

Understanding Breast Cancer

A guide for people with cancer, their families and friends



For information & support, call **13 11 20**

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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.

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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 or call your local Cancer Council.



Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.



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About this booklet

This booklet has been prepared to help you understand more about early and locally advanced breast cancer. It does not cover advanced (metastatic) 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 also include information about support services.

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). 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 the Australian clinical practice guidelines for breast cancer.¹



If you or your family have any questions or concerns, 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).



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Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



Tips

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. These abnormal cells may turn into cancer.

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.

How cancer starts

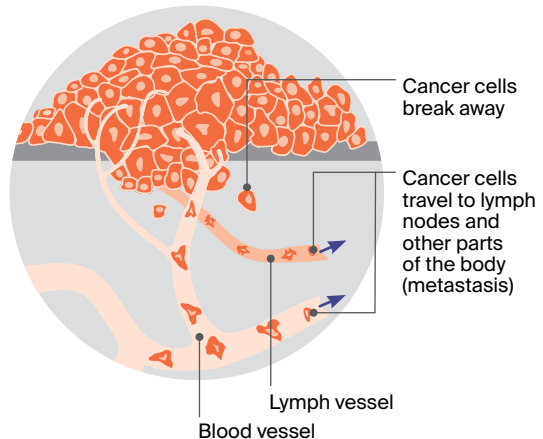
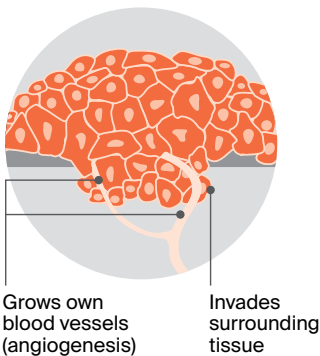


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops in a tissue or organ 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.

How cancer spreads

Malignant cancer



The breasts

The breasts sit on top of the upper ribs and a large chest muscle. They cover the area from the collarbone (clavicle), to the armpit (axilla) and across to the breastbone (sternum). Some breast tissue extends into the armpit and is called the axillary tail.

Female breasts are mostly made up of:

- **lobes** – each breast has 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 when breastfeeding
- **fatty/fibrous tissue** – all breasts contain some fatty or fibrous tissue (including connecting tissue called stroma), no matter what their size.

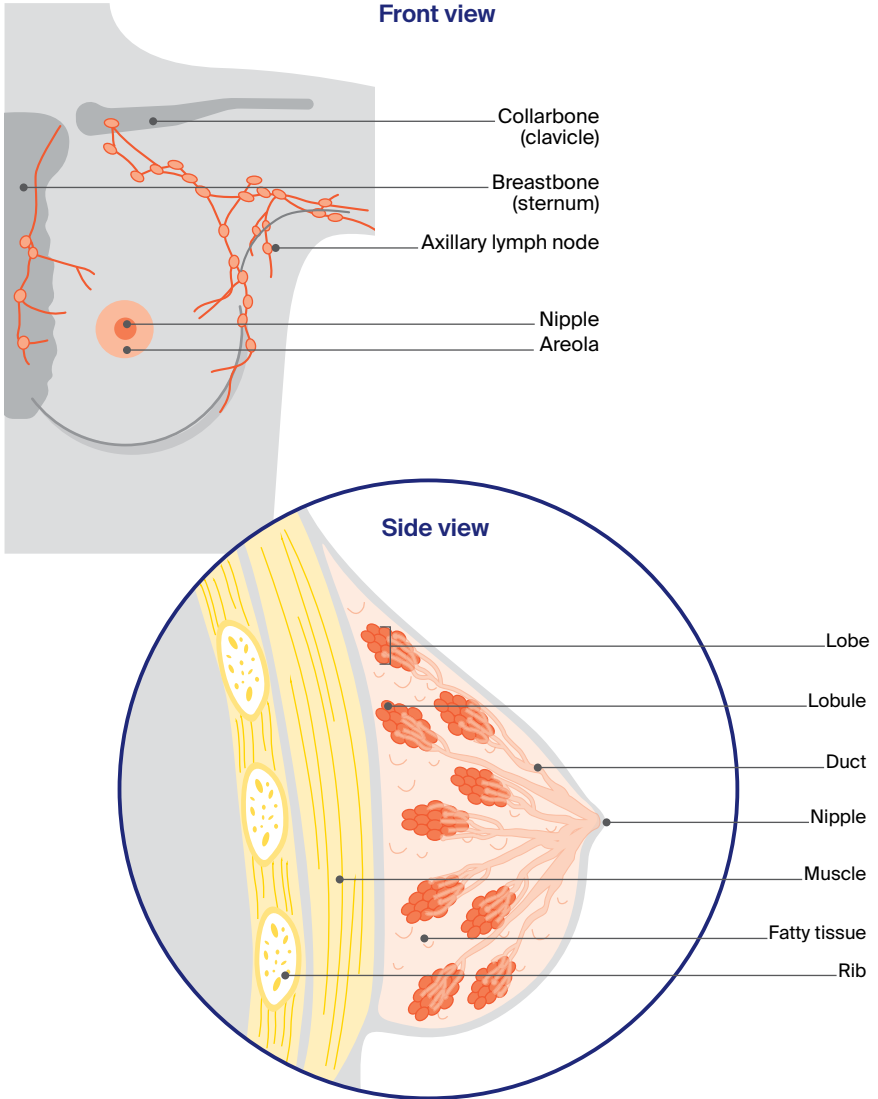
Most younger women have dense or thicker breasts, because they contain more lobules than fat. Male breasts have ducts and fatty/fibrous tissue. They contain no, or only a few, lobes and lobules.

The lymphatic system

The lymphatic system is an important part of the immune system, and protects against disease and infection. Working like a drainage system, it removes fluid from body tissues back into the blood. It is made up of a network of thin tubes called lymph vessels. These lymph vessels connect to groups of small, bean-shaped lymph nodes (or glands).

There are lymph nodes throughout the body, including in the armpit, neck, abdomen, groin and near the breastbone. The first place breast cancer cells usually spread to is the axillary lymph nodes in the armpit.

The breasts



Key questions

Q: What is breast cancer?

A: Breast cancer is the abnormal growth of cells in the breast. It usually starts in the lining of the breast ducts or lobules, and can grow into cancerous (malignant) tumours. Most breast cancers are found when they are invasive. This means that 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). Advanced breast cancer is when cancer cells have spread (metastasised) outside the breast to other parts of the body. This booklet covers early and locally advanced breast cancer only.

Q: How common is breast cancer?

A: There are about 20,000 people diagnosed with breast cancer in Australia every year.²

Women – Breast cancer is the most common cancer in Australian women (apart from common skin cancers) – one in seven will be diagnosed in their lifetime.² Young women get breast cancer, but it is more common over the age of 40, and risk increases with age. In rare cases, pregnant or breastfeeding women get breast cancer – so see a doctor about any persistent lump noticed during pregnancy.

