Cancer Council

Understanding Breast Cancer

A guide for people with cancer, their families and friends

Cancer information

Cancer Council Helpline
13 11 20
www.cancervic.org.au

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The illustration on page 7 is based on a Cancer Australia breast diagram.

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Note to reader

Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or other health professional's advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

Interpreting service: Deaf or hearing or speech impaired

If you use text-based communication, call the Cancer Council Helpline (13 11 20) through the National Relay Service (NRS) 13 3677. If you can hear and still use your voice, but have a speech impairment, call the Cancer Council Helpline through NRS 1300 555 727.

Cancer Council
Victoria

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Introduction

This booklet has been prepared to help you understand more about early breast cancer. Many people feel understandably shocked and upset when told they have breast cancer. We hope this booklet will help you understand how early breast cancer is diagnosed and treated. We also include information about support services.

We cannot advise you about the best treatment for you. You need to discuss this with your doctor, and you may also be able to speak to a breast care nurse. However, we hope this information will answer some of your questions and help you think about the questions you want to ask your doctors or other health carers.

You may like to pass this booklet to your family and friends. It does not need to be read from cover to cover – just read the parts that are useful to you. If you're reading this booklet for someone who doesn't understand English, call Cancer Council Helpline 13 11 20 for services in different languages.

How this book was developed

This booklet was developed with help from medical experts and people with breast cancer. The information is based on clinical practice guidelines for breast cancer, and publications from Cancer Australia were used as source material.

This booklet is about early breast cancer. For information about other types of breast cancer, visit Cancer Australia's website, **http://canceraustralia.nbocc.org.au**, or call the Helpline.

Contents

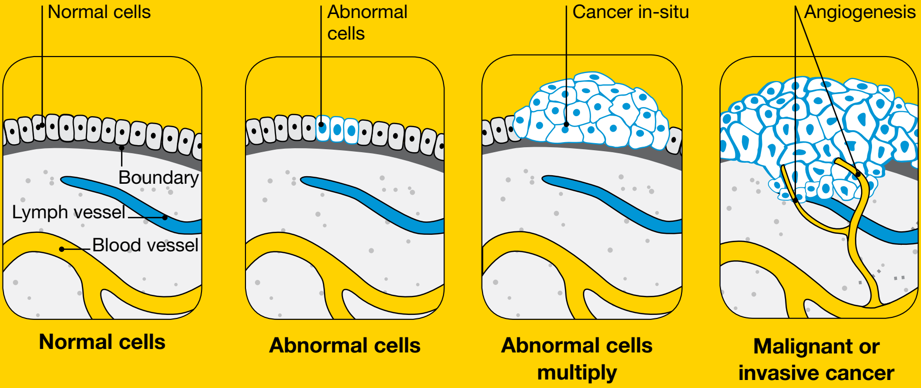
What is cancer?

Cancer is a disease of the cells, which are the body's basic building blocks. Our bodies constantly make new cells to help us grow, to replace worn-out cells and to heal damaged cells after an injury.

Normally cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. This uncontrolled growth may result in a lump called a tumour or may develop into abnormal blood cells.

A tumour can be benign (not cancer) or malignant (cancer). A benign tumour does not spread to other parts of the body. A malignant tumour is made up of cancer cells, which grow out of control and are able to spread. The cancer that first develops

How cancer starts

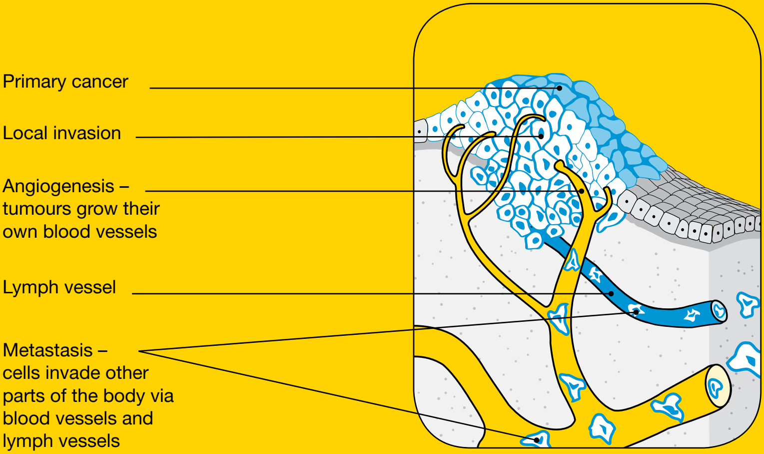


Normal cells **Abnormal cells** **Abnormal cells multiply** **Malignant or invasive cancer**

in a tissue or organ is called the primary cancer. When it first develops, a malignant tumour may not have invaded nearby tissue. This is sometimes called cancer in-situ (carcinoma in-situ), non-invasive cancer or pre-cancer. As the tumour grows it may spread, becoming invasive cancer.

Cancer cells can spread to other parts of the body by travelling through the bloodstream or lymphatic system. They may continue to grow into another tumour at this new site. This 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 still called breast cancer, even though the person may be experiencing symptoms caused by problems in the bones.

How cancer spreads



The breasts

Women and men both have breast tissue.

