

# Guide for women with early breast cancer



Endorsed by:

Breast  
Cancer  
Network  
Australia



**Australian Government**  
**Cancer Australia**

# Guide for women with early breast cancer



*Guide for women with early breast cancer*

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*\* On 30 June 2011, National Breast and Ovarian Cancer Centre (NBOCC) amalgamated with Cancer Australia to form a single national agency, Cancer Australia, to provide leadership in cancer control and improve outcomes for Australians affected by cancer.*

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# Introduction

## Who this book is for

This book is for people who have been diagnosed with early breast cancer. It contains information to help you understand your diagnosis and treatment options. 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 early breast cancer. Men with breast cancer may also find the information helpful. More information about breast cancer in men is available at [www.canceraustralia.gov.au/breastcancerinmen](http://www.canceraustralia.gov.au/breastcancerinmen).

### Other types and stages of breast cancer

A range of information about different types and stages of breast cancer is available at [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources). Ask your doctor for the information most relevant for you.

## 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 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 at an early stage in your journey.** At the beginning of each section, there is a summary of key points, and at the end there is space for you to make notes or write down any questions for your healthcare team. 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

## Receiving a diagnosis of breast cancer

When your doctor first says the word '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 normal feelings.

**Sharing your feelings, even painful feelings, with others can help you cope with your diagnosis of 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 remember what is said.

***"I went on my own to my first appointment and it went straight over my head. So the doctor very kindly said, 'Come back later with family or someone if you want and I'll discuss it again.'"***

***"You value your life more after you've had breast cancer. You live your life every day and do not take anything for granted."***





Breast Cancer Network Australia's *My Journey Kit* is a free resource for women newly diagnosed with breast cancer. The Kit, which has been developed by women with breast cancer, includes a comprehensive Information Guide and a Personal Record. The Kit can be ordered online at [www.bcna.org.au](http://www.bcna.org.au) or by calling 1300 785 562.

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.

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.



Cancer Australia has information about breast cancer in Chinese, Arabic, Vietnamese, Greek and Italian. A DVD called *My Story* which tells the stories of Aboriginal and Torres Strait Islander women diagnosed with breast cancer is also available to order from the Cancer Australia website. To order or download a copy of any of these resources go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call 1800 624 973.

## 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 your doctor or breast care nurse 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**.

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## How this book was developed

The information in this book was developed with input from health professionals and women who have had breast cancer. The book is based on Cancer Australia clinical practice guidelines. Copies of the clinical practice guidelines are available to view or download from the Cancer Australia website at [www.canceraustralia.gov.au](http://www.canceraustralia.gov.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:**

**Notes:**

# Breast cancer: the facts

This section explains what early breast cancer is, including what we know about what causes it, how common it is and what we know about survival following treatment.

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# About early breast cancer

Date of development: October 2008

## Summary

- Cancer develops when the body's cells grow in an uncontrolled way and spread into the body's tissues.
- Early breast cancer is breast cancer that is contained in the breast and may or may not have spread to lymph nodes in the armpit. Some cancer cells may have spread outside the breast and armpit area but cannot be detected.
- It is not possible to say what causes breast cancer in an individual.
- Known risk factors for breast cancer include being a woman, getting older and having a strong family history of breast cancer (you will find a definition of family history in relation to breast cancer in this section).

## What is cancer

**Cancer is the name for a group of diseases that develop when the body's cells grow in an uncontrolled way and spread into the body's tissues.**

Normally, cells in the body grow and divide in a controlled way. Sometimes this process gets out of control. When cells grow in an uncontrolled way and spread into the body's tissues, this is called **invasive cancer**. The site where the cancer starts is called the **primary cancer**. Sometimes cancer cells can break away from the original cancer and travel in the bloodstream or **lymphatic system** to other parts of the body. If cancer cells from the original cancer start growing in another part of the body, this is called a **metastasis** (also known as a **secondary** or **advanced cancer**).



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



**Metastasis:** the name for cancer that spreads to another part of the body. Also known as a **secondary cancer**.

## What does a breast look like on the inside?

To understand what breast cancer is, it helps to know what a breast looks like on the inside. Breasts are made up of **lobules** and **ducts**, surrounded by fatty and connective tissue. The lobules produce breast milk and the ducts carry the milk to the nipple (see picture). The lymph nodes closest to the breast are in the armpit (axillary nodes). There are also lymph nodes under the breastbone (internal mammary nodes) and in the neck (supraclavicular nodes).

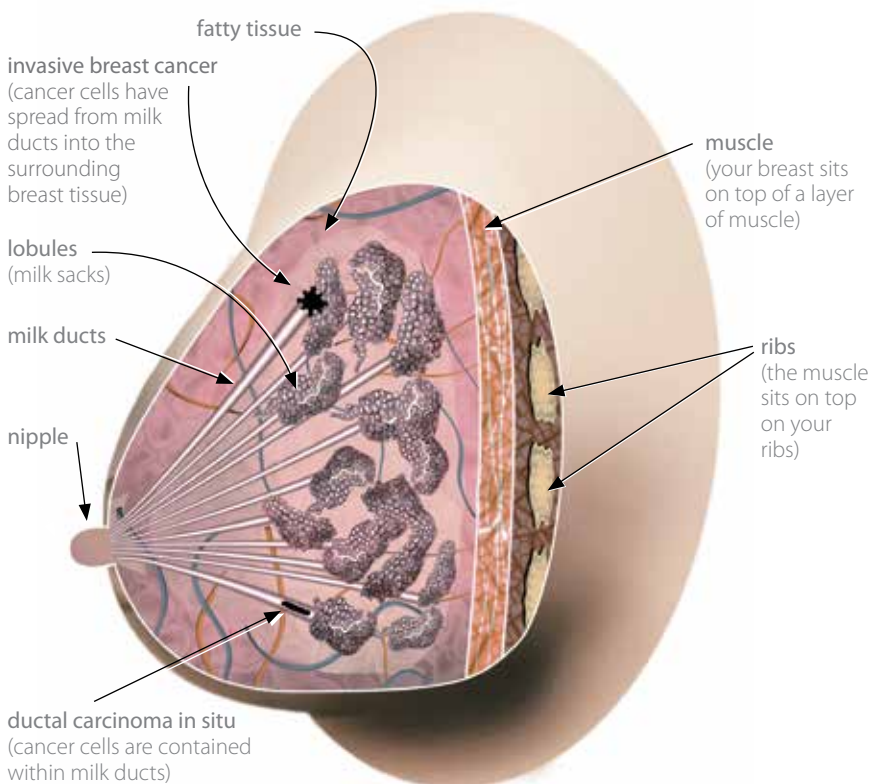


Illustration of a woman's breast, showing ductal carcinoma in situ and invasive breast cancer



For more information about lymph nodes, see the ‘Surgery to the armpit (axilla)’ chapter in the ‘Treatment’ section.

## **What is early breast cancer?**

Early breast cancer is cancer that is contained in the breast and may or may not have spread to lymph nodes in the breast or armpit. Some cancer cells may have spread outside the breast and armpit area but cannot be detected.

Early breast cancer can develop in the ducts or lobules of the breast. The cancer cells spread outside the ducts or lobules into the breast tissue and may form a lump. This is called ‘invasive breast cancer’. Sometimes breast cancer cells spread to other parts of the body, such as the bones or the liver. If this happens, the cancer is referred to as a secondary breast cancer, not bone cancer or liver cancer.

Other types of breast cancer include:

- ductal carcinoma in situ (DCIS) — non-invasive breast cancer that is confined to the ducts of the breast
- lobular carcinoma in situ (LCIS) — non-invasive breast cancer that is confined to the lobules of the breast
- Paget’s disease of the nipple — rare form of invasive breast cancer that affects the nipple and the area around the nipple (the areola)
- inflammatory breast cancer — rare form of invasive breast cancer that affects the blood vessels in the skin of the breast, causing the breast to become red and inflamed
- locally advanced breast cancer — invasive breast cancer that has spread to areas near the breast, such as the chest wall.

***“I thought I was invincible and when I found that I was vulnerable that was a big, big shock.”***

***“The doctor said to me, ‘You’ve got breast cancer’. I immediately switched off. He wasn’t talking to me, he was talking to someone totally different.”***





Cancer Australia has information for women with secondary breast cancer (also called **metastatic** or **advanced** breast cancer) and the other types of breast cancer listed before. Ask your doctor for the information most relevant for you. Or, to download or order Cancer Australia resources, visit [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call Cancer Australia on 1800 624 973.

## What causes breast cancer?

It is not possible to say what causes breast cancer in an individual. However, some features are more common among women who have developed breast cancer. These features are called **risk factors**.

**Having one or more risk factors for breast cancer does not mean you will definitely develop breast cancer. In fact, many women with breast cancer have no obvious risk factors.**

Known risk factors for breast cancer include:

- being a woman
- getting older
- inheriting a faulty gene (called a gene mutation) that increases the risk of breast cancer
- having a strong family history of breast cancer.



A strong family history means having three or more first- or second-degree relatives on the same side of the family with breast or ovarian cancer. A family history on your father's side is just as important as on your mother's side.

For more information about risk factors for breast cancer visit Cancer Australia's online information resource and calculator, *Your risk and breast cancer*, at [www.canceraustralia.gov.au/breastcancer/risk](http://www.canceraustralia.gov.au/breastcancer/risk).

***"Initially you go through this, 'Why did this happen to me, I'm a good person'. But I got past that and thought, '...it's just bad luck.'"***

## How is breast cancer found?

Breast cancer can be found in different ways. You or your doctor may have noticed a change in your breast, or the cancer may have been found after a routine mammogram or after a biopsy for another reason.

Your doctors will have done a series of tests to find out whether the change in your breast was due to cancer. These tests will have included a physical examination, imaging tests (for example a mammogram, ultrasound or MRI) and one or more biopsies.



**Mammogram:** a way of examining the breasts using low-dose X-rays.

**Ultrasound:** a way of examining the breasts and/or the armpit area using high frequency sound waves.

**MRI:** magnetic resonance imaging — a way of examining the breasts, armpit or chest using magnetic fields.

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

***“Talking to other people really does help immensely.”***



## Questions to ask your healthcare team

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

- What type of breast cancer do I have?
- 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?

This image shows a full page of white paper with horizontal dashed lines, typical of primary school writing paper. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

# Breast cancer statistics

Date of development: May 2012

## Summary

- One in 8 women and 1 in 688 men will be diagnosed with breast cancer before the age of 85 years in Australia.
- Breast cancer is most common in women aged 50 years and older.
- Early breast cancer can be treated successfully. Most people who are diagnosed and treated for early breast cancer will not die from the disease.

## How common is breast cancer?

Breast cancer is the most common invasive cancer among Australian women. One in 8 women will be diagnosed with breast cancer before the age of 85 years. Breast cancer can occur at any age but is more common in older women. In 2008, about a quarter of women diagnosed with breast cancer were younger than 50 years, about half were 50–69 years and about a quarter were 70 years and older.

Men can also develop breast cancer. Breast cancer is much less common in men than in women. One in 688 men will be diagnosed with breast cancer before the age of 85 years. Breast cancer is more common in men aged 50 years and older.

## Will I die from breast cancer?

**Early breast cancer can be treated successfully. Most people diagnosed and treated for early breast cancer will not die from the disease.**

Some people want to know how likely they are to survive breast cancer. Looking at statistics about other people who have been diagnosed and treated for breast cancer can be helpful. However, it is important to remember that these are overall statistics. Everyone's situation is different.

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Breast cancer survival is measured by counting the number of people who are alive five years after treatment. Most people live much longer than five years, but the statistics are measured in this way.

Of all the women diagnosed with breast cancer in Australia between 2000 and 2006, over 88% were still alive five years later. This includes women with early breast cancer and those with secondary breast cancer. Survival for women with early breast cancer alone is higher than this. For women with small cancers (10 mm or less in diameter), 5-year survival is almost as high as that for women without breast cancer.

In general, survival for men with breast cancer is similar to that for women with breast cancer when the stage of the disease at diagnosis is the same.

***“I asked my GP, ‘Am I going to die from breast cancer?’ and she said, ‘No, probably not’. I’ve always focused on that.”***

**Notes:**

# Making sense of test results

This section explains what your different test results mean. Some of this information will only be available after you have surgery for breast cancer.

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# The pathology report

Date of development: October 2008

## Summary

- A **pathologist** examines the cells or tissue removed from your breast during a biopsy or breast surgery.
- The test results are written in a **pathology report**.
- The pathology report will help you and your doctors decide what treatments are best for you.

## What is a pathology report?

After a biopsy or breast surgery, the cells or tissue are sent to a **pathologist**. The pathologist looks at the cells or tissue under a microscope and writes the results in a **pathology report**. This will usually take a couple of days. The information in the pathology report will help you and your doctors decide what treatments are best for you. You may find it helpful to keep a copy of your test results. You can also ask for a copy of your pathology report.



For more information about treatment options for early breast cancer, see the 'Treatment' section.

## What information is in the pathology report?

The pathology report usually includes the information listed below.

### Your diagnosis

For early breast cancer, the diagnosis is 'invasive breast cancer'.

### Size and location

The report shows the size of your breast cancer and where it is located in your breast. This will affect what treatments are recommended for you, including the type of surgery.



## Hormone receptors

The report shows whether your breast cancer is positive or negative for **hormone receptors**. This will affect whether hormonal therapies are recommended for you. There are two types of hormone receptors — oestrogen receptors and progesterone receptors. If there are hormone receptors on your breast cancer cells, your breast cancer is said to be oestrogen receptor-positive (ER+) or progesterone receptor-positive (PR+).



**Hormone receptors:** proteins in a cell that allow hormones to bind to the cell. Hormone receptors must be present for the cell growth to be influenced by hormones.

## HER2 status

The report shows whether there are HER2 receptors on your breast cancer cells. This is called the **HER2 status** of your breast cancer cells. This will affect whether treatment with trastuzumab (Herceptin®) is recommended for you.



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

## Lymph nodes

The report shows whether there are cancer cells in the **lymph nodes** in your armpit (axilla) or near your breast. This information will usually only be available after breast surgery and may affect whether chemotherapy is recommended for you.



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

## Surgical margin

The surgeon will remove the breast cancer and some healthy looking tissue around the cancer. The healthy looking tissue is called the **surgical margin**. If there are no cancer cells in the healthy looking tissue, it is likely that all the cancer has been removed. In this case, the surgical margin is said to be 'clear'. This information will only be available after breast surgery. If the surgical margin is not considered to be 'clear', you may need to have more surgery. This is important to ensure that all of the cancer is removed.

## Grade of breast cancer

The **grade** of the cancer shows how fast the cancer cells are growing. The cancer grade is numbered from 1 to 3. A low grade (Grade 1) means that the cancer is growing slowly. A high grade (Grade 3) means that the cancer is growing more quickly.

The higher the grade means the cancer is more active. This means it is more likely that the cancer has spread outside the breast and armpit area. The higher the grade means it is more likely that systemic treatments (treatments that affect the whole body, such as hormonal therapy or chemotherapy) will be recommended.

***"Because everything happened fairly quickly once the diagnosis was made, it was like a whirlwind somehow and I was also in shock I suppose, and I didn't take a lot in. Afterwards I wanted to know what my diagnosis meant, in simple terms."***

## Stages of breast cancer

Your doctor might talk about the **stage** of your breast cancer. The stage is a way of summarising the information from the pathology report. Stages of breast cancer are numbered from I to IV. Early breast cancer may be called Stage I, Stage IIA or Stage IIB (2-5 cm). These stages are described in the table opposite.

| Stages of early breast cancer |                               |  |
|-------------------------------|-------------------------------|--|
| Stage                         | Size of the cancer            | Have cancer cells been found in the lymph nodes? |
| Stage I                       | < 2 cm                        | No (node negative)                               |
| Stage II                      | < 2 cm                        | Yes (node positive)                              |
|                               | 2 -5 cm                       | No (node negative)                               |
|                               | No cancer found in the breast | Yes (node positive)                              |
| Stage IIB                     | 2 -5 cm                       | Yes (node positive)                              |

Stages IIB (>5cm), III and IV refer to either locally advanced breast cancer or secondary breast cancer. For more information about locally advanced breast cancer or secondary breast cancer, visit [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au).

## What makes breast cancer more likely to come back or spread?

Early breast cancer can be treated successfully. For most women, breast cancer will not come back after treatment.

Sometimes breast cancer is found later in the same breast or in other parts of the body. Everyone is different and there is no way of telling for sure whether breast cancer will or will not come back. Doctors use the information in the pathology report to work out how likely it is that breast cancer will come back or spread to other parts of the body. The main features known to affect the chance of breast cancer coming back or spreading are listed in the following table. These are general statements based on experience with women who have had breast cancer.

| Features that can affect the chance of breast cancer coming back or spreading |  |  |
|---|--|--|
| Information in the pathology report   | The breast cancer is <u>less</u> likely to come back or spread if: | The breast cancer is <u>more</u> likely to come back or spread if: |
| Size  | Cancer is smaller (less than 2 cm)                                 | Cancer is larger (more than 2 cm)                                  |
| Lymph nodes in the armpit   | No cancer cells in the lymph nodes                                 | Cancer cells in the lymph nodes                                    |
| Hormone receptors   | Cancer cells have hormone receptors and you have hormonal therapy  | Cancer cells do not have hormone receptors                         |
| HER2  | Cancer cells are HER2-negative                                     | Cancer cells are HER2-positive                                     |
| Grade   | Grade of cancer is low (Grade I)                                   | Grade of cancer is high (Grade 3)                                  |
| Surgical margin   | Surgical margin is clear   | Surgical margin is not clear                                       |

If your breast cancer has one or more of the features in the right hand column, it does not mean that breast cancer will definitely come back or spread. Talk to your doctor about your individual situation.



## Questions to ask about your test results

Listed below are some questions about your test results you might want to ask your healthcare team.

- Where is my breast cancer?
- Can I have a copy of my pathology report?
- Can you explain my pathology report to me?
- Is my breast cancer hormone receptor-positive or HER2-positive?  
What does this mean for me?
- How likely is it that my breast cancer will come back/spread?
- Can you write down what you have told me so that I can read it again later?

[illegible]

## Frequently asked questions

### What does it mean if my breast cancer is hormone receptor-positive?

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. If your breast cancer is hormone receptor-positive, your doctor may recommend that you have treatment with a hormonal therapy. If your breast cancer is hormone receptor-negative, there are other treatments that are suitable for you.



For more information about hormonal therapies, see the 'Hormonal therapies' chapter in the 'Treatment' section.

### What does it mean if my breast cancer is HER2-positive?

'HER2-positive' means that the breast cancer cells have higher than normal levels of a protein called HER2. The HER2 protein affects how quickly cells divide in response to certain growth factors. Trastuzumab (Herceptin®) is a biological therapy that works by stopping HER2-positive cancer cells from growing and dividing. About one in five patients have HER2-positive breast cancer. If your breast cancer is HER2-positive, your doctor may recommend that you have treatment with a targeted therapy.



