



Secondary Breast Cancer Matepukupuku ā-Ū Tuarua



Understanding Cancer

A guide for people with secondary breast cancer

ANY CANCER, ANY QUESTION 0800 CANCER (226 237) Cancer Information Helpline

Your general practitioner: phone _____

Your cancer team: phone _____

Your local Cancer Society: phone _____

24-hour emergency: phone 111

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You can get copies of Cancer Society booklets and information sheets from your local Cancer Society, by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by downloading them from our website www.cancernz.org.nz.

“*When I was diagnosed I was very frightened and vulnerable to misinformation and suggestion by well-meaning people. I wanted, and mostly got, information and positive encouragement, which gave me hope.*”
Phil

About this booklet

This booklet is for people, mostly women, who have a diagnosis of secondary breast cancer. It may also be useful for the people around you, such as your family/whānau, friends or carers.

It will help you to understand what secondary breast cancer is and the physical and emotional impacts it can have on you and those close to you.

The booklet discusses living with secondary breast cancer and understanding what the future may hold. It looks briefly at symptoms and treatments and lists sources of help and support available to you.

For some people, having information about what is happening to them can be a way of taking back some control at a time when you may be feeling overwhelmed and powerless.

Mō ngā tāngata kua puta te whakatau mō te pā o te matepukupuku ā-ū tuarua, tēnei pukapuka, ko te nuinga o rātou, he wāhine. Tērā pea ka whai kiko anō mō ngā tāngata tata ki a koe, pērā ki tō whānau, o hoa, o kaitiaki rānei. E whai ana te pukapuka ki te āwhina i a koe, kia tino mārama ai koe ki tēnei mea, te matepukupuku ā-ū, me ōna papātanga ā-tinana, ā-ngākau hoki ki a koe me te hunga tata ki a koe.

Kapi ai tēnei pukapuka i te āhua o te noho me te mate nei, me te āhua o te whakatika i a koe mō ngā rā e tū mai ana. Ka titiro poto nei ki ngā tohumate me ngā momo maimoatanga, me te whakarārangi i ngā pū āwhina, tautoko hoki e wātea ana ki a koe.

Mō ētahi tāngata, mā te whai i ngā pārongo e pā ana ki ngā āhuatanga ka puta ki a rātou tētahi huarahi ki te whakahoki anō i te mana ki a rātou, i ngā wā ka taumahatia, ka kore whai kaha rānei.

The booklet is divided into sections. Some sections may not be about



your present situation. You may like to ask your cancer treatment team which sections you will find useful, or you can phone the Cancer Information Helpline 0800 CANCER (226 237) to talk about this.

We would value your feedback on this booklet. There is an online form you can fill in here:

www.cancernz.org.nz/cancer-information/other-links/feedback/

Contents

| | |
|--|----|
| <u>Section one: Understanding secondary breast cancer</u> | 5 |
| Key points | 6 |
| What is breast cancer? | 6 |
| What is secondary breast cancer? | 9 |
| <u>Section two: Diagnosing secondary breast cancer</u> | 10 |
| Key points | 11 |
| Symptoms | 11 |
| The bone | 11 |
| The liver | 12 |
| The lungs | 14 |
| The brain | 14 |
| Diagnostic tests | 16 |
| A bone scan | 16 |
| An ultrasound scan | 16 |
| CT scan | 16 |
| Chest X-ray | 16 |
| MRI scan | 16 |
| PET scan | 17 |
| Questions you may want to ask about your diagnosis | 17 |
| <u>Section three: Secondary breast cancer treatment</u> | 19 |
| Key points | 20 |
| Talking with doctors | 22 |
| Asking for a second opinion | 23 |
| Treatment for secondary breast cancer | 23 |
| Hormone therapies | 24 |
| Tamoxifen hormone treatment | 25 |
| Aromatase inhibitors | 25 |
| Ovarian function suppression (preventing the ovaries from working) | 25 |
| Goserelin | 26 |
| Surgery to remove the ovaries | 26 |
| Radiation treatment | 26 |
| Side effects of radiation treatment | 27 |
| Chemotherapy | 28 |
| How chemotherapy medications are given | 28 |
| Side effects of chemotherapy | 28 |
| Targeted treatments | 30 |
| Bone-strengthening medication | 30 |
| Taking part in a clinical trial | 31 |
| Controlling the symptoms and side effects of secondary breast cancer | 32 |
| Managing pain | 32 |
| Morphine for cancer pain | 32 |
| Radiation treatment for cancer pain | 32 |
| Coping with fatigue | 33 |

| | |
|---|----|
| Breathing problems | 34 |
| Feeling sick (nauseous) | 34 |
| Fertility and contraception | 35 |
| Dealing with constipation | 35 |
| Difficulty sleeping | 36 |
| Anxiety and depression | 37 |
| Headaches | 37 |
| Lymphoedema | 38 |
| Hypercalcaemia | 38 |
| Strengthening a weakened bone | 38 |
| Spinal cord compression | 38 |
| Some questions you may want to ask about your treatment | 39 |
| <u>Section four: Living with secondary breast cancer</u> | 40 |
| Key points | 41 |
| Finding out that your breast cancer has spread | 42 |
| Emotional support to cope with your reactions | 43 |
| Psychological, counselling and social worker support | 44 |
| Cultural and spiritual support | 46 |
| Traditional Māori healing | 46 |
| Pacific traditional healing | 47 |
| Complementary and alternative therapies | 48 |
| Relaxation techniques | 49 |
| Support groups | 50 |
| Exercise and diet | 51 |
| Changes in your employment | 52 |
| If you continue to work | 52 |
| If you can no longer work | 53 |
| Using your work entitlements | 53 |
| Returning to work | 54 |
| Relationships and sexuality | 55 |
| Talking with your child | 56 |
| How can families/whānau help you? | 57 |
| Home care | 59 |
| Palliative care | 59 |
| Advance care planning | 60 |
| Financial assistance | 60 |
| Interpreting services | 61 |
| More questions you may want to ask | 61 |
| <u>Appendix A: Suggested reading and websites</u> | 62 |
| Glossary (What does that word mean?) | 64 |
| Notes | 66 |
| Cancer Society of New Zealand Inc.—Te Kāhui Matepukupuku o Aotearoa publications | 67 |
| Cancer Society information and support services | 68 |
| Acknowledgements | 70 |



**Section one:
Understanding secondary
breast cancer**

Key points

- When breast cancer spreads, for example to the bones, it is called secondary breast cancer.
- The most common parts of the body that breast cancer spreads to are the bones, the liver and the lungs. It can also spread to the brain, although this is less common.
- A diagnosis of secondary breast cancer means that the cancer cannot be cured, but often it can be controlled.

Ngā kōrero matua

- Ka rauroha ana te matepukupuku ā-Ū, hei tauira - ka rauroha ana ki ngā kōiwi, ka kīia he matepukupuku ā-ū tuarua tērā.
- Ko ngā momo wāhi rauroha ai te matepukupuku ā-Ū, ko ngā kōiwi, ko te ate, me ngā pūkahukahu.
- Ka āhei anō ki te rauroha ki te roro, heoi anō, kāre e tino kitea ana i tēnei.

What is breast cancer?

Breast cancer is the third most common cancer diagnosed in New Zealanders. In 2015 there were 3,315 new registrations of breast cancer—3,292 of these were in women and 23 in men.

Women and men both have breast **tissue**. In women, breasts are made up of milk glands, connective tissue and fat. The milk glands consist of milk sacs (lobules) where milk is made, and ducts that take the milk to the nipple.

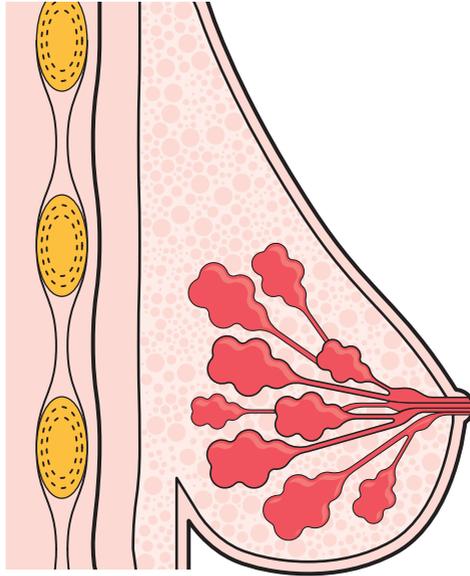


Image: Macmillan Cancer Support UK

During puberty males produce increased amounts of the male hormone testosterone, which suppresses the development of lobules in their breast tissue.

