



Breast Cancer
Foundation NZ



Thriving

After Breast Cancer
The years ahead



The woven ribbon

This represents the coming together of people and whānau and the strength gained through these relationships.



Artist

Sian Montgomery-Neutz

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We would like to sincerely thank Sian Montgomery - Neutz for the artwork she has provided for our booklet.

The artist gives permission for the whole image to be used for the purposes of the Thriving After Breast Cancer booklet design. Permission must be sought for either of the images to be used for any other purpose outside of that stated above.



Welcome

This booklet has been designed to give you information and support following your breast cancer treatment. It provides a space for you to record information about your diagnosis, treatment and follow-up plan. Breast cancer treatment plans vary, so not all of the information within this booklet will be relevant to your situation.

We want this to be a resource for you to use and a place for you to note your feelings, thoughts and plans for the future.



**Breast Cancer
Foundation NZ**

Diagnosis summary

Date of diagnosis

Age at diagnosis

Which breast

Type of breast cancer

Grade

Size

No. of nodes removed

No. of nodes positive

Oestrogen receptor status

ER positive

negative

Progesterone receptor status

PR positive

negative

HER-2 receptor status

HER-2 positive

negative

Family History

Yes

No

Genetic assessment or referral

Yes

No

Menopausal status at diagnosis

pre

peri

post

Additional Information

Treatment

Treatment Centre

Summary of treatment - Not all breast cancers are the same, so some of the treatments below may not have been appropriate for you

Type of surgery and date(s)

Type of chemotherapy

Date commenced

Date completed

Was the dose reduced?

Site of radiation therapy

Number of treatments

Date completed

Additional Information

Hormone therapy (if ER or PR positive) Yes No

Drug name

Date started

Planned duration

If on tamoxifen and you are or become post-menopausal, the hormone therapy may be changed after 2 or 3 years. Please talk with your specialist or GP about this

Herceptin (if HER-2 positive) Yes No

If yes, date completed

Did you participate in a clinical trial? Yes No

If yes, name of trial

Additional Information

Patient and clinical notes

Follow-up

You may require regular clinical examination checks for the first 3 years after your treatment. This may be with your GP or a specialist.

It is important that your follow-up clinic appointments are separated in time and that you are not seeing two different specialists within a few weeks – it's better to be having regular checks throughout the year. If your follow-up appointments seem to be falling all at the same time, let your GP or specialist know.

You might find it useful to note who your follow-up is scheduled with:

Surgeon

Medical Oncologist

Radiation Oncologist

GP

Breast nurse specialist

Mammograms

Mammograms should restart after treatment on a yearly basis for at least 10 years, and longer for those who were under 50 at diagnosis. Mammograms can be ordered by your GP or your specialist.

Even if you have had a mastectomy, your other breast still needs a yearly mammogram.

Month yearly mammogram due:

Mark on your calendar which month your yearly mammogram is due. If you have not received an appointment for a mammogram by the end of that month, contact your GP or specialist.

Bone density scans

If your hormone therapy is an aromatase inhibitor (anastrozole, letrozole or exemestane) then you should be undergoing regular bone density monitoring. You may be recommended to have a bone density scan every two years but the frequency can change depending on how strong your bones are. The reason for doing a bone density scan is that aromatase inhibitors can make your bones thinner.

Monitoring the strength of your bones ensures your GP or specialist has you on the right type of hormone therapy. It will also tell them if you need any other medication to keep your bones healthy.

Bone density scans should not be confused with bone scans. Bone scans are done to assess if your breast cancer has spread to your bones.

Issues to discuss at follow-up appointments

- A change in your menopausal status e.g. if you were pre- or peri-menopausal at diagnosis and now your periods have stopped.
- If another member of your family/whānau develops breast cancer
- If you wish to consider delayed breast reconstruction
- How long you are going to continue on hormonal therapy? (if applicable)
- Any side-effects or symptoms of concern – see section on concern about breast cancer recurrence p.24
- Emotional or psychological concerns

Important dates to remember

Will I feel different?

