Step by Step

INFORMATION

Together we're stronger

Tangata tū pakari tonu

PRINCIPAL
FUNDER

Breast Cancer
Foundation NZ

bcac breast cancer
aotearoa coalition

Step by Step

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aotearoa coalition

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PO Box 90224
Victoria Street West
Auckland 1142
New Zealand

@ bcac@breastcancer.org.nz
www.breastcancer.org.nz
www.facebook.com/BreastCancerAotearoaCoalition
@BCACNZ

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A letter from Libby Burgess

Chairperson of the Breast Cancer Aotearoa Coalition (BCAC)

Tēnā koe – greetings

If you have breast cancer – ***Step by Step*** is for you.

Step by Step is a taonga (treasure), produced by the women of BCAC who have all experienced breast cancer, and handed to you as you face your own diagnosis.

It has information to guide you, advice to reassure you, and wisdom to comfort you.

Step by Step demystifies much of the medical language you will hear and provides you with the knowledge to help you make your own choices about treatment and care.

I urge you to take ***Step by Step*** and make it your own. Use it to help guide you through this experience, organise your treatment and gather your thoughts and feelings.

To our Māori and Pasifika women, who are more likely to be diagnosed with breast cancer, I say ***Step by Step*** is for you and your whānau. It will help you understand what's ahead and find the strength to face it.

To all of you reading this, I wish you well. Know that as you begin treatment for breast cancer, a community of women stands behind you. Together we're stronger. Tangata tū pakari tonu.

Reach out now and let us take your hand so we can move forward together.

Libby Burgess

LIBBY BURGESS

How Step by Step works

Step by Step contains three elements to help guide you through your breast cancer experience.

An information book that:

- helps you to understand your breast cancer and the different treatments you may be offered
- gives you tips on what to expect and where to find resources and assistance
- provides lists of breast cancer-related organisations and the types of support, activity or information they provide
- offers details of books, websites and other resources you may find useful.

A comprehensive diary for you to:

- record and organise information about your diagnosis, treatment and recovery
- keep track of appointments, events and contacts
- write questions for your medical team and record their answers.

A journal for you to:

- write or draw about your experiences and feelings at this emotionally challenging time
- collect messages of support from others to help give you strength.

Facing a breast cancer diagnosis is a huge challenge. All of us at BCAC hope that ***Step by Step*** will help to ease the fear and give you the strength and courage to face what lies ahead.

Throughout ***Step by Step*** you will find the following icons, that point you in the direction of further information that may help you:

✚	advice on medical or health information
👥	support services available to women with breast cancer
♥	ideas and tips on taking care of yourself physically and emotionally
♀	quotes from women who have been through breast cancer

The Breast Cancer Aotearoa Coalition (BCAC)

Breast Cancer Aotearoa Coalition (BCAC) is a coalition of more than 30 breast cancer-related groups and is run by breast cancer survivors.

We have used our experience of this disease to develop the ***Step by Step*** support pack to help you as you face breast cancer. We want you to know that you are not alone and to have the information you need to make well-informed decisions about your treatment and care.

BCAC is an incorporated society with charitable status and we strive to provide a voice for New Zealanders with breast cancer to ensure everyone diagnosed receives world-class treatment and care.

Our key aims are to:

- **Inform:** by providing evidence-based information about breast cancer for women and their families to help them make decisions about treatment and care
- **Support:** newly diagnosed women by giving them our ***Step by Step*** resource pack to help them through the early stages of diagnosis
- **Represent:** the views of women with breast cancer to decision-makers and healthcare providers to ensure world-class treatment and care is available in New Zealand
- **Promote:** the practice of breast awareness and the free breast screening programme to ensure breast cancer is diagnosed and treated early
- **Improve:** breast cancer outcomes for everyone, especially Māori and Pasifika women
- **Network:** to ensure communication and sharing of resources and information among New Zealand's breast cancer-related groups.

With the input and support of our individual members, member groups, and many others throughout New Zealand, we are truly stronger together, hence our motto in Māori, Tangata tū pakari tonu.

PO Box 90224
Victoria Street West
Auckland 1142
New Zealand

bcac@breastcancer.org.nz

f BreastCancerAotearoaCoalition

@BCACNZ

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Coping

You’ve just received some very difficult news. You may be feeling a whole lot of things all at once – fear, sorrow, anger, anxiety. It’s normal to feel these emotions, so one of the most important things you can do for yourself right now is *take time.*

Information can reduce your fear of the unknown, but it takes time to absorb. There are so many things that you may not be sure about right now. Perhaps the biggest fear is ‘am I going to die?’ Remember, the majority of women survive breast cancer. Move forward with that knowledge and the knowledge that you’ll be receiving excellent care and treatment.

Take time to review the medical information you’ve been given. Catch your breath, let those emotions work themselves out so that you can take charge, review treatment options and make the decisions that are right for you.

Letting others know about your diagnosis

Family and friends

One of the first things you’ll have to do after you’ve been diagnosed is to tell family and friends. This can often be one of the hardest parts of dealing with breast cancer.

You may be feeling scared, confused and uncertain. It may be difficult for you to give such ‘enormous’ news to those you love and to deal with their emotions as well. If you find it difficult to tell others of your diagnosis, you may prefer to ask a close family member or friend to talk to people for you.

It’s important to remember that these are your loved ones and they will want to help, but they may need time to absorb and process this challenging information. They may not know what to say or do, but with time and understanding they will find the strength to support you.

Your friends and family can help you to fight breast cancer. They are on this journey with you, so rely on them, talk to them, and let them help you in any way they can.

Remember too, that your needs come first and if you don't feel like talking or having people around, just say so. People will respect your wishes and understand your needs.

Remember your spouse or partner is a source of strength. Turn to this person with your fears and worries and do not shut them out as you face breast cancer. A close friend or family member can also be a great support. Do not be afraid to contact them and share your concerns or take them with you to medical appointments. Together you are stronger.

Your children

If you have children, how much you tell them will depend on how old they are. Give them age-appropriate information and don't burden them with too many details. Remember to tell them what will be happening for them while you are receiving treatment and who will be looking after them.

Do keep an eye on your children or have your partner or a close family friend do so. This is a difficult time for them as well and they can react in different ways. Seek help for them from a counsellor if you think they need it.

The Cancer Society has a useful booklet, Cancer in the family: Talking to your children. Download it from their website www.cancernz.org.nz or call 0800 CANCER (226 237) for a copy. The UK website www.macmillan.org.uk also has a useful section on talking to children about cancer.

"Medikidz explain Breast Cancer" is a comic book designed for children 8-12 years. For a free copy go to www.breastcancerfoundation.org.nz/resources

Kenzie's Gift supports the emotional well-being and good mental health of children, young people and families affected by serious illness or bereavement. Visit www.kenziesgift.com

Your employer

It can be unsettling telling your employer that you have breast cancer and that you will need time off for treatment. You may wonder how your employer will react, what it will mean for your future job security, and how you will feel about returning to work when the time comes.

Most employers are understanding and will give you sick leave or leave without pay for treatment. If you are self-employed it may be more difficult for you take time out for treatment. If you are able, get others to cover for you as much as possible.

It's important not to stress about work issues at this time. You need to focus on your health and wellbeing so that you can get better as quickly as possible.

If treatment means you are facing financial hardship, contact Work and Income New Zealand to see what assistance they can provide. They offer short-term financial assistance through the Jobseeker Support Benefit and long-term assistance through the Supported Living Payment. See www.workandincome.govt.nz or call 0800 559 009 for details.

The Cancer Society provides grants to assist individuals and families facing financial hardship as a result of cancer treatment. The grants cover such things as transport costs, household expenses, special equipment, counselling services etc. Contact your local branch of the Cancer Society for details or call 0800 CANCER (226 237).

The Ministry of Health also provides travel grants for those who have to travel a long way or frequently for medical treatment. The Ministry's CarePlus system delivers services at a reduced cost to those who require a lot of support from the health system. Find out more on the Ministry website www.health.govt.nz

The organisation Bellyful, www.bellyful.org.nz, delivers food, free-of-charge, to families struggling with illness. They operate in most main centres throughout New Zealand.

Support Crew is a free online support platform that assists you to coordinate meals, transport, cleaning and any other help you need from friends and family. To create a Support Page for yourself or someone else, go to www.supportcrew.co

Help to get you through

A diagnosis of breast cancer can throw you off course. But dealing with a diagnosis is easier when you feel empowered, informed and in charge. Knowing what you are dealing with can help to keep your emotions in check, so let's look at some ways to help keep you on an 'even keel'.

Tips for information gathering

Ask questions

- Write down questions for your medical team before appointments
- Take a friend or family member who can make notes for you during consultations and discuss what was said afterwards
- Ask your doctor if you can record consultations
- Keep asking questions until you understand – don't be afraid to ask anything, it's your body and your right to know
- Use the diary in this pack to organise and record information.

Seek a second opinion if you want to

- Taking time to do this may make you feel more in control and better prepared for what is to come
- You are perfectly entitled to do this. Just tell your doctor you would like a second opinion and ask for the name of another doctor. You don't have to argue or justify your decision.

Talk to someone who has been there

- Talk to and/or read a book by someone who has experienced breast cancer
- Hearing about others' experiences makes it easier to cope by giving you a better understanding of what you are dealing with, what will happen and how things may affect you.

Tips for taking care of yourself

Don't be afraid to ask for and accept offers of help

- Friends, family, professionals and support groups can all offer amazing assistance. See ***Step by Step's*** "We're here to help" section (pages 85-102) for a list of support groups.

Take 'time out' for you

- Cancer will be dominating your thoughts for the next few weeks but don't forget that you still have a life, one that can bring you joy and pleasure so take a 'cancer break' whenever you can
- Meet up with friends and do something you really enjoy. Have a weekend away with loved ones. Enjoy a massage or walk on the beach.

Let your feelings out

- Writing a journal can provide you with a powerful means to express your emotions, so use the journal in this pack to write about your experiences and feelings
- Collect some mementos – photos, cards, notes – things you enjoy looking at and that bring you strength and comfort
- Relax and feel the strength of your body with meditation, yoga or pilates
- Use other ways to express yourself – dance, drawing or music
- Seek the support of a professional counsellor or psychologist.

Be gentle on yourself and conserve your energy

- Don’t try to be all things to all people
- If you don’t want to do something, just say “no thank you”. People will understand.

And remember... life is precious

- Celebrate it by finding some joy in every day, even if it’s just a walk down the driveway to smell the climbing roses at the garden fence.

A diagnosis of breast cancer

One of many paths may have brought you to this diagnosis of breast cancer. Perhaps you felt a lump, or a routine mammogram revealed something unusual. Intuition may have told you that a change you noticed in your breast wasn't quite right.

Deciding to have it checked was the best thing you could have done.

You will have had a biopsy, where tissue was removed for microscopic examination and further testing – perhaps a core biopsy or a fine needle biopsy. Pathology results have confirmed breast cancer and now your specialist is outlining treatment options. Words like 'surgery', 'sentinel node biopsy', 'axillary dissection' and perhaps 'chemotherapy' and 'radiation therapy' are floating around in your head.

It's time to take a breath and let us walk with you through some of these terms and what they may mean for you.

What happens next?

The following section is intended as a simple guide only – a roadmap drawn for you by women who have faced a similar diagnosis and experienced their own journeys with breast cancer.

Here we describe the main breast cancer treatments available for most women, but by no means all women. The first step is often surgery but, in some cases, radiation therapy and/or chemotherapy will be administered before surgery (this is known as neo-adjuvant therapy). Your surgeon and/or oncologist will give you all the information you need about this.

Always ask your specialists plenty of questions to make sure you fully understand the treatment options available to you after your diagnosis.

You may want to ask for copies of all reports, blood tests, pathology, and other test results to be shared with you so that you have your own record of your diagnosis and medical treatment. It's a good idea to record the details in your ***Step by Step Diary*** *because it can be easy to lose track of everything that you've had done.*

Take someone with you to appointments with your cancer doctors. Your supporter can take notes and then discuss information with you afterwards. There is so much to take in and having your partner or friend with you can be very helpful.

Understanding your breast cancer

The aim of surgery is to remove the cancer from the breast. Information from your surgery, your initial biopsy, and your pathology report will provide more details about the type of breast cancer you have. This information may include:

- tumour size
- the grade and stage of your cancer
- reports on lymph node involvement
- data on your cancer's sub-type, e.g. hormone receptor or HER2 positive
- details on whether the cancer has spread past the breast
- information on which medicines are likely to be effective against your cancer.

Types of tumours

A tumour is determined to be either "in situ" (non-invasive), meaning the cancer remains within the milk ducts or milk lobules of the breast; or "invasive", meaning the cancer has spread into normal breast tissue or other parts of the body such as the lymph nodes.

There are four main tumour types. These are:

- *DCIS (Ductal Carcinoma In Situ)*
This pre-cancer is non-invasive and the abnormal cells are confined to the milk ducts.
- *LCIS (Lobular Carcinoma In Situ)*
This is not technically cancer, but is a marker of an increased risk of developing cancer in either breast.
- *Invasive Ductal Carcinoma (IDC)*
This is the most common type of invasive breast cancer and involves a cancer that has started in the milk ducts and has spread into the normal breast tissue.
- *Invasive Lobular Carcinoma (ILC)*
This invasive cancer starts in the milk lobules and then spreads into the surrounding normal breast tissue.

There are other less common types of breast cancer, including Inflammatory Breast Cancer and Paget's Disease. For more details on these types of breast cancer, visit BCAC's website www.breastcancer.org.nz and www.breastcancerfoundation.org.nz

Grades of breast cancer

A pathologist will examine a tissue sample taken either during a biopsy or during surgery to determine the grade of your cancer. This compares the appearance of the cancer cells to normal cells to see how different they are. There are three main grades (see table next page):

GRADE 1: Well differentiated

These cancer cells look slightly different from normal cells and are usually slow growing.

GRADE 2: Moderately differentiated

These cancer cells look less normal and are usually faster growing.

GRADE 3: Poorly differentiated

These cancer cells look quite different from normal cells and are generally fast growing.

Stages of breast cancer

Information from your biopsy and surgery, along with other tests, such as imaging procedures like a bone scan, ultrasound, or a chest x-ray will be used to "stage" your cancer. The "stage" determines how far the cancer has spread from the original tumour.

The stages of early breast cancer are:

Stage 0	Pre-cancer that has not spread beyond the ducts of the breast (also known as ductal carcinoma in situ or DCIS).
Stage I	Cancer cells are found outside the ducts in normal breast tissue.
Stage II	Tumour size is 20-50mm and/or cancer has spread to the underarm lymph nodes.
Stage III	Tumour size is greater than 50mm and/or has spread to underarm lymph nodes.

The stages of locally advanced or metastatic breast cancer in which cancer has spread to other parts of the body, are:

Stage IIIB/C	Locally advanced: the tumour (any size) has spread to the skin of the breast, chest wall, internal mammary lymph nodes, or supraclavicular lymph nodes (those above the collar bone).
Stage IV	Metastatic, secondary or advanced: the tumour has spread beyond the breast, underarm, internal mammary node or supraclavicular lymph nodes to other parts of the body such as the lungs, liver, bone, brain or distant lymph nodes.