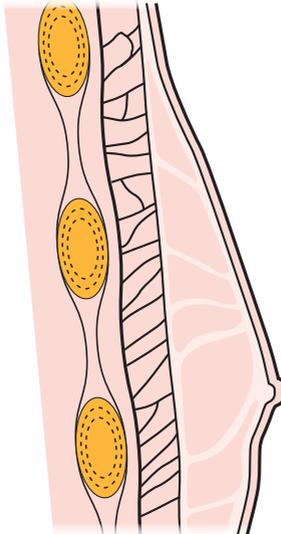


Image: Macmillan Cancer Support UK

Breast tissue is made up of millions of **cells** that are like tiny ‘building blocks’. Breast cancer is a disease of these breast tissue cells. Normally, cells reproduce and grow in an orderly way. However, sometimes an abnormal cell develops that can continue to reproduce and grow into a **tumour**. Tumours can be **benign** (not cancerous) or **malignant** (cancerous).

A malignant tumour is made up of cancer cells. When it first develops, the malignant tumour may be confined to its original (**primary**) site. If these cells are not treated they may spread beyond their normal boundaries and into surrounding tissues (invasive cancer).

Breast cancer that comes back in the same breast is called a local **recurrence**. When it spreads to areas around the breast, such as the skin, the muscles on the chest wall, the **lymph nodes** under the breastbone (sternum), between the ribs, or the nodes above the collarbone (clavicle), it is called regional recurrence. Both of these types of recurrence will need further treatment, but they are not **secondary** breast cancer.

This booklet provides information on secondary breast cancer. For more information about primary breast cancer, see our booklet *Breast Cancer/Te Matepukupuku o ngā Ū*.

What is secondary breast cancer?

Secondary breast cancer occurs when breast cancer cells spread from the first (primary) tumour in the breast through the lymphatic or blood system to other parts of the body. You will most commonly hear this referred to as **metastatic** breast cancer, **advanced** breast cancer, secondary tumours or secondaries.

When breast cancer spreads, for example to the bones, it is called secondary breast cancer. The cells that make up the tumour in those bones are breast cancer cells. This is very different from having primary bone cancer. The difference between primary and secondary cancer is important for treatment. The treatment for secondary breast cancer in the bone is designed to treat breast cancer, while the treatment for primary bone cancer is designed to treat bone cancer.

Sometimes secondary breast cancer is diagnosed at the same time as primary breast cancer, or it may be diagnosed without an earlier diagnosis of primary breast cancer. The most common parts of the body to which breast cancer spreads are the bones, the liver and the lungs. It can also spread to the brain, although this is less common.

A diagnosis of secondary breast cancer means that the cancer cannot be cured, but often it can be controlled, sometimes for many years.

The aim of treatment for secondary breast cancer is to keep you as well as possible for as long as possible. One of the first things that people often want to know when they get their diagnosis is how long they have to live. This is difficult to predict as each person is an individual and no two cancers behave in the same way. Your specialist will have an understanding of the likely progress of your secondary breast cancer and can talk to you about what you might expect.



**Section two:
Diagnosing secondary
breast cancer**

Key points

- Every person's experience of secondary breast cancer is different.
- Tests can be used to identify whether cancer has spread and where it has spread to.

Ngā kōrero matua

- He rerekē ngā wheako a tēnā, a tēnā, e pāngia ana ki te matepukupuku.
- Ka āhei te whakamahi i ngā whakamātautau kia mōhio ai mehemea kua rauroha te matepukupuku, kia mōhio ai hoki kua rauroha ki whea.

Sometimes people see their GP when they have symptoms such as pain or they are unusually tired. Your GP may arrange tests to check if these symptoms are due to the spread of your breast cancer. Secondary breast cancer can be diagnosed in a number of ways.

Symptoms

Every person's experience of secondary breast cancer is different.

Your symptoms will depend on the part of your body affected by secondary breast cancer, and you may not have many symptoms. However, if you feel you have had a change in your health and you are worried about it, it is important to discuss your concerns with your doctor. The following section describes symptoms that you may experience.

The bone

Pain

Secondary breast cancer in the bone can cause pain. Diagnosis is made by **bone scan**, X-ray and sometimes **CT scan**.

Weakness in the bone

A secondary cancer in the bone may gradually damage some of the bone tissue, causing the bone to become weaker. Early treatment may be considered to prevent **fractures** (radiation treatment, medication and/or surgery).

Spinal cord compression (pressure on your spinal cord)

If cancer has spread to the bones in your spine, this may cause pressure on your spinal cord. This is known as spinal cord compression. See page 38 for more information.

Hypercalcaemia (high levels of calcium in the blood)

Extra calcium sometimes leaks into the blood when bones are damaged by secondary cancer. Hypercalcaemia is diagnosed by a blood test and is usually treated with medication. If your blood calcium is high you may be feeling sick, tired or confused, be more thirsty than usual, have headaches or be constipated. See page 38 of this booklet for more information about hypercalcaemia.

The liver

Breast cancer that has spread to the liver may cause symptoms including:

- weight loss
- lack of appetite
- tiredness
- nausea (feeling sick)
- jaundice (yellowing of the skin)
- discomfort or pain around the liver (the right side of the abdomen)
- swelling of the abdomen (**ascites**)
- right shoulder-tip pain.

Diagnosis is made by blood tests or CT, **ultrasound** or **MRI scan** (see pages 16-17 for more information).



The lungs

Cancer within the lungs or on the lining of the lungs may cause the following symptoms:

- shortness of breath
- dry cough
- tiredness
- chest pain.

Cancer cells sitting on the outside of the lungs can irritate the lining that covers the lungs (the pleura). This may cause fluid to build up, which presses on the lungs and can make breathing difficult.

Difficulty breathing can be frightening, but there are many ways to relieve breathlessness with treatment.

Seek medical attention immediately if you:

- experience breathing problems
- cough up blood
- have chest pain or
- feel very unwell.

Diagnosis is made by chest X-ray, ultrasound scan or CT scan (see pages 16-17).

The Cancer Society has an information sheet, *Breathlessness (being short of breath)*, which offers suggestions that may help if you are having difficulty breathing. It is available on our website www.cancernz.org.nz.

The brain

Breast cancer that has spread to the brain may cause symptoms of:

- headaches
- nausea and/or vomiting
- weakness in an arm or a leg

- unsteadiness while walking
- changes in vision or speech
- seizures
- confusion, disorientation or personality changes (rare).
- Diagnosis is made by CT or MRI scan (see pages 16-17).



Diagnostic tests

The tests discussed below can be used to work out whether there is evidence that your breast cancer has spread, and if so where to.

Bone scan

A bone scan is a test that may show areas of bone that are affected by secondary breast cancer. A small amount of a radioactive substance is injected into a vein. Abnormal bone absorbs more radioactivity and shows up on a scanner. Sometimes old fractures, injuries or areas of arthritis also show up on a scan.

Ultrasound scan

Ultrasound scans can be used to build up a picture of the liver or kidney or to find fluid around the lungs or abdomen.

CT scan

CT scans are special types of X-rays that take cross-sectional pictures of the body. CT scans are usually done at a hospital or radiology service and can be used to find areas of cancer that may not be found by X-ray alone. CT scans can also show enlarged lymph nodes. A contrast dye is injected into a vein to enhance the detail of the pictures.

Chest X-ray

A chest X-ray may show whether there is any secondary breast cancer in the lungs and may also reveal any build-up of fluid on the outside lining of the lungs.

MRI scan

An MRI scan uses magnetic fields and radio waves to build a picture of the organs inside the body. The MRI machine is similar to a CT scanner but has a longer central hole, more like a cylinder (tube). Scanning is very noisy. Earphones (with or without music) are offered to reduce the noise. Some people benefit from medication to help them relax before a scan.



PET scan

A **PET (Positron emission tomography) scan** is a technique used to build up pictures of the metabolic activity of the body and cancer. You are injected with a glucose solution containing a very small amount of radioactive material. The scanner can ‘see’ the radioactive substance. Damaged or cancerous cells show up as areas where the radioactive material and glucose are being taken up. A PET-CT scan is a PET scan that is combined with a CT scan.

