

MY BREAST CANCER JOURNEY

A guide for Aboriginal and
Torres Strait Islander women
and their families.



Australian Government
Cancer Australia

START YOUR JOURNEY

Open this flap to see a map of the breast cancer journey and contents pages.



ABOUT THIS BOOKLET

This booklet contains information to help you understand more about early breast cancer. Your family and friends might also find this information helpful.

There is more information in Cancer Australia's *Guide for women with early breast cancer*. Ask your doctor if you don't have a copy or download from www.canceraustralia.gov.au

Write down important information, like the names of your doctors and nurses, or questions for your doctor.

The meaning of some of the medical words used in this booklet are explained on pages 21-23.

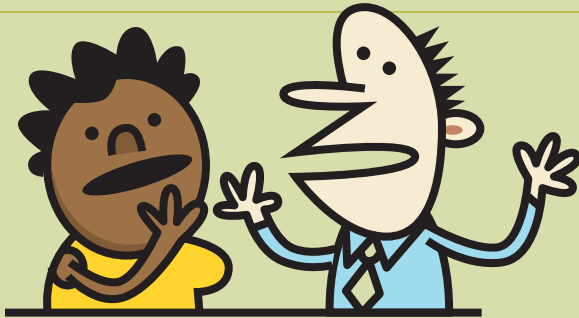


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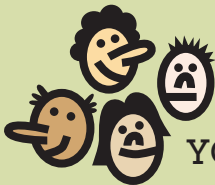
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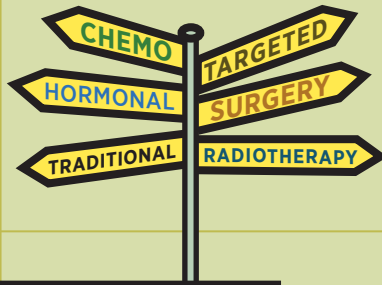
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MY BREAST CANCER JOURNEY: A GUIDE FOR ABORIGINAL AND TORRES STRAIT ISLANDER WOMEN AND THEIR FAMILIES

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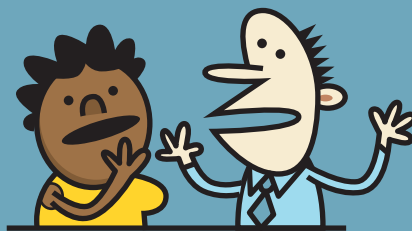
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Diagnosis



Being diagnosed with breast cancer can come as a big shock. This part of the booklet will help you understand more about your diagnosis, how you might be feeling and what will happen next.

Why you have been given this booklet

You have been given this booklet because you, or someone close to you, has been diagnosed with early breast cancer.

How you might be feeling



worried

shame



scared or uncertain

lonely



sad or angry

All these feelings are normal. It can help to speak with someone about how you are feeling.

“When you’re first told, you go through like a shock thing, then crying, and then you’re angry.” Noongar woman, WA

Continued next page →

Your family and community

Having support from your family and community during your diagnosis and treatment is very important. Partners, family and friends may find your diagnosis and treatment stressful and worrying. It may help to bring them to your appointments to help them find out more and it may help them to talk to someone for support.

Talking to your family and community

Here are some tips to think about when speaking to your partner, family and friends about your diagnosis and how you are feeling:

- Think about how much information you would like to share before talking.
- Be honest and clear when answering their questions.
- Talk openly with your partner about how you are both feeling.
- Tell them how they can help you.

Who can help you and your family?



Family and friends.

Aboriginal and Torres Strait Islander Health Worker in your community, your doctor or a nurse.

Another woman in your community who has had early breast cancer or another type of cancer.

Calling the Cancer Council Helpline on 13 11 20.

Your doctor may be a man or a woman. If you would prefer to talk to a woman about your breast cancer, tell your Aboriginal and Torres Strait Islander Health Worker or nurse.

Talking to your kids

Your kids may feel scared or worried. Decide what information they can cope with. Be honest and talk to them about feelings as well as the facts.