Men – About 160 Australian men are diagnosed with breast cancer each year – most aged over 50. It is treated in the same way as for women. Visit breastcancerinmen.canceraustralia.gov.au for specific information, or download *Men get breast cancer too* from bcna.org.au/understanding-breast-cancer/breast-cancer-in-men.

Transgender, non-binary and gender-diverse – Any transgender woman taking medicines to boost female hormones and lower male hormones has an increased risk of breast cancer (compared to a man). A transgender man, who has had breasts removed in a nipple-sparing mastectomy (usually called top surgery), can still get breast cancer – though the risk is very low. This is thought to be because small amounts of breast tissue may remain after surgery.

Q: Does breast cancer run in families?

A: Most people with breast cancer don't have a family history, but a small number may have inherited a gene fault (also called a mutation or pathogenic variant) that increases their breast cancer risk.

BRCA1 and BRCA2 – These are the most common gene mutations linked to breast cancer. Women in families with BRCA1 or BRCA2 are at increased risk of breast and ovarian cancers. Men in families with BRCA2 may be at increased risk of breast and prostate cancers.

Other types – These include BARD1, BRIP1, NF1, RAD51C, CDH1, PTEN, STK11, TP53, PALB2, ATM and CHEK2. More gene mutations linked to breast cancer are being found all the time.

To find out if you have inherited a gene mutation, talk to your doctor or breast cancer nurse about visiting a family cancer clinic or genetic oncologist. In particular, women diagnosed before 40, those with triple negative breast cancer, and men with breast cancer should ask for a referral. Genetic testing is useful for people with a high chance of a gene fault, as it may help to work out the best treatment options. Medicare usually pays for testing if you have breast cancer and an increased chance of a mutation.

What are the risk factors for breast cancer?

Many factors can increase your risk of breast cancer, but they do not mean that you will definitely develop it. You can also have none of the known risk factors

Personal factors



- Being female is the biggest risk factor – 99% of breast cancer cases are diagnosed in women.
- Risk increases with age for both men and women.
- About three quarters of breast cancer cases are in women over the age of 50. Free breast screening is available.
- Dense breast tissue (as seen on a mammogram) increases your risk.
- Breast implants or breast augmentation does not increase your risk of breast cancer.

Lifestyle factors



- Being overweight or gaining weight after menopause. Losing weight to a healthy range can lower this.
- Drinking alcohol – the more that you drink, the higher your risk. If you choose to drink, the alcohol guidelines suggest you drink no more than 10 standard drinks a week, and no more than 4 standard drinks on any one day.
- Not getting enough exercise or not being physically active.
- Smoking tobacco may increase your risk.

Family history



- About 5–10% of breast cancers are due to an inherited breast cancer gene such as BRCA1 or BRCA2 (see page 9).
- Most people with breast cancer do not have a strong family history. However, having several close relatives (e.g. mother, sister, aunt) on the same side of the family who have had breast or ovarian cancer may increase your risk.
- Several close relatives on the same side of the family with prostate or pancreatic cancer may increase your risk.

and still get breast cancer. If you are worried, speak to your doctor. For more information, see breastcancerriskfactors.gov.au or petermac.org/iprevent.

Hormonal factors



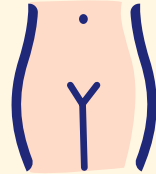
- Using menopause hormone therapy (MHT) containing both oestrogen and progesterone, for long periods of time and over many years.
- Taking the pill (oral contraceptive) for a long time (small increase).
- Using some hormonal IUDs for a long time (small increase).
- You or your mother using diethylstilboestrol (DES) during pregnancy.
- Transgender women taking gender-affirming hormones for more than 5 years.

Medical history



- Having been previously diagnosed with breast cancer, LCIS or DCIS (see next page).
- Some non-cancerous conditions of excessive growth of breast cells (hyperplasia).
- Having radiation therapy to the chest area for Hodgkin lymphoma.
- Males with a rare genetic syndrome called Klinefelter syndrome. Those with this syndrome have three sex chromosomes (XXY) instead of the usual two (XY).

Reproductive factors



- Never having given birth may increase risk.
- Starting your first period (menstruating) before the age of 12 may increase your risk.
- Being older than age 30 when you gave birth to your first child increases your risk.
- Not having ever breastfed may increase your risk.
- Going through menopause after the age of 55 may increase your risk.

What are the different types of breast conditions and breast cancers?

Non-invasive breast conditions

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

ductal carcinoma in situ (DCIS)

- abnormal cells in the ducts of the breast
- may develop into invasive breast cancer
- treatment is the same as invasive breast cancer, but chemotherapy is not used

lobular carcinoma in situ (LCIS)

- abnormal cells in the lobules of the breast
- increases risk of developing cancer
- needs regular mammograms or other scans to keep a check on
- may be treated with hormone-blocking therapy or surgery in some cases

Invasive breast cancers

Invasive means that the cancer cells have grown and spread into the surrounding tissue. The two main types of invasive breast cancer are named after the breast area that they start in.

invasive ductal carcinoma (IDC)

- starts in the breast ducts
- about 80% of breast cancers are IDC

invasive lobular carcinoma (ILC)

- starts in the breast lobules
- about 10% of breast cancers are ILC

Less common breast cancers include angiosarcoma, inflammatory breast cancer, medullary carcinoma, mucinous carcinoma, Paget disease of the nipple (or breast) and papillary carcinoma. Phyllodes tumour is a rare breast condition.

If invasive breast cancer spreads beyond the breast tissue and the 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.

Q: What are the symptoms?

A: Not everyone who is diagnosed with breast cancer has symptoms.

Breast changes may not mean cancer, but see a doctor if you have:

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

Q: Which health professionals will I see?

A: You may be sent for tests after a screening mammogram, or your general practitioner (GP) may arrange tests to check your symptoms. If these tests don't rule out cancer, you will usually be referred to a specialist or breast clinic. If breast cancer is diagnosed, you'll see a breast surgeon or a medical oncologist, who will talk to you about your treatment options. Often these will be discussed with other health professionals at 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 pages 14–15). You may not see all members of the MDT.



For an overview of what to expect at every stage of your cancer care, visit cancer.org.au/cancercareguides/breast-cancer.

This is a short guide to what is recommended, from diagnosis to treatment and beyond.

Health professionals you may see

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

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

** Specialist doctor*

Diagnosis

If you notice any breast changes or a mammogram shows up something, your GP will ask about your medical history and any family history of breast cancer. They will do a physical examination, checking both breasts and the lymph nodes in your armpit 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 page 18). 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 any lump or other breast changes found during a physical examination. It can also show changes that are small or can't be felt during a physical examination. If you have breast implants, it's important to let staff know before you have the mammogram.

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.

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 (3D) image. Tomosynthesis may be better for finding small breast cancers, particularly in dense breast tissue.

