

Treatment services
and support
for women
with breast cancer

Treatment Services and Support for Women with Breast Cancer

Finding out you have breast cancer is very hard.

Everyone has different feelings about it.

BreastScreen Aotearoa can help you with

services and support.

If you have any questions, talk to the Breast Care nurse at your BreastScreen Aotearoa centre or call the Cancer Information Service.

0800 226 237



What to do if you find out you have breast cancer

- · Get some support from family and friends
- Talk about your choices with the surgeon or nurse at your BreastScreen Aotearoa centre or your GP
- Take your time to make your decision
- Ask for things to be told to you again if you are not sure about anything.

Treatments

- Breast cancer treatments are very good these days
- The doctor at BreastScreen Aotearoa will tell you about them and help you to make a decision.

What sort of treatment you will have will depend on:

- The type and size of your cancer
- If it has spread beyond your breast
- Your age and general health
- Your choice.

What are the main types of treatment?

- Taking out the cancer and some normal tissue around it
- Mastectomy removal of the breast
- Radiotherapy x-rays to kill the cancer cells
- Chemotherapy drugs to treat the cancer
- Hormonal pills to help stop some cancers growing.

Remember

- Breast cancer can be treated
- Strong feelings are normal
- Fears are natural
- It can take you a while to make up your mind
- Don't be afraid to ask questions.

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Treatment Services and Support

For information on services and support in your region, see information in back pocket of booklet.

BREAST CANCER TREATMENT SERVICES AND SUPPORT

Finding out you have cancer is difficult and stressful.

This booklet will help to identify questions and concerns you may have. It will also provide information about your options and the support and information that is available in your region. This may help you to make decisions about treatment.

Women respond in different ways to the news that they have breast cancer and will want different kinds of help and information. BreastScreen Aotearoa is able to provide a range of services and support to women diagnosed with breast cancer to help them cope during this time. Many women who have been treated for breast cancer go on to lead healthy, satisfying lives.

Some women fear they may need to have their breast removed, others worry about the effect of cancer treatment – will I need drugs which could make my hair fall out?

Some women want a lot of information and are able to ask lots of questions. Some don't want to know anything when they are first told but have questions later.

There are many misconceptions about cancer in the community, and during this time friends may say things to you that are well meaning but wrong. At our present state of knowledge, there is little women can do during their lives to prevent breast cancer and the causes of the disease are not well understood. Any woman can get breast cancer no matter how healthily she has led her life.

For more information about the causes of breast cancer, talk to the Breast Care nurse at your BreastScreen Aotearoa Centre or call the Cancer Information Service. Phone 0800 226 237.

The staff at the BreastScreen Aotearoa Centre are there to help you and to answer your questions. They understand that it may be very difficult to make some important decisions, and they are there to offer the level of support and information you need.

Early treatment gives a better chance of survival, and many women can be offered breast-conserving surgery that means they will not lose their breast.

Your decision about treatment

When women are told they have breast cancer, most want the support of family and friends and time to make decisions about the next step.

Cancers take many years to develop, so the treatment of breast cancer detected by a screening mammogram is not usually a medical emergency.

The surgeon at BreastScreen Aotearoa will discuss the treatments that are recommended for you and advise you as to how long you can take to think about your options and decide.

The centre will also have a Breast Care or specialist nurse available for you and your family to talk with at the time of diagnosis and while you consider your treatment options.

You can choose to discuss your options with the surgeon or Breast Care nurse at the BreastScreen Aotearoa Centre. You may also want to talk to your general practitioner. It is a good idea to bring a supportive person along to help you remember what the doctor and nurse say. You are encouraged to take written notes or tape these discussions.

It is important to ask for information to be repeated or explained if you are not sure what you are being told.

CONSIDERING YOUR OPTIONS

To help make the best decision for you, you'll need to know what treatments are available and which treatments are likely to be most effective for you. These need to be considered along with how you feel about yourself and your body. This booklet explains the main options for your treatment and where treatments are available. It also suggests questions you may want to ask before or during your next appointment.

The public health system is able to offer a full range of treatments for women with breast cancer, and all these services are free. Women who have to travel to a main centre for treatment will have travel and accommodation needs. These are free or subsidised in many cases, but sometimes there will be a cost. Transport and Accommodation Assistance may also be available. Freephone 0800 281 222

The staff at the BreastScreen Aotearoa Centre or your family doctor and the hospital treatment service should give you information on:

- how the public health system is able to offer a full range of free treatments and services for women with breast cancer
- all available options for treatment, including the advantages and disadvantages
- treatments that are available in the private sector, the costs involved, the possible advantages and disadvantages and how quickly treatment is available
- the implications of options such as radiotherapy that may require travel to a main centre and the assistance available to help you and your family if required
- where you can access further information.

