at high doses and for a long time  Do not use with aspirin and NSAIDs

Type of drug	Examples	Can be useful for:	Things to note
Benzodiazepines	Diazepam e.g. Valium®	Muscle spasm pain	Can cause drowsiness
Antidepressants	Amitriptyline e.g. Endep®	Pain that involves the nerves	Can be used in combination with morphine or opioid drugs
Anticonvulsants	Carbamazepine e.g. Tegretol®  Gabapentin e.g. Gabatin®	Pain that involves the nerves	Can be used in combination with morphine or opioid drugs
Antibiotics	Choice of antibiotics depends on the cause of infection	Pain caused by an infection	May be used in combination with other medications

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

### Ways of taking drugs to manage cancer pain

There are different ways of taking or giving drugs to manage cancer pain. Importantly, taking pain medication in tablet or liquid form is as effective as other forms. This can make it easier to manage your medication at home. The method used will vary according to the drug, the level of pain and whether you have other symptoms, such as feeling sick.

**Tablets or liquids** — thought to be the best way to take painkillers and allows the dose to be adjusted to meet your needs.

**Suppositories** — if you are feeling sick or vomiting, drugs can be given as a suppository, which is inserted into your rectum (back passage).

**Patches** — some pain relief drugs are available as skin patches.

**Injections** — some painkillers and other drugs used to manage cancer pain in the short term are given as an injection into the skin or muscle. This can be helpful if you are feeling sick or vomiting.

**Pumps** — if you are experiencing severe cancer pain or pain after surgery, you may have a small pump attached to a needle under your skin or to a tube inserted into a vein. The pump can be set to deliver drugs continuously or at intervals to keep your pain under control. Some pumps allow you to control the drugs by pressing a button — so you can increase the dose when you feel uncomfortable. This is called patient-controlled analgesia.

**Injections into the spine or brain** — morphine or other drugs can be injected into the spine or brain if pain cannot be controlled with other treatments.

### Remembering to take painkillers

Some people find it difficult to remember to take regular medications. However, it is best not to leave painkillers lying around as a reminder to take them. It is important that you store painkillers carefully. Keep them away from children and make sure you label them properly. You might find it helpful to set an alarm on your clock, mobile phone or computer to remind you to take your drugs. Some people like to keep a record in a pain diary of when they have taken their medication.

### More information about morphine and opioid drugs

**Opioids can be useful drugs at all stages of cancer treatment.**

It can take a while to get used to taking strong painkillers such as morphine and opioid drugs. Possible side effects are listed below. **If you experience side effects, it is important not to stop taking your painkillers.** Talk to your doctor about any side effects that are concerning you.

**Drowsiness** — you may feel drowsy when starting or increasing your dose. This usually wears off once you get used to the drug. If you continue to feel drowsy, contact your doctor. Talk to your doctor about what effect the painkillers will have on your ability to drive or do other activities. More information about driving while taking painkillers may also be available from the road and transport authority in your State/Territory.

**Constipation** — morphine and fentanyl cause constipation. Your doctor will probably give you a laxative to take at the same time to help with this.

**Dry mouth** — this is a common side effect of morphine and other opioid drugs. Drinking liquids and chewing gum can help.

**Nausea and vomiting** — some people feel sick when they start taking morphine or other opioid drugs. Your doctor can give you an anti-emetic for the first week or so of treatment.

**Itchiness** — this is a less common side effect of treatment. See your doctor if itchiness occurs.

**Vivid dreams** — some people describe very vivid and 'loud' dreams with some painkillers.



**Anti-emetics:** drugs used to control nausea and vomiting.

It is more common to experience side effects such as drowsiness or muscle twitches while the body is getting used to the required dose of painkiller. Talk to your doctor if these symptoms are troubling you.

### Other medical treatments for pain

There are other medical treatments that can help to control pain caused by secondary breast cancer.

- **Radiotherapy** is the most effective way of controlling pain in the bones and can be useful for pain in other parts of the body.
- **Surgery** can be helpful to manage certain types of cancer pain.



For more information about radiotherapy and surgery, see the 'Treatment' section.

### Non-medical pain relief methods

There are a number of other ways to control pain that do not involve using drugs. These can be helpful on their own or in combination with medical treatments.

- **Relaxation** — relaxation methods such as abdominal breathing, progressive muscle relaxation and yoga, can ease cancer pain.
- **Acupuncture** — involves placing small needles in key areas of the body and can ease pain. Ask a member of your healthcare team about how to find a qualified acupuncture practitioner.
- **Massage** — some women find that massage and aromatherapy can help with relaxation and coping with pain. Massage should not be used on swollen or inflamed parts of the body. Massage should not be used if you are having radiotherapy. Vigorous massage should not be used on parts of the body where there is known to be a cancer.
- **Cold and hot packs** — some women and health professionals suggest that cold packs can help to relieve pain where there is swelling or inflammation, and that hot packs can help to relieve back or joint pain.
- **Support** — support from friends, family, trained counsellors, other health professionals or other sources may help you to cope with your pain.
- **Transcutaneous electrical nerve stimulation (TENS)** — this is a way of stimulating the body's own natural painkillers and can be helpful for relieving pain in particular parts of the body.

*"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."*

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



## Questions to ask about managing pain

Listed below are some questions you might want to ask a member of your healthcare team about managing pain.

- What pain relief drugs do you recommend for me and why?
- How often should I take the drugs you are recommending?
- What are the side effects of the drugs you are recommending?
- Whom should I contact if I develop side effects?
- Are there ways I can manage the side effects?
- Are there other ways I can help to relieve my pain?
- Can the pain relief drugs interact with other medicines I am taking?
- If I am taking pain relief drugs, can I drink alcohol?
- Can I still drive while I am taking pain relief drugs?
- Whom should I contact if my pain changes/gets worse?

You may like to write your own questions here:

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## Frequently asked questions

### What happens if my painkiller becomes less effective?

There are many different drugs that can be used to manage pain. If the painkiller you are taking stops working, or if your pain gets worse, your doctor can recommend whether to increase the dose or try another drug. Do not stop taking your painkillers without first talking to your doctor.



## Managing other symptoms

Date of development: November 2009

### Summary

- The symptoms of secondary breast cancer and side effects of treatment will depend on where your cancer is and what treatments you are having.
- Your symptoms might change with time.
- Treatments are available to control and relieve symptoms of secondary breast cancer and side effects of treatment.
- It is important to tell the people managing your care about any new symptoms or side effects or if a symptom or side effect gets worse.

### Symptoms of secondary breast cancer

Not all the symptoms you experience will be due to the secondary breast cancer. Some may be the result of treatment and others may be caused by other illnesses or medical conditions. Your doctor should tell you about possible side effects of treatments you are receiving and how to manage them.

**It is important that you tell the people managing your care about any new symptoms or if a symptom gets worse.**

When you describe a symptom, try to provide as much information as possible. You may find it helpful to keep a diary of how frequent or severe your symptoms are. You can also keep a record of how well your symptoms are being controlled to take with you when you meet with your doctor.

***“Live for today and make the most of it. I don’t think there are magic solutions.”***

***“When I catch up with people I haven’t seen for a while they’ll say ‘Wow you look so great, is everything fine?’ and I say ‘Well no I’m not OK, metastatic breast cancer is a chronic disease.’”***

## Managing symptoms and side effects

This section lists the possible symptoms of secondary breast cancer or side effects of treatment and how to control or manage them. **It is extremely unlikely that you will have all of these symptoms.** The treatment recommended for some symptoms and side effects may depend on what is causing the symptom.

### Hypercalcaemia

**What is it?** High level of calcium in the blood

**What causes it?** Cancer in the bone:

- increase in the amount of calcium absorbed into the blood from the bones
- inability of the kidneys to get rid of the excess calcium

**What are the symptoms?** Increased urination, excessive thirst, dehydration, vomiting, constipation, muscle weakness, drowsiness, confusion

**How to treat it** Fluids to treat the dehydration  
Treatment with drugs called **bisphosphonates** to stop damage to the bone  
A change in the hormonal therapy or chemotherapy used

***“Be prepared. For example, make sure you have the necessary medications/creams before side effects take hold; it is invariably a holiday period when they strike and it’s more difficult to obtain them then.”***

### Tiredness (fatigue)

Over half of women with secondary breast cancer feel tired.

**What causes it?** The cancer itself

- Low levels of red blood cells in the blood (anaemia)
- Changes in the body’s metabolism
- Side effects of treatment

## How to manage it

Travelling for treatment  
Coping with pain or other symptoms  
Being worried or anxious about living with cancer  
Depression  
Sleeping difficulties  
Finding out what is causing the tiredness can help to find ways to manage it  
Gentle exercise  
Red blood cell transfusion (for women with significant anaemia)



**Anaemia:** a condition in which there are fewer red blood cells in the blood than normal.

## Tips to help you to conserve your energy

The following tips are based on the experience of health professionals and women themselves:

- make sure symptoms such as pain are controlled properly
- save your energy for things you enjoy doing
- take things easy and break tasks down into manageable steps
- try to get enough sleep
- build in rest periods during your day
- work out the best time of day for you to do things
- organise some practical help before you start chemotherapy — help with childcare or preparing meals can give you more time to recover
- encourage friends and family to have short, frequent visits rather than longer ones
- eat a well-balanced diet
- pace yourself and think about using aids or devices that will help you to conserve your energy and help you to get around more easily.