For more information about Targeted therapies, see the 'Targeted therapies' chapter in the 'Treatment' section.







# Treatment

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

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# Understanding your treatment options

Date of development: October 2008

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

## Summary

- The aim of treatment for early breast cancer is to remove the breast cancer and any cancer cells that may be left in the breast, armpit or other parts of the body but cannot be detected.
- Your treatment options will depend on your individual situation.
- A range of health professionals will be involved in managing your treatment and care. This is called multidisciplinary care.
- Your doctors will help you to decide which treatments are best for you.
- It is OK to take a week or two to decide about your treatment. This will not affect the outcome of your treatment.
- If you are pregnant when you are diagnosed with 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 breast cancer.

## Overview of treatment options

**The aim of treatment for early breast cancer is to remove the breast cancer and any cancer cells that may be left in the breast, armpit or other parts of the body but cannot be detected.**

Following are the treatments usually offered to women with early breast cancer. More detail about each treatment is provided in later chapters. Everyone is different and treatments that may be suitable for one woman may not be suitable for another. Talk to your doctors about which treatments are recommended for you.

*“I like the way my doctor treated me and my husband. He wasn’t just talking about my breast or research or being very clinical. He took time to get to know me and the family and never stood over me.”*

## Breast surgery

Surgery for breast cancer involves either:

- **breast conserving surgery:** removal of the breast cancer and a small area of healthy tissue around it, or
- **mastectomy:** removal of the whole breast.

Both types of surgery usually also involve removal of one or more **lymph nodes** from the armpit.



Other names for breast conserving surgery are **lumpectomy, complete local excision, partial mastectomy** and **wide local excision**.

## Radiotherapy

Radiotherapy uses X-rays to destroy any cancer cells that may be left in the breast, chest wall or armpit after breast surgery but cannot be detected. Radiotherapy is almost always recommended after breast conserving surgery. Radiotherapy is sometimes recommended after mastectomy.

## Chemotherapy

Chemotherapy uses drugs to destroy cancer cells that may be left in the body but cannot be detected. Chemotherapy may be used with other breast cancer treatments. Treatment with chemotherapy is usually recommended if there is a risk that cancer cells may have spread outside the breast and armpit area.

## Hormonal therapies

Hormonal therapies are drugs used to treat women who have hormone receptors on their breast cancer cells. Hormonal therapies may be used alone or with other breast cancer treatments.



**Hormone receptors:** proteins in a cell that allow hormones to bind to the cell. Hormone receptors must be present for the cell growth to be influenced by hormones.

## 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 may be used with other breast cancer treatments. The most common targeted therapy is trastuzumab (Herceptin®). Lapatinib (Tykerb®) is another targeted therapy that is approved on the Pharmaceutical Benefits Scheme (PBS) for treatment of a certain type of secondary breast cancer.



For the latest information on targeted therapies, visit [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au).

For more information about therapies for breast cancer that are approved on the Pharmaceutical Benefits Scheme, visit [www.pbs.gov.au](http://www.pbs.gov.au).

## 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.

***“At my first appointment I had half an hour with the breast nurse. She explained what would happen so by the time I started going through with everything, I was fully aware of where I was going to end up and just how it was all done.”***

## Complementary and alternative therapies

Complementary therapies are treatments or therapies that can be used alongside conventional treatments and have been shown to enhance quality of life and improve overall wellbeing. Relaxation therapy and meditation are examples of complementary therapies. Alternative therapies are treatments used instead of conventional treatments. There is no evidence that alternative therapies have any benefit in the treatment of breast cancer.

## Your multidisciplinary treatment team

During your cancer journey, you will meet a number of health professionals. Your treatment team will help you decide which treatments are best for you. They will also support you through your journey. Meeting lots of different health professionals can be quite daunting. You will usually have one main contact person who can answer any questions you have. This person may change at different points during your journey. **Ask a member of your treatment 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 breast care nurse about who will be involved in discussions about your treatment plan.**



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

The health professionals who are likely to be involved in your care include:

- **general practitioner (GP):** provides ongoing care and works with other members of your treatment team
- **surgeon:** specialises in surgery, including biopsies
- **pathologist:** examines cells, tissue and blood from the body
- **radiologist:** examines mammograms, ultrasounds and other imaging results and may perform biopsies or help locate cancers prior to surgery
- **radiation oncologist:** specialises in radiotherapy
- **radiation therapist:** assists in planning and giving radiotherapy
- **medical oncologist:** specialises in cancer drugs such as chemotherapy, hormonal therapies and targeted therapies
- **breast care nurse:** specialises in caring for people with breast cancer



- **oncology nurse:** specialises in caring for people with cancer.

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

- **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
- **physiotherapist, occupational therapist, lymphoedema therapist:** assist with exercise after treatment and managing lymphoedema
- **plastic surgeon:** specialises in breast reconstruction after breast surgery
- **genetic counsellor:** provides advice for women with a strong family history of breast cancer.



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

**Lymphoedema:** swelling of the arm that can sometimes develop after treatment for breast 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. For more information about lymphoedema see the 'Lymphoedema' chapter in the 'When treatment is over' section.

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. **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.

***"Having a multidisciplinary team was a great plus because it meant everyone, the whole team, was working together and discussing my case. I think that was far better than just being treated in isolation."***

## Travelling for treatment

If you live outside a major city, you may need to travel to see a specialist surgeon, radiation oncologist or medical oncologist. Once your treatment plan has been decided, you will probably be able to have chemotherapy at a hospital in your nearest regional town. However, you may need to travel for surgery and radiotherapy. 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.

## 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. Before you start treatment, you may need time to ask questions and talk to your healthcare team, your family and friends or other women who have experienced breast cancer.

It is OK to take a week or two to decide about treatment. This can give you time to choose the treatment that is right for you and to make practical arrangements. Taking a week or two to decide will not affect the outcome of your treatment.

***"But when it boils down to it, it's your decision, nobody else's. You can only decide what's right for you."***

***"It took me about two-and-a-half weeks to think about coming back to get treatment. I thought, 'This is a foreign thing going into my body, what's going to happen?'"***

***“He said, ‘Go away and think about it for a week’. And I thought that was really great because when you get all that information you need to sit down and think out all the options that you have.”***

### **Tips for talking to your healthcare team**

Some people find it overwhelming to receive lots 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 treatment team. The following tips might be helpful for you:

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

***“I walked straight out of the surgeon’s office and got in the car and rang my GP. I felt the need to go and talk to another medical person.”***

## Treatment and pregnancy

### Treatment during pregnancy

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

If you are pregnant when you are diagnosed with breast cancer:

- you can have **breast surgery** with only a slight risk of miscarriage; the risk of miscarriage is lower after the first trimester
- **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** (Herceptin®) are not recommended during pregnancy.

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

### Pregnancy during treatment

It is recommended that you do not become pregnant during treatment for 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 'When treatment is over' section.



## Questions to ask about your treatment

Listed below are some questions you might want to ask when first talking with your healthcare team about your treatment for breast cancer.

- Who are the members of my treatment team?
- Who will be my main contact person?
- Who will be involved in discussions about my treatment?
- Who can I contact if I have questions about my treatment?
- Can I bring a friend/family member to my appointments?
- Can I tape record our discussion?
- Can you write down what you have told me?
- What impact will being pregnant have on the timing of my treatment?
- Will I need to travel for treatment?
- Can you refer me for a second opinion?
- Who should I contact in an emergency?
- Will I be supported by a breast care nurse?

You may like to write your own questions here:

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## **Frequently asked questions**

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

A diagnosis of breast cancer can be overwhelming. You will be given lots 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 found in this section under 'Making decisions about treatment' useful.

### **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 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.

# Breast surgery

Date of development: October 2008

## Summary

- Breast surgery for early breast cancer involves removal of part of the breast (breast conserving surgery) or the whole breast (mastectomy).
- In most cases, breast surgery also involves removal of one or more lymph nodes from the armpit (axilla).
- The type of breast surgery offered or recommended to you will depend on your individual situation and your preference.
- Breast conserving surgery followed by radiotherapy is as effective as mastectomy for most women with early breast cancer.

## Choosing which type of breast surgery to have

There are two types of breast surgery: breast conserving surgery and mastectomy. These are described in detail below. **The type of breast surgery offered or recommended to you will depend on your individual situation and your preference.**

Things to consider include:

- your age
- the size and grade of your cancer (including the size of the cancer in relation to the size of your breast)
- whether the cancer is in more than one place in your breast
- how likely it is that breast cancer will come back or spread
- whether you have had genetic testing which confirms you are carrying BRCA1 or BRCA2 gene mutations
- what your body will look like after surgery
- whether you have previously had radiotherapy to the breast area
- your general health and whether you have other medical conditions.

- **Compression sleeve** — this is a tightly fitting elastic sleeve worn on the affected arm. Studies suggest that wearing a compression sleeve can help to reduce the swelling associated with lymphoedema. The sleeve stops fluid from building up and moves excess fluid out of the affected area. Your doctor may recommend that you wear a compression sleeve if your arm swells, or during certain activities, such as sport or air travel. Wearing a compression sleeve may be combined with other forms of treatment, such as manual lymphatic drainage (see below).

**Compression sleeves should be fitted professionally and replaced when they lose their elasticity.**

- **Manual lymphatic drainage (MLD) or decongestive physiotherapy** — this is a special form of massage of the affected area. The aim of manual lymphatic drainage is to improve the way in which the lymphatic vessels are working and reduce the build-up of fluid. It uses long, slow, gentle strokes to help move the lymph fluid from the affected area through the remaining lymph vessels to nearby or distant lymph nodes. Such treatments should be designed by a qualified lymphoedema practitioner. Your practitioner can also teach a carer or family member how to do this technique at home.
- **Compression bandaging** — is usually done in combination with manual lymphatic drainage to reduce swelling in the breast or to reduce severe swelling in the arm before a compression garment is fitted. It may also be used if your skin is very fragile or damaged. Compression bandages should be replaced every day.



Ask your GP, surgeon, breast care nurse or lymphoedema practitioner for more information about how to manage lymphoedema.



- **Compression sleeve** — this is a tightly fitting elastic sleeve worn on the affected arm. Studies suggest that wearing a compression sleeve can help to reduce the swelling associated with lymphoedema. The sleeve stops fluid from building up and moves excess fluid out of the affected area. Your doctor may recommend that you wear a compression sleeve if your arm swells, or during certain activities, such as sport or air travel. Wearing a compression sleeve may be combined with other forms of treatment, such as manual lymphatic drainage (see below).

**Compression sleeves should be fitted professionally and replaced when they lose their elasticity.**

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- **Compression bandaging** — is usually done in combination with manual lymphatic drainage to reduce swelling in the breast or to reduce severe swelling in the arm before a compression garment is fitted. It may also be used if your skin is very fragile or damaged. Compression bandages should be replaced every day.



Ask your GP, surgeon, breast care nurse or lymphoedema practitioner for more information about how to manage lymphoedema.

Breast conserving surgery is an option if the breast cancer is small enough compared to the size of your breast:

- to allow removal of the cancer and some healthy tissue around it and
- to give an acceptable appearance.

### **What does breast conserving surgery involve?**

Breast conserving surgery usually involves:

- removal of the cancer and a small area of healthy tissue around it
- radiotherapy to the breast after surgery.

Some people also have radiotherapy to lymph nodes in the armpit and/or lower neck.



For more information about radiotherapy, see the 'Radiotherapy' chapter in this section.

For more information about surgery to remove lymph nodes, see the 'Surgery to the armpit (axilla)' chapter in this section.

If you are having breast conserving surgery, you will probably be asked to arrive at hospital on the day of surgery. The operation is done under a general anaesthetic. The operation itself usually takes up to one-and-a-half hours. There will also be preparation time and you will need time to recover from the anaesthetic. You could be in hospital anywhere between one day and one week, depending on your individual situation.

### **What happens after breast conserving surgery?**

After breast conserving surgery, you will have a dressing over the surgery site. If lymph nodes are removed from your armpit, a plastic tube (called a drain) will usually be inserted under your arm. The drain removes blood and fluid that collects during the healing process. It will usually be removed after a few days.

After surgery, the pathologist will look at the breast tissue and lymph nodes that have been removed. The results will help you and your doctors decide what other treatments are best for you. If there are cancer cells in the surgical margin around your breast cancer, you may need more surgery. Some women may need a mastectomy.

## Recovering from breast conserving surgery

Your wounds from surgery should be fairly well healed after about a week. During the first few weeks after surgery, the wounds will be sensitive and need extra care. Many women feel tired and need a lot of rest, even after their wounds have healed. You may feel ready to go back to work or normal activities after a couple of weeks. Or you may need longer to recover.

Your physical recovery after surgery is important, but is only part of the recovery process. You will also need time to recover emotionally. Some women feel upset about their body image, sexuality or self-esteem after breast conserving surgery. Although it is not always easy, talking to your doctor or breast care nurse about how you are feeling can help.



Cancer Australia's booklet, *Cancer — how are you travelling?* explains the emotional, psychological, physical and practical challenges of a diagnosis of cancer, and what can help. To order a copy, go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call 1800 624 973. Also see the 'Finding support' section for more information about your feelings during and after breast cancer treatment.

## What does breast conserving surgery look like?

After breast conserving surgery, you will have a scar on your breast. The scar will become less obvious with time. Your breast size and shape is also likely to change. The position of the scar and the shape of your breast after surgery will depend on where the breast cancer is and how much breast tissue is removed. In some cases, the shape and size of the breast may be different to the other breast and may affect symmetry.

If your breast size and shape change a lot, you may choose to use an external breast prosthesis or have further surgery to improve symmetry (ie breast reconstruction or reducing the size of the other breast).



For more information about breast prostheses and breast reconstruction, see the 'Breast prostheses and breast reconstruction' chapter in this section.

You may want to ask your surgeon to show you some pictures of other women who have had breast conserving surgery.



Breast conserving surgery of the right breast

## Side effects of breast conserving surgery

Everyone responds differently to breast conserving surgery. Some side effects happen to most people, others happen only occasionally. Some side effects happen straight after surgery, others take longer to develop. Most side effects can be reduced or managed with appropriate care.

**Talk to your doctors about any side effects you are worried about or think you are developing.**

*Common* side effects of breast conserving surgery:

- pain, discomfort or numbness in the breast and/or armpit while the wounds are healing — this usually settles after a few weeks
- bruising or swelling around the wound in your breast (or under your arm if you have had lymph nodes removed)
- stiffness in your arm or shoulder — you may find it helpful to do some approved exercises after surgery; talk to your surgeon, breast care nurse or physiotherapist for advice
- if you have had lymph nodes removed, you may have some tingling in your arm or shoulder — this may improve with time, but feeling in these areas may change permanently
- fluid may collect in or around the scar in your breast or armpit — this is called a **seroma** and may need to be drained using a fine needle and a syringe; this can be done by the breast care nurse or another health professional in the clinic or by your GP
- mild pain in the arm and/or armpit — this can last a year or more after surgery if you have had lymph nodes removed.

Side effects that *sometimes* develop after breast conserving surgery:

- if you have had lymph nodes removed from your armpit, you might have swelling in your arm, breast, hand or chest that lasts after the initial side effects of surgery are over; this is called **lymphoedema** and can develop a few months or years after surgery.

*Rare* side effects of breast conserving surgery:

- infection or bleeding in the scar in your breast or armpit; some women may need further surgery.



For more information about lymphoedema, see the 'Lymphoedema' chapter in the 'When treatment is over' section.

## Mastectomy

**Mastectomy involves removal of the whole breast.**

Mastectomy is usually recommended if:

- the breast cancer is large compared to the size of the breast or
- there is more than one cancer in the breast (**multifocal disease**).

Mastectomy may also be recommended after breast conserving surgery if:

- there are cancer cells in the surgical margin around the breast cancer that was removed
- breast cancer comes back in the same breast
- you have previously had radiotherapy to the breast area.

Some women choose to have a mastectomy as their first surgery, to avoid having radiotherapy or further surgery to the breast.



**Surgical margin:** the area of healthy looking tissue around the breast cancer removed by surgery; if there are no cancer cells in the surgical margin it is said to be 'clear'.

## What does mastectomy involve?

Mastectomy usually involves:

- removal of the entire breast (usually including the nipple)
- removal of one or more lymph nodes from the armpit — this is usually done through the same incision so there are no separate scars under the arm.

If you are at increased risk of breast cancer coming back in the chest area, you may have radiotherapy to the chest wall after mastectomy. Some people also have radiotherapy to lymph nodes at the base of the neck and occasionally to the armpit.



For more information about radiotherapy, see the 'Radiotherapy' chapter in this section.

For more information about surgery to remove lymph nodes, see the 'Surgery to the armpit (axilla)' chapter in this section.

If you are having a mastectomy, you will probably be asked to arrive at the hospital on the day of surgery. The operation usually takes 1–2 hours. There will also be preparation time and you will need time to recover from the anaesthetic. You could be in hospital anywhere between one day and one week, depending on your individual situation. If you have a breast reconstruction at the same time as your mastectomy, your surgery is likely to take longer and you may need to stay in hospital longer than if you have a mastectomy only.



For more information about breast reconstruction, see the 'Breast prostheses and breast reconstruction' chapter in this section.

## What happens after mastectomy?

After a mastectomy, you will have a dressing over the surgery site. If you have lymph nodes removed from your armpit, you will usually have a plastic tube (called a drain) inserted under your arm. The drain removes blood and fluid that collects during the healing process. It will usually be removed after a few days.

You can wear a soft temporary **external breast prosthesis** while your wounds are healing. Once your wounds have healed, you can be fitted for a permanent prosthesis.



**External breast prosthesis:** an artificial breast; also called a breast form.

You will usually be given a soft temporary prosthesis while you are in hospital. Ask your surgeon or breast care nurse for more information.



For more information about external breast prostheses, including Government reimbursements and where in your area you can be fitted for a breast prosthesis, see the 'Breast prosthesis and breast reconstruction' chapter in this section.

## Recovering from a mastectomy

Your wounds should be fairly well healed after about a week. During the first few weeks after surgery, the wounds will be sensitive and need extra care. Many women feel tired and need a lot of rest, even after their wounds have healed. You may feel ready to go back to work or normal activities after a couple of weeks, or you may need longer to recover. If you have a breast reconstruction at the same time as your mastectomy, you will probably take longer to recover than if you have a mastectomy only.

After a mastectomy, you may be aware of a difference in weight between the two sides of your body, particularly if your other breast is large. A breast prosthesis or breast reconstruction can help balance the weight and improve your posture.



For information about breast prostheses and breast reconstruction, see the 'Breast prostheses and breast reconstruction' chapter in this section.

Your physical recovery after surgery is important, but is only part of the recovery process. You will also need time to recover emotionally. Many women feel a sense of grief about losing their breast. Some women feel upset about their body image, sexuality or self-esteem. Although it is not always easy, talking to your doctor or breast care nurse about your feelings can help.



