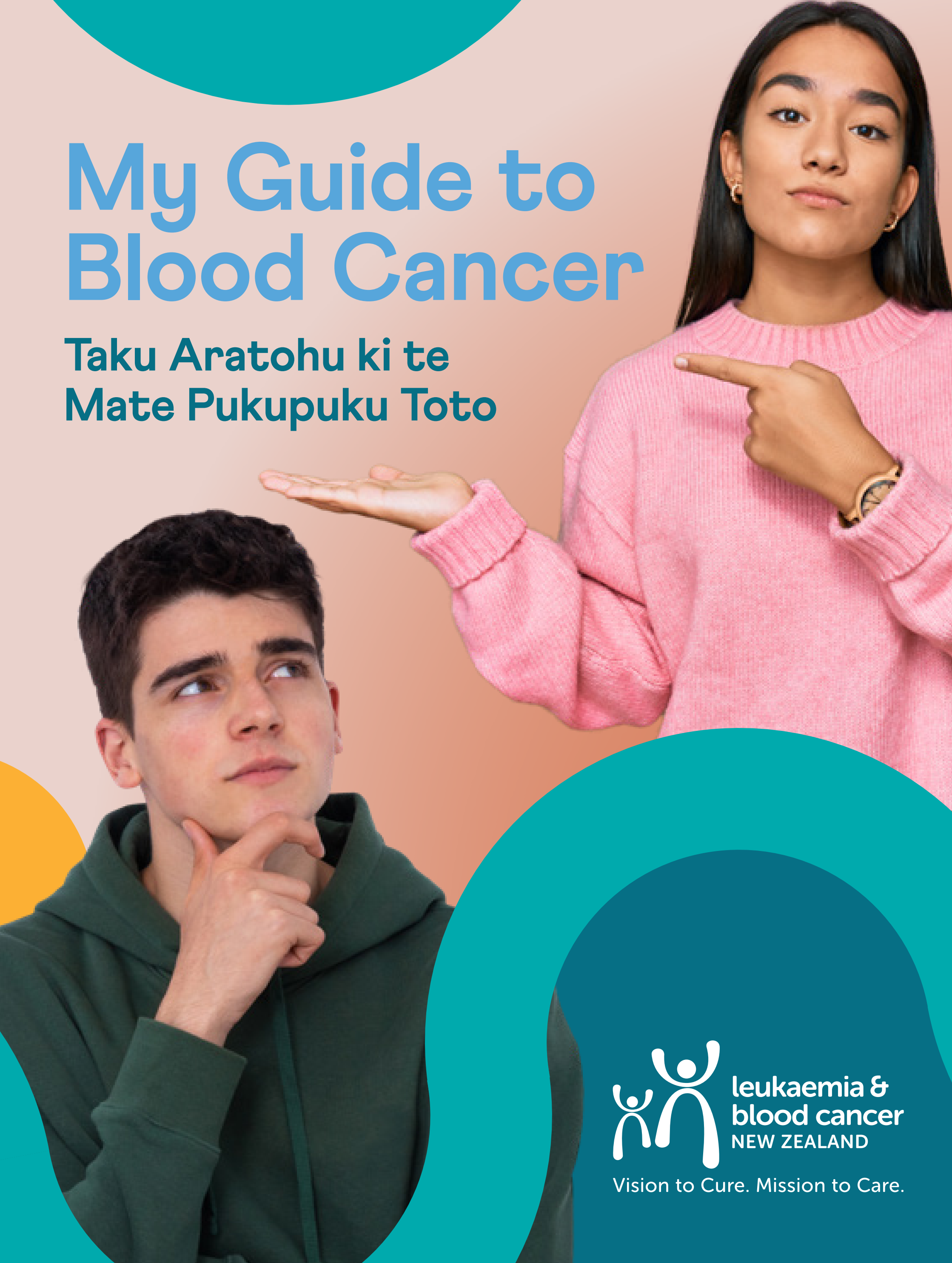
My Guide to Blood Cancer

Taku Aratohu ki te Mate Pukupuku Toto



leukaemia &
blood cancer
NEW ZEALAND

Vision to Cure. Mission to Care.