Questions you may wish to ask about your diagnosis

When you first learn you have secondary breast cancer you may have many questions. We suggest that you think about the questions you would like to have answered, and what you do not want to be told, before you visit your cancer treatment team.

You may wish to think about the asking your treatment team about:

- how far your cancer has spread
- the stage your cancer is
- if your cancer is curable
- other tests you might need before treatment starts
- the treatment advised for your cancer.



**Section three:
Secondary breast cancer
treatment**

Key points

- Secondary breast cancer may respond to several types of treatment: hormone therapy, radiation treatment, chemotherapy, targeted treatment.
- The treatment suggested for you will depend on your type of secondary breast cancer, the parts of your body the cancer is affecting, and your wishes.
- Before any treatment begins, make sure you have discussed the choices with your cancer treatment team. Ask for a second opinion if you want one.
- It is common to experience some side effects during treatment. Every person's side effects are unique.
- The best way to control the symptoms of secondary breast cancer is to treat the cancer itself.
- Pain, fatigue and nausea are some of the symptoms of secondary breast cancer.
- Tell your cancer treatment team if you are experiencing symptoms of secondary breast cancer. They will be able to suggest treatment.

Ngā kōrero matua

- Tērā pea ka urupare te matepukupuku ā-ū ki te maha o ngā momo maimoatanga
 - Haumanu taiaki
 - Maimoa iraruke
 - Hahau
 - Paturopi monoclonal
- Ka hāngai te maimoatanga ka whakataunakitia mōu, ki tō momo matepukupuku ā-ū kua pā ki a koe, me ngā wāhi o tō tinana kei te pā, ki tāu e hiahia ana rānei.
- E rangona noatia ana ētahi papātanga ki te taha i te wā o te maimoatanga. He ritenga kore tā tēnā, tā tēnā, o ngā papātanga ki te taha.
- Ko te huarahi pai hei whakahaere i ngā tohumate o te matepukupuku ā-ū, ko te maimoa i te matepukupuku.
- Ko te mamae, ko te hiamoe, me te hiaruaki ētahi o ngā tohumate o te matepukupuku ā-ū.
- He ritenga kore te wheako a tēnā, a tēnā, o ngā tohumate matepukupuku ā-ū.
- Kōrero ki tō rata mehemea e whai wheako tohumate ana koe o te matepukupuku ā-ū. Ka āhei rātou ki te taunaki maimoa mōu.



Talking with doctors

“You don’t always have lots of time to make decisions and get information, and doctors aren’t always available when you need them, so make the most of your time with them.”
Moira

Before you see the doctor it may help to write down any questions you may have. Let your doctor know how much information you want to know at that appointment. We suggest you have a support person with you at your appointment with the cancer doctor.

“It was really helpful taking a friend with me. She was able to take notes and we could talk about it later. She picked up some things that I totally missed.”
Cam

Te kōrero ki o rata

I mua i tō haere ki te kite i tētahi rata, tērā pea hē pai ki te tuhi i ō pātai ki tētahi pepa. Mō tētahi taurira rārangi pātai tērā pea ka hiahia koe ki te whakamahi.

Hē mea pai hoki mēnā ka whai tangata tautoko koe i tō haerenga ki te kite i tō rata matepukupuku.

Asking for a second opinion

You may want to ask another doctor about your cancer or treatment. You can ask your cancer doctor or GP to refer you to another cancer doctor. You are entitled to a second opinion if you want one.

Treatment for secondary breast cancer

Secondary breast cancer may respond to several types of treatment:

- hormone therapy
- radiation treatment
- chemotherapy
- targeted therapies.

The treatment suggested for you will depend on the type of breast cancer you have, the parts of your body the cancer is affecting, and your wishes.

“I got a little scared by the tests: it was a shock. I don’t remember what was said but my husband did. He had all the questions.”
Beth



Hormone therapies

Many breast cancer cells contain proteins known as oestrogen receptors and progesterone receptors. A cancer that contains a certain number of these cells is described as hormone-receptor positive.

Hormone-receptor-positive breast cancers may be treated by hormones, whereas hormone-receptor-negative breast cancers do not respond to hormone therapy and are treated with chemotherapy.

Hormone therapy can reduce symptoms and shrink the cancer. It can work well for slow-growing cancers affecting the bone, the skin or the fatty tissue under the skin.

Most hormone therapies work by decreasing the amount of oestrogen in the body, or by stopping the cancer cells using oestrogen to grow. Side effects are rarely serious but can affect quality of life. There are many hormone therapies available, giving doctors the option of trying several types.

The hormone treatment prescribed depends on whether you are pre- or post-menopausal. The common hormone treatments include the following.

Tamoxifen hormone treatment

Tamoxifen is one of the most commonly used hormone treatments. This treatment can be used by women of all ages. Tamoxifen is taken as a tablet daily and treatment continues for as long as it continues to provide effective management of your cancer.

Side effects of Tamoxifen

Tamoxifen has been used by thousands of women worldwide for many years and has proved to be a safe medicine with few side effects.

Common side effects include:

- hot flushes/mood swings
- vaginal dryness and an increased discharge from the vagina
- in pre-menopausal women, changes in periods.
(Please note Tamoxifen is not a contraceptive.)

Aromatase inhibitors

Aromatase inhibitors work by preventing oestrogen being produced. They are only used by post-menopausal women.

Common side effects include:

- hot flushes
- vaginal dryness
- joint pain/stiffness.

Ovarian function suppression (preventing the ovaries from working)

Pre-menopausal women may have ovarian function suppression alongside an aromatase inhibitor. This will bring on an early menopause.

Ovarian function suppression can be achieved by:

- switching off the ovaries with medication
- surgery.

Goserelin

Goserelin is a medication that switches off the ovaries, stopping them making oestrogen. The medicine does not act directly on the ovaries; it works on the part of the brain that is responsible for stimulating the ovaries to produce oestrogen. The treatment is given as a regular injection under the skin of the abdomen for as long as it provides effective management of your cancer.

Side effects of Goserelin

Goserelin causes early menopause. If goserelin is stopped, your periods may return.

Surgery to remove the ovaries

An operation to remove the ovaries is called an oophorectomy. Periods will stop after surgery and you will have menopausal symptoms straight away.

Radiation treatment

Radiation treatment uses high-energy rays to destroy cancer cells. Radiation treatment can shrink cancers in some parts of the body and help relieve pain.

Radiation treatment is usually recommended to:

- relieve bone pain
- prevent and treat spinal cord compression (see page 38)
- prevent or treat fractures after bone surgery (see page 38)
- prevent or treat fractures without surgery
- treat regional recurrence on the skin and in the lymph nodes
- treat cancer in the brain.



Side effects of radiation treatment

These depend on the dose, the number of treatments and the part of the body that is treated.

Side effects are not common, but may include:

- tiredness
- nausea (feeling sick) if the treatment is given to the abdomen or pelvis. This can be relieved by anti-sickness medications (antiemetics)
- hair loss in the area treated
- a short period of increased pain when you first begin treatment. Continue to take your pain medication as usual
- depending on the dose of radiation, skin in the treatment area becoming dry, flaky, red, itchy or sore—similar to sunburn. If your skin gets very sore it may peel and blister.

For more information on radiation treatment, talk to your team at the radiation centre or phone the Cancer Information Helpline **0800 CANCER (226 237)** for our booklet *Radiation Treatment/ Haumanu Iraruke* or find it online www.cancernz.org.nz.

Chemotherapy treatment

Chemotherapy is the use of anti-cancer medication to destroy cancer cells. The medication circulates in the bloodstream, reaching cancer cells throughout the body. Chemotherapy treatment may shrink the cancer or prevent it growing bigger.

Chemotherapy is usually recommended when your:

- cancer is not hormone sensitive
- hormone treatments are no longer controlling cancer growth or symptoms and/or
- breast cancer is progressing.

“*Chemo was a bit easier than I expected it to be. The anti-sickness drug worked pretty well.*”
Nicola

How chemotherapy medications are given

Chemotherapy medications are given by mouth or by injection into a vein.

Side effects of chemotherapy

Chemotherapy medications can damage normal cells as well as cancer cells, leading to side effects that may include:

- nausea—this can usually be managed with anti-emetics. Vomiting is rare
- hair loss—some chemotherapy medications cause temporary hair loss
- tiredness
- change in appetite
- diarrhoea or constipation
- nail changes.



