

CANCER AUSTRALIA

LEARNER'S RESOURCE



Providing information and support to Aboriginal and
Torres Strait Islander women with breast cancer



Australian Government
Cancer Australia

CANCER AUSTRALIA

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PROVIDING INFORMATION AND SUPPORT TO ABORIGINAL AND TORRES STRAIT ISLANDER WOMEN WITH BREAST CANCER

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Learner's Resource: Providing Information and Support to Aboriginal and Torres Strait Islander Women with Breast Cancer was prepared and produced by Cancer Australia.

CANCER AUSTRALIA

Locked Bag 3 Strawberry Hills NSW 2012

Tel: +61 2 9357 9400

Fax: +61 2 9357 9477

Freecall: 1800 624 973

Website: www.canceraustralia.gov.au

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Breast cancer: the facts

Early breast cancer journey

Awareness and early detection

Investigation and diagnosis of breast cancer

Treatment options for breast cancer

Breast cancer follow-up care

Psychosocial issues and support

Multidisciplinary team approach

Resources

Learner's Resource:
Helping health workers
provide information and
support to Aboriginal
and Torres Strait Islander
women with breast cancer.

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Overview of resource

The Learner's Resource is part of a suite of resources developed by Cancer Australia to support implementation of the unit of competency HLTAHW431A *Provide information and support to women with breast cancer* for Aboriginal and Torres Strait Islander Health Workers.

Supporting resources

The Cancer Australia supporting resources include:

- ***Learner's Resource: Providing information and support to Aboriginal and Torres Strait Islander women with breast cancer – Handbook.***
- *Learner's Guide: Providing information and support to Aboriginal and Torres Strait Islander women with breast cancer – Activities and assessments.*
- *Facilitator's Guide: Providing information and support to Aboriginal and Torres Strait Islander women with breast cancer – Facilitator's notes.*
- *Learner's Presentation: Providing information and support to Aboriginal and Torres Strait Islander women with breast cancer – Facilitator's slides.*

Aim

The Learner's Resource provides Aboriginal and/or Torres Strait Islander Health Workers with information to support Aboriginal and Torres Strait Islander women through their breast cancer journey following a diagnosis of early breast cancer.

Where possible information relating to Aboriginal and Torres Strait Islander women has been included. There is limited research and evidence relating to this specific population group so information relating to Aboriginal and Torres Strait Islander people with cancer in general has been included.

Outcomes

Together with the Learner's Guide, the Learner's Resource covers the knowledge and skills required for the unit of competency HLTAHW431A *Provide information and support to women with breast cancer*.

Essential outcomes of the Learner's Resource and Learner's Guide are to:

- promote awareness and early detection of breast cancer
- provide information and support to clients being investigated for a breast cancer symptom
- provide information and support to clients being treated for early breast cancer
- provide information and support to clients to complete breast cancer follow-up care.



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Cancer Australia Staff

The following staff were involved in the development of this resource:

- Hannah Nancarrow, *Senior Project Officer*
- Janelle Webb, *Project Officer*
- Caroline Nehill, *Manager*
- Ornella Care, *Manager*

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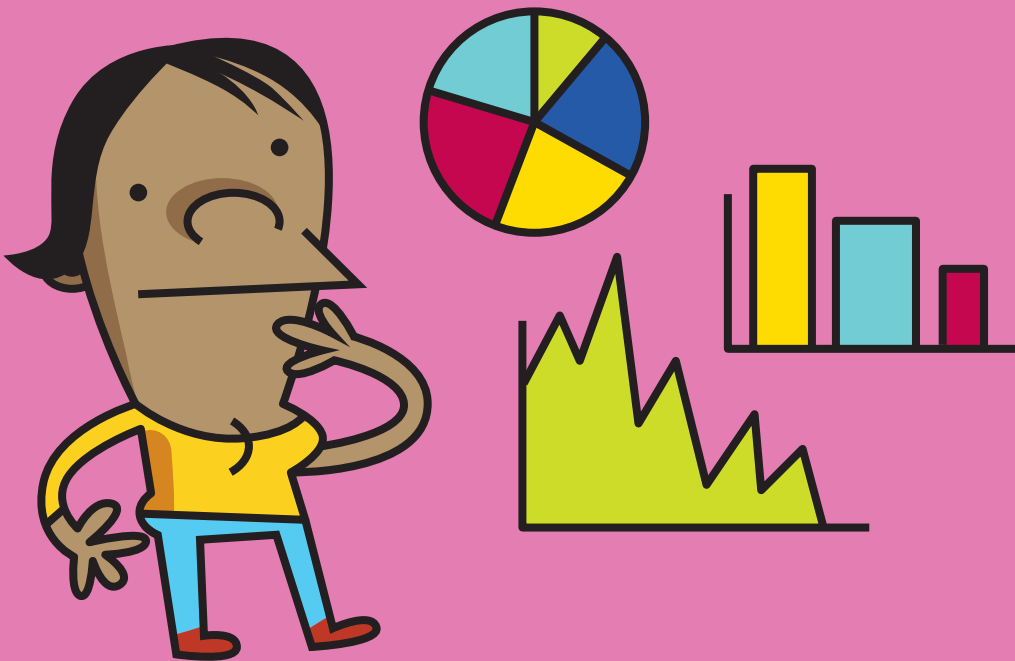
Contact us

If you have any queries please contact Cancer Australia directly on 02 9357 9400.

*On 30 June 2011, National Breast and Ovarian Cancer Centre (NBOCC) amalgamated with Cancer Australia to form a single national agency, Cancer Australia, to provide leadership in cancer control and improve outcomes for Australians affected by cancer.

1.

Breast cancer: the facts



This chapter gives you an overview of breast cancer, and provides some statistics about breast cancer in Australia. It includes the most up-to-date information on incidence, mortality and survival for invasive breast cancer in Australian women.^[1]

1.1 What is breast cancer?

Breasts are made up of lobules and ducts surrounded by fatty and connective tissue. The lobules produce breast milk and ducts carry milk to the nipple (*Figure 1*).

Breast cancer occurs when cells in the ducts or lobules grow abnormally. The abnormal cells form growths called cancers. There are different types of breast cancer.

- **Non-invasive breast cancer:** is when the cancer cells stay in the ducts and lobules of the breast and do not spread. e.g. ductal carcinoma in situ.
- **Invasive breast cancer:** is when the cancer cells spread beyond the ducts and lobules into the surrounding tissue.

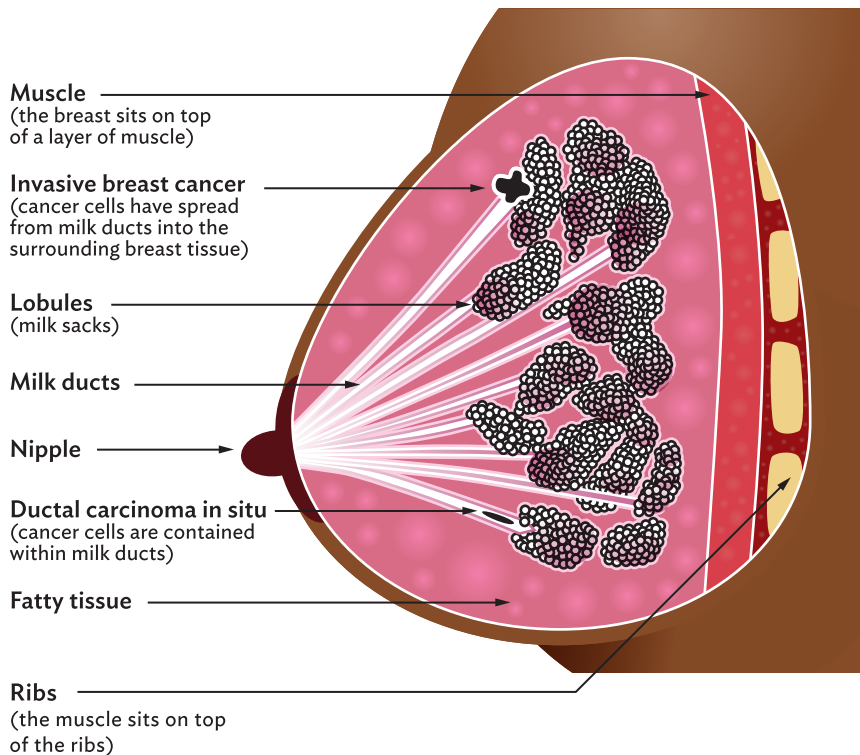


FIG 1: Picture of a woman's breast showing invasive breast cancer and ductal carcinoma in situ (a type of non-invasive breast cancer). Sourced from NBOCC, *Guide for women with early breast cancer*.

Non-invasive breast cancer

Ductal carcinoma in situ (DCIS)

Ductal carcinoma in situ (DCIS) is a type of non-invasive breast cancer that is contained within the milk ducts of the breast. Women cannot die from DCIS.

FAST FACTS

Women diagnosed with DCIS are about four times more likely to develop an invasive breast cancer compared with other women of a similar age in Australia.^[2]

Invasive breast cancer

Early breast cancer

Early breast cancer is an invasive cancer that is contained in the breast and may or may not have spread to the lymph nodes in the breast or armpit. Women with early breast cancer have no detectable cancer cells outside the breast and armpit area. The majority of breast cancer cases are diagnosed when the breast cancer is still confined to the breast.

Secondary breast cancer

Sometimes breast cancer cells travel in the bloodstream or lymphatic system to other parts of the body. This is called secondary breast cancer (also known as metastatic breast cancer or advanced breast cancer). The most common places that breast cancer spreads to are the bones, liver, lungs and brain.

Other types of invasive breast cancer

- **Paget's disease of the nipple:** a rare form of invasive breast cancer that affects the nipple and the area around the nipple (the areola).
- **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.
- **Locally advanced breast cancer:** an invasive breast cancer that has spread to areas near the breast, such as chest wall.

FAST FACTS

Women diagnosed with smaller tumours (10mm or less) have better survival rates than women diagnosed with larger tumours (30mm or more), 98% and 73% five-year survival respectively.^[1]

1.2 Breast cancer in Australia

How common is breast cancer?

The incidence rate for breast cancer is the number of new cases diagnosed per 100,000 women within a given time frame. Measuring the incidence of breast cancer gives us information about groups of people at greater risk of developing the disease.

Incidence of invasive breast cancer in Australia

Breast cancer is the most commonly diagnosed cancer among women in Australia (*Figure 2*). In 2012 it was predicted that approximately 14,600 women would be diagnosed with breast cancer in Australia that year.^[1]

On average, 40 women are diagnosed with breast cancer each day in Australia.^[1]

FAST FACTS

In the year 2020, it is predicted that 17,210 Australian women will be diagnosed with breast cancer.^[1]

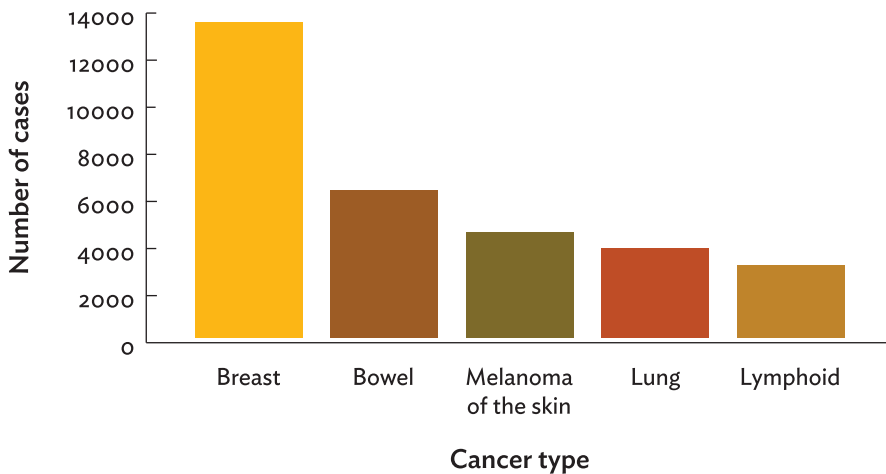


FIG 2: Five most commonly diagnosed cancers in Australian women, 2007. Data sourced from: AIHW *Cancer in Australia: an overview 2010*^[3]

While breast cancer can occur in younger women, about three out of four breast cancer cases occur in women aged 50 years and older (Figure 3).

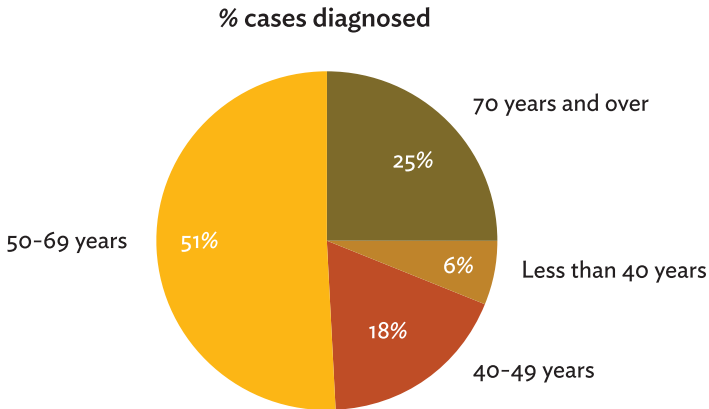


FIG 3: Age at diagnosis of breast cancer in Australian women, 2008. Sourced from Cancer Australia *Breast cancer in Australia: An overview, 2012*.

Differences in breast cancer incidence

The incidence of breast cancer varies in different parts of Australia. About 30% of women diagnosed with breast cancer live outside a major metropolitan city. Women living in major cities at the time they are diagnosed with breast cancer have a higher incidence rate of breast cancer than those in more remote areas (Figure 4).

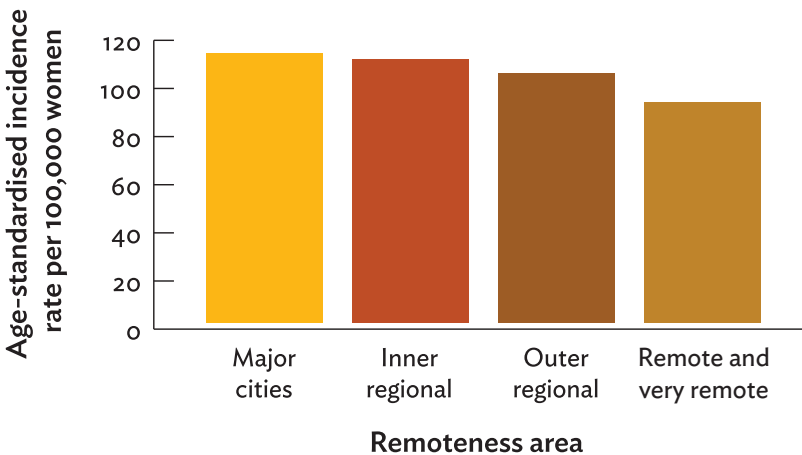


FIG 4: Incidence of breast cancer by remoteness in Australian women, 2004-2008. Sourced from Cancer Australia *Breast cancer in Australia: An overview, 2012*.

NOTE: Age-standardised rates take into account the ageing population.

Women living in areas with a higher socioeconomic status have a significantly higher incidence rate of breast cancer compared with women living in other areas. This may be because lifestyle factors, such as diet and drinking habits, which may be linked to an increased risk of breast cancer, are different in these areas. *Risk factors for breast cancer are described in more detail in Section 3.2 Breast cancer risk factors.*

Incidence of breast cancer in Aboriginal and Torres Strait Islander women

MYTH: Aboriginal and Torres Strait Islander women do not get breast cancer.

FACT: Breast cancer is the most common cancer affecting Aboriginal and Torres Strait Islander women.

Breast cancer is the most common cancer among Aboriginal and Torres Strait Islander women – almost twice as common as lung cancer (Figure 5). However, Aboriginal and Torres Strait Islander women are less likely than non-Indigenous women to be diagnosed with breast cancer.

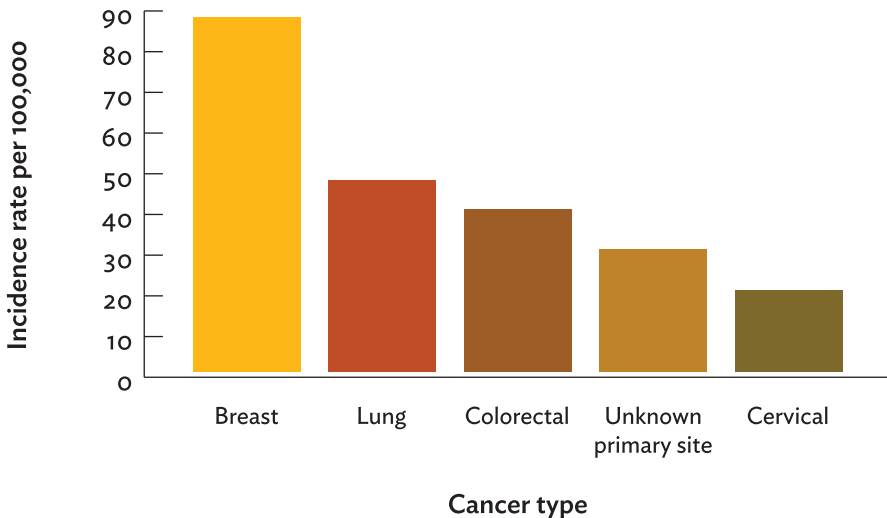


FIG 5: Incidence of breast cancer compared with other cancers in Aboriginal and Torres Strait Islander women, 2000–2004. Data sourced from AIHW, *The Health and Welfare of Aboriginal and Torres Strait Islander peoples, 2008.*

Breast cancer mortality

Mortality is the number of people who die from a disease.

Breast cancer mortality in Australia

Breast cancer was the second most common cause of cancer death in women in 2007 (Figure 6). On average, seven women die from breast cancer every day in Australia.

FAST FACTS

2,680 women died from breast cancer in Australia in 2007.^[1]

Breast cancer accounts for one in every 25 deaths in women from any cause in Australia.^[1]

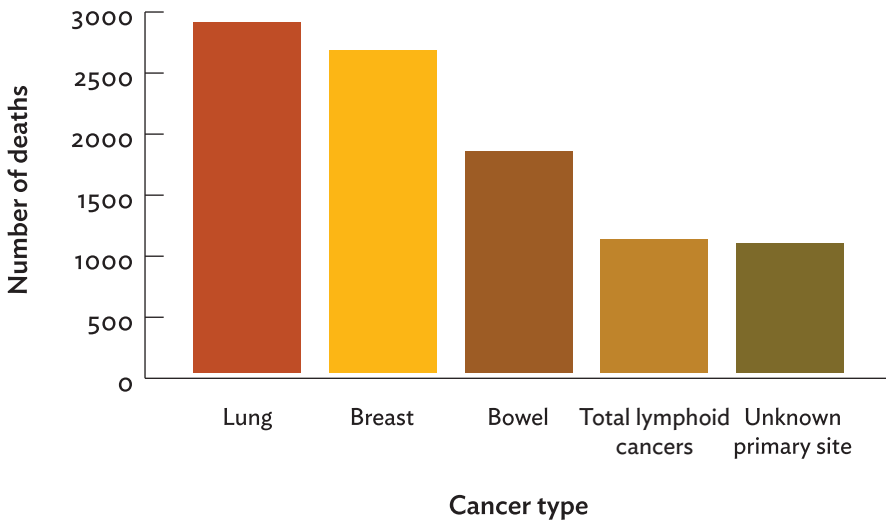
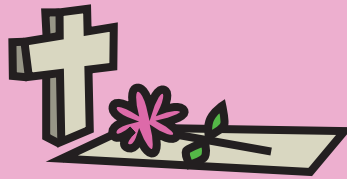


FIG 6: Five most common types of cancer death in Australian women, 2007. Sourced from Cancer Australia *Breast cancer in Australia: An overview, 2012*.

While the incidence rate of breast cancer increased between 1994 and 2007, the mortality rate has dropped by 29% over the same period (Figure 7). This means that although more women were diagnosed with breast cancer during this time period, the chance of survival was greater.

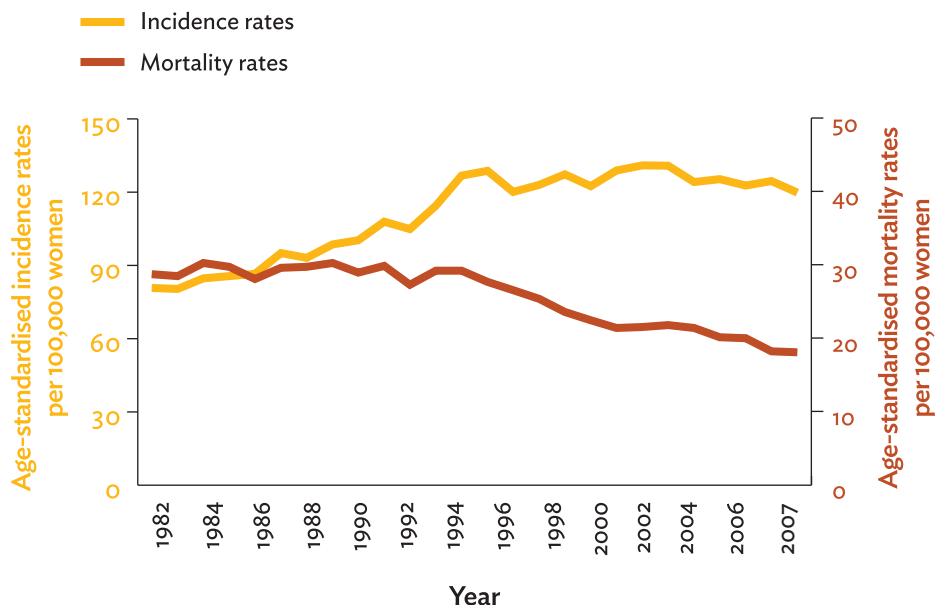


FIG 7: Rates of incidence and mortality from breast cancer in Australian women, 1982-2007. Sourced from Cancer Australia *Breast cancer in Australia: An overview, 2012*.

NOTE: Age-standardised rates take into account the ageing population.

Breast cancer mortality in Aboriginal and Torres Strait Islander women

Breast cancer mortality rates for Aboriginal and Torres Strait Islander women are roughly equivalent to those of non-Indigenous women (21 and 23 deaths per 100,000 women, respectively).^[1]

Breast cancer survival

Relative survival rates tell us the likelihood that a woman will still be alive at a specified point in time (such as five years) following a diagnosis of cancer, compared to the expected survival of similar-aged women in the general population.

Breast cancer survival in Australian women

Women diagnosed with breast cancer are surviving significantly longer than ever before. Out of every 100 women diagnosed with breast cancer 25 years ago, only 73 women were alive 5 years later.

Today, 89 out of every 100 women survive 5 years after a diagnosis of breast cancer (Figure 8). Improvements in survival are due to earlier detection of breast cancer through population-based mammography screening and improved treatments for breast cancer.

