



Chemotherapy, Immunotherapy and Targeted Treatment

Ngā Maimoa Hahau, Haumanutaunga, me te Whakahāngai



Understanding Cancer

Chemotherapy, Immunotherapy and Targeted Treatment

ANY CANCER, ANY QUESTION

0800 CANCER (226 237)

Cancer Information Helpline

Your general practitioner: phone _____

Your cancer team: phone _____

Your local Cancer Society:_____

24-hour emergency phone 111

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Ka āhei koe ki te tono kape o ngā puka me ngā whārangi pārongo a te Kāhui Matepukupuku mai i tō Kāhui Matepukupuku ā-rohe, mā te waea atu ki te Waea-āwhina Pārongo Matepukupuku 0800 CANCER (226 237) mō tētahi kape, me tikiāke rānei i tō mātou paetukutuku www.cancernz.org.nz.

More information about the Cancer Society can be found at the back of this booklet.

We value your feedback on the information we provide, such as this booklet. There is an online form you can fill in here:

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

About this booklet

The area of cancer treatment is expanding. While chemotherapy remains a key cancer treatment, there are now new ways to treat some types of cancer. Alongside surgery and radiation treatment, these include immunotherapy and targeted treatment.

This booklet provides you with information about chemotherapy, immunotherapy and targeted treatment for cancer.

It looks at each of these treatments, giving you practical information to help answer the questions you may have about them. You will be given more information when you meet your cancer treatment team.

The Cancer Society has a separate booklet on radiation treatment: Radiation Treatment/Haumanu Iraruke.

Kei te whakawhānui haere te taha maimoa matepukupuku. Ahakoa ka noho tonu te mahi hahau hei maimoa matua, kua puta ake ētahi ara hou mō te maimoa i ētahi momo matepukupuku. I te taha o te mahi hāpara me te maimoa iraruke, ko ngā maimoa haumanu-taunga me te maimoa whakahāngai ētahi.

Ka whakarato tēnei puka i ngā pārongo ki a koe e pā ana ki te hahau, te haumanu-taunga me ngā maimoa whakahāngai mō te matepukupuku.

Ka whakamāramatia ia o ngā maimoa nei me tana hoatu pārongo whai kiko hei āwhina ki te whakautu i ngā pātai, tērā pea ka puta ki a koe. Ka whakawhiwhia koe ki ētahi atu pārongo i te wā ka tūtaki koe i tō rōpū maimoa.

The words in **bold** in the text are explained in the glossary (what this word means) at the end of the booklet. Key information in this booklet is translated into Māori.

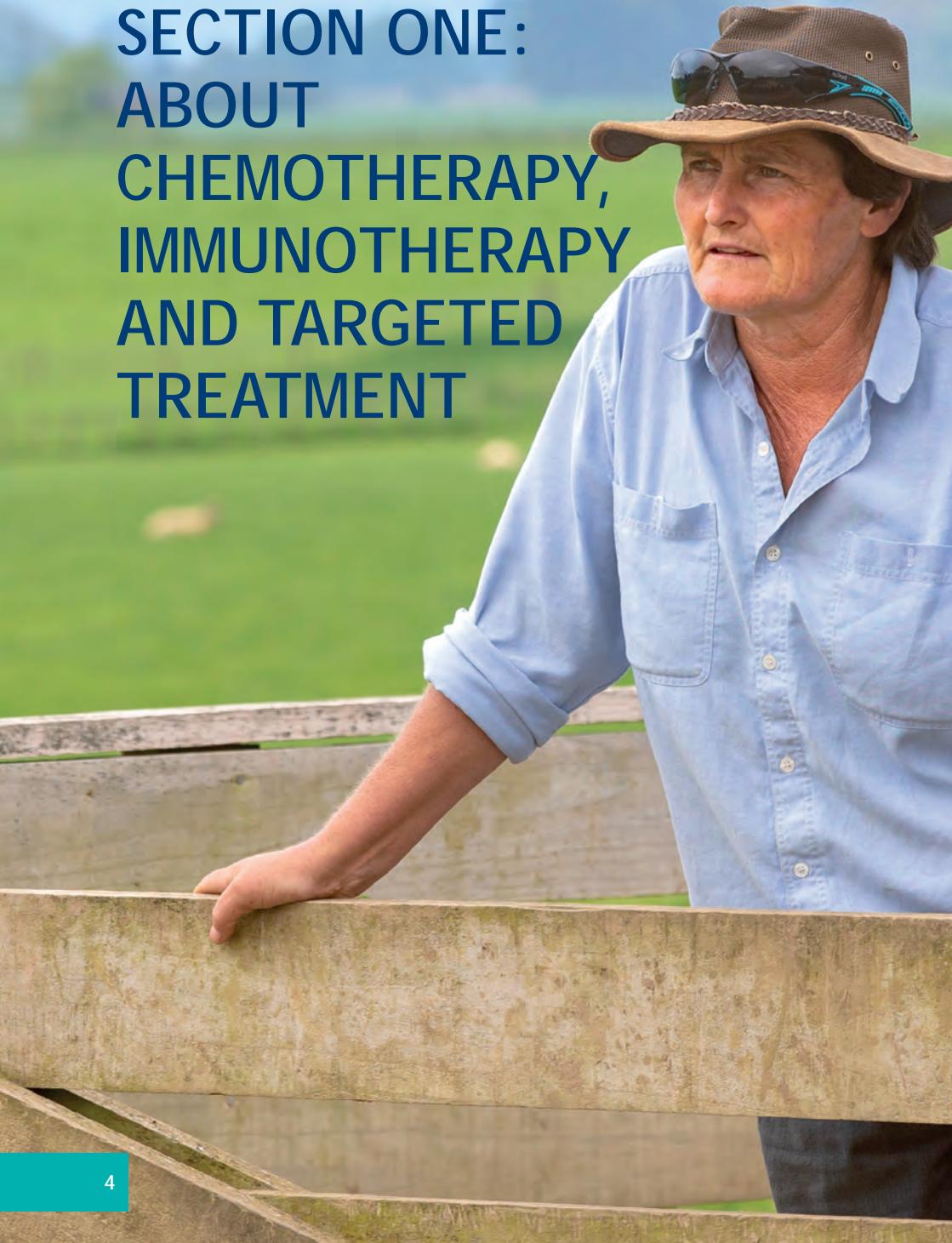


// When I was first diagnosed I set some key values to help me manage during treatment. They've given me strength at times when I've needed to focus day to day instead of on the overwhelming nature of this journey. They are: Courage - be brave, gather knowledge, and remember I can only control the controllable. Heart - smile lots, be positive. Trust - the process, myself, the health professionals and the outcome. //
Rachel

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SECTION ONE: ABOUT CHEMOTHERAPY, IMMUNOTHERAPY AND TARGETED TREATMENT



The area of cancer treatment is expanding. While chemotherapy remains a key cancer treatment, there are now new ways to treat some types of cancer. These include immunotherapy and targeted treatment.

This section explains all of these treatments. They all use medication to stop cancer cells growing while doing the least possible damage to normal cells.

Key points

- Cancer is a disease of our body's cells.
- Chemotherapy is the treatment of cancer using anti-cancer medication. The aim is to kill cancer cells while doing the least possible damage to normal cells.
- Chemotherapy travels through the bloodstream to stop or slow the growth of rapidly dividing cancer cells.
- Occasionally chemotherapy can be given directly into spinal fluid (intrathecal). It can be given as an infusion or a tablet.
- Chemotherapy also affects healthy cells, and you may experience side-effects as a result. It can cause changes in your bone marrow, mouth, stomach, bowel, skin, hair and reproductive organs.
- Immunotherapy is a type of cancer treatment that helps your immune system to fight cancer. It is given as an infusion.
- The side-effects of immunotherapy are different from those of other cancer treatments. You may experience flu-like symptoms, and immunotherapy can cause the immune system to be over-active.
- Targeted treatment targets the damaged genes or proteins of cancer cells to stop the cancer growing and spreading, and there are usually fewer side-effects. It can be given as an infusion or a tablet. Skin problems are a common side-effect of targeted treatment.
- Cancer treatment vaccines work differently from the vaccines used

to prevent disease. Cancer vaccines try to get the immune system to attack cancer cells in the body.

- The aim of the treatment will depend on the type of cancer you have and how far it has spread.
- Some side-effects may need urgent medical attention.

- He mate te matepukupuku pā ki ngā pūtau o te tinana.
- He maimoatanga matepukupuku te mahi hahau mā te whakamahi i te rongoā patu matepukupuku. Ko te whāinga, ko te patu i ngā pūtau matepukupuku me te whai kia kaua e nui rawa ngā pūtau pai e mate.
- Ka haere te hahau mā te ia toto ki te aukati i te tipu, ki te pōturi rānei i te tipu o ngā pūtau matepukupuku e tere wehewehe ana.
- I ētahi wā, hoatuna tauaro ai te hahau mā roto i te wai tinana o te aho tuaiwi (intrathecal). Ka āhei hoki te hoatu mā te whakaawetanga, mā te pire rānei.
- Ka pā hoki te hahau ki ngā pūtau ora, ā, tērā pea ka rongo koe i ētahi papātanga nā runga i tēnei. Ka puta anō hoki he panoni ki tō mongamonga, ki tō waha, tō puku, tō kiri, ō makawe, me ū taihemahema.
- He momo maimoatanga te haumanu-taunga ka āwhina i tō pūnaha taunga ki te patu i te matepukupuku. Ka hoatuna hei infusion.
- He rerekē ngā papātanga ki te taha o te haumanu-taunga ki ērā o ētahi atu momo maimoa matepukupuku. Tērā pea ka puta he tohumate rite ki ngā tohumate o te rewharewha, ā, i ētahi wā ka kaha hohe rawa te mahi o te pūnaha taunga nā te haumanu-taunga.
- Ka whakawhāiti te maimoa whakahāngai i ngā pūtau, i ngā pūmua rānei o ngā pūtau matepukupuku kua kino,

ki te aukati i te tipu me te rauroha haere, ā, i te nuinga o ngā wā, ka iti ake ngā papātanga ki te taha. Ka hoatuna hei infusion, hei pire rānei. He papātanga e kiteatia nuitia ana te raruraru kiri nā runga i te maimoa whakahāngai.

