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# Breast cancer

## A handbook for Aboriginal and Torres Strait Islander Health Workers and Health Practitioners



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Helping Health Workers provide information and support to Aboriginal and Torres Strait Islander women with breast cancer.



Breast cancer: a handbook for Aboriginal and Torres Strait Islander Health Workers and Health Practitioners resource was prepared and produced by:

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- the Aboriginal and/or Torres Strait Islander Health Workers, Health Practitioners and other health professionals who reviewed the draft and provided valuable input and feedback

## Acknowledgement of country and cultural diversity

Cancer Australia acknowledges the Traditional Owners of country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to Elders past and present, and to emerging leaders.

## Wording in this handbook

Cancer Australia recognises that ‘Aboriginal and Torres Strait Islander people’ is the preferred term for referring to Aboriginal peoples and Torres Strait Islander people collectively. This term recognises the distinct cultures, languages and homelands of Australia’s Indigenous communities.

In this handbook, we use the term ‘Health Workers’ to refer to Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners.



# Introduction

.....

**This handbook has been written to help Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners provide breast cancer information and support to women in their community.**

**The handbook may also be useful for Aboriginal Liaison Officers, nurses and other health professionals working with Aboriginal and Torres Strait Islander people.**

**The content of this handbook focuses mainly on the needs of women affected by breast cancer. It is important to know that, while uncommon, men can get breast cancer as well. You can read about this in [Chapter 1](#) and find out about where to get more information on breast cancer in men.**

## Key Information:

This handbook contains information about:

- What breast cancer is (page 4)
- How women can reduce their risk of breast cancer (page 12)
- The importance of breast awareness and early detection (page 13)
- How breast cancer is diagnosed (page 17)
- Treatments for breast cancer (page 26)
- Social and emotional wellbeing and support (page 52)
- Follow-up care after treatment (page 75)
- What happens if breast cancer comes back or spreads (page 81)

## Your role as an Aboriginal and/or Torres Strait Islander Health Worker or Practitioner:

As an Aboriginal and/or Torres Strait Islander Health Worker or Practitioner, you have an important and multifaceted role in providing information, supporting your community and empowering patients.

You can encourage women to lead healthy lifestyles and attend breast screening. You can support women as they navigate an unfamiliar healthcare system. And you can advocate for women to ensure their social and emotional needs are met by your local health services, and services further away.

You may not be involved in the support and care of women along their entire breast cancer journey, but you can still help by making sure women have the information they need along the way.

It is important that local protocols are followed when providing information and care. If you are not local to the region in which you are providing support, you should find out about local protocols and customs. You may also need to assist other healthcare professionals to deliver culturally appropriate care.



# Your role

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**This handbook includes tips to help you provide information, support and guidance about breast cancer to women in your community.**

**As the roles of Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners can be different in each workplace, it's best to check what the roles and responsibilities are in your workplace first and to use these tips in line with your local context.**



### Talking about cancer:

Women need clear information about breast cancer risks, signs and symptoms, tests and treatment options. They may be worried, frightened or embarrassed when talking about breast cancer. You can help by providing simple information and encouraging women to ask questions.

It's okay if you don't have all the answers. You can let the woman know that you will find out the answer, for example from a doctor or nurse, and let her know at the next appointment. The following tips may be useful to help women feel more comfortable talking about breast cancer.

- Explain that any information a woman shares with you and her healthcare team is confidential.
- Ask the woman if she would like you or a family member to be with her when she meets with her doctor or specialists.
- Encourage her to talk about how she feels and what she is worried about.
- Handle embarrassing or worrying topics directly and sensitively.

Check to see whether she has understood what her doctors have told her. Explain medical jargon, use diagrams and pictures and write out information for the woman and her family to take away if helpful.

### Looking after yourself:

**Talking about cancer and supporting people with cancer can be stressful and emotionally draining. It's important to look after your own health and seek support if needed.**

**Talking to your colleagues and manager about how you're feeling can be a good place to start.**

**Many workplaces have employee assistance programs that can offer professional counselling services. The following organisations can also provide support.**

#### **i** For more information

- Cancer Council Helpline: 13 11 20
- Lifeline: 13 11 14



# Chapter 1: Breast cancer: the facts

## Key points:

- Breast cancer occurs when cells in the breast grow in an abnormal and uncontrolled way.
- Breast cancer is the most common cancer among Aboriginal and Torres Strait Islander women.
- Although uncommon, breast cancer can also occur in men.

## What is breast cancer?

Cancer is a disease in which the body's basic building blocks – the cells – change and grow in an uncontrolled way. The abnormal cells – cancer cells – can grow into (invade) and damage the surrounding tissue. Sometimes the cancer cells spread to other parts of the body, causing more damage.

Breast cancer occurs when cells in the breast grow abnormally. The cancer cells form growths called tumours. Cancer cells can grow in the ducts or lobules of the breast (Figure 1).

Sometimes the cancer cells stay in the ducts and lobules of the breast. This is called '**non-invasive breast cancer**'. When cancer cells spread into the surrounding breast tissue and outside the breast, this is called '**invasive breast cancer**'.

## Non-invasive breast cancer

### Ductal carcinoma in situ (DCIS)

Ductal carcinoma in situ (DCIS) is the most common type of non-invasive breast cancer that stays in the ducts of the breast. DCIS cannot usually be felt as a breast lump or other breast change.

Most cases of DCIS are found following a breast screen. Most women with DCIS are not aware of any symptoms at diagnosis.

A woman cannot die from DCIS unless it develops into invasive breast cancer.

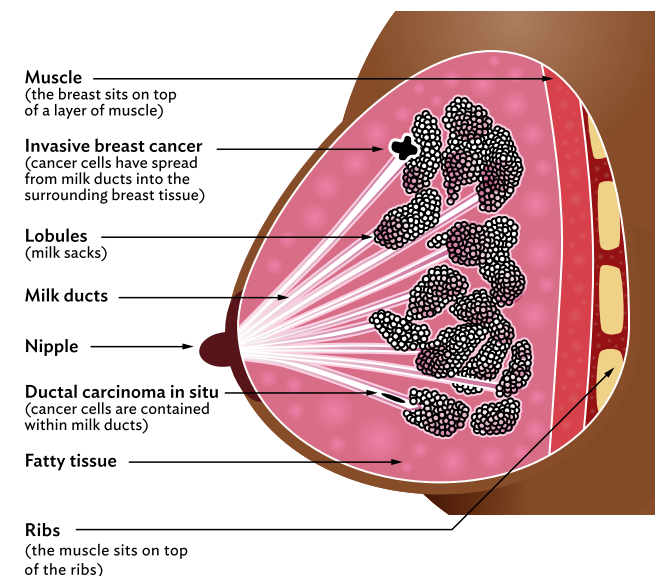


Figure 1. Illustration of a woman's breast showing invasive breast cancer and ductal carcinoma in situ

<sup>1</sup> The lobules of the breast produce breast milk, and the ducts carry milk to the nipple.

## Lobular carcinoma in situ (LCIS)

Lobular carcinoma in situ (LCIS) is a type of non-invasive breast cancer that stays in the lobules of the breast. LCIS cannot usually be felt as a breast lump or other breast change. Most cases of LCIS are found when a woman has a biopsy for another reason. A woman cannot die from LCIS alone. It does not need to be treated if there are no other abnormal changes to the breast. Having LCIS can increase your risk of developing invasive breast cancer later on, so it is important to have close follow-up.

**Having DCIS or LCIS increases a woman's risk of developing invasive breast cancer.<sup>1</sup> Management and follow-up is important to prevent and monitor for invasive breast cancer.**

## Invasive breast cancer

### Early breast cancer

Early breast cancer is invasive breast cancer that has spread from the ducts and lobules of the breast into the surrounding breast tissue. Cancer cells may spread to lymph nodes in the breast or armpit on the same side. In women with early breast cancer, no cancer cells are found elsewhere in the body, outside the breast and armpit area. In Australia, early breast cancer is more common than other types of breast cancer.

### Locally advanced breast cancer

Locally advanced breast cancer is invasive breast cancer that has spread to areas near the breast, such as the chest wall.

Locally advanced breast cancer has one or more of the following features:

- may be large (typically bigger than 5 cm)
- may have spread to several lymph nodes in the armpit or other areas near the breast or collarbone
- may have spread to other tissues around the breast, such as skin, muscles or ribs.

In women with locally advanced breast cancer, there are no signs that cancer cells have spread beyond the breast / chest area to other areas of the body.

### Metastatic breast cancer

Metastatic breast cancer (also known as secondary or advanced breast cancer) is invasive breast cancer that has spread from the breast to other parts of the body, such as the bones, liver, lungs and brain.

In Australia, metastatic breast cancer is less commonly diagnosed than early breast cancer.<sup>2</sup>

### Other types of invasive breast cancer

Some rarer types of invasive breast cancer are:

- Paget's disease of the nipple: a type of invasive breast cancer that affects the nipple and the area around the nipple (the areola)
- Inflammatory breast cancer: a type of invasive breast cancer that affects the blood vessels in the skin of the breast, causing the breast to become red and inflamed.

## Your Role

### Breast cancer in Aboriginal and Torres Strait Islander women

Breast cancer is the most commonly diagnosed cancer among Aboriginal and Torres Strait Islander women.<sup>3</sup>

Each year, about 150 Aboriginal and Torres Strait Islander women are diagnosed with breast cancer and about 35 women die from the disease.<sup>4</sup>

The good news is that finding breast cancer early can increase the likelihood of successful treatment and recovery.

#### **i** For more information

You can learn more about the statistics of breast cancer in Aboriginal and Torres Strait Islander women from the following websites.

- Cancer Australia: Aboriginal and Torres Strait Islander cancer statistics  
[www.canceraustralia.gov.au/affected-cancer/indigenous/cancer-statistics](http://www.canceraustralia.gov.au/affected-cancer/indigenous/cancer-statistics)
- Australian Institute of Health and Welfare: Cancer in Aboriginal and Torres Strait Islander people of Australia [www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians/contents/table-of-contents](http://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians/contents/table-of-contents)

**Delivering supportive and positive messages to your community:**

Many women in your community will know someone who has had cancer and passed away. Because of this, women may be scared about getting breast cancer. You can change that perception through positive messaging and health promotion.

Most women whose breast cancer is found and treated early will go on to live long and healthy lives. You can remind the women in your community about these positive outcomes.

You can change that perception through positive messaging and health promotion.

**Key messages for your community:**

- Breast cancer is not a death sentence.
- Women who find breast cancer early, before it has spread, and complete treatment will have the best chance of surviving.
- Talking about your own experience with breast cancer can help other women.
- Treatments for breast cancer are getting better all the time.
- Side effects of treatment can be managed well with medicines.

## Breast cancer in Aboriginal and Torres Strait Islander men

Although uncommon, breast cancer can also occur in men. It's important for men who find a change in their breasts to not let embarrassment or uncertainty prevent them from seeing a doctor as soon as possible.

Finding breast cancer early, before it has spread, gives the best chance of successful treatment.

### **i** For more information

You can learn more about breast cancer in men from the following websites.

- Cancer Australia: Understanding breast cancer in men <https://www.canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/breast-cancer-men>
- Cancer Council Australia: Breast cancer in men [www.cancer.org.au/cancer-information/types-of-cancer/breast-cancer-in-men](http://www.cancer.org.au/cancer-information/types-of-cancer/breast-cancer-in-men)

## Chapter 2: Finding Breast cancer early

### Key points:

- There are several things that can increase a woman's risk of getting breast cancer.
- Finding breast cancer early can increase the likelihood of successful treatment.
- You can support and encourage early detection of breast cancer among women in your community by:
  - encouraging women to have a free breast screen every two years from the age of 50 to 74
  - encouraging women to get to know the normal look and feel of their breasts, letting them know what changes to look for, and supporting them to get any new or unusual changes checked by a health professional.

Finding breast cancer early can increase the likelihood of successful treatment and recovery.

Aboriginal and Torres Strait Islander Health Workers are in an ideal position to promote the importance of breast awareness and finding breast cancer early with women in your community.



## What causes breast cancer?

There are several things that can increase a woman's risk of developing breast cancer. These are called risk factors.

Having one or more risk factors for breast cancer does not mean that a woman will get breast cancer. Some women who get breast cancer have no obvious risk factors, besides being a woman. The good news is that all women can take steps to improve their overall health and reduce their risk of breast cancer.

## Breast cancer risk factors

Some of the main things that are known to increase the risk of breast cancer are listed below. Some of these risk factors, like getting older or having a family history of breast cancer, cannot be changed. Others, such as diet and exercise, can be changed.

## Personal and health factors

- **Being a woman.** Not all women get breast cancer, but being a woman is the strongest risk factor. Men can get breast cancer too – but their risk is much lower.<sup>5</sup>
- **Getting older.** Breast cancer can occur at any age, but is more common in older women.<sup>5</sup>
- **Socioeconomic status.** Women who live in areas of higher socioeconomic status have a higher incidence of breast cancer than women who live in more disadvantaged areas.<sup>5</sup>
- **Breast density.** Women who have very dense breast tissue have a higher risk of breast cancer than women with little or no dense breast tissue.<sup>5</sup> Breast density is something that can only be seen on a breast screen. It is not related to how breasts look or feel.
- **Breast conditions.** Having invasive breast cancer in one breast makes a woman two to six times more likely to develop cancer in the other breast. Other conditions, like DCIS, LCIS and ductal hyperplasia, can also increase a woman's risk.<sup>5</sup>
- **Hormones.** Hormones play a role in breast cancer risk. Starting periods at a young age (before 12 years), taking the contraceptive pill, using combined hormone replacement therapy, and reaching menopause at an older age (after 55 years), can all affect a woman's risk of breast cancer.<sup>5</sup>
- Certain other aspects of a woman's health can increase the risk of breast cancer, including:
  - being taller (> 175 cm)<sup>5</sup>
  - having a history of other types of cancer, such as Hodgkin lymphoma, or thyroid cancer<sup>5</sup>
  - being exposed to high doses of ionising radiation in the chest area (such as having radiation therapy for Hodgkin lymphoma or childhood cancers).<sup>5</sup>



## Family history and genetic factors

- **Family history.** Having a family history of breast cancer, especially having one or more first-degree relatives with breast cancer, can increase a woman's risk of breast cancer.<sup>5</sup>

## Lifestyle factors

- Some aspects of a woman's lifestyle can increase her risk of breast cancer, including:
  - being overweight or obese after menopause
  - smoking
  - drinking alcohol.<sup>5</sup>

## What doesn't cause breast cancer?

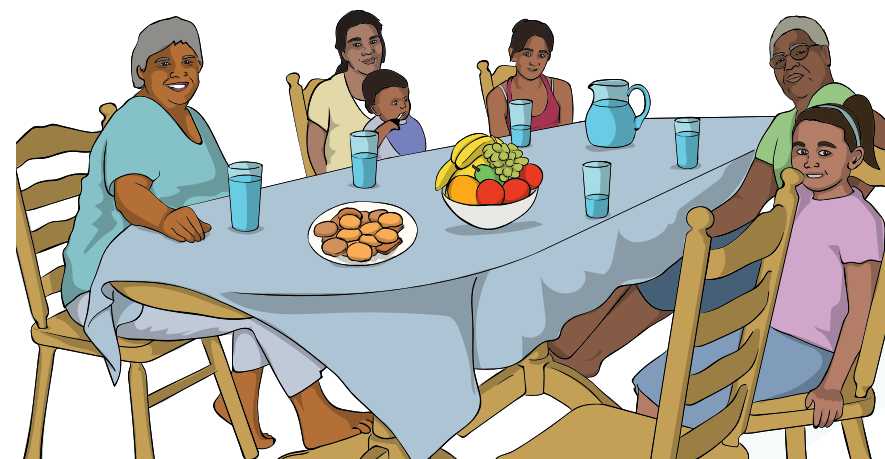
There are a number of factors for which there is no evidence to support a link with breast cancer.

This might mean that these factors do not increase the risk of getting breast cancer, or it may mean that high quality research has not been done or that the results of research are conflicting.

Factors that have not been shown to increase breast cancer risk include:

- having an abortion
- wearing a bra or different types of bra
- having silicone breast implants
- using underarm deodorant or antiperspirant
- stress
- pollution in the environment.

**You cannot get breast cancer from being near someone, caring for someone or touching someone with cancer.**



## More about family history and genetics

Family history is an important breast cancer risk factor. The risk of developing breast cancer is higher if more than one first-degree relative has been affected by the disease. A woman's risk of developing breast cancer also increases if her family members were diagnosed with the disease at a young age.

The link between family history and breast cancer risk may be due to common lifestyle factors, such as where and how family members live. It may also mean that the family members share a gene that increases cancer risk.

There are some rare gene mutations that have been linked to an increased risk of breast and ovarian cancer. These include the BRCA1 and BRCA2 genes. A family history of ovarian cancer also increases the risk of breast cancer. It may be appropriate for some women who have a strong family history to be referred to a family cancer clinic for genetic counselling and genetic testing.

### **i** For more information

If a woman in your community is concerned about her family history of breast cancer, she can be referred to a Family Cancer Clinic to discuss her genetic risk factors and have her family history assessed.

If a woman with breast cancer is worried that her family members might be at increased risk of breast cancer due to her own diagnosis, you can suggest her family members see their local doctor. The doctor can undertake a risk assessment and determine if the family members require any extra monitoring or screening in the future.

You can find a list of general Clinical Genetic Services throughout Australia through the Centre for Genetics Education (NSW Health) <https://www.genetics.edu.au/SitePages/Genetic-Services.aspx>

## Your role

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**Raising awareness of the risk factors for breast cancer:**

**It is important that women know the risk factors for breast cancer. The good news is that all women can take steps to improve their overall health and reduce their risk of breast cancer.**

**You can help by:**

- educating women in your community about risk factors for breast cancer
- supporting women to speak to their local doctor if they are concerned about their family history of breast cancer
- encouraging women to have a healthy lifestyle to reduce their risk of breast cancer

## Reducing the risk of breast cancer

The good news is that there are things women can do to reduce their risk of breast cancer. You can support women in your community to reduce their risk of breast cancer by promoting a healthy lifestyle.

### Women can reduce their risk by:



#### Breast feeding

Support women with breastfeeding. The longer a woman breastfeeds, the greater the benefits.



#### Maintaining a healthy weight

Encourage women to choose nutritious foods and exercise regularly to maintain a healthy weight.



#### Getting active

Suggest fun ways to get women moving – like brisk evening walks or dance classes.



#### Not smoking

Support women to quit smoking to improve their overall health.



#### Drinking less alcohol

Talk with women about alcohol-free alternatives.

## Finding breast cancer early

Two important things that women can do to increase their chances of finding breast cancer early are:

1. have a breast screen every two years after they turn 50
2. get to know the normal look and feel of their breasts and knowing what changes to look out for.

## Breast screening

A breast screen – also called a screening mammogram – is an X-ray that takes a picture of the inside of the breast. Breast screening can highlight unusual changes in the breast that may be due to breast cancer.

Breast screening can pick up changes before a woman or her doctor notices any physical changes such as a lump.

In Australia, all women aged between 50 and 74 years are invited to have a breast screen every two years. It is important that women attend breast screening even if they feel well and have no symptoms.

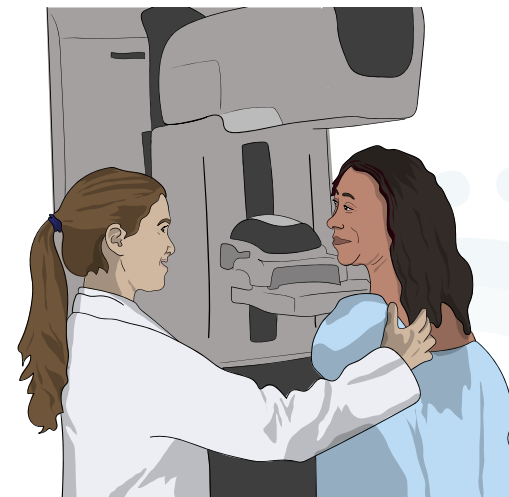
Women aged over 40 years can also attend breast screening. However, mammograms may not be as effective in younger women because their breast tissue is denser and changes are more difficult to see.