How your body and mind may change after treatment

Following treatment, you may be aware of many different changes to your body. The effects of treatment can persist for months to years after treatment. Some effects may only become apparent years later.

Emotional Changes After Treatment

- You may find it strange not attending hospital on a regular basis for assessment and treatment. This may make you feel very isolated or anxious.
- Support of family and friends can be very helpful at this time, but if this kind of anxiety is causing you significant problems, let your GP or breast care nurse know.
- Fatigue and sleep disturbance are common and normal after all breast cancer treatments and may take many months to resolve.
- You may find your mood alters after treatment. In many people, this will only be mild and will not interfere with day-to-day activities. However, some people can have significant difficulties with their mood and this can have a severe impact on their daily life. If this happens to you, let your GP, specialist or breast care nurse know.

Free Breast Cancer Foundation NZ funded counselling is available when you need someone to talk to. Your doctor or breast care nurse can refer you for this or you can phone **0800 BC NURSE** for more information. Counsellors are available all around the country for anyone who has ever been diagnosed with breast cancer.

- The emotional impact of your diagnosis and treatment may only hit you after you have finished treatment. This is a normal reaction, but if it is interfering with your daily life, let your GP or breast care nurse know.
- Books are an excellent resource to help you with your thoughts and emotions, and there are some very high quality self-help materials online (general as well as cancer-specific).
- Peer support is also really important and there are various ways to access this. Breast Cancer Foundation NZ has an online support community — mybc. Download to your phone from the app store, or visit **www.mybc.care**

For face-to-face peer support, contact your local Cancer Society branch for advice on which groups meet in your area.

There are also health psychology services focused on helping people affected by cancer, and these are available through Breast Cancer Foundation NZ www.breastcancerfoundation.org.nz/counselling or talk to your GP about accessing counselling through your DHB or your local Cancer Society.

Continued over...

You can find support through any of the Breast Cancer Foundation services below;

0800 BC NURSE (0800 226 8773)

www.breastcancerfoundation.org.nz/counselling

Or make an appointment to talk to your GP.



Physical changes after surgery and/or radiotherapy

- **Breast changes.** Your treated breast may be a different size or shape and may feel firmer. This may be permanent.
- **Nerve pain.** You may notice tenderness in your treated breast/chest wall and altered sensation in this area (sometimes described as burning). This sensation may also be felt in the armpit and can extend down the arm on that side. It may settle over time, but a small percentage of people experience long-term discomfort and may benefit from referral to a pain specialist.
- **Cording.** You may be aware of “cording” on the treated side. These are uncomfortable, tight bands which can be felt down your arm and may even extend into your hand. Referral to a lymphoedema therapist is advised to manage this, as it may increase the risk of developing lymphoedema. To find out if you qualify for BCFNZ lymphoedema therapy funding, visit www.breastcancerfoundation.org.nz/lymphoedema.
- **Skin changes.** The skin on your treated breast or chest may feel different and have reduced sensation. If you had radiation therapy, it may be more tanned than the other side. Fine blood vessels (telangiectasia) may become visible.
- **Arm/shoulder mobility.** If you had treatment to the lymph nodes in your armpit, your shoulder on that side may feel stiff. If this affects you, try to keep the shoulder mobile by doing the post-breast surgery exercises. Rehabilitation courses such as PINC/Next Steps may also help.
- **Lymphoedema.** You could develop lymphoedema in your arm or breast any time after your surgery or radiation therapy, particularly if the lymph nodes were removed from your armpit or you had radiation therapy to that area. Lymphoedema is an accumulation of fluid in the tissues of your arm or breast on the treated side, which results in permanent swelling. It is important to treat lymphoedema as soon as it is detected, as this is more likely to keep it under control.