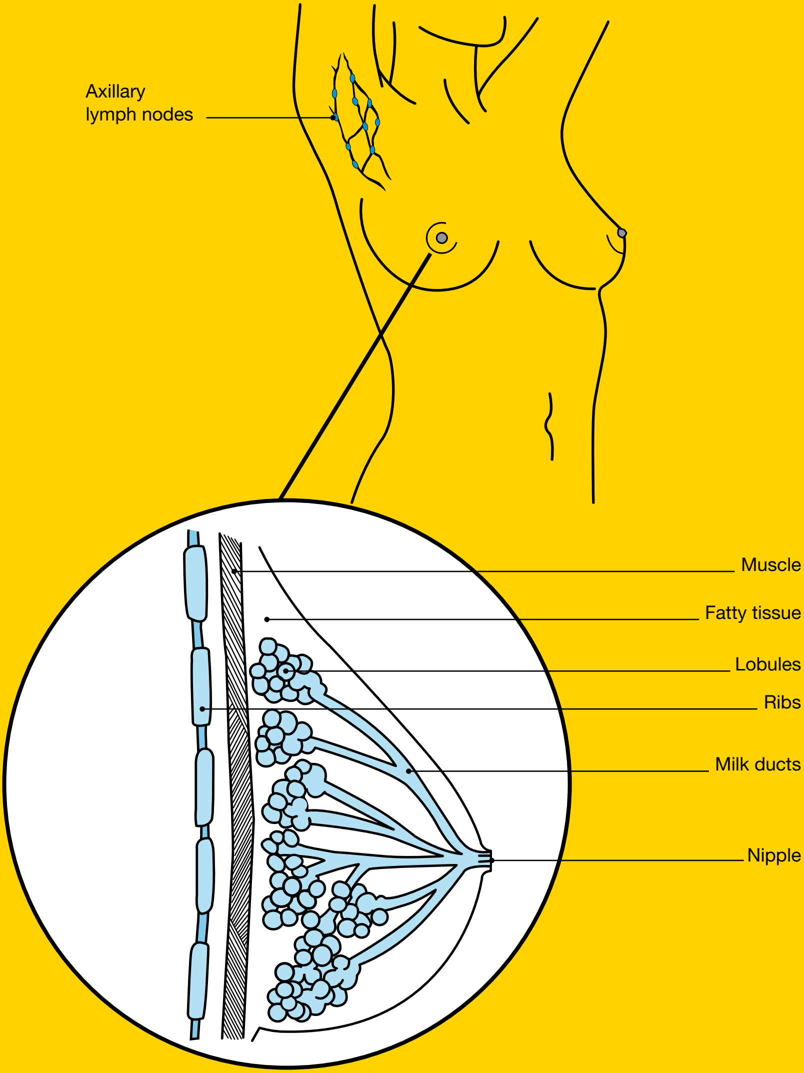
In women, breasts are made up of milk glands. The milk gland consists of lobules, where milk is made, and tubes called ducts that take milk to the nipples.

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 tissue and fatty tissue. Some breast tissue extends into the armpit (axilla). This is known as the axillary tail.

The armpits contain a collection of lymph nodes (also called lymph glands), which are part of the lymphatic system. The lymphatic system is part of the immune system and protects the body against disease and infection.

The breasts


Axillary
lymph nodes
Muscle
Fatty tissue
Lobules
Ribs
Milk ducts
Nipple

Key questions

Q: What is breast cancer?

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

Women and men can both get breast cancer, although it is rare in men. Men's symptoms are similar to women's.

Q: What types are there?

A: When the cells that look like breast cancer are still confined to the ducts or lobules of the breast, it is called pre-invasive breast cancer. The most common type of pre-invasive breast cancer is ductal carcinoma in-situ (DCIS).

Most breast cancers are found when they are invasive. This means the cancer has spread outside the ducts or lobules of the breast into surrounding tissue. The most common types are invasive ductal cancer (IDC) and invasive lobular cancer (ILC). There are several categories of invasive breast cancer:

Early breast cancer – Cancer cells are found in the breast and may have spread to lymph nodes in the armpit.

Locally advanced breast cancer – The cancer has spread to places near the breast, such as the chest (including the skin, muscles and bones of the chest), but it isn't found in other areas of the body.

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 (LCIS). LCIS is not cancer but if you have it, you may be at an increased risk of developing cancer. Your medical team will monitor you with regular mammograms (see page 13).

Q: What are the symptoms?

A: 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 of the skin, 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.

Changes to your breast don't necessarily mean you have breast 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).

tip

Women aged 50–69 should have regular screening mammograms through BreastScreen. Call **13 20 50** for a free appointment.

Q: What are the causes?

A: The exact cause of breast cancer is not known, but some factors increase the risk:

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

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's syndrome. Men with this syndrome have three sex chromosomes (XXY) instead of the usual two (XY).

Inherited breast cancer gene

Each person inherits a set of genes from each parent. Sometimes there is a fault in one copy of a gene, which stops that gene working properly. This fault is called a mutation.

About one in 20 cases of breast cancer may be caused by an inherited gene fault. The two most common breast cancer genes are called BRCA1 and BRCA2.

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**.

Q: How common is it?

A: Breast cancer is the most common cancer in Australian women. About 13,000 women are diagnosed each year. One in nine women will be diagnosed with breast cancer by the age of 85.

Breast cancer is rare in men. About 100 men are diagnosed in Australia each year. This represents less than 1% of all breast cancers.

Although it can occur at any age, breast cancer is more common in older women. The average age at diagnosis is 60. About one-quarter of women who are diagnosed are younger than 50 years of age.

Diagnosis

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

Physical examination

Your doctor will feel your breasts and the lymph nodes under your arms. They will also 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 scan can find changes that are too small to be felt through 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. Many women find this procedure uncomfortable, but it's over in about 20 seconds.

Sometimes, the doctor will feel a lump that is not shown on a mammogram and other tests will need to be done.

> “The mammogram was a little uncomfortable, but it didn't hurt. I certainly don't look forward to it every year, but it's only a few minutes of discomfort. It's good to do it regularly for peace of mind.” *Patient*

Hormones and breast cancer

Some types of breast cancer are sensitive to hormones. Hormones are chemical messengers in the body that transfer information. The ovaries produce the hormones oestrogen and progesterone, which can cause cancer to grow.

The pathologist will test breast tissue for proteins found inside some cancer cells. These proteins are called receptors. In breast cancer they are called hormone receptors because they allow oestrogen and progesterone to attach to the cancer cell.

- A cancer cell that has oestrogen receptors is called oestrogen receptor positive (ER+).
- A cell that has progesterone receptors is called progesterone receptor positive (PR+).
- Cells without receptors are hormone receptor negative.

Knowing whether a breast cancer contains hormone receptors helps your doctors decide on treatment. Breast cancers that are ER+ or PR+ are more likely to respond to hormonal treatments, which reduce oestrogen in the body (see page 36). A tumour that is oestrogen receptor negative (ER-) will not benefit from hormonal treatment, but other treatments are available.

HER2 receptor

HER2 (human epidermal growth factor receptor 2) is a protein found on the surface of some cancer cells. Tumours that have high levels of these receptors are HER2-postive (HER2+). These tumours tend to divide and grow more rapidly than other types of cancer.

About one in five women have HER2+ cancer cells. They usually have treatment tailored to their situation, such as Herceptin® (see page 39).

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.

Biopsy

Your doctor will suggest a biopsy if an abnormal or unusual area of tissue is found 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. You may need to have more than one biopsy.

There are a few ways of doing a biopsy:

Fine needle aspiration – 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, 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.

A mammogram or ultrasound is used to help guide the needle. This type of biopsy may be uncomfortable or painful.