Ultrasound

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

The person doing the ultrasound will spread gel on your breast, and then move a small device called a transducer over the breast area and 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 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 breast implants. It may also be used if other imaging test results are not clear or to help plan breast surgery.

Before the MRI, you will usually 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 a large machine, shaped like a cylinder. The scan can take 30–40 minutes. It is painless but loud, so you'll wear earplugs. Some people feel claustrophobic. If you think you may feel anxious, speak to your doctor before the appointment. You may be offered a mild sedative.



A national program gives free access to breast cancer screening tests for all women over 40. Call 13 20 50 or visit health.gov.au/initiatives-and-programs/breastscreen-australia-program.

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 checks the sample under a microscope for any cancer cells.

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 and soreness 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. 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 16–18 show that you have breast cancer, you may have further tests to check whether the cancer has spread to other parts of your body. Not everyone will need all these tests.

Blood tests – A blood sample may be taken to check your general health, bone marrow and liver function, and to test for specific tumour markers.

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 abnormal areas of the bone. After a few hours, the bones are viewed with a scanning machine, which sends images to a computer. A bone scan is painless and the radioactive material is not harmful. You should drink plenty of fluids the day of the test and the day after it.

CT scan – A CT (computerised tomography) scan uses x-ray beams to take pictures of the inside of the body. It looks 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, called contrast, makes the pictures clearer. For the scan, you lie flat on a table while the CT scanner, which is a large doughnut shape, takes pictures. It is painless and takes about half an hour.

PET scan – In a PET (positron emission tomography) scan, a small amount of low-level radioactive solution is injected into a vein in the arm or hand. Any cancerous areas take up more of the radioactive solution and show up brighter in the scan.



Before a scan, tell the doctor if you have any allergies or had a reaction to dyes during previous scans. Also tell them if you have diabetes or kidney disease or are pregnant or breastfeeding.

Staging breast cancer

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

The most common staging system for breast cancer is the TNM system. Letters and numbers describe how big the tumour is (T), if cancer has spread to nearby lymph nodes (N), or if it has spread to the bones or other organs, which is known as having metastasised (M).

The staging system also shows other details about the breast tumour such as oestrogen and progesterone receptor status, HER2 status (see pages 22–23) and the grade of the cancer.

Sometimes your doctor will also do further tests to examine the changes in the cancer cells and how likely it is the cancer may come back. These are called gene activity tests (see page 23).

Early breast cancer – This 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 – This 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.

Metastatic breast cancer – This is stage 4 and means breast cancer has spread to other parts of the body. It is also called secondary or advanced breast cancer. It is different to locally advanced breast cancer.

The staging system for breast cancer is complicated 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 growing slowly.
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 growing fast.

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).

The survival rates for people with breast cancer have increased significantly over time due to more people taking part in screening, better tests and scans, and improved medicines and treatments.

Doctors often 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 when 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



ER+ and/or PR+

70–80% of all breast cancers

The hormones oestrogen and progesterone are produced naturally in the body. A receptor is a protein on the surface of the cell. Normal breast cells have oestrogen receptors (ER) and progesterone receptors (PR). Breast cancers that have too many of these receptors are known as ER positive (+) or PR positive (+). This lets more oestrogen or progesterone enter the cell, where it stimulates cancer cell growth.

ER+ and PR+ cancers are usually treated with hormone therapy drugs (or endocrine therapy) that block the receptor, or drugs that reduce the amount of hormones that the body makes (aromatase inhibitors). If the cancer has low levels of receptors (ER-), these drugs are generally not used.

HER2 status



HER2+

15–20% of all breast cancers

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 (HER+). Tumours with low levels are called HER2 negative (HER2-).

It is often recommended that people with HER2+ breast cancer have chemotherapy and targeted therapy before they have surgery. This is known as neoadjuvant chemotherapy or neoadjuvant therapy.

You may also have chemotherapy or other therapy after surgery. This is known as adjuvant therapy.

Triple negative breast cancer



ER-, PR- and HER2-

10–20% of all breast cancers

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

Triple negative cancers do not respond to hormone therapy or to the targeted therapy drugs used for HER2+ cancers. The current treatment options for people with triple negative breast cancer include chemotherapy before and/or after surgery and some other types of targeted therapy drugs. Triple negative breast cancers usually respond well to chemotherapy. Radiation therapy may also be given after some types of surgery.

Women who have not been through menopause and people with a BRCA1 mutation (see page 9) are at higher risk of having triple negative breast cancer.

What are gene activity tests?

Known as molecular assays, genomic assays, or a gene expression profile, these tests look at which genes are active in the cancer cells. The patterns they show help to predict the risk of cancer returning. This can help guide treatment plans.

These tests may be suggested for some early breast cancers (ER+ and HER-) to see whether chemotherapy is needed. For example, if the risk of cancer returning is high, chemotherapy may be needed. If the risk is low, hormone therapy, or no extra therapy, may be suggested.

The current molecular assays used include Oncotype DX, EndoPredict, Prosigna and MammaPrint. They are not usually covered by Medicare or private health funds and can cost several thousand dollars.

Ask your medical oncologist if a gene activity test is of use for you. The standard pathology tests done on all breast cancers may be all that's needed for your treatment plan.

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
 - PET scan.
-

Staging and grading

- 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.
-

Key information about the cancer

- Hormone receptor status (ER+/- and PR+/-) shows whether the cancer may respond to hormone therapy.
 - HER2 status (HER2+/-) shows whether the cancer may respond to chemotherapy and targeted therapy.
 - Molecular assays look at gene patterns in cancer cells. They can help show if chemotherapy would be useful in early breast cancer.
-

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, as it may not affect the success of the treatment to wait a short time. Ask them to explain the options, and take what time 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 – it may be possible 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 says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. 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 your specialist 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 breast care nurse.

Consider a second opinion – You may want to ask for a second opinion from another specialist, to confirm or clarify your specialist’s recommendations, or to 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. Doctors run clinical trials 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, clinical trials 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 or breastcancertrials.org.au

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

Treatment

Treatment for early or locally advanced breast cancer varies from person to person. The treatment that's best 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 treatment you want to have.

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

Treatment options by stage of breast cancer

You will usually have more than one treatment, and they could be given in different orders or combinations.

Early breast cancer – The main options are either breast-conserving surgery (see page 29) with radiation therapy, or a mastectomy (surgery to remove the whole breast, see page 30).

Often surgery for breast cancer is followed by a combination of chemotherapy, radiation therapy, hormone therapy or targeted therapy, depending on the features of the cancer. The treatment that is given after you have surgery is called adjuvant therapy, and it reduces the risk of the cancer coming back.

Chemotherapy or targeted therapy given before surgery is neoadjuvant therapy. Usually suggested for HER2+, triple negative and inflammatory breast cancers, it is also sometimes advised for hormone positive cancer.

