



# Understanding Breast Cancer

A guide for people with cancer,  
their families and friends

Cancer  
information

For information & support, call

**13 11 20**



## Understanding Breast Cancer

A guide for people with cancer, their families and friends

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*Understanding Breast Cancer* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

Editor: Jenny Mothoneos. Designer: Julia Gee. Printer: SOS Print + Media Group.

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### Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

### Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



### Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

**Telephone** 02 8063 4100 **Facsimile** 02 8063 4101 **Email** [info@cancer.org.au](mailto:info@cancer.org.au) **Website** [cancer.org.au](http://cancer.org.au)

ABN 91 130 793 725

# About this booklet

This booklet has been prepared to help you understand more about early and locally advanced breast cancer. Many people feel shocked and upset when told they have breast cancer. We hope this booklet will help you, your family and friends understand how breast cancer is diagnosed and treated.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 67 for a question checklist).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 68). We also include information about support services. You may also like to pass this booklet to family and friends for their information.

## How this booklet was developed

This information was developed with help from a range of health professionals and people affected by breast cancer. It is based on international clinical practice guidelines for breast cancer.<sup>1</sup>

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



**Cancer  
Council  
13 11 20**

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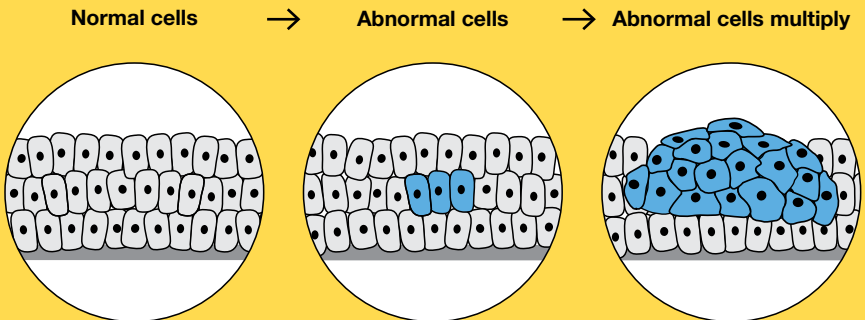
# What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as breast cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

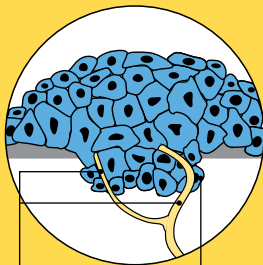
## How cancer starts



cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, breast cancer that has spread to the liver is called metastatic breast cancer, even though the main symptoms may be coming from the liver.

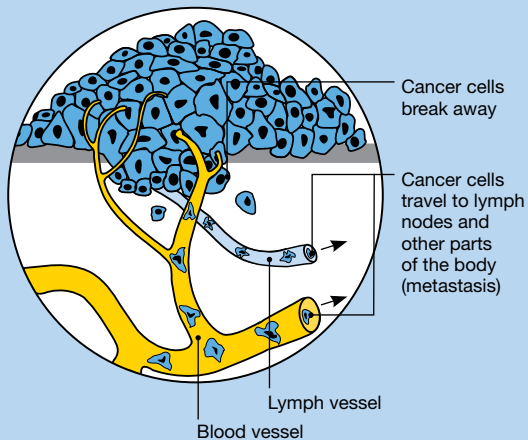
→ **Malignant cancer**



Grows own  
blood vessels  
(angiogenesis)

Invades  
surrounding  
tissue

**How cancer spreads**





# The breasts

Everyone has breast tissue.

Female breasts are mostly made up of:

- **lobes** – each breast is divided into 12–20 sections called lobes
- **lobules** – each lobe contains glands that can produce milk; these milk glands are called lobules or glandular tissue
- **ducts** – the lobes and lobules are connected by fine tubes called ducts; the ducts carry milk to the nipples.

Male breast tissue has ducts but few or no lobes and lobules.

All breasts also contain fibrous and fatty tissue. Some breast tissue extends into the armpit (axilla).

Most younger females have dense breasts, because they have more glandular tissue than fat in them.

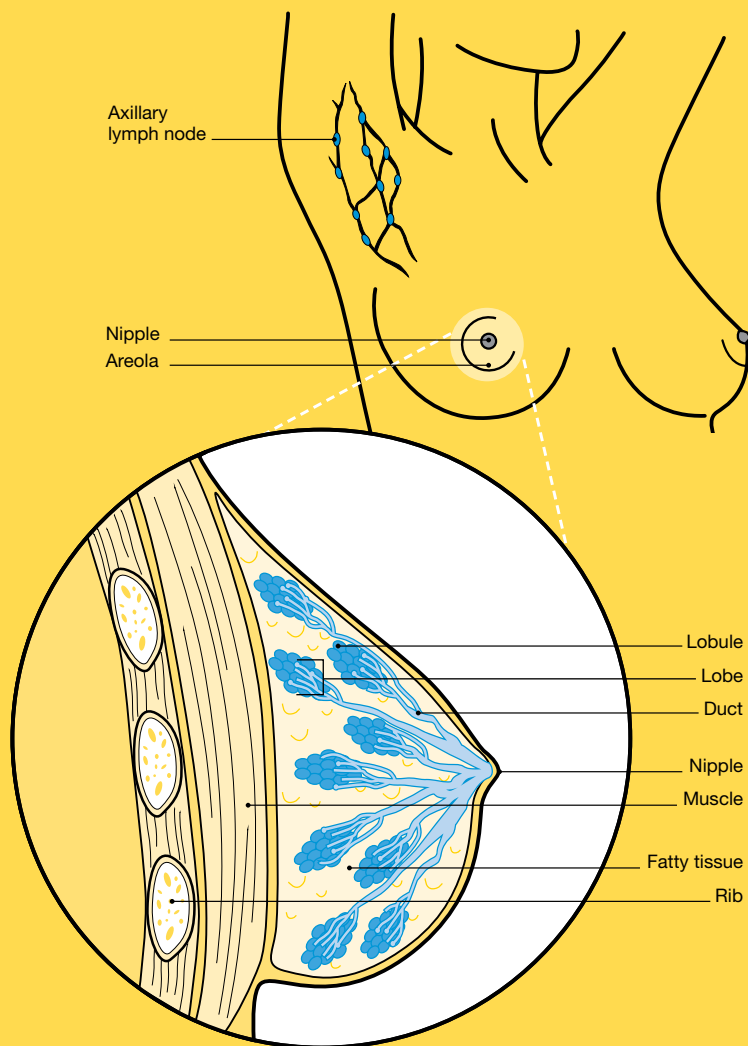
## The lymphatic system

The lymphatic system is an important part of the immune system. It protects the body against disease and infection. It is made up of a network of thin tubes called lymph vessels that are found throughout the body. Lymph vessels connect to groups of small, bean-shaped structures called lymph nodes or glands.

Lymph nodes are found throughout the body, including in the armpits, neck, abdomen and groin, and behind the breastbone (sternum). The lymph nodes in the armpit (axillary lymph nodes) are often the first place cancer cells spread to outside the breast.



## The breasts





## Key questions

### Q: What is breast cancer?

**A:** Breast cancer is the abnormal growth of the cells lining the breast ducts or lobules. These abnormal cells have the potential to spread to other parts of the body. Most breast cancers are found when they are invasive. This means the cancer has spread from the breast ducts or lobules into the surrounding breast tissue. Invasive breast cancer can be early, locally advanced or advanced (metastatic).

### Q: Who gets breast cancer?

**A:** Anyone can develop breast cancer. While it is much more common in women, men can also get breast cancer – see *How common is breast cancer?* on page 13. Breast cancer in males is usually diagnosed and treated in the same way as it is for females. For more information for men diagnosed with breast cancer, visit [breastcancerinmen.canceraustralia.gov.au](http://breastcancerinmen.canceraustralia.gov.au) or download *Men get breast cancer too* from [bcna.org.au/understanding-breast-cancer/breast-cancer-in-men](http://bcna.org.au/understanding-breast-cancer/breast-cancer-in-men).

Transgender and gender-diverse people can also get breast cancer.

A transgender woman who is taking medicines to boost female hormones and lower male hormones may have an increased risk of developing breast cancer.

A transgender man who has a mastectomy is still at risk of developing breast cancer. This is likely due to small amounts of breast tissue that may remain after surgery.

## What are the different types of breast conditions?

### Non-invasive breast conditions

Also called carcinoma in situ. These are a precancerous condition where the cells look like cancer cells, but have not invaded nearby tissues.

#### ductal carcinoma in situ (DCIS)

- abnormal cells in the ducts of the breast
- may develop into invasive breast cancer
- treated in a similar way to invasive breast cancer, but chemotherapy is not used

#### lobular carcinoma in situ (LCIS)

- abnormal cells in the lobules of the breast
- increases the risk of developing cancer in either breast
- needs regular mammograms or other scans

### Invasive breast cancer

There are two main types of invasive breast cancer. They are named after the area of the breast they start in.

#### invasive ductal carcinoma (IDC)

- starts in the ducts
- accounts for about 80% of breast cancers

#### invasive lobular carcinoma (ILC)

- starts in the lobules
- makes up about 10% of breast cancers

There are other less common types of breast cancer. These include inflammatory breast cancer, Paget's disease of the nipple, medullary carcinoma, mucinous carcinoma and papillary carcinoma.

If invasive breast cancer spreads beyond the breast tissue and nearby lymph nodes, it is called advanced or metastatic breast cancer. For more information, call Cancer Council **13 11 20**, or visit **bcna.org.au** or **canceraustralia.gov.au**.

## What are the risk factors?

Many factors can increase your risk of breast cancer. But having risk factors does not mean that you will develop breast cancer. For more information, see [breastcancerriskfactors.gov.au](http://breastcancerriskfactors.gov.au) or [petermac.org/iprevent](http://petermac.org/iprevent).