FAST FACTS

Overall, 89 out of every 100 women with breast cancer survive 5 or more years beyond their diagnosis.^[1]



FIG 8: Five year relative survival rates for Australian women with breast cancer by period of diagnosis. Sourced from Cancer Australia *Breast cancer in Australia: An overview, 2012*.

Breast cancer survival is highest for women diagnosed with early breast cancer.

Breast cancer survival in Aboriginal and Torres Strait Islander women

Survival rates are lower for Aboriginal and Torres Strait Islander women diagnosed with breast cancer than for non-Indigenous women (Figure 9).

FAST FACTS

97 out of every 100 women diagnosed with localised breast cancer will survive 5 years beyond their diagnosis.^[1]

40 out of every 100 women diagnosed with secondary breast cancer will survive 5 years beyond their diagnosis (NSW data 2002-2006).^[1]

Aboriginal and Torres Strait Islander women have a lower 5-year crude survival than non-Indigenous women following a diagnosis of breast cancer. (Crude survival is the proportion of women alive at a specified point in time, e.g. 5 years, after a diagnosis of breast cancer).



FIG 9: Average crude survival rates for both 100 non-Indigenous women and 100 Aboriginal and Torres Strait Islander women. Sourced from Cancer Australia *Breast cancer in Australia: An overview, 2012*.

Why is breast cancer survival lower in Aboriginal and Torres Strait Islander women?

The difference in survival from breast cancer between Aboriginal and Torres Strait Islander women and non-Indigenous women is reflective of survival rates for all Aboriginal and Torres Strait Islander people with cancer. The difference in survival rates compared to non-Indigenous people may be due to a number of factors.



Aboriginal and Torres Strait Islander women are:

- less likely than non-Indigenous women to have a screening mammogram^[4]
- may choose not to visit a doctor when they notice changes in their breasts.^[5]

As a result of these factors, breast cancer may be more advanced when diagnosed.^[6-8]

We also know that the Aboriginal and Torres Strait Islander population are:

- less likely to undergo cancer treatment^[6-8]
- less likely to complete cancer treatment^[6]
- more likely to have 1 or more other health problems such as heart disease and/or diabetes.^[6]

FAST FACTS

On average, 69 out of every 100 Aboriginal and Torres Strait Islander women are still alive at 5 years or more after a breast cancer diagnosis compared with 83 non-Indigenous women.^[1]

2.

Early breast cancer journey



In this chapter you will be introduced to the early breast cancer patient journey. You will learn about the care given to women at different stages of the breast cancer process.

The early breast cancer journey

The ‘early breast cancer journey’ is used to describe the delivery of healthcare over a period of time. For breast cancer, the journey starts with breast cancer awareness and early detection and flows through diagnosis to treatment and follow-up care.

When a woman experiences a breast cancer symptom, or is diagnosed with breast cancer, she will enter and move through the breast cancer journey.

The flow of the breast cancer journey is shown below in *Figure 10*.

At each stage there are things that you, as an Aboriginal and Torres Strait Islander Health Worker, need to know about so you can help navigate women through the journey by providing information and support. Each step is described in further detail in the following sections of the *Learner’s Resource*.

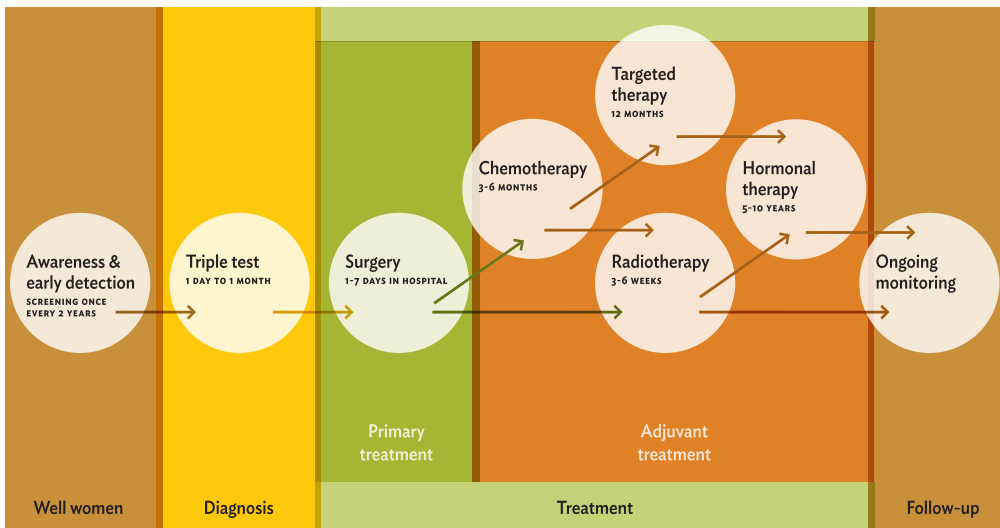


FIG 10: Early breast cancer journey

NOTE: These are approximate durations only and may change over time and may differ for each individual.

Awareness and early detection

Women who do not have breast cancer are referred to as 'well women'. Awareness and early detection of breast cancer is covered in detail in *Section 3: Awareness and early detection*.

FAST FACTS

There is evidence that early detection in women aged 50-69 years results in an increased rate of successful treatment and recovery from breast cancer.^[4]

Diagnosis

If any abnormalities in the breast tissue are found during a screening mammogram, a woman will be recalled for further investigation. In other cases, a woman may go to see her doctor because she has a symptom of breast cancer.



Diagnosis is described more in *Section 4: Investigation and diagnosis of breast cancer*.

Treatment

The primary treatment for breast cancer is surgery. Treatment given in addition to surgery is called adjuvant treatment. Adjuvant treatments include radiotherapy, chemotherapy, hormonal therapies and targeted therapies.

Treatments for breast cancer are covered in *Section 5: Treatment options for breast cancer*.

Follow-up

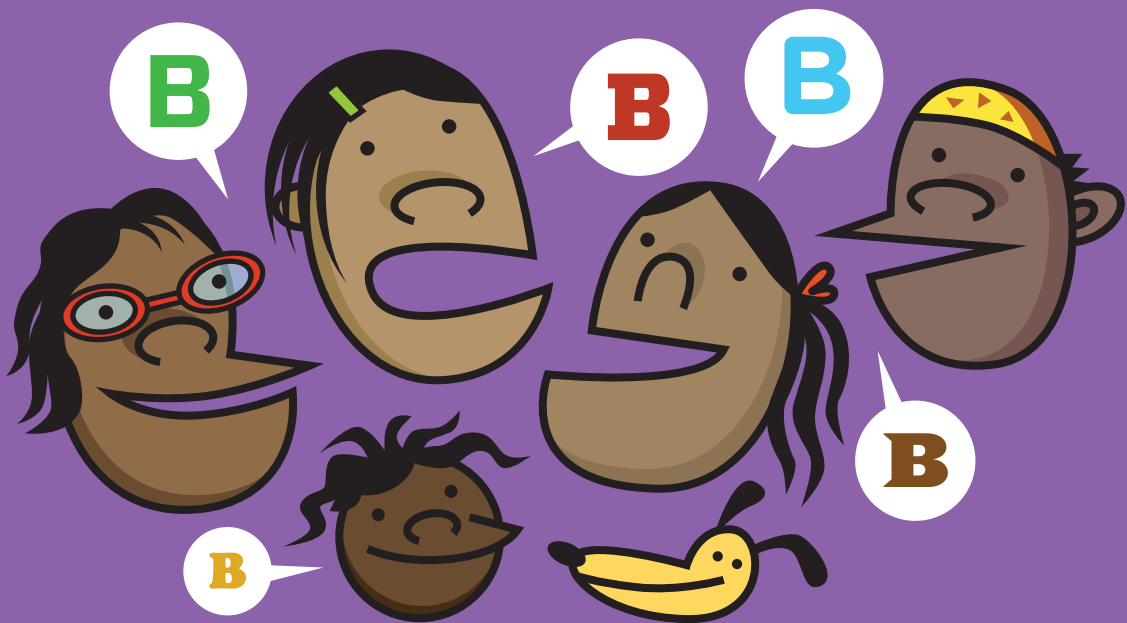
Follow-up care is recommended after treatment for early breast cancer. Follow-up care allows a doctor to check whether breast cancer has come back, look for side effects of treatment and give practical and emotional support.

Follow-up is described in more detail in *Section 6: Breast cancer follow-up care*.

3.

Awareness and early detection

3.



In this chapter you will learn about the risk factors for breast cancer and how breast cancer can be detected. You will also learn about things that you can do as an Aboriginal and Torres Strait Islander Health Worker to help encourage breast awareness in your community.

3.1 Breast cancer awareness

It is important that all Aboriginal and Torres Strait Islander women are breast aware and know what they can do to help find breast cancer early. Finding breast cancer early means there are more treatment options and the chances of survival are greatest.

Aboriginal and Torres Strait Islander Health Workers are in an ideal position to promote positive health behaviours in Aboriginal and Torres Strait Islander women.

It is important for Aboriginal and Torres Strait Islander Health Workers to promote attendance at population-based mammographic breast screening. This is the best early detection method available for reducing deaths from breast cancer.

However, more than half of breast cancers are diagnosed after a woman or her doctor notices a change in the breast. This shows how important it is that women are aware of the normal look and feel of their breasts and are confident in reporting unusual breast changes.

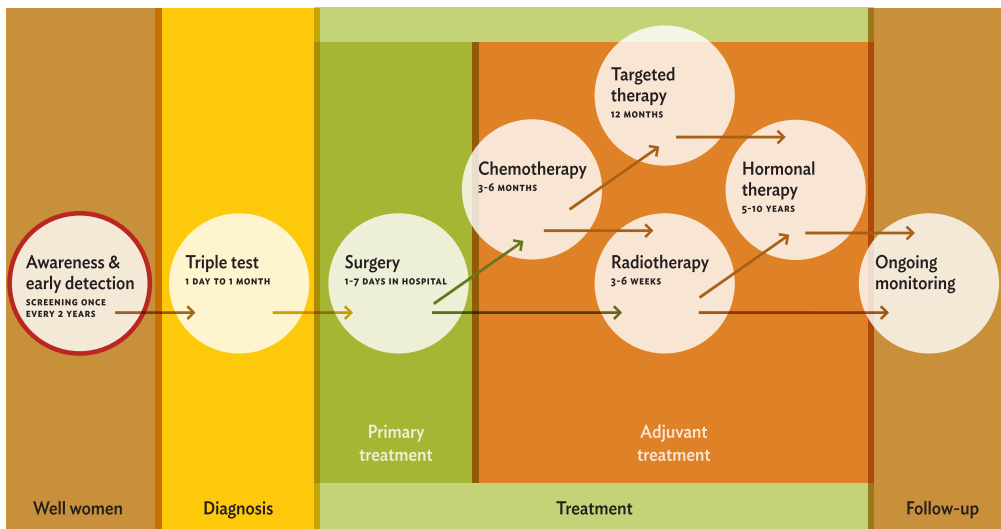


FIG 11: Early breast cancer journey

NOTE: These are approximate durations only and may change over time and may differ for each individual.

3.2 Breast cancer risk factors

What causes breast cancer?

It is not possible to say what causes breast cancer in an individual. However, we do know some features that are more common in women who develop breast cancer. These features are called 'risk factors'.

Having one or more risk factors for breast cancer does not mean that a woman will definitely develop breast cancer. In fact, many women with breast cancer have no obvious risk factors.

MYTH: You can get breast cancer from being near someone with cancer.

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

There are different types of risk factors for breast cancer. Some risk factors have a stronger link to developing breast cancer than others. Some factors may even decrease the risk of developing breast cancer.

The risk factors listed below are grouped by how strongly they increase the risk of breast cancer.

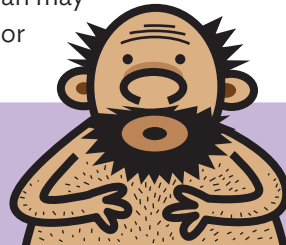
Main risk factors for breast cancer

Factors linked to a moderate to strong increase in the risk of breast cancer

- **Being a woman:** Being a woman is the strongest risk factor for breast cancer. It is important to remember that not all women get breast cancer, and not all men avoid breast cancer. Being a woman may simply mean exposure to different environments or events that can increase the risk of breast cancer.

FAST FACTS

Women are 100 times more likely to develop breast cancer than men.^[37]



- **Age:** Getting older is one of the strongest risk factors for breast cancer. Although breast cancer can occur at any age, it is more common in older women. Most breast cancers are diagnosed after menopause. It is believed that as we get older, damage to the DNA in our body builds up. This damage may increase the risk of developing breast cancer.

FAST FACTS

For a woman in her 30s, the risk of breast cancer is about 1 in 250, whereas for a woman in her 70s, it is about 1 in 30.^[37]

- **Living in a developed westernised country:** The number of women who develop breast cancer is higher in wealthier, westernised countries, such as Australia. The risk of developing breast cancer is also higher among the wealthier women who live in these countries. This suggests that certain lifestyle factors related to a westernised, wealthy lifestyle are linked to an increased risk of breast cancer.
- **Family history:** 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.

FAST FACTS

Women with a mother, sister or daughter (a first-degree relative) with breast cancer are about twice as likely to develop breast cancer as those women without an affected first-degree relative. A woman with three or more first-degree relatives with breast cancer is over three times more likely to develop the disease than women with no affected first-degree relative.

- **Breast conditions:** Women diagnosed with invasive breast cancer in one breast are two to six times more likely to develop cancer in the other breast. There are a number of other breast conditions that are also linked with an increased risk of breast cancer. These include lobular carcinoma in situ (LCIS), ductal carcinoma in situ (DCIS) and atypical ductal hyperplasia.
- **Breast tissue density:** Another strong risk factor for breast cancer is how dense a woman's breast tissue is. Women who have very dense breast tissue are four to six times more likely to develop breast cancer than women who have little or no dense breast tissue.
- **Hormones:** Hormones are chemicals that carry messages through our body and cause certain processes to happen. Factors such as a woman's reproductive and menstrual history, whether she has reached menopause and whether she uses exogenous hormones can affect her risk of breast cancer. This suggests that hormones play a role in breast cancer risk. Women who have high levels of circulating oestrogens (female hormones) after menopause are at increased risk of breast cancer.

FAST FACTS

Women with the highest levels of circulating oestrogens (women with levels in the top 20%) have a two-fold increased risk of breast cancer compared with women who have low levels of circulating oestrogens (women with levels in the bottom 20%).^[37]

FAST FACTS

Hormones produced by the body are called endogenous hormones. Hormones taken as a supplement or medicine are called exogenous hormones.



Other risk factors associated with breast cancer include:

- reaching menopause at an older age (over 55 years)
- use of combined hormone replacement therapy (used to help reduce symptoms of menopause)
- use of oral contraceptive pill (“the pill”)
- starting menstruation (periods) at a young age (younger than 12 years).

Personal and lifestyle factors

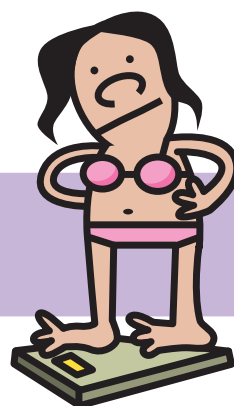
Personal and lifestyle factors are personal features and behaviours that may increase a person’s risk of developing a disease. Examples of personal factors include body shape and size. Examples of lifestyle factors include diet or physical activity levels. A number of personal and lifestyle factors are associated with risk of breast cancer; some of these factors can be changed.

Personal and lifestyle factors associated with a modestly increased risk of breast cancer include:

- being taller (greater than 175 cm)
- being overweight or obese after menopause (body mass index greater than or equal to 25 kg/m²)
- drinking three or more standard alcoholic drinks per day
- a previous personal history of some types of cancer other than breast cancer, including melanoma, colorectal, ovarian, endometrial and thyroid cancer
- being exposed to high doses of ionising irradiation, especially before age 20 (a person may be exposed to ionising radiation in their environment, or as a result of having X-rays; high-dose exposure is very rare in everyday life).

FAST FACTS

A person’s body mass index (BMI) is their weight in kilograms divided by their height in cm².



Factors that have NOT been shown to impact on breast cancer risk

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.

These factors include:

- having an abortion
- breathing in second-hand smoke (research results are not consistent)
- pollution in the environment
- wearing a bra or different types of bra
- having silicone breast implants
- use of underarm deodorant or antiperspirant, *and*
- stress.

Factors associated with a DECREASED risk of breast cancer

The good news for Aboriginal and Torres Strait Islander women is that they are, on average, more likely than other Australian women to display the factors associated with a decreased risk of breast cancer. ^[9] This may help protect Aboriginal and Torres Strait Islander women against breast cancer. ^[10]

Other factors associated with a decreased risk of breast cancer include

- giving birth to at least one child
- having your first child early (younger than 25 years)
- breastfeeding
- having more than one child.



Personal and lifestyle factors that decrease breast cancer risk

Regular physical activity can decrease the risk of developing breast cancer. Going for a brisk walk a few times a week can decrease a person's risk compared with doing no exercise at all.

Messages for Aboriginal and Torres Strait Islander women about reducing risk of breast cancer

It is important to promote a healthy lifestyle to help Aboriginal and Torres Strait Islander women reduce their risk of developing breast cancer. Some examples are listed below.

- **Limiting the number of alcoholic drinks to two or less per day:** Drinking alcohol is linked with an increased breast cancer risk. Alcohol should be limited to no more than two standard drinks a day.
- **Maintaining a healthy body weight:** Obesity increases the risk of breast cancer in post-menopausal women. Women can maintain a healthy body weight by eating healthy foods, including fruit and vegetables.
- **Being physically active:** Exercising for 4 or more hours a week can lower breast cancer risk. Exercise can include brisk walking outside, even housework. All exercise helps.
- **Quitting smoking:** Smoking has been linked to most cancers in the body. Smoking cessation (quitting) will not only reduce the risk of developing cancer but will also improve overall health.



3.3 Promotion of awareness and early detection

There are two things that Aboriginal and Torres Strait Islander women can do to increase the likelihood of finding breast cancer early:

1. have a screening mammogram every 2 years – particularly for women aged 50-69 years of age; *and*
2. become familiar with your breasts and know the breast changes to look out for.

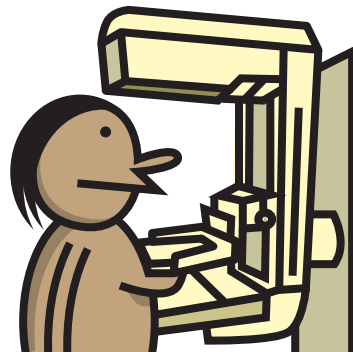
Mammographic screening

A mammogram is an X-ray picture that allows doctors to see inside the breast. A mammogram will only show doctors what the inside of a breast looks like at the time it is taken. For this reason, it is very important for all Aboriginal and Torres Strait Islander women to have a regular screening mammogram so that any unusual changes to the breast can be found at an early stage.

MYTH: You can get cancer from mammograms.

FACT: Mammograms find cancer that is already there. They do NOT cause cancer.

It is recommended that women aged 50–69 years have a screening mammogram every 2 years as this is the age group in which the benefit of mammography screening has been shown to be the greatest.



Mammograms become more effective after a women turns 50. This is because, generally, breasts become less dense as women get older, particularly after menopause, making it easier to see abnormal areas on the X-ray. Mammograms are not as effective for women in the 40–49 year age group as they are for older women because breasts are denser at this age, making any early signs of breast cancer more difficult to see.

About BreastScreen Australia

BreastScreen Australia is a population-based free screening program for breast cancer. BreastScreen actively recruits and screens women aged 50–69 years for free 2-yearly screening mammograms. BreastScreen also provides free breast screening for women aged 40–50 years, although screening is less effective in women younger than 50 years of age.

BreastScreen has branches in all states and territories with over 500 locations nationwide. Services in each state and territory vary in size. Some cover vast geographical areas (relocatable and mobile screening units); others only cover part of a city (fixed screening units).

An appointment is required to attend BreastScreen for a screening mammogram.

Breast screening for Aboriginal and Torres Strait Islander women

Aboriginal and Torres Strait Islander women are less likely to participate in breast screening than non-Indigenous women. ^[1]

Lower participation in mammographic screening may mean that Aboriginal and Torres Strait Islander women are diagnosed with breast cancer when the disease is more advanced. This may contribute to the poorer survival rates in this population.

FAST FACTS

Only 36% of Aboriginal and Torres Strait Islander women between the ages of 50–69 years have had a screening mammogram. In comparison more than half the non-Indigenous population of women in this same age range have had a screening mammogram. ^[1]

The breast screening process

A breast screening appointment usually takes about 20 minutes. Two X-rays are taken of each breast. To get a clear picture, the breast must be flattened as much as possible by gentle squeezing from above and below the breast. Flattening of the breast can be uncomfortable, but the X-ray takes only about 10 to 15 seconds. A very low dose of radiation is used in the screening mammogram.

The first mammogram is performed in a screening unit (fixed or mobile). If anything unusual is found in a women's breast, she is called back to an assessment centre, where the abnormality is assessed.

Breast changes

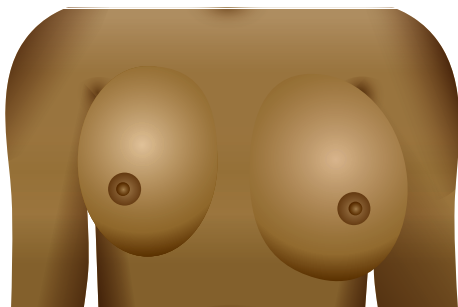
It is important for all women to get to know the normal look and feel of their breasts and to look out for any new or unusual changes. All women should do this regularly: daughters, mothers, aunties and even granddaughters.

Women do not need to be experts or use a special technique to check their breasts for signs of breast cancer. They can get to know the normal look and feel of their breasts as part of everyday activities like showering, dressing, putting on body lotion or simply looking in the mirror. This is something women can do at any age.