'What does my pathology report mean?' is a booklet produced by Roche Products (NZ) Ltd, a pharmaceutical company. This guide will help you to make sense of your report and the terms used. It's available from your specialist or breast nurse, or you can download it from www.cancerinfo.co.nz

HER2 and Hormones

Some breast cancers can be stimulated to grow by hormones or other proteins present in your body. Your pathology report will outline whether your breast cancer is responsive to either of the female hormones, oestrogen and progesterone; or if it overproduces the HER2 protein. This information will be used to determine which treatments are likely to work best for you. The majority of breast cancers are 'hormone (oestrogen and/or progesterone) receptor positive' which indicates that they will probably respond to hormone therapy (see p. 53). If your tumour is 'HER2 positive', therapy targeted to the HER2 receptor could be useful (see p. 51). Your doctor will explain how your pathology report results could influence the choice of treatment for you.

The chart below outlines these kinds of breast cancer:

Oestrogen Receptor Positive	Your breast cancer responds to the hormone oestrogen and may grow faster when this hormone is present. Hormone therapy may be prescribed to help treat this kind of cancer.
Progesterone Receptor Positive	Your breast cancer responds to the hormone progesterone and may grow faster when this hormone is present. Hormone therapy may be prescribed to help treat this type of cancer.
HER2 Positive	Your breast cancer produces more of the HER2 protein that affects how quickly the cancer cells grow. Medicines such as trastuzumab (Herceptin®) are often effective in treating this type of cancer.
Triple Negative Breast Cancer	Your breast cancer is not responsive to oestrogen, progesterone or HER2 proteins and does not respond to medicines that block them. This type of breast cancer behaves aggressively and standard chemotherapy is usually recommended.
BRCA1 or BRCA2 Breast Cancer	This is a hereditary type of breast cancer that is affected by mutations in the BRCA1 and/or BRCA2 genes. About five per cent of all breast cancers are the result of BRCA gene mutations. These breast cancers usually occur at a young age, are often aggressive and are frequently Triple Negative.

Pharmaceutical company, Roche, has a useful website for women diagnosed with HER2 positive breast cancer, www.cancerinfo.co.nz

If you have been identified as having the BRCA 1 or 2 gene mutation then you might like to contact BCAC member group the Gift of Knowledge that supports women with hereditary breast and ovarian cancer. Contact them at www.giftofknowledge.co.nz

Gene expression profiling tests

In some cases, particularly where standard pathology results suggest an intermediate risk of recurrence, useful additional information might be obtained from a gene expression profiling test on your biopsy samples. These tests use relatively new technology to build a profile of the tumour's molecular biology. From this, a more detailed estimate of the risk of the cancer recurring can be made and, with some of the tests, the amount of benefit that might be derived from treating with chemotherapy can also be estimated. Current examples include Mammaprint, Oncotype Dx and Endopredict. These tests are available, but not yet publicly funded, in New Zealand. Talk to your medical team to see if you might benefit from a gene expression profiling test.

Hereditary breast cancer

Between five and ten percent of breast cancers have a familial pattern. Less than half of these are currently known to be associated with inherited gene mutations. BRCA1 and BRCA2 mutations are the most well-known of these, but are found only in 1-2 % of breast cancers. If you have a family history of breast or ovarian cancer, especially in your first degree relatives when they were under 50 (mother, sister or daughter) with other features such as early age of diagnosis or having cancer of both breasts, or a male relative has had breast cancer, particularly hormone receptor negative breast cancers, then it may be worth asking for a referral to a Genetic Service for a review of your family history.

Some families will be offered genetic testing to look for mutations in genes associated with breast cancer. This information could help with decisions about your own treatment. It could also help other family members to be aware of their own chance of getting breast cancer so that they can take steps to ensure early detection. Your specialist will be able to help estimate your risk and refer you to be assessed if necessary. Genetic counselling and testing is carried out by the Genetic Health Service NZ, and by some private providers, and a referral from your doctor is needed. Breast Cancer Foundation NZ can also help you assess your risk and refer you if necessary. Phone 0800 BCNurse (0800 226 8773).

For more information on hereditary breast cancer, visit BCAC's website www.breastcancer.org.nz. You can also read about family risk at www.breastcancerfoundation.org.nz

Early breast cancer

Most new diagnoses are classed as early breast cancer (Stages 0 to III). Your treatment options will vary depending on the characteristics of your cancer and other factors such as your menopausal status, but will probably follow a general pathway beginning with surgery and perhaps also including radiotherapy, chemotherapy, targeted and/or hormone therapy.

Secondary breast cancer

About 4% of women diagnosed with breast cancer will have secondary (Stage IV) disease. This is also known as metastatic or advanced breast cancer. This means that cancer cells have travelled from your breast through your blood and lymphatic system and started to grow in other organs or tissues in your body. The parts of your body most likely to be affected are the bones, liver, lungs or, more rarely, brain, although cancer has the potential to spread anywhere in the body.

You may have already been through a previous experience with early breast cancer, or this could be your first diagnosis. Women often want to understand why they have developed secondary breast cancer, especially if they have previously had treatment for early breast cancer. Unfortunately, even the best treatment for early breast cancer does not always remove every cancer cell. Most commonly, secondary breast cancer develops from cells that have escaped. Sometimes, cancer cells have already started to travel around the body when cancer in the breast is found.

As yet, secondary breast cancer cannot be cured. However, advances in treatment mean that some women with secondary breast cancer are now living for many years. Some people with secondary cancer are now able to manage their disease in a similar manner to living with a chronic illness – with ongoing treatments providing periods of wellness between periods of ill health.

Treatment for secondary breast cancer does not follow a simple formula. Everyone's cancer is different. Cancer cells can be found in different parts of the body, and different women can respond differently to the same treatments. This is why treatments are tailored to individual women. Factors like your age, menopausal status, medical history, general health, work situation, life goals and personal preferences all need to be taken into account. For most women, treatment for secondary breast cancer will be based on systemic therapies (chemotherapy, hormone therapy and/or targeted therapy) which can travel throughout the whole body and treat the cancer wherever it is. Your oncologist may have to trial various drug combinations to find a programme that is most effective in controlling your cancer. In some cases, your treatment may also involve surgery and/or radiotherapy.

Sweet Louise offers support and services (in some areas) for women diagnosed with secondary breast cancer. Call the Sweet Louise support coordinators on 0800 11 22 77 or visit www.sweetlouise.co.nz

Sweet Louise also produces an excellent information book – A guide to life with secondary breast cancer – which can be obtained from www.sweetlouise.co.nz

Metavivors NZ is a Facebook group solely for those with secondary breast cancer. The group aims to provide support, information, friendship and strength to all those who find themselves facing a diagnosis and treatment for secondary breast cancer. Search Metavivors NZ on www.facebook.com

Surgery

A diagnosis of breast cancer usually requires surgery and your surgeon will discuss the options she or he feels are best for you. You may have to wait for days or sometimes weeks between your initial diagnosis and surgery. This can be a difficult and stressful time as you worry about the cancer, but breast cancer is very rarely an emergency and there is no change to your prognosis in those weeks. Try to remain calm and focus on the steps you're taking to prepare yourself for surgery.

Your surgery needs to do two things: remove the cancer, and check if the cancer has spread to the lymph nodes in your armpit (axilla).

Your surgical options may include:

- removal of the tumour and part of the breast surrounding it (called a partial mastectomy, lumpectomy or wide local excision, or breast conserving surgery)
- removal of the whole breast (a full mastectomy)
- removal of the sentinel lymph node(s) from the armpit.

Mastectomy may be done with or without breast reconstruction. Breast conserving surgery may also require partial reconstruction if a large proportion of the breast needs to be removed.

Your surgeon will advise whether he or she needs to remove lymph nodes from the armpit or just sample them with a sentinel node biopsy.

Sometimes, after a breast conserving procedure, the cancer may be found on microscopic examination to come up to or very close to the margin of excision. This may require a second operation to take more breast tissue, or even a mastectomy. After your breast surgery and before you leave hospital, you will be given an exercise programme to follow. Your surgeon will probably also give you some pain medication and instructions on how to care for your bandages and the tubes and drains that have been inserted into the breast wound to help drain the excess fluid that builds up as a normal part of the healing process.

Discuss all surgical options thoroughly with your surgeon and be sure you fully understand what she or he is recommending for you. Read about the surgical procedures recommended so you can discuss them properly and take time to make your decision.

Read the surgery decision aid at www.breastcancerfoundation.org.nz to compare the surgical options.

Remember that information is power. Speak with women who have experienced breast cancer who are often very happy to share and support women who are starting their journey. Contact your local Breast Cancer Support organisation on 0800 273 222 to get in touch with women who've been through treatment. You can also speak with a specialist breast nurse at the Breast Cancer Foundation NZ by phoning 0800 BCNURSE (0800 226 8773).

Connect and share your thoughts with others in a similar situation. Mybc is an online support community for New Zealanders with breast cancer. You can join at www.mybc.care

"As far as having my breast removed, it didn't bother me if that was what was going to have to happen and my partner was in full support – he was going to love me either way. It's only a boob at the end of the day!" Lisa

Neo-adjuvant therapy

In some cases, especially if you have Triple Negative or HER2 positive breast cancer with a tumour bigger than 2 cm, you might be offered chemotherapy before your surgery. This is called neo-adjuvant therapy (chemotherapy immediately after surgery is called adjuvant therapy). The aim of neo-adjuvant therapy is to shrink your tumour and kill off any other breast cancer cells that might be elsewhere in your body before surgery.

This may be recommended:

- If you have inflammatory breast cancer
- To reduce the size of your tumour so that you can have breast conserving surgery (lumpectomy) instead of mastectomy, or to improve the cosmetic outcome of your surgery
- To give you time to have genetic testing if you have a strong family history of breast cancer. This may influence recommendations for breast surgery, especially breast reconstruction options
- To see if the chemotherapy can completely destroy the tumour locally, as the cancer can be very sensitive before it has been treated by surgery.

In some cases, neo-adjuvant hormone therapy might be given for locally advanced, oestrogen receptor positive disease. Neo-adjuvant therapy is not suitable for everyone's breast cancer, and it might not be your personal preference even if it is medically suitable. As with all parts of your treatment plan, your medical team will discuss the pros and cons of this approach with you first.

See BCAC's website www.breastcancer.org.nz for more information on neo-adjuvant therapy.

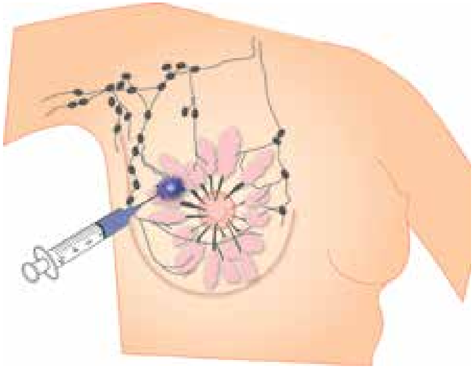
The "Neoadjuvant Patient Decision Aid" may be useful resource in discussions with your oncologist. Get it from https://www.breastcancertrials.org.au/file/44/Neoadjuvant-Patient-Decision-Aid or BCAC's website.

Lymph nodes and lymphoedema

In some cases, cancer cells will have moved from the original tumour site to the lymph nodes under your arm. If you have invasive breast cancer your surgeon will need to perform a further surgical procedure to determine whether the lymph nodes are involved (axillary staging). This is likely to be either a sentinel node biopsy or an axillary dissection which can be performed at the same time as your breast surgery.

Sentinel node biopsy

A sentinel node biopsy involves injecting a very small amount of weakly radioactive fluid into the tumour site or under the areola (alongside the nipple) a few hours or the day before your surgery. A coloured dye can also be injected at the time of surgery. The fluids drain slowly from the breast and collect in the first lymph nodes that drain your breast. These are called the sentinel or 'guardian' nodes. If the cancer has spread to the lymph nodes from the breast then it will almost always have travelled to the sentinel nodes first.



Sentinel node biopsy

At the time of your surgery, your surgeon will remove the sentinel node(s) for testing. If the sentinel node is clear of cancer cells then you will usually not need any more nodes removed. If the sentinel node is positive for cancer, then the surgeon may recommend proceeding with an axillary dissection, or axillary radiotherapy, or sometimes no further axillary treatment.

Axillary dissection

An axillary dissection involves surgery to clear lymph nodes from the axilla. This is often done at the same time as your breast surgery, but can be done at a later date.

Side effects of sentinel node biopsy and axillary dissection

Very few women who have a sentinel node biopsy will experience lymphoedema in the affected arm. However, all patients who have an axillary dissection have a lifelong risk of developing lymphoedema in the affected arm or breast, although the incidence of this occurring is low. Lymphoedema is a swelling caused when lymph fluids can no longer drain efficiently because the lymph drainage channels (lymphatics) have been divided, blocked or scarred from surgery or radiation therapy.

Triggers for lymphoedema may include sunburn, mosquito bites, high Body Mass Index (BMI) and heavy lifting. Lymphoedema is not triggered by blood pressure tests or blood tests performed on that arm.

It is important that you receive education about how to look after your arm after an axillary dissection as lymphoedema can be prevented with lifestyle modifications, exercises and prevention strategies. This is available through physiotherapy clinics in the public and private systems. Breast Cancer Foundation NZ offers lymphoedema therapy funding with a lymphoedema therapist (criteria apply). For more information go to www.breastcancerfoundation.org.nz/support or call 0800 BC NURSE (0800 226 8773).

The key to managing your lymphoedema risk is education, prevention and getting early treatment if it appears. Your surgeon and breast nurse should discuss a strategy with you to minimise the risk of developing lymphoedema.

After surgery, you can help to reduce your risk of developing lymphoedema by taking the following precautions:

- always use gloves when gardening
- protect your arm from sunburn
- avoid having injections in the treated arm if possible
- treat any cuts or abrasions quickly to minimise infection
- wear a compression sleeve when travelling on a long-haul flight.

If lymphoedema does develop, it can be managed through:

- light touch massage
- wearing compression garments
- kinesio taping
- special care of the affected limb
- protecting skin from cuts, insect bites and scratches
- targeted exercise.

Lymphoedema does not affect all women after breast surgery but it is still important to know how to care for your arm to prevent it. You may want to take note of your arm's original measurements (the girth at the wrist, forearm and upper arm) to help gauge whether swelling is occurring. Some clinics have a device called an L-dex which helps to measure the fluid in your arm before and after surgery. A change in L-dex number can be an early sign of developing lymphoedema before you notice symptoms such as swelling. This means that you can take action early.

Your breast nurse will have information for you about lymphoedema prevention, symptoms to look for, and what to do if they occur. She may recommend that you purchase a compression garment (or compression sleeve) for your arm as a preventative measure. Sleeves can be purchased through aftercare product suppliers (those who also provide breast prostheses and associated products). Pretty patterned sleeves can also be purchased online from US suppliers

Lymphedivas (https://lymphedivas.com/shop-all/arm-sleeves/). Many hospital physiotherapists also provide free compression sleeves, so ask your breast nurse about this option too.