### Female specific

#### personal factors

older age; dense breast tissue as seen on a mammogram

#### lifestyle factors

being overweight or gaining weight after menopause; drinking alcohol every day; not being physically active

#### medical factors

using menopause hormone therapy (MHT) that contains both oestrogen and progestogen; taking the pill for a long time (small increase); taking diethylstilboestrol (DES) during pregnancy; having radiation therapy to the chest for Hodgkin lymphoma; having atypical ductal hyperplasia or proliferative disease without atypia; previous diagnosis of LCIS or DCIS

#### reproductive factors

starting first period younger than 12; being older than 30 at the birth of first child; not giving birth; not having breastfed; going through menopause after 55

#### family history factors

a family history of breast cancer and/or a particular type of ovarian cancer in first-degree relatives (e.g. mother, sister) on the same side of the family, especially if diagnosed at a young age

## Male specific

|                               |   |
|-------------------------------|---|
| <b>personal factors</b>       | older age   |
| <b>medical factors</b>        | a rare genetic syndrome called Klinefelter syndrome – males with this syndrome have three sex chromosomes (XXY) instead of the usual two (XY)   |
| <b>family history factors</b> | a family history, with several first-degree relatives (male or female) who have had BRCA2 breast cancer; a relative diagnosed with breast cancer under the age of 40; or several relatives diagnosed with ovarian, colon or prostate cancer |

## Inherited breast cancer gene

Most people diagnosed with breast cancer don't have a family history of the disease. However, a small number of people may have inherited a gene fault that increases their breast cancer risk. Everyone inherits a set of genes from each parent, so they have two copies of each gene. Sometimes there is a fault in one copy of a gene. This fault is called a mutation or pathogenic variant.

The two most common gene mutations linked to breast cancer are the BRCA1 and BRCA2 genes. Other types include CDH1, PTEN, STK11, TP53, PALB2, ATM and CHEK2. Women in families with an inherited BRCA1 or BRCA2 change are at increased risk of breast and ovarian cancers. Men in families with an inherited BRCA2 change may be at an increased risk of breast and prostate cancers. To find out if you have inherited a gene mutation, you can visit a family cancer clinic. Talk to your doctor or breast cancer nurse.

## Q: What are the symptoms?

**A:** Some people have no symptoms and the cancer is found during a mammogram (a low-dose x-ray of the breast) through the National Breast Cancer Screening Program.

If you do have symptoms, they could include:

- a lump, lumpiness or thickening, especially if it is in only one breast
- a change in the size or shape of the breast
- a change to the nipple, such as a change in shape, crusting, sores or ulcers, redness, a clear or bloody discharge, or a nipple that turns in (inverted) when it used to stick out
- a change in the skin of the breast, such as dimpling or indentation, a rash, a scaly appearance, unusual redness or other colour changes
- swelling or discomfort in the armpit
- ongoing, unusual pain that is not related to your normal monthly menstrual cycle, remains after your period and occurs in one breast only.

Most breast changes aren't caused by cancer. If you have symptoms, see your doctor without delay.



For an overview of what to expect during all stages of your cancer care, visit [cancerpathways.org.au/optimal-care-pathways/breast-cancer](https://cancerpathways.org.au/optimal-care-pathways/breast-cancer). This is a short guide to what is recommended, from diagnosis to treatment and beyond.

## Q: How common is breast cancer?

**A:** Breast cancer is the most common cancer in Australian women (apart from common skin cancers). About 17,000 women are diagnosed with breast cancer each year, and one in eight will be diagnosed by the age of 85.<sup>2</sup>

Although breast cancer can occur at any age, it is more common in women over 40. Almost 70% of breast cancers are diagnosed in women aged 40–69, and about 25% are diagnosed in women aged 70 and over. In rare cases, women are diagnosed during pregnancy.

About 150 men are diagnosed with breast cancer in Australia each year, and most of these men are over 50.

## Q: Which health professionals will I see?

**A:** You may be recalled for further tests after a screening mammogram or your general practitioner (GP) will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist breast service for further tests.

If breast cancer is diagnosed, you will first see a breast surgeon, or in some cases a medical oncologist, who will consider your treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care (see next two pages). You may not need to see all members of the MDT.

## Health professionals you may see

|  |   |
|--|---|
| <b>GP</b>                                | assists you with treatment decisions and works in partnership with your specialists in providing ongoing care   |
| <b>breast physician*</b>                 | diagnoses breast cancer and coordinates treatment for breast cancer in some clinics   |
| <b>breast surgeon*</b>                   | assesses breast changes; performs breast surgery and biopsies; some breast surgeons also perform breast reconstruction and plastic surgery procedures (known as an oncoplastic breast surgeon*) |
| <b>reconstructive (plastic) surgeon*</b> | performs breast reconstruction after mastectomy   |
| <b>radiation oncologist*</b>             | treats cancer by prescribing and overseeing a course of radiation therapy   |
| <b>medical oncologist*</b>               | treats cancer with drug therapies such as chemotherapy, hormone therapy, targeted therapy and immunotherapy (systemic treatment)  |
| <b>radiologist*</b>                      | analyses x-rays, mammograms, ultrasounds and other scans  |
| <b>radiographer</b>                      | performs x-rays, mammograms and other scans   |
| <b>breast care nurse</b>                 | provides breast cancer care; also provides information and referrals during and after treatment   |
| <b>nurse</b>                             | administers drugs and provides care, information and support throughout treatment   |



|  |   |
|--|---|
| <b>anaesthetist*</b>                           | administers anaesthetic before surgery and monitors you during the operation  |
| <b>radiation therapist</b>                     | plans and delivers radiation therapy  |
| <b>pathologist*</b>                            | examines cells and tissue samples that are removed from the breast to work out the type and extent of the cancer                            |
| <b>physiotherapist, occupational therapist</b> | assist with physical and practical problems, including restoring movement and mobility after treatment, and recommending aids and equipment |
| <b>exercise physiologist</b>                   | prescribes exercise to help people with medical conditions improve their overall health, fitness, strength and energy levels                |
| <b>lymphoedema practitioner</b>                | educates people about lymphoedema prevention and management, and provides treatment if lymphoedema occurs; often a physiotherapist          |
| <b>social worker</b>                           | links you to support services and helps you with emotional, practical or financial issues   |
| <b>dietitian</b>                               | recommends an eating plan to follow during treatment and recovery   |
| <b>psychiatrist*, psychologist, counsellor</b> | help you manage your emotional response to diagnosis and treatment  |
| <b>genetic counsellor</b>                      | provides advice for people with a strong family history of breast cancer or with a genetic condition linked to breast cancer                |

\* *Specialist doctor*



# Diagnosis

If you have any breast changes or a mammogram shows something suspicious, your GP will ask about your medical history, including your family history of breast cancer. They will also perform a physical examination, checking both your breasts as well as the lymph nodes under your arms and above your collarbone.

To find out if the changes have been caused by cancer, your GP may arrange some tests, such as a mammogram, ultrasound, breast MRI and possibly a biopsy (see pages 18–19). They may refer you to a specialist for these and other tests.

## Mammogram

A mammogram is a low-dose x-ray of the breast tissue. It can check a lump or other change found by the physical examination. It can also show changes that can't be felt during a physical examination.

Your breast is placed between two x-ray plates. The plates press together firmly for a few moments to spread the breast tissue out so that clear pictures can be taken. You will feel some pressure, which can be uncomfortable. Both breasts will be checked. If you have breast implants, let staff know before you have the mammogram.

**Tomosynthesis** – Also known as three-dimensional mammography or digital breast tomosynthesis (DBT), tomosynthesis takes x-rays of the breast from many angles and uses a computer to combine them into a three-dimensional image. This form of breast imaging may be more accurate in some situations such as finding small breast cancers, particularly in dense breast tissue.

## Ultrasound

An ultrasound uses soundwaves to create a picture of breast tissue. It will often be done if a mammogram picks up breast changes, or if you or your GP can feel a lump.

The person performing the ultrasound will spread a gel on your breast, and then move a small device called a transducer over the area and the lymph nodes in your armpit. This sends out soundwaves that echo when they meet something dense, like an organ or a tumour. A computer creates a picture from these echoes. The scan is painless and takes about 15–20 minutes.

## Breast MRI

A magnetic resonance imaging (MRI) scan uses a large magnet and radio waves to create pictures of the breast tissue on a computer. Breast MRI is mainly used for people who are at high risk of breast cancer or who have very dense breast tissue or implants. It may also be used if imaging tests results are not clear and to help plan breast surgery.

Before a breast MRI, you will have an injection of a contrast dye to make any cancerous breast tissue easier to see. You will lie face down on a table with cushioned openings for your breasts. The table slides into the machine, which is large and shaped like a cylinder. The scan may take 30–40 minutes. It is painless but can be noisy. You will usually be offered earplugs or headphones to listen to music. Some people feel anxious or claustrophobic in the cylinder. If you think you may become distressed, mention it beforehand to your medical team. You may be given a mild sedative to help you relax.

## Biopsy

If breast cancer is suspected, a small sample of cells or tissue is taken from the lump or area of concern. A specialist doctor called a pathologist examines the sample and checks it for cancer cells under a microscope.

There are different ways of taking a biopsy and you may need more than one type. The biopsy may be done in a specialist's rooms, at a radiology practice, in hospital or at a breast clinic. Bruising to your breast is common after any type of biopsy.

**Core biopsy** – The piece of tissue (a core) is removed with a needle. Local anaesthetic is used to numb the area, and a mammogram, ultrasound or MRI scan is used to guide the needle into place.

**Vacuum-assisted core biopsy** – A needle attached to a suction-type instrument is inserted into a small cut in the breast. A larger amount of tissue is removed with a vacuum biopsy, making it more accurate in some situations. The needle is usually guided into place with a mammogram, ultrasound or MRI. This biopsy is done under a local anaesthetic, but you may feel some discomfort.

**Fine needle aspiration (FNA)** – A thin needle is inserted into an abnormal lymph node or other tissue, often with an ultrasound to help guide the needle into place. A local anaesthetic may be used to numb the area where the needle is inserted.

**Surgical biopsy** – If a needle biopsy is not possible, or if the biopsy result doesn't provide a clear diagnosis, you may have a surgical biopsy

to remove all or part of a lump found on a screening mammogram or other imaging technique. A wire or other device is inserted to act as a guide during the surgery, and then the tissue is removed under general anaesthetic. This is usually done as day surgery.

## Further tests

If the tests described on pages 16–19 show that you have breast cancer, you may have further tests to check whether the cancer has spread to other parts of your body.

**Blood tests** – Samples may be taken to check your general health, and to look at your bone marrow and liver function for signs of cancer.