Surgical biopsy – If the lump is too small to be biopsied using the methods above, a surgical biopsy is done. Before the biopsy, a needle and 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 scanner to guide the needle.

The biopsy is then done in a separate operation using a general anaesthetic. The lump and a small area of normal breast tissue around the lump are removed, along with the wire.

This operation is usually done as day surgery but some women have an overnight stay in hospital.

If the surgical biopsy removes all the cancer, you won't need further surgery. You may have other treatment, such as radiotherapy.

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 report (sometimes called a pathology or radiology report).

tip

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

Blood tests

Blood samples may be taken to check your general health.

Chest x-ray

Your doctor may take a painless 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 an injection of a dye into a vein in your arm. You may also be asked to drink a liquid. 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.

PET scan

A PET (positron emission tomography) scan is a specialised test. It takes pictures of the body to detect tissue abnormalities. A small amount of radioactive material 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.

MRI scan

An MRI (magnetic resonance imaging) scan uses magnetism and radio waves to build up detailed cross-section pictures of the body. The scan involves lying on a treatment table in a metal cylinder that is open at both ends. A dye may be injected into your veins before a scan.

Some people feel anxious lying in the narrow metal cylinder. Talk to your health care team before the scan if you are uncomfortable. It may be helpful to take a mild sedative or talk to the person operating the scan through an intercom. An MRI is painless and is usually over in an hour.

A PET and MRI are not routine tests but they may be used if other types of scans don't give doctors the information they need.

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.

Amanda's story

I was diagnosed with breast cancer in April, when I was 35 years old.

I felt a lump in my breast and had a mammogram and an ultrasound. The scans showed I had cancer.

My doctor followed up with a biopsy and some other scans to see if the cancer had spread throughout my body.

The waiting and not knowing the results were the worst. I found it helpful to take a friend to my appointments for some support. It was good to have someone else there with me.

Once I knew the details about my diagnosis and the plan of attack, I felt better. It really does make you feel more secure to know what is ahead of you.

During my treatment, I had good days and bad ones but I got through it. I found it very comforting to speak with other women with breast cancer and share stories.

The breast care nurses have also been wonderful – they are there for support and I have leaned on them when I've needed to.

Staging breast cancer

The tests described on pages 16–19 show if the cancer has spread to other parts of your body. Working out how far the cancer has spread is called staging. Stages of breast cancer are numbered from 1–4. Early cancers are classified in the stages below:

Stage 1	The tumour is less than 2 cm in diameter, and has not spread to the lymph nodes.
Stage 2A	The tumour is less than 2 cm in diameter, and has spread to the lymph nodes or it is larger (2–5 cm) and has not spread.
Stage 2B (early)	The tumour is 2–5 cm in diameter, and has spread to the lymph nodes.

Stages 2B (advanced), 3 and 4 refer to advanced breast cancer. For information about these stages, call Cancer Council Helpline 13 11 20 or visit http://canceraustralia.nbocc.org.au.

Grading breast cancer

The cancer will also be given a grade. The grade shows how fast the cancer is growing. The higher the grade, the more likely that you'll have chemotherapy after surgery.

Grade 1	Low grade. Cells look abnormal and grow faster than normal cells but not as fast as grade 2.
Grade 2	Intermediate grade. Cells look a little more abnormal and grow faster than grade 1 but not as fast as grade 3.
Grade 3	High grade. Cells are very abnormal and faster growing.

Prognosis

Prognosis means the expected outcome of a disease.

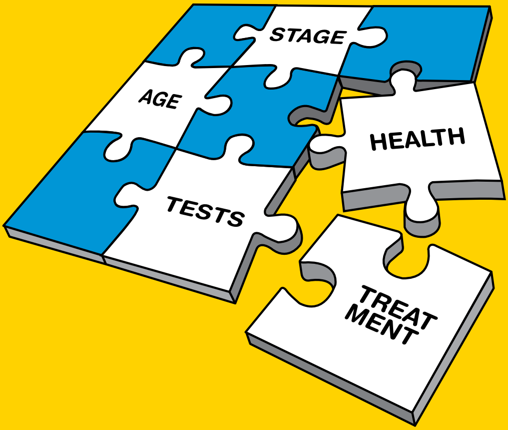
Most people with early breast cancer can be treated successfully. Survival rates have increased significantly over time due to better diagnostic tests and scans, earlier detection, and improvements in treatment methods.

According to recent statistics, the five-year survival rate for breast cancer is approximately 88%.

A cure may still be possible for people with more advanced breast cancer. For other people, treatment can reduce symptoms and improve quality of life.

Assessing prognosis

You will need to discuss your prognosis with your doctor, but it is not possible for any doctor to predict the exact course of your disease. Test results, the growth rate and size of the tumour, how well you respond to treatment, and other factors such as age, fitness and your medical history are all important considerations in assessing your prognosis.



Which health professionals will I see?

You will be cared for by health professionals who specialise in different aspects of your treatment. Specialist health professionals are highly skilled in a specific field.

Specialist health professionals

breast surgeon	specialises in surgery and performs biopsies
pathologist	examines cells and tissue that is removed from the breast to determine the type and extent of the cancer
radiologist	specialises in reading x-rays, such as mammograms
medical oncologist	prescribes and coordinates chemotherapy, hormone therapy and targeted drug therapies

Allied health professionals

physiotherapist and occupational therapist	assist in restoring range of movement after surgery and educate patients about lymphoedema management
social worker	links you to support services and help you with any emotional, physical or practical problems
nurses, including breast care nurses	support and help you through all stages of your treatment

You may also see other allied health professionals who work alongside the doctors and nurses. Allied health professionals provide important care and support services. The following health professionals may be in the multidisciplinary team:

radiation oncologist	prescribes and coordinates radiotherapy
reconstructive (plastic) surgeon	performs breast reconstruction for women who have had a mastectomy
GP (general practioner)	explains information provided by specialists, helps you with treatment decisions and assists you in obtaining practical and emotional support

counsellor, psychologist and psychiatrist	provide emotional support and help manage anxiety and depression
genetic counsellor	provides advice for people with a strong family history of breast cancer

Key points

- There are many different tests used to diagnose breast cancer.
- Your doctor will feel your breasts and upper body (physical examination), 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.
- A biopsy is when a small sample of tissue is removed from your body. There are a few ways of doing a biopsy. The doctor will use a needle to take out the tissue.
- Some types of breast cancer are sensitive to hormones. The hormones oestrogen and progesterone may cause the cancer to grow. Knowing if the cancer cells have hormone receptors helps your doctors decide on treatment.
- You may have other tests and scans to see if the cancer has spread to other parts of your body. Tests can include blood tests; x-rays; and CT, MRI and PET scans.
- The breast cancer will be assigned a stage to describe how far it has spread. The cancer will also be given a grade. This will tell you how fast the cancer cells are growing and how abnormal they look.
- Prognosis is the expected outcome of the disease. Most women with early breast cancer can be treated successfully, so it generally has a good prognosis.
- A range of health professionals will work as a team to care for you. This multidisciplinary team may include a surgeon, nurses, a medical oncologist and a radiation oncologist.