### **i** For more information

BreastScreen Australia <https://www.health.gov.au/initiatives-and-programs/breastscreen-australia-program> provides free 2-yearly breast screening in all states and territories for Aboriginal and Torres Strait Islander women aged 50–74 years.

BreastScreen Australia has over 500 locations across Australia. Mobile screening vans bring breast screening to regional, rural and remote locations.

Call your state or territory BreastScreen Australia service on 132 050 for information about breast screening or to book an appointment. The phone service will connect you to your nearest service for the cost of a local call.



## Your role

### What does breast screening involve?

A breast screen is **free** and takes **about 20 minutes** to complete. The screening will be conducted by a female member of staff. During the screening, two x-rays are taken of each breast.

To get a clear picture, the x-ray machine will press firmly on each side of the breast. This can be a little uncomfortable, but it only lasts for a few seconds.

You may like to talk with your local BreastScreen service to find out about where women in your community can get a breast screen.



### Encouraging and supporting breast screening:

Participation in breast screening by Aboriginal and Torres Strait Islander women is increasing. In 2018–19, around 2 in 5 Aboriginal and Torres Strait Islander women aged between 50–74 years of age had a breast screen.<sup>6</sup> You can help by:

- talking to women about the importance of finding breast cancer early
- explaining how a breast screen can help find breast cancer early
- encouraging and supporting women to take part in the BreastScreen program; you might consider organising a breast screening event or a group visit to a BreastScreen service
- reassuring women that breast screens are done by a woman
- finding out what supports your local BreastScreen service offers for Aboriginal and Torres Strait Islander women and letting women in your community know
- encouraging women who have had breast screening to tell their story; this may help other women feel less embarrassed or nervous about attending breast screening.

## Your role

### Breast awareness

More than half of all breast cancers are diagnosed after a woman or her doctor notices a change in her breast. It's important for women to get to know the normal look and feel of their breasts and keep a look out for any new or unusual changes. Most breast changes are not due to breast cancer. However, it's important that women get new or unusual changes checked by a health professional. That way, if the change is due to breast cancer, treatment can start as early as possible. Women can get to know the normal look and feel of their breasts as part of everyday activities, like showering, dressing or looking in the mirror.

### What are some practical things you can do to support the early detection of breast cancer?

#### Develop health promotion resources

The most effective health promotion resources are those developed locally. Consider developing local resources that encourage women to:

- be familiar with the normal look at feel of their breasts
- attend their local breast screening service.

Resources might include teaching aids and a poster with stories from women in the community who have been screened. Or you might want to hold local information sessions with women in the community. It may be a good idea to involve your local community in the development of these health promotion resources.

#### Develop a relationship with your local BreastScreen service

It can be helpful for you to get to know your local BreastScreen service. This may be a permanent service in your town or could be a mobile service that visits regularly. Find out what supports are available for Aboriginal and Torres Strait Islander women so you can let women in your community know. Keep a calendar of when the local health service is promoting breast cancer awareness (e.g. October – Breast Cancer Awareness Month) or when the BreastScreen van is in town. It can also help to leave your contact details at BreastScreen or the local health service for any women who need to get in touch.

#### Encouraging women to check their breasts and visit their doctor if they notice a change:

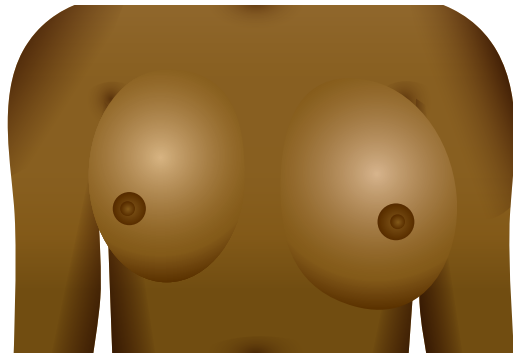
**You can encourage women to get to know the normal look and feel of their breasts by explaining how easy it is to do as part of everyday activities. You may want to develop or share health promotion and education materials to help women in your community understand the importance of being breast aware.**

**You can let women know that most breast changes aren't due to cancer. But it's important that a woman who notices a change sees her doctor to be sure.**

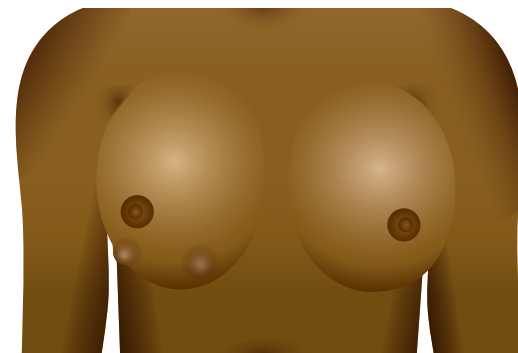
#### You can help by:

- offering to attend the appointment with the woman or arranging for a support person to go with her
- talking to the woman about what might happen at the appointment and reassuring her about any concerns
- talking with doctors at your local health service and helping them to deliver culturally appropriate care.

**Breast changes to look out for include:**

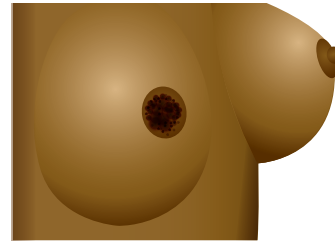


A change in the size or shape of one breast

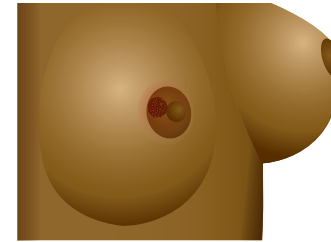


A new lump or lumpiness, especially if it's only in one breast (lumps may not be visible but can be felt)

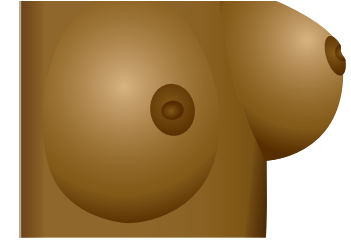
**A change to the nipple, such as:**



Crusting

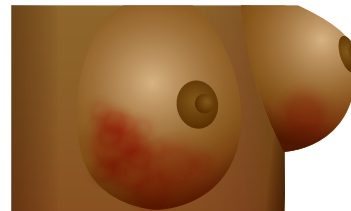


Redness or ulceration

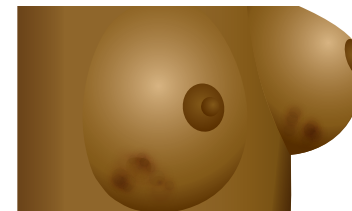


Inversion (where the nipple turns in)

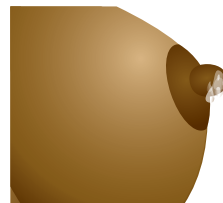
**A change in the skin of the breast such as:**



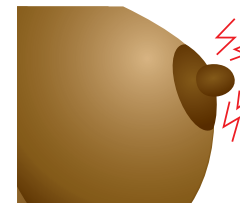
Redness



Dimpling



A nipple discharge that occurs without squeezing



Any unusual pain that doesn't go away

# Chapter 3: Investigating symptoms and diagnosing breast cancer

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## Key points:

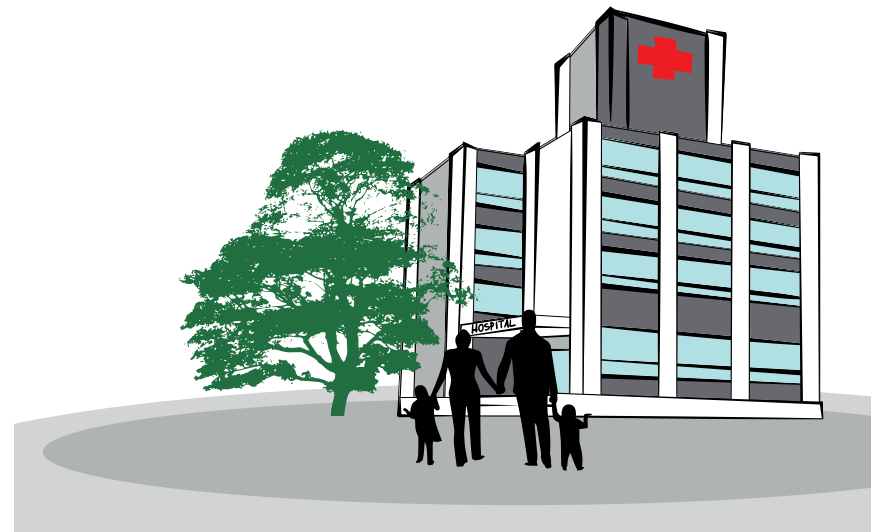
- **Breast cancer is diagnosed using ‘the triple test’; a three-step approach involving medical history and physical examination, breast imaging and biopsy.**
- **The results of these tests help doctors to determine the best treatment options for a woman.**
- **Being tested for and diagnosed with breast cancer can be a frightening and confusing time for women in your community. You have an important role to play in supporting them through their investigation and diagnosis.**

If a woman has a new breast symptom, like a lump, or the results of her breast screening are unclear, she will need to undergo some further testing to find out if she has breast cancer or not.

It’s important to know that not all testing leads to a diagnosis of breast cancer. Being tested for, and diagnosed with, breast cancer can be a frightening and confusing time.

Women have to take in and understand detailed information and undergo diagnostic tests all while coming to terms with having a potentially life-threatening disease.<sup>7</sup> Sometimes, this can be made harder by the complicated language used by doctors during diagnosis.

Women may know little about breast cancer until they are diagnosed. The shock and confusion of their diagnosis may leave them unsure of their treatment options and the benefits of these treatments.





## How is breast cancer diagnosed?

When a woman visits her doctor with concerns about a change in her breast, her doctor will use 'the triple test' to investigate the change.

The triple test involves three different diagnostic components. These components are carried out in order. It is not always necessary to conduct all three components. Results from one component will help the doctor decide whether the next component is needed.

The three diagnostic components used in the triple test are:

1. medical history and clinical breast examination
2. breast imaging (mammogram and/or ultrasound)
3. biopsy (core biopsy and/or fine needle aspiration biopsy)

The triple test is **positive** if any of the three examinations show an unusual or suspicious result that could be cancer.

The triple test is **negative** if all the results on all three parts of the triple test are negative, and this gives good reassurance that the symptom is not due to breast cancer.

The triple test is more accurate at finding breast cancer than just having one of the examinations on its own. When done correctly, the triple test can detect over 99.6% of breast cancer.<sup>10</sup>

## Medical history and clinical breast examination

When a woman first visits a doctor with a breast cancer symptom, the doctor will ask her about her medical history and will give her a physical examination.

The doctor is likely to ask questions about:

- the woman's symptoms and any pain she is having
- if she has had any breast problems in the past
- her menstrual history
- whether she has ever been pregnant
- whether she takes any medicine
- her family history of cancer.

The doctor may also ask about the woman's social situation and emotional wellbeing, as part of a holistic review of her physical and mental health.

In the physical examination, the doctor will look at and feel the woman's breasts and armpits for any signs of cancer in the breast and the area around the breast. The doctor will also examine other parts of the body to check for anything unusual that may be causing or linked to the woman's symptoms.

A physical examination is an important step in looking for signs of breast cancer; however, it is not completely reliable. If a physical examination detects changes that may be due to cancer, the other triple test examinations are needed to confirm whether the changes are due to breast cancer.

## Breast imaging

Imaging tests give doctors a picture of the inside of a woman's breast and the areas near the breast. There are different types of imaging tests used to detect breast cancer:

- **Mammogram:** an X-ray of the breast. A mammogram is used to take a picture of an abnormal area of the breast, to help find out what is causing the lump or another clinically detected symptom. A mammogram is taken of both breasts to compare the two and to look for changes.
- **Ultrasound:** a way of examining the breasts and/or armpit area using high-frequency sound waves. A breast ultrasound is a useful way of investigating abnormal areas in most cases of suspected invasive breast cancer. Ultrasound can be used to find small breast cancers, and can be useful in younger women with dense breast tissue because mammograms don't show changes clearly in these women.

The imaging tests used depend on the woman's age and breast density.

Typically, a mammogram and an ultrasound should both be performed for women 35 years and over. An ultrasound is used first for women younger than 35 years. A mammogram is then used in addition to the ultrasound if the findings on the ultrasound are abnormal.

## Biopsy

A biopsy involves removing a sample of breast tissue for examination under a microscope to confirm a diagnosis of breast cancer. If the tissue removed is breast cancer, this examination can provide information about the type of breast cancer.

There are two types of biopsy that may be used as part of the triple test to diagnose breast cancer.

- **Core biopsy:** Core biopsy involves removing a sample of cells from the abnormal area of breast tissue with a needle.
- **Fine needle aspiration biopsy (FNAB):** FNAB involves removing cells from the breast using a smaller needle.

A core biopsy or FNAB can be done in a breast clinic by a doctor who specialises in imaging or breast cancer. If there is no obvious lump in the breast, a mammogram or breast ultrasound may be used to show the abnormal area from which the cells or tissue should be taken.

After the biopsy, the cells or tissue are sent to a pathologist to check whether the breast change is due to breast cancer.

If either of these tests show signs of breast cancer, the woman will be referred to a breast surgeon for management.

## What do the test results mean?

The pathologist will write a pathology report summarising the results of the biopsy. Following a core biopsy or FNAB, the report will show whether breast cancer cells have been detected.

The pathology report will also provide detailed information about the breast cancer that will be useful to guide treatment options. An example of a pathology report for invasive breast cancer is at (Figure 2).

## Pathology report

The terms that typically appear in a pathology report, and what they mean for treatment, are listed in Table 1. You can use this as a reference to help women in your community understand what their results mean.

Doctors use the information in a woman's pathology report to work out the best treatment options for her. The doctor will discuss these treatment options with the woman and provide her with the information she needs to make a decision about her treatment.

Figure 2. Pathology report

**Patients name:** \_\_\_\_\_ **Laboratory number:** \_\_\_\_\_

**Diagnostic summary**

**Specimen type:** \_\_\_\_\_  
**Location:** \_\_\_\_\_  
**Tumour type:** \_\_\_\_\_

**Lesion size**

**Invasive tumour size/s (mm):** \_\_\_\_\_  
**Total extent of lesion (DCIS + invasive carcinoma)\* (mm):** \_\_\_\_\_  
\*If greater than invasive tumour size

**Histological grade**

Mitotic rate (per 10 high power fields):	
Mitosis score (1–3):	
Tubular formation score (1–3):	
Nuclear grade (1–3):	
<b>Histological grade (1–3):</b>	

**Peritumoural lymphovascular invasion:**

absent  suspicious  present  present and extensive

**Involvement of skin/muscle:**

absent  present  intermediate  high  
Please specify:

**DCIS in specimen**

Nuclear grade:  low  intermediate  high  
 Necrosis: \_\_\_\_\_ Architecture: \_\_\_\_\_  
 Calcification: \_\_\_\_\_

**Resection margins**

Invasive carcinoma at resection margin:

No  Yes  Orientation of involved margin: \_\_\_\_\_  
Distance from nearest specified margin(s):  Extent of involvement (mm): \_\_\_\_\_

DCIS at resection margin:

No  Yes  Orientation of involved margin: \_\_\_\_\_  
Distance from nearest specified margin(s):  Extent of involvement (mm): \_\_\_\_\_

LCIS at resection margin:

No  Yes

**Atypical lobular hyperplasia/lobular carcinoma in situ:**

Absent  Present  classical  pleomorphic

**Page's disease of nipple:**

absent  present

**Non-neoplastic breast changes:**

\_\_\_\_\_

**Microcalcification:**

absent  present  
Specify associated pathology:

**Hormone receptor assay status (if performed)**

**ER result:**  Positive  Negative  
 Percentage of nuclei stained: \_\_\_\_\_ %  
 Predominant staining intensity: \_\_\_\_\_

**PR result:**  Positive  Negative  
 Percentage of nuclei stained: \_\_\_\_\_ %  
 Predominant staining intensity: \_\_\_\_\_

**HER2 status:**  
 Immunohistochemistry score: \_\_\_\_\_  
 FISH (please specify) result: \_\_\_\_\_

**Sentinel lymph nodes**

Metastatic carcinoma present in \_\_\_\_\_ of \_\_\_\_\_ sentinel lymph nodes examined

	Involvement	Size of metastasis
Node 1:	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Node 2:	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Node 3:	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Node 4:	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Node 5:	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Node 6:	<input type="checkbox"/> Yes <input type="checkbox"/> No	

Extent of extranodal carcinoma (mm): \_\_\_\_\_

**Axillary lymph node dissection**

Metastatic carcinoma present in \_\_\_\_\_ of \_\_\_\_\_ lymph nodes examined

	Number involved	Number identified
Level 1:		
Level 2:		
Level 3:		
Apical:		

Nature of nodal involvement:  
 focal  diffuse

Extent of extranodal carcinoma (mm): \_\_\_\_\_

**Comments**

\_\_\_\_\_

Table 1. Understanding a pathology report

Term	Detail	What does this mean for treatment?
<b>Diagnosis</b>	Whether the change is due to breast cancer, and the type of breast cancer.	Used to determine a woman's treatment options.
<b>Size and location</b>	The size of the cancer and where it is in the breast.	Used to decide which type of surgery is needed.
<b>Hormone receptors</b>	Whether the cancer is positive or negative for hormone receptors. There are two types of hormone receptors – oestrogen receptors (ER) and progesterone receptors (PR).	If hormone receptors are found on the breast cancer, hormonal therapy may be recommended. Hormonal therapies stop hormone receptor-positive breast cancer cells from growing.
<b>HER2 status</b>	Whether the cancer is positive or negative for human epidermal growth factor receptor 2 (HER2).	If HER2 receptors are found on the breast cancer, treatment with a targeted therapy such as Herceptin® may be recommended.
<b>Lymph node</b>	Whether there are cancer cells in the lymph nodes in the armpit or near the breast.	If breast cancer cells are found in the lymph nodes in the armpit or near the breast, treatment with chemotherapy or radiation therapy may be recommended.
<b>Surgical margin</b>	During breast cancer surgery, the cancer tissue is removed together with an area of healthy-looking tissue around the cancer. The surgical margin describes whether there are cancer cells in the healthy-looking tissue that has been removed.	If cancer cells are found in the healthy-looking tissue surrounding the breast cancer that has been removed, a woman may need to have more surgery.
<b>Grade</b>	How fast the cancer cells are growing (on a scale of 1–3). A low grade (Grade 1) means the cancer is growing slowly. A high grade (Grade 3) means the cancer is growing more quickly.	A faster growing cancer is more likely to spread outside the breast and armpit area. If the grade of a cancer is higher, treatment with systemic treatments (treatment that affect the whole body such as chemotherapy) are more likely to be recommended.
<b>Stage</b>	How big a cancer is and whether it has spread to other parts of the body (5 main stages – see next section).	The stage will be used to decide whether other treatments are needed in addition to surgery.

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



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

Sometimes breast cancer is found later in the same breast or in other parts of the body. Everyone is different and there is no way of telling for sure whether breast cancer will or will not come back.

The doctors will use the information in the pathology report to work out how likely it is that cancer will come back or spread to other parts of the body.

The main features known to affect the chance of breast cancer coming back or spreading include:

- Size of the tumour
- lymph node involvement
- Hormone receptor status
- HER2 status
- whether the surgical margin is clear or not.

## Stages of breast cancer:

The stage of a cancer is used to describe its size, whether it has spread and how far it has spread in the body.

The stages of breast cancer are numbered from 0 to 4:

- Stage 0 refers to 'pre-invasive' breast cancer such as [DCIS or LCIS](#). That is, cancer that is confined to the ducts or lobules of the breast.
- Stage 1, Stage 2A and Stage 2B refer to early breast cancer. That is, breast cancer that has not spread beyond the breast.
- Stage 3A, Stage 3B, Stage 3C and Stage 4 refer to advanced breast cancer (locally advanced breast cancer or metastatic breast cancer). That is, breast cancer that has spread beyond the breast.

### For more information

You can find out more detail about each stage of breast cancer in the Understanding the stage of breast cancer Table at [www.canceraustralia.gov.au/cancer-types/breast-cancer/symptoms-and-diagnosis/stages-breast-cancer](http://www.canceraustralia.gov.au/cancer-types/breast-cancer/symptoms-and-diagnosis/stages-breast-cancer)

## What are some practical things you can do to support women through investigations and diagnosis?

### Develop a relationship with your local health services

Having a good relationship with local health services can help you support women in your community through the steps of having breast cancer symptoms investigated.

