



For more information on anything covered in this booklet talk to your specialist, doctor or nurse, or visit

Introduction, Nau Mai, Haere Mai

A diagnosis of advanced HER2-positive (HER2+) breast cancer is difficult news to hear. Having someone with you – your partner, whanau or a good friend – can be of great comfort, so call them to come and be with you, to share your feelings and talk through this news you have received.

You may be feeling so many things – shock, anger, sadness, fear, loneliness – and you might feel all of these at once. There is uncertainty, worry for yourself and your family. As a mother you expect to see your children grow up, to grow old with your partner and now you are not sure how your diagnosis will affect your life.

On page 18 you will find support organisations that are there when you need them. If you find contacting them is a little too hard, have your partner, a friend or whanau call for you. Some useful websites are listed too, including Skylight which offers support for children and young people coping with a loved one's diagnosis.

This booklet is about advanced HER2-positive breast cancer and treatment with Herceptin. It offers information and practical advice to support and guide you at this emotional time. Asking your partner, a friend or someone from your whanau to read it again with you later may be helpful in understanding all the information.

If you would like more information go to www.cancertreatments.co.nz

All words highlighted like **this** are in the Glossary at the back of this booklet on pages 19 Models have been used throughout this booklet for illustrative purposes only.





© To begin

- Information is power
- Take time for yourself
- You are not alone

An emotional time

A diagnosis of HER2-positive breast cancer has placed you on an emotional roller-coaster. Everyone else is making decisions for you, telling you what they think is best

It feels like you have no say over what is happening to your own body. But there are some things you can do.

Information is power

Information can help at a time when you feel you have little control over the news you have received and the effect it will have on your life.

Do ask questions – lots of them! Make a list to take with you when you see your oncologist or breast nurse. Ask your partner, a friend or support person to go to appointments with you so they can make notes. It can be hard to remember everything that is said during a consultation.

This booklet will offer information to help with decisions regarding your treatment and care. There are many other sources of information such as the internet, books and articles. Speaking openly and honestly to those who will care for you is important too.

The more information you have, the better prepared you will be to make decisions. If there is something you are not sure about, keep asking your doctor or nurse until you feel comfortable.





Take time for yourself

There are ways you can help yourself and look after 'you'. Here are some ideas. Spend time with your family. Enjoy the little things every day – what's in the garden, a visit with friends, sunshine, a walk. Treat yourself.

Your whanau and friends will be worried so let them know what you need. Tell them how you feel, not just what is going on with your treatments or your breast cancer.

Every day responsibilities may feel overwhelming – work, family and so many other commitments. Now may be the time to assess some of those things, take time out if you can and ask for help. Diagnosis is an exhausting time and the upcoming treatments will be tiring. Those close to you will understand if you decide to put some things on hold for a while.

You are not alone

Family, friends, whanau and your medical team are there to support and care but sometimes you might feel lonely. Please remember that you are not alone. Talking to another woman in the same situation – or to someone who is trained to help you – can bring comfort, support and advice. Page 18 has a list of organisations.

© What happens next?

- Prepare for a lot of information
- Ask as many questions as you need to
- Your doctors will ask you to take further tests

A lot of information will come your way

Talking to doctors, understanding test results and being given advice means there is much to learn and a lot to take in. It is good to have your partner, friend or whanau with you so they can take notes and discuss the information with you afterwards.

So many questions!

Your doctors will ask you a lot of questions about your health and your family history. But it's not all one way. You can ask too – and even if a question sounds silly, go ahead and ask.

Why all the tests?

Your doctors need to know exactly what kind of breast cancer you have so they can determine the best treatment for you. They may ask you to have a **CT** scan, a bone scan or an **MRI** so they can learn as much as they can about your breast cancer

Doctors may also ask you to have a heart scan before starting certain treatments.

These tests can be used to monitor how well your treatment is going or for possible side effects so they may be repeated after a few treatments.



Treating HER2-positive advanced breast cancer

HER2-positive advanced breast cancer is usually treated with medication that goes through the whole body. This is called 'systemic treatment'. HER2-positive advanced breast cancer can be controlled for periods of time with specific treatments such as **chemotherapy, radiotherapy** and biological therapies like Herceptin.

Chemotherapy and radiotherapy

Chemotherapy goes through your whole body to stop the growth of new **cancer** cells. Radiotherapy targets a specific area (like the breast) to stop cells growing in that part of the body.

