

# Step <sup>by</sup> Step

INFORMATION

PRINCIPAL  
FUNDER



THE NEW ZEALAND  
BREAST CANCER  
FOUNDATION

*Together we are stronger*

Tangata tū pakari tonu



# Step <sup>by</sup> Step



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First edition 2008  
Second edition 2009  
Third edition 2014

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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 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 are stronger. Tangata tū pakari tonu.

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



  
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.

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# Step One – Taking charge

## Coping

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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

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### 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](http://www.cancernz.org.nz) or call 0800 CANCER (226 237) for a copy. The UK website [www.macmillan.org.uk](http://www.macmillan.org.uk) also has a useful section on talking to children about cancer.*

## 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.winz.govt.nz](http://www.winz.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](http://www.health.govt.nz).*



*The organisation Bellyful, [www.bellyful.org.nz](http://www.bellyful.org.nz), delivers food, free-of-charge, to families struggling with illness. They operate in most main centres throughout New Zealand.*

## Help to get you through

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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.

### *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 77 - 93) 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.



*Together we are stronger*

Tangata tū pakari tonu





## Step Two – Finding out about your breast cancer

### A diagnosis of breast cancer

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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?

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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, pathology, and other test results to be copied to 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

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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 whether the cancer is responsive to certain hormones
- 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 cancer is non-invasive and the cancer 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 both breasts.
- *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 tubular carcinoma of the breast; medullary carcinoma of the breast; and Inflammatory Breast Cancer. For more details on these types of breast cancer, visit BCAC's website [www.breastcancer.org.nz](http://www.breastcancer.org.nz).*

## Grades of Breast Cancer

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



*Sweet Louise offers support and services (in some areas) for women diagnosed with advanced breast cancer. Call the Sweet Louise support coordinators on 0800 11 22 77 or visit [www.sweetlouise.co.nz](http://www.sweetlouise.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 overproduces the HER2 protein.



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.
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.myjourney.co.nz](http://www.myjourney.co.nz). This includes comments and tips from other New Zealand women who have had this diagnosis.*



*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](http://www.giftofknowledge.co.nz)*

## Surgery

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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 your treatment has not actually begun. Try to remain calm and focus on the steps you're taking to prepare yourself for surgery.

Your surgery will probably involve one of the following:

- removal of the tumour and part of the breast surrounding it (called a partial mastectomy, lumpectomy or wide local excision)
- removal of the whole breast (a full mastectomy)
- removal of the whole breast and associated lymph nodes under the arm (modified radical mastectomy).

Your surgeon will advise whether he or she needs to remove lymph nodes from the armpit to see if the cancer has spread from the breast to other parts of your body. This may be done by a sentinel node biopsy, or an axillary dissection during the operation to remove the cancer from your breast (see page 23).

Sometimes your surgeon will have a plan in mind for a lumpectomy, but once in surgery this may change if the cancer is more widespread than first thought. You may need to be prepared for a full mastectomy rather than a lumpectomy. This is something you and your surgeon will discuss prior to your operation.

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.*



*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 New Zealand Breast Cancer Foundation by phoning 0800 BCNURSE.*



*"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*

## The lowdown on lymph nodes and lymphoedema

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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 or a very large tumour your surgeon will need to perform a further surgical procedure to determine whether the lymph nodes are involved. This is likely to be either a sentinel node biopsy or an axillary dissection which can be performed at the same time as your cancer surgery.

### Sentinel node biopsy

A sentinel node biopsy involves injecting a very small amount of weakly radioactive fluid and /or coloured dye into the tumour site or under the areola (nipple) a few hours or the day before your surgery. The coloured fluid drains slowly from the breast and collects in the one or two lymph nodes that drain your breast. These are called the sentinel or 'guardian' nodes. If the cancer has spread from the breast then it will have travelled to the sentinel nodes first.

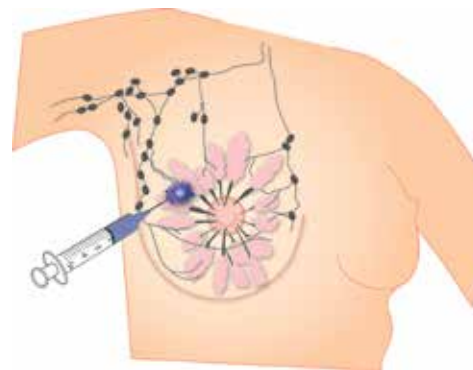
At the time of your surgery, your surgeon will remove the sentinel node(s) for testing. If the sentinel node is clear of cancer cells then you will usually not need any more nodes removed. If the sentinel node is positive for cancer, then the surgeon will recommend proceeding with an axillary dissection.

### **Axillary dissection**

An axillary dissection involves surgery to remove several lymph nodes. 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 nodes have been removed, blocked or scarred from surgery or radiation therapy.



*Sentinel node biopsy*



*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.*



### ***Lymphoedema – what is it and what can I do about it?***

The lymphatic system works to remove excess fluid and proteins from body tissues. Lymph is a watery liquid containing dead cells, protein and other waste and it flows through the body in our lymph vessels, which connect to the lymph nodes. These nodes act as filters, removing foreign material and bacteria.

Axillary lymph nodes are located in the armpit, and surgery for breast cancer may involve the removal of some or all of these nodes. This surgery can cause blockages and scarring which prevent the lymph from draining in the affected arm. This can lead to swelling of the arm or breast, known as 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). 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.co.nz](http://www.lymphoedemanz.co.nz) to find a qualified therapist near you or contact the Cancer Society on [www.cancernz.org.nz](http://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](http://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. Contact them on 09 625 6463.*



*"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.*







## Step Three – Taking care of business

### After surgery

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#### 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.