Therapy for lymphoedema prevention and treatment is highly specialised. Always check first to ensure a therapist is appropriately qualified. If in doubt, visit the Lymphoedema Therapists website at www.lymphoedemanz.org.nz to find a qualified therapist near you. Call 0800 BCNURSE (0800 226 8773) or visit www.breastcancerfoundation.org.nz, or contact the Cancer Society on www.cancernz.org.nz or 0800 226 237 for a recommendation.

The Cancer Society of NZ produces two helpful pamphlets on lymphoedema: Understanding Lymphoedema and Living with Lymphoedema. See their website www.cancernz.org.nz or phone them on 0800 226 237 for copies.

The Lymphoedema Support Network is a member of BCAC and provides an excellent source of current information about the latest in lymphoedema treatment and care. Visit www.lymphoedema.org.nz

"I cope with it as well as I can. It's quite frustrating at times … but as long as you keep up your exercise, look after yourself and have regular lymphatic drainage done it makes it a lot easier to deal with." Lisa.

After surgery

Rest, recover and exercise

Although you may not feel too much discomfort or pain from your breast surgery, you will feel very tired and the surgical area will need extra care and looking after.

You'll need some rest, but it's important to return to normal daily activities as soon as possible, i.e. be as physically active as current abilities and conditions allow. Recent research shows that exercise can counteract many of the adverse physical and psychological effects of cancer.

The Clinical Oncology Society of Australia (COSA) recommends that all people with cancer should avoid inactivity and progress towards and, once achieved, maintain participation in:

- at least 150 minutes of moderate intensity or 75 minutes of vigorous-intensity aerobic exercise (e.g. walking, jogging, cycling, swimming) each week; and
- two to three resistance exercise (i.e. lifting weights) sessions each week involving moderate to vigorous-intensity exercises targeting the major muscle groups.

Ask your medical team for their advice on an exercise programme suited to your situation.

Pinc Cancer Rehabilitation Programme is an exercise programme designed specifically to help women diagnosed with cancer regain their physical strength and incorporate exercise into their lifestyle. Contact them at www.pincandsteel.com

The Breast Cancer Foundation NZ provides funding for 4 PINC Rehab sessions with a certified PINC physiotherapist. BCFNZ also funds places on the PINC Next Steps group exercise classes. Conditions apply. Download a PINC programme application form from BCFNZ's website to see if you qualify.

You might need to take it easy for a while after surgery, so organise some help to keep the household running. Ask friends to take the kids to school or to stop by and hang out washing. Accept offers of help. Let people know what you need because they want to help and will welcome your suggestions. www.supportcrew.co offers a free online service to help coordinate offers of support from friends and family.

Strange sensations

You may feel some numbness in the armpit, upper arm, breast and chest wall as a result of nerve damage during surgery. As the nerves repair, you may feel even more odd sensations in these areas – burning, tingling, itching, or the skin may feel as if it has been grazed.

There may also be some swelling. Usually this is relatively minor but larger collections of fluid (called seromas) are not uncommon, especially in the armpit or under the mastectomy scar. Fluid is usually absorbed by the body over time but seromas can be uncomfortable. In such cases, the fluid can be drained away by your surgeon or a breast nurse using a syringe.

Side effects will settle over time but this can take several weeks or even months. Discuss them with your surgeon and breast nurse during your follow-up visits. If you are concerned, don't hesitate to call your breast nurse for advice.

Tubes and drains

Surgery for breast cancer usually involves a hospital stay of one to three days or longer for those who have a breast reconstruction. Some of us are sent home with drain tubes in place. These drains run into a collection bottle and remove blood and lymph fluid that can accumulate in the armpit or other areas after surgery. Your breast nurse will give you information about how to care for the drain tubes and collection bottle(s), who to contact should you need help, and who will remove the tubes and when.

Be sure you have all the information and support you need before leaving hospital so that you feel comfortable. If you are worried at any time, if your drain tubes become blocked, or if you have swelling or discomfort call your breast nurse. She is there to help and will advise on all aspects of post-surgical care and follow-up appointments.

It can be a little awkward walking round with tubes and bottles. Try placing the bottles in a carry bag, or wear a long cardigan or loose shirt so they are not so visible. 'Bum bags' are excellent as you can have free hands and not have to worry about carrying something around and forgetting about it.

Scars

Your mastectomy surgery will leave a scar and some women can find this challenging.

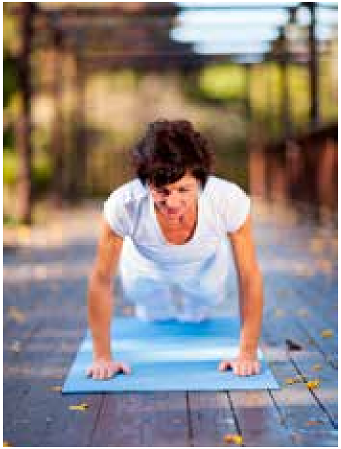
All scars are different. Some will be straight, some bumpy, some filled with fluid. Keeping the wound clean and free from infection is the first step to limiting scarring so be sure that the tubes and drains inserted to help remove fluid are working properly.

Once the wound site has healed over, gentle massage can be very helpful in decreasing scarring. Massaging the skin across the scar from top to bottom is the best approach. You may find it helpful to see a sensitive and qualified massage therapist to do this or to teach you how to do it effectively for yourself.

Some surgeons recommend taping scars to help with the healing process. There are also various creams and lotions which some women find help to reduce the redness of mastectomy scars. Speak with your surgeon about these options to see what he or she recommends for you.

Many women who have had mastectomies say they are amazed at how well the scars heal with time and how little they notice them. As with many things, the best way to deal with a scar is to give it time to heal and fade.

Exercising is important



Your breast nurse will give you some special exercises to help regain mobility in your affected arm and shoulder. It is important to do these exercises regularly to keep your arm moving freely.

If you have had lymph nodes removed, you may experience a condition called 'cording' where a pulling sensation can be felt from the armpit to the upper arm, elbow or even down to the wrist. The causes of cording are not fully understood but the condition can be painful and uncomfortable. Your breast nurse will offer advice on how best to deal with cording – usually this will involve:

- applying a warm pack or special creams to the affected area
- taking standard pain medication (such as paracetamol)
- gentle stretching exercises.

The symptoms will disappear over time.

Breast reconstruction

If your treatment includes the removal of all or part of your breast, reconstructive surgery may be an option. This may be carried out at the same time as your initial surgery – known as immediate reconstruction. Alternatively, you may prefer to wait until your cancer treatment is over before you consider reconstructive options – known as delayed reconstruction. This may also be the advice of your surgeon and is often the case if your surgeon prefers to wait until you have recovered from chemotherapy and/or radiation therapy before having further surgery.

Reconstruction is a process to endeavour to provide a breast shape for women undergoing mastectomy. Reconstruction is not for all women, but for women who are keen to have this done, studies have shown that reconstruction may enhance self-esteem, body image, femininity and sexuality.

The process involves more major surgery than mastectomy alone, and also raises the risk of a complication of surgery. The reconstructed breast is quite different from a normal breast. There is reduced and altered sensation, and there are scars on the breast, and elsewhere if tissue from elsewhere has been used. The reconstructed breast is different in movement, feel and shape, from a normal breast. All forms frequently require more than one operation to obtain the final result.

Breast reconstruction is your choice. For many women reconstruction aids recovery and helps them feel better about themselves. However, it is not the right choice for everyone and it may not be appropriate for you. Discuss your options with your plastic surgeon. A reconstructed breast will never look or feel the same as your own breast; it provides the illusion of a breast.

There are three commonly used methods of reconstruction:

- *Implant and expander forms of reconstruction*
  These can be done in single stage process with a definitive implant or permanent expander placed at the initial operation. Alternatively, a two-stage process may be best. At the first operation a tissue expander is placed under the muscle of the chest wall. This will be expanded over time. At a second operation the tissue expander is removed and replaced with a silicone gel implant. A second operation gives an opportunity to correct asymmetry, but means having a second anaesthetic and procedures. Frequently, some form of artificial dermal matrix (ADM) is used with implant techniques to help create and control the implant pocket. This technique gives good size and balance. As your body changes with time further surgery may be required, and fat grafting is also increasingly being used to improve contour and shape after implant reconstruction.

- *Latissimus dorsi flap, often with an implant*
  Skin and muscle from the back is brought forward onto the chest to reconstruct the breast. Usually a tissue expander or implant is also needed to achieve a good size and shape match. This approach often achieves a more natural breast

shape. It will leave a scar on the back, your shoulder strength will take some months to recover and overall recovery is longer than implant reconstruction alone.

- *Abdominal tissue reconstruction*
  This procedure involves moving skin and fat from your abdomen to reconstruct the breast and there are several techniques that can be used. One is a pedicled TRAM flap in which the blood supply to tissue taken from the abdomen remains intact. The other option is a free TRAM flap or DIEP Flap in which microsurgery is used to re-establish the blood supply once the tissue has been moved to the chest. Often these approaches provide enough tissue to enable the surgeon to create a natural breast shape without the need for an implant. However, this kind of surgery is extensive. It can result in weakness and bulging in the abdominal area (especially pedicled rather than free techniques) and requires a longer recovery period.

- *Further surgery*
  Often further surgery is required to your unaffected breast such as a lift or a reduction, or an augmentation, to help achieve a better balance. The reconstructed breast often requires adjustment. Finally, you may wish to consider reconstruction of a nipple and areola. This is usually done many months after the initial surgery. Some women choose to have a nipple tattooed on. If you do this make sure you use someone who specialises in this technique. Ask your medical team for recommendations.

Many women decide not to have reconstructive surgery at all and this is a valid decision. If you make this choice you could then consider wearing a breast prosthesis (see page 59). These are choices to discuss fully with your surgeon, your breast care nurse and someone close to you.

Reconstructive surgery is a big step. Think about your options carefully before making any decisions. Remember you can always do it later. However, if you have delayed reconstruction in the public health system you may have to wait some time for your surgery.

It is always a good idea to ensure that the option of reconstruction is recorded in your notes as part of your treatment plan (even if you aren't sure) to avoid unnecessary delays in the public system.

Breast reconstruction surgery is a special kind of surgery. Make sure your surgeon is qualified in reconstructive surgery and seek advice on choosing the best and most experienced surgeon for the kind of reconstructive surgery you choose.

See the Cancer Australia website, www.canceraustralia.gov.au for a useful resource on breast reconstruction. The Breast Cancer Foundation NZ's website www.breastcancerfoundation.org.nz also provides useful information about reconstructive options.

Lady Ink is an organisation that specialises in areola and nipple re-pigmentation. It is run by Debbie who is a breast cancer survivor herself. Visit www.ladyink.co.nz

"I was happy that I could look down and see two breasts there and I had something to fill my bra with and I didn't have to worry about getting dressed on a daily basis." Toni

Young women and fertility

Each year around 200 New Zealand women aged 40 and under will be diagnosed with breast cancer. If you're a young woman with breast cancer, you may be facing a host of issues that older women won't necessarily be dealing with – one of these may be fertility.

As a younger woman, you may not have had children or may not have completed your family before you need to undergo chemotherapy. Chemotherapy affects your fertility by damaging the ovaries and it can cause your periods to become irregular or even stop. If you're considering having children after cancer treatment, you need to be aware that chemotherapy may reduce the likelihood that you'll fall pregnant at a later date. Recent research has shown that treatment with a medicine (e.g. goserelin (Zoladex®)) to suppress the ovaries during chemotherapy can help to preserve fertility in some women.

As a younger woman, if you think you may want children you should make time to see a fertility specialist as soon as possible after your diagnosis and well before you have treatment such as chemotherapy. A fertility specialist can talk to you about the various options available to you to help preserve your fertility and increase your chances of having a child at a later date if that's something you want. Options can include freezing embryos for later use; freezing eggs for later use; or using a donor egg.

Fertility procedures need to be carried out quickly for those having cancer treatment because it's important that they're done before chemotherapy starts, so make sure you secure an appointment with a fertility specialist before or soon after your surgery.

For further information on the various fertility preservation options available to women with breast cancer, see BCAC's website www.breastcancer.org.nz (search 'fertility') and Fertility Associates website www.fertilityassociates.co.nz

The American website www.fertilehope.org has a lot of useful information about fertility and cancer.

If you're a young woman wanting to talk to others in the same situation, try BCAC member group, Breast Cancer Support. You can contact them on 0800 273 222.

Mybc is an app which enables young women with breast cancer to connect with each other and share experiences. www.mybc.care

Younger women can often also face issues around sexuality, body image and relationships. For help and support visit the New Zealand site for young women with breast cancer, www.shockingpink.org.nz and the international site www.youngsurvival.org.

Treatments

Adjuvant treatments for breast cancer

Based on the pathology report describing the details of your cancer your specialist may recommend other treatment in addition to your surgery. This is known as "adjuvant therapy". This treatment could include radiation therapy and/or medicines, such as chemotherapy; hormone therapy; or targeted therapy such as trastuzumab (Herceptin®).

Once your specialist knows the details of your cancer she or he will be able to explain to you the treatments that have been shown to reduce the chance of your cancer returning and increase your opportunity of living a long and healthy life.

If adjuvant therapy is recommended for you, your surgeon will refer you to another member of your medical team, a radiation oncologist and/or a medical oncologist. A radiation oncologist is a doctor with specialist training in treating breast cancer with radiation therapy, while a medical oncologist is a doctor with specialist training in treating breast cancer with medicines (chemotherapy).

Your oncologist will outline your treatment options; provide you with the information you need to choose the best course for you; and then supervise your treatment plan. If you are having both chemotherapy and radiation therapy you may have both medical and radiation oncologists working with you at different times.

It's a good idea to record after hours contact numbers for your medical team, so that if you have any problems or concerns while undergoing treatment you can speak with someone about it right away. There is a place in the ***Step by Step Diary*** *for you to write these down.*

This is a good time to use your ***Step by Step Diary*** *because you'll have a number of appointments with different people. Fill in the personal details section and when you see someone for the first time, just hand over the diary so they can read the relevant information. Your diary can also help you keep track of your treatments, note down questions and write about side effects you may experience.*

Radiation therapy

What is it and what will it do for me?

Using radiation to kill cancer cells is known as radiation therapy or radiotherapy. It is most often used following a partial mastectomy (lumpectomy or wide local excision) and sometimes after a full mastectomy. Radiation therapy is given to kill any cancer cells that may still be present in the breast and/or the draining lymph nodes in the armpit (axilla) and around the collar bone (supraclavicular fossa). It has been shown to be very effective in reducing the risk of the cancer recurring locally in the breast or chest wall tissue. A radiation oncologist will oversee your treatment and will talk to you about what is involved with radiation therapy and the possible side effects of the treatment. There are different ways radiation therapy can be delivered. The most common form of treatment is external beam radiation therapy. In some women, with very early breast cancer, partial breast radiation therapy may be used. This could be intraoperative radiation therapy.