This may be a local hospital, BreastScreen service or an Aboriginal Community Controlled Health Service.

Once you know the services and health professionals involved, you can let women in your community know what to expect.

You can also liaise with local services to help health professionals involved in the investigation and diagnosis of breast cancer understand the needs and concerns of women in your community.

### Help women understand the information they have been given

Health professionals can use complicated language when talking about breast cancer tests and results. Some women find the language used unclear and intimidating.

Women may feel uncomfortable asking questions and are left confused about what tests they need and what the results mean.

You can help a woman to understand the information she has been given. Use this handbook as a resource to explain the different parts of her pathology report and the treatments that may be appropriate for her.



## Your role

### Ensure women are given appropriate emotional support

Being diagnosed with breast cancer can come as a big shock to a woman, her family and community. It's important that a woman's emotional needs are looked after during this time. Soon after a woman is diagnosed with breast cancer, her healthcare team should assess her emotional wellbeing and support options.

If she is showing signs of distress, depression or anxiety, the woman should be offered referral to an appropriate counselling or psychological support service.<sup>11</sup> You can advocate on behalf of women to ensure their emotional needs are addressed. You can also check in with family and community to answer their questions and address any concerns they may have.

#### For more information

You can use the Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) to assess the unmet supportive care need of women in your care. The tool is delivered verbally and takes about 15 minutes to complete.

Visit [www.scnatip.org](http://www.scnatip.org) to learn more.



You can also read more about ways to manage a woman's emotional support needs in [Chapter 5](#).

### Supporting women through investigations and diagnosis:

You play an important role in supporting women through their investigation and diagnosis by:

- helping women to understand what tests they may have and why they are needed
- helping women understand what is involved in each test and answering their questions
- supporting the delivery of culturally safe information and care
- helping women, their families and communities to understand and come to terms with a breast cancer diagnosis.

## Case study: Meet Kathleen

Kathleen is a 58-year-old mother of three, and a proud Wiradjuri woman. She has been married to her husband Ron for 33 years, and she works as a bookkeeper for a local school.

Kathleen had a routine breast screen when the BreastScreen van was visiting her regional town. She had been encouraged to attend screening by her local Aboriginal and Torres Strait Islander Health Worker during a community fete.

The results of her breast screen indicated that Kathleen needed further assessments done. So, she went to visit the team of specialists recommended by BreastScreen. Kathleen found this experience very nerve-racking. She was unfamiliar with the healthcare centre that she had to visit and was unsure about the additional tests that she needed.

During her assessment appointment, Kathleen had:

- a clinical breast examination – to check for any palpable lumps in her breasts
- another breast X-ray (mammogram)– to get a closer look a suspicious area that was shown on her screening mammogram
- a biopsy of the suspicious area – to test for breast cancer cells in the tissue.

The results of these tests were sent to Kathleen's GP, who let her know that they had found a small, early breast cancer that would need to be removed. Kathleen was referred to a breast surgeon to discuss her treatment options.

Kathleen's GP has a close relationship with the local Aboriginal and Torres Strait Islander Health Worker. She arranged for Kathleen to meet with the Health Worker to discuss her treatment options. Kathleen was grateful for this extra support and asked the Health Worker to come with her to her first appointment with the breast surgeon.

### What can we learn from Kathleen's experience?

1. Aboriginal and Torres Strait Islander Health Workers can play an important role in encouraging women to attend routine breast screening. They also have an important role to play in helping women understand information about their diagnosis and treatment.
2. Because Kathleen participated in routine breast screening, her breast cancer was found at an early stage, before it could even be felt. This means Kathleen has better treatment options available to her and a higher chance of survival.





# Chapter 4: Treating breast cancer

## Key points:

- There are many effective treatments available for breast cancer, and treatments are improving all the time.
- The treatment(s) recommended for an individual woman will depend on the type of breast cancer, including the stage and grade of the cancer and whether the cancer is positive or negative for hormone receptors (ER and PR) or HER2.
- Treatment for early breast cancer usually involves surgery. Additional treatments may also be used, including radiation therapy, chemotherapy, hormonal therapies, and targeted therapies.
- Breast conserving surgery involves removing the cancer from the breast and a small amount of healthy tissue around it.

Receiving treatment for breast cancer is daunting and stressful. Women can feel confused about treatment options and potential side effects. They can be uncomfortable being away from home, being in hospital, or being treated by an unfamiliar health professional. Concerns about treatment can lead to women not having or not completing treatment.

A woman's preferences about treatment might be influenced by where she lives, her beliefs and her community.



This chapter provides you with information on the treatment of early or locally advanced breast cancer. For information on the treatment of metastatic disease, you can refer to [Chapter 7](#).



## Overview of treatment options

Treatment for early or locally advanced breast cancer aims to remove the cancer and reduce the risk of it coming back or spreading. The primary treatment for early breast cancer is surgery. Other treatments that may be used in addition to surgery include:

- radiation therapy
- chemotherapy
- hormonal therapies
- targeted therapies.

Treatments used after surgery are called adjuvant therapies. Sometimes, treatments are given before surgery to increase the likelihood that surgery will be successful. When a treatment is used before surgery, it is called neoadjuvant therapy. The combination of treatments recommended for a woman will depend on the type of breast cancer, including the stage and grade, and whether the cancer is positive or negative for oestrogen and progesterone hormone receptors (ER and PR) or HER2.

Some treatments may be available within a woman's local community, other treatments may require a woman to travel further afield. The need to travel for treatment and be away from family and community for an extended period, may be an important factor in treatment decision-making.



You can read more about the practical issues associated with travelling for treatment in [Chapter 5](#).

# Your Role

## Supporting women during treatment:

**You play an important role in providing information and support for women as they undergo treatment. You can also act as a critical link between a woman, her family and her treatment team.**

### You can help by:

- explaining the different types of treatment and what they involve
- providing practical support for women and their families if the woman needs to travel for treatment (See [Chapter 5](#) for more information)
- helping women manage side effects of treatment
- encouraging women and their families to talk to their doctors about any bush medicines they may be using
- encouraging women to ask about any clinical trials that may be suitable for them
- talking to women about what is important to them and their family
- building a relationship with a woman's healthcare team and providing guidance to them about any cultural issues
- attending face-to-face or telehealth appointments with a woman.

**While you don't have to know every detail, it's useful for you to understand the main treatment options for breast cancer, what's involved in treatment and what the possible side effects might be. This will help you answer questions from the woman and her family.**

## Multidisciplinary care

Treatment and support for women with breast cancer involves a number of different medical, nursing and allied health professionals.

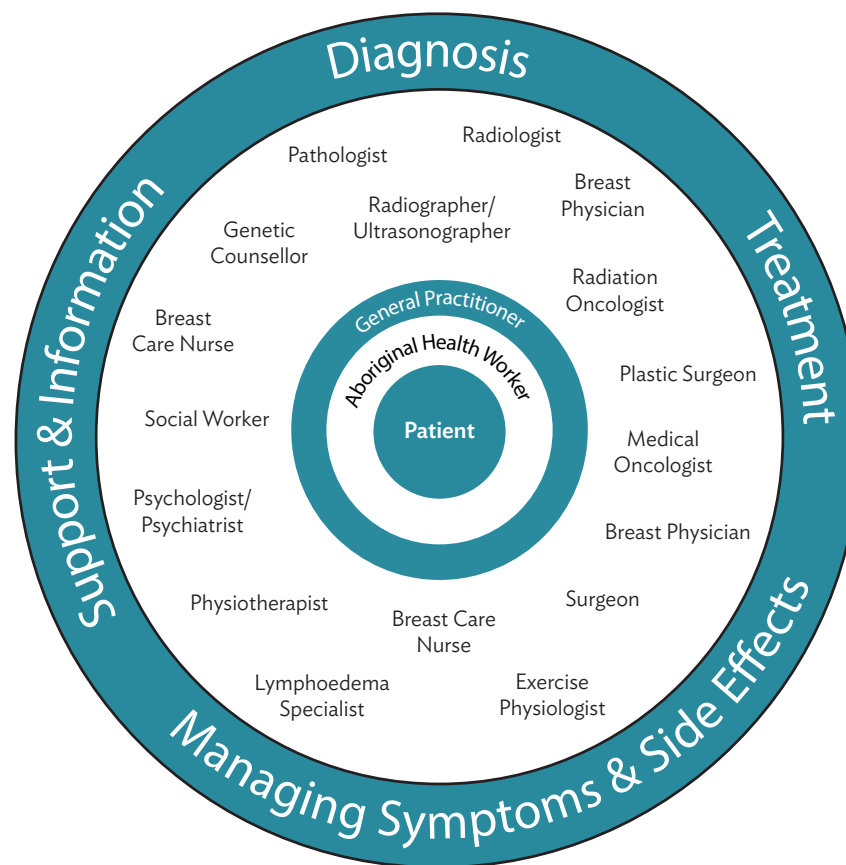
This is called multidisciplinary care. Multidisciplinary care helps to make sure that the treatment and care is planned and delivered to take account of the woman's physical and supportive care needs.

The multidisciplinary team includes a core team of health professionals likely to be involved in planning and delivering the woman's initial treatment, and other health professionals who may be involved in the woman's treatment and care at different times. The multidisciplinary team will include both men and women.

As an Aboriginal and/or Torres Strait Islander Health Worker, you are an important member of this team.



## Members of the early breast cancer multidisciplinary team at different stages of the early breast cancer journey



## Your role

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### Multidisciplinary team meetings

Multidisciplinary team meetings are meetings of health professionals who recommend a treatment plan for people diagnosed with cancer. Meetings may be face-to-face, or via teleconference or videoconference if health professionals are in different locations.

During a multidisciplinary team meeting, health professionals will talk about each woman who has been diagnosed with breast cancer in the hospital or region. They will review the woman's history and general health, her cancer test results and her supportive care needs. They will then recommend a treatment plan to be discussed with the woman by her treating doctor. The multidisciplinary team will also discuss the care needs of women who require a change in the management of their breast cancer or in whom breast cancer has spread.



### Contributing to the multidisciplinary team:

**It is important that treatment plans for Aboriginal and Torres Strait Islander women consider their cultural needs as well as any family needs, kinship obligations or cultural and community issues.**

### You can help to inform the treatment plan by:

- talking to health professionals in the team about the woman, her family and community
- providing guidance and information to the team on social and cultural issues.

You can also help women understand how each member of the team may be involved in their care.

You may also be a central contact person for the woman at different times during her treatment and care.

## Breast surgery

The aim of surgery for breast cancer is to remove the cancer tissue from the breast and areas close to the breast.

There are two types of surgery for treatment of early breast cancer:

- breast conserving surgery – removal of the cancer and a small amount of healthy tissue from the breast
- mastectomy – removal of the entire breast.

During surgery, some lymph nodes from the armpit may also be tested or removed to look for signs that breast cancer has spread outside the breast. You can read more about lymph node procedures in the section on [Armpit surgery](#).

The choice of surgery will depend on the size and stage of breast cancer, the woman's health and personal circumstances, and the woman's preference.



## Breast conserving surgery

Breast conserving surgery is also called a lumpectomy, complete local excision, or wide local excision.

**It involves removing the cancer from the breast and a small amount of healthy tissue around it.**

Breast conserving surgery is usually considered if the size of the cancer compared to the size of the breast means that the cancer can be removed while giving a good cosmetic result.

More and more, larger cancers are being shrunk before surgery with neoadjuvant chemotherapy or hormonal therapy to allow this type of surgery to be performed.

Breast conserving surgery is almost always followed by radiation therapy to reduce the risk of the cancer coming back.

Breast conserving surgery is as effective as mastectomy for most women with early breast cancer when followed by radiation therapy.

## Practice point

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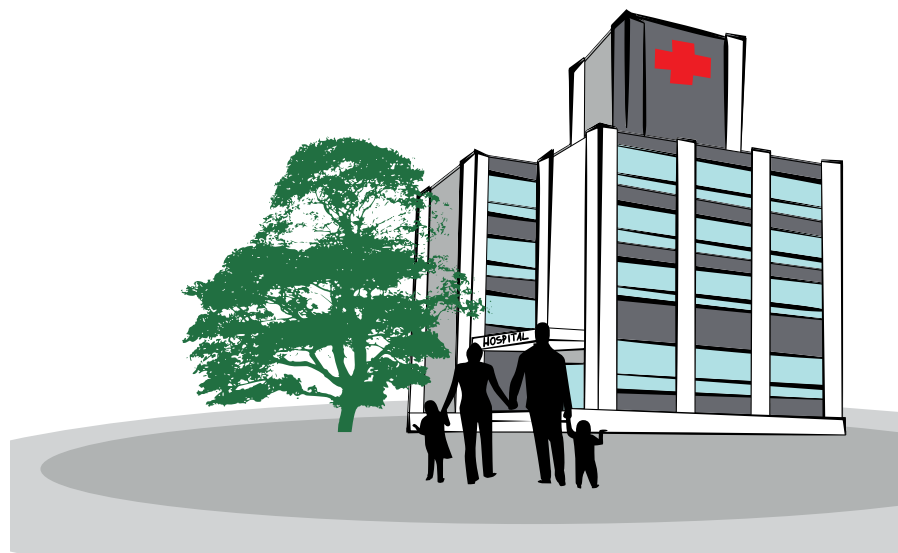
### **Mastectomy**

Mastectomy is surgery to remove the whole breast, and usually one or more lymph nodes from the armpit.

Mastectomy is usually recommended if the breast cancer is large compared to the size of the breast or if there is more than one cancer in the breast (multifocal disease).

A mastectomy may also be considered in women with genetic mutations or if a woman chooses to have a mastectomy over breast conserving surgery.

Some women who are at increased risk of cancer coming back may have radiation therapy to the chest wall or nearby lymph nodes after mastectomy.



### **Deciding about breast surgery:**

**The choice of surgery is an individual one. A woman's healthcare team should keep her fully informed of her options, including the risks and benefits of each procedure.**

### **Women should be informed that:**

- breast cancer can come back, even after surgery
- more surgery may be needed if the surgical margin removed during the operation tests positive for breast cancer cells
- breast conserving surgery will mean that the woman may not need to wear a breast prosthesis or have a breast reconstruction, which may mean less impact on a woman's body image and sexuality.

## Armpit surgery

Lymph nodes are small, rounded glands located throughout the body that act like filters for fluid travelling around the lymphatic system (See image). Fluid from the body's tissues drain into lymphatic vessels, and travel through lymph nodes, where substances that could be harmful to the body, such as bacteria or cancer cells, are trapped and removed.

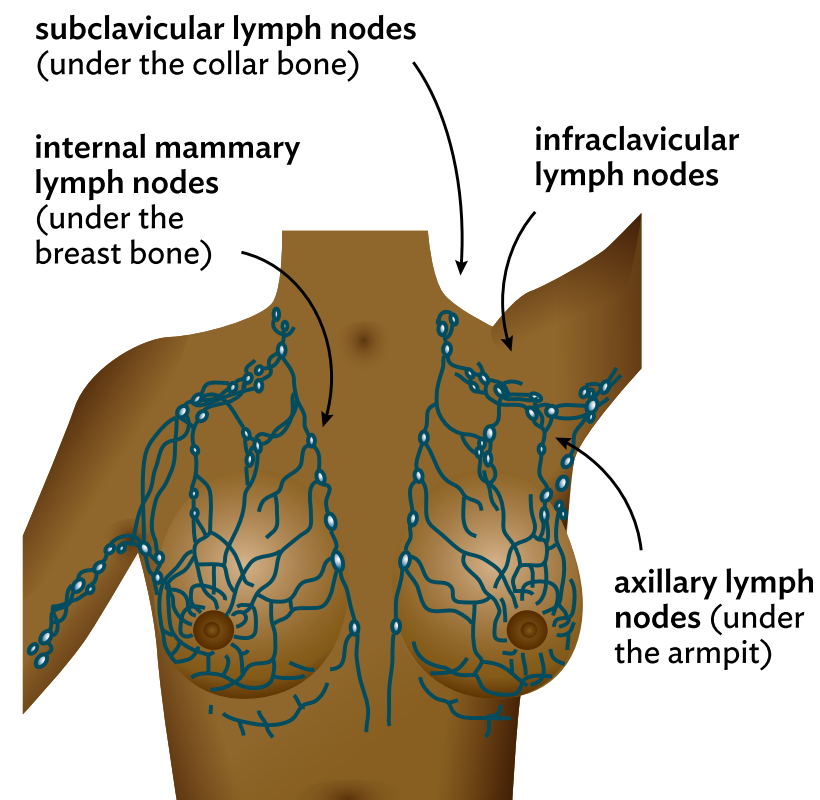
The lymph nodes in the armpit are often the first place that breast cancer spreads to outside the breast. In 2011, approximately one in eight women with breast cancer have cancer cells in the lymph nodes in their armpit when breast cancer is diagnosed (stage 3/locally advanced).<sup>12</sup>

When a woman is first diagnosed with breast cancer, her doctor will check the armpit to check for any enlarged lymph nodes. This can be a sign that cancer cells have spread. However, the best way to find out whether cancer cells have spread to the lymph nodes is to remove one or more lymph nodes during surgery and examine them under a microscope.

There are two ways of removing lymph nodes from the armpit:

- **sentinel node biopsy** (removal of one or a few lymph node(s) from the armpit)
- **axillary lymph node dissection** (removal of some or all of the lymph nodes from the armpit).

Sentinel node biopsy has fewer side effects than axillary dissection but is not available at every hospital.





### **Sentinel node biopsy**

The sentinel node is the lymph node (or nodes) closest to the breast tissue. If breast cancer has spread, the sentinel node is the most likely lymph node to have cancer in it.

For women with breast cancer, the sentinel node is usually in the armpit, but it may be in another nearby area of the body, such as in the chest, between the ribs, under the breast or above the collarbone. To find the sentinel node, a mix of blue dye and low-grade radioactive fluid is injected into the breast around the area of the cancer.

The dye travels through the lymphatic system and highlights the location of the lymph node(s) where the breast cancer is most likely to spread first. The sentinel node(s) are then removed by the surgeon and sent for testing. If the sentinel node(s) have cancer cells, further surgery may be recommended to test some or all the remaining lymph nodes (axillary dissection).

### **Axillary dissection**

An axillary dissection involves removing several or all of the lymph nodes from the armpit. Unlike sentinel node biopsy, there is no need for a dye injection prior to this procedure.

It may be done at the time of breast conserving surgery or mastectomy, or as a separate operation as a result of a positive sentinel node biopsy. The number of lymph nodes removed will vary from person to person.



## Side effects of surgery

The side effects of breast and armpit surgery depend on the type of surgery that has been undertaken. For armpit surgery, the risk of side effects is lower for sentinel node biopsy. The table below lists some known side effects surgery.

**Table 2. Side effects of breast surgery**

Side effects	Details	What can help?
<b>Pain/discomfort</b>	Can occur around the area affected by surgery.	Pain relief medicine and loose clothing can help reduce discomfort.
<b>Stiffness</b>	Can occur in the arm or shoulder.	Arm and shoulder exercises, guided by a physiotherapist or exercise physiologist may be recommended.
<b>Seroma</b>	Fluid can collect in or around the scar in the breast or armpit.	The fluid may be drained using a fine needle / syringe. This can be done by a breast care nurse or another member of the healthcare team.
<b>Numbness/ tingling</b>	Can occur in the arm of shoulder if lymph nodes have been removed.	This may improve with time, but feeling in these areas may change permanently.
<b>Infection/ bleeding</b>	Can occur in the scar in the breast or armpit.	A woman's healthcare team will work with her to address any signs of infection. Further surgery may be needed.
<b>Lymphoedema</b>	Swelling of the arm, hand, breast or chest that can occur if many or all of the lymph nodes are removed.	Women should be referred to a qualified lymphoedema practitioner or clinic. Keeping physically active can help the flow of the lymph fluid. Taking good care of the skin is also important, including keeping the skin moist and protecting it from the sun and insect bites with sunscreen and insect repellent. Massage and wearing a compression garment or bandage can help. Maintaining a healthy body weight. Using the unaffected side for blood pressure measurements or injections.
<b>Cellulitis</b>	An infection of the skin caused by bacteria.	A woman's healthcare team will work with her to treat any signs of cellulitis. Antibiotics may be required.