For more information about practical support during treatment for breast cancer, see the 'Finding support' section.

*"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."*

## Exercise

A normal reaction to feeling tired is to rest. However, research shows that exercise can help to reduce fatigue caused by chemotherapy and other treatments. Although it may not be what you would expect, exercise during and after treatment can help you to feel less tired. Exercise can also reduce your chances of weight gain and has been shown to help to improve sleep, body image and mood. Gentle exercise like walking is ideal. Try to go for a walk on days when you feel well enough. Some women find that more strenuous exercise is also helpful. Talk to a physiotherapist or another member of your healthcare team about a suitable exercise program for you.

*"Exercise does help sometimes. The best exercise I found is dragon boat paddling. It also helps you relax as the main thing you have to think about is keeping in time with everyone else; all worries are forgotten."*

*"I walk three kilometres every day if possible. It helps with fatigue and gives me time for mental quietness."*

## Nausea and vomiting

Over half of women who have chemotherapy feel sick. You might feel sick or vomit even if you are not having chemotherapy.

**What causes it?** Treatments for secondary breast cancer such as chemotherapy and radiotherapy (less common with taxane chemotherapy)

Nervousness before the next cycle of chemotherapy (this is called **anticipatory vomiting**)

Drugs for pain or symptom relief

Hypercalcaemia  
Cancer in the brain or liver  
A blocked bowel (bowel obstruction)

**How to treat it** Depends on the cause of the nausea  
Treatment with drugs called **anti-emetics**  
Treatment with drugs called **steroids**  
Diet modification  
Relaxation



**Anti-emetics:** drugs used to control nausea and vomiting. They are usually given at the same time as chemotherapy.

**Steroids:** drugs used to relieve swelling and inflammation.

*"I have a remedial massage once a month. It helps to alleviate the pain and discomfort from the metastases."*

### Tips to help to prevent nausea and vomiting

The following tips are based on the experience of health professionals and women themselves:

- have frequent small meals instead of bigger main meals
- avoid fatty or fried foods
- rest before and after eating
- do not lie down during or after eating
- make sure you drink enough fluids
- see a dietitian for advice about what you should eat
- do some relaxation training — this can be particularly helpful if your nausea is caused by nervousness.

*"I found that having hypnotherapy and being able to relax deeply whilst receiving chemotherapy reduced the anxiety and the pain and the after effects."*

### Loss of appetite

About a quarter of women with secondary breast cancer lose their appetite.

**What causes it?** The cancer itself

Treatments for secondary breast cancer  
Drugs for pain or symptom relief  
Being less active

**How to treat it** Seek advice from a dietitian

Eat smaller, more frequent meals  
Treatment with drugs such as **medroxyprogesterone** or **steroids**

### Tips to help you to eat more

The following tips are based on the experience of health professionals and women themselves:

- eat small meals and snacks as often as you can during the day
- eat a variety of foods and try to include foods that are high in fibre
- choose foods you think you will enjoy and treat yourself when you feel like it
- use ready-made foods if you are too tired to cook
- drink protein and carbohydrate drinks if you find it difficult to eat solid food
- do not force yourself to eat if you cannot face it but take advantage of those times when you do feel able to eat.

*"Certainly I did find regular, gentle exercise to be most beneficial."*

## Difficulty sleeping

**What causes it?** Side effects of some drugs

Anxiety or depression

Pain

**How to manage it** Finding out what is causing sleeping difficulties can help to find ways to manage it

Treatment with drugs to help you to sleep

## Tips to help you to sleep better

The following tips are based on the experience of health professionals and women themselves:

- tell your healthcare team about any pain or other symptoms you have
- do some gentle exercise each day — ask your doctor, nurse or physiotherapist about exercises you can do even if you are in bed or sitting down for much of the day
- try and get into a routine during the day with visits from friends to keep you busy and stop you from dozing during the day
- avoid coffee, tea and other drinks with caffeine in them in the afternoon and evening
- have a warm drink such as herbal tea or warm milk before you go to bed
- try deep breathing and relaxation
- have a massage from a qualified massage therapist or a friend or partner
- have a warm bath before you go to bed
- try putting essential oils, such as lavender oil, on your pillow
- if you have problems sleeping, use the time to read or listen to music.

If you are having problems sleeping because you are anxious or worried, talk to a member of your healthcare team. You might find it helpful to talk to a counsellor or psychologist.

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

*“I still continue with yoga each week. Meditation, while it can take time to master, is invaluable for pain control or to help with sleeping.”*

## Constipation

Constipation is common in women with secondary breast cancer, particularly if you are taking painkillers.

**What causes it?** Side effects of drugs, especially painkillers

A low-fibre diet

Not drinking enough fluids

Not eating enough

Being less active

**How to treat it** Drink more fluids

Increase the amount of fibre in the diet

Treatment with oral laxatives

Suppositories or enemas (if required)

Gentle exercise

## Tips to help to prevent and relieve constipation

The following tips are based on the experience of health professionals and women themselves:

- do gentle exercise — ask your doctor, nurse or physiotherapist about exercises you can do even if you are in bed or sitting down for much of the day

- eat fresh fruits, vegetables, cereals and grains
- abdominal massage can be helpful
- drink more water or other fluids.

Talk to your doctor before using any laxatives or medication for constipation.

*"I'm amazed that anybody can get something so destructive and yet be well, be coping with life and doing everything you do without any symptoms."*

### Hair loss

Hair loss is a side effect of chemotherapy. Not all chemotherapy drugs cause hair loss.

**What causes it?** Side effects of chemotherapy drugs, especially anthracyclines and taxanes

### Tips to help you to cope with hair loss

The following tips are based on the experience of health professionals and women themselves:

- to help to slow down hair loss, use gentle hair products and avoid blow drying your hair, having it permed or using curlers, straighteners or tongs
- use a soft hair brush
- think about cutting your hair short so that it is less upsetting if your hair falls out
- wear a scarf, hat or wig to cover your head while your hair grows back
- depending on where you live you might be able to go to a free *Look Good... Feel Better* workshop; workshops are available in capital cities and other major centres and provide tips and advice about dealing with changes to the way that you look while having treatment.



For more information about *Look Good... Feel Better* workshops in your area, call the **Cancer Council Helpline** on **13 11 20**.

*"My friends and I have found that being able to talk to someone who understands helps reduce the anxiety of managing the symptoms and therefore also reduces the tension and the fear and consequently the pain."*

### Mouth ulcers

Mouth ulcers can be painful and can affect what and how much you eat.

**What causes them?** Chemotherapy  
Other unknown reasons

**How to treat them** Treatment with painkillers such as soluble paracetamol  
Treatment with a pain-relieving (analgesic) gel  
Treatment of thrush or other mouth or throat infections

### Tips to help to relieve mouth ulcers

The following tips are based on the experience of health professionals and women themselves:

- brush your teeth and gums with a very soft brush after every meal to prevent infection
- use an analgesic gel from the chemist or sodium bicarbonate (baking soda) mouthwash to help to relieve discomfort
- you might need to take pain relief such as paracetamol.

**Talk to your doctor before using a mouthwash, as some mouthwashes (especially those that contain alcohol) can make ulcers worse.**

## Lymphoedema

**What is it?** Swelling of the arm, breast, hand or other area of the body due to a build-up of fluid

**What causes it?** Removal of, or damage to lymph nodes by surgery or radiotherapy

**What are the symptoms?** A feeling of heaviness, tightness or fullness in the affected part of the body

Swelling of the affected part of the body (you may notice indentations in the skin from tight clothing, jewellery or shoes)

Aching, pain or tension in the affected part of the body

**How to treat it** Good skin care

Exercise

Raising the affected part of the body

Wearing a compression garment (an elastic bandage or sleeve)

Massage of the affected area by a trained lymphoedema therapist

### Tips to prevent and relieve symptoms of lymphoedema

The following tips are based on the experience of health professionals and women themselves:

- reduce the risk of infection by keeping the skin healthy and avoiding damage by cuts, insect bites, scratches or burns
- avoid sunburn or overheating the affected area (for example, through hot baths or saunas)
- try to keep to a healthy weight
- avoid tight or poorly fitting clothing
- see a qualified lymphoedema therapist for more advice.



National Breast and Ovarian Cancer Centre has developed information about lymphoedema for people with cancer. To order a copy of *Lymphoedema — what you need to know*, visit [www.nbooc.org.au/resources](http://www.nbooc.org.au/resources) or call 1800 624 873. The booklet is also available in Chinese, Vietnamese, Greek, Italian and Arabic. A brochure for Indigenous women is also available.

