



Understanding Breast Cancer

A guide for people with cancer,
their families and friends

Cancer
information

Cancer Council Helpline

13 11 20

www.cancercouncil.com.au

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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 appropriate independent professional advice relevant to your specific situation 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 NSW

Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs.

This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit Cancer Council's website at www.cancercouncil.com.au or phone 1300 780 113.



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Introduction

This booklet has been prepared to help you understand more about early 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, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

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. You may also like to pass this booklet to your family and friends for their information.

How this book 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 National Health and Medical Research Council's clinical practice guidelines for breast cancer, and publications from Cancer Australia were used as source material.

If you're reading this book for someone who doesn't understand English, let them know that Cancer Council Helpline **13 11 20** can arrange telephone support in different languages. They can also call the Translating and Interpreting Service (TIS) direct on **13 14 50**.



Contents

What is cancer?	4
The breasts	6
Key questions	8
What is breast cancer?.....	8
What are the different types?	8
How common is breast cancer?	9
What are the symptoms?	10
What are the risks?.....	11
Diagnosis	13
Physical examination.....	13
Mammogram	13
Ultrasound	13
Breast MRI.....	14
Biopsy	14
Testing the tumour cells for hormone receptors and genes.....	16
Further tests	18
Staging breast cancer	20
Grading breast cancer.....	21
Prognosis	21
Which health professionals will I see?.....	22
Making treatment decisions	25
Talking with doctors	25
A second opinion	26
Taking part in a clinical trial	26

Treatment	27
Surgery	28
Radiotherapy	41
Chemotherapy	44
Targeted therapies.....	45
Hormone therapy	46
Aromatase inhibitors	48
Ovarian treatments	48
Living with breast cancer	51
Nerve pain	51
Lymphoedema.....	51
Cording.....	53
Menopause and fertility	54
Using a breast prosthesis.....	55
Wigs.....	56
Looking after yourself	58
Relationships with others	59
Sexuality and intimacy	60
Life after treatment	61
Seeking support	63
Practical and financial help	63
Talk to someone who's been there.....	63
Caring for someone with cancer	65
Useful websites	66
Question checklist.....	67
Glossary	68



What is cancer?

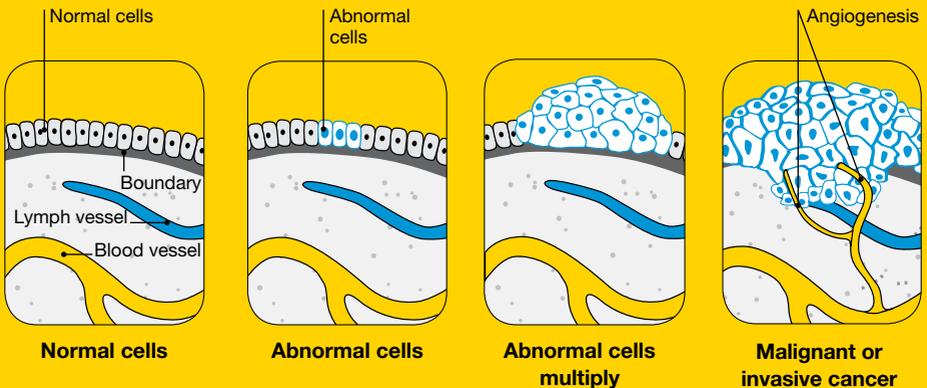
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

Benign tumour – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

Malignant tumour – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels (angiogenesis).

If cancerous 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 bones is called metastatic breast cancer, even though the person may be experiencing symptoms caused by problems in the bones.

How cancer spreads

Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

Metastasis –
cells invade other
parts of the body via
blood vessels and
lymph vessels





The breasts

Women and men both have breast tissue.

In women, breasts are made up of milk glands. A milk gland consists of:

- **lobules** – where milk is made
- **ducts** – tubes that carry milk to the nipples.

In men, the development of the lobules is suppressed at puberty by testosterone, the male sex hormone.

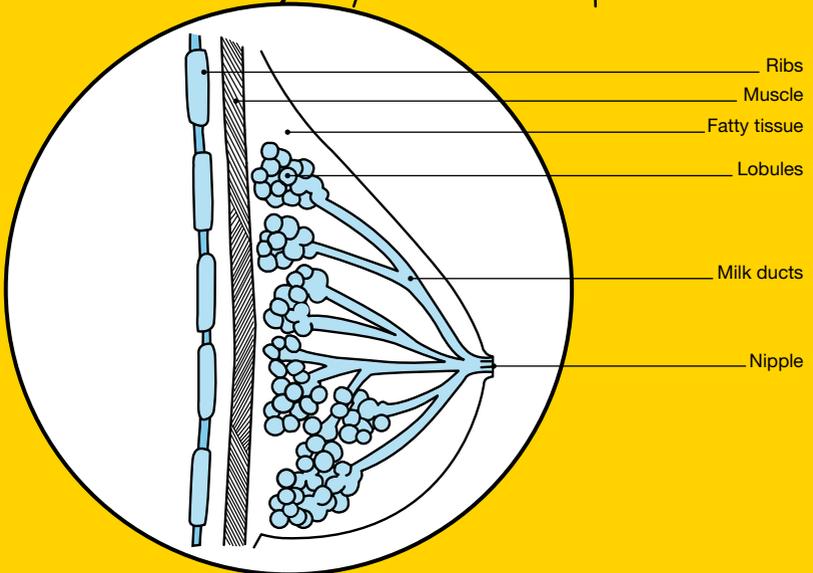
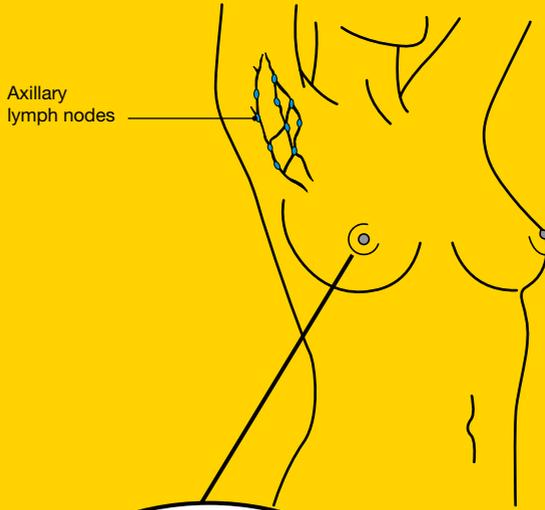
Both female and male breasts contain supportive fibrous and fatty tissue. Some breast tissue extends into the armpit (axilla). This is known as the axillary tail.

Lymphatic system

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

Lymph nodes are found throughout the body, including the armpits (axillary), the breastbone, the neck, abdomen and groin.

The breasts





Key questions

Q: What is breast cancer?

A: Breast cancer occurs when the cells lining the breast lobules or ducts grow abnormally and out of control. A tumour can form in the lobules or ducts of the breast.

Women and men can both get breast cancer, although it is rare in men.

Q: What are the different types?

A: There are several types of breast cancer.

Non-invasive breast cancer

Ductal carcinoma in situ (DCIS) – Abnormal cells are contained within the ducts of the breast.

Invasive breast cancer

Early breast cancer – This means the cancer has spread from the ducts or lobules into surrounding breast tissue. It may also have spread to lymph nodes in the armpit. Most breast cancers are found when they are invasive.

The most common types are invasive ductal carcinoma (IDC) and invasive lobular carcinoma (ILC).

Locally advanced breast cancer – The cancer has spread to other areas near the breast, such as the chest (including the skin, muscles and bones of the chest).

Secondary breast cancer

Metastatic breast cancer – Cancer cells have spread from the breast to other areas of the body, such as the bones, liver or lungs. This is also called advanced breast cancer.



Some women have abnormal cells in the lobules of the breast. This is called lobular carcinoma in situ or LCIS. This is not cancer. While LCIS increases the risk of developing cancer, most women with this condition will not develop breast cancer. Your medical team will monitor you with regular mammograms (see page 13) or other types of breast imaging.

Q: How common is breast cancer?

A: Breast cancer is the most common cancer in Australian women, representing 28% of all cancers in women. About 14,000 women are diagnosed each year. One in eight women will be diagnosed with breast cancer by the age of 85.