## Breast prosthesis and breast reconstruction

After breast surgery, women may feel self-conscious about the way they look or they may feel incomplete.

Some women choose to reshape their breast using an external breast prosthesis or through breast reconstruction surgery.

### Prosthesis

An external breast prosthesis is an artificial device worn inside a woman's bra to give shape to the clothing.

Prostheses can be used after a mastectomy and sometimes after breast conserving surgery.

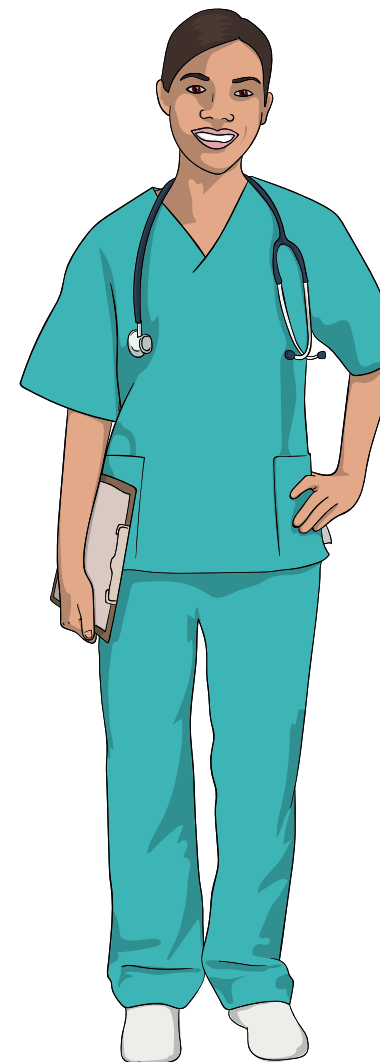
The prosthesis is designed to match the colour, size and shape of the woman's other breast. It is specially weighted so that it feels and moves like the other breast.

There are different types of breast prostheses:

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

Some women wear a bra with a pocket in it to hold their prosthesis in place. Special mastectomy bras can be purchased, or pockets can be sewn into bras.

Some women use a self-adhesive prosthesis that sticks to the chest using special glue.



## Practice point

### Choosing a breast prosthesis

Choosing the right prosthesis depends on the type of surgery a woman has undergone, her body shape and her preference. The cost of a prosthesis will vary, depending on the type of prosthesis.

Women should see a specialist prosthesis fitter to fit their prosthesis. They can organise the fitting of a temporary or permanent prosthesis.

Poorly fitted prostheses can cause postural pain. Women should be monitored to ensure any changes in swelling following surgery or any skin changes due to radiation therapy do not impair the fit of their prosthesis.



### The External Breast Prostheses Reimbursement Program:

**The External Breast Prostheses Reimbursement Program is an Australian Government program that provides reimbursement for both new and replacement external breast prostheses to all eligible women who have had a mastectomy as a result of breast cancer. Cost limits apply.**

#### **i For more information**

For more information about the program and eligibility criteria visit the Medicare Australia website at [www.servicesaustralia.gov.au/medicare](http://www.servicesaustralia.gov.au/medicare) and search 'External Breast Prostheses Reimbursement Program' from the home page.

## Reconstruction

All women undergoing mastectomy should be offered the opportunity to discuss options for breast reconstruction.<sup>13</sup>

Breast reconstruction can be done at the same time as a mastectomy (immediate reconstruction), or it may be done later (delayed reconstruction).

There are different types of breast reconstruction, including:

- **reconstruction using implants.** This is usually a two-stage procedure. Initially, tissue expanders are inserted at the time of mastectomy. Follow-up surgery to insert the implants is carried out by the breast surgeon at a later stage. Smaller breasts may be reconstructed at the time of mastectomy with an implant.
- **reconstruction using muscle/tissue** (known as a 'flap' reconstruction). This involves transplanting tissue from another part of the body, such as the abdomen, thigh or upper back. This usually involves a plastic or reconstructive surgeon.

Choosing to have a breast reconstruction can be a difficult decision. Women should be informed about their options so they can balance the advantages and disadvantages of reconstruction after mastectomy and decide if the timing suits their particular circumstances.

### **i** For more information

You can hear more about breast reconstruction after mastectomy from a patient and a breast surgeon in Cancer Australia's Influencing best practice in breast cancer video series <https://youtu.be/GoaPJZxyiZ8>.

NOTE: This video includes men discussing breast cancer. It is intended for a healthcare professional audience.



## Radiation therapy

Radiation therapy uses X-rays to destroy cancer cells that may be left in the breast, chest or armpit after breast cancer surgery. Radiation therapy is a localised treatment, which means it only treats the area of the body it is aimed at. Radiation therapy is recommended:

- after breast conserving surgery, to destroy any cancer cells that may be left in the breast and reduce the risk of cancer coming back in the breast
- after mastectomy for women at high risk of breast cancer coming back in the chest wall.

Radiation therapy to the lymph nodes in the armpit and/or lower neck may also be recommended for women who have not have armpit surgery, or for those at high risk of breast cancer coming back in the lymph nodes.

### What does radiation therapy involve?

Before starting radiation therapy, a woman will meet with a radiation oncologist to plan and manage her treatment. At the next appointment, she will meet the radiation therapist and have a computerised tomography (CT) scan of the treatment area. To ensure that the same area is treated each time, the radiation therapist will make some measurements, and will sometimes make a few small marks on the skin in the form of small mole-like tattoos. Radiation therapy is usually given once a day on weekdays, for three to six weeks. The radiation treatment is delivered by a radiation therapist who works closely with the radiation oncologist in a radiation therapy centre. Each radiation therapy treatment usually takes only a few minutes. However, time to change and waiting for the machine to become available can increase it to an hour each day.

### Side effects of radiation therapy

Radiation therapy is painless, however some women may experience side effects during or after treatment. The side effects of radiation therapy depend on the strength of the dose and the area that is being treated. The table on the following page (Table 3) lists some known side effects of radiation therapy.

## Practice point

### Access to radiation therapy:

**Not all hospitals can provide radiation therapy. It is generally available in capital cities or major regional towns. Women living in regional or remote areas may need to travel long distances for radiation therapy. And they will be away from home for long periods of time while they receive their treatment. These factors can play a role in a woman's decision to have breast conserving surgery or mastectomy. You can support women in your community with this decision by telling them about the travel.**

### **i** For more information

Services available to them, such as:

- **Patient Assisted Travel Schemes** <https://www.bcna.org.au/resource/fact-sheet-patient-assisted-transport-schemes/>
- **Cancer Council transport**, accommodation, and home help <https://www.cancercouncil.com.au/get-support/transport-accommodation-and-home-help>

Table 3. Side effects of radiation therapy

Side effects	Details	What can help?
<b>Skin irritation and darkening</b>	Radiation therapy can cause skin on the breast/chest to become red and dry like sunburn. Towards the end of treatment, skin may blister or peel. Skin can also appear darker for a few months after treatment.	Having a good skin care routine can help reduce skin irritations. Women may find it helpful to wash with a mild soap or cleanser and use a light moisturising cream. Wear sun protective clothes and use sunscreen when in the sun.
<b>Fatigue/tiredness</b>	Tiredness can build up slowly during treatment and may last for a few months after treatment finishes.	Light exercise, such as walking, can help to boost energy levels and reduce fatigue. It can help to spread out daily activities and limit activities that bring on tiredness.
<b>Tenderness/aches</b>	Tenderness or ‘twinges’ of pain in the breast or the chest can continue for up to a year or longer after treatment.	This usually settles with time. A woman’s healthcare team can work with her to find a pain relief strategy that works best for her.
<b>Lymphoedema</b>	If radiation therapy has been given to the armpit, there may be swelling in the arm, hand, breast or chest.	Women should talk to their healthcare team if they notice any swelling. They should be referred to a qualified lymphoedema practitioner or clinic. Keeping physically active can help the flow of the lymph fluid. Taking good care of the skin is also important, including keeping the skin moist and protecting it from the sun and insect bites with sunscreen and insect repellent. Massage and wearing a compression garment or bandage can help. Maintaining a healthy body weight.
<b>Changes in appearance</b>	The breast may change in size or become firmer during or after treatment. Blood vessels may become visible in the treated area, making the skin look red or purple. Hair will fall out in the area of the body being treated.	If a woman feels self-conscious or upset about her appearance, she may benefit from speaking with a psychologist or counsellor.

## Chemotherapy

Chemotherapy, often called ‘chemo’, uses drugs to destroy cancer cells. Chemotherapy works by killing cells that are rapidly dividing, such as breast cancer cells.

Chemotherapy also kills normal cells that are rapidly dividing. However, unlike cancer cells, normal cells can repair the damage and recover.

The aim of chemotherapy is to destroy cancer cells in the breast and armpit, and any cells that may have spread to other areas of the body.

Chemotherapy helps to lower the risk that breast cancer will come back and can increase the chance of surviving breast cancer.

Chemotherapy may be used:

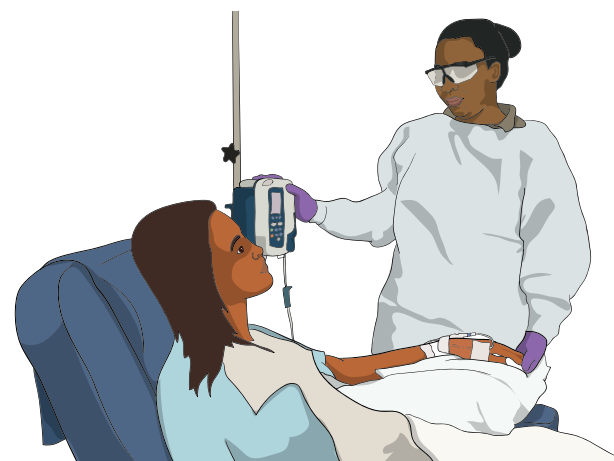
- before surgery to shrink the cancer and allow for breast conserving surgery (neoadjuvant chemotherapy)
- after surgery, to reduce the chance of the cancer coming back.

If the patient is also undergoing radiation therapy or hormonal therapy, these treatments will not start until chemotherapy is completed. Not all women with breast cancer will have chemotherapy.

The decision about whether chemotherapy is used will depend on a number of things like a woman’s general health, her personal preference and the type of breast cancer that she has.

### **i** For more information

You can hear more about the role for chemotherapy before surgery in Cancer Australia’s Influencing best practice in breast cancer video series <https://youtu.be/6TZBrwrsv5E>.



## Important note



### An important note about side effects:

Sometimes chemotherapy can cause side effects that are rare but can be quite serious.

**A woman should talk to her healthcare team straight away, or go to the hospital emergency department, if she has any unusual symptoms, such as:**

- chest pain
- high fever (temperature of 38°C or above), shivers or chills
- bleeding or bruising
- shortness of breath
- vomiting or diarrhoea that won't stop
- drowsiness
- confusion

You can read more about managing treatment side effects in the **eviQ Guide for Aboriginal Health Workers** <https://www.eviq.org.au/getmedia/8a05e996-10bf-48ff-88df-b2c1b8800868/Aboriginal-Health-Worker-Booklet.aspx?ext=.pdf>.

### What does chemotherapy involve?

There are several different types of chemotherapy drugs, including:

- taxanes
- anthracyclines
- cyclophosphamide
- 5-fluorouracil.

Typically, a combination of two types of drugs will be given. The combination will depend on the type of breast cancer, the woman's age, her general health and what other treatments she is receiving.

The most common way for chemotherapy to be given is by an intravenous infusion. This is a 'drip' into a vein in the hand or arm. Some chemotherapy drugs are given as tablets. Sometimes a combination of tablets and intravenous infusion may be used.

Chemotherapy is given in 'cycles'. Each cycle involves a short treatment followed by a rest period in which there is no treatment. Most cycles vary between 2-3 weeks. This gives the body a chance to recover between treatments.

The number of cycles, and the length of the treatment and rest periods, will depend on the type of chemotherapy being used and the type of breast cancer being treated. The overall length of chemotherapy could be between 3-6 months.



## Side effects of chemotherapy

Most medicines used in chemotherapy can cause side effects. Most side effects are temporary and can be managed. Women should talk to their healthcare team if they have side effects during or after chemotherapy.

The table below lists some of the known side effects of chemotherapy for breast cancer. The side effects of chemotherapy depend on the medicines being used.

**Table 4. Side effects of chemotherapy**

Side effects	Details	What can help?
<b>Nausea and/or vomiting</b>	Common side effects of chemotherapy. Nausea usually starts a few hours after treatment and may last for a few days.	Anti-sickness medicine can be given to help with nausea and vomiting.
<b>Changes to bowel habits</b> (constipation or diarrhoea)	Some chemotherapy, pain-relief and anti-sickness medicines can cause constipation or diarrhoea.	Drinking lots of clear liquids can help. Medicines can also be prescribed to help with constipation or diarrhoea.
<b>Hair loss</b>	Can range from mild thinning to total hair loss, including body hair. Usually starts 2–3 weeks after the first treatment. Not all chemotherapy drugs cause hair loss.	Using a large comb or hairbrush with soft bristles can help. Cutting the hair short before it falls out may be less upsetting. Suggest the woman considers using a wig or scarf. Cancer Council Helpline (13 11 20) can help women find a wig.

## Practice point

### Keep an eye out for infections:

**Any infection during chemotherapy can be serious and potentially life-threatening. Infections can be treated effectively with antibiotics. Be aware of and provide information to women on the following symptoms:**

- fever (a temperature higher than 38° C)
- chills
- severe sweats.

### Other symptoms of infection include:

- loose bowels
- a burning sensation when urinating
- severe cough or sore throat
- unusual vaginal discharge or itching
- redness, swelling or tenderness around a wound, sore, pimple, boil, or the site drip site for chemotherapy.

**If these symptoms develop, a woman should seek immediate medical advice as treatment with strong antibiotics may be required.**

<p><b>Tiredness/ fatigue</b></p>	<p>Common side effect of chemotherapy and can last 3 to 6 months after treatment is over.</p>	<p>Gentle exercise, such as walking, can help to reduce fatigue caused by chemotherapy.<sup>14</sup></p> <p>Mind-body strategies or complementary therapies, such as yoga, meditation and acupuncture may also help.</p> <p>Women should be referred to a physiotherapist or accredited exercise physiologist for support with exercising during and after chemotherapy.</p> <p>Practising a good sleep routine can help to reduce sleep disturbances.</p>
<p><b>Numbness or tingling in the hands and feet</b></p>	<p>Known as peripheral neuropathy.</p> <p>This is a side effect of some chemotherapy medicines.</p>	<p>Women should tell their health care team if this happens.</p> <p>The dose of chemotherapy may need to be adjusted.</p>
<p><b>Mouth ulcers</b></p>	<p>Can develop as a result of chemotherapy.</p> <p>Can be painful and affect how much a woman can eat.</p>	<p>Encouraging women to take extra care of their mouth during chemotherapy.</p> <p>Treatments are available to help patients manage the pain associated with mouth ulcers.</p> <p>Brushing teeth and gums with a very soft brush after every meal to prevent infection.</p> <p>Using an analgesic gel from the chemist or sodium bicarbonate mouthwash to alleviate discomfort.</p>

## Hormonal therapies

Hormonal therapies, also called endocrine therapies, are treatments for women who have hormone receptors on their breast cancer cells. This is called hormone receptor-positive cancer.

### Hormonal therapies different from hormone replacement therapies used to treat menopause.

When cancer cells are hormone receptor-positive, it means the growth of the cancer cells is affected by the female hormones, oestrogen and progesterone. Hormonal therapies lower the level of female hormones in the body or change the way the body responds to female hormones, to stop the cancer cells from growing. Hormonal therapies can also reduce the risk of breast cancer coming back. Most women will be recommended to take hormone therapy for five years. However, some women may be recommended to continue taking hormonal therapy for up to ten years after initial treatment to improve long-term survival.

There are many different types of hormonal therapies. The type of therapy used for a woman with hormone receptor-positive cancer will depend on whether she has reached menopause.

- **Anti-oestrogens** – work by stopping oestrogen from getting into the breast cancer cells. The most common anti-oestrogen is called tamoxifen.
- **Aromatase inhibitors** – work by stopping androgens from being changed into oestrogen. Aromatase inhibitors are only used in women after menopause. Examples of aromatase inhibitors include anastrozole (Arimidex®), letrozole (Femara®), exemestane (Aromasin®).
- **Ovarian suppression treatments** – work by stopping the ovaries from making oestrogen. Ovarian suppression treatments are only used in women who have not yet reached menopause. An example is goserelin (Zoladex®).



## Rare side effects to look out for

### Side effects of hormonal therapy

Everyone is different in how they respond to treatment with hormonal therapies. Some side effects are common to all hormonal therapies and some only happen with certain therapies.

All hormonal therapies can cause menopausal symptoms, such as hot flushes, vaginal dryness and reduced sex drive. The severity of these symptoms will vary between women. There are treatments that can help with these symptoms and they may improve when treatment is stopped. If the woman is premenopausal before starting hormone therapy, she may become post-menopausal after completing hormone therapy.

If a woman experiences side effects, she should advise her healthcare team so they can find a strategy to manage the side effects and keep her on treatment, to reduce her risk of breast cancer coming back.

If a woman hopes to have children in the future, it is important that she talks to her doctor before treatment. She may be referred to a fertility clinic to talk about her options.

Other side effects of hormonal therapies can include:

- tender breasts
- tiredness
- nausea
- swollen legs (fluid retention)
- an increased risk of osteoporosis
- bone and joint pain.

Rarely, Tamoxifen can cause:

- blood clots
- stroke
- changes in vision
- changes to the lining of the uterus
- an increased risk of endometrial cancer

**A woman should see a doctor immediately if she experiences irregular vaginal bleeding, chest pain or swelling, tenderness or pain in an arm or a leg.**





### Targeted therapies

Some breast cancer cells have high levels of the HER2 protein on their surface. These breast cancers are called HER2-positive and tend to grow more aggressively.

Targeted therapies are treatments that have been developed to specifically target the HER2 protein and stop the cancer cells from growing and dividing.

Targeted therapies can also lower the risk of breast cancer coming back in the breast and other parts of the body.

The most common targeted therapy for breast cancer is trastuzumab (e.g. Herceptin®).

### What does targeted therapy involve?

Trastuzumab (e.g. Herceptin®) is typically given after primary treatment with surgery, in combination with chemotherapy and/or radiation therapy.

It is administered as an intravenous drip (into the vein) or a subcutaneous injection (under the skin) every three weeks for one year.

Trastuzumab may be given in combination with other targeted therapies such as pertuzumab (an infusion) or neratinib (a tablet).

## Side effects of targeted therapy

Targeted therapies typically have fewer side effects than other drugs used to treat breast cancer. This is because the drug only affects certain types of cells. The table below lists some known side effects of trastuzumab (the most common targeted therapy used to treat breast cancer).

**Table 5. Side effects of targeted therapy with trastuzumab (e.g. Herceptin®).**

Side effects	Details	What can help?
Heart problems	<p>The biggest side effect of trastuzumab is the risk of heart problems, called cardiomyopathy.</p> <p>Before starting trastuzumab, a woman will undergo tests to make sure she doesn't have any heart problems.</p> <p>Symptoms of heart problems include feeling faint because of low blood pressure, breathing difficulties, tightness in the chest, chest pains, shortness of breath or an irregular heartbeat.</p>	<p>A woman's treatment team will monitor her heart function during her treatment. She will have regular scans, called echocardiograms, to check her heart.</p> <p>A woman should be educated about the signs that could indicate a heart problem, and supported to visit her doctor if she feels unwell.</p>
Chills or fever	<p>Can occur in patients taking trastuzumab.</p>	<p>Medicines are available to manage chills and fever.</p> <p>A woman's healthcare team will be able to determine what medicines are safe for her to use.</p>

## Practice point

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### Clinical trials

Some treatments for breast cancer are still being tested in clinical trials.

Clinical trials are used to find out how well a new treatment or combination of treatments works compared with the standard treatments currently used. Clinical trials and research are also used to see whether there are better ways to help control symptoms or side effects of treatment and improve a woman's wellbeing.