Look Good Feel Better offer free classes for any person having cancer treatment
www.lgfb.co.nz/classes

Most chemotherapy medications can affect the bone marrow, which produces blood cells. If bone marrow function is reduced by chemotherapy, side effects may include:

- a lowered resistance to infection
- bruising or bleeding even from minor cuts (an occasional side effect).

You will have regular blood tests throughout chemotherapy treatment to check your blood cell levels. If you have a low blood cell count, your treatment may be delayed because you are at higher risk of infection. If you develop an infection you will be given antibiotics.

If you develop a fever (if your temperature is 38 degrees Celsius or over) or you feel unwell even with a normal temperature, do not wait to see what happens—take action quickly. Contact your cancer treatment team and follow the advice given.

Ki te puta te kirikā ki a koe (he pāmahana 38 mahana C, neke atu rānei tōu), ki te māuiui rānei koe ahakoa te pai o tō pāmahana, kua e whakakeke - me tere tonu to whakatikatika. Whakapā atu ki to tapuhi matepukupuku, to rata rānei, ka whai i ngā tohutohu ka hoatuna.

If you want more information about chemotherapy, please ask your local Cancer Society for our booklet *Chemotherapy/Hahau* or find it online at www.cancernz.org.nz.

Targeted treatments

Targeted treatments attach to the proteins on, or in, cancer cells to interfere with signals that tell the cancer cells to grow. Targeted treatments include monoclonal antibodies. These are medications that target specific proteins on the surface of the cells and trigger the body's immune system to attack the cancer cells. Examples of targeted therapies used in breast cancer are the monoclonal antibodies trastuzumab (Herceptin) and pertuzumab (Perjeta). They are only beneficial to people who have 'HER2-positive' breast cancer.

Roughly 20 percent of breast cancers are known as HER2-positive cancers. This means they have too many 'copies' of a protein called HER2, which makes cancer cells grow and divide. Trastuzumab and pertuzumab work by locking on to the HER2 proteins on the surfaces of the cells, to stop them dividing and growing. Each medication locks on to a different part of the protein. They are often given in combination with chemotherapy.

Side effects of targeted therapies can include an allergic reaction, swelling and wheezing or shortness of breath at the time of the infusion. You will be monitored closely by staff for these and for tiredness, joint and muscle aches. You may be more likely to get an infection. Contact your cancer treatment team straight away if you have any signs of infection or any other symptoms you are concerned about.

Herceptin and Perjeta can affect the way your heart works. You will be monitored for this during your treatment.

Bone-strengthening medication

If you have secondary breast cancer affecting your bones, you may be offered bone-strengthening medication such as bisphosphonates.

Bisphosphonates are a group of medications that can slow bone breakdown while allowing new bone to be produced as normal. They can reduce bone pain, control the level of calcium in the blood (hypercalcaemia—see page 38) and reduce the long-term risk of

complications such as fractures. They are usually given over a few hours through an intravenous drip (into the vein). Side effects can include 'flu-like symptoms.

Taking part in a clinical trial

There are many new and emerging treatments for secondary breast cancer and there may be clinical trials available that you could join.

Sometimes these trials give you access to better medications than would be available outside a study. At other times, trials test drugs that have not been used in many people before and it may be unclear how effective the treatments are and what side effects they might have. You should discuss this with your specialist.

Clinical trials are a vital part of the search to find better treatments for cancer, to test new and modified treatments, and to see if they are better than existing treatments.



Many people all over the world have taken part in clinical trials that have improved cancer treatments, but not all drugs tested in trials turn out to be helpful. The decision to take part in a clinical trial is yours.

If you are asked to take part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for your treatment.

Controlling the symptoms and side effects of secondary breast cancer

The best way to control the symptoms and side effects of secondary breast cancer is to treat the cancer itself.

Managing pain

People with secondary breast cancer may experience different types of pain. There is a wide range of pain-relieving medications (**analgesics**).

Pain relief works best if taken regularly. Tell your cancer treatment team if your prescribed medications are not easing your pain, as there are likely to be other pain-relieving medications that you can try.

Morphine for cancer pain

Morphine is a commonly used medication for severe pain. The dose can be changed to suit each person. When morphine is used in its proper role as a pain reliever it is given in controlled doses and people do not become addicted.

Radiation treatment for cancer pain

Radiation treatment can be very good at relieving pain caused by secondary cancer in the bone, and can be given as either a single treatment or a number of treatments that are given daily. Radiation treatment used in this way usually causes very few side effects.

You will need to keep taking your usual pain-relieving medication as it can take several weeks for radiation treatment to be fully effective.

As your pain begins to improve, you may want to talk to your doctor or nurse about reducing the dose of your pain medications.

For more information about radiation treatment, see page 26.

Coping with fatigue

Cancer fatigue has come to be recognised as one of the most common symptoms of secondary cancer. It has many causes, from psychological factors such as the stress of coping with the diagnosis, to physical ones such as the side effects of treatment or the progression of the cancer.

“ I save my energy for work. No-one knows at work so at work suddenly I’m not Pat with cancer, I’m just me. ”
Pat

Each person’s experience of cancer fatigue is unique, but the following suggestions may help you to cope.

- Tell your doctor about the fatigue, as its cause may be treatable.
- Plan your days so you have a balance of activity and rest.
- Try to have short, achievable periods of exercise each day.
- If you are having a bad day, try to accept it and enjoy the good days.
- Take short naps throughout the day.
- Prepare yourself for a special occasion by resting beforehand.
- Try to eat well. If your appetite is poor, choose high-calorie foods for energy.
- Choose relaxing activities such as watching TV or listening to music or a talking book.
- Accept offers of help from other people to save your energy for things you enjoy.

For more information, read our information sheet *Managing cancer fatigue*.



Breathing problems

One of the common causes of breathing problems in people with secondary breast cancer is a pleural effusion (a build-up of fluid around a lung). This fluid can press on the lung, making it harder for you to breathe and causing a feeling of breathlessness. This is managed by removing the fluid.

There may be other reasons for breathlessness, such as anaemia or a chest infection.

Always seek medical attention if breathing becomes difficult.

The Cancer Society has an information sheet, *Breathlessness (being short of breath)*, that offers suggestions for when you are having difficulty breathing. You can find it on our website www.cancernz.org.nz.

Feeling sick (nauseous)

There are many reasons for people with secondary breast cancer feeling sick, but there are ways to manage this symptom.

The following suggestions may be helpful:

- eat small meals at frequent intervals
- avoid fatty or fried foods
- rest before and after eating
- do not lie flat during or after eating
- drink plenty of fluids
- see a dietitian or nurse for dietary advice
- try relaxation exercises
- do something enjoyable as a distraction from feeling sick.

There is a range of anti-sickness medicines that work in different ways. **Let your cancer treatment team know if you are feeling sick** or any prescribed medication is not effective. Most anti-sickness medicines take 20-30 minutes to work. See page 38 for information on hypercalcaemia, as nausea can be a symptom of this and needs urgent treatment.

Fertility and contraception

You may become infertile, either temporarily or permanently, during treatment. Talk to your doctor about this before you start treatment.

Despite the possibility of infertility, contraception should be used (if the woman has not gone through menopause) to avoid pregnancy. This is because there is a risk of miscarriage or birth defects for children conceived during treatment. If you are pregnant now, talk to your cancer treatment team about it straight away.

Dealing with constipation

If you are taking pain relievers containing morphine, if treatment has affected your appetite, or if there is too much calcium in your blood, you may experience constipation.

Some ideas that could help are:

- increasing the fibre in your diet by eating fresh fruit (such as kiwifruit, vegetables and grains)

- increasing the amount of water you drink. Drink at least eight glasses (1500 millilitres) of fluid each day
- following a gentle exercise programme.

Difficulty sleeping

People with secondary breast cancer may feel tired but find it hard to sleep. Insomnia can be caused by the side effects of some medications, anxiety or pain.

Suggested remedies include:

- doing gentle exercise such as walking or a simple exercise programme
- developing a schedule of gentle activities or visits from friends so you maintain a normal daily routine
- avoiding coffee, tea and caffeine drinks later in the day
- having a herbal tea, especially before going to bed
- doing deep breathing and relaxation exercises
- taking a warm bath
- having a gentle massage for relaxation
- talking to friends, family/whānau or a counsellor.