It is important for you to have time to talk to the surgeon and nurse and to ask any questions you may have.

When you are ready, either the BreastScreen Aotearoa Centre staff or your family doctor will refer you for treatment.

What are the main types of treatment for breast cancer?

Medical specialists involved in diagnosing and treating breast cancer in New Zealand are up-to-date with the best treatments. The specialist you see will be able to discuss this with you.

The type of surgery and whether you may need other treatment following surgery will depend on many factors such as:

- the type, size and position of your breast cancer
- whether or not it has spread beyond the breast
- your age and general health
- · personal choice.

The surgeon you choose for your treatment will discuss these issues with you in detail and assist you to decide which option is best for you. The breast care nurse will also discuss your options.

The different types of treatment most commonly used for breast cancer are:

- Surgical removal of the cancer with some normal breast tissue surrounding it. This surgery is usually followed by radiation therapy. This is known as breast conserving treatment as most of the breast is preserved. The operation is sometimes called a lumpectomy, wide local excision, breast conserving surgery, sector resection or partial mastectomy.
- Mastectomy means removal of the whole breast containing the cancer.

With both of these treatments, some or all of the lymph nodes are removed from the armpit to check if the cancer has spread into the lymphatic system – the body's drainage system. Depending on all of the findings from the surgery, further treatment may be recommended in the form of chemotherapy, radiotherapy or hormonal treatment.

- Radiotherapy (also known as radiation therapy) uses powerful x-rays
 to destroy any remaining cancer cells. Radiotherapy is not usually
 required after a mastectomy for small cancers found by
 mammograms.
- **Chemotherapy** is the treatment of cancer by drugs. The aim is to destroy cancer while having the least possible effect on normal cells.
- Hormonal treatment helps prevent the growth of some cancers.

Breast reconstruction may be suitable for some women who are having a mastectomy. You can talk to your surgeon about this option. Remember to ask when this might be performed.

Your appearance after breast-conserving surgery may not be noticeably different, but there is a range of comfortable inserts available for your bra, if you want one. When your wound has healed, you can obtain one of these from specialist lingerie shops. Government assistance is available to assist with the cost.

Where are breast cancer treatment services provided?

- Comprehensive specialist breast cancer treatment services are available to you free of charge from at least one public hospital in your region.
- Breast surgery is available at a number of hospitals. Generally speaking, the smaller the hospital the less likely it is that the surgeon specialises in breast surgery. However, there are exceptions to this and you can discuss this with the surgeon or nurse at the BreastScreen Aotearoa Centre or your general practitioner.
- Wide local excision of a lump that the surgeon can feel can be performed at any hospital that has mammography X-ray facilities to check the lump has been completely removed.

- If the cancer is too small to feel, you may need to have a fine wire inserted into the breast under local anaesthetic, before the operation, to help the surgeon locate exactly which area to remove. This procedure is performed with a special mammogram or ultrasound machine and an experienced radiologist and is only available at some hospitals.
- You may need a range of treatments over time, such as radiotherapy and chemotherapy. This is provided by a team of health professionals who work together to plan your care. This type of team care is available in a number of centres (refer to regional leaflets in the back of this booklet). You will be referred to one of these centres if necessary.
- Specialist surgeons are available in the private sector, but treatment by them must be paid for. Some limited cancer services are also available privately.

How do you know which treatment is best for you?

- To help you make a decision about treatment, staff at your BreastScreen Aotearoa Centre will give you full information about the services available in your region.
- The surgeon you see at the BreastScreen Aotearoa Centre will discuss the best treatment choices for you. He or she may be one of the surgeons who perform surgery in the public hospital or privately. It is important in these circumstances that you understand all the choices you have for surgery and treatment available in your area and do not feel pressured to use the services of the particular surgeon you see at the Centre. You could discuss the options with your family, the Breast Care nurse or your family doctor.
- You should be given full information about the advantages and disadvantages of all treatments and how well they work in treating breast cancer.