For information about your feelings during and after breast cancer treatment, see the 'Finding support' section.



***“After the surgery I couldn’t really lift my arm so I couldn’t brush my hair or drive the car. I joined the Encore program and that was a fantastic way to get the movement back into my arm. Now my arm is as good as it was before.”***

To find out more about the Encore Program see ‘Useful Links’.

### **What does a mastectomy look like?**

After a mastectomy, you will have a scar that runs across or down your chest. The scar will become less obvious with time. The picture below is of a woman who has had a mastectomy. You might want to ask your surgeon to show you some other pictures of women who have had a mastectomy.



**Mastectomy of the right breast**

## Side effects of mastectomy

Everyone responds differently to mastectomy. Some side effects happen to most people, others only happen occasionally. Some side effects happen straight after surgery, others take longer to develop. Most side effects can be reduced or managed with appropriate care.

**Talk to your doctors about any side effects you are worried about or think you are developing.**

Common side effects of mastectomy:

- pain, discomfort or numbness in the chest while the wounds are healing — this usually settles in a few weeks
- fluid may collect around the scar in your chest — this is called a **seroma** and may need to be drained using a fine needle and a syringe; this can be done by the breast care nurse or another health professional in the clinic or by your GP
- stiffness in your arm or shoulder — you may find it helpful to do some approved exercises after surgery; talk to your surgeon, physiotherapist or breast care nurse for advice
- numbness or tingling in your arm or shoulder, if you have had lymph nodes removed — this may improve with time, but feeling in these areas may change permanently
- mild pain in the armpit or upper arm – this can last a year or more after surgery if you have had lymph nodes removed.

Side effects experienced by some women after mastectomy:

- swelling or bruising around the wound in the chest or armpit — this usually settles in a few weeks
- if you have had lymph nodes removed from your armpit, it is possible that your arm, hand or chest may swell up; this is called **lymphoedema** and can develop a few months or years after surgery.

Rare side effects of mastectomy:

- infection or bleeding in the scar in the chest — some women might need further surgery.



For more information about lymphoedema, see the 'Lymphoedema' chapter in the 'When treatment is over' section.

***"I started swimming because I was having problems with my arm. That really did help."***



## Questions to ask about breast surgery

Listed below are some questions you might want to ask about breast surgery.

- What type of surgery is best for me?
- What will surgery involve?
- Do you specialise in breast cancer surgery? Can you refer me to someone who specialises in breast cancer surgery?
- Where will the scars be and what will they look like?
- How long will I be in hospital?
- How long will I take to recover?
- What side effects can I expect?
- Who should I contact if side effects happen?
- How much will the surgery cost?

This image shows a full page of white paper with horizontal dotted 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.

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## Frequently asked questions

### How do I choose a breast surgeon?

Surgeons with an interest in breast surgery can join the Royal Australasian College of Surgeons Section of Breast Surgery. Full members of this section take part in a national audit to ensure they are delivering high quality care. To view a list of breast surgeons participating in the national audit go to [www.surgeons.org](http://www.surgeons.org). Alternatively ask your surgeon if they are a member of the Breast Section of the Royal Australasian College of Surgeons.

### How soon can I have a shower or bath after breast surgery?

You should be able to have a shower or bath about 24 hours after breast surgery.

# Surgery to the armpit (axilla)

Date of development: October 2008

## Summary

- The lymph nodes in the armpit (axilla) are often the first place that breast cancer will spread to outside the breast.
- The aim of surgery to remove lymph nodes from the armpit is to find out whether breast cancer has spread outside the breast, remove the cancer cells, and help plan further treatment.
- Surgery to the armpit may involve removing several or all lymph nodes (axillary dissection) or removal of one or a few lymph nodes (sentinel node biopsy).

## What are lymph nodes?

There are **lymph nodes** all around the body, including the armpit, groin, stomach, chest and neck. Lymph nodes are small, rounded glands that can range in size from about 1 mm to 25 mm. The number of lymph nodes varies in different people. There are usually around 15–30 lymph nodes in the armpit.

Lymph nodes act like filters. They are connected to small vessels called lymphatic vessels, which are close to the blood vessels. Fluid from the body's tissues usually drains into lymphatic vessels. This fluid is called lymph. Lymphatic vessels carry lymph to the lymph nodes, where substances that could be harmful to the body, such as bacteria or cancer cells, are trapped and removed. This helps to protect the body from infection. The lymph then passes back into the blood.

The lymph nodes in the armpit (axilla) drain lymph fluid from nearby areas, including the breast. The lymph nodes in the armpit are often the first place that cancer cells spread to outside the breast. About one in three women with breast cancer have cancer cells in the lymph nodes in their armpit when their breast cancer is diagnosed.

If there are cancer cells in the lymph nodes in the armpit, you may feel a lump in the armpit. However, many women are not aware of any changes. Cancer cells in the lymph nodes can usually only be seen under a microscope and cannot be felt or seen on X-rays or scans.

**Lymph nodes can become enlarged for many reasons, including having a cold or an infection. If you can feel a lump in your armpit, this does not necessarily mean that cancer has spread to your armpit.**

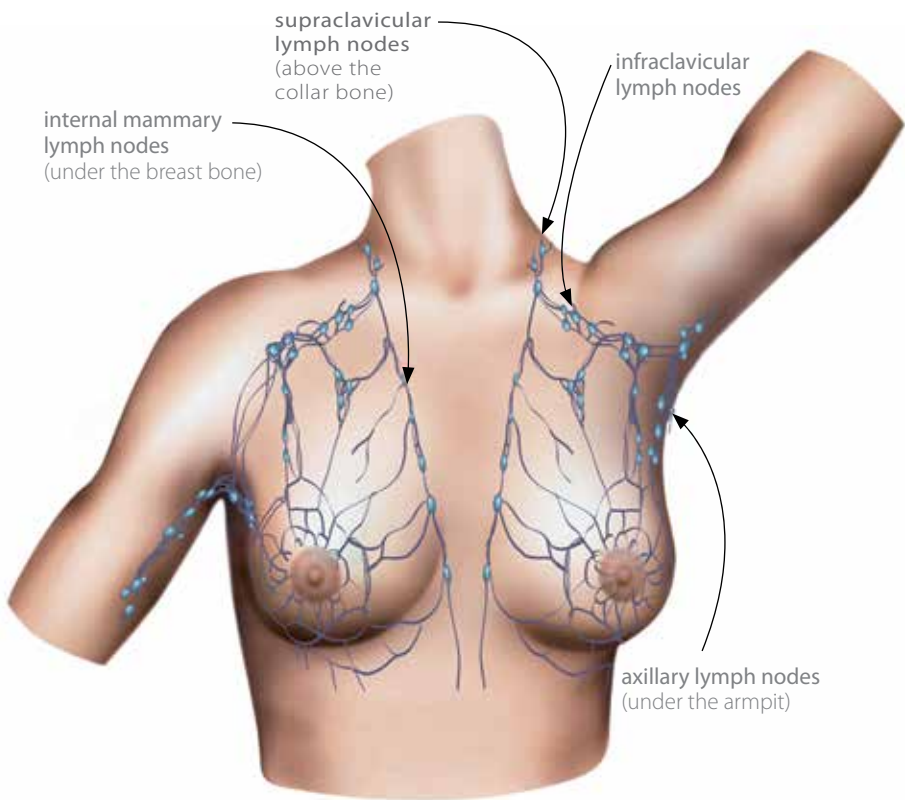


Illustration of lymph nodes near the breast

## Why are lymph nodes removed from the armpit?

The aim of removing lymph nodes from the armpit is to:

- find out whether breast cancer has spread to the lymph nodes
- remove any breast cancer that may be in the armpit area
- help plan further treatment.

## Removing lymph nodes from the armpit

At the time of diagnosis, your doctor will feel under your armpit to see if your lymph nodes can be felt. However, the best way to find out if there are cancer cells in the armpit is to remove one or more lymph nodes by surgery and examine them under a microscope. There are two ways of removing the lymph nodes:

- removal of some or all of the lymph nodes from the armpit — this is called **axillary dissection** or **axillary clearance**
- removal of the first lymph node (or nodes) in the armpit to which cancer cells are likely to spread from the breast — this is called **sentinel node biopsy**; if there are cancer cells in the sentinel node(s), you will probably have further surgery to remove some or all of the remaining nodes.

## Deciding about axillary surgery

Whether you have surgery to the armpit, and by which method, will depend on how likely the surgeon thinks that you have cancer cells in your lymph nodes. Sentinel node biopsy is a test that helps doctors work out your prognosis and decide which treatment options are best for you. It is associated with fewer side effects than axillary dissection, including a lower risk of lymphoedema. However, it is a relatively new test and is not available in every hospital.

Your surgeon will talk to you about which types of axillary surgery are recommended or available for you. Ask as many questions as you need to. **If sentinel node biopsy is offered to you, ask your surgeon about his/her experience with this method.**



## Things that affect whether you have axillary dissection or sentinel node biopsy

| <b>Axillary dissection may be recommended for you if:</b>   | <b>You may be offered sentinel node biopsy if:</b>        |
|---|---|
| Your doctor can feel the lymph nodes in your armpit and thinks that they may already contain cancer cells | Your doctor cannot feel the lymph nodes in your armpit    |
| Your breast cancer is larger than 3 cm  | Your breast cancer is 3 cm or smaller                     |
| Your breast cancer is in more than one area of your breast  | Your breast cancer is in one area of your breast          |
| You are allergic to radioactive substances/ blue dye  | Your surgeon is trained and experienced in this technique |
| You are pregnant or breastfeeding   |   |

A small number of women do not have lymph nodes removed from the armpit. This includes:

- women who are at very low risk of breast cancer spreading outside the breast
- women who have other serious health conditions that affect their treatment options.

If you do not have lymph nodes removed from the armpit, you may be offered radiotherapy to the armpit to treat any cancer cells that may be there but cannot be detected.

If you do not meet the current criteria for sentinel node biopsy, you may be invited to join a clinical trial (research project) that will still allow you to have a sentinel node biopsy. Such trials may or may not be suitable for your situation. Ask your surgeon for more information.



For more information about clinical trials, see the 'Clinical trials' chapter at the end of this section.

## Axillary dissection

### What does axillary dissection involve?

Axillary dissection involves removing several or all of the lymph nodes from the armpit. If possible, this will be done during breast surgery (breast conserving surgery or mastectomy) and may be done through the same incision as the breast surgery itself. However, it may be done as a separate operation. Because the number of lymph nodes in the armpit varies from person to person, the number of lymph nodes removed and the length of the operation will be different for each woman. Ask your surgeon about what will be involved for you.

The lymph nodes are then examined by a pathologist. The number of lymph nodes that have cancer cells in them will help your doctors decide what other treatments are best for you. Other treatments may involve systemic therapies (therapies that treat the whole body), such as chemotherapy or hormonal therapy, and less commonly, radiotherapy to the armpit.



For more information about other treatments for breast cancer, see the later chapters in this section.

### Side effects of axillary dissection

Possible side effects of axillary dissection:

- fluid may collect in the armpit — this is called a **seroma** and may need to be drained using a needle and a syringe; this can be done by your doctor, breast care nurse or another health professional in the clinic or by your GP
- **wound infection** — because the armpit is sweaty and bacteria are present on the skin, the wound can sometimes become infected; your surgeon may give you antibiotics after the surgery to treat any infections that may arise
- **stiffness** in your arm or shoulder; this may develop soon after surgery as scar tissue forms in the armpit; you may find it helpful to do some approved exercises after surgery; talk to your surgeon, physiotherapist or breast care nurse for advice

- **numbness** of the arm, shoulder, armpit and parts of the chest can occur because the nerves that supply sensation to the skin may need to be cut in order to remove the lymph nodes; this will usually improve with time but there may be some areas that will always stay numb
- your arm may swell up; this is called **lymphoedema** and may occur because lymphatic vessels have been disrupted by the breast cancer treatment; this can develop a few months or years after surgery
- because lymph fluid may not drain out of your arm as well as it did before the surgery, you may be at higher risk of developing an **infection** in your arm called **cellulitis**; you should take precautions when using your arm for activities that could graze or break your skin, like gardening.

If your arm becomes red and swollen, you should see your GP and start antibiotics as soon as possible.



**Cellulitis:** an infection of the skin caused by bacteria.



For more information about lymphoedema, see the 'Lymphoedema' chapter in the 'When treatment is over' section.

### If there are cancer cells in the lymph nodes

If cancer cells are found in the lymph nodes removed from the armpit, there is a higher chance that cancer has spread into the bloodstream as well. In this case, your doctors will probably recommend that you have a **systemic treatment** such as chemotherapy or hormonal therapy. Systemic treatments treat the whole body to destroy cancer cells and stop more cancer cells from developing. If a large number of lymph nodes contain cancer cells, your doctor may also recommend that you have radiotherapy to the armpit to destroy any cancer cells that may be left in the armpit but cannot be removed by surgery.



For more information about other treatments for breast cancer, see the later chapters in this section.

## Sentinel node biopsy

### What does sentinel node biopsy involve?

It is important that sentinel node biopsy is done by a surgeon who is trained and experienced in this method. Ask your surgeon about his/her experience in using sentinel node biopsy.

Sentinel node biopsy is a way of checking to see whether there are cancer cells in the lymph nodes in the armpit without removing all of the lymph nodes. The sentinel node is the first lymph node to which breast cancer cells may spread outside the breast. Although some women may have one sentinel node, some may have two or three sentinel nodes. Sometimes the sentinel node is in another part of the body — for example, in the chest between the ribs under the breast or above or under the collarbone. Studies of sentinel node biopsy have not involved women who are pregnant or breastfeeding. If you are pregnant or breastfeeding, sentinel node biopsy will not be an option for you.

Sentinel node biopsy is usually done during surgery to remove the primary tumour from the breast (breast conserving surgery or mastectomy). Sometimes it may be performed as a separate procedure.

There are different ways of finding the sentinel node. The best way is to use a combination of two substances — one is a low-grade radioactive fluid (isotope) and the other is a blue dye. The dye and radioactive fluid show the surgeon to which lymph node(s) breast cancer cells are most likely to travel.



**Isotope:** a radioactive substance.

The radioactive fluid (usually about 1–2 ml) is injected into the breast around the cancer or under the areola (the area around the nipple) before surgery. A special scan is done to find out to which lymph node(s) the radioactive fluid has travelled. During surgery, a blue dye is also injected into the breast. The blue dye will travel to the lymph nodes via the lymphatic vessels and the sentinel lymph node(s) should turn blue. The surgeon can see the blue sentinel node(s) and detect the radioactive substance using a type of Geiger counter called a gamma probe. The surgeon can then remove the sentinel node(s).

The aim at this stage is to find the sentinel node. Finding blue dye and radioactivity in the lymph node/s does not necessarily mean there are cancer cells in the nodes. The lymph node(s) still need to be looked at under the microscope to check for cancer cells.

Sometimes, either the blue dye or the radioactive fluid alone is used to look for the sentinel node. However, fewer studies have been done using blue dye or radioactive fluid alone to show whether these are as good at finding the sentinel node as the combined method.

If more than one sentinel node is found, all the sentinel nodes are removed. If another enlarged lymph node is found in the armpit without dye in it, the surgeon will usually remove this node as well. If the sentinel node is not in the armpit, the surgeon will remove it if this can be done safely.

The sentinel node(s) are then examined by a pathologist. In some cases, this may be possible during surgery although this service is not always available. Regardless of whether the nodes are examined during surgery, the nodes still need to be examined by the pathologist in the laboratory. This means the final result may not be available for a few days.

The length of time it takes to do sentinel node biopsy varies for individual women. Ask your surgeon about what will be involved in your procedure.

### **If there are cancer cells in the sentinel node**

If there are cancer cells in the sentinel node, you may need further surgery to remove more lymph nodes from the armpit to check how many lymph nodes are affected. If the sentinel node is examined during surgery, it may be possible to remove the remaining lymph nodes during the same operation. However, for many women, a second operation is needed.

### **Is sentinel node biopsy always accurate?**

It is important to be aware that in a small number of women (less than 5% of cases), the sentinel node does not have cancer cells, even though there are cancer cells in other lymph nodes in the armpit. This is called a 'false-negative result'. Your surgeon should discuss this with you before your surgery.

A false-negative result sometimes occurs because lymphatic vessels running to the lymph nodes that have cancer cells in them are blocked by cancer cells. This means that the dye goes into other normal lymph nodes instead. To minimise the chance of a false-negative result, your surgeon may remove any enlarged nodes that are found at the time of surgery, even if they do not contain the dye.

### **If the sentinel node cannot be found**

In a small number of cases, it is not possible to find the sentinel node at the time of surgery. In this situation, you will be advised to have an axillary dissection instead.

### **Side effects of sentinel node biopsy**

**Clinical trials have shown that sentinel node biopsy is associated with a lower risk of arm problems than axillary dissection.** This means that the risk of numbness, shoulder stiffness and lymphoedema is lower than with axillary dissection.

There is a small risk of allergic reaction to the radioactive fluid or blue dye used to find the sentinel node. Allergic reactions are usually mild and easily treatable. Rarely, women may experience a severe allergic reaction (less than one in 5000 cases). Your doctor may decide not to use the blue dye for sentinel node biopsy if there is reason to think you may be at significant risk of allergy to the blue dye.

If blue dye is used to find the sentinel node, your urine may turn blue for 24 hours after surgery. The skin of your breast may also become blue but this will fade with time.

There will be some pain associated with sentinel node biopsy, and injection of the radioactive isotope sometimes stings.

## Questions yet to be answered about sentinel node biopsy

Sentinel node biopsy is a relatively new test. Studies have shown that it is an accurate way of finding out whether cancer cells have spread to the armpit. However, there are still some things we do not know, such as:

- whether sentinel node biopsy is accurate for finding cancer in the armpit in people with large breast cancers or with breast cancer in more than one area of the breast
- whether sentinel node biopsy is accurate for finding cancer in the armpit in people who have chemotherapy before breast surgery
- whether sentinel node biopsy is accurate for finding cancer in the armpit in people whose breast cancer has come back in the breast
- whether it is better to check the sentinel nodes for cancer cells during or after breast surgery
- what effect finding a sentinel node that is not in the armpit (for example, under the breastbone) has on survival from breast cancer
- whether having sentinel node biopsy affects breast cancer coming back or survival from breast cancer
- what is the optimal management of sentinel node-positive women.



## Questions to ask about surgery to the armpit (axilla)

Listed below are some questions you might want to ask about surgery to the armpit.

- Do I need surgery to my armpit?
- What type of surgery to the armpit do you recommend?
- When will I have surgery to the armpit? Will I have surgery to the armpit at the same time as my breast surgery?
- How long will the operation take?
- What can I do to make myself more comfortable during the procedure?