Photo courtesy of Auckland Radiation Oncology

External beam radiation therapy

This is the most common type of radiation therapy used to treat breast cancer in New Zealand. The radiation therapy is given over a period of three to six weeks (between 15 and 30 treatments). The treatment is given daily, Monday to Friday with the weekends off. Each treatment only takes a few minutes and you are usually in the department for about 30 minutes each day.

You will have an initial planning CT scan of the area to be treated. After the CT scan, a couple of permanent dots will be tattooed on your body to help guide the radiation therapist to the correct area to be treated. These dots are barely noticeable and they look like a freckle on the skin. The information from this planning CT scan will be used to produce a radiation plan that covers the area needing treatment based on the stage and grade of the breast cancer. The radiation plan aims to minimise the radiation dose to the surrounding normal tissues.

Each day when you come in for your treatment, a special x-ray machine called a linear accelerator will be used to deliver the radiation therapy. The radiation therapists operate this machine to give you the treatment prescribed by your radiation oncologist.

You will be asked to change into a hospital gown, lie on the treatment couch, and the radiation therapist will then use the tattooed dots to get you in the right position for your treatment. Once you are in the right position the linear accelerator will deliver the radiation therapy to the treatment area. You will not feel or see anything during the delivery of the radiation therapy. It is like having an x-ray taken.

Partial breast radiation therapy

Some women with small, low grade breast cancer may be suitable for intraoperative radiation therapy, in which radiation therapy is given during the surgery to remove the breast cancer. In theatre, after the cancer is removed from the breast, a small probe is placed in the surgical cavity and a one-off dose of radiation treatment is delivered to this area. This usually takes between 25 and 40 minutes. The probe is then removed and the surgical wound closed. As the radiation treatment is delivered to a much smaller area of the breast compared to whole breast radiation therapy it reduces the dose of radiation delivered to the normal surrounding tissues and therefore has the potential for fewer side effects.

After surgery, the tissue removed during your operation is analysed. Depending on the results, some women will need no further radiation treatment, while some women may still require further external beam radiation (for 3 to 5 weeks) in addition to the initial intraoperative radiation therapy.

Intraoperative radiation therapy is only suitable for up to 30% of women with breast cancer. Speak with your doctor if you think you may meet the criteria for this treatment.

Early side effects of radiation therapy

The actual delivery of radiation therapy is painless, but the therapy can have side effects over the course of treatment and in the weeks after treatment completion. You may experience:

- tiredness
- the irradiated skin may become red, blistered or peel, like a bad case of sunburn
- breast swelling and breast pain.

Your medical team will advise on skin care before, during and after radiation therapy, and will give you detailed information about other potential side effects (see late side effects below). You may be offered Mepitel Film, a thin, transparent dressing applied before treatment that can reduce skin reactions to radiation.

If you live close to the radiation treatment centre, you may be able to return to work during this phase of your treatment as the treatment sessions are so short, but remember to get lots of rest and relaxation.

Late side effects of radiation therapy

These are side effects that can develop in the months or years after radiation therapy. Not all patients will experience any or all of these side effects and the severity can vary. Late side effects include:

- change in the size of the breast
- change in the texture of the breast or chest wall tissue
- breast or chest wall pain
- scarring of the lung that was in the radiation treatment area (does not usually cause any significant symptoms)
- potential for increased risk of heart disease in left sided breast cancer patients if the heart is exposed to a significant radiation dose during treatment (your radiation oncologist will discuss this with you). Breath holding techniques are being used to limit the heart's exposure to the radiation field
- lymphoedema if the armpit is treated.

Driving back and forth to hospital can be tiring, especially if you are going in every day for radiation therapy. Ask someone to drive you and keep you company while you are undergoing treatment. You and your driver will become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regular visitors at the oncology unit so do enquire about parking. There may be special areas or a display card for the car that will make parking easier.

If you live in a rural area or in a town or city that does not have a hospital offering radiation therapy services, you will have to travel daily for treatment. You may be able to get a subsidy to help cover the cost of your travel, see www.health.govt.nz. Another alternative may be staying in a New Zealand Cancer Society lodge near the treatment centre, see www.cancernz.org.nz or call 0800 226 237 for more details.

Check out BCAC's web video on radiation therapy and hear from women who've had radiation therapy and those who deliver the treatment: www.breastcancer.org.nz/share-your-story/web-videos

Check BCAC's website for information on radiation therapy clinical trials which may be recruiting patients in NZ and offer opportunities for new types of treatment.

"I actually really liked radiation. I found radiation therapy really easy and I really liked the fact I could drive myself there and back because I just needed to regain that sense of independence." Jenny

Chemotherapy

What is it and what will it do for me?

Chemotherapy involves the use of chemical agents (drugs) to attack any breast cancer cells that may still be present at the original cancer site or in other parts of the body. The cancer cells may have spread from the original tumour site in the breast and if left untreated, could potentially multiply and cause secondary tumours to form in another part of the body.

Chemotherapy is administered as a 'course' of several injections (infusions) into the bloodstream. Usually you will receive a dose of chemotherapy and then have a period of days or weeks to recover before another dose is administered. Each chemotherapy session usually lasts at least an hour and could last several hours. Most chemotherapy treatment programmes last between three and six months.

If your treatment team is concerned about finding your veins for chemotherapy infusions, they may ask a surgeon to insert a small device called a port-a-cath under the skin on your upper chest (on the opposite side to your breast cancer) to make it easier to inject repeated doses. The port-a-cath is a small silastic dome, about the size of a coin, which is inserted under the skin and attached to the chest wall. It connects to a thin silicone tube which is fed into a vein in your neck. Chemotherapy medicine and other intravenous drugs are then injected straight into the port.

A port-a-cath usually stays in place for the duration of your chemotherapy and targeted therapy treatment.

A port-a-cath should cause no pain if it's inserted properly. It does need to be kept clean to prevent infection. Be sure to report any pain or discomfort from the device to your doctor or nurse as soon as you can.

If you have decided to receive chemotherapy you will then meet a member of the medical oncology team who will take details from you; explain the treatment; familiarise you with the waiting room and where to make a cup of tea; and show you around the suite where chemotherapy is administered.

As with any treatment, be sure to ask lots of questions to make sure you fully understand:

- the drugs being used
- the length of the course
- the benefits to you
- potential side effects.

Chemotherapy drugs travel throughout the body and destroy cells that multiply rapidly, such as cancer cells. However, the drugs will also affect normal cells that multiply rapidly, such as cells in the lining of your gut, hair follicles and blood cells. The rest periods between chemotherapy doses give the normal cells in your body time to recover.

There are many different chemotherapy drugs and they are often used in combination to provide the most effective treatment.

The main types used to treat early breast cancer are:

- Anthracyclines, such as epirubicin and doxorubicin, and
- Taxanes, such as paclitaxel and docetaxel.

Other chemotherapy drugs include:

- Platinum-containing compounds, such as carboplatin and cisplatin
- Alkylating agents, such as cyclophosphamide, or
- Antimetabolites, such as methotrexate, fluorouracil, capecitabine and gemcitabine.

BCAC's website, www.breastcancer.org.nz, has more information on chemotherapy drugs.

The type of medicine you're prescribed will depend on the type of breast cancer you have, the stage it is at, and your general health. Your chemotherapy programme may use a combination of the drugs above, or it may use different drugs.

Each type of drug and combination of drugs may have different side effects. Below is a list of possible side effects. Remember, you will not experience all of these; some of them are very uncommon and most can be minimised and often prevented from occurring. Most side effects are predictable in terms of their onset, duration and severity and they are almost always reversible.

Side effects

Depending on the drugs you are taking during chemotherapy you may experience side effects such as:

- increased risk of certain infections. This is greatest 7 to 14 days after chemotherapy, but infections can occur at any time on chemotherapy
- nausea and loss of appetite
- hair loss
- fatigue
- weight changes (gain is more common than loss)
- mouth ulcers
- joint or muscle pain in arms or legs
- tingling, burning or numbness in hands and feet (it is important to report these symptoms to your medical team as soon as possible)
- constipation or diarrhoea
- a metallic taste in the mouth
- itchy skin
- allergic reactions – flushing, skin rash or shortness of breath

- heart damage
- nail changes
- disruption to your menstrual cycle (this can cause early onset of menopause and reduced chances of future pregnancy).

Many women will be prescribed medicines at the same time as chemotherapy to help alleviate some of the more common side effects. To help reduce nausea and vomiting, steroids and other medicines known as "anti-emetics" are routinely used with chemotherapy regimens.

Some chemotherapy treatments can cause your periods to stop for a time or bring about an early menopause (periods stop permanently). Speak with your medical oncologist about the likelihood of this happening to you. If you are planning to have children, talk about fertility issues as early as possible before you start chemotherapy (see page 37). If it is likely you will experience menopausal symptoms – or perhaps experience an early menopause – then it may be helpful to find out more about these changes and how they will affect you. Some side effects of menopause can be unpleasant (e.g. hot flushes, vaginal dryness, mood changes, and loss of interest in sex) so discussing ways to prevent or minimise these can be helpful.

The lowering of oestrogen associated with chemotherapy and some hormonal therapies can also affect your bone density over the long-term, potentially leading to osteoporosis later on. Discuss this with your medical oncologist too. She or he may recommend taking a bone density test after you've completed chemotherapy and prior to commencing some hormonal therapies so that density can be monitored over time. Reducing the risk of osteoporosis could involve targeted exercise, vitamin D tablets or other prescribed medication, such as bisphosphonates.

Dental problems, such as inflamed gums, fractured teeth or cavities, can become more noticeable and painful during chemotherapy, so it's wise to have a dental check-up before you start treatment.

Hair loss is a common side effect of chemotherapy. Your medical oncologist or breast nurse will provide you with information about the Wig, Hairpiece and Headwear government subsidy that is explained on page 58 of this book.

If you experience side effects that are very pronounced, worry you or that you cannot manage, let your specialist team know right away. A number of medicines can help alleviate the side effects of chemotherapy and these can be added to, altered or balanced to make you feel better.

Take the time to understand the information and advice you are given by your specialists so you can be sure to make good choices about your treatment. Undertaking a lengthy course of treatment may mean you have to make some changes to your lifestyle, your employment and your family situation so it is important to make informed decisions.

Maintaining a regular exercise programme during chemotherapy can help you to cope better and have fewer side effects.

'Look Good Feel Better' is a fun and free service offered to women undergoing cancer treatment to help restore and enhance the appearance of patients both during and after treatment. The service offers guidance, information and makeover expertise at beauty workshops throughout New Zealand that will literally make you 'look good and feel better'. Visit www.lgfb.co.nz or call 0800 TOLGFB (0800 865 432) for more details.

Check out BCAC's web video on chemotherapy and hear from women who've had chemotherapy and how they coped with it: www.breastcancer.org.nz/share-your-story/web-videos.

“The first lot of chemo I had was disastrous. I was violently ill, but we got all that sorted with a change in the medication and after that I went through it without a problem.” Kath

Targeted therapy

Targeted therapies are drug therapies, but unlike chemotherapy which affects all multiplying cells, these medicines work by attacking specific proteins produced by abnormal genes in cancer cells. This means they are generally less toxic to healthy cells and have fewer side effects than chemotherapy.

Each can only be used against a particular type of breast cancer. For example, trastuzumab (Herceptin®), pertuzumab (Perjeta®) and lapatinib (Tykerb®) can be used to reduce the growth and spread of HER2 positive breast cancer, because they block the function of the HER2 protein that drives this type of breast cancer.

If you are prescribed trastuzumab (Herceptin®) for early stage HER2 positive breast cancer, you will be offered a treatment programme in which the drug is normally injected once every three weeks for around 12 months.

Other targeted therapies include fulvestrant (Faslodex®), T-DM1 (Kadcyla®), palbociclib (Ibrance®) and everolimus (Afinitor®). These are all approved for use in New Zealand but they may not yet be subsidised, so you might have to pay to receive them. Each treatment is only effective in some forms of breast cancer. If you feel they might be useful for you, please discuss this with your medical oncologist.

Check www.breastcancer.org.nz for updates on the status of breast cancer medicines in New Zealand.

You can read more about targeted therapy on BCFNZ’s website: www.breastcancerfoundation.org.nz/breast-cancer/treatment-options

If your breast cancer is HER2 positive and you would like to get in touch with other women who have experienced this

type of cancer, you might like to contact the BCAC member group, HER2 Heroes, for advice and support. Contact them through the BCAC website: www.breastcancer.org.nz

Bone-specific therapy - bisphosphonates

Bisphosphonates are a group of medications which have been commonly used to combat bone loss and lower the risk of fracture in people with osteoporosis and in cancer which has metastasized to the bone.

However, many studies have shown that bisphosphonate therapy can inhibit the development of bone metastases and improve survival when given as adjuvant treatment to post-menopausal women with early breast cancer. This includes women who are having their ovarian function suppressed. Bisphosphonates can be given intravenously or in tablet form.

Your medical team will discuss whether this treatment is appropriate for you.

Hormone therapy

The breast cancer removed during your surgery or biopsy will be tested for 'hormone receptor status' and your pathology report will state whether your tumour was ER (oestrogen receptor) and/or PR (progesterone receptor) positive or negative. Your specialist will use this information to decide whether you would benefit from hormone therapy, also known as endocrine therapy. For instance if your tumour is ER positive (probably responsive to oestrogen) you will usually be offered therapy to reduce or eliminate the oestrogen in your body. The main types of oestrogen blockers are tamoxifen (Genox®) and the aromatase inhibitors, such as anastrazole (Rolin®), letrozole (Letrole®) and exemestane (Pfizer Exemestane®). All of these are available as pills.

Unlike tamoxifen, which can be taken if you're pre-menopausal, aromatase inhibitors are only effective in post-menopausal women or women who are on a treatment that suppresses their ovaries (e.g. goserelin (Zoladex®)).

Depending on your level of risk, hormone therapy may be prescribed for between five and ten years and your oncologist may suggest you change therapies, depending on your side effects or any changes in menopausal status.

Side effects of hormone therapy may include:

- hot flushes and sweats
- changes to your menstrual cycle
- vaginal dryness
- loss of interest in sex
- nausea
- painful joints
- mood changes
- tiredness.

It's really important to keep taking your hormone therapy pills for the prescribed length of time because they are very effective in reducing the recurrence of breast cancer. If you're having problems dealing with the side effects of your medication, speak to your doctor. He or she may be able to help with the management of any side effects or switch you to a different hormone therapy.

For more information about hormone therapy go to www.breastcancerfoundation.org.nz/treament-options/hormonal-therapy. You can also download patient information sheets for tamoxifen and aromatase inhibitors.

Regular exercise is very important for managing the side effects of any hormone therapy and may be effective in reducing joint pain when taking aromatase inhibitors.

Non-ionic cream, available over-the-counter from pharmacies, is a cheap vaginal moisturizer and lubricant. Replens and Yes Vaginal Moisturiser are other alternatives.

"The side effects have definitely lessened over the years. I am dedicated to taking my aromatase inhibitor because I know it's something I can actively do to help reduce the risk of the cancer returning." Rowena

Availability, costs and funding of treatment

How cancer medicines are approved and funded

There is enormous effort going into cancer research around the world which is leading to a succession of new treatments. New cancer medicines are generally developed and commercialised by overseas pharmaceutical companies.