What to look out for (these may all be early signs of lymphoedema)

- Heaviness, aching or transient swelling in the affected arm or breast
- Increased tightness of rings or jewellery
- Redness, heat, swelling. These may be signs of infection in the tissues or skin due to lymph stasis

A referral to a lymphoedema therapist is required for treatment, which may involve a combination of complex lymphatic massage and the use of compression sleeves and kinesio taping. If you are concerned you may be developing lymphoedema, please contact your GP, breast cancer specialist or breast nurse for a referral to your DHB or BCFNZ funded lymphoedema therapist.

Physical changes after chemotherapy

- **Hair regrowth.** Your hair will start to grow back once treatment has finished, and it may be curlier and/or greyer compared to before chemotherapy. If you usually colour your hair, it is safe to use colour products once your chemotherapy treatment is completed.
- **Altered sensation.** Any tingling or altered sensation in your hands and feet after chemotherapy may take months to resolve.
- **“Chemo brain”.** You may experience some difficulty with concentration and/or short term memory. This is often referred to as “chemo-brain”. It’s important to try to get adequate sleep, as fatigue can make these issues worse. Stress reduction techniques such as yoga and meditation may help and regular exercise can make you feel more alert.
- **Fatigue.** Many people experience fatigue after breast cancer treatment. Usually, energy levels recover after treatment finishes, but this commonly takes time and in some cases full recovery may take 12 months or more. It is natural to want to return to pre-treatment levels of activity straight away but it is often best to introduce activity slowly and rest when you need to in the months following treatment.
- **Weight gain.** It’s not uncommon for people to gain weight during and after chemotherapy treatment. This may be due to a combination of factors. If you are struggling to maintain a healthy weight, ask your breast cancer specialist or breast nurse for a referral to a dietitian.
- **Skin and nail changes.** Changes to skin and particularly nails caused by chemotherapy may take months to resolve. Nails may be discoloured, weaker and break more easily and may have visible lines, blemishes and indentation. Your skin may be drier than usual. To reduce the risk of infection, keep nails trimmed and clean and moisturise your skin. Nail polish can cover blemishes until they grow out.
- **Menstrual cycle changes.** If you were still having periods at the time of your chemotherapy, you may have begun to experience menopause-like symptoms. Your periods may permanently stop, or may take months to restart.
- **Menopause.** If you go into menopause after chemotherapy, you may be aware of hot flushes and skin and vaginal dryness. There are ways to manage these symptoms and your breast cancer specialist or breast nurse will be happy to discuss these with you. There is no need for you to feel embarrassed raising this issue.
- **Fertility.** Your ability to have children may be affected by your chemotherapy. If you are uncertain as to whether you can still have children, your specialist or breast care nurse or fertility doctor will be happy to discuss this further with you.

Continued over...

Physical changes on Herceptin

Herceptin usually doesn't affect people once the treatment has finished. Rarely during treatment it can affect the function of your heart and therefore your specialist will have closely monitored your heart function during this time.

Physical changes on hormone/endocrine therapy

- Hot flushes are a very common side effect of hormone therapy. They can vary in their intensity and frequency and in most people are manageable. However if you are suffering severe problems with hot flushes/night sweats let your GP/specialist or breast care nurse know, as there are non-hormonal treatments that may help.
- Joint pains or stiffness may occur when taking an aromatase inhibitor (anastrozole, letrozole or exemestane). If you are having significant problems, let your GP/specialist or breast care nurse know. Regular exercise has been shown to help with this.
- Very rarely tamoxifen can cause a deep vein thrombosis (DVT). This is a very uncommon side-effect, but you must contact your GP if one of your legs becomes swollen, red and tender, as these can be the signs of a DVT.
- Tamoxifen can cause a thickening of the lining of the womb/uterus or, very rarely, an endometrial cancer. If you are taking tamoxifen and still having your periods, let your GP know if there is any significant change in bleeding. If you have gone through menopause and you are on tamoxifen, let your GP know if you develop any vaginal bleeding, spotting or pelvic pain.

Hot flushes are a very common side effect of hormone therapy.

Joint pains or stiffness may occur when taking an aromatase inhibitor.

Rare side effects can occur taking Tamoxifen.