- What are the risks and benefits of the surgery you are recommending?
- What kind of training and experience do you have in sentinel node biopsy? How long have you been undertaking sentinel node biopsy?
- Can you refer me to someone who has training in sentinel node biopsy?
- Will I need further surgery if you find cancer cells in my sentinel node?
- Are there any clinical trials I can join?

You may like to write your own questions here:

[illegible]



## Frequently asked questions

### Will the radioactive substance make me radioactive?

The amount of radioactivity in the radioactive fluid used to locate the sentinel node is very low. It is similar to the level used in many scans for investigations of other medical conditions. It will not make you radioactive and it is safe for you to have close contact with your family immediately afterwards.

### Will surgery to the armpit be painful?

All surgery results in some pain and different people feel pain at different levels. The pain associated with a sentinel node biopsy is much less than a full axillary dissection and is generally not severe. The armpit will often feel 'tight' after surgery.

### How long does it take the blue dye and radioactive fluid to reach the sentinel node?

The radioactive fluid can take anywhere between 10–20 minutes or up to 4–6 hours to travel to the lymph glands. Repeat scans may be taken at various time intervals up to several hours after the injection of the radioactive fluid. You may wish to read a book or magazine, or listen to a personal music player to calm you while you are waiting.

The blue dye travels to the lymph nodes more quickly, usually within a few minutes of the injection. Therefore, the blue dye is best used during the operation after you have been anaesthetised.

### How soon can I use deodorant after surgery to the armpit?

Once the wound has healed, you can use deodorant. It is probably best to wait for up to a week after the surgery to make sure that the wound is healing well.

### How soon can I shave my armpit after surgery to the armpit?

It is important to make sure that the wound is healing well before trying to shave the armpit. It is probably best to wait for 1–2 weeks after the surgery but you should take extra care when shaving as the skin may be quite numb in the early weeks after the procedure. If you usually wax or have laser treatments to your armpit, speak to your doctor before restarting these.

# Breast prostheses and breast reconstruction

Date of development: October 2008

## Summary

An external breast prosthesis is an artificial breast used after mastectomy and sometimes after breast conserving surgery to give shape to your clothes.

Breast reconstruction involves rebuilding a breast shape after breast surgery using an implant or tissue from another part of your body.

Breast reconstruction should be discussed as an option for women who have a mastectomy.

Breast reconstruction can be done at the same time as mastectomy or may be done months or years after surgery.

There are different types of breast reconstruction.

## Breast prostheses

An external breast prosthesis is an artificial breast that is worn inside your bra to give shape to your clothes. A prosthesis can be used after a mastectomy and sometimes after breast conserving surgery. The prosthesis is designed to match the colour, size and shape of your other breast. It is specially weighted so that it feels and moves like your other breast.

Not everyone chooses to wear a prosthesis after breast surgery and it can take a while to get used to wearing one. Many women find that wearing a prosthesis helps them feel better about how they look after surgery. A prosthesis can also help improve balance and posture. If you do choose to wear a prosthesis, other people will not be able to tell that you are wearing one. You can also get a special prosthesis to wear inside your swimming costume.

## Choosing a breast prosthesis

There are different types of breast prostheses:

- a **temporary prosthesis** is a soft, light prosthesis given to you at the hospital to wear for the first 6 weeks or so after surgery
- a **permanent prosthesis** is properly weighted and fitted to match your other breast
- a **lightweight breast form** is specially designed for swimming and can be worn inside your swimming costume
- a **partial prosthesis** (also called a **shaper, bra booster** or **shell prosthesis**) may be suitable for some women after breast conserving surgery.

Some women wear a bra with a pocket in it to hold their prosthesis in place. You can buy special mastectomy bras or you can sew pockets into your own bras. Other women use a self-adhesive prosthesis that sticks to the chest using special glue.

It is important to get your prosthesis fitted by a specialist prosthesis fitter. Choosing the right prosthesis for you will depend on a number of things. These include the type of surgery you have, your body shape, the cost and your preference.



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.

***“Now that I’ve got this new prosthesis on it looks excellent because it makes you look normal. All you have to do is slide it in your bra... I’m the closest to having a perfect balance and it does my neck good... a lot of people have a lot of problems with their neck and their back when they don’t have the right balance — it makes you feel good, lifts your confidence and you feel great when people say to you ‘Oh gee, you’ve got a nice outfit on. Gee it looks nice’. After you wear it all the time you don’t know that you’ve got it on.”***



For further information about where to find a breast prosthesis in your area, ask your health professional or contact the **Cancer Council Helpline** on **13 11 20**.

## **Breast reconstruction**

Breast reconstruction involves rebuilding a breast shape after breast surgery using an implant or tissue from another part of your body. It may involve several operations. Breast reconstruction can sometimes be done at the same time as the mastectomy (immediate reconstruction) or it may be done later (delayed reconstruction).

One of the benefits of a breast reconstruction is that you do not need to wear a breast prosthesis. Having a breast reconstruction can also help to reduce feelings of grief or loss after breast surgery and can lead to fewer sexual or self-esteem problems. Some women say that having a breast reconstruction means they are reminded less about their cancer. When deciding about breast reconstruction, bear in mind that your new breast will not look and feel like the old one. Depending on the type of reconstruction you choose, you may have scars on your breast and on other parts of your body.

***“After my surgery it was important for my healing that I had the reconstruction.”***

## **Types of breast reconstruction**

If you decide to have a breast reconstruction, the type of reconstruction recommended for you will depend on your body shape, your general health and your preference. Following is a summary of the different types of breast reconstruction.



For more information about breast reconstruction, talk to your breast surgeon or ask for a referral to a plastic surgeon.

## Reconstruction using implants

Breast implants are usually made from silicone gel and are inserted onto the chest wall, underneath the muscle and skin of the chest. Before inserting the implant, a special bag, called a **tissue expander**, is inserted underneath the muscles on the chest wall. Over the next few weeks or months, fluid is injected into the bag about once a week to stretch the muscle and skin. When the expander bag has reached the right size, a second operation is performed to remove the bag, and the permanent implant is inserted.

Advantages of breast reconstruction using an implant:

- the operation is relatively simple
- hospital stays and recovery periods are usually quite short
- surgery and scarring is only in and around the breast area.

Disadvantages of breast reconstruction using an implant:

- the reconstructed breast may not be as natural looking as with other types of breast reconstruction
- scar tissue can form around the implant making the breast feel firm and uncomfortable
- the implant may have to be replaced later, or removed if you get an infection
- if you have radiotherapy after an implant there is a risk that the tissue around the implant could become harder and that the implant will appear smaller with time.

## Reconstruction using back muscle transfer (Latissimus dorsi flap)

Breast reconstruction using back muscle transfer involves moving a flap of muscle, skin and fat from your back to your chest to form a new chest 'mound'. There are different ways of moving the tissue from your back to your chest. Ask your plastic surgeon about the advantages and

disadvantages of the different techniques. Usually a saline implant is placed behind the new breast 'mound' to increase the size of the reconstructed breast and match the size of your other breast. This type of operation may not be possible for you if you do not have enough tissue on your back.

Advantages of breast reconstruction using back muscle transfer:

- it produces a more natural looking breast than implant-only reconstructions
- the reconstructed breast will change in size if you gain or lose weight.

Disadvantages of breast reconstruction using back muscle transfer:

- you will have a scar on your back
- you could lose some strength in your arm
- there is a small risk the tissue moved to your chest will not 'take', meaning the tissue will die; if this happens you will need another operation
- your hospital stay and your recovery time will be longer than with implant-only reconstruction.

### **Breast reconstruction using abdominal muscle transfer (TRAM flap)**

Breast reconstruction using abdominal muscle transfer usually involves moving a flap of muscle, fat and skin from the stomach to the chest to form a new breast 'mound'. There are different ways of moving the tissue from your stomach to your chest. This type of operation may not be possible for you if you do not have enough tissue on your stomach.

Advantages of breast reconstruction using abdominal muscle transfer:

- it produces the most natural looking breast
- the reconstructed breast will change in size if you gain or lose weight.

Disadvantages of breast reconstruction using abdominal muscle transfer:

- you will have a scar across your stomach
- you could lose strength in your stomach muscles
- you may be at risk of developing a hernia

- there is a small risk the tissue moved to your chest will not ‘take’, meaning the tissue will die; if this happens you will need another operation
- your hospital stay and your recovery time will be longer than with implant-only reconstruction
- you will not be able to drive or lift heavy objects for several weeks after surgery.

### Other types of breast reconstruction

There are other types of breast reconstruction that use tissue from other parts of the body:

- skin and fat from the stomach (DIEP flap)
- tissue from the buttocks (buttock transfer or free gluteal flap)
- tissue from the other breast (breast sharing reconstruction).

In general, the advantages and disadvantages of these types of reconstruction are similar to those listed for the TRAM flap and back-muscle transfer reconstructions.

### Nipple reconstruction

It is possible to reconstruct a nipple after breast surgery. This can be done using skin from your breast or tissue from another part of the body. The area around the nipple can be coloured to match the other breast using a tattoo. The reconstructed nipple will not have any feeling. Some women prefer to use a nipple prosthesis, which can be attached to the reconstructed breast using special glue. You may wish to talk about different options with your breast care nurse who can refer you back to your specialist if needed.

### Deciding about breast reconstruction

If you are thinking about having a breast reconstruction, it is important to have realistic expectations. You need to understand what is involved and how your breast might look afterwards. The aim is to create a natural shape when you are clothed. **Talk to your surgeon about the timing of breast reconstruction and the type(s) of breast reconstruction that may be suitable for you.**

Things to think about include the cost of surgery and how long you will take to recover. Your decision might also depend on whether an expert surgeon is available to do the operation and what other treatments you may need.

Some women who have a breast reconstruction after breast surgery choose to have surgery to the other breast as well so that both breasts look similar.

You may find it helpful to talk to other women who have had breast reconstructions or to look at photographs of women who have had similar operations. Ask your plastic surgeon to show you photographs of women who have had the types of reconstruction you are considering. Weigh up the risks, side effects and benefits of each type of operation and what is important for you.

***“My breast is really good but my tummy hasn’t been the same since. It depends on how you weigh things up I guess. I’m really happy with the breast.”***



## **Questions to ask about breast prostheses and breast reconstruction**

Listed below are some questions you may want to ask about breast prostheses and breast reconstruction.

- Where can I get a breast prosthesis? How much will it cost?
- If I have a breast reconstruction, can it be done in the same operation as my breast surgery?
- If I decide to have a breast reconstruction later, how long will I have to wait?
- If I decide not to have a breast reconstruction now, can I change my mind later?
- If I have a breast reconstruction, how will it affect the timing or types of other treatment available to me?
- What type of breast reconstruction do you recommend for me?
- How much will breast reconstruction cost?



- Do you specialise in breast reconstruction? If not, can you refer me to someone who specialises in breast reconstruction?
- How will my breast look and feel after breast reconstruction?
- Can you show me photographs of different breast reconstructions?

You may like to write your own questions here:

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## Frequently asked questions

### How long does a breast prosthesis last?

A breast prosthesis will usually need to be replaced every two years or so.

### How much does a breast prosthesis cost?

You can get a temporary soft prosthesis free of charge — ask your breast care nurse or surgeon for more information. The *External breast prostheses reimbursement program* is an Australian Government initiative that provides reimbursement for both new and replacement permanent external breast prostheses to all eligible women who have had a mastectomy as a result of breast cancer. Cost limits apply.



For more information, visit the Medicare Australia website at [www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au), call Medicare on 13 20 11 or visit a Medicare office.

### How much does breast reconstruction cost?

The cost of breast reconstruction will depend on many things. These include the type of reconstruction, whether you are a public or private patient, and the fees charged by the surgeon and other health professionals involved in the operation. If you have a private health fund, ask an advisor about whether some or all of the costs can be covered by your health insurance policy.

### How long does it take to recover from a breast reconstruction?

The time it takes to recover from a breast reconstruction is different for each woman. It also depends on the type of reconstruction. Usually women can get back to normal activities 4–6 weeks after an implant reconstruction. Recovery after reconstruction using tissue from the back or stomach can take longer.

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### **How safe are breast implants?**

The technology and safety of silicone implants has improved greatly in recent years. Implants using saline are also available but the cosmetic result is usually not as good.

### **Does having a breast reconstruction affect whether breast cancer will come back?**

There is no evidence that breast reconstruction affects whether breast cancer comes back. There is also no evidence that having a breast reconstruction stops breast cancer being diagnosed if it does come back.

# Radiotherapy

Date of development: October 2008

## Summary

- Radiotherapy uses X-rays to destroy any cancer cells that may be left in the breast or armpit after surgery for breast cancer.
- Radiotherapy to the breast is recommended after breast conserving surgery.
- Radiotherapy to the chest wall is sometimes recommended after mastectomy.
- Radiotherapy to the armpit or lower neck is occasionally recommended after breast conserving surgery or mastectomy.

## What is radiotherapy?

**Radiotherapy uses X-rays to destroy cancer cells that may be left in the breast, chest or armpit after breast cancer surgery.**

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

## When is radiotherapy recommended?

- **Radiotherapy to the breast** is recommended after breast conserving surgery to remove any cancer cells that may be left in the breast and to reduce the risk of breast cancer coming back in the breast.
- **Radiotherapy to the chest wall** is sometimes recommended after mastectomy for women at high risk of breast cancer coming back in the chest wall.
- **Radiotherapy to the lymph nodes in the armpit and/or lower neck** is occasionally recommended after either type of breast surgery, for women who do not have surgery to the armpit, or for those at high risk of breast cancer coming back in the lymph nodes.

**Talk to your doctor about whether radiotherapy is recommended for you.**



For more information about the risk of breast cancer coming back, see the 'Making sense of test results' section.

## What does radiotherapy involve?

The timing of your radiotherapy will depend on when services are available, how quickly you recover from surgery and what other treatments you are having. If you are having chemotherapy, radiotherapy will usually start when chemotherapy ends. If you are not having chemotherapy, radiotherapy will usually start after surgery.

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 then be asked to visit the hospital for a planning visit with a radiation therapist. This will usually be on a separate occasion to your treatment. During the planning visit, a CT scan will be taken of your chest. Marks will 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 planning visit usually takes about 45 minutes.



**CT scan:** a special type of X-ray that provides a three-dimensional picture of the inside of the body. The initials stand for 'computerised tomography'.

Once radiotherapy starts, you will usually have treatment once a day, five days a week for 3–6 weeks. You will be given an appointment time for your visits. Each radiotherapy session will be in a treatment room with a radiotherapy machine. The radiation therapist will leave the room while the machine is on but will still be able to see you and can speak to you through an intercom.

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

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 each day.

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.



A woman being prepared for radiotherapy



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

## Side effects of radiotherapy

Receiving radiotherapy is painless. However, you may have some side effects during or after treatment. Some side effects might develop months after treatment is over.

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.

***“If I start to feel tired I’ll think, ‘Right, just slow down a bit’. I’m learning to say, ‘No I’m not doing it today, I’ll do it later or I’ll get someone else to help me do it.’”***

Common side effects during or after radiotherapy:

- the skin of the treated breast can become red and dry like sunburn; this can begin as early as the second week of treatment and usually improves a few weeks after treatment is over
- the skin can become darker — it may stay that way for a few months after treatment but usually fades with time
- you will probably feel more tired than usual during treatment and for a few weeks after treatment is over.

Side effects that you *might* experience during or after radiotherapy:

- tenderness, aches or ‘twinges’ in the breast or chest — this may continue for up to a year or be longer lasting but usually settles with time
- the breast may become smaller or larger and may become firmer during or after treatment
- the skin of the breast may blister or peel towards the end of treatment — this usually settles a few weeks after treatment ends
- blood vessels may become visible in the treated area, making the skin look red or purple — this is a rare side effect of radiotherapy that can occur many months or years later
- if you have radiotherapy to the armpit, you may develop persistent swelling in your arm, hand or chest; this is called **lymphoedema** and can develop a few months or years after treatment
- if you have radiotherapy to the armpit, you may lose your hair in the treated area
- if you have radiotherapy to the lower neck you may develop a sore throat temporarily — talk to your doctor about pain relief options if this happens to you.



For more information about lymphoedema, see the 'Lymphoedema' chapter in the 'When treatment is over' section.

The following side effects of radiotherapy are *very rare* but can be quite serious. **Talk to your radiation oncologist if you have the following symptoms:**

- a combination of dry cough, mild fever, shortness of breath and tiredness — these may be symptoms of a condition called pneumonitis in which the lung becomes inflamed; treatment is available and **pneumonitis** usually lasts for less than a month
- pain in the ribs — this may be due to rib fracture because the bones have become weakened by treatment.

***"I was very very tired. I hated this tiredness. I resented it."***

### **Skin care during radiotherapy**

The following information may help you 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 radiotherapy or nursing staff if you develop a skin reaction or if your skin reaction gets worse.**

Things that can make the skin reactions worse:

- 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.



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

- **wear sun protective clothes or use sunscreen** over the treated area when you are in the sun
- **avoid irritants** — protect the skin in the treated area from damage by abrasion (for example, shaving with a wet razor), chemicals (for example, perfumes, deodorants, hair dyes) and temperature extremes during your course of radiotherapy
- **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 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 long will radiotherapy last?
- What side effects can I expect? How can I manage them?
- Who should I contact if side effects develop?
- Can I still work while I'm having radiotherapy?
- Can I still drive while I'm having radiotherapy?

- When will I have radiotherapy if I'm having other treatments for breast cancer?
- Will radiotherapy affect whether I can have a breast reconstruction?
- Will radiotherapy affect whether I can breastfeed?
- How much will radiotherapy cost?

You may like to write your own questions here:

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## Frequently asked questions

### Will having radiotherapy make me radioactive?

No.

### Can I breastfeed if I have radiotherapy?

If you have radiotherapy, you will probably not be able to breastfeed from the treated breast because your breast will no longer produce milk. If you are able to breastfeed from the treated breast, there is no evidence that this is unsafe for your baby.

### What can I do to relieve symptoms?

If your skin becomes red, dry, itchy or develops blisters during or after radiotherapy, ask your treatment team about creams and dressings to help make you more comfortable.

### Can I wear a bra if I'm having radiotherapy?

You can continue to wear a bra over the month or so of radiotherapy treatment. If your skin becomes sensitive, you may find it more comfortable to wear a cotton bra with no underwire or seams. Some women like to wear a cotton t-shirt or handkerchief under their bra to reduce irritation.

### What should I do if my skin doesn't get better?

Sometimes skin reactions get worse in the week or two after radiotherapy ends. If your skin is not healed within about two weeks of completing radiotherapy treatment, contact your radiation oncologist, radiation therapist or breast care nurse.