Although it can occur at any age, breast cancer is more common in older women. More than two in three (69%) are diagnosed in women aged 40–69. About one in four (25%) are diagnosed in women aged 70 and over. Nearly 80% of women diagnosed had IDC, while about 11% had ILC.

About 130 men are diagnosed in Australia each year. This represents less than 1% of all breast cancers.

Q: What are the symptoms?

A: Some people have no symptoms but if you do, you may notice a change in your breast or your doctor may find an unusual breast change during a physical examination.

Signs to look for include:

- a lump, lumpiness or thickening
- changes to the nipple, such as a change in shape, crusting, a sore or an ulcer, redness, unusual discharge, or a nipple that turns in (inverted) when it used to stick out
- changes to the skin of the breast, such as dimpling, unusual redness or other colour changes
- an increase or decrease in the size of the breast
- a change to the shape of the breast
- swelling or discomfort in the armpit
- persistent, unusual pain that is not related to your normal monthly menstrual cycle, remains after a period and occurs in one breast only.

Breast changes don't necessarily mean you have cancer. However, if you have any symptoms, have them checked by your doctor without delay. Some women have no symptoms and the breast cancer is found on a screening mammogram (see page 13).



Women aged 50–74 should have regular screening mammograms through BreastScreen. Call **13 20 50** to make a free appointment.

Q: What are the risks?

A: In women, the exact cause of breast cancer is not known, but some factors increase the risk. These include:

- getting older (most common in women over 50)
- having several close relatives, such as a mother, father, sister or daughter, diagnosed with breast cancer on the same side of the family
- if you have had breast cancer before
- if you have had certain breast conditions, such as atypical ductal hyperplasia, ductal carcinoma in situ or lobular carcinoma in situ.

Some lifestyle factors, such as being overweight or drinking more than one standard alcoholic drink a day, may also slightly increase the risk.

Having some of these risk factors does not necessarily mean that you will develop breast cancer. Most women with breast cancer have no known risk factors, aside from getting older.

In men, breast cancer usually occurs over the age of 60. It is most common in men who have:

- several close family members (male or female) who have had breast cancer
- a relative diagnosed with breast cancer under the age of 40
- several relatives with cancer of the ovary or colon
- a rare genetic syndrome called Klinefelter syndrome. Men with this syndrome have three sex chromosomes (XXY) instead of the usual two (XY).

Inherited breast cancer gene

Most women diagnosed with breast cancer do not have a family history of the disease.

However, a small number of women with breast cancer (about one in 20) have inherited a gene fault that increases their risk. The two most common breast cancer genes are called BRCA1 and BRCA2.

Everyone inherits a set of genes from each parent, so they have two copies of each gene. Sometimes there is a fault in one copy of a gene, which stops that gene working properly. This fault is called a mutation.

Women in families with an inherited gene change are at an increased risk of breast and ovarian cancer. Men in these families may also be at an increased risk of breast and prostate cancer.

People with a strong family history of breast cancer can be tested to see if they have inherited a gene change. If you would like to know more about genetic testing, talk to your doctor or breast care nurse, or call Cancer Council Helpline **13 11 20**.



Diagnosis

Several tests are commonly used to find out if your breast change is due to cancer.

Physical examination

Your doctor will feel your breasts and the lymph nodes under your arms. They will take a full medical history and ask about your family history.

Mammogram

A mammogram is a low-dose x-ray of the breast tissue. This x-ray can find changes that are too small to be felt during a physical examination. Your breast is pressed between two x-ray plates, which spread the breast tissue out so clear pictures can be taken. Both breasts are checked. This procedure can be uncomfortable, but it's over in about 20 seconds.

If the lump your GP could feel during the physical examination is not shown on a mammogram, other tests will need to be done.

Ultrasound

An ultrasound is a painless scan that uses soundwaves to create a picture of your body. A gel is spread on your breast and a small device called a transducer is moved over the area. This sends out soundwaves that echo when they meet something dense, like an organ or tumour. A computer creates a picture from these echoes. The scan takes about 15–20 minutes.

Breast MRI

This form of breast imaging uses a large magnet in a scanner to image breast tissue. Breast MRI (magnetic resonance imaging) is more sensitive than mammography or breast ultrasound. It is commonly used to screen women at high-risk of breast cancer, but it can also be used in women with very dense breast tissue. Breast MRI is becoming more widely available, however it requires special expertise to interpret the results.

During the scan, you may have an injection of a contrast dye to make any potential cancerous breast tissue easier to see. To have the breast MRI, you will lie facedown on a screening table with cushioned openings for your breasts. The table slides into the machine. This test can take 30–60 minutes.

Biopsy

Your doctor will suggest a biopsy if an abnormal or unusual area is felt in your breast. During a biopsy, a small amount of tissue is removed from your breast. A pathologist examines the removed tissue and checks for cancer cells under a microscope. There are a few ways of taking a biopsy, and you may need more than one.

Fine needle aspiration (FNA) – A thin needle is used to take some cells from the breast lump or abnormal area. Sometimes an ultrasound is used to help guide the needle. The test is a bit uncomfortable – it can feel similar to having blood taken. It is usually done in a specialist's rooms, by a pathologist in a hospital outpatient department or at a radiology practice.

Core biopsy – A wider needle is used to remove a small piece of tissue, called a core, from the lump or abnormal area. It is usually done under local anaesthetic, so your breast is numb, though you may still feel some pain or discomfort. During this procedure, a mammogram, ultrasound or MRI is used to help guide the needle.

🗨️ I had a core biopsy by ultrasound and didn't find it very painful. Afterwards I had a small amount of bruising. I have heard other women say I was lucky, and they experienced more pain and bruising. 🗨️ *Maria*

Vacuum-assisted stereotactic biopsy (VAB) – This is also performed under local anaesthetic. Lots of small tissue samples are removed using a suction-type instrument and computer-guided technology.

Surgical biopsy – If the abnormal area is too small to be biopsied using the methods above, a surgical biopsy is done. Before the biopsy, a guide wire may be put into the breast to help the surgeon find the abnormal tissue. You will be given local anaesthetic, and the doctor may use an ultrasound or mammogram to insert the wire. This is done in the radiology department.

The biopsy is then done in a separate operation using a general anaesthetic. The lump and a small area of breast tissue around it are removed, along with the wire. This biopsy is usually done as day surgery, but some women have an overnight stay in hospital.

Testing the tumour cells for hormone receptors and genes

A pathologist will examine the breast tissue. The sample comes from a biopsy or tissue removed during surgery. The findings of these tests will be outlined in a pathology report, which will include the size and location of the tumour, the grade of the cancer, whether there are cancer cells close to the edge of the breast tissue and whether there are cancer cells in your lymph nodes. The pathology report will help your doctor decide what treatments are best for you. Additional tests will be done to show if the cancer has receptors for hormones or growth factors.

Hormone receptors

Hormones affect some types of breast cancer. Hormones are chemical messengers in the body that transfer information. Before menopause, the ovaries produce the hormones oestrogen and progesterone. These hormones can cause cancer to grow.

A hormone receptor is a protein in a cell. In breast cancer, hormone receptors receive signals from oestrogen and progesterone to promote cancer cell growth. There are two types of hormone receptors: oestrogen receptors and progesterone

receptors. About two out of every three breast cancers contain hormone receptors.

- Cancer cells that have oestrogen receptors are called oestrogen receptor positive (ER+).
- Cancer cells that have progesterone receptors are called progesterone receptor positive (PR+).
- Cells without receptors are hormone receptor negative.

A cancer that is ER+ or PR+ is more likely to respond to hormone treatments (see pages 46–47).

HER2 status

The HER2 (human epidermal growth factor receptor 2) test looks for a protein that is found on the surface of cells. This protein causes the cell to grow and divide in an uncontrolled way. Tumours that have high levels of these receptors are referred to as HER2-positive (HER2+).

About one in five women have HER2+ cancer cells. Treatment with targeted therapies, such as Herceptin® (see pages 45–46) is usually recommended.

Genomic assays

The use of the Oncotype DX Breast Cancer Assay or Oncotype DX test is still new in Australia, but it is widely used in the United States.

In Australia, this test costs \$5000, and is not currently covered by either Medicare or private health funds.

The Oncotype DX test uses a sample of breast tissue to analyse a group of 21 genes. These genes help predict the risk of breast cancer coming back after treatment and if you are likely to benefit from chemotherapy after surgery (adjuvant chemotherapy).