- Rerekē te mahi a ngā kano ārai mate mō te maimoa matepukupuku ki ngā kano ārai mate mō te kaupare mate. Ka whakarite kē ngā kano ārai mate ki te aki i te pūnaha taunga ki te patu i ngā pūtau matepukupuku kai roto i te tinana.
- Ka hāngai te whāinga o te maimoa ki te momo matepukupuku kua pā ki a koe, tae noa ki te whānui o tōna rauroha.
- Me wawe tonu te whai atawhāinga hauora mō ētahi o ngā papātanga ki te taha.

What is cancer?

Cancer is a disease of our body's cells - the tiny building blocks that make up the organs and tissues of our bodies.

Normally our cells grow and divide in an orderly way. Cells receive signals from the body telling them when to divide and grow. When a cell is no longer needed or gets damaged, it gets a signal to stop working and die.

The process of making new cells is controlled by a small number of important genes - the codes that tell our cells how to grow and behave. Sometimes these genes are damaged. If a cell is unable to repair damage to a gene, it may begin to grow in an uncontrolled way.

If damaged cells keep dividing and making more abnormal cells, they will eventually form a lump. This is how cancer begins.

He mate ki ngā pūtau tinana te matepukupuku - ko ngā poraka waihanga itiiti tērā ka waihanga i ngā whēkau me ngā kiko ki ō ūtātou tinana.

I te nuinga o te wā, tipu ai, wehe whakatepe ai o ūtātou pūtau. Ka whiwhi tohu ngā pūtau mai i te tinana ki te aki i a rātou mō te wā me whakawehē, me te tipu hoki, Ka kore ana e hiahiatia te pūtau, ka tūkino rānei, ka whiwhi tohu ia kia mutu, kia mate hoki.

Whakahaeretia ai te hātepe mō te waihanga i ngā pūtau hou mā ētahi ira hiranga, iti rawa - ko ngā tikanga e aki ana i ūtātou pūtau, pēhea tipu ai, pēhea te whano. I ētahi wā ka kino ēnei ira. Ki te kore tētahi pūtau e āhei ki te whakatika i te kino kua puta ki te ira, tērā pea ka heahea te tipu.

Ki te whakawehē haere tonu ngā pūtau kua tūkinotia me tā rātou mahi pūtau tino rerekē, a tōna wā ka puta he puku. Koinei te tīmatatanga o te matepukupuku.

Why you might have treatment

The aim of the treatment will depend on the type of cancer you have and how far it has spread. You may be given chemotherapy, immunotherapy or targeted treatment to:

- cure your cancer
- shrink the cancer before an operation
- help radiotherapy to work more effectively
- relieve some of the symptoms caused by your cancer
- reduce the possibility of your cancer coming back
- help you live longer.

Doctors will recommend the best treatment for you based on your cancer type and stage, your genetic make-up, your age and your

general health. Because of this you may receive different treatments from someone else, even if their cancer type is the same type as yours.

Ka taunaki ngā rata i te maimoa pai rawa mōu e ai ki tō momo matepukupuku me te wāhangā kua eke atu, tō waihangā iranga, tō pakeke me tō hauora whānui. Nā tēnei, tērā pea ka rerekē tō maimoa ki tētahi atu, ahakoa rite tonu tō rātou momo matepukupuku ki tōu.

Chemotherapy treatment

What is chemotherapy?

Chemotherapy is the treatment of cancer using anti-cancer medication. The aim is to kill cancer cells while doing the least possible damage to normal cells.

He aha te hahau?

He maimoatanga mō te matepukupuku te hahau mā te whakamahi i ngā whakapōauau patu-matepukupuku. Ko te whāinga, ko te patu i ngā pūtau matepukupuku me te whai kia iti noa iho te tūkino i ngā pūtau pai.

How chemotherapy works

Chemotherapy travels through the bloodstream to stop or slow the growth of rapidly dividing cancer cells. Cancer cells exposed to chemotherapy medication are less likely to grow back than non-treated cancer cells.

Chemotherapy also affects healthy cells. The effects of chemotherapy on healthy cells cause the side-effects. Healthy cells have the potential to grow again.

Why you might have chemotherapy

Depending on the type of cancer you have, chemotherapy may be the only treatment you need. However, it is often used with other treatments such as surgery or radiation treatment.

Chemotherapy can be used to help shrink your cancer before other treatments such as surgery or radiation are used (**neo-adjuvant therapy**).

If chemotherapy is given after other treatments such as surgery or radiation, it is used to treat any cancer cells that may remain (**adjuvant therapy**), reducing the chance of your cancer returning.

For some types of cancer, chemotherapy given at the same time as radiation can make cancer cells more sensitive to radiation treatment (**chemoradiation**). The combination of treatments may be more effective than having chemotherapy or radiation treatment alone.

Chemotherapy may be used for long periods of time to control the growth of your cancer.

Chemotherapy can be used as a **palliative** treatment to relieve symptoms, such as pain, when your cancer can no longer be cured.

The side-effects of chemotherapy

Chemotherapy can also affect fast-growing healthy cells, such as those in the bone marrow, digestive tract, skin, hair and reproductive organs. This damage to healthy cells is what causes side-effects during chemotherapy treatment. Most side-effects should go within a few weeks, while others can last longer.

Side-effects that need urgent medical attention

Some side-effects of chemotherapy can be very serious. You must contact your cancer treatment team or go to your nearest hospital emergency department **immediately and tell them you are receiving chemotherapy treatment** if you develop any of the following symptoms:

- *Fever - a temperature over 38°C*
- *Chills - shivers or shakes, feeling hot or cold*
- *Vomiting that continues after taking anti-sickness medication*
- *Diarrhoea - four or more loose bowel movements than usual and/or diarrhoea*
- *Gum or nose bleeds, or unusual bleeding (if bleeding does not stop after 10 minutes of ice and pressure)*
- *Pain - burning or blood in urine*
- *Chest pain*
- *Difficulty breathing*

It is important that you do not wait until the next morning or after the weekend to seek assistance.

I ētahi wā, he tino taumaha tonu ngā papātanga ki te taha o te mahi hahau. Me kakama te whakapā atu ki tō rōpū maimoa, me haere rānei ki te wāhi mate ohorere o te hōhipera pātata ki a koe i taua wā tonu, ka kōrero atu ki a rātou kei raro koe i ngā maimoatanga hahau mehemea ka puta tētahi o ngā tohumate e whai ake nei:

- te kirikā - he pāmahana 38°C, neke atu ranei.
- te makariri - te tuawiri, te whērūrū, te rongo i te wera, i te mātao rānei
- te ruaki haere tonu whai muri i tō kai rongoā e tika ana mō te aukati i te hia ruaki
- te korere - ki te haere koe ki te wharepaku nui ake i te whā ngā wā/ki te hia korere rānei
- te toto ki ō pūniho, ki tō ihu rānei, ki te rere rerekē tō toto (ki te kore e mutu te rere o te toto whai muri i te tekau meneti o te panipani ki te hukapapa, te mahi i te pēhitanga rānei)
- te mamae - he toto kei roto i tō mimi, he wera rānei ka mimi ana koe
- te mamae ki tō uma
- te uaua ki te whakahā



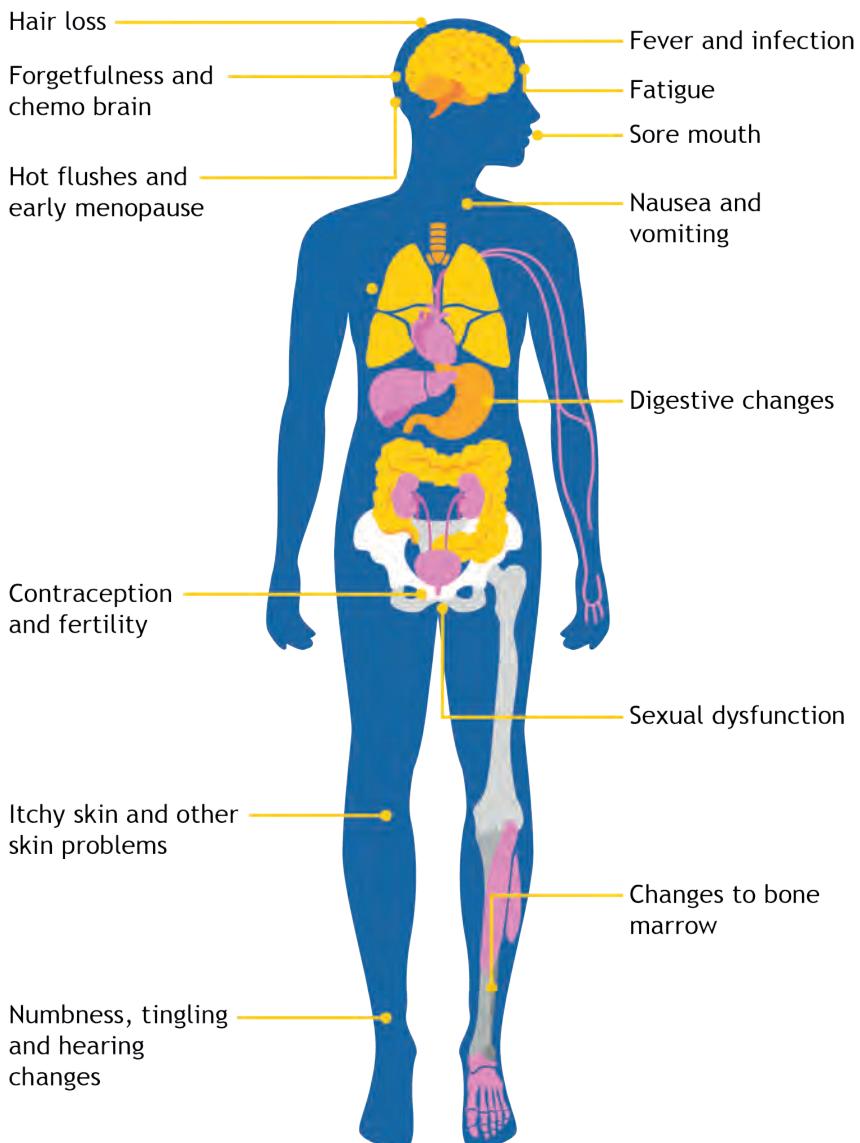
I found the hospital admitted you very quickly, which is great. I did feel like I shouldn't burden the hospital and I would end up waiting forever. This was not the case and I found you'll be seen promptly.