Clinical trials are not available in every hospital. It can be useful to know about clinical trials that may be available for women in your community. You can find out more by asking the healthcare team in the hospital where the woman is receiving treatment.

### Complementary therapies and bush medicine

Complementary therapies are treatments or therapies that can be used alongside conventional treatments to improve quality of life and overall wellbeing. Examples include relaxation therapy and meditation.

Some Aboriginal and Torres Strait Islander women may also wish to use bush medicine alongside conventional treatments.

**Encourage women to tell their doctor about complementary therapies and bush medicine:**

**Some complementary therapies and bush medicine can reduce the effectiveness of conventional treatments provided by the doctors. It is important that women tell doctors about any complementary therapies or bush medicines they are using or thinking about using.**

**You can help by encouraging women to talk to their doctors about complementary therapies and bush medicine. Women may be advised to pause use of some therapies while they are having certain treatments for breast cancer.**



## What are some practical things you can do to support women during treatment?

### Share information about breast cancer treatments

Information can be empowering for women as they decide about what treatment options are best for them. But sometimes, the amount of information that a woman needs to process can be overwhelming. You can help women understand more about breast cancer treatments by sharing information with them in a way that suits them. Everyone processes information differently, so you may like to yarn with the women in your community about their information preferences.

Some women may like to chat with you over a cup of tea; others may prefer to read an information booklet or brochure. You can also work with the woman's healthcare team to help provide information about treatment options in a way that is understandable for the woman, her family and community.

### Involve the family in discussions

Involving family and/or community in treatment decision-making can help a woman feel supported as she balances the many things that may influence her decision, such as family, work and kinship obligations.

Giving family a place to yarn and ask questions can help them support the woman as she thinks about and goes through treatment. Family and community support can also help the woman continue with treatment in an unfamiliar environment.

Involving the family in treatment discussions can also help the healthcare team:

- identify appropriate family members who can help translate important health information

- appreciate the priority of family obligations
- understand what is important for the woman and her family
- understand the range of other factors affecting the woman's health and the support available to her.

### Develop a navigational aid for breast cancer treatment

It is important for women to know what may happen to them, where they might have to travel to for treatment, and how long they may need to be away from home. This will help them understand the breast cancer journey. A visual navigational aid will support this process. You can liaise with local health professionals and health services to source the information you need to develop the resource.

#### **i** For more information

Cancer Australia has developed the resources: *My Breast Cancer Journey: A guide for Aboriginal and Torres Strait Islander women and their families* and *Cancer – what to expect – Information for Aboriginal and Torres Strait Islander people who have cancer*. The booklets can be downloaded from the Cancer Australia website. <https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/my-breast-cancer-journey-guide-aboriginal-and-torres-strait-islander-women-and-their-families> and <https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/cancer-what-expect>



## Case Study: Meet Bernadette and Robyn

Bernadette is a 42-year-old single mother and a proud Kalkatungu woman. She works part-time as an administrator for the local government while she raises her two young boys.

Robyn is the local Aboriginal and Torres Strait Islander Health Worker who has been supporting Bernadette through her treatment.

### Bernadette's story

### Robyn's story

#### Hearing about treatment options

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• Bernadette was diagnosed with early breast cancer after finding a lump in her breast.</li> <li>• Her GP referred her to a breast surgeon in Townsville. The breast surgeon first met with Bernadette via videoconference so that Bernadette didn't have to travel to the appointment.</li> </ul> | <ul style="list-style-type: none"> <li>• The telehealth consultation was held at Robyn's office, so that Robyn could help Bernadette to understand her treatment options.</li> </ul> |
|---|--|

#### Making a treatment decision

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• Bernadette's breast surgeon recommended that she have breast conserving surgery and a sentinel node biopsy to check for lymph node spread. She would also need adjuvant radiation therapy and hormonal therapy.</li> <li>• Bernadette's closest hospital does not offer sentinel node biopsies or radiation therapy. So, she would need to travel to receive her treatment. This meant she would be away from her children and her community for an extended period of time.</li> <li>• Her other option was to undergo a mastectomy and axillary dissection closer to home.</li> </ul> | <ul style="list-style-type: none"> <li>• Robyn could see that Bernadette was struggling to make a decision about her treatment options.</li> <li>• Robyn helped by arranging to meet with Bernadette and her family to discuss treatment options. Robyn hoped that Bernadette's family could reassure her that she would be supported no matter what decision she made.</li> <li>• Robyn also provided Bernadette with information about travel, accommodation and at home supportive services.</li> </ul> |
|--|--|

- Bernadette was confused and anxious about making her treatment decision. She was having difficulty balancing what she felt was best for her, with the needs of her children, family and community.

### Having treatment

- Bernadette decided to have breast conserving surgery and a sentinel lymph node biopsy in Townsville.
- This was followed 4 weeks later by a course of radiation therapy.
- She is now receiving hormonal therapy – which she can have at home.
- Bernadette was away from home for one week for surgery and 3 weeks for radiation therapy.
- Bernadette received assistance for travel and accommodation through the Patient-assisted travel scheme.
- While she was away from home, her parents cared for her children with the support of her community.

- Robyn kept in touch with Bernadette during her treatment. She formed a relationship with Bernadette’s healthcare team, so that she could act as a liaison between Bernadette’s family and the health professionals involved in her treatment.
- Robyn was able to share information with Bernadette and her family to keep them informed of Bernadette’s progress.
- Robyn also provided Bernadette’s healthcare team with information explaining Bernadette’s cultural needs.

### What can we learn from Bernadette and Robyn’s story?

1. Involving appropriate family and/or community members in treatment decision making can help a woman to feel supported as she balances the many things that may influence her decision, such as family, work and kinship obligations.
2. Aboriginal and Torres Strait Islander Health Workers can play an important role in liaising between a woman, her family and her healthcare team.

# Chapter 5: Social and emotional wellbeing

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## Key points:

- There are social and emotional challenges that a woman with breast cancer may face. These can include worries about her future, her family, her body and her health.
- It's important to encourage women to be open and honest about how they are feeling, so they can get help with the social and emotional challenges that they are facing.
- Social support and emotional care is just as important as physical care during treatment and care for breast cancer.
- The local health service will be able to provide women with information on social and emotional wellbeing (SEWB) and connect women with support services, such as an SEWB team. Some services may have cancer support groups, men's and women's groups, and elders' groups.

Women with breast cancer may experience a number of emotional, physical and practical challenges throughout their diagnosis, treatment and care for breast cancer. These are called psychosocial issues.

They can include:

- fear and worry about having treatment
- fear and worry about the future
- concerns for family and community
- how to manage physical issues such as side effects of treatment
- practical concerns, such as travelling for treatment, costs of treatment or needing time off work.

For some women, challenges associated with breast cancer can cause anxiety or depression. The issues are often connected. For example, physical issues can affect how a woman feels about herself, and concerns about travel or costs of treatment can cause worry and anxiety.

### **i** For more information

- Aboriginal Medical Services Alliance Northern Territory provides information and training on SEWB: <https://www.amsant.org.au/aod-and-mental-health-program-support/>
- Aboriginal Health and Medical Research Council of NSW provides an overview of the SEWB framework: [www.ahmrc.org.au/programs/practice-support/workforce-strengthening/sewb/](http://www.ahmrc.org.au/programs/practice-support/workforce-strengthening/sewb/)
- The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) has an SEWB support unit available: <https://www.vaccho.org.au/sewb-support-unit/>
- The Kimberley Aboriginal Medical Service has a SEWB team available: <http://kams.org.au/kamsc-services/social-emotional-well-being/>

The concept of social and emotional wellbeing (SEWB) is the foundation for physical and mental health for Aboriginal and Torres Strait Islander people.<sup>15</sup> It encompasses connections to both the mind and body, and the family, community, culture and country in which they exist.

The seven overlapping domains of wellbeing that typically characterise SEWB are shown in the diagram on the right. The model recognises good health as more than just the absence of disease or illness.<sup>15</sup>



## A Model of Social and Emotional Wellbeing



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## Your role

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### Emotional issues

Not everyone feels the same when they are diagnosed and treated for breast cancer. How a woman feels emotionally can be affected by:

- how information is given to her – for example, whether news about her diagnosis was delivered sensitively and with empathy
- her past experiences – for example, whether a family or community member has had cancer and how their care was managed
- her age, stage of life and social role – for example, whether she has children or other family members to look after
- the physical burden of her cancer and other health conditions
- the treatments she receives and whether she needs to travel away from home or country for treatment
- her prognosis – whether the cancer has been found early or late, and if it has spread.

Feelings of fear, distress, anger and disbelief are common. It can take time to accept a diagnosis of breast cancer.



### Supporting women through breast cancer diagnosis and treatment:

**You can play an important role in encouraging women to talk about how they are feeling. They might want to talk to you, or to other members of their healthcare team or to family or community members.**

**You can also help women access social and emotional wellbeing and services.**

**Although emotional and practical care may be the role of family members, there is a lot you can do to help.**

## Your role

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### Depression

It's natural for a woman to feel sad when she is diagnosed with cancer. Sometimes feelings of sadness don't go away. This may be a sign of depression. Signs that a woman may be depressed include wanting to stay in bed, being irritable and not wanting to get involved with community or social activities.

#### **i** For more information

- **Cancer Council Helpline:** telephone 13 11 20. Open between 9am and 5pm, Monday to Friday, for the cost of a local call from anywhere in Australia (mobile calls charged at mobile rates). Cancer Council also provides online support through Cancer Connections, where you can ask questions and participate in groups, forums and blogs:  
<https://www.cancer.org.au/online-resources/cancer-council-online-community>
- **Lifeline:** telephone 13 11 14. Open 24 hours a day, every day of the year for the cost of a local call or free from your mobile. [www.lifeline.org.au/get-help/online-services/crisis-chat](http://www.lifeline.org.au/get-help/online-services/crisis-chat)
- **beyondblue:** telephone 1300 22 46 36. Open 24 hours a day, 7 days a week for the cost of a local call (mobile calls charged at mobile rates). Online support available 3pm – midnight (AEST), every day at: [www.beyondblue.org.au/get-support/get-immediate-support](http://www.beyondblue.org.au/get-support/get-immediate-support)  
beyondblue's website has information for Aboriginal and Torres Strait Islander people:  
<https://www.beyondblue.org.au/who-does-it-affect/aboriginal-and-torres-strait-islander-people>

### Helping women with depression:

Women who are depressed may require treatment or therapy from a GP, a psychologist or psychiatrist. This may involve counselling and sometimes may involve medicines like antidepressants.

### You can help by:

- asking women regularly about how they are feeling
- looking out for signs of depression, such as irritability, social withdrawal, and difficulty coping
- referring women who may be depressed to a doctor for specialist help
- suggesting women contact services that can help (see For more information box)

# Your role

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## Shame

Shame is a powerful emotion. It is much more than a sense of guilt or embarrassment. A woman may feel ashamed when she acts, or is made to act, in a way that is not accepted by her community. A woman may also feel shame if she believes she did something to cause her breast cancer.

## Self-image

Women may experience changes in the way they feel about their body after treatment for breast cancer. This could be because of scarring or body changes after surgery, or the side effects of treatment like weight gain and hair loss.

## Relationships

A diagnosis of breast cancer can place a strain on a woman's relationships, particularly with their partner. A cancer diagnosis can be just as overwhelming and distressing for partners and other close family members as it is for the woman diagnosed. Diagnosis and treatment for breast cancer can also pose a challenge to establishing new relationships. Women may find it difficult to know how, when and how much to tell a new friend or partner about their cancer.

## Sexuality and intimacy

Breast cancer can change how a woman feels about sexuality and intimacy. This is closely connected to body image, self-esteem and mood, and how well she is feeling. Some women may find it difficult to yarn about feelings related to sexuality and intimacy. It is important for all health professionals involved in a woman's care to let her know there is support available that can be tailored to her needs.<sup>16</sup>

## Supporting women with emotional issues:

**Some women may find it difficult to talk about how they feel.**

## You can help by:

- **providing accurate information to help women understand what to expect during their diagnosis, treatment and care**
- **listening and encouraging women to ask questions and talk about their concerns and feelings with you and with their family and community**
- **reassuring women that no-one deserves to get cancer and that their breast cancer is not contagious**
- **referring women to other health professionals and organisations that may be able to help**
- **starting a support group for women in your community with breast or other women's cancers to give women a chance to talk and share their stories with each other and hear from people and services who can help.**

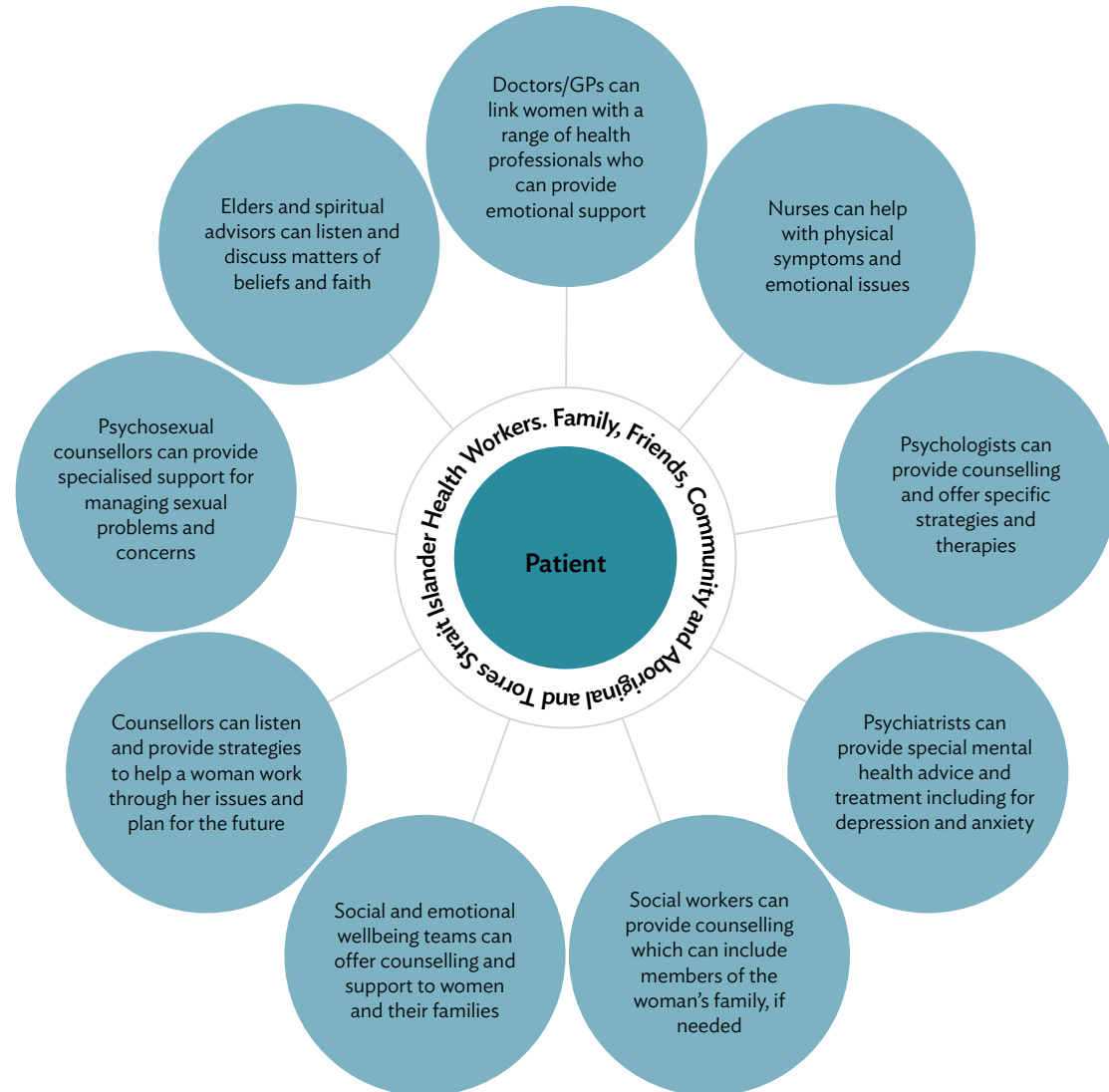
# Who can help with emotional issues?

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Different members of the healthcare team, as well as a woman's family and friends, can provide emotional support for women with breast cancer.



## The main people who can help with emotional issues





## Physical issues

Women with breast cancer can experience a range of physical symptoms and side effects of treatment.

These can include:

- nausea and vomiting
- tiredness/fatigue
- pain
- hair loss
- lymphoedema (swelling in an area of the body)
- early menopause and fertility issues.

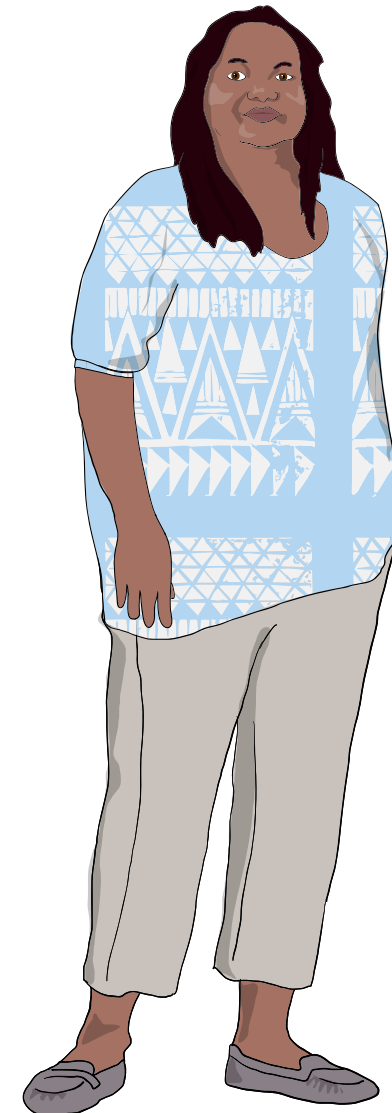
Some women also say they find it difficult to concentrate or think clearly during chemotherapy. This is sometimes called 'chemo fog'.

Help is available to manage symptoms and side effects. It's important for women to yarn about any physical symptoms or side effects of treatment they are experiencing so that help can be provided.

Some of the common physical issues associated with breast cancer and its treatment are described on the following pages.



To find out more about the side effects of treatment for breast cancer, go to [Chapter 4](#).



# Your role

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## **Nausea/vomiting**

Nausea ('feeling sick') and vomiting are common side effects of chemotherapy. A woman might feel sick or vomit even if she is not having chemotherapy.

Nausea or vomiting may be caused by cancer treatments and drugs, nervousness before chemotherapy, hypercalcaemia, or a blocked bowel.

Nausea and vomiting can usually be controlled using drugs called anti-emetics. Anti-emetics are usually given at the same time as chemotherapy.

Usually patients take anti-emetics regularly for the first 2–4 days after chemotherapy.

## **Tiredness/fatigue**

Tiredness and fatigue are a common side effect of radiation therapy and chemotherapy. It's different from normal tiredness because it often doesn't go away after rest.

Women may feel exhausted and lack energy for day-to-day activities. This can continue for several months, or even a year after treatment.

Tiredness can also be caused by the physical and emotional impact of diagnosis and treatment, including worry or the effort of travelling to hospital for tests and treatment.

Things that can make tiredness and fatigue worse include poor nutrition, sleep disorders and menopause.

## **Helping women with fatigue:**

**Whatever the cause, tiredness and fatigue can be distressing and affect a woman's quality of life. Fatigue can be linked to depression in some women.**

### **You can help by:**

- **encouraging women to do some gentle exercise, such as walking, to help boost energy levels and reduce fatigue**
- **suggesting that women spread out their daily activities and limit activities that bring on tiredness**
- **referring women who may be depressed to a health professional to talk about available treatments.**

## Your role

### Pain

Pain may be caused by the symptoms of breast cancer or may be a side effect of treatment. Pain can be treated. Understanding what's causing the pain can help health professionals work out the best way of managing it.

Ways of managing pain include pain-relieving medicines, relaxation therapy, massage and educational programs to help with pain control. Severe pain that is difficult to control using these methods may require specialist pain management from a doctor.