Intimacy and fertility

Sex and fertility after breast cancer treatment

Breast cancer treatment can impact sexual health, relationships and body image, and it can be difficult to adapt to these changes.

Loss of libido, little or no orgasm and pelvic or genital pain (generally or on penetration) is common among breast cancer survivors, but there are things you can do to get back on track. While often a sensitive topic to bring up with your doctor, if your sex life is suffering, it's worth reaching out. Your doctor can recommend a range of management strategies – such as vaginal moisturisers, counselling, sex therapy and pelvic floor physiotherapy.

If you're sexually active during chemotherapy or hormone therapy, you must use non-hormonal or barrier contraception, like IUD or condoms, to avoid becoming pregnant as these treatments can harm a developing baby. It's also important to use condoms at certain times to protect your partner against chemotherapy. Your nurse will advise you about this. Condom use is encouraged for male patients for the first 6-12 months after treatment has finished, to prevent your partner becoming pregnant in case your sperm has been affected.

It is recommended that women who have had breast cancer should not use the oral contraceptive pill or hormone implants such as Depo Provera. Hormone-secreting IUDs may be used in certain circumstances, when recommended by a specialist.

Breast cancer treatment can impact on your fertility; it can stop your periods and make you go into early menopause. This doesn't always happen, however, and you may still be able to have children after treatment. Your doctor or fertility expert is able to provide information about your specific risk.

Pregnancy after you've finished treatment doesn't increase the risk of the breast cancer returning. There's no 'best time' to conceive, although many oncologists will advise waiting two years after your treatment has ended before trying to get pregnant.

If you're taking long-term treatment, like tamoxifen, and wish to become pregnant, you must discuss this with your specialist and GP so they can advise you on the risks and potential impact of stopping the treatment to conceive.

Ultimately, the decision to have children after breast cancer is yours, but let your specialist know so they can give you all the information you need to make an informed decision.



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Travel

Travelling after breast cancer treatment

You may feel anxious about travelling after your treatment has finished. Travelling isn't normally a problem, but's a good idea to discuss this with your specialist first, as recovery time and risk of infection can vary depending on your unique treatment pathway. You may also experience fatigue, so it may be best to wait for 4 to 6 weeks to see how you're feeling.

When you do travel, it's important to take precautions. Make sure you know the location of the medical centre nearest to your accommodation, so if you do run into problems, you'll know where to go. It's also a good idea to carry any documentation with you about your treatment and your doctor's contact details.

The evidence for the benefits of wearing a compression sleeve if you're flying after having lymph nodes removed is limited and sometimes conflicting – you might want to discuss this with your lymphoedema therapist. It is always a good idea to stay hydrated and walk around every so often during a longer flight to help with circulation.

Wait until you feel well enough to travel; this could be 4-6 weeks.

Stay hydrated, move around on long flights to keep circulation moving.

Take any treatment documentation with you.

Work and finances

Work and financial support after breast cancer treatment

During your breast cancer treatment, you might not have been able to continue your usual work hours or commitments. This, along with the cost of treatment, can have an impact on your income and finances.

Returning to work

Once treatment finishes you may plan to return to work or slowly increase your working hours. For some, returning to work after breast cancer treatment can be a very positive step, helping you to move forward and regain some normality. For others, it isn't as easy as they imagined and side effects of treatment such as fatigue, difficulty concentrating and adjusting to life after a breast cancer can be difficult.

Any decision to return to work will depend on how you are feeling, the type of work you are doing and your financial situation. It's best to discuss this decision with your specialist team and your employer. A phased return to work is often an option and can help you gradually adjust to your normal working pattern.

Financial support

Even when you've finished your active treatment, you can still feel financial pressures. There are people who can help - social workers in particular are a great source of support and information. If you require a referral to a community social worker you should ask your GP, breast cancer specialist or breast nurse.

You can find more detailed information about financial support and your entitlement to benefits and services on the BCFNZ and Cancer Society websites.

