A Guide to Breast Health
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Acknowledgements

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- Disability Services Commission staff;
- BreastScreen WA program staff;
- Sheena Sullivan and Dr Emma Glasson from Edith Cowan University;
- Disability Services Queensland;
- National Health Service (NHS) Cancer Screening Programme; and
- Victorian Breastscreening Program.
Message from the Minister

Although breast cancer is the most common cause of cancer death for Australian women in recent years, there has been a steady reduction in breast cancer mortality. Thanks to an intensive community education program, early detection through mammography screening has played a significant role in this decline and it is extremely gratifying to see that the life-saving breast health message has been heard by women.

But has this message reached women with intellectual disabilities? Research both in Australia and overseas has found that many of these women are unlikely to be aware of breast health messages or seek screening, without the support of others. As a result, many women could be missing out on potentially life-saving procedures.

“A Guide to Breast Health” has been produced by the Disability Services Commission and BreastScreen WA to ensure that women with intellectual disabilities, their families, medical practitioners and others who support them are aware of the importance of regular examination and screening.

A user-friendly publication, it clearly spells out in pictures why women need regular examinations, how the mammograms are carried out and the importance of sharing concerns and feelings with others. Importantly, it also includes advice for family members and carers on assisting the woman to participate in breast screening and dealing with the issues that may arise subsequently.

People with disabilities are living longer and healthier lives and there is an increased awareness among people themselves, their families and carers of the need to maintain a healthy lifestyle. This publication will go a long way towards assisting this endeavour and more importantly, may save lives.

Sheila McHale MLA
Minister for Disability Services (2004)
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Breast awareness is for all women.

Breasts come in all shapes and sizes.
Your breasts may change at times.

You should check your breasts for changes after your period.
This is how you look for changes.

Can you see:

■ a lump?
■ changes to the nipple?
■ changes to the skin?
■ discharge and/or bleeding?
■ a change in the shape or size of a breast?
LOOK
A good place to feel your breasts is in the shower and in your bed.

Feel for:

- lumps;
- hard bits; or
- tender or painful areas.
If you notice any changes it is important to tell someone you trust.

This might be your:

- family member or a friend;
- health professional like a doctor, nurse or health worker;
- Local Area Coordinator;
- husband or partner; or
- social trainer, carer or support worker.
Clinical Breast Examination

If you feel a lump or notice any changes to your breasts you should go to your doctor.

Get your doctor to check your breasts.

Talk to someone you trust. They can go with you to the doctor.
You and a friend arrive at the medical centre.
The doctor will talk to you about the breast check.

The doctor will ask you to take your top and bra off so she/he can look at and feel your breasts.
The doctor will look at your breasts.
The doctor will feel your breasts.

When the doctor is doing the breast check it is ok to tell her/him to stop.
The doctor will talk to you about the breast check.

The doctor might ask you to have a different type of check called a mammogram.
Well done for completing your breast examination.
Mammography Screening

It is recommended that women 50 years and over have a free screening mammogram at BreastScreen WA every two years.

A mammogram is an X-ray of the breast.
You may receive a letter inviting you to have a mammogram or someone may recommend that you have one.

Talk to someone you trust. They can help you make a decision.

This might be your:
- family member or a friend;
- health professional like a doctor, nurse or health worker;
- Local Area Coordinator;
- husband or partner; or
- social trainer, carer or support worker.
You have a mammogram to check if your breasts are healthy.

When you have a mammogram they place each breast between two plates. This might hurt a little bit or feel uncomfortable, but only for a few seconds.
Doctors can recommend you have a mammogram.

You need to decide if you want to have a mammogram.
You and a friend arrive at the breast screening clinic.

All BreastScreen WA clinic staff are female.
When you arrive at the clinic you will:

- give your name to the receptionist; write some details on a form; and give your consent for the mammogram;

- wait in the reception area.
You will be shown to a change room.
You will be asked to take off your top and bra.

You can put your top back on or a disposable gown will be provided.

Your friend can stay with you if you want her to.
The radiographer who will do your mammogram will show you the X-ray machine and explain what she will do.
The radiographer will take two X-rays of each breast. She will need to place each breast between two plates. This might hurt a little bit or feel uncomfortable, but only for a few seconds.