Things that may help

- Talking
- Giving simple answers to questions
- Maintaining routine
- Negotiating tasks
- Telling children it is not their fault
- Encouraging kids to participate in sport and normal activities
- Giving information in stages
- Allowing others to offer support
- Letting kids talk about difficult things
- Encouraging kids to work out problems themselves
- Letting the school know
- Maintaining rules and consequences
- Letting them see that you are upset sometimes

Things that will NOT help

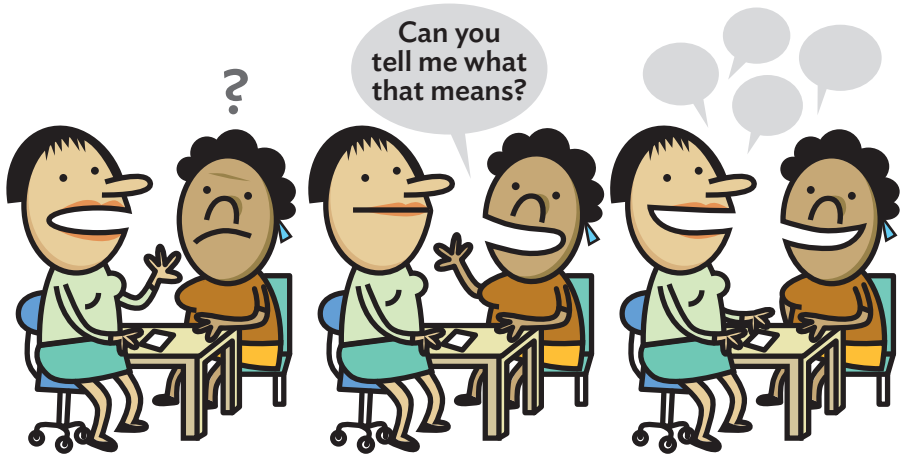
- Keeping secrets
- Overloading kids with information
- Letting go of structure and rules
- Giving orders
- Telling kids to 'be good for Mummy'
- Expecting kids to spend all of their time at home 'because time together is precious'
- Talking about possible outcomes far in the future
- Thinking you can do it on your own
- Rushing to reassure
- Trying to fix everything for them
- Keeping everything private
- Letting discipline slip because of guilt
- Pretending everything is OK

Things to remember

- Talking about how you're feeling can help.
- A social worker, counsellor, psychologist or psychiatrist can provide help in this area.
- Talk to your local Aboriginal and Torres Strait Islander Health Worker, doctor or nurse for more information.
- Your family might like to read this booklet to understand your treatment.

Ask questions

Asking questions is a good way to learn about breast cancer.



You may not always understand what the doctor says.

Don't be afraid to ask lots of questions.

Below are some example questions:

- Can I bring a family member with me to my appointments?
- Can you write down what you have told me so that I can read it later?
- Can I have a copy of my pathology report and can you explain it to me?

Write your own questions here:

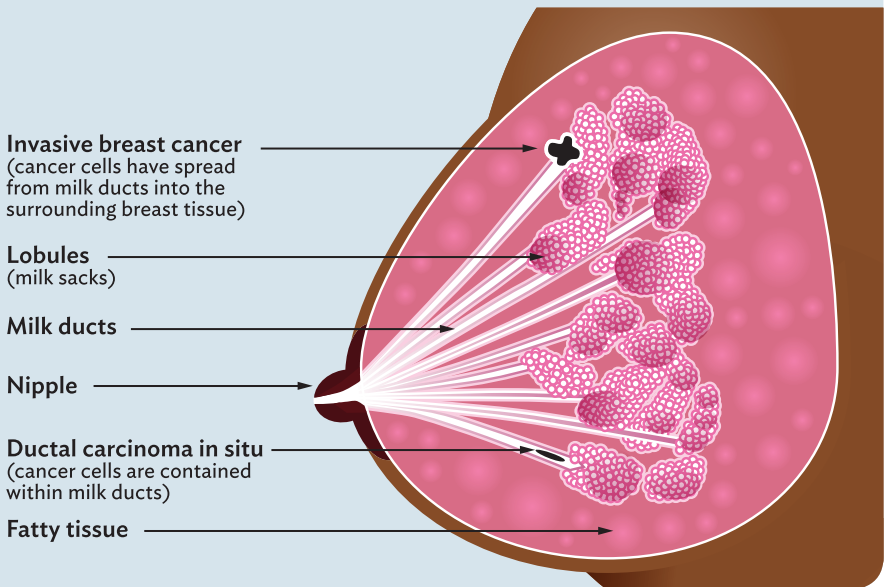
“A month before I was diagnosed I had a new granddaughter and that’s been my inspiration to get better. She’s five this year and my five years are coming up.” Yamitji woman, WA

What is breast cancer?