Locally advanced breast cancer – Often treated with chemotherapy before surgery (called neoadjuvant therapy) to shrink the cancer. If the cancer is HER+, you'll also usually have targeted therapy before surgery. It is common to be offered a mastectomy. If the chemotherapy has shrunk the cancer, you may be offered breast-conserving surgery instead. Surgery is usually followed by radiation therapy, hormone therapy and/or targeted therapy, depending on the cancer type.

Surgery

Treatment for early or locally advanced breast cancer usually includes surgery. Which surgery your doctor suggests will depend on the type and stage of the cancer, where it is in the breast, the size of your breast, and what you prefer. In most cases, you will have one or more lymph nodes removed from the armpit. This is called axillary surgery (see pages 32–33). Some people also choose to have a new breast shape made during the operation (breast reconstruction, see page 31).

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 usually not suitable for males because there is not enough breast tissue in the male breast. Research has shown that for most early breast cancer, having breast-conserving surgery followed by radiation therapy

(pages 40–42) works just as well 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. The Neoadjuvant Patient Decision Aid may help you decide on any pre-surgery therapy – myneoguide.com.

Breast-conserving surgery

When only part of the breast is removed, it is called breast-conserving surgery. It is also known as a lumpectomy or wide local excision.

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

A pathologist looks at the tissue under a microscope to check for an area of healthy cells around the cancer – known as a clear margin.

The pathologist will also give information about:

- the size and grade of the cancer (see pages 20–21)
- whether there are cancer cells near the edge (margin) of the removed breast tissue
- whether the cells are hormone receptor positive and/or HER2+ 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 guide your doctors on what other treatment may be best for you. If there are cancer cells found close to the edge of the removed tissue (which is called an involved or positive margin), there is a higher risk of the cancer returning. You may need to have further surgery for more tissue to be removed (called a re-excision or wider excision). Your doctor may also suggest that you have a mastectomy (see page 30).

After breast-conserving surgery, you'll usually have radiation therapy to destroy any cancer cells that may be left in the breast or armpit.

Mastectomy

Surgery to remove the whole breast is called a mastectomy or single mastectomy. Removal of both breasts is called a bilateral mastectomy. A mastectomy may be recommended if:

- you have the BRCA1 or BRCA2 gene mutation
- 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 have inflammatory breast cancer
- cancer has come back or you have a new cancer in the same breast.

You may prefer to have a mastectomy instead of breast-conserving surgery – even if you have a very small cancer. You won't usually be given radiation therapy after a mastectomy, though it may be offered in some situations.

The nipple is usually removed in a mastectomy. In some cases, the surgeon may 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 opposite page), and can have a skin-sparing or nipple-sparing mastectomy, the reconstruction is usually done at the same time.

If you don't have a reconstruction, you have the option of wearing a soft breast form with 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 then 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, this does increase the risk of developing another breast cancer, so your surgeon may

recommend a double mastectomy (bilateral mastectomy) to remove both breasts.

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. Then you can make a final decision once you are informed about all your options.

Breast reconstruction

Breast reconstruction is surgery to make a new breast shape, which is also called a breast mound. The surgery may be done using a silicone implant, using tissue from another part of your body, or a combination of the two.

It may be possible to 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.

Some people decide not to have a reconstruction and prefer to “go flat”, while others choose to wear a breast prosthesis (see page 55).

► See our *Breast Prostheses and Reconstruction* booklet.

Removing lymph nodes

The axillary lymph nodes, which are in and around the armpit, are where cancer cells from the breast usually spread to first. Removing some or all of these lymph nodes helps your doctor to check for any cancer 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 lymph node biopsy (SLNB) – When breast cancer spreads outside the breast, it first goes to particular lymph nodes in the armpit or near the breastbone (sternum). These are called 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, the rest of the lymph nodes are left in place. If there is more than a small amount of disease in the sentinel nodes, you may have axillary lymph node dissection or radiation therapy.

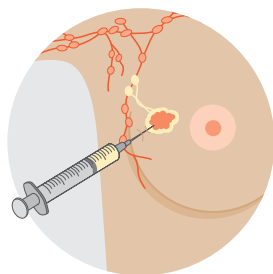
Axillary lymph node dissection (ALND) – Also called axillary lymph node clearance (AC). If cancer is found in the lymph nodes, then most or all of the axillary lymph nodes (usually 10–25) will be removed to reduce the risk of the cancer coming back (recurrence) in the armpit. The results also guide what other treatment your doctor recommends.

Side effects – You may have arm or shoulder stiffness, weakness, reduced movement and pain; numbness in the arm, shoulder, armpit and parts of the chest; seroma – which is fluid collecting near the surgical scar; lymphoedema (see pages 51–52); and cording (see page 53). Side effects are usually worse after axillary lymph node dissection because more lymph nodes are removed.

Finding the sentinel nodes

To work out which lymph nodes are sentinel nodes, one or a combination of these procedures is used:

1. Lymphatic mapping

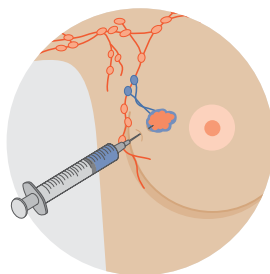


A small amount of a harmless radioactive material is injected into the skin over the breast cancer tumour.

A CT scan is then taken to show which lymph nodes the radioactive material flows to first. These are most likely to be the sentinel nodes.

Lymphatic mapping is done either on the day of the biopsy, or the day before the biopsy.

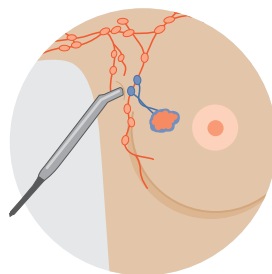
2. Blue dye injection (not always used)



If dye is being used, it will be injected into the breast. The dye moves into the lymphatic vessels and stains the sentinel nodes first. This is done under general anaesthetic during the biopsy.

Because of the dye, you may notice blue-green urine (wee) and bowel movements (poo) when you go to the toilet the next day. You may also have a blue patch on the breast for weeks or longer. Your skin may look a bit grey, but will fade once the dye washes out in your urine.

3. Handheld probe



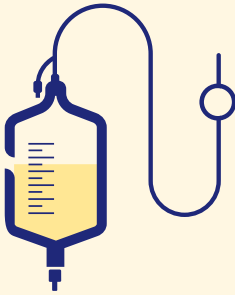
As well as looking at where the blue dye travels to first (if used), the surgeon uses a small handheld device called a probe during the biopsy to detect the radioactive substance injected during the lymphatic mapping.

This helps to check that the sentinel nodes have been located and the surgeon can then remove them for testing.

What to expect after surgery

If you have any questions about your recovery and how best to look after yourself when you get home, ask the doctors and nurses caring for you. If you are referred to a breast care nurse, they can give you information about what to expect after surgery and provide support.