Some Aboriginal and Torres Strait Islander women may use bush medicines to help manage their pain. It's important to know about any bush medicines a woman may be using, to make sure these don't interfere with breast cancer treatments.



### Helping women with pain:

**Pain can be distressing and can affect a woman's quality of life. Effective treatments are available.**

### You can help by:

- encouraging women to yarn about any pain they are experiencing
- explaining that there are various ways of managing pain, including medicines and non-medical methods
- encouraging women and their families to talk to their doctors about any bush medicines they may be using to manage pain
- referring women to a doctor for advice about how to manage severe pain symptoms.



### **Hair loss**

Hair loss is a side effect of chemotherapy. Not all chemotherapy drugs cause hair loss. However, the drugs most frequently used to treat early breast cancer are likely to cause hair loss.

Hair loss from chemotherapy can range from mild thinning of the hair to total hair loss, including body hair. The hair usually grows back within weeks or months of stopping chemotherapy.

Although losing hair may not seem serious compared with coping with breast cancer, many women find it upsetting. Losing hair may affect a woman's feelings about herself and her sexuality.

To help to slow down hair loss, a woman can use a soft hair brush and gentle hair products and avoid blow drying her hair, having it permed or using curlers, or straighteners.

A woman may like to think about cutting her hair short so that it is less upsetting if it falls out.

#### **i For more information**

Look Good... Feel Better workshops are available in capital cities and other major centres, providing tips and advice about dealing with changes to the way that a woman looks while having treatment.

You can find out more at [lgfb.org.au](http://lgfb.org.au)

# Your role

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## Lymphoedema

Lymphoedema after breast cancer is a persistent swelling of the arm or breast that occurs because of a build-up of lymph fluid following the removal of lymph nodes from the armpit. Lymphoedema can have a major impact on a woman's self-image, self-esteem and quality of life. Lymphoedema usually develops gradually. It can develop months or even years after treatment for breast cancer. Lymphoedema can make it difficult for women to use the affected arm, can increase the risk of infections, and can make a woman feel self-conscious.

Women can lower their risk of lymphoedema by using their treated arm in daily activities, keeping active, and maintaining a healthy weight. Lymphoedema can be managed effectively with appropriate care. Spotting it early is key for limiting its impact on a woman's quality of life. Lymphoedema management focuses on reducing and controlling swelling, improving the range of movement in the affected area, and protecting the skin.

## Strategies to manage lymphoedema

- **Gentle exercise** can reduce swelling by helping lymph to flow through the lymphatic vessels.
- **Elevation**, such as supporting the raised limb on several pillows, can help reduce the symptoms of lymphoedema in the early stages of the condition.
- **Wearing a compression sleeve or compression bandage** can help stop fluid from building up and to help move excess fluid out of the affected area.
- **Specialised massage/physiotherapy**, known as manual lymphatic drainage (MLD) or decongestive physiotherapy, uses long, slow, gentle strokes to help move lymph fluid from the affected area.
- **Daily attention to skin care** can help keep the skin healthy and reduce the risk of infection.

## Supporting women with lymphoedema:

**Management strategies for lymphoedema are effective, especially if lymphoedema is spotted early.**

## You can help by:

- **encouraging women who have had lymph nodes removed or treated to keep an eye out for the early signs of lymphoedema, including feelings of heaviness, tightness or swelling in the arm, hand or chest**
- **explaining that strategies are available to manage lymphoedema**
- **encouraging women to visit their doctor if they notice signs of lymphoedema. Their doctor may refer them to a specialised physiotherapist or lymphoedema therapist for advice about how to manage lymphoedema.**

## Your role

### Early menopause

Menopausal symptoms are a common side effect of hormonal therapies and some chemotherapy drugs for breast cancer. In some younger women, menopausal symptoms may be temporary, and the woman may resume having periods when treatment stops. However, for some women, menopause caused by breast cancer treatment is permanent.

Menopausal symptoms can start quite quickly and may be more severe than in natural menopause. Symptoms include hot flushes, mood swings, trouble sleeping, tiredness and vaginal dryness.

Onset of menopause at a younger age can lead to feelings of sadness, grief and low self-esteem. Women may feel 'old before their time' or less feminine.

Medicines are available that can help manage the symptoms of menopause.



### Helping women with symptoms of early menopause:

**The sudden onset of menopause can be physically and emotionally difficult for women.**

### You can help by:

- suggesting that women tell their doctor about any menopausal symptoms so that they can find out about treatments that can help
- encouraging women to yarn about how they are feeling
- referring women who are experiencing feelings of sadness or depression to a counsellor for support.

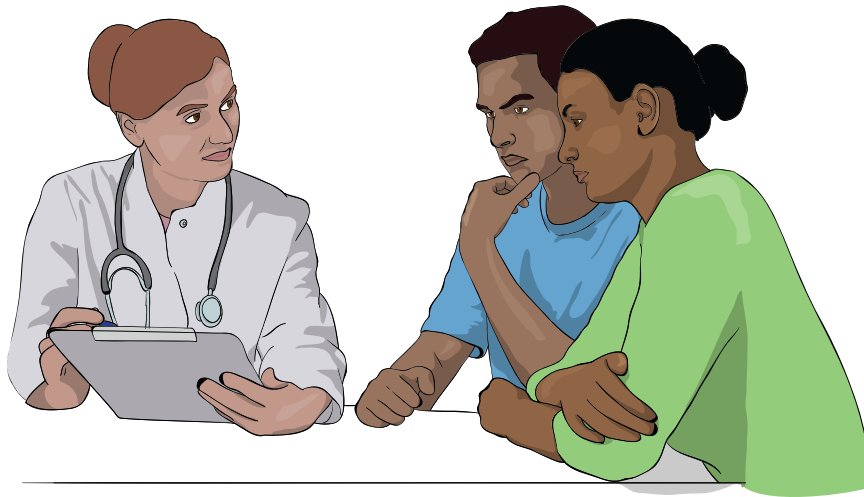
## Your role

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### Fertility

Some treatments for breast cancer, like chemotherapy and hormonal therapies, can affect a woman's ability to get pregnant and have children naturally. If a woman is diagnosed with breast cancer and hopes to have children in the future, it is important for her to talk to her doctor before starting treatment. She may be referred to a fertility clinic to talk about her options.

If a woman is uncomfortable talking about fertility with you, you could arrange for a nurse or health professional from outside the community to talk to her. The woman's partner should also be provided with opportunities to talk about this. You could arrange for a male doctor or Health Worker to talk to a woman's husband or male partner.



### Helping women talk about fertility:

**Infertility can be emotionally difficult for a woman. Feelings of sadness, grief and low self-esteem are common.**

### You can help by:

- encouraging women who hope to have children to talk to their doctor about fertility options
- referring women who become infertile due to treatment to a counsellor for support.

## Practice Point

### **i** For more information

You can read more about menopause and breast cancer in Managing menopausal symptoms after breast cancer: A guide for women <https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/managing-menopausal-symptoms-after-breast-cancer-guide-women>



**Contraception during and after breast cancer treatment:**

Even though some breast cancer treatments may cause menopausal symptoms and reduce fertility, this does not mean that it is impossible for a woman who is having breast cancer treatment to get pregnant.

Encourage women to use contraception during treatment for breast cancer.

Use of 'the pill' (oral contraceptive pill) or other contraception containing hormones, such as implants or injections is generally not recommended for women after breast cancer. Encourage women to use barrier methods of contraception, such as condoms, diaphragms, copper intrauterine device or surgical options.

It is important to remind women that it is still possible to catch sexually transmitted infections (STIs) at any age, even after menopause. Condoms are the most effective way of protecting against STIs.

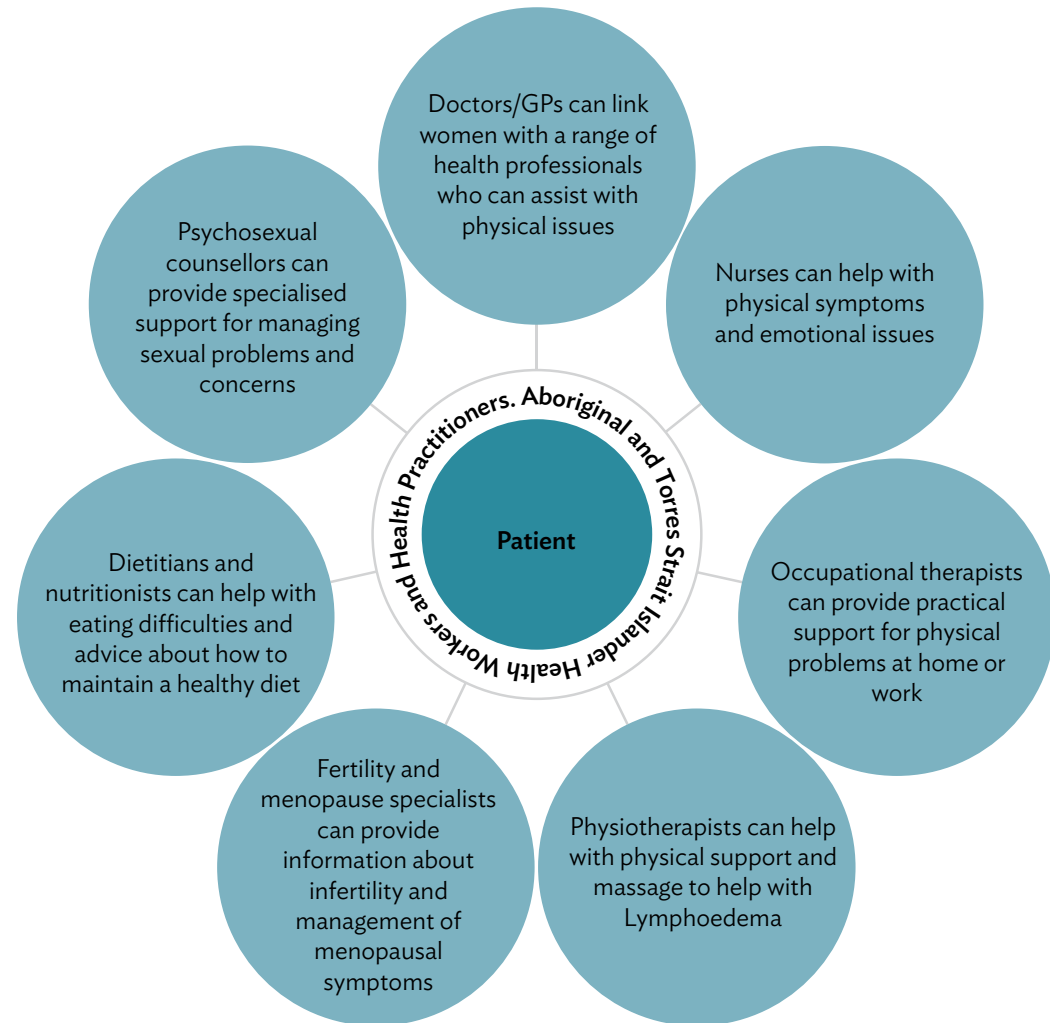


# Who can help with physical issues?

Different members of the healthcare team can provide support for physical issues.



## The main people who can help with physical issues



## Practical issues

Women may need to think about a number of practical issues during diagnosis and treatment for breast cancer. These may include:

- the costs of treatment and care
- travel and accommodation for treatment
- having time off work
- managing family responsibilities such as childcare or looking after family / community
- accessing specific items like wigs or prostheses.

Concerns about practical issues can affect how a woman feels, especially if it interrupts daily activities or family and community life.

## Costs of breast cancer

The cost of testing and treatments for breast cancer vary depending on whether a woman:

- is treated in the private or public system
- lives in a rural area and needs to travel and/or spend time away from home during treatment
- has private health insurance
- has a healthcare card.

Diagnosis and treatment for breast cancer can also affect a woman's ability to work for a short or long period of time.

Other family members may also have their work affected if they need to travel with the woman for treatment.

The financial impact of breast cancer can add to feelings of stress and anxiety.

Women and their family members may find it useful to talk to a social/welfare worker about what financial and practical support services are available.

It may also be helpful for women to contact their local Medicare office about the 'safety net' on costs of medications and medical bills.

If the woman has private health insurance, Medicare can contact the insurer to discuss likely rebates and benefits.



# Your role

## Travelling for treatment: what support is available?

Not all tests and treatments for breast cancer are available in every hospital. Some women may need to travel for breast cancer tests, treatment and care.

If a woman needs to have tests or treatment in a hospital away from home, she may be able to get help with the cost of travel and accommodation.

- All States and Territories have patient-assisted travel schemes (PATS) to help people that have to travel long distances for specialist medical treatment that is not available locally. Conditions vary between State and Territories so check with your nearest service or contact your local hospital.
- Depending on the woman's situation and where she lives, she may also be able to get assistance with childcare, meals and general home help. Some women may also be eligible for a sickness allowance while having treatment.
- Some hospitals allow consultations with doctors to be done using telehealth or videoconference. This can reduce the need for women and their families to travel.



## Helping with practical and financial support:

**It is important that women have information about travel, accommodation and other financial assistance available to them.**

### You can help by:

- providing women and their families with information about sources of financial and practical support available in your region
- helping women understand the likely costs of treatment and care so that they can plan for what might be needed
- referring women to local support groups or health professionals and organisations who may be able to provide advice and support
- talking to the woman's healthcare team about whether telehealth appointments are possible, and being with the woman for such appointments.

### Who can help with practical issues?

Different members of the healthcare team and other services can help with some of the practical issues for women with breast cancer.

- **Cancer care coordinators and nurses:** can be very helpful in providing a link between local services and the specialist doctors.
- **Social/welfare workers:** can provide information about financial and practical services available.
- **Local Medicare offices:** can provide information about the 'safety net' on costs of medicines and medical bills and other information about rebates and benefits.
- **Cancer Council:** the local Cancer Council in your state can provide information and support on transport, accommodation, home help and financial assistance available to women.

In some Australian hospitals, Aboriginal and Torres Strait Islander Hospital Liaison Officers co-ordinate support, organise subsidised transport, liaise with treatment staff, talk through treatment options and generally help communications between staff and patients. These Health Workers are highly valued by the women who have access to their support.<sup>7</sup>

### **i** For more information

Cancer Council helpline <https://www.cancer.org.au/support-and-services/cancer-council-13-11-20>

The Cancer Council helpline is a free, confidential telephone support service available in each state and territory.

Anyone can call the Cancer Council Helpline on 13 11 20.



## Support for women with breast cancer

Providing emotional and practical support to women with breast cancer is often considered to be the role of family members. However, sometimes family members may be unable to offer this support, particularly when a patient has to travel to receive treatment. It's important for women with breast cancer to have the opportunity to talk about their cancer and how they are feeling. The table below lists some of the different forms of support that can help a woman get through the emotional, practical and physical challenges of diagnosis and treatment. It should be noted that not all of these services will be tailored to meet the cultural needs of Aboriginal and Torres Strait Islander women.

**Table 6. Sources of support for people with breast cancer**

Details	What can help?
Peer support groups	Give women the chance to meet and talk with people who have been through or are going through similar experiences. Often people say they feel less anxious and alone, and more optimistic about the future, after meeting with a support group.
One-on-one support	Could be for women who may not feel comfortable in a group situation and may prefer one-on-one support from someone who has been through a similar experience.
Programs	Are provided in many hospitals or cancer centres, where the woman and her family can receive information about cancer and discuss how they are coping.
Local Aboriginal Medical Service (AMS) or other cultural health services	The local AMS or health service will be able to provide women with information on SEWB and connect women with social and emotional support services, such as an SEWB team or Aboriginal Health Worker. Some services may have cancer support groups, men's and women's groups or elders' groups.
Family or couples therapy	Can be helpful to improve communication about how the different members of the family are feeling.
Therapies or treatments	Provided by a psychologist or psychiatrist can help women who are experiencing high levels of distress and anxiety to improve quality of life, reduce anxiety and depression and help with physical symptoms. These include therapies to change unhelpful thoughts or behaviours, learn specific coping skills or relaxation techniques.
Relaxation therapy	Can help to control pain and can help with anxiety.
Exercise and education	In breathing control and relaxation techniques can help to reduce nausea, vomiting and breathing difficulties.

# Your role



## Tailoring support for women:

**Counselling and support services available to women with breast cancer may not be culturally appropriate for Aboriginal and Torres Strait Islander women and their families.**

## You can help by:

- tailoring support options to reflect the cultural and spiritual needs of an individual woman, as well as the local environment and services available in her area.
- identifying support that may be available remotely or via telehealth.

Support centres	
Day centres	Are often attached to hospitals, hospices or nursing homes. These centres are open during the day and often provide transport to and from the home. In some locations there are specific Aboriginal and Torres Strait Islander day centres or programs.
Hospitals	Can provide short or long-term treatment. Access to a public hospital will depend on the level of need and whether there are beds available.
Nursing homes	Offer short or long-term stays. They will charge a fee for the care provided.



## Practice point

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### Support for family and community

Being diagnosed with breast cancer can have a big impact on a woman, but it can also have a significant impact on those close to her – such as her partner, children, family and community.

They may also need encouragement to ask questions and seek support. They might also need advice about how they can help the woman.

#### Partners

Many partners are reluctant to seek help for themselves because they feel the need to be ‘strong’.

Partners can accompany women to appointments to provide support and ask questions. **It is important to get permission and consent from a woman first about whether to invite her partner into an appointment.** Separate appointments can also be made for a woman’s partner to discuss how they are feeling.



#### The importance of family and kinship:

**Family and kinship are a central aspect of wellbeing for a woman with breast cancer.**

**Her family responsibilities may influence her treatment decisions.**

**Involving family in the decision-making process may increase the acceptability of treatment options, as well as completion of, and compliance with, treatments.**

# Your role

## Children

Children are likely to be affected by their mother's cancer. It can be difficult for children to adjust, especially if their mother looks different or is in hospital and away from home. Children may play up to get attention or become insecure. Helping families to have open and honest communication with their children, especially older children, is generally helpful. Here are some tips for talking to children about cancer.

- Ask children what they are worried about.
- Talk about feelings as well as facts.
- Answer questions honestly and simply and correct any misunderstandings.
- Try to explain what will happen next.

Reassure them that cancer is not their fault – this is particularly important for young children.

### **i** For more information

Information and/or support for children and young people experiencing cancer is available from:

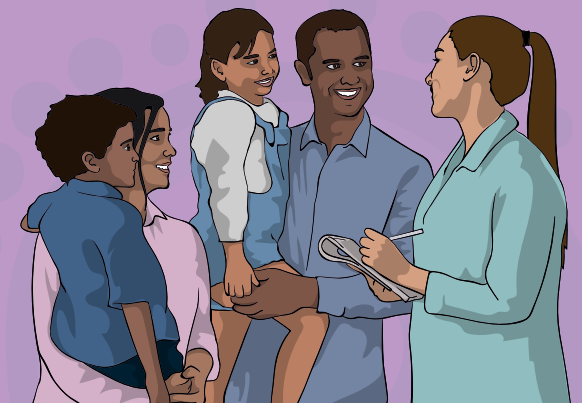
- **Cancer Council Australia:**
  - Talking to kids about cancer: <https://www.cancer.org.au/cancer-information/types-of-cancer/childhood-cancers/talking-to-kids-about-cancer>
  - Cancer in the school community: [www.cancer.org.au/about-cancer/living-with-cancer](http://www.cancer.org.au/about-cancer/living-with-cancer)
- **CanTeen:**
  - Canteen provides counselling and support for people aged 12-25 living with cancer including cancer patients, their brothers and sisters and young people with parents or primary carers with cancer.
  - 1800 835 932 or [www.canteen.org.au](http://www.canteen.org.au)

## Supporting family and community:

**A diagnosis of breast cancer can affect family and community. It is important that partners, family and community can talk about how they are feeling and ask questions when they need to.**

## You can help by:

- giving family members the opportunity to talk about their feelings and experiences
- letting family members know about available support services and information
- arranging for a male doctor or Health Worker to talk to a woman's husband or male partner.





## What are some practical things you can do to support a woman through social and emotional challenges?

### Keep a list of social and emotional wellbeing services in your community

You could pull together a list of cancer treatment and support services for Aboriginal and Torres Strait Islander women in your area.

You could do your own research as well as consult with health services in your community to help you generate this list.