Genetic links

Breast cancer in the family/whānau

Breast cancer is common and mostly develops by chance. However some women and men have an increased risk of developing breast cancer due to hereditary factors. This only occurs in approximately 1 in 20 breast cancer cases.

You are potentially at risk of having an inherited form of breast cancer if:

- 2 or more close family members (mother, sister, daughter, aunt, grandmother) have had breast cancer or ovarian cancer
- Close family members were under 50 when they were diagnosed with breast or ovarian cancer
- A close family member has been diagnosed with breast cancer in both breasts
- A male family member has a diagnosis of breast cancer

It is important you let your GP or specialist know if there is any family history of breast or ovarian cancer. It is also important to tell your GP or specialist if close family members develop breast or ovarian cancer as this may change your risk of having an inherited form of breast cancer.

If your specialist thinks you may have an inherited form of breast cancer, you will be referred to a Genetics clinic for further discussion.

The Genetics team will make a thorough assessment of your risk and may suggest testing you for genetic mutations associated with inherited breast cancer.

For more information on this issue

www.breastcancerfoundation.org.nz/inherited-risk

0800 BC NURSE (0800 226 8773)

www.giftofknowledge.co.nz

www.genetichealthservice.org.nz

0508 364 436

An increased risk of developing breast cancer due to hereditary factors only occurs in approximately 1 in 20 breast cancer cases.





Ask your GP to refer you to a plastic surgeon for a discussion about your options for breast reconstruction.

Reshaping

Breast reconstruction and prostheses

Reconstruction

Delayed breast reconstruction is available to women once they have completed all their breast cancer treatment. This is available through the public hospital system but there is usually a wait of many months. If you want to have breast reconstruction and are no longer on active follow-up, ask your GP to refer you to a plastic surgeon for a discussion about your options for breast reconstruction.

There may be support for travel and accommodation for patients who live at a distance from the treating hospital. Discuss this with your surgeon.

To be considered for a delayed breast reconstruction you need to:

- Stop smoking if you are a smoker
- Have a body mass index of under 30
- Have no evidence of active breast cancer

Prostheses

The Ministry of Health provides grants to enable women who have had a mastectomy to buy a breast prosthesis and pocketed mastectomy bras. Partial prostheses are also available for women who have a significant difference in breast size following breast conservation surgery.

You can reapply for the grant every four years. Your surgical fitter can help you with this. Alternatively, contact **HealthPac on 0800 458 448** quoting your NHI number to find out when you are entitled to reapply.

A certificate from your doctor or breastcare nurse is required for the initial claim, but not for subsequent claims.

Ongoing concerns

Concern about breast cancer recurrence

It's normal to have some concern about the cancer coming back. This can lead to some uncertainties about life and lead to challenges when you are trying to move on.

By completing your recommended breast cancer treatment you have reduced your recurrence risk as much as possible. However, it's not possible for doctors to give anyone a 100% guarantee that their breast cancer has been completely cured. All breast cancers are different and some have a higher risk of recurrence after treatment than others.

If your level of anxiety is making life difficult, free counselling is available through the Breast Cancer Foundation, Cancer Society or your DHB.

Routine blood tests, x-rays or CT scans to test for recurrence in people without any symptoms have not been shown to be helpful in early breast cancer and often cause unnecessary anxiety.

Continue to be breast aware – know how your breasts normally look and feel and check for any unusual changes. Visit www.anychanges.co.nz to refresh your knowledge on how to do this.

While normal aches, pains and mild illnesses will still occur, it's important to be aware of any changes that may suggest a breast cancer recurrence. If you develop any new problems, ask your GP for an immediate referral back to the oncologist or breast clinic. If you were treated privately, you can contact the private breast clinic directly.

A specialist will review your symptoms, and arrange the appropriate test or scan for you.

What to look out for

- A lump or skin changes in either breast/chest wall, armpit or neck.
- Significant new back or bone pain (especially if associated with numbness or weakness of your legs), often worse at night.
- Persistent cough or shortness of breath.
- New and persistent upper abdominal discomfort, nausea.
- Persistent headache unrelieved by over-the-counter medications, new visual disturbance or loss of balance.
- New swelling of the arm.
- Loss of appetite, or unexplained weight loss or gain.
- Any symptoms that last for 2 weeks or more that you cannot explain.