# Chemotherapy

Date of development: October 2008

## Summary

- Chemotherapy involves using one or more drugs to kill cancer cells that may have spread outside the breast and armpit area to other parts of the body but cannot be detected.
- Chemotherapy can lower the risk of breast cancer coming back and can increase the chance of surviving breast cancer.
- Not everyone with early breast cancer will have chemotherapy. The decision about whether to recommend chemotherapy will depend on your risk of breast cancer coming back, the stage and grade of your breast cancer, whether you have hormone receptors on your breast cancer cells, your general health and your preference.
- There are a number of different types of chemotherapy drugs, each with different side effects.
- Most chemotherapy is given as an intravenous drip, but some drugs are given as tablets.
- Most side effects of chemotherapy can be managed with medical care.

## What is chemotherapy?

Chemotherapy is the name for some drugs used to treat cancer. Chemotherapy is a type of **systemic treatment** because it treats the whole body. Other systemic treatments include hormonal therapies and targeted therapies such as trastuzumab (Herceptin®). The aim of chemotherapy is to destroy any cancer cells that may have spread outside the breast and armpit area to other parts of the body or are left in the breast and armpit area but cannot be detected. Chemotherapy is not an alternative to hormonal therapy or trastuzumab (Herceptin®). Depending on the type, stage and grade of your breast cancer, you may have one or more of these treatments.

***“You can still lead a normal life while having treatment. You may feel a bit sick sometimes but there’s nothing to stop you going out with your friends or going to the movies.”***



For more information about hormonal therapies and trastuzumab (Herceptin®), see the later chapters in this section.

Chemotherapy works by killing cells that are rapidly dividing, such as cancer cells. As well as killing cancer cells, chemotherapy also kills normal cells that are rapidly dividing. 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.



**Bone marrow:** the substance within the bones that makes different types of blood cells.

For women with early breast cancer, treatment with chemotherapy can lower the risk of breast cancer coming back or spreading to other parts of the body. Chemotherapy can also increase the chance of surviving breast cancer.

## **When is chemotherapy recommended?**

Chemotherapy can be used in addition to other treatments for breast cancer. Not all women with early breast cancer will have chemotherapy. The decision about whether you have chemotherapy will depend on your individual situation. Your doctors will consider a number of things:

- your risk of breast cancer coming back or spreading to other parts of the body after treatment — the higher your risk, the more likely it is that chemotherapy will be recommended for you
- whether you have hormone receptors on your breast cancer cells and are having hormonal therapy — if you do not have hormone receptors you are more likely to have chemotherapy

- whether your breast cancer cells are positive for HER2 and you are having trastuzumab (Herceptin®) — if you are having trastuzumab it is usual to start this while you are still receiving your chemotherapy; the most common pattern is for you to receive three or four cycles of chemotherapy alone, followed by three or four cycles of chemotherapy with trastuzumab; however, some patients will receive trastuzumab with every cycle of chemotherapy
- your general health
- your preference.

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



For more information about what affects the risk of breast cancer coming back or spreading to other parts of the body, see the 'Making sense of test results' section.

## Types of chemotherapy

Several different types of chemotherapy are used to treat early breast cancer. If you have chemotherapy, you may have one drug or you may have a combination of drugs. **The most effective chemotherapy treatments involve more than one drug.** The drugs recommended for you will depend on what other treatments you are receiving, the type, stage and grade of your breast cancer and your age.

Chemotherapy drugs are grouped based on how they work. The main groups, or classes, of chemotherapy used to treat breast cancer are:

- **anthracyclines** such as epirubicin (Pharmorubicin®), doxorubicin (Adriamycin®)
- **mitotic inhibitors** such as taxanes, eg paclitaxel (Taxol®), docetaxel (Taxotere®)
- **antimetabolites** such as 5-fluorouracil (5FU), methotrexate
- **alkylating agents** such as cyclophosphamide.

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

Each group of chemotherapy drugs works in a slightly different way. All of them kill cancer cells by stopping them from dividing or damaging them in some way. Because the drugs all work differently, they have different side effects. **Talk to your doctor about the chemotherapy drugs available for you and the side effects of these treatments.** You might find it helpful to write down which drugs you are receiving. This can be useful if you change doctors in future.



Breast Cancer Network Australia's *My Journey Kit* for women newly diagnosed with breast cancer includes a Personal Record, which can be used for recording treatment details and side effects. The Kit has been developed by women with breast cancer and is available free of charge. The Kit can be ordered online at [www.bcna.org.au](http://www.bcna.org.au) or by calling 1300 785 562.

## What does chemotherapy involve?

The timing of chemotherapy will depend on what other treatments you are having. Usually chemotherapy will start after breast surgery. Some women may have chemotherapy before surgery. If you are having radiotherapy or hormonal therapy, these treatments will not start until chemotherapy is completed.

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 the side effects of these treatments. 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 or breast surgeon. If this happens, the doctor will talk regularly to a medical oncologist in another hospital about your treatment. Alternatively, you may decide to travel to another hospital to meet a medical oncologist to talk about your options and receive your treatment.



A woman receiving intravenous chemotherapy by drip



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

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 to give chemotherapy into. 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 deliver 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.

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 may 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.

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. The number of cycles, the length of the treatment period and the length of the rest period will depend on the stage and grade of your breast cancer and the type of chemotherapy. The overall length of your chemotherapy program could be between 3–6 months.

***"I originally didn't want chemotherapy because I didn't want to look sick. I got a lot of information about that and came back a few weeks later with a decision that I would have it."***

The success of chemotherapy depends on having the right dose at the right time. Sometimes your dose might be changed or delayed to help manage the side effects of treatment. If you are concerned about what effect a delay or change in dose will have, talk to your doctor.



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Delivering intravenous chemotherapy into the blood stream

The following are two examples of chemotherapy cycles.

**Example1:** Rebecca has chemotherapy treatment in a 3-week cycle. She has intravenous chemotherapy (through a drip into a vein in her hand) every third Tuesday. Her treatment will take 12 weeks. Rebecca's chemotherapy treatment calendar looks like this:

| Week | Mon | Tues              | Wed | Thur | Fri | Sat | Sun |         |
|------|-----|-------------------|-----|------|-----|-----|-----|---------|
| 1.   |     | I.V.<br>Treatment |     |      |     |     |     | Cycle 1 |
| 2.   |     |                   |     |      |     |     |     |         |
| 3.   |     |                   |     |      |     |     |     |         |
| 4.   |     | I.V.<br>Treatment |     |      |     |     |     | Cycle 2 |
| 5.   |     |                   |     |      |     |     |     |         |
| 6.   |     |                   |     |      |     |     |     |         |

...and so on until week 12.

**Example 2:** Carol has chemotherapy in a 4-week cycle. She has intravenous chemotherapy (through a drip into a vein in her arm) on two Mondays in a row followed by a 2-week break and so on. She also takes chemotherapy tablets at home during the two 'treatment weeks' of the cycle. Her treatment will take 24 weeks. Carol's chemotherapy treatment calendar looks like this:

| Week | Mon                           | Tues   | Wed    | Thur   | Fri    | Sat    | Sun    |         |
|------|-------------------------------|--------|--------|--------|--------|--------|--------|---------|
| 1.   | I.V.<br>Treatment<br>+ tablet | tablet | tablet | tablet | tablet | tablet | tablet | Cycle 1 |
| 2.   | I.V.<br>Treatment<br>+ tablet | tablet | tablet | tablet | tablet | tablet | tablet |         |
| 3.   |                               |        |        |        |        |        |        |         |
| 4.   |                               |        |        |        |        |        |        |         |
| 5.   | I.V.<br>Treatment<br>+ tablet | tablet | tablet | tablet | tablet | tablet | tablet | Cycle 2 |
| 6.   | I.V.<br>Treatment<br>+ tablet | tablet | tablet | tablet | tablet | tablet | tablet |         |
| 7.   |                               |        |        |        |        |        |        |         |
| 8.   |                               |        |        |        |        |        |        |         |

...and so on until week 24.

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## 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 drug. Or the side effects you experience may be more or less intense than for other women.

This section lists some of the side effects of chemotherapy. The list may seem long or overwhelming. It is unlikely that you will have many or all of these side effects. It is also important to remember that having chemotherapy can have great benefits, including a higher likelihood of surviving breast cancer.

***“The oncologist said chemo could prove to be helpful for me. But if I really didn’t want to do it, then that would be up to me.”***

**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 when they happen, how long they last and what the symptoms are so that you can discuss them with your doctor, breast care nurse or oncology nurse at your next appointment.

***“For me, the six months of chemo were two weeks of feeling really ordinary but then feeling OK for the next two weeks. I would get back to normal and I would think, ‘Yeah, I can do this.’ ”***

Tell a member of your healthcare team 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.

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.

*Common* side effects of chemotherapy include:

- nausea and vomiting
- fatigue (tiredness)
- hair loss
- diarrhoea or constipation
- weight gain or weight loss
- depression or anxiety
- menopausal symptoms (temporary or permanent)
- sexual difficulties
- mouth ulcers
- skin or nail changes or reactions
- muscle aches and pains (more common with taxane drugs)
- numbness and tingling in the fingers and toes (more common with taxane drugs)
- swelling in the arms and legs (more common with taxane drugs).

*Less common* side effects of chemotherapy include:

- feeling 'vague' or 'in a fog'.

The following side effects of chemotherapy are *rare but can be quite serious*. Symptoms to look out for are listed in the section below. **Talk to your medical oncologist, GP or breast care nurse if you develop any of these side effects:**

- infection due to a low level of white blood cells
- bleeding or bruising
- kidney or bladder problems
- heart problems (with anthracycline drugs only)
- bone marrow problems
- allergic reactions.

## Managing side effects of chemotherapy

Most side effects of chemotherapy can be managed. Suggestions about how to manage some of the more common side effects are listed below.

### Nausea and vomiting

Nausea ('feeling sick') and vomiting are common side effects of chemotherapy. These symptoms are less common with chemotherapy programs that involve taxanes. Nausea and vomiting can usually be controlled using drugs called **anti-emetics**. Anti-emetics are usually given at the same time as chemotherapy. Your doctor may recommend that you take anti-emetics regularly for the first 2–4 days after chemotherapy. You may also find it helps to eat smaller meals more often while you are having chemotherapy rather than larger meals.

Some women are nervous or worried before their next cycle of treatment and this can make them feel sick or vomit. This is called **anticipatory vomiting**. Talk to a member of your healthcare team if this happens to you. There are effective treatments available such as relaxation training if you have anticipatory nausea or vomiting.

***"I looked at chemotherapy as a competition. There was a finishing ribbon and every day was a step closer."***

### Fatigue

Feeling tired is a common side effect of chemotherapy and can last 3–6 months after treatment is over. You might find it useful to organise some practical help before you start treatment. For example, help with childcare or making meals can give you more time to recover.



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

A normal reaction to feeling tired is to rest. However, research shows that exercise can help to reduce fatigue caused by chemotherapy. Although it may not be what you would expect, exercising during and

after treatment can help you to feel less tired. It can also reduce your chance of weight gain. Gentle exercise like walking is ideal. Some women find that more strenuous exercise is also helpful. Exercise has also been shown to help improve sleep, body image and mood. Talk to your doctor or breast care nurse about the types of exercise that may be suitable for you.

***“Diet and exercise are the one thing that a cancer survivor actually has control over. As well as the physical benefits they might bring, it helps emotionally to know that you are doing everything in your power to avoid a recurrence.”***

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. However, the drugs most frequently used to treat early breast cancer are likely to cause hair loss. If you do lose all or some of your hair, it will grow back within weeks or months of stopping chemotherapy.

Hair loss is more common with chemotherapy programs that include anthracyclines and taxanes. **Ask your doctor about the risk of hair loss from the chemotherapy program 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 may be more curly, thicker or finer than it was before treatment. It may grow back a slightly different colour. 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 a member of your healthcare team about how you are feeling.**



For more information about your feelings during and after diagnosis and treatment for breast cancer, including your body image and sexuality, see the 'Finding support' section.

You may find it helpful to cut your hair short so that it is less upsetting if your hair falls out. You might like to wear a scarf, hat or wig to cover your head while your hair grows back.

***“Losing my hair was probably a bad thing but I have found that the anticipation of everything is worse than when it actually happens.”***

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 chemotherapy. Workshops are available in capital cities and other major centres.



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

## **Diarrhoea and 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.

Constipation can be treated by drinking more fluids, eating more fruit and vegetables, and using laxatives. Exercise can also be helpful in reducing constipation. **Talk to your doctor before using any laxatives or medication for constipation.**

## **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. Doing gentle exercise can help prevent weight gain during



chemotherapy. Talk to your doctor or breast care nurse about what exercises are suitable for you, or call the **Cancer Council Helpline** on **13 11 20** for information about eating and exercise during cancer treatment.

***“I unexpectedly put on a lot of weight after all the chemotherapy and I didn’t expect that.”***

### **Depression and anxiety**

Some women feel depressed, sad or teary before, during and after chemotherapy. Others feel anxious, worried, nervous or upset. Some feelings of sadness, depression and anxiety are normal. If your feelings are severe, interfering with 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 during and after diagnosis and treatment for breast cancer, see the ‘Finding support’ section. This section also includes information about available resources.

***“During chemotherapy I was having anxiety attacks. It seems really stupid now but at the time they were pretty intense.”***

### **Menopausal symptoms and permanent menopause**

About two-thirds of women who are younger than 50 when their breast cancer is diagnosed will go through menopause because of their treatment. Other women may experience temporary menopausal symptoms. 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 you have not yet reached menopause and hope to have children in the future, talk to a fertility specialist before making treatment decisions and starting treatment.**



For more information about breast cancer, menopause and fertility, see the 'Breast cancer, menopause and fertility' chapter in the 'When treatment is over' section.

Cancer Australia has information for younger women with breast cancer who may be at risk of early menopause. To order a copy of the booklet *Breast cancer and early menopause: a guide for younger women*, go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call 1800 624 973.

## 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 your feelings during and after diagnosis and treatment for breast cancer, 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 to take extra care of your mouth during chemotherapy. Talk to your medical oncologist or chemotherapy nurse about what you can do to help reduce the risk of mouth ulcers.

If you develop mouth ulcers:

- 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 mouthwash to help relieve discomfort
- you might need to take pain relief such as paracetamol.

**Talk to your doctor or nursing staff before using a mouthwash, as some mouthwashes can make ulcers worse.**

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.

## **Skin and nail problems**

Some women have minor skin or nail problems while they are having chemotherapy. These include redness, itching, peeling, dryness or acne. Some women's nails become darker, brittle or cracked. Some chemotherapy drugs can 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. More common symptoms 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.**

## **Feeling vague or 'in a fog'**

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

## Swelling in the arms or legs

Swelling or fluid retention may occur, particularly in the arms and/or legs. It is most common in the feet and ankles due to the effects of gravity. This side effect is most commonly associated with the use of some taxane chemotherapy drugs. 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 caused by chemotherapy is not the same as **lymphoedema** and rarely requires any specific treatment. However, your medical oncologist may prescribe treatment if the swelling is severe.



For more information about lymphoedema, see the 'Lymphoedema' chapter in the 'When treatment is over' section.

## Infection

Chemotherapy drugs will reduce the number of white blood cells your body produces. Your doctor will regularly 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, you might be at increased risk of developing an infection. The risk of infection is highest for people who have drugs called taxanes at the same time as anthracyclines. If you are having docetaxel (a taxane) at the same time as an anthracycline, your doctor may recommend a drug called a growth factor (G-CSF) after each chemotherapy treatment to lower the risk of infection.



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

**G-CSF:** (granulocyte colony stimulating factor) — a growth factor used to increase the number of white blood cells in the blood.

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

- a fever (a temperature higher 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, you can call the out-of-hours number given to you by your doctor. If you see your GP, ask them to arrange for a blood test and for them to 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 about any signs or symptoms of reduced platelets. Symptoms to look out for include:

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

If these signs develop during the night or on a weekend, you can call the out-of-hours number given to you by your doctor or contact your local hospital emergency department. Unusual bruising or bleeding can be treated by a platelet transfusion.



**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 prevent kidney and bladder problems. If you do develop kidney or bladder problems, they will usually happen a few days or more 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 more after treatment.

### **Other rare or uncommon side effects of chemotherapy**

Other rare side effects of chemotherapy include:

- heart problems (cardiac toxicity) — with anthracyclines
- problems with bone marrow — most commonly with anthracyclines
- allergic reactions — with taxanes.

If these side effects develop during treatment the chemotherapy drugs will be changed, or the dose decreased. If you have an allergic reaction to chemotherapy, you may be given drugs before your next dose to lower the chance of this happening again.

### **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 best sequence in which to give chemotherapy drugs and when to give them in relation to radiotherapy and/or surgery
- the long-term side effects of treatment, particularly for some of the newer drugs
- how different drugs of the same type compare in terms of side effects and effectiveness
- how effective different drugs are in treating breast cancer at different stages, for example, breast cancer that has not spread to the lymph nodes.



## Questions to ask about chemotherapy

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

- 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?
- 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?
- Who should I contact if I have side effects or other problems?
- Is there an out-of-hours phone number I can call if I develop serious side effects during the night or on weekends?
- Will chemotherapy affect my ability to have children?
- What do I need to consider when deciding whether or not to work while having chemotherapy?
- If I'm taking complementary therapies, how will they affect the chemotherapy?
- What exercises do you recommend while I'm having chemotherapy?
- What sort of food should I eat while I have chemotherapy?



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

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## **Frequently asked questions**

### **How do I decide whether to have chemotherapy?**

Your doctor will talk to you about whether chemotherapy is recommended for you. Ask your doctor about the possible benefits and side effects of treatment. You might find it helpful to talk to other women who have had chemotherapy to find out what is involved.

### **How often will I have treatment?**

The frequency of treatment will depend on which chemotherapy drugs are recommended for you.

### **Will chemotherapy make me lose my hair?**

Some women who have chemotherapy lose their hair. The chance of you losing your hair will depend on which drugs you receive. Talk to your doctor or breast care nurse about whether hair loss is a risk with the treatments that are recommended for you.

# Hormonal therapies

Date of development: October 2008

## Summary

- Hormonal therapies (sometimes called endocrine therapies) are treatments for women who have hormone receptors on their breast cancer cells.
- Hormonal therapies stop the growth of cancer cells that may be left in the body after other breast cancer treatments but cannot be detected.
- 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 stop hormone receptor-positive breast cancer cells from growing.

**Your doctor will only recommend hormonal therapies as part of your treatment if your cancer cells are hormone receptor-positive.**



**Hormone receptors:** proteins in a cell that allow hormones to bind to the cell. 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 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 recommended for women who have hormone receptors on their breast cancer cells. They may be used in addition to surgery, radiotherapy and chemotherapy, or on their own. Hormonal therapies are usually given after other treatments for breast cancer.

Hormonal therapies reduce the risk of breast cancer coming back (in the breasts and in other parts of the body). Some hormonal therapies have also been shown to increase the chance of survival for women with breast cancer. These include the hormonal therapy tamoxifen, some aromatase inhibitors and removal of the ovaries by surgery. Studies with some newer drugs have not been running long enough for us to be able to measure whether the effect of treatment on survival is the same as or better than tamoxifen. **Ask your doctor what is known about the hormonal therapy recommended for you.**

## Menopause and oestrogen production

All women produce the female hormone oestrogen; however, it is made differently by the body 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 40's and early 50's. 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.