This would be a valuable resource for hospital staff – they could give out the list to any women going through cancer treatment.

### Start a support group for Aboriginal and Torres Strait Islander women with cancer

You may consider starting a support group for women to get together, to yarn and share information with each other.

Groups can meet as regularly as they would like to, but generally once a month is the normal schedule. You could organise guest speakers to present on different topics each month.



# Chapter 6: Follow-up after treatment

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## Key points:

- **Regular follow-up after treatment for breast cancer is important to check for signs that breast cancer has come back or spread, and to manage any long-term side effects of treatment.**
- **Follow-up includes regular physical examinations and breast imaging (breast X-ray or ultrasound)**
- **Requirements for follow-up will vary according to the individual woman's breast cancer, what treatments she received and her general health.**

Many women look forward to finishing their hospital-based treatment for breast cancer. However, for some women, the end of treatment can be a worrying time. They may feel nervous or upset about no longer seeing members of their healthcare team regularly. Others feel worried about what the future holds and if the cancer will come back.

## Follow-up care

Regular follow-up care is recommended for women who have finished treatment for breast cancer to help:

- check for signs that cancer may have come back
- look for signs that cancer may have spread to other parts of the body
- manage long-term side effects of treatment, including menopause and infertility
- monitor physical and supportive care needs.

The approach to follow-up care after treatment for breast cancer will vary according to the type of cancer a woman had, her risk factors and her individual needs.



## Your role

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### Follow-up appointments

Follow-up after breast cancer typically involves:

- **regular physical examinations** to check both breasts and discuss any physical side effects or emotional issues a woman is experiencing
- **breast imaging** (mammogram and/or ultrasound) to look for any changes in the breasts.

Follow-up appointments may happen with a woman's specialist or with her general practitioner (GP).

For women with early breast cancer, follow-up appointments will happen every 3–6 months for the first two years after active treatment has finished and will then decrease over time.

Some women assume that they should be having regular scans and blood tests. However, studies have shown that having more tests does not improve the length or quality of life for women who have been treated for breast cancer.



### Supporting women after treatment :

You play an important role in supporting women after treatment has finished.

You can help by:

- **supporting women to attend follow-up appointments**
- **reminding women about the importance of continuing to take medications for as long as required**
- **providing information and lifestyle advice for life after treatment, such as dietary requirements, self-care and information on accessing prostheses**
- **having a yarn and helping women manage worries that their cancer will return or that a family member will develop breast cancer**
- **providing information to the woman's immediate family**
- **educating women about the signs and symptoms to look out for, that may indicate breast cancer has returned**
- **referring women to other agencies or support places, and providing relevant contact information for SEWB, medical support and Aboriginal Medical Services**

The table below shows the recommended schedule for follow-up appointments and tests for women with early breast cancer.

**Table 7. Recommended follow-up schedule for early breast cancer**

Method	Year 1 and 2	Years 3–5	After 5 years
History and clinical examination	Every 3–6 months	Every 6–12 months	Every 12 months
Mammography (and ultrasound if required)	Every 12 months*	Every 12 months	Every 12 months
Other scans or tests (e.g. Chest X-ray, bone scans, blood tests)**	Only if there are signs or symptoms that suggest the cancer has come back		

\* Time from date of diagnosis

\*\* MRI may be considered in specific high-risk groups

# Your role

## What are some practical things that you can do to support follow-up care?

### Talk with women about their follow up appointments

Regular follow-up means that if the breast cancer comes back or if a new breast cancer develops it can be treated sooner. Helpful reminders to women to go for their follow-up appointments will help women to continue to be supported during follow up.

### Coordinate and liaise with local health professionals and specialists who may be in different locations

As women finish active treatment, depending on local practice, they may transition out of hospital-based follow-up care and into the care of their GP, under a shared care arrangement. You can help to coordinate a woman's care by working with her specialist, GP and other community providers.



### Talking to women about follow-up appointments:

**Follow-up appointments are a good opportunity for women to talk to their doctor about any side effects they are experiencing or any worries they have once treatment is over.**

You can help by encouraging women to:

- keep their follow-up appointments
- continue to take any prescribed medicines for as long as required
- tell the doctor about any side effects or symptoms
- yarn about any worries they have about their follow-up.

In between follow-up appointments, if you see a woman who has had breast cancer, you can help by:

- asking how she is feeling now treatment is over
- providing information about relevant support services
- coordinating and liaising with local health professionals and specialists who are providing follow-up care and who may be in different locations.

# Chapter 7: Treatment and care for women if breast cancer comes back or spreads

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## Key points:

- In some women, breast cancer can spread beyond the breast area to other parts of the body. This is called metastatic or advanced breast cancer.
- Sometimes breast cancer has already spread by the time a woman is first diagnosed. In other women, breast cancer can come back after treatment for early breast cancer and can spread to other parts of the body.
- While there is no cure for metastatic breast cancer, treatments are available to control the spread of the disease and help women to live well for longer.
- Some women with metastatic breast cancer might decide not to have more treatment. It is important to respect a woman's choice about her treatment.
- Early introduction of palliative care is important to help women manage symptoms, control pain and help women and their families with social and emotional wellbeing.
- Advance care planning can help a woman decide who will make decisions about her care, if she is no longer able to make decisions herself.
- The transition to end-of-life care should be coordinated between the palliative care team and the woman's specialist doctors.
- It is important that the woman, her family and community feel well supported during this time.



## Your role

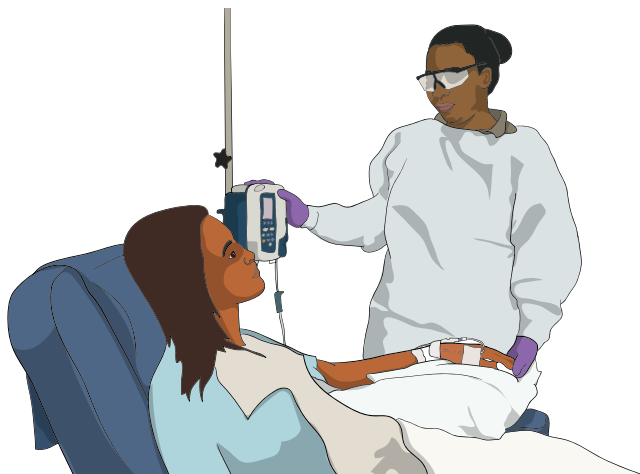
In some women, breast cancer can spread beyond the breast area to other parts of the body. This is called metastatic or advanced breast cancer.

The most common places that breast cancer can spread are the bones, lungs, brain and liver.<sup>17</sup>

For some women, breast cancer has already spread by the time they are first diagnosed.

Breast cancer can also come back or spread to other parts of the body following treatment for early breast cancer. This is called recurrence and it can occur in a small proportion of women.

There is no cure for metastatic breast cancer. However, effective treatments are available to help slow down and control the spread of the disease, meaning women can live well for longer.



**Supporting women when breast cancer comes back or spreads:**

**If breast cancer comes back after treatment, it can be very challenging and upsetting for a woman, her family and community. They may not fully understand what a recurrence of breast cancer means, or they may think that nothing can be done to help.**

**You can help to ensure that the woman's treatment team has explained what the diagnosis means and has given the woman and her family clear information about treatment options available and about the likely outcomes of treatment.**

**You can support the woman and her family to think about what is most important to them as they consider her treatment options, including the benefits and side effects of those options.**

## Treatment when cancer comes back or spreads

If cancer comes back or spreads, women will be offered treatment to:

- control the growth and spread of the cancer;
- relieve symptoms; and/or
- improve or maintain quality of life.

Significant research advancements in recent years have led to the development of treatments that can control the growth and spread of metastatic breast cancer, meaning women can live well for longer.<sup>18</sup>

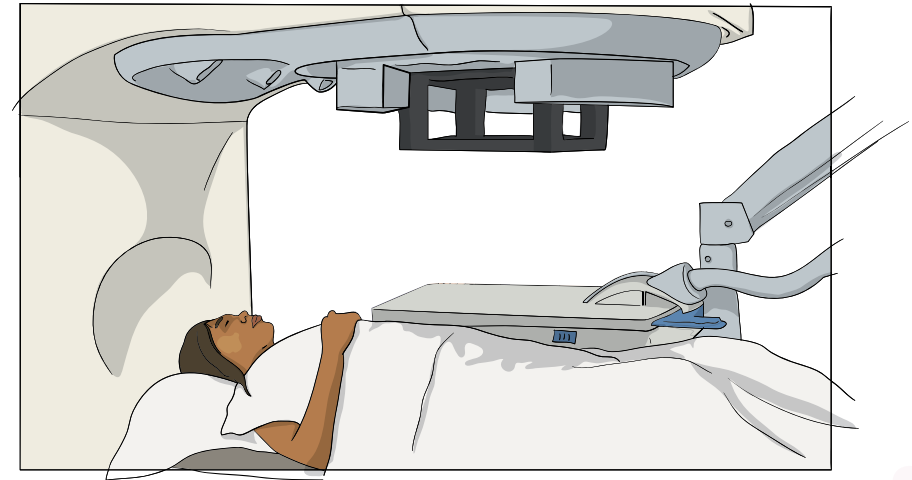
The approach to treatment will be different for each woman and will depend on where the cancer has spread and what treatments she has received previously.

Treatments that are suitable for one woman may not be suitable for another.

A woman may need to try several different treatments before finding one that works for her.

## What treatments are available?

Treatment for metastatic breast cancer usually involves one or more medicines, such as hormonal therapy, chemotherapy, and/or targeted therapy. Treatment may also involve radiation therapy and/or surgery.





The table below gives a snapshot of how these treatments can be used for metastatic breast cancer.

**Table 8. Treatment options in metastatic breast cancer**

Treatment	How it is used
<b>Hormonal therapies</b>	<p>Used in breast cancers that need female hormones (oestrogen) to grow. Hormone therapy lowers oestrogen levels or stops it from binding to the cancer cells.</p> <p>Used to slow or stop the growth of metastatic breast cancer and can help to relieve symptoms.</p> <p>Can shrink the size of a cancer tumour in some women.</p> <p>Usually recommended as the first treatment for women with metastatic disease who have hormone receptors on their breast cancer cells.</p> <p>Usually given before chemotherapy. If cancer is growing quickly, especially if it's in the liver or lungs, chemotherapy may be given first.</p>
<b>Chemotherapy</b>	<p>Used to slow or stop the growth of metastatic breast cancers and relieve symptoms in women who:</p> <ul style="list-style-type: none"> <li>- do not have hormone receptors on their cancer cells; or</li> <li>- do have hormone receptors on their cancer cells, but have stopped responding to hormonal therapies; or</li> <li>- have fast-growing cancer, especially if it's in the liver or lungs.</li> </ul>
<b>Targeted therapies</b>	<p>Can be used to stop the growth of particular types of metastatic breast cancer cells, such as cells with the HER2 protein on the surface.</p> <p>Usually used in combination with other treatments.</p>
<b>Radiation therapy</b>	<p>May be used to reduce the size of tumours from metastatic breast cancers.</p> <p>May also help to relieve pain, especially if cancer is growing in the bones. It can also be used for breast cancer that has spread in the brain.</p>
<b>Surgery</b>	<p>Not routinely used to treat metastatic breast cancer. However, it may be used to control spread and reduce symptoms of cancer that has spread to the bones, lungs or brain.</p> <p>If a woman is first diagnosed when cancer has already spread to other parts of the body, breast surgery may be considered to control the cancer in the breast after initial treatment with medicine.<sup>17</sup> However, this is not always the case.</p>

In addition to these therapies, some women may be involved in a clinical trial, and may choose to use complementary medicines or bush therapies.

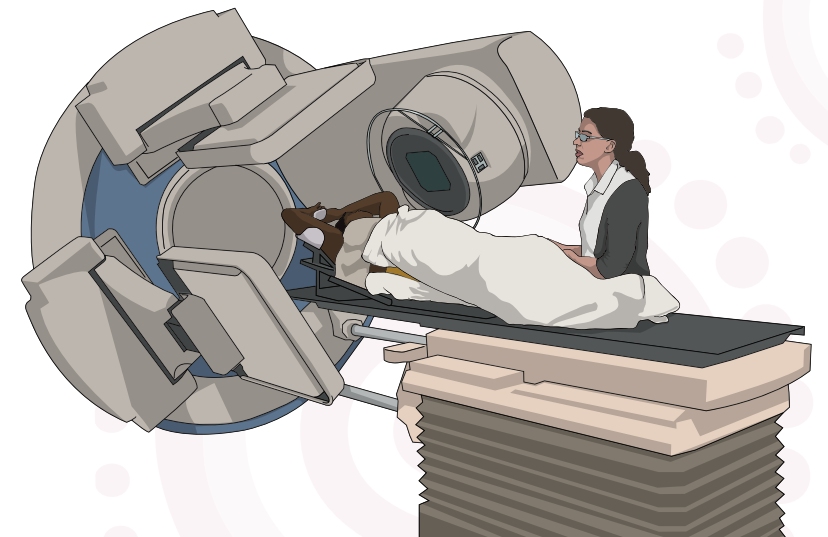
Some treatments may be available within a woman's local community, other treatments may require a woman to travel away from home. Travelling for treatment will have time, cost and support implications.

You can read more about the practical implications of treatment in [Chapter 5](#). A woman may become very sick during this period and may not be able to return to Country. It is important that a woman is provided with all of this information as she makes her treatment decisions.

**Some women with breast cancer that has spread to other parts of the body may choose not to have treatment at all. A woman's choice about her treatment should be respected. It is important that a woman who chooses not to undergo treatment is still offered supportive care to relieve her symptoms.**



You can read more about clinical trials and complementary therapies in [Chapter 4](#).



## Your role

### Palliative care

Palliative care helps people with a life-limiting illness to live as actively and comfortably as possible.<sup>19</sup>

This type of care focuses on care needs and aims to prevent and relieve suffering. The goal is to improve the quality of life for both patients and their families. Care and support may include:

- Relief of pain and other symptoms
- Resources such as medical equipment
- Assistance for families to come together to talk about sensitive issues
- Support for people to help meet cultural obligations
- Support for emotional, social and spiritual concerns
- Counselling and grief support.

Palliative care services can be provided at home, in a hospital or at a hospice. Patients can move between these places if their needs change.

### When should palliative care be considered?

A woman with metastatic breast cancer can receive palliative care at any time. It is not just in the last weeks of life. Early referral to palliative care can improve the quality of life, and in some cases survival, for women with breast cancer.

### Who provides palliative care?

Palliative care is delivered by many different services and people. Some parts of palliative care need input from a specialist doctor or nurse. Others can be provided by the woman's doctor, Aboriginal and/or Torres Strait Islander Health Worker or Health Practitioner, Hospital Liaison Officer, health and community care worker, or by a spiritual healer. Family and community can also be involved.

### Supporting palliative care:

#### You can help by:

- **connecting with palliative care services in your local community to understand what services are available**
- **explaining to the woman and her family and community how palliative care can help**
- **helping doctors and nurses understand what care and support the woman and her family need, including help with managing pain**
- **providing community-based care and liaising with the palliative care team and other services for women who want to be cared for at home.**

## Planning for the future

While treatment for metastatic breast cancer can extend a woman's life for many years, it cannot cure the disease. It can be important for women with metastatic breast cancer, their families and communities to start planning for the future. This can mean:

- considering palliative care to help improve her quality of life
- making decisions about ongoing medical care
- making a will and an advance care plan
- thinking about her wishes for end-of-life.

## Advance care planning

An advance care plan is a plan written by a woman that details her preferences for important healthcare and personal decisions, in case she loses her ability to make decisions for herself in future. Advance care planning can provide a woman, her family and community the opportunity to talk about who will make decisions that affect her care, if she can no longer make those decisions herself. Advance care planning for Aboriginal and Torres Strait Islander women can help to ensure the care they receive at the end of life considers their individual wishes, beliefs and cultural heritage.<sup>20</sup>

Advance care planning may involve:

- discussing the woman's prognosis (how she is expected to respond to treatment) and possible future scenarios
- appointing someone who will make decisions if the woman is unable to, and involving this person in ongoing discussions

- deciding on the goals of care, now and in future
- discussing the woman's choice for place of care and planning a return to country, if desired
- writing the plan in a way that everyone understands
- making sure the woman's health professional(s) and family know that the advance care plan has been written and how to access it if needed.

While advance care planning relates to care at the end-of-life, it is helpful to talk with a woman about these issues when she is feeling well and able to think about what is most important for her.

### **i** For more information

**Advance Care Planning Australia** has information and resources to support a respectful and appropriate approach to advance care planning for Aboriginal and Torres Strait Islander people.

[www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-for-aboriginal-and-torres-strait-islander-peoples](http://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-for-aboriginal-and-torres-strait-islander-peoples)

**Palliative Care Australia** has developed a video to support healthcare professionals to talk about advance care planning in a culturally safe way.

<https://palliativecare.org.au/discussing-choices-indigenous-advance-care-planning/>

## Your role

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### At the end of life

As a woman nears end of life, her care may transition from her specialist treatment team to a specialist palliative care team. The palliative care team will help to ensure a woman is comfortable and pain-free. It is important that a woman and her family understand the reason for this transition in care, and that they feel supported during this time.

Some women may wish to return to country and to be close to their family for the final stages of their life. However, this may be complicated if the patient is receiving palliative care in a hospital setting.<sup>21</sup> You can work in partnership with a woman's treatment team and local health services to explore the possibilities for fulfilling a woman's wishes.

In the immediate period before a woman passes, you may be expecting her family and friends to gather to help prepare her for the next stage of her journey.

If a woman is receiving end of life care in a hospital or hospice setting, you can talk with her treatment team to find out what options might be available to accommodate this.

This may include making a room available for family and friends or extending visiting hours so family and community can visit.<sup>21</sup>

### End of life care:

#### Discussing end-of-life care

**For many Aboriginal and Torres Strait Islander people, yarning about 'death' and 'dying' can be uncomfortable. Discussing end-of-life with a woman in your care can be seen as 'tempting it'. Women may consider end-of-life to be family business that should not be discussed with others.**

**You have an important role to play in guiding women and their families through this phase, and to ensure it is managed in a culturally safe and respectful way by all those involved in a woman's care.**

- **Check with a woman and her family to see if they have a preferred way for yarning about death or dying (e.g. finishing up, passing, sorry business)<sup>19</sup>**
- **Understand that a woman may choose not to discuss something with you<sup>20</sup>**
- **Ask a woman who she would like to be involved in discussions about her healthcare. She may want family or community members to act as decision makers towards the end of her life if she is unable to make decisions for herself<sup>19</sup>**
- **Contact other members of a woman's treatment team to pass on any important cultural information or wishes<sup>20</sup>**

## Addressing care needs

You also have an important role to play in helping to balance a woman's healthcare needs with her cultural and spiritual wishes for end of life. You can help by:

- communicating between the treatment team, the woman and her family about preferences for end-of-life care
- explaining to family why the healthcare team might recommend that she stays in hospital or in a hospice for pain and symptom control
- explaining to healthcare teams the cultural and spiritual significance of the place of dying for Aboriginal and Torres Strait Islander people, and the importance that a woman may place on her need to return to country at the end of her life
- providing community-based care and liaising with the palliative care team and other services for women who want to be cared for at home
- working with the healthcare team and hospital or hospice services to help family and community see the woman at the end of her life, for example by finding a space for large family meetings or relaxing the rules around visitor numbers.

## After passing

After a woman has passed away from breast cancer, you can continue to play an important role in supporting her family and friends.<sup>21</sup>

It is important to have sensitivity and respect for the family and communities protocols and practices during this time. These practices may be sacred and not discussed openly.<sup>21</sup>

You can help by:

- Discussing 'what happens next' with the family so they understand the typical processes of the healthcare system after a person has passed
- Understanding a families sacred protocols and communicating these appropriately with the healthcare team
- Working with the healthcare team to ensure a smooth transition of the woman back to her community for burial.

### **i** For more information

Palliative Care Australia's 'Dying to talk' initiative has developed a Discussion Starter to help Aboriginal and Torres Strait Islander people being a discussion about end of life.

