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UNDERSTANDING CANCER

Secondary Breast Cancer Matepukupuku Tuarua ā-Ū



A guide for women with secondary breast cancer



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Publications Statement

The Cancer Society’s aim is to provide easy-to-understand and accurate information on cancer and its treatments and the support available.

Our cancer information booklets are reviewed every four years by cancer doctors, specialist nurses, and other relevant health professionals to ensure the medical 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.

This edition of *Secondary Breast Cancer/ Matepukupuku Tuarua a-U* includes new features in response to suggestions from those who review our booklets, and to meet the needs of our readers. Our key messages and important sections have been translated into te Reo Māori. Our translations have been provided by Te Taura Whiri i te Reo Māori/ the Māori Language Commission’s Hohepa MacDougall, and have been peer reviewed by his colleagues. Hohepa chose the whakatauki (Māori proverbs) for this edition from *Nga Pepeha a Nga Tipuna: The Sayings of the Ancestors* edited by Neil Grove, Hirini Moko Mead, Victoria University Press, Wellington, 2003.

The personal quotes included in this booklet are from interviews with women who have been diagnosed with metastatic breast cancer. The interviews were conducted by the Cancer Society of New Zealand. We thank New Zealand writers Joy Cowley and her publisher Pleroma Christian Supplies, Trish Harris, and Renée for allowing the Society to reproduce their poems and writing in this edition.

Other titles from the Cancer Society of New Zealand/Te Kāhui Matepukupuku o Aotearoa

Booklets

- Advanced Cancer/Matepukupuku Maukaha
- Bowel Cancer/Mate Whēkau Pukupuku
- Chemotherapy/Hahau
- Eating Well/Kia Pai te Kai
- Lung Cancer/Matepukupuku Pūkahukahu
- Melanoma/Tonapuku
- Prostate Cancer/Matepukupuku Repe Ure
- Radiation Therapy/Haumanu Iraruke
- Sexuality and Cancer/Hōkakatanga me te Matepukupuku
- Understanding Grief/Te Mate Pāmamae
- What Do I Tell the Children?/He Aha He Kōrero Maku Ki Āku Tamariki?

Brochures

- | | |
|-------------------------|-----------------------------------|
| When Someone Has Cancer | Being Active When You Have Cancer |
| When You Have Cancer | Talking To A Friend With Cancer |



Secondary breast cancer

This booklet is for women who have had 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 aims to help you understand what secondary breast cancer is and the physical and emotional impact it can have on you and those around you. It covers living with the disease and coming to terms with the future. It looks briefly at symptoms and treatments and lists sources of help and support available to you.

For some women, having information about what is happening to them can be a way of taking back some control at a time when they may be feeling overwhelmed and powerless. Although we refer to ‘women’ throughout the text, men who have been diagnosed with secondary breast cancer may also find the information relevant and helpful.

The words in **bold** in the text are explained in the glossary at the end of the booklet.

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Matepukupuku Tuarua ā-Ū

He pukapuka tēnei mō ngā wāhine kua kitea kei te mate i te matepukupuku tuarua ā-ū. Tērā pea he whai painga mō ngā tangata tata ki a koe, pērā ki tō whānau, ō hoa, ngā tāngata whakaaro rānei. Ko te whāinga, ko te āwhina kia mārama koe ki te matepukupuku tuarua ā-ū me ngā pānga ā-tinana, ā-wairua ki runga i a koe me ngā tāngata tata ki a koe. E kōrero ana mō te oranga o te tangata i te taha o te mate nei me te titiro whakamua. Ka titiro ki ngā tohu mate me ngā maimoatanga, tae noa ki ngā rārangi rauemi tautoko, āwhina hoki, e wātea ana mōu.

Mō ētahi wāhine, mā te whai mōhiotanga e pā ana ki tō rātou mate, e taea e rātou te whakatikatika i a rātou kia whai kaha anō i runga i ngā taumahatanga.

Ahakoia he hāngai te nuinga o ngā kōrero ki te wahine, ā, he pai tonu pea mō ngā tāne kua kitea kei te pāngia ki te matepukupuku tuarua ā-ū.

He whakāmarama kei te rārangi kupu i muri i te pukapuka nei, mō ngā kupu kua **miramirahia**.

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What is breast cancer?

Breast tissue is made up of millions of cells which are like tiny building blocks. Breast cancer is a disease of these breast tissue cells. Normally, cells reproduce and grow in an orderly way. As one cell wears out another replaces it. However, sometimes an abnormal cell develops that continues 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 this 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).

How does secondary breast cancer develop?

Breast cancer that comes back in the same breast is called 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.

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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 may hear this referred to as **metastases**, advanced breast cancer, secondary tumours, or secondaries.

Pēhea te whanake o te matepukupuku tuarua ā-ū?

Ka puta te matepukupuku tuarua ā-ū i te wā ka rauroha haere ngā pūtau matepukupuku ā-ū, mai i te puku tuatahi i roto i te ū, ki ētahi atu wāhi o te tinana mā te pūnaha **waitinana**, mā te pūnaha ia toto rānei. Kua rongo pea koe i tēnei e kīia ana ko **metastases**, ko te matepukupuku maukaha, ko ngā puku tuarua, ko ngā tuarua rānei.

When breast cancer spreads, for example to the bones, it is called secondary breast cancer. The cells that make up the tumour in that bone 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 may be diagnosed at the same time as the primary breast cancer or it may be diagnosed without an earlier diagnosis of primary 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, although it can be controlled, sometimes for years.

Ki te kitea te matepukupuku tuarua ā-ū, kāore he oranga i tēnei mate, heoi, ka taea te whakamau, mō te wā roa tonu i ētahi wā.

The aim of treatment of secondary breast cancer is to improve quality of life and prolong survival. 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 will 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.



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“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**

Finding out

When you hear the news that your breast cancer has spread you may experience a mixture of emotions. Some women say 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 roller coaster. 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.

A small number of women find out they have breast cancer when it has already spread from their breast to another part of their body. You may experience a mixture of very difficult emotions. You may have been unaware that you were ill and on getting the news you may feel shocked and find it hard to believe.

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

Symptoms

Every woman’s experience of secondary breast cancer is different. General symptoms that women may experience include unusual tiredness, loss of appetite, and feeling unwell.

Ngā tohumate

He rerekē ngā wheako a tēnā wahine, a tēnā wahine mō te matepukupuku tuarua ā-ū. He tino rerekē te kaha o te pānga o ngā tohumate ā, ki ētahi wahine he iti noa iho, kua kore rānei he tohumate. Ko ētahi o ngā tino tohumate, ko te hiamoe noa, ko te kore hiakai me te āhua pāngia ki te mate.



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The bone

Some women experience few or no symptoms, but secondary breast cancer in the bone can cause a constant aching pain. This pain may increase with activity and may also make sleep difficult. Bone pain is caused by:

- cancer pressing on the bone
- cancer in the bone pressing on nerves
- fracture (breaking) of the bone.

A secondary cancer in the bone may gradually damage some of the bone tissue, causing the bone to become weaker. Early treatment by **radiation treatment**, drugs, and surgery may prevent fractures.

Hypercalcaemia (high levels of calcium in the blood)

Calcium sometimes seeps into the blood when bones are damaged by secondary cancer. Hypercalcaemia is diagnosed by a blood test and is usually easily treated (see page 42 for more information).

Diagnosis is made by bone scan, plain X-ray, sometimes CT scan (see pages 14-15).

Tokotoko tao, kotahi te tūranga, tokotoko rangi ka ngaro te kai, ka ngaro te tangata

The liver

Symptoms may include:

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

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The liver is a large organ that can work efficiently, even when part of it is ‘out of action’. Many of the symptoms of secondary breast cancer affecting the liver may be relieved with appropriate treatment/therapy.