## Types of hormonal therapies

There are different ways of reducing the level of female hormones in the body.

**Talk to your doctor about whether hormonal therapies are suitable for you. If hormonal therapies are suitable for you, the types of therapies recommended will depend on whether you have reached menopause. If you are not sure whether you have reached menopause, talk to your doctor.** When deciding whether to recommend hormonal therapies, your doctor will also consider your risk of breast cancer coming back, and your general health.

### 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, usually for five years.

### Aromatase inhibitors

Aromatase inhibitors work by stopping androgens from being changed to oestrogen. Examples of aromatase inhibitors include anastrozole (Arimidex®), letrozole (Femara®), 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 chemotherapy.

Aromatase inhibitors are taken as a single tablet every day, usually for five years.

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

### **Side effects of hormonal therapies**

Some side effects are common to all hormonal therapies, and some only happen with certain therapies. Everyone is different in how they respond to treatment. 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 therapies 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 breast care nurse for more information. The severity of these symptoms varies between women and between different treatments. These side effects often improve after treatment stops.



For more information about the side effects of treatment on sexuality, see the 'Finding support' section.

Treatment with hormonal therapies can sometimes cause permanent menopause. If you have not yet reached menopause and hope to have children in the future, talk to a fertility specialist about your options before starting treatment.

### **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 lining of the womb (uterus) 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.

It is important to balance the risk of these rare side effects against the fact that anti-oestrogens lower the risk of breast cancer coming back and dying from breast cancer.

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

## Additional side effects of aromatase inhibitors

Side effects of aromatase inhibitors include:

- pain in bones or joints (arthralgia)
- an increased risk of osteoporosis, which may increase your risk of bone fractures.

Your doctor may measure your bone density before prescribing an aromatase inhibitor if you are at increased risk of osteoporosis. If you are starting treatment with an aromatase inhibitor, your doctor may also recommend that you take calcium and vitamin D tablets. 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.**

If you have pain in your bones or joints, you may find it helpful to take a painkiller such as paracetamol.

Long-term side effects of aromatase inhibitors are still being studied. For example, studies are investigating the effects of aromatase inhibitors on memory, concentration and heart disease.



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

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

## 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 naturally. 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.**



## Deciding about hormonal therapies

### Before menopause

- **If you have not yet reached menopause** and your cancer cells have hormone receptors, it is usually recommended that you take tamoxifen.
- **If your risk of breast cancer coming back is very low** (for example, if your breast cancer is very small and has not spread to your lymph nodes) your doctor may not recommend tamoxifen for you.

Your doctor may ask whether you are interested in joining a clinical trial comparing different combinations of chemotherapy, an ovarian treatment and anti-oestrogens.



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

Your doctor may also recommend an ovarian treatment, with or without tamoxifen.

**If you have not yet reached menopause and having children is important to you, talk to your doctor about your options before starting hormonal therapy.**

### After menopause

- **If you have reached menopause and** your cancer cells have hormone receptors, it is usually recommended that you take either tamoxifen or an aromatase inhibitor.
- **If your risk of breast cancer coming back is low** (for example if your breast cancer is very small and has not spread to any lymph nodes), your doctor may not recommend hormonal therapy for you.

If you were treated for breast cancer some time ago, you may already be taking tamoxifen.

- **If you have reached menopause and started tamoxifen less than five years ago**, you may benefit from changing to an aromatase inhibitor.
- **If you have reached menopause and have recently completed five years of tamoxifen treatment**, you may benefit from further treatment with an aromatase inhibitor.

The decision about whether to change treatments or have further treatment with an aromatase inhibitor will depend on your risk of breast cancer coming back. The higher your risk, the more likely it is that your doctor will recommend that you change or have further treatment.

### **Questions yet to be answered about hormonal therapies**

As with many breast cancer treatments, there are important things we still do not know about hormonal therapies. 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 an aromatase inhibitor should be taken (at the moment aromatase inhibitors are usually prescribed for five years)
- whether it is better to use tamoxifen and an aromatase inhibitor in sequence (one after the other) and if so, in which order
- the effects of aromatase inhibitors on memory, concentration and heart disease
- how best to manage the loss in bone strength caused by aromatase inhibitors
- whether hormonal therapies can be used to prevent breast cancer in women who have not been diagnosed with the disease.



## Questions to ask about hormonal therapies

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

- How can I benefit from hormonal therapy?
- 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?
- Who should I contact if side effects develop?
- How can I manage side effects if they develop?
- Will the side effects stop when I finish treatment?
- When will I start hormonal therapy if I am having other treatments?
- Will hormonal therapy affect my ability to have children?
- Do I still need to use contraception if I am having hormonal therapy?

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## Frequently asked questions

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

Your pathology report shows whether there are hormone receptors on your breast 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 completed your family
- your risk of breast cancer coming back.

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

### How do the risks and benefits of different hormonal therapies compare?

The long-term benefits and risks of taking tamoxifen are well known. Tamoxifen reduces the risk of breast cancer coming back and improves survival. Studies have shown that treatment with an aromatase inhibitor reduces the risk of breast cancer coming back more than tamoxifen. Studies have not been going long enough to say whether aromatase inhibitors improve survival more than tamoxifen. Also, we do not yet know the long-term side effects of aromatase inhibitors.

- For post-menopausal women with **a higher risk of breast cancer coming back**, the short-term benefits of aromatase inhibitors outweigh the risks of side effects (both known and unknown).
- For post-menopausal women with **a lower risk of breast cancer coming back**, it is possible that long-term side effects of aromatase inhibitors (as yet unknown) outweigh the short-term benefits of treatment compared with tamoxifen.

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

The recommended doses of hormonal therapies are the only ones that have been tested. Taking lower doses or less frequent doses is not a good idea. If you have side effects, 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?**

Yes. Your GP can renew your script, even if your oncologist first prescribed it.

### **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 mobility 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 my hormonal therapy, should I take a double dose?**

No. Just take the next dose as normal.

### **If I change from tamoxifen to an aromatase inhibitor, can I change back later if side effects worry me?**

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



# Targeted therapies

Date of development: October 2008

## Summary

- Targeted therapies (also known as biological therapies) are drugs used to treat certain types of cancer cells.
- Trastuzumab (Herceptin®) is used to treat breast cancers with higher than normal levels of the HER2 protein.
- 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. The most common targeted therapy for early breast cancer is trastuzumab (Herceptin®). The number of available targeted therapies is likely to increase with time as we get more evidence about other treatments. For example, another targeted therapy called lapatinib (Tykerb®) is currently available for women with breast cancer that has spread to other parts of the body, and it is also being studied in clinical trials for women with early breast cancer.

## What is trastuzumab (Herceptin®)?

Trastuzumab (Herceptin®) is a drug used to treat a type of breast cancer called 'HER2-positive breast cancer'. 'HER2-positive' means that the breast cancer cells have higher than normal levels of a protein — called HER2. Trastuzumab works by stopping HER2-positive cancer cells from growing and dividing. About one in five patients have HER2-positive breast cancer.



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



Trastuzumab lowers the risk of breast cancer coming back (in the breast and in other parts of the body) and increases survival for women with HER2-positive early breast cancer.

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

## **When is trastuzumab recommended?**

Trastuzumab is recommended for people with HER2-positive early breast cancer. In people with very small cancers and no involved lymph nodes, the benefit of treatment with trastuzumab is not yet known. The current recommendation is to give trastuzumab at the same time as chemotherapy (usually after breast cancer surgery). Trastuzumab can only be given with some types of chemotherapy. This means that trastuzumab treatment may not start right at the beginning of chemotherapy. 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 (I.V.) infusion. A healthcare professional gives the infusion once a week or once every three weeks. You and your doctor will decide how frequently trastuzumab is given. 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.

Your first dose of trastuzumab will be higher. This is called a 'loading dose'. It will usually take about 90 minutes and can be slowed or stopped if you feel uncomfortable. If you do not react to the first infusion, the other infusions will be quicker and the dose will be lower.

The current recommendation is to give trastuzumab for one year. Clinical trials are studying the effects of giving trastuzumab for less or more time.

## 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 anthracycline chemotherapy (epirubicin, doxorubicin, adriamycin).** Ask your doctor whether your chemotherapy will change if you receive trastuzumab.

**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 feeling faint because of 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 side effects of trastuzumab

Other possible side effects of trastuzumab include reactions such as chills and fever. Clinical trials looking at the side effects of trastuzumab in women with early breast cancer have not been running for many years. Therefore, we do not yet know the long-term side effects of trastuzumab. 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.**

## Questions yet to be answered about trastuzumab

As with many breast cancer drugs, there are important things that we still do not know about trastuzumab. 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 trastuzumab, including effects on the heart
- the ideal length of time for which trastuzumab should be given
- the ideal combination of trastuzumab with other treatments like chemotherapy, hormonal therapy and radiotherapy
- the effects of taking trastuzumab at the same time as hormonal therapies
- the use of trastuzumab during pregnancy, and the effects on fertility.



## Questions to ask about trastuzumab

Listed below are some questions you may like to ask about trastuzumab.

- Can I benefit from treatment with trastuzumab?
- What are my other treatment options if trastuzumab is not suitable for me?
- How much will trastuzumab cost?
- When will I start trastuzumab if I am having other treatments?
- Will I need to go to hospital to receive trastuzumab?
- How often will I have treatment?
- Will I need any extra tests? How much will any extra tests cost?
- What are the possible side effects of trastuzumab?
- When are side effects likely to occur?
- Who should I contact if side effects happen?
- How can I manage side effects if they develop?
- Will the side effects stop or improve when I finish treatment?
- Can I take part in any clinical trials?

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## **Frequently asked questions**

### **How do I know if I am HER2-positive?**

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

### **How do I know if trastuzumab will be of benefit to me?**

Trastuzumab will only be suitable for you if your breast cancer cells are HER2-positive. About one in five patients with breast cancer have HER2-positive breast cancer.

### **How often will I need to receive treatment?**

Trastuzumab can be given weekly or 3-weekly. Your doctor will decide the best dosage and treatment regimen for you.

### **What happens if I have to stop trastuzumab for any reason before one year of treatment?**

We do not yet know the ideal length of time for which trastuzumab should be given. The current recommendation is to give trastuzumab for one year. One small clinical trial suggested that treatment with nine weeks of trastuzumab may be enough to give benefit to some women with early breast cancer.

### **Will trastuzumab treatment make me lose my hair?**

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

# Clinical trials

Date of development: October 2008

## 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 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 were 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 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 standard treatment.

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

Advantages of joining a clinical trial:

- 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 breast cancer in the future.

Disadvantages of joining a clinical trial:

- you can't choose which treatment you have
- the newer treatment might not be more effective than standard treatments
- the newer treatment might have more or different side effects compared with 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
- if you are in the control group, you will not receive the newer treatment.

It is up to you whether you choose to join a clinical trial. If you decide to join a 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 treatments and care available. **The quality of your care and treatment will not be affected.**

**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 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 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.

### 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.

### Who 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.

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

If you join a clinical trial, you have a right to access the results once the trial is completed.

### 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 large numbers of patients in several 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: October 2008

## Summary

- Complementary therapies are a range of approaches to care aimed at enhancing quality of life and improving 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, stop it from coming back or stop it from spreading to other parts of the body.
- 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 surgery, radiotherapy, chemotherapy, hormonal therapies or targeted therapies.

Complementary therapies may include acupuncture, relaxation therapy and meditation, gentle exercise, guided imagery, music or art therapy, massage, aromatherapy, 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. There is no evidence to support the use of alternative therapies in the treatment of breast cancer.

***“I started doing tai chi and that’s become part of my life. I started walking at six o’clock in the morning and that’s now also become part of my life.”***

***“I do yoga, which I find wonderful.”***

## **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.**

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.**

***“I was using Chinese herbs before I was diagnosed so I discussed this with my oncologist.”***

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



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).

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.**

[illegible]

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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. It is important that you tell your doctor about any treatments you are taking or are 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 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.



**Notes:**

# When treatment is over

This section explains what happens after treatment finishes, including what follow-up tests are important and how you might feel when treatment is over. It also provides information about some of the longer-term effects of treatment for breast cancer, including effects on fertility and menopause, as well as lymphoedema.

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# Follow-up after breast cancer

Date of development: October 2008

## Summary

- Follow-up is recommended after treatment for breast cancer to check whether breast cancer has come back, to monitor side effects of treatment and to provide practical and emotional support.
- If you are receiving a hormonal therapy such as tamoxifen or an aromatase inhibitor, you will have follow-up tests while you are taking these therapies.
- Follow-up tests usually involve physical examinations and breast imaging tests such as mammograms and/or ultrasound.
- Follow-up does not involve X-rays, scans or blood tests unless you have symptoms that suggest the cancer has spread outside the breast.

**If you notice a change in the look or feel of your breast(s), or in your general health between follow-up appointments, see your GP or specialist as soon as possible.**

## Finishing treatment

Many women look forward to finishing their treatment (surgery, radiotherapy or chemotherapy). However, for some women, the end of treatment can be a confusing or worrying time. Some women feel nervous or upset at the thought of no longer seeing members of their healthcare team regularly. Others feel worried about what the future holds. **If the thought of finishing treatment is making you feel anxious or upset, talk to a member of your healthcare team.**



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

## Why are follow-up tests important?

**Regular follow-up is recommended after treatment for early breast cancer.**

Women who have been diagnosed and treated for early breast cancer have an increased risk of breast cancer coming back or developing in the other breast. Regular follow-up means that if breast cancer does come back or if a new breast cancer develops, it can be treated promptly. Follow-up also allows your doctors to check for any side effects from treatment and to monitor any long-term treatments you are taking such as hormonal therapies. It also provides an opportunity for you to talk about how you are feeling.

***“I don’t want to spend my life frightened that the breast cancer might come back. It probably will never come back.”***

Some women find it reassuring to have regular follow-up tests. Others feel anxious around the time of their appointments. Both reactions are normal. **Talk to your doctors if you feel anxious around the time of follow-up tests as help is available.**

## What do follow-up appointments involve?

**Follow-up after treatment for breast cancer involves regular physical examinations and breast imaging tests (mammogram and/or ultrasound).**

Appropriate follow-up does not involve chest X-rays, bone scans or blood tests unless you have symptoms which suggest that cancer has spread outside the breast or armpit area.

Some women assume that they should be having regular scans and blood tests. 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.

Your follow-up schedule will be planned based on your individual circumstances. A general outline is given below. Talk to your healthcare team about your individual follow-up plan. If you are involved in a clinical trial, you may have some tests in addition to those listed here. 'Treatment' as listed below refers to surgery, chemotherapy and radiotherapy. If you are receiving a hormonal therapy such as tamoxifen or an aromatase inhibitor, you will have follow-up tests while you are taking these therapies.



For more information about clinical trials, see the 'Clinical trials' chapter in the 'Treatment' section.

## Physical examinations and history

Your doctor will ask you about any symptoms you have experienced since your last visit and will do a physical examination of both breasts (or your chest area if you have had a mastectomy), your arm and other parts of your body if relevant. How often you have this done will depend on your individual situation and how long it has been since you finished treatment. In general, the recommended timing for physical examination/history is:

- **years 1–2 after treatment:** every 3–6 months
- **years 3–5 after treatment:** every 6–12 months
- **more than 5 years after treatment:** every year.

Your physical examinations could be more or less often than this.

## Imaging tests

You will have a mammogram and/or ultrasound to look for changes in your breasts. You will usually have these tests before you see your doctor, so that you can discuss the test results. In general, it is recommended that you have a mammogram once a year, with the first mammogram one year after your diagnosis.

## Talking to your doctor

Follow-up appointments are a good opportunity to talk to your doctor about how you are feeling. You can also tell your doctor about any side effects of treatment you have had since your last visit. You may want to keep a note of things to ask your doctor at your follow-up appointment.

## What happens after follow-up appointments?

For most women, no changes are found during follow-up appointments. However, if your mammogram or ultrasound shows an abnormal area, or if your doctor finds a lump during the physical examination, you will need to have further tests. This may include more imaging tests and a biopsy.

## What happens between follow-up appointments?

**If you notice a breast change or any other symptoms that concern you between follow-up appointments, do not wait until your next appointment. See your GP or specialist as soon as possible.**

Many women think that when they have finished treatment their emotions will be 'back to normal'. However, breast cancer may continue to have an impact on how you are feeling even when treatment is over. Your emotional wellbeing is just as important after treatment for breast cancer as it is during treatment. Some women feel anxious or depressed for several years after treatment has finished. If you are experiencing feelings that are concerning you, support is available. Talk to your doctors or other health professionals about how you are feeling. If you feel you would like more support, ask to speak to a counsellor, psychologist or psychiatrist.

***"Of course every year when you go back and have tests, there's always something in the back of your mind saying, 'let's hope it's all good'."***



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

To find out more about support available in your local area, contact the **Cancer Council Helpline** on **13 11 20**.

## Breast cancer and family history

If you have been diagnosed with breast cancer, you may be worried about whether other members of your family will also develop the disease.

**A diagnosis of breast cancer does not mean that other members of your family will develop breast cancer.**

Many women have someone in their family who has had breast cancer; this can happen by chance, as the disease is so common. Family history becomes more important when there are more relatives with breast cancer on the same side of the family, especially if the cancer occurs in a woman before 50 years of age. Most women will not develop breast cancer, even if they have a close relative with breast cancer.

Rarely, breast cancer can be caused by a fault in a gene, known as the BRCA1 or BRCA2 gene, which can be passed within families from one generation to another. These gene faults can be inherited from either the mother's or the father's side of the family. If you have a strong family history of breast cancer, your doctor may refer you for genetic testing at a specialist family cancer clinic.



**BRCA1 and BRCA2 gene:** If a woman has inherited a fault in one of these genes, she has a high chance of developing breast or ovarian cancer, although it does not mean that she is certain to develop cancer. The names of these genes come from the abbreviation of 'breast cancer one' and 'breast cancer two'.



To find out more about your family history of breast cancer, talk to your doctor. You can ask your doctor for a referral to a specialist family cancer clinic for genetic testing.





## **Questions to ask about follow-up after breast cancer**

Listed below are some questions you might want to ask about follow-up after breast cancer:

- How often will I need follow-up tests?
- What will my follow-up tests involve?
- Where should I go for my follow-up tests?
- Who will tell me the results?
- Who should I contact if I have questions between follow-up appointments?
- What symptoms should I look out for?
- Who should I tell if I notice a new symptom?
- Who can I talk to about how I'm feeling?
- Who can I talk to about my family history of breast cancer?
- What will my follow-up care cost?

[illegible]

## Frequently asked questions

### **Can I continue to have my mammograms at BreastScreen?**

After you have been diagnosed with breast cancer you may no longer be able to have your mammograms at BreastScreen, depending on which state or territory you live in. Ask your GP or specialist, and if you are no longer able to have your mammograms at BreastScreen, they will give you a referral to a radiology clinic for your mammogram and/or ultrasound.