Women who are suitable for this test include:

- those with ER+ or PR+ tumours
- those who have 0–3 positive lymph nodes.

Talk to your doctor if you would like to know more about this test. A pathologist will take a portion of the tumour tissue, which will be sent to America, where all Oncotype DX testing is currently done. Your doctor will usually receive the results within 2–3 weeks.

Further tests

If the tests described on the previous pages show you have breast cancer, one or more tests may be done to see if the cancer has spread to other parts of your body. The test and scan results will be written in a pathology report.

Blood tests

Blood samples may be taken to check your general health, and also to look at your bone and liver function for signs of cancer.

Chest x-ray

Your doctor may take an x-ray of your chest to check your lungs for signs of cancer.

CT scan

A CT (computerised tomography) scan is a type of x-ray procedure that takes pictures of the inside of the body. Unlike a standard x-ray, which takes a single picture, a CT scan uses a computer to compile many pictures of the body. It can show if the cancer has spread to the lymph nodes or other organs.

To make the scan pictures clearer and easier to read, you may have to fast (not eat or drink). You will also be asked to drink a liquid and have an injection of a dye into a vein in your arm. This can make you feel hot all over for a few minutes.

You will lie flat on a table while the CT scanner, which is large and round like a doughnut, takes pictures. This painless test takes about 30–40 minutes.

Bone scan

A bone scan may be done to see if the breast cancer has spread to your bones. A small amount of radioactive material is injected into a vein, usually in your arm. This material is attracted to areas of bone where there is cancer.

After a few hours, the bones are viewed with a scanning machine, which sends pictures to a computer. This scan is painless and will not make you radioactive. You should drink plenty of fluids on the day of and the day after the test.

PET scan

A PET (positron emission tomography) scan is a specialised test, which is rarely done for breast cancer. It uses low-dose radioactive glucose to measure cell activity in different parts of the body.

A small amount of glucose is injected into a vein, usually in your arm. You will need to wait for about an hour for the fluid to flow through your body.

You will then lie on a treatment table that moves through a scanning machine. This body scan will show 'hot spots' where the fluid has accumulated – this happens where there are active cells, like cancer cells.

While a PET scan is not a routine test, it may be used if other types of scans don't give doctors the information they need.



tip

There are extra costs associated with some tests and scans, depending on whether you are treated in a public or private hospital. Talk to your medical team for information about how much you will be charged.

Staging breast cancer

The tests described on pages 18–19 show if the cancer has spread to other parts of the body. Working out how far the cancer has spread is called staging. Stages are numbered from I to IV.

Stages of early breast cancer

Stage I	The tumour is less than 2 cm in diameter and has not spread to the lymph nodes in the armpit.
Stage IIA	The tumour is less than 2 cm in diameter and has spread to the lymph nodes in the armpit.
	The tumour is between 2 cm and 5 cm in diameter and has not spread to the lymph nodes in the armpit.
Stage IIB (early)	The tumour is 2–5 cm in diameter and has spread to the lymph nodes.

Stages IIB (advanced), III and IV refer to advanced breast cancer. For information about these stages, call Cancer Council Helpline **13 11 20** or visit <http://canceraustralia.gov.au>.

Grading breast cancer

The cancer will also be given a grade. The grade describes how fast the cancer is growing.

Grading	
Grade 1 (low grade)	Cancer cells look a little different from normal cells. They are usually slow growing.
Grade 2 (intermediate grade)	Cancer cells do not look like normal cells. They are growing faster than grade 1 but not as fast as grade 3.
Grade 3 (high grade)	Cancer cells look very different from normal cells. They are fast growing.

Prognosis

Prognosis means the expected outcome of a disease.

Most people with early breast cancer can be treated successfully. Survival rates have increased significantly over time due to better diagnostic tests and scans, earlier detection and improvements in treatment methods. According to recent statistics, the five-year survival rate for women with IDC, the most common type of breast cancer, is 90%¹.

A cure may still be possible for people with other types of breast cancer. For many, treatment can improve quality of life.

Which health professionals will I see?

You will be cared for by health professionals who specialise in different aspects of your treatment. You may also see other allied health professionals who work alongside the doctors and nurses.

Specialist health professionals

breast surgeon	specialises in surgery and performs biopsies; some breast surgeons also perform breast reconstruction and specialised oncoplastic procedures as part of the breast cancer surgery
oncoplastic breast surgeon	specialises in the use of plastic surgery techniques to achieve good appearance after surgery
pathologist	examines cells and tissue that is removed from the breast to determine the type and extent of the cancer
breast care nurses	specialist nurses who are trained in breast cancer care and provide information and support through all stages of treatment and ongoing care
radiologist	specialises in reading x-rays, such as mammograms
radiation oncologist	prescribes and coordinates radiotherapy
radiation therapist	plans and delivers radiation treatment
medical oncologist	prescribes and coordinates chemotherapy, hormone therapy and targeted drug therapies

Allied health professionals provide important care and support services. The following health professionals may be in your multidisciplinary team (MDT).

GP (general practitioner)	explains information provided by specialists, helps you with treatment decisions, assists you in obtaining practical and emotional support, and works in partnership with your specialist in providing your ongoing care
reconstructive (plastic) surgeon	performs breast reconstruction for women who have had a mastectomy
lymphoedema therapist	educates patients about lymphoedema management and provides treatment if lymphoedema occurs
physiotherapist, occupational therapist	assist in restoring range of movement after surgery
nurses	support and help you through all stages of your treatment
genetic counsellor	provides advice for people with a strong family history of breast cancer
counsellor, psychologist, psychiatrist	provide emotional support and help manage anxiety and depression



Key points

- Several tests are used to diagnose breast cancer.
- Your doctor will feel your breasts and upper body, and you will probably have an x-ray of the breast (mammogram) to check for any changes.
- You may have an ultrasound, which is a painless scan that uses soundwaves to create a picture of your body.
- You may have a breast MRI, which is used to assess dense breast tissue and involves an injection of dye.
- A biopsy is when a small sample of tissue is removed from your breast. There are a few ways of doing a biopsy.
- Some types of breast cancer are sensitive to hormones that can cause the cancer to grow. Knowing if the cancer cells have hormone receptors helps your doctors recommend treatment.
- You may have other tests, such as blood tests, x-rays, and CT and PET scans to see if the cancer has spread to other parts of your body.
- Knowing how far the cancer has spread (stage) helps your doctors plan treatment. The cancer will also be given a grade, which describes how fast the cancer cells are growing.
- Prognosis is the expected outcome of the disease. Most women with early breast cancer can be treated successfully.
- A range of health professionals will work together to care for you. This multidisciplinary team may include a surgeon, nurses, a medical oncologist and a radiation oncologist.



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. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 67 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor 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 doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor or nurse may suggest 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.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call the Helpline for a free copy of *Understanding Clinical Trials and Research* or visit www.australiancancertrials.gov.au.

Treatment

Treatment for early breast cancer aims to remove the cancer and reduce the risk of the cancer spreading or coming back.

Treatment may include surgery, radiotherapy, chemotherapy, hormone therapy and targeted therapies. Usually more than one treatment is used.

Your doctors will consider the following factors to recommend the best treatment for you. The choice of treatment will depend on:

- your test results
- where the cancer is in the breast
- if the cancer has spread
- whether the cancer has the oestrogen, progesterone or HER2 receptor protein
- your age and general health
- your preferences.

As there are different categories of breast cancer, the most suitable treatment varies from person to person. You may want to read Cancer Australia's book, *Guide for women with early breast cancer*. You can download it from <http://canceraustralia.gov.au> or call 1800 624 973 for a copy.

Men who have early breast cancer have similar treatment options to women. Men often feel embarrassed that they have what is considered a woman's disease. Resources for men are available at <http://breastcancerinmen.canceraustralia.gov.au>.



Surgery

Surgery for breast cancer will involve one of the following:

- **breast conserving surgery** – removes part of the breast
- **mastectomy** – removes the whole breast.

In most cases, breast surgery also involves removing one or more lymph nodes from the armpit (see pages 34–35).

Which surgery should I have?

Some women are offered a choice between breast conserving surgery and a mastectomy. In this situation, it can feel like a difficult decision to make.

for most women with early breast cancer²⁻⁶. The chance of the cancer coming back (recurrence) is the same regardless of which surgery you choose.