Herceptin

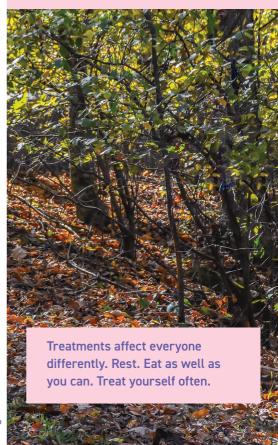
Herceptin is a biological therapy that stops the growth and multiplication of breast cancer cells that make too much of a protein called **HER2**. It does this by binding to HER2 proteins and blocking signals that tell the cells to grow. HER2 is explained on page 8 and there is more about Herceptin on pages 9 to 15.

HER2-positive breast cancer is a type of breast cancer where there are abnormally large quantities of the HER2 protein.

Approximately 1 in 5 women with breast cancer are HER2-positive. To learn more about HER2 go to www.cancertreatments.co.nz

Women diagnosed with HER2-positive breast cancer are eligible to receive funded Herceptin treatment in New Zealand.* There is more information about Herceptin – what it is, how it works, the way it is given to you and side effects you may have - on pages 9 to 15.

* Herceptin intravenous (IV) infusion is fully funded. Herceptin **subcutaneous (SC) injection** is currently not funded which means that patients need to pay for this medicine themselves.



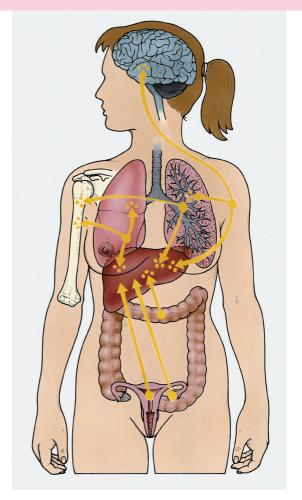
Advanced Breast Cancer

Advanced breast cancer is also known as metastatic or 'secondary' cancer. This means the cancer has spread beyond the breast and armpit area. There are treatments available that can help manage the symptoms and slow down the spread or progression of advanced breast cancer.

What is advanced breast cancer?

Breast cancer cells from the original tumour have spread beyond your breast, underarm, and internal mammary lymph nodes.

These cells have appeared in other parts of your body such as your lungs, liver, bone, or brain.





HER2

HER2 is a protein found on all normal cells in your body. HER2 tells cells to grow.

Too much HER2 on a breast cell can make it turn into a HER2-positive cancer cell.

Knowing your HER2 status will help to determine the best treatment for you.

What is HFR2?

HER2 is a protein on the surface of all normal cells in your body. HER2 helps regulate the way cells grow and divide into other cells.

So what is HER2-positive breast cancer?

When there is too much HER2 is present or over expressed on the outside of some of your cells, these cells become 'abnormal'. The abnormal cells start multiplying rapidly and producing more abnormal cells. This group of abnormal cells is termed a tumour.

Women with HER2-positive breast cancer are more likely to:

- Respond well to biological therapy which specifically targets HER2 proteins
- · Respond poorly to standard therapies
- Have a higher risk of cancer recurring after initial therapy

How do you know if your cancer is HER2-positive?

There are a number of tests available to determine different cancer types. One of these is to test for too much HER2 and it is needed to identify the best treatment for you.



HER2 receptors



HER2 means Human Epidermal Growth Factor Receptor Type 2

HER2-positive is often written as HER2+

HER2-negative is often written as HER2-

© HERCEPTIN (trastuzumab)

Herceptin was introduced for the treatment of women with HER2-positive breast cancer in 1998, and has been available to New Zealand women since 2001. Over the past 20 years, Herceptin has been used to treat more than 1.5 million women worldwide.

What is Herceptin?

Herceptin is an anticancer therapy for women with HER2-positive breast cancer. The active ingredient is trastuzumab (traz-too-zoo-mab), a biological treatment known as a **monoclonal antibody**.

How effective is Herceptin?

Women with advanced breast cancer who receive Herceptin in combination with chemotherapy live on average 8.5 months longer than women who receive chemotherapy alone. Herceptin also maintains or improves quality of life for women compared to chemotherapy alone.

What is a monoclonal antibody?

A monoclonal antibody is a type of biological therapy that uses the body's natural immune defences. Unlike conventional treatments such as surgery, radiotherapy and chemotherapy, Herceptin only targets and kills cancer cells that have too much of the HER2 protein.

Herceptin is not a chemotherapy, but like all treatments can have some side effects. It's important you know what these are – see page 15 for more information.



Herceptin is funded in New Zealand to treat women with HER2-positive advanced breast cancer.*

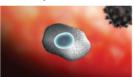
Herceptin in combination with chemotherapy helps patients live longer (overall survival), compared to chemotherapy alone.

How does Herceptin work?