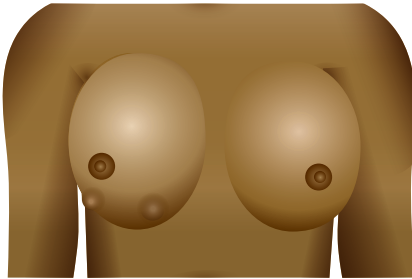
Knowing what is normal for each individual woman will help in finding any new or unusual breast changes. **The majority of breast changes aren't due to cancer, but it's important for women who find a breast change that is unusual to see a doctor to be sure.**

Breast changes women should look out for

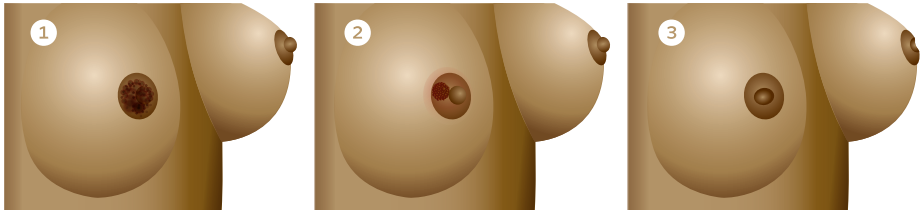
1. A **change** in the **size** or **shape** of the breast



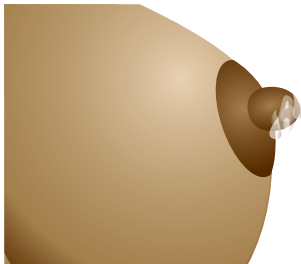
2. A **new lump** or **lumpiness**, especially if it's only in **one breast** (lumps may not be visible)



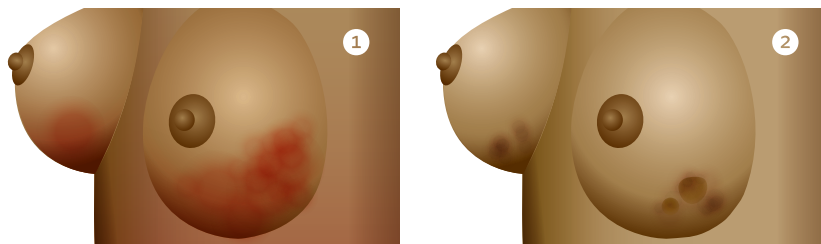
3. A **change** to the **nipple**, such as ① **crusting**, ② **ulcer, redness** or ③ **inversion** (where nipple turns in)



4. A **nipple discharge** that occurs without squeezing



5. A **change** in the **skin** of the breast such as ① **redness** or ② **dimpling**



6. Any **unusual pain** that doesn't go away

3.4 Promoting awareness and early detection in Aboriginal and Torres Strait Islander women

Research tells us that many Aboriginal and Torres Strait Islander people think that cancer is a 'death sentence'. That is, they are scared of getting cancer and believe that if they get it, they will die. ^[11-13]

MYTH: A diagnosis of breast cancer means that you will die.

FACT: Women who find breast cancer early before it has spread and complete treatment will have the best chance of surviving.

Awareness of breast cancer

Most Aboriginal and Torres Strait Islander women know someone who has had cancer, and many of these people have died from the disease. ^[5, 13-14] Because of this fear, Aboriginal and Torres Strait Islander women may not have regular breast screening or do not go to see their doctor if they have any breast symptoms.

Factors that limit early detection of breast cancer

Late presentation

In women who put off seeing their doctor, breast cancer may not be found until it is at an advanced stage. This is called 'late presentation'. Late presentation of breast cancer is not uncommon among Aboriginal and Torres Strait Islander women. It may happen because there are no quality healthcare services available in the area, or because individuals are not used to visiting their doctor. It may also happen because women do not trust their local healthcare services. ^[5, 13]

Fear

Studies have shown that although some Aboriginal and Torres Strait Islander women would go directly to a doctor if they found a breast lump, many would not in the hope that the lump would go away.

Embarrassment

Many Aboriginal and Torres Strait Islander women are embarrassed to feel and look at their breasts for signs of breast cancer. They are not confident that they can do it properly and spot symptoms. It is known that these women do not look at and feel their breasts regularly enough to know if there has been a change.^[5]

For some Aboriginal and Torres Strait Islander women, it is not always possible to find privacy to check their breasts because their houses are busy and full of people.^[5]

Screening

Generally Aboriginal and Torres Strait Islander women view breast screening as something that is only for people who have a known family history of breast cancer.^[5] Research has also found that for some Aboriginal and Torres Strait Islander women the fixed appointment system is a barrier to attending screening appointments.^[5] Some women are also embarrassed to attend breast screening.^[5, 13]

Practical ideas for promoting breast awareness and early detection in your community

Well Women's Workshops

Cancer Australia has developed a Community Education Resource for health workers to promote breast health and encourage breast awareness and early detection of breast cancer in Aboriginal and Torres Strait Islander women. This resource supports health workers to undertake a **Well Women's Workshop** that involves storytelling, and a face-to-face approach to the delivery of breast awareness and early detection messages.

After attending a **Well Women's Workshop**, Aboriginal and Torres Strait Islander women will be able to:

- understand the importance of early detection in surviving breast cancer
- understand the role of mammographic screening and the importance of attending BreastScreen every 2 years – particularly for women in the target age range 50–69 years of age

- identify breast symptoms and how to be breast aware
- identify who they can talk to if they find a change in their breast.

Resources can be accessed via the Cancer Australia website at:
www.canceraustralia.gov.au/publications-and-resources



Organise a group of women to attend screening together

In some communities, it has been found to be helpful to organise a breast screening event for Aboriginal and Torres Strait Islander women. Having a group of women get together and go as a group to attend mammography screening may decrease the embarrassment in attending and the fear in comparison to attending alone.

Encourage Aboriginal and Torres Strait Islander women who have had their breasts checked to tell their story

Storytelling is a traditional way of passing on information in Aboriginal culture. Some people are very experienced and highly regarded as storytellers. Storytelling can be a very powerful tool for sharing health information and can be good foundation on which to build knowledge and discussion.

Remember to keep confidentiality in your mind at all times. Always check that you have permission to share personal stories or let a person know beforehand if you plan to ask them to share their story with a wider audience.

Case study ^[38]

In the Northern Territory, one community established a culturally appropriate community based women's health service to improve women's health and to improve cervical cancer screening. This resulted in an increase in the eligible women who were screened from 51% to 78%.

To do this they:

- used every opportunity to talk to the women in the camps, homes and women's centre
- established a team comprising the Registered Nurse and the Aboriginal Health Worker
- provided training for staff, in cultural awareness for non-Indigenous staff and in women health issues for the Aboriginal and Torres Strait Islander Health Worker
- established a specific 'women's room' in the clinic
- developed specific communication aids, such as a female reproductive model, teaching aids and a poster of Aboriginal and Torres Strait Islander women in the community who had been screened.

Develop health promotion resources

The most effective health promotion resources are those developed locally. Consider developing local resources that encourage women to be breast aware and attend their local breast screening service.

When developing health promotion resources you should:

- involve interested local people and health professionals
- test and evaluate materials with a small group of locals first. ^[15]

Often the best way to approach the development of a resource is to organise a workshop. The health team will have a chance to look at issues together with interested local people. ^[15-16]

Promote key messages in all activities and resources related to breast cancer

Key Messages to the community

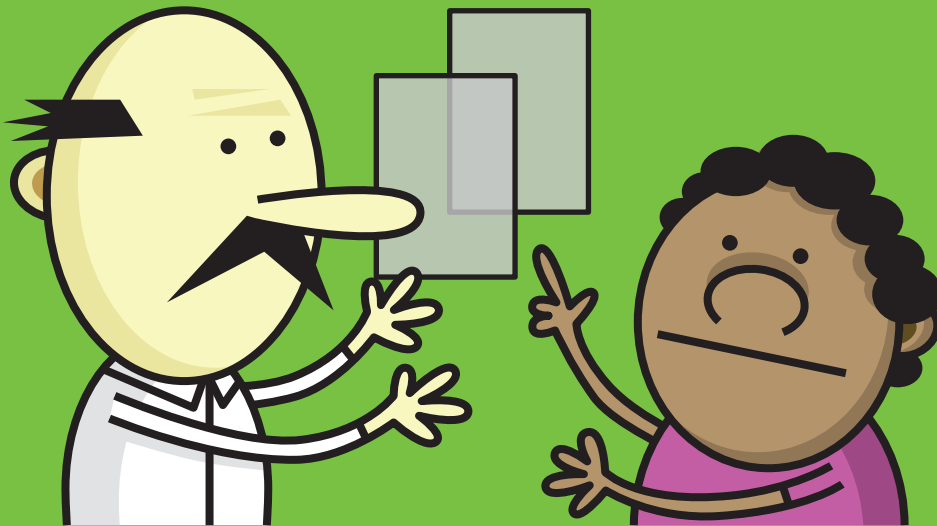
1. Find it early and survive! Early detection of breast cancer occurs through:
 - having a mammogram every 2 years – particularly for women aged 50-69 years of age
 - knowing the look and feel of your breasts to look for any changes.
2. It is not possible to say what causes breast cancer in an individual woman but living a healthy lifestyle can reduce your chance of developing breast cancer.



4.

Investigation and diagnosis of breast cancer

4.



This chapter describes the steps that Aboriginal and Torres Strait Islander women will need to go through if they have a breast cancer symptom.

It is important that Aboriginal and Torres Strait Islander women are supported through their investigation and diagnosis of breast cancer to make sure they receive the appropriate information so they can make informed decisions about the rest of their treatment.

Aboriginal and Torres Strait Islander Health Workers can play a key role in supporting women through the process of symptom investigation for breast cancer. Usually this process is guided by one doctor who takes responsibility for bringing together and interpreting the results of the clinical examination, medical imaging and pathology. This could be the GP at the local health service or a surgeon.

It is important, as an Aboriginal and Torres Strait Islander Health Worker, that you are aware of the triple test and the referral pathway. Ensuring a woman understands the tests that she will be having, and why she will be having them, can help to reduce her anxiety about the process.

Communicating clearly and developing trust with patients and their families and carers is important in supporting patients. This involves using basic communications skills to get the message across and communicating between healthcare professionals. *See Section 7.3 Communication skills.*

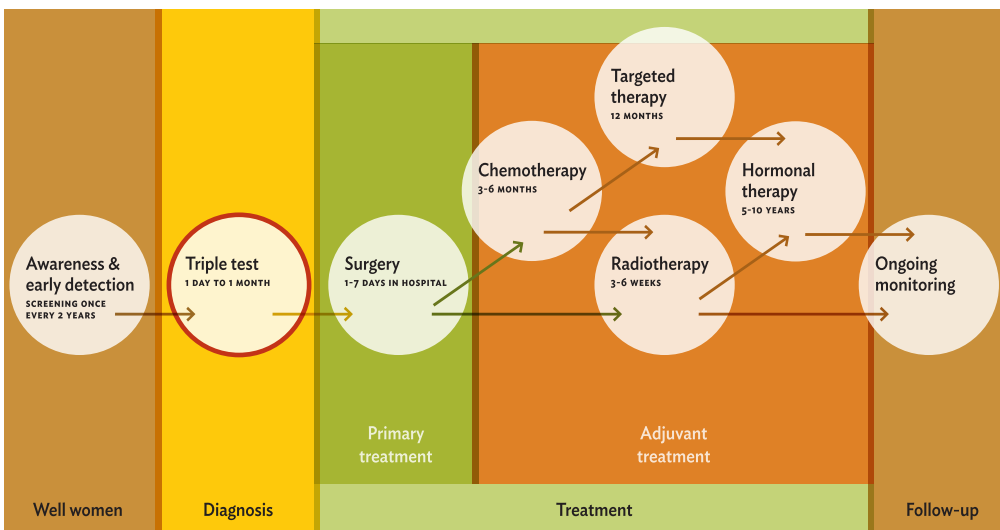


FIG 12: Early breast cancer journey

NOTE: These are approximate durations only and may change over time and may differ for each individual.

4.1 How is breast cancer diagnosed?

To investigate a new breast symptom it is necessary to perform the 'triple test'.



The triple test

The three components of the triple test are:

1. history and clinical breast examination
2. medical imaging: mammography and/or ultrasound
3. non-excision biopsy: fine needle aspiration cytology (FNAC) and/or core biopsy.

FAST FACTS

A biopsy involves a sample of breast tissue being removed and examined in a laboratory to confirm a diagnosis of breast cancer.

It is important that the three parts of the triple test are carried out in order so that the results can be interpreted correctly. It is not always necessary to conduct all three parts of the test.

The triple test is **positive** if any of the three parts show an unusual or suspicious result that could be cancer. The triple test is **negative** if all parts give good reassurance that the symptom is not due to breast cancer.

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:

- her symptoms and any pain she is having
- her menstrual history
- whether she has ever been pregnant
- whether she takes any medicine
- her family history of cancer.



These questions are important to help give the doctor a clear understanding about the woman's background. The doctor may also ask about the women's social situation. This helps the doctor to see if she is at risk of increased emotional distress.

The physical examination involves an examination of both breasts and armpits for signs of cancer in the breast and the area around the breast. A thorough examination of the rest of the body is also performed to check for signs that the disease has spread to other parts of the body.

A physical examination is an important step in assessing a woman for signs of breast cancer; however, it is not completely reliable. The other components of the triple test need to be carried out to confirm a breast cancer diagnosis.

Medical imaging

There are different types of imaging tests for breast cancer:

- **Mammogram:** an X-ray of the breast.
In women with a lump or another clinically detected symptom of breast cancer, a mammogram is used to examine the size and spread of the abnormal area. A mammogram is also taken of the other breast 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. An ultrasound is also helpful in

women with dense breast tissue because mammograms may not show the abnormal area clearly in these women.

Ultrasound has been shown to be useful in finding small breast cancers, particularly in younger women with dense breast tissue which is not suitable for mammography.

The imaging tests used depend on the woman's age and breast density. Typically, a mammogram is used first for women aged 50 years or older and an ultrasound is used first for women younger than 35 years. For women aged 35–49, either test may be used first.

Another type of imaging test called magnetic resonance imaging (MRI) may be used for young women, particularly if they have a strong family history of breast cancer.

Non-excision biopsy

A biopsy involves removing a sample of breast tissue for examination by a pathologist to confirm a diagnosis of breast cancer and find out about the type of breast cancer. There are two types of biopsy that may be used to help diagnose 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.

- **Fine needle aspiration biopsy (FNAB):** FNAB involves sampling of cells from the breast tissue. The cells are removed from the breast using a small needle and suction.
- **Core biopsy:** Core biopsy uses a wide bore or cutting needle to remove a sample of breast tissue.



4.2 Test results and what they mean

Cells or tissue removed from a woman’s breast during a biopsy or breast surgery are examined by a pathologist.


The pathology examination has three main aims:

1. To provide a diagnosis of breast cancer.
2. To confirm whether the cancer has been removed completely.
3. To provide extra information useful for treatment, such as tumour markers and oestrogen receptors.

The test results are written in a pathology report. An example of a pathology report for invasive breast cancer (carcinoma) is below in *Figure 13*.

The pathology reporting of breast cancer

Synoptic report - invasive carcinoma



<p>Patient's name: _____</p> <p>Laboratory number: _____</p> <p>Diagnostic summary</p> <p>Specimen type: _____ Location: _____ Tumour type: _____</p> <p>Lesion size</p> <p>Invasive tumour size in (mm): _____ <small>*If greater than invasion tumour size</small></p> <p>Micrological grade</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td>Grade (see 11 high, cover field)</td> <td></td> </tr> <tr> <td>Grade (see 11-12)</td> <td></td> </tr> <tr> <td>Grade (see 11-12)</td> <td></td> </tr> <tr> <td>Grade (see 11-12)</td> <td></td> </tr> </table> <p>Paritumoural lymphovascular invasion:</p> <p><input type="checkbox"/> absent <input type="checkbox"/> suspicious <input type="checkbox"/> present and extensive</p> <p>Involvement of skin/muscle:</p> <p><input type="checkbox"/> absent <input type="checkbox"/> present <input type="checkbox"/> Pleural specify: _____</p> <p>DCIS in specimen</p> <p>Nuclear grade: <input type="checkbox"/> low <input type="checkbox"/> intermediate <input type="checkbox"/> high</p> <p>Heros: _____ Calcification: _____</p> <p>Reaction margins</p> <p>Invasive carcinoma at reaction margin:</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Dissect from nearest specified margin <input type="checkbox"/> Orientation of involved margin <input type="checkbox"/> Extent of involvement (mm)</p> <p>DCIS at reaction margin:</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Dissect from nearest specified margin <input type="checkbox"/> Orientation of involved margin <input type="checkbox"/> Extent of involvement (mm)</p> <p>LCIS at reaction margin:</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes</p> <p>Atypical lobular hyperplasia/lobular carcinoma in situ:</p> <p><input type="checkbox"/> Absent <input type="checkbox"/> Present <input type="checkbox"/> Atypical <input type="checkbox"/> Pleomorphic</p>	Grade (see 11 high, cover field)		Grade (see 11-12)		Grade (see 11-12)		Grade (see 11-12)		<p>Paget's disease of nipple:</p> <p><input type="checkbox"/> absent <input type="checkbox"/> present</p> <p>Non-neoplastic breast changes:</p> <p>_____</p> <p>Microcalcification:</p> <p><input type="checkbox"/> absent <input type="checkbox"/> present</p> <p><small>Specify associated pathology:</small></p> <p>_____</p> <p>Hormone receptor assay status (if performed)</p> <table border="1" style="width: 100%; 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Based on the recommendations contained within The pathology reporting of breast cancer. A guide for pathologists, surgeons, radiologists and oncologists 2008. To access the guide visit www.nibcc.org.au or phone 1800 624 973 © National Breast and Ovarian Cancer Centre 2008.

FIG 13: Pathology Report

Pathology report

The information included in a pathology report is listed below.

Diagnosis

In the example report for early breast cancer the diagnosis is 'invasive breast cancer'.

Size and location

The report shows the size of the breast cancer and where it is in the breast. This will affect what treatments are recommended for the woman, including the type of surgery.

Hormone receptors

The report shows whether the breast cancer is positive or negative for hormone receptors. This will affect whether hormonal therapies are recommended for the woman.

FAST FACTS

There are two types of hormone receptors – oestrogen receptors and progesterone receptors. If there are hormone receptors on the breast cancer it is said to be oestrogen receptor positive (ER+) or progesterone receptor positive (PR+).



HER2 status

The report shows whether there are HER2 receptors on the breast cancer cells. This can affect the type of treatment the woman will receive, specifically whether they will receive trastuzumab (Herceptin®).

Lymph nodes

The report shows whether there are cancer cells in the lymph nodes in the armpit or near the breasts. This information is usually only available after breast surgery and may determine if the woman will need to have chemotherapy.

Surgical margin

When the breast cancer is removed by the surgeon a margin of healthy looking tissue surrounding the cancer is also removed. This is called the surgical margin.

If there are no cancer cells in the surgical margin it is likely that all the cancer has been removed. In this case the surgical margin is said to be 'clear'. This information will only be available after breast surgery.

Grade of breast cancer

The grade of the cancer shows how fast the cancer cells are growing. The cancer grade is numbered from 1 to 3. A low grade (Grade 1) means that the cancer is growing slowly. A high grade (Grade 3) means that the cancer is growing more quickly. If the cancer is growing more quickly, it is more likely to have spread outside the breast and armpit area. When the grade of the cancer is higher, it is more likely that systemic treatments (treatments that affect the whole body) will be recommended.

Stages of breast cancer

The stage of breast cancer is a way of summarising the information from the pathology report. Stages of breast cancer are numbered from I to IV (Table 1).

- Early breast cancer may be called Stage I, Stage IIA or Stage IIB (2–5 cm).
- Secondary (advanced) breast cancer may be called Stage IIB (advanced), Stage IIIA, Stage IIIB, Stage IIIC or Stage IV.



TABLE 1: Stages of breast cancer

	Stage	Size of the cancer	Have cancer cells been found in the	
			Lymph nodes? (node negative/positive)	Other parts of the body?
Early Breast Cancer	Stage I	< 2 cm	No	No
	Stage IIA	<2 cm	Yes	No
		2-5 cm	No	No
		No cancer found in the breast	Yes	No
	Stage IIB	2-5 cm	Yes	No
Secondary Breast Cancer	Stage IIB	>5 cm	No	No
	Stage IIIA	<2 cm	Yes	No
		2-5cm	Yes	No
		>5 cm	Yes	No
		No cancer found in the breast	Yes	No
	Stage IIIB	Any size but the cancer has spread to nearby muscles and skin	Yes or No	No
	Stage IIIC	Any size	Yes	No
	Stage IV	Any size	Yes or No	Yes



What makes breast 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.

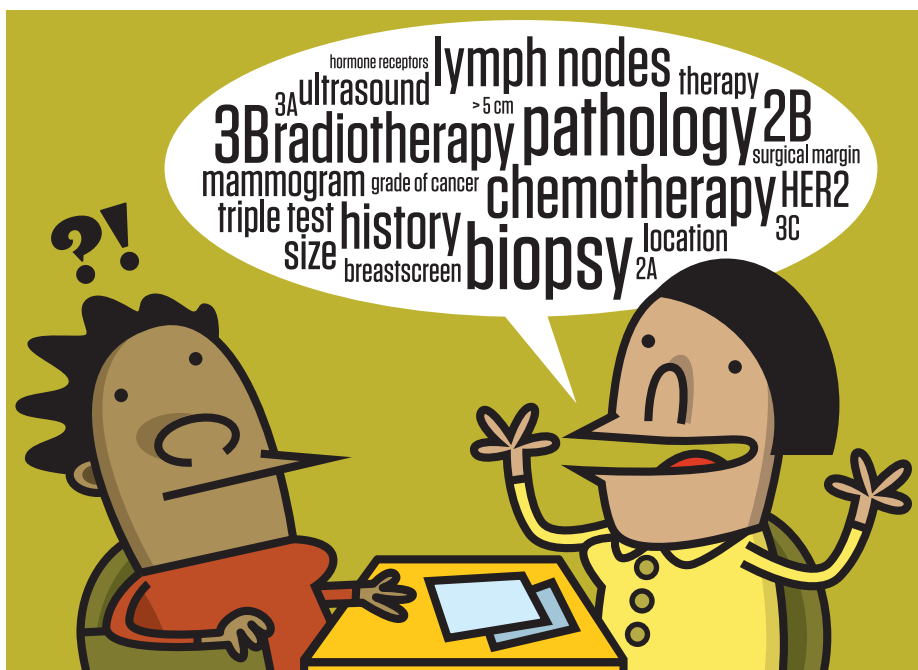
The doctors will use the information in the pathology report to work out how likely it is that cancer will come back or spread to other parts of the body. The main features known to affect the chance of breast cancer coming back or spreading are listed in Table 2 (*see below*). These are general statements based on experience with women who have had breast cancer.

TABLE 2: Features that can affect the chance of breast cancer coming back or spreading

Information in the pathology report	The breast cancer is <i>less likely</i> to come back or spread if	The breast cancer is <i>more likely</i> to come back or spread if
Size	Cancer is smaller (less than 2 cm)	Cancer is larger (more than 2 cm)
Lymph nodes in the armpit	No cancer cells in the lymph nodes	Cancer cells in the lymph nodes
Hormone receptors	Cancer cells have hormone receptors and you have hormonal therapy	Cancer cells do not have hormone receptors
HER2	Cancer cells are HER2-negative	Cancer cells are HER2-positive
Grade	Grade of cancer is low (Grade 1)	Grade of cancer is high (Grade 3)
Surgical margin	Surgical margin is clear	Surgical margin is not clear

4.3 Investigation and diagnosis of breast cancer in Aboriginal and Torres Strait Islander women

Being investigated 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. [5]



For Aboriginal and Torres Strait Islander women this can be made harder by the complicated language used by doctors during diagnosis. Some women find this language intimidating and unclear.