Dressings and tubes



A dressing will cover the wound to keep it clean. This may be changed while in hospital but is usually removed after about a week. You may have one or more drainage tubes to drain fluid from the surgical site into a bag. These can stay in for 1-2 weeks. Nurses will show you how to look after the drains and wound at home, or a community nurse or GP may help you.

A wound infection can happen at any time. If you have any redness, pain, heat, fever, swelling or wound discharge let your doctor, breast care nurse or surgeon know right away. You may need antibiotics to manage the infection.

Recovery time



The time it takes to recover from breast surgery will depend on the type of surgery you've had and your own health. 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 relief



Pain after an axillary lymph node dissection or a mastectomy is more likely than after breast-conserving surgery. You'll have pain relief through a drip (intravenous or IV), an injection or as tablets. You'll also be given pain medicine when you go home.

Your hospital stay will depend on the surgery you have and how well you recover.

Breast-conserving surgery – You usually go home that day, or stay overnight.

Mastectomy – You usually stay in hospital overnight.

Reconstruction after mastectomy – You usually stay in hospital for several days.

Preventing blood clots



While in bed, you should try to do some deep breathing exercises, and move your legs around to help prevent blood clots in the deep veins of your legs (deep vein thrombosis or DVT). As soon as you're able, you'll be asked to get up and walk around. You may wear elastic (compression) stockings or use other devices to help prevent clots. Your doctor might also prescribe medicine that lessens the risk of any blood clots forming.

Avoid cuts



Your treatment team may advise you to wait for a time if you want to shave or wax your armpits.

Shower carefully



Keep the wound clean, and gently pat it dry after showering. Avoid baths.

Moisturise



Gently massage the area with moisturiser once any stitches or adhesive strips are removed and the wound has completely healed.

Don't use deodorant



If the wound is under your arm, avoid using deodorant until it has completely healed.

What your breast looks like after surgery

How your breast will look after surgery depends on the type of surgery that you have, as well as the size of your breast and your body shape. It can take up to a few weeks for any bruising and swelling of the surgery area to go away.

After breast-conserving surgery – The size and position of the scar will depend on how much tissue is removed. The scar will usually be less than 10 cm and near where the cancer was or along the areola. But this can vary depending on your breast size and how much cancer needs to be removed. It can also change if you need to have further surgery to remove more tissue. If a larger area needs to be removed, surgical techniques known as oncoplastic surgery can reshape the breast after breast-conserving surgery.

After a mastectomy – The scar will be across the skin of the chest. If you have surgery to the lymph nodes, the scar will also 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.

Impact on self-esteem – Scars or changes to how your breast looks can affect how you feel about yourself (self-image and self-esteem, see page 56). It's common to feel a sense of loss if you've had a mastectomy (or part of your breast removed), and you may find that your sense of femininity or sense of identity has been affected.

Seeking support – Talking to someone who has had breast cancer surgery can be helpful. Cancer Council's Cancer Connect program may be able to link you to others who've had a similar experience. Speaking with a counsellor or psychologist for emotional support and coping strategies can also help. Call Cancer Council 13 11 20 for details.

Breast appearance after surgery

What your breast looks like after surgery will vary from person to person, and depend on the type of breast surgery and how much tissue is removed. The pictures below give some examples, however ask your surgeon for more photographs to help you choose the surgery that's right for you.



Breast-conserving surgery

Two years after surgery to left breast. The scar can still be seen but has healed and faded a little. The size of the scar varies but can be around 10 cm. The surgery was followed by radiation therapy.



Mastectomy

Left breast removed, with no reconstruction. All possible breast tissue has been removed and the scar runs horizontally across the chest wall. This photo is some time after surgery and shows results once the scar has healed.



Nipple-sparing mastectomy with implant reconstruction

Left 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 a breast reconstruction using tissue from the back. Tissue from the abdomen, buttock or thigh can also be used for a reconstruction. 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 the best ways to deal with them. 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 weeks or months. Research shows that exercise during and after cancer treatment is safe and can help improve fatigue. YWCA offers a free exercise program for people who've had breast cancer surgery – call 0449 904 011 or visit ywcaencore.org.au. Cancer Council may also run an exercise program near you – call 13 11 20. Your GP may be able to create a management plan for Medicare-funded exercise physiology or physiotherapy.

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

Shoulder stiffness – Arm and shoulder pain, weakness, stiffness and reduced movement are common after surgery and after radiation therapy. Ask your treatment team when you can start exercising your arm. A physiotherapist can show you exercises to reduce shoulder stiffness or pain. This may move fluid near the surgical scar (seroma) and help prevent lymphoedema (see pages 51–52).

- ▶ See our *Arm & Shoulder Exercises After Surgery* poster on your local Cancer Council website (see back cover for addresses).

Numbness and tingling – Surgery can bruise or injure nerves and cause numbness and tingling in the armpit, upper arm or chest area. You may also notice a loss of feeling in your breast or nipple. These changes often improve within a few weeks, but may take longer. Sometimes the numbness or tingling may not go away completely. A physiotherapist or occupational therapist can give you 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 an axillary lymph node dissection. The build-up of fluid can be uncomfortable, but is not harmful. 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.

Lymphoedema – Fluid building up in the tissue of the arm or breast may cause swelling after any lymph node surgery. It's common to have some swelling of your arm or breast after surgery, but this usually settles in the weeks afterwards. If this swelling builds up over weeks or months, this usually means you have lymphoedema. It can happen any time, even years after surgery (or radiation therapy) to the lymph nodes. See page 52 for ways to manage the symptoms of 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.” 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 or cause pain. 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 usually 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 has cancer cells – 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 3–4 weeks after chemotherapy has finished. In some cases, radiation therapy 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 sometimes marks are put on your skin so the radiation therapists treat the exact same area each time. These marks are usually 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. Most people 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 are having radiation therapy in a private centre, the cost is not usually covered by private health insurance, so you may have to pay a gap fee. Speak to your treatment team about whether you can have treatment in a public hospital if you are worried about the cost.

Side effects of radiation therapy

Radiation therapy may cause the following side effects:

Red and dry skin – Most people have some redness around the treated area. The skin may become dry and itchy, look sunburnt, blister, or become moist and weepy. It usually returns to normal 4–6 weeks after radiation therapy ends. The nurses will show you how to care for your skin. Ask them which moisturiser would be most helpful for you.

Skin problems – Sometimes skin may become very irritated or peel (radiation dermatitis). The treatment team will monitor your skin, and you may need dressings, or special creams or gels, to help the area heal.

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

Aches – You may feel minor aches, twinges or shooting pain in the breast area during or after treatment. It should ease and become less frequent.

Swelling – Some people have swelling or fluid (breast oedema) that can last for up to a year or longer. Radiation therapy to the armpit increases the risk of swelling in the arm (lymphoedema, see pages 51-52).

Hair loss – Radiation therapy to the breast won't make you lose the hair on your head, but you will usually lose hair from the treated armpit.