Research has shown that breast conserving surgery, with sentinel lymph node biopsy followed by radiotherapy, is as effective as mastectomy

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

Breast conserving surgery

Surgery to remove the breast cancer and some surrounding healthy tissue is called breast conserving surgery. It is also called lumpectomy or wide local excision. Breast conserving surgery is offered if the cancer is small compared to the size of your breast.

The surgeon removes the smallest amount of breast tissue possible. This will leave a scar and will change the size and, potentially, the shape of the breast, as well as the position of the nipple.

Oncoplastic breast conserving surgery combines oncological and plastic surgical techniques to reshape the breast and preserve its appearance. This specialised surgical technique is performed by only some breast surgeons.

The removed breast tissue is sent to a laboratory for examination by a pathologist, who looks at the tissue to see if there is an area of healthy cells around the cancer – this is known as a clear margin. The pathologist will create a report, which will include information about the size and grade of the cancer, whether lymph nodes are involved and if the cells are hormone and HER2 receptor positive or negative (see pages 16–17).

If cancer cells are found at the edge of the removed tissue, this increases the chance of cancer returning. You may need more tissue removed (re-excision or wider excision), or a mastectomy may be recommended.

After surgery, radiotherapy to the whole breast is usually recommended to destroy any undetected cancer cells that may be left in the breast or armpit and to keep the cancer from coming back (recurrence).

Some women also need chemotherapy, hormone therapy or targeted therapy. This will depend on the grade and stage of the cancer.

Lumpectomy

This woman has had a wide local excision followed by radiotherapy. This is how the scar looks two years after surgery.



Lumpectomy with oncoplastic surgery

This woman has had a wide local excision with a scar around the areola. After surgery her left breast is a slightly different size. Surgery was followed by radiotherapy. Appearance at one year after surgery.





Elizabeth's story

I was diagnosed with breast cancer at age 60. I noticed a small hard lump in my left breast that was the size of a pea. I went off and had a mammogram. It showed no sign of breast cancer, but the lump was still there so I decided to investigate it further. A scan was done and showed a suspicious area.

A fine needle biopsy and core biopsy followed. The results of the fine needle biopsy, which I got straight away, showed positive to breast cancer. The core biopsy results came back a few days later identifying the type of cancer I had.

I had a lumpectomy and a sentinel node removed. The sentinel node had cancer in it so I had to go back for a full axillary clearance, and then I had chemo. Four doses, one every three weeks. I was supposed to have 12 doses of taxol. They were on a weekly schedule but I only had 8.

This was followed with radiation and I've bounced back from there. At the time I did question whether I needed to have a mastectomy but they said no, we're finding the results of a lumpectomy are just as a good. So I opted for that.

Now I have an indentation in my breast but it doesn't look that odd. Just like a dimple. And you can't see the scar at all. The surgeon went around the outside of my nipple.

I think I lost more of my armpit having to have the axillary clearance than I did of my breast. If you look closely I have one fairly thick solid armpit but the other one has a big hole. But nobody has ever mentioned it to me so it's just one of those things. For example, if I went topless on the beach people probably wouldn't know. I was fairly happy with the result. And hey, I'm alive and that's the best result.

Mastectomy

Surgery to remove the whole breast is called a mastectomy.

You may be offered a mastectomy if:

- there is more than one cancer in different areas of the breast
- the cancer is large compared to the size of the breast
- you have had radiotherapy before to treat another cancer
- clear margins cannot be obtained after one or two breast conserving procedures.

Some people may feel more comfortable having a mastectomy, particularly if they are unable to have radiotherapy.

During a mastectomy, the nipple is also usually removed. The chest muscles are not removed. Some or all of the lymph nodes in the armpit closest to your affected breast may also be taken out (see pages 34–35).

While your surgical wound heals, you can wear a soft temporary breast prosthesis (form) inside your bra. The surgical wound heals in about 3–6 weeks, and then you can be fitted for a breast form (see pages 55–56). Some women may choose to have a surgical breast reconstruction (see page 34).

In some cases, the surgeon may be able to perform a skin-sparing or nipple-sparing mastectomy. This means that more of the normal skin – with or without the nipple – is kept. This allows the surgeon to do an immediate breast reconstruction with either a temporary implant (tissue expander), permanent implant or using tissue from another part of your body.

Mastectomy

This woman has had the left breast removed. At this stage, she has not had a reconstruction. She may choose to do so later or she may choose to wear a breast form.



Mastectomy with an implant reconstruction

This woman has had a right mastectomy and reconstruction using an implant. She has not had a nipple reconstruction. She has the option to do this later if she chooses.



Breast reconstruction

A breast reconstruction is a type of surgery in which a breast shape is created using a silicone or saline implant, tissue from another part of your body, or a combination of both.

Some women have the reconstruction at the same time as the mastectomy (immediate reconstruction). Others are advised to, or prefer to wait for several months or longer (delayed reconstruction). If you're not having an immediate reconstruction but think you might consider it in the future, mention this to your surgeon as it help them plan the surgery.



To find out more talk to your surgeon or call Cancer Council Helpline **13 11 20** for a copy of *Breast Protheses and Reconstruction* or view it online.

Removing lymph nodes

Lymph nodes (glands) are found throughout the body, including the armpit. They are small, bean-shaped collections of lymph cells that protect the body against disease and infection. The lymph nodes are part of the lymphatic system.

The lymph nodes in the armpit are often the first place breast cancer cells spread to outside the breast. To check if breast cancer has spread to the lymph nodes, some or all of them are removed. Removing the lymph nodes helps get rid of any cancerous lymph nodes and gives information about the stage of the cancer.

There are different types of lymph node surgery:

Sentinel lymph node biopsy – The sentinel node is the first lymph node that breast cancer cells may spread to outside the breast. There can be more than one sentinel node. Usually it is in the armpit but it can also be found near the breast bone (sternum). Removing only the sentinel node/s will cause fewer side effects than axillary surgery (see below).

To find the sentinel node, a small amount of radioactive substance is injected around the nipple and areola area before surgery. A scan is taken to show which node the substance flows to first. During surgery, a blue dye is injected around the nipple and areola area. The dye moves into the lymphatic vessels. The nodes that are radioactive or become blue first are known as the sentinel lymph nodes. The surgeon will remove these so they can be tested for cancer cells.

If the sentinel nodes are clear of cancer cells, no further surgery is needed. If the sentinel node/s contain cancer cells, axillary surgery is needed.

Axillary (lymph node) surgery – This may be done at the same time as the breast surgery or as a separate operation. It is known as axillary clearance or axillary dissection. The doctor will remove between 10–20 lymph nodes and send them to a pathologist for examination. The pathologist will provide a report showing the number of nodes removed and how many contain cancer cells. These results help your doctor recommend further treatment.



Page's story

I was diagnosed with breast cancer 11 years ago at age 41. I'd been to aqua aerobics and afterwards when I was getting dressed and putting on deodorant, I noticed a flat spot on my breast. It looked like my nipple was pointing upward.

I thought this was unusual so I went to my GP for a check-up. My doctor referred me to have my first mammogram, then I also had an ultrasound and needle biopsy. I was diagnosed with stage 2 cancer. It was quite a large 40 mm tumour near the centre of my chest.

A few weeks later, I had a mastectomy of my left breast. Before surgery, the doctor didn't know if the cancer had spread or if they would have to take my entire breast. During surgery, they removed about two-thirds of the breast, then the next day they told me that the pathology results meant I had to have further surgery to remove the

rest of the breast. This was discouraging, but I understand why they did it, and I was actually fine with having the whole breast removed. What's the use of having one-third of a breast left?

Afterwards, I had to have several weeks of chemotherapy and radiotherapy treatment.

My cousin's wife had breast cancer about eight years before, and I remember the advice she gave me. She said, "Page, this isn't going to be your year – it's going to be a hard year. But you'll get through it and you won't look back." She was right.

I used a silicone breast form for about nine years. About two years ago, I decided to have reconstructive surgery. The surgeon lifted my right breast and used some tissue from my tummy to create a left breast. I'm very happy with the result of the surgery.

What to expect after surgery

The length of your hospital stay will depend on the type of breast surgery you've had and how well you are recovering. Most people are able to walk around and shower the day after surgery. If you have any questions, ask the doctors and nurses caring for you. Many people are referred to a breast care nurse for information and support.