If difficulty sleeping is affecting your ability to cope day to day, talk to your doctor for further guidance. Sometimes a short course of medication to help you sleep will help.

“ I listen to music and I read a lot—reading is an escape—I go to bed early to read. ”
Alexandria



Anxiety and depression

Feelings of anxiety and depression are often described by people diagnosed with secondary breast cancer. These feelings can happen at any time. You may have trouble sleeping, concentrating, eating and/or getting up in the morning. You may also be irritable or find yourself crying at the slightest thing.

If you are feeling this way, you do not have to ignore it. It can sometimes be hard to acknowledge that you are having difficulty coping. Friends and family/whānau can offer empathy and support, but you may prefer to talk to someone who is specially trained in helping people to deal with emotional distress. See the next section on **living with secondary breast cancer** for further information.

Headaches

Muscular tension, exhaustion or increased levels of calcium in the blood (hypercalcaemia—see the next page) may cause headaches. It is important to let your cancer treatment team know if you are having regular headaches, as sometimes they are a sign that cancer has spread. Symptoms caused by cancer that has spread to the brain can be helped by radiation treatment and/or steroid medication.

Lymphoedema

Lymphoedema is swelling in an area of the body due to the **lymph vessels** being blocked. In people with breast cancer, the arm and chest wall on the side of treatment may be affected. Causes include the cancer itself, and previous surgery or radiation treatment on the area.

The best treatment for lymphoedema is a programme of exercise, massage and skin care, and a properly fitted compression sleeve or bandaging. Damage to the lymph nodes means it is not usually possible to reverse the swelling, so the aim of treatment is to control the swelling on a long-term basis.

Contact your local Cancer Society for details of lymphoedema therapists available in your area. See the Cancer Society information sheets *Understanding lymphoedema* and *Living with lymphoedema*.

Hypercalcaemia

Hypercalcaemia (high levels of calcium in the blood) can occur when you have secondary breast cancer in your bones. It is treated in hospital with medications to help reduce the levels of calcium in your blood, and any symptoms you may have been experiencing will resolve as your blood levels return to normal.

Strengthening a weakened bone

If your bones have been weakened by the spread of cancer, you may need regular medication (bisphosphonates) to help maintain their strength. If your bones are at increased risk of breaking, it may be necessary to have an operation to protect the bones from further damage. This is sometimes done before radiation treatment begins to treat secondary breast cancer that has spread to the bones.

Spinal cord compression

The spinal cord is the large nerve that runs from the base of the brain to the bottom of the back. It is protected by the bones of the spine (vertebrae). Secondary breast cancer in the vertebrae is quite common. For a small number of people, the spread of cancer to the

spine causes pressure on the spinal cord, causing pain and, in extreme cases, damage to the spinal cord.

Report any of the following symptoms to your cancer treatment team as soon as they occur:

- tingling or numbness in an arm(s), hand(s) or leg(s)
- difficulty walking
- trouble passing urine
- constipation or diarrhoea.

Early treatment—usually steroid medications, radiation treatment, surgery or a combination of these—offers the best chance of avoiding permanent damage to the spinal cord.

Some questions you may want to ask about your treatment

You might like to find out:

- what the risks, benefits and possible side effects are of each treatment
- if you will have to stay in hospital, or if you will be treated as an outpatient
- how long the treatment might take
- if there will be any costs for you
- what further treatment you might need and when it would begin
- where you can go for a second opinion if you want one
- what will happen if you choose not to be treated
- if treatment might affect your ability to look after your children or grandchildren
- if you can get help with transport to your treatment
- information on any health professional who can come to your appointments and spend time with you afterwards to explain what was said (be an advocate)
- other treatments that might be available that aren't currently funded.



**Section four:
Living with secondary
breast cancer**

Key points

- When you hear the news that your breast cancer has spread, you may experience a mixture of emotions.
- Feelings can range from disbelief and denial to shock, anger, numbness and helplessness.
- There are a number of ways that secondary breast cancer may affect you and your relationships.
- There are many practical ways that you can be supported when you have cancer.
- Eating a balanced diet, exercise and relaxing are an important part of learning to live with secondary breast cancer. Traditional healing, complementary or alternative healing are some ways to help you to feel better and cope more easily with your cancer treatment.

Ngā kōrero matua

- Tērā pea, ka rongo ana koe kua rauroha to matepukupuku ā-Ū, ka puta he henumitanga o ngā kāre ā-roto.
- He rerekē ngā kāre ā-roto ka puta, mai i te kore whakapono, te uapare, te ohorere, te riri, te kēkerewai, te paraheahea hoki.
- He tini anō ngā momo wā ka whai papātanga te matepukupuku ā-Ū ki a koe, me o hononga.
- He maha tonu ngā ara ā-mahinga hei tautoko i a koe i te wā whai matepukupuku ā-Ū koe.
- Ko te kai pai, te korikori i te tinana, me te whakangohe ētahi mea nui o te noho me te matepukupuku ā-ū tuarua. Ko te hauora taketake, ko te hauora whakahāngai, ko te hauora whiringa rānei ētahi huarahi hei āwhina i a koe, kia piki ake tō āhua, me te whakamāmā ake i tō whai maimoatanga.

Finding out that your breast cancer has spread

When you hear the news that your breast cancer has spread, you may experience a mixture of emotions. Some people say that the diagnosis of secondary breast cancer is more traumatic than when they were first diagnosed, because the hope of a cure is replaced with the realisation that this is no longer possible.

Feelings can range from disbelief, denial and shock to anger, numbness and helplessness. You may feel as though you are on an emotional rollercoaster. You may be angry, making you short-tempered with those around you. Your mind may race ahead with worries about what is going to happen. You may be concerned for people close to you or disappointed about plans that may not go ahead.

“ You know when I was told, I didn’t feel angry. I didn’t have the energy to waste on being angry. I thought, I’ve got to fight this. ”
Colleen

“ The breast cancer doctor and his nurse came in. They were all very serious and said it was back. I had been so convinced that it wasn’t going to be cancer I hadn’t worried. ”
Stephanie

A small number of people find out they have breast cancer when it has already spread from their breast to another part of their body.

In the first days or weeks after your diagnosis you may find it hard to think clearly. It may take time to get things into perspective and start to take some control of your situation.

Many people feel that there is nothing they can do when they are told they have cancer. They feel out of control and helpless for a while. However, there are practical ways you can help yourself.

Emotional support to cope with your reactions

Hearing that you have secondary breast cancer may bring up a range of emotional reactions. You may feel angry, resentful or let down. It is common to feel that you are no longer in control of your body or your life.

It is not known exactly why some cancers spread, but it may be reassuring to know that there was nothing you could have done differently to prevent it.

Coping with the diagnosis will be an ongoing process for you, your family/whānau and your friends. There are no easy answers when it comes to facing a life-changing illness. Every person is different and will find their own way of coping with their difficult situation. Talking with family/whānau and friends may give loved ones the opportunity they have been waiting for to offer support.

Talking to someone outside the family/whānau may also be helpful. A counsellor or hospital chaplain can be good sources of support for many people, whatever their spiritual beliefs.

“A group of friends gathered together for an afternoon so that I could make my announcement. And that was really great. They were able to say, ‘What is it we can do?’ which was neat.”
Colleen



Psychological, counselling and social worker support

No matter how you are feeling, support services are available to you. If you speak to your GP they can refer you to someone such as a counsellor or psychologist who can help you work through feelings of loss and grief.

Psychologists and counsellors

- encourage you to talk about any fears, worries or emotions you may be feeling
- help you to work through feelings of loss or grief
- help you to resolve problems so that you can find more pleasure in your life
- teach you ways to handle any anxiety you may have
- show you meditation or relaxation exercises to help ease physical and emotional pain
- can help you to communicate better with your family/whānau.

To find a psychologist or counsellor, contact your GP, your local Cancer Society or phone the Cancer Information Helpline **0800 CANCER (226 237)**.

Social workers

Social workers are available to help support you and your family/whānau through the social and emotional changes a cancer diagnosis brings. If you do not already have a social worker, your cancer treatment team can arrange a referral.

Social workers:

- provide information and support to help you manage the impacts your cancer may have on you and your family/whānau
- help to set up support services, including help at home (domestic assistance) and help with personal care, so that you can stay independent at home
- help with accommodation for you and your family/whānau if you need to travel away from home for treatment
- help make travel arrangements if you are having treatment out of town
- offer advice and information about financial support available
- make referrals to other support agencies
- take part in multidisciplinary meetings.