If you have concerns that your breast cancer may have come back, contact your GP or specialist, do not wait for your scheduled appointment to discuss your concerns.

If you develop any new problems, ask your GP for an immediate referral back to the breast clinic.



Health & Wellbeing

What can you do to stay healthy?

Enjoying a healthy diet, avoiding excessive weight gain and doing regular exercise are important if you have had breast cancer.

Exercise

- Try to do some regular exercise. WHO recommendations for adults aged 18-64 are for 150 minutes of moderate aerobic exercise per week or 75 minutes of vigorous exercise. An equal combination of vigorous and moderate aerobic exercise is also beneficial.
- Ask your GP about Green Prescriptions
- PINC & STEEL provides cancer rehabilitation programmes involving individual sessions with a physio (PINC) and group exercise sessions (Next Steps).
For more information phone Breast Cancer Foundation NZ on **0800 BC NURSE** (0800 226 8773)

Diet

- Try to eat at least 5 portions of fruit and vegetables every day.
- Limit alcohol.
- Avoid excess red meat in your diet and unhealthy saturated fats.
- More advice on a healthy diet can be found on the Heart Foundation website www.heartfoundation.org.nz/healthy-living or you can be referred to a dietician for advice.

Weight

- Weight gain commonly occurs during treatment for a combination of reasons.
- Try to lose any excess weight gained during treatment.
- It is best to lose weight slowly, so don't lose motivation if the weight is not dropping off quickly.
- If you were overweight before treatment, why not use this opportunity to try to lose this weight?

There is good evidence that maintaining a healthy weight can reduce the risk of breast cancer recurrence in post-menopausal women.

Smoking

- If you smoke, ask your GP or any healthcare professional how to get help with quitting or smoking cessation.

Sun exposure

- Keep safe in the sun, always cover up and wear sun screen to avoid sunburn.
- It's important to protect areas affected by lymphoedema and the parts of the body which have had treatment such as radiation therapy.

General health checks

You should consider attending your GP once a year for a general check-up. Continue regular screening for other health issues e.g. cervical cancer, bowel cancer, skin cancer. You may continue to have flu vaccines.



Extra Info

Useful contacts and websites

For additional support and information you may find the following resources useful.

New Zealand Breast Cancer Groups and Cancer Information Resources

Breast Cancer Foundation NZ

www.breastcancerfoundation.org.nz

Webinars about life after breast cancer, and managing ongoing symptoms

www.breastcancerfoundation.org.nz/webinars

mybc, BCFNZ's online breast cancer community

www.mybc.care or download the app on your phone

Breast Cancer Aotearoa Coalition

www.breastcancer.org.nz

Breast Cancer Support

www.breastcancersupport.co.nz

Cancer Society NZ

www.cancernz.org.nz

Shocking Pink (support for young women)

www.shockingpink.org.nz

Gift of Knowledge (support for people with BRCA mutations)

www.giftofknowledge.co.nz

International Breast Cancer Groups and Cancer Information Resources

National Breast and Ovarian Cancer Council

www.breast-cancer.canceraustralia.gov.au

Macmillan Cancer Support

www.macmillan.org.uk

Cancer Research UK

www.cancerresearchuk.org

Breastcancer.Org

www.breastcancer.org

You may find it useful to fill in the name and contact details of members of your healthcare team who also support your recovery following treatment:

Iwi Cancer Co-ordinator

Social Worker

Counsellor

Lymphoedema Therapist

Physiotherapist

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If you feel there is further information you would like to see in this booklet or have other feedback, then please contact us: **breastnurse@bcf.org.nz**



The mangopare

This design reflects strength, growth, transformation, movement from one phase to the next, kaitiaki and relationships or strength gained from/through the support of others.



Artist

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**Breast Cancer
Foundation NZ**

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