## Skin changes

**What are they?** Skin redness, cracking, itching, peeling, dryness or acne

Nail changes

Increased sensitivity to the sun

**What causes them?** Treatment with chemotherapy containing capecitabine (Xeloda®)

Radiotherapy (although this is uncommon with the doses used for secondary breast cancer)

**How to treat it** Moisturising creams (ask a health professional for advice about what type to use)

Vitamin B6 (pyridoxine)

Steroids (for severe cases)

Referral to an occupational therapist may be helpful

### Tips to prevent and relieve symptoms of skin changes

The following tips are based on the experience of health professionals and women themselves:

- wear sun protective clothes or use sun screen when you are in the sun
- avoid irritants — protect the skin from chemicals (for example, perfumes, deodorants, hair dyes or hair spray)
- keep skin folds dry

- keep hydrated — drink plenty of fluids, as dehydration is a common cause of skin dryness
- avoid extreme weather conditions like severe cold and hot weather — these conditions can aggravate dry skin
- wash clothes in a mild detergent — look for detergents labelled 'allergen free' or 'unscented'.

## Movement problems

**What causes it?** Muscle weakness

Muscle wasting

Pain (especially bone pain)

Nerve problems

Pressure on the spinal cord

**How to treat it** Finding out what is causing movement problems can help to find ways to improve movement

Physiotherapy

Care to prevent pressure sores

Pain relief before any tests or activities that make the pain worse

*"I'm not my 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."*

## Headaches

See your doctor if you have a headache that does not go away or is getting worse.

**What causes them?** Muscular tension  
Tiredness/exhaustion  
Hypercalcaemia  
Cancer in the brain

**How to treat them** Identifying and treating the cause of headaches, if possible, can help to prevent or manage them  
Treatment with pain relief

## Tips to help to prevent headaches

The following tips are based on the experience of health professionals and women themselves:

- avoid bright lights and loud noises
- lying with your head slightly elevated can help when the problem is due to cancer in the brain.

*"I found it important to be honest about my pain — not allowing the pain to take hold."*

## Pressure sores

**What are they?** Sores or broken skin on a pressure point on the body that develop due to the pressure of lying or sitting

**What causes them?** Lying or sitting in one position for long periods of time  
How to Try and move or change position as much as possible avoid them If you are confined to bed, palliative care or community nurses can show your carers how to move you properly  
Special mattresses are available and may be useful (see our community nurse or palliative care team for more information)

## More severe symptoms

The following symptoms are less common but may be a sign of an underlying problem that requires medical care. It is important to let a health professional know if you experience the following problems.

### Enlarged abdomen

**What causes it?** Constipation

Cancer in the liver

Fluid in the abdomen

Blockage in the bowel

Inflammation (swelling) of the bowel due to treatment with chemotherapy or radiotherapy

Steroids

**How to treat it** Treatment depends on the underlying cause

The most important step is to work out why the abdomen is enlarged

### Breathing problems

It is important to see your doctor immediately if you suddenly have difficulty breathing or if your symptoms become worse.

**What causes it?** Infection

Low level of red blood cells in the blood (anaemia)

Cancer in the lungs

Fluid around the lungs

Fluid around the heart

Rare side effect of chemotherapy with taxanes or radiotherapy

Blood clots in the lungs

**How to treat it** Treating the underlying cause of the breathing problems

Removing fluid from around the lungs

Counselling or relaxation therapy

Find a position that makes breathing easier, such as sitting upright

Pacing activities (alternating periods of activity with periods of rest)

Treatment with antidepressants or anti-anxiety drugs

Treatment with morphine or other opioid drugs

### Confusion or other changes in thinking

See your doctor if you or your family notice a change in your memory or thinking ability.

**What is it?** Range of symptoms can include confusion, agitation, disorientation, problems with concentration, change in behaviour, problems remembering things

**What causes it?** Anxiety and depression

Infection

Drugs used to treat secondary breast cancer and symptoms

Cancer in the brain

Hypercalcaemia

Hypoglycaemia (low blood sugar)

Liver or kidney failure

Low oxygen levels due to cancer in the lungs

**How to treat it** Treatment depends on the symptoms and the cause  
The most important step is to work out the most likely cause of the problem



### Tips if you experience confusion or changes in thinking

The following tips are based on the experience of health professionals and women themselves:

- while doctors are working out why the problem has arisen, it is important that you have a family member or friend with you
- surround yourself with familiar things and things that keep you motivated
- keep a night light on when you go to bed as it is easy to become disoriented in the dark
- do not drive your car while the problem is being investigated
- try to maintain a quiet and calm environment; some people find meditation helpful.

## Incontinence

Incontinence is a rare symptom of secondary breast cancer. If you lose control over your bladder or bowel, talk to your doctor or community nurse about how to control it and make yourself more comfortable.

See your doctor as soon as possible if you suddenly lose control over your bowel and bladder as this may be due to pressure on your spinal cord.



## Questions to ask about managing symptoms

Listed below are some questions you might want to ask a member of your treatment team about managing symptoms.

- What is causing my symptoms?
- What can be done to manage my symptoms?
- Are there things I can do to help to relieve/prevent symptoms?
- Whom should I contact if my symptoms get worse?
- How will these symptoms affect my quality of life?

You may like to write your own questions here:

This image shows a full page of a document template designed for handwriting practice. It consists of approximately 20 evenly spaced, horizontal blue dashed lines running across the entire width of the page. The background is plain white, providing a clear guide for letter height and placement. There are no margins, text, or other markings present.

## Frequently asked questions

### Should I worry about taking strong painkillers?

No. Pain is a warning system to alert health professionals to a problem. Once the problem has been identified, it is most important to relieve the pain. This is why stronger painkillers might be given to you. If pain is not relieved it can interfere with your ability to move freely and interact with others. This can often be worse than the possible side effects of the painkillers.

### Should I expect to have many unrelieved symptoms as part of having secondary cancer?

Like pain, it is possible to manage or relieve other symptoms of secondary breast cancer. In many cases, adequate symptom relief can easily be achieved.

### Will I be distracting my doctors and nurses from their job of treating my cancer by telling them about my symptoms?

No. Uncontrolled symptoms are a burden and may interfere with your ability to tolerate cancer treatments. It is important that you tell the people looking after you about any symptoms or side effects you experience so that solutions can be sought to ensure you feel as comfortable as possible, regardless of where you are in your cancer journey.

## Breast cancer, menopause and fertility

Date of development: November 2009

### Summary

- Treatment for breast cancer may cause younger women to become menopausal. The menopause may be temporary or permanent.
- If menopause is permanent, this means you will no longer be able to have children naturally.

### Breast cancer and menopause

About two-thirds of women who are younger than 50 years of age when their breast cancer is diagnosed, will go through menopause because of treatment. Menopausal symptoms are a common side effect of hormonal therapies and some chemotherapy drugs. Sometimes the menopause is temporary and sometimes it is permanent. The closer you are to the age of natural menopause, the more likely it is that the menopause will be permanent.

Regardless of whether menopause is temporary or permanent, you may experience menopausal symptoms during treatment. Some women who have already gone through menopause also experience menopausal symptoms with certain treatments. For example, drugs such as tamoxifen, and aromatase inhibitors — anastrozole (Arimidex®), letrozole (Femara®) and exemestane (Aromasin®) — can cause symptoms such as hot flushes.



National Breast and Ovarian Cancer Centre has developed a booklet about menopause for younger women with breast cancer. To order a copy, go to [www.nbocc.org.au/resources](http://www.nbocc.org.au/resources) or call 1800 624 873.

### Symptoms of menopause

Whether your menopause is temporary or permanent, you may experience some or all of the following symptoms:

- hot flushes
- mood changes
- sleep disturbance
- vaginal dryness and/or discharge
- a decrease in libido (sex drive)
- no menstrual periods, or irregular menstrual periods.

Some women have menopausal symptoms for only a few months, while other women have them for much longer. You are also at risk of developing **osteoporosis**. Ask your doctor for advice about preventing osteoporosis. Your doctor can also monitor you for osteoporosis, and recommend treatment if it develops.

A range of medical treatments, lifestyle changes and complementary therapies are used by women to manage their menopausal symptoms.

**Talk to your doctor about the options for managing menopausal symptoms and weigh up the benefits and risks of the different options for you.**



**Osteoporosis:** thinning of the bones that can lead to bone pain and fractures.

## Will treatment affect my ability to become pregnant?

The issue of pregnancy for women with secondary breast cancer is quite complex. There are a number of things to consider. Some treatments for breast cancer can affect a woman's ability to become pregnant (her fertility). Some treatments have this effect during the treatment period only, while others have a permanent effect. If your periods stop for a year or more, it is likely that your menopause will be permanent. If your menopause is permanent, you will be unable to have children naturally.