Kia ora

This booklet has been written specifically to help you as an adolescent or young person (AYA) to navigate your blood cancer or blood condition diagnosis, treatment, recovery, and all the life stuff that goes along with it.

Being told you have a blood cancer or blood condition can come as a huge shock. In between the busyness of life, study and/or work, big health changes are not usually something most young people are thinking about. Life may look different for a while, but there is support available to make it as easy as possible.

You can read this booklet from start to finish, or you can refer to the contents to find the sections that are useful to you right now.

Your family/whānau and friends might also find it helpful to read this booklet, to understand some of what you may experience.

It is not the intention of this booklet to recommend any particular form of treatment to you. There also may be sections of this booklet that aren't relevant to your diagnosis or treatment.

This booklet is available in hard copy or you can download the PDF on the Leukaemia & Blood Cancer New Zealand (LBC) website at www.leukaemia.org.nz. The website also has different fact sheets and booklets with more detailed information.

Contents

My diagnosis

My treatment

Understanding side effects

Life with cancer

Beyond cancer

Appendices

My diagnosis

Taku tautohu

The word diagnosis means the process of identifying a disease or condition. By now you would have had many different tests and investigations, which helped the doctors identify that you have a blood cancer or condition.

Ask your doctor or nurse to help you fill in the details on the next page so you have quick access to their names and contact information.

My diagnosis is:

My treatment centre is:

My treatment is called:

My consultant is:

Phone number:

My AYA keyworker is:

My LBC Support Services Coordinator is:

Phone number:

> "When I got my first diagnosis my partner asked the doctor, "Who does Kate talk to if she has any questions, this is a lot to take in" and we got the phone numbers of who to contact if we needed. That was invaluable as over the next days I had some complications and was able to get help."
>
> Kate

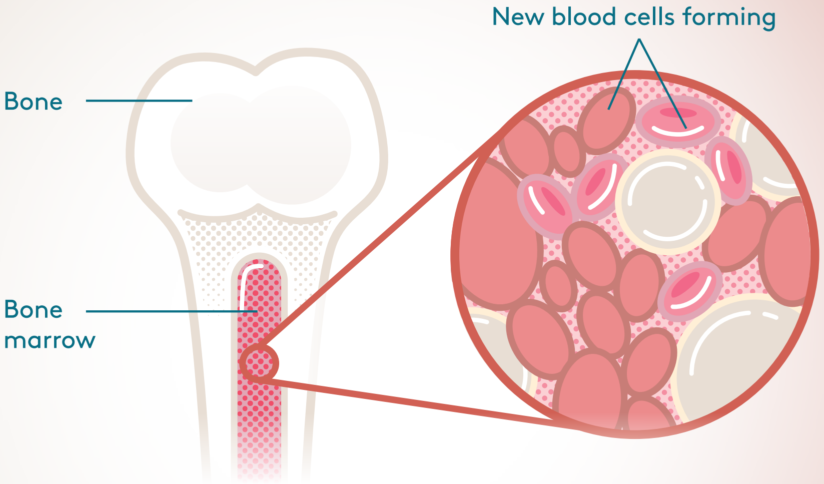
Bone marrow, blood stem cells and blood cells

To understand what is happening in your body, it is helpful to know a bit about blood and blood cells.

Bone marrow

Bone marrow is the spongy material inside your bones (see Figure 01). All your blood cells are made in your bone marrow – this is called haematopoiesis (he-ma-toe-po-ee-sis). There are three main types of blood cells: red blood cells, white blood cells and platelets.

Figure 01



Bone marrow

You might like to think of the bone marrow as the blood cell factory. The main workers of the factory are the blood stem cells.