Tubes – You may have several tubes in place after a lumpectomy, mastectomy, reconstruction or axillary surgery, and a dressing will cover the wound to keep it clean. An intravenous drip will give you fluid as well as medication. There may also be a drain in your breast to take fluid from the surgical site. The drains are usually taken out 1–3 days after surgery and the dressing is usually removed after about a week.

If you have had axillary surgery you may also have a drain from this site, which is usually removed in 3–7 days.

Some people are discharged with drains still in place, but this will depend on your situation and your doctor's advice. The nurse will teach you how to manage the drains at home.

Blood clots – While you are in hospital, it's important to move your legs when you are in bed, and when you are able, get up and walk around. You may be required to wear graduated compression stockings or use other devices. This helps prevent blood clots. Your doctor might also prescribe you medication to lower the risk of clots.

Pain – You will be given pain relief by injection or tablets, and you will also be given pain medication when you go home. Any bruising and swelling at the surgery site will usually settle down in 2–3 weeks.

Sense of loss – Breast surgery may change the appearance of your breast, and this can affect how you feel about yourself (self-esteem). You may feel a sense of loss if you've had a mastectomy. It is normal to grieve over the loss of your breast.

Talking to someone who has also had breast surgery might be helpful. Cancer Connect may be able to link you to someone who has also had a similar experience to you. Call Cancer Council for more information.

Arm exercises – After the drains are removed you can slowly begin to exercise your arm. This will help it feel better and get back to normal faster.

For a guide to exercises you can do after surgery, call 13 11 20 for a copy of Cancer Council's exercise poster. Please note this resource may not be available in all states and territories.

“ The breast care nurse showed me some exercises to do. I started them immediately and did them everyday without fail for four years. It is now five years since my treatment and I still include them in my exercise program. ” Elizabeth

Side effects of surgery

After surgery, you will find that the swelling will go down, bruising will fade and scars will gradually become less obvious.

Fatigue – Feeling tired and having no energy is common. Treatment and the emotional impact of the diagnosis can be tiring. Fatigue may continue for months or, in some cases, for years.

Shoulder stiffness – Gentle exercises can help prevent or manage shoulder stiffness. Some people regain shoulder movement quickly, others may require further physiotherapy. Ask your breast care nurse, a physiotherapist or occupational therapist about suitable exercises.

Numbness of the arm – Surgery can cause bruising or injury to nerves, which may cause numbness and tingling in the chest and arm area. The numbness often improves within a few weeks but may take longer or, for some people, not go

away completely. Shoulder exercises will help improve movement.

Seroma – Fluid may collect in, or around, the scar in the breast or lymph nodes. The breast care nurse, your specialist or GP, or a radiologist can drain the fluid using a fine needle and syringe.

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

Lymphoedema – The arm may swell due to fluid build up following lymph node surgery or sometime later. See pages 51–53 for more information.

Most side effects can be managed. Talk to your doctor or breast care nurse about ways to deal with any of the side effects you experience.

What to expect when you get home



Resuming activities

- Recovery time varies.
- Most people start to feel better about two weeks after surgery. Get plenty of rest in the first few days after coming home from hospital.
- Take it easy and only do what is comfortable.
- Check with your surgeon and/or breast care nurse about when you can start doing your regular activities. For example, some surgeons tell you to avoid driving until the stitches come out or for a few weeks until your arm is more agile.



Wound care

- Talk to your surgeon and breast care nurse about the best way to look after your wound.
- Keep the wound clean and dry. Shower carefully and pat the wound dry.
- Bruising and swelling will improve with time.
- Gently massage the area with a moisturiser such as sorbeline once the stitches have been removed.
- Use roll on deodorant, if necessary, but avoid spray-on deodorant.
- Wear a bra or soft crop top when it is comfortable to do so.
- Report any redness, pain, swelling or wound discharge to your surgeon or breast care nurse.

Radiotherapy

Radiotherapy uses high-energy x-rays to kill cancer cells or stop them growing. This treatment is recommended:

- after breast conserving surgery to help destroy any undetected cancer cells that may be left behind in the breast and reduce the risk of the cancer coming back (adjuvant treatment)
- sometimes after a mastectomy, depending on the risk of the cancer coming back in the chest area
- if lymph nodes from under the arm were removed and the risk of the cancer coming back in this area is thought to be high.

You will usually start radiotherapy four weeks after surgery. If you're having chemotherapy after surgery, radiotherapy treatment will begin when chemotherapy has finished.

Planning treatment

Treatment is carefully planned to have the greatest effect on the cancer cells and to limit the damage as much as possible to your surrounding healthy body tissues. Planning consists of several steps, which may occur over a few appointments.

Before you start treatment, you will have a planning session at the radiotherapy centre. During this visit, x-rays are taken to pinpoint the area to be treated and marks will be put on your skin so that the radiation therapist treats the same area each time.

These marks are small dots (tattoos) and may be temporary or, in some cases, permanent. Talk to your radiation oncologist if you are uncomfortable with having a permanent tattoo.

Having treatment

Once treatment starts, you will probably have radiotherapy once a day from Monday to Friday for 5–6 weeks. Usually you can have outpatient treatment and go to the radiotherapy centre each day.

Each radiotherapy session will be in a treatment room. Although you will only get radiation for 1–5 minutes, you might be in the treatment room for 10–30 minutes. Most of the time is spent positioning you and the treatment machine.

You will lie on a table under the radiotherapy machine. The radiation therapist will leave the room then turn on the machine, but you can talk to staff through an intercom. Radiotherapy is not painful but you need to lie still while the treatment is given.

Getting to and from appointments



Assistance with transport

If you live in a regional or rural area, you may need to travel for radiotherapy treatment.

Every state and territory has a scheme that provides financial help to people who need to travel long distances to access specialist medical treatment not available in their local area.

Patient transport schemes are not usually full subsidy schemes. You are often required to contribute towards the cost. To apply contact the relevant State or Territory government department. For more details, talk to the hospital social worker or call Cancer Council Helpline.

Side effects of radiotherapy

Radiotherapy may cause the following side effects:

Tiredness – You may feel tired or fatigued 1–2 weeks after radiotherapy starts and during treatment. This usually eases a few weeks after treatment finishes.

Red and dry skin – The skin near the treatment site may become red and dry after a few weeks of treatment. The skin usually returns to normal 4–6 weeks after treatment ends. Radiotherapy nurses will show you how to care for your skin. Sorbolene cream applied twice a day can be helpful.

Inflammation & blistering – Less commonly, your skin may become very irritated. This will be closely monitored by the treatment team.

Aches and swelling – You may feel minor aches or shooting pains that last for

a few moments. Some women develop fluid in the breast (breast oedema).

These changes to the breast may be ongoing for up to 12 months, but can last up to five years. This treatment may also increase the chance of developing lymphoedema (see pages 51–53 for more details). Always talk to your doctor about any changes you experience.

Radiotherapy to the breast does not cause hair loss. It also does not make you radioactive – it is safe to spend time with friends and family.

For more information on radiotherapy and ways to deal with side effects, call **13 11 20** for a free copy of Cancer Council's *Understanding Radiotherapy* booklet or visit your local website.

Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. Chemotherapy is usually given before radiotherapy and may be used if:

- the cancer needs to be shrunk or controlled before surgery (neoadjuvant chemotherapy)
- the risk of the cancer returning is high, to try to prevent the breast cancer coming back or spreading to other parts of the body
- the cancer isn't sensitive to hormone therapy (see pages 46–47)
- cancer returns after surgery or radiotherapy, to gain control of the cancer and to relieve symptoms.

There are several different types of chemotherapy drugs used to treat breast cancer. The drug combination you are given will depend on the type of breast cancer you have and what other treatments you are having. Common drugs include doxorubicin, cyclophosphamide, fluorouracil, docetaxel, paclitaxel and carboplatin. Your medical team may also refer to the drugs by their brand (trade) names.

Chemotherapy is usually given through a vein (intravenously). You will usually be treated as a day patient but occasionally an overnight stay may be recommended. The number of chemotherapy sessions can vary depending on the combination of drugs prescribed by your oncologist. Commonly, chemotherapy is given one day every three weeks for 3–6 months. The recovery time after each treatment session is called a cycle. This gives your body time to recover before the next session.

Side effects of chemotherapy

The side effects caused by chemotherapy depend on the drugs used. Most side effects are temporary and they often can be prevented or reduced.

less likely to cause nausea or vomiting. Let your treatment team know about the side effects you experience so they can help you manage them.