In order for a company to market a new cancer medicine in New Zealand, it must first apply to Medsafe, the government organisation responsible for ensuring that new medicines are safe and effective. Medsafe undertakes a rigorous evaluation of all available data and evidence, and decides whether a particular medicine can be approved (or 'registered') for a particular therapeutic use in New Zealand.

Once Medsafe has approved a medicine, doctors can prescribe it. Doctors can prescribe these medicines for the conditions approved by Medsafe and also for other conditions ("off-label use"). However, the medicine will not be publicly funded (i.e. free or subsidised to the patient) until it is approved by the government's drug-buying agency, PHARMAC.

For more information on how medicines are approved and funded in New Zealand, visit www.breastcancer.org.nz

Alternative ways to access medicines

In some circumstances, doctors can also prescribe unapproved medicines (under Section 25 of the Medicines Act), provided this is within their scope of practice, they provide an adequate standard of professional and ethical care, and they have the patient's consent to do so. There is also provision under this Act for unapproved medicines to be imported into New Zealand (Section 29).

Some women who are self-funding their medicines have travelled overseas to obtain them more cheaply than in New Zealand. Always discuss this option with your doctor first and make sure that you deal only with reputable medical facilities overseas.

Sometimes pharmaceutical companies set up patient access schemes for unfunded medicines (for example, see Roche's website: http www.cancerinfo.co.nz/accessing-treatment). Ask your specialist if one of these schemes might be helpful for you.

Clinical trials

Participating in a clinical trial can be a good way to:

- Help in the development of better cancer treatments for everyone
- Gain access to a new and potentially better treatment
- Ensure that you are closely monitored and receive close attention during your treatment.

Do not worry that you may be "missing out" if you are assigned to the control group in a trial. It does not work that way. Ethical standards require that all participants receive the best current standard of care and you will be monitored very closely even if you are not receiving the experimental treatment.

Further information on clinical trials can be found at: https://www.breastcancer.org.nz/AboutBC/Clinical-trials

The Breast Cancer Foundation NZ has a clinical trials database which enables you to search for trials in New Zealand and Australia: www.breastcancerfoundation.org.nz/breast-cancer/clinical-trials

Public and private cancer care

Breast cancer treatment is one of the essential services provided by New Zealand's public healthcare system. This service is available to all residents, regardless of insurance status. Some of us receive our diagnosis and all of our breast cancer treatment through the public system.

Those of us with health insurance cover, or able to pay privately, are more likely to have had our diagnostic tests, surgery, and perhaps also our radiotherapy and chemotherapy, carried out in private practice.

Private care can be speedier than public, and you will have more choice in the specialists you see (although most cancer specialists work in both the public and private systems). While private surgical services are widely available, private access to other cancer treatments can vary depending on where you live.

You may find that you will want to have some of your care in a private setting and some in the public hospital. Some cancer medicines are very expensive, and if they are publicly-funded it may be better to receive them in the public system. All residents are entitled to public care, even if they have received some of their cancer treatments in private practice.

Directories of New Zealand cancer specialists can be found by searching under your region at https://www.healthpoint.co.nz

Health insurance cover for cancer care

If you have health insurance that covers specialist visits, imaging, surgical and other treatments, then this should be useful in helping to cover much of your cancer care and follow-up. Most major health insurance providers in New Zealand now also offer a cancer support package, usually a lump sum paid upon diagnosis, that you can choose to spend however best suits your circumstances. This can be very useful for accessing expensive medicines not covered by the public system. In most cases you will have had to sign up for this policy before your diagnosis. However, some insurers will provide cover if you have previously had a cancer diagnosis, after a stand-down period. Consulting an insurance broker could be helpful in finding a company that will cover you after a cancer diagnosis. Insurance for prophylactic surgery is also available and may be of interest to you and your relatives if there is a genetic component to your breast cancer. Visit the websites of health insurers for more information.

Optional extras

In this section you will find information about obtaining wigs, headwear, breast prostheses and associated products (bras and swimwear).

Wigs, hairpieces and headwear

This section will not apply to everyone but could be of assistance if you have chemotherapy and experience hair loss. Generally, women undergoing chemotherapy will find they start to suffer hair loss after the second treatment. You may find you wake up with hair over your pillow or you start to notice hair falling out in the shower or on your clothes. Some women choose to shave their heads before beginning chemotherapy. Either way, a wig can be a good option to help restore confidence and self-esteem. But there are also many attractive hats and scarves available and many women like to wear a hat to bed because they find their head can get cold.

The Government currently subsidises wigs for adults with temporary hair loss up to $400 a year. If your wig costs more than this, you will need to pay the remainder. The Wigs and Hairpieces Service Payment (WHSP) is administered by Sector Operations on behalf of the Ministry of Health and is paid either directly to you, or to the supplier of the product(s).

The subsidy can be claimed if you are a New Zealand citizen or resident and if you are undergoing a treatment for breast cancer which causes hair loss. To claim the subsidy you will need a Medical Certificate with your NHI number from your specialist.

Your specialist should provide you with a list of wig suppliers in your area or you can contact your local division of the Cancer Society for help.

For further information about the Wigs and Hairpieces Service Payment call Sector Operations on: 0800 855 066.

Breast prostheses

If you decide to delay reconstructive surgery, or not have it at all, then you might want to look at how you can create the appearance of a natural breast by using a prosthesis (for mastectomy) or breast form (for lumpectomy).

After surgery and before discharge from hospital, your breast nurse will talk to you about whether wearing a prosthesis may be appropriate for you. If you decide it is, she will provide you with a temporary soft prosthesis that can be used while the surgical area is healing. After healing (generally five to six weeks post op), you may wish to obtain a permanent breast prosthesis.

Photo courtesy Anita BreastCare

What is a breast prosthesis?

A breast prosthesis is a mould made of silicone-based material that resembles the shape and weight of a breast. The prosthesis fits into a special bra. Today's prostheses are well made, expertly fitted, comfortable to wear and very natural-looking. Many breast prostheses can be worn in water (salt or chlorinated) and most suppliers offer a range of special swimwear or can modify swimsuits to accommodate them.

Wearing a prosthesis can help with balance and posture and make you feel more confident about your appearance.

Before leaving hospital, your breast nurse will show you a breast prosthesis and a mastectomy bra and discuss information on wearing these. She will advise how long you can wear the soft temporary prosthesis before a silicone one is recommended.

All about the breast prosthesis subsidy

The Government offers a subsidy for a prosthesis and other related products (for example special bras) after surgery for breast cancer.

The current subsidy is $600 per side, rolling over every four years as long as you have not had breast reconstruction. The subsidy is administered by Sector Operations on behalf of the Ministry of Health and is available to New Zealand citizens or residents.

For more information on the breast prosthesis subsidy ask for the Ministry of Health brochure 'Breast Prosthesis Service Payments Fact sheet' or visit www.health.govt.nz. You can also call Sector Operations on 0800 855 066.

Your first fitting

Fitting women with a prosthesis and bra requires special training. The suppliers of these products in New Zealand offer a wide range and their specialist fitters are capable, experienced, careful and considerate. Your breast nurse will have given you information about specialist fitters in your area and when you are ready you can call to make an appointment with the fitter of your choice. You will have to take your medical certificate confirming you've had a mastectomy or lumpectomy with you. You may also like to take someone with you for moral support.

Photo courtesy Anita BreastCare

Suppliers and Stockists

Anita BreastCare in Silverdale (north of Auckland) stocks protheses and bras. They also have independent stockists throughout the country. Call 0800 264 822 or (09) 427 5283 to make an appointment or for the stockist nearest to you (North and South Islands).

Naturalwear is a dedicated post mastectomy breast care provider. There is a showroom in Auckland and they can make home visits by appointment in most regions of New Zealand. Call Naturalwear on 0800 612 612 or visit www.naturalwear.co.nz

Smith and Caughey has been fitting women at their downtown Auckland store, 261 Queen St, for over thirty years. They feature a selection of prostheses and bras from the Amoena and Anita lines, and a wide range of other special bras and swimwear. Call for an appointment on (09) 916 0844.

J Ballantyne & Co, City Mall, Christchurch also has experienced fitters available to help find the right product for you. Ph (03) 379 7400 for more information.

The Fitting Room in Christchurch stocks breast protheses and associated products. Call them on 0800 478 348 or visit the website www.thefittingroom.co.nz

Medical Matters in Wellington supplies German breast protheses. Visit www.medicalmatters.co.nz or call (04) 566 4660 for further details.

Complementary therapies

Complementary therapies are techniques that may help you to cope with breast cancer treatment and manage the psychological, social and physical burdens treatment can entail.

Complementary therapies should not be used as a replacement or alternative to conventional and scientifically proven medicine.

However, if they help you cope with side effects, relieve some symptoms and improve your quality of life then they can be a valuable addition to your treatment programme. You may like to check out Professor Shaun Holt's book, *Complementary Therapies for Cancer - What works, what doesn't ... and how to tell the difference* (Craig Potton Publishing, 2010) for a guide on complementary techniques.

Always check with your doctor before beginning a complementary therapy. BCAC strongly advises against using "alternative medication" as a replacement for conventional medication. These "alternative" medications have not been scientifically validated or proven to be effective in fighting cancer and could interfere with your conventional treatment programme.

Some common complementary therapies include:

- Acupuncture
- Massage
- Yoga
- Meditation
- Counselling
- Keeping a journal
- Music and art therapy
- Prayer.

Coping with treatment and life afterwards

Everyone deals with the emotional fall-out of breast cancer in their own way. Fear, uncertainty, anger, sadness, anxiety and loss of control are feelings you may carry with you when you are diagnosed and beyond. Working through these feelings and giving voice to some of your fears and worries can help.

A few ways to cope and ease some of this stress can be:

- talking to a friend
- making an appointment with a qualified counsellor or psychologist
- getting peer support from a woman who has been through breast cancer
- attending a support group to share your experience and hear how others have coped
- using online forums or support groups
- writing down your thoughts or feelings in the ***Step by Step Journal***
- writing a blog or online record
- trying mindfulness/meditation to help clear your mind of negative thoughts.

Research shows that women who have had breast cancer are more prone to depression and anxiety. These are very real side effects and should not be ignored. If you're feeling overwhelmed, continually anxious or depressed, speak with your doctor or make an appointment with a qualified counsellor or psychologist.

A counsellor or psychologist can support you with different types of therapy that can be effective for anxiety and depression. Many women say these sessions were helpful because they could talk openly in a way they could not with friends or family. Some people find just one or two sessions is enough to help them, while others find ongoing professional support useful.

Some hospitals may have a psychologist on staff you can use and some private breast clinics will also have a psychologist or counsellor you can access. The Cancer Society of New Zealand also has counsellors and psychologists available.

The Breast Cancer Foundation NZ funds three free counselling sessions for anyone who has ever been diagnosed with breast cancer. Counsellors are available throughout New Zealand. Download a referral form on the Foundation's website www.breastcancerfoundation.org.nz or phone 0800 BC Nurse (0800 226 8773).

Remember that you are not alone; many New Zealand women have experienced breast cancer and have found ways to cope and thrive beyond their diagnosis and treatment. There is a 'breast cancer community' out there and connecting with this, informally or formally, online or in 'real life', can be a powerful support for you.

See the member group listings at the end of this booklet, go to www.breastcancer.org.nz, or join our Facebook group (click on Groups on our Facebook page: https://www.facebook.com/BreastCancerAotearoaCoalition/)

BCAC has a list of qualified counsellors and psychologists who specialise in helping those with serious illnesses on our website, www.breastcancer.org.nz. Or you can contact your local branch of the Cancer Society of New Zealand on 0800 226 237 or find a professional near you by checking out www.psychology.org.nz or www.nzac.org.nz

BCAC member Jan Haworth runs Life 2.0, a programme of one-to-one and group courses to help people feel normal again after cancer. For more information, see www.life20.co.nz

BCAC member group, Breast Cancer Support, offers peer support counselling in which you can speak with a woman who has experienced breast cancer. Call them on 0800 273 222

"Before I had my mastectomy I met with two women who had had breast cancer and that was probably my life-saver being able to see them three or five years down the track". Toni

“The limited life feelings do not go away but with work become more balanced. They are sneaky feelings. They generally sneak up when you least expect it or when life feels pretty good. I experience them like a prick in the brain and coldness seeps over me. I use visualization – see them as a blue dye that I imagine bleaching out – getting rid of the blue dye pronto!” Ellen

“Most women I know put it behind them and want to forget. They actually don’t forget but say that to others as they want to live normally. The fear of recurrence is pretty natural and I don’t think you need counselling – it should not disturb your life.” Rowena

Body image and sexuality

Some women find they struggle with body image after surgery and treatment for breast cancer, while others experience no such issues. Some women may feel betrayed by their bodies; others may see themselves as disfigured; some may feel the loss of a breast or breasts affects their sense of womanhood; and some say it affects their sexuality and intimate relationships.

A breast prosthesis can help to give you a normal breast shape in clothing and this allows some women to feel more comfortable. Others find that breast reconstruction helps them feel more positive about their body, but further surgery is not the right option for everybody. Often it just takes time and understanding to adjust to your ‘new body’.

Breast cancer treatment can also affect your sexuality and your physical relationship with your partner. You may experience a loss of libido, feel uncertain about your sexual attractiveness, feel uncomfortable with the physical changes to your body, and emotionally exhausted from dealing with diagnosis and treatment. All of this can have an impact on your relationship and can make sexual intimacy difficult.

Don’t assume that your partner does not find you attractive following surgery and treatment. Many are thrilled to simply have their partners alive and well and many people say getting through breast cancer has made them stronger as a couple.

Most partners are more than ready to take the time to slowly build up to an intimate life again so make sure you keep the lines of communication open. Recognizing the importance of expressing affection and maintaining intimacy will help your relationship so just aim to start slowly. Don't hesitate to discuss these issues with your breast care nurse or your GP; they may be able to help. Some couples also find a session with a counsellor can be useful if they are struggling with intimacy.

For more information, see the articles on 'Sexuality and Intimacy' and 'Husbands/Partners' on the BCAC website: www.breastcancer.org.nz

Useful tips for getting back to sex can be found in the article 'Sex after breast cancer' at www.breastcancercare.org.uk

"It isn't natural to look at, but it's still my wife. Our lives have changed and things are different, but when your wife gets sick, well my love just got deeper. You realise that you can cope with a lot more than you think you can cope with."
Gavin

Men with breast cancer

Around 25 men will get breast cancer in New Zealand every year. Often these men will have a strong family history of breast cancer or ovarian cancer and they may carry a BRCA gene mutation associated with breast cancer.

However, many men assume that breast cancer is a woman's disease and either do not seek help or are too embarrassed to ask for help if they notice any unusual changes in the breast or nipple area.

Those who have been diagnosed often feel embarrassed or ashamed to tell others about their breast cancer, because it is a disease that is most often associated with women. Some men feel they may be ridiculed or that their masculinity will be questioned when they have been diagnosed with breast cancer. Friends, family and supporters should never make you feel like this. Start by telling close friends and family about your disease so that they can support you. You may also like to seek professional psychological help to talk about some of your feelings.