Cultural and spiritual support

Hospitals throughout New Zealand have trained health workers available to support your spiritual, cultural and advocacy needs. They may include Māori and Pacific health workers who will work with you and your family/whānau.

Hospital chaplains are available to offer support through prayer and quiet reflection. Community-based health workers at your local marae and Pacific health services may also be good sources of support.

For more information on this topic, see our information sheet *Cancer and spirituality*.

Tautoko ā-ahurea, ā-wairua hoki

Ka whai ngā hōhipera huri noa i te motu i ngā kaimahi hauora kua whakangungutia hei tautoko i ō hiahiatanga ā-wairua, a-ahurea, ā-whaitaua hoki. Tērā pea, hē puna āwhina ngā kaimahi hauora kei tō marae ā-rohe, kei tētahi ratonga hauora Moana-nui-ā-Kiwa rānei. E wātea ana hoki ngā minita ō te hōhipera ki ngā tangata katoa, ahakoa te whakapono, te kore whakapono rānei, me tā rātou whakarato tautoko mā te karakia me te hurihuringa mārie. Kōrero ki tō rōpū atawhai hauora mō ngā ratonga e wātea ana. Mō te roanga o ngā pārongo e pā ana ki tēnei kaupapa, tirohia tā mātou whārangi pārongo *Cancer and spirituality*.

Traditional Māori healing

Traditional healing has been an integral part of Māori culture for generations. Values, belief systems and teachings from kaumātua and tohunga alike have seen Māori focus on total wellbeing encompassing taha tinana, taha hinengaro, taha wairua and taha whānau (the physical domain, the domain of mind and behaviour, the spiritual domain and the family/whānau or social domain).

When Māori are faced with tough decisions on health care or treatment, some opt for traditional healing methods. These can include rongōā Māori, romiromi or mirimiri, to name a few customary remedies based

on native plants, massage therapy and spiritual healing.

If you are thinking about using these treatments, please talk about them with your treatment team. Both parties aim to provide you with the best possible care that has minimal side effects. If you have difficulty expressing your needs to your treatment providers, find someone to advocate on your behalf so that both traditional Māori healers and hospital treatment specialists are able to work together to support you on your cancer journey.

Hauora Māori

Mai rā anō te hauora Māori i noho ai hei wāhanga o te ahurea Māori. Nā ngā uaratanga, te pūnaha whakapono me ngā akoranga a ngā kaumātua me ngā tohunga i kitea ai te arotahi a te Māori ki te oranga kotahi e rarawhi ana i te taha tinana, te taha hinengaro, te taha wairua me te taha whānau.

Ka huri ētahi Māori ki ngā kaupapa hauora Māori i ētahi wā mēnā he uaua ki te whakatau ko tēhea, ko tēhea o ngā momo maimoa me whai. Tae noa rā ki te rongoā Māori, te romiromi, te mirimiri rānei, hei tauira atu. Ka hāngai katoa ki tarutaru otaota whenua me ngā rākau, te haumanu romiromi me te whakaoranga ā-wairua.

Mehemea he uaua ki te korere i o hiahia ki ngā kaiwhakarato maimoatanga, rapua tētahi tangata hei kaitaunaki mōu, kia āhei ai ngā tohunga hauora me matanga maimoa o ngā hōhipera ki te mahi ngātahi.

Pacific traditional healing

Traditional healing has long been used by Pacific people to help in recovery. It involves taking a holistic approach to treating the person, where their mental, emotional, physical and spiritual needs are looked after together, rather than as separate parts. The treatment offered to each person depends on their needs. Medicinal plants and herbs may be used during the treatment process, as well as stones and massage.

It is possible to use both Western and traditional medicine as part of your healing journey. Each has its place and benefits.

You may think that the doctor and the traditional healer do not need to know about what each other is doing. But it is important that they do in order to make sure that the medicines you are taking are working well together and they are not causing any problems. Traditional plant medicines can sometimes react with Western medications.

If you find it hard to tell your doctor or nurses about the traditional healing methods being used by your healer, it may be helpful for your doctor or nurses to talk directly to your healer or even a close family/whānau member who knows what treatments you are receiving.

Complementary and alternative therapies

Complementary therapies are massage, meditation, acupuncture and other relaxation methods that are used **alongside** medical treatments. They may help you to feel better and cope more easily with your cancer treatment.

“*When it was painful I transported myself to the market at home with fresh fruit. I remembered songs that have no words that reminded me of home, like streams and natural sounds. I imagined myself at moments throughout my lifetime—special places on the beach, certain things we did as children. I took myself there.* **”**
Silei

Alternative therapies include some herbal and dietary methods, which are used **instead** of medical treatment. Many are promoted as cancer cures. However, none of these methods have been proven to be effective in treating cancer.

It is important to let your cancer treatment team know if you are taking any complementary or alternative therapies, because some treatments may be harmful if they are taken at the same time as medical treatments. For more information, see the Cancer Society's booklet *Complementary and Alternative Medicine* on our website www.cancernz.org.nz.

Relaxation techniques

Some people find that relaxation or meditation helps them to feel better. The hospital social worker, nurse or your local Cancer Society may know whether the hospital runs any relaxation programmes, or may be able to advise you on local community programmes.

The Cancer Society has some relaxation resources, available on CD or through our website www.cancernz.org.nz.

- Download a free copy of Cancer Society Auckland-Northland Division's *Relaxation and mindfulness* CD on our website: <http://bit.ly/2hiJpbO>
- Download a free copy of Cancer Society Wellington Division's *Relaxation and Visualisation* CD on our website: <http://bit.ly/2gmRdaN>

Massage for relaxation

In some regions the Cancer Society offers a therapeutic massage service to support people's physical and emotional wellbeing while they are undergoing cancer treatment.

Each specially trained massage therapist provides a gentle, relaxing massage. This may relieve muscle pain and tension, help you to sleep better and even lift your mood. Many people undergoing cancer treatment find this therapeutic touch extremely soothing.

There may be a small cost to use this service.

Contact your local Cancer Society to see if this service is offered in your region. If it is not offered, our staff can help you to find other massage services in your area.

Distraction

The distraction technique is another way to get your mind off your worries. It involves learning to focus on the things around you so that you can shut out negative thoughts.

Support groups

For some people, meeting others who are in a similar situation can help to decrease feelings of anxiety, isolation or fear. Support groups offer you the opportunity to share your experiences and learn different ways of dealing with problems. The Cancer Society and the organisation **Sweet Louise** offer support groups that you may find helpful. However, groups may not be available across the country. Phone the Cancer Information Helpline **0800 CANCER (226 237)** for further information.





Exercise and diet

Research has indicated that people who keep active cope better with their treatment. Discuss with your doctor what exercise is best for you.

The Cancer Society has a pamphlet, *Being active while you have cancer*, available through your local Cancer Society and on our website www.cancernz.org.nz.

A balanced, nutritious diet will help to keep you well and able to cope with any side effects of treatment. The Cancer Society's booklet *Eating Well during Cancer Treatment / Kia Pai te Kai te wā Maimoatanga Matepukupuku* provides useful advice about nutrition and diet during this time. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)**, by contacting your local Cancer Society office, or www.cancernz.org.nz.

Changes in your employment

Whether you are able to continue working while you are having treatment for your cancer will depend on four things:

- the type of treatment you are having
- the stage of your cancer
- your overall health
- the type of work that you do.

Some people having treatment for secondary breast cancer are still able to go to work, while others find that they need rest or feel too unwell to continue their usual work routines. Your doctor may suggest that you consider taking some time off work during your treatment and recovery.



If you continue to work

Whether or not you tell your employer and colleagues about your cancer is up to you. If your ability to do your job is not affected, you may not want to tell your employer straightaway. Most people find

that there are things that can be done to make it easier for them to continue to work. Talk with your employer about what you might need while you are having treatment.

It is useful to consider the following things if you continue to work.

- Talk to your employer about your need for time off for hospital appointments and treatment. Give them as much notice as possible and let them know when you will be able to return to work.
- Where possible, plan your treatment for later in the day or before the weekend to give you some time to recover.
- Consider the possibility of working from home on the days that you are feeling tired.
- Having some extra help at home may mean that you have more energy for work.
- Make a list of your key duties at work so that when you are out of the office other people are able to help.