Other side effects – These are called late effects and can develop months or years after radiation therapy. 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 heart problems, but this usually happens only if you have treatment to your left breast or if you smoke. Hardening of tissues (fibrosis) may happen months or years after treatment. In rare cases, radiation therapy may cause a second cancer.

▶ See our *Understanding Radiation Therapy* booklet.



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.

Chemotherapy

Chemotherapy uses drugs to kill cancer cells or slow their growth. It is called systemic treatment because the drugs circulate throughout the bloodstream.

When chemotherapy is used before surgery to shrink or control the cancer it's called neoadjuvant chemotherapy. When used after surgery to reduce the risk of the cancer returning it's called adjuvant chemotherapy.

Chemotherapy is often used for breast cancers that aren't sensitive to hormone therapy, are HER2+ or triple negative, or for inflammatory breast cancers. It is sometimes used for hormone sensitive breast cancers.

Having chemotherapy

Different types of chemotherapy drugs are used to treat early and locally advanced breast cancer. The choice of drugs 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, epirubicin and paclitaxel. Your treatment team may also refer to the drugs by their brand names, or letters like AC or FEC. Your medical oncologist will talk to you about the most suitable types of chemotherapy drugs, 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. Drugs are usually 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.

Nausea – You may feel sick or have vomiting for a few hours after each treatment. It's common to also feel sick a few days after a first treatment. Not everyone feels sick and you'll be given medicine to help prevent it.

Diarrhoea – You may have loose, watery stools and feel like you urgently need to go to the toilet. Talk to your treatment team if you feel unwell. You may be given medicine to manage diarrhoea.

Hair loss

You may lose the hair on your head, your eyebrows, eyelashes, underarm hair, pubic hair and facial hair.

Hair loss often begins 2–3 weeks after starting treatment. It starts gradually, and becomes more rapid 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. Cold caps may cause discomfort during chemotherapy, so speak to your treatment team for

advice. Generally, hair starts to grow back after your treatment ends.

If you think you might like to try wearing a wig, see page 55 for more information. The Look Good Feel Better program can help you to manage the appearance-related effects of cancer treatment and boost self-esteem. This may include sessions on make-up, skin care and hair styling. Call 1800 650 960 or visit lgfb.org.au.

► See our *Hair Loss* fact sheet.

Swelling – This is also called oedema. Some medicines used alongside chemotherapy drugs can cause the body to hold on to excess fluid (also called fluid retention). This can affect the arm and the trunk, but it is usually temporary and goes away when treatment ends.

Changes to fertility – Your periods may become irregular or stop during chemotherapy. This may be temporary with periods returning to normal after treatment. Sometimes periods may stop permanently, causing infertility (see page 57). Chemotherapy can lower the number of sperm produced, which can cause temporary or permanent infertility. If you may want to have children in the future, talk to your cancer specialists about your options and ask for a referral to a fertility specialist before your treatment starts.

▶ See our *Fertility and Cancer* booklet.

Other side effects – Tiredness, mouth ulcers and constipation are all common side effects. Chemotherapy can also lower your immune system, increasing the risk of infection. You might notice changes in thinking and memory (cancer-related cognitive impairment or “chemo brain”, see page 54) or tingling in your hands or feet (peripheral neuropathy, see page 53). Anti-nausea or anti-allergy medicines given with chemotherapy can disturb sleep for a few nights. Talk to your treatment team about how to manage any of these side effects.

Although the risk is small, sometimes chemotherapy can damage the heart muscle, which can affect how blood is pumped around the body (cardiomyopathy). Your heart health will be assessed before, during, and after treatment.

Rarely, chemotherapy can cause a type of blood cancer.

▶ See our *Understanding Chemotherapy* booklet.

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. It is also used to reduce the risk of certain conditions, including LCIS and some DCIS (see page 12), developing into invasive breast cancer.

There are different types of hormone therapy – the one you have depends on your age, type of breast cancer and if you have reached menopause.

Tamoxifen

Tamoxifen is suitable for anyone, whether you have been through menopause or not. You need to take a daily tablet for 5–10 years.

Side effects – In females, tamoxifen can cause menopausal symptoms (see page 57), although it doesn't bring on menopause. In males, the side effects can include low sex drive (libido) and erection problems. Tamoxifen increases the risk of blood clots – see a doctor immediately if you have swelling, soreness or warmth in an arm or leg. There is a very small risk of developing cancer of the uterus (also called endometrial cancer), particularly if you have gone through menopause. Let your treatment team know if you have any unusual vaginal bleeding.

You are unlikely to have all of these side effects, and they usually improve as treatment continues and after it ends. Your doctor and breast care nurse can help you to manage any side effects.



Tell your doctor if you take an antidepressant. Some (but not all) may affect how well tamoxifen works, and you may need to look at which medicine is best for your situation.

Aromatase inhibitors

After menopause, the ovaries stop making oestrogen. However, both females and males make small amounts of oestrogen in body fat and the adrenal glands. Taking aromatase inhibitors will help reduce how much oestrogen is made in the body. This is important because oestrogen can cause some cancers to grow.

Aromatase inhibitors are mostly used if you have been through menopause, have had your ovaries removed or are male. They are sometimes used if you haven't been through menopause, but have a high risk of the cancer returning. In this case, you may also be given an injection of goserelin, at least a week before chemotherapy starts, to stop your ovaries producing oestrogen (see page 48). Examples of aromatase inhibitors include anastrozole, exemestane and letrozole. They are taken daily as a tablet, usually for 5–10 years.

Side effects – Aromatase inhibitors can cause thinning and weakening of the bones (osteoporosis). Your bone health will be monitored during treatment and you may be prescribed a drug to protect your bones. Consider seeing a physiotherapist or exercise physiologist for an exercise plan. Other side effects 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.

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 stops oestrogen production. It 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 help protect the ovaries during chemotherapy, so it is often given to people who want to preserve their fertility.

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

Targeted therapy

Targeted therapy drugs attack specific features of cancer cells to stop the cancer growing and spreading. The drugs that are currently available do not work for all types of breast cancer. They are mostly useful for HER2+ breast cancers (see page 22). The drug abemaciclib is used for both HER2+ and HER2- breast cancers. For early or locally advanced breast cancer, the most common targeted therapy drug used is trastuzumab.

Trastuzumab

Your treatment team may refer to trastuzumab by a brand name, such as Herceptin, Kanjinti or Ogivri. It is also known by the brand name Herceptin, though this version is now rarely used in Australia. Trastuzumab works by attaching itself to HER2+ breast cancer cells, destroying the cells or reducing their ability to divide and grow. Trastuzumab also encourages the body's own immune cells to help find and destroy the cancer cells.

Trastuzumab is used in combination with chemotherapy. It has been shown to increase the effect of chemotherapy drugs on early breast cancer. Most people have trastuzumab 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, for up to 12 months. The first four doses are given while you are having chemotherapy treatment.