The Cancer Society of New Zealand produces a useful booklet called Breast Cancer in Men. You can order it by phoning 0800 226 237 or visiting their website www.cancernz.org.nz

BCFNZ can provide copies of Male Breast Cancer – Taking Control by Prof. John Boyages. Email breasthealth@bcf.org.nz to order a copy.

Look Good Feel Better now runs "Feel Stronger, Live Better" classes for men with cancer. Find out more at www.lgfb.co.nz

The UK website, Breast Cancer Care, has excellent information about breast cancer in men. Visit their website; http://www.breastcancercare.org.uk/information-support

Other informative websites: The US Male Breast Cancer Coalition http://www.malebreastcancercoalition.org/ and HIS Breast Cancer https://www.hisbreastcancer.org/

Once you have finished treatment, you may want to know if there are any steps you can take to ensure your breast cancer doesn't come back. There's no guaranteed way to prevent breast cancer from returning, but studies have shown that there are things you can do to help reduce the risk of recurrence. The following are our recommendations.

Follow-up care

You will be put into a schedule of follow-up appointments with your specialists after your treatment, tailored to you and your diagnosis. This will be anywhere from 3- to 12-monthly for two to five years.

If you're worried that your breast cancer may have come back, do not wait until your scheduled appointment, contact your GP immediately. You should always seek medical advice if you experience any of the following symptoms:

- a lump or skin changes in either breast or in your armpit or neck
- unexplained weight loss or gain
- a persistent cough or shortness of breath
- significant back or bone pain
- any symptoms that last for two weeks or more.

Further to your regular follow-up check-ups, you should have an annual mammogram for the next ten years. You may also need regular bone density scans if you are taking an aromatase inhibitor (e.g. anastrozole, letrozole or exemestane) as part of your ongoing treatment programme. These scans are usually done every two years to measure your bone strength which can be affected by these medications. If you are post-menopausal, you may be offered treatment (bisphosphonates) to help with bone density.

It's also important to continue to manage your weight and maintain a regular exercise programme after your breast cancer treatment has finished.

Māori and Pasifika women are more likely to be diagnosed with breast cancer than other women so should be extra vigilant about having all follow-up checks. If you're Māori or Pasifika, do not put off seeing your GP if you notice any further changes in your breasts.

Exercise

Studies have shown that women who exercise regularly can reduce the risk of breast cancer recurring. Try to incorporate some moderate or vigorous exercise into your life, either every day or every second day. Walking, cycling, jogging and swimming are all good, and adding some resistance exercises (e.g. lifting weights) two or three times per week is also recommended (www.cosa.org.au). Discuss your exercise regime with your specialist or GP because there

may be some exercises that you should avoid in order to limit the pressure on your arms or shoulders and to reduce the likelihood of lymphoedema developing.

Try some of the exercise programmes designed specifically for women with breast cancer: the Pinc Cancer Rehabilitation programme, or one of the many dragon boating teams for women diagnosed with breast cancer. See ***Step by Step's*** *'We're here to help' section on pages 85-102 for more details.*

It can often take between nine and twelve months to return to your pre-treatment energy levels. Don't be hard on yourself if you find things more tiring than you used to.

Nutrition

Latest research suggests that a healthy diet and in particular, a healthy weight, may help to reduce the risk of breast cancer coming back.

If you've had chemotherapy, you may find that you've actually put on weight during treatment. Work towards keeping your weight within a healthy range for your height by eating a diet low in saturated fats and carbohydrates and exercising regularly.

More research still needs to be done to look at the links between breast cancer and certain foods, but you should try and stick to the following diet advice:

- eat lots of fruits and vegetables
- limit your intake of fat to less than 20 per cent of your daily calories
- reduce your intake of carbohydrates
- enjoy foods high in omega-3 fatty acids, such as oily fish like tuna and salmon

- consume foods high in Vitamin D, such as eggs, fish and mushrooms
- avoid too much red meat and charred foods
- limit your consumption of alcohol.

Medicines

If you've had oestrogen receptor (ER) positive breast cancer and you're taking medication such as tamoxifen or an aromatase inhibitor, such as anastrozole, letrozole or exemestane, make sure you continue to take your medication. Studies have shown that the long-term use of these medications can dramatically reduce the risk of breast cancer recurring. Sometimes the side effects of these drugs can be difficult to manage. Speak to your specialist if this is a problem for you. He or she may well be able to help you with this.

For more information on living well after breast cancer see www.breastcancerfoundation.org.nz/support/moving-forward-after-treatment. BCFNZ also provides a free booklet – *Thriving After Breast Cancer – The Years Ahead.* Order a copy at www.breastcancerfoundation.org.nz/resources/order-free-resources or email breasthealth@bcf.org.nz

Informative websites

The internet offers a vast amount of information about breast cancer and this in itself can be confusing, daunting and even frustrating!

Information sourced on the internet is not a substitute for advice and help from your specialists so it's always a good idea to discuss information you have found with your medical team.

Using search engines like www.google.com can help you locate specific information. Make sure you check out the websites of our member groups which contain useful New Zealand-based information. The following websites will also help you on your journey for quality information.

www.breastcancer.org.nz – This is the website for the Breast Cancer Aotearoa Coalition (BCAC). It provides an excellent resource for understanding breast cancer treatment and care, as well as providing details about the ways in which you can access support. It includes stories and videos from other New Zealand women who've experienced breast cancer and is a great resource for keeping up with local and international breast cancer news and research.

www.breastcancerfoundation.org.nz – The website for the Breast Cancer Foundation NZ provides information about the diagnosis and treatment of breast cancer plus a comprehensive directory of support services across New Zealand. BCFNZ also provides educational resources free of charge. For more assistance and information about breast cancer phone toll-free: 0800 BC NURSE (0800 226 8773) and speak with their specialist breast nurse.

www.bcna.org.au – This is an excellent website from Breast Cancer Network Australia. There is a wealth of information about breast cancer, treatments and care that New Zealand women will find helpful.

www.breastcancer.org – An American site providing excellent, user-friendly information about breast cancer treatments and care – information is easy to find and is written with the lay person in mind.

www.breastcancerhealth.org – Created by physicians, Breast Cancer Health is designed to improve the lives of those undergoing treatment and long-term breast cancer survivors.

www.breastcancercare.org.uk – A British site that aims to provide information and support to people affected by breast cancer. It offers easy-to-read information about treatment and also provides a forum, blog and publications where further details about breast cancer can be found.

www.komen.org – The Susan G. Komen Foundation aims to save lives and end breast cancer forever by empowering people, ensuring quality care for all and energising science to find the cures.

www.canceraustralia.gov.au – The website of Cancer Australia has some excellent information for women diagnosed with breast cancer and covers a range of breast cancer topics in detail.

www.cancer.gov – This is the website of the United States National Cancer Institute and contains much information on breast cancer diagnosis, treatment and research.

www.lbbc.org – The Living Beyond Breast Cancer website is an American site containing a whole host of information on breast cancer, whether you've just been diagnosed; have finished treatment; have been given the all-clear; or you're living with metastatic disease.

www.youngsurvival.org – A global organisation dedicated to the unique issues faced by young women with breast cancer. Get excellent information and support here, especially through their online forum.

www.cancerchat.org.nz – An online forum run by the Cancer Society of New Zealand. There's a specific forum for breast cancer that you can use to connect with others or to ask questions of a dedicated cancer nurse.

www.cancerinfo.co.nz – A website set up by the pharmaceutical company Roche for New Zealanders with cancer.

www.sweetlouise.co.nz – Sweet Louise provides support and information for people with secondary breast cancer.

www.macmillan.org.uk – A comprehensive and informative website that provides more than 6000 pages of up-to-date cancer information, practical advice and support for cancer patients, their families and carers.

Good books

There are a number of excellent books written about breast cancer diagnosis, treatment and recovery. Please visit BCAC's website www.breastcancer.org.nz or contact us directly for a current list of books suggested by our members. Your local library should be able to obtain most of these for you. The Breast Cancer Foundation NZ has a selection of free books (www.breastcancerfoundation.org.nz/resources). Your division of the Cancer Society has a comprehensive reference library too and can provide lists of recommended reading. Some private breast clinics also have books their patients can borrow.

Glossary of breast cancer terms

ADM – artificial dermal matrix, a sheet of material either synthetic, or manufactured from a biological material such as pig or cow skin or intestine, used to help with reconstruction.

Adjuvant therapy – Additional treatment to increase the effectiveness of the main treatment (often surgery), such as chemotherapy, systemic therapy or radiotherapy. The goal of adjuvant therapy is to eliminate undetectable microscopic cancer cells that may have travelled to other parts of the body.

Alendronate (Fosamax®) – A bisphosphonate drug used to reduce bone loss in the adjuvant setting or for metastatic breast cancer.

Anastrozole (Rolin®, Aremed®, Arimidex®, DP-Anastrozole®) – An aromatase inhibitor, used as hormone therapy to suppress oestrogen production and prevent recurrence of ER positive breast cancer in post-menopausal women, or in combination with ovarian function suppression in pre-menopausal women.

Androgen – Male sex hormone which is also produced at lower levels in women. Drugs that inhibit androgen receptors can be useful in the treatment of some kinds of breast cancer.

Aromatase inhibitors (AIs) – A class of drugs used to treat breast cancer by stopping oestrogen production in post-menopausal women. After menopause, small amounts of oestrogen are still produced with the help of an enzyme called aromatase. AIs such as letrozole, anastrozole and exemestane block aromatase, and therefore the production of oestrogen.

Atypia – Used to describe cells which have lost their normal appearance but are not as abnormal as cancer cells.

Axilla – Armpit.

BRCA – A breast cancer susceptibility gene mutation, in either of the genes called BRCA1 or BRCA2. These are 'tumour-suppressor' genes, present in everyone. The mutation of these genes is associated with hereditary breast and ovarian cancer.

Calcifications – Small calcium deposits in breast tissue that can be seen on a mammogram. Deposits are the result of cell death and can occur with either benign or malignant changes.

Capecitabine (Brinov®, Xeloda®) – Cytotoxic chemotherapy drug which interferes with DNA synthesis in cancer cells.

Carboplatin (DBL carboplatin®, Carboplatin Ebewe®, Carbaccord®) – Cytotoxic chemotherapy drug which interferes with cancer cell division.

Carcinoma – A malignant new growth; cancer.

Chemotherapy – the use of drugs that kill cancer cells, or prevent or slow their growth.

Cisplatin (DBL Cisplatin®, Cisplatin Ebewe®) – Cytotoxic chemotherapy drug which interferes with cancer cell division.

Contralateral – on the other side; in the other breast.

Core needle biopsy – Removal of a small plug of a breast tumour or lump for microscopic examination.

Cyclophosphamide (Endoxan®, Procytox®, Cytoxan®) – Cytotoxic chemotherapy drug, of the alkylating agent group, which inhibits DNA synthesis in cancer cells.

Cytology – Microscopic examination of cells.

Cytotoxin – A drug that can kill cells.

DCIS – Ductal carcinoma in situ; a precancerous change where the cells look like breast cancer but are confined within the ducts of the breast.

Denosumab (Xgeva®, Prolia®) – Monoclonal antibody-based drug that helps to prevent bone loss in metastatic breast cancer.

Docetaxel (DBL Docetaxel®, Docetaxel Sandoz®, Taxotere®) – Cytotoxic chemotherapy drug from the taxane group.

Doxorubicin (Doxorubicin Ebewe®, Arrow-Doxorubicin®) – Cytotoxic chemotherapy drug from the anthracycline group. Doxorubicin liposomal (Caelyx®, Doxil®) is doxorubicin in a different formulation that assists in its delivery to the cancer cells.

Ductal – In the ducts or originating in the ducts of the breast.

Ducts – Tubular structures in the breast that can carry milk from the lobules to the nipple.

Epirubicin (Epirubicin Ebewe®) – Cytotoxic chemotherapy drug, from the anthracycline group.

ER-positive – Estrogen (oestrogen) receptor positive breast cancer is a type where oestrogen receptors can be detected in in standard histology tests. When present, it indicates that endocrine therapy may be useful.

Estrogen – American spelling of oestrogen.

Estrogen receptor (ER) – A protein found in some cells to which oestrogen (and some drugs) can bind. When bound, the receptor binds to DNA in the cell and alters the expression of genes. In breast cancer, high ER expression is associated with a positive response to hormone therapy.

Everolimus (Afinitor®) – A drug that targets and inhibits a protein in cells called mTOR, thus interfering with cancer cell proliferation; used in treatment of metastatic breast cancer.

Exemestane (Pfizer Exemestane®) – An aromatase inhibitor used as hormone therapy to suppress oestrogen production and prevent recurrence of ER-positive breast cancer in post-menopausal women, or in combination with ovarian function suppression in pre-menopausal women.

Fine needle aspiration (FNA) – A very thin hollow needle attached to a syringe is used to take a small amount of tissue from a suspicious area, which is then checked for cancer cells.

FISH – Fluorescence in situ hybridisation; a technique for staining tissue obtained from a biopsy, so that particular types of cells (in this case cancer cells) can be seen under a microscope and studied for expression of certain receptors e.g. HER2.

Fluorouracil (Fluorouracil Ebewe®) – Cytotoxic chemotherapy drug that blocks DNA synthesis in cancer cells.

FSH – Follicle-stimulating hormone; a hormone produced by the pituitary gland (in the brain) which is important for regulating ovulation.

Fulvestrant (Faslodex®) – A selective anti-oestrogen used in the treatment of metastatic breast cancer. Given by monthly injection.

Gemcitabine (DBL Gemcitabine®, Gemcitabine Ebewe®, Gemzar®) – Cytotoxic chemotherapy drug that blocks DNA synthesis in cancer cells.

Gene expression – The process by which genes direct the production of proteins in cells.

Goserelin (Zoladex®) – A hormone-based drug that suppresses ovarian function; used to treat pre-menopausal women with hormone receptor-positive breast cancer.

Grade – A description of how abnormal the cancer cells of some tissue look under a microscope. This reflects the extent of gene damage and may predict how quickly the cancer cells may grow and spread.

Gray – Unit of radiation dosage.

HER2 – Human epidermal growth factor receptor 2; a protein involved in cell division. In HER2 positive breast cancer, the HER2 gene is over-expressed, and cancer cell growth is stimulated. Targeted therapy with drugs such as trastuzumab (Herceptin®) can shut down this activity.

Histology – The study of tissues under the microscope.

Hormonal therapy – Treatment of cancer by alteration of the hormonal balance. Some cancers will only grow in the presence or absence of certain hormones (such as hormone receptor positive or oestrogen receptor positive breast cancers).

Hormone – Chemicals secreted by various organs in the body that help regulate growth, metabolism, and reproduction.

HR-positive – See ER-positive.

Hyperplasia – Abnormal, excessive growth of cells that are benign.

Infiltrating duct carcinoma – An invasive carcinoma of the breast in which the cancer cells extend beyond the ducts and into other breast tissue; the most common type of breast cancer.