Research has shown that some Aboriginal and Torres Strait Islander women knew little about breast cancer treatment at all until their diagnosis, and as a result of shock and difficulties in understanding their doctors, they were often unsure about their treatment options and the benefits of these treatments.

Practical ideas for supporting women through investigation of a breast cancer symptom

Develop relationships with related health services

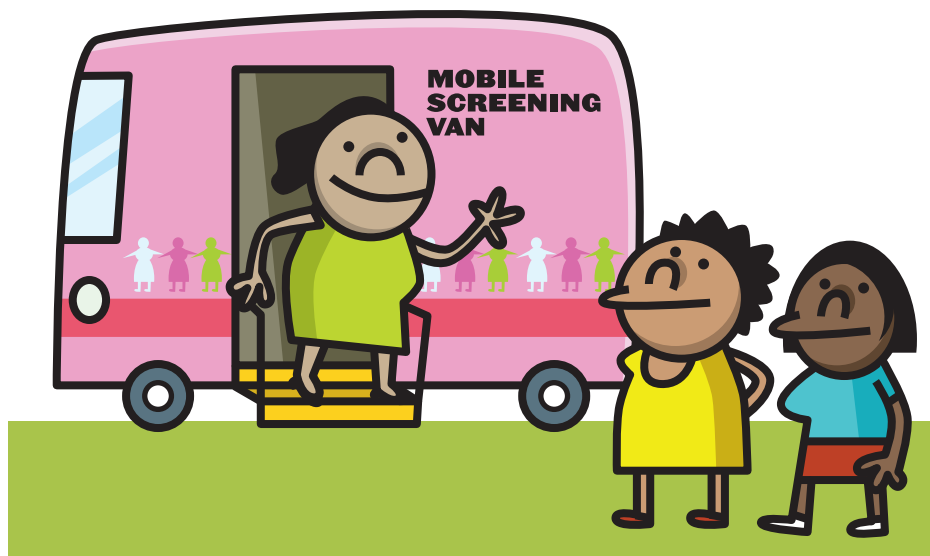
To effectively support an Aboriginal and Torres Strait Islander woman through the steps of being investigated for a new breast symptom it is important to develop relationships with the services that will be involved.

These services are likely to be:

- **BreastScreen:** this may be a permanent service in a town or could be a visiting service (e.g. BreastScreen van)
- **Aboriginal Community Controlled Health Service:** a woman may come through her local service if she was worried about a breast symptom she was experiencing.

It may help to leave your contact details at the BreastScreen van, or health service.

It may also be helpful to keep a calendar of when the BreastScreen van is in town, or when the local health service is promoting breast cancer awareness (e.g. October – Breast cancer awareness month).



Promote key messages in all activities and resources related to breast cancer

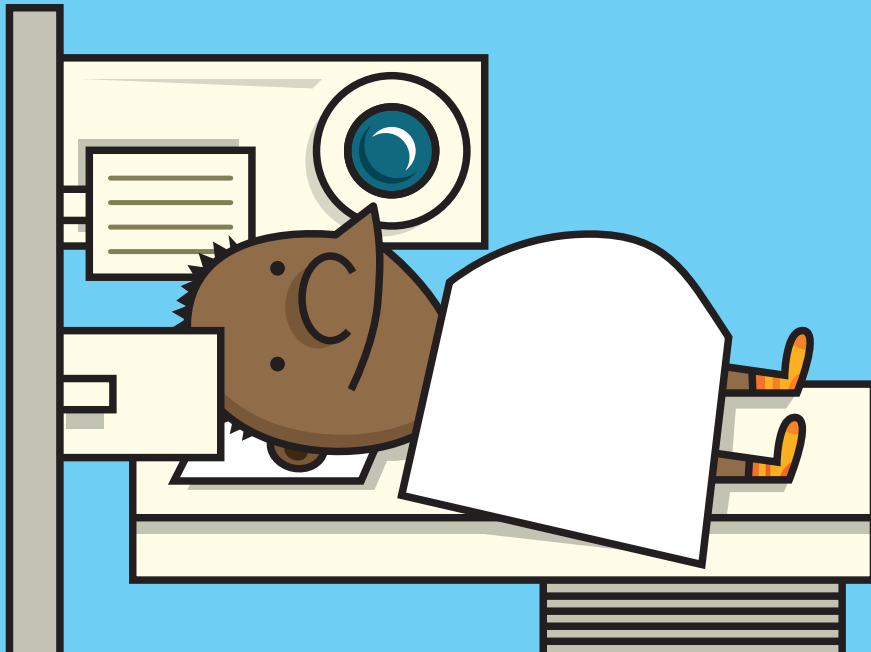
Key Messages to the community

1. A diagnosis of breast cancer is not a death sentence.
2. Women who find breast cancer early, before it has spread, and complete treatment will have the best chance of surviving.



5.

Treatment options for breast cancer



In this chapter you will learn about the treatments required for breast cancer, including the different types of surgery and adjuvant treatments available.

5.1 Treatment options for breast cancer

The primary treatment for breast cancer is surgery. Adjuvant treatments include radiotherapy, chemotherapy, hormonal therapies and targeted therapies. Adjuvant treatment is given in addition to the primary treatment.

Treatment for breast cancer is seen as a stressful time for Aboriginal and Torres Strait Islander women.^[5] While some Aboriginal and Torres Strait Islander women see that treatment is necessary, there is still uncertainty about medical treatments of cancer, especially the effects of surgery to the breast.

Aboriginal and Torres Strait Islander Health Workers are crucial in providing information and support for Aboriginal and Torres Strait Islander women as they undergo treatment. It is important that you understand the main treatment options, what is involved and what the possible side effects might be.

When reading about side effects, be aware that everyone responds differently to breast cancer treatments. Some side effects happen to most people, others happen only occasionally. Some side effects happen straight away, others take longer to develop. Most side effects can be reduced or managed with care.

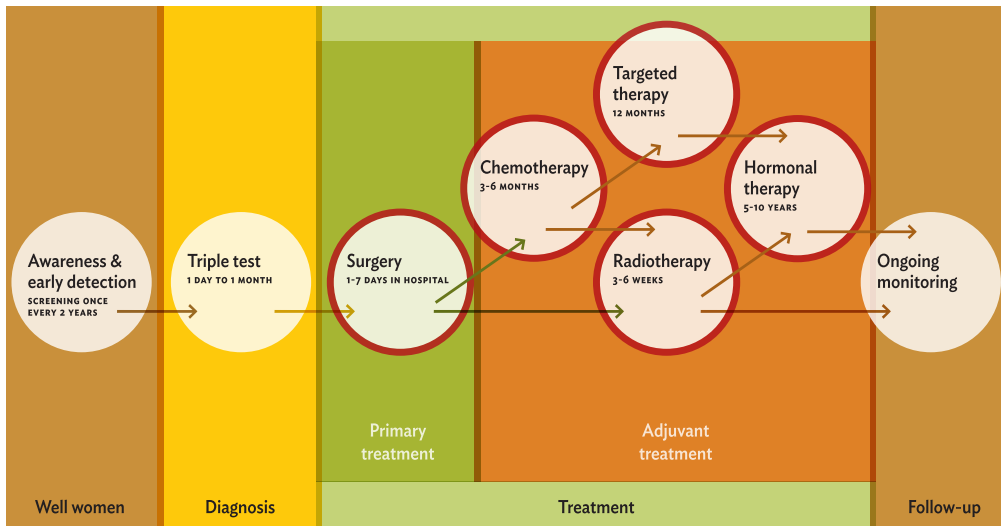


FIG 14: Early breast cancer journey

NOTE: These are approximate durations only and may change over time and may differ for each individual.

5.2 Breast surgery

The aim of surgery for breast cancer is to remove the primary tumour and any local spread of the disease. Complete removal of the tumour and any spread means there is less risk of the cancer coming back.

There are two types of surgery for the treatment of primary breast cancer:

1. breast conserving surgery
2. mastectomy.

MYTH: Breast conserving surgery is not as good as removing the whole breast.

FACT: Breast conserving surgery followed by radiotherapy is as effective as mastectomy for most women.

Breast conserving surgery

Breast conserving surgery involves removing the breast cancer and a small amount of healthy tissue around it (called the surgical margin).

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

FAST FACTS

Breast conserving surgery may also be called a lumpectomy, complete local excision (CLE), partial mastectomy or wide local excision.



What does breast conserving surgery involve?

Breast conserving surgery usually involves:

- removal of the cancer and a small area of healthy tissue around it
- radiotherapy to the breast after surgery (adjuvant treatment).

A biopsy of the lymph nodes in the armpit (sentinel node biopsy) or removal of some of these lymph nodes (axillary dissection) will also be done.

What does breast conserving surgery look like?

After breast conserving surgery, the woman will have a scar on her breast. The scar will become less obvious with time. The breast size and shape is also likely to change. The position of the scar and the shape of the breast after surgery will depend on where the breast cancer is and how much breast tissue is removed. In some cases, the shape and size of the breast may be different to the other breast. If the breast size and shape change a lot, the woman may choose to use an external breast prosthesis or have further surgery to even out the breasts (i.e. breast reconstruction or reducing the size of the other breast).

Side effects of breast conserving surgery

Common side effects of breast conserving surgery

- Pain, discomfort or numbness in the breast and/or armpit while the wounds are healing – this usually settles after a few weeks.
- Bruising or swelling around the wound in the breast (or under the arm if lymph nodes have been removed).
- Stiffness in the arm or shoulder – the woman may need approved exercises after surgery; talk to the surgeon, breast care nurse or physiotherapist for advice.
- If lymph nodes have been removed, there may be tingling in the arm or shoulder – this may improve with time, but feeling in these areas may change permanently.
- Seroma – where fluid may collect in or around the scar in the breast or armpit. This may need to be drained using a fine needle and a syringe; this can be done by the breast care nurse or another health professional in the clinic.
- Mild pain in the arm and/or armpit — this can last a year or more after surgery if lymph nodes have been removed.

Side effects that *sometimes* develop after breast conserving surgery

Lymphoedema – if lymph nodes have been removed from the armpit, there might be swelling in the arm, breast, hand or chest that lasts after the initial side effects of surgery are over. Lymphoedema can develop a few months or years after surgery.

Rare side effects of breast conserving surgery

Infection or bleeding in the scar in the breast or armpit; some women may need further surgery.

Mastectomy

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

What does mastectomy involve?

Mastectomy usually involves

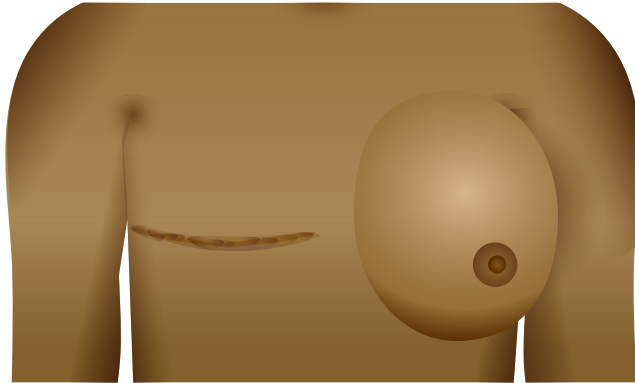
- removal of the entire breast (usually including the nipple);
- removal of one or more lymph nodes from the armpit – this is usually done through the same incision so there are no separate scars under the arm.

If patients are at increased risk of breast cancer coming back in the chest area they may have radiotherapy to the chest wall after mastectomy. This is not common. Some people also have radiotherapy to lymph nodes at the base of the neck and occasionally to the armpit.

What does a mastectomy look like?

After a mastectomy, there will be a scar that runs across or down the chest. The scar will become less obvious with time. The picture adjacent shows what a mastectomy may look like.

Image of mastectomy



Side effects of mastectomy

Common side effects of mastectomy

- Pain, discomfort or numbness in the chest while the wounds are healing – this usually settles in a few weeks.
- Seroma – where fluid may collect in or around the scar in the breast or armpit. This may need to be drained using a fine needle and a syringe; this can be done by the breast care nurse or another health professional in the clinic.
- Stiffness in the arm or shoulder – the woman may need approved exercises after surgery; talk to the surgeon, breast care nurse or physiotherapist for advice.
- Numbness or tingling in the arm or shoulder, if lymph nodes have been removed – this may improve with time, but feeling in these areas may change permanently.
- Mild pain in the arm and/or armpit – this can last a year or more after surgery if lymph nodes have been removed.

Rare side effects of mastectomy

Infection or bleeding in the scar in the chest – some women might need further surgery.

Side effects that *sometimes* develop after mastectomy

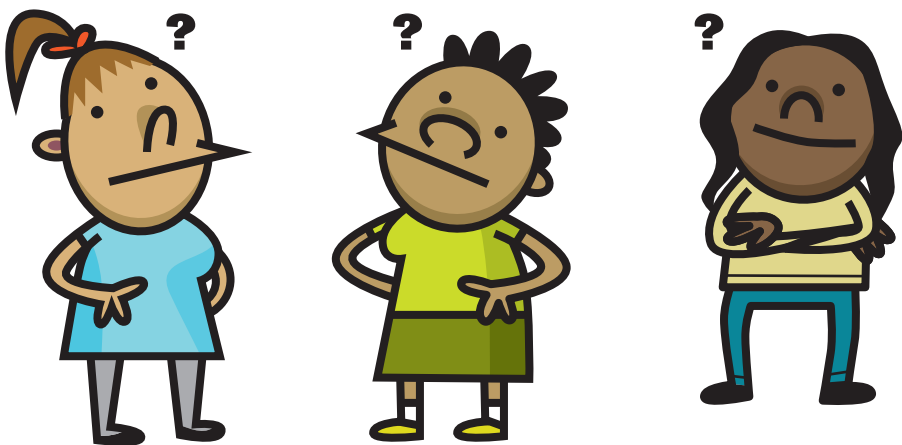
- Swelling or bruising around the wound in the chest or armpit – this usually settles in a few weeks.
- Lymphoedema – if lymph nodes have been removed from the armpit, there might be swelling in the arm, breast, hand or chest that lasts after the initial side effects of surgery are over. Lymphoedema can develop a few months or years after surgery.

Deciding about breast surgery

The choice of surgery is an individual one. Each woman should be 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 use a breast prosthesis or have a breast reconstruction, which may mean less impact on a woman's body image and sexuality.

Breast conserving surgery followed by radiotherapy is as effective as a mastectomy for most women with early breast cancer.



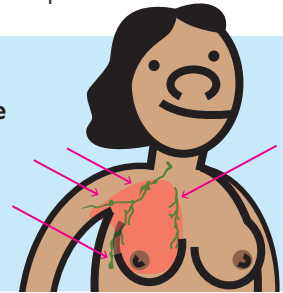
5.3 Axilla (armpit) surgery

Lymph nodes

Lymph nodes are small, rounded glands that can range in size from about 1 mm to 25 mm. There are lymph nodes all around the body, including the armpit, groin, stomach, chest and neck. The number of lymph nodes varies in different people. There are around 15–30 lymph nodes in the armpit.

FAST FACTS

The lymph nodes in the armpit are often the first place that cancer cells spread to outside the breast. About one in three women with breast cancer have cancer cells in the lymph nodes in their armpit when their breast cancer is diagnosed.^[39]

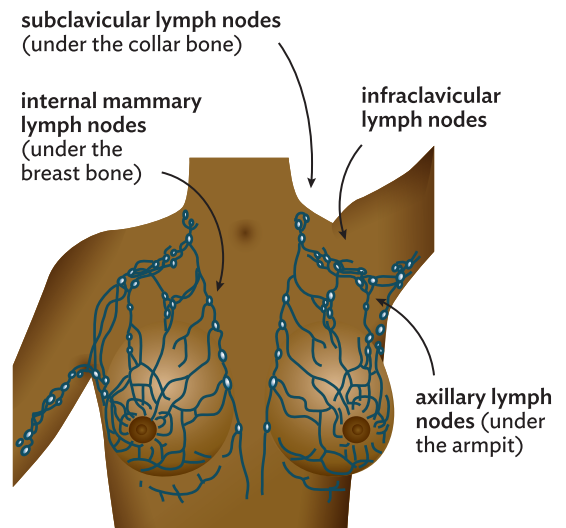


Lymph nodes act like filters. They are connected to small vessels called lymphatic vessels, which are close to the blood vessels. Fluid from the body's tissues usually drains into lymphatic vessels. This fluid is called lymph. Lymphatic vessels carry lymph to the lymph nodes, where substances that could be harmful to the body, such as bacteria or cancer cells, are trapped and removed. This helps to protect the body from infection. The lymph then passes back into the blood. The lymph nodes in the armpit (axilla) drain lymph fluid from nearby areas, including the breast.

Why are lymph nodes removed from the armpit in women with breast cancer?

Lymph nodes are removed from the armpit to:

- find out whether breast cancer has spread to the lymph nodes
- remove any breast cancer that may be in the armpit area
- help plan further treatment.



What happens if there are cancer cells in the lymph nodes?

If cancer cells are found in the lymph nodes removed from the armpit there is a higher chance that cancer has spread into the bloodstream as well. In this case, it may be recommended the woman has systemic treatment. Systemic treatments treat the whole body to destroy cancer cells and stop more cancer cells from developing. Types of systemic treatment include chemotherapy or hormonal therapy.

If a large number of lymph nodes contain cancer cells, radiotherapy to the armpit may be recommended. This will destroy any cancer cells that may have been left in the armpit but cannot be removed by surgery.

Removing lymph nodes from the armpit

At the time of diagnosis, the doctor will check the armpit to see if any of the lymph nodes can be felt. This may be a sign that there are cancer cells in the lymph nodes. However, the best way to find out if there are cancer cells in the armpit is to remove one or more lymph nodes by surgery and examine them under a microscope.

There are two ways of removing the lymph nodes

1. **Axillary dissection or axillary clearance:** removal of some or all of the lymph nodes from the armpit
2. **Sentinel node biopsy (SNB):** removal of the first lymph node (or nodes) in the armpit where cancer cells are likely to spread from the breast; if there are cancer cells in the sentinel node(s), further surgery may be required to remove some or all of the remaining nodes.

Deciding about axillary surgery

The choice to have surgery to the armpit, and which method the surgeon will use, will depend on how likely it is that the woman has cancer cells in her lymph nodes.

SNB has fewer side effects than axillary dissection, including a lower risk of lymphoedema. However, it is not available in every hospital.

Axillary dissection

Axillary dissection involves removing several or all of the lymph nodes from the armpit. If possible, this will be done during breast surgery (breast conserving surgery or mastectomy) and may be done through the same cut as the breast surgery itself. However, it may be done as a separate operation.

The lymph nodes are then examined by a pathologist. The number of lymph nodes that have cancer cells in them will help the doctors decide what other treatments are best.



FAST FACTS

The number of lymph nodes in the armpit varies from person to person. This means that the number of lymph nodes removed and the length of the operation will be different for each woman.

Side effects of axillary dissection

Possible side effects of axillary dissection

- **Seroma:** where fluid may collect in or around the scar in the breast or armpit. This may need to be drained using a fine needle and a syringe; this can be done by the breast care nurse or another health professional in the clinic.
- **Wound infection:** because the armpit is sweaty and bacteria are present on the skin, the wound can sometimes become infected; antibiotics may be given to the woman after surgery.
- **Stiffness in the arm or shoulder:** the woman may need approved exercises after surgery; talk to the surgeon, breast care nurse or physiotherapist for advice.
- **Numbness of the arm, shoulder, armpit and parts of the chest:** can occur because the nerves that supply sensation to the skin may need to be cut in order to remove the lymph nodes. This will usually improve with time but there may be some areas that will always stay numb.

- **Lymphoedema:** if lymph nodes have been removed from the armpit and/or lymphatic vessels have been disrupted by the breast cancer treatment, there might be swelling in the arm, breast, hand or chest that lasts after the initial side effects of surgery are over. Lymphoedema can develop a few months or years after surgery.
- **Cellulitis:** an infection of the skin caused by bacteria.



Sentinel node biopsy

Sentinel node biopsy is a way of checking to see whether there are cancer cells in the lymph nodes in the armpit without removing all of the lymph nodes.

The sentinel node is the first lymph node where breast cancer cells may spread outside the breast. Some women may have one sentinel node, and some may have two or three. Sometimes the sentinel node is in another part of the body — for example, in the chest, between the ribs, under the breast or above or under the collarbone.

FAST FACTS

Studies of sentinel node biopsy have not involved women who are pregnant or breastfeeding. If a woman is pregnant or breastfeeding, sentinel node biopsy will not be an option.



Sentinel node biopsy is usually done during surgery to remove the primary tumour from the breast (breast conserving surgery or mastectomy). Sometimes it may be performed as a separate procedure.

During a sentinel node biopsy, a mix of blue dye and a low-grade radioactive fluid (isotope) is injected into the breast. The mix travels through the lymphatic system from the breast to the lymph nodes in the armpit. This shows the surgeon where the breast cancer cells are most likely to travel first. The surgeon can see the blue sentinel node/s and detect the radioactive substance using a type of Geiger counter called a gamma probe. The surgeon can then remove the sentinel node/s.

Finding blue dye and radioactivity in the lymph node/s does not necessarily mean there are cancer cells in the lymph nodes. The lymph node/s still need to be examined by a pathologist.

What if there is more than one sentinel node?

If more than one sentinel node is found, all the sentinel nodes are removed. If another enlarged lymph node is found in the armpit without dye in it, the surgeon will usually remove this node as well. If the sentinel node is not in the armpit, the surgeon will remove it if this can be done safely.

It is important to be aware that in a small number of women, the sentinel node does not have cancer cells, even though there are cancer cells in other lymph nodes in the armpit. This is called a 'false-negative result'.

FAST FACTS

False-negative results occur in less than 5% of women.^[39]

A false-negative result sometimes occurs because lymphatic vessels running to the lymph nodes that have cancer cells in them are blocked by cancer cells. This means that the dye goes into other normal lymph nodes instead.

To minimise the chance of a false-negative result, the surgeon may remove any enlarged nodes that are found at the time of surgery, even if they do not contain the dye.

What if the sentinel node cannot be found?

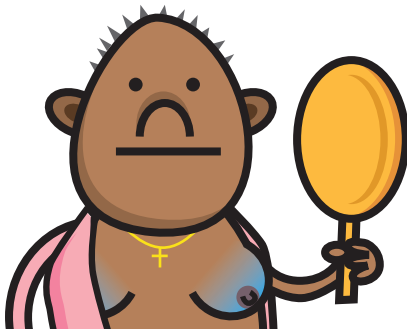
In a small number of cases, it is not possible to find the sentinel node at the time of surgery. In this situation, the woman will be advised to undergo an axillary dissection instead.

Side effects of sentinel node biopsy

Clinical trials have shown that sentinel node biopsy is associated with a lower risk of arm problems than axillary dissection. This means that the risk of numbness, shoulder stiffness and lymphoedema is lower than with axillary dissection.