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



Several new drugs have been developed as additional treatments after trastuzumab for people with HER2+ breast cancer, including pertuzumab and trastuzumab emtansine (T-DM1). Your doctor will advise if these are appropriate for you.

PARP inhibitors

There are a number of new drugs for people who have inherited a BRCA mutation, or whose cancer has developed BRCA mutations. These are called PARP inhibitors. Ask your doctor whether these drugs may be 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 test results on the cancer, the stage and grade, whether it is hormone receptor positive, HER2+ or triple negative, and your age and general health.

Treatments before surgery

Chemotherapy before surgery is usually offered to people with locally advanced, HER2+ or triple negative, or inflammatory breast cancer, or before breast-conserving surgery. This is called 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 tissue margin
 - mastectomy – removes the whole breast
 - axillary surgery – removes some or all of the lymph nodes from the armpit to check for cancer; can be done through a sentinel lymph node biopsy or axillary lymph node dissection.
 - breast reconstruction – re-creates the shape of your breast during or after a mastectomy; you may choose to delay this surgery or not have a breast reconstruction.
-

Other treatments

After surgery you may have chemotherapy, radiation therapy, hormone therapy for hormone receptor positive breast cancer, or targeted therapy for HER2+ breast cancer.

Managing side effects

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

Lymphoedema

Lymphoedema is the 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 may cause lymphoedema. These include surgery to remove lymph nodes and radiation therapy to the armpit. People who have had surgery followed by radiation therapy to the armpit are more at risk of lymphoedema.

Lymphoedema can affect people at any time – during active treatment or months or even years afterward. Many people who are at risk never develop lymphoedema. Signs to look for include swelling of part of your arm or your whole arm; 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 or 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. Lymphoedema is easier to manage when diagnosed and treated early.

Preventing and managing lymphoedema

Who provides treatment

If you have, or are at risk of developing lymphoedema, see a lymphoedema practitioner. You may have treatment from 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. Exercise and skin care can help, as well as lymph taping or low-level laser treatment given 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 practitioner or breast care nurse where you can be fitted for the bra.

How to find a lymphoedema practitioner

The Australasian Lymphology Association has a national register of trained lymphoedema practitioners. Visit lymphoedema.org.au and click on "Find a Practitioner".

How to find more information

► See our *Understanding Lymphoedema* fact sheet.

Cording

Cording (axillary web syndrome) can happen weeks or months after any type of breast surgery. It is 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, chest or breast which may limit how you move. Doing gentle stretching exercises the first weeks after surgery can help, or try massage, physiotherapy, or low-level laser treatment by a lymphoedema practitioner. Cording usually improves over a few months.

Nerve pain

Mastectomy, sentinel lymph node biopsy and axillary lymph node dissection can cause nerve pain in the arm or armpit, and mastectomy can cause nerve pain in the chest wall. This may feel like pins and needles, tingling or stabbing pain. It usually settles within a few weeks. If nerve 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 chemotherapy-induced peripheral neuropathy (CIPN), and it can cause weakness, numbness, pins and needles and, occasionally, burning or shooting pain. These symptoms are usually temporary and start to get better over a matter of months, but they can be permanent.

If you have any symptoms, tell your health care team. Your doctor will help you manage pain from any permanent nerve damage.

A psychologist or counsellor can teach you coping strategies to manage any ongoing pain. A physiotherapist and occupational therapist can help you improve or manage symptoms.

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

Thinking and memory changes

Some people with breast cancer notice changes in how they think and remember information. This is called cancer-related cognitive impairment, or referred to as “chemo brain”, “cancer fog” or “brain fog”. The exact cause is unknown, but studies suggest these changes may be caused by the cancer, emotions such as anxiety and depression, cancer treatments (not just chemotherapy), anaesthetic given for surgery, and side effects such as fatigue, insomnia, pain and hormone changes.

For most people, thinking and memory problems get better within the first year of finishing treatment. Others may have long-term effects. If you have severe or lasting changes to your thinking and memory skills, you can see a clinical psychologist or neuropsychologist for cognitive rehabilitation. Speak to your health care team about the services available at your hospital or from a psychologist.

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



Ways to cope with thinking and memory changes

- Adjust your daily routine, e.g. write lists, keep a diary, use smartphone reminders or alarms, pace yourself and avoid distractions.
- Try not to multitask. Instead focus on one thing at a time.
- Do the most demanding tasks at the time of day when your energy levels are best.
- Maintain a healthy lifestyle, e.g. exercise, relax, eat healthy foods, get enough rest and sleep.
- Improve your thinking and memory, e.g. crosswords, puzzles, brain training.
- Tell your family, friends and health care team about any changes and ask for help.

Breast prostheses

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. It helps 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 the 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 fitter near you, call Cancer Council 13 11 20 or ask your breast care nurse.

▶ See our *Breast Prostheses and Reconstruction* booklet.

Wigs and headwear

If you lose your hair during chemotherapy, you may choose to wear a wig, scarf, turban or hat while it's growing back. Or you might feel comfortable leaving your head bare. You could try out a few options over time and see what feels like the right thing for you.

You can buy or borrow a wig – some hospitals and treatment centres provide wigs for free or a small fee. Your local Cancer Council may also provide a free wig service. Call Cancer Council 13 11 20 or ask your treatment team about borrowing or buying wigs. Check with your private health fund, as some may cover part of the cost of a wig.

Changes to body image and sexuality

Breast cancer can affect how 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. Try to see yourself as a whole person (body, mind and personality) instead of focusing on the parts that have changed. Talking to your partner and learning to get undressed naturally in front of them may also help.

Breast and areola appearance – 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 can tattoo the look of an areola and nipple onto the breast following a mastectomy. Areola tattoos are typically done on breasts with implants, with and without nipple reconstruction. Or you may choose a decorative tattoo to cover scars. For some people this is a way to take control of their body and express themselves.

Low libido – 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.

Vaginal dryness – Some treatments for breast cancer can cause vaginal dryness, which can make penetrative sex 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 penetration 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.



After treatment you shouldn't use any hormone-based contraceptives ("the pill" or hormone implants or injections). It is best to use condoms, diaphragms or intrauterine contraceptive devices (IUDs).

Menopause and infertility

Chemotherapy can cause your periods to stop for a time, or it may cause them to stop permanently (early menopause). Symptoms of menopause 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 how to relieve symptoms.

If chemotherapy causes menopause, you won't be able to have children naturally. Talk to your doctor before treatment starts, as there may be ways to reduce the risk of early menopause or to preserve your fertility.

If you find out you might not be able to get pregnant and have 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.

Feelings of loss and change

It's common to feel emotional after a diagnosis of cancer. You may feel a sense of grief or loss – of your health and wellbeing, your femininity, your dreams or freedoms, even what you can wear. Grief can feel like waves of sadness or being teary, and usually settles over time. The busyness of cancer treatment may mean you don't feel grief until it's over. If concerned, call Cancer Council 13 11 20 to talk to someone.