Ipsilateral – On the same side; the same breast.

Lapatinib (Tykerb®) – A drug which is a tyrosine kinase inhibitor that interferes with the function of the HER2 receptor and interferes with the biochemical pathways that drive the growth of HER2 positive breast cancers.

Letrozole (Letrole®, Femara®) – An aromatase inhibitor used as hormone therapy to suppress oestrogen production and prevent recurrence of ER-positive breast cancer in post-menopausal women, or in combination with ovarian function suppression in pre-menopausal women.

Lobular – Pertaining to the lobules of the breast (glands which make milk).

Lymph – Clear fluid circulating through the body in the lymphatic system (part of the immune system); it contains white blood cells and antibodies.

Lymph nodes – Little glands or nodules that form part of the lymphatic system.

Lymphoedema - A condition in which excess fluid collects in tissue and causes swelling. It may occur in the arm after lymph vessels or lymph nodes in the underarm are removed at surgery or treated with radiation.

Magnetic resonance imaging (MRI) – A non-invasive method of imaging, which allows the form and metabolism of tissues and organs to be visualised (also known as nuclear magnetic resonance).

Medical oncologist – A specialist in using medicines in treating breast cancer.

Medroxyprogesterone acetate (Provera®) – A progestin sometimes used in metastatic hormone receptor positive breast cancer.

Megestrol acetate (Apo-megestrol®) – A progestin sometimes used in metastatic hormone receptor positive breast cancer.

Methotrexate (Trexate®, Hospira®, Methotrexate Sandoz®, DBL Methotrexate Onco®, Methotrexate Ebewe®) – Cytotoxic chemotherapy drug.

Metastasis – The spread of cancer from one part of the body to another through the lymphatic system or bloodstream. The cells in the new cancer location are the same type as those found in the original sites.

Micrometastasis – Small numbers of cancer cells that have spread from the original (primary) tumour to other parts of the body and are too few to be picked up in a screening or diagnostic test.

Monoclonal antibody (mab) – A protein made in a laboratory that can bind to a specific substance. There are many different kinds of monoclonal antibodies. Cancer drugs with names ending in '-mab' are monoclonal antibodies designed to block particular substances that are needed for cancer growth (some have other names too).

Nab-paclitaxel (Abraxane®) – Cytotoxic chemotherapy drug from the taxane group. This is a 'nanoparticle albumin-bound' formulation of paclitaxel.

Necrosis – The death of an individual cell or groups of cells in living tissue that is sometimes seen in carcinomas.

Neo-adjuvant chemotherapy – The administration of drugs before surgery or radiation therapy, with the goal of shrinking tumours or preventing metastasis.

Neoplasia – Abnormal or uncontrolled cell growth. A neoplasm is any abnormal growth, benign or malignant, but the term is often used to describe cancer.

Node-negative – Cancer that has not spread to the lymph nodes.

Node-positive – Cancer that has spread to the lymph nodes.

Oestradiol – One of several forms of oestrogen found in the body (American spelling: estradiol).

Oestrogen – Hormone responsible for the development and regulation of the female reproductive system (American spelling: estrogen).

Paclitaxel (Taxol®) – Cytotoxic chemotherapy drug from the taxane group.

Palbociclib (Ibrance®) – A CDK4/6 inhibitor (targeted therapy) used to treat ER positive breast cancer.

Palmidronate (Pamisol®) – A bisphosphonate drug used to reduce bone loss in metastatic breast cancer.

Pathology – The study of disease. Tissue taken during biopsy is examined microscopically and subjected to various chemical tests. Results from pathology tests reveal the characteristics of a patient's cancer so that the most appropriate treatments can be prescribed.

Pembrolizumab (Keytruda®) – A targeted drug that blocks the PD-1 receptor, helping to prevent cancer cells from evading attack by the immune system; used to treat Triple Negative breast cancer.

Pertuzumab (Perjeta®) – A HER2 inhibitor (targeted therapy) used for treating HER2 positive breast cancer.

PET-CT (Positron emission tomography and computed tomography) – An advanced imaging technique combining an injected material (18F fluorodeoxyglucose) which is taken up by cancer cells and a CT scan.

Progesterone – A hormone with key roles in menstruation, pregnancy, and embryogenesis; it is also involved in breast development, immune response and brain function. It may stimulate or inhibit growth of hormone receptor positive breast cancer depending on dose.

Radiation oncologist – A specialist in radiation treatment of cancer.

Radiation therapy/radiotherapy – Treatment with ionising radiation. High-energy rays are used to damage cancer cells and prevent them from growing and dividing in a particular, targeted area of the body.

Risk factor – Something that increases the chance of developing a disease.

Staging – Performing examinations and tests to determine the extent of cancer within the body.

Systemic therapy – Treatment using substances that travel through the bloodstream, reaching and affecting cells all over the body. Chemotherapy, endocrine (hormone) and targeted therapy are all systemic therapies.

Targeted therapy – A general term for a medication or drug that targets a specific pathway in the growth and development of a tumour.

Tamoxifen (Genox®) – A selective oestrogen receptor modulating (anti-oestrogen) drug, used to treat hormone receptor positive and oestrogen receptor positive breast cancers.

Taxanes – A class of chemotherapy drugs based on compounds originally isolated from yew trees (e.g. paclitaxel and docetaxel) that can block cancer cell division.

Trastuzumab (Herceptin®) – A drug which targets and blocks the HER2 receptor, reducing cancer cell growth in HER2 positive breast cancer.

Trastuzumab-emtansine (TDM1, Kadcyla®) – A drug which uses the ability of trastuzumab to target HER2 positive breast cancer cells to precisely deliver a cytotoxic drug, emtansine, to those cells.

Triple Negative breast cancer – Breast cancer that lacks receptors to oestrogen, progesterone and HER2; it will not respond to drugs that block these.

Vinorelbine (Navelbine®, Vinorelbine Ebewe®) – A cytotoxic chemotherapy drug.

Zoledronic acid (Zometa®) – A bisphosphonate (modified bone mineral). Used to reduce the risk of bone complications of treatment and/or recurrence in early breast cancer and fractures from bone secondary tumours.

Step Seven – We're here to help

The Breast Cancer Aotearoa Coalition (BCAC) is made up of many groups and within these organisations are women who have 'been there too' and can help. Please let us.

The women of BCAC offer you their strength and companionship throughout your journey. We are with you at the start, every step of the way and will be waiting for you when the 'all finished' day arrives. You are never alone.

In this section of this book you will find listings for BCAC support organisations and people who can help you get back on track with life.

The member groups of BCAC offer a wide spectrum of support, information and advocacy. To help you locate this support more easily, the groups have been listed under headings.

National organisations such as the Cancer Society of New Zealand also offer extensive support to women and their families.

BCAC welcomes breast cancer-related groups and individuals with an interest in supporting our work. Membership is free. If you'd like to belong, visit our website, www.breastcancer.org.nz, click on about us and email us to send you a membership form.

For further information, or for help sourcing support in your area:
email BCAC bcac@breastcancer.org.nz,
visit our website at www.breastcancer.org.nz,
call the Breast Cancer Foundation New Zealand's free phone line 0800BCNURSE (0800 226 8773)
see the support pages at www.breastcancerfoundation.org.nz
or contact your local Cancer Society on 0800 CANCER (0800 226 237)

bcac breast cancer
aotearoa coalition

Breast Cancer Aotearoa Coalition (BCAC) Member Groups

Breast Cancer
Foundation NZ

Breast Cancer Foundation NZ

☎ 0800 902 732 / 09 304 0766
☎ 0800 BCNurse (0800 226 8773)
@ breastnurse@bcf.org.nz
🌐 www.breastcancerfoundation.org.nz
✉ PO Box 99-650, Newmarket, Auckland 1149
📱 www.mybc.care

Breast Cancer Foundation NZ is a non-government funded charitable trust with a focus on promoting awareness of breast cancer, providing information and education. It provides research and medical grants as well as scholarships and funds the Breast Cancer Foundation National Register. We are committed to our vision of zero deaths from breast cancer by pushing new frontiers in early detection, treatment and support.

BCFNZ supports breast cancer patients with free counselling, rehabilitation, advice line and our MYBC online community.

BREAST CANCER ACTION TRUST
Keeping Abreast

Breast Cancer Action Trust

👤 Debbie & Tim Short
☎ 07 544 3418
@ bcat@mount-tutu.co.nz
🌐 www.mount-tutu.co.nz/Breast_Cancer_Action_Trust.htm
✉ C/- 1190 Ohauiti Road, R.D. 3, Tauranga 3173

After our successful 125,000 signature Breast Screening Petition to expand the breast screening age to 45-69 years (previously 50-64 years), we periodically offer subsidised and fully paid mammograms to women on reduced income aged 40-45 years. The programme called “Save the Women” is available at selected health centres in the Bay of Plenty.

Well Women and Family Trust

👤 Jane Piper, General Manager
☎ 09 846 7886
@ admin@wons.org.nz
🌐 www.wons.org.nz
✉ PO Box 41021, St Lukes, Auckland 1346

The Well Women and Family Trust is committed to working with and assisting the community, other service providers and government to keep our women and their families well.

Our core services include:

- Health professional training and education
- Provision of clinical services (Mobile Cervical Screening and Breast Health for women in need)
- Health promotion services in the community

Key to this success is an emphasis on working with communities of need to assist them in accessing culturally-appropriate quality health care.

The Gift of Knowledge

👤 Nicola Coom, Founder
🌐 www.giftofknowledge.co.nz
🐦 @goknz
f The Gift of Knowledge

The Gift of Knowledge exists to connect, support, educate and advocate for New Zealanders impacted by hereditary cancer, specifically breast and ovarian cancer (BRCA). Our goal is that every high risk New Zealander will have access to relevant information and support to make informed decisions that save their life.

Shocking Pink

@ info@shockingpink.org.nz
🌐 www.shockingpink.org.nz
✉ PO Box 10023, Christchurch 8145

Shocking Pink is a nationwide charity based in Christchurch, set up to support young women with breast cancer. Visit their website which provides online resources and information.

Age Concern – He Manaakitanga Kaumatua

☎ 04 801 9338
@ national.office@ageconcern.org.nz
🌐 www.ageconcern.org.nz
✉ PO Box 10-688, Wellington 6143

Age Concern works to serve the needs of older people. Providing community support for older women facing health challenges is an important part of our work.

Breast Cancer Support Incorporated (BCS)

👤 National Coordinator
☎ 0800 273 222 (0800 BreaCanSupport)
@ support@breastcancersupport.co.nz
🌐 www.breastcancersupport.co.nz
✉ PO Box 10150, Dominion Rd, Auckland 1446

BCS offers peer support and information to women experiencing breast cancer. Our trained volunteers have 'been there too' and share their own experience of breast cancer from a positive, personal perspective to provide information, advice, and reassurance. BCS Support Groups meet monthly throughout the Auckland area (including a Young Women's Group), and in Christchurch. We provide national one-to-one support via telephone, Skype, and face-to-face (not available in all areas – please check with us). We can also help women find support within their local areas.

Breast Cancer Support Northland Trust

☎ 0800 227 687 or 021 0838 3877
@ info@breastcancernorthland.co.nz
✉ PO Box 476, Whangarei

We are a group of breast cancer survivors who offer practical and emotional support to women diagnosed with breast cancer. We hold regular meetings where people can get information and support, and organise public meetings and panel discussions to help educate the public about breast cancer.

Breast Cancer Foundation NZ

☎ 0800 BC Nurse (0800 226 8773)
@ breastnurse@bcf.org.nz
📱 www.mybc.care

BCFNZ breast nurses provide support across the country, so no matter where you are in New Zealand, you don't have to go through breast cancer alone. MYBC is an online community for all new Zealanders affected by breast cancer, including supporters – a place to connect and share experiences with others, ask questions and get support.

Other support services include free counselling, physiotherapy and lymphoedema therapy (criteria apply).

Breast Cancer Support Service Tauranga Trust

👤 Helen Alice
☎ 07 571 3346 / 022 436 575
@ manager@breastcancerbop.org.nz
🌐 www.breastcancerbop.org.nz
✉ PO Box 618, Seventh Ave, Tauranga 3140

Breast Cancer Support Service Tauranga Trust offers support, information and resources to people diagnosed with breast cancer and their families in the Bay of Plenty area. The Trust provides emotional and practical support by those who have had breast cancer themselves. Other services include group support and education sessions, support for partners, mindfulness workshops, dinner delivery services, lymphoedema education sessions, counselling and oncology massage services and financial assistance where there is financial hardship.

HER2 Heroes (for those with HER2 positive breast cancer)

👤 Chris Walsh
☎ 021 865 597
@ dr.christine.walsh@gmail.com
✉ 53 Rua Ave, Waiterere Beach, Levin

HER2 Heroes is an informal group of women who have been diagnosed with HER2 positive breast cancer. We welcome the fellowship and involvement of all women diagnosed with HER2 positive breast cancer and offer support, information, and tips on treatment.

Horowhenua Pink Ladies Breast Cancer Support

👤 Margaret Martin
☎ 06 368 6050 or 021 254 3605
@ horopinkladies@hotmail.com
✉ 32 Marlborough Street, Levin 5510
f Horowhenua Pink Ladies Breast Cancer Support Group

The aim of the group is to support local women who have a breast cancer diagnosis. We hold monthly meetings in Levin on the 3rd Wednesday of each month, where we have morning tea and a speaker. We do visit patients and present them with a gift basket, which includes gift vouchers for hot meals for women returning home from surgery or treatment. We also promote breast screening in our community and hold regular outings at local events to encourage women to get their two-yearly check. Free transport is also offered to attend breast screening appointments.

KenziesGift
Healthy Minds, Happy Hearts

Kenzie's Gift

👤 Nic Russell
☎ 027 345 2514
@ hello@kenziesgift.com
🌐 www.kenziesgift.com
✉ PO Box 632, Pukekohe 2340

Kenzie's Gift is a charitable Trust committed to improving the emotional well-being and mental health of children, young people and their families affected by serious illness or bereavement. Services include specialised, one-on-one support provided by registered child and adolescent psychotherapists, journey kits and information resources.

By providing early intervention, Kenzie's Gift fosters coping and resilience strategies to assist in supporting, restoring and maintaining emotional well-being and good mental health. Our services provide a safe and secure environment where children and young people can fulfill their potential.

Life 2.0
Living life after cancer

Life 2.0

👤 Jan Haworth
☎ 021 22 77 069
@ jan@life20.co.nz
🌐 www.life20.co.nz
f Life 2.0 https://www.facebook.com/LivingLifeAfterCancer

Get tools, tips and strategies for making changes after cancer which can help your body recover, increase energy, reduce stress, and help reduce the risk of cancer returning. Topics include eating well, keeping active, managing stress and anxiety, plus a whole lot more.

Join a group course for a fun and supportive environment with others who've been through the same experience, or, opt for one-to-one sessions totally tailored to your needs. Life 2.0 uses the latest scientific evidence on lifestyle changes and helps you regain a sense of control over your life, so you can start moving forward with confidence.