**Talk to your doctor if you are concerned about the effect of treatment on your fertility.**

## Contraception during and after breast cancer treatment

Treatments for breast cancer may reduce fertility temporarily or permanently. However, this does not mean it is impossible to become pregnant during or after treatment.

There is no evidence about whether or not it is safe to take the oral contraceptive pill ('the pill') or use implants (Implanon®) during or after treatment for breast cancer. Therefore, it is recommended that you use non-hormonal forms of contraception, such as condoms, diaphragms, intrauterine contraceptive devices (IUDs) or male or female sterilisation. It is still possible to catch sexually transmitted infections (STIs) after menopause. Condoms are the most effective way of protecting against STIs.

**If you were pre-menopausal before breast cancer and you are sexually active, talk to a member of your healthcare team about suitable methods of contraception for you.**

## Coping with infertility

Infertility can be very hard to come to terms with, and not only for women who were planning to have children in the future. Even if you were not planning to have children before your diagnosis, or if you already have children, it can be upsetting to know that the choice is taken away because of infertility.

Talk to a member of your healthcare team about your feelings and concerns. You may also find it helpful to talk with other women in a similar situation or a counsellor, psychologist or psychiatrist. Ask your doctor for a referral, or call the **Cancer Council Helpline** on **13 11 20**.



## Questions to ask about the effect of breast cancer treatment on fertility and menopause

Listed below are some questions you might want to ask a member of your healthcare team about the effect of breast cancer treatment on fertility and menopause.

- Will my diagnosis and treatment for secondary breast cancer affect my ability to have children in the future?
- What contraception should I use while I am having treatment?
- How can I manage my menopausal symptoms?
- Will this treatment affect my risk of developing osteoporosis? Can this be monitored?

You may like to write your own questions here:

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## Frequently asked questions

### Is it safe to use hormone replacement therapy (HRT) after a diagnosis of secondary breast cancer?

Hormone replacement therapy (HRT) is a very effective treatment for menopausal symptoms. However, it is generally not recommended for women with breast cancer.

Studies of HRT after breast cancer have shown mixed results. We do not know whether HRT is definitely safe in women with breast cancer. The most common forms of HRT are 'combined HRT' which contain the hormones oestrogen and progestogen. Some treatments only use progestogen. These treatments are not as effective as those containing oestrogen. We do not yet know whether it is safe for women with breast cancer to take progestogen.

Some women's menopausal symptoms are severe and cannot be controlled with other treatments. HRT may be recommended for these women to relieve severe symptoms and lower the risk of fractures from osteoporosis. If you have questions, discuss these with your doctor.

### Can I use a topical vaginal oestrogen?

Many women experience vaginal dryness, either as a side effect of early menopause caused by treatment or as a side effect of hormonal therapies. Topical oestrogens can increase the level of oestrogen in the body. If you are taking an aromatase inhibitor (which works by blocking the production of oestrogen), it is best to avoid topical oestrogens. If you need to use a topical oestrogen, it may be better to take a hormonal therapy such as tamoxifen, which works by blocking oestrogen receptors, as the increase in oestrogen levels will be less important.

# Finding support

This section provides information about how you, your partner and your children might feel after a diagnosis of breast cancer and where to find emotional and practical support.

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## Finding support

Date of development: November 2009

### Summary

- You may face a range of emotional, psychological, physical and practical challenges during your cancer journey.
- Your emotional wellbeing is as important as your physical wellbeing during your treatment for cancer.
- There are many sources of help and support, including your treatment team, partner, family, friends and support groups.
- It is important to be open and honest with your partner and children about your diagnosis and how you are feeling. They may also need support to help them to manage their feelings.
- You may be eligible for financial and practical assistance during treatment.

### Your feelings

The experience of being diagnosed with secondary breast cancer is very personal. Many people find the news that cancer has come back more devastating than their original diagnosis. It is likely that you will experience a range of emotions and feelings. These feelings are common. Everyone has their own coping strategies, beliefs and strengths. You and those close to you will find your own way to cope with your diagnosis. However, it can be reassuring to know that other women with secondary breast cancer have felt what you are feeling.

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

***"Although I have many friends and supporters, I am still the only one going through this and having 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."***

**Sharing your thoughts and feelings with others can help you to adjust to your diagnosis of secondary breast cancer.**

The road ahead will be a bumpy one. There will be difficult times but there are still opportunities ahead. Many women find that their diagnosis gives them a new perspective on life and makes them rethink what is important to them. For some women, the experience of being diagnosed and treated for secondary breast cancer provides opportunities they would not have considered before their diagnosis. You may discover your strengths and weaknesses. You may deepen your relationships with others or form new friendships. You may explore your spirituality. It is not always easy, but many women find that with time they are able to adjust to their diagnosis and get pleasure from the things that are important to them.

***"In the support group I could tell people what a bloody awful week it has been because for other people I have to be so positive."***

***"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."***



Breast Cancer Network Australia's *Hope & Hurdles* Pack is a free resource for women diagnosed with secondary breast cancer. The pack, which has been developed by women with breast cancer, contains booklets, brochures, magazines and CDs that offer information, support and hope for women and their families. BCNA's *Hope & Hurdles* Pack can be ordered online at [www.bcna.org.au](http://www.bcna.org.au) or by calling 1300 887 340.

### How you might be feeling

Women describe a number of feelings after a diagnosis of secondary breast cancer. If you have gone through diagnosis and treatment for breast cancer before, you may feel angry or frustrated that the breast cancer has come back. Some women blame themselves or feel they are being punished for something they have done. It is important to remember that we do not

know why breast cancer comes back for some women and not for others. There is nothing you have done to cause your breast cancer to come back. You should be reassured that you and your doctors made the best possible decisions about your original treatment at the time.

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

It can be very difficult to face an uncertain future and it is natural to feel a sense that you are no longer in control. Talk to the people managing your care and those close to you and ask for as much information as you feel you need. You and those close to you may find it helpful to set short-term goals to work towards.

It is likely that your feelings will change or become more intense at different times. You may feel shocked, angry, scared, anxious, sad or depressed. You may feel a sense of loneliness or isolation or that you have lost your identity. Some people find themselves asking questions about the meaning of life, or may find their beliefs are shaken by their diagnosis.

**If any of your feelings are overwhelming you or preventing you from sleeping or doing everyday activities, talk to your doctor, nurse or another health professional. Treatments and therapies are available and can help.**

Listed below are some quotes from other women with secondary breast cancer. You may find these quotes helpful as you think about how you feel about your diagnosis.

*"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."*

*"Everyone is their worst critic. Be kinder to yourself in every way. Nobody's perfect."*

## Seeking help and support

It is very important that you are supported through your diagnosis and treatment for secondary breast cancer. There are many different sources of support. Your healthcare team can provide you with support and advice. You might find it helpful to share your feelings with your partner or another family member or friend. Some women also find it helpful to talk to other women with secondary breast cancer. If you feel you would benefit from talking to a specialist or having some additional therapy, talk to a member of your treatment team.

*"I think in many ways it has been a kind disease. I have gained so much from it. I have met so many friends."*



Breast Cancer Network Australia (BCNA) produces a free national magazine called *The Beacon*. *The Beacon* is written by women with breast cancer, for women with breast cancer, their families and friends. A special supplement to *The Beacon*, *The Inside Story* is specifically for women with secondary breast cancer. To find out more about the magazine and supplement, or to subscribe, visit [www.bcna.org.au](http://www.bcna.org.au) or contact BCNA on 1800 500 258 (free call).

Some of the things that might help are listed below:

- **Relaxation** — can help to control pain and reduce feelings of anxiety.
- **Muscle relaxation and imagery** — can help with anxiety and can help to reduce symptoms.
- **Support groups** — some women find it helpful to meet with other people in the same situation to share their experiences, concerns and fears; meetings can be face-to-face or held over the telephone or internet.
- **Counselling** — counselling with a trained health professional can help you to think more clearly about your feelings and help you to deal with issues that may have been brought up by your diagnosis and treatment.

- **Anti-depressants or anti-anxiety medication** — medication can be valuable to get you through difficult times. You will usually only need to take medication for a short period of time. Taking medication does not mean that you are 'weak' or 'crazy'. Talk to your doctor about the benefits and side effects of medications that might be helpful for you.



In some States/Territories, the Cancer Council can put you in touch with other women who have had breast cancer. To find out more about the Cancer Connect program, call the **Cancer Council Helpline** on **13 11 20**.

*"In our community, cancer is taboo — no-one talks about cancer at all."*

## Deciding about work

If you were working when you were diagnosed, you may find yourself wondering whether you should continue. Some women who feel well enough find that continuing to work helps them to feel valued, and they feel comforted by being around familiar people and situations. Other women find that their diagnosis makes them want to make changes in their work life. You may decide you want to stop work so that you have more time to do the things that are important to do. Or you may decide to change jobs, work part time, or do some volunteer work.

Your decision about whether to continue working will depend on your health, your finances and your priorities. Talk to those close to you about your decision. If you would like some additional help in making decisions, ask your doctor to refer you to a counsellor or social worker.