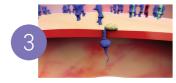
Herceptin is a targeted therapy that attacks HER2-positive cancer cells and works in four different ways:



activating the body's own immune system...



...to kill HER2 cancer cells

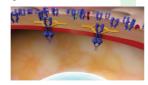




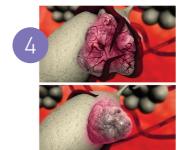
preventing the formation of a very active form of the HER2 protein



blocking HER2 activated cell growth...



...by binding to HER2 proteins



stopping the formation of new blood vessels that feed the cancer

^{*}Herceptin intravenous (IV) infusion is fully funded. Herceptin **subcutaneous (SC) injection** is currently not funded which means that patients need to pay for this medicine themselves.

Receiving Herceptin

There are 2 ways you can receive Herceptin –either as an intravenous (IV) infusion (drip) or a subcutaneous (SC) injection (under the skin).

Herceptin treatments are usually given once every 3 weeks

How is Herceptin given to you?

Herceptin IV given by a drip through a fine tube (cannula) inserted into one of your veins (an infusion). Herceptin IV is fully funded.

Herceptin SC is given by an injection in the thigh. Herceptin SC is currently not funded which means that patients need to pay for this medicine themselves.*

You will usually receive Herceptin in the cancer department at a hospital or clinic. You may receive Herceptin by itself or in combination with other breast cancer treatments. Your specialist will decide which combination of treatments is best for you.

How long will the infusion take?

The first infusion of Herceptin will generally be given over 90 minutes.

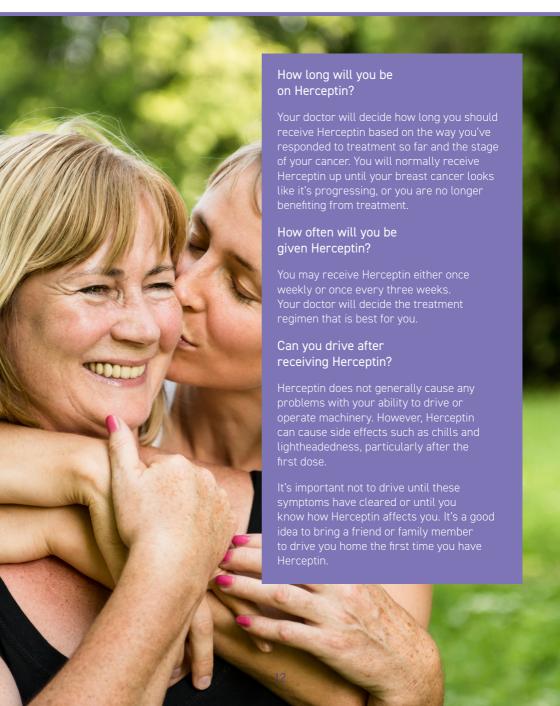
After the infusion you will need to wait for a short time to make sure you don't have a reaction to the Herceptin. If the initial infusion was well tolerated, the subsequent doses will generally take 30 minutes. The infusion may take longer if it is slowed or interrupted, if you experience side effects or have an allergic reaction.

How long does the SC injection take?

Herceptin SC is given as an injection under the skin in the thigh over two to five minutes. Doses are given every three weeks.

^{*}Herceptin intravenous (IV) infusion is fully funded. Herceptin subcutaneous (SC) injection is currently not funded which means that patients need to pay for this medicine themselves.





Safety

If you have any side effects, tell your doctor or healthcare professional right away.

Herceptin treatment may be stopped until your side effects are resolved.



Before starting Herceptin

Tell your doctor if:

- you have a history of:
 - coronary artery disease
 - high blood pressure
 - heart failure
 - abnormal beating of the heart
 - angina (chest pain)
- you have previously been treated with chemotherapy medicines known as anthracyclines (e.g. doxorubicin)
- if you have any breathing or lung problems
- you are pregnant or plan to become pregnant
- you are breast-feeding or plan to breast-feed
- you are allergic to any other medicines or any other substances such as foods, preservatives or dyes
- you are taking any other medicines, including vitamins or herbal remedies you've bought from a pharmacy, supermarket or health food shop

Important: It is never too late to tell your doctor about any of the above, even if you are already on Herceptin.



During the course of your Herceptin therapy

Important information

- tell all doctors and other healthcare professionals treating you that you are receiving Herceptin
- tell your doctor or healthcare professional if you have any chest pain, difficulty breathing, shortness of breath and/or swelling of your feet and hands while you're receiving Herceptin
- tell your doctor if you become pregnant while receiving Herceptin
- tell your doctor if you feel Herceptin is not helping your condition
- do not take any other medicines
 [whether prescription or not] without
 telling your doctor or consulting
 a pharmacist first
- be careful driving or operating machinery until you know how Herceptin affects you

Will you need medical tests during treatment?