Lymphoedema Support Network

☎ 021 0886 8351
@ lymphoedema.info@nzord.org.nz
✉ PO Box 56214, Dominion Road, Auckland 1446

Lymphoedema Support Network is a voluntary organisation with over 100 members in New Zealand. Our aim is to make the condition of lymphoedema better known in the wider community and to support those who have the condition in any way we can.

Mamazon Club **(for lesbians with breast cancer)**

@ louisemalone2882@gmail.com

As lesbian survivors of breast cancer we share a social context that is not always recognised or understood by medical and support personnel with whom we interact during our breast cancer diagnosis, treatment and recovery. This can create additional stresses and difficulties for us as patients and for our partners and wider families during these processes. We have formed a group in order to provide support for each other in an environment of similarity and understanding. Beyond recovery, we enjoy each others' company and celebrate survival in a social context.

Metavivors New Zealand

👤 To enquire about joining this online group please email us at BCAC

@ bcac@breastcancer.org.nz

🌐 https://www.breastcancer.org.nz/metavivors-nz

f Metavivors NZ

Metavivors NZ is a safe and supportive online community for New Zealanders living with metastatic breast cancer (also known as advanced breast cancer, secondary breast cancer, or stage 4 breast cancer). It aims to provide support, information, friendship and strength to all those who find themselves facing diagnosis and treatment for advanced breast cancer. This Facebook page is closed, which means that your posts and comments can only be seen by other members. As well as offering this mutual support, Metavivors NZ aims to provide a voice for people with advanced breast cancer in New Zealand in order to raise awareness of their specific needs and to advocate for medicines, treatment options and support.

Te Ha o Te Oranga o Ngati Whatua (*Māori* health)

👤 Elana Rahui, Breast/Cervical Screeing Co-ordinator

☎ 09 439 3013 or 027 508 8572

☎ Dargaville 09 439 3013

@ elana.rahui@tehaoranga.co.nz

✉ Dargaville Hospital, Awakino Road, Dargaville 0340

Te Ha o Te Oranga o Ngati Whatua is the health provider arm of Te Runanga o Ngati Whatua and is an integral part of the ongoing coordination, delivery and growth of health services for the more than 73,000 Māori who reside within the Ngati Whatua rohe.

In addition to the delivery of a range of health services, Te Ha o Te Oranga o Ngati Whatua seeks to build strong relationships with other health providers within the rohe to enable access to the services needed to help achieve the health gains sought by our people.

***Sweet Louise* (for those with incurable breast cancer)**

☎ 0800 11 22 77
@ info@sweetlouise.co.nz
🌐 www.sweetlouise.co.nz
✉ PO Box 13-7343 Parnell, Auckland 1151

Sweet Louise is a charitable organisation providing support and services for women and men living with secondary breast cancer. Our purpose is to improve quality of life by offering a comprehensive range of support, practical services, and therapies designed to enhance well-being. Services range from gardening, house cleaning and baking to massage and creative therapies; all are available through a unique free voucher system. Support is also provided in the way of regular meetings, home and hospital visits and ongoing contact for Sweet Louise members.

Rotorua Breast Cancer Trust

@ info@rbct.co.nz
🌐 www.rbct.co.nz

The Rotorua Breast Cancer Trust (RBCT) focuses on ensuring women affected by breast cancer in the Rotorua area have the same opportunities for care and support as in other parts of the country. They want to be able to help in practical ways such as providing information and education as well as general support.

Terrier Race Against Time

Jennie Law
@ gisterrierracing@gmail.com
✉ Kainui Station, Private Bag 7513, Gisborne

Terrier Race Against Time (TRAT) was formed in 2006 after a group of local Gisborne women got together over a glass of wine and a common love of terriers, and came up with an idea for a way to raise money to help local people with breast cancer – terrier racing. The money raised allows TRAT to provide a support pack for each person diagnosed with breast cancer in the Tairawhiti district. Each pack has $500 of vouchers and includes books, a pedometer and useful information as well as BCAC's ***Step by Step*** pack. The vouchers can be used for things such as petrol, childcare, gardening or pampering.

Support Crew

Kelly Banks and Janine Williams
☎ 0211 566 566
@ supportangel@supportcrew.co.nz
www.supportcrew.co
f www.facebook.com/supportcrew
https://www.instagram.com/supportcrew_angel/

Support Crew is a free online support platform that easily co-ordinates meals, transport, cleaning or any other help that's needed from friends and family. You can create a Support Page for yourself or someone else at www.supportcrew.co

Simply create a Support Page, invite friends and family, tell them how they can help (meals, cleaning etc), and keep them updated on how you're doing. Brilliant when asking for help is difficult and when people want to help but don't know how. Now there's an easy way to turn that freezer full of lasagnes into the trip to hospital that you really need!

Look Good Feel Better

👤 Clare O’Higgins and Carol de Joux
☎ 09 370 0602 / 0800 865 432
@ info@lgfb.co.nz
🌐 www.lgfb.co.nz
✉ PO Box 99414, Newmarket, Auckland 1149

Look Good Feel Better is a free service offered to women undergoing treatment for cancer. Our aim is to help restore and enhance the appearance of cancer patients both during and after treatment. We offer guidance, information and makeover expertise at beauty workshops throughout New Zealand that will literally make women look good and feel better.

PINC Cancer Rehabilitation Program (Previously known as Pink Pilates)

👤 Lou James
☎ 021 826 420
@ admin@pincandsteel.com
🌐 www.pincandsteel.com

The PINC Cancer Rehabilitation program provides individualised prescribed rehabilitation to women with breast cancer. The programs are delivered by Certified Cancer Rehab Physiotherapists. They are specifically designed to help maximise recovery, regain physical and emotional strength, and improve body confidence and control. PINC rehabilitation sessions cater for all ages, levels of fitness and mobility. To find a PINC Certified Cancer Rehab Physiotherapist near you visit www.pincandsteel.com or email admin@pincandsteel.com. The PINC & STEEL Cancer Rehabilitation Trust is dedicated to fundraising to support people diagnosed with cancer, to inspire and allow everyone the opportunity to rehabilitate and regain their confidence using the PINC Cancer Rehabilitation Program and help women incorporate exercise into their lifestyle forever. Visit www.pincandsteel.com for a funding application.

Alleviate

Amanda Levey
(09) 630 7844
amanda.levey@alleviate.co.nz
www.alleviate.co.nz

Alleviate Ltd offers highly professional and innovative creative arts therapy programmes and one-on-one therapy for women who have been diagnosed with breast cancer. This can include movement/dance, art-making, drama, music and creative writing. We aim to give women a range of resources to assist them to access their own sense of what will improve their well-being, quality of life and self-care, and to move towards coming to terms with their life-changing experience.

Breast Cancer Cure

General Manager - Phillipa Green
0800 227 828 (administration)
admin@breastcancercure.org.nz
www.breastcancercure.org.nz
PO Box 91-127, Victoria Street West, Auckland 1142

Breast Cancer Cure is New Zealand's only not-for-profit organisation established solely to find a cure for breast cancer. Research continues to be pivotal in developing our understanding and preventing, managing and curing breast cancer. It is at the heart of progress made to date, and essential we continue to drive improvements, to stop people dying from the disease. We're committed to achieving our goal of finding a cure for breast cancer and with your support, we believe that is very achievable.

Waikato Breast Cancer Research Trust (WBCRT)

👤 Jenni Scarlet (Secretary)
☎ 07 839 8726 Ext 97916
@ jenni.scarlet@waikatodhb.health.nz
🌐 www.wbcrt.org.nz
✉ Breast Cancer Research Office, Hockin Building, Waikato Hospital, Private Bag 3200, Hamilton 3240

The WBCRT is a charitable trust which enables local and international breast cancer research and clinical trials. For the past 20 years the Waikato research team have been involved in research and clinical trials introducing new surgical, drug and radiotherapy treatments. We also research for better quality of life, reducing side effects of treatments, improving communication and more. The WBCRT also administers the Waikato Breast Cancer Register (part of the NZ Breast Cancer Register). This vital register tracks breast cancer rates, treatments and outcomes providing insights for medical research to improve outcomes for Waikato and New Zealand women and men who are diagnosed.

Boobops

👤 Fiona Birchall
☎ 021 887 864
@ info@boobops.co.nz
🌐 www.boobops.co.nz
✉ PO Box 14-209, Tauranga Mail Centre 3143

The sport of dragon boating has been identified as particularly beneficial for women after surgery for breast cancer.

The support and camaraderie is amazing, providing so much more than paddling buddies - a real sisterhood and a life-changing experience of fun, fitness and laughter.

BUSTING
WITH LIFE
DRAGON BOAT TEAM

Busting With Life

@ info@bustingwithlife.org.nz

🌐 www.bustingwithlife.org.nz

Joining a dragon boat team allows you to be involved in something positive after a breast cancer diagnosis. You become part of a fun group of women who have travelled that same path and come through the other side. Dragon boating is a great way to regain confidence, get fit, make friends and have some fun along the way.

Busting With Life was the first all BC team to form in New Zealand in 1998 and having just celebrated 20 years of paddling in 2018 we are still going strong, based in the Auckland area. We would love to chat with you about the joys of dragon boating.

Pink Dragons

@ info@pinkdragons.org.nz

🌐 https://pinkdragons.org.nz/

What makes dragon boating so successful for breast cancer survivors? It is an easy entry sport because people at different levels can be doing the same sport on the same boat. It is a challenging sport, but also fun and keeps you fit. It's like having a support group on water and it makes you determined to work hard and paddle strong for the team. We are always looking for breast cancer survivors to join our team so please contact us.

Waikato Treasure Chests

@ waikatotreasurechests17@gmail.com
f Waikato Treasure Chests

We are a group of people with a common bond – breast cancer. We have embarked on a journey not of our choosing but we have chosen to take control of our health and wellbeing by paddling in a dragon boat. It is through dragon boating that we have come to know some wonderfully strong women and men throughout New Zealand and overseas. We have learned to have fun again! Camaraderie, involvement in community and a love of life bind our team both on and off the water. New members are very welcome.

Taranaki Dragons

👤 Kathleen Moriarty
☎ 06 752 0722
✉ 527 Manutahi Road, RD3, New Plymouth

👤 Norma Haley
☎ 06 758 6265
✉ 11 Taunton St, New Plymouth
@ taranakidragons@gmail.com
🌐 www.taranakidragons.co.nz
f Taranaki Dragons

Our dragon boat team aims to encourage Taranaki women and men from all walks of life to develop a healthy and active lifestyle. We encourage the participation of breast cancer survivors and people who have not personally experienced breast cancer to engage with the sport. We participate in regattas throughout New Zealand and we promote a positive attitude and having fun, while building strength and fitness. New members welcome.

Cancer Society of NZ

👤 National Office
☎ 0800 CANCER (22 62 37)
@ admin@cancer.org.nz
🌐 www.cancernz.org.nz
✉ PO Box 12-700, Wellington

The Cancer Society provides support and information for people affected by cancer. We provide high-quality information resources, and a wide range of supportive care and rehabilitation programmes. Health promotion is a key part of our organisation to assist in the prevention and early detection of cancer. Our volunteer services support all the Society activities of fundraising and communications. The Cancer Society is a non-profit organisation which receives no direct financial support from government and we are instrumental in cancer research.

Acknowledgements

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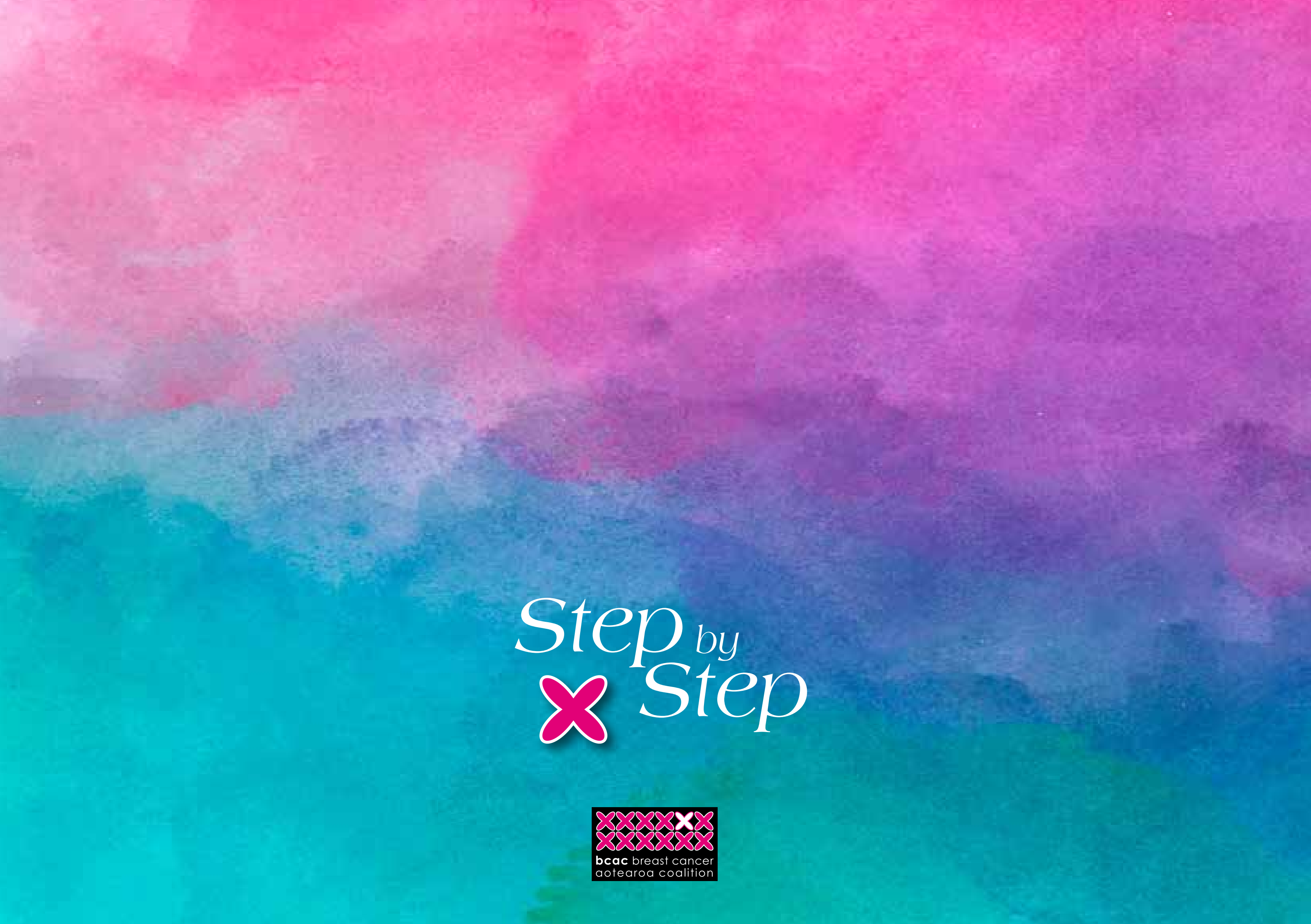

Step by Step

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