The body is made up of many tiny cells. These cells grow and divide. Breast cancer develops when cells in the breast grow differently to other cells. Early breast cancer is invasive cancer contained in the breast and may or may not have spread to lymph nodes in the breast or armpit.

Important things to know

- Breast cancer can happen to any woman, young or old.
- Having early breast cancer does not mean that you will die. More and more women are surviving breast cancer every year.
- Women who find breast cancer early, before it has spread, and complete treatment will have the best chance of surviving.



What do your test results mean?

You will have some tests to work out what type of breast cancer you have and whether it has spread outside your breast. The results of these tests will be given to you and explained by your doctor, nurse or Aboriginal and Torres Strait Islander Health Worker.

Here are some explanations about what the results mean.

Test result	Why it is important
Size and location	Tells your doctor how big the breast cancer is and where it is in the breast.
Lymph nodes	Lymph nodes are glands in your body that help you to fight infection. Testing the lymph nodes near your breast helps the doctor know whether breast cancer cells have spread.
Surgical margin	The surgical margin is an area of healthy tissue around the breast cancer. Testing the surgical margin helps the doctor know whether all of the breast cancer was removed from the breast during breast surgery.
Grade of breast cancer	Tells your doctor how slow or fast the breast cancer is growing. The cancer grade is numbered from 1 to 3. Grade 1 cancers are slow growing. Grade 3 cancers are faster growing.
Hormone receptor status	Helps the doctor know what types of medicine can be used to treat the breast cancer.

Ask your doctor, nurse or Aboriginal and Torres Strait Islander Health Worker to explain your test results if you don't understand them.

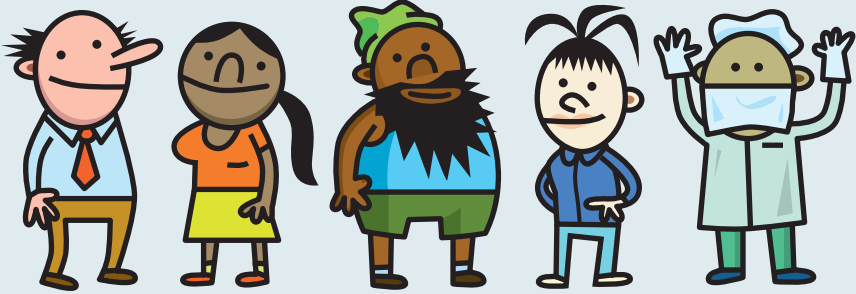


What happens next?

After you have been diagnosed with early breast cancer, your doctor will talk to you about your treatment options.

Your treatment team

You will see many health professionals on your cancer journey.



Health professional

Role in your care

General Practitioner (GP)

Your local doctor who provides ongoing care. They will be able to help other doctors understand your medical history.

YOUR GP'S NAME:

PHONE:

Aboriginal and Torres Strait Islander Health Worker

Understands your culture and beliefs. Can offer support and answer questions.

NAME:

PHONE:

Aboriginal Liaison Officer

Understands your culture and beliefs. Can offer support, and talk with other members of your treatment team.

NAME:

PHONE:

Continued next page →

Breast Care Nurse (BCN)

A nurse with specialised knowledge of breast cancer who will help and support you through your cancer journey.

NAME: PHONE:

Oncology Nurse

Specialises in caring for people with cancer. Will care for you during and after your treatment, and may help to deliver some treatments.

NAME: PHONE:

Surgeon

Performs operations.

NAME: PHONE:

Radiation Oncologist

Specialises in radiotherapy.

NAME: PHONE:

Medical Oncologist

Specialises in chemotherapy, hormonal therapy or targeted therapy.