If you can no longer work

Some people choose not to work when they are diagnosed with **advanced cancer** or having treatment for their cancer. Even with extra time off and good planning, it is sometimes too hard to continue working. If work has been a big part of your life, it can be hard to adjust. It may be useful to talk to a friend, family/whānau member or counsellor about your feelings.

Using your work entitlements

When you are diagnosed with cancer you may find yourself having to negotiate sick leave, leave without pay or annual leave. These leave entitlements are outlined in your employment agreement and minimum statutory leave requirements are contained in law (www.employment.govt.nz).

Most employees get a minimum five days paid sick leave a year after the first six months of continuous employment. At any time when an employee is not entitled to sick leave, the employer can agree to the

use of sick leave in advance of their entitlement, to be deducted from their next entitlement.

If you have used all your sick leave but are unable to work while you have treatment, you can request leave without pay or to use some of your annual leave.

Leave without pay is when an employer lets an employee take time off work but does not pay them for this time off. It does not stop your employment, and you can usually return to the same position, terms and conditions after taking leave without pay (unless you and your employer agree otherwise). Employees are not **entitled** to leave without pay. You can only take it if your employer agrees.

Returning to work

Deciding to return to work after you have had a period of time away can be difficult. For many people a job can start to bring back some normality, routine and financial security. It is common to feel nervous and to question whether you will be able to do your job in the same way as you did before.

It is useful to discuss a plan with your manager that will help you to return to work gradually. If you can, think about what parts of your role are the most important and focus on these until you feel stronger. It is also a good idea to make sure that you have the opportunity to take regular breaks throughout the day, and that you make use of this time to have a small snack and a glass of water to help keep up your energy levels.

You might find that your co-workers respond in many ways when you go back to work. It can help to think ahead and have a plan for how you will respond to their questions so that you do not feel pressured to share information or explain things if you are not comfortable doing this.

If you have any employment difficulties, talk to Community Law or seek legal advice from someone with experience in employment law.

Relationships and sexuality

There are a number of ways that secondary breast cancer may affect your relationships and sexuality. You may have:

- a reduced sex drive
- menopausal symptoms brought on by treatment
- changes to your body image
- difficulty being physically active due to pain.

“It is quite a big issue that’s ongoing and I feel a bit guilty. He loves me, he does understand and that’s sad too, but I’m glad I’m here.”
Ruth

Sexuality means different things to different people. It is about who you are, how you see yourself and how you connect with others. There are many ways you can be sexual and intimate—it is much more than sexual intercourse.

“Sex is what we do, sexuality is about who we are and intimacy is about sharing the secret corners of ourselves.”
Grits (1990); Don Edgar (1997)

Even if you are not ready for sex, it does not mean you cannot enjoy being close. Be creative and take opportunities to express your sexuality in new ways.

Talk to someone you trust if you have concerns about your sexual relationship. Friends, family/whānau members, nurses or your doctor may be able to help. The Cancer Society can also provide information about counsellors who specialise in this area.

You may find the Cancer Society’s booklet *Sex and Cancer/Hōkakatanga me te Matepukupuku* useful.



Talking with your child

What you choose to tell children about your illness will depend on how old they are and your relationship with them. All children need to know that they will be looked after even if you cannot always do it yourself.

Children's understanding of illness varies depending on their age and family/whānau experiences. The Cancer Society's booklet *Cancer in the Family* offers suggestions to help you talk with your child/children about cancer.

Skylight is an organisation that offers support, information and counselling to young people experiencing loss and change. To get in touch with Skylight, phone 0800 299 100 or visit their website www.skylight.org.nz.

How can families/whānau help you?

Cancer can affect your whole family/whānau. You may want to offer support but not know how. Here are some suggestions that may be useful:

- Learn about breast cancer and its treatment. This will help you to understand what the person you are supporting is facing. However, be careful about offering advice.
- Talk about your feelings together and be honest about what worries you.
- Try not to worry about what to say. Often listening while they talk or just being there with them is a good way to show you care.
- Offer to go to appointments with them as a support person. You can take part in the discussions, take notes or simply listen.
- Respect that your family/whānau member or friend may want to talk to their doctor alone.
- Try not to do too much. Give the person the opportunity to do things for themselves—they will probably appreciate the chance to be useful.
- Look after yourself and give yourself time to rest. Taking care of yourself will help you to take good care of them.
- You may find that other people want to know about the health of your loved one. It may be useful to ask one person to be a spokesperson for your family/whānau, who will share this information with others. Or you may like to use email or text messaging rather than talk to everyone yourself.
- Accept that sometimes you will need help from others. Consider joining a local support group, and do not be afraid to ask for help from other friends or relatives, or from the services available in your community.

When a loved one is diagnosed with cancer, your routines and family/whānau roles may change. The person who was the major source of income may now be unable to work and may be dependent on others.

A partner who used to share responsibility for doing household chores may now have to take on extra tasks or get a job.

Maintaining your usual social life and hobbies may be difficult or impossible for a while. Cancer is not a normal event, so it is important to acknowledge this and not try to carry on with everything as before. There are a number of things you can do that may help you to cope. For example:

- prepare simpler meals
- be more relaxed about housekeeping standards
- ask family/whānau to help more around the house.

“ I said to them, ‘Look, you just have to support me now. It’s my time.’ It was role reversal. ”
Silei

For more information on this subject, you can read the Cancer Society’s booklet *Supporting Someone with Cancer / Te Manaaki i Tētahi e Māuiui ana nā te Matepukupuku.*



Home care help

Nursing care is available at home through district nursing or your local hospital or **hospice**—your doctor or hospital can arrange this. You may be entitled to assistance with household tasks during your illness. For information on the availability of this assistance, contact your hospital social worker or Community Health Service.

Palliative care

Palliative care is about caring for people with secondary breast cancer and improving their quality of life. It is not just about care at the end of life. Palliative care can be offered at home in the community or in a hospital, a rest home or a hospice. It is provided by specialist doctors, nurses, social workers, spiritual care workers, whānau and Pacific health care workers.

Palliative care aims to:

- help you to enjoy the best quality of life you can for as long as possible
- make sure that your physical, practical, emotional and spiritual needs are looked after as well as possible
- help manage symptoms of cancer or the effects of treatment
- help you to feel in control of your situation
- make the time you have as positive as it can be for you and your family/whānau.

It is a good idea to ask for palliative care early—being able to deal with problems or issues early rather than waiting until they become difficult to manage can help to reduce stress for both you and your family/whānau.

You may also be faced with decisions and choices that are confusing or difficult to make during your illness. The palliative care team may be able to explain things to you, and help you to find answers.

In general, palliative care services are free, but there may be a charge for hiring some equipment for home care.

For more information on advanced cancer, read the Cancer Society's booklet *Advanced Cancer/Matepukupuku Maukaha*.

Atawhai Taurima

Ka arotahi te atawhai taurima ki te whakapiki i te kounga oranga—kaua ko te atawhai anake mō te wā e whakamatemate ana rātou. Ka taea te whakarato i roto i te hapori, i tētahi hōhipera, tētahi kāinga whakatā, ki te kāinga, ki tētahi ratonga 'hospice' rānei.

Advance care planning

Advance care planning is about helping you to think and talk about the end of your life, and about the treatments and care you might want. This will then guide your family/whānau and doctors if you can no longer tell them yourself.

Advance care planning is voluntary with, no-one can force you to do it. For more information, visit the Advance Care Planning website www.advancecareplanning.org.nz.

Financial assistance

Help may be available for transport and accommodation costs if you are required to travel some distance to your medical and treatment appointments. Your treatment centre or local Cancer Society can advise you on the sort of help available.

“It's like a home away from home [Cancer Society accommodation]. We do all our own cooking and washing. You still have to look after those things yourself. It's not like hospital. It's really good to meet people, talk about it, but you've got your own room and your own time.”
Melinda

Financial help may be available through your local Work and Income office. Work and Income (0800 559 009) has pamphlets and information about financial assistance. Short-term financial help is available through Jobseeker Support and longer-term help is provided through the Supported Living Payment. Extra help may be available through accommodation supplements and assistance with medical bills.

For more information, read the Cancer Society information sheets *Benefits and entitlements* and *Benefits and entitlements: What happens when you apply for Work and Income support?* available on our website www.cancernz.org.nz.