**Bone scan** – A bone scan may be done to see if the breast cancer has spread to your bones. A small amount of radioactive material is injected into a vein, usually in your arm. This material is attracted to areas of bone where there is cancer. After a few hours, the bones are viewed with a scanning machine, which sends pictures to a computer. A bone scan is painless and the radioactive material is not harmful. You should drink plenty of fluids on the day of the test and the day after.

**CT scan** – A CT (computerised tomography) scan uses x-ray beams to take pictures of the inside of the body. It is used to look for signs that the cancer has spread. Before the scan, you will be given an injection of dye into a vein in your arm. This dye, known as contrast, makes the pictures clearer. For the scan, you will lie flat on a table while the CT scanner, which is large and shaped like a doughnut, takes pictures. This painless test takes 30–40 minutes.



Before having scans, tell the doctor if you have any allergies or have had a reaction to contrast during previous scans. You should also let them know if you are diabetic, have kidney disease or are pregnant.

## Staging breast cancer

The tests described on pages 16–19 show whether the breast cancer has spread to other parts of the body. This is called staging. It helps you and your health care team decide which treatment option is best for you.

The staging system most commonly used for breast cancer is the TNM system. In this system, letters and numbers are used to describe how big the tumour is (T), whether the cancer has spread to nearby lymph nodes (N), and whether the cancer has spread to the bones or other organs, i.e. whether it has metastasised (M).

In 2018, the staging system was updated to include details about the tumour such as oestrogen and progesterone receptor status, HER2 status (see pages 22–23) and grade of the cancer. Oncotype Dx score may also be considered.

Early breast cancer is stage 1 or 2. The cancer is contained in the breast and may or may not have spread to lymph nodes in the armpit. Locally advanced breast cancer is stage 3. It means the cancer is larger than 5 cm, has spread to tissues around the breast such as the skin, muscle or ribs, or has spread to a large number of lymph nodes. The staging system for breast cancer is complex so ask your doctor to explain how it applies to you.

## Grading breast cancer

The grade describes how active the cancer cells are and how fast the cancer is likely to be growing.

### grade 1 (low grade)

Cancer cells look a little different from normal cells. They are usually slow growing.

### grade 2 (intermediate grade)

Cancer cells do not look like normal cells. They are growing faster than grade 1 cancer cells.

### grade 3 (high grade)

Cancer cells look very different from normal cells. They are usually fast-growing.

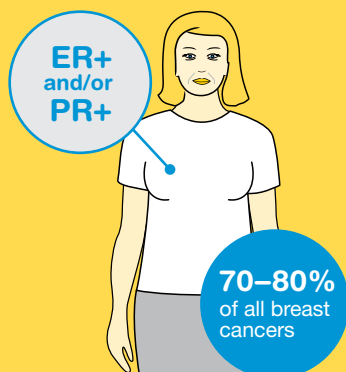
## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis with your doctor, but it is not possible for anyone to predict the exact course of the disease. To work out your prognosis, your doctor will consider the stage and grade of the cancer, as well as features such as the cancer's hormone receptor and HER2 status (see pages 22–23).

Survival rates for women with breast cancer have increased significantly over time due to better tests and scans, earlier detection and improved treatment methods. Doctors commonly use five-year survival rates as a way to discuss prognosis. This is because research studies often follow people for five years – it does not mean you will survive for only five years. Compared with other cancers, breast cancer has one of the highest five-year survival rates if diagnosed early.

## Tests on breast tissue

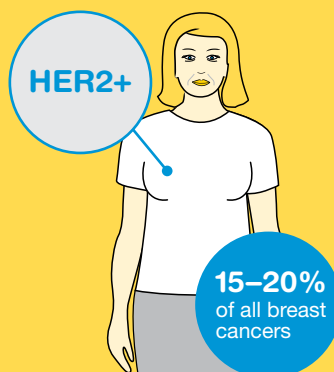
If tests on the biopsy sample show that it is breast cancer, extra tests will be done to work out the features shown here and help plan treatment. The results will be included in the pathology report.



### Hormone receptor status

Hormones are chemicals in the body that transfer information. The hormones oestrogen (ER) and progesterone (PR) are produced naturally in the body.

A hormone receptor is a molecule in a cell. Most breast cancers have cells that receive signals from oestrogen or progesterone receptors, so these hormones may help the cancers grow. These cancers are called hormone receptor positive (ER+ and/or PR+) or hormone-sensitive cancers. They are likely to respond to hormone therapy that blocks oestrogen. Breast cancers without receptor cells are called hormone receptor negative (ER– and PR–) cancers and hormone therapy is generally not used.

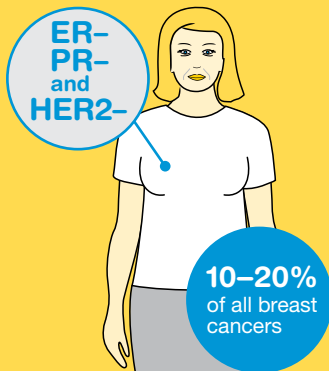


### HER2 status

HER2 (human epidermal growth factor receptor 2) is a protein that is found on the surface of all cells and controls how cells grow and divide.

Tumours that have high levels of these receptors are called HER2 positive (HER2+). Tumours with low levels are called HER2 negative (HER2–). HER2+ cancers tend to be more aggressive than HER2– cancers. It is often recommended that people with HER2+ breast cancer have chemotherapy and targeted therapy before surgery. This is known as neoadjuvant chemotherapy.





### Triple negative breast cancer

Some breast cancers are hormone receptor negative (ER- and PR-) and HER2 negative (HER2-). These are called triple negative breast cancers.

Triple negative cancers do not respond to hormone therapy or to targeted therapy drugs used for HER2 positive cancers.

The current treatment options for people with triple negative breast cancer include chemotherapy before or after surgery and some other types of targeted therapy drugs.

### Gene activity tests

Also known as genomic assays or molecular assays, these tests look at the patterns of certain genes within the cancer cells. These patterns may help predict the risk of the cancer coming back, and this information helps guide treatment. For example, if there is a high risk of the cancer coming back, you may need chemotherapy.

Many tests have been developed and research around the use and effectiveness of gene activity tests is ongoing. The genomic assays that are currently available are only for breast cancer that is ER+ and HER2-. They include the Oncotype DX, EndoPredict, Prosigna and MammaPrint assays. These tests are not recommended for everyone, and can cost up to several thousand dollars. At the time of printing they are not covered by Medicare or private health funds.

For more information about these tests, talk with your medical oncologist. Keep in mind that the standard pathology tests that are done on all breast cancers often provide enough information to guide treatment plans.



## Key points about diagnosing breast cancer

**Main tests** Tests to diagnose breast cancer include:

- physical examination
- mammogram (breast x-ray)
- ultrasound
- breast MRI
- biopsy (taking a tissue sample).

**Other tests** Other tests can give more information about the cancer to help guide treatment. These tests may include:

- blood tests
- bone scan
- CT scan.

**Key information about the cancer**

- The stage shows how far the cancer has spread. Early breast cancer is stage 1 or 2. Locally advanced breast cancer is stage 3. Cancer that has spread to other parts of the body is stage 4.
- The grade describes how similar the cancer cells look to normal cells and indicates how fast the cancer is likely to grow.
- Hormone receptor status (ER+/- and/or PR+/-) shows whether the cancer may respond to hormone-blocking therapy.
- HER2 status (HER2+/-) shows whether the cancer may respond to targeted therapy.
- Gene activity tests look at gene patterns within cancer cells. These can help work out if chemotherapy would be effective.



# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

**Know your options** – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 13) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

**Record the details** – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes can help or you might like to ask if you can record the discussion. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

**Ask questions** – If you are confused or want to check anything, it is important to ask questions. Try to prepare a list before appointments (see page 67 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or breast care nurse.

**Consider a second opinion** – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

**It's your decision** – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

➤ See our *Cancer Care and Your Rights* booklet.

### Should I join a clinical trial?

Your doctor or nurse may suggest that you take part in a clinical trial. Clinical trials are run to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments

and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, breast care nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

➤ See our *Understanding Clinical Trials and Research* booklet.



# Treatment

Treatment for early or locally advanced breast cancer varies from person to person. The most suitable treatment for you will depend on your test results, where the cancer is in the breast, the cancer's stage and grade (see pages 20–21), and whether the cancer is hormone receptor and/or HER2 positive or triple negative (see pages 22–23). Your doctor will also consider your age and general health, and what you want.

Research shows that exercising before, during and after treatment can help people diagnosed with breast cancer – see page 58.

## Treatment options by type of breast cancer

Usually more than one treatment is used, and treatments may be given in different orders and combinations.

**Early breast cancer** – The main options are either breast-conserving surgery (see page 29) and radiation therapy or a mastectomy (see page 30). Often surgery is followed by a combination of chemotherapy, hormone therapy or targeted therapy depending on the features of the cancer. This is known as adjuvant therapy and it reduces the risk of the cancer coming back.

**Locally advanced breast cancer** – Often treated with chemotherapy before surgery. This is known as neoadjuvant chemotherapy. If the cancer is HER positive, you'll also have targeted therapy. It's common to be offered a mastectomy. If you have responded well to chemotherapy and the cancer has shrunk, you may be offered breast-conserving surgery. Surgery may be followed by radiation therapy, hormone therapy and/or targeted therapy depending on the features of the cancer.

## Surgery

For most people, treatment for early or locally advanced breast cancer will include surgery. The type of surgery recommended for you will depend on the type and stage of the cancer, where it is in the breast, and the size of your breast as well as your personal preferences.

In most cases, you may have one or more lymph nodes removed from the armpit, known as axillary surgery (see pages 32–33). Some people also have surgery to make a new breast shape (breast reconstruction, see page 31) during the operation.

Sometimes chemotherapy is given before surgery to shrink the tumour. This is known as neoadjuvant chemotherapy. It may be recommended for HER2 positive, triple negative or locally advanced breast cancer. Often surgery is followed by other treatments.

### Which surgery should I have?

The two types of surgery are breast-conserving surgery and mastectomy. Depending on your situation, you may be offered a choice between the two. Breast-conserving surgery is not usually suitable for males.

Research has shown that for early breast cancer having breast-conserving surgery

followed by radiation therapy (pages 40–43) is as effective as a mastectomy. The chance of the cancer coming back in another part of the body is the same for both types of surgery.

The operations have different benefits, risks and side effects. Talk to your doctor about the best option for you.