Side effects may include tiredness, mouth ulcers or weight changes. Most people who have chemotherapy for breast cancer lose their head and body hair. Some treatment centres provide cold caps, which often prevent total head hair loss. The chemotherapy medications used today are

For some women their periods can become irregular or stop during chemotherapy, but return to normal after treatment. For others, chemotherapy may cause periods to stop permanently (menopause). For information see page 54.

Targeted therapies

Also known as biological therapies, these stop the growth of cancer cells that have a higher than normal level of a protein known as HER2, which stimulate cancer cells to grow.

Herceptin®

Trastuzumab (known as Herceptin®) is a common type of targeted therapy for breast cancer. It works by attaching itself to HER2 positive breast cancer cell receptors. This can destroy cells and reduce their ability to divide and grow. Herceptin® also encourages the body's own immune cells to help destroy the cancer cells.

Herceptin® also increases the effect of chemotherapy drugs on breast cancer. Several trials have shown that Herceptin® used in combination with chemotherapy for women with HER2 positive early breast cancer works better than chemotherapy alone.

You will receive this drug via an infusion into a vein. You will usually have treatment weekly or every three weeks. The first infusion may take up to 90 minutes. The following infusions are over 30 minutes, and will continue for up to 12 months.

Your medical team will monitor you for side effects. The most common side effects include fever, runny nose, diarrhoea, headache and a rash. Herceptin® can affect the way your heart works. You will have tests to check your normal heart function before starting with Herceptin®, and at regular intervals during treatment. Talk to your doctor about what to expect.

Hormone therapy

Hormone therapy, also called endocrine therapy, is for people who have hormone receptors (ER or PR) on their breast cancer cells. The aim of hormone therapy is to slow or stop the growth of hormone receptor positive cancer cells.

Ask your doctor if hormone therapy is suitable for you. There are different ways of reducing the level of female hormones in the body. This will depend on your age, the type of breast cancer you have and whether you have reached menopause. To read more about hormone receptor cancer cells, see page 16.

Tamoxifen

Tamoxifen is known as an anti-oestrogen drug. It works by stopping cancer cells responding to oestrogen. Tamoxifen is usually started after surgery or following radiotherapy or chemotherapy treatment. It is taken as a daily tablet over five years. This drug can be given to women of any age, regardless of whether they have reached menopause, but it is usually given to pre-menopausal women.

Tamoxifen does not cause menopause but the side effects are similar. The most common side effects include hot flushes, trouble sleeping, vaginal dryness or discharge, low mood, weight gain and irregular periods. Tamoxifen may also increase the risk of blood clots – see your doctor immediately if you have any swelling, soreness or warmth in your arm or leg. If you are having other surgery or travelling long distances, you may need to stop taking tamoxifen beforehand to lower the risk of blood clots. You can resume taking it when surgery or travel is completed.

Any side effects you experience will usually improve as treatment continues and when it ends. Your doctor and breast care nurse can give you information about ways to manage these side effects.

A rare side effect of tamoxifen is increased risk of uterine cancer in post-menopausal women. See your doctor if you notice any unusual bleeding. If you're taking tamoxifen for more than five years, you should have annual gynaecological examinations.



Aromatase inhibitors

Aromatase inhibitors help prevent the growth of oestrogen-dependent cancer cells by reducing the amount of oestrogen made in the body. They are used only in post-menopausal women.

Examples of aromatase inhibitors include anastrozole (Arimidex®), exemestane (Aromasin®) and letrozole (Femara®). They are taken daily, usually for five years.

Side effects may include loss of bone density, vaginal dryness, joint and muscle pain, low mood, hot flushes and weight gain. For people with arthritis, the joint pain can be quite debilitating.

Ovarian treatments

For women who have not reached menopause, treatments that stop the ovaries from producing oestrogen, temporarily or permanently, may be recommended.

Temporary ovarian treatment – These treatments include the drug goserelin (Zoladex®), which stops oestrogen production. This drug is suitable for women who have breast cancer that is sensitive to oestrogen. Zoladex® is injected into the body to bring on a temporary menopause.

You may experience side effects such as low sex drive, hot flushes, mood swings, trouble sleeping, vaginal dryness and headaches. Ask your doctor for ways to best manage these side effects.

“ I took Zoladex® throughout chemotherapy. When treatment ended, my periods came back normal. I’m hoping to try for a baby soon. ” *Jane*

Permanent ovarian treatment – Ovarian ablation can stop the ovaries from producing oestrogen permanently. Ovarian ablation is done by having surgery to remove the ovaries (oophorectomy) or having radiotherapy to the ovaries.

These treatments will bring on permanent menopause. This means you will no longer be able to become pregnant. You may have some menopausal symptoms, including hot flushes and vaginal dryness, and your risk of osteoporosis may increase. See page 55 for ways to prevent osteoporosis.



Key points

- Your choice of treatment for early breast cancer will depend on many factors, such as your test results, if your cancer is hormone sensitive and your age.
- There are two types of surgery: breast conserving surgery and mastectomy. In breast conserving surgery, only the cancerous part of your breast is removed. If you have a mastectomy, the whole breast is removed.
- After surgery, you may have a breast reconstruction to recreate the shape of your breast. Some women choose not to have this surgery.
- The breast cancer may spread to the axillary lymph nodes. The doctor can remove lymph nodes to check if they are cancerous. This can be done through a sentinel lymph node biopsy, axillary clearance or dissection.
- The recovery time after surgery varies, depending on the type of surgery you have. Most women are in hospital for 1–7 days.
- You may also have other treatments, such as radiotherapy (x-ray treatment) or chemotherapy (drug treatment). Both types of treatment aim to kill or damage the cancer cells. They can cause side effects such as tiredness or hair loss.
- Herceptin® is a type of targeted therapy for breast cancer. It works by attaching itself to certain breast cancer cell receptors. Some women take this drug for a year.
- Hormone therapy is for people who have hormone receptors on their breast cancer cells. The treatment aims to stop the cells from growing. A common hormone treatment is called tamoxifen.



Living with breast cancer

Side effects of treatment can vary. Some people will experience a few side effects, others will have more.

Nerve pain

Some people have long term nerve pain after surgery, particularly mastectomy and axillary dissection. This pain may feel like pins and needles. Nerve pain usually settles within a few weeks. If it's ongoing, speak to your doctor about ways to manage the pain.

Lymphoedema

Lymphoedema is a swelling of part of the body, usually a limb such as the arm. When lymph nodes have been damaged or removed, lymph fluid may not be able to drain properly. This causes fluid build-up resulting in swelling.

Lymphoedema can occur as a result of some cancer treatments such as after radiotherapy to the armpit or surgery to remove axillary lymph nodes. People who have had surgery followed by radiotherapy to the armpit are more at risk.

Signs of lymphoedema include swelling, heaviness or fullness in the arm; redness and skin warmth. These signs may begin gradually, and may come and go. Some people experience pain or fever, which may mean an infection in the arm with lymphoedema. If you have swelling, see your doctor as soon as possible. Symptoms are easier to manage if lymphoedema is picked up and treated early.

Preventing and treating lymphoedema

Lymphoedema can develop months or years after treatment – some people who are at risk never develop it.

In many hospitals, a lymphoedema specialist will assess you before you have surgery. Some hospitals have specialist physiotherapists who can work with you to reduce your risk of developing lymphoedema. You can do simple exercises such as shoulder rolls, elbow bends and hand clenching.

Reducing your risk of lymphoedema

What to do

- ✓ use a gentle moisturiser to keep skin healthy
- ✓ wear shoes, gloves or long sleeves when gardening or washing dishes
- ✓ wear loose clothing and jewellery
- ✓ clean any cuts (on the affected side of your body) straightaway and see a doctor if the area becomes hot, red or swollen
- ✓ be as physically active as you can
- ✓ eat a healthy diet and maintain a healthy body weight

What to avoid

- ✗ sunburn
- ✗ cuts, burns and insect bites
- ✗ tattoos or piercings
- ✗ repetitive tasks and heavy lifting for long periods of time
- ✗ blood pressure cuffs and having injections on the affected side
- ✗ saunas, hot baths and spas

Swelling can be reduced by wearing a professionally-fitted elastic sleeve or by massage from a trained lymphoedema drainage therapist, physiotherapist, nurse or occupational therapist.