Diagnosis is made by CT scan, ultrasound or MRI (see pages 14-15).

The lungs

Symptoms may include:

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

Cancer within the lungs or on the lining of the lungs may cause the above symptoms. Cancer cells lodging 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. Some women notice a definite change in their breathing.

Seek medical attention immediately if you:

- experience breathing problems
- cough up blood
- feel worse.

Difficulty breathing can be frightening, but there are many ways of relieving this breathlessness with appropriate treatment.

Diagnosis is made by chest X-ray or CT (see pages 14-15).

The brain

Symptoms may include:

- headaches – such headaches do not go away and may gradually get worse
- feeling sick and vomiting
- weakness in an arm or leg
- unsteadiness while walking
- changes in vision
- seizures
- confusion, disorientation, or personality changes (rare).

The brain is a large organ which, like the liver, will often work very well even when part of it is affected by secondary breast cancer.

Many of the symptoms described above may be treated with appropriate therapy.

Diagnosis is made by CT scan or MRI (see pages 14-15).



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Diagnostic tests

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

A bone scan is a sensitive test which may pick up tiny portions of bone that have been affected by secondary breast cancer. A minute amount of a radioactive substance, which is injected into a vein, travels around the body in the bloodstream. 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 scans of the liver can be used to build up a clear picture of the liver. Blood tests may be used to find out if the liver is working properly, but these tests cannot pinpoint the cause of any problems.

CT scans of the liver are special types of X-rays that take cross-sectional pictures of your body. Having a CT scan is painless but you must lie still on your back for about 30 to 40 minutes. A contrast dye may be injected into a vein to increase the detail of the pictures. The contrast dye may give you a brief sensation of being hot all over.

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. CT scans of the chest are often done. These give good details of secondaries in the chest.

A CT scanner takes a series of cross-sectional pictures of the head to build up a very accurate picture of any secondary breast cancer cells affecting the brain. You will have to lie on a couch with your head inside the scanner for this test (see above). As with the liver CT scan, a contrast dye may be used (see above).

MRI (Magnetic Resonance Imaging) is another type of scanner that may be used. This uses radio waves and a powerful magnet to create images. The scanning process is slower than a CT scan and quite noisy.

A Positron Emission Tomography (PET) scan is occasionally used to diagnose secondary cancer. A PET scan is a technique that is used to build up clear and very detailed pictures of the body. You will be given an injection of a glucose solution containing a very small amount of radioactive material. Damaged or cancerous cells show up as areas where the glucose is being taken up.



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Treatment

Secondary breast cancer may respond to several types of treatments:

- hormone therapies
- radiation treatment
- **chemotherapy**
- monoclonal antibodies.

Maimoatanga

He maha tonu ngā momo maimoa mō te matepukupuku tuarua ā-ū:

- ngā haumanu taiaki
- ngā haumanu iraruke
- hahau
- monoclonal paturopi.

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

You may find it useful to have your partner, friend, or family/whānau with you when you talk to the doctor. Taking a list of your questions could be helpful. Before any treatment begins, make sure you have discussed the choices with your doctor. Ask for a second opinion if you want one.

“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 proportion of these cells is described as oestrogen-receptor positive, or hormone-receptor positive.

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

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

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Most hormone therapies work by decreasing the amount of oestrogen in the body, or by stopping the cancer cells accessing oestrogen. Side effects of hormone therapy can sometimes be annoying, but they are rarely serious. There are many different hormone treatments available; giving doctors the option of trying several types.

Ngā haumanu taiaki

Ko te mahi a te nuinga o ngā haumanu taiaki, ko te whakaiti i te oestrogen kei roto i te tinana, ko te ārai rānei i ngā pūtau matepukupuku kia kore e toro atu ki ngā oestrogen. He āhua hōhā ngā pānga kei te taha o te haumanu taiaki engari, ehara i te mea he mōrearea. He nui ngā momo maimoatanga taiaki e wātea ana, nā reira e taea e ngā rata te whakamātau i te maha o ngā momo huarahi.

The hormone treatment prescribed depends upon whether you are pre- or post-menopausal. Some of the common hormone treatments include:

Tamoxifen

Tamoxifen (Nolvadex-D or Genox) is one of the most commonly used hormone treatments. This treatment can be used by women of all ages. Women taking tamoxifen continue producing oestrogen, but the treatment prevents cancer cells using this oestrogen. Tamoxifen is taken as a tablet daily and treatment continues while the secondary cancer cells respond to the drug.

Side effects

Tamoxifen has been used by thousands of women world-wide for many years, and has proved to be a safe drug with few side effects.

Side effects are usually mild but may include:

- hot flushes/mood swings
- a tendency to put on weight
- vaginal dryness and an increased discharge from the vagina
- in pre-menopausal women, periods may become lighter or irregular. (Tamoxifen cannot be relied on for contraception.)

Less common side effects

Tamoxifen may cause cancer of the uterus some years later but this is almost always curable. There is a small risk of blood clots when taking tamoxifen.

The benefits of tamoxifen far outweigh the risks in most women. Women with secondary breast cancer in a bone who are starting tamoxifen should be aware that it can make the bone pain worse and cause a raised level of calcium in the blood with symptoms of nausea, vomiting, and thirst. It is important to tell your doctor if this occurs. This is a temporary side effect of the drug.



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Aromatase inhibitors

Aromatase inhibitors work by inhibiting oestrogen from being produced. They are only used by post-menopausal women. Anastrozole (Arimidex) and letrozole (Femara) are two aromatase inhibitors.

Side effects are usually mild but may include:

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

Less common side effects

- nausea (feeling sick) and diarrhoea
- vaginal bleeding – this usually happens in the first few weeks of treatment or when changing from one hormone to another
- mild hair thinning
- headaches
- tiredness.

Rare side effects

- blood clots
- roughly a 1% chance of breaking a bone whilst on treatment.

Progesterone

Progesterone is a hormone that occurs naturally in the body. Very occasionally, progesterone tablets are given if tamoxifen and aromatase inhibitors stop working. The most common types are medroxyprogesterone acetate (Provera) and megestrol acetate (Megace).

Side effects

Progesterone has few side effects. A few women may feel sick but most women find that progesterone increases their appetite, resulting in weight gain.

Other possible side effects include:

- slight muscle cramps
- fluid retention
- a vaginal discharge.

Ovarian ablation (removing or preventing the ovaries from working)

Pre-menopausal women can sometimes have their secondary breast cancer treated by preventing their ovaries from producing oestrogen. This will bring on an early menopause.

Ovarian ablation can be achieved by:

- hormone manipulation
- surgery
- radiation treatment.



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Hormone manipulation

Hormone manipulation involves taking a drug to ‘switch off’ oestrogen production from the ovaries.

Goserelin (Zoladex)

Goserelin is a drug that switches off the ovaries, preventing them from producing oestrogen. The drug does not act directly on the ovaries, but works on the part of the brain which is responsible for stimulating the ovaries to produce oestrogen. Goserelin is an effective treatment for pre-menopausal women with secondary breast cancer because it decreases the amount of oestrogen circulating in the blood. The treatment is given as an injection under the skin of the abdomen every 28 days for as long as it is effective.

Side effects

Goserelin causes early menopause. Most menopausal symptoms can be treated and side effects will decrease as the body gets used to a lower level of hormones. If goserelin is stopped your periods may return.