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 doctor will advise you on the best treatment for your breast cancer. The choice of treatment will depend on:

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

If you talk to other people with breast cancer, remember there are different categories of breast cancer and the best treatment for one person may not be the best treatment for another. Each person's situation is different.

You may want to read Cancer Australia's booklet, *Guide for Women with Early Breast Cancer*. For a copy call 1800 624 973 or visit the website http://canceraustralia.nbocc.org.au.

Men who have early breast cancer have similar treatment options to women.

Breast care nurse: a helping hand

During treatment for breast cancer it is natural to feel overwhelmed by what is happening. A breast care nurse can help you make sense of your treatment by offering support, information and resources. They can also coordinate your care across different treatment methods.

Breast care nurses are available at most large hospitals. Ask your doctor if a breast care nurse is part of your multidisciplinary team. If one is not available, ask your treatment team who to contact if you have questions about your ongoing care.

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 page 29).

It can be difficult to decide which type of surgery to have. Some women do not want to have their whole breast removed. Research has shown that breast conserving surgery, with sentinel node biopsy followed by radiotherapy, is as effective as mastectomy for most women with early breast cancer.

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

Breast conserving surgery

Surgery to remove the breast cancer and some surrounding healthy tissue is called breast conserving surgery. It is also called lumpectomy, complete local excision, partial mastectomy 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 as possible. This will leave a scar and the breast may change slightly in shape and size.

The tissue is sent to a lab for examination by a pathologist. The pathologist examines the removed breast tissue to see if there is an area of healthy cells all around the cancer – this is known as a clear margin. The pathologist will create a report, which will state if the cells are hormone receptor positive or negative (see page 14).

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 a mastectomy may be recommended.

Radiotherapy may be given to the breast after surgery to destroy any cancer cells that may be left in the breast or armpit.

Mastectomy

Surgery to remove the whole breast is called a mastectomy. 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 page 29).

You may be offered a mastectomy if the cancer is large compared to the size of the breast or if it is in more than one area.

For some small tumours that are not near the nipple, the surgeon may be able to perform a nipple-sparing or skin-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 a permanent implant or using tissue from another part of your body.

While your surgical wound heals, you can wear a soft temporary breast prosthesis (form) inside your bra. After complete healing (about 6–8 weeks), you may choose to be fitted for a breast form – see page 54 – or schedule a surgical breast reconstruction.

Breast reconstruction

A breast reconstruction is a type of surgery in which a breast shape is created using either 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 prefer to wait for several months or longer (deferred reconstruction).

For more information about reconstruction, talk to your surgeon or a reconstructive (plastic) surgeon. You can also call Cancer Council Helpline **13 11 20** for more information about breast reconstruction.

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, they are removed. There are two ways of removing the lymph nodes.

Sentinel 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 following page).

The sentinel node is found using a combination of techniques. A small amount of radioactive substance is injected around the cancer before surgery. A scan is taken to show which node the substance has travelled to. During surgery, a blue dye is injected around the cancer in your breast. The dye moves into the lymphatic vessels. The nodes that become blue or radioactive first are known as the sentinel nodes, and the surgeon will remove only those nodes 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 nodes contain cancer cells, axillary surgery will be needed.

Axillary (lymph node) surgery – This may be done at the same time as your breast surgery or as a separate operation. The doctor will remove the least possible amount of your lymph nodes. The lymph nodes are sent to a pathologist for examination. The pathologist will provide a report that shows how many nodes were removed and how many contain cancer cells. For instance, if 17 nodes were removed and four contained cancer cells, the report will read: 4/17. These results help your doctor recommend further treatment.

Physical side effects

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

Shoulder stiffness – Exercises can help prevent or manage shoulder stiffness. A physiotherapist or occupational therapist can help.

Numbness of the arm – Surgery may damage nerves, causing your arm, and perhaps shoulder, to feel numb. The numbness will improve but may not go away completely. Shoulder exercises will help improve movement.

Lymphoedema – The arm may swell following lymph node surgery or sometime later. See page 41.

Fatigue – Feeling tired and having no energy may be a major problem. Treatment and the emotional impact of the diagnosis can be tiring. Your tiredness may continue for quite a while after treatment.

Most side effects can be managed. Talk to your doctor about any side effects you experience.

Recovery after surgery

You may be in hospital for 1–7 days, depending on the type of surgery you have, your recovery rate and whether you have any help at home.

You will have several tubes in place after the 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 dressing is usually removed after about a week, and the tubes are usually taken out within 3–5 days.

If you have had axillary surgery you will 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.

When you are in hospital, it's important to move your legs when you are in bed, then get up and walk around when you are able. This helps prevent blood clots. Your doctor may also prescribe you medication to lower the risk of clots.

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 clear up in 2–3 weeks.

Exercising your arm as soon as possible after surgery will help it feel better and get back to normal faster. See page 50 for information.

Overall recovery time after surgery varies. Check with your surgeon about what you can do – for example, some surgeons tell you to avoid driving for a few weeks, until your arm is more agile. Most people start to feel better after about two weeks. Take it easy and only do what is comfortable.

Your feelings about surgery

Breast surgery may change your appearance, and this can affect your self-esteem. You may feel a sense of loss if you have had a mastectomy. It is normal to grieve over the loss of your breast. See page 53 for more information about body image.

Talking to someone who has also had surgery might be helpful. Cancer Council Connect may be able to link you to someone who has also had breast cancer. Call the Helpline 13 11 20 for more information.

Further treatment

A week after your operation, your doctor will have all the test results and will discuss the need for any further treatment such as radiotherapy, chemotherapy or hormone therapy. Further treatment will depend on the stage of the cancer and whether there is a clear margin around the cancer. You should be given a treatment plan and copies of your pathology reports for your own record.

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 cancer cells left in the breast and reduce the risk of the cancer coming back. It is also occasionally given after a mastectomy.