- You can ask for information about all treatments, including chemotherapy, radiotherapy or breast reconstruction, even though they may not have been suggested to you.
- It is your decision whether or not to have surgery or any other treatments that may have been recommended to you. It is important to consider your options carefully.
- The surgeon or your GP may also suggest you see a Cancer Specialist (Oncologist) to discuss any further treatment options that may be recommended, such as radiotherapy or chemotherapy, and you can request a referral.
- Some centres have Breast Cancer Support Groups. Before and after your surgery, it is possible to speak with women who have had breast cancer treatments.



OUESTIONS YOU MAY WISH TO ASK

Here are some questions you may have. It will take time to answer all your questions. They will not all be answered in one meeting or by one person.

Some of these questions are best answered by the Specialist and Breast Nurse at the BreastScreen Aotearoa Centre.

The surgeon you choose for your treatment and the Breast Care Nurse at the hospital will answer other questions.

Your family doctor will also be able to help.

- What kind of cancer do I have?
- Why have I got breast cancer?
- Has the cancer spread?
- Could you provide me with a copy of my breast pathology report, and will this be explained to me?
- How can I find a surgeon I feel comfortable with?
- · How do I find a surgeon who specialises in breast surgery?
- Will I be able to choose my surgeon in the public health system?
- How long will I have to wait for surgery?
- Can you say how successful an operation or other treatment may be?
- Will surgery have any side effects?
- How long will I be in hospital?
- How long will I need to be off work?
- Who can I talk to about cultural issues regarding, for example, what happens to my breast if it is removed?
- Will I need radiotherapy? Where will I have to go for that, and how long will it take? What are the side effects?
- Will I need chemotherapy? Where will I have to go for that, and how long will it take? What are the side effects?

- How can I tell if my treatment is 'working'?
- Will there be help with travel arrangements? Will someone be able to come with me? Where will we stay?
- Will I need hormone treatment? How long will it take, and what are the side effects?
- What are the chances of breast cancer recurring at a later time with the treatment option you are recommending?
- What is my life expectancy? Am I likely to be alive two years from now? Five years? Ten years? Twenty years? Thirty years?
- What are the implications for my sisters and daughters in relation to their health?
- Is it possible to find out if breast cancer runs in my family?
- How long has this cancer been developing?
- Am I likely to have cancer developing in my other breast?
- How can I avoid developing another breast cancer?
- What can I do to ensure my daughter does not develop breast cancer?
- Who will be responsible for my follow-up care?
- What help can I receive if I should experience any pain?
- What type of help can I receive, eg, home help, travel and accommodation assistance:
 - when I am in hospital
 - for me
 - my family (especially my children)?
 - when I leave hospital
 - for me
 - my family (especially my children)?
- How do I know if what I'm feeling is normal?
- Who can I ask for help if I need it?

How do you find out more about breast cancer and what help is available?

Other information and assistance is available from many sources such as:

- The Cancer Society Information Service. Phone 0800 226 237
- Breast Cancer Support Services
- Breast Cancer Network
- General Practitioner
- Practice Nurse
- Maori Hauora Support Services
- · Local women's health groups in your community
- All public hospitals have a social worker to help you during your treatment. They will be able to advise you regarding issues such as accommodation if you need to travel for treatment
- Books from the Cancer Society, Breast Care Nurses and local libraries
- 'Look Good Feel Better', a free nationwide service.



WHAT HAPPENS AFTER TREATMENT?

The specialist responsible for your treatment will tell you when and how often you will need to be seen again. Your GP is also likely to be involved in your follow-up care.

You should have a mammogram and a clinical examination every year as part of the follow-up after surgery for breast cancer. This should be arranged by your surgeon, oncologist or GP and will not be part of the national breast screening programme. You will be able to have two yearly screening with BreastScreen Aotearoa again, five years after your breast cancer diagnosis, if you are still aged 45 to 69 years. You may also be advised by your doctor to continue having a mammogram on the alternate years at the hospital.

Many women feel devastated when mastectomy is the option recommended. Lots of reassurance is needed at this time from loved ones that the surgery will make no difference to how they feel about you. Most families are able to offer this reassurance and loving support, but in the absence of such support, women may need to talk to a support service or to another woman who has had a mastectomy.

Shortly after surgery, you can be fitted with a modern prosthesis or breast form and your clothes will look just as good as before. This can be done as soon as the wound has healed sufficiently. The prosthesis is a soft silicone body shape to be worn inside a bra or swimsuit. The government pays for this. A positive attitude will mean that in time you can come to view your altered body shape as just part of the whole, unique, beautiful person that you are.