## Breast-conserving surgery

Surgery to remove part of the breast is called breast-conserving surgery. It is also called a lumpectomy or wide local excision.

The surgeon removes the tumour and some of the healthy tissue around it, so you can keep as much of your breast as possible. This will leave a scar, and may change the size and shape of the breast and the position of the nipple.

The removed tissue is looked at under a microscope by a pathologist to see if there is an area of healthy cells around the cancer – known as a clear margin. The pathologist's report will include information about:

- the size and grade of the cancer (see page 21)
- whether there are cancer cells near the edge (margin) of the removed breast tissue
- whether the cells are hormone receptor positive and/or HER2 positive or triple negative (see pages 22–23), unless this has already been reported on the core biopsy results
- whether the cancer has spread to any lymph nodes (see pages 32–33).

The pathology report will help guide further treatment. If cancer cells are close to the edge of the removed tissue (an involved or positive margin), there is a greater chance of the cancer returning. You may need more tissue removed (re-excision or wider excision), or your doctor may recommend a mastectomy (see next page).

After breast-conserving surgery, you will generally be recommended to have radiation therapy to destroy any cancer cells that may be left in the breast or armpit, and to help keep the cancer from coming back. In some cases, radiation therapy is not required.

## Mastectomy

Surgery to remove the whole breast is called a mastectomy. You may be recommended to have a mastectomy if:

- there is cancer in more than one area of the breast
- the cancer is large compared to the size of the breast
- you have had radiation therapy to the same breast before and so cannot have it again
- it's difficult to get a clear margin around the tumour
- you find out that you have the BRCA1 or BRCA2 gene mutation at the time of your breast cancer diagnosis.

You may decide that you would prefer a mastectomy rather than breast-conserving surgery. You can choose a mastectomy even for a very small cancer. After a mastectomy, it's not common to have radiation therapy but it may be offered in some situations.

Usually the nipple is removed with the breast. In some cases, the surgeon may be able to perform a skin-sparing or nipple-sparing mastectomy. This means that more of the normal skin – with or without the nipple – is kept. If you have decided to have a reconstruction (see page opposite), the skin- or nipple-sparing mastectomy is usually done at the same time.

If you don't have an immediate reconstruction, you can wear a soft breast form and a specially designed bra while your surgical wound heals. Breast Cancer Network Australia provides a free bra and temporary soft form. To order a kit, speak to your breast care nurse. After the wound has healed and the area is comfortable, you can be fitted for a permanent breast prosthesis (see page 55).



## What about the other breast?

If you need a mastectomy because of cancer in one breast, you may think it's safer to have the other breast removed as well.

For most people, the risk of getting cancer in the other breast is low. If you have the BRCA1 or BRCA2 gene mutation, the

mutation increases the risk of developing another breast cancer and your surgeon may recommend a double mastectomy. Whether to have a double mastectomy is a complex decision and it's best to talk with your treatment team about the risks and benefits.

## Breast reconstruction

A breast reconstruction is a type of surgery to make a new breast shape. Sometimes the reconstructed breast is called a breast mound. The surgery may be done using a silicone implant, tissue from another part of your body, or a combination of both.

Sometimes you can have a breast reconstruction at the same time as a mastectomy (immediate reconstruction). You may prefer to wait for several months or years before having a reconstruction (delayed reconstruction). If you're not having an immediate reconstruction but might consider it in the future, discuss this with your surgeon before surgery, as it will help them to plan the mastectomy. Sometimes you may have to travel to a different hospital to have a reconstruction.

If you decide not to have a reconstruction at all, you can choose to wear a breast prosthesis (see page 55) or live with the changes to your body.

➤ See our *Breast Prostheses and Reconstruction* booklet.

## Removing lymph nodes

The lymph nodes in the armpit (axillary lymph nodes) are often the first place breast cancer cells spread to outside the breast. Removing some or all of the lymph nodes helps check for spread. The operation to remove lymph nodes is called axillary surgery. It is usually done during breast surgery but may be done in a separate operation. There are two main types of axillary surgery.

**Sentinel node biopsy** – When breast cancer first spreads beyond the breast, it is likely to go to particular lymph nodes in the armpit or sometimes near the breastbone (sternum). These are known as the sentinel nodes. A sentinel node biopsy finds and removes them so they can be tested for cancer cells (see opposite page).

If there are no cancer cells in the sentinel nodes, no other lymph nodes will be removed. If there is more than a small amount of disease in the sentinel nodes, you may have axillary dissection or radiation therapy.

**Axillary dissection (clearance)** – If cancer is found in the lymph nodes, then most or all of the axillary lymph nodes (usually 10–20) will be removed to minimise the risk of the cancer coming back (recurrence) in the armpit. The results will also guide what other treatments your doctor recommends.

**Side effects** – These may include arm or shoulder stiffness; numbness in the arm, shoulder, armpit and parts of the chest; seroma (fluid collecting near the surgical scar); lymphoedema (see pages 51–52); and cording (see page 53). Side effects are usually worse after axillary dissection because more lymph nodes are removed.

## Finding the sentinel nodes

To work out which lymph nodes are the sentinel nodes, you may have a combination of the following:

### 1 Lymphatic mapping

This is done either the day before or the day of the biopsy. A small amount of a radioactive material is injected into the skin over the tumour. A scan is taken to show which nodes the substance flows to first. These are likely to be the sentinel nodes.

### 2 Blue dye injection (not always used)

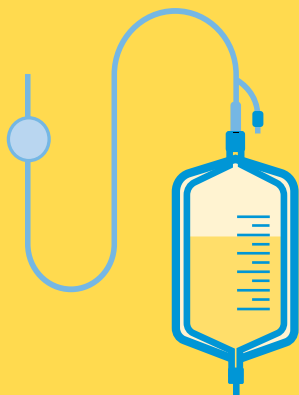
For the biopsy, you will have a general anaesthetic. If dye is being used, it will be injected into the breast. The dye moves into the lymphatic vessels and stains the sentinel nodes blue first. Because of the dye, you will have blue-green urine and bowel movements the next day, and may have a blue patch on the breast for some weeks or months. You may also notice that your skin looks slightly grey, but this will fade once the dye washes out in your urine.

### 3 Hand-held probe

As well as looking at where the blue dye travels to first, the surgeon uses a small hand-held device called a probe during the operation to detect the radioactive substance that was injected during the lymphatic mapping. This helps to confirm that the correct sentinel nodes have been identified and the surgeon can then remove them for testing.

## What to expect after surgery

If you have any questions about your recovery, ask the doctors and nurses caring for you. Many people are referred to a breast care nurse for information and support. How long you stay in hospital will depend on the type of surgery you have and how well you recover. If you have breast-conserving surgery, you can usually go home the same day. If you have a mastectomy, you usually need to stay in hospital overnight. If you have a reconstruction after mastectomy, you will usually need to stay in hospital for several days.



### Dressings and tubes

A dressing will cover the wound to keep it clean. This will usually be removed after about a week. You may have one or more drainage tubes in place to drain fluid from the surgical site into a bag. These may remain in place for up to 10 days, depending on the type of surgery.

Some people are discharged from hospital with drains still in place, but this will depend on your situation and your doctor's advice. Nurses will teach you how to look after the drains and wound at home (see box opposite), or a community nurse or your GP may help you care for the drains.

### Moving your legs

While you are in bed, you will be advised to move your legs to help prevent blood clots, and to walk around when you are able. You may have to wear elastic (compression) stockings or use other devices to help prevent blood clots in the deep veins of your legs (deep vein thrombosis or DVT). Your doctor might also prescribe medicine that lowers the risk of clots.



### Recovery time

The time it takes to recover from breast surgery will depend on the type of surgery you've had. You may feel better after a few days, or it may take a few weeks or longer if you have a mastectomy with a reconstruction.



## Pain

Pain after breast-conserving surgery is not common. If you've had an axillary clearance dissection or mastectomy, you are more likely to have pain. You will be given pain relief through a drip (intravenous or IV), an injection or as tablets, and you will be given pain medicine when you go home.

## Caring for your wound

After surgery, the wound will need extra care. If you have any questions, ask your health care team.

|                            |  |
|----------------------------|--|
| <b>bathe carefully</b>     | It's okay for the dressing to get wet in the shower. Afterwards gently pat the wound dry with a soft, clean towel. It's best not to have a bath.   |
| <b>avoid cuts</b>          | Talk to your treatment team if you want to shave or wax your armpits. They may advise you to wait for a short time.  |
| <b>follow-up</b>           | A wound infection can happen at any time. Report any redness, pain, heat, fever, swelling or wound discharge to your surgeon or breast care nurse. You may need antibiotics to manage the infection. |
| <b>moisturise</b>          | Gently massage the area with moisturiser once the wound has completely healed.   |
| <b>don't use deodorant</b> | If the wound is under your arm, avoid using deodorant until it has completely healed.  |

## What your breast looks like after surgery

Any bruising and swelling at the surgery area will usually improve after 2–3 weeks.

The position and size of the scar will depend on how much tissue is removed. If you have breast-conserving surgery, the scar is usually small and near where the cancer was or nearby. If you have a mastectomy, the scar will be across the skin of the chest. If you have surgery to the lymph nodes, the scar will be in the armpit. At first the scar will be firm, slightly raised and red. Over the next few months it will flatten and fade.

### Breast appearance after surgery

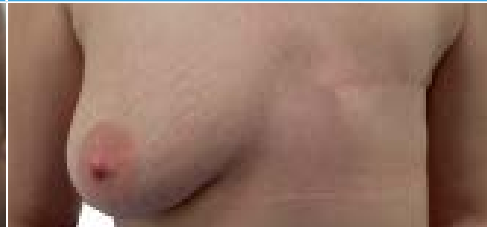
How your breast looks after surgery will depend on the type of surgery and how much tissue is removed. A range of individual factors such as your body shape and the size of your breasts will also affect appearance.

#### Breast-conserving surgery



Two years after surgery to left breast. The surgery was followed by radiation therapy.

#### Mastectomy



Left breast removed, with no reconstruction.

Changes to how your breast looks can affect how you feel about yourself (self-image and self-esteem, see page 56). You may feel a sense of loss if you've had part of your breast removed or a mastectomy and find that your sense of identity has been affected.