There is a small risk of allergic reaction to the radioactive fluid or blue dye used to find the sentinel node. Allergic reactions are usually mild and easily treatable. Rarely, women may experience a severe allergic reaction (less than one in 5000 cases).

If blue dye is used to find the sentinel node, urine may turn blue for 24 hours after surgery. Sometimes the skin of the breast becomes blue but this will fade with time. There will be some pain associated with sentinel node biopsy, and injection of the radioactive isotope sometimes stings.



5.4 Breast reconstruction and prosthesis

After treatment for breast cancer, women may feel worried about what they look like, feel less attractive and have low self-esteem following a mastectomy. ^[17]

There are two ways a woman may choose to reshape her breast:

1. **breast reconstruction** is a type of surgery to reform a new breast
2. **breast prosthesis** is an artificial device a woman can wear to give shape to her clothes.

It is the women's choice as to what she would prefer if any.

Breast reconstruction

Breast reconstruction involves rebuilding a breast shape after breast surgery. This may be done using an implant or tissue from other parts of the body. Breast reconstruction does not interfere with the treatment of breast cancer.

Choosing to have a breast reconstruction may be difficult for some women. The procedure can sometimes be done at the same time as the mastectomy (immediate reconstruction) or it may be done later (delayed reconstruction). Opinions vary as to which method is best. Women should be informed about the procedure, so they can balance the advantages and disadvantages of reconstruction after mastectomy.

If a woman decides to have a breast reconstruction, the type of reconstruction recommended will depend on their body shape, general health and preference.

There are several types of reconstructions:

- reconstruction using implants – breast implants are usually made from silicone gel and are inserted into the chest wall, underneath the muscle and skin of the chest
- reconstruction using back muscle transfer (Latissimus dorsi flap) – breast reconstruction using back muscle transfer involves moving a flap of muscle, skin and fat from the back to the chest to form a new chest 'mound'

- breast reconstruction using abdominal muscle transfer (TRAM flap) – breast reconstruction using abdominal muscle transfer usually involves moving a flap of muscle, fat and skin from the stomach to the chest to form a new breast ‘mound’.

There are other types of breast reconstruction that use tissue from other parts of the body:

- skin and fat from the stomach (DIEP flap)
- tissue from the buttocks (buttock transfer or free gluteal flap)
- tissue from the other breast (breast sharing reconstruction).

It is possible to reconstruct a nipple after breast surgery using skin from the breast or tissue from another part of the body.

External breast prosthesis

An external breast prosthesis is an artificial device that is worn inside the 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:** is soft, light prosthesis given to women at the hospital to wear for the first 6 weeks or so after surgery
- **a permanent prosthesis:** is properly weighted and fitted to match the other breast
- **a lightweight breast form:** is 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.

Choosing an external breast prosthesis

Choosing the right prosthesis depends on the type of surgery a woman has undergone, her body shape, the cost and her preference. Surgeons performing a mastectomy should ensure that women are aware of the services available to them.

It is important that women see a specialist prosthesis fitter to fit their prostheses. They can organise the fitting of a temporary or permanent prosthesis (while some patients are suitable for immediate reconstruction, others who have delayed reconstruction will need to use an external prosthesis).

Follow-up should include assessment of post-mastectomy wound oedema, neuralgia, and radiation skin change or swelling that may impair the correct fitting and use of an external prosthesis.

As an Aboriginal and Torres Strait Islander Health Worker it is important to be aware of the consequences of a poor prosthesis fitting, such as postural pain.



External breast prostheses reimbursement program

The External Breast Prostheses Reimbursement Program is an Australian Government initiative 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.

For more information about the program and eligibility criteria visit the Department of Human Services website at www.humanservices.gov.au. Search for 'External breast prostheses reimbursement program'.

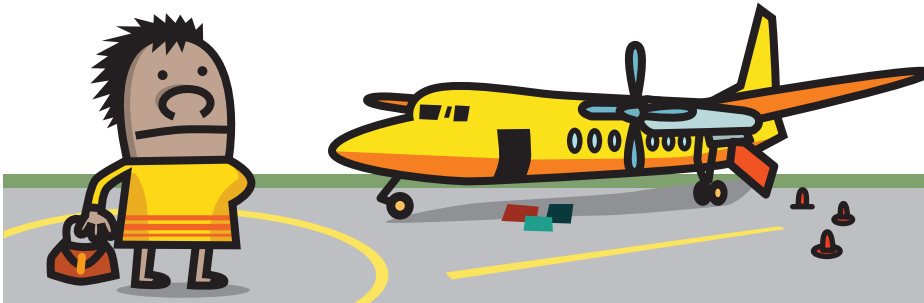
Medicare can also be contacted on 13 20 11 or by visiting a Medicare office.

5.5 Radiotherapy

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

Radiotherapy has been used in the treatment of breast cancer since the late 1890's. Today it is commonly used after breast conserving surgery and less commonly after mastectomy.

Not all hospitals can provide radiotherapy. It is usually available in hospitals or specialised clinics in capital cities or major regional towns. Many Aboriginal and Torres Strait Islander women may need to travel long distances for radiotherapy.



When is radiotherapy recommended?

- Radiotherapy to the breast is recommended after breast conserving surgery. It removes any cancer cells that may be left in the breast and reduces the risk of breast cancer coming back in the breast.
- Radiotherapy to the chest wall is **sometimes** recommended after mastectomy for women at high risk of breast cancer coming back in the chest wall.
- Radiotherapy to the lymph nodes in the armpit and/or lower neck is **occasionally** recommended after either type of breast surgery, for women who do not have surgery to the armpit, or for those at high risk of breast cancer coming back in the lymph nodes.

What does radiotherapy involve?

The timing of radiotherapy depends on when services are available, how quickly the woman recovers from surgery, and what other treatments the woman is having. For a woman having chemotherapy, radiotherapy will usually start when chemotherapy ends. For woman not undergoing chemotherapy, radiotherapy will usually start after surgery.

Before starting radiotherapy

- Before a woman starts radiotherapy, she will meet with a radiation oncologist. The oncologist will plan the treatment and discuss what is involved.
- The women will then be asked to visit the hospital for a **planning visit** with a radiation therapist. This will usually be on a separate occasion to the treatment.
- During the planning visit, a CT scan will be taken of the chest. Marks will be put on the skin to show the radiation therapist where to direct the radiotherapy.
- These marks are small and may be temporary or permanent. If they are temporary, it is important not to wash them off.
- The planning visit usually takes about 45 minutes.

FAST FACTS

Each radiotherapy treatment usually takes only a few minutes. However, time to change and wait for the machine to become available can increase it to an hour each day.

Starting radiotherapy

- Once radiotherapy starts, treatment occurs once a day, 5 days a week for 3–6 weeks.
- An appointment time is given for each visit. Each radiotherapy session will be in a treatment room with a radiotherapy machine.
- The radiation therapist will leave the room while the machine is on but will still be able to see the woman and can speak through an intercom.



Fig 15: Woman receiving radiotherapy

Side effects of radiotherapy

Receiving radiotherapy is painless. However, some women may experience side effects during or after treatment. Some side effects might develop months after treatment is over.

Common side effects during or after radiotherapy

- **The skin of the treated breast can become red and dry like sunburn:** this can begin as early as the second week of treatment and usually improves a few weeks after treatment is over.
- **The skin can become darker:** it may stay that way for a few months after treatment but usually fades with time.
- **Fatigue:** this is usual during treatment and for a few weeks after treatment is over.

Side effects that may be experienced during or after radiotherapy

- **Tenderness, aches or ‘twinges’ in the breast or chest:** this may continue for up to a year or longer but usually settles with time.
- **The breast may become smaller or larger, and may become firmer during or after treatment.**
- **The skin of the breast may blister or peel towards the end of treatment:** this usually settles a few weeks after treatment ends.
- **Blood vessels may become visible in the treated area, making the skin look red or purple:** this is a rare side effect of radiotherapy that can occur many months or years later.
- **Lymphoedema:** if radiotherapy has been applied to the armpit there might be swelling in the arm, breast, hand or chest. Lymphoedema can develop a few months or years after treatment.
- **Loss of hair to the treated area.**
- **Sore throat:** for woman who have undergone radiotherapy to the neck area.

Side effects that are very rare but can be quite serious

Talk to a radiation oncologist if the patient has the following symptoms:

- **pneumonitis:** symptoms include dry cough, mild fever, shortness of breath and tiredness; treatment is available and pneumonitis usually lasts for less than a month
- **pain in the ribs:** this may be due to rib fracture because the bones have become weakened by treatment.



Skin care during radiotherapy

It is important for women undergoing radiotherapy to have a good skin care routine. To reduce skin reactions caused by radiotherapy, women may find it helpful to wash with a mild soap or cleanser and use a light moisturising cream.

Things that can make the skin reactions worse

- Having chemotherapy at the same time as radiotherapy
- Being overweight
- Other health problems, such as diabetes
- Having sun-damaged skin
- Smoking



Other suggestions for skin care during radiotherapy

Based on the experiences of women, and on doctors' and nurses' observations, the following may be helpful during radiotherapy:

- Wear sun protective clothes or use sunscreen over the treated area when in the sun.
- Avoid irritants – protect the skin in the treated area from damage by abrasion (for example, shaving with a wet razor), chemicals (for example, perfumes, deodorants, hair dyes) and temperature extremes during your course of radiotherapy.
- Keep skin folds dry.

5.6 Chemotherapy

Chemotherapy is the name for some drugs used to treat cancer. Chemotherapy is a type of systemic treatment because it treats the whole body. Other systemic treatments include hormonal therapies and targeted therapies such as trastuzumab (Herceptin®).

The aim of chemotherapy is to destroy any cancer cells that may have spread outside the breast and armpit area to other parts of the body. It also aims to destroy cells that are left in the breast and armpit area but cannot be detected. Chemotherapy is not an alternative to hormonal therapy or trastuzumab (Herceptin®). Depending on the type, stage and grade of the breast cancer, a woman may have one or more of these treatments.

Chemotherapy works by killing cells that are rapidly dividing, such as cancer cells. As well as killing cancer cells, chemotherapy also kills normal cells that are rapidly dividing. However, unlike cancer cells, normal cells can repair the damage and can recover.

The main areas of the body that are affected by chemotherapy are the mouth, stomach and bowel (gut), skin, hair and bone marrow. Damage to these normal cells are side effects of chemotherapy.

MYTH: Chemotherapy only makes you sicker.

FACT: Chemotherapy can have great benefits, including a higher likelihood of surviving breast cancer but it can make people feel sicker while they are having treatment.

FAST FACTS

For women with early breast cancer, treatment with chemotherapy can lower the risk of breast cancer coming back or spreading to other parts of the body. Chemotherapy can also increase the chance of surviving breast cancer.

When is chemotherapy recommended?

Chemotherapy can be used in addition to other treatments for breast cancer. Not all women with early breast cancer will have chemotherapy. The decision about whether chemotherapy is used will depend on each woman's situation.

The treating doctors will consider a number of things:

- the risk of breast cancer coming back or spreading to other parts of the body after treatment – if the risk is high, the more likely it is that chemotherapy will be recommended
- whether there are hormone receptors found on the breast cancer cells and the woman is undergoing hormonal therapy – if there are no hormone receptors it is more likely chemotherapy will be recommended
- whether the breast cancer cells are positive for HER2 receptors and the woman is having trastuzumab (Herceptin®) – if trastuzumab is being given then it is usual that this will start while they are still receiving chemotherapy
- general health
- patient preference.

Types of chemotherapy

Several different types of chemotherapy are used to treat early breast cancer. Chemotherapy may involve one drug or a combination of drugs. The most effective chemotherapy treatments involve more than one drug. The drugs recommended will depend on what other treatments are being given, the type, stage and grade of the breast cancer and the patient's age.

FAST FACTS

Combinations of chemotherapy are often referred to using the initials of the drugs being used. For example, FEC chemotherapy is a combination of 5-fluorouracil, epirubicin and cyclophosphamide.

Chemotherapy drugs are grouped based on how they work. The main groups, or classes, of chemotherapy used to treat breast cancer are:

- anthracyclines such as epirubicin (Pharmorubicin®), doxorubicin (Adriamycin®)
- mitotic inhibitors such as taxanes, e.g. paclitaxel (Taxol®), docetaxel (Taxotere®)
- antimetabolites such as 5-fluorouracil (5FU), methotrexate
- alkylating agents such as cyclophosphamide.

Each group of chemotherapy drugs works in a slightly different way. All of them kill cancer cells by stopping them from dividing or damaging them in some way. Because the drugs all work differently, they have different side effects.

What does chemotherapy involve?

The timing of chemotherapy will depend on what other treatments the patient is undergoing. Usually chemotherapy will start after breast surgery. Some women may have chemotherapy before surgery. If the patient is also undergoing radiotherapy or hormonal therapy, these treatments will not start until chemotherapy is completed.

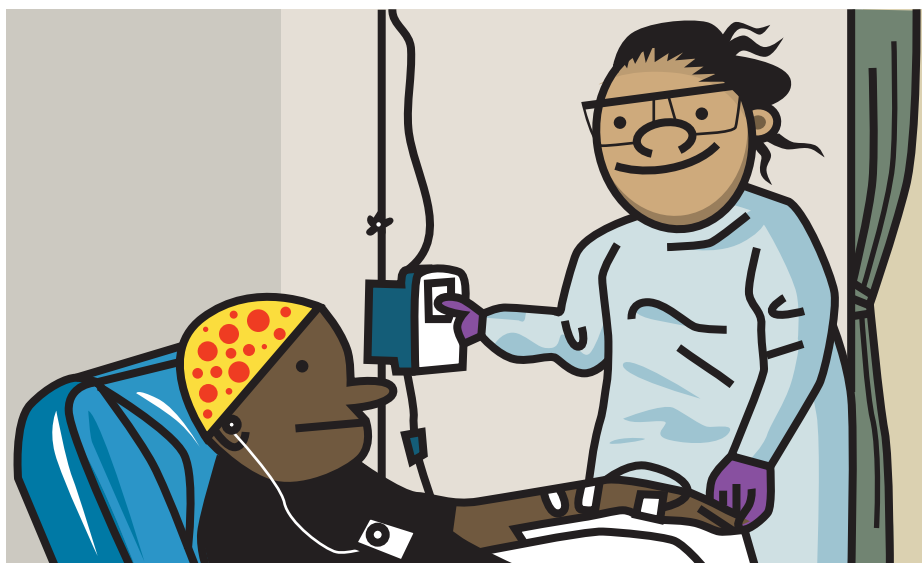


FIG 16: Woman receiving chemotherapy

Before starting chemotherapy

Before treatment starts, the woman will meet with a medical oncologist to discuss the types of chemotherapy recommended and the side effects of these treatments. Not all hospitals have a medical oncologist. If a woman lives in an area where there is no medical oncologist, her treatment may be managed by another doctor such as a GP or breast surgeon. If this happens, the doctor will talk regularly to a medical oncologist in another hospital about the treatment. Alternatively the woman could travel to another hospital to meet a medical oncologist to talk about options and receive treatment.

Starting chemotherapy

The most common way to give chemotherapy is by injection into a vein. This is called intravenous chemotherapy. The drugs are given using a 'drip', usually into the hand or arm. Some chemotherapy drugs are given as a tablet. There could be a combination of tablets and intravenous chemotherapy.



Sometimes it can be difficult to find a suitable vein to give chemotherapy into. If this happens the patient may need to have a long-term access device (infusaport or Portacath®) or a PICC line (peripherally inserted central catheter). This involves putting a thin, soft plastic tube into a vein in the chest or arm that can be left in for weeks or months. The tube can be used to deliver chemotherapy into the vein. Sometimes, the tube connects to a disc (the 'port') under the skin of the chest. It will be possible to see or feel a bump under the skin but there will not be anything visible on the outside of the body. Once chemotherapy starts, treatment will be given in a clinic or hospital as an outpatient. This means the patient will not have to stay overnight. If treatment is given through a drip, the patient may choose to stay for the duration of the week of treatment. Chemotherapy is administered by a chemotherapy nurse. For patients in rural areas it may be possible for a nurse to visit the home to administer the treatment, though this is rare.

Continuing chemotherapy

Chemotherapy is usually given in 'cycles'. Each cycle involves a short period of treatment followed by a rest period in which there is no treatment. This gives the body a chance to recover between treatments. The number of cycles, the length of the treatment period and the length of the rest period will depend on the stage and grade of the breast cancer and the type of chemotherapy. The overall length of the chemotherapy program could be between 3–6 months.

Side effects of chemotherapy

Chemotherapy drugs affect individual women in different ways. Some women have fewer or more side effects than other women receiving the same drug, or the side effects experienced could be more or less intense than for other women.

This section lists some of the side effects of chemotherapy. The list may seem long or overwhelming. It is unlikely that each woman will have many or all of these side effects. It is also important to remind women that having chemotherapy can have great benefits, including a higher likelihood of surviving breast cancer.

It is possible to have chemotherapy with very few side effects. If this happens to a patient, it does not mean that the chemotherapy is not working for them.

Common side effects of chemotherapy

- Nausea and vomiting
- Fatigue (tiredness)
- Hair loss
- Diarrhoea or constipation
- Weight gain or weight loss
- Depression or anxiety
- Menopausal symptoms (temporary or permanent)
- Sexual difficulties
- Mouth ulcers
- Skin or nail changes or reactions

- Muscle aches and pains (more common with taxane drugs)
- Numbness and tingling in the fingers and toes (more common with taxane drugs)
- Swelling in the arms and legs (more common with taxane drugs).

Less common side effects of chemotherapy

- Feeling 'vague' or 'in a fog'.

Side effects that are rare but can be quite serious

Talk to an oncologist or GP if a woman has the following symptoms:

- infection due to a low level of white blood cells
- bleeding or bruising
- kidney or bladder problems
- heart problems (with anthracycline drugs only)
- bone marrow problems
- allergic reactions.

Managing side effects of chemotherapy

Most side effects of chemotherapy can be managed. As an Aboriginal and Torres Strait Islander Health Worker, you will need to support women as they experience side effects of chemotherapy. Suggestions about how to manage some of the more common side effects are listed below.

Nausea and vomiting

Nausea ("feeling sick") and vomiting are common side effects of chemotherapy. Over half of women who have chemotherapy feel sick. 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.

Nausea and vomiting are less common with chemotherapy programs that involve taxanes.

Tips to help a woman manage her nausea or vomiting

- There are certain drugs which may help treat nausea. You should refer a woman on to her doctor to discuss this further.
- Suggest some dietary changes, including eating small, more frequent meals, cutting down on fried or fatty foods and drinking plenty of fluid.
- Relaxation before treatment to reduce anxiety and nervousness.

Fatigue

Feeling tired is a common side effect of chemotherapy and can last 3–6 months after treatment is over. Over half of women with secondary breast cancer feel tired. This is caused by a number of factors related to the cancer itself, including low levels of red blood cells, changes in metabolism, side effects of treatment, depression or sleeping difficulties.

Research shows that exercise can help to reduce fatigue caused by chemotherapy. Although you might not expect it to, exercise during and after treatment can help in feeling less tired. It can also reduce weight gain.

Tips to help a woman manage her tiredness:

- Gentle exercise – research shows that exercise can help to reduce fatigue caused by chemotherapy and other treatments. Gentle exercise like walking is ideal. You may wish to refer a woman on to a physiotherapist or for a suitable exercise program.
- A red blood cell transfusion may be appropriate for women with significant anaemia. A woman should see her doctor to discuss this further.
- Conserve energy – you can suggest ways a woman can save her energy, including taking breaks throughout the day, or organising some help during chemotherapy.
- Support the patient with organising practical help before they start treatment. For example, help with childcare or making meals can give more time to recover.

Fatigue can also be due to anaemia caused by chemotherapy for which the treating doctor may recommend a red blood cell transfusion.

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. When the hair grows back it may be more curly, thicker or finer than it was before treatment. It may grow back a slightly different colour. 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.

Hair loss is more common with chemotherapy programs that include anthracyclines and taxanes.

Tips to help a woman cope with hair loss:

- To help to slow down hair loss, a woman can use gentle hair products and avoid blow drying her hair, having it permed or using curlers, straighteners or tongs.
- Use a soft hair brush.
- A woman may like to think about cutting her hair short so that it is less upsetting if it falls out.



NOTE: *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.

Constipation can be caused by chemotherapy and some anti-emetic drugs, or it can develop because treatment can result in inactivity.

Diarrhoea and constipation

Some women experience diarrhoea or constipation during chemotherapy but this can be controlled by medication. Constipation can be treated by drinking more fluids, eating more fruit and vegetables, and using laxatives. A woman should talk to her doctor before using any laxatives or medication for constipation.

Tips to help a woman prevent or relieve constipation:

- Drinking more fluids.
- Increase the amount of fibre in the diet.
- Treatment with oral laxatives.
- Suppositories or enemas (if required).
- Gentle exercise – exercise can also be helpful in reducing constipation.

Weight gain or weight loss

Some women lose their appetite during chemotherapy and lose weight. It is important to encourage women to try to eat small meals and snacks as often as they can throughout the day. Other women find that they put on weight during treatment. Doing gentle exercise can help prevent weight gain during chemotherapy.

Depression and anxiety

Some women feel depressed, sad or teary before, during and after chemotherapy. Others feel anxious, worried, nervous or upset. Some feelings of sadness, depression and anxiety are normal. Sometimes these feelings can be so severe they impact on things at home, or affect relationships. There are treatments available that can help. *See Section 7. Psychosocial issues and support.*

Menopausal symptoms and permanent menopause

About two-thirds of women who are younger than 50 when their breast cancer is diagnosed will go through menopause because of their treatment.

Other women may experience temporary menopausal symptoms. The closer the age of natural menopause, the more likely it is that menopause will be permanent. If menopause is permanent, the woman will be unable to have children naturally after treatment. *See Section 6.4 Breast cancer, menopause and fertility.*

Sexual difficulties

Many women have some sexual difficulties during chemotherapy treatment. This can be because they are unwell or because of how they feel about their body due to side effects of treatment. Some women experience these feelings for a while after treatment is over.

Mouth ulcers

Mouth ulcers can develop due to chemotherapy and other unknown reasons. Mouth ulcers usually occur about 5–10 days after starting chemotherapy and clear up within 1–2 weeks. It is important to encourage women to take extra care of their mouth during chemotherapy. They can be painful and can affect what and how much a woman can eat.

There are treatments available to help a woman manage the pain of mouth ulcers. A woman should discuss the available treatments with her doctor or pharmacist. Talk to the medical oncologist or chemotherapy nurse about what else the woman can do to help reduce the risk of mouth ulcers.

Tips to help a woman relieve mouth ulcers

- Brushing teeth and gums with a very soft brush after every meal to prevent infection.
- Suggest that using an analgesic gel from the chemist or sodium bicarbonate mouthwash may help to relieve discomfort.
- Taking pain relief such as paracetamol.