If you do continue to work, you may find it difficult to talk with your colleagues or friends about your experience of being diagnosed with secondary breast cancer. If you want to, you can share your experience with just a few close friends or colleagues. Sharing your feelings could lead to valuable support.



The Cancer Council NSW has produced a booklet about returning to work after a diagnosis of cancer. To download a copy of the booklet, go to [www.cancercouncil.com.au](http://www.cancercouncil.com.au), select 'How you can help' and then choose 'Companies and workplaces' from the left-hand menu.

Breast Cancer Network Australia has produced a brochure called *Helping a friend or colleague with breast cancer*. To download a copy of the brochure, go to [www.bcna.org.au](http://www.bcna.org.au) and choose 'Information' and then 'Brochures', or to obtain a printed copy, call BCNA on 1800 500 258 (free call).

*"People come up to me and say 'You're so brave'. I don't see myself as being brave. I'm just doing whatever I have to do to get through this."*

## Your family and friends

Secondary breast cancer can have a significant impact on those close to you — your partner, children, family and friends. They will probably find the journey difficult and need support. They might also need advice about how they can help you.

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

**A diagnosis of cancer can show up strengths and weaknesses in your relationships. Talk to your doctor, nurse or other health professional if you are having difficulties in your relationships or if you feel that a family member is not coping.**

If you live alone or if you do not have supportive family or friends close by, you can try seeking support from other places. You might find that a local community group is supportive or that neighbours can provide help. You may also find support from your healthcare team, a support group or a religious organisation.



*“My husband’s not the easiest person to talk to. He doesn’t show his emotions. I know he’s upset.”*

*(From partner) “Some friends cope well and others, they don’t know what to say.”*

## Your partner

If you have a partner, he or she may feel many of the same emotions as you following your diagnosis. Partners can experience higher levels of stress than the person diagnosed with cancer. They also have different information needs. Everyone is different and will have his or her own way of coping.

**It is important that you and your partner are open with each other about how you are feeling.** Going to appointments together can provide you with support and can give your partner the opportunity to ask questions. Your partner may want to make a separate appointment with your doctor or another member of the team to discuss how they are feeling. Or you may like to see a counsellor or other trained professional together.

*“Lacking a partner never worried me up until this point, but I suppose it would be nice to have someone to really share with.”*



National Breast and Ovarian Cancer Centre has information resources for the partners of women with breast cancer. For web-based information, go to [www.nbocc.org.au/partners](http://www.nbocc.org.au/partners).

To order an audio CD called *When the woman you love has advanced breast cancer*, go to [www.nbocc.org.au/resources](http://www.nbocc.org.au/resources) or call 1800 624 973.

Mensline offers telephone counselling and support for men — call 1300 789 978 or visit [www.menslineaus.org.au/](http://www.menslineaus.org.au/).

## Your carers

Whether or not you have a partner, you may have other close friends or family members who support you through your cancer journey. It is important that your carers also feel supported and know where to find help

if needed. Some palliative care services offer ‘carer training’ to provide carers with practical skills and emotional support. Respite care is also available to give your carer ‘time out’ when needed.



To find out more about services available to help to support carers, ask your GP or another member of your healthcare team or call the **Cancer Council Helpline** on **13 11 20**.

## Tips to help you and your partner and others close to you to cope with your diagnosis

The following tips are based on the experience of health professionals and women themselves:

- think of your partner, family and friends as a support team — try not to rely on just one or two people
- talk to those close to you about how you are feeling and encourage them to do the same
- tell people what you need — sometimes they might want to help but might not know what to do
- recognise that you do not always have to stay positive — tell each other if you feel tired or irritable
- encourage those close to you to have time away from you — this will help to give them the energy to support you when you need it
- find time to do enjoyable things together and choose activities that suit how much energy you have
- talk to a member of your healthcare team if you are concerned about any of your relationships or about the impact of your diagnosis on those close to you.

## Your children

**If you have children, they are likely to be affected by your diagnosis. Depending on their age, children may know something is wrong without you even telling them.**

The following information is aimed particularly towards dependent children. However, even if your children are adults with children of their own, your diagnosis can be upsetting. Having open and honest communication is generally helpful. Your adult children might find it helpful to access further information about supports through the **Cancer Council Helpline** on **13 11 20**.

Change can be frightening for children. It can be difficult for them to adjust, especially if you look different or are in hospital. You may want to talk to your children about what is happening to you so they understand what is going on. Answer their questions as honestly as possible in words they can understand. What they imagine to be happening is possibly more upsetting to them than the reality will be, once it is explained.

***“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.”***

The effect of your diagnosis on your children may be reflected in their behaviour. They may behave differently to gain attention, or become insecure and refuse to leave your side or your partner’s side. If you are concerned about your children’s behaviour at school, you may decide to tell the teacher about your breast cancer so that he or she understands the reason for the change in behaviour.

Children may worry about what your diagnosis means for them — whether they will be left alone and whether they might also develop cancer. Teenagers may be particularly vulnerable. They may be worried about how you are coping, as well as dealing with their own feelings, and may take on the role of helping to run the house. Adolescence is a time of great change, and fear about a parent’s illness adds to the teenager’s burden.

It is important for you and your partner to ask your children how they are feeling and to recognise their distress. Some suggestions about how to talk to your children about your cancer are listed below.

- Try to understand what it is that they fear will happen. This will help you to decide what information they can handle and how it should be given.

- Talk to them about feelings as well as facts.
- Give simple, honest answers to their questions and correct any misunderstandings. Children respond well when they feel they are being given time especially for them.
- Try to explain what will happen next.
- Do not make promises you may be unable to keep.
- Maintain a sense of routine and encourage them to play with their friends and participate in their usual activities.
- Build in special times with your children — depending on your level of energy — such as reading a book together, singing, watching TV together or playing cards.
- Reassure them that the breast cancer is not their fault — this is especially important for younger children.
- Teenagers may have mixed emotions, loyalties and coping abilities because of their own stage of development. In some respects, they thrive on being regarded as an adult, but during times of illness in the family, it can be really hard going. Be aware of this and look for signs that an adolescent needs a little extra support and encouragement. It is important that they are allowed to talk about death and how this makes them feel. If they find it hard to talk to you, there may be a relative or friend with whom they can share their feelings.

If you are worried about your children, you can ask your doctor to refer them to a counsellor, social worker, psychologist or psychiatrist; or some or all of the family can see a family therapist.



National Breast and Ovarian Cancer Centre has developed a website for children who have a parent with cancer: Visit [www.myparentscancer.com.au](http://www.myparentscancer.com.au).

The Cancer Council NSW has developed a booklet about talking to children about cancer. To download a copy of *When a parent has cancer: how to talk to your kids*, go to [www.cancercouncil.com.au](http://www.cancercouncil.com.au).



CanTeen has developed a website [www.nowwhat.org.au](http://www.nowwhat.org.au) for young people who have a parent or family member with cancer.

*"You just feel it's not fair. You feel cheated out of a few years of watching your grandchildren."*

## Secondary breast cancer and body image

Secondary breast cancer and its treatment can affect how you feel about your body. This is not unusual and can happen regardless of your age or stage of life. Some treatments can cause you to gain or lose weight. You might find that you lose weight because you feel sick or lose your appetite. Or you might find that you put on weight because you are not as active as you used to be. Some treatments can also cause hair loss or skin changes.

**Talking to others about your concerns or feelings about your body image can help.**

Depending on where you live, you might be able to go to a *Look Good... Feel Better* workshop. These are free of charge and provide tips and advice about dealing with changes to the way that you look while having treatment. Workshops are available in capital cities and other major centres.



For more information about *Look Good... Feel Better* workshops in your area, call the **Cancer Council Helpline** on **13 11 20**.

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

## Secondary breast cancer and sexuality

A diagnosis of secondary breast cancer can affect your relationship with your partner, including your sexual relationship. The different treatments often have a significant effect on how women feel about themselves and their attractiveness. This can happen to any woman, whether or not she has a partner. Your partner may also feel less able to be sexual with you because he or she is worried about hurting you.

Some of the sexual difficulties that may arise as a result of treatment include:

- feeling less attractive because of treatment
- lower libido because of feeling unwell, tired or worried
- vaginal dryness caused by different drugs
- difficulty being physically active because of pain or disability.

Even if it is difficult, try to talk with your partner about how you are feeling and share your fears and concerns. Ways can be found to adapt to your situation and help you to feel closer to each other. If sexual intercourse is difficult or not what you want to do, explore being sexual in other ways. Or increase the affection in your relationship by holding hands, back rubs and cuddles. There are some practical things that can help to overcome some of the physical changes due to treatment. Water-based lubricants, vaginal moisturisers and creams can help with vaginal dryness. Talk to someone you feel comfortable with in your healthcare team to find out more.

You and your partner may find it helpful to talk to a health professional about your concerns — you can do this together or separately. You may want to ask for advice from a trained specialist such as a relationship counsellor or sex therapist.