Surgery

An operation to remove the ovaries is called an oophorectomy. The operation may be performed with an instrument called a laparoscope, which leaves one or two small scars near the navel. An alternative for a woman who has had previous abdominal surgery is removal of the ovaries through a short cut made below the bikini line. Periods will stop after surgery and you will have menopausal symptoms straight away.

Radiation treatment

Radiation treatment involves giving high-energy X-rays to stop the ovaries working. This is an effective treatment but has largely been replaced by the use of drugs, such as goserelin, or surgery.

Radiation treatment

Radiation treatment uses high-energy rays to destroy cancer cells while doing as little harm as possible to normal cells. Radiation treatment can shrink cancers in some parts of the body and help relieve pain.

Haumanu iraruke

Ko tā te haumanu iraruke mahi, ko te patu i ngā pūtau matepukupuku mā ngā pūhihi tino kaha, me te whakaiti i te patunga o ngā pūtau māori. Ka taea e ētahi o ngā haumanu iraruke te whakaheke i te pupuhitanga o ētahi matepukupuku ki ētahi wāhanga o te tinana, ā, mā tēnei e iti ake ai te mamae.

Radiation treatment can be given to a number of sites in the body at the same time.



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Radiation treatment is usually recommended:

- to relieve bone pain, often given as a single dose
- to prevent and treat spinal cord compression (see page 43)
- after orthopaedic surgery to prevent or treat fractures (see page 42) to prevent or treat fractures without surgery
- to shrink the cancer and help the bone heal
- to treat regional recurrence in the skin and lymph nodes
- to treat cancer in the brain.

Side effects

These are highly dependent on the dose, number of treatments, and the site in the body that is treated.

Most women experience few side effects but those experienced may include:

- tiredness
- feeling sick if the treatment is given to the abdomen or pelvis. This can be relieved by anti-sickness drugs (anti-emetics)
- hair loss at the site if radiation treatment is given to the brain. Hair may not regrow if radiation is given in this area.

The position you have to lie in for the few minutes during radiation treatment may be uncomfortable. It may help to take pain relief 30 minutes before your treatment. For more information on radiation treatment, call the **Cancer Information Helpline 0800 CANCER (226 237)** for our booklet *Radiation Treatment/Haumanu Iraruke*. You can also contact your local Cancer Society to receive a copy, or download this booklet from our website: www.cancernz.org.nz.

Chemotherapy

Chemotherapy is the use of anti-cancer drugs to destroy cancer cells. These drugs circulate in the bloodstream reaching cancer cells throughout the body. Chemotherapy treatment may shrink the cancer or prevent it from growing bigger.

Hahau

Ko te hahau, ko te whakamahi i ngā whakapōauau patu matepukupuku hei whakamate i ngā pūtau matepukupuku. Ka haere ēnei whakapōauau mā te iatoto kia tae ki ngā pūtau kei roto i te tinana. Tērā pea ka heke te rahi o te kōpuku o te matepukupuku maimoa hahau, tērā pea ka pupuri noa iho kia kore e nui ake.



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“I am pleased to say my first round of chemo I handled very well. I was very tired but I didn’t have the bad nausea.”
Stephanie

Chemotherapy is usually recommended when:

- women do not have oestrogen receptors on their cancer and will not benefit from hormones; or
- hormone treatments are no longer controlling cancer growth or symptoms; and/or
- the disease is rapidly progressing.

Several drugs may be given at the same time (known as combination chemotherapy).

How are chemotherapy drugs given?

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

Side effects

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

- feeling sick and vomiting, which can often be prevented with prescribed drugs
- hair loss – any hair lost as a result of chemotherapy will grow back within a few months after treatment finishes. It is possible your new hair may be a different texture or colour
- tiredness
- lack of appetite – it is better to eat five or six snacks a day
- diarrhoea or constipation.

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

- 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 levels of blood cells. Blood transfusions can be given if your red blood cell or platelet levels are low, or your doctor may delay the next treatment to allow the marrow to recover. If you have a low white blood cell level you have a risk of infection. If you develop an infection you will be given antibiotics.



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If you want more information about chemotherapy please ask your local Cancer Society for our booklet *Chemotherapy/Hahau*. Copies can also be obtained by ringing the **Cancer Information Helpline 0800 CANCER (226 237)** or by downloading this booklet from our website: **www.cancernz.org.nz**.

If you develop a fever (if your temperature is 38 degrees or over) or you feel unwell, even with a normal temperature, don't wait to see what happens – take action quickly. Contact your cancer nurse or doctor and follow the advice given.

Monoclonal antibodies

Trastuzumab (Herceptin)

Roughly 20% of breast cancers have too many ‘copies’ of a protein called HER2 (sometimes known as HER2neu, C-ERBB2). Trastuzumab, also called Herceptin, works by sticking to the HER2 protein (also known as receptors), so that the cancer cells are no longer stimulated to grow. It also helps the body’s immune system destroy breast cancer cells. It is only beneficial to women who produce too much of the protein. It is often combined with chemotherapy.

Controlling the symptoms and effects of secondary breast cancer

The best way of controlling the symptoms of secondary breast cancer is to treat the cancer itself. Sometimes treatments work quickly and there is an immediate improvement in symptoms. However, if treatments take several weeks to work there are various ways of controlling symptoms.

Te tautāwhi i ngā tohumate me ngā pānga o te matepukupuku tuarua ā-ū.

Ko te huarahi pai rawa atu mō te tautāwhi i ngā tohumate o te matepukupuku tuarua ā-ū, ko te tere whakahaere maimoatanga mō te matepukupuku ake. I ētahi wā tere mahi ai ngā maimoatanga, ā, tere tonu te pai haere o ngā tohumate. Heoi anō, mehemea he maha tonu ngā wiki e haere tonu ana ngā maimoatanga, he nui tonu ngā huarahi ki te tautāwhi i ngā tohumate.

Pain

Women with the same cancers may experience different levels of pain. Experiencing pain does not necessarily mean that the cancer is more serious than if you have no pain. There is a vast range of pain-relieving medications (analgesics) available. For many people mild pain relief such as paracetamol (Panadol) and/or anti-inflammatory drugs

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such as Nurofen are sufficient. However, sometimes pain is more severe and morphine is more effective. Pain relief works best if taken regularly. If pain is a problem with your secondary breast cancer, taking medication regularly even when pain is not present is a more effective way to get the best pain relief for you.

Tell your doctor or nurse if your pain relief is not easing the pain, because there are many other alternatives you can try. Anxiety and depression make pain feel worse. You may wish to talk to your doctor or consider counselling.

Pain relief can be taken as tablets and injections. Pain caused by secondary breast cancer in a bone can be quite severe. Radiation treatment can be good at easing this pain but medication may also be needed while treatment is being planned, or while you are waiting for the radiation treatment to work.

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.

Ko te morphine tētahi o ngā rongoā e whakamahia ai mō ngā mamae tino kino. Ka taea te whakarite i te horopeta mō ia tangata. Ki te āta whakamahi te morphine hei whakaiti ake i te mamae, ka āta hoatu ngā horopeta ā-tautāwhi, kia kore ai e warawara te tangata.

Some women find when starting on morphine that they may feel drowsy, but this problem usually only lasts for a few days. Ask your doctor if you can drive or use heavy machinery. Taking morphine may also make you feel sick and you may need an anti-sickness tablet (anti-emetic) for the first few morphine doses.

Constipation is a common side effect of morphine. Plenty of fluids and fibre in the diet will help prevent constipation and you will also need a laxative prescribed to keep your bowel movements regular.

Seek early advice from your GP or nurse if you experience constipation.

Bisphosphonates are a new group of drugs which can reduce bone pain, control the level of calcium in the blood (hypercalcaemia – see page 42), 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). They have few side effects.