Ben



The diagram below describes some of the common side-effects of chemotherapy treatment. See more details in section five of this booklet.

Common side-effects of chemotherapy





Immunotherapy

What is immunotherapy?

Immunotherapy is a type of cancer treatment that helps your own immune system to fight cancer.

How does immunotherapy work?

Your immune system protects you from disease by killing bacteria and diseases. It also helps to fight cancer. A T cell is one type of immune cell that does this.

Sometimes a part of your immune system is 'turned off' so it no longer recognises the abnormal cell growth that causes cancer. Immunotherapy helps to 'turn on' this part of your immune system so that it can identify and attack cancer cells.

// The doctors gave me six months. I've had Pembrolizumab and I'm going strong 18 months later. I'm feeling really good. //
Karen

Why you might have immunotherapy

Currently, immunotherapy is mostly used with people who have advanced cancer. It is not yet as widely used as surgery, chemotherapy and radiation treatment.

In New Zealand, checkpoint inhibitor immunotherapies pembrolizumab (Keytruda) and nivolumab (Opdivo) are now available and subsidised for use in advanced melanoma.

Immunotherapy is being studied for use in many other types of cancer. The treatment is not right for everyone, so talk to your doctor to find out whether you might benefit from it.

Types of immunotherapy

Checkpoint inhibitors

Cancer cells can trick the immune system by turning off the T cells, stopping them recognising and attacking the cancer cells.

T cells have proteins on them that turn on the immune system when it needs to fight infection, and other proteins that turn off the immune system when it is no longer needed. These are called checkpoints.

Medications called checkpoint inhibitors turn the T cells back on so they can recognise and attack the cancer cells. You can find more detail on these treatments in appendix 1.

Cancer vaccines as a treatment

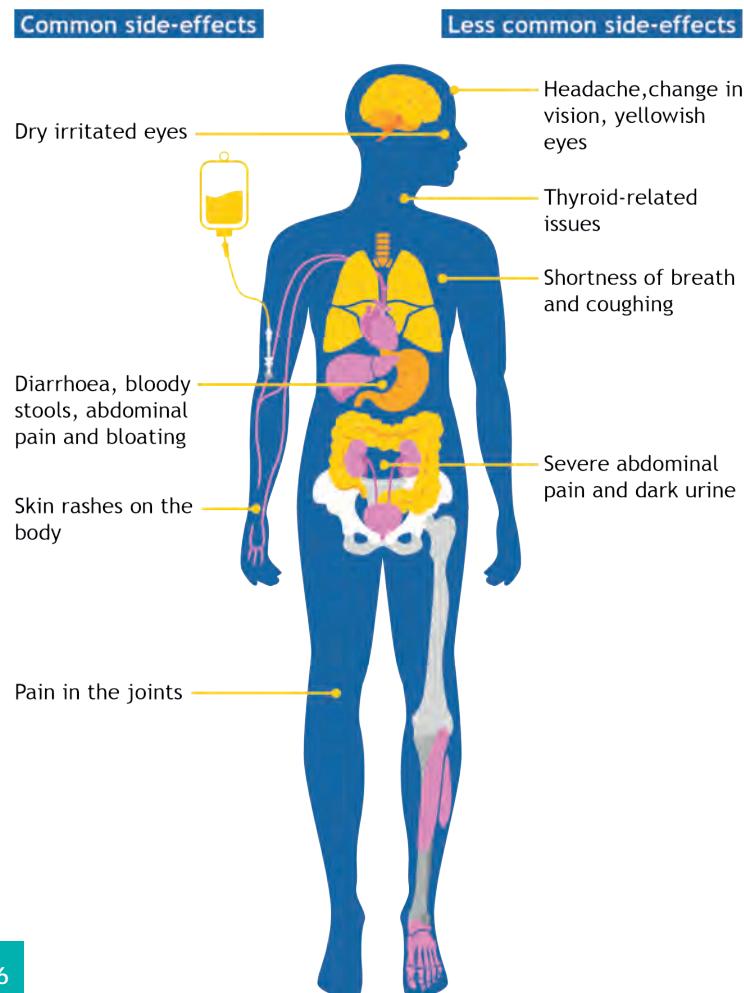
Cancer treatment vaccines work differently from the vaccines used to prevent viruses (**diseases**).

Cancer vaccines aim to get the immune system to attack cancer cells in the body. Instead of preventing diseases, they are used to get the immune system to attack a disease that already exists. An example of this is the BCG vaccine used to treat some types of bladder cancer.

What are the side-effects of immunotherapy?

The side-effects of immunotherapy vary depending on the type of treatment you receive and how your body responds. Side-effects will be different from those of other cancer treatments. Immunotherapy can cause flu-like symptoms and your immune system to be over-active, resulting in a range of side-effects. This is your body's expected response to the treatment.

Possible side-effects are shown in the diagram below:



Targeted treatment

What is targeted treatment?

This is a type of treatment that targets the damaged genes or proteins of cancer cells to stop the cancer growing and spreading. It is sometimes called biological therapy.

How targeted treatment works

Targeted treatment medication travels through the bloodstream. Each medication blocks a specific target, for example a damaged gene or protein, on or within a cancer cell. Blocking these targets can kill cancer cells or slow their growth. The signs and symptoms of cancer reduce or disappear and damage to healthy cells is minimal.

Why you might have targeted treatment

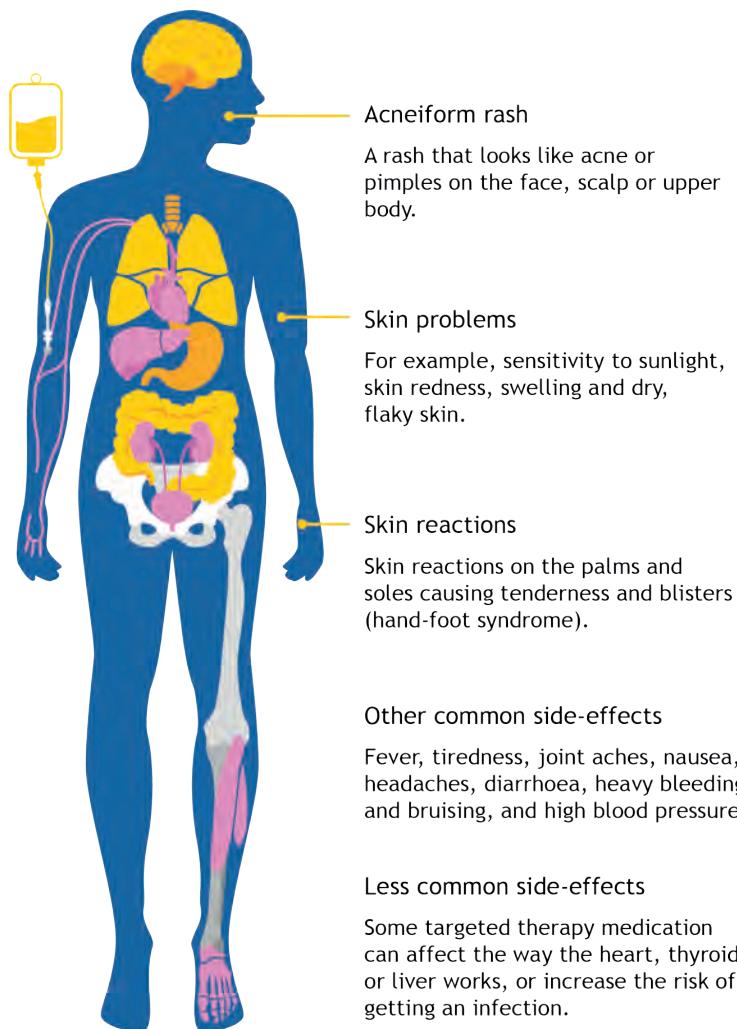
If your cancer contains a change in a specific gene or protein that is helping your cancer to grow, you may benefit from targeted treatment. To find out if your cancer contains these changes, your doctor will take a tissue sample from your cancer and send it to a laboratory for molecular testing. It may take anywhere from a few days to a few weeks to receive the results.

Targeted treatment may be used:

- after surgery to destroy any remaining cancer cells
- to treat advanced cancer that hasn't responded to other treatment, or cancer that has come back
- as maintenance treatment for advanced cancer to try to prevent the cancer coming back.

Possible side-effects of targeted treatment

Although targeted treatment reduces harm to healthy cells, it can still have side-effects. These vary greatly, depending on the medication used and how your body responds. Some people don't experience any side-effects and others have more than one. This diagram shows the side-effects you may experience.



Skin changes after targeted treatment

Skin problems are common with targeted treatment. It is important to report any skin changes or rashes to your cancer treatment team. Do not be tempted to use any over-the-counter products to help ease any discomfort. Your doctor may prescribe you an antihistamine or steroid cream to help with itching or dryness.

It is important to protect your skin from exposure to UV (ultra-violet) rays as it may make skin changes worse.

The types of targeted treatment you may be given

Targeted treatment uses medications to target specific genes or proteins either inside cancer cells or on their surface. Targeted treatment only works if a cancer cell has the gene or protein that the medication is trying to block - so it isn't given to everyone.

Most targeted treatments are either monoclonal antibodies or small-molecule inhibitors.

Monoclonal antibodies

Monoclonal antibodies are man-made copies of immune system proteins (antibodies). Monoclonal antibodies block a target on the outside of a cancer cell so that it can't do its job. Types of monoclonal antibodies include:

- HER2-targeted agents
- angiogenesis inhibitors
- anti-CD20
- EGFR inhibitors.

Some monoclonal antibodies work like immunotherapies by attaching themselves to specific proteins on cancer cells.