Skin and nail problems

Some women have minor skin or nail problems while they are having chemotherapy. These include redness, itching, peeling, dryness or acne. Some women's nails become darker, brittle or cracked. Some chemotherapy drugs can make a woman's skin more sensitive to the sun. It is recommended that women avoid being in the sun for long periods, and use sunscreen when outdoors.

Most skin and nail problems are not serious. However, if a rash or sudden severe itching develops, or a woman has difficulty breathing, she should seek medical treatment immediately. These may be symptoms of a severe allergic reaction that requires treatment as soon as possible.

Tips to help a woman manage skin changes

- Some moisturising creams, vitamins and medicines can help with skin changes. You should suggest a woman speak with her doctor or pharmacist for advice on the best products to use.
- Wear sun protective clothes or use sun screen when in the sun.
- Avoid irritants such as perfumes, deodorants, hair dyes or hair spray.
- Keep skin folds dry.
- Keep well hydrated, as dehydration is a common cause of skin dryness.
- Avoid extreme weather conditions like severe cold and hot weather – these conditions can aggravate dry skin.
- Wash clothes in a mild detergent – a woman should look for detergents labelled ‘allergen free’ or ‘unscented’.

Nerve and muscle problems

Some chemotherapy drugs can cause nerve and muscle problems during treatment. Severe problems are uncommon. More common symptoms include tingling, burning or numbness in the hands or feet. Some women have problems with balance or have weak or sore muscles for a few days after chemotherapy.

Lymphoedema

Lymphoedema is swelling of the arm, breast, hand or other area of the body due to a build-up of fluid following the removal of lymph nodes. It is most common in the feet and ankles due to the effects of gravity. This side effect is most commonly associated with the use of some taxane chemotherapy drugs. The risk of arm or leg swelling can be reduced by giving another medication before chemotherapy. Symptoms will slowly improve once treatment is over. Arm and leg swelling caused by chemotherapy is not the same as lymphoedema and rarely requires any specific treatment.

Tips to help a woman manage lymphoedema

- Reduce the risk of infection by keeping the skin healthy and avoiding cuts, insect bites, scratches or burns.
- Avoid sunburn or overheating the affected area (for example, through hot baths or saunas).
- Gentle exercise which includes raising the affected part of the body.
- Wearing a compression garment (an elastic bandage or sleeve).
- Massage of the affected area by a trained lymphoedema therapist.

Feeling vague or 'in a fog' (less common)

Some women feel 'vague' or mildly confused or have memory problems while having chemotherapy. This is sometimes called 'chemo brain' or 'chemo fog'. This can last for some months after treatment is over. The causes of these feelings are currently being studied.

Infection (rare)

Chemotherapy drugs will reduce the number of white blood cells produced by the body. If the white blood cell count drops, this will usually happen 1–2 weeks after treatment. If this happens, there is an increased risk of infection.

A side note on infection

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.

A drug called a growth factor (G-CSF) may be recommended after each chemotherapy treatment to lower the risk of infection.

FAST FACTS

The risk of infection is highest for women who have drugs called taxanes at the same time as anthracyclines.

Bleeding or bruising (rare)

In rare cases, chemotherapy can make patients bleed or bruise easily. This is because chemotherapy can affect cells in the blood called platelets. If chemotherapy affects the platelets, this will usually happen 1–2 weeks after treatment.

Symptoms to look out for include:

- easy bruising
- bleeding from gums or nose
- reddish urine
- black or bloody bowel motions (stools).

Unusual bruising or bleeding can be treated by a platelet transfusion.

Kidney and bladder problems (rare)

Some chemotherapy drugs can irritate the bladder or cause damage to the kidneys. In very rare cases, this damage can be permanent. Drinking plenty of fluid can help prevent kidney and bladder problems. If kidney or bladder problems do happen, they will usually happen a few days or more after chemotherapy treatment.

Symptoms include:

- pain or burning when passing urine
- frequent urination
- a need to urinate straight away
- reddish or bloody urine
- fever or chills.

With some chemotherapy drugs, it is normal to have reddish urine for 24 hours after treatment, the treating specialist should advise.

Other rare or uncommon side effects of chemotherapy

Other rare side effects of chemotherapy include:

- heart problems (cardiac toxicity) — with anthracyclines
- problems with bone marrow — most commonly with anthracyclines
- allergic reactions — with taxanes.

If these side effects develop during treatment the chemotherapy drugs will be changed, or the dose decreased.

Questions yet to be answered about chemotherapy

There are still things we do not know about many cancer drugs. Clinical trials to answer these questions are ongoing and more information will become available in the future.

Some of these questions include:

- the best order in which to give chemotherapy drugs and when to give them in relation to radiotherapy and/or surgery
- the long-term side effects of treatment, particularly for some of the newer drugs
- how different drugs of the same type compare in terms of side effects and effectiveness
- how useful different drugs are in treating breast cancer at different stages, for example, breast cancer that has not spread to the lymph nodes.

5.7 Hormonal therapies

Hormonal therapies are treatments for women who have hormone receptors on their breast cancer cells. When breast cancer cells have hormone receptors on them, it means the growth of the cancer cells is affected by female hormones.

FAST FACTS

There are two types of hormone receptors:

- 1. oestrogen receptors (ER); and**
- 2. progesterone receptors (PR).**

About two-thirds of women with breast cancer have hormone receptor-positive breast cancer.



Breast cancer cells with hormone receptors on them are said to be 'hormone receptor positive'. Hormonal therapies lower the level of female hormones in the body, or change the way the body responds to female hormones, to stop hormone receptor-positive breast cancer cells from growing.

Hormonal therapies used to treat breast cancer are not the same as hormone replacement therapy (HRT) used to manage symptoms of menopause.

Hormonal therapies reduce the risk of breast cancer coming back (in the breasts and in other parts of the body). Some hormonal therapies have also been shown to increase the chance of survival for women with breast cancer. These include the hormonal therapy tamoxifen, some aromatase inhibitors and removal of the ovaries by surgery.

When are hormonal therapies recommended?

Hormonal therapies are recommended for women who have hormone receptors on their breast cancer cells. They may be used in addition to surgery, radiotherapy and chemotherapy, or on their own. Hormonal therapies are usually given after other treatments for breast cancer.

Menopause and oestrogen production

All women produce the female hormone oestrogen; however, it is made differently by the body before and after menopause.

- Before menopause (pre-menopause), oestrogen is made mainly by the ovaries.
- Around the time of menopause (peri-menopause), the ovaries stop making female hormones, including oestrogen. This usually happens when women are in their late 40's and early 50's. Symptoms of menopause include irregular menstrual cycles, hot flushes and problems sleeping.
- After menopause (post-menopause), monthly menstrual periods have stopped. The body still makes small amounts of oestrogen by changing hormones called androgens into oestrogen. Androgens are produced by the adrenal glands, which are above the kidneys. A hormone called aromatase changes androgens into oestrogen. Aromatase is produced mainly by fatty tissue.

Types of hormonal therapies

There are different ways of reducing the level of female hormones in the body. If hormonal therapies are recommended, the types of therapies will depend on whether the patient has reached menopause.

Anti-oestrogens

Anti-oestrogens work by stopping breast cancer cells from getting oestrogen. The most common anti-oestrogen is called tamoxifen.

FAST FACTS

Tamoxifen is taken as a single tablet every day, usually for 5 years. Tamoxifen can be used to treat women of any age, regardless of whether they have reached menopause.

Aromatase inhibitors

Aromatase inhibitors work by stopping androgens from being changed to oestrogen. Examples of aromatase inhibitors include anastrozole (Arimidex[®]), letrozole (Femara[®]), exemestane (Aromasin[®]).

Aromatase inhibitors are not suitable if:

- the woman has not yet reached menopause
- the woman is in the middle of menopause
- the woman's menstrual periods have stopped temporarily because of chemotherapy.

FAST FACTS

Aromatase inhibitors are taken as a single tablet every day, usually for 5 years. Aromatase inhibitors are only effective for women who have gone through menopause permanently.

Ovarian treatments

Ovarian treatments work by stopping the ovaries from making oestrogen. Drugs like goserelin (Zoladex[®]) temporarily stop the ovaries from making oestrogen. They only work while a woman is taking the drug. This is called ovarian suppression.

Oestrogen production can be stopped permanently by removing the ovaries (oophorectomy) or giving radiotherapy to the ovaries.

FAST FACTS

Ovarian treatments are only suitable for women who have not yet reached menopause.



Side effects of hormonal therapies

Some side effects are common to all hormonal therapies and some only happen with certain therapies. Everyone is different in how they respond to treatment. For some of the newer drugs, such as aromatase inhibitors, we do not yet know all the long-term side effects.

All hormonal therapies can cause menopausal symptoms such as hot flushes, vaginal dryness and reduced libido (sex drive).

There are treatments that can help with these problems and the severity of these symptoms varies between women and between different treatments. These side effects often improve after treatment stops.

Treatment with hormonal therapies can sometimes cause permanent menopause. If a woman has not yet reached menopause and hopes to have children in the future, it is important she talk to a fertility specialist about options before starting treatment.

Side effects of tamoxifen

Rare side effects of tamoxifen include an increased risk of:

- blood clots
- stroke
- changes in vision.

Tamoxifen can also cause changes to the lining of the womb (uterus) and in rare cases has been associated with an increased risk of cancer of the uterus.

A woman must see a doctor immediately if they experience the following unusual symptoms, in particular:

- irregular vaginal bleeding
- chest pain
- warmth, pain, swelling or tenderness in an arm or leg.

Irregular vaginal bleeding does not mean the woman has cancer of the uterus but a doctor will need to examine to be sure.

It is important to balance the risk of these rare side effects against the fact that anti-oestrogens lower the risk of breast cancer coming back and dying from breast cancer. Tamoxifen may have some other benefits in addition to treating breast cancer, including reducing a woman's risk of osteoporosis and lowering her cholesterol level.

Side effects of aromatase inhibitors

Side effects of aromatase inhibitors include:

- pain in bones or joints (arthralgia)
- an increased risk of osteoporosis, which may increase the risk of bone fractures.

Because aromatase inhibitors affect bone density the doctor may measure bone density before prescribing an aromatase inhibitor if at increased risk of osteoporosis and may also recommend calcium and vitamin D tablets.



Long-term side effects of aromatase inhibitors are still being studied. For example, studies are investigating the effects of aromatase inhibitors on memory, concentration and heart disease.

Side effects of ovarian treatments

Surgery to remove the ovaries, or radiotherapy to the ovaries, causes permanent menopause. Women who have these treatments can no longer have children naturally. Drugs that stop the ovaries from working also cause menopause, but this usually only lasts while the woman is taking the drugs. However, the effects of these drugs may be permanent if close to natural menopause when starting treatment.

5.8 Targeted therapies

Targeted therapies are drugs used to treat certain types of cancer cells. Targeted therapies are only effective for people with particular types of cancer cells.

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

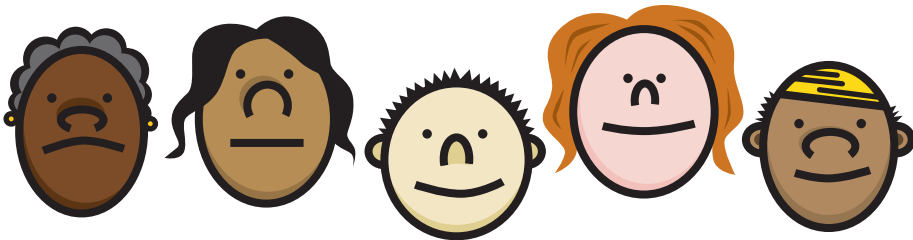
What is trastuzumab (Herceptin®)?

Trastuzumab (Herceptin®) is a drug used to treat a type of breast cancer called 'HER2-positive breast cancer'. 'HER2-positive' means that the breast cancer cells have higher than normal levels of a protein called HER2. Trastuzumab works by stopping HER2-positive cancer cells from growing and dividing. Trastuzumab lowers the risk of breast cancer coming back (in the breast and in other parts of the body) and increases survival for women with HER2-positive early breast cancer.

For breast cancer cells that are not HER2-positive, trastuzumab will have no benefit.

FAST FACTS

About one in five patients have HER2-positive breast cancer.



When is trastuzumab recommended?

- Trastuzumab is recommended for people with HER2-positive early breast cancer.
- In people with very small cancers and no involved lymph nodes, the benefit of treatment with trastuzumab is not yet known.
- The current recommendation is to give trastuzumab at the same time as chemotherapy (usually after breast cancer surgery). Trastuzumab can only be given with some types of chemotherapy. This means that trastuzumab treatment may not start right at the beginning of chemotherapy.
- Trastuzumab can be given at the same time as radiotherapy. However, we do not yet know the long term effects of giving trastuzumab at the same time as radiotherapy.

What does treatment with trastuzumab involve?

Trastuzumab is given by slow intravenous (iv) infusion (injection into the vein). A healthcare professional gives the infusion once a week or once every 3 weeks. How often trastuzumab is given is decided by the doctor and the woman taking the treatment. The dose will depend on the weight of the woman.

The first dose of trastuzumab is higher. This is called a 'loading dose'. It usually takes about 90 minutes and can be slowed or stopped if the patient is feeling uncomfortable. If a woman has a reaction to the first infusion, you can reassure her that the other infusions are quicker, and the dose is lower.

The current recommendation is to give trastuzumab for 1 year. Research is being done to study the effects of giving trastuzumab for less or more time.

Side effects of trastuzumab

Heart problems

The biggest side effect of trastuzumab is the risk of heart problems. Trastuzumab is generally not recommended for women with pre-existing heart problems.

Before a woman is given trastuzumab, she will have to take one of two tests to ensure she doesn't have any heart problems. These tests are:

- an echocardiogram, *or*
- a multi-gated acquisition (MUGA) scan.

If heart problems develop while the woman is receiving trastuzumab, the checks may become more frequent, and the woman will be told to visit a specialist heart doctor called a cardiologist. 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.

Other side effects of trastuzumab

Other possible side effects of trastuzumab include reactions such as chills and fever. Clinical trials looking at the side effects of trastuzumab in women with early breast cancer have not been running for many years. Therefore, we do not yet know the long-term side effects of trastuzumab.

Questions yet to be answered about trastuzumab

As with many breast cancer drugs, there are important things that we still do not know about trastuzumab. Clinical trials to answer these questions are ongoing. More information will become available in the future. **Some of these questions include:**

- the long-term effects of trastuzumab, including effects on the heart
- the ideal length of time for which trastuzumab should be given
- the ideal combination of trastuzumab with other treatments like chemotherapy, hormonal therapy and radiotherapy
- the effects of taking trastuzumab at the same time as hormonal therapies
- the use of trastuzumab during pregnancy, and the effects on fertility.

5.9 Complementary and alternative therapies – ‘bush medicine’

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

Alternative therapies are treatments used instead of conventional treatments. There is no evidence to support the use of alternative therapies in the treatment of breast cancer.



Your role

As an Aboriginal and Torres Strait Islander health worker, it is important to be aware of this when women talk about using ‘bush medicine’.

It is important to discuss this with the treating doctor to find out about the safety of any complementary treatments or therapies a woman may use, or consider using. Encourage Aboriginal and Torres Strait Islander women and their families to talk to their doctors about their beliefs of these therapies and to report any traditional bush medicine they may be using.

Encourage open communication about traditional bush medicine between patients and doctors.

This can assist the treating clinician in making a comprehensive assessment of the patient in developing the treatment.

5.10 Treatment for breast cancer in Aboriginal and Torres Strait Islander women

Research about Aboriginal and Torres Strait Islander people's use of cancer services is limited.

What we do know

- Aboriginal and Torres Strait Islander people are **less likely** to complete treatment for cancer than non-Indigenous people. This is true across all treatments for cancer including surgery, radiotherapy and chemotherapy.^[6]
- Aboriginal and Torres Strait Islander women also **face a number of barriers** in receiving quality care and treatment.^[6]
- Aboriginal and Torres Strait Islander women are also **less likely** to complete breast reconstructive surgery.^[18]
- Aboriginal and Torres Strait Islander women are **just as likely** as non-Indigenous women to undergo breast-conserving surgery.^[19]
- A study in Far North Queensland found that Indigenous women had larger breast cancer on presentation with nodular involvement.^[20]
- Aboriginal and Torres Strait Islander people have higher cancer mortality rates than non-Indigenous people.^[21]

Barriers to accessing cancer treatment for Aboriginal and Torres Strait Islander women

Living in a remote area

Approximately over a quarter of the Aboriginal and Torres Strait Islander population live in remote or very remote areas compared to only 2% of non-Indigenous Australians. Research suggests that, in general, the further a home is located from a major treatment centre, the poorer the cancer outcome.^[22]

Access to services in remote areas is a major factor for women when deciding on their cancer treatment. Women may need to consider things like access to transport and spending time away from their families.

Language barrier

In one study there were substantial differences in receiving treatment for Aboriginal and Torres Strait Islander people who spoke English at home compared to those who spoke an Indigenous language. [8]

Isolation from the family and community

The cultural view of health being linked with community means some Aboriginal and Torres Strait Islander women with breast cancer would prefer to wait for their sickness to pass rather than abandon family and community responsibilities. [14, 24] This may make them unwilling to access some treatment options for their cancer.

Breast cancer treatment which limits a woman's ability to perform her social role could be viewed as 'unhealthy' by Aboriginal women. As a result they may be resistant to undergo surgery or chemotherapy which can affect their contribution to the community, even if only temporarily.

Family responsibilities

Being apart from family, and particularly from children, can mean extra stress and worry for women who are already in need of comfort and support. [27]. Women from remote communities may be reluctant to place their personal health above the welfare of their children and family, and to leave their community and travel to health services for treatment. [5]

Lack of knowledge

Aboriginal and Torres Strait Islander peoples uptake of treatment is limited by a lack of knowledge about cancer treatment and different views of health.

Research in Queensland found that women chose to discontinue treatment because it was not making them feel well and impacted on their ability to care for their children or grandchildren. [5]

Lack of suitable culturally sensitive services

Research in Queensland found that Aboriginal and Torres Strait Islander people were required to fit in to programs and services that were not appropriate for the Aboriginal and Torres Strait Islander culture. The programs were not as effective as they could have been in meeting Indigenous people's needs.^[29-30] This further highlights the importance of cultural awareness when providing health care to Aboriginal and Torres Strait Islander women.

Access of Aboriginal and Torres Strait Islander Health Workers

The vast majority of Aboriginal and Torres Strait Islander women prefer female health workers to male workers, particularly for matters relating to breast cancer and cervical cancer, which are considered 'women's business'.^[29, 31]



However, predominantly male staff, high staff turnover, and relatively few Aboriginal and Torres Strait Islander Health Workers are common in many rural and remote areas of Australia.^[30, 32]

5.11 **Role of the Aboriginal and Torres Strait Islander Health Worker**

Practical ideas to support women through treatment

Share information and current research regarding breast cancer treatments

There are many options for sharing information and no clear way for doing it.

Information sharing is a process and how it is shared is as important as the information itself. It can change the impact of the information, make it memorable and determine how it is used.

Good team work between non-Indigenous and Indigenous staff, and between the health team and other community members, is important for effective sharing of information.

Partnerships need to be built on sound communication and mutual respect.

Some do's and don'ts ^[16]

- Do think about the language and the most appropriate way to explain things clearly.
- Do think about how to ask questions in a way which invites people to respond, to share knowledge and concerns.
- Don't overload the patient with new information- be realistic about what can be shared at each point in time in the time available and what can be achieved as a result of the sharing.
- Don't underestimate the patient.



Involve the family in discussions

Involving appropriate family and/or community members in decision making with the individual patient can be important to support women during treatment.

There are a lot of factors that impact on Aboriginal and Torres Strait Islander women's decisions about treatment. Working with the family can benefit both the health staff and the family. ^[16]

Advantages for the health staff:

- identifying appropriate family members who can help translate important health information
- appreciating the priority of family obligations
- understanding what is important to the family and the individuals within it
- understanding the range of factors impacting on the family's health, such as the family's living environment, level of income, available resources.

Advantages for the family:

- talking about issues that affect individual health, such as money, food availability, who looks after people, beliefs and knowledge
- having their questions answered about the health of another family member
- supporting a family member in their required treatment or to participate in healthy behaviours
- increasing their knowledge and understanding about how to care for the family member
- receiving ongoing support and feedback on how things are going.

It is important for you to be aware and educate other health professionals about the Aboriginal and Torres Strait Islander view of health and the requirement to consider a woman's obligations of kinship. Treatment options can be designed to support women to continue to fulfil these obligations.

Develop a navigational aid of 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 aid in this process. Liaise with local health professionals and health services to source the information you need to develop the resource.

Discuss 'traditional bush medicine'

In some parts of Australia, the use of traditional bush medicine by Aboriginal and Torres Strait Islander people is still widely reported.

Encourage Aboriginal and Torres Strait Islander women and their families to talk to their doctors about their beliefs of these therapies and to report any traditional bush medicine they may be using. Encouraging open communication about traditional bush medicine between patients and doctors is important. This can assist the treating clinician in making a comprehensive assessment of the patient in developing the treatment.

Promote key messages in all activities and resources related to breast cancer

Key Messages to the community

- Effective treatments are available and improving all the time.
- Completing treatment is important to survival and most side effects of treatments can be managed well with medicines.



6.

Breast cancer follow-up care



This chapter gives you an understanding of follow-up care for women who have been treated for breast cancer. You will learn about finishing treatment, follow-up testing and the importance of attending appointments.

Breast cancer follow-up care

The role of the Aboriginal and Torres Strait Islander Health Worker in follow-up care is to support the women to undertake long term follow-up care. This means supporting the women to attend appointments, continue to take medications everyday for as long as required and to be aware of symptoms of breast cancer or side effects of treatment drugs.

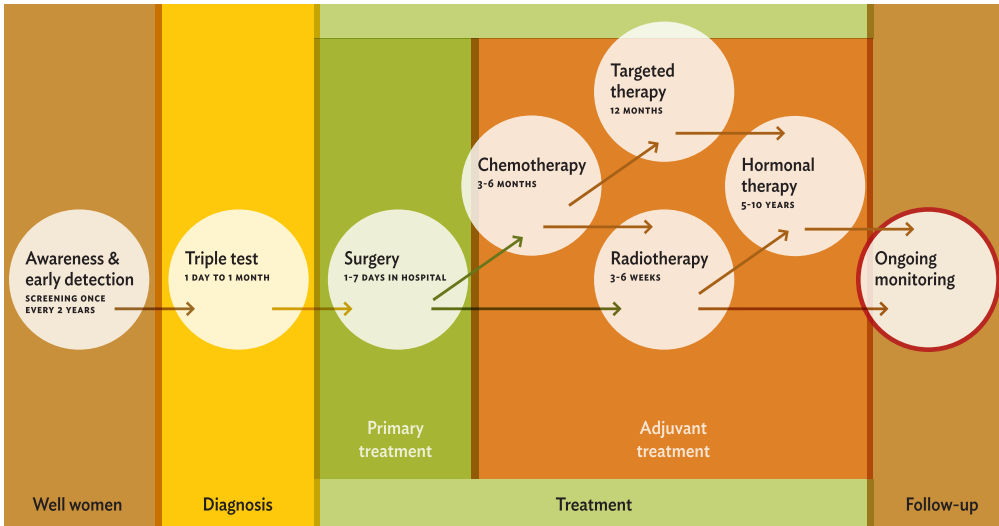


FIG 17: Early breast cancer journey

NOTE: These are approximate durations only and may change over time and may differ for each individual.