It's a good idea to avoid lifting and some household chores, like vacuuming and hanging out washing, immediately after surgery. However, gentle exercise and movement will generally help your recovery so try to do what you can. Exercise, such as walking, is good for your physical and emotional health so, if you're up to it, try and get out at least once a day. A bit later on you'll need to incorporate special exercises to help restore mobility in your affected arm and shoulder. Try to rearrange things at home so that you get the time and space you need to recover well and look after yourself.



*You will 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.*

#### 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.



*YWCA Encore is a free floor and pool based exercise programme designed for women who have had surgery for breast cancer. Exercises help improve flexibility and mobility that can be affected by surgery. Programmes are available throughout New Zealand. For more information call 0800 ENCORE (362 673).*



*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](http://www.pincandsteel.com)*



## Breast reconstruction

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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.

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:

- *Implants*

This method usually involves two stages. 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. This technique gives good size and balance. As your body changes with time further surgery may be required.

- *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 and 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 and requires a longer recovery period.

- *Further surgery*

Often further surgery is required to your unaffected breast such as a lift or a reduction 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.

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 51). 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.*



*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](http://www.canceraustralia.gov.au) for a useful resource on breast reconstruction.*



*"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

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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 because it can damage 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.

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/fertility](http://www.breastcancer.org.nz/fertility) and Fertility Associates website [www.fertilityassociates.co.nz](http://www.fertilityassociates.co.nz)*



*The American website [www.fertilehope.org](http://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 Breast Cancer Support's Young Women's Group. You can contact them on 0800 273 222.*



*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.co.nz](http://www.shockingpink.co.nz) and the international site [www.youngsurvival.org](http://www.youngsurvival.org).*

## Treatments

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### Adjuvant treatments for breast cancer

Based on the pathology report describing the details of your cancer your specialist may recommend additional treatment. 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.

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

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### ***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. It has been shown to be very effective in reducing the risk of the cancer recurring.



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. These include external beam radiation therapy and, for some women with very early breast cancer, intraoperative radiation therapy may be an option.

### **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 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.

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 special x-ray machine will deliver the radiation therapy to the area affected by cancer. You will not feel or see anything during the delivery of the radiation therapy. It is like having an x-ray taken.



## **Intraoperative Radiation Therapy**

Some women with small, low grade breast cancer may be able to have intraoperative radiation therapy, in which radiation therapy is given at the same time as surgery to remove the breast cancer. During your surgery a small probe is placed at the cancer site and a small one-off dose of radiation treatment is given. This usually takes between 25 and 40 minutes. 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 in addition to the initial intraoperative radiation therapy.

Intraoperative radiation therapy is only suitable for around 10 to 15 per cent of women with breast cancer. Speak with your doctor if you think you may meet the criteria for this treatment.

### *Side effects of radiation therapy*

The actual delivery of radiation therapy is painless, but the therapy can have side effects over time. You may experience:

- tiredness
- the irradiated skin may become red, blistered or peel, like a bad case of sunburn
- breast swelling and breast pain
- lymphoedema if the armpit is irradiated (see page 26)

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.

You may be able to return to work during this phase of your treatment because the treatment sessions are so short and easily slot into your normal day, but remember to get lots of rest and relaxation.



*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 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](http://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](http://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](http://www.breastcancer.org.nz/share-your-story/web-videos)*



*"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

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### 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 metal disc, 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 chest. 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 destroy normal cells that multiply rapidly, such as hair 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. Some of the most common combinations of chemotherapy medications used to treat breast cancer are:

- AC: adriamycin and cyclophosphamide
- TC: docetaxel and cyclophosphamide
- TCH: docetaxel, carboplatin and trastuzumab
- FEC-D: fluorouracil, epirubicin and cyclophosphamide, followed by docetaxel (or variants of this combination.)

The type of medicine you're prescribed will depend on the type of breast cancer you have, your general health and sometimes your menopausal status. Your chemotherapy programme may use one of the drug combinations above; it may use different drugs; or a different combination of drugs. There are no set rules with chemotherapy – each programme is designed to target an individual's specific cancer.

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 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 10 to 14 days after chemotherapy
- nausea and loss of appetite

- hair loss
- fatigue
- weight changes (gain can be more common than loss)
- mouth ulcers
- joint or muscle pain in arms or legs
- tingling, burning or numbness in hands and feet
- 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
- infertility.

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 often 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 34). 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 49 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.*





*'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](http://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](http://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

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Targeted therapies are drug therapies, but unlike chemotherapy which affects all cells, these medicines work by attacking specific elements of the cancer cells. This means they are generally less toxic to healthy cells and have fewer side effects than chemotherapy.

They can only be used against particular types of breast cancer. For example, trastuzumab (Herceptin®), lapatinib (Tykerb®) and pertuzumab (Perjeta®) can be used to reduce the growth and spread of HER2-Positive breast cancer, because they block the production 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 injected either once a week or once every three weeks for around 12 months. Your oncologist may insert a small device called a port-a-cath (see page 40) under the skin on your upper chest to make it easier to inject repeated doses.



New targeted therapies such as T-DM1 (Kadcyla®) and pertuzumab (Perjeta®) have recently become available in New Zealand. However, neither of these medicines is yet subsidised in New Zealand, so you would have to pay to receive them.



*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](http://www.breastcancer.org.nz)*

## Hormone therapy

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The breast tissue removed during your surgery 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 (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 and the aromatase inhibitors, such as anastrozole (Arimidex®), letrozole (Femara®) and exemestane (Aromasin®). All of these are available as pills.

Unlike tamoxifen, which can be taken if you're pre-menopausal, aromatase inhibitors can only be used if you are post-menopausal.