Small-molecule inhibitors

Small-molecule inhibitors describe many of the other types of targeted treatment medication that are not monoclonal antibodies. Small-molecule inhibitors block a target inside a cancer cell to stop its action. Types of small-molecule inhibitors include:

- tyrosine-kinase inhibitors
- PARP inhibitors
- mTOR inhibitors
- CDK4/6 inhibitors.

You can find more detail on each of these treatments in Appendix 1.

How treatments may act with other medications

Chemotherapy, immunotherapy and targeted treatment can interact with common medicines and cause harmful side-effects. It is important to let your cancer care team know about any other medicines or supplements you are taking so they can check for any known interactions. It is also a good idea to talk with your cancer care team before having any vaccinations.

SECTION TWO: MAKING TREATMENT DECISIONS



Key points

- The treatment recommended for you will depend on the type of cancer and the stage you are at, your health and other treatments you may have had.
- You will see a combination of health professionals during your treatment that will include oncologists, specialist cancer nurses, registrars and house surgeons (doctors).
- Your treatment could last anywhere from several weeks to several months depending on how your body responds.
- You may need to consider getting a second opinion or taking part in a clinical trial.
- Cancer Connect is a free telephone peer-support programme that may be useful to you.

- Ka hāngai te maimoa ka taunakitia mōu ki te momo matepukupuku me te wāhangā kua eke tō matepukupuku, ki tō oranga me ētahi atu maimoa tērā pea i whāia e koe.
- Ka kite koe i tētahi kōwhiringa mātanga hauora i te wā o tō maimoatanga, tae noa ki ngā mātai **matepukupuku**, ngā mātanga tapuhi matepukupuku, ngā pouroki, me ngā rata hoki.
- Tērā pea ka haere o maimoatanga mō te maha o ngā wiki, ki te maha o ngā mārama, e ai ki te uruparenga o tō tinana.
- Tērā pea me whakaaro koe ki te whai tohutohu tuarua, ki te whakauru ki tētahi whakamātau haumanu.
- He hōtaka tautoko aropā utukore te Cancer Connect, tērā pea ka whai hua mōu.



How treatment decisions are made

Your cancer treatment team will discuss the treatment options for your cancer with you. Which treatment is recommended for you will depend on:

- the type of cancer you have
- how far your cancer has spread (the stage)
- other cancer treatments you may have had
- your general health
- if treatment is funded or not.

If you are offered a choice of treatments, including no treatment for now, you will need to weigh up the advantages and disadvantages. If only one type of treatment is recommended, you may want to ask your cancer treatment team to explain why other treatment choices have not been advised.

If you have blood cancer, 'watch and wait' may be a key part of treatment. While this waiting can feel difficult it is shown that you are no more at risk of your cancer getting worse than those receiving treatment. The decision to start treatment needs to be managed

carefully as your blood cells and platelets are already weakened. A side-effect of treatment is to weaken them further. Your treatment team will monitor you very closely.

Funded immunotherapy and targeted treatment are only available when certain criteria are met. Please discuss these with your specialist.

Ki te whakaratoa koe me he kōwhiringa o ngā maimoatanga, tae noa ki te kore maimoa, me ata whakaaro hia e koe ngā piki me ngā heke. Mehemea kotahi noa iho te momo maimoa ka taunakitia, tērā pea ka hiahia koe ki te pātai i tō rōpū maimoa matepukupuku ki te whakamārama te take kīhai i whakaratoa ētahi atu kōwhiringa.

Ka wātea anake ngā maimoa haumanutaunga me te whakahāngai i te wā ka tutuki ētahi paearu. Me kōrero mō ēnei me tō matanga.

Some immunotherapies and targeted treatments need specific testing on a sample of a tumour before a decision can be made on which treatment is right for you. If you have a pre-existing health condition chemotherapy, immunotherapy or targeted treatment may not be right for you.

Making decisions about treatment is not always easy. It is important to not be rushed into a decision - it needs to be the right one for you.

Ehara ngā whakataunga mō te whai maimoa i te mea māmā. He mea nui, kia kaua e tere rawa tō whakatau ko tēhea - ko te mea nui, ko te mea e tika ana mōu.

|| At first I wondered if ignorance was bliss, but after a week I thought, 'No'. It's my body and I want to know what is going to happen, and I want to know if I make a decision what will happen. ||
Silei



Your cancer treatment team

You will see many health professionals during your treatment. These include oncologists, specialist cancer nurses, registrars and house surgeons (doctors). You may see a social worker, radiation specialists , or a **dietician**. If you have blood cancer you may see a haematologist.

Before you see your cancer treatment team, it may help to write down any questions you have. Taking notes during the session and bringing a family/whānau member or friend will be helpful. Some people like to record the discussion, but you would need to let the doctor know you wish to do this.

If there is something you do not understand, it is OK 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?

// I'm the type of person to ask questions, and they [the team] were really kind. Not patronising 'kind'. They were very patient explaining to me. //
Silei

Mehemea kāore koe i te mārama ki tētahi mea, he pai noa te kī:

- tēnā koa, whakamāramatia mai anō?
- kīhai au i te tino mārama ki tikanga o tō kōrero
- tēnā koa, tuhia mai he pikitia, tuhia mai rānei te korero

Your cancer treatment team will keep a close eye on you during your treatment. You may have blood tests and scans along the way to see how the treatment is working.

How long your treatment might last

Your treatment could last anywhere from a few weeks to many months. Treatment cycles are usually two to four weeks apart. Spacing out your treatment in this way gives your body a chance to recover from any side-effects. Some treatments, such as blood cancer treatments, require a tablet being taken for a much longer time.

Talking with others

Once you have discussed treatment options with your doctor and family/whānau, you may want to talk them over with someone else. Talking it over can help you to decide what choice is right for you.

You may be interested in Cancer Connect, run by the Cancer Society. This is a free telephone peer-support programme. Phone the Cancer Information Helpline 0800 CANCER (226 237) for more information on this programme.

A second opinion

At any time you may want to get a second opinion from another cancer specialist. You can ask your cancer treatment team or your GP to make a referral for you.

Taking part in a clinical trial

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

Sometimes these trials give you access to better medications than would be available outside a study. Trials are also used to test the effectiveness and side-effects of medications that have not been widely used so that they may be used in the future. You should discuss this with your cancer treatment team.

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

In randomised clinical trials you will either receive the standard treatment currently available or the new treatment being tested. Many people all over the world have taken part in clinical trials that have improved cancer treatments, but not all medications tested in trials turn out to be helpful.

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



Finding out more from your cancer treatment team

You may like to learn more from your cancer treatment team.

Consider asking questions about:

- the possible advantages and disadvantages of chemotherapy, immunotherapy and targeted treatment
- the side-effects you might experience
- the difference that waiting would make
- whether treatment would cure or simply control your cancer
- what would happen if you don't have treatment
- how long your treatment might last and how often you will have to have it
- how your treatment will be given
- if you will need to stay in hospital
- how treatment might affect your day-to-day life now and in the future
- how likely it is that the treatment will work for your situation
- if there is anything you need to be particularly careful about during and/or after treatment.

SECTION THREE: WHAT TO EXPECT FROM TREATMENT



Key points

- A blood sample may be taken before you have treatment.
- You may be treated at hospital as an outpatient.
- Many people keep working during their treatment and arrange time off or apply for sick leave for hospital appointments.

- Tērā pea ka tangohia he toto i mua i tō whai i te maimoa
- Tērā pea ka whai tō maimoatanga ki roto i te hōhipera, hei tūroro noho kāinga rānei.
- Mahi tonu ai te nuinga o te hunga i te wā e whai maimoa ana, ā, me tā rātou whakarite whakamatuatanga mate mō ngā haerenga ki te hōhipera.



Before treatment is given

Before you have treatment, a blood sample may be taken. This test is to ensure that it is safe for you to continue receiving your treatment. Tests may include a full blood count, kidney and liver function tests, and sometimes tumour markers.

Will you have to stay in hospital?

Usually you will have to spend a few hours at the treatment centre for each treatment, as an outpatient. It is a good idea to take a book or something to listen to, or you may want to take a friend/whānau member to talk to.

Some people need to stay in hospital for a short period of time for each treatment. If you live more than 100 kilometres away from the treatment centre, ask your cancer treatment team if you qualify for subsidised accommodation through the National Travel Assistance Scheme. In some special situations travel or accommodation may be approved for distances less than 100 km.



Continuing to work while receiving treatment

Many people keep working during their treatment and arrange time off or apply for sick leave for hospital appointments. Some people discuss the option of working part-time with their employers. Others take extended breaks for the whole course of their treatment. You may find it useful to read our information sheets on: *Managing cancer in the workplace* and *Cancer, insurance, legal and employment issues*.

If you can no longer work because of the effects of your cancer, you may be entitled to receive income support from the Ministry of Social Development - Work and Income. For more information, talk to a social worker or see the Cancer Society's information sheets *Benefits and entitlements* and *Benefits and entitlements: What happens when you apply for Work and Income support?*. If you are not eligible to receive income support but are having difficulty managing your finances, you may find it useful to talk to a budget advisory service. The website www.moneytalks.co.nz can direct you to some useful support.

You might like to ask your cancer treatment team:

- how you might know that your treatment is working
- if you can drive after treatment
- what special precautions you need to take at home
- if you need to stay in hospital and, if so, for how long.

SECTION FOUR: HOW TREATMENT WILL BE GIVEN



Key points

- Medications to treat your cancer can be given in different ways. These can be taken orally or via **intravenous** (IV) cannula, central venous access devices (CVADs) and injections.
- If you are having chemotherapy or other treatments at home, such as tablets or through a pump, there are some precautions you need to take.
- It is important to let your cancer treatment team know about any other medications or supplements you are taking so they can check for any known interactions.