Talking to someone who has had breast surgery might be helpful. Cancer Connect may be able to link you to someone who has had a similar experience to you. Speaking with a counsellor or psychologist for emotional support and coping strategies may also help. Call Cancer Council 13 11 20 for details.

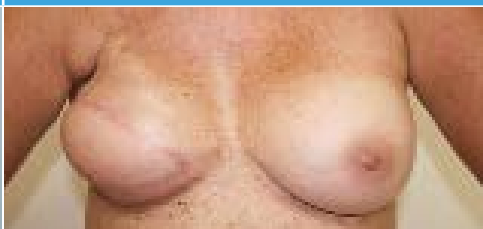
Ask your surgeon to show you some examples to help you choose the surgery that is right for you.

#### Nipple-sparing mastectomy with implant reconstruction



Right breast removed with a nipple-sparing mastectomy, followed by reconstruction using an implant. If it is not possible to keep the nipple, there is the option of having a nipple reconstruction later.

#### Mastectomy with a flap reconstruction



Right breast removed, followed by reconstruction using tissue from the back. A reconstruction can also be done with tissue from the abdomen, buttock or thigh. You can choose to have a nipple reconstruction later.

## Side effects of surgery

Some common side effects are discussed below. Talk to your health care team about ways to deal with the side effects of surgery. For more information, see the *Managing side effects* chapter (pages 51–57).

**Fatigue** – Cancer treatment and the emotional impact of the diagnosis can be tiring. Fatigue is common and may continue for a few weeks or months. Research shows that exercise during and after cancer treatment can help improve fatigue. YWCA offers a free exercise program for people who have had breast cancer surgery – call 1800 305 150 or visit [ywcaencore.org.au](http://ywcaencore.org.au).

- ▶ See our *Fatigue and Cancer* fact sheet or *Exercise for People Living with Cancer* booklet.

**Shoulder stiffness** – This is common after surgery. Gentle arm and shoulder exercises can help prevent or manage shoulder stiffness. Ask your treatment team when you can start exercising your arm. A physiotherapist can show you arm and shoulder exercises to prevent or treat shoulder stiffness. These will help move any fluid that has collected near the surgical scar (seroma), prevent shoulder stiffness and help to prevent lymphoedema (see opposite page).

- ▶ See our *Arm & shoulder exercises after surgery* poster on your local Cancer Council website (see back cover for addresses).

**Numbness and tingling** – Surgery can cause bruising or injury to nerves, which may cause numbness and tingling in the armpit, upper arm or chest area. This often improves within a few weeks, but it may take longer. Sometimes it may not go away completely. A physiotherapist or occupational therapist can suggest exercises that may help.



**Seroma** – Fluid may collect in or around the surgical scar and cause a balloon-like swelling. This is most common after a mastectomy. A seroma can also develop in the armpit after axillary dissection. The build-up of fluid is not harmful, but can be uncomfortable. A breast care nurse, your specialist or GP, or a radiologist can drain the fluid using a fine needle and a syringe. This procedure isn't painful, but it may need to be repeated over a few appointments.

**Change in breast, nipple or arm sensation** – This is usually temporary, but it may be permanent for some people.

**Lymphoedema** – Fluid building-up in the tissue of the arm or breast may cause swelling after lymph node surgery. See pages 51–52 for ways to manage lymphoedema.

👤 My experience is that lymphoedema is very manageable if you notice the signs early. Although I'd had lots of lymphoedema education I actually missed the signs and didn't realise I had it until I developed cellulitis. 👤 *Suzanne*

**Cording** – Also known as axillary web syndrome, cording is caused by hardened lymph vessels. It feels like a tight cord running from your armpit down the inner arm, sometimes to the palm of your hand. Some people can see and feel raised cord-like structures across their arm, and these cords can limit movement. See page 53 for ways to manage cording.

## Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation to kill cancer cells or damage them so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams.

Radiation therapy is recommended:

- after breast-conserving surgery
- after a mastectomy – if pathology results suggest the risk of recurrence is high or if the cancer has spread to the lymph nodes you may have radiation to the chest wall and lymph nodes above the collarbone
- if the sentinel node is affected – you may have radiation to the armpit instead of axillary dissection.

You will usually start radiation therapy within eight weeks of surgery. If you're having chemotherapy after surgery, radiation therapy will begin about three to four weeks after chemotherapy has finished. In some circumstances, radiotherapy may be offered after neoadjuvant chemotherapy and before surgery.

## Planning radiation therapy

Treatment is carefully planned to have the greatest effect on the cancer cells and to limit damage to the surrounding healthy tissues. Planning involves several steps, which may occur over a few visits.

You will have a planning session at the radiation therapy centre. During this appointment, you will have a CT scan to pinpoint the area to be treated, and marks will be put on your skin so the radiation

therapists treat the same area each time. These marks are small dots (tattoos), and they may be temporary or permanent. Talk to your radiation therapists if you are worried about these tattoos.

## Having radiation therapy

You will probably have radiation therapy daily from Monday to Friday for 3–6 weeks. Usually you can have radiation therapy as an outpatient and go to the treatment centre each day.

Each radiation therapy session will be in a treatment room. Although you will get radiation for only 1–5 minutes, setting up the machine can take 10–30 minutes. You will lie on a table under the machine. The radiation therapist will leave the room and then switch on the machine, but you can talk to them through an intercom.

Radiation therapy is not painful, but you will need to lie still while it is given. If the cancer is located on the left side, the radiation therapist may ask you to take a deep breath for 20–30 seconds during the treatment. This helps to inflate the lungs and rib cage, to move them away from the radiation field and minimise damage to the heart. This technique is known as deep inspiration breath hold.



If you live in a regional or rural area, you may need to travel for radiation therapy. Patient assisted travel schemes (PATS) may help with the cost of travel and accommodation. For details, talk to the hospital social worker or call Cancer Council **13 11 20**.

## Side effects of radiation therapy

Radiation therapy may cause the following side effects:

**Tiredness** – You may start to feel tired or lack energy for day-to-day activities 1–2 weeks after radiation therapy begins. Fatigue usually eases a few weeks after treatment finishes.

**Red and dry skin** – The skin at the treatment area may become dry and itchy. Your skin may look red or sunburnt after a few weeks of treatment. It usually returns to normal 4–6 weeks after treatment ends. The nurses will show you how to care for your skin. Sorbolene cream applied twice a day can be helpful.

**Skin problems** – Less commonly, your skin may peel or become very irritated. The treatment team will closely monitor your skin, and you may need dressings or creams to help the area heal.

**Aches** – You may feel minor aches or shooting pains that last for a few moments during treatment.

**Swelling** – Some people develop fluid in the breast (oedema) that can last for up to 12 months or, in some cases, longer. Radiation therapy to the armpit may increase the chance of developing lymphoedema in the arm (see pages 51–52). Talk to your radiation oncologist or radiation oncology nurse about any changes you experience.

**Hair loss** – Radiation therapy to the breast may cause you to lose hair from the treated armpit but doesn't cause you to lose head hair.

Other side effects can develop months or years after radiation therapy. These are called late effects. Part of the lung behind the treatment area may become inflamed, causing a dry cough or shortness of breath. There is a slight risk of radiation therapy causing heart problems, but this usually happens only if you have treatment to your left breast or you smoke. In rare cases, radiation therapy may cause a second cancer.

➤ See our *Understanding Radiation Therapy* booklet.

## Chemotherapy

Chemotherapy uses drugs to kill cancer cells or slow their growth. It may be called systemic treatment because the drugs circulate throughout the bloodstream. Chemotherapy may be used at different times:

- before surgery to shrink or control the cancer (neoadjuvant chemotherapy)
- if the cancer is not sensitive to hormone therapy and/or is HER2 positive (see page 22)
- after surgery to reduce the risk of the cancer returning (adjuvant).

## Having chemotherapy

Different types of chemotherapy drugs are used to treat early and locally advanced breast cancer. The choice of drug will depend on the type of cancer, how far it has spread and what other treatments you are having. Usually you will have a combination. Common drugs include doxorubicin, cyclophosphamide, fluorouracil, docetaxel and paclitaxel. Your health professionals may also refer to the drugs by their brand names. Your medical oncologist will talk to you about the most suitable types of chemotherapy, as well as their risks and side effects.

Chemotherapy is given through a vein (intravenously). You will usually be treated as an outpatient, but occasionally you may have to stay in hospital overnight.

Most people will have chemotherapy for 3–6 months. Usually drugs are given once every three weeks, although some are given on a faster schedule (e.g. once every two weeks or once a week).

### Side effects of chemotherapy

Chemotherapy damages cells as they divide. This makes the drugs effective against cancer cells, which divide rapidly. However, some normal cells – such as hair follicles, blood cells and cells inside the mouth or bowel – also divide rapidly. Side effects happen when chemotherapy damages these normal cells. Unlike cancer cells, normal cells can recover, so most side effects are temporary.

**Hair loss** – You may lose the hair on your head, and your eyebrows, eye lashes, underarm hair, pubic hair and beards can also be affected. It's common for hair loss to begin two to three weeks after starting treatment. You'll probably lose some hair gradually at first, and then more rapidly over the next few weeks.

Some treatment centres provide cold caps, which may prevent total head hair loss, but this depends on the drugs used. For information about cold caps, speak to your treatment team.

Generally, hair begins to grow back after treatment ends. See page 55 for information about wigs. The Look Good Feel Better program helps people manage the appearance-related effects of cancer treatment.

This may include sessions on make-up, skin care and hair styling to boost self-esteem during treatment. Call 1800 650 960 or visit [lgfb.org.au](http://lgfb.org.au).

› See our *Hair loss* fact sheet.

**Nausea** – You may feel sick with or without vomiting for several hours after each treatment. You will be given medicine to prevent nausea.

**Infertility** – Some women find that their periods become irregular or stop during chemotherapy. Periods may return to normal after treatment or they may stop permanently (menopause, see page 57), causing infertility. For men, chemotherapy can lower the number of sperm produced, which can cause temporary or permanent infertility. If you may want to consider having children in the future, talk to your cancer specialists about the options and ask for a referral to a fertility specialist before your treatment starts.

› See our *Fertility and Cancer* booklet.