Hormone therapy may be prescribed for between five years and ten years and your oncologist may suggest you switch therapies, e.g. take tamoxifen for two years and then switch to an aromatase inhibitor for three years.

*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.*



*"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*



## Optional extras

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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 HealthPac 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 the HealthPac contact centre on: 0800 458 448.*





## 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.

### *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.

*Photo courtesy Anita BreastCare*



### ***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, rolling over every four years as long as you have not had breast reconstruction. The subsidy is administered by HealthPac and is available to New Zealand citizens or residents. It will cover the cost of the following:

- breast prostheses or breast forms (these may include standard breast forms, swim forms, foam fillers, shell prostheses and lumpectomy shells)
- special bras to hold the breast prosthesis or breast form
- surgical bras and normal bras
- modifications to bras or swimwear to hold a prosthesis or breast form
- prosthetic nipples.



*For more information on the breast prosthesis subsidy ask for the Ministry of Health brochure 'Breast Prosthesis Service Payments Fact sheet' or visit [www.moh.govt.nz](http://www.moh.govt.nz). You can also call the HealthPac enquiry line on 0800 458 448.*

### ***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.





A specialist fitter will attend to you in a comfortable, warm, quiet and private fitting room. She will guide you through the process of being fitted; show you all the options available to you; explain product care; and make you feel relaxed, at ease and well informed. If appropriate, the fitter will talk to you about lymphoedema and discuss the use and fitting of a preventive compression garment.

She will complete the subsidy claim on your behalf (or you can make the claim yourself if you prefer). If the cost of your products is over the subsidy limit then you will need to pay the balance. The fitter will give you receipts for your products and it's a good idea to put these somewhere safe so you can keep track of your subsidy and know when you are eligible to claim again.

### ***Suppliers and Stockists***

Anita BreastCare in Silverdale (north of Auckland) stocks prostheses 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 has shops in Auckland, Hamilton and Wellington with a stockist in Tauranga and travels throughout the North Island. For more information, call Naturalwear on 0800 612 612 or visit the website [www.naturalwear.co.nz](http://www.naturalwear.co.nz).



*Photo courtesy Anita BreastCare*

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.

Christchurch Breast Cancer Support Services, 246 Manchester Street, stocks breast prostheses. Ph (03) 379 5835.

J Ballentyne & 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 prostheses and associated products. Call them on 0800 478 348 or visit the website [www.thefittingroom.co.nz](http://www.thefittingroom.co.nz)

Medical Matters in Wellington supplies German breast prostheses. Visit [www.medicalmatters.co.nz](http://www.medicalmatters.co.nz) or call (04) 366 4660 for further details.



*Together we are stronger*

Tangata tū pakari tonu





## Step Four – Managing Your Feelings

### Coping with treatment and life afterwards

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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.

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.



*BCAC has a list of qualified counsellors and psychologists who specialise in helping those with serious illnesses on our website, [www.breastcancer.org.nz](http://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](http://www.psychology.org.nz) or [www.nzac.org.nz](http://www.nzac.org.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*

## Body image and sexuality

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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 many 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.



*Look Good Feel Better is an organisation dedicated to helping restore and enhance the appearance of women with cancer during and after treatment. Find out more at [www.lookgoodfeelbetter.co.nz](http://www.lookgoodfeelbetter.co.nz)*



*"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

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Around 20 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.

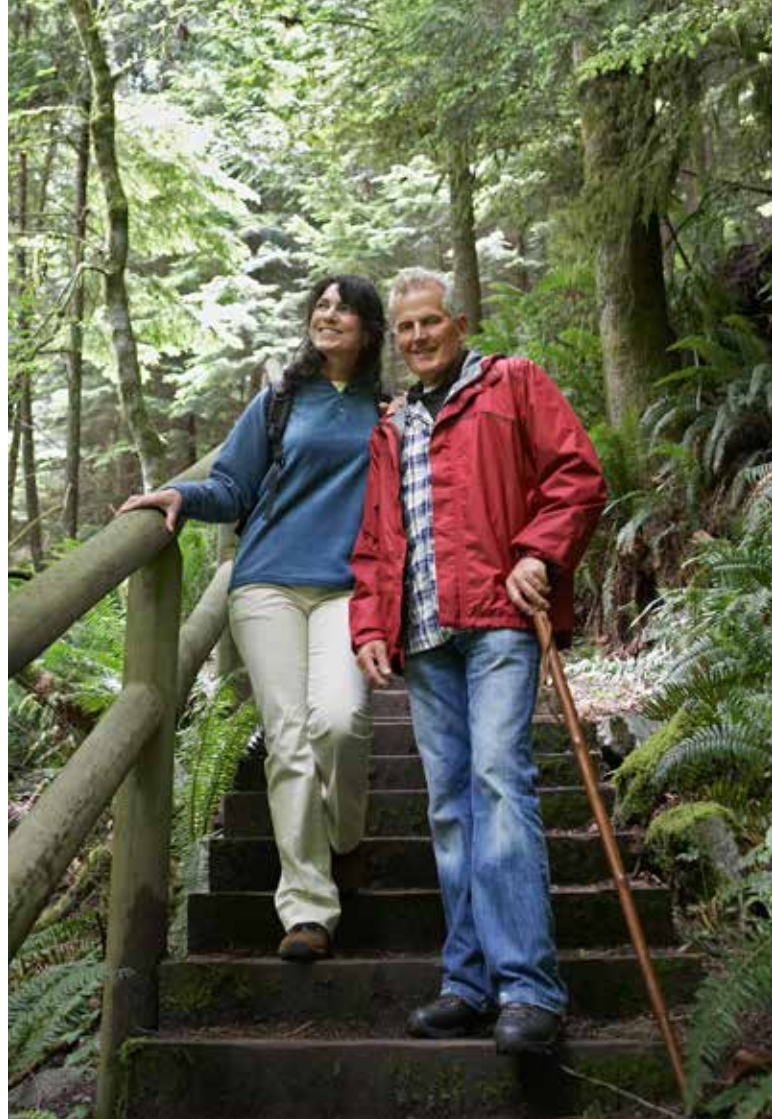
Those who have been diagnosed often feel embarrassed or ashamed to tell others about their breast cancer, because it is a disease that is most often associated with women. Some men feel they may be ridiculed or that their masculinity will be questioned when they have been diagnosed with breast cancer. 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](http://www.cancernz.org.nz).*