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IMPORTANT POINTS TO REMEMBER

- Breast cancer can be a very treatable disease
- Strong emotions are normal for women at this time
- · Fears are natural
- It is important to realise that breast cancer is not usually a medical emergency
- It is usually possible to take several weeks to sort through emotions, seek answers to questions and choose options without endangering your health
- Don't be afraid to ask questions
- If at any stage you don't understand what you are being told, ask for an explanation
- A positive attitude is one of the best weapons in the fight against cancer.

To assess the effectiveness and the quality of the Programme, BreastScreen Aotearoa wishes to notify you that the following information may be collected:

- any information relating to treatment you have received for your breasts in the past and may require in the future
- any relevant clinical information, your mammograms and reports.

The information will be collected from public and private providers by the Ministry of Health or its agents, eg, another entity designated by the National Screening Unit or BreastScreen Aotearoa, the New Zealand Health Information Service, or the Cancer Registry through your National Health Index Number (NHI). This information will be used to monitor the quality of the national breast screening programme, BreastScreen Aotearoa. It is only by monitoring the care and outcome of all women who have mammograms that the ongoing quality of the Programme can be properly assessed.



REFERENCES AND FURTHER READING

These books may be accessed from the Cancer Society Information Service, your local library or ask the Breast Nurse if she can help find them.

Dr Susan Love's Breast Book.
Susan M. Love, Karen Lindsey & Marcia Williams. Harper Collins,
2nd ed. 1995.

A Woman's Decision: Breast care, treatment and reconstruction. Karen Berber & John Bostwick III. St Martin's Griffin, 1998.

The Unremarkable Nipple: A journey with breast cancer Sue McLeod. Dunmore Press, Palmerston North, 2004.

Take Charge of Your Breast Cancer: A guide to getting the best possible treatment.

John S. Link. Owl Books, 1st Owl ed. New York, 2002.

There are a number of Internet sites with information such as:

National Screening Unit www.breastscreen.govt.nz

Cancer Society of New Zealand www.cancernz.org.nz

Women's Health Action Trust www.womens-health.org.nz

BreastScreen Victoria, Australia www.breastscreen.org.au

NSW Breast Cancer Institute – BreastNet www.bci.org.au

Cancer Australia
www.canceraustralia.gov.au

Cancer Research UK www.cancerresearchuk.org

American Cancer Society Breast Cancer Network www.cancer.org

American Cancer Society www.cancer.org

National Cancer Institute www.cancer.gov



Breast Reconstruction

After a woman has her breast removed, it is possible for a specialist surgeon to surgically recreate a breast shape using skin and deeper tissue from the back or lower abdomen. This can be done at the same time as the mastectomy or after, and with or without an implant.

Breast Screen

Screening tests are used in apparently well people to identify those who possibly have a disease from those who do not. Mammography is a screening test used to detect breast changes long before they can be felt.

BreastScreen Aotearoa

The national breast screening programme in New Zealand was established in December 1998. The programme aims to reduce deaths from breast cancer among New Zealand women by detecting cancers when they are too small to be felt. It offers free screening mammograms to all women aged 45–69 years who have no serious signs or symptoms of breast cancer.

Chemotherapy

The treatment of cancer by drugs. The aim is to destroy cancer cells while having the least possible effect on normal cells.

Hook wire

Sometimes an abnormality is too small to feel. Just before surgery a mammogram or ultrasound can be used to place a fine wire into the abnormal part of the breast. This wire guides the surgeon to the correct area during surgery.

Hormonal Treatment

The use of drugs that mimic natural hormones, (chemical messages) in order to check the growth of some cancers. This is sometimes called endocrine therapy.

Lymph nodes

Glands found throughout the body, which help filter bacteria and other harmful cells from the lymph fluid. During surgery for breast cancer, some or all of the lymph nodes in the armpit are removed to check for cancer cells.

Mammogram

A mammogram is an X-ray of the breast.

It can be used:

- as a wellness check for women with no symptoms a screening mammogram
- with other tests to check a breast lump or a change that can be seen or felt a diagnostic mammogram.

Mastectomy

Removal of the whole breast

Oncology

Study and treatment of cancer

Prosthesis

Artificial substitute for a missing part of the body, as in breast prosthesis

Radiotherapy

The use of X-rays to treat cancer cells

Ultrasound Scan

The use of high-frequency sound waves to produce an image of the inside of the body. It is sometimes used with a mammogram to gain more information.