**Other side effects** – Common side effects include tiredness, mouth ulcers and constipation. Chemotherapy can also lower your immune system, increasing the risk of infection. Some people experience changes in thinking and memory (cancer-related cognitive impairment or “chemo brain”) or pins and needles (peripheral neuropathy). Sometimes chemotherapy can damage the heart muscle, which can affect how blood is pumped around the body (cardiomyopathy). Although the risk is small, your heart health will be assessed before starting treatment and continue during treatment. Rarely, chemotherapy can cause a type of blood cancer.

› See our *Understanding Chemotherapy* booklet and pages 51–57.

## Hormone therapy

Hormone therapy, also called endocrine therapy or hormone-blocking therapy, slows or stops the effect of oestrogen. It is used to treat breast cancer that is hormone receptor positive (see page 22). Hormone therapy is often used to lower the risk of the cancer coming back.

There are different types of hormone therapy. The type you have will depend on your age, the type of breast cancer and whether you have reached menopause.

### Tamoxifen

Tamoxifen can be given to females of any age, regardless of whether they have reached menopause, and to males. It is commonly taken as a daily tablet for 5–10 years.

In females, tamoxifen can cause menopausal symptoms (see page 57), although it does not cause menopause. In males, the side effects can include low sex drive (libido) and erection problems.

Taking tamoxifen increases the risk of blood clots – see your doctor immediately if you have any swelling, soreness or warmth in an arm or leg. There is a small risk of developing cancer of the uterus (also called endometrial cancer) if you have gone through menopause, so see your doctor if you notice any unusual vaginal bleeding.

You will probably not experience all of these side effects. Side effects usually improve as treatment continues and after it has finished. Your doctor and breast care nurse can give you information about ways to manage the side effects of tamoxifen.



## Aromatase inhibitors

After menopause, the ovaries stop making oestrogen, but small amounts are still made in body fat. Taking aromatase inhibitors will help reduce how much oestrogen is produced in the body.

Aromatase inhibitors are mostly used if you've been through menopause or had your ovaries removed. If you have not been through menopause and are at high risk of the cancer coming back, you may have aromatase inhibitors as well as an injection of goserelin (brand name Zoladex) to stop the ovaries producing oestrogen.

Examples of aromatase inhibitors include anastrozole, exemestane and letrozole. They are taken daily as a tablet, usually for 5–10 years.

Aromatase inhibitors can cause thinning and weakening of the bones (osteoporosis). Your bone health will be monitored during treatment and your doctor may prescribe a drug to protect your bones.

Other side effects of aromatase inhibitors may include joint and muscle pain, vaginal dryness, low mood, hot flushes and weight gain. If you have arthritis, aromatase inhibitors may worsen joint stiffness and pain. Exercise or medicines from your doctor may help with this.

## Ovarian suppression

If you have not been through menopause, drugs or surgery can stop the ovaries from producing oestrogen. This is known as ovarian suppression. It may also be recommended as an additional treatment for people taking tamoxifen or for premenopausal women taking an aromatase inhibitor instead of tamoxifen.

**Temporary ovarian suppression** – The drug goserelin (brand name Zoladex) stops oestrogen production. The drug is given as an injection into the belly once a month for 2–5 years to bring on temporary menopause. Side effects are similar to those of permanent menopause (see page 57). The drug may also be given to people having chemotherapy who wish to preserve their fertility because it helps protect the ovaries.

**Permanent ovarian treatment** – Ovarian ablation is treatment that permanently stops the ovaries from producing oestrogen. It usually involves surgery to remove the ovaries (oophorectomy). Ovarian ablation will bring on permanent menopause. This means you will no longer be able to become pregnant.

## Targeted therapy

Targeted therapy drugs attack specific targets inside cancer cells. The drugs that are currently available do not work for all types of breast cancer. They are useful only for HER2 positive breast cancers (see page 22). For early or locally advanced breast cancer, the main targeted therapy drug is trastuzumab (brand name Herceptin). Other drugs are available for advanced breast cancer.

### Herceptin

Trastuzumab is usually referred to by the brand name Herceptin although there are other drugs similar to trastuzumab now available in Australia. These are known as biosimilar medicines and include Herzuma, Kanjinti and Ogivri. Herceptin works by attaching itself to HER2 positive breast cancer cells, destroying the cells or reducing

their ability to divide and grow. Herceptin also encourages the body's own immune cells to help destroy the cancer cells. Herceptin is used together with chemotherapy. It has been shown to increase the effect of chemotherapy drugs on early breast cancer. Most people have Herceptin via a drip into a vein (infusion), but some people have it as an injection under the skin.

The first infusion takes about 90 minutes. This is called the loading dose. The following infusions take 30–60 minutes each. You will usually have a dose every three weeks, and they will continue for up to 12 months. The first four doses are given while you are having chemotherapy treatment.

Your medical team will monitor you for side effects. These are usually caused by the chemotherapy. This means that once chemotherapy finishes and you are continuing with Herceptin alone, most side effects ease. For example, hair grows back, there is no nausea or vomiting, and you no longer need regular blood tests.

Although side effects from Herceptin itself are uncommon, they can include headache, fever and diarrhoea. In some people, Herceptin can affect how the heart works, so you will have tests to check your heart function before and during treatment.



A number of new drugs have been developed and tested as additional treatments after Herceptin for people with HER2 positive breast cancer. Talk to your doctor about whether these are appropriate for you.



## Key points about treating early or locally advanced breast cancer

### Choice of treatment

The treatments you are offered will depend on many factors, such as your test results, whether the cancer is hormone receptor positive, HER2 positive or triple negative, and your age and general health.

### Treatments before surgery

Chemotherapy before surgery is offered to people with locally advanced and high-risk cancers. This is known as neoadjuvant chemotherapy. Some people also have radiation therapy before surgery.

### Surgery

Early and locally advanced breast cancer is usually treated with surgery:

- breast-conserving surgery – removes only the cancerous part of the breast and a margin of tissue
- mastectomy – removes the whole breast
- breast reconstruction – re-creates the shape of your breast during or after breast-conserving surgery or a mastectomy; you may choose to delay this surgery or not have a reconstruction
- axillary surgery – removes some or all of the lymph nodes from the armpit to check if they are cancerous; can be done through a sentinel node biopsy or axillary dissection.

### Other treatments

You may also have other treatments such as chemotherapy, radiation therapy, hormone therapy for hormone receptor positive breast cancer, or targeted therapy for HER2 positive breast cancer.



# Managing side effects

It will take some time to recover from the physical and emotional changes caused by treatment for breast cancer. Treatment side effects can vary. Some people will experience just a few side effects, while others will have more.

## Lymphoedema

Lymphoedema is a swelling (oedema) that develops when lymph fluid builds up in the tissues of part of the body, such as an arm or breast. When lymph nodes have been damaged or removed, lymph fluid may not be able to drain as it should and instead builds up in the tissues, causing swelling.

Some breast cancer treatments, such as surgery to remove lymph nodes or radiation therapy to the armpit, can cause lymphoedema. People who have had surgery followed by radiation therapy to the armpit are more at risk of experiencing this side effect.

Lymphoedema can affect people at any time – during active treatment or months or years after treatment. Most people who are at risk never develop lymphoedema.

Signs to look for include swelling; a feeling of tightness, heaviness or fullness in the fingers, wrist or the whole arm; and aching in the affected area. These signs may begin gradually, and they may come and go. Some people experience pain, redness or fever, which can be caused by an infection called cellulitis in the area with lymphoedema. If you have any of these symptoms, see your doctor as soon as possible. The condition is easier to manage if it is diagnosed and treated early.

## Preventing and managing lymphoedema

### Who provides treatment

If you are at risk of developing lymphoedema or for ongoing care, see a lymphoedema practitioner. This may be an occupational therapist, physiotherapist or nurse with specialist training in treating and managing lymphoedema.

### When to start treatment

See a lymphoedema practitioner for regular check-ups after cancer treatment, rather than waiting for signs to appear. Taking action at an early stage can help reduce the risk of developing lymphoedema and the severity of lymphoedema if it does develop.

### What treatment involves

The swelling can be reduced by wearing a professionally fitted compression sleeve or by massage from a lymphoedema practitioner. You may also benefit from low-level laser treatment by a lymphoedema practitioner.

If you develop lymphoedema in the breast (breast oedema) you may be more comfortable wearing a bra designed for breast oedema. Ask your lymphoedema physiotherapist or breast care nurse where you can be fitted for the bra.

### How to find a lymphoedema practitioner

The Australasian Lymphology Association maintains an online national register of trained lymphoedema practitioners. Visit [lymphoedema.org.au](http://lymphoedema.org.au) and click on “Find a Practitioner”.

### How to find more information

- See our *Understanding Lymphoedema* fact sheet.

## Cording

Also known as axillary web syndrome, cording can happen weeks or months after surgery. It's caused by hardened lymph vessels and feels like a tight cord running from your armpit down the inner arm, sometimes to the palm of your hand. You may see and feel raised cord-like structures across your arm, and these "cords" may limit movement. Sometimes cording may occur on the chest wall or breast.

This condition usually improves over a few months. Gentle stretching exercises during the first weeks after surgery can help. If there is no improvement or it is getting worse, try physiotherapy, massage or low-level laser treatment by a lymphoedema practitioner.

## Nerve pain

Mastectomy, sentinel node biopsy and axillary dissection can cause nerve pain in the arm, and mastectomy can cause nerve pain on the chest wall. This may feel like pins and needles. It usually settles within a few weeks. If pain is ongoing, ask your doctor about ways to manage it.

Certain chemotherapy drugs can damage nerves in the hands and feet. This is called peripheral neuropathy or chemo-induced peripheral neuropathy (CIPN), and it can cause numbness, pins and needles and, occasionally, pain. These symptoms are usually temporary, but can be permanent. If you have any symptoms, tell your health care team so they can adjust your treatment. Your doctor will help you manage pain from any permanent nerve damage. A psychologist or counsellor can also teach you coping strategies to manage any ongoing pain.

➤ See our *Understanding Peripheral Neuropathy and Cancer* fact sheet.

## Thinking and memory changes

Some people diagnosed with breast cancer notice changes in the way that they think and remember information. This is called cancer-related cognitive impairment, but people may also refer to it as “cancer fog” or “chemo brain”.

The exact cause is unknown, but studies show that thinking and memory changes may be caused by the cancer itself, emotions such as anxiety and depression, cancer treatments, medicines given for surgery such as anaesthetic, and treatment side effects, such as fatigue, trouble sleeping, pain and hormone changes.