▶ See our *Emotions 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 and maintain a healthy weight. Many people gain weight during and after breast cancer treatment, which studies show increases the risk of cancer coming back. Drinking alcohol also increases your risk of breast cancer. If you choose to drink, the recommended guidelines are no more than 10 standard drinks a week and no more than 4 drinks in one day. 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 for People Living with Cancer* booklet.

Staying active

You may think it's important to rest during treatment and recovery, but research shows that exercise benefits most people.

Being active can help manage side effects such as tiredness, improve circulation, lift mood, and speed up recovery. Exercise also helps avoid the weight gain that is associated with breast cancer treatments. There is strong evidence that

exercise can reduce the risk of breast cancer returning. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

For help developing an exercise program to suit you, see an accredited exercise physiologist or physiotherapist.

► 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 whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

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

Relationships – Having cancer can affect your relationships with family, friends and colleagues in many different ways. Cancer is stressful, tiring and upsetting, and this may strain your relationships. The experience of cancer 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, may prevent successful treatment of the cancer and can be harmful. 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 breast cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

► 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, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. 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. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.

Follow-up appointments

After your treatment ends, you will have regular appointments with your cancer specialist and GP to monitor your ongoing health. This is known as shared care. Your doctors will see how you are going on hormone therapy (if this is part of your ongoing treatment), help you to 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. You will also be able to discuss how you're feeling and mention any concerns you may have.

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 needed, 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 sign of cancer, women aged between 50 and 74 can continue to have a free mammogram through the national breast cancer screening program.

When a follow-up appointment or test is approaching, many people find that they think more about the cancer and 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.

Between follow-up appointments, let your doctor know immediately of any symptoms you notice or health problems.

What if the cancer returns?

For some people, breast cancer does come back after treatment, which is called a recurrence. This is why regular check-ups are important. 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.

There are some things that increase the risk that cancer may come back. These include if the cancer was large or the grade was high when first diagnosed, if it was found in the lymph nodes, or if the surgical margin was not clear. If the cancer was hormone receptor negative or if adjuvant therapy (e.g. radiation therapy, chemotherapy, hormone therapy) was recommended after surgery but was not started or completed, this may also increase your risk. This doesn't mean the cancer will definitely come back or spread.

Regularly looking at and feeling your breasts to know what's normal – being “breast aware” – can help find cancer in the treated or other breast.

If you have had a double mastectomy with or without a reconstruction, you should also regularly look at and feel your new shape and get to know your “new normal”. Tell your specialist, breast care nurse or GP if you notice any changes. Breast cancer can also return in other parts of the body, such as the bones, liver or lungs. Most symptoms will not be a recurrence, but if you have new or ongoing pain, a persistent cough or have lost weight without trying, let your doctor know that you have had breast cancer.

It's important to continue taking medicines your doctor tells you to, even months or years after your treatment. Talk to them before you stop taking anything, as it may be helping to stop the cancer returning.

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 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.

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. Visit 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.

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 by location.

Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Information resources



Cancer Council produces booklets and fact sheets on more than 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.

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.

Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

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.

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	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Guides to Best Cancer Care	cancer.org.au/cancercareguides
Australasian Lymphology Association	lymphoedema.org.au
Australasian Menopause Society	menopause.org.au
Australian Breast Device Registry	abdr.org.au
Breast Cancer Network Australia	bcna.org.au
Breast Cancer Trials	breastcancertrials.org.au
Breast Surgeons of Australia & NZ	breastsurganz.org
Breconda (breast reconstruction)	breconda.bcna.org.au
Cancer Australia	canceraustralia.gov.au
Healthdirect Australia	healthdirect.gov.au
Management of Early Breast Cancer	guidancebreastcancer.gov.au
McGrath Foundation	mcgrathfoundation.com.au
National Breast Cancer Foundation	nbcf.org.au
Reclaim Your Curves	reclaimyourcurves.org.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk

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/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?
 - 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

- What are the risks and possible side effects of each treatment?
 - Will I have a lot of pain? What will be done about this?
 - 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?
-

After treatment

- How often will I need check-ups after treatment?
 - If the cancer returns, how will I know? What treatments could I have?
-

Glossary

adjuvant therapy

A treatment given after the main treatment 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 made 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 dissection or surgery

The removal of some lymph nodes in the armpit.

axillary lymph nodes

Lymph nodes in and around the armpit.

axillary web syndrome

See cording.

biopsy

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

bone scan

A technique to create images of bones on a computer screen. A small amount of radioactive dye is injected into a vein. It collects in abnormal areas of the bone and is detected by a scanning machine.

BRCA1 or BRCA2 mutation

A gene fault or mutation that increases the risk of 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 to rebuild the breast shape after the breast, or part of it, is removed.

cancer-related cognitive impairment

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

clear margin

When the surrounding tissue removed during surgery does not contain cancer cells.

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 called axillary web syndrome.

CT scan

A computerised tomography scan using x-rays to create a detailed, cross-sectional picture.

diethylstilboestrol (DES)

A synthetic hormone drug identified as a cause of breast cancer.

ductal carcinoma in situ (DCIS)

Abnormal cells in the breast ducts that may increase the risk of 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 or gene expression profile.

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 protein found on all cells in the body.

hormone receptors

Proteins on the surface of the 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 breast tissue around them.

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 two X chromosomes (XXY) instead of one (XY).

lobe

A section of the female breast that contains lobules.

lobular carcinoma in situ (LCIS)

Abnormal cells in the lobules of the breast that increase the risk of developing 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 tissue.

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 (menstruation) end.

metastasis (plural: metastases)

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

MRI scan

Magnetic resonance imaging scan. A scan using magnetic fields and radio waves to take detailed cross-sectional pictures of the body.

neoadjuvant therapy

Chemotherapy or other therapy given before surgery to help 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 made 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 disease of the nipple

Cancer that develops in the breast ducts and spreads to the skin of the nipple and 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 (the peripheral nerves).

PET scan

Positron emission tomography scan. A scan in which a person is injected with a small amount of radioactive glucose solution to help show up cancerous areas.

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 mastectomy in which the whole 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 cancer cell features to stop the cancer growing and spreading.

tomosynthesis

A digital x-ray mammogram machine that creates a three-dimensional picture.

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.

wide local excision

A surgical procedure to remove a cancer or tissue and some healthy tissue around it.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
 - cancervic.org.au/glossary
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References

1. Cancer Australia, *Guidance for the Management of Early Breast Cancer: Recommendations and Practice Points*, Cancer Australia, Surry Hills, 2020.
2. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia*, AIHW, Canberra, 2021, viewed 31 January 2022, available from aihw.gov.au/reports/cancer/cancer-data-in-Australia.



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 experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. communications.gov.au/accesshub/nrs

*Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).*

For information & support
on cancer-related issues,
call **Cancer Council 13 11 20**

Visit your local Cancer Council website

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