It is uncommon to have radiotherapy to the lymph nodes in your armpit after surgery as it may increase the chance of developing lymphoedema.

Treatment is carefully planned to do as little harm as possible to your normal body tissues. 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 oncologist treats the same area each time. These marks are small dots and may be temporary or permanent (tattoos).

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.

Side effects

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 your treatment ends. Radiotherapy nurses will show you how to care for your skin.

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

Radiotherapy to the breast does not cause hair loss. It also does not make you radioactive – it is safe to interact with your 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 booklet about radiotherapy.

> “I was lucky not to have any side effects from radiotherapy and went on with my daily workload. My employer was very supportive of my regular visits to the surgeon and radiotherapy treatment.” *Patient*

Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. Chemotherapy may be used:

- if 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
- when cancer returns after surgery or radiotherapy, to gain control of the cancer and to relieve symptoms
- if the cancer doesn’t respond to hormone therapy (see page 36).

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 cyclophosphamide, docetaxel, doxorubicin, carboplatin and fluorouracil. Your medical team may also refer to the drugs by their brand (trade) names.

Chemotherapy is usually given through a vein (intravenously). You will have about 4–6 chemotherapy sessions every 2–3 weeks over several months. You usually will be treated as a day patient but occasionally an overnight stay may be recommended. The recovery time after each treatment session is called a cycle. This gives your body time to recover before the next session.

Side effects

The side effects caused by chemotherapy depend on the drugs used. Most side effects are temporary and steps can often be taken to prevent or reduce them.

Side effects may include feeling sick (nauseous), vomiting, tiredness, mouth ulcers or weight changes. Most people who have chemotherapy lose their head and body hair.

Some women's periods 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 43.

Hormone therapy

Hormone therapy, also called endocrine therapy, is for people who have ER+ hormone receptors 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. 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 14.

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 premenopausal women.

Tamoxifen does not cause menopause but its side effects may be similar. The most common side effects include hot flushes, headaches, a skin rash, trouble sleeping, vaginal dryness or discharge, weight gain and irregular periods. You may have some or none of the side effects. More serious side effects may include blood clots – see your doctor immediately if you have new swelling or soreness in your arm or leg, or a warm spot in your limb.

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 cancer of the uterus. See your doctor as soon as possible if you have any unusual bleeding. If you're having tamoxifen for more than five years, you should have annual gynaecological examinations.

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. 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.

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 menopause. This means you will no longer be able to become pregnant. You may have some menopausal symptoms, including hot flushes and a dry vagina, and your risk of osteoporosis may increase. See pages 43–44 for information about managing 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.” *Patient*

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 in women who have reached menopause.

Examples of aromatase inhibitors include anastrozole (Arimidex®), exemestane (Aromasin®) and letrozole (Femara®). Side effects may include osteoporosis, vaginal dryness, hot flushes and weight gain.

Herceptin®

Trastuzumab (commonly known as Herceptin®) is a common type of targeted therapy for breast cancer. It works by attaching itself to HER2+ 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.

You will receive this drug through an injection or infusion into your vein. You will usually have treatment every three weeks. The first infusion may take up to 90 minutes. You may be given this drug for a few years.

Your medical team will monitor you for side effects. The most common side effects include fever, runny nose, nausea and vomiting, diarrhoea, headache and a rash. Talk to your doctor about what to expect.

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 lymph nodes in the armpit (axilla). The doctor can remove lymph nodes to check if they are cancerous. This can be done through a sentinel node biopsy or axillary (lymph node) surgery.

- 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.

- 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.

- 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 few years.

Managing side effects

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

Lymphoedema

Lymphoedema is a swelling of part of the body, usually a limb such as the arm.

If lymph nodes have been damaged or removed, it may prevent lymph fluid from draining properly. This causes fluid build-up and swelling. Signs of lymphoedema include redness; swelling; skin warmth; a feeling of pain, heaviness or fullness in the arm; and fever.

Lymphodoema can occur after radiotherapy to the armpit or surgery to remove lymph nodes from under the arm. People who have had surgery followed by radiotherapy to the armpit are more at risk.

If you have swelling, see your doctor as soon as possible. Symptoms are better managed if treated early.

Preventing and treating lymphoedema

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

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

Infection can make the swelling worse. To prevent infection in the affected arm:

- keep the skin moisturised
- avoid sunburn
- avoid cuts, burns and insect bites
- avoid repetitive tasks and heavy lifting
- avoid using blood pressure cuffs and having injections.

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

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 – go to www.bcna.org.au.

For more information see the Lymphoedema Association of Australia website, www.lymphoedema.org.au. You can also contact Cancer Australia for a copy of their *Lymphoedema – What You Need to Know* booklet.

tip

A directory of lymphoedema practitioners is available at **www.nlpr.asn.au**.

> “I had some lymphoedema in my right arm. This causes little trouble unless it is a particularly hot day or if I have exercised too much. I have regular massages to keep the fluid moving.” *Patient*

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 menopause.

Menopause may be temporary or permanent. If your periods stop permanently, this will cause an early menopause.

Some of the symptoms of a temporary or permanent menopause include hot flushes and sweats, trouble sleeping, vaginal dryness, passing urine more often, lower sex drive, tiredness, sleeplessness, dry skin, aches and pains, mood swings, poor concentration, weight gain, osteoporosis and loss of confidence and memory. Not everyone has every symptom and they can range from mild to severe. Talk to your doctor or breast care nurse about ways to manage any menopausal symptoms.

Permanent menopause means you will not be able to become pregnant. If menopause is temporary, you may still be able to have children.

If fertility is important to you, talk to your doctor before treatment starts about your risk of infertility and ways it might be preserved. You may be able to store eggs for use in the future. 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 may be devastated that you won't have your own children or additional children, and you may worry about the impact of this on your relationship. It's normal to feel this way even if your family is complete.

As well as talking to your partner, discussing your situation with a counsellor, breast care nurse or oncologist can be beneficial.

Preventing osteoporosis

Women who experience menopause 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
- make healthy eating choices, including low-fat dairy and high-calcium food
- talk to your doctor about medication.

For more information, go to **www.osteoporosis.org.au** or call **(02) 9518 8140**.