NSAIDs (non-steroidal anti-inflammatory drugs) are effective in treating bone pain and pain caused by inflammation. They work by reducing the inflammation in the bone caused by secondary cancer cells. They may affect the stomach and should be taken with food. If you have any problems discuss these with your doctor or nurse.



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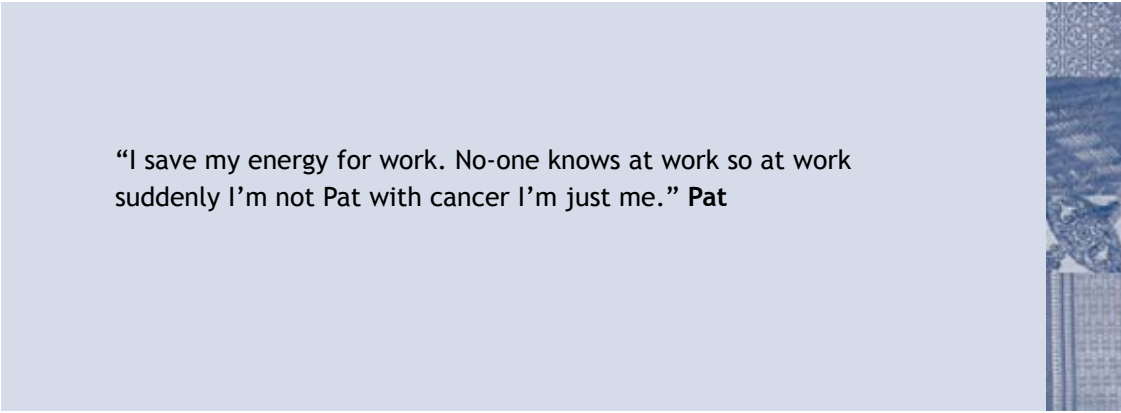
Your doctor can also prescribe sleeping tablets or a mild relaxant if pain is making sleeping difficult. Heat and gentle massage will also help ease aches and pains. A good long soak in the bath, a well protected hot-water bottle or wheat bag, and some baby oil or lotion massaged into the skin can often make a difference. Alternatively, a well-protected ice pack may be helpful.

If your pain medication is not working it is important to go back to your doctor.

There are many different ways pain can be controlled. Very occasionally, pain proves difficult to control and referral to a pain clinic run by specialist doctors and nurses could be helpful.

Fatigue

Cancer fatigue has come to be recognised as one of the most common and distressing symptoms of secondary cancer. Everyone knows what it feels like to be tired sometimes, but cancer fatigue can be unrelenting. 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. Fatigue can have a significant impact on your ability to cope with your illness and your treatment. It can also affect your everyday activities and reduce your independence so that your quality of life is affected.



“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 cope better:

- 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.

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- 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.

Breathing problems

One of the common causes of breathing problems may be pleural effusion (see page 12). This fluid can press on the lung making it harder to expand the lungs fully and causing a feeling of breathlessness. This is treated by draining off the fluid using a narrow tube, which is inserted into the chest between the ribs. This drain may be left in overnight to drain off as much fluid as possible. Breathlessness will reduce when the pleural effusions have been drained. The membranes between the lung and the chest wall can be stuck together by the injection of a drug, which reduces the risk of this happening again.

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

Always seek medical attention if breathing becomes difficult.

Ngā mate whakahā

Rapua he āwhina hauora ki te puta he mate whakahā.

Taking morphine is one of the best ways to relieve breathlessness. Your doctor may prescribe a small dose of morphine, which will steady your breathing rate and relieve anxiety. It will help your breathing if you sit up rather than lie completely flat when resting or sleeping. Using extra pillows in bed or getting a large triangular support pillow can help you stay more upright. Fresh air in the room might help ease your breathlessness. Please phone the **Cancer Information Helpline 0800 CANCER (226 237)** to receive a booklet or the CD *Living with Cancer Related Breathlessness* from your local Cancer Society office.

Nausea (feeling sick)

There is a range of anti-sickness drugs that work in different ways. Let your doctor know if you feel sick, or if the drug is not working. Most anti-sickness drugs take about 20 to 30 minutes to work.

Some women have also found the following suggestions helpful:

- Eat small meals at frequent intervals.
- Avoid fatty or fried foods.
- Rest before and after eating.
- Don't lie flat during or after eating.

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- Drink plenty of fluids.
- See a dietitian or nurse for dietary advice.
- Try relaxation exercises.
- Do something enjoyable as a distraction from feeling sick.

Constipation

Constipation is common, especially if you are taking pain relievers containing morphine, if treatment has made you lose your appetite, or if there is too much calcium in your blood (see page 42).

Some ideas that could help are:

- increasing the fibre in your diet by eating fresh fruit, e.g. kiwi fruit, vegetables, and grains
- increasing the amount of water you drink. Drink at least eight glasses (1500ml) of fluid each day
- following a gentle exercise programme.

Difficulty sleeping

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

Suggested remedies include:

- gentle exercise such as walking or a simple exercise programme

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

- developing a schedule of gentle activities or visits from friends so you maintain a normal daily rhythm
- avoiding coffee, tea, and caffeine drinks later in the day
- having a warm milk and honey drink or a herbal tea, especially before going to bed
- deep breathing and relaxation exercises
- taking a warm bath
- having a gentle massage for relaxation
- talking to friends, family, or a counsellor.

Sometimes a short course of sedatives or sleeping pills may be required.

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Anxiety and depression

Anxiety and depression are very common among women diagnosed with secondary breast cancer. They can make you touchy and irritable. They can stop you eating and sleeping properly. They can make your muscles tense and your heart race. Concentrating may become difficult. Sometimes anxiety can become so overwhelming that it results in panic attacks, causing further fear and worry. In some cases it can lead to depression.

Realising that there is a problem and going in search of help are two big steps in the right direction. The next stage is to talk about who can help. Friends and family/whānau can offer sympathy and support, but you may prefer to talk to someone who is specially trained in helping people deal with emotional problems.

They may recommend practical techniques, some of which you can learn and practise by yourself. These can help you feel more positive and more in control of your life when you may be feeling helpless and out of control.

Some of these techniques include:

Relaxation and visualisation

Relaxation techniques may enable you to relax your body and your mind. You can practise relaxation using tapes at home or by going to a class. Try to get into the habit of noticing the tension in your body and letting it go.

Visualisation means using your mind to create pictures. It is often linked to relaxation. For example, you may simply use it to help you relax by imagining yourself in a favourite place where you feel happy, peaceful, and strong.

Distraction

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.

Cognitive therapy

Many people find that they automatically think the worst when they are diagnosed with cancer. Cognitive therapy is an approach that can help you to be more realistic and help you to see things differently. If you want to know more about this approach talk to your GP or health care professional.

Support groups

For some women, meeting together with others who are in a similar situation can help to decrease feelings of anxiety, isolation, or fear. Support groups offer the opportunity to share your experiences and learn different ways of dealing with problems. Call the **Cancer Information Helpline 0800 CANCER (226 237)** for further information.

Some women find that they become depressed because of breast cancer. This can happen at any stage. It is difficult adjusting to a life-challenging illness. You may find yourself stuck, unable to get beyond thinking that you are going to die, or that you will not live to see your children grow up.



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You may feel that all the enjoyment has gone out of life and you can't imagine things ever getting better. You may have trouble sleeping, eating, getting up in the morning, be irritable, or find yourself crying at the slightest thing. If you are feeling this way you don't have to ignore it and struggle on. It's sometimes difficult to acknowledge that you are depressed, finding it difficult to cope, and that you need professional help.