Yes. Your heart function may be regularly monitored during Herceptin therapy.

Every three months you may have an echocardiogram (ultrasound heart scan) or a MUGA (Multiple Gated Acquisition heart scan) so your doctor can check your heart function.

Your doctor may pause or stop your Herceptin treatment if your heart function is being affected. Herceptin treatment can be restarted in some circumstances if your doctor considers it safe to do so.

You may also need to have blood tests, X-rays and **CT** or MRI scans to help your doctor check for side effects and monitor your body's reaction to Herceptin therapy.

Please keep all of your doctor appointments so your progress can be checked.

© Side Effects:

Herceptin helps most people with HER2-positive breast cancer but it may have some unwanted side effects in some people.

All medicines can have side effects. Sometimes they are serious, most of the time they are not. You may need medical treatment if you get some of the side effects.

Ask your doctor, nurse or pharmacist to answer any questions you may have.

As Herceptin may be used with other medicines that treat breast cancer, it may be difficult for your doctor to tell whether the side effects are due to Herceptin or due to the other medicines.

For a full list of Herceptin side effects, please see the Herceptin Consumer Medicines Information, available from: www.medsafe.govt.nz/consumers/cmi/h/herceptin.pdf

Tell your doctor if you notice anything else that is making you feel unwell, even if it isn't on this list. Please do not be alarmed by this list of possible side effects: it's important you know what they are. This isn't a complete list of all the possible side effects. Others may occur in some people and there may be some side effects that we don't yet know about.

Will your hair fall out?

Herceptin is generally well tolerated and does not have the same side effects as chemotherapy, such as hair loss, severe nausea and vomiting and increased risk of infection. However, if you receive Herceptin AND chemotherapy you may also experience the side effects of the chemotherapy medicine you are being treated with. See the Herceptin Consumer Medicines Information for a list of side effects you may experience.





What can you do to help yourself?

- · Healthy eating
- · Regular exercise
- Take time to relax and treat yourself

This page has been put together with the help of the Cancer Society. You can find out more at www.cancernz.org.nz

Looking after yourself during treatment with Herceptin and other therapies can make a big difference to how you feel in body, mind and spirit. Time with loved ones, having fun, eating well, exercising and getting plenty of rest can really help. Meditation, yoga and visualisation can be valuable additions to your daily or weekly routine. Prayer and your personal faith and beliefs are of great comfort too.

Eating well

Eating a balanced diet with lots of fruit and vegetables is always good. Foods high in antioxidants and other nutrients are especially valuable and remember to keep your fluids up too. Sometimes you may not feel like eating much so small amounts of food are okay.

Eating safe

Food hygiene is important when you're having cancer treatment. Your body's immune system is more easily affected by bacteria so take extra care about what you eat and how the food has been stored and prepared.

Relax

Rest and relaxation can aid your body's recovery. Exercise – even just a short walk - can increase energy levels and help you relax and sleep better.

Take time every day to rest and enjoy yourself. Laughter is good medicine! Meditation, aromatherapy baths, listening to music, reading a good book, writing a journal or delighting in the company of family and friends are all really good ways to relax.

Regular exercise

Just 30 minutes of moderate physical activity on most days of the week can make you feel better. Arrange for a friend to call by and walk with you.

Put some music on and dance around the house! Light work in the garden on a sunny day is enjoyable and good for you too. If you are unsure about the amount or type of exercise, ask your doctor for some advice.





- ☆ Skylight helping children and young people deal with change, loss and grief www.skylight.org.nz

These links are related to breast cancer or cancer. While the sites have been carefully chosen, we are not responsible for the content of these websites.

Resources: Support organisations

- Sweet Louise Sweet Louise aims to help women with advanced breast cancer lead more positive lives.
 Toll Free: 0800 11 22 77
 Web: www.sweetlouise.co.nz
- Cancer Society of NZ Call the Cancer Information Line for the division nearest you.
 Toll Free: 0800 CANCER (0800 226 237)
 Web: www.cancernz.org.nz
- NZ Breast Cancer Foundation Phone: (09) 304 0766
 Toll Free: 0800 902 732
 Web: www.nzbcf.org.nz
- Breast Cancer Aotearoa Coalition www.breastcancer.org.nz

Glossary of terms

Antigen - a foreign body or substance that stimulates antibodies to be produced.

Cancer - any type of **malignant** growth or tumour caused by the abnormal and uncontrolled division of cells in the body.