Key points

- Side effects from treatment vary, depending on the type of treatment you have.
- Lymphoedema is a swelling of part of the body, such as the arm. It may happen if the lymph nodes are damaged and don't drain properly.
- There are ways to prevent lymphoedema or treat it. For example, exercises or compression sleeves may reduce the swelling.
- Some treatments, such as chemotherapy, can cause a woman's periods to stop (menopause). This can cause symptoms like hot flushes, vaginal dryness and tiredness. Talk to your medical team about how to manage menopausal symptoms.
- Menopause can cause infertility. If you would like to have children, talk to your doctor about ways to reduce the risk of infertility. You can ask for a referral to a fertility clinic.
- Menopausal women are more likely to have weak or thin bones. This is called osteoporosis. To prevent osteoporosis, you can do regular weight-bearing exercise, eat high-calcium food and take medication.

Making treatment decisions

Sometimes it is difficult to decide on the right treatment. You may feel that everything is happening so fast you don't have time to think things through, but there is usually time to consider what sort of treatment you want.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed by information, others want as much information as they can find. Making sure you understand enough about your disease, the treatment and its side effects will help you make your own decisions.

- If you are offered a choice of treatments, you will need to weigh up their advantages and disadvantages. Consider how important any side effects are to you, particularly those that affect your lifestyle.
- If you have a partner, you may also want to talk about treatment options with them. You can also talk to friends and family.
- If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been offered.

You have the right to accept or refuse any treatment.

Some people with more advanced breast cancer will choose treatment, even if it only offers a small chance of cure. Others want to make sure the benefits of treatment outweigh any side effects so they have the best possible quality of life. Some people may choose options that don't try to cure the cancer but make them feel as well as possible.

Finding a specialist

Many people with breast cancer say the most difficult part, after dealing with the shock of the diagnosis, is working out where to go for treatment and care.

Cancer Australia's *Directory of Hospital Breast Cancer Services* is an online listing of services provided at public and private hospitals and clinics around Australia for women with breast cancer. See http://canceraustralia.nbocc.org.au.

You can also ask your GP about any recommended specialists.

Talking with doctors

When your doctor first tells you that you have cancer it is very stressful and you may not remember many details about what you are told. You may want to see the doctor a few times before deciding on treatment.

If your doctor uses medical terms you don't understand, it's okay to ask for a simpler explanation. You can also check a word's meaning in the glossary (see page 66).

Before you see the doctor it may help to write down your questions – see the list of suggested questions on the page 65. Taking notes or recording the discussion can also 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.

Your doctor or breast care nurse may provide you with a breast cancer information kit (see page 55). This includes information booklets and a diary to record information about your diagnosis and treatment. Your breast care nurse may be able to talk to you about how to use these resources to make you feel more in control and organised.

tip

If you have several questions for your doctor, you may want to book a longer appointment.

A second opinion

Getting a second opinion from another specialist may be a valuable part of your decision-making process. It can confirm or clarify your doctor's recommendations and reassure you that you have explored all of your options.

Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients 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 may decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor may suggest you consider taking part in a clinical trial. Doctors conduct clinical trials to test new or modified treatments to see if they are better than current treatments. Over the years, clinical trials have improved cancer treatment standards and led to better outcomes for patients.

If you are unsure about joining the trial, ask for a second opinion from an independent specialist.

If you decide to join a randomised controlled trial, you will be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other.

Being part of a trial gives you important rights. You have the right to withdraw at any time; doing so will not jeopardise your treatment for cancer.

For more information about clinical trials – such as questions to ask your doctor and how to find a trial that is suitable for you – call Cancer Council Helpline 13 11 20.

> “I participated in a research study – this involved blood samples being taken during my first three chemo sessions and in the morning after these treatments. I thought it might help improve the treatment for someone else in the future.” *Patient*

Looking after yourself

Cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help reduce stress and improve well-being. Addressing changes in your emotions and relationships early on is also very important.

Healthy eating

Eating nutritious food will help you to keep as well as possible and cope with cancer and treatment side effects. A dietitian can help you to plan the best foods for your situation. Helpline can send you information about nutrition and cancer.

Being active

You will probably find it helpful to stay active and to exercise regularly if you can. Physical activity – even if gentle or for a short duration – helps to improve circulation, reduce tiredness and elevate mood.

The amount and type of exercise you choose to do will depend on what you are used to, how well you feel and what your doctor advises.

You can make small changes to your daily activities if you aren't used to exercise or haven't exercised for a while. If you have had one or both of your breasts removed, your medical team may help you do arm exercises to help you recover and prevent lymphoedema (see page 41). Ask your medical team what is best for you.

YWCA Encore program

YWCA Encore is a free eight-week information and exercise program for women who have had breast cancer treatment. Using floor and pool exercises, the program strengthens and tones your arms, shoulders and chest, helps you regain mobility and improves your general fitness. To find out more call **1800 305 150** or visit **www.ywcaencore.org.au**.

Relationships with others

The strong emotions you experience as a result of cancer may affect your relationships.

Your experiences may cause you to make some changes in your life or develop a new outlook on your values, priorities and life in general. Sharing those thoughts and feelings with your family, friends and work colleagues may strengthen your relationships.

If you feel uncomfortable talking about your feelings, take your time and approach others when you are ready. People usually appreciate insight into how you are feeling and guidance on providing support during and after treatment.

While you are giving yourself time to adjust to cancer, do the same for your friends and family. Everyone will react in a different way – by putting on a happy face, playing down your anxiety, or even ignoring you. They are also adjusting in their own way to changes.

Complementary therapies

Complementary therapies are treatments that may help you cope better with side effects such as pain. They may also increase your sense of control over what is happening to you, decrease your stress and anxiety, and improve your mood.

There are many types of complementary therapies, including acupuncture, massage, relaxation, meditation and herbal medicine. While some cancer treatment centres offer complementary therapies as part of their services, you may have to go to a private practitioner. Self-help CDs or DVDs can also guide you through some different techniques.

Let your doctor know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your conventional treatment. For example, herbs and nutritional supplements may interact with your medication, resulting in harmful side effects. Massage, acupuncture and exercise therapies may also need to be modified if you have lowered immunity, low platelets or fragile bones. Call Cancer Council Helpline 13 11 20 for more information and resources about complementary therapies.

Alternative therapies are commonly defined as those used instead of conventional treatments. These therapies may be harmful if people with cancer delay or stop using conventional treatments in favour of them. Examples include high-dose vitamin supplements, coffee enemas and magnet therapy.

Sexuality, intimacy and cancer

Having cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, the way you and your partner communicate, and your self-confidence. Knowing the potential challenges and addressing them will help you adjust to these changes.

Some people with cancer have the support of a partner, while others do not. If you meet a new partner during or after cancer treatment, it can be difficult to talk about cancer with them, particularly if it has had an impact on your sexuality.