Blood stem cells

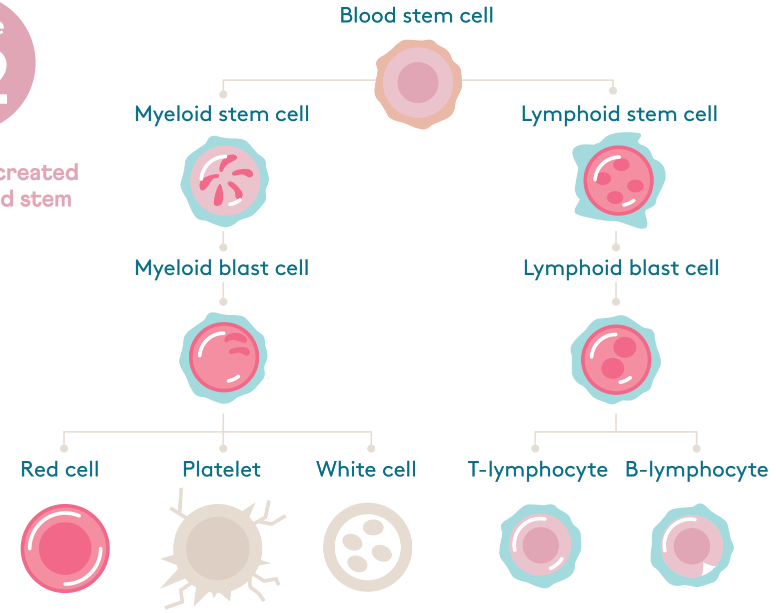
Blood stem cells are found in the bone marrow and create the new blood cells in your body.

The job of blood stem cells is to:

- Make exact copies of themselves
- Divide and make two different cell groups: myeloid (my-ill-oid) stem cells and lymphoid (lim-foid) stem cells.

Myeloid and lymphoid stem cells create the blood cells for your body, including white blood cells, red blood cells and platelets. In Figure 02 you can see that the blood stem cell has divided to create a myeloid stem cell and a lymphoid stem cell.

Figure 02



The cells created from blood stem cells

Your blood

Blood is made up of plasma, red blood cells, white blood cells and platelets.

Plasma

Plasma is the light-yellow coloured fluid that carries blood cells around your body.

Red blood cells

Red blood cells contain haemoglobin (heem-a-glow-bin), which moves oxygen from the lungs to all parts of the body. Haemoglobin also carries carbon dioxide to the lungs where it is breathed out. A low level of haemoglobin in your body is called anaemia (a-nee-me-a). Symptoms of anaemia are explained further on page 39.

White blood cells

White blood cells fight infection. For example, if bacteria enter your bloodstream through a cut, the white blood cells attack and kill the bacteria cells before they divide and spread. If your white blood cell count is low, you are more at risk of getting an infection. Neutrophils (new-tra-fills) are a type of white blood cell that act as your system's first line of defence and kill bacteria and fungi. Neutropenic (new-tra-pee-nik) is the term used to describe a low number of neutrophils in your blood.

The lymphatic system

The lymphatic system is made up of a large network of tubes (like blood vessels) that branch out into all the tissues of the body (see Figure 03).

These tubes contain lymph, a colourless watery fluid that carries lymphocytes (lim-fo-sites), which are specialised white blood cells that fight infection. There are three types of lymphocytes: B-cells, T-cells and natural killer (NK) cells. These cells protect us by making antibodies and destroying harmful bugs such as bacteria and viruses. The lymphatic system forms part of the immune system, which protects our bodies against disease and infection.

Clusters of small bean-shaped organs called lymph nodes (or lymph glands) are found throughout the lymphatic system. The lymph nodes are filled with lymphocytes and act as important filtering stations, cleaning the lymph fluid as it passes through them. Bacteria, viruses and other harmful substances are removed and destroyed.

When you have an infection (like a sore throat) you may notice that the lymph nodes around your neck become swollen and sore. This is because the lymphocytes that live there become activated and multiply in response to the virus or bacteria causing the infection.

The spleen (an organ on the left side of the abdomen), thymus (a gland found behind the breastbone), tonsils and adenoids (glands in the throat) and bone marrow (spongy material inside bones) all contain lymphatic tissue and are therefore considered to be part of the lymphatic system. Lymphatic tissue is also found in the stomach, gut and skin.