Interpreting services

New Zealand's Code of Health and Disability Services Consumers' Rights states that everyone has the right to have an interpreter present during a medical consultation. If you do not speak English as your first language or you are deaf, you may find it helpful to use an interpreter when you have your hospital appointments. Speak to a member of your health care team about arranging interpreters in your local area.

More questions you may want to ask

You might like to consider asking more questions on:

- how often your check-ups will be and what they will involve
- any problems you should watch out for
- when you will be able to return to work
- when you will be able to drive again
- if the treatment will affect your sexual relationship
- if your children or family/whanau are at increased risk of getting this cancer too
- what you should tell your family/whānau
- the services that are available to support you and your family/whanau.

Appendix A: Suggested reading and websites

Following a cancer diagnosis, many people look for information about new types of treatment, the latest research findings and stories about how other people have coped. Contact your Cancer Society library or local library for some good-quality resources.

Reading

Lillie D. Shockney, Gary R. Shapiro. (2011). *100 Questions and Answers about Advanced and Metastatic Breast Cancer*. 2nd ed. Massachusetts: Jones and Bartlett Publishers.

Armed with Chocolate Frogs: Living with advanced breast cancer. (2006). Edited by Debbie Fry. Victoria: Kate Carey Productions.

When Cancer Returns: Support for people with cancer. (2012). National Cancer Institute, National Institutes of Health, U.S. Department of Health and Human Services; CreateSpace Independent Publishing Platform. www.cancer.gov/publications/patient-education/when-cancer-returns.pdf

Hadassa Field. (2013). *The Cancer That Wouldn't Go Away: A story for kids about metastatic cancer*. North Carolina: lulu.com
(Recommended for four- to eight-year-olds)

Websites

You may be interested in looking for information about secondary breast cancer on the internet. While there are very good websites available, be aware that others may provide incorrect information. We suggest that you discuss any information you find with your medical team.

We recommend that you begin with the Cancer Society's website www.cancernz.org.nz. The following may also be helpful.

Cancer Australia

<http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/living-breast-cancer/issues-women-whose-breast-cancer-has-spread>

Breast Cancer Care (UK)

www.breastcancercare.org.uk/information-support/secondary-metastatic-breast-cancer

Macmillan Cancer Support (UK)

www.macmillan.org.uk/information-and-support/breast-cancer-secondary/understanding-cancer

Sweet Louise (New Zealand)

www.sweetlouise.co.nz

Skylight (New Zealand)

Skylight helps children and young people to deal with change, loss and grief.

www.skylight.org.nz

Breast Cancer Aotearoa Coalition (New Zealand)

www.breastcancer.org.nz/Support/Secondary

Glossary

(What does that word mean?)

Most of the words listed here are used in this booklet. Others are words you are likely to hear used by doctors and other health professionals who will be working with you.

advanced cancer—cancer that is unlikely to be curable. May also be called secondary or metastatic cancer. Also known as secondaries.

analgesic—a medication that relieves pain.

ascites—a swelling of the abdomen that is caused by fluid build-up.

benign—not cancerous—benign cells are not able to spread elsewhere in the body.

bisphosphonates—medication used to help strengthen bones.

bone scan—a picture of a bone that can show cancer, other abnormalities and infection. When a mildly radioactive substance is injected, cancerous areas in the bone pick up more of the substance than normal bone would.

cells—the basic ‘building blocks’ of the body. They are able to reproduce themselves unless they are abnormal or damaged.

chemotherapy—a treatment for cancer that uses medications to destroy cancer cells or prevent or slow further growth.

CT (computerised tomography) scan—previously known as a CAT scan. A series of X-rays taken from different angles that provide more detailed information than a normal X-ray.

fracture—a break in a bone.

hospice—a place or service that provides care for people whose illnesses are no longer curable.

immune system—the body’s natural defence system.

lymph nodes—small, bean-shaped structures that are part of the lymphatic system. The lymph nodes filter lymph fluid to remove bacteria and other harmful agents, such as cancer cells.

lymph vessels—a network of vessels that connect the lymph nodes and give structure to the lymphatic system.

lymphatic system— part of the immune system, which protects the body.

malignant tumour—a tumour that is cancerous and likely to spread if it is not treated.

metastases—tumours that develop when cancer cells break away from the original (primary) tumour. For example, someone with breast cancer may have metastases in their bones.

morphine—a strong medication used to treat pain.

MRI (magnetic resonance imaging) scan— a scan that uses radio waves and magnetic fields to produce images of the inside of a body.

palliative care—treatment that aims to promote comfort, relieve symptoms and maximise quality of life.

PET (positron emission tomography) scan—a technique used to build up clear and very detailed pictures of a body. The person is injected with a glucose solution containing a very small amount of radioactive material. The scanner can ‘see’ the radioactive substance. Damaged or cancerous cells show up as areas where the glucose is being taken up.

primary—the original cancer.

prognosis—information about the likely outcome of a person’s disease.

radiation treatment—the use of radiation to kill or damage cancer cells so that they cannot multiply.

recurrent cancer—a cancer that returns sometime after treatment has ended.

secondary—the same as metastasis.

tissue—a collection of cells of a similar type.

tumour—a new or abnormal growth of tissue on or in a body. Tumours can be benign (not cancerous) or malignant (cancerous).

ultrasound scan—a scan that uses soundwaves to create a picture of the inside of a body.

Notes

You may wish to use this space to write down any questions for or advice given by your doctors, nurses or health providers at your next appointment.

Cancer Society of New Zealand Inc.—Te Kāhui Matepukupuku o Aotearoa publications

Publications statement

Our aim is to provide easy-to-understand and accurate information on cancer and its treatments. Our Living with Cancer information booklets are reviewed and updated by cancer doctors, specialist nurses and other relevant health professionals to ensure that the information is reliable, evidence based and up to date. The booklets are also reviewed by consumers to ensure they meet the needs of people with cancer and their carers.

Other titles from the Cancer Society of New Zealand

Advanced Cancer/Matepukupuku Maukaha

Breast Cancer/Te Matepukupuku o ngā Ū

Bowel Cancer/Matepukupuku Puku Hamuti

Cancer in the Family

Chemotherapy/Hahau

Coping with Cancer

Emotions and Cancer

Getting on with Life After Treatment/Te Hoki Anō ki tō Toioranga Whai Muri i te Maimoatanga

Radiation Treatment/Haumanu Iraruke

Supporting Someone with Cancer/Te Manaaki i Tētahi e Māuiui ana nā te Matepukupuku

Brochures

Being Active When You Have Cancer

Questions You May Wish to Ask

Cancer Society information and support services

The Cancer Information Service is a Cancer Society phone line where you can talk about your concerns and needs with specially trained health professionals. Phone the Cancer Information Helpline **0800 CANCER (226 237)**.

Your local Cancer Society offers a range of services for people with cancer and their families/whānau. These may include:

- information and support
- volunteer drivers providing transport to treatment
- accommodation while you are having treatment away from home.

The range of services offered differs in each region, so contact your local Cancer Society to find out what is available in your area. See where each Cancer Society is located at the end of this booklet.

National Office

PO Box 651, Wellington 6140
Telephone: 04 494 7270

Auckland Division

PO Box 1724, Shortland Street, Auckland 1140
Telephone: 09 308 0160
Covering: Northland

Waikato/Bay of Plenty Division

PO Box 134, Waikato Mail Centre, Hamilton 3240
Telephone: 07 838 2027
Covering: Tauranga, Rotorua, Taupō, Thames and Waikato

Central Districts Division

PO Box 5096, Terrace End, Palmerston North 4441

Telephone: 06 356 5355

Covering: Taranaki, Wanganui, Manawatū, Hawke's Bay and Gisborne/East Coast

Wellington Division

52-62 Riddiford Street, Newtown, Wellington 6021

Telephone: 04 389 8421

Covering: Marlborough, Nelson, Wairarapa and Wellington

Canterbury/West Coast Division

PO Box 13450, Armagh, Christchurch 8141

Telephone: 03 379 5835

Covering: South Canterbury, West Coast and Ashburton

Otago/Southland Division

PO Box 6258, Dunedin North, Dunedin 9059

Telephone: 03 477 7447

Covering urban and rural Otago and Southland

Cancer Information Helpline

0800 CANCER (226 237)

www.cancernz.org.nz

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www.cancernz.org.nz

ANY CANCER, ANY QUESTION
0800 CANCER (226 237)
Cancer Information Helpline