6.1 Understanding follow-up care

Finishing treatment

Many women look forward to finishing their hospital-based treatment (surgery, radiotherapy or chemotherapy). However, for some women, the end of treatment can be a confusing or worrying time. Some women feel nervous or upset at the thought of no longer seeing members of their healthcare team regularly. Others feel worried about what the future holds.

MYTH: After treatment is finished and I go home, that is it, it's all over.

FACT: Follow-up care after treatment is an important part of surviving breast cancer.

Follow-up care

Why are follow-up tests important?

Regular follow-up is recommended after treatment for early breast cancer. Women who have been diagnosed and treated for early breast cancer have an increased risk of breast cancer coming back or developing in the other breast. Regular follow-up means that if breast cancer does come back or if a new breast cancer develops, it can be treated promptly.

Follow-up also allows doctors to check for any side effects from treatment and to see how long-term treatments, such as hormonal therapies, are going. It also provides an opportunity for the patient to talk about how they are feeling.

Some women find it reassuring to have regular follow-up tests. Others feel anxious around the time of their appointments. Both reactions are normal.

Talk to the patient and ask how they feel about follow-up tests and offer support.

Follow-up appointments

Follow-up after treatment for breast cancer involves:

- regular physical examinations; *and*
- breast imaging tests (mammogram and/or ultrasound).



Appropriate follow-up does not involve chest X-rays, bone scans or blood tests unless there are symptoms which suggest that cancer has spread outside the breast or armpit area or there is a high risk of breast cancer coming back.

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.

A follow-up schedule is planned based on the individual circumstances of the patient. A general outline is given below. If the patient is receiving a hormonal therapy such as tamoxifen or an aromatase inhibitor, they will have follow-up tests while taking these therapies.

Physical examinations and history

Follow-up appointments involve taking a history and doing a physical examination. The doctor will ask about symptoms experienced by the patient since the last visit and will do a physical examination of both breasts (and the chest area if there was a mastectomy), arms and other parts of the body if relevant. The frequency of follow-up appointments will depend on the woman's situation and how long it is since treatment was finished. The recommended timing for physical examination/history is shown on the next page.

TABLE 3: NBOCC Recommended Follow-up Schedule

Method	Years 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 indicated)	Every 12 months*	Every 12 months	Every 12 months
Chest X-ray, bone scan, CT, PET or MRI scans†, full blood count, biochemistry and tumour markers	Only if clinically indicated on suspicion of recurrence		

* First mammogram 12 months post diagnosis

† Use of MRI may be considered in specific high-risk groups

The frequency of physical examinations could be more or less often than this.

Imaging tests

Follow-up appointments also involve a mammogram and/or ultrasound to look for changes in the breasts. The appointments for the imaging tests are organised before the appointment with the doctor so the results can be discussed at the follow-up appointment with the doctor.

Talking to the doctor

Follow-up appointments are also a good opportunity for the patient to talk to the doctor about their feelings regarding breast cancer now that the treatment is over. It is also an opportunity for them to talk about any side effects of treatment they may have had since their last visit.

As an Aboriginal and Torres Strait Islander Health Worker it is important to stress the need for women to tell their doctor about any side effects or symptoms they are experiencing.

What happens after follow-up appointments?

For most women, no changes are found during follow-up appointments. However, if the mammogram or ultrasound shows an abnormal area, or if there is a lump identified during the physical examination, further tests will be conducted. This may include more imaging tests and a biopsy.

What happens between follow-up appointments?

If there is a breast change or any other symptoms between follow-up appointments, it is important the woman does not wait until the next appointment. They must see the GP or specialist as soon as possible.

6.2 Lymphoedema

Lymphoedema after breast cancer is a persistent swelling of the arm or breast that occurs because of a build-up of fluid. If left untreated this build-up of fluid can be difficult to control.

What is lymphoedema?

Fluid from the body's tissues usually drains into lymphatic vessels. These are small vessels close to the blood vessels. The fluid is called lymph. Lymphatic vessels carry the lymph to lymph nodes, where substances that could be harmful to the body, such as bacteria, are removed. This helps to protect the body from infection. The lymph then passes back into the blood. There are lymph nodes all around the body, including the armpit, groin, abdomen, chest and neck.

During treatment for breast cancer, lymph nodes may be removed from the armpit or breast region by surgery or damaged by radiotherapy. This can cause lymph fluid to build up in the arm or breast, causing the arm or breast to swell.

Lymphoedema usually develops gradually. It can develop months or even years after treatment for breast cancer. The risk seems to be higher for people who have undergone both surgery and radiotherapy to the armpit. However, many people who have lymph nodes removed and radiotherapy to the armpit do not develop the condition.

Lymphoedema is not the same as the swelling or pain in the breast, armpit or arm that immediately follows surgery or radiotherapy to the breast or armpit.

Signs and symptoms of lymphoedema

Early signs of lymphoedema include:

- a feeling of heaviness, tightness or fullness in the arm or breast
- swelling of the arm, breast or hand (the woman may notice indentations in the skin from tight clothing or jewellery)
- aching, pain or tension in the arm, hand, chest or breast area.

How is lymphoedema managed?

There is no known cure for lymphoedema, but it can be managed with appropriate care. The aim of management is to reduce and control swelling, improve the range of movement of the affected area and prevent infections. Some of the ways to manage lymphoedema are listed below.

- **Skin care:** daily attention to skin care is essential as the skin provides a barrier against infection.
- **Exercise:** studies suggest that gentle exercise can help to reduce the symptoms of lymphoedema by helping lymph to flow through the lymphatic vessels. Exercise can also help maintain a healthy body weight. This is important, as excess body weight may slow the flow of lymph.
- **Elevation:** experts believe that raising the limb, for example by supporting the arm on several pillows, can help reduce the symptoms of lymphoedema in the early stages of the condition.
- **Compression sleeve:** this is a tightly fitting elastic sleeve worn on the affected arm. Studies suggest that wearing a compression sleeve can help to reduce the swelling associated with lymphoedema. The sleeve stops fluid from building up and moves excess fluid out of the affected area. Wearing a compression sleeve may be combined with other forms of treatment, such as manual lymphatic drainage (see below). Compression sleeves should be fitted professionally and replaced when they lose their elasticity.
- **Manual lymphatic drainage (MLD) or decongestive physiotherapy:** is a special form of massage of the affected area. The aim of manual lymphatic drainage is to improve the way in which the lymphatic vessels are working and reduce the build-up of fluid. It uses long, slow, gentle strokes to help move the lymph fluid from the affected area through the remaining lymph vessels to nearby or distant lymph nodes. Such treatments should be designed by a qualified lymphoedema practitioner.
- **Compression bandaging:** is usually done in combination with manual lymphatic drainage to reduce swelling in the breast or to reduce severe swelling in the arm before a compression garment is fitted. It may also be used if the skin is very fragile or damaged. Compression bandages should be replaced every day.

6.3 Breast cancer and family history

Aboriginal and Torres Strait Islander women diagnosed with breast cancer may be worried about their family also developing the disease. A diagnosis of breast cancer does not necessarily mean that other members of their family will develop breast cancer.

Many women have someone in their family who has had breast cancer. This can happen by chance, as the disease is common. Family history becomes more important when there are more relatives with breast cancer on the same side of the family, especially if the cancer occurs in a woman before 50 years of age. Most women will not develop breast cancer, even if they have a close relative with breast cancer.

Rarely, breast cancer can be caused by a fault in a gene, known as the BRCA1 or BRCA2 gene, which can be passed within families from one generation to another. These gene faults can be passed on from either the mother's or the father's side of the family.

If there is a strong family history of breast cancer, then the doctor may refer the patient for genetic testing at a specialist family cancer clinic.

FAST FACTS

A strong family history means having three or more close family members with breast cancer. For example mother, sister, grandmother or aunty all from the same side of the family. This means from either patient's mother's family or father's family.

6.4 Breast cancer, menopause and fertility

About two-thirds of women who are younger than 50 years of age when their breast cancer is diagnosed, will go through menopause because of treatment. Menopausal symptoms are a common side effect of hormonal therapies and some chemotherapy drugs. Sometimes the menopause is temporary and sometimes it is permanent.

Symptoms of menopause

Regardless of whether menopause is temporary or permanent, woman may experience menopausal symptoms during treatment.

Symptoms to be aware of include:

- hot flushes
- mood changes
- sleep disturbance
- vaginal dryness and/or discharge
- a decrease in libido (sex drive)
- no menstrual periods, or irregular menstrual periods.

A range of medical treatments, lifestyle changes and complementary therapies are used by women to manage their menopausal symptoms. You should refer women on to a doctor or nurse if they have further questions about managing these symptoms.

FAST FACTS

The closer the woman is to the age of natural menopause, the more likely it is that the menopause will be permanent.





FAST FACTS

Some women who have already gone through menopause may also experience menopausal symptoms with certain treatments.

Treatment and infertility

The issue of pregnancy for women with breast cancer is quite complex. There are a number of things for the patient to consider. Some treatments for breast cancer can affect a patient's ability to become pregnant. Some treatments have this effect during the treatment period only, while others have a permanent effect.

Infertility can be very hard to come to terms with, and not only for women who were planning to have children in the future.

Contraception during and after breast cancer treatment

Treatments for breast cancer may reduce fertility, temporarily or permanently. However, this does not mean it is impossible to become pregnant during or after treatment.

There is no evidence about whether or not it is safe to take the oral contraceptive pill ('the pill') or use implants (Implanon®) during or after treatment for breast cancer. As a result, you should encourage women to use non-hormonal forms of contraception, such as condoms, diaphragms, intrauterine contraceptive devices (IUDs) or male or female sterilisation.

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

6.5 The financial cost of breast cancer

As an Aboriginal and Torres Strait Islander Health Worker, you may have to answer questions about the financial services available to women with breast cancer.



There are many costs related to breast cancer testing and treatment. These may include the cost of treatment and support, travel and accommodation costs, childcare or the cost of wigs or medical equipment.

Factors that affect the cost of breast cancer

The costs of testing and treatment for breast cancer can differ between women. The costs may vary depending if women:

- are treated in the public or private system
- if working, decide to continue working or not
- live in a rural area and need to travel for treatment
- have private health insurance
- have a healthcare card.

Women 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 talk to their local Medicare office about the 'safety net' on costs of medications and medical bills. Medicare can contact the woman's private health insurer to discuss their likely rebates and benefits.

Providing information on financial assistance during treatment

Financial assistance during treatment

If a patient needs to have treatment in a hospital far away from home, they may be able to get help with the cost of accommodation and travel. Depending on the situation and where they live, they 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.

Government-assisted travel schemes

Each State and Territory has a government-funded scheme to help patients who have to travel long distances to obtain specialist treatment that is not available locally. The names for these schemes vary but may include:

- Patient-Assisted Transport Scheme (PATS)
- Transport for Health
- Isolated Patient Transport and Accommodation Assistance Scheme (IPTAAS).

Superannuation for people with a terminal illness

Current legislation allows individuals with a terminal illness to access their superannuation as a tax-free lump sum. In order to do this the patient will need certificates from two medical practitioners (one of whom is a specialist) stating that they have a terminal illness with a life expectancy of 12 months or less.



6.6 **Follow-up treatment and care for Aboriginal and Torres Strait Islander women**

Little research has been conducted on follow-up treatment for cancer amongst Aboriginal and/or Torres Strait Islander people.

We do know, however, from evidence on survival from cancer among Aboriginal and Torres Strait Islander and non-Indigenous Australians, that the risk of dying for all cancers combined is elevated. ^[33]

Despite the little research available for the Aboriginal and Torres Strait Islander population, studies show the need to:

- prevent cancers, particularly those with a higher risk of death
- detect cancers earlier
- promote completing treatment.

See Section 5.10 Treatment for breast cancer in Aboriginal and Torres Strait Islander women.



6.7 Role of the Aboriginal and Torres Strait Islander Health Worker

Assist with reminding the patient of their follow-up appointments and what to expect

Aboriginal and Torres Strait Islander women who have been diagnosed and treated for early breast cancer are at a higher risk of breast cancer coming back or developing in the other breast.

Regular follow-up means that if the breast cancer does come 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 in ensuring women continue to undertake ongoing surveillance.

Communicate effectively

Use basic communication skills as described in Section 7.3

In addition during contact with the woman in follow-up care the following steps are recommended:

- ask the patient how they are feeling about their treatment
- listen to fears and concerns
- ask the patient about their support networks e.g. partner, children and extended family
- provide the patient and their family and carers with information about support services and peer support programs and how they can be accessed.

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

Women will move through a variety of treatment settings and service providers. It will help to coordinate the appointments and be the liaison if required.

Promote key messages to all Aboriginal and Torres Strait Islander women and their families who have completed hospital-based treatment

Key messages to the community

Follow-up after treatment is an important part of surviving breast cancer and involves:

- attending appointments for physical examination
- regular mammograms.



7.

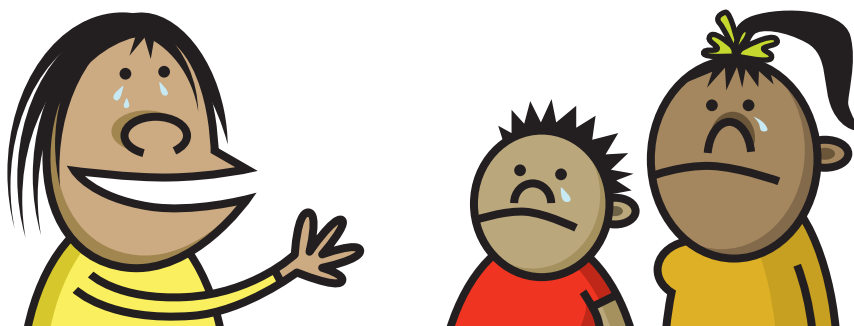
Psychosocial issues and support



This chapter provides guidance to you as an Aboriginal and Torres Strait Islander Health Worker on ways you can support the woman, her partner, family and community through the breast cancer experience.

Psychosocial issues and support

As an Aboriginal and Torres Strait Islander Health Worker, your role in providing psychosocial support to a woman with breast cancer is likely to vary according to the individual woman's needs and those of the people close to her. Your role may involve providing emotional and practical support to the woman and her family, and/or referring the woman on to receive clinical or specialised support. It is important that you are able to help the woman and her family identify and access the emotional and practical support they need.



7.1 Psychosocial issues

Women with breast cancer may experience a number of psychosocial issues throughout their journey. These include emotional, psychological, physical and practical challenges.

Aboriginal and Torres Strait Islander women are likely to face challenges related to the fear of their cancer diagnosis, fears about the future, concern for their family and community, and questions about the physical side effects of treatment and practical aspects such as travel and treatment costs. More specific emotional issues can range from concerns about body image, treatment, and periods of anxiety or depression.

MYTH: A woman has to be strong and face breast cancer alone.

FACT: It is important for women with breast cancer to be open and honest with family and health professionals so that they can access the help and support they need.

FAST FACTS

As an Aboriginal and Torres Strait Islander Health Worker, you play a key role in giving women the opportunity to discuss their feelings and experiences. This emotional care and practical support is referred to as 'psychosocial care'. Providing psychosocial care and support means taking into account the woman's social role, her spiritual beliefs and concerns.



Emotional Issues

Not everyone feels the same about the diagnosis and treatment of cancer. When first diagnosed with breast cancer, most women feel anger, shock, distress, disbelief or fear about their future. Other women may experience feelings of grief, hopelessness or loss.

Many women find it difficult to talk about their feelings. Everyone experiences a range of emotions at different times throughout life, but when these feelings are related to a cancer diagnosis, they can last for longer periods of time and affect different areas of life.

A woman's response to breast cancer diagnosis may be affected by:

- **her diagnosis:** was finding out the results from her tests difficult? Did the doctor explain the information well?
- **her past experiences and lifestyle:** has a family member passed away from breast cancer before?
- **her age, stage of life and social role:** does she have a family?
- **the physical burden of her cancer:** does she have to travel away from home to receive treatment?
- **her prognosis:** has her cancer been found early?

Shame

For Aboriginal and Torres Strait Islander women, managing feelings of shame may also be a challenge. Shame is more than a sense of guilt or embarrassment. It is a powerful emotion that can develop when a woman feels that she has lost touch with her cultural identity. This may relate to kinship, ritual and spiritual relationships and responsibilities.

Shame may be experienced when a woman acts, or is forced to act, in a way that is not accepted by her community. Her actions may clash with her social and spiritual duty. Shame may also be experienced when an individual is singled out for either praise or blame.

Psychological issues

As well as affecting general emotional wellbeing, living with cancer can also affect a woman's psychological wellbeing. Breast cancer may change how a woman feels about herself, and how she relates to other people in her life.

Women may experience:

- changes in the way they feel about their body after treatment for cancer; this could be because of scarring or body changes after surgery or side effects of treatment like weight gain and hair loss
- changes in the way they feel about their sexuality and intimacy; this is closely connected to body image, self-esteem and mood, and how well they are feeling
- strain on relationships with people close to them, particularly their partner; a cancer diagnosis can be just as overwhelming and distressing for partners and other close family members as it is for the person diagnosed
- challenges in establishing a new relationship; many people find it difficult to know how, when and how much to tell someone new about their cancer.

More serious challenges

Some women will have more severe emotional reactions to their breast cancer diagnosis. This can lead to high levels of anxiety and depression. Up to half of women with early breast cancer will experience some degree of depression or anxiety.

Specialised care is needed for people experiencing depression or suicidal thoughts. This will usually involve a combination of therapies to change thoughts or behaviours and medication such as anti-depressants. **It is important to refer women on to their doctor to get support to diagnose and manage more severe emotional reactions.**

What to do

- Ask regularly about the woman's emotional concerns.
- Be aware of symptoms such as irritability, social withdrawal, and increased difficulty coping in general.

Physical issues

Women with breast cancer experience a range of physical symptoms and side effects of treatment. These can include nausea and vomiting, pain, ongoing fatigue, fertility problems and lymphoedema (swelling in an area of the body). Some women also say they find it difficult to concentrate or think clearly during chemotherapy.

It is important to assess whether the physical symptoms or treatment side effects are affecting the woman's quality of life. Some women find that a diagnosis of cancer has a bigger impact on some parts of their life than others. The impact of cancer may change at different stages along the cancer journey.

Practical issues

For Aboriginal and Torres Strait Islander women with breast cancer there are many practical issues to think about. These can include the costs of treatment, support services, travel, accommodation, childcare or specific items such as wigs or prostheses. There are also ongoing finances to think about if there is no regular income for the woman.

The practical challenges can also have an impact on the family. Sometimes people feel guilty that their cancer treatment means the rest of the family has to make changes to the way they are used to doing things. Concern about these practical issues can affect how the woman is feeling, especially if it interrupts her daily activities.

Remember, emotional care and social support is just as important as physical care during the cancer journey.

International perspective

A review of international studies explored breast cancer experiences of women from diverse ethno-cultural groups, including Asian American, Canadian Aboriginal, Hispanic and African American women.^[9]

The review revealed

- A common view of breast cancer as a 'white women's' disease, which strongly influenced reactions to breast cancer diagnosis: women felt they weren't going to survive as they hadn't met or seen any people of the same cultural background on TV who had survived breast cancer.
- Women felt their ethno-cultural background was an important factor in the way they were treated by healthcare professionals during their breast cancer treatment and follow-up and the difficulties this created for them.
- A huge sense of loss, both physical and emotional which spanned the breast cancer journey.
- Family members were perceived to be central to accepting, coping and recovering from breast cancer with support being demonstrated in diverse culturally specific ways; reliance on reflection and spirituality appeared to increase when cancer entered their lives and was illustrated by greater reliance on prayer, meditation, church attendance and consultation with spiritual leaders.

7.2 Providing support to women

As an Aboriginal and Torres Strait Islander Health Worker, it is your role to explain the support services available to women, including how they can be accessed. It may help to encourage women to seek support from their family, friends, support services and local cancer organisations.



Bear in mind when thinking about the support needs of Aboriginal and Torres Strait Islander women that it is important to consider cultural and spiritual perspectives on health and illness, such as:

- the importance of considering the physical, social, emotional, cultural and spiritual wellbeing of the individual and of the community and the environment as a whole
- the view of the body as the centre of social relationships, and the close link between health and family, community and other signifiers of identity
- the important link between being healthy and being able to fulfil a social role within the community.

Meeting the support needs of Aboriginal and Torres Strait Islander women

Currently little is known about the preferences of Aboriginal and Torres Strait Islander people for support through diagnosis, treatment and into survivorship.^[33] We do know there is a need for greater financial, social and psychological support for Aboriginal people with cancer.^[24] Some general examples of support are provided in the following sections, but as an Aboriginal Health Worker you may need to tailor some of the options to reflect the cultural and spiritual needs of the individual woman.

Treatment is a time of great stress for women with breast cancer and many women have fears associated with treatment options such as surgery.^[34] However, there is little culturally appropriate professional counselling available for Aboriginal people and their families.^[24]

Providing emotional and practical support is often considered to be the role of family members.^[5] Family members may be unable to provide practical assistance, particularly when a patient has to travel to receive treatment, and may themselves need support from outside the family.^[5, 24] However, some women may prefer to talk to a professional counsellor.

FAST FACTS

In a few 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 liaise between staff and patients. These Health Workers are highly valued by Aboriginal and Torres Strait Islander people who have had access to their support.^[5]



Where possible, it is important for women to be able to talk to counsellors who have a rapport with and commitment to the community and who will respect confidentiality.^[5, 24] Bear in mind that mainstream counselling services are generally not well equipped to meet the needs of Aboriginal and Torres Strait Islander clients.^[5, 24]

Case study

In Western Australia researchers studied how cultural beliefs impact on the experience of Aboriginal and Torres Strait Islander people with cancer support services. ^[33, 35-36]

A number of barriers to these services were noted:

- Aboriginal and Torres Strait Islander people had low expectations of the health service due to previous experience with racism and discrimination.
- there was a lack of acknowledgement of the extended family during treatment in the hospital environment.

There were also communication barriers due to a lack of interpreters, and the perceived poor communication with medical staff. ^[35-36]

Types of support available for women with breast cancer

There are different forms of support that can help a woman to get through the emotional, practical and physical challenges of a breast cancer diagnosis and treatment. It's important for the woman to have the opportunity to talk about her cancer and how she is feeling.

- **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.
- **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.

Who can provide support?

There are a range of health professionals who can provide support for psychosocial issues.