Long periods of physical inactivity, such as travelling, may contribute to lymphoedema. Talk to your doctor or specialist about wearing a compression sleeve during air, rail or car travel. You can download a fact sheet about lymphoedema and travel from Breast Cancer Network Australia – visit www.bcna.org.au.

To find out more, contact Cancer Australia for a copy of the *Lymphoedema – what you need to know* booklet. The Australasian Lymphology Association website, www.lymphoedema.org.au, has a directory of lymphoedema practitioners.

Cording

This feels like a tight cord running from your armpit down the inner arm, sometimes to the palm of your hand. Cording, also known as axillary web syndrome, can happen weeks or months after surgery or lymph node dissection. It is due to hardened lymph vessels. Some people are able to see and feel raised cord-like structures across their arm, and this can restrict arm movement.

Cording usually gets better over a few months. Gentle stretching during the first couple of weeks after surgery can help. If the cording doesn't seem to be improving or is getting worse, try physiotherapy or massage. Laser treatment from a lymphoedema specialist may also help.

Menopause and fertility

Some treatments for early breast cancer cause your periods to stop (menopause) and can affect your ability to become pregnant (fertility). Chemotherapy drugs usually cause an interruption to a woman's periods. This may be temporary or permanent. If your periods stop permanently, this is known as early menopause.

Some of the symptoms of menopause include hot flushes and sweats, trouble sleeping, vaginal dryness, lower sex drive, tiredness, dry skin, aches and pains, mood swings, poor concentration, weight gain and osteoporosis. Symptoms can range from mild to severe. Talk to your doctor or breast care nurse about ways to manage any symptoms.

If preserving your fertility is important to you, talk to your doctor before treatment starts about your options and ask for a referral to a fertility clinic. If you learn you may be permanently infertile, you may feel a great sense of loss. You might be devastated that you won't have your own children or additional children, and you might worry about the impact of this on your relationship. It's normal to feel this way even if your family is complete. To find out more, call 13 11 20 for a free copy of Cancer Council's *Fertility and Cancer* booklet or access it online.



Permanent menopause means you will not be able to become pregnant. If the interruption to your periods is temporary, you might still be able to have children.

Preventing osteoporosis

Women who experience menopause, especially if it is earlier than usual, are at an increased risk of developing osteoporosis. This is the thinning of the bones. Bone weakness can lead to fractures and pain.

To prevent osteoporosis:

- do regular weight-bearing or resistance exercise with weights
- talk to your doctor about medication.
- make healthy eating choices, which include low-fat dairy and high-calcium foods

For more information, go to www.osteoporosis.org.au or call the toll free information line on **1800 242 141**.

Using a breast prosthesis

A breast prosthesis (breast form) is a synthetic breast or part of a breast that appears real when worn in a bra or under clothing. It can be used after a mastectomy or after breast conserving surgery.

In the first couple of months after surgery, you may choose to wear a temporary soft breast form. This will be more comfortable next to your scar. A free bra and temporary soft breast form is available through Breast Cancer Network Australia. To order a *My Care Kit*, visit www.bcna.org.au or talk to your breast care nurse or treatment team.

Once your scar has healed (usually by six weeks), it should be comfortable to be fitted for a permanent breast prosthesis.

This is usually made from silicone and has the shape, feel and weight of a natural breast. A prosthesis can help you maintain good posture and prevent neck and back problems.

The cost of a permanent prosthesis ranges from about \$250–\$450. Financial assistance towards the cost of a breast prosthesis is available from Medicare. Women with private health insurance may be able to get a further rebate for a prosthesis depending on their cover.

More information on how to buy a breast form and what to expect at a fitting is available from Cancer Council. Call 13 11 20 for a copy of *Breast Prostheses and Reconstruction*.

Wigs

If you lose your hair during chemotherapy treatment, you may want to wear a wig, scarf or hat while it's growing back.

You can borrow a wig – some hospitals and cancer care units have wig libraries where wigs are free or available for a small fee. You can also buy a wig, though some types can be expensive. Ask your treating hospital or call Cancer Council Helpline to find out more.

Some private health funds cover part of the cost of purchasing wigs – check with your health fund.



Key points

- Side effects vary, depending on the treatment you have.
- Lymphoedema is a swelling of part of the body, such as the arm. It can happen if the lymph nodes are damaged or removed and the fluid is unable to drain properly.
- There are ways to prevent or treat lymphoedema. For example, exercises, massage or wearing a compression sleeve may reduce or prevent swelling.
- Cording, also known as axillary web syndrome, feels like a tight cord running from the armpit to the palm of the hand. It usually gets better over several months but gentle stretching can help.
- Some treatments, such as chemotherapy, can cause a woman's periods to stop. This may be temporary or permanent. This can cause symptoms of menopause such as hot flushes, vaginal dryness and tiredness. Talk to your doctor about how to manage any symptoms.
- If you would like to have children, talk to your doctor before treatment begins about ways to reduce the risk of infertility, and ask for a referral to a fertility clinic.
- Following menopause, bones may become weaker. This is called osteoporosis. Doing regular weight-bearing exercises, eating high-calcium foods and taking medication can help.
- After a mastectomy, the breast can be replaced with a temporary soft breast form or you can be fitted for a permanent breast prosthesis. This has the shape and feel of a natural breast, and helps prevent back and neck pain.



Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

Nutrition – Eating healthy food can help you cope with treatment and side effects. A dietitian can suggest ways to manage special dietary needs or eating problems. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet or download it from your local Cancer Council website.

Staying active – Physical activity may help to reduce tiredness, improve circulation and boost mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more details about the benefits of exercise, and includes simple exercises to try.

Complementary therapies – These are used with conventional medical treatments and may increase your sense of control, decrease stress and anxiety, and improve your mood. Examples include massage, relaxation and acupuncture. Let your doctor know about any therapies you are using or thinking about trying. To find out more read *Understanding Complementary Therapies*.



Alternative therapies are used instead of conventional treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful.

Helpful resources



YWCA Encore – This free 8-week information and exercise program is for women who have had breast cancer surgery. It uses floor and pool exercises to strengthen and tone the arms, shoulders and chest. The YWCA Encore program helps women regain their mobility and improve their general fitness.

1800 305 150
www.ywcaencore.org.au

Look Good...Feel Better – This free program teaches techniques to help restore appearance, confidence and self-image during treatment.

1800 650 960
<http://lgfb.org.au>

My Journey Kit – Breast Cancer Network Australia's My Journey Kit contains information, resources and tips for women newly diagnosed with breast cancer.

1800 500 258
www.bcna.org.au

Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways, for example by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

Sexuality and intimacy

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you may be advised to use barrier types of contraception (e.g. condoms) for a certain period of time. These provide protection against any cytotoxic drug by-products that may be secreted in body fluids, and help to avoid pregnancy. Your doctor will talk to you about the precautions to take.

Call 13 11 20 for free copies of *Sexuality, Intimacy and Cancer* and *Emotions and Cancer*, or download the booklets from the website.

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a

short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible.

The organisation [beyondblue](http://www.beyondblue.org.au) has information about coping with depression and anxiety. See www.beyondblue.org.au or call **1300 224 636** to order a fact sheet.

Life after treatment

For most people, the cancer experience doesn't end when treatment ends. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry if every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to 'normal life', but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

Cancer Council Helpline 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

Follow-up

After your treatment, you will need regular check-ups with your specialist to confirm that the cancer hasn't come back. At these appointments, your doctor will examine you and ask about any symptoms you have had. Most women will have a mammogram every year.

Suggested timing for follow-up appointments



1–2 years after treatment	every 3–6 months
3–5 years after treatment	every 6–12 months
more than 5 years after treatment	every year

If your doctor is concerned the cancer has spread, you may have a CT scan, chest x-ray or bone scan. If you have any health problems between follow-up appointments, let your doctor know immediately. You can also see your GP if you have any questions and for ongoing support. Check-ups will become less frequent over time if you have no further problems.

What if the cancer returns?

For most people, early breast cancer will not come back after treatment. However, it is possible for the breast cancer to come back in the treated breast or in other parts of the body. This is called a recurrence.

Factors that may make the cancer more likely to recur include:

- a larger sized cancer
- if cancer was found in the lymph nodes
- if the cancer was hormone-receptor negative
- if the grade of the cancer was high
- if the surgical margin was not clear.

Having one or more of these factors doesn't necessarily mean the cancer will come back or spread, but it may mean you are more likely to have other treatments after surgery.