NAME: PHONE:

Some other health professionals you may meet

- Physiotherapist
- Occupational therapist
- Pharmacist
- Social worker
- Plastic surgeon
- Dietician
- Radiologist
- Pathologist

Having lots of different health professionals involved in your treatment is called multidisciplinary care. This is the best type of care.

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Types of treatment

There are different types of treatment for early breast cancer. You might have one or more types of treatment. You can have a say in what treatment you have.

Breast cancer surgery

What is it?

An operation to remove the cancer.

What might be done

- The surgeon may take out the breast cancer only (called a lumpectomy or breast conserving surgery).
- The surgeon may take out some lymph nodes from near your breast.
- The surgeon may remove the whole breast (called a mastectomy).

What is involved

- Breast surgery can take 1 to 2 hours.
- You might be in hospital from 1 day to 1 week.
- Depending on where you live, you may need to travel some distance to a hospital for breast surgery.



Continued next page →

Radiotherapy

What is it?

A type of x-ray used to kill cancer cells in the area it targets.

When you might have it

After surgery to your breast or armpit.

What is involved

- Usually you will have radiotherapy once a day for 5 days a week.
- You will lie on a bed while you have treatment – each treatment will only take a few minutes and you will need time to get changed and wait.
- Treatment will usually last from 3 to 6 weeks.
- Depending on where you live, you may need to travel to a hospital for it.



Chemotherapy

What is it?

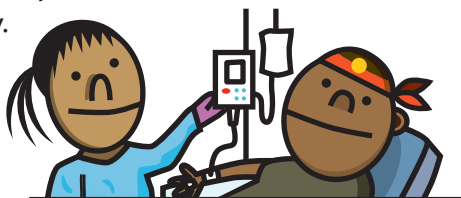
A medicine that kills cancer cells that may have spread to other parts of the body.

When you might have it

Before or after breast surgery.

What is involved

- It may be put in your arm or hand (like a drip) or taken as a tablet.
- Treatment will be given in 'cycles'. For example once a week for 3 weeks followed by a rest week. The overall length of your chemotherapy program could be between 3 to 6 months.
- It will usually be given at a hospital in your town or nearest regional town.



Hormonal therapy

What is it?

A type of drug that stops the growth of certain types of breast cancer cells.



When you might have it

If your breast cancer cells have hormone receptors on them.

What is involved

- You usually take a tablet for a number of years.
- Types of therapy depend on your stage of life and hormone levels.

Targeted therapies

What are they?

Drugs that treat certain types of breast cancer cells.

When you might have them

If your breast cancer cells have certain receptors on them. For example, trastuzumab (Herceptin©) is used in women with a receptor called HER2 on their breast cancer cells.

What is involved

- Treatment varies depending on the type of breast cancer.
- It may involve having some extra tests before or during treatment.

Traditional bush medicine

Don't forget to tell your treatment team if you are using, or thinking of using, any traditional bush medicines.





Questions about your treatment

Asking questions is a good way to learn about your treatment. Below are some example questions.

- Who is in my treatment team?
- Who is my main contact person?
- Will I need to travel for treatment?



Write your own questions here:

“The one thing I can say was good about my chemo experience was the staff up on the ward. They were very supportive; always try to make you feel happy.” Yidinji woman, QLD

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How treatment can make you feel

Treatment for breast cancer may cause changes to your body and make you unwell. Speaking about how you are feeling and doing healthy things can help you feel better.

Possible side effects of breast cancer treatments

- Pain or soreness in areas where you have had treatment
- Losing your hair
- Feeling sick or vomiting
- Losing weight
- Feeling tired (fatigue)
- Trouble going to the toilet
- Going to the toilet too often.



If you have any side effects, tell your doctor, nurse or Aboriginal and Torres Strait Islander Health Worker. There are treatments available and things you can do which can help you feel better.

Treatment for breast cancer can make you feel



worried



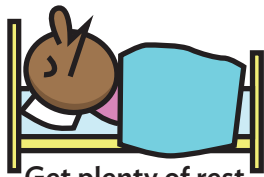
sad



hopeful

All these feelings are normal. It can help to speak with someone about how you are feeling.