### **What should I do if I notice a change in my breast?**

If you find a change in your treated breast (or chest wall if you had a mastectomy) or in your other breast between follow-up appointments, see your GP or specialist as soon as possible. It is important that you do not wait until your next appointment.

# Lymphoedema

Date of development: October 2008

## Summary

- Lymphoedema after breast cancer is a persistent swelling of the arm or breast that occurs because of a build-up of fluid.
- Lymphoedema can develop after treatment for breast cancer because of damage to or removal of lymph nodes from the armpit or breast area.
- Lymphoedema usually develops gradually and can occur months or even years after treatment is finished.
- There is no known cure for lymphoedema but the symptoms can be managed.

## What is lymphoedema?

**Lymphoedema after breast cancer is a persistent swelling of the arm or breast that occurs because of a build-up of fluid.** If left untreated this build-up of fluid can be difficult to control.

Fluid from the body's tissues usually drains into lymphatic vessels. These are small vessels close to the blood vessels. The fluid is called lymph. Lymphatic vessels carry the lymph to lymph nodes, where substances that could be harmful to the body, such as bacteria, are removed. This helps to protect the body from infection. The lymph then passes back into the blood. There are lymph nodes all around the body, including the armpit, groin, abdomen, chest and neck.

During treatment for breast cancer, lymph nodes may be removed from the armpit or breast region by surgery or damaged by radiotherapy. This can cause lymph fluid to build up in the arm or breast, causing the arm or breast to swell.

Lymphoedema usually develops gradually. It can develop months or even years after treatment for breast cancer. The risk seems to be higher for people who have several lymph nodes removed and for those who have both surgery and radiotherapy to the armpit. However, many people who have lymph nodes removed and radiotherapy to the armpit do not develop the condition.

**Lymphoedema is not the same as the swelling or pain in the breast, armpit or arm that immediately follows surgery or radiotherapy to the breast or armpit.**



For more information about the side effects of treatment, see the 'Treatment' section.

Cancer Australia's booklet, *Lymphoedema – what you need to know*, provides information about lymphoedema for people who have been treated for cancer. To order a copy go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call 1800 624 973.

## **Signs and symptoms of lymphoedema**

Early signs of lymphoedema to look for include:

- a feeling of heaviness, tightness or fullness in the arm or breast
- swelling of the arm, breast or hand (you may notice indentations in the skin from tight clothing or jewellery)
- aching, pain or tension in the arm, hand, chest or breast area.

**Some of these early signs and symptoms may come and go. If you notice one or more of the changes above, you should discuss these with your doctor.**

Some changes are not caused by lymphoedema but are side effects of surgery or radiotherapy. These include reduced range of movement, loss of muscle strength, changes in sensation and tingling in the arm or fingers.

**Tell your doctor or breast care nurse promptly about any changes that develop after the initial side effects of treatment have passed.**

## How to reduce the risk of lymphoedema

It is not possible to tell who will develop lymphoedema after treatment for breast cancer. Studies to reduce the risk of lymphoedema have looked at surgical or radiotherapy techniques that are less damaging to the lymphatic system. These include a technique called sentinel node biopsy.



For more information about sentinel node biopsy, see the 'Surgery to the armpit' chapter in the 'Treatment' section.

There are some things you can do that may help to reduce your risk of developing lymphoedema or to help stop the condition from getting worse.

### Skin care

**Caring for your skin is essential to prevent or control lymphoedema.**

The skin is an important barrier against infection. If it is broken, bacteria can enter the body and cause infection. An infection may cause lymphoedema or make it worse. Suggestions on how to keep your skin healthy and prevent infections:

- keep the skin supple using a moisturising cream such as sorbolene
- avoid drying out your skin and consider using a soap-free alternative
- clean any scratches, grazes or cuts immediately using an antiseptic solution, use an antibacterial cream and cover the area with a clean, dry plaster
- if shaving the armpit, use an electric razor instead of a wet razor
- avoid tattoos and body piercing
- consider ways that you can protect your skin, for example, wear gloves while washing dishes, gardening or handling pets.

## Keeping active

It is essential that you keep active to help fluid circulate in the treated area.

Suggestions:

- follow a gentle exercise routine and if you want to exercise more vigorously, work up to this slowly and always warm down slowly
- talk to your doctor or a lymphoedema practitioner if you have questions about what activities are best for you
- maintain a healthy weight with regular exercise
- avoid long periods of inactivity.

## Things to avoid

Try not to do activities that will put extra strain on the lymphatic system or stop lymph flow.

For example, avoid:

- sunburn to the affected area
- hot baths, spas and saunas
- strenuous exercise in hot weather
- poorly fitting or tight clothing.

Being overweight can also increase the risk of developing lymphoedema.

It has been suggested that long-distance air, road or train travel may increase the risk of lymphoedema. While the evidence for this is not strong, it may be helpful to wear a compression garment and to perform gentle exercises while you travel.

We do not yet know whether certain medical procedures done on the affected arm increase the risk of lymphoedema. These include having blood samples or blood pressure taken or having injections or intravenous drips. **It is suggested that, as a precaution, you use the unaffected arm for blood pressure measurements, injections or drips whenever possible.**

## How is lymphoedema managed?

There is no known cure for lymphoedema, but it can be managed with appropriate care.

The aim of management is to reduce and control swelling, improve the range of movement of the affected area and prevent infections. The treatments recommended will vary depending on the severity of symptoms and how long you have had lymphoedema. Some of these methods are still being tested.

**Talk to your doctor about what treatment options may be suitable for you. A qualified lymphoedema practitioner can help — ask your breast care nurse or doctor for a referral.**



**Lymphoedema practitioner:** An occupational therapist, physiotherapist or nurse who is specifically trained to treat lymphoedema.

Some of the ways to manage lymphoedema are listed below.

- **Skin care** — daily attention to skin care is essential as the skin provides a barrier against infection.
- **Exercise** — studies suggest that gentle exercise can help to reduce the symptoms of lymphoedema by helping lymph to flow through the lymphatic vessels. Exercise can also help maintain a healthy body weight. This is important, as excess body weight may slow the flow of lymph.



Ask about exercises that you can do at home — on your own or with the help of a carer.

- **Elevation** — experts believe that raising the limb, for example by supporting the arm on several pillows, can help reduce the symptoms of lymphoedema in the early stages of the condition.



## Treating infections

If you have lymphoedema and the affected area swells quickly or becomes red and warm, you should arrange an urgent appointment with your doctor.

Tell your doctor that you may have **cellulitis** (an infection of the skin and underlying tissue) that needs to be treated with antibiotics.

If you develop an infection, your doctor may advise you to:

- rest in bed and keep your arm raised
- use a compression sleeve — if this is comfortable enough for you to manage
- stop having manual lymphatic drainage if it is part of your routine care, until the cellulitis has passed.

It is also important to treat skin conditions such as tinea, eczema or dermatitis as soon as possible, as they can also make the lymphoedema worse.

## Treatments for which there is little or no evidence of benefit

There are some therapies for which there is little or no evidence of benefit in the treatment of lymphoedema.

## Drug treatments

It is important to note that:

- diuretics are not effective in reducing the symptoms of lymphoedema
- some medications may make lymphoedema worse; these include steroids and some blood pressure medications
- drugs that contain chemicals called benzopyrones or bioflavonoids are not effective for the treatment of lymphoedema.

There are a range of alternative treatment options that have been used in the treatment of lymphoedema. However, there are limited research findings about these treatments. Examples include ultrasound therapy, hyperbaric oxygen therapy, vitamin E supplements, microwave therapy, acupuncture and moxibustion (burning of herbal leaves on or near the body), mulberry leaf, aromatherapy oils, magnetic fields, vibration and hyperthermia.

Research is ongoing into methods for preventing, diagnosing and managing lymphoedema. This research will help to provide more evidence-based information in the future. **Talk to your doctor or lymphoedema practitioner about new developments.**

### **Emerging treatments**

- **Laser therapy** — studies have looked at using laser therapy to help soften scar tissue and improve the function of the lymphatic vessels. A small number of studies suggest that this treatment may have some benefits, but further research is needed to work out the best approach to treatment.
- **Pneumatic pumps** — these are single or multi-chambered pumps that go around the arm. The pumps inflate and deflate at intervals. A small number of studies suggest that this treatment may have some benefits, especially when combined with other treatments such as manual lymphatic drainage, compression garments and massage. However, further research is needed to work out the most effective kind of pump, pumping time and pressure. If used inappropriately, this technique can cause damage to the soft tissue and make the lymphoedema worse.
- **Surgery** — surgery for lymphoedema is generally only recommended when other treatment options have not been effective. Surgical techniques can include liposuction or microsurgery to bypass blocked lymphatic vessels.

## Coping with lymphoedema

If you develop lymphoedema, you may experience a range of feelings in addition to the physical symptoms of the condition. You may feel upset, embarrassed or sad about how your arm or breast looks. For some people, the physical effects of lymphoedema can also affect lifestyle and work.

If you are diagnosed with lymphoedema, it is not uncommon to feel upset or sad. Most people find that these feelings ease with time, as they learn how to manage the condition.

Talking to others can help. You may find it helpful to talk to those close to you and let them know how you are feeling. Or you may prefer to talk to a member of your treatment team, such as your GP or breast care nurse. Talking with other people who have lymphoedema can also help.



To find out about support groups in your local area, call the **Cancer Council Helpline** on **13 11 20**.

**If you have feelings of anxiety or depression that are overwhelming you, talk to your GP.** Treatments are available that can help. You may find it helpful to talk to a specialist, such as a counsellor, psychologist, or therapist, about how you are feeling.



## Questions to ask about lymphoedema

Listed below are some questions you might like to ask your doctor or lymphoedema practitioner about lymphoedema.

- Who should I contact if I have concerns about lymphoedema?
- What treatment do you recommend for my lymphoedema?
- What is the evidence that the treatment you are recommending will work?

- Can you refer me to a qualified lymphoedema practitioner?
- How much will it cost to see a lymphoedema practitioner?
- Where can I get a compression sleeve fitted?
- When should I wear my compression sleeve?
- How much will my compression sleeve cost?
- What type of moisturiser should I use?
- Can I keep some antibiotics at home?
- Who should I contact if I notice signs of an infection?
- What types of exercises can I do?
- How might my lifestyle be affected?
- How might my work be affected?
- Are there any techniques I can use at home to help my lymphoedema?
- If I change doctors, should I tell them about my breast cancer treatment?
- Who can I talk to about how I am feeling?

This image shows a full page of white paper with horizontal dashed lines, typical of primary school handwriting practice paper. The lines are evenly spaced and run across the entire width of the page. There are no margins, text, or other markings present.

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## Frequently asked questions

### How common is lymphoedema?

We do not know exactly how many people develop lymphoedema in the arm or breast after treatment for breast cancer. Estimates vary from one in ten people to one in three people treated for breast cancer.

### How can I find a lymphoedema practitioner?

To find a qualified lymphoedema practitioner, ask your breast care nurse or doctor or contact the **Cancer Council Helpline** on **13 11 20**.

# Breast cancer, menopause and fertility

Date of development: October 2008

## Summary

- Treatment for breast cancer may cause you to become menopausal. The menopause may be temporary or permanent.
- If you have not reached menopause when you are diagnosed with breast cancer, treatment may affect your ability to have children. It is important to discuss with your doctor your plans for having children before you start treatment.

## Breast cancer and menopause

About two-thirds of women who are younger than 50 when their breast cancer is diagnosed will go through menopause because of their 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.



Cancer Australia's booklet, *Breast cancer and early menopause: a guide for younger women*, provides information for younger women with breast cancer who may be at risk of early menopause. To order a copy, go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call 1800 624 973.

## 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 treat you 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?

Some treatments for breast cancer can affect your ability to become pregnant (your fertility). Once your treatment has finished there is no reliable test to find out if you can still become pregnant. If you do fall pregnant after treatment for breast cancer, there is no evidence that this will increase your risk of breast cancer coming back.



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.

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



For information about pregnancy during treatment for breast cancer, see the 'Treatment' section.

## **Surgery or radiotherapy to the ovaries and fertility**

**Surgery and radiotherapy to the ovaries causes permanent infertility.**

If you have your ovaries removed by surgery, or if you have radiotherapy to the ovaries, you will no longer be able to have children naturally.

## **Chemotherapy and fertility**

**Some chemotherapy drugs can cause a woman to become infertile.**

Some women (usually women younger than 35 years) find that their periods return once chemotherapy finishes. However, this may not necessarily mean that you will be able to have children naturally.

The effect of chemotherapy on your fertility will depend on a number of things, including your age and the type of drugs you receive. These effects can also vary between different women of the same age.

**Talk to your oncologist or a fertility specialist about your individual situation before you start treatment.**

***“One of the reasons holding me back from chemo was that I wanted to be able to have children in the future.”***

## **Hormonal therapies and fertility**

Treatment with hormonal therapies does not cause infertility. However, a woman's fertility may fall naturally while she is taking hormonal therapies. Most hormonal therapies for breast cancer are given for five years. After five years, a woman's fertility will have fallen naturally because she is older.

Although hormonal therapies for breast cancer can cause your periods to stop, this does not necessarily mean that you cannot become pregnant. If you are sexually active while you are taking a hormonal therapy, it is important to use an effective contraceptive if you do not wish to become pregnant during this time.

**If you wish to become pregnant during the five years of hormonal therapy, it is important to discuss the risks and benefits of this with your oncologist.**

### **Contraception 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, copper 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.**

### **Having children after breast cancer**

If your fertility is affected permanently, this means that you will be unable to have children naturally after treatment. You might be able to have children using *in vitro fertilisation* (IVF). Embryos can be produced from your own eggs and your partner's sperm before you start treatment for breast cancer, and then frozen. If you are no longer fertile, it may be possible to use another woman's eggs. The embryos are implanted into your womb after you have finished treatment. Note that IVF is not always successful, especially when using frozen embryos.

***“We decided to leave it in the lap of the gods and see if we were able to fall pregnant. And we did twice so we feel very lucky.”***

There are other options for protecting your fertility although several are only in the early stages of research and we do not yet know how effective they are. When considering these options, it is also important to ensure that the treatment you are receiving for your breast cancer will still be effective.

**Ask for a referral to a fertility expert before you start treatment for breast cancer, to find out your options for increasing the chances of a future successful pregnancy.**

### **Coping with infertility**

Infertility can be very hard to come to terms with, not only for women who are 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.

***“I’ve always put off having children for my career and not being able to have children is something for the first time that I’m grappling with and it makes me feel really sad.”***

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, a fertility expert or gynaecologist, counsellor, psychologist or psychiatrist. Ask your doctor for a referral, or call the **Cancer Council Helpline** on **13 11 20**.

### **Breastfeeding and breast cancer**

Most women who have had radiotherapy after breast conserving surgery find they cannot breastfeed from the treated breast because it does not produce milk. However, a few women find that they are able to breastfeed from their treated breast. There is no evidence to suggest that breastfeeding from the treated breast will be unsafe for you or your baby.

You can safely breastfeed from your untreated breast if you have had radiotherapy.



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

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

- Will the treatment you are recommending affect my ability to have children in the future?
- Who can I talk to about my options for having 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 osteoporosis? Can this be monitored?

This image shows a full page of white paper with horizontal dashed lines, typical of primary school handwriting practice paper. The lines are evenly spaced and run across the entire width of the page. There are no margins, text, or other markings present.

## Frequently asked questions

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

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

Studies of HRT after breast cancer have shown mixed results. We do not know whether HRT is definitely safe for women who have had 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 to take progestogen after breast cancer.

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.

# Finding a new 'normal'

Date of development: October 2008

## Summary

- A diagnosis of breast cancer can change how you think and feel about things.
- Some women find that diagnosis and treatment for breast cancer gives them a new perspective on life.
- Some women find it difficult to adjust to life after treatment for breast cancer.
- Returning to work or other regular activities after treatment is helpful for some women. Other women look for new or different activities.

## Re-establishing priorities

A diagnosis of breast cancer can change how you think and feel about things. These changes and their effects will not be the same for all women, but it can be reassuring to know that other women share some of the same feelings and experiences.

***“Yes it may be a terrible stage of your life, but life will go on once it’s all finished. It may not seem like it but life will go on and things will get back to normal, or relatively normal.”***

Treatment for breast cancer can last for some time and some women find it hard to come to terms with treatment ending. Your family, friends and colleagues may expect you to be ‘back to normal’ when treatment is over. But for you, ‘normal’ may not mean quite the same thing as it did before your diagnosis.

***“The thing about breast cancer is that once treatment is completed, you find yourself back in the normal world but changed. There’s a bit of a feeling of being lost and not knowing what to make of it now.”***

It can be helpful to talk to your friends and family about how you are feeling. If you are anxious or worried about what the future holds, talk to a member of your treatment team. Remember, the feelings of anxiety, sadness, fear or worry will not last forever. Most people find that things improve with support and with time.

***“I’ve been to hell and back again, absolutely, and I never thought there was going to be a light at the end of the tunnel. But it’s turned around and I’ve become quite well now and I’ve been able to do some amazing things.”***

***“It wasn’t till about two years down the track when I didn’t fall asleep on the couch watching a video on a Friday night and I thought ‘hey, I must be getting better.’”***

Some women find that a diagnosis of breast cancer gives them a new perspective on life and makes them rethink what is important to them. You may find yourself considering new directions for your work or social activities or you may find you make new friends through your cancer journey. For some women, the experience of being diagnosed and treated for breast cancer provides opportunities they would not have considered before their diagnosis.

***“Breast cancer has changed my outlook on life and has made me a stronger person.”***

***“My family and friends took the view that after my treatment was over I would be the same person but of course you aren’t the same person.”***

## **Returning to work**

If you were employed, whether paid or voluntary, or involved in a regular activity when you were diagnosed, you may find it helpful to return to this job or activity shortly after treatment. This could make you feel valued and give you the comfort of being around familiar people. Talk to your employer or organisation about making your hours more flexible for a period before, during and after treatment.



***“I actually just resigned from my job about a month or two before I was diagnosed but I’ve gone back to work full time since.”***

You may find it difficult to talk with your colleagues or friends about your experience of being diagnosed with 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.

***“How do I tell an employer why I haven’t worked for the last year?”***



Cancer Australia’s website contains information for people who have finished treatment for early breast cancer. Visit [www.canceraustralia.gov.au/breastcancer/lifeafter](http://www.canceraustralia.gov.au/breastcancer/lifeafter) for more information.

Cancer Council NSW has produced a booklet about returning to work after a diagnosis of cancer. To download a copy of *Cancer, work and you*, go to [www.cancercouncil.com.au](http://www.cancercouncil.com.au).

Breast Cancer Network Australia has produced a brochure *Helping a friend or colleague with breast cancer*. To download a copy go to [www.bcna.org.au](http://www.bcna.org.au), or to order a copy call 1800 500 258.