Sexual intercourse may not always be possible during and after treatment, but closeness and sharing are vital to a healthy relationship. Call 13 11 20 for more information, including a free booklet about sexuality and intimacy.

Changing body image

Cancer treatment can change the way you feel about yourself (your self-esteem). You may feel less confident about who you are and what you can do. This is common whether your body has changed physically or not.

Give yourself time to adapt to any changes. Try to see yourself as a whole person instead of focusing only on the parts of you that have changed. For practical suggestions about hair loss, weight changes and other physical changes, call the Helpline.

Look Good… Feel Better program

This free program teaches techniques to help restore appearance and self-esteem during treatment.

Call **1800 650 960** or visit **www.lgfb.org.au**.

Using a breast prosthesis

Many women who have a mastectomy choose to wear a breast prosthesis (breast form). This is a synthetic breast or part of a breast that appears real when worn in a bra or under clothing.

Most breast prostheses are made from silicone and have the shape and feel of a natural breast. Weighted prostheses can help you maintain good balance and posture.

You may wear a temporary, soft breast form in the first couple of months after surgery, until being fitted for a silicone form. A free bra and soft temporary breast form is available through Breast Cancer Network Australia. To order a My Care Kit, talk to your breast care nurse or treatment team.

More information on how to buy a breast form and what to expect at a fitting is available from the Cancer Council. Call 13 11 20 to talk to a Helpline consultant.

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 the Cancer Council Helpline to find out more.

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

My Journey Kit

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

The *My Journey Kit* contains an information guide about breast cancer and a personal record book for writing down treatment details. This can help you keep track of your appointments.

The kit also contains a copy of Cancer Australia's *Guide for Women with Early Breast Cancer* booklet.

The *My Journey Kit* is free, and it can be ordered online at **www.bcna.org.au** or by calling **1800 500 258**.

Life after treatment

You may be surprised to find out that life after cancer treatment can present its own challenges. You will need to take some time to adjust to physical and emotional changes.

You may have mixed emotions. Beforehand, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious rather than secure. You might worry about every ache and pain and wonder if the cancer is coming back.

Some people say that after cancer they have changed priorities and see life with a new clarity. For example, you may decide to travel, spend more time with family, or do volunteer work.

Although you might feel pressure to return to normal life, you may find that you don't want your life to return to how it was before cancer.

You might find it helpful to:

- take time to adjust to physical and emotional changes
- re-establish a new daily routine at your own pace
- maintain a healthy diet and lifestyle
- schedule regular checkups with your doctor
- share your concerns with family and friends and tell them how to support you
- call Cancer Council Helpline 13 11 20 to connect with other people who have had cancer, or to request a free booklet about life after cancer.

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, talk to your doctor, breast care nurse or Cancer Council Helpline. You may be clinically depressed, and counselling or medication may help you. Some people are eligible to receive a Medicare rebate for a number of sessions with a psychologist. For information, call Medicare on 132 011.

After treatment: follow-up

After your treatment, you will need regular checkups to monitor your health and confirm that the cancer hasn't come back.

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 five years after treatment	annually

If your doctor is concerned the cancer has spread, you may have an MRI 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.

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 is hormone-receptor negative
- if the grade of the cancer is high
- if the surgical margin is not clear.

Having one or more of these factors doesn't necessarily mean your cancer will come back or spread. If your cancer has any of these features, you can still be treated successfully.

You should be breast aware, which means you look at your breasts and feel them regularly to know what is normal for you. Being breast aware and having regular checkups can help find a recurrence early so it can be treated.

Seeking support

When you are first diagnosed with cancer, and throughout the different stages of your treatment and recovery, it is normal to experience a range of emotions, such as fear, sadness, anxiety, anger and frustration. If sadness or anxiety is ongoing or severe, talk to your doctor.

It may help to talk about your feelings. Your partner, family members and friends can be a good source of support, or you might prefer to talk to:
- members of your treatment team
- a counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group – see page 61
- Cancer Council Helpline.

If you need assistance, such as help around the house, it may be difficult to tell people what would be useful. Some people prefer to ask a family member or friend to coordinate offers of help. Your friends and family might want to do provide practical assistance, such as doing running errands.

You may find that while some people you know are supportive, others may not even know what to say. Cancer Council has information about emotions and cancer that may help.

If you have children, the prospect of telling them you have cancer can be frightening and unsettling. The book *Talking to Kids about Cancer* can help you prepare for this conversation. To download this booklet, go to www.cancercouncil.com.au.

Practical and financial help

A serious disease often causes practical and financial difficulties. This can add to the stress and anxiety you may already be feeling about having cancer and going through treatment.

Many services are available to help so you don't have to face these difficulties alone:

- Financial assistance, through benefits and pensions, can help pay for prescription medicines and travel to medical appointments.
- Home nursing care is available through community nursing services or local palliative care services.
- Meals on Wheels, home care services, aids and appliances can make life easier.

To find out more, talk to the hospital social worker, occupational therapist or physiotherapist, or Cancer Council Helpline 13 11 20.

Learning more about cancer

If you want to learn more about cancer and coping with it, ask your local Cancer Council or hospital about education programs or seminars.

Programs may cover many cancer-related issues, such as symptoms, treatment, side effects, diet, palliative care and complementary therapies. Attending a program may also give you an opportunity to meet other people affected by cancer.

Talk to someone who's been there

Getting in touch with other people who have been through a similar experience can be beneficial. There are many ways to contact others for mutual support and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Ask your nurse or social worker to tell you about support groups in your area. There are several breast cancer support groups, including groups for lesbians and young women with cancer. Call the Helpline to find out how you can connect with others.

Support services available in your community

Face-to-face support groups – often held in community centres or hospitals

Online discussion forums – where people can connect with each other any time – see **www.cancerconnections.com.au**

Telephone support groups – for certain situations or types of cancer, which trained counsellors facilitate

Caring for someone with cancer

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

Many cancer support groups are open to carers as well as people with cancer. A support group can offer a valuable opportunity to share experiences and ways of coping. You may feel more comfortable talking about the challenges and rewards of caring with other carers.

Help for male carers

When a woman is diagnosed with breast cancer, there is often a man in her life – such as a husband, partner, son, brother or father – who is also affected.

Male partners usually find the diagnosis of breast cancer difficult to cope with. However, men sometimes have different ways of dealing with their feelings. Sometimes men feel like they need to be strong and less emotional.