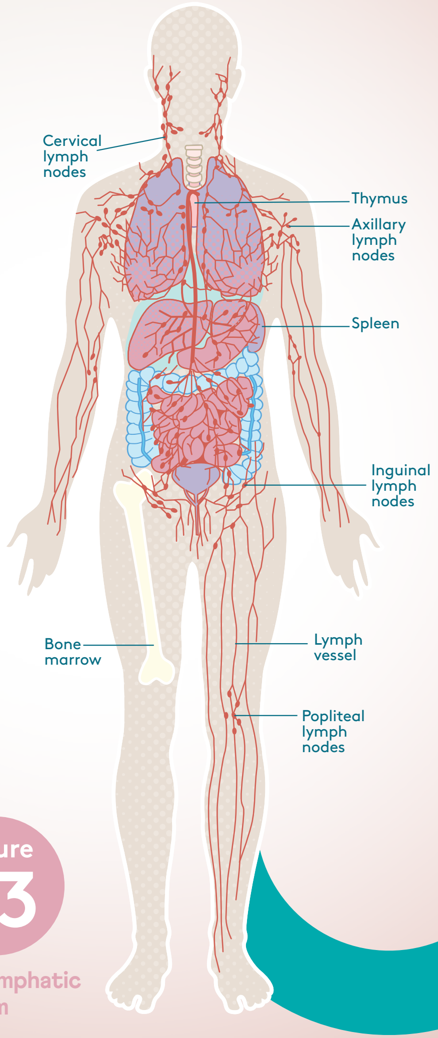


Figure 03

The lymphatic system

What is a blood cancer?

Cancer of the blood occurs when one of the types of blood cells, which are produced in your bone marrow, grow in an uncontrolled or abnormal way. The type of blood cancer you have depends on the type of cell, and the stage of development the cell had reached when the abnormal change occurred.

When something is wrong with your blood, it can affect your overall health, and if left untreated symptoms can get worse.

A haematologist is a specialist doctor who treats blood-related cancers and conditions. There is more detailed information on page 15 about the different doctors and health care professionals you may meet.

Types of blood cancers and conditions

There are many different types of blood cancers and blood conditions. Common blood cancers include leukaemia, lymphoma and myeloma.

Blood cancers that most commonly affect adolescent and young adults (AYA) are:

- Acute lymphoblastic leukaemia (ALL)
- Acute myeloid leukaemia (AML)
- Hodgkin lymphoma (HL)
- Non-Hodgkin lymphoma (NHL).

You'll find a glossary of terms at the back of this booklet if you need help along the way.

More information is available online

In leukaemias, the abnormal cells are usually only found in the bone marrow and blood. In lymphomas, the abnormal cells are found in the lymphatic tissues (also known as lymph nodes or glands) but in some people the bone marrow can also become involved.

There are also a number of other blood cancers or blood conditions which are not leukaemias or lymphomas. Some of these include:

- **Aplastic anaemia**
- **Myelodysplastic syndromes**
- **Myeloproliferative disorders**
- **Sickle cell disease.**

More information is available online

Why did I get a blood cancer?

Usually the cause of blood cancers or blood conditions is unknown. It is important to know that it is not your fault, and you did not do anything wrong.

Some important things to remember are:

- You cannot catch blood cancers from other people, and you won't pass it on to those around you.
- There is no evidence that blood cancers can be caused by anything you eat or drink.
- Most blood cancers are not hereditary (passed on from your parents or to your children).

What happens after I've been told I have a blood cancer or condition?

You are likely going to experience a range of feelings and emotions after being told you have a blood cancer or condition. These feelings may include shock, anger, sadness, denial and worry. It is normal to have a range of emotions. Over time, you will find ways to adapt and gradually adjust to a new sense of normal.

It can also feel like an overwhelming time with more appointments, meeting new health professionals and having more tests and investigations. You may need other tests to help show more about what's going on. These tests may include:

- **Bone marrow biopsy**
- **Lumbar puncture**
- **Genetic testing (done from blood or bone marrow samples)**
- **Imaging tests (e.g. X-ray, ultrasound, CT scan, MRI scan)**

The results of these tests will be really important when your doctor discusses your treatment options. There may also be a few practical things to sort out, such as getting a central line put in (see page 27).