## **Questions to ask about what happens when treatment finishes**

Listed below are some questions you might want to ask towards the end of your treatment.

- Who should I contact if I have questions now that treatment is over?
- Can I return to the kinds of activities I was doing before my treatment started?
- What should I tell my employer about my breast cancer?
- Are there any changes to my lifestyle that might help my recovery?

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## Frequently asked questions

### **Who can I talk to for advice about returning to work after breast cancer?**

Some people find that a diagnosis of breast cancer makes them rethink their work priorities. You may decide to try a different career path or change to part-time work. If you find you are still tired when treatment is over, talk to your employer or organisation about making your hours more flexible for a period of time.

A discussion with your personnel manager or supervisor early after your return to work will be useful in clarifying expectations.

**Notes:**

# 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: October 2008

## 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 manage their feelings.
- You may be eligible for financial and practical assistance to help during treatment.

## Your feelings

A diagnosis of breast cancer marks the beginning of a journey full of emotional, psychological, physical and practical challenges. Some of these challenges are experienced by many women with breast cancer, others by only a few women. It is not always easy, but over time, most women find they are able to cope with the changes caused by their diagnosis and return to the things that are important to them.



The booklet, *Cancer — how are you travelling?* explains the emotional, psychological, physical and practical challenges of a diagnosis of cancer, and what can help. To order a copy, go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call 1800 624 973.

Cancer Australia's website contains information for people who have finished treatment for early breast cancer. The site deals with common feelings women and those close to them may feel when treatment for breast cancer is over. Visit [www.canceraustralia.gov.au/life-after-breast-cancer](http://www.canceraustralia.gov.au/life-after-breast-cancer) for more information.



Breast Cancer Network Australia's website contains personal stories from women and men about how breast cancer has affected their lives. To view the stories go to [www.bcna.org.au](http://www.bcna.org.au).

## How you might be feeling

Women describe a number of feelings after a diagnosis of breast cancer. These are listed below. You might find that your feelings change or become more intense at different points in your cancer journey. Some people say the feelings are strongest when they are first diagnosed. Others say their emotions hit them later when they have time to reflect on what has happened. For many people these feelings ease with time. Women often report that they feel a range of emotions, including feeling 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 blame themselves for their breast cancer or find themselves questioning why breast cancer has happened to them.

***"I went through a lot of denial. A lot of things I had to work through myself because nobody was there to walk that path with me."***

If any of your feelings are overwhelming you or preventing you from sleeping or doing everyday activities, talk to a member of your healthcare team. Treatments and support are available and can help.

***"I felt as if I was moving within a large black cloud that completely enveloped me from head to toe. And it took me a long time to settle back down to a different life — a life that encompassed breast cancer."***

## Seeking help and support

Having support during your diagnosis and treatment is very important. There are many different sources of support. Your treatment 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 who have experienced 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.

***“Certainly after the diagnosis I was more aware about relaxation and trying to get out there and walk along the beach and make time and probably not take things so seriously that before seemed so terribly important.”***



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. To find out more about the magazine, or to subscribe, visit [www.bcna.org.au](http://www.bcna.org.au) or call BCNA on Freecall 1800 500 258.

Some of the things that might help are listed below.

- **Relaxation** — can help to control pain.
- **Muscle relaxation and imagery** — can help with anxiety and can help reduce nausea and vomiting.
- **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 clarify your feelings and help you deal with issues that may have been brought up by your diagnosis and treatment.

Up to half of women with early breast cancer will experience some degree of depression or anxiety. If this is severe or doesn't settle over time, anti-depressants or anti-anxiety medication can be very effective, in combination with other treatments such as relaxation therapy. There is no evidence that anti-depressants are addictive, and most people will only require this medication for a few months, but sometimes it can be longer depending on your particular situation. Most of the medication for anxiety will only be used for a few weeks. Needing medication does not mean you are 'weak' or 'crazy', and many people who have taken medication feel so much better that they wish they had started treatment earlier. **Talk to your doctor about the benefits and side effects of medications that might be helpful for you.**



***“I talked to the counsellor at the hospital. It would have been an hour and I just sat and it all came out and it was great because she just sat there and listened.”***

***“I saw a psychologist connected with the breast unit. She was good, really nice and kind and understanding and she suggested progressive muscle relaxation therapy.”***



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

## **Your family and friends**

A diagnosis of breast cancer can have a significant impact on those close to you — your partner, children, family and friends. They may find the journey difficult and need encouragement to seek support. They might also need advice about how they can help you. Many women find that friends and family are very supportive, but sometimes it can be disappointing when people do not offer the support you feel you need.

***“I seemed to be supporting more people than were supporting me.”***

Talk to a member of your healthcare team if you are having difficulties in your relationships or if you feel that a family member is having trouble coping.

Even if you have support from family and friends, remember that there are also other sources of support. You might find that a local community group is supportive or that neighbours can provide help. You may also find support from your treatment team, a support group or a religious organisation.

***“I think it’s difficult for the people around you, it’s frustrating, there is not really much that people can do, except be there.”***

## Your partner

Many partners also find the diagnosis and treatment distressing but are reluctant to seek help for themselves because they feel they need to be 'strong'.

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. If you are concerned about your partner, encourage them to seek information, talk to their GP or call the **Cancer Council Helpline** on **13 11 20**.

***"To me it didn't change who she was, the fact that she only had one breast. It didn't change the woman I loved." (From partner)***

***"My husband wasn't at all supportive, he could not handle it."***



Cancer Australia provides resources for the partners of women with breast cancer. To order an audio CD called *When the women you love has early breast cancer*, go to [www.canceraustralia.gov.au/resources](http://www.canceraustralia.gov.au/resources) or call 1800 624 973.

## 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 information below 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 support through the **Cancer Council Helpline**.

***“My eldest son is petrified, he just wants to hear that everything’s OK. My middle son is 18 and he’s a little bit more open; he had an experience of cancer with a friend that survived so he has a positive attitude and my youngest just doesn’t want to know about it.”***

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 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.

***“My children, especially my fourteen-year-old daughter, asked heaps of questions: ‘Will I get it? How will mum change? Is she going to look OK?’ — questions that were important to her.”***

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 that of your partner. 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.

It is important for you and your partner to ask each of 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.
- Reassure them that even if things are not good at the moment there will be better times.
- Do not make promises you may be unable to keep.
- Maintain a sense of routine and encourage them to socialise with their friends and participate in their usual activities.
- Reassure them that the breast cancer is not their fault — this is especially important for younger children.
- Adolescents may have mixed emotions, loyalties and coping abilities. 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.

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



Cancer Australia has information for children who have a parent with cancer: [www.canceraustralia.gov.au/myparentscancer](http://www.canceraustralia.gov.au/myparentscancer).

Cancer Council NSW has developed a booklet about talking to children about cancer. To download a copy of *Talking to kids about cancer* go to [www.cancercouncil.com.au](http://www.cancercouncil.com.au).

CanTeen provides information and support for young people who have a family member with cancer: [www.canteen.org.au](http://www.canteen.org.au).

## Breast cancer and sexuality

Treatment for breast cancer can affect your relationship with your partner, including your sexual relationship. Different treatments can affect how women feel about themselves and their attractiveness. This can happen to any woman, whether or not she has a partner.

Some of the sexual difficulties that may arise as a result of treatment include:

- feeling less attractive because of treatment
- breast tenderness after treatment
- lower libido because of feeling unwell, tired or worried
- vaginal dryness due to the impact of different drugs.

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 feel closer to each other.

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

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.

***“The sex thing comes down to between the couple, there’s no real rules.” (From partner)***

There are some practical things that can help 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.

***“How do I deal with the aspect of what I’ve been through with somebody new? At what point do you say to them ‘Guess what, I’ve had breast cancer; guess what, I’ve had a mastectomy.’”***

## 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. Talking with someone you feel comfortable with in your healthcare team may help you and your partner feel more supported.



To find out about support services specifically for lesbian women, contact your local women's health centre or the **Cancer Council Helpline** on **13 11 20**.

## Practical support

After a diagnosis of cancer, there may be a number of practical things to think about. These may include the cost of treatment and support, travel and accommodation costs, childcare, or the cost of prostheses and wigs.

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 for a while. 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.**

***"After I started my chemotherapy I had to be off work and so we were living on one income and we had four children and two young ones and that cost a lot. So financially we were struggling a bit."***

## Cost of treatments

Talk to your doctors about the likely cost of medical tests and treatments. The cost will depend on whether:

- you are treated in the public or private system
- you are working and need to take time off
- you live in a rural area and need to travel for treatment
- you have private health insurance.

You may find it useful to talk to a social worker about what financial and practical support services are available. Ask your breast care nurse or another member of your healthcare team about how to access a social worker. It may also be helpful to talk to your local Medicare office about the 'safety net' on costs of medications and medical bills.

## Cost of prostheses

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 and families' then 'External breast prostheses reimbursement program'. You can also call Medicare on 132 011 or visit a Medicare office.

For further information about where to find a breast prosthesis in your area, ask your health professional or contact the **Cancer Council Helpline** on **13 11 20**.

## 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.

## 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 Travel Scheme (PATs) — WA
- Transport for Health — Isolated Patient Transport and Accommodation Assistance Scheme (IPTAAS) — NSW
- Interstate Patients Transport and Accommodation Service (IPTAS) — ACT.

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.



To find out about what financial and practical help may be available for you, talk to the breast care 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.



## Questions to ask your healthcare team about practical support

Listed below are some questions you might want to ask your GP, specialist or breast care nurse about practical support during treatment for breast cancer.

- What will the treatment you are recommending cost?
- Will I need to have time off work?
- If I take time off work, how do I apply for temporary income support?
- Will I need to travel for treatment?
- Am I eligible for help with travel and accommodation costs?
- How can I find out about help with childcare while I am being treated?
- How can I find out about home help while I am being treated?
- How can I find out about counselling or psychological support?
- How can I find out about help with the costs of prostheses or wigs?





## 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 insurance?
- Which treatments are not covered by my insurance?
- Does my insurance cover other services, such as the cost of breast prostheses or wigs?
- If I claim for a particular treatment now, does that affect what treatments I can claim for later?
- What is the gap between the cost of treatment and the private medical insurance rebate?

You may like to write your own questions here:

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## **Frequently asked questions**

### **How do I know if I am anxious?**

Some of the signs of anxiety include constantly feeling agitated or angry. You may have difficulty sleeping or you may have trouble concentrating or making decisions. You may find yourself avoiding distressing situations or you may get sudden feelings of panic or fear.

### **How do I know if I am depressed?**

Some of the signs of depression include feeling low or flat and losing interest in things you used to enjoy. You may feel tearful or find it hard to see the funny side of things. You may have difficulty sleeping or lose your appetite (although bear in mind this can also be a side effect of some treatments).

# Useful links

In addition to the information you receive from your treatment 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:

**Cancer Australia:** [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)

The Cancer Australia website provides evidence-based information about a range of cancers, including breast cancer. Cancer Australia is the national authority on cancer control, funded by the Australian Government. It was established to benefit all Australians who are diagnosed with cancer, their families and carers.

**Breast Cancer Network Australia:** [www.bcna.org.au](http://www.bcna.org.au)

This website has a range of breast cancer information and resources developed by women with breast cancer, including kits for women with early and 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. This website has links to State and Territory groups.

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**Cancer Council Australia: [www.cancer.org.au](http://www.cancer.org.au)**

This website has links to the 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 services to young people aged 12-24 living with cancer, including young people who have an immediate family member with cancer. This website has links to upcoming support programs in each State and Territory.

**YWCA Encore: [www.ywcaencore.org.au](http://www.ywcaencore.org.au)**

Encore is a gentle exercise program conducted by women for women who have had breast cancer and who may have undergone mastectomy, lumpectomy and/or breast reconstruction. This site provides information about where Encore programs are held, eligibility and cost.

**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. They also hold regular 'ask the expert' online forums on different breast cancer topics.

**Cancerbackup: [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)**

This is the UK's leading cancer information service.

\*Please note that some of the information on websites from other countries may only apply to people in those countries.

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**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.

There are many internet sites about cancer and breast cancer. You may also like to ask your doctor or breast care 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

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| <b>Adjuvant:</b>                                    | treatment given in addition to primary (initial) treatment. For breast cancer, the primary treatment is surgery and adjuvant treatments include chemotherapy, radiotherapy, hormonal therapies and targeted therapies. |
| <b>Alkylating agent:</b>                            | a class of chemotherapy, eg cyclophosphamide.  |
| <b>Alternative therapies:</b>                       | treatments used instead of conventional treatments.  |
| <b>Anaemia:</b>                                     | a condition in which there are fewer red blood cells in the blood than normal.   |
| <b>Anthracycline:</b>                               | a class of chemotherapy, eg epirubicin (Pharmorubicin®), doxorubicin (Adriamycin®).  |
| <b>Antimetabolite:</b>                              | a class of chemotherapy, eg 5-fluorouracil (5FU), methotrexate.  |
| <b>Anti-oestrogen:</b>                              | a type of hormonal therapy, eg Tamoxifen.  |
| <b>Aromatase inhibitor:</b>                         | a type of hormonal therapy, eg anastrozole (Arimidex®), letrozole (Femara®), exemestane (Aromasin®).   |
| <b>Axilla:</b>                                      | the armpit.  |
| <b>Axillary dissection/<br/>axillary clearance:</b> | removal of some or all of the lymph nodes from the armpit.   |
| <b>Biopsy:</b>                                      | removal of cells or tissue from the body for examination under a microscope.   |
| <b>Bone marrow:</b>                                 | the substance within the bones that makes different types of blood cells.  |

- BRCA1 and BRCA2 gene:** these are genes that normally prevent a woman developing breast or ovarian cancer. If a woman has a fault in one of these genes, she has a high chance of developing breast or ovarian cancer, although it does not mean that she is certain to develop cancer.
- Breast conserving surgery:** removal of the breast cancer and a small area of healthy tissue around it; also called a lumpectomy, complete local excision, partial mastectomy or wide local excision.
- Breast form:** see 'External breast prosthesis'.
- Cellulitis:** an infection of the skin caused by bacteria.
- Chemotherapy:** treatment for cancer using drugs.
- Clinical trials:** studies that compare new treatments with standard treatments.
- Complementary therapies:** are treatments or therapies that can be used alongside conventional treatments to enhance quality of life and improve overall wellbeing.
- Complete local excision:** see 'Breast conserving surgery'.
- CT scan:** a special type of X-ray that provides a three-dimensional picture of the inside of the body. The initials stand for 'computerised tomography'.
- Deep inferior epigastric perforator (DIEP) flap:** a type of breast reconstruction using the blood vessels, fat and skin from the stomach.
- Diethylstilbestrol:** a drug prescribed to women during the 1930s to 1970s to prevent miscarriage and treat other complications of pregnancy.

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| <b>Ductal carcinoma in situ (DCIS):</b>               | non-invasive breast cancer that is confined to the ducts of the breast.  |
| <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>External breast prosthesis:</b>                    | an artificial breast; also called a breast form.   |
| <b>Granulocyte colony stimulating factor (G-CSF):</b> | a growth factor used to increase the number of stimulating factor white blood cells in the blood.  |
| <b>HER2:</b>  | proteins on a cell that allow a growth factor to bind to the cell. HER2 affects how quickly the cell grows. HER2 is also called HER2-neu or c-erbB2 receptors. |
| <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. Hormone receptors affect whether the cell growth is influenced by hormones.                        |
| <b>Hormone replacement therapy (HRT):</b>             | hormones (oestrogen, progesterone, or both) given to women after menopause. They are used to ease symptoms of menopause.                                       |
| <b>Inflammatory breast cancer:</b>                    | rare form of invasive breast cancer that affects the blood vessels in the skin of the breast, causing the breast to become red and inflamed.                   |



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| <b>Intrauterine device (IUD):</b>        | a small device which is inserted into the uterus by a doctor to prevent pregnancy. There are two types of IUD, one which contains copper and another which contains the hormone progesterone. |
| <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>Latissimus dorsi flap:</b>            | a type of breast reconstruction using back muscle transfer; involves moving a flap of muscle, skin and fat from your back to your chest to form a new chest 'mound'.                          |
| <b>Libido:</b>                           | sex drive.  |
| <b>Lobular carcinoma in situ (LCIS):</b> | non-invasive breast cancer that is confined to the lobules of the breast.   |
| <b>Locally advanced breast cancer:</b>   | invasive breast cancer that has spread to areas near the breast, such as the chest wall.  |
| <b>Lumpectomy:</b>                       | see 'Breast conserving surgery'.  |
| <b>Lymphatic vessels:</b>                | tiny vessels next to blood vessels that collect fluid and waste products from the body's tissues.   |
| <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 or breast that can sometimes develop after treatment for breast cancer.   |
| <b>Magnetic resonance imaging (MRI):</b> | a way of producing a picture of the inside of the imaging body using magnetic fields.   |

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| <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, eg 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>Oestrogen:</b>                            | a type of female hormone.  |
| <b>Oncologist:</b>                           | a doctor who specialises in treating cancer.   |
| <b>Osteoporosis:</b>                         | thinning of the bones; can increase the risk of fracture.  |
| <b>Paget's disease of the nipple:</b>        | rare form of invasive breast cancer that affects the nipple and the area around the nipple (the areola).   |
| <b>Partial mastectomy:</b>                   | see 'Breast conserving surgery'.   |
| <b>Pharmaceutical Benefits Scheme (PBS):</b> | a scheme managed by the Australian Government that provides medicines at a subsidised price to Australian residents who hold a current Medicare card and to overseas visitors from countries with which Australia has a Reciprocal Healthcare Agreement. |
| <b>Platelets:</b>                            | blood cells produced by the bone marrow that help the blood to clot.   |

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| <b>Pneumonitis:</b>                    | a side effect of radiotherapy in which the lung becomes inflamed.   |
| <b>Progesterone:</b>                   | a type of female hormone.   |
| <b>Radiotherapy:</b>                   | treatment for cancer in a particular area of the body using X-rays.   |
| <b>Risk factors:</b>                   | things that increase your chance of developing breast cancer.   |
| <b>Sentinel node biopsy:</b>           | removal of the first lymph node(s) in the armpit to which cancer cells are likely to spread from the breast.  |
| <b>Seroma:</b>                         | fluid that collects in or around a scar.  |
| <b>Sexually transmitted infection:</b> | an infection that is passed from person to person via sexual activity.  |
| <b>Surgical margin:</b>                | the area of healthy looking tissue around the breast cancer removed by surgery; if there are no cancer cells in the surgical margin it is said to be 'clear'. |
| <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 called 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.   |

**Transverse rectus abdominis myocutaneous (TRAM) flap:** a type of breast reconstruction using fat, skin and a muscle from the stomach.

**Ultrasound:** a way of producing a picture of the inside of the body using sound waves.

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

**Wide local excision:** see 'Breast conserving surgery'.

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