*The UK website, **Breast Cancer Care**, has an excellent booklet about breast cancer in men. Download it from their website; <http://www.breastcancercare.org.uk/breast-cancer-information/about-breast-cancer/men-breast-cancer>*







## Step Five – Looking after yourself

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

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You should have at least six-monthly checks with either your GP or specialist for three years after your treatment. 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 six-monthly check-ups, you should have an annual mammogram for the next ten years at least.

You may also need regular bone density scans if you are taking an aromatase inhibitor (eg anastrozole (Arimidex®), letrozole (Femara®) or exemestane (Aromasin®)) 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 your specialist believes your breast cancer may be hereditary or if you've had several close relatives who've had breast

cancer, you may need to undergo a genetic test to see if you carry a gene mutation (BRCA1 or BRCA2) that means you're more susceptible to breast, and possibly ovarian cancer.



*For more information on genetic testing in New Zealand see the Genetics Health Service website [www.genetichealthservice.org.nz](http://www.genetichealthservice.org.nz)*



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

## Exercise

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Studies have shown that women who exercise regularly can reduce the risk of breast cancer recurring. Try to incorporate some moderate exercise into your life, either every day or every second day. It doesn't have to be arduous, a simple walk will do. 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 YWCA Encore swimming programme, 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 77-93 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

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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

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





## Step Six – Reading and Research

### Good books

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There are a number of excellent books written about breast cancer diagnosis, treatment and recovery. Many of these books can be found at the local library. 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.

Every woman will find her own unique path to recovery. BCAC does not endorse the content of any of these books or websites but offers these lists as a menu from which to make your own choices.

### Practical information

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**Dr Susan Love's Breast Book** – Susan Love, MD with Karen Lindsey (De Capo Press, 5th Edition, 2010)

Excellent, approachable, understandable information about breast cancer – highly recommended.

**Tools and Tips from the Trenches** – Mary Olsen Kelly (Books Beyond Borders LLC, South Lake Tahoe, 2006)

This little book delivers personal and practical advice for breast cancer survivors, family and friends.

**The Breast Cancer Book** – Val Sampson and Debbie Fenlon (Vermilion, Random House, London, 2002)

A helpful and supportive look at the breast cancer journey covering conventional treatments and how complementary therapies can play a part in treatment and recovery.

**Breast Care: Information and Advice on All Aspects of Breast Care** – Trevor Smith (The Breast Centre Ltd, Auckland, 2008)

A book written by New Zealand breast surgeon, Trevor Smith, which covers all aspects of breast care, including a detailed section on breast cancer diagnosis, treatment and recovery.

**The Unofficial Guide to Surviving Breast Cancer** – Stacie Zoe Berg with Richard Theriault, MD (IDG Books Worldwide, Florida, 1999)

A comprehensive reference that examines all aspects of breast cancer in an easy-to-read fashion. This guide covers preventive methods, research, treatment of all kinds, screening and new therapies.

**The Breast Reconstruction Guidebook: Issues and Answers from Research to Recovery** – Kathy Steligo (Carlo Press, 2005).

This American book provides a comprehensive look at mastectomy and the many different reconstruction options available. It's a valuable resource for anyone considering reconstruction surgery to help work through the many choices to be made.

### *New Zealand breast cancer stories*

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**Beating Our Breasts** – Compiled by Margaret Clark (Cape Catley, Auckland 2000)

One of the first collections of stories by New Zealand women experiencing breast cancer, *Beating our Breasts* is a book full of wisdom, courage, humour, information and honesty. Inspirational stories from women who have 'been there'.

This book is available free-of-charge from the New Zealand Breast Cancer Foundation – call 0800 902 732 for a copy.

**Welcome to the Amazon Club** – Jane Bissell (Longacre Press, Dunedin, 2004)

Jane Bissell writes a daily journal about her first year with breast cancer. An honest, open, humorous and informative account, this book offers hope, courage, guidance, information and strength to women experiencing breast cancer (available from [www.janebissell.co.nz](http://www.janebissell.co.nz)).

**The Pink Party** – Jane Bissell (Klarer Lasserre, Auckland 2007)

The writer of *‘Welcome to the Amazon Club’* tells of the joys, fears, achievements and celebrations in her own life after breast cancer and in the lives of two other women. Colleen is living with secondary breast cancer and Manon has faced inflammatory breast cancer. Honest, inspirational, joyous (available from [www.janebissell.co.nz](http://www.janebissell.co.nz)).

**Surviving Breast Cancer** – Carolyn Weston (Random House, Auckland, 2008)

Journalist Carolyn Weston was diagnosed with breast cancer in 2005. Carolyn has collated 11 tales from ‘ordinary’ New Zealand women who have each received a breast cancer diagnosis. Courageous stories from the ‘front line.’ This book is available free-of-charge from the New Zealand Breast Cancer Foundation – call 0800 902 732 for your copy.