Look after yourself during and after treatment



Get plenty of rest



Eat healthy food



Drink lots of water



Quit smoking



Cut down on grog
(alcohol)



Do some gentle exercise

Who can help you?



Family
and friends.

Aboriginal
and Torres
Strait Islander
Health Worker
in your
community,
your doctor
or a nurse.

Support
group in
the hospital.

Another
woman in your
community
who has had
breast cancer
or another
type of cancer.

Calling the
Cancer
Council
Helpline
on 13 11 20.

Questions about how you are feeling

Below are some example questions:

- Who can I talk to about how I am feeling?
- Is there a counsellor or psychologist you would recommend?

Write your own questions here:

4



Going away for treatment

Depending on where you live, you may need to go to the city for some or all of your treatment.

Help with travel

There are patient support schemes to help you pay for travel and accommodation during treatment. Support schemes are different in each State and Territory. Talk to your local Aboriginal and Torres Strait Islander Health Worker, doctor or nurse for more information.

Personal support for you

You can bring a support person with you. Your support person may be a family member or a friend. Some hospitals have rules about how many more support people can be with you during treatment.

Before you leave home

Here is a list of things you might need to do before you leave home. Fill in the list with anything else you need to do.

- Find help to look after children or grandchildren.
- Get leave from work.
- Ask someone to mind your home.
- Check any bills that are due.

Continued next page →



- Check what the weather will be like where you are going so you know what clothes to bring.
- Ask the Aboriginal Liaison Officer or Social Worker what financial support could be available for you.
- _____
- _____
- _____
- _____

Call the Cancer Council Helpline on 13 11 20 to find out more about practical help available.

What to bring to hospital

- Referral letter from your doctor.
- Travel and accommodation paper work.
- Medicare card and any pension or concession cards.
- Regular medicine you may be taking.
- Identification (such as a driver's license).
- Mobile phone and charger.
- Comfortable clothes.
- Money or bank card.



It is a good idea to label your belongings so they don't get lost.

Hospital rules

Different hospitals will have different rules.

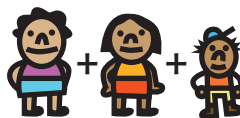
Check with your hospital about:



Times when you can use your mobile phone

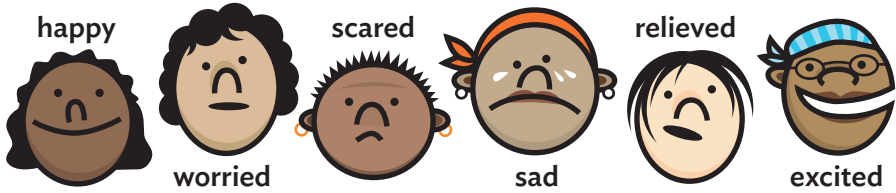


Times when your family and friends can visit



The number of family and friends who can visit at one time

When you leave hospital, you might feel



If you feel worried or nervous about finishing treatment, speak to your doctor, nurse or Aboriginal and Torres Strait Islander Health Worker.

You might bring home



Discharge information

Give this information to your local doctor when you get home.

New medicine

Ask your doctor or nurse if you're confused about your medicine.

You might like some help when you get home

Your nurse or your Aboriginal Liaison Officer can arrange for a health worker to visit you at home, and make sure you're OK.

Questions about going away

Asking questions can help you find out about going away for treatment and staying in hospital. Below are some example questions:

- Will I need to travel for treatment?
- If I take time off work, how do I apply for temporary income support?
- Can I get help with travel and accommodation costs?
- How can I find out about home help while I am going through treatment?

Write your own questions here:

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Follow-up care

Follow-up care after treatment is an important part of surviving breast cancer. For most women, no changes are found during follow-up appointments. Going to your follow-up appointments means that if breast cancer does come back or if a new breast cancer develops, it can be treated quickly.

Why you should return for follow-up care even if you feel good

- To check that the breast cancer hasn't come back.
- To see if you have any side effects.
- To talk about how you are feeling.



How often you should go

- Every 3-6 months. This will become less.
- Your doctor will tell you when you need to visit.
- You may need to travel for this appointment.
- Find out if you can take someone along with you to support you.



What will happen

You will have a scan, called a mammogram and/or an ultrasound, once a year.