- He maha ngā huarahi taea ai te hoatu i te rongoā hei maimoa i tō matepukupuku. Ka taea mā te waha, mā te pūkawe whāngai-ā-iaia (IV), cannula, mā ngā taputapu whai wāhi uaua matua (CVADs) me ngā werongā rānei.
- Mehemea kei te whakamahi koe i te hahau, i ētahi atu maimoa rānei i te kāinga, pērā ki ngā pire, mā te papu rānei, tērā ētahi whakatūpato me matua whai koe.
- He mea nui kia whakamōhio koe i tō rōpū maimoa mēnā kei te kai rongoā atu koe, whakapiri rānei, kia pai ai tā rātou tirotiro mehemea he taunekeneke atu anō e mōhiotia ana.

Oral treatments

Some medications are given as tablets that you take at home. It is very important that you take your tablets when and how they are prescribed. Make sure you understand the side-effects and who to contact if you have problems. Even though you're having this treatment at home, it is no different from medications given at the hospital in the way it works and the possible side-effects.



Cannula

A cannula is a small tube that is put into a vein in your arm or the back of your hand. It is put in by the nurse when you go for treatment and removed before you go home. A treatment cycle is up to three weeks.

If you have a drip (IV infusion) you'll feel a brief sting as the cannula goes in and then the pain should stop. If the pain continues, or starts during the infusion, let the cancer nurse know immediately.

Often, two or more medications are given together. You'll probably be given your medication by slow injection or drip into a vein through the cannula, or via a portable infusion pump.

Central venous access devices (CVADs)

When there is difficulty finding a suitable vein or when treatment will be given for a long period of time, you may need a central venous access device (CVAD).

A CVAD will be put in under an anaesthetic (general or local) and may be left in for many months. When in place the line may be stitched in



or covered with a special dressing to keep it in place. It allows the medication to be delivered directly into your bloodstream.

Types of CVADS commonly used are peripherally inserted central catheters (PICCs), portacaths and Hickman catheters.

Peripherally inserted central catheter (PICC)

A PICC is inserted into a vein through the skin in the bend or upper part of the arm, and threaded through until the end of the tube lies in a vein near your heart.





Portacath (an implantable port)

A portacath is a thin, soft tube with a rubber disc at the end. It is inserted under the skin, usually on your chest, with the tube going into a vein near your heart. A needle is passed through your skin and into the port. Once in place, you can feel and see the port as a small lump underneath the skin. Nothing shows on the outside of your body. The skin over the port can be numbed with an anaesthetic cream or spray first.

Hickman catheter

Hickman catheters are long, thin tubes inserted under the skin on your chest and into a large vein near your heart. They are stitched in place and usually remain there for the length of your treatment.



Possible problems with CVADs

The two main possible problems with CVADs are blockage and infection. If you notice any changes like the ones below it is important to contact your treatment team immediately:

- High temperature (over 38°)
- Soreness, redness or darkening around the CVAD or fluid leaking from the skin around the area
- Swelling of your arm, chest, neck or shoulder
- Pain in your chest, arm or neck
- Feeling shivery or unwell after your CVAD has been flushed.

Intrathecal (into the spinal column)

Many medications do not reach the brain, the spinal cord or the fluid surrounding them. If you are having intrathecal treatment your doctor will inject the treatment through a needle into your cerebrospinal fluid (the fluid surrounding and protecting the brain and spinal cord). This procedure is called a lumbar puncture and is done under local anaesthetic.

Treatments at home

If you are having chemotherapy or other treatments at home, such as medications through a pump, there are some things to remember:

- Medications may need to be stored in a particular way, such as in the fridge. Always follow the instructions given.
- Other people in your household should avoid direct contact with your cancer medications and avoid picking them up with bare hands. They should be stored out of reach of children.
- If you are having continuous intravenous treatment via a small, portable transfusion device and you notice the drug leaking from the pump or tube, you should close the clamps on the pump, wrap it in a plastic bag and wash your hands. Most treatment centres

provide spill or leakage kits that include instructions on what to do if your pump leaks. You should contact your cancer treatment team immediately afterwards.



Using other medications and treatments

Many cancer treatments can interact with common medicines and cause harmful side-effects. Some alternative, complementary and traditional healing methods may react with the treatment you receive.

He nui tonu ngā maimoa matepukupuku ka pāhekoheko me ngā rongoā pātahi, me te aha, ka puta ngā pānga weriweri ki te taha. Tērā pea ka hohe ētahi hātepe whakaoranga whiringa, whakaoranga rerekē, me ngā whakaoranga taketake rānei, ki te maimoa ka whiwhi koe.

It is important to let your cancer treatment team know about any other medications or supplements you are taking, so they can check for any known interactions. It is also a good idea to talk with your cancer treatment team before having any vaccinations.

He mea nui kia whakamōhio koe i tō rōpū maimoa mēnā mō ētahi atu rongoā, whakapiri rānei kai te whai koe, kia pai ai tā rātou tirotiro mehemea he taunekeneke atu anō e mōhiotia ana. He mea nui hoki ki te kōrero ki tō rōpū maimoa i mua i tō whai i ngā kano ārai mate.

You might like to think about asking your cancer treatment team about:

- anything you need to be careful about during treatment and after treatment
- what side-effects you might expect
- how long your treatment might take
- if you can take your usual medications.



SECTION 5: LOOKING AFTER YOURSELF DURING TREATMENT



Key points:

- Side-effects can begin within days of starting treatment, but it is more common for them to occur weeks or even months later.
- If you are experiencing any treatment-related side-effects it is important that you speak to your cancer treatment team.
- A high temperature (over 38°) can be a sign that your body has an infection. Or you may feel unwell, have the chills, be shivering and/or have headaches without a high temperature. Do not wait to see what happens. Contact your cancer treatment team or go to your nearest hospital emergency department immediately and tell them you are receiving treatment for cancer.
- Fatigue is a very common side-effect and can be difficult to cope with.
- You may experience many different side-effects after treatment and there are ways to manage them.
- The Cancer Society has an information sheet, Coping with the Side Effects of Chemotherapy and Radiation Treatment, which is available on our website www.cancernz.org.nz.

- Tērā pea ka tīmata ngā pānga ki te taha i ngā rā whai muri tata i te tīmatatanga o tō maimoa, engari i te nuinga o te wā, kia pau rā anō ngā wiki ngā mārama rānei, katahi anō ka puta.
- Mehemea kei te rongo koe i ētahi pānga ki te taha nā runga i te maimoa, he mea nui kia kōrero koe ki tō rōpū maimoa matepukupuku.
- He tohu pea te pāmahana teitei (nui ake i te 38°) kua puta he whakapokenga ki tō tinana. Tērā pea kei te rongo koe i te māuiui, te makariri, kei te tuawiri koe, kei te ānini rānei tō māhunga, hāunga te whai pāmahana nui. Kaua rawa e tatari kia kite koe kei te aha. Me whakapā wawe atu koe ki tō rōpū maimoa, me haere rānei ki te wāhi matepukupuku ohorere o te hōhipera pātata ki a koe, ka kōrero atu kei te whai maimoa matepukupuku koe.
- Ko te ngenge tētahi pānga ki te taha e kiteatia nuitia ana, ā, he uua ki te whakahaere i ētahi wā.
- Tērā pea ka rongo koe i te maha o ngā papātanga ki te taha rerekē whai muri i te maimoa, ā arā hoki ētahi huarahi hei whakahaere i ēnei.
- Kei te Kāhui Matepukupuku tētahi whārangī pārongo: Coping with the Side Effects of Chemotherapy and Radiation Treatment: fever, nausea (feeling sick), kei runga i tō mātou paetukutuku www.cancernz.org.nz.

Managing common side-effects

Side-effects can begin within days of starting treatment, but it is more common for them to occur weeks or even months later.

If your side-effects are severe, your cancer treatment team may reduce the dose to see if that helps. Most side-effects are temporary and will lessen once you have completed your treatment. Occasionally

they are permanent. Your cancer treatment team will discuss the risks with you.

Some side-effects of targeted treatment may be more severe or last longer than those of other types of treatment and may need to be managed differently. If you are experiencing any treatment-related side-effects, it is important that you speak to your cancer treatment team.

There are many ways that side-effects can be managed.

Infection, high temperature and feeling unwell

A high temperature (over 38°) can be a sign that your body has an infection. You may also have other symptoms, such as chills, shivering and headaches.

It is also possible to have an infection without having a high temperature – you may just feel unwell.

During treatment for your cancer, the number of white blood cells (cells that fight infection) may be reduced. This will mean that your body is unable to fight infection in the usual way. The risk of infection is serious and the first sign of increased temperature or feeling generally unwell requires urgent medical attention.

Do not wait to see what happens.

It is important to contact your cancer treatment team or go to your nearest hospital emergency department immediately, and tell them you are receiving treatment for cancer.

He tohu pea te pāmahana teitei (nui ake i te 38°) kua puta he whakapokenga ki tō tinana. Tērā pea kua whai koe i ētahi atu tohumate, pērā ki te makariri, te tuawiri me te ānini o te māhunga.

Ka taea te whai whakapokenga hāunga te whai pāmahana teitei rawa - tērā pea kei te māuiui noa iho koe.

Ka heke haere pea ngā pūtau toto mā (ngā pūtau patu whakapokenga) i te wā o te maimoa mō tō matepukupuku. Ko te tikanga o tēnei, kīhai tō tinana e āhei ki te patu i te whakapokenga ā-māori nei. He taumaha te mōrea o te whakapokenga, me kakama tonu te whai tirohangā hauora ohorere i tō mōhiotanga tuatahi kei te piki tō pāmahana, kei te māuiui rānei koe .

Kaua e tatari noa iho kia puta tētahi mea.

He mea nui kia whakapā wawe atu koe ki tō rōpū maimoa, haere rānei ki te wāhi mate ohorere o te hōhipera pātata ki a koe, ka kōrero atu ki a rātou, **kei te whai maimoa koe mō te matepukupuku.**

Signs of anaemia - low red blood cells

During treatment for your cancer, the number of red blood cells (cells that carry oxygen around your body) may be reduced. You may feel tired, low in energy, dizzy, light-headed or breathless. These are all symptoms of anaemia.

Your cancer treatment team will take regular blood tests to check the levels of red blood cells in your body. If these become too low and you are experiencing symptoms, you may need a blood transfusion. Your cancer treatment team will talk to you about the risks and benefits of this.