The radiographer and your friend will stand behind a screen during the X-ray. The radiographer will tell you when she is taking the X-ray and ask you to keep still.
KEEP STILL
It is okay to ask the radiographer to stop the X-ray.

You must keep still until the radiographer removes the plates.
STOP
After the radiographer has finished the X-rays you can wait in the change room.

The radiographer will need to check the quality of the X-ray before you go.

If the quality of the X-ray is ok you can get dressed and go.
Well done for completing your mammogram.

You will receive the results of your X-ray in two weeks time.
If your Mammogram results are normal

Two weeks later your results will arrive in the mail.

Talk about the results with someone you trust.

This letter tells you that your mammogram is normal.

You will receive another letter inviting you for a mammogram in two years.

You still need to be breast aware.
Being Breast Aware

Remember your breasts may change at times.

You should check your breasts for changes:

- after your period; or
- on the same day each month.
These are the changes to look for:

■ a lump, lumpiness or thickening of the breast tissue;
■ changes to the nipple;
■ discharge from the nipple;
■ changes to the skin (puckering or dimpling);
■ a change in the shape or size of a breast;
■ any persistent or unusual pain.
LOOK
A good place to feel your breasts is in the shower and in your bed.

Feel for:

- lumps;
- hard bits; or
- tender or painful areas.
FEEL
If you notice any changes it is important to tell someone you trust.

This might be your:

- family member or a friend;
- health professional like a doctor, nurse or health worker;
- Local Area Coordinator;
- husband or partner; or
- social trainer, carer or support worker.
If You Need Further Tests

A breast assessment nurse will telephone you to discuss the mammogram result. Further tests may be recommended to focus on the area of the breast that needs to be examined in more detail. The nurse will suggest an appointment time for you to have further tests.
You should speak with someone you trust. They can help you make a decision. You need to decide if you want to have the tests.
If you decide to have further tests take someone you trust with you.
Further information for supporters and carers
Introduction

A support person may be a carer, friend, family member or paid supporter. People in supporting roles play an important part in the lives of people who have a disability. In the area of health, support people are able to assist a person with a disability to understand health issues and access services. It is not expected that supporters are health experts but they require information and an awareness of services to meet basic health needs.

Being breast aware and having a mammogram is important because breast cancer is the most common cancer for women in Australia. One in 8 women will develop breast cancer at some point in their lives. Having a mammogram could save a life.

Being aware of breast changes and health checks is important for all women through the lifespan. If the woman you support has trouble being breast aware please request an annual clinical breast examination by her doctor (as part of any health review). If the woman is over 50 years of age and has no symptoms, a mammogram is recommended every two years. If symptoms are present, the women needs to see her doctor regardless of whether she has had a mammogram.

Screening guidelines can change depending on family history so if there is uncertainty about the guidelines or of any breast changes, check with the doctor.
How to use this booklet

This booklet provides information for people in supporting roles so they can communicate the need for breast awareness and to facilitate access to appropriate services. The level of involvement will vary depending on the specific needs of each person. The supporter should read the booklet before reading through it with the woman. The booklet may also be used during appointments as a communication tool.

It is imperative that the supporter allows time to provide support, answer questions honestly, explore feelings and discuss attending appointments. It is vital that the person with a disability understands what will happen and why, and chooses to go, because making an informed and prepared decision will increase the likelihood of a successful procedure.

Below are some questions a person in a supportive role may like to consider.

- How can I facilitate involvement in decisions about breast health? Should other carers or family members be involved in this process?
- How will I be able to facilitate consent and what will I do if consent is not possible?
- What will be the reaction if recalled for further assessment, tests or treatment?
- It is important to see a female doctor. What might happen if it is a male doctor?
Am I prepared for the possibility of raising fear and anxiety about cancer?
Am I prepared for the possibility of raising fear and anxiety about medical personnel and procedures if the experience is traumatic?

(Adapted from The Victorian Breast Screening Program 1996)¹

Capacity to consent

It is important that the woman having a clinical breast examination and/or a mammogram understands what she is consenting to.

It is important for her to have:

- a basic understanding of what breast screening is, what it is for, and why she has been invited or referred;
- an understanding of its principal benefits, risks and alternatives, for example, understanding that breast screening does not always locate the problem;
- an understanding that an abnormal mammogram means having further tests;
- the capacity to retain information sufficiently to make an effective decision; and
- the choice to attend, or not attend, free from pressure.