**She’s Got Breast Cancer** – compiled by Peter Calder (New Zealand Breast Cancer Foundation, 2013)

A New Zealand book for men, compiled by Peter Calder and featuring interviews with 18 Kiwi men whose wives, partners, and in one case mother, have been diagnosed with breast cancer. For your free copy, contact the New Zealand Breast Cancer Foundation on 0800 902 732 or email them on [breasthealth@nzbcf.org.nz](mailto:breasthealth@nzbcf.org.nz).

*Personal stories*

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**Bald in the Land of Big Hair** – Joni Rodgers (Headline Book Publishing, New York, 2001)

At thirty-two, Joni Rodgers was diagnosed with non-Hodgkin’s lymphoma. Joni tells her deeply moving story of ‘industrial-strength drugs, healing herbs, love, sex, prayer, kids, career, and the search for a wig that won’t make her look like Betty Rubble.’

**It’s Not About the Bike** – Lance Armstrong (Allen and Unwin, Australia, 2002)

Controversial world-renowned cyclist and athlete Lance Armstrong writes of his experience with cancer, survival, recovery and competition in the Tour de France. An inspirational story of life being lived to the full after cancer.

**Spirited Women: Journeys with breast cancer** – Petrea King (Random House, Sydney, 1995)

Australian women speak frankly and bravely about how breast cancer has changed their lives but has also provided unexpected opportunities for growth.

### *A bit of humour*

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**Cancer Vixen** – Marissa Acocella Marchetto (Alfred A. Knopf, 2006)

In vivid color and with a taboo-breaking sense of humor, Marisa tells the story of her eleven-month, ultimately triumphant bout with breast cancer – from diagnosis to cure, and every challenging step in between.

### *Menopause*

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**Strong Women, Strong Bones** – Miriam E Nelson PhD with Sarah Wernick PhD (Lothian, Melbourne, 2000)

Everything you need to know to prevent, treat and beat osteoporosis.

**Dr Susan Love's Menopause and Hormone Book** – Dr Susan Love with Karen Lindsay (Three Rivers Press, USA, 2003)

A more detailed look at menopause and hormonal changes.

### *Complementary therapies, General well-being*

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**Complementary Therapies for Cancer: What works, what doesn't and how to tell the difference** – Professor Shaun Holt (Craig Potton Publishing, 2010).

An excellent resource that lists a wide range of complementary therapies and details the scientific evidence to support or debunk them. All therapies are ranked according to their effectiveness in helping those with cancer.



**Enhancing Cancer Care: Complementary Therapy and Support** – Edited by Dr Jennifer Barraclough and produced by Oxford University Press (2008)

A practical, evidence-based technical guide to complementary cancer therapies.

**Well-Being: Essential Guide to Vibrant Good Health for Women** – Lynda Wharton (Harper Collins, Auckland, 2007)

An holistic self-help guide for women who want to live a balanced lifestyle with an emphasis on preventative health. The book includes comprehensive sections on breast cancer and menopause.



**You Can Conquer Cancer** – Ian Gawler (Hill of Content, Australia, 1984)

Cancer survivor Ian Gawler used his personal experience to write this practical and inspiring guide for recovery and healing.

**Chicken Soup for the Breast Cancer Survivor's Soul** – Jack Canfield, Mark Victor Hansen and Mary Olsen Kelly (Health Communications Series, Florida, 2006)

From the "*Chicken Soup series*"; with stories, poems, quotes and cartoons "to inspire, support and heal."

**After Breast Cancer: Answers to the Questions You're Afraid to Ask** – Musa Mayer (Patient Centred Guides, 2003)

A book for those who have completed treatment. The author, a breast cancer survivor, talks frankly about the feelings of uncertainty and fear that breast cancer patients commonly face when their treatment ends.

**Breast Cancer Husband: How to Help Your Wife (and Yourself) during Diagnosis, Treatment and Beyond** – Marc Silver (Rodale Inc, 2004)

A book for the husbands who support their wives through breast cancer. It offers a candid look at the reality of treatment and life after breast cancer. An excellent book that provides a road map for men who join their wives on this difficult and challenging journey.

## Informative websites

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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.nzbcf.org.nz** – The website for the New Zealand Breast Cancer Foundation provides information about the diagnosis and treatment of breast cancer plus a comprehensive directory of support services across New Zealand. NZBCF also provides educational resources free of charge. For more assistance and information about breast cancer phone toll-free: 0800 BC NURSE 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.myjourney.co.nz](http://www.myjourney.co.nz)** – A website set up by the pharmaceutical company Roche for New Zealand women with HER2-Positive breast cancer. It contains details about breast cancer treatment, in particular trastuzumab (Herceptin®).

**[www.macmillan.org.uk](http://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.

## Other resources

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### The Cancer Society of New Zealand

Each division of the Cancer Society offers excellent resources about breast cancer covering everything from diagnosis to after-care. Your breast nurse will provide you with information about the Cancer Society and the services offered. If you require more assistance, call the Cancer Society help line on 0800 CANCER (0800 22 62 37) or visit their website at **[www.cancernz.org.nz](http://www.cancernz.org.nz)**.





## Step Seven – The Road Ahead

### Onwards and upwards!

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Diagnosis can make time stand still. You feel as if you cannot go forwards and you cannot go back. Then a hand is extended to you, one that holds hope and information. Reach out with courage, grasp it and take the first step. Hours pass, one after another, then the days, one at a time and that's how you get there, by taking little steps. That's the way forward.

Every day brings an accomplishment to be proud of and sometimes these don't come easy with breast cancer. We need to be brave on days when we want to run and hide; we have to hold it together when we want to fall apart; we hang on to hope during the darkest hours of pain, fear, and despair. Such accomplishments are hard won so acknowledge that strength within you and never underestimate the courage that goes with it.