<https://palliativecare.org.au/campaign/aboriginal-torres-strait-islander-discussion-starter/>



## Resources

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**In addition to the information provided by your service or organisation you might find it helpful to get information from different sources.**

### Cancer Council Helpline

Call the Cancer Council Helpline on 13 11 20 for up-to-date, local information that is relevant for you, and the person with cancer that you are supporting.

If your patient is not able to access the internet, the Cancer Council Helpline may be able to print out information from relevant websites and mail these to the patient.

### Useful links

While the internet can be a helpful source of information, it's important to bear in mind that this information may not always be accurate. If you are accessing information to use with your patients, use careful judgment and always check what type of organisation has provided the information.

Your patients may also be accessing information on the internet, via their mobile phone, a personal computer or at local libraries and in internet cafes.

### Australian websites that may be helpful

#### Cancer Australia

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

Cancer Australia is the national authority on cancer control, funded by the Australian Government.

The Cancer Australia website provides evidence-based information about a range of cancers, including breast cancers. The website includes an Aboriginal and Torres Strait Islander specific page.

#### Breast Cancer Network Australia

[www.bcna.org.au](http://www.bcna.org.au)

This website has a range of breast cancer information and resources developed by women with breast cancer, including kits for women with early and secondary breast cancer, a quarterly magazine and personal stories written by people affected by breast cancer.

**Australian Indigenous HealthInfoNet**

[www.healthinfonet.ecu.edu.au](http://www.healthinfonet.ecu.edu.au)

This is a website that is a 'one-stop info-shop' for people interested in information on health and wellbeing of Aboriginal and Torres Strait Islander people. There is information on cancer among Aboriginal and Torres Strait Islander peoples under the Chronic Conditions tab.

This website also provides a map of all Aboriginal and Torres Strait Islander health/medical services:

<https://healthinfonet.ecu.edu.au/key-resources/health-professionals/health-workers/map-of-aboriginal-and-islander-healthmedical-services/>

**Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer**

This resource provides guidance to health services and health professionals to ensure that cancer care is responsive to the needs of Aboriginal and Torres Strait Islander people. Consumer resources that outline what patients should expect on the cancer pathway, and the

care they should be offered, are also available.

[www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/optimal-care-pathway-aboriginal-and-torres-strait-islander-people-cancer](http://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/optimal-care-pathway-aboriginal-and-torres-strait-islander-people-cancer)

**Quick Reference Guide:**

[www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/quick-reference-guide](http://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/quick-reference-guide)

**Consumer resources:**

[www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/cancer-what-expect](http://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/cancer-what-expect)

**Optimal care pathways for specific tumour**

**types**, including breast cancer, outline the approach to best cancer care for a range of cancer types.

<https://www.cancer.org.au/health-professionals/optimal-cancer-care-pathways>

**Cancer Council Australia**

[www.cancer.org.au](http://www.cancer.org.au)

This website has links to the State and Territory Cancer Councils, which have information about cancer resources available in each State and Territory.

**BreastScreen NSW – Information for Aboriginal women**

[www.breastscreen.nsw.gov.au/about-screening-mammograms/information-for-aboriginal-women](http://www.breastscreen.nsw.gov.au/about-screening-mammograms/information-for-aboriginal-women)

This webpage from Cancer Institute NSW provides helpful information and frequently asked questions about screening mammograms for Aboriginal women.

**CanTeen**

[www.canteen.org.au](http://www.canteen.org.au)

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



### **YWCA Encore**

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

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

### **Palliative Care Australia**

[www.palliativecare.org.au](http://www.palliativecare.org.au)

Palliative Care Australia is the national peak body for palliative care, which aims to work towards high quality palliative care for all Australians. The website provides information for patients, health professionals and carers and a national directory of palliative care services.

### **Caresearch**

[www.caresearch.com.au](http://www.caresearch.com.au)

CareSearch provides trustworthy information about palliative care for patients, carers and families as well as for the health professionals providing their care.

Comprehensive information to support the health care workforce and carers in providing palliative care for Aboriginal and Torres Strait Islander people is available through this website.

### **Carers Australia**

[www.carersaustralia.com.au](http://www.carersaustralia.com.au)

This website provides information and links to a network of State and Territory Carers Associations to deliver a range of essential national carer services, including specific services and resources for Aboriginal and Torres Strait Islander carers.

### **Other useful contacts**

#### **Centrelink**

[www.servicesaustralia.gov.au](http://www.servicesaustralia.gov.au)

Disability, sickness and carers: telephone 13 27 17  
Provides information about government support and financial assistance.

#### **Medicare**

[www.servicesaustralia.gov.au/medicare](http://www.servicesaustralia.gov.au/medicare)

Aboriginal and Torres Strait Islander Access line:  
telephone 1800 556 955  
General enquiries: telephone 13 20 11  
Provides information about Medicare claims.

#### **Department of Veterans Affairs**

[www.dva.gov.au](http://www.dva.gov.au)

General enquiries: telephone 13 32 54  
Provides information about support and assistance available to Veterans.

## Useful materials

### **Cancer Australia: Stages of breast cancer**

A helpful webpage that provides definitions for each stage of breast cancer.

<https://www.canceraustralia.gov.au/cancer-types/breast-cancer/symptoms-and-diagnosis/stages-breast-cancer>

### **My Breast Cancer Journey: A guide for Aboriginal and Torres Strait Islander women and their families**

This booklet contains information to help Aboriginal and Torres Strait Islander women, their family and friends understand early breast cancer. It outlines the clinical management of the breast cancer journey to support Aboriginal and Torres Strait Islander women through breast cancer.

<https://www.canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/my-breast-cancer-journey-guide-aboriginal-and-torres-strait-islander-women-and-their-families>

### **Cancer treatment side effects – A guide for Aboriginal Health Workers**

Developed by Cancer Institute NSW in collaboration with Aboriginal Health Workers, this booklet provides important and practical information to help you support your patients during their cancer treatment.

<https://www.cancer.nsw.gov.au/about-cancer/document-library/cancer-treatment-side-effects-a-guide-for-aborigin>

### **Aboriginal and Torres Strait Islander Discussion Starter**

Developed by Palliative Care Australia, this is a series of resources to support health care workers open conversations with their patients around end-of-life care in a culturally safe way.

They include a culturally appropriate step-by-step guide to make difficult discussions about death that bit easier and a set of cards that can be used as a tool to start the conversations.

<https://palliativecare.org.au/campaign/aboriginal-torres-strait-islander-discussion-starter/>

### **National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017–2023**

Developed by the Department of the Prime Minister and Cabinet, this Framework provides a dedicated focus on Aboriginal and Torres Strait Islander social and emotional wellbeing and mental health. It sets out a comprehensive and culturally appropriate stepped care model that is equally applicable to both Indigenous specific and mainstream health services.

<https://www.niaa.gov.au/resource-centre/indigenous-affairs/national-strategic-framework-mental-health-social-emotional-wellbeing-2017-23>

### **NSW Aboriginal Mental Health and Wellbeing Strategy 2020–25**

Developed by the NSW Ministry of Health, this Strategy is designed to support and assist NSW Health services in delivering respectful and appropriate mental health services in partnership with Aboriginal services, people and communities.

<https://www.health.nsw.gov.au/mentalhealth/resources/Publications/aborig-mh-wellbeing-2020-2025.pdf>

## Glossary

### A

**Adjuvant.** Treatment given in addition to primary (initial) treatment. For breast cancer, the primary treatment is surgery and adjuvant treatments include chemotherapy, radiation therapy, hormonal and targeted therapies.

**Alkylating agent.** A class of chemotherapy, e.g. cyclophosphamide

**Alternative therapies.** Used instead of conventional treatments.

**Anaemia.** A condition in which there are fewer than normal red blood cells in the blood.

**Anthracycline.** A class of chemotherapy, e.g. epirubicin (Pharmorubicin<sup>®</sup>), doxorubicin (Adriamycin<sup>®</sup>).

**Antimetabolite.** A class of chemotherapy, e.g. 5-fluorouracil (5FU), methotrexate.

**Anti-emetic.** A drug used to control nausea and vomiting.

**Anti-oestrogen.** A type of hormonal therapy, e.g. tamoxifen.

**Aromatase inhibitor.** A type of hormonal therapy, e.g. anastrozole (Arimidex<sup>®</sup>), letrozole (Femara<sup>®</sup>), exemestane (Aromasin<sup>®</sup>).

**Ascites.** The abnormal accumulation of fluid in the abdominal or peritoneal cavity.

**Axilla.** The armpit.

### **Axillary dissection/ axillary clearance.**

Removal of some or all of the lymph nodes from the armpit.

### B

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

**Bone marrow.** A spongy material within some bones that makes different types of blood cells.

**BRCA1 and BRCA2.** These are genes that normally prevent a patient gene developing breast or ovarian cancer. If a patient has a fault in one of these genes, she has a high chance of developing breast or ovarian cancer, although it does not mean that she is certain to develop cancer.

**Breast conserving surgery.** Removal of the breast cancer and a small area of healthy tissue around it; also called a lumpectomy, complete local excision, partial mastectomy or wide local excision.

**Breast form.** See 'External breast prosthesis'

### C

**Cellulitis.** An infection of the skin caused by bacteria.

**Chemotherapy.** Treatment for cancer using drugs.

**Clinical trials.** Studies that compare new treatments with standard treatments.

**Complementary therapies.** Treatments or therapies that can be used alongside conventional therapies.

**Complete local excision.** see 'Breast conserving surgery'

**CT scan.** Computerised tomography — a special type of X-ray that provides a three-dimensional picture of the inside of the body.

## D

**Deep inferior epigastric perforator (DIEP) flap.** A type of breast reconstruction using the blood vessels, fat and skin from the stomach.

**Ductal carcinoma in situ (DCIS).** Non-invasive breast cancer that is confined to the ducts of the breast.

**Dyspepsia.** Another name for indigestion.

## E

**Echocardiogram.** A type of ultrasound test that looks at the size, shape and function of the heart.

**Endocrine therapies.** Another name for hormonal therapies.

**Ethics committee.** A group of experts who review clinical trial protocols to make sure that the rights of the patients involved are protected.

**External breast prosthesis.** An artificial breast; also called a breast form.

## G

**Granulocyte colony stimulating factor (G-CSF).** A growth factor used to increase the number of white blood cells in the blood.

## H

**Hand-foot syndrome.** Redness, tenderness, and peeling of the skin on the palms of the hands and soles of the feet, caused by certain chemotherapy drugs.

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

**Hormonal therapies.** Drugs used to treat women who have hormone receptors on their breast cancer cells. Also called endocrine therapies.

**Hormone receptors.** Proteins in a cell that allow hormones to bind to the cell, causing it to grow and divide. Hormone receptors must be present for the cell growth to be influenced by hormones.

**Hormone replacement therapy (HRT).**

Hormones (oestrogen, progesterone or both) given to women after menopause. Used to ease symptoms of menopause.

**Hypercalcaemia.** A high level of calcium in the blood.

## I

**Inflammatory breast cancer.** A rare form of invasive breast cancer that affects the blood vessels in the skin of the breast, causing the breast to become red and inflamed.

**Intrauterine device (IUD).** A small device which is inserted into the uterus by a doctor to prevent pregnancy. There are two types of IUD, one which contains copper and another which contains the hormone progestogen.

**Intravenous infusion.** A method of putting fluids, including drugs, into the bloodstream through a cannula or needle.

**Isotope.** a radioactive substance.

## L

**Latissimus dorsi flap.** A type of breast reconstruction using back muscle transfer; involves moving a flap of muscle, skin and fat from your back to your chest to form a new chest 'mound'.

**Libido.** Sex drive.

**Lobular carcinoma in situ (LCIS).** Non-invasive breast cancer that is confined to the lobules of the breast.

**Locally advanced breast cancer.** Invasive breast cancer that has spread to areas near the breast, such as the chest wall.

**Lumpectomy.** See 'Breast conserving surgery'.

**Lymphatic vessels.** Tiny vessels next to blood vessels that collect fluid and waste products from the body's tissue.

**Lymph nodes.** Glands in the armpit and other parts of the body that protect the body from infection.

**Lymphoedema.** Swelling of the arm that can sometimes develop after treatment for breast cancer.

## M

**Magnetic Resonance Image (MRI).** A way of producing a picture of the inside of the body using magnetic fields.

**Mammogram.** a way of taking a picture of the breast using a low-dose x-ray.

**Mastectomy.** Removal of the whole breast.

**Metastasis.** The name for a cancer that spreads to another part of the body.

**Mitotic inhibitor.** A class of chemotherapy, e.g. paclitaxel (Taxol®), docetaxel (Taxotere®).

**Multidisciplinary care.** A team approach to cancer treatment and planning.

**Multi-gated acquisition scan (MUGA).** A test that measures how well the heart pumps blood.

## N

**Nuclear medicine.** A method of diagnostic imaging that uses very small amounts of radioactive material. The patient is injected with a liquid that contains the radioactive substance, which collects in the part of the body to be imaged. Sophisticated instruments detect the radioactive substance in the body and process that information into an image.

## O

**Oestrogen.** A type of female hormone.

**Oncologist.** A doctor who specialises in treating cancer.

**Oophorectomy.** Surgical removal of the ovaries.

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

## P

**PET scan.** Positron emission tomography — a scan used to show any areas in the body where cells are more active than usual.

**Paget's disease.** A rare form of invasive breast cancer that affects the nipple: the nipple and the area around the nipple (the areola).

**Palliative care.** Specialised care for people who have a disease that cannot be cured. Palliative care focuses on helping to control physical symptoms such as pain, on emotional wellbeing, on relationships with others and on spiritual needs.

In later stages, palliative care can also help people to prepare for death.

**Partial mastectomy.** See 'Breast conserving surgery'.

**Pathology.** Tests that involve examining blood, tissue or cells from the body.

**Pharmaceutical Benefits Scheme (PBS).** A scheme managed by the Government that provides medicines at a subsidised price to Australian residents who hold a current Medicare card and to overseas visitors from countries with which Australia has a Reciprocal Healthcare Agreement.

**Platelets.** Blood cells produced by the bone marrow that help the blood to clot.

**Pleura.** The membrane that lines the rib cage and covers the lungs.

**Pleural aspiration.** Drainage of fluid from around the lungs.

**Pneumonitis.** A side effect of radiation therapy in which the lung becomes inflamed.

## R

**Radiology.** Tests that involve taking pictures of different parts of the body.

**Radiation therapy.** Treatment for cancer in a particular area of the body using x-rays. Also known as radiotherapy.

**Receptor.** A protein on or in a cell to which a substance such as a hormone or a drug can attach.

**Risk factors.** Things that increase your chance of developing breast cancer.

## S

**Sentinel node biopsy.** Removal of the first lymph node(s) in the armpit to which cancer cells are likely to spread from the breast.

**Seroma.** Fluid that collects in or around a scar.

**Sexually transmitted infection.** An infection that is passed from person to person via sexual activity.

**Social and emotional wellbeing (SEWB).**

The foundation for physical and mental health for Aboriginal and Torres Strait Islander peoples. A holistic concept which results from a network of relationships between individuals, family, kin and community. It also recognises the importance of connection to land, culture, spirituality and ancestry, and how these affect the individual.

**Steroids.** Drugs used to relieve swelling and inflammation.

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

**Systemic treatment.** Drugs such as chemotherapy or hormonal therapy that treat the whole body to destroy cancer cells.

**T**

**Targeted therapies.** Drugs that stop the growth of particular types of cancer cells. Also known as biological therapies.

**Thrush.** An infection caused by yeast that appears as white patches on the tongue or mouth.

**Transfusion.** The transfer of blood or blood products from a donor to another person.

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

**U**

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

**Uterus.** Another name for the womb.

**W**

**Wide local excision.** See 'Breast conserving surgery'.

## References

1. Cancer Australia 2018. Risk factors for breast cancer: A review of the evidence. Cancer Australia, Surry Hills, NSW.
2. Australian Institute of Health and Welfare 2022. Cancer data in Australia. Canberra: Accessed: July 2022; <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/data>.
3. Australian Institute of Health and Welfare 2021. Cancer in Australia 2021. Cancer series no. 133. Cat. no. CAN 144. Canberra: AIHW.
4. Australian Institute of Health and Welfare. Cancer in Aboriginal and Torres Strait Islander people of Australia. Web Report. Cat. no: CAN 109. Last updated 15 March 2018. Available at: <https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians/contents/cancer-type/breast-cancer-in-females-c50> [Accessed April 2021].
5. Cancer Australia. Breast Cancer Risk Factors [Website]. Available at: <https://www.breastcancerriskfactors.gov.au/risk-factors> [Accessed April 2021].
6. Australian Institute of Health and Welfare 2021. BreastScreen Australia monitoring report 2021. Cat. no. CAN 140. Canberra: AIHW.
7. McMichael C, Kirk M, Manderson L, Hoban E, Potts H. Indigenous women's perceptions of breast cancer diagnosis and treatment in Queensland. Aust N Z J Public Health. 2000; 24(5): 515-9.
8. Women's Health Goulbourn North East (WHGNE). Exposed: A literature review of the issues of women's cancer in Australian Indigenous Communities. Wangaratta, Victoria 2010.
9. Brady M. The Grog Book: Strengthening Indigenous Community Action on Alcohol. Revised edition. Canberra: Australian Government, Department of Health and Ageing; 2005.
10. Cancer Australia, 2017. Investigation of a new breast symptom: A guide for general practitioners, Cancer Australia, Surry Hills, NSW
11. Cancer Australia, 2020. Guidance for the management of early breast cancer: Recommendations and practice points, Cancer Australia, Surry Hills, NSW.
12. Australian Institute of Health and Welfare 2022. Cancer data in Australia. Canberra: Accessed: July 2022; <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/data>.
13. Cancer Australia 2016. Cancer Australia Statement – Influencing best practice in breast cancer. Cancer Australia 2016; Surry Hills: NSW.
14. Clinical Oncology Society of Australia. 2018. COSA position statement on exercise in cancer care. Accessed April 2021 from: <https://www.cosa.org.au/media/332488/cosa-position-statement-v4-web-final.pdf>.
15. Commonwealth of Australia 2017. National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing Canberra: Department of the Prime Minister and Cabinet.
16. Cancer Australia. Starting the conversation: Supporting sexual wellbeing for women with breast cancer. 2013.
17. Breast Cancer Network Australia. What is metastatic breast cancer? [Website]. Available at: [https://www.bcna.org.au/metastatic-breast-cancer/what-is-metastatic-breast-cancer/#:~:text=Metastatic%20breast%20cancer%20is%20breast,stage%20IV%20\(4\)%20breast%20cancer](https://www.bcna.org.au/metastatic-breast-cancer/what-is-metastatic-breast-cancer/#:~:text=Metastatic%20breast%20cancer%20is%20breast,stage%20IV%20(4)%20breast%20cancer) [Accessed June 2021].



18. Breast Cancer Network Australia. Hope and Hurdles: Metastatic breast cancer information guide [Booklet]. Available at: [https://www.bcna.org.au/media/7845/hh-  
mbc-informationguide-web.pdf](https://www.bcna.org.au/media/7845/hh-<br/>mbc-informationguide-web.pdf) [Accessed June 2021].
19. PEPA Project Team (2020). The Program of Experience in the Palliative Approach Learning Guide for Aboriginal and Torres Strait Islander Health Professionals, Queensland University of Technology, Brisbane [https://pepaeducation.com/wp-content/uploads/2021/01/IPEPA\\_AHP-LearningGuide\\_Online.pdf](https://pepaeducation.com/wp-content/uploads/2021/01/IPEPA_AHP-LearningGuide_Online.pdf).
20. Advance Care Planning Australia. Advance Care Planning for Aboriginal and Torres Strait Islander Peoples [Website]. Available at: <https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-for-aboriginal-and-torres-strait-islander-peoples> [Accessed June 2021]
21. Queensland Health. Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying (version 2), December 2015.





The artwork 'Our Journeys' represents the experience of Aboriginal and Torres Strait Islander people with cancer. The white dots are the journey of each individual; the patterned areas are the different landscapes and regions of Australia; and the colours are the different cancer types. Cancer Australia, as the leading agency shaping cancer control in Australia, is depicted by the central ochre meeting place which draws stakeholders together to share ways to improve cancer outcomes. The kangaroo prints and the fish leading to and from the meeting place represent the flow of information and engagement between Cancer Australia and Aboriginal and Torres Strait Islander people.



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