Signs of low platelets

During treatment for your cancer, the number of platelets in your blood (cells that help the blood to clot and prevent bleeding) may be reduced.

Low platelet levels can increase the risk of bleeding, and you may bruise easily. You may notice that you bleed easily when cleaning your teeth or experience nose bleeds. **Any signs of unusual bleeding should be reported to your cancer treatment team immediately.**

Your cancer treatment team will take regular blood tests to check the platelet levels in your blood. If these become too low and you are experiencing symptoms, you may need a platelet transfusion. Your cancer treatment team will talk to you about the risks and benefits of this.



Fatigue (feeling unusually tired)

Fatigue is a very common side-effect of treatment and can be difficult to cope with. It often gets worse as treatment goes on, making it hardest to manage towards the end of and after treatment.

Your fatigue will begin to ease when treatment is over. But it can take several months until you feel your energy increasing.

Tips to manage fatigue:

- Staying active during treatment may help you to manage fatigue.
- Regular gentle exercise, such as short walks, has been shown to be helpful in relieving fatigue.
- Do only as much as you feel comfortable doing.
- Plan rest times in your day while aiming to keep your usual day and night routines.
- Drink plenty of fluids and eat well.
- Ask for some help from family/whānau, friends and neighbours - tell them what you need.

Read the Cancer Society information sheets *Cancer-related fatigue* and *If you have difficulty sleeping* for more information.

Feeling sick (nauseous) or vomiting (being sick)

Not everyone feels sick or vomits after treatment, and immunotherapy and targeted treatment are unlikely to make you feel sick.

Medication is often given to prevent sickness occurring. It is easier to prevent sickness than to treat it once it has started. If you do feel sick you will find that it usually starts several hours after treatment.

Anti-sickness and anti-nausea medication has greatly improved in

recent years. It is important to take your medication for nausea as prescribed.

If nausea or vomiting continues for longer than 24 hours or you are unable to hold down any fluids, contact your cancer treatment team. After hours - contact your cancer treatment team or go to your nearest emergency department or after-hours service.

If you are feeling sick here are some ideas to try:

- Eat lightly before each treatment.
- Eat smaller amounts more often.
- Eat your main meal at the time of the day when you feel best.
- Dry toast or crackers often helps.
- Try drinking clear, cool drinks.
- It may help to avoid alcohol and limit caffeine, milk products and high-fat foods.
- If cooking or cooking smells makes you feel sick, ask others to cook for you, or prepare meals between treatments and freeze them.
- Some people find relaxation or meditation helps them to feel better.

The Cancer Society has an information sheet, *Coping with the Side Effects of Chemotherapy and Radiation Treatment: Fever, nausea (feeling sick)*, which is available on our website.

Contact your local Cancer Society or phone the Cancer Information Helpline 0800 CANCER (226 237) for advice on relaxation programmes or see our website www.cancernz.org.nz.



Bowel problems

Some cancer treatments are known to cause diarrhoea and constipation. You may be prescribed medication to control these. Make sure you take these medicines as prescribed.

Drink plenty of liquid to replace the fluid you are losing with diarrhoea and try to avoid:

- alcohol
- caffeine
- milk products
- high-fat foods
- high-fibre foods.

If diarrhoea or constipation persists it can make you very unwell. Seek urgent medical attention and advice from your cancer treatment team.

If you are constipated, try to eat more fibre (cereals, raw vegetables and fruit) and drink plenty of liquid. Gentle exercise, such as short walks, can help to improve constipation. Talk to your cancer treatment team for more advice.

Sore or dry mouth and throat

Cancer treatment medication can give you a sore mouth or mouth ulcers.

If your mouth is very sore, or you get ulcers or thrush (a white coating in the mouth), see your cancer treatment team straight away for advice on treatment.

It is important to keep your teeth, gums and mouth very clean during your treatment to help stop infections. Your cancer treatment team can show you how to do this. Use a very soft toothbrush or a cotton bud for your teeth and gums, and avoid vigorous or rough brushing.

Use a mouthwash regularly. Ask your cancer treatment team for advice or you can make one yourself by mixing one teaspoon of salt and one teaspoon of baking soda (sodium bicarbonate) in four cups of warm water. Use it four times a day after meals or as often as you need to.

Eat soft foods and have lots to drink. Avoid anything with a high acid level such as grapefruit, tomatoes or oranges, and avoid spicy foods and alcohol. Use a lip salve or ointment on your lips if they are dry.

If your mouth or throat is dry and you have trouble swallowing, try some of these ideas:

- Suck on ice blocks.
- Drink lots of liquids.
- Moisten foods with butter or sauces.
- Dunk dry biscuits in tea.
- Ask your dentist, doctor or nurse about artificial saliva.
- Blend foods, and eat soups and ice cream.
- Smoking and vaping should be avoided.

You may find the Cancer Society booklet *Living with a dry mouth/Te noho me te waha maroke* helpful.

Changes in appetite

Treatment can affect your appetite. Your sense of taste and the texture of food may change during treatment. You may find that all foods taste the same, have no flavour or taste metallic.

It is important to try to eat as well as you can to keep up your energy levels and avoid weight changes. If you do not feel like eating, try eating small snacks often. Keep snacks such as nuts, grated cheese and dried fruit handy.

- You might find the Cancer Society's booklet *Eating Well during Cancer Treatment/Kia Pai te Kai i te wā Maimoatanga Matepukupuku* helpful.
- A Cancer Society information sheet, *Taste changes with chemotherapy and radiation treatment*, is available on our website.
- Talk to your cancer treatment team for more advice. They may be able to refer you to the hospital or a community dietitian.



Losing your hair

Some people don't lose their hair during treatment for cancer. Other people find that their hair becomes thin and dry, while some people lose all the hair from their head and their body. Whether this happens to you depends on what medication you are given.

If you do lose your hair it is usually a result of treatment with some chemotherapy medications, rather than immunotherapy or targeted treatment.

Your cancer treatment team will advise you if this is a likely side-effect of your treatment.

Your hair may start to fall out two or three weeks after your first treatment, or it may take a while. Your scalp may feel hot or itchy just before your hair starts to fall out.

// When in turmoil or doubt, choose change. I chose change to 'control a controllable' - cutting my long hair short then shorter still and dyed in two bright colours. On the first day of my chemotherapy I shaved it. I'm enjoying the opportunity to reinvent, create and embrace the 'new me'. //

Rachel



Managing hair loss

Many people find losing their hair very upsetting. For most people hair will grow back. Until it does you might want to wear a wig, a scarf or a hat.

If you choose a wig it is a good idea to look at wigs before you start losing your hair so you can make sure it matches your style and colour. The Government offers a subsidy to help pay for the cost of a wig. You must get a certificate from your cancer treatment team that states you are entitled to a wig.

Some people don't bother with wigs. They stay bald or cover up with scarfs or hats. What you do is up to you. There is no medical reason for your having to cover up your head. However, your scalp will be more sensitive to the sun than normal, so you should wear a hat and a high-protection sunscreen (SPF 30+) on your scalp when you are in the sun. In the winter your head may feel much colder than it normally would.

It takes between 4 and 12 months for your hair to regrow after treatment. Your head may be quite itchy as your hair begins to grow back and it is not unusual for new hair to have a different texture or colour.

Here are some tips for looking after your hair:

- Use gentle hair products and conditioner for dry hair.
- Pat hair dry after washing it and gently brush with a wide-toothed comb.
- Avoid using hairdryers, straighteners, tongs or curlers.
- Avoid perming or colouring your hair if it is brittle or your scalp is dry.
- If you want to colour your hair, use a mild, vegetable-based colourant and test a strand of your hair first - ask your hairdresser for advice.
- Some hairdressers suggest that it is best to wait for six months after treatment before colouring your hair.

The Cancer Society has an information sheet, *Managing Hair Loss*, which is available on our website.

Losing your eyebrows and eyelashes

There are make-up techniques that you can use to draw in eyebrows if you lose hair in this area. Or you can have your eyebrows tattooed if your hair loss is expected to be permanent.

If your eyes are irritated due to the loss of eyelashes, ask your cancer treatment team about eye drops that may help.

Look Good Feel Better workshops

Look Good Feel Better helps people affected by cancer to manage the appearance-related side-effects of cancer treatment. It provides free practical classes with skincare, make-up and headwear demonstrations. The goal that participants leave feeling empowered and ready to face their cancer diagnoses with confidence.

There are now some classes for men. These are relaxed, one-and-a-half-hour practical sessions focused on hair, skin, body and mind.

You can find out more about these workshops on the Look Good Feel Better website www.lgfb.co.nz.

// I went to a group a while back - it was to do with make-up. I thought only women used make-up. But I found it really useful and interesting. I learned about using face cream, lip balm and hand cream for dry skin after chemo treatment. Also protecting your skin from the sun and what food to eat if you feel sick. I'd advise anyone to go to a workshop if they get the chance. //

Kerry

Effects on your nerves

Numbness and tingling (peripheral neuropathy)

Some medications cause pins and needles, tingling and a loss of feeling in fingers or toes or both, muscle weakness (particularly in the legs), a change in hearing, or ringing in the ears. This is called peripheral neuropathy. Chemotherapy treatments are most likely to cause this condition.

If tasks such as doing up buttons or tying shoelaces become too difficult, let your cancer treatment team know before your next treatment. A slight change in your treatment may be needed, so make sure you tell your cancer treatment team if this develops.

Peripheral neuropathy usually gets better when treatment is over, but sometimes it is permanent.

Other nerve effects

Some medication can make you feel anxious, restless, dizzy or sleepy, or cause headaches. If you have any of these symptoms it is important to tell your cancer treatment team. They may be able to prescribe medicines that can help with some of these side-effects.

Itchy skin and other skin problems

Your skin may redden, peel or become dry and itchy. You may also notice drying and cracking of your fingers around the nails. Nails may become discoloured, brittle or ridged and you may get some acne. Tell your cancer treatment team about any skin problems. Many over-the-counter products won't be suitable to use, although Vaseline is recommended in some instances. Ask your cancer treatment team

for suggestions on what may help.