- **General practitioners (GPs):** provide a link to a range of health professionals who can assist with emotional care and practical support services.
- **Nurses:** provide ongoing support throughout the cancer journey. Nurses are usually very experienced in helping people to cope with physical symptoms and are familiar with the emotional issues faced by people with cancer. They can provide advice about other health professionals who can provide more specific support.
- **Social workers:** provide advice about finances and practical support. They can also provide counselling, which can include other members of the patient's family, if needed.
- **Psychologists:** provide counselling and can offer specific therapies.
- **Psychiatrists:** are doctors who specialise in mental health and the way the brain functions. In addition to counselling, they can treat conditions such as depression and anxiety and prescribe medication if necessary.
- **Counsellors:** listen and provide therapy to work out exactly what issues the patient is facing and what they would like to do next.
- **Occupational therapists:** provide practical support to overcome physical problems or barriers at home or work. Some occupational therapists are qualified to provide specific treatments such as lymphoedema massage.

- **Physiotherapists:** provide physical support, massage and manipulation to help with mobility, reduce pain and assist with problems such as lymphoedema.
- **Speech therapists:** help with speech, eating and swallowing difficulties.
- **Dieticians or nutritionists:** help to overcome eating difficulties and maintain a healthy diet.
- **Spiritual advisors:** can listen and discuss matters of faith.



Support centres

Listed below are some of the services that can provide care outside the home. The services available can depend on location.

- **Day centres:** are often attached to hospitals, hospices or nursing homes and are available to provide support. 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:** public and private 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.
- **Hospices/palliative care units:** specialise in the care of people who are living with and dying from cancer. They focus on controlling pain and other symptoms. Some people go to hospices for a short period to help to control symptoms. Palliative care units may be wards in local hospitals.
- **Nursing homes:** offer short- or long-term stays. They will charge a fee for the care provided.



7.3 Communication skills

Aboriginal and Torres Strait Islander women need accurate information about breast cancer and the relevant treatment options so they can understand their diagnosis and what lies ahead. Communicating with women involves more than providing information – it includes an explanation, problem solving and acknowledging the woman's feelings.

The following skills should be drawn upon when talking to women about their breast cancer experience.

Supportive communication

- Explain how confidentiality is achieved between a patient and their healthcare professional.
- Ask the woman if they would like someone (e.g. family) to be with them during any consultation with their doctors or specialists.
- Show care and concern for the woman in the way you listen and respond to her. Remember to have open and attentive body language.
- Express empathy and listen actively.
- Allow and encourage the woman to express her feelings, e.g. crying, talking about concerns, fears, anger, anxieties, etc.
- Handle embarrassing or disturbing topics directly and sensitively.

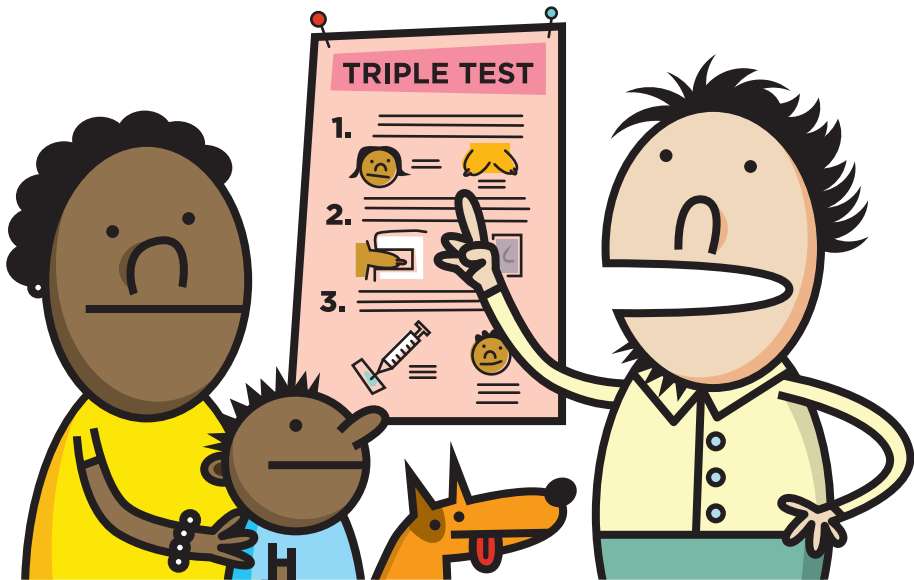
Delivering medical information in plain English

- Assess the woman's understanding before providing additional information.
- Explain difficult terms and avoid medical jargon.
- Provide information clearly. Group information by specific topics.

Help with understanding

- Encourage the woman to ask questions and seek understanding.
- Make use of simple diagrams and pictures where appropriate.
- Repeat and summarise important information.

- Reinforce important information by using one or more of the following aids:
 - writing down relevant information
 - taping the consultation as needed and if wanted
 - sending a summary letter as follow-up.



Ongoing support

- Assess the woman's level of family or social support.
- Provide the names and contact details of relevant woman's or other organisations to obtain more information.
- Refer to a psychologist, counsellor or other professional for support as required.



7.4 Supporting the family

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 friends. They may find the journey difficult and will need encouragement to seek support. They might also need advice from the woman about how they can help her.

For Aboriginal and Torres Strait Islander people family and kinship is central to wellbeing. It is important to be aware that family responsibilities may impact greatly on treatment decisions and that involving family in the decision-making process may increase the acceptability of treatment options, as well as completion of, and compliance with, treatments.

Partners

Many partners find the diagnosis and treatment of breast cancer distressing, but are reluctant to seek help for themselves because they feel the need to be 'strong'. Partners can experience higher levels of stress than the woman diagnosed with cancer. They also have information needs.

Women should be encouraged to have open communication with their partner about how each person is feeling. Partners can accompany women to appointments to provide support and ask questions. Separate appointments can also be made for a woman's partner to discuss how he/she is feeling.



FAST FACTS

It can be difficult for children to adjust, especially if their mother looks different or is in hospital. Children may reflect the effects of the diagnosis in their behaviour; they may behave differently to gain attention, or become insecure.



Children

Children are likely to be affected by their mother's diagnosis of cancer. Depending on their age, children may know something is wrong without being told. Helping women to have open and honest communication with their children, especially older children, is generally helpful.

Here are some key points for women to keep in mind when communicating with their children:

- Try to understand what it is the children fear will happen. This will help to decide what information they can handle and how it should be given.
- Talk to them about feelings as well as facts.
- Give simple, honest answers to their questions and correct any misunderstandings.
- Try to explain what will happen next.
- Reassure them that even if things are not good at the moment, there will be better times.
- Reassure them breast cancer is not their fault – this is important for young children.
- Adolescents may have mixed emotions, loyalties and coping abilities. In some respects, they thrive on being regarded as an adult, but during times of illness in the family, it can be really hard going. Adolescents may need additional support and encouragement.



Things that may help	Things that will NOT help
Talking	Keeping secrets
Maintaining routine	Letting go of structure and rules
Negotiating tasks	Giving orders
Telling children it is not their fault	Telling children to 'be good for Mummy'
Encouraging children to participate in sport and normal activities	Expecting children to spend all of their time at home 'because time together is precious'
Giving information in stages	Talking about possible outcomes far in the future
Allowing others to offer support	Thinking you can do it all on your own
Letting children talk about difficult things	Rushing to reassure
Encouraging children to work out problems themselves	Trying to fix everything for them
Letting the school know	Keeping everything private
Maintaining rules and consequences	Letting discipline slip because of guilt
Letting them see that you are upset sometimes	Always adopting a façade and pretending everything is ok

Helpful websites for children

nBOCC developed a website for children who have a parent with cancer: www.myparentscancer.com.au

The Cancer Council nsw has developed a booklet about talking to children about cancer, which can be downloaded at: www.cancercouncil.com.au

CanTeen provides information and support for young people who have a family member with cancer: www.canteen.org.au



7.5

Role of the Aboriginal and Torres Strait Islander Health Worker

Some practical ideas for supporting a woman

Generate a list of psychosocial support and practical services in your community

A community on the north coast of NSW developed a list of cancer treatment and support services for Aboriginal and Torres Strait Islander women. This was a valuable resource the hospital staff, Aboriginal Medical Services and other health professionals could give to women going through cancer treatment. Consultation ensured all services in the community had input which was coordinated by the breast care nurse.

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians affected by breast cancer, and consists of a network of individual members and member groups. Member groups provide mostly face-to-face support for women and families in community's around the country. BCNA can provide links between groups and provide training for the group facilitator/leader.

Start a support group for Aboriginal and Torres Strait Islander women with breast cancer or even all cancers

Start a support group for Aboriginal and Torres Strait Islander women to get together, to network 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 may want to organise guest speakers to present on different topics.

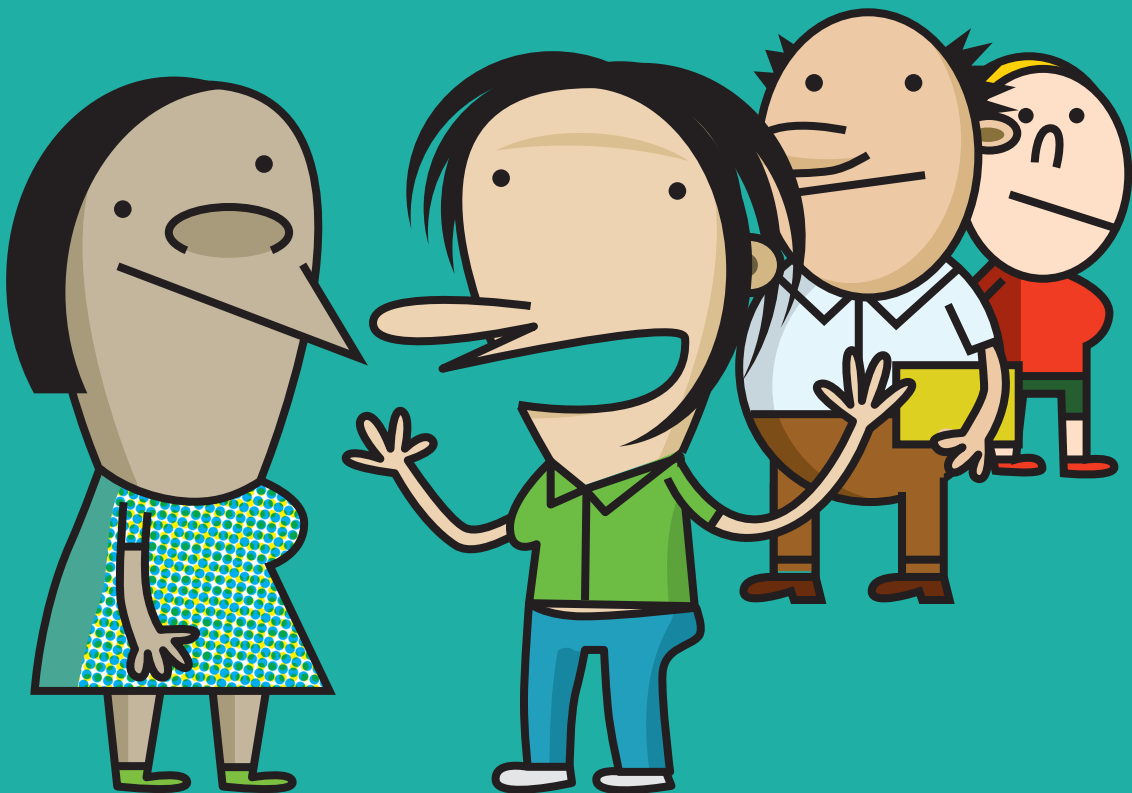
Promote key messages to all Aboriginal and Torres Strait Islander women with breast cancer

Key Messages to the community

- A woman may feel worried about the future, her family, her body or her health but it is important to encourage her to be open and honest with family and health professionals.
- Supportive care is an important component of a woman's overall breast cancer care – it is just as important as her physical care throughout her cancer journey.

8.

Multidisciplinary team approach



This chapter outlines the importance of the Aboriginal and Torres Strait Health Worker within the multidisciplinary healthcare team.

Multidisciplinary team approach

As an Aboriginal and Torres Strait Islander Health Worker you bring a range of skills, knowledge and understanding to the health service. In providing care and support to a woman with breast cancer, you will work alongside a number of healthcare professionals. Part of your role within this multidisciplinary team is to uphold cultural values for the woman during her treatment and provide cultural information to the other healthcare professionals.



8.1 **What is multidisciplinary care?**

The treatment and supportive care of women with breast cancer involves a number of different medical and allied healthcare professionals.

Evidence indicates that a team approach to cancer care – in which healthcare professionals together consider all relevant treatment options and develop an individual treatment plan for each patient – can reduce mortality and improve quality of life for the patient. This team approach to healthcare is known as multidisciplinary care (MDC).

8.2 Principles of multidisciplinary care

As an Aboriginal and Torres Strait Islander Health Worker, you can use the principles of multidisciplinary care developed by NBOCC to work together with other healthcare professionals in providing care to women with breast cancer. The principles recognise that MDC should be flexible, and may work differently for the treatment of different women and in different locations.

NOTE: On 30th June 2011, National Breast and Ovarian Cancer Centre (NBOCC) amalgamated with Cancer Australia to form a single, national agency, Cancer Australia, to provide leadership in cancer control and improve outcomes for Australians affected by cancer.

The principles of multidisciplinary care involve

- a team approach, involving core disciplines essential to the provision of good care, with input from other specialities as required.
- communication among team members regarding treatment planning.
- access to the full therapeutic range for all patients, regardless of geographical remoteness or size of institution.
- provision of care in accord with nationally agreed standards.
- involvement of patients in decisions about their care.

FAST FACTS

Evidence suggests that decisions made by a multidisciplinary team are more likely to be in line with guidelines of care. Patients are also more likely to be satisfied with the treatment they receive from a multidisciplinary team.



8.3 **A team approach**

There will be a number of healthcare professionals providing support to a woman during her treatment for breast cancer. The people involved in her care may change at different points in the cancer journey. This can be quite daunting for the woman. It may be appropriate for you as her Aboriginal and Torres Strait Islander Health Worker, to be a central contact person for her at each stage of her journey.

The diagram below shows some of the healthcare professionals a woman may meet during her treatment. You may need to work with, or make contact with these health professionals when a woman is receiving hospital-based treatment, follow-up treatment, or when she goes back to her community:

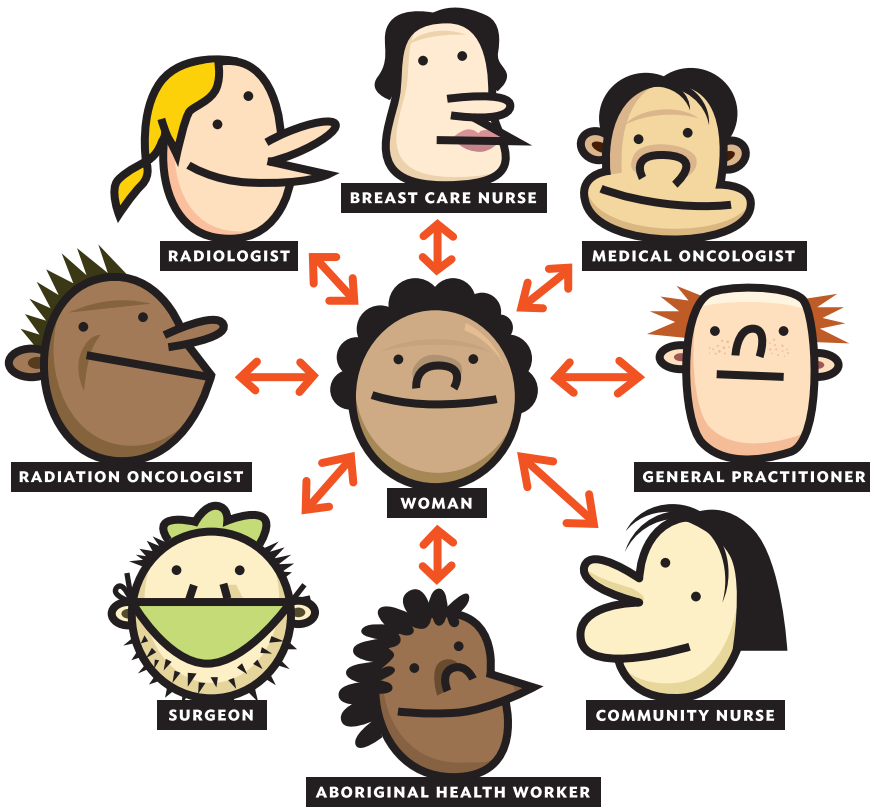


Fig 18: The main health professionals involved in the treatment of a woman with breast cancer

MULTIDISCIPLINARY TEAM APPROACH

The full list of health professionals who may be involved in a patient's cancer treatment and supportive care include:

- **breast care nurse:** specialises in caring for people with breast cancer
- **community/district nurse:** provides care and support for people at home
- **community palliative care team:** provides practical support and symptom relief at home
- **dietician:** specialises in providing advice about what to eat
- **general practitioner (GP):** provides ongoing care and works with other members of the treatment team
- **medical oncologist:** specialises in cancer drugs such as hormonal therapies, chemotherapy and targeted therapies
- **oncology nurse:** specialises in caring for people with cancer
- **palliative care specialist, palliative care nurse:** specialises in providing practical support and symptom relief
- **pastoral care/religious representative:** provides spiritual support
- **pathologist:** examines cells, tissue and blood from the body
- **pharmacist:** specialises in supplying, dispensing and manufacturing drugs
- **physiotherapist, occupational therapist:** assists with exercise and pain management
- **psychologist, psychiatrist or counsellor:** specialises in providing emotional support and managing anxiety and depression
- **radiation oncologist:** specialises in radiotherapy
- **radiation therapist:** assists in planning and giving radiotherapy
- **radiologist:** examines scans, X-rays and other imaging results
- **research nurse:** assists in the planning and coordination of clinical research studies and clinical trials
- **social worker:** specialises in providing emotional support, counselling and advice about some practical and legal matters
- **surgeon:** specialises in surgery, including biopsies
- **welfare worker:** provides practical support and advice.

8.4 **Role of the Aboriginal and Torres Strait Islander Health Worker**

As an Aboriginal and Torres Strait Islander Health Worker you specialise in providing information, health care and practical support in a culturally appropriate way.

It is important to promote your role in the multidisciplinary team by regularly communicating with the woman's healthcare team. When possible, you may like to attend a MDC meeting for the Aboriginal and Torres Strait Islander women with breast cancer who you support.



r.

Resources



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

Throughout this book, we recommend that you call the Cancer Council Helpline on **13 11 20** for up-to-date, local information that is relevant for you and the women you are supporting.

Useful links

‘Surfing’ the internet can be a useful way to find information. However, keep in mind that the information you find may not always be accurate. Use careful judgment, and check what type of organisation has put the information on the internet.

The internet can be accessed using a personal computer at home, or at local libraries and in internet cafés. If the woman is not able to access the internet, refer to the Cancer Council Helpline on 13 11 20 and ask them to print out information from websites and mail it to the woman.

Australian websites that may be helpful



Cancer Australia

www.canceraustralia.gov.au

The Cancer Australia website provides evidence-based information about a range of cancers, including breast cancer. Cancer Australia is the national authority on cancer control, funded by the Australian Government.

Breast Cancer Network Australia

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.healthinonet.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.

CanSpeak

www.canspeak.org.au

This is a national network of consumers and consumer organisations representing people affected by cancer (formerly Cancer Voices Australia).

The Cancer Council Australia

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.

CanTeen

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

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.

Other useful contacts

CentreLink

www.humanservices.gov.au

Disability, sickness and carers:
13 27 17

Information about government support and financial assistance.

Department of Veterans Affairs

www.dva.gov.au

General enquiries: 13 32 54

Information about support and assistance available to Veterans.

Medicare

www.humanservices.gov.au

General enquiries: 13 20 11

Information about Medicare claims.



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Useful materials

A cancer journey for remote Indigenous patients in the Northern Territory

This booklet has been produced by the Northern Territory Government Department of Health and Families with funding from CanNET. The booklet is an educational tool that details the cancer journey using plain language and images. The booklet begins with a description of cancer and goes on to discuss prevention, early detection, and testing. Different types of cancer are also discussed and information is provided on support, going to hospital, treatment, and follow-up care.

The booklet is accompanied by a DVD that contains information reflected in the book:
www.cancerlearning.gov.au/docs/indig_can_journey.pdf



A cancer journey: a cancer story for remote Indigenous patients in the Northern Territory [DVD] (2009)

The Northern Territory Department of Health and Families program – CanNET – has put together a DVD explaining how cancer originates providing information on different types of cancer and its presence in remote Indigenous communities.

BOTH THE BOOKLET AND DVD CAN BE ORDERED FROM:

Acute Care Policy and Services Development
NT Department of Health and Families

PO Box 40596
Casuarina NT 0811
P: (08) 8999 2778

Aboriginal cancer journeys: our stories of kinship, hope and survival (2010)

A collaboration between Aboriginal Health & Medical Research Council and the Cancer Council New South Wales, the booklet contains different stories and experiences from Aboriginal people affected by cancer. Some stories are about the experience of being diagnosed with cancer, others are about the experience of caring for someone with cancer and some are about undertaking treatment.

The booklet also contains individual fact sheets included in a pocket in the back cover of the booklet. These fact sheets provide additional information about cancer, treatment and care options, as well as information to consider before undertaking any form of treatment.

ORDER FROM:

Cancer Council New South Wales
153 Dowling Street
Woolloomooloo NSW 2011

P: (02) 9334 1900

F: (02) 9334 1741

E: feedback@nswcc.org.au

Beat breast cancer, have a free X-ray: regular breast X-rays save lives (2009)

BreastScreen WA has developed a brochure and poster to encourage Aboriginal and Torres Strait Islander women to have regular breast X-rays. These health promotional materials incorporate culturally meaningful language and artwork to explain the importance of, and the process involved in having breast X-rays.

ORDER FROM:

BreastScreen WA
9th Floor, Eastpoint Plaza
233 Adelaide Terrace
Perth WA 6000

P: (08) 9323 6700



Glossary

A.

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

Alkylating agent:
a class of chemotherapy,
e.g. cyclophosphamide.

Alternative therapies:
treatments 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®), doxorubicin (Adriamycin®).

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®), letrozole (Femara®), exemestane (Aromasin®).

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 gene: these are genes that normally prevent a patient 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: non-invasive breast cancer that is confined to (DCIS) 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.

RESOURCES

I.

Inflammatory breast cancer: 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 (MUGA)

scan: 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: is 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 Australian

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.

Pleural cavity: the space between the membrane that lines the rib cage and covers the lungs.

Pneumonitis: a side effect of radiotherapy in which the lung becomes inflamed.

Progesterone: a type of female hormone.

Radiology: tests that involve taking pictures of different parts of the body.

Radiotherapy: treatment for cancer in a particular area of the body using X-rays.

RESOURCES

R.

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.

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'.

White blood cells: blood cells produced by the bone marrow that help the body to fight infections.

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