Depression can be caused by chemical changes in the body, so in some cases a course of anti-depressant drugs may be recommended to correct this imbalance. It can take two or three weeks before you see the effects and start to feel better and you may need to take drugs for four to six months. Taking anti-depressants doesn't mean you'll become dependent on them, but they can be an extra support during a difficult period.

Headaches

Causes of headaches can include muscular tension, exhaustion, too much calcium in the blood (hypercalcaemia – see page 42), and cancer in the brain. Headache symptoms caused by cancer in the brain can be helped by radiation treatment and dexamethasone tablets. These corticosteroid drugs reduce the pressure caused by swelling and inflammation. Corticosteroids are usually given in short courses.

“The counsellor was very helpful and let me go on about the most terrifying things I could think of: she just let me talk about them.” Viv

Haere e whai i te waewae o Uenuku,
kia ora ai te tangata

Lymphoedema

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

The best treatment for lymphoedema is a programme of exercise, massage, 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 and, therefore, the aim of treatment is to control the swelling on a long-term basis.

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A specialist breast care nurse or lymphoedema therapist will work closely with you to treat your lymphoedema. Contact your local Cancer Society for details of lymphoedema therapists available in your area. Lymphoedema therapists work in private practices and have a range of charges.

Hypercalcaemia

Hypercalcaemia (high levels of calcium in the blood) which occurs due to secondary breast cancer in the bone can make you feel very tired and sick. Other symptoms include headache, increased urination, excessive thirst, dehydration, constipation, feeling disorientated, and drowsiness. You may be admitted to hospital for short-term treatment with bisphosphonates (see page 31). This quick treatment should make you feel much better within a couple of days. Treatment can be repeated as often as necessary.

Strengthening a weakened bone

Your doctor may recommend an operation to strengthen a weakened bone which is at risk of breaking. While you are under a general anaesthetic, a metal pin will be inserted into the centre of the bone and a metal plate will be fixed to the weakened bone. The pin and plate can remain permanently in place to protect the bone. Most women stay in hospital for up to a week after surgery, but can usually get up and start walking about after a couple of days. Sometimes this operation is done before radiation treatment, which is being given to treat secondary cancer in the bone.

The operation may be needed if there is a chance the bone may break before the radiation treatment (see page 23) has destroyed the cancer cells. Bisphosphonates also have a role in strengthening bones that are at risk of breaking.

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). If secondary breast cancer is present in the vertebrae it may cause pressure on the spinal cord. Although secondary breast cancer in the vertebrae is quite common, only a small number of women will actually develop spinal cord compression.

Symptoms may include pain or damage to the nerves at the level of the compression. If the nerves are damaged in the lower part of the spine this may lead to tingling or numbness, or loss of power and movement in one or both legs. If damage is higher in the spine there may be a loss of power and sensation in one or both arms or hands. Because the nerves of the spinal cord control the bladder and bowel there may be difficulty urinating or changes in bowel function.



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Report any of the following symptoms to your doctor as soon as they occur:

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

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

Relationships and sexuality

The physical changes of having secondary breast cancer and its treatments often have a profound effect on how women feel about themselves and their attractiveness, whether they have a partner or not. Dealing with any changes is an ongoing process of adjustment.

There are a number of ways secondary breast cancer may impact on sexuality:

- reduced libido because of feeling unwell, anxious, or tired, being in pain, or from side effects of treatments
- menopausal symptoms, such as vaginal dryness and hot flushes brought on by treatment
- feeling less attractive because of breast surgery, hair loss, or illness
- difficulty being physically active due to pain.

“It is quite a big issue that’s on going 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

Māna anō e whakamāui ake

If you have a partner it is important to keep communication open – for both of you to share your fears and needs. You may be able to find creative ways to meet these needs, identifying possible solutions that suit you both. While some women may quickly resume their usual pattern of love making, for others it may take longer. If you and your partner need to make changes, it’s important to remember that sexual intercourse is only one of the ways you can express affection for one another.

Communicating and sharing your feelings can result in greater openness, sensitivity, and physical closeness between you both. Gestures of affection, gentle touches, cuddling, and fondling also reassure you of your need for each other.

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Ngā hononga me te hōkakatanga

Ko tētahi o ngā pānga o te mahi hahau ko te kore pirangi ai nā te mea he anuanu koe, hiamoe rawa koe, kua hia ruaki, kei te mamae koe. He mea hira kia kaha tonu koe ki te kōrerorero me tō hoa, kia kaha kōrua ki te whitiwhiti kōrero mō ōu hiahia. Tērā pea ka kitea e koe ētahi huarahi auaha hei whakatutuki i ēnei, hei kaupare atu i ngā matakū me te kimi huarahi pai rawa mōu.

When you feel ready for intercourse itself, you may find some positions more comfortable than others. If sexual intercourse is painful because of vaginal dryness, then creams such as KY Jelly, Sylk, or Replens may be useful. Talk to someone you trust if you are experiencing ongoing problems with sexual relationships. Friends, nurses, or your doctor may be able to help. Your local Cancer Society can also provide information about counsellors who specialise in this area.

For more information you may like to pick up a copy of the Society’s booklet *Sexuality and Cancer/ Hōkakatanga me te Matepukupuku* from your local Cancer Society office. Phone the **Cancer Information Helpline 0800 CANCER (226 237)** to be sent a copy or download a copy from the Society’s website: **www.cancernz.org.nz**.

Telling ourselves the stories

Those fabulous opening words, Once Upon a Time, never fail to cast their spell on me. I let go of everything else in my head, and settle into the story being told. That same magic is there when we tell our cancer story.

This alchemy operates on many levels. It informs others and, more importantly perhaps, informs us as well - sometimes it’s not till we write the words on a page that we (and others) realise the intensity of the journey we’re travelling.

There is the magic of putting words on a page, words which affirm, strengthen, and shed light. There are things we can tell - the story that we’ve never told anyone else, sometimes never thought about till we find the freedom of writing about them.

There is also a kind of triumph. We’ve told the story, the words are there - they will last longer than we do, will be part of the huge patchwork of stories which speak of our experiences in this new world. Our stories matter. There is a magic about that.

Renée

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Support

Emotional support

Discovering you have secondary breast cancer may bring up a range of understandable emotional reactions, including feeling angry, resentful, and let down. It is common to feel shocked and to feel you are no longer in control of your body or your life.

Feelings can be muddled and change quickly. This is quite normal and there is no right or wrong way to feel. It is not clearly known exactly why some cancers spread, but it may help you to know that nothing you have done has caused this situation. Coping with the diagnosis is an ongoing adjustment process for you, your family/whānau, and friends.

Tautoko ā-wairua

Tērā pea ka pōraruraru katoa tō wairua, ka rēre o kare-āroto. Ehara i te mea kino, ka pā tēnei āhua ahakoa te aha. Kāore i te tino mōhiotia te take ka rauroha haere ētahi matepukupuku, ko te mea kē, kia kua koe e mahara nōu ake te hē i pēnei ai.

Friend

Good on you, friend,
for being a life to me.
You came when I needed you.
I didn't have to ask.
You didn't have to say.
You just turned up out of the blue,
carrying no luggage,
both hands free to carry mine,
and somehow, you made it look
as though I was doing you a favour
by letting you be there.

It beats me how you knew
what a burden I was bearing.
You know, I can't believe
that I talked so much
or that you could be attentive
for such a long time.
But I do know that when I left you,
the sun was shining,
a bird was singing
and there was a beautiful day
waiting to be used.



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So good on you, friend, for being there,
and letting me tell my story,
and for giving to me my story
and for giving to me three ways,
as a friend,
as a teacher of what friendship
is all about,
and as a channel of something
that I call wholeness.