You should be 'breast aware', which means you look at your breasts and feel them regularly to know what is normal for you. This can help pick up a new cancer in the other breast. Being breast aware and having regular check-ups can also help find a local recurrence early so it can be treated.



Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

You may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in these support settings because they aren't trying to protect their loved ones.

Types of support

There are many ways to connect with others for mutual support and to share information. This includes:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as www.cancerconnections.com.au.

Talk to your nurse, social worker or Cancer Council Helpline about what is available in your area.

“ 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 feel like I have to explain. ” Sam



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit www.carersaustralia.com.au for more information and resources.

Helpful resources



Caring for Someone with Cancer – booklet produced by Cancer Council	13 11 20
When the woman you love has early breast cancer – podcast and CD produced by Cancer Australia	1800 624 973 http://canceraustralia.gov.au
My Parents Cancer – website for children aged 13–19 years whose parent has been diagnosed with breast cancer	www.myparentscancer.com.au
'I wish I could fix it': Supporting your partner through breast cancer – booklet produced by BCNA for male and female partners	www.bcna.org.au/fact-sheets-and-booklets#partner



Useful websites

The internet has many useful resources, although not all websites are reliable. The websites below are good sources of information.

Australian

Cancer Council Australia	www.cancer.org.au
Cancer Australia	http://canceraustralia.gov.au
Carers Australia	www.carersaustralia.com.au
Department of Health	www.health.gov.au
Department of Human Services	www.humanservices.gov.au
Healthdirect Australia	www.healthdirect.gov.au
beyondblue.....	www.beyondblue.org.au
Australasian Lymphology Association.....	www.lymphoedema.org.au
Breast Cancer Network Australia	www.bcna.org.au
National Breast Cancer Foundation	www.nbcf.org.au

International

American Breast Cancer Foundation	www.abcf.org
American Cancer Society.....	www.cancer.org
Breast Cancer Care UK.....	www.breastcancercare.org.uk
Cancer Research UK.....	www.cancerresearch.org.uk
Macmillan Cancer Support.....	www.macmillan.org.uk
US National Cancer Institute	www.cancer.gov



Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of breast cancer do I have?
- How far has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I see for my check-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?



Glossary

adjuvant therapy

A treatment given with or shortly after another treatment to enhance its effectiveness.

advanced cancer

Cancer that has spread from the original cancer (metastasised).

anti-oestrogen

Drugs used to treat cancer that depend on hormones to grow.

aromatase inhibitors

Drugs that help prevent the growth of oestrogen-dependent cancer cells by reducing the amount of oestrogen in a post-menopausal woman's body.

atypical ductal hyperplasia

A non-cancerous condition of the cells in the lining of the milk ducts in the breast.

axilla

The armpit.

axillary lymph nodes

Lymph nodes in and around the armpit.

axillary surgery

The removal of some lymph nodes in the armpit, to check whether cancer has spread.

axillary tail

Breast tissue that extends into the armpit.

axillary web syndrome

See cording.

benign

Not cancer or malignant. Benign lumps are not able to spread to other parts of the body.

biopsy

The removal of a small sample of tissue from the body, for examination under a microscope, to help diagnose a disease.

BRCA1 and BRCA2 gene

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

breast care nurse

A registered nurse who has done special studies in breast cancer nursing.

breast conserving surgery

Surgery to remove part of the breast. Also called a lumpectomy.

breast form/prosthesis

An artificial breast worn in a bra cup or attached to the body to recreate the look of a natural breast.

breast oedema

Swelling caused by too much fluid in the breast tissue.

breast reconstruction

The surgical rebuilding of a breast after a mastectomy.

chemotherapy

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

clear margin

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

cording

Tight cord feeling running from the armpit down the inner arm to the hand. Also known as axillary web syndrome.

ducts

The canals within the breast that pass milk from the lobules to the nipple.

ductal carcinoma in situ (DCIS)

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

genes

The tiny units that govern the way the body's cells grow and behave. Genes are inherited from both parents.

grade

A score that describes how quickly the cancer cells are growing.

HER2

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

hormone receptors

Proteins in a cell that bind to specific hormones.

hormones

Chemical messengers in the body that control the actions of certain cells or organs.

hormone therapy

A treatment that blocks the body's natural hormones that help cancer grow. Also called hormone treatment.

invasive breast cancer

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

invasive ductal carcinoma

A cancer that started in the milk duct but has spread into the normal tissue

around it.

invasive lobular carcinoma

A cancer that started in the milk lobules but has spread into the normal breast tissue around it.

Klinefelter syndrome

A genetic disorder where a man has three sex chromosomes (XXY) instead of the normal two (XY).

lobular carcinoma in situ (LCIS)

Abnormal cells in the lobes of the breast.

lobules

The milk-producing glands in the breast.

lumpectomy

The removal of part of the breast. Also called breast conserving surgery.

lymph nodes

Small, bean-shaped collections that form part of the lymphatic system. Also called lymph glands.

lymphoedema

Swelling caused by a build-up of lymph fluid.

malignant

Cancer. Malignant cells can spread (metastasise) and can eventually cause death if they cannot be treated.

mammogram

An x-ray of the breast.

mastectomy

Surgically removing the whole breast.

menopause

When a woman stops having periods (menstruating). This can happen naturally or because of treatment.

metastasis

A cancer that has spread from another part of the body. Also known as secondary cancer.

non-invasive

Cancer that is confined to the ducts or lobules of the breast.

oestrogen

The main female sex hormone produced mostly by the ovaries.

oestrogen receptor positive (ER+)

Breast cancer cells that have a receptor protein to which oestrogen will attach. Breast cancer cells that are ER+ depend on the hormone oestrogen to grow.

Oncotype DX Gene Assay Test

A test that analyses the activity of a group of genes that affect how a cancer is likely to behave and respond to treatment.

osteoporosis

A breakdown of tissue making bones weaker.

ovarian ablation

Stopping the ovaries from producing oestrogen, which is done surgically (oophorectomy) or with radiotherapy.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms of cancer.

pathologist

A specialist who studies diseases to understand their nature and cause,

and who interprets the results of tests (such as a biopsy or blood count).

pathology report

The written test results done on tissue removed during biopsy or surgery.

plastic surgeon

A doctor who can surgically reshape or rebuild a part of the body. Also known as reconstructive surgeon.

primary cancer

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

progesterone

A hormone produced by the ovaries that prepares the lining of the uterus (endometrium) for pregnancy.

progesterone receptor positive (PR+)

Breast cancer cells that have a receptor protein to which progesterone will attach. Breast cancer cells that are PR+ depend on the hormone progesterone to grow.

radiotherapy

The use of x-rays or gamma rays to kill cancer cells or injure them.

recurrent cancer

A cancer that grows from cells of the primary cancer that have resisted treatment, or cancer that has spread to another part of the body.

sentinel node

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

sentinel node biopsy

Removal of the sentinel node. If this is clear, no further lymph nodes are removed.

sentinel node mapping

A way to identify the sentinel lymph node by injection of a radioactive substance, blue dye or both near the tumour.

seroma

A collection of fluid under a wound after an operation.

staging

Performing tests to determine how far a cancer has spread.

targeted therapies

Types of treatments that use drugs or other substances to identify and attach specific types of cancer cells.

tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.

ultrasound

A non-invasive scan that uses soundwaves to create a picture of part of the body. An ultrasound scan can be used to measure the size and position of a tumour.

Can't find what you're looking for?

For more cancer-related words, visit www.cancerCouncil.com.au/words or www.cancervic.org.au/glossary.

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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 Pink Ribbon Day, 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 Helpline 13 11 20

Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk confidentially with oncology health professionals about any concerns. Helpline consultants can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au) to help you communicate with a Cancer Council Helpline consultant.

For more information, go to www.cancercouncil.com.au.

Regional offices

Central and Southern Sydney

Woolloomooloo
02 9334 1900

Hunter and Central Coast

Charlestown
02 4923 0700

North Sydney

Crows Nest
02 9334 1600

Northern

Byron Bay
02 6639 1300

Southern

North Wollongong
02 4223 0200

Western

Wagga Wagga
02 6937 2600

Western Sydney

Parramatta
02 9354 2000



Cancer Council
Helpline

13 11 20

For support and information on cancer and cancer-related issues, call Cancer Council Helpline. This is a confidential service.

For further information and details please visit our website: www.cancerCouncil.com.au