*(From partner) "Things change and you can't really go back to the way you were before. It is 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."*

## Same-sex couples

You may feel that a lot of attention is placed on heterosexual couples and that lesbian sexuality is not mentioned when the impact of breast cancer on sexuality is discussed. It is up to you whether you let your treatment team know about your sexuality. However, if you feel comfortable with your treatment team, telling them may help you to feel more supported.



To find out about support services specifically for lesbian women, contact your local women's health centre or call the **Cancer Council Helpline** on **13 11 20**.

## Practical support

As you go through treatment, or when the cancer progresses, you may no longer be able to do all the things you would normally do at home. It can be difficult to come to terms with losing your independence. **However, accepting help and support can help you to save your energy for the things that are important to you.**

Concern about practical issues can affect how you are feeling, especially if it interrupts your daily activities. You may be worried about who will look after the children or another family member while you are in hospital, or how you will cope financially if you are unable to work. Sometimes women feel guilty about the impact of their cancer and its treatment on the family. **It is important to remember that you do not have to go through this alone. Support and assistance is available through your healthcare team.**

***"It's important to do the things that you really want to do, and leave the other things to take care of themselves."***

## Costs of treatment

Talk to your doctors about the likely costs of medical tests and treatments. These may include the cost of treatment and support, travel and accommodation costs, childcare or the cost of wigs or medical equipment.

The costs may depend on whether you:

- are treated in the public or private system
- decide to continue working or not
- live in a rural area and need to travel for treatment
- have private health insurance
- have a healthcare card.

You may find it useful to talk to a social worker or welfare worker about what financial and practical support services are available. It may also be helpful to talk to your local Medicare office about the 'safety net' on costs of medications and medical bills. You can also contact your private health insurer to discuss your likely rebates and benefits.



*The External breast prostheses reimbursement program is an Australian Government initiative that provides reimbursement for both new and replacement external breast prostheses to all eligible women who have had a mastectomy as a result of breast cancer. Cost limits apply. For more information about the program and eligibility criteria, visit the Medicare Australia website at [www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au). Select 'For individuals' from the tab options, then select 'Services and programs' and click on 'External breast prostheses reimbursement program'. You can also call Medicare on 13 20 11 or visit a Medicare office.*

*For further information about where to find a breast prosthesis in your area, ask your health professional or call the **Cancer Council Helpline** on **13 11 20**.*

## Financial assistance during treatment

If you need to have treatment in a hospital far away from your home, you may be able to get help with the cost of accommodation and travel. Depending on your situation and where you live, you may also be able to get assistance with childcare, meals and general home help. You might also be eligible for a sickness allowance while you are having treatment.

## Government-assisted travel schemes

Each State and Territory has a government-funded scheme to help patients who have to travel long distances to obtain specialist treatment that is not available locally. The names for these schemes vary but may include:

- Patient-Assisted Transport Scheme (PATS)
- Transport for Health
- Isolated Patient Transport and Accommodation Assistance Scheme (IPTAAS)
- Interstate Patients Transport and Accommodation Service (IPTAS).



To find out about what financial and practical help may be available for you, talk to the nurse or social worker at your hospital, your community nurse, or call the **Cancer Council Helpline** on **13 11 20**. Your local council, Centrelink and the Department of Veterans Affairs can also provide information.

### Superannuation for people with a terminal illness

Current legislation allows individuals with a terminal illness to access their superannuation as a tax-free lump sum. In order to do this you need certificates from two medical practitioners (one of whom is a specialist) stating that you have a terminal illness with a life expectancy of 12 months or less.



To find out about superannuation for people with a terminal illness, visit the Australian Taxation Office website at [www.ato.gov.au](http://www.ato.gov.au) or call 13 28 61.

Breast Cancer Network Australia has developed a fact sheet about accessing superannuation for women with secondary breast cancer. To download a copy, visit [www.bcna.org.au](http://www.bcna.org.au) and select 'Information' and then 'Fact sheets', or to obtain a printed copy call BCNA on 1800 500 258 (free call).

### Support in your home

If you find you are less able to manage at home, help may be available for you and your family. Listed below are some of the people and organisations who may be able to provide help and care at home. The services available to you will depend on where you live and your circumstances.



Ask your general practitioner or nurse for more information about the services available in your area or call the **Cancer Council Helpline** on **13 11 20**.

- **General practitioner** — may be responsible for your ongoing care and can help to arrange other support services for you at home.

- **Social worker** — can help to find the right people to help you at home.
- **Community/district nurse** — can visit you at home at regular intervals according to your needs and can help with things like bathing, changing dressings, giving medications and providing support to you and your carers.
- **Breast care nurse/care coordinator** — may be able to continue to provide you with support and care while you are at home.
- **Occupational therapist** — can provide you with practical advice and aids to help you at home, such as walking frames, wheelchairs, shower chairs or can recommend minor changes to your home that will make it easier for you to get around.
- **Physiotherapist** — can help to keep you mobile and provide pain relief and massage. Some physiotherapists specialise in exercises for people with cancer or lymphoedema.



To find a physiotherapist in your area, visit the Australian Physiotherapy Association website at [www.physiotherapy.asn.au/](http://www.physiotherapy.asn.au/) and select 'Find a Physio'.

- **Palliative care team** — can help to control your pain and other symptoms and provide support for you and those close to you.
- **Home care** — a range of public and private services are available for eligible women to help with things like cleaning, shopping, cooking, personal care and respite care for those who are looking after you.
- **Private nursing agencies** — provide a 24-hour service in some areas to cover nursing care and practical support.
- **Meals-on-wheels** — deliver meals to people who cannot leave their homes (requires a referral from a health professional).
- **Volunteer carers** — volunteer carers can come and visit you for a set time each week or fortnight to chat or help with telephone calls or letter writing, or just to be there.

- **Church/religious groups** — some church or religious groups provide support for their members with things like shopping.

### Support outside your home

If your illness progresses, you may feel you need to be looked after in a hospital, hospice or palliative care unit. Or you may decide you need some additional support for a short time to give your carers a break. This is called **respite care**.

Listed below are some of the services that can provide care outside your home. The services available for you will depend on where you live.



Ask your general practitioner, social worker, community nurse or breast care nurse for more information about the services available in your area.

- **Day centres** — are often attached to hospitals, hospices or nursing homes and are available to give your carers some 'time out'. These centres are open during the day and often provide transport to and from your home.
- **Hospitals** — public and private hospitals can provide short- or long-term care. Access to a public hospital will depend on your level of need and whether there are beds available.
- **Hospices/palliative care units** — specialise in the care of people who are living with and dying from cancer. They focus on controlling pain and other symptoms. Some people go to hospices for a short period to help to control symptoms or to give their carers a rest. Some hospices also have accommodation available for carers. Some are public, some are funded by a charity and some are attached to private hospitals. Palliative care units may be wards in local hospitals.
- **Nursing homes** — some nursing homes offer short- or long-term stays to give your carers a break. They will charge a fee for the care provided.

*"I'm learning to accept help a bit. I was terribly proud. And I think part of that is learning to know that you deserve help."*



### Questions to ask your healthcare team about practical support

Listed below are some questions you might want to ask your GP, specialist or nurse about practical support.

- What will the treatment you are recommending cost?
- Will I need to have time off work?
- Am I eligible for help with travel and accommodation costs?
- Can I get help with other costs of treatment and care?
- How can I find out about help and support at home?
- How can I find out about help with childcare?
- What support is available to give my carer a rest?
- Where is my nearest hospice/palliative care unit?
- Can you give me a list of people/organisations that provide local supportive care?



### Questions to ask your health fund about treatment costs

Listed below are some questions you might want to ask your health fund about treatment costs during treatment for breast cancer.

- Which treatments are covered by my policy?
- Which treatments are not covered by my policy?
- Does my policy cover other services, such as the cost of wigs?
- Does my policy cover palliative care services such as respite care?
- Does my policy cover convalescent stays, for example after a particular procedure or treatment?

- You may like to write your own questions here:

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# Putting your affairs in order

This section explains some of the things you may want to consider when facing the possibility of dying. It may be difficult for you to read this chapter. Read it when you feel you are able to do so. You may want to read it on your own or with your partner or someone else close to you.

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## Putting your affairs in order

Date of development: November 2009

**You and those close to you may find it difficult to read this chapter. Read it when you feel you are able to.**

### Summary

- Planning for what will happen when you die can bring a sense of relief and help you to focus on living.
- Stopping active treatment does not mean that steps cannot be taken to help to maintain your quality of life.
- Think ahead and make plans when you feel able to.
- Talk to your doctors and those close to you about your decisions about when to stop treatment.
- Think about practical aspects such as making a Will and letting others know about your preferences for your care while you are still feeling well.

### Facing the possibility of dying

No-one likes to think about dying. Thinking about dying can be upsetting and may make you feel anxious, depressed, scared or experience a sense of loss. These are all normal feelings. However, planning for what will happen when you die can bring a sense of relief and leave you free to focus on living and the things that are important to you.