It is especially important to cover up your skin and use a high-protection sunscreen (SPF 30+) in the sun when having chemotherapy.

Forgetfulness and concentration problems (chemo-brain)

Many people say they find it hard to concentrate, focus and remember after chemotherapy. This is often called chemo-brain.

This can be very frustrating and it may help to know it can happen to anyone who has treatment. It is not clear if these problems are caused by chemotherapy alone, but the problem usually gets better with time.

There are useful ways of managing chemo-brain, such as:

- eating well, taking regular exercise and getting enough rest
- creating lists and reminders
- doing memory exercises.

Effects on your kidneys

Some cancer treatments can affect how well your kidneys work (kidney function). Before each treatment your kidney function may be checked with a blood test to make sure your kidneys are working normally. It is useful to drink plenty of fluids throughout treatment.

Managing hormone changes

Treatment can affect your menstrual cycle. Some women may enter early menopause and experience hot flushes. Thyroid function may be affected, particularly when having immunotherapy. This may result in weight changes and fatigue.

Keeping active, eating well and following the advice of your cancer treatment team for any suggested medication, such as thyroid medication, will help in managing these side-effects. The Cancer Society information sheet, *Early menopause and cancer*, is available on our website.

Relationships and sexuality

For some people, being diagnosed with cancer and having treatment have no effects on their sexuality or sex lives. For others they can have profound impacts and affect how they feel about themselves and their relationships.

The side-effects of treatment may mean that you do not feel like having sex. You may feel too tired, feel sick or be in pain. It is important to keep talking with your partner and sharing how you are both feeling. Sex drive usually returns soon after treatment ends.

Sexual intercourse is only one of the ways you can express affection for each other. Talking with your partner and sharing your feelings can result in greater openness, sensitivity and physical closeness. Gestures of affection, gentle touches, cuddling and fondling can also reassure you and your partner of your need for one another.



“Sex is what we do, sexuality is about who we are and intimacy is about sharing the secret corners of ourselves.”

Grits (1990);
Don Edgar (1997)

You may find it useful to read the Cancer Society booklet *Sex and Cancer/Hōkakatanga me te Matepukupuku* which is available on our website.

Contraception and fertility

It is important to use effective contraception during treatment and for a few months afterwards to avoid pregnancy. This is because the medication could harm a growing baby. Your cancer treatment team can advise you about the effects of medication on fertility.

During treatment it is usually best to use a condom because side-effects, such as sickness and diarrhoea, can make the contraceptive pill less effective.

For men, treatment may reduce the number of sperm produced. This can sometimes cause infertility, which may be temporary or permanent. The ability to have and keep an erection may also be affected, but this is usually temporary.

For women, medication can affect fertility and can reduce the hormones made by the ovaries. You may notice changes in your monthly periods, which can sometimes stop altogether. It is still possible to become pregnant, even with irregular periods.

Some cancer treatments can cause symptoms of early menopause, including hot flushes, irritability, sleep disturbance, achy bones and vaginal dryness. Menopausal symptoms are likely to be temporary for younger women. For some women closer to natural menopause, periods may not return once treatment is completed.

Vaginal thrush is common if you are having chemotherapy, especially if you are taking steroids or antibiotics. You can be prescribed treatment for this.

Pregnancy

If you know you are pregnant before starting treatment, or become pregnant during treatment, tell your cancer treatment team straight away. They will talk things over carefully with you and your partner and will explain the possible risks of continuing treatment during pregnancy.

Treatment and breastfeeding

Breastfeeding during cancer treatment is not advised. This is because the medication could be passed to your baby through breast milk. You may be able to express extra milk before treatment starts and freeze it to use later.

You may be able to start breastfeeding after treatment, but this will depend on whether you are having any other treatment that could interfere with breastfeeding. Your cancer treatment team will tell you about this. Having treatment will not affect your ability to breastfeed in the future.

Protecting your partner

If you have sex in the first few days after having treatment for your cancer, you will need to use a condom. This is to protect your partner against any chemotherapy medication in semen or vaginal fluid.

Cancer cannot be passed on to your partner and sex should not make the cancer worse, unless you are advised otherwise by your cancer treatment team.

SECTION SIX: LIVING WELL WITH CANCER



Most of your side-effects should begin to ease within a few weeks of treatment ending. Sometimes they last for a few months, and occasionally you may be left with long-term effects.

Coping with a cancer diagnosis will be an ongoing process for you, your family/whānau and your friends. There are no easy answers when it comes to facing a life-changing illness. Every person is unique and will find their own way of coping with their difficult situation.

Talking with family/whānau and friends may give loved ones the opportunity they have been waiting for to offer support. Talking to someone outside the family/whānau may also be helpful. Counsellors and hospital chaplains can be good sources of support .

You may find the Cancer Society booklet, *Getting on with life after treatment/Te hoki anō ki tō toioranga whai muri i te maimoatanga*, helpful to read.



Psychological, counselling and social worker support

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

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

Cancer Society support groups

For some people, meeting others who are in similar situations can help to decrease feelings of anxiety, isolation and fear. Support groups offer you the opportunity to share your experiences and learn different ways of dealing with problems.

The Cancer Society offers support groups that you may find helpful. You may be interested in Cancer Connect, run by the Cancer Society. This is a free telephone peer-support programme. Groups may not be available throughout the country. Phone the Cancer Information Helpline 0800 CANCER (226 237) for further information.

Cultural and spiritual support

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

You may like to contact one of the Māori health professionals who work with district health boards throughout New Zealand to deliver health and disability services to mostly Māori clients.

A list of providers is available from the Ministry of Health website at www.health.govt.nz.

Hospital chaplains are available to people of all faiths and no faith, and offer support through prayer and quiet reflection. Community-based health workers at your local marae and Pacific health services may also be good sources of support.

Interpreting services are available

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

There are a number of cancer information resources that have been translated and are available on international websites. To find out what these are, phone the Cancer Information Helpline 0800 CANCER (226 237).

Lifestyle changes to help you cope with cancer

Cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help to reduce stress and improve wellbeing. Addressing changes in your emotions and relationships early on is also very important.

There are a number of things that might help you to cope, such as:

- preparing simpler meals
- being more relaxed about housekeeping
- asking children, family/whānau or friends to help more around the house.

“I had to allow myself not to feel guilty that the house was messy. It doesn't matter that the floor was not shiny or spick and span. After a month I realised all these things [a clean house and total order] did not matter. It's the people inside these walls who mattered.

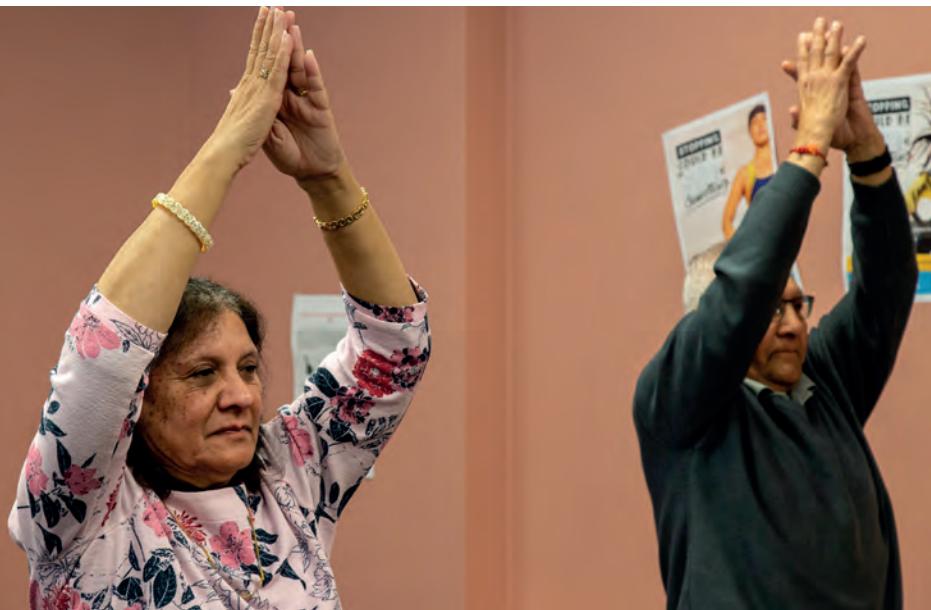
Silei

”

A number of support services are available to you if you are having difficulty coping with your cancer diagnosis or adjusting to the lifestyle changes your cancer diagnosis may bring. For more information, see the Cancer Society booklets *Coping with Cancer and Eating Well During Cancer Treatment/Kia Pai te Kai te wā Maimoatanga Matepukupuku* on our website www.cancernz.org.nz.

The importance of exercise

Research indicates that regular, gentle exercise may help with fatigue and lift your mood. Talk with your cancer treatment team about what exercise is best for you.



“ *Running definitely kept me sane during chemo. Don't get me wrong, it was tough and I could have given up many times, but I made it part of my routine and made sure that on days I felt well enough I went for a run - fresh air and a sense of achievement were enough to help me face the next round. Top tip - steroid days are usually the best days for having the energy to get out there. You can do it, one step at a time.* **”**

Claire

For more information, see the Cancer Society's pamphlet *Being Active When You Have Cancer* on our website www.cancernz.org.nz.

How families/whānau can help

As a friend or family/whānau member of someone who is diagnosed with cancer, you are also learning to cope with your own feelings and emotions. You may want to help but not know what to do.

Here are some suggestions that may be useful:

- Learn about cancer and its treatment. This will help you to understand what the person you are supporting is coping with.
- Be thoughtful about offering advice. Listening while they talk or just being there with them are good ways to show you care.
- Talk about your feelings together and be honest about what worries you.
- Offer to go to appointments with them. You can be there for support, take notes or, when appropriate, take part in the discussions.
- Respect that your family/whānau member or friend may want to talk to their cancer treatment team alone.



The Cancer Society offers a range of resources to support you. We suggest you read our booklet *Supporting Someone with Cancer/Te manaaki i tētahi e māuiui ana nā te matepukupuku*.