Joy Cowley

Secondary breast cancer can create a lot of uncertainty in your life and for many people this can be the hardest aspect to deal with. It can be an extra strain if you have children, especially if they are young. Making day-to-day plans may help reduce the stress of this uncertainty and ‘living in the present’ can mean you get more out of each day.

Uncertainty about the future can make you feel very worried about your partner and family/whānau. You may be concerned about their feelings and also fearing that they may not be able to cope in the future. Often it is hard to talk about these worries. However, it is important to try and keep communication going as this can strengthen relationships and help prevent any resentment or guilt from growing.

There are no easy answers when it comes to facing a life-challenging illness. Every person is different and will find his or her own way of coping with their difficult situation. Talking with family and friends about fears of death can give loved ones the opportunity they have been waiting for to help and support you.

Kāore he whakautu māmā mō te pānga mai o tētahi mate mōrearea. He rerekē tēnā, ki tēnā, nā reira mā ia tangata e hua ai tōna ake huarahi mō ngā āhuatanga pēnei. Mā te kōrerero ki te whānau me ngā hoa e pā ana ki ngā matakū o te hemo, e whai wā ai rātou e aroha mai ana, ki te āwhina, ki te tautoko i a koe.



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Doctors cannot predict how long your life is likely to be after diagnosis. Treatment can successfully keep the disease under control, sometimes for several years. Some people with secondary breast cancer find that their lives are not affected very much by the cancer. The disease may become like any other chronic illness: something which causes problems from time to time, but which they can live with by dealing with each difficulty as it arises.

Talking to someone outside the family may also be helpful. A counsellor, religious or spiritual adviser, or the hospital chaplain can be good sources of support for many people, whatever their spiritual beliefs. You may find support or self-help groups helpful. Your doctor, nurses, social worker, and others involved in your care will also be willing to help. Seeking professional help is not a sign of failure. It shows a positive attitude to your worries.

Tērā pea, he whai hua te kōrero ki tētahi kei waho o te whānau. He pai tonu ki te maha o ngā tāngata, ngā kaitohutohu, ngā pou hāhi, me ngā minita hōhipera hei tautoko i a rātou ahakoa te whakapono. Tērā pea he whai hua ngā rōpū āwhina-whaiaro, rōpū tautoko ki a koe. Kāre e kore, ka hiahia tō rata, ngā tapuhi, tō tauwhiro, me ētahi atu e tiaki ana i a koe ki te āwhina i a koe. Ehara i te mea whakaiti tangata te whai āwhina ngaio, engari he tohu pai kei te whakatau koe i ō āwangawanga.

“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. And I answered – a phone call now and again.” **Colleen**

Whilst talking to others is important, sometimes you may need time to yourself to deal with your own feelings. Taking time out is a natural way of trying to come to terms with difficult emotions.

There may be times when you feel the situation is getting too much for you. When this happens it may help to talk to your doctor or nurse. They may recommend medication to provide the short-term support you need to get through a difficult time until you have built up your own reserves of emotional strength again. Some people find complementary therapies, such as relaxation and meditation helpful. (See the ‘Complementary and alternative therapies’ section on pages 61-62.)

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Talking with your children

How much you tell children will obviously depend on how old they are. All young children need to know that it is not their fault. They also need to know that you may have to go into hospital. Slightly older children can probably understand a simple explanation of what is wrong. Adolescent children can obviously understand much more. All children need to know what will happen to them while you are in hospital, who will look after them, and how their daily life will be affected.

Te kōrero ki ngā tamariki

Mā te pakeke o ngā tamariki e tohu i a koe ki te āhua o ngā kōrero ka hoatu e koe. Me mōhio ngā tamariki nohinohi ēhara nō rātou te hē. Me mōhio rātou, kāore e kore, ka haere te tangata mate ki te hōhipera. Pai noa iho ngā tamariki āhua pakeke ake ki te mōhio mō te mate, ā, ka taiohi ana, e tika ana kia mōhio ki ngā kōrero katoa, he nui ake hoki ō rātou māramatanga. Me mōhio katoa ngā tamariki ka ahatia rātou i te wā kei te hōhipera koe, arā; mā wai rātou e tiaki, ngā rerekētanga ki ngā mahi o ia rā, ia rā.

Sometimes children rebel or become quiet. Keep an eye on them or ask someone else to and ask for help if you need it, for example, from the school counsellor or a hospital social worker.

For a copy of the booklet *What Do I Tell The Children?/ He Aha He Kōrero Māku Ki Āku Tamariki?*, contact your local Cancer Society. Phone the **Cancer Information Helpline 0800 CANCER (226 237)** or download the booklet from our website: **www.cancernz.org.nz**.

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**.

Cancer Society information and support services

Your local Cancer Society provides confidential information and support. Local centres offer a range of services for people with cancer and their families/whānau.

These may include:

- volunteer drivers providing transport to treatment
- accommodation
- support and education groups.

The range of services offered differs in each region so contact your local Cancer Society and speak to support services staff to find out what is available or phone the **Cancer Information Helpline 0800 CANCER (226 237)**.



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“I couldn’t focus. I would try to do something that I’d done a hundred times before and I wouldn’t know how to do it. I was getting extremely frustrated. I actually thought I was having a mental breakdown, and my husband was getting worried. He spoke to someone at the Society and was told about something called ‘chemo brain’. I hadn’t been told about it. Just knowing that there was a name for it and that it was normal was a relief.” **Stephanie**

Pārongo a te Kāhui Matepukupuku o Aotearoa me ngā ratonga tautoko

Ka whakarato tautoko me te pārongo nohotapu ngā Rōpū matepukupuku ā-Rohe. Waea atu ki tō Kāhui Matepukupuku ā-rohe kia kōrero ki ngā kaimahi ratonga tautoko, me waea atu rānei ki tēnei nama waea **Waeaāwhira Pārongo Matepukupuku 0800 CANCER (226 237)**. He whānui ngā momo ratonga a ngā pokapū matepukupuku ā-rohe mō ngā tāngata matepukupuku me ō rātou whānau.

Anei ētahi:

- Urungi tūao mō ngā waka kawē tangata whai maimoatanga
- wāhi noho
- rōpū tautoko, rōpū mātauranga.

Cancer support groups

Cancer support groups offer mutual support and information to people with cancer and often to their families/whānau. It can help to talk with others who have gone through the same experience. Support groups can also offer many practical suggestions and ways of coping. Ask your hospital or local Cancer Society for information on cancer support groups in your area.

Home care

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.

Beyond the physical

When we are unwell or in a situation that we feel threatening, it’s not uncommon to start asking those deep questions: Why are we here? What is the meaning of life? What are our values? It can be a time when even those of us who do not have a faith or a sense of spirituality feel aware of something that is ‘other’ within us. Exploring resources, like those listed below that are focused on the ‘inner journey’ may be helpful.

James K Baxter. *Collected Poems*. Oxford University Press, Wellington, first published 1980.

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Glenn Colquhoun. *Playing God*. Steele Roberts Publishers, Wellington, 2003. (ISBN 1-877228-75-3)

Joy Cowley. *Psalms Down Under*. Pleroma Christian Supplies, New Zealand, 1996.

Viktor Frankl. *Man’s Search for Meaning*. Washington Square Press, Simon and Schuster, New York, 1963.

Palliative care services

Palliative care services have particular expertise in dealing with pain and other symptoms. They can offer emotional support to you and your family/whānau at all stages of your illness. These services may be offered by your local hospital or hospice.

What is palliative care?