(Adapted from the NHS Cancer Screening Programmes 2000)²
Behavourial consent

For the screening to be undertaken the woman needs to:

■ cooperate with the radiographer/doctor;
■ not be unduly anxious;
■ respond to simple requests; and
■ show no signs of agitation or distress.

(Adapted from the NHS Cancer Screening Programmes 2000)²

If a woman shows signs of distress at any time, the health professional will stop the screening procedure.

Further information and resources on breast health are located on the back of this booklet.
Breast Awareness

Being breast aware is being aware of the usual look and feel of breasts and knowing about normal changes that may occur from month to month and as people age. Knowing what is normal for your breasts makes it easier to detect any unusual changes. The earlier a problem is detected the greater the chance of successful treatment.

Everyone should be breast aware. Clinical breast examination by a doctor, nurse or other trained health worker can be incorporated into a yearly health review as it can assist in the detection of breast abnormalities. Remember, most breast changes are harmless.

It is important to note that people who have an intellectual disability often do not relate symptoms to a disease. Therefore, supporters need to be aware that women with intellectual disabilities may not realise the importance of a breast change.

Noticing changes

Breasts come in all shapes and sizes and will change throughout our lives. Menstrual cycles, pregnancy, age, medication and weight can all change the size, shape and feel of breasts.
Some changes to look out for include:

- a lump, lumpiness or thickening of the breast tissue;
- changes to the nipple;
- discharge from the nipple;
- changes in the skin (puckering, dimpling, change in colour);
- persistent, unusual pain; and
- a change in the shape or size of a breast.

If any of these features are noticed or there is abnormal breast pain, a woman should see her doctor immediately. Remember, most breast lumps are harmless.

**Most breast changes are not breast cancer, however it is always important to have any changes checked out straight away by your doctor. Don’t delay.**
Clinical Breast Examination

Clinical breast examination is the examination of the breasts by a trained clinician.

When women are having breast examinations they will be asked to:

■ remove their top and bra;
■ sit upright and place their arms by their side, on their hips and head; and
■ lie down, placing their arm behind their head.

The health professional will look and feel the woman’s breasts to find any abnormalities by pressing firmly on each breast, nipple and armpit to feel for lumps. To maintain privacy a sheet may be placed over the chest during the examination.

People who have an intellectual disability often do not relate symptoms to a disease. Therefore, supporters need to be aware that a woman with a disability may not realise the importance of a breast change. Asking the doctor to check the woman’s breasts once a year can assist in detecting breast abnormalities.

When to book an appointment

If the woman is menstruating, the most appropriate time for a breast examination is soon after her period has finished.
Preparation tips for an appointment

- Book an extended appointment with the health professional.
- Book the appointment with a female or trusted health professional.
- Wear a two-piece outfit so that trousers or a skirt can be left on during the examination.
- Bring the “A Guide to Breast Health” booklet to the appointment.

Clinical breast examination results

If a health professional finds a breast abnormality she or he will refer the woman for further tests.
Mammography

A mammogram is an X-ray picture of the breast tissue. Mammography is used to show the presence of a lump before it can be felt or used for diagnosis if a lump has been detected.

The woman having the mammogram has to be carefully positioned on the X-ray machine and must be able to hold the position for several seconds. To optimise the quality of the image and to minimise the radiation dose, the breast must be compressed. This is an uncomfortable procedure, and for some women it may be painful. The radiographer will move away to stand behind a protective screen until the X-ray is taken. Usually two X-rays are taken of each breast, one from the side and one from the top. As the radiographer moves away, the woman having the mammogram may try to pull out of the breast compression plates, however, gentle reassurance may help to prevent this and encourage her to keep still.

When should mammography screening occur?

BreastScreen WA provides a free mammography screening service across the state. The BreastScreen WA program specifically targets women in the 50 to 69 year age group. Women aged 40-49 may also attend mammography screening but the test is less beneficial for women in this age group.

A mammogram can also be performed at a private radiology clinic for a fee.
Who is suitable for mammography screening?