**Thinking about and planning for your death can be overwhelming. It is important for you and those close to you to do this when you feel the time is right for you.**

***"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?"***

## Unfinished business

Many women with secondary breast cancer find that facing an uncertain future makes them think about the relationships and friendships that are important to them. You may not have been in touch with friends or family for a while or you may have had a disagreement with someone and feel you would like to make amends. You may decide the time is right to say something to a friend you have always wanted to say. You should not feel you have to resolve all the problems in your past or present relationships. However, this can be a time for healing and strengthening the relationships and friendships that are important to you.

Some women find themselves thinking about the past. You may decide you want to visit the place where you were born, or look through old photographs. This can give you a chance to think about your life and the experiences you have had.

Some women decide to write letters or cards to people they are close to, or put together a journal, tape or CD to be given to children or grandchildren in the future.

**Whatever you do is a personal experience. You need to do what is right for you at the time.**

### Spiritual or religious comfort

Some women with secondary breast cancer find that religious beliefs and spirituality become more important to them as they think about dying. You may find your diagnosis has deepened your faith or has made you question it. You may find it useful to talk to a religious representative about questions you have, even if you have not attended a service for a while. Other women find that sitting quietly and thinking or meditating can help with their thoughts and spirituality.

***"I feel a bit cross with God I must admit because I've been in Church all my life. But I feel God's let me down a bit."***

*"I'm not concerned about dying. I have firm beliefs about dying and spirituality — 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."*

## Making the decision to stop treatment

Living with secondary breast cancer involves having different treatments, often over a number of years. In later stages, the cancer may spread more widely and treatments may become less effective. **Even when treatments stop working, pain and symptom control and support will be available to make you as comfortable as possible.**

Making the decision about when to stop treatment is difficult. Ask for as much information as you need from your healthcare team and talk with your doctors, nurses, your family and friends about the benefits and side effects of treatments. Remember, there is no cure for secondary breast cancer. Many women say that what is important to them is the quality of the life they have left and what they do with the time they have.

The decision about whether and when to stop treatment is yours to make. If you feel differently to your partner or those close to you, it may be helpful to talk to a counsellor or psychologist to work through your thoughts and concerns.

Deciding to stop treatment does not mean giving up hope. Everyone will find hope in their own way — whether it is about finishing something that is important to you, spending time with family and friends or thoughts about an afterlife, if that is what you believe.

*"I know that the cancer's there and spreading. I hope that when it spreads it makes up its mind to spread, it spreads quickly and gets it over with."*

## Thinking about dying

Many people are scared of dying. This is only natural. However, dying can be a very peaceful process. Those who work with people who are dying often say there is a sense of calm around the person who is dying.

The process of dying for women with secondary breast cancer does not happen in an instant. The body usually gets weaker over time and this can help women to let go.

You can be reassured that everything will be done to keep you as free of pain and as comfortable as possible. You will be able to have loved ones around you. Some women say they would like to die at home and this is often possible.

It can be difficult to talk to others about your fears and thoughts about dying. And it can be difficult for your loved ones to talk to you about their fears and grief with you. Sharing your feelings can help you to come to terms with dying and can bring you closer together. You and those close to you may also find it helpful to talk about your questions or concerns with a member of your healthcare team.

*"I hope my family will accept it even if I die. You see I don't believe that death is everything and that's been a great help."*

## Practical aspects

Although difficult, it is important to think about the practical aspects of preparing for death. Planning in advance can make sure that your wishes are carried out. It can also help to avoid any painful decisions that your family or partner may need to make if you do not tell them your wishes.

Legal requirements will vary depending on where you live. Some things to think about are listed below.

- **Preparing a living will** — talk to your family and friends about whether you wish to be kept alive or resuscitated if you stop breathing. You can also write a **living will** or an **advanced healthcare directive** stating your wishes. Talk to your doctor about what you want and how to make sure your wishes are carried out.
- **Naming a power of attorney** — there are four types of power of attorney:
  - ◊ **Power of attorney** — someone you trust who can make decisions about your care at a given point in time if you are not

able to decide for yourself; if you wish, a power of attorney can also manage your financial arrangements if you are unable to do this for yourself

- ♦ **Enduring power of attorney (financial)** — someone you appoint who can make financial or legal decisions for you if at some time in the future you are unable to make those decisions for yourself
- ♦ **Enduring power of attorney (medical treatment)** — someone you appoint who can make medical treatment decisions for you if at some time in the future you are unable to make those decisions for yourself
- ♦ **Enduring power of guardianship** — someone you appoint who can make decisions related to your lifestyle, such as where you will live, if at some time in the future you are unable to make those decisions for yourself.

These names may vary slightly by State and Territory — talk to your healthcare team or a solicitor for more information.

**Before you appoint someone, it is important to discuss with them the kinds of decisions they might be asked to make. They need a clear understanding of your views and wishes.**

- **Making a will** — a will outlines who should receive your possessions and property after you die. It can also contain instructions for your funeral arrangements. If you do not make a will, a government body will decide for you. This may not be in line with your wishes and can be expensive. Talk to a solicitor about drawing up a Will. It is better to do this while you are feeling well.

**Remember to tell a family member or close friend about where you keep any legal documents and how to contact your solicitor.**

Other things to think about and discuss with those close to you include:

- how any children younger than 18 will be cared for
- your wishes for your funeral arrangements

- whether you would prefer to die at home or in a hospice, palliative care unit or hospital.

Your thoughts might change over time and it is important to let others know if you change your mind.

*“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 sorts of things.”*

*(From partner) “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.”*



## Questions to ask your doctor or a solicitor about your affairs

Listed below are some questions you might want to ask your doctor or a solicitor about your affairs.

- How do I make a will?
- How do I make a living will/advanced healthcare directive?
- How do I appoint a power of attorney?
- What will happen at the end? Can I have my family with me?

You may like to write your own questions here:

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## Frequently asked questions

### How do I make a living will/advanced healthcare directive?

Some people find it reassuring to know that their close family or friends know what is best for them if they are not able to communicate their wishes themselves. An advanced care directive or living will can be designed in different ways. It would usually include your instructions about what medical treatment you would like to consent to or refuse if you were not able to communicate this yourself. You may find it helpful to talk with health professionals about specific scenarios that may arise in your situation and what the benefits or burdens of different treatments may be in these situations. You should also talk with your family about your wishes.

### How do I decide when I should stop treatment?

There may come a time when your quality of life could be better without further treatment. Health professionals will work with you to monitor the benefits and side effects of your treatment. It is important to talk with them about options if the treatment is not helping you. If you do decide to stop your treatment, health professionals will continue to provide any treatments that are needed to ensure you are comfortable.

### What will it be like at the end?

Health professionals who work with people who have a terminal illness say that often people who are dying become drowsier in their final days of life and less aware of what is going on around them. As far as we know, this is not distressing or frightening. Other symptoms (like pain or shortness of breath), if they occur, can be controlled with medications. Your healthcare team will do their best to make sure you are as comfortable as possible. Assistance from a palliative care team may be helpful to enable you to die in the place of your choosing, where feasible. Your healthcare team, with assistance from a palliative care team as needed, can also provide support to your family and those close to you.

## Useful links

In addition to the information you receive from your healthcare team, you might find it helpful to get information from different sources. Throughout this book, we recommend that you call the **Cancer Council Helpline** on **13 11 20** for up-to-date, local information that is relevant for you.

‘Surfing’ the internet can also be a useful way to find information. However, keep in mind that the information you find may not always be accurate. Use careful judgment, and check what type of organisation has put the information on the internet.

The internet can be accessed using a personal computer at home, or at local libraries and in internet cafés. If you are not able to access the internet, you can call the **Cancer Council Helpline** on **13 11 20** and ask them to print out information from websites and send it to you.

### **Some Australian websites that you may find helpful include:**

**National Breast and Ovarian Cancer Centre:** [www.nbocc.org.au](http://www.nbocc.org.au)  
Resource order line: 1800 624 973

This website has up-to-date information about breast cancer. The site includes evidence-based information for women and those close to them.

**Breast Cancer Network Australia:** [www.bcna.org.au](http://www.bcna.org.au)  
Information line: 1800 500 258

This website has a range of breast cancer information and resources developed by women with breast cancer, including a free kit called the *Hope & Hurdles* Pack for women with secondary breast cancer, a quarterly magazine and personal stories written by people affected by breast cancer.

**Cancer Voices Australia:** [www.cancervoicesaustralia.org.au](http://www.cancervoicesaustralia.org.au)

This is a national network providing a forum for people in Australia affected by cancer. The website has links to State and Territory groups.

**Cancer Council Australia:** [www.cancer.org.au](http://www.cancer.org.au)

**Cancer Council Helpline:** 13 11 20

This website has links to State and Territory Cancer Councils, which have information about cancer resources available in each State and Territory.