Palliative care is an approach that improves the quality of life of patients and their families/whānau, who are facing the problems associated with life-challenging illnesses, through early identification, assessment, and treatment of pain and other problems: physical, emotional, and spiritual.

Palliative care:

- uses a team approach to address the needs of people with cancer and their families/whānau, including bereavement counselling if needed
- provides relief from pain and other distressing symptoms

Morning hymn

You are the wind: fill up my sails
You are the water: run fast beneath my feet
And I will sing in the wind
And dance over the water
May I journey without fear
In all your seasons.
In emptiness, let me find fullness,
In imprisonment, let me find freedom.

Joy Cowley



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- offers support to help the family/whānau manage during the patient’s illness and in their own bereavement
- integrates the psychological, spiritual, and cultural aspects of people with cancer’s care
- will enhance quality of life, help the patient live as actively as possible, and may also positively influence the course of an illness
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- can be done early in the course of the illness along with other therapies that are intended to prolong life, such as chemotherapy or radiation treatment, including those investigations needed to better understand and manage distressing clinical complications.

Palliative care should also be available to you wherever you may be – at home, in hospital, or at a rest home. It can be given by your GP, community nurses, hospital, primary care teams, or rest home staff. If more care is needed, specialist palliative care teams may help. You may receive help from the hospital palliative care team and your local hospice service.

Complementary and alternative therapies

Complementary therapy is a term used to describe any treatment or therapy that is not part of the conventional treatment of a disease.

Examples include:

- acupuncture
- Māori remedies
- positive imagery
- spiritual healing
- art
- relaxation therapy/meditation
- yoga
- aromatherapy/massage.

Alternative therapy is a term used to describe any treatment or therapy that may be used as an alternative to conventional treatments.

Examples include:

- homeopathy
- naturopathy
- Chinese herbs.

It is important to let your doctor 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 conventional treatments.



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“I like having facials done. I do that for a bit of ‘a pamper’.” Viv

Tauārai i te pō, titoko i te ao mārama

Ngā haumanu tautoko me te rerekē

He mea nui me mōhio tō rata mehemea kei te whai koe i ētahi haumanu rerekē nā te mea, kāore pea ētahi o ēnei maimoatanga e noho pai i te taha o ngā rongoā o nāiane.

Some women find improvements to their quality of life and sense of wellbeing from complementary and alternative therapies. However, at present there is no evidence that such therapies can cure secondary breast cancer or extend the life of women who have secondary breast cancer.

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 about what sort of help is available.

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 for people who are unable to work. Short-term financial help is available through the Sickness Benefit and longer-term help is provided through the Invalids Benefit. Extra help may be available, for example, through accommodation supplements and assistance with medical bills.

More information is available on the Ministry of Social Development’s website: **www.msd.govt.nz** or by phoning **0800 559 009**.



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Interpreting services

New Zealand’s Health and Disability Code states that everyone has the right to have an interpreter present during a medical consultation. Family or friends may assist if you and your doctor do not speak the same language, but you can also ask your doctor to provide an interpreter if using family members is inappropriate or not possible.

Ratonga whakamāori ā-waha

E takoto ana te kōrero i te New Zealand Health and Disability Code, e āhei ana te tangata ki te whai kaiwhakamāori i te wā o ngā hui hauora. Pai noa iho mēnā ka āwhina tētahi o te whānau, tētahi hoa rānei, mehemea he rerekē tō reo ki tō te rata. He pai noa iho hoki te tono kaiwhakamāori mā tō rata mehemea kāore i te tika, kāore rānei e taea e tētahi o te whānau.

Try It For Size

Slip the day
around yourself
like a silk shirt.

Wriggle your skin
against its
cool
soothing
edges
and button it up
one
two
three
four

collar of sky
tuck of hills
shake of sun
and you.

Trish Harris



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“A neighbour said to me, The first thing you did after getting secondary breast cancer was plant lettuces, and I thought what a marvellous thing. But you know, growing things is very important. I love vegetables because they provide the meal. It’s always handy when they [family] turn up.”

“It has become very important to me to be not a cancer victim or sufferer. I am a person living with cancer.” **Paula**

What can I do to help myself?

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.

Diet and food safety

A balanced, nutritious diet will help to keep you as well as possible and cope with any side effects of treatment. The Cancer Society’s booklet called *Eating Well/Kia Pai te Kai* gives useful advice and recipes. Phone your local Cancer Society office for a copy of this booklet. Call the **Cancer Information Helpline 0800 CANCER (226 237)**, or download the booklet from our website: **www.cancernz.org.nz**.

The hospital will also have a dietitian who can help and advise you.

Te kai tika me te haumaruru kai

Mā te kai tika, e āwhina i a koe ki te noho ora me te ārai i ngā pānga kino ka whai i ngā maimoatanga. Kei roto i te pukapuka *Eating Well / Kia Pai te Kai* a Te Rōpū Mate Pukupuku, ētahi tohutohu whai kiko mō te kai pai me ētahi tohutaka. Waea atu ki tō Te Kāhui Matepukupuku ā-Rohe (regional Cancer Society) mō tētahi kape o te pukapuka nei, me waea atu rānei ki a **Waeaāwhira Pārongo Matepukupuku 0800 CANCER (226 237)** mō tētahi kape, me tikiake i tō mātou paetukutuku **www.cancernz.org.nz**. Kei te hōhipera hoki tētahi tohunga mō te kai pai, hei āwhina anō.

Food safety is of special concern to cancer patients, especially during treatment which may suppress immune function. To make food as safe as possible it is recommended that patients follow the guidelines below:

- Wash your hands thoroughly before eating.
- Keep everything used for preparing, cooking, and serving food clean. Wash your hands before preparing food.
- Wash fruit and vegetables.
- Handle raw meat, fish, poultry, and eggs with care and clean thoroughly any surfaces that have been in contact with these foods.



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- Keep raw meats separate from cooked food.
- Cook meat, poultry, and fish thoroughly and use pasteurised milk and juices.
- Cover and refrigerate food promptly to minimise bacterial growth.
- When eating in restaurants, avoid foods that may have bacterial contamination, such as salad bars, sushi, and raw or undercooked meats, fish, poultry, and eggs.
- If there is any concern about the purity of your water, for example, if you use well water, have it checked for bacterial content.

Exercise

Many people find regular exercise helps. Research has indicated that people who remain active cope better with their treatment. The problem is that while too much exercise is tiring, too little exercise can also make you tired. Therefore, it is important to find your own level. Discuss with your doctor what is best for you.

Relaxation techniques

Some people find relaxation or meditation helps them to feel better. The hospital social worker, nurse, or local Cancer Society will know whether the hospital runs any relaxation programmes, or may be able to advise you on local community programmes. You may find yoga, tai chi, or meditation help you to relax.

Seeking advice from health professionals

If you feel uncomfortable or unsure about your treatment, it is important that you discuss any concerns with those involved in your care, including your general practitioner.

Questions you may wish to ask

1. How extensive is my cancer?
2. What stage is it?
3. What treatment do you advise for my cancer?
4. Why is this treatment recommended?
5. Are there other treatment choices for me?
6. What are the risks and possible side effects of each treatment?
7. What is the aim of the treatment?
8. How long is the treatment for?
9. Is there a cost for this treatment?
10. How do I know if the treatment is working?
11. What if the treatment doesn't work?
12. What happens if I don't have treatment?
13. If I choose not to have treatment either now or in the future, what services are available to help me?
14. If I need further treatment, what will it be like and when will it begin?



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15. Will I still be able to have children?
16. Will the treatment affect my sexual relationships?
17. How frequent will my check-ups be and what will they involve?
18. Can I have a second opinion?
19. Can you refer me to someone else?
20. Can you suggest any books I can read?