Mammography is a procedure that is technically difficult and requires a high degree of cooperation between the radiographer and the woman having the mammogram. The following questions need to be considered before deciding whether a woman with a disability is suitable for mammography screening; if some of these requirements cannot be performed this should be discussed with a doctor before the appointment.

Is the woman receiving the mammogram able to:

- understand the procedure when it is explained?
- comprehend and cooperate with simple requests?
- cope in unfamiliar situations and environments with the assistance of a familiar supporter?
- independently hold her head up and hold her arms clear of both her chest and the breast support table while the mammogram is taken?
- support herself while her breast is held between the plates, particularly if she normally uses a wheelchair for mobility and support?
- tolerate discomfort?
- remain still for several seconds?
- does she have sufficient muscle control to maintain the position required?

(Adapted from NHS Cancer Screening Programmes 2000)²
If the woman is unsuitable for mammographic breast cancer screening it is essential that she discusses an alternative screening method with her doctor.

**Women who have Down syndrome**

Mammographic screening may not be beneficial for women with Down syndrome. Women with Down syndrome have a very low risk of breast cancer and are sensitive to the radiation used in X-rays, including mammography X-rays. A woman should discuss alternatives to mammographic screening with her doctor; this may include regular clinical breast assessments.

**How often should screening occur?**

The Department of Health in Western Australia recommends women over the age of 50 have a mammogram every two years if no symptoms are present. A referral or invitation is not required to make a mammography appointment. If a woman has been to BreastScreen WA previously she will automatically receive an invitation letter every two years.

In between X-rays, it is important to continue to be breast aware and see a health professional if any unusual breast changes occur.
BreastScreen WA Clinics

All metropolitan services provide access for women who use a wheelchair.

The outer metropolitan/country support mobile service is not suitable if the woman uses a wheelchair. The outer metropolitan service visits Serpentine, Pinjarra, Mandurah, Armadale, Beverley, York and Northam. If the woman lives in these areas BreastScreen WA can arrange an appointment at an alternative clinic.

The mobile screening services that visit rural areas are equipped with a ramp and handrail to allow access for most wheelchairs. Because the ramp gradient is steep, arrangements can be made to assist women with mobility difficulties to enter and leave the mobile unit. Please advise before the appointment if assistance is required.

Getting ready for a mammogram

When booking a screening appointment, request an extended appointment so no one is rushed. Once an appointment has been made, a helpful memory tool is to mark the calendar and write down the phone number, address and time of the appointment in the back of this booklet.

At the clinic the woman will be shown to a changing room and asked to remove her bra. The woman can put her own top back on or use a disposable gown during the mammogram. Talcum powder or deodorant should not be used on the day because they can show on X-ray pictures.
A preliminary visit to the clinic can be requested to familiarise the woman with the X-ray machine and environment prior to the date of mammography screening.

**Mammography results**

The results will arrive in the mail approximately two weeks after visiting BreastScreen WA for mammography screening. Results are also sent to the woman’s doctor, unless requested otherwise.

**What happens if they find something?**

If the mammogram finds a possible abnormality a Breast Assessment Nurse will contact the woman to discuss the results and explain the need for any further tests. The nurse will arrange an appointment time for her to have these tests.

It is important that supporters and professionals take time to explain what this means and to explore how the woman feels about it.

Most abnormalities on the breast X-ray that need further investigation are not cancerous. If further tests indicate cancer, treatment options and implications for treatment need to be discussed with a health professional such as a doctor.

Remember, even if a breast cancer is found, the sooner it is found, the better the chance of successful treatment.
Service Expectations

Supporter’s advocacy tips

■ Make an extended appointment time so no one feels rushed.
■ Inform the health professional if the woman you are supporting has difficulty speaking and how she will indicate yes or no if experiencing any undue discomfort.
■ Don’t be afraid to ask questions or say if you haven’t understood.