For most people, thinking and memory problems get better within the first year of finishing treatment. Others may experience more long-term effects. Ways to cope with changes include:

- adjust your daily routine, e.g. write lists, use smartphone reminders, avoid distractions, pace yourself
- maintain a healthy lifestyle, e.g. exercise, relax, eat healthy foods
- improve your thinking and memory, e.g. crosswords, brain training
- tell your family and friends, and ask your health care team for help.

If you have severe or lasting changes to your thinking and memory skills, you can also see a clinical psychologist or neuropsychologist for cognitive rehabilitation. Speak to your health care team about accessing cognitive rehabilitation services, which may be available through some hospitals or psychologists.

- See our *Understanding Changes in Thinking and Memory* fact sheet and listen to our “Brain Fog and Cancer” podcast episode.



## Breast prosthesis

A breast prosthesis is a synthetic breast or part of a breast that is worn in a bra or attached to the body with adhesive. They help give the appearance of a real breast and can be used after breast surgery.

**Temporary prosthesis** – In the first month or two after surgery, you may choose to wear a temporary light breast prosthesis called a soft form. This will be more comfortable next to your scar. A free bra and soft form are available through Breast Cancer Network Australia as part of the *My Care Kit*. To order a kit, speak to your breast care nurse.

**Permanent prosthesis** – When you have recovered from treatment you can be fitted for a permanent breast prosthesis. A permanent breast prosthesis is mostly made from silicone gel and has the shape, feel and weight of a natural breast. It is recommended that you see a trained fitter who can help you choose the right prosthesis. To find a local fitter, call Cancer Council 13 11 20 or ask your breast care nurse.

➤ See our *Breast Prostheses and Reconstruction* booklet.

## Wigs and head wear

If you lose your hair during chemotherapy, you may want to wear a wig, scarf, turban or hat while it's growing back. Another option is to leave your head bare. You can buy or borrow a wig – some hospitals and cancer care units provide wigs for free or a small fee. Your local Cancer Council may also provide a wig service. Call Cancer Council 13 11 20 or ask your treatment team for more details about borrowing or buying wigs. Some private health funds cover part of the cost of wigs – check with your health fund.

## Changes to body image and sexuality

Having breast cancer can affect the way you feel about yourself (self-esteem) and make you feel self-conscious. You may feel less confident about who you are and what you can do. Give yourself time to adapt to any changes. Try to see yourself as a whole person (body, mind and personality) instead of focusing on the parts that have changed.

You may find that having a breast reconstruction or wearing a breast prosthesis improves your self-confidence. Or you may prefer to not have a reconstruction and “go flat”.

Areola tattooing is the process of tattooing the areola and nipple onto the breast following a mastectomy. Areola tattoos are typically done on breasts with implants, with and without nipple reconstruction. For some people getting a decorative tattoo to cover scars is a way to take control of their body and express themselves in a beautiful way.

Breast cancer can also reduce your desire for sex (libido). You may miss the pleasure you felt from the breast or nipple being stroked or kissed during sex. This may be the case even if you have a reconstruction. If breast stimulation was important for arousal before surgery, you may need to explore other ways of becoming aroused.



After treatment, you should not use a hormone-based contraceptive (“the pill” or hormone implants or injections). It is best to use condoms, diaphragms or intrauterine contraceptive devices (IUDs).

Some treatments for breast cancer can cause vaginal dryness, which can make penetration during intercourse painful.

For most people, sex is more than arousal, intercourse and orgasms. It involves feelings of intimacy and acceptance, as well as being able to give and receive love. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

- ▶ See our *Sexuality, Intimacy and Cancer* booklet and listen to our “Sex and Cancer” podcast episode.

## Menopause and infertility

Chemotherapy can cause your periods to stop for a time and affect your ability to become pregnant. If your periods stop permanently (early menopause), you won't be able to have children naturally. If you may want to have children in the future, it is important to talk to your doctor before your treatment starts. There may be ways to reduce the risk of early menopause or to preserve fertility.

Symptoms of menopause can include hot flushes, trouble sleeping, vaginal dryness, reduced sex drive (libido), tiredness, dry skin, mood swings, weight gain and osteoporosis. Talk to your doctor or breast care nurse about ways to relieve the symptoms of menopause.

If you learn you may not be able to conceive a child, you may feel a great sense of loss. Talking to a counsellor or someone in a similar situation may help – call Cancer Council 13 11 20 for information about counselling services and support groups in your area.

- ▶ See our *Fertility and Cancer* booklet.



# Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

**Eating well** – Healthy food can help you cope with treatment and side effects. It can also help you maintain a healthy weight. Many people gain weight during and after breast cancer treatment. Studies show that weight gain after treatment can increase risk of recurrence. A dietitian can explain how to manage any special dietary needs or eating problems, and choose the best foods for your situation.

▶ See our *Nutrition and Cancer* booklet.

## Staying active

If you are being treated for cancer or recovering, you may have thought it was important to rest, but research shows that exercise benefits most people with cancer during and after treatment.

Being active can manage some of the side effects of treatment such as tiredness, improve circulation, lift mood, and speed up recovery. Exercise also helps to reduce the weight gain that is commonly associated with breast cancer treatments.

There is strong evidence that exercise can also reduce the risk of breast cancer coming back. The right exercise for you depends on what you are used to, how you feel and your doctor's advice. The most appropriate health professionals to design an exercise program for people with cancer are accredited exercise physiologists or physiotherapists.

▶ See our *Exercise for People Living with Cancer* booklet.

**Work and money** – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.


➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

**Relationships** – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

➤ See our *Emotions and Cancer* booklet.

**Complementary therapies** – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.



# Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the cancer is coming back. Some people say that they feel pressure to return to "normal life". It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer. They may also refer you to a survivorship program or resources. These may help you adjust to your life after treatment.

► See our *Living Well After Cancer* booklet.

## Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit [beyondblue.org.au](http://beyondblue.org.au). For 24-hour crisis support, call Lifeline **13 11 14** or visit [lifeline.org.au](http://lifeline.org.au).

## Follow-up appointments

After your treatment, you will have regular appointments with your cancer specialist and GP to monitor your health. This is known as shared care. Your doctors will see how you are going on hormone therapy (if this is part of your treatment), help manage any long-term side effects such as lymphoedema, peripheral neuropathy or heart issues, and check that the cancer hasn't come back or spread. During these check-ups, you will usually have a physical examination.

Check-ups after breast cancer treatment are likely to happen every 3–6 months for two years. They will become less frequent after that if you have no further problems.

You are likely to have a mammogram and, if necessary, an ultrasound every year. You won't need a mammogram if you've had a double mastectomy. If there is a concern the cancer may have come back, you may have a bone scan and a CT, PET or MRI scan. After five years with no recurrence, women aged between 50 and 74 can continue to have a mammogram through the national breast cancer screening program.

When a follow-up appointment or test is approaching, many people may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety. You can also listen to our podcasts on cancer tests and managing fear – visit [cancercouncil.com.au/podcasts](http://cancercouncil.com.au/podcasts).

Between follow-up appointments, let your specialist know immediately of any symptoms or health problems. You can also see your GP if you have any questions and for ongoing support.

## What if the cancer returns?

In most cases, early breast cancer will not come back (recur) after treatment. Although the risk is higher with locally advanced breast cancer, most people will not experience a recurrence.

Factors that may make the cancer more likely to come back in the treated breast or in other parts of the body include:

- the cancer was large at the first diagnosis
- the cancer was found in the lymph nodes
- the cancer was hormone receptor negative
- the grade of the cancer was high
- the surgical margin was not clear
- not having or not completing the adjuvant therapy (e.g. radiation therapy, chemotherapy, hormone therapy) that was recommended after surgery.

Having one or more of these factors doesn't necessarily mean the cancer will come back or spread.

Being "breast aware" can help detect cancer in the other breast. This means regularly looking at your breasts and feeling them to know what is normal for you. Being breast aware and having regular check-ups can also help find a recurrence early so it can be treated.

If you have had a bilateral mastectomy with or without a reconstruction, you should also regularly look at and feel your new shape and get to know your new normal. Report any changes to your specialist, breast care nurse or GP.





## Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services
- exercise programs.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or breast care nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ My family members don’t really understand what it’s like to have cancer thrown at you, but in my support group, I don’t have to explain. ” Sam

## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

### Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



### Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

### Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



### Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

### Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).



## Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

| Australian                                 |  |
|--|--|
| Cancer Council Australia                   | <a href="http://cancer.org.au">cancer.org.au</a>                                 |
| Cancer Council Online Community            | <a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>             |
| Cancer Council podcasts                    | <a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a> |
| Australasian Lymphology Association        | <a href="http://lymphoedema.org.au">lymphoedema.org.au</a>                       |
| Australasian Menopause Society             | <a href="http://menopause.org.au">menopause.org.au</a>                           |
| Australian Breast Device Registry          | <a href="http://abdr.org.au">abdr.org.au</a>                                     |
| Beyond Blue                                | <a href="http://beyondblue.org.au">beyondblue.org.au</a>                         |
| Breast Cancer Network Australia            | <a href="http://bcna.org.au">bcna.org.au</a>                                     |
| Breast Surgeons of Australia & New Zealand | <a href="http://breastsurganz.org">breastsurganz.org</a>                         |
| Breconda (breast reconstruction)           | <a href="http://breconda.bcna.org.au">breconda.bcna.org.au</a>                   |
| Cancer Australia                           | <a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>               |
| Carer Gateway                              | <a href="http://carergateway.gov.au">carergateway.gov.au</a>                     |
| Healthdirect Australia                     | <a href="http://healthdirect.gov.au">healthdirect.gov.au</a>                     |
| McGrath Foundation                         | <a href="http://mcgrathfoundation.com.au">mcgrathfoundation.com.au</a>           |
| National Breast Cancer Foundation          | <a href="http://nbcf.org.au">nbcf.org.au</a>                                     |
| Reclaim Your Curves                        | <a href="http://reclaimyourcurves.org.au">reclaimyourcurves.org.au</a>           |
| Services Australia                         | <a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>           |
| International                              |  |
| American Cancer Society                    | <a href="http://cancer.org">cancer.org</a>                                       |
| Cancer Research UK                         | <a href="http://cancerresearchuk.org">cancerresearchuk.org</a>                   |
| Macmillan Cancer Support (UK)              | <a href="http://macmillan.org.uk">macmillan.org.uk</a>                           |



# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

**Support services** – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit [carergateway.gov.au](http://carergateway.gov.au).