Chemotherapy - treatment with medicines that attack and kill rapidly growing cells, including normal cells.

CT - Computed Tomography is a procedure that uses a computer linked to an x-ray machine to make a series of detailed pictures of areas inside the body.

HER2 - a protein found on all cells that helps cells grow and divide. It stands for **H**uman **E**pidermal Growth Factor **R**eceptor Type **2**.

Hormones - substances produced by organs or cells in your body that affect bodily processes. An example is oestrogen.

Lymph - clear fluid that contains white blood cells and travels through the lymph system.

Lymph nodes - pea-sized collections of tissue near the breast under the arm, above the collarbone, and in the chest. They are also found in many other parts of the body.

Lymphatic system - tissues and organs that produce and carry lymph fluid from tissues to the circulatory system. The lymphatic system is a major component of the immune system.

Malignant - a cancerous or potentially dangerous growth.

Metastatic - when cancer cells have spread to other parts of the body.

Monoclonal antibody - an antibody produced outside the body and is designed to target specific **antigens**. A target could be the HER2 protein on the surface of some breast cancer cells.

MRI - Magnetic Resonance Imaging is a radiology technique that uses magnetism, radio waves, and a computer to produce images of body structures.

MUGA - <u>Mu</u>ltiple <u>G</u>ated <u>A</u>cquisition heart scan

Radiotherapy or Radiation therapy-

cancer treatment that uses x-rays, gamma rays, and alpha and beta particles to destroy cancer cells. Radiotherapy is localised to the tumour area.

Receptor - a specific molecule of a cell that recognises and binds with other specific molecules, such as **hormones**.

Subcutaneous injection - an injection given under the skin.



Notes	

Notes



Consumer medicine Information

Herceptin® (trastuzumab), 150mg and 440mg vials for intravenous (IV) infusion and 600mg/5ml solution for subcutaneous (SC) injection, is a **Prescription Medicine** used to treat patients with breast cancer whose tumour has tested positive to HER2.

Do not use Herceptin if: you have early breast cancer and have had an LVEF test (measures how well your heart can pump blood) of less than 45% or you have symptoms of heart failure; you have had an allergic reaction to Herceptin; or benzyl alcohol, or any proteins of Chinese hamster origin.

Tell your doctor if: you have a history of coronary artery disease, poorly controlled high blood pressure, heart failure, cardiac arrhythmia (an abnormal or rapid heartbeat), angina (chest pain); or if you have previously received chemotherapy treatment with medicines known as anthracyclines; you have breathing or lung problems; you are pregnant or breast-feeding, or plan to become pregnant or breast-feed; you are allergic to any other medicines or any other substances such as foods, preservatives or dyes; you are currently taking any other medicines; if you started any new medication within seven months of stopping any previous Herceptin treatment.

Tell your doctor immediately or go to your nearest Accident and Emergency Centre if you notice any of the following: swelling of your face, lips, tongue or throat with difficulty breathing; severe shortness of breath, difficulty breathing or wheezing; severe chest pain spreading out to the arms, neck, shoulder and/or back; rash, itching or hives on the skin; fever or chills; feeling sick (nausea); headache; dizziness; diarrhoea; abnormal or irregular heartbeat; severe swelling of the hands, feet or legs; severe coughing. Possible common side effects may also include: getting tired more easily after light physical activity; shortness of breath, especially when lying down or if it disturbs your sleep; runny or blocked nose or nosebleeds; difficulty sleeping, anxiety or depression; confusion; weakness or soreness in muscles and/or joints; increased cough; feeling dizzy, tired, looking pale; flu and/or cold symptoms, frequent infections with fever, severe chills, sore throat or mouth ulcers; hot flushes; diarrhoea; changes in weight (gain or loss); decrease in or loss of appetite; redness, dryness or peeling of the hands or feet; pain in hands or feet; unusual hair loss or thinning; nail problems; eye problems such as producing more tears, swollen runny eyes or conjunctivitis (discharge with itching of the eyes and crusty eyelids); pain or reaction at the site of injection.

Herceptin has risks and benefits. Ask your oncologist if Herceptin is right for you. Use strictly as directed. If symptoms continue or you have side effects, see your healthcare professional. For further information on Herceptin, please talk to your healthcare professional or visit www.medsafe.govt.nz for Herceptin Consumer Medicine Information.

Herceptin IV is a funded medicine for patients with HER2-positive breast cancer who meet pre-defined criteria. A prescription charge and normal Doctor's fees may apply.

Herceptin SC is not funded by PHARMAC. You will need to pay the full cost of this medicine. A prescription charge and normal oncologist fees may apply.

Consumer panel dated May 2020
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