Your doctor will:

- ask how you're feeling
- check if you have any symptoms
- feel your breasts, chest area, arms and maybe other parts of your body to check for any lumps.



Other issues

Lymphoedema after breast cancer is swelling of the arm or breast due to build-up of fluid. If left untreated this can become difficult to manage.

Signs to look out for:

- a feeling of heaviness, tightness or fullness in the arm or breast
- swelling of the arm, breast or hand
- aching, pain or tension in the arm, hand, chest or breast area.

Tell your doctor or Health Worker if you notice any of these signs. Lymphoedema can be managed with appropriate care.

Looking forward

Having breast cancer can change how you think and feel about things.



Happy feelings

- Feeling fit and healthy.
- Having new goals.
- Appreciating your friends, family and community more.



Sad feelings

- Worried about the cancer coming back.
- Sad that things may have changed (like changes to your body, or changes to your relationships).

If your sad feelings are very strong, speak with your Aboriginal and Torres Strait Islander Health Worker, doctor or nurse.

Remember, it's OK to ask for help when you need it.



Have a yarn

Every woman's cancer journey is different. It can help to speak with other women in your community who have had cancer, and hear their stories.



“Strong women talking, gathering together, weaving, going bush and telling stories helped me.” Tiwi woman, NT

Contact Breast Cancer Network Australia or Cancer Council Australia to find out if there are local support groups in your area (contact details at the end of this booklet).

Questions about follow-up care

Below are some example questions:

- How often will I need follow-up tests?
- What will my follow-up tests involve?
- Who do I talk to about lymphoedema?
- Do you know of any support groups in my area?



Write your own questions here:

What does that word mean?

Throughout your cancer journey, you will hear a lot of medical words. Here are some common words to do with breast cancer.

Remember that it is OK to ask your doctor or nurse to explain something that you do not understand.

Word	Meaning
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.
Alternative therapy	Treatments used instead of conventional treatment.
Aromatase inhibitor	A type of hormonal therapy, e.g. anastrozole (Arimidex [®]), letrozole (Femara [®]), exemestane (Aromasin [®]).
Axilla	The armpit.
Biopsy	Removal of cells or tissue from the body for examination under a microscope.
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.

Continued next page →

Word	Meaning
Chemotherapy	Treatment for cancer using drugs.
CT scan	A special type of x-ray that provides a three dimensional picture of the inside of the body. The initials stand for 'computerised tomography'.
Endocrine therapies	Another name for hormonal therapies.
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.
Intravenous infusion	A method of putting fluids, including drugs, into the bloodstream through a cannula or needle.
Lumpectomy	See 'Breast conserving surgery'.
Lymph nodes	Glands in the armpit and other parts of the body that protect the body from infection.
MRI scan	A way of producing a picture of the inside of the body using magnetic fields. The initials stand for 'magnetic resonance imaging'.
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.

Word	Meaning
Multidisciplinary care	A team approach to cancer treatment and planning.
Oncologist	A doctor who specialises in treating cancer.
Pathology	Tests that involve examining blood, tissue and cells in the body.
Radiotherapy	Treatment for cancer in a particular area of the body using x-rays.
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'.
Targeted therapies	Drugs that stop the growth of particular types of cancer cells. Also known as biological therapies.
Ultrasound	A way of producing a picture of the inside of the body using sound waves.

Write down any other new words you may have heard when talking about breast cancer:

You can find the meaning of more words by talking to your Aboriginal or Torres Strait Islander Health Worker, doctor or nurse.



Helpful contacts



Cancer Australia

www.canceraustralia.gov.au

Cancer Australia is the lead national cancer control agency. The Cancer Australia website provides evidence-based information about a range of cancers, including breast cancer.

Cancer Council Australia

Helpline: 13 11 20

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.

Breast Cancer Network Australia

Free call: 1800 500 258

www.bcna.org.au

Breast Cancer Network Australia (BCNA) works to ensure that women diagnosed with breast cancer, and their families, receive the very best information, treatment, care and support possible.

CanTeen

Free call: 1800 226 833

www.canteen.org.au

This website provides support services to young people aged 12-14 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.

Acknowledgements

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