It may seem a little hard to imagine right now, but the day will come when your immediate treatment for breast cancer will be finished. You'll have follow up visits and checkups and your oncologist may have prescribed ongoing hormonal treatments but the surgery, chemotherapy and radiation will be behind you. Finishing treatment is a huge achievement and worthy of celebration but there is still a lot of healing to be done. Physically you will need lots of time – and emotionally and spiritually, you may need even more. Look after your body but don't forget to care for and nurture your spirit and soul too.

There is so much to look forward to after treatment for breast cancer. Hold onto that thought.

The end of treatment can bring feelings of uncertainty and apprehension. When treatment is finished, you may feel like there is nothing standing between you and your cancer any more. You'd like to get on with life again, but life has changed and the way forward is not too clear. You have learned that the majority of women survive breast cancer these days but you may be worrying that you won't be one of them. It's normal to feel a little bit lost and alone at this time.

Information from your doctors is always helpful to calm fears and apprehensions. You'll be an expert at asking questions by now so keep doing so to receive the information you need.

You may wish to join a breast cancer support group in your area. There's nothing like chatting with women who have 'been there too'. Talking out your worries and sharing your joys with someone who understands can really help.

Your feelings should settle over time but if they don't, there is nothing wrong with seeking professional help from a counsellor or social worker. Sometimes it is really helpful to speak to someone who is not emotionally involved with you. They can suggest strategies to help you cope. Ask your specialist or GP to refer you to someone.

Many women who experience breast cancer say that their lives have been greatly changed by it – for the better. Although it may be hard to believe right now that something good and positive can come from all this, trust that it will.

If there is one thing a journey with breast cancer teaches us, it is that we each have a great capacity for strength, hope, courage and compassion. This realisation can empower us to know, without doubt, there is very little we cannot do or change in our lives.

American breast cancer specialist Dr John Link said that every woman with breast cancer is 'the hero of her own life'. Believe it.

### Take one for the road...

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Treat yourself every day. Swim in the sea, walk in the park, buy fragrant flowers for the house, eat ice cream on a winter afternoon!

Having quality time with friends and family is so important.

Rest, eat well and exercise often.

Let your family and friends know what you need and how they can help. They will appreciate it and so will you.

If feelings of fear and uncertainty do not diminish over time, seek professional help. It can be really good to talk to someone who is not emotionally involved.

Join a breast cancer support group in your area. Talking to women who've 'been there' can comfort and reassure. Later on, you may be able to help others too.

Write about your triumphs and joys. Dance a lot, sing out loud, paint and draw.

It's your body and your life. Love it, live it and celebrate both – often!



*Together we are stronger*

Tangata tū pakari tonu







## Step Eight – 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](http://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, contact your local Cancer Society on 0800 CANCER (0800 226 237), email BCAC [bcac@breastcancer.org.nz](mailto:bcac@breastcancer.org.nz), call the New Zealand Breast Cancer Foundation's free phone line 0800 BCNURSE or see the Breast Cancer Service Directory at [www.nzbcf.org.nz](http://www.nzbcf.org.nz).*



## Breast Cancer Aotearoa Coalition (BCAC) Member Groups



### *The New Zealand Breast Cancer Foundation*

-  Patricia Field
-  0800 902 732 / 09 304 0966
-  [patriciaf@nzbcf.org.nz](mailto:patriciaf@nzbcf.org.nz)
-  [www.nzbcf.org.nz](http://www.nzbcf.org.nz)
-  PO Box 99-650, Newmarket, Auckland

The New Zealand Breast Cancer Foundation is a non-government funded charitable trust with a focus on promoting awareness of breast cancer, providing information and education, and raising funds to support breast cancer related initiatives, outreach services supporting women with breast cancer, plus research scholarships, medical grants, community education and breast cancer patient registers. We are committed to preventing New Zealanders developing and dying from breast cancer through education, awareness, research, medical support and development, community outreach and advocacy.



### *Breast Cancer Network (NZ) Inc*

-  Bonnie Reid - Administrator
-  09 636 7040
-  [admin@bcn.org.nz](mailto:admin@bcn.org.nz)
-  [www.bcn.org.nz](http://www.bcn.org.nz)
-  PO Box 24-057, Royal Oak, Auckland 1345

Our focus is on information and education. *Upfront U Kaiaora*, our bimonthly magazine, is a voice for women throughout New Zealand. It covers a wide range of topics including diagnosis and treatment, environment and lifestyle associated with breast cancer, reports on research, news, events, letters and personal stories. Our present projects are based on the recommendations of the First National Conference for those affected by Breast Cancer (2007). Copies of the conference recommendations, conference proceedings and leaflets about reducing breast cancer risk are available. Volunteers are always welcome. Membership and subscription to *Upfront U Kaiaora* costs \$40 per year.

**BREAST CANCER ACTION TRUST****Breast Cancer Action Trust**

-  Debbie Short
-  0800 124 377
-  bcat@mount-tutu.co.nz
-  [www.savethewomen.org.nz](http://www.savethewomen.org.nz)
-  C/- 1186 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 now 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. Further information can be found on our website.






**Breast Health NZ**

-  Sue Mcleod
-  09 407 9564
-  [www.breast.co.nz](http://www.breast.co.nz)
-  82 Riverview Road, Kerikeri

Breast Health NZ is a non-profit website displaying information for anyone affected by breast cancer. The focus is on breast cancer, breast awareness and breast nurture.



### *Well Women and Family Trust*

 Monique Fredatovich, 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  
 info@giftofknowledge.co.nz  
 www.giftofknowledge.co.nz  
 @goknz  
 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 Christchurch-based group set up to support young women with breast cancer. Visit their website which provides online resources and information.

### *IBC Australasia*

- 🌐 [www.ibcaustralasia.org](http://www.ibcaustralasia.org)

IBC Australasia is an information and support site aimed at helping patients with Inflammatory Breast Cancer (IBC) and their carers along their journey with this aggressive form of breast cancer.