Palliative care services

Palliative care is not just about care at the end of life. It is for people with advanced cancer and the focus is on improving their quality of life. Support can be offered in a hospital, a rest home, your own home or a hospice, and care is provided by specialist doctors, nurses, social workers and spiritual care workers.

It is a good idea to ask about palliative care early. Being able to deal with any problems or concerns early rather than waiting until they become difficult to manage can help to reduce stress for both you and your family/whānau. In general, palliative care services are free. However, there may be a charge for the hire of some equipment for home care.

For more information on palliative care, see the *Cancer Society's booklet Advanced Cancer/Matepukupuku Maukaha* on our website www.cancernz.org.nz.

Advance care planning

Advance care planning can begin at any time. It is about helping you to think and talk about the treatments and care you might want.

This gives you and your treatment team an opportunity to work together to ensure that your choices about treatment and care in the future are heard. An advance care plan will guide your doctors and family/whānau in making decisions if you are unable to make them yourself. Advance care planning is voluntary - no-one can force you to do it. For more information on advance care planning, visit the Advance Care Planning website www.advancecareplanning.org.nz.

Appendix 1: Types of immunotherapy and targeted treatment

Funded immunotherapy and targeted treatment are only available when certain criteria are met. Please discuss these with your specialist.

Targeted treatment - monoclonal antibodies		
HER2-targeted agents	These treatments either stop or slow the growth of HER2-positive cells. HER2 is a protein that causes some cancers to grow uncontrollably.	Trastuzumab (Herceptin) is used to treat HER2-positive cancers such as breast, stomach and oesophageal cancers.
Angiogenesis inhibitors	These treatments attach to the vascular endothelial growth factor (VEGF) receptor proteins on cancer cells. VEGF is a protein that helps new blood vessels to form.	Bevacizumab (Avastin) is used to treat cancers that make a lot of VEGF receptor proteins, including cervical, colorectal, non-small cell lung, glioma and ovarian cancers.
Anti-CD20	These treatments target a protein called CD20. CD20 is found on B cells (a type of white blood cell).	Rituximab (Mabthera) is used to treat cancers that have high numbers of abnormal B cells, for example some types of non-Hodgkin lymphoma.
EGFR inhibitors	These treatments attach to the epidermal growth factor receptor (EGFR) protein. EGFR can make some cancer cells grow faster.	Cetuximab (Erbitux) is used to treat cancers that make a lot of EGFR protein, including colorectal cancer and some types of head and neck cancer.

Targeted treatments - small-molecule inhibitors

Tyrosine kinase inhibitors	<p>These medications block an enzyme from sending signals that tell a cancer cell to grow. Tyrosine kinases are enzymes that affect a cell's growth and division.</p>	Imatinib (Gleevec) is used to treat some forms of leukaemia.
PARP inhibitors	<p>These medications stop a protein called PARP from repairing damaged DNA inside a cell, causing it to die. Poly(ADP-ribose) polymerase (PARP) is an enzyme that helps to repair damage to DNA.</p>	Olaparib (Lynparza) is used to treat some ovarian, fallopian tube and peritoneal cancers.
mTOR inhibitors	<p>Treatment with these medications stops cancer from making new cells to slow the growth and spread of the cancer. Mammalian target of rapamycin (mTOR) is a protein that controls cell growth and division.</p>	Everolimus (Afinitor) is used to treat some kidney cancers.
CDK4/6 inhibitors	<p>These medications block the proteins CDK4 and CDK6, which tell cells to grow and divide. These proteins can become overactive when there are too many hormone receptors.</p>	Palbociclib (Ibrance) is used to treat ER-positive, HER2-negative, advanced breast cancer. It is used in combination with hormone therapy (an aromatase inhibitor, or fulvestrant for those who have had prior hormone treatment).

Immunotherapy treatments

PD-1 inhibitors	<p>These medications target and block a protein called PD-1 on the surface of a type of immune cell called a T cell. Blocking PD-1 triggers the body's immune system to fight cancer cells.</p>	<p>Nivolumab (Opdivo) is used to treat advanced melanoma. It can also be used to treat some lung cancers, some kidney cancers and some types of head and neck cancer. It can occasionally be used in Hodgkin lymphoma.</p> <p>Pembrolizumab (Keytruda) is also used for melanoma, some lung cancers, Hodgkin lymphoma and some head and neck cancers.</p>
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Appendix 2: Suggested reading and websites

Reading

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

Websites

- Macmillan Cancer Support (United Kingdom)
www.macmillan.org.uk
- Cancer Council Victoria (Australia)
www.cancervic.org.au
- eviQ Australia www.eviq.org.au/patients-and-carers
- Cancer Council Australia
 - www.cancer.org.au/aboutcancer/treatment/chemotherapy.html
 - www.cancer.org.au/aboutcancer/treatment/immunotherapy.html
 - www.cancer.org.au/aboutcancer/targetedtherapy
- Cancer.Net (United States) www.cancer.net

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

Glossary

(What does that word mean?)

Adjuvant - additional cancer treatment given after the primary treatment.

Anaemia - a low red-blood-cell count.

Anaesthetic (general or local) - a general anaesthetic uses medications to cause loss of consciousness (this puts you into a deep sleep so you don't feel pain). Local anaesthetic numbs only a certain area.

Antihistamine - medications used mainly to treat allergies such as hay fever, hives and itching. They may be used to help reduce feeling sick (nausea) and being sick (vomiting).

Cells - the 'building blocks' of the body. A human is made of millions of cells, which are adapted for different functions. Cells are able to reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.

Chemoradiation - a combination of chemotherapy and radiotherapy. It is also sometimes called **chemoradiotherapy**. It may be given before surgery, to help shrink the cancer and reduce the risk of cancer coming back.

Dietician - an expert who gives advice about food and diet.

Infection - a disease in a part of your body that is caused by bacteria or a virus.

Infusion pump - a small, portable device that allows a patient to have their chemotherapy medication at home.

Interactions - an effect produced by a combination of two or more medications together which is different from the effect of each if used alone.

Intravenous (IV) - giving fluids and medicines using a needle or a thin

tube (a catheter) that is put into a vein.

Lumbar puncture - the insertion of a hollow needle into the lower spinal canal to withdraw fluid for diagnosis or to give medications.

Medical oncologist - a specialist doctor who treats cancer using medications such as chemotherapy, immunotherapy, targeted treatment and hormone treatments.

Neo adjuvant - a treatment given as a first step before the main treatment, which is usually surgery.

Palliative - controlling the symptoms of a disease rather than curing it.

Platelet - a type of blood cell that helps stop bleeding by plugging up holes in blood vessels after an injury.

Primary - a malignant tumour that starts in one site of the body, where it is known as the primary tumour.

Scans - the use of X-rays, high-frequency sound waves or radioactive substances to make detailed pictures of the inside of a body. Scans commonly used in cancer include MRI, CT, PET, ultrasound, bone, brain and liver scans.

Tumour marker - a substance found in tissue, blood and other body fluids. It can be used to help diagnose cancer, plan treatment, monitor the effects of treatment or see if cancer has returned.

Vaccine - a modified version of a germ or other substance related to a disease, which is given, usually by injection, to stimulate the immune system to resist that disease.

Viruses - very small organisms (micro-organisms) that cause infections. They can grow and reproduce only in living cells.

Cancer Society of New Zealand Inc - Te Kāhui Matepukupuku o Aotearoa

Cancer Society information and support services

The Cancer Information Helpline is a Cancer Society service on **0800 CANCER (226 237)**, where you can talk about your concerns and needs with cancer nurses.

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

These services may include:

- volunteer support, including drivers providing transport to treatment
- accommodation while you are having treatment away from home
- support and education groups.

The range of services offered differs in each region, so contact your local Cancer Society to find out what is available in your area.

For information on practical support and the emotional impacts of cancer, we suggest that you read our booklet *Coping with Cancer*: Your guide to support and practical help. You can get a copy from your local Cancer Society, by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by downloading it from our website (www.cancernz.org.nz).

National Office

PO Box 651, Wellington 6140

Telephone: 04 494 7270

Auckland Division

PO Box 1724, Shortland Street, Auckland 1140

Telephone: 09 308 0160

Covering: Northland

Waikato/Bay of Plenty Division

PO Box 134, Waikato Mail Centre, Hamilton 3240

Telephone: 07 838 2027

Covering: Tauranga, Rotorua, Taupō, Thames and Waikato

Central Districts Division

PO Box 5096, Terrace End, Palmerston North 4441

Telephone: 06 356 5355

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

Wellington Division

52-62 Riddiford Street, Newtown, Wellington 6021

Telephone: 04 389 8421

Covering: Marlborough, Nelson, Wairarapa and Wellington

Canterbury/West Coast Division

PO Box 13450, Armagh, Christchurch 8141

Telephone: 03 379 5835

Covering: South Canterbury, West Coast and Ashburton

Otago/Southland Division

PO Box 6258, Dunedin North, Dunedin 9059

Telephone: 03 477 7447

Covering: Urban and rural Otago and Southland

Cancer Information Helpline

0800 CANCER (226 237)

www.cancernz.org.nz

Other titles from the Cancer Society

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

Advanced Cancer/Matepukupuku Maukaha

Advanced Melanoma of the Skin/Tonapuku Maukaha o te Kiri

Bowel Cancer/Matepukupuku Puku Hamuti

Breast Cancer/Te Matepukupuku o ngā ū

Early Stage Melanoma of the Skin/Wāhanga Tōmua Tonapuku ki te Kiri

Eating Well during Cancer Treatment/Kia Pai te Kai te wā Maimoatanga Matepukupuku

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

Living with Dry Mouth/Te Noho me te Waha Maroke

Prostate Cancer/Matepukupuku Repeure

Radiation Treatment/Haumanu Iraruke

Secondary Breast Cancer/Matepukupuku ā-ū Tuarua

Sex and Cancer/Hokakatanga me te Matepukupuku

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

Brochures

Being Active When You Have Cancer

Questions You May Wish to Ask

Copies of Cancer Society booklets, brochures and information sheets are available from your local Cancer Society, by phoning the Cancer Information Helpline 0800 CANCER (226 237) or by downloading them from our website (www.cancernz.org.nz).

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www.cancernz.org.nz

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