If there are answers you do not understand, feel comfortable to say:

- “Would you please explain that again?”
- “I am not sure what you mean.”
- “Would you please draw a diagram, or write it down?”

Suggested reading and websites

Reading

Joy L. Fincannon & Katherine V. Buss. *Couples Confronting Cancer: Keeping your relationship strong*. American Cancer Society, USA, 2003.

iSource National Breast Cancer Centre. *A Guide for Women with Metastatic Breast Cancer*. National Breast Cancer Centre, Sydney, Australia, 2001.
(Also available online at http://www.nbcc.org.au/resources/documents/MCG_metastaticguide.pdf)

Phil Kerslake. *Life, Happiness & Cancer: Survive with action and attitude*. Steele Roberts Publishers, Wellington, New Zealand, 2006.

Mayer Musa. *Advanced Breast Cancer: A guide to living with metastatic breast cancer*. O’Reilly & Associates, second edition, USA, 1998.



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Websites

Breast Cancer Care (UK) www.breastcancercare.org.uk

Breasthealth (AUS) www.nbcc.org.au

Cancer Backup (UK) www.cancerbackup.org.uk

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

Hospice New Zealand www.hospice.org.nz

Skylight (NZ) www.skylight.org.nz

The suggested websites are not maintained by the Cancer Society of New Zealand. We only suggest sites we believe offer credible and responsible information, but we cannot guarantee that the information on such websites is correct, up-to-date, or evidence-based medical information. We suggest you discuss any information you find with your cancer care health professionals.

This Booklet, *Secondary Breast Cancer/Matepukupuku Tuarua ā-Ū*, is part of a series titled *Understanding Cancer*, which is published by the Cancer Society. These booklets and booklets from the *Living with Cancer* series can be viewed and downloaded from our website, www.cancernz.org.nz.

Ngā whakāmarama mō ngā whakatauki

Explanation of proverbs

The whakatauki (proverbs) below are followed by the English translation, then with an explanation in Māori and English.

- Page 11 Tokotoko tao, kotahi te tūranga, tokotoko rangi ka ngaro te kai, ka ngaro te tangata
The spear of wood, one at a thrust, the spear of heaven, food disappears, people disappear.
- Ki te patua te tangata me te tokotoko tao, ko te tangata kotahi e mate ana, engari ki te patua e te tokotoko rangi (arā ngā mate kōnene o tāwāhi) nui te ātetenga. Only one person suffers from the blow of a wooden spear, but the spear from heaven has widespread effect – used in modern oratory in reference to diseases which spread with devastating results.
- Page 41 Haere e whai i te waewae o Uenuku, kia ora ai te tangata
Go in search of the footprints of Uenuku, so that humankind may be nurtured.
- Ko tētahi kōrero, he tangata matau a Uenuku, a ko ia te mea mōhio ki ngā huarahi whai orange – nā reira whāia ōna tapuwae.
It was known that Uenuku was a very wise person who knew the secrets of health, personal safety, and welfare.



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Page 45 Māna anō e whakamāui ake
May the person be restored to health.

He kōrero tēnei e tūmanako ana ka puta he oranga ki te tangata.
This is often heard when someone is suffering a serious illness.

Page 62 Tauārai i te pō, titoko i te ao mārama
Screen from Hades, prolonger of life.

He kōrero mō rātou ka tere huri ki te āwhina i te tangata.
Applied to one who is quick to turn to assist people in need/danger.

Glossary

benign – a tumour that is not malignant, not cancerous, and won’t spread to another part of your body.

bone scan – a picture of the bones that can show cancers, 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.

chemotherapy – the use of special (cytotoxic) drugs to treat cancer by killing cancer cells or slowing their growth.

lymph or lymphatic – the lymphatic system is part of the immune system, which protects the body against ‘invaders’, like bacteria and parasites. The lymphatic system is a network of small lymph nodes connected by very thin lymph vessels, which branch into every part of the body. Lymph fluid flows through this system and carries cells that help to fight disease and infection.

lymph glands or nodes – small kidney bean shaped sacs scattered along the lymphatic system. The lymph nodes filter the lymph fluid to remove bacteria and other harmful agents, such as cancer cells. There are lymph nodes in your abdomen, neck, armpit, and groin.

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



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metastasis (plural = metastases) – another cancer that has grown in a different part of the body because of the spread of cancer cells from the original site. For example, someone with breast cancer may have metastases in their bones – also called secondary cancer.

palliative – controlling the symptoms of a disease rather than curing it.

positron emission tomography (PET) scan – a technique that is used to build up clear and very detailed pictures of the 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 – a malignant tumour starts in one site of the body where it is known as the primary tumour.

radiation treatment – the use of radiation, usually X-rays, to kill cancer cells or injure them so they cannot grow and multiply. Radiation treatment can also harm normal cells, but they are usually able to repair themselves.

recurrence – when a disease comes back again after what seemed to be a cure.

secondary – the same as metastasis.

tumour – a swelling or lump. Tumours can be benign (not cancerous), or malignant (cancerous).

ultrasound – sound waves of a very high frequency used to examine structures within the body.

Notes

You may wish to use this space to write down any questions you want to ask your doctors, nurses, or health providers at your next appointment.

Whakamahia tēnei wāhi wātea hei tuhi pātai e hiahia ana koe ki te pātai i tō rata, ngā tapuhi, ngā kaiwhakarato hauora rānei mō te wā e hoki atu ai koe.



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Cancer Information Helpline

0800 CANCER (226 237)
www.cancernz.org.nz



Feedback

Secondary Breast Cancer / Matepukupuku Tuarua ā-Ū

We would like to read what you thought of this booklet, whether you found it helpful or not. If you would like to give us your feedback please fill out this questionnaire, cut it out, and send it to the Information Manager at the address at the bottom of the following page.

1. Did you find this booklet helpful?

Yes ☐ No ☐

Please give reason(s) for your answer.

2. Did you find the booklet easy to understand?

Yes ☐ No ☐

Please give reason(s) for your answer.

3. Did you have any questions not answered in the booklet?

Yes ☐ No ☐

If yes, what were they?



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4. What did you like the most about the booklet?

5. What did you like the least about the booklet?

6. Any other comments?

Personal information (optional)

Are you a person with cancer, or a friend/relative/whānau/ member? _____

Gender: Female ☐ Male ☐ Age _____

Ethnicity (please specify): _____

Thank you for helping us review this booklet. The Editorial Team will record your feedback when it arrives, and consider it when this booklet is reviewed for its next edition.

Please return to: The Information Manager, Cancer Society of New Zealand, PO Box 12700, Wellington 6011.



Information, support, and research

The Cancer Society of New Zealand offers information and support to people with cancer and their families. Information is available on specific cancers, treatment, and living with cancer.

The Cancer Society is a major funder of cancer research in New Zealand. The aim of research is to determine the causes, prevention, and effective methods of treating various types of cancer.

The Society also undertakes health promotion through programmes, such as those encouraging SunSmart behaviour, healthy eating, physical activity, and discouraging smoking.

We would appreciate your support

The Cancer Society receives no direct financial support from Government so funding comes only from donations, legacies, and bequests. You can make a donation by phoning 0900 31 111, through our website, or by contacting your local Cancer Society.

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Photography

Cancer affects New Zealanders from all walks of life, and all regions of our beautiful country. This cover photo of Mountain daisies (*Celmisia verbascofolia*) in the head of the Routeburn left branch was taken by Rob Suisted.

Volunteers

Many thanks to the Cancer Society volunteers who agreed to be photographed for our booklet covers.

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