**CanTeen:** [www.canteen.org.au](http://www.canteen.org.au)

This website provides support to young people aged 12–24 living with cancer and includes information for young people who have an immediate family member with cancer. The website has links to upcoming support programs in each State and Territory.

**Carers Australia:** [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

**Carer Advisory and Counselling Service:** 1800 242 636

This website has information for people who support others with a disability, mental illness, chronic condition or who are frail aged. The website has links to State and Territory groups.

**Palliative Care Australia:** [www.palliativecare.org.au](http://www.palliativecare.org.au)

This website has information about palliative care services available in each State and Territory.

**Some websites from other countries\* that you may find helpful include:**

**American Cancer Society:** [www.cancer.org](http://www.cancer.org)

This website gives information about cancer, including breast cancer. The site also has information about the society itself, its publications and programs.

**Breastcancer.org:** [www.breastcancer.org](http://www.breastcancer.org)

This website provides practical and simple information about all aspects of breast cancer. Regular online 'ask the expert' forums are held on different breast cancer topics.

\*Please note that some of the information on websites from other countries may only apply to people in that country.

**Cancerbackup:** [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)

This is the leading cancer information service in the UK.

**Breast Cancer Care:** [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

This is a UK-based charity providing information for women with breast cancer.

**National Cancer Institute:** [www.cancer.gov](http://www.cancer.gov)

This website provides information developed by the National Cancer Institute in the USA for healthcare professionals, cancer researchers and the general public.

**Winston's Wish:** [www.winstonswish.org.uk](http://www.winstonswish.org.uk)

This is a charity in the UK that provides support and guidance to families, professionals and anyone concerned about a grieving child, professionals and anyone concerned about a grieving child.

There are many internet sites about cancer and breast cancer. You may also like to ask your doctor or nurse about other internet sites that could be suitable for you.

## Other useful contacts

**Centrelink:** [www.centrelink.gov.au](http://www.centrelink.gov.au)

Information about government support and financial assistance.

Disability, sickness and carers: 13 27 17

**Department of Veterans Affairs:** [www.dva.gov.au](http://www.dva.gov.au)

Information about support and assistance available to veterans.

General enquiries: 13 32 54

**Medicare:** [www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au)

Information about Medicare claims.

General enquiries: 13 20 11

## Glossary of terms

<b>Alkylating agent:</b>	a class of chemotherapy, e.g. cyclophosphamide.
<b>Alternative therapies:</b>	treatments used instead of conventional treatments.
<b>Anaemia:</b>	a condition in which there are fewer than normal red blood cells in the blood.
<b>Anthracycline:</b>	a class of chemotherapy, e.g. epirubicin (Pharmorubicin®), doxorubicin (Adriamycin®).
<b>Antimetabolite:</b>	a class of chemotherapy, e.g. 5-fluorouracil (5FU), methotrexate.
<b>Anti-emetic:</b>	a drug used to control nausea and vomiting.
<b>Anti-oestrogen:</b>	a type of hormonal therapy, e.g. tamoxifen.
<b>Aromatase inhibitor:</b>	a type of hormonal therapy, e.g. anastrozole (Arimidex®), letrozole (Femara®), exemestane (Aromasin®).
<b>Ascites:</b>	the abnormal accumulation of fluid in the abdominal or peritoneal cavity.
<b>Biopsy:</b>	removal of cells or tissue from the body for examination under a microscope.
<b>Bone marrow:</b>	a spongy material within some bones that makes different types of blood cells.
<b>Chemotherapy:</b>	treatment for cancer using drugs.
<b>Clinical trials:</b>	studies that compare new treatments with standard treatments.
<b>Complementary therapies:</b>	treatments or therapies that can be used alongside conventional treatments to enhance quality of life and improve overall wellbeing.

<b>CT scan:</b>	computerised tomography — a special type of X-ray that provides a three-dimensional picture of the inside of the body.
<b>Dyspepsia:</b>	another name for indigestion.
<b>Echocardiogram:</b>	a type of ultrasound test that looks at the size, shape and function of the heart.
<b>Endocrine therapies:</b>	another name for hormonal therapies.
<b>Ethics committee:</b>	a group of experts who review clinical trial protocols to make sure that the rights of the patients involved are protected.
<b>Hand–foot syndrome:</b>	redness, tenderness, and peeling of the skin on the palms of the hands and soles of the feet, caused by certain chemotherapy drugs.
<b>HER2:</b>	a protein on a cell that allows a growth factor to bind to the cell, causing the cell to grow and divide. HER2 is also called HER2-neu or c-erbB2.
<b>Hormonal therapies:</b>	drugs used to treat women who have hormone receptors on their breast cancer cells. Also called endocrine therapies.
<b>Hormone receptors:</b>	proteins in a cell that allow hormones to bind to the cell, causing it to grow and divide. Hormone receptors must be present for the cell growth to be influenced by hormones.
<b>Hormone replacement therapy (HRT):</b>	hormones (oestrogen, progesterone or both) given to women after menopause. Used to ease symptoms of menopause.
<b>Hypercalcaemia:</b>	a high level of calcium in the blood.
<b>Intravenous infusion:</b>	a method of putting fluids, including drugs, into the bloodstream through a cannula or needle.
<b>Isotope:</b>	a radioactive substance.

<b>Libido:</b>	sex drive.
<b>Locally advanced breast cancer:</b>	invasive breast cancer that has spread to areas near the breast, such as the chest wall.
<b>Lymphatic vessels:</b>	tiny vessels next to blood vessels that collect fluid and waste products from the body's tissue.
<b>Lymph nodes:</b>	glands in the armpit and other parts of the body that protect the body from infection.
<b>Lymphoedema:</b>	swelling of the arm that can sometimes develop after treatment for breast cancer.
<b>Magnetic Image resonance (MRI):</b>	a way of producing a picture of the inside of the body using magnetic fields.
<b>Mammogram:</b>	a way of taking a picture of the breast using a low-dose X-ray.
<b>Mastectomy:</b>	removal of the whole breast.
<b>Metastasis:</b>	the name for a cancer that spreads to another part of the body.
<b>Mitotic inhibitor:</b>	a class of chemotherapy, e.g. paclitaxel (Taxol®), docetaxel (Taxotere®).
<b>Multidisciplinary care:</b>	a team approach to cancer treatment and planning.
<b>Multi-gated acquisition (MUGA) scan:</b>	a test that measures how well the heart pumps blood.
<b>Nuclear medicine:</b>	a method of diagnostic imaging that uses very small amounts of radioactive material. The patient is injected with a liquid that contains the radioactive substance, which collects in the part of the body to be imaged. Sophisticated instruments detect the radioactive substance in the body and process that information into an image.



<b>Oestrogen:</b>	a type of female hormone.
<b>Oncologist:</b>	a doctor who specialises in treating cancer.
<b>Oophorectomy:</b>	surgical removal of the ovaries.
<b>Osteoporosis:</b>	thinning of the bones that develops as a result of ageing.
<b>PET scan:</b>	positron emission tomography — a scan used to show any areas in the body where cells are more active than usual.
<b>Palliative care:</b>	specialised care for people who have a disease that cannot be cured. Palliative care focuses on helping to control physical symptoms such as pain, on emotional wellbeing, on relationships with others and on spiritual needs. In later stages, palliative care can also help people to prepare for death.
<b>Pathology:</b>	tests that involve examining blood, tissue or cells from the body.
<b>Platelets:</b>	blood cells produced by the bone marrow that help the blood to clot.
<b>Pleura:</b>	the membrane that lines the rib cage and covers the lungs.
<b>Pleural aspiration:</b>	drainage of fluid from around the lungs.
<b>Pleural cavity:</b>	the space between the membrane that lines the rib cage and covers the lungs.
<b>Pneumonitis:</b>	a side effect of radiotherapy in which the lung becomes inflamed.
<b>Progesterone:</b>	a type of female hormone.
<b>Radiology:</b>	tests that involve taking pictures of different parts of the body.

<b>Radiotherapy:</b>	treatment for cancer in a particular area of the body using X-rays.
<b>Receptor:</b>	a protein on or in a cell to which a substance such as a hormone or a drug can attach.
<b>Seroma:</b>	fluid that collects in or around a scar.
<b>Steroids:</b>	drugs used to relieve swelling and inflammation
<b>Systemic treatment:</b>	drugs such as chemotherapy or hormonal therapy that treat the whole body to destroy cancer cells.
<b>Targeted therapies:</b>	drugs that stop the growth of particular types of cancer cells. Also known as biological therapies.
<b>Thrush:</b>	an infection caused by yeast that appears as white patches on the tongue or mouth.
<b>Transfusion:</b>	the transfer of blood or blood products from a donor to another person.
<b>Ultrasound:</b>	a way of producing a picture of the inside of the body using sound waves.
<b>Uterus:</b>	another name for the womb.
<b>White blood cells:</b>	blood cells produced by the bone marrow that help the body to fight infections.

**[www.nbocc.org.au](http://www.nbocc.org.au)**

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