### **Age Concern – He Manaakitanga Kaumatua**

- ☎ 04 801 9338
- @ [national.office@ageconcern.org.nz](mailto:national.office@ageconcern.org.nz)
- 🌐 [www.ageconcern.org.nz](http://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)**




- 👤 Support Coordinator
- ☎ 0800 273 222 (0800 BreaCanSupport)
- @ [support@breastcancersupport.co.nz](mailto:support@breastcancersupport.co.nz)
- 🌐 [www.breastcancersupport.co.nz](http://www.breastcancersupport.co.nz)
- ✉ PO Box 10150, Dominion Rd, Auckland 1446

BCS offers support and information from a positive, personal experience, for women diagnosed with breast cancer. Trained volunteers who have experienced breast cancer themselves offer support and encouragement to others. Our Support Groups ('Breast Friends') meet regularly within the greater Auckland area, including a group for younger women (20 to 45 years). We offer one-to-one support over the telephone or face to face visits at home, in a social setting, or in hospital.

BCS can also help women throughout New Zealand find support within their local areas.








### ***Breast Cancer Support Northland Trust***

-  Kathleen Paterson
-  0800 227 687 or 021 046 8718
-  [bcsnorthland@gmail.com](mailto:bcsnorthland@gmail.com)
-  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 Support Service Tauranga Trust***

-  Lea Lehndorf
-  07 571 3346 / 027 571 3346
-  [support@breastcancerbop.org.nz](mailto:support@breastcancerbop.org.nz)
-  [www.breastcancerbop.org.nz](http://www.breastcancerbop.org.nz)
-  PO Box 618, Seventh Ave, Tauranga 3140

Breast Cancer Support Service Tauranga Trust offers support, information and resources to women diagnosed with breast cancer and their families in the Bay of Plenty area. The Trust has a group of trained volunteer visitors who have all experienced breast cancer, and are available for one-on-one support. This may involve phone contact, home and/or hospital visits. Other services include group support meetings, support for partners, younger women's support, meditation sessions, lymphoedema education meetings, a Helping Hands service and a free counselling service. Use of an extensive library and regular newsletters are also provided.







***HER2 Heroes (for those with HER2 positive breast cancer)***

 Chris Walsh  
 06 367 3930  
 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.

***Kenzie's Gift***

 Nic Russell  
 09 446 1100  
 kenziesgift@kenziesgift.com  
 www.kenziesgift.com  
 PO Box 32-148, Devonport, Auckland



Kenzie's Gift focuses on the emotional well-being of families, women and children affected by cancer and works in the Auckland region. It was established to reduce the emotional and psychological trauma families face through painful and frightening cancer treatments and the uncertainties of living with cancer. Kenzie's Gift aims to meet these needs through the therapeutic interventions of play therapy; family therapy; art and music therapy; educational resources; and an interactive forum for families to share their stories and get advice from professionals.

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

 Sam McLean  
 09 820 3130  
 021 155 5560  
 sam.mclean9@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.

**Lymphoedema Support Network**

 Joy Donohoe  
 09 625 6463  
 donofam@ihug.co.nz

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.



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

-  Roslyne Peters
-  09 300 8573 or 027 508 8572
-  Helensville 09 420 8523
-  Wellsford 09 423 8538
-  Dargaville 09 439 3013
-  [roslyne.peters@tehaoranga.co.nz](mailto:roslyne.peters@tehaoranga.co.nz)
-  80 Stapleford Crescent, Browns Bay, North Shore 0630

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 secondary breast cancer)*

-  Support Coordinators
-  0800 11 22 77
-  [info@sweetlouise.co.nz](mailto:info@sweetlouise.co.nz)
-  [www.sweetlouise.co.nz](http://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. These services range from gardening, house cleaning and baking to massage, creative therapies and regular member meetings, and are available through a unique free voucher system. Voucher-based services are currently available only in North Island areas (will extend as resources permit) but support is available to Members nationwide via the toll free line and the website.



### ***Rotorua Breast Cancer Trust***

@ rbct@paradise.net.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***

👤 Carol Mitchison

@ 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 women with breast cancer – terrier racing. The money raised allows TRAT to provide a support pack for each woman diagnosed with breast cancer in the Tairāwhiti 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.









**encore**  
after breast cancer  
gentle exercise programme

Proudly supported by



### ***YWCA Encore***






-  Marlene Sorby
-  0800 ENCORE (0800 362 673)
-  09 370 0075
-  [encore@akywca.org.nz](mailto:encore@akywca.org.nz)
-  [www.akywca.org.nz](http://www.akywca.org.nz)
-  PO Box 8749, Symonds St, Auckland 1150

YWCA Encore is a free, eight week long exercise programme designed for women who have had breast cancer surgery at any time in their lives. It is based around floor and pool-based exercises and relaxation techniques and is designed to be safe, fun and therapeutic.

The programme runs nationwide, for details and programmes in your area please see our website [www.akywca.org.nz](http://www.akywca.org.nz) or call us on 0800 ENCORE.



### ***Look Good Feel Better***

-  Clare O'Higgins and Carol de Joux
-  09 308 0245
-  [info@lgfb.co.nz](mailto:info@lgfb.co.nz)
-  [www.lgfb.co.nz](http://www.lgfb.co.nz)
-  PO Box 1724, Shortland Street, Auckland 1140

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  
 [info@pinc.co.nz](mailto:info@pinc.co.nz)  
 [www.pincandsteel.com](http://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](http://www.pincandsteel.com) or email [info@pinc.co.nz](mailto:info@pinc.co.nz). 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](http://www.pincandsteel.com) for a funding application.