Cancer Australia produces information for men. The audio CD *When the Woman You Love Has Early Breast Cancer* may be helpful. For a free copy, call **1800 624 973**.

More specific information for husbands and boyfriends of women with breast cancer may also be available from Cancer Council Helpline **13 11 20**.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. The hospital social worker can give you information about these services.

There are also many organisations and groups that can provide you with specific information and support, such as Carers Australia. Call 1800 242 636 or visit www.carersaustralia.com.au.

Call Cancer Council Helpline 13 11 20 to find out more about different services or to request a free copy of the booklet *Caring for Someone with Cancer*.

Help for young carers

There are many people under 25 years of age who are caring for someone with breast cancer.

Carers Australia offers specific information and support for young carers. Go to **www.youngcarers.net.au**.

Cancer Australia has a website for children aged 13–19 years whose parent has been diagnosed with breast cancer. Information on this website can help teenagers learn more about cancer, find out what might happen to their parent, and work out how cancer might affect their life. Visit **www.myparentscancer.com.au**.

Useful websites

Australian

Your local Cancer Council

Australian Capital Territory	**www.actcancer.org**
New South Wales	**www.cancercouncil.com.au**
Northern Territory	**www.cancercouncilnt.com.au**
Queensland	**www.cancerqld.org.au**
South Australia	**www.cancersa.org.au**
Tasmania	**www.cancertas.org.au**
Victoria	**www.cancervic.org.au**
Western Australia	**www.cancerwa.asn.au**

National websites

Cancer Institute NSW	**www.cancerinstitute.org.au**
Cancer Australia	**http://canceraustralia.nbocc.org.au**
Breast Cancer Action Group NSW	**www.bcagnsw.org.au**
Breast Cancer Network Australia	**www.bcna.org.au**
Westmead Breast Cancer Institute	**www.bci.org.au**
National Lymphoedema Practitioners Register	**www.nlpr.asn.au**

International

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

Question checklist

- What type of breast cancer do I have?
- What is the stage and grade of the cancer?
- What treatment do you recommend and why?
- What are the possible side effects of each treatment?
- How long do I have to make my treatment decision?
- Will doctors who specialise in breast cancer treat me? Are they part of a multidisciplinary team?
- Are there other treatment choices for me? If not, why not?
- What happens if I do nothing?
- Are there any clinical trials I should know about?
- How long will treatment take? How much will it affect what I can do?
- Will I have to stay in hospital? If so, for how long?
- How much will it cost?
- What will be done about pain I have during treatment?
- How long will it take to recover from my treatment?
- If I need further treatment, what is it likely to be?
- Will I have problems with sex and fertility?
- After treatment, will I need checkups? What do they involve?
- Can you refer me to someone else for a second opinion?
- Is my cancer hereditary? If so, what do you recommend?

Glossary

You may come across new terms when reading this booklet or talking to health professionals. You can check the meaning of other health-related words on Cancer Council's website at www.cancercouncil.com.au/words.

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).

aromatase inhibitors
Drugs that help prevent the growth of oestrogen-dependent cancer cells by reducing the amount of oestrogen in a postmenopausal 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.

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.

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 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 a malignant tumour is surgically removed some surrounding tissue will be removed with it. If this surrounding tissue does not contain any cancer cells, it is said to be a clear margin.

duct
The canal within the breast that passes milk from the lobules to the nipple.

ductal carcinoma in situ (DCIS)
Pre-invasive breast cancer that is confined to the breast ducts.

genes
The tiny units that govern the way the body's cells grow and behave. Genes are found in every cell of the body and are inherited from both parents.

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.

Klinefelter's 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. This happens when lymph nodes do not drain properly.

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

mammogram
An x-ray of the breast which can detect cancers when they are still too small to be felt.

menopause
When a woman stops having periods (menstruating). This can happen naturally (usually around the age of 52 years), or from removing the ovaries, chemotherapy or hormone therapy.

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

oestrogen
The main female sex hormone produced mostly by the ovaries.

ovarian ablation
Stopping the ovaries from producing oestrogen by surgically removing the ovaries or giving a dose of radiotherapy to the ovaries.

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).

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.

radiation oncologist

A doctor who specialises in treating cancer using radiotherapy.

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them, so they cannot grow and multiply.

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.

staging

Performing tests to determine how far a cancer has spread.

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.

Notes

How you can help

At Cancer Council we're dedicated to defeating cancer. As well as funding more cancer research than any other charity in the state, we advocate for the highest quality of care for cancer patients and their families, and create cancer-smart communities by empowering people with knowledge about cancer, its prevention and early detection. We also offer direct financial assistance for those people in hardship as a result of having cancer. These achievements would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events like 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 donation, whether large or small, will make a meaningful contribution to our fight to defeat cancer.

Buy sun protection products from our website or retail stores: Every purchase helps you prevent cancer and contributes financially to our work.

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 cancer issues and help us defeat cancer by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council does research to investigate the causes, management, outcomes and impacts of different cancer types.

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

Cancer Council Helpline 13 11 20

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

For the cost of a local call (except from mobiles), you, your family, or friends can talk about your concerns and needs confidentially with experienced cancer nurses. Helpline nurses can send you information and put you in touch with support services in your area.

If you need information in a language other than English, you can call the Multilingual Cancer Information Line. See the back cover for details.

You can call the Cancer Council Helpline, Monday to Friday, 9am to 5pm. If calling outside business hours, you can leave a message and your call will be returned the next business day.

Cancer Council Publications

If you found this booklet helpful, you might want to request another free resource from the Cancer Council. Call the Helpline if you would like a copy of any of the following resources:

Treatment and side effects

- Coping with chemotherapy
- Coping with radiotherapy
- Complementary and alternative cancer therapies

Coping with cancer and recovery

- Nutrition and exercise
- Life with cancer
- Cancer pain
- Sexuality and cancer
- When cancer won’t go away

Cancer Council
Helpline
13 11 20

Cancer information in your language

Do you speak a language other than English? Do you have questions about cancer? For the cost of a local call, you can confidentially talk to a nurse from the Cancer Council Helpline with the help of an interpreter.

Simply follow these steps:

1. Call **13 14 50**, Monday to Friday 9am to 5pm.
2. Say the language you need.
3. Wait on the line for an interpreter (may take up to 3 minutes).
4. Ask the interpreter to contact Cancer Council Victoria Helpline **13 11 20**.
5. You will be connected to the interpreter and a cancer nurse.

For further information and details please visit our website: **www.cancervic.org.au**

UNDERSTANDING BREAST CANCER

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