What you should expect when working with screening staff conducting clinical breast examination and mammography screening

Staff will:

■ speak directly to the woman having the mammogram and ask her to guide them as to what assistance she requires;
■ avoid jargon and technical terms;
■ give information in small blocks;
■ be careful not to use a patronising tone of voice; and
■ constantly talk and provide immediate feedback on her progress.
The person supporting the woman with a disability can advocate for the screening staff to:

- ask permission to involve the carer or support worker in the screening process;
- establish if the woman’s disability is likely to create special needs. If necessary, communicate these needs to relevant workers to avoid explanations and/or ask for assistance;
- show, explain and encourage the woman to touch the X-ray machine and put her hand on the plate to gain an expectation of the pressure;
- offer assistance with undressing and positioning at the X-ray machine but to be prepared to have the offer declined;
- treat a wheelchair as part of her personal space and to be sensitive to this when needing to handle it. Where possible, sit down to have a conversation if the woman uses a wheelchair;
- be aware of the possibility of having more than one disability, some of which may be hidden; and
- treat the woman with both privacy and respect. For example, if she is unable to use the standard changing room, ensure that she is given a private place to undress and also that she has access to a gown.

(Adapted from The Victorian Breast Screening Program 1996)
Facts About Breast Cancer

What is breast cancer?
Breast cancer is a group of abnormal cells that develop in the breast tissue and continue to grow and multiply. Eventually, these cells may form a lump in the breast. If the cancer is not removed or controlled the cancer cells can spread into other parts of the body and may eventually cause death.

How is breast cancer caused?
We do not know what causes breast cancer.

The disease is more frequent among:

- women aged over 50;
- women who have a significant family history of breast cancer; and
- women who have had breast cancer before.

What is significant family history?
Women are considered to have a significant family history if they have the following:

- A first degree relative (mother, sister, daughter, father, son, brother) with breast cancer diagnosed before the age of 50.
● A first degree relative with cancer in both breasts (diagnosed at any age).

● Two or more first degree relatives with breast cancer (diagnosed at any age).

Women 40 years and over who have a significant family history are eligible for a FREE screening mammogram every year with BreastScreen WA.

**Is there anything else I can do?**

The evidence linking healthier lifestyles and a reduction in breast cancer is inconclusive. However, leading a healthier lifestyle has wide ranging benefits. Health benefits can be gained by:

● choosing foods from each of the five food groups every day;

● being physically active every day;

● drinking plenty of water;

● limiting alcohol consumption to one standard drink per day with two or more alcohol free days per week; and

● not smoking.
Additional Information and Resources

BreastScreen WA

Provides a free, fully accredited evidenced-based mammography screening service for women over 40 years, particularly those aged 50–69 years.

Appointments: 13 20 50
Information: 9323 6700 or 1800 800 033 (toll-free for country callers)
TTY: 1800 241 708
Facsimile: 9323 6799
Website: www.breastscreen.health.wa.gov.au
Email: breastscreenwa@health.wa.gov.au
Translating and Interpreting Service (TIS): 13 14 50

Local General Practitioner/Doctor or Medical Centre

For information, clinical breast examination and referrals.
Women’s Health Services

Female staff are available to perform clinical breast examinations, breast awareness education and referrals.

Reception: 9227 8122 or 1800 998 399 (toll-free for country callers)

FPWA
(Formerly Family Planning Association of WA)

Female doctors are available by appointment for confidential breast checks and referrals.

General enquires: 9227 6177
Sexual health helpline: 9227 6178 or 1800 198 205 (toll-free for country callers)
Email: info@fpwa.org.au
Website: www.fpwa.org.au

Women’s Health Centres

There are many Women’s Health Centres located around the state. Check your local telephone directory for one near you.
The Cancer Council of Western Australia

A non-government, community supported organisation providing information, resources and support services for all types of cancers including a telephone information and counselling service (Cancer Helpline).

Cancer Helpline: 13 11 20
(for the cost of a local call statewide)
8am–8pm weekdays, 9am–3pm Saturdays
9381 6562 (TTY)

Head Office: 9212 4333
Website: www.cancerwa.asn.au
Email: inquiries@cancerwa.asn.au

Activ Library

For various resources on intellectual disability.

Reception: 9387 0458
Website: www.activ.asn.au
Email: library@activ.asn.au
References


Acknowledgements

Sections of the text used in this booklet are based on BreastScreen WA publications.

Appointments Calendar

Once you are over 50 years of age you should have a mammogram every two years. Write below the date of your last mammogram and clinical breast examination (CBE).

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When visiting a doctor ask about:

- blood pressure;
- body mass index/healthy weight;
- cholesterol levels;
- diabetes;
- osteoporosis;
- hormone replacement therapy;
- menopause; and
- contraception and family planning.