***Alleviate***

 Amanda Levey  
 (09) 630 7844  
 [amanda.levey@alleviate.co.nz](mailto:amanda.levey@alleviate.co.nz)  
 [www.alleviate.co.nz](http://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.



### *The Breast Cancer Research Trust*

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

We are a not-for-profit organisation dedicated to one goal; to find a cure for breast cancer by 2018. The incidence rate of breast cancer in New Zealand is now 1 in 9. An incidence rate of 1 in 9 means 1 woman every 3 hours will be diagnosed, nearly 2 women per day will die from the disease. Breast cancer is claiming the lives of at least 660 New Zealand women every year, and more than 2600 are diagnosed with it. There is an urgent need to find a CURE for breast cancer and stop it in its tracks. Should you wish to contribute to our cure goal, or become involved in some capacity, please visit [www.breastcancercure.org.nz](http://www.breastcancercure.org.nz) or contact us on [admin@breastcancercure.org.nz](mailto:admin@breastcancercure.org.nz).



### *Waikato Breast Cancer Trust*

-  Jenni Scarlet (Secretary)
-  07 839 8726 Ext 97916
-  [jenni.scarlet@waikatodhb.health.nz](mailto:jenni.scarlet@waikatodhb.health.nz)
-  [www.wbct.org.nz](http://www.wbct.org.nz)
-  PO Box 97, Waikato Mail Centre, Hamilton 3240

The Waikato Breast Cancer Trust (WBCT) is a charitable trust enabling research and education into breast cancer. We investigate diagnosis, prevention and treatment in the Waikato area and beyond. Over the past 10 years the Trust has supported more than 30 different studies/clinical trials including radiotherapy, drug trials and new surgical treatments for breast cancer. In addition to local studies, our research team works collaboratively with international groups, actively participating in international breast cancer research. The WBCT also supports the Waikato Breast Cancer Register. This is a comprehensive register of data on Waikato women with newly diagnosed breast cancer. This enables audit and research to improve outcomes for Waikato and New Zealand women with breast cancer.





### **Boobops**



 Judith Butler  
 027 365 1553  
 [info@boobops.co.nz](mailto:info@boobops.co.nz)  
 [www.boobops.co.nz](http://www.boobops.co.nz)  
 PO Box 799, Te Puke

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**

 [info@bustingwithlife.org.nz](mailto:info@bustingwithlife.org.nz)  
 [www.bustingwithlife.org.nz](http://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 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*

-  Robin Gamble
-  09 630 6423
-  [info@pinkdragons.org.nz](mailto:info@pinkdragons.org.nz)
-  [www.pinkdragons.org.nz](http://www.pinkdragons.org.nz)
-  28 Epsom Avenue, Epsom, Auckland

We are a dragon boating team formed in 2005 to empower breast cancer survivors to assume responsibility for their own health and wellbeing through participation in the strenuous sport of dragonboating. The team consists of 20 paddlers, a sweep and a caller/drummer. We race in both Open and Breast Cancer Teams' categories in various dragon boat festivals. We are based in Auckland and train in the "pond" at Westhaven Marina. New members welcome – so join us – get fit and have some fun.



### *Waikato Treasure Chests*

-  Dallas Honey
-  07 846 5363
-  [brian.dallas@xtra.co.nz](mailto:brian.dallas@xtra.co.nz)
-  [www.waikatotreasurechests.co.nz](http://www.waikatotreasurechests.co.nz)
-  312 Marshmeadow Road, RD4 Hamilton

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

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

BCAC extends a sincere thank you to the Breast Cancer Network Australia (BCNA) for their generosity in allowing us to use the material and resources contained within their inspirational 'My Journey Kit' upon which **Step by Step** is based. We particularly thank former CEO Lyn Swinburne for her support of BCAC and for her wisdom, guidance, advice and friendship.

We would like to thank the following people who have contributed to the development of the third edition of **Step by Step** by offering their expertise and advice – Medical Oncologists Dr Marion Kuper, Dr David Porter and Dr Richard Isaacs; Breast Surgeon, Dr Erica Whineray-Kelly; Radiation Oncologist, Dr Maria Pearse; specialist breast care nurse Janice Wood; and the women of BCAC.

We wish to extend our gratitude to the New Zealand Breast Cancer Foundation for its generous donation as principal funder, helping BCAC to ensure that **Step by Step** remains a key resource for New Zealanders with breast cancer.

We wholeheartedly thank our major sponsor, Arnott's Tim Tam, for their ongoing support of BCAC and **Step by Step**.

We also appreciate the support of the Ministry of Health and BreastScreen Aotearoa and their donation towards **Step by Step**.

We're grateful to those who agreed to be photographed for **Step by Step** – Moana Papa, Winnie van 't Hof, Carlene Wolfgram, Melissa Murphy, Greer Davis, and Emma Crowley. And our thanks to Minna Pesonen and Martin Heffer for their wonderful work in capturing these women on film.

A special thanks to Kirsty Jones for her skill and hard work in writing and managing the production of the third edition of **Step by Step**. We also extend our thanks to Celia Motion for her contribution and support in seeing **Step by Step** through to publication. And we acknowledge Jane Bissell's efforts in bringing the wisdom of her own experience of breast cancer in writing the first edition of **Step by Step**.

We deeply appreciate our friends at Graphic Design Services, Martine and Carolina, for their ongoing support of BCAC and **Step by Step**. Our thanks also go to Sentra Printing.

And finally, BCAC acknowledges Libby Burgess for her unwavering energy and determination to improve the lives of New Zealand women with breast cancer through **Step by Step** and BCAC.

*Together we are stronger*



Tangata tū pakari tonu

Step<sup>by</sup>  
X Step