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Australia** – Carers Australia provides information and advocacy for carers, and is the national peak body representing them to the Australian Government. Visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

- See our *Caring for Someone with Cancer* booklet and listen to our “Cancer Affects the Carer Too” podcast episode.



# Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

## Diagnosis

- What type of breast cancer do I have?
- Has the cancer spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this cancer available in this hospital?
- Will a multidisciplinary team be involved in my care? Will I see a breast care nurse?
- Are there clinical guidelines for this type of cancer?

## Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- How long do I have to make a decision?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

## Side effects and after treatment

- What are the risks and possible side effects of each treatment? How will they be managed?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?
- How often will I need check-ups after treatment?
- If the cancer returns, how will I know? What treatments could I have?



# Glossary

## **adjuvant treatment**

Treatment given to lower the risk that the cancer will come back.

## **advanced cancer**

Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

## **areola**

Coloured rim of tissue around the nipple.

## **aromatase inhibitors**

Drugs that help reduce the amount of oestrogen in the body.

## **atypical ductal hyperplasia**

An abnormal but non-cancerous condition of the cells in the lining of the milk ducts.

## **axilla**

The armpit.

## **axillary lymph nodes**

Lymph nodes in and around the armpit.

## **axillary surgery or dissection**

The removal of some lymph nodes in the armpit.

## **axillary web syndrome**

See cording.

## **biopsy**

Removal of tissue for examination under a microscope to diagnose a disease.

## **biosimilar drugs**

Drugs that are similar, but not identical, copies of targeted therapy drugs.

## **BRCA1 or BRCA2 mutation**

A gene change that increases the risk of getting breast, ovarian or prostate cancer.

## **breast-conserving surgery**

Surgery that removes a lump without removing the entire breast. Also called a lumpectomy or wide local excision.

## **breast form**

The term used by manufacturers for an artificial breast. See breast prosthesis.

## **breast oedema**

Swelling caused by too much fluid in the breast tissue.

## **breast prosthesis (plural: prostheses)**

An artificial breast worn inside a bra or attached to the body with adhesive to re-create the shape of a natural breast. Also called a breast form.

## **breast reconstruction**

Surgery that rebuilds the breast shape after all or part of the breast is removed.

## **cancer-related cognitive impairment**

Thinking and memory problems that may be experienced after treatment. Also called chemo brain or cancer fog.

## **cellulitis**

An infection of the skin. It can occur after lymph glands have been removed.

## **chemotherapy**

A cancer treatment that uses drugs to kill cancer cells or slow their growth.

## **cold cap**

A cap that is connected to a cooling system and worn on the head during chemotherapy to help prevent hair loss.

## **cording**

Tight cords of tissue running down the inside of the arm. Also known as axillary web syndrome.

## **ductal carcinoma in situ (DCIS)**

Abnormal cells in the breast ducts that may increase the risk of developing invasive breast cancer.

## **ducts**

The tubes that carry milk to the nipple.

### **early breast cancer**

Cancer that has not spread beyond the breast or the axillary lymph nodes.

### **genes**

The microscopic units that determine how the body's cells grow and behave. Genes are found in every cell of the body and are inherited from both parents.

### **genomic assay**

A test that provides information about the risk of the cancer coming back and whether chemotherapy will be of benefit. Also called a molecular assay.

### **grade**

A number that describes how similar cancer cells look to normal cells and how quickly the cancer is likely to grow.

### **HER2**

Human epidermal growth factor receptor 2. A type of protein found on many cells in the human body.

### **hormone receptors**

Proteins in a cell that bind to specific hormones.

### **hormones**

Chemicals in the body that send information between cells to control growth and reproduction.

### **hormone therapy**

A treatment that blocks the body's natural hormones, which sometimes help cancer cells grow. Also called endocrine therapy or hormone-blocking therapy.

### **inflammatory breast cancer**

Cancer that affects the lymphatic vessels in the skin of the breast causing the breast to become red and swollen.

### **invasive breast cancer**

Cancer that has spread from the lining of the breast ducts or lobules into the surrounding breast tissue.

### **invasive ductal carcinoma**

Cancer that started in the breast ducts but has spread into the tissue around them.

### **invasive lobular carcinoma**

Cancer that started in the breast lobules but has spread into the tissue around them.

### **Klinefelter syndrome**

A genetic disorder in males caused by having an extra X chromosome (XXY) instead of one (XY).

### **lobe**

A section of the female breast that contains lobules.

### **lobular carcinoma in situ (LCIS)**

Abnormal cells in the breast lobules that increase the risk of getting breast cancer.

### **lobules**

The milk-producing glands in the breast.

### **locally advanced breast cancer**

Cancer that is larger than 5 cm, has spread to tissues around the breast such as the skin, muscle or ribs, or has spread to a large number of lymph nodes.

### **lumpectomy**

See breast-conserving surgery.

### **lymphatic system**

A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat, and produces immune cells.

### **lymph nodes**

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

### **lymphoedema**

Swelling caused by a build-up of lymph fluid.

### **lymph vessels**

Thin tubes that carry clear fluid known as lymph all over the body.

### **mammogram**

A low-dose x-ray of the breast.

### **margin/surgical margin**

An edge of tissue removed during surgery. Clear or negative margin means no cancer cells were found on the edge of the tissue. Positive margin means cancer cells were found on the edge of the tissue and further surgery is usually required.

### **mastectomy**

Surgery to remove the whole breast.

### **menopause**

When periods (menstruating) end.

### **metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body. Also called secondary or advanced cancer.

### **neoadjuvant chemotherapy**

Chemotherapy given before surgery to make treatment more successful.

### **nipple-sparing mastectomy**

A type of mastectomy where the breast skin, nipple and areola are not removed.

### **non-invasive breast condition**

Precancerous breast condition that is confined to the ducts or lobules of the breast. Also called carcinoma in situ.

### **oestrogen**

A sex hormone produced mainly by the ovaries. For post-menopausal women, the hormone is produced in the fat cells.

### **oncoplastic breast-conserving surgery**

An operation in which the cancer is removed, and plastic surgery techniques are used to preserve the appearance of the breast as much as possible.

### **osteoporosis**

Thinning and weakening of the bones that can lead to bone pain and fractures.

### **ovarian ablation**

Stopping the ovaries from producing oestrogen by surgically removing the ovaries (oophorectomy) or giving a dose of radiation therapy to the ovaries.

### **Paget's disease of the nipple**

Cancer that develops in the breast ducts and spreads to the skin of the nipple and the areola.

### **pathologist**

A specialist doctor who interprets the results of tests.

### **peripheral neuropathy**

Weakness, numbness, tingling or pain, usually in the hands and feet, caused by damage to the nerves that are located away from the brain and spinal cord (peripheral nerves).

### **progesterone**

A sex hormone made mostly by the ovaries. It prepares the lining of the uterus for pregnancy.

### **radiation therapy**

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. Also called radiotherapy.

### **reconstructive surgeon**

A doctor who has had advanced surgical training in the restoration of skin and



tissue to near-normal appearance and function. Also called a plastic surgeon.

#### **recurrence**

The return of a disease after a period of improvement (remission).

#### **screening**

An organised program to identify disease in people before any symptoms appear.

#### **sentinel node**

The first lymph node that breast cancer cells may spread to outside the breast.

#### **sentinel node biopsy**

Removal of the sentinel node.

#### **seroma**

A collection of fluid under a wound after surgery. This is not harmful but may need to be drained.

#### **skin-sparing mastectomy**

A type of mastectomy in which the whole of the skin of the breast, except the nipple and areola, is kept.

#### **staging**

Performing tests to work out how far a cancer has spread.

#### **targeted therapy**

Drugs that attack specific features of cancer cells, known as molecular targets, to stop the cancer growing and spreading.

#### **triple negative breast cancer**

A breast cancer that does not have receptors for the hormones oestrogen or progesterone or for the growth factor HER2, which are all known to fuel breast cancer growth.

#### **tumour**

A new or abnormal growth of tissue on or in the body.

#### **ultrasound**

A scan that uses soundwaves to create a picture of part of the body.

#### **Can't find a word here?**

*For more cancer-related words, visit:*

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)

## **References**

1. F Cardoso et al. on behalf of the ESMO Guidelines Committee, "Early breast cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 30, 2019, pp. 1194–1220.
2. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia; Australian Cancer Incidence and Mortality (ACIM) books: breast cancer*, AIHW, Canberra, 2018.



## How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

**Join a Cancer Council event:** Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**Help us speak out for a cancer-smart community:** We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



# Cancer Council

## 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

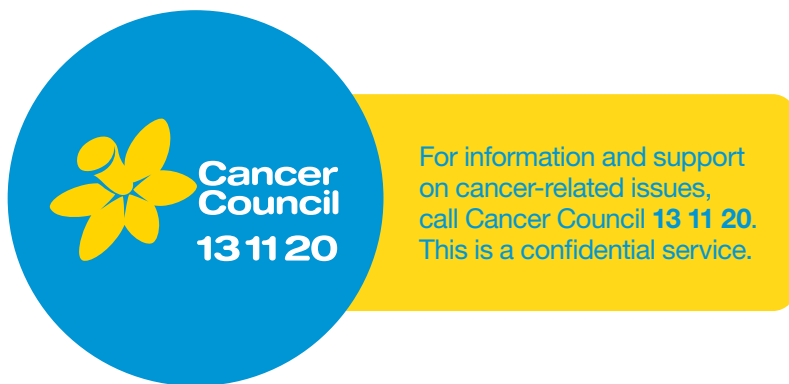
Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**If you need information in a language other than English, an interpreting service is available. Call 13 14 50.**

**If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)**



## Visit your local Cancer Council website

**Cancer Council ACT**  
actcancer.org

**Cancer Council NSW**  
cancercouncil.com.au

**Cancer Council NT**  
nt.cancer.org.au

**Cancer Council Queensland**  
cancerqld.org.au

**Cancer Council SA**  
cancersa.org.au

**Cancer Council Tasmania**  
cancertas.org.au

**Cancer Council Victoria**  
cancervic.org.au

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cancerwa.asn.au

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cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*