Tests and investigations

Your doctor will confirm what type of blood cancer or condition you have after doing a variety of tests and investigations. Your blood tests get sent to a laboratory where specialised doctors will examine the sample under a microscope. You may also have a biopsy of a lump, lymph node or bone marrow.

They will also talk with you and ask you questions about how you've been feeling, any symptoms you've noticed and how it has been impacting your life.

Blood cancers and conditions affect everyone differently, so the types of tests you have may be different to what someone else has. You may need a few different tests before you are given a diagnosis, and to work out a treatment plan.

Physical examination and medical history

Your doctor will look and feel for any swelling of the glands in your neck, armpits and groin. They will also check your abdomen (tummy) and chest for any signs of swelling or fluid collection. Your doctor will also ask you about any other symptoms you might have, such as weight loss, sweating, bleeding or pain.

Your doctor will ask you about your past medical history, including any previous illnesses, health problems or bleeding. They will also need to know about any prescribed or over-the-counter medications or drugs you take regularly.

Lymph node biopsy

A lymph node biopsy is a procedure where all or part of a lymph node is removed and sent to be examined in the laboratory. It can take at least a few days for the sample to be tested and for the results to come through.

Blood test

Full blood count (FBC)

An FBC (or complete blood count [CBC]) measures the number and appearance of red blood cells, white blood cells and platelets.

Blood chemistry test

Blood chemistry tests measure the amounts of different chemicals in your blood. They provide important information on how well your organs and body systems are working, e.g. your liver and kidneys. This provides a baseline for your disease and general health, which can be compared to later results to see how you are progressing.

Other tests

- You may be tested for common viruses, or viruses that can affect your treatment such as hepatitis B, hepatitis C, Epstein-Barr virus (EBV) and human immunodeficiency virus (HIV).
- Your antibody levels may also be tested as low levels may mean you are more likely to get infections.
- You might have other tests that are specific to your diagnosis.

Scans and imaging

Many people require X-rays or other imaging tests for diagnosis or monitoring.
These might include:

- **Chest X-ray** – To detect a chest infection or any other abnormalities.
- **Electrocardiogram (ECG) and echocardiogram (ECHO)** – To see how well your heart is working.
- **Computer-assisted tomography (CT or CAT) scan or ultrasound** – May be used if there is concern about specific localised involvement or damage caused by the lymphoma.
- **Magnetic resonance imaging (MRI) scan** – May be used in diagnosis and monitoring of lymphoma to show very clear pictures of specific areas such as the brain and spinal cord (see below for more detailed information about an MRI procedure).
- **Positron emission tomography (PET) scan** – A type of specialised CT scan that uses radioactive glucose to identify increased levels of tissue activity due to lymphoma.

MRI scan

MRI uses a strong magnetic field, radiofrequency waves and a computer that produce detailed images of parts of your body. The MRI machine (scanner) contains a large magnet with a tunnel through the middle, which stays open at both ends. The staff will ask you some questions and ask you to remove any accessories (e.g. hairclips, jewellery, glasses). They will help position you on the scanner bed and will always be available to answer your questions or concerns. During your scan the staff will leave the room but talk with you through an intercom. Let the staff know if you have a fear of confined spaces (claustrophobia) so they can support you with this during your procedure.
The MRI scanner is noisy but it is not painful.

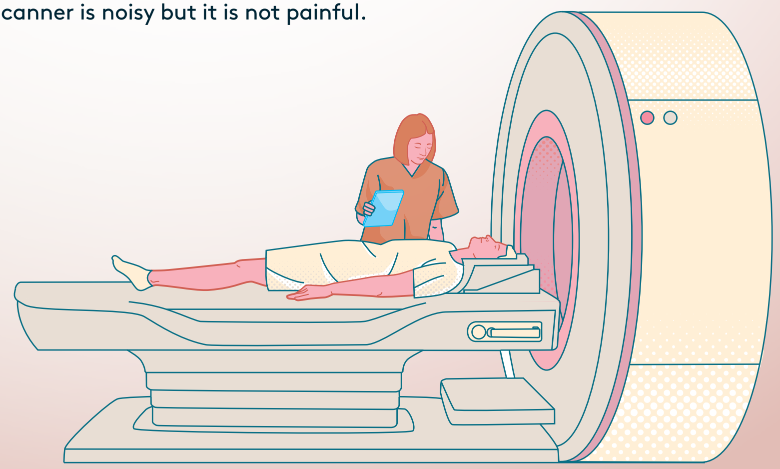


Figure 04

MRI scan

Bone marrow biopsy

A bone marrow biopsy is a test where a doctor takes samples of your bone marrow and sends them to a laboratory to be looked at under a microscope. A bone marrow sample is usually taken from the back of your hip bone (iliac crest) (see Figure 05).

A bone marrow biopsy can be done when you are staying overnight in hospital or as an outpatient (you visit the hospital for the procedure).

Your doctor will probably give you a drug that makes you feel relaxed and sleepy (a sedative) before the biopsy starts. You may also be given pain relief. Your doctor will give you a local anaesthetic, which is a small injection that is put into your skin where the biopsy is going to be done, to make the area numb so you don't feel anything. Sometimes a bone marrow biopsy is done under general anaesthetic (where you are put to sleep) instead.

To do a bone marrow biopsy, your doctor inserts a needle through your numbed skin into the bone and then into the bone marrow. Bone marrow has liquid and solid parts. A small sample of your bone marrow liquid is taken out. This is called bone marrow aspirate. A sample of the solid part of the bone marrow is also taken. This is called a bone marrow trephine (tre-fine).

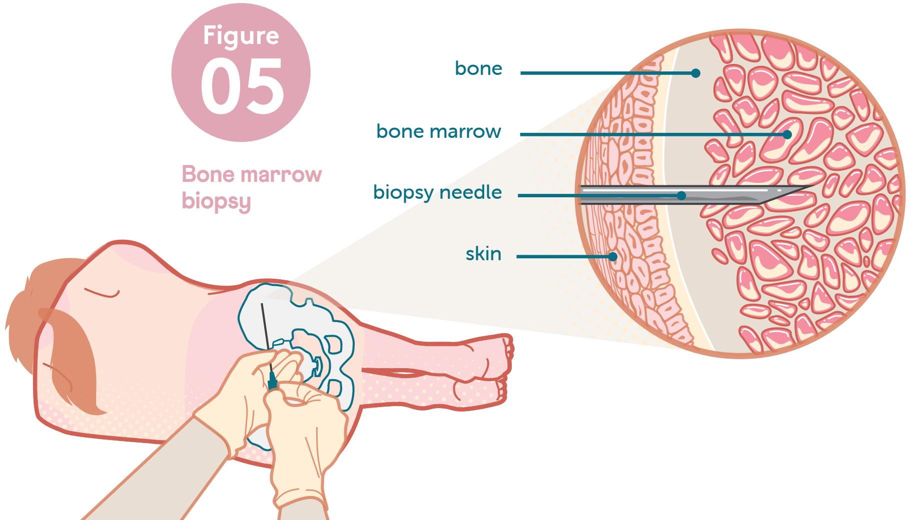
Some people may find a bone marrow biopsy a little uncomfortable. Everyone is different. It is a good idea to bring a support person with you when you have a bone marrow biopsy. If you have a sedative or general anaesthetic, you will still feel a bit drowsy afterwards. Your support person can make sure you get home safely.

After the biopsy, your doctor or nurse will put a plaster or small dressing over the biopsy site. You may need paracetamol to help ease some discomfort in the area afterwards. Your doctor or nurse will talk to you about this.

After your bone marrow sample has been analysed by the laboratory you will have an appointment with your haematologist to talk about the results. You may have other bone marrow biopsies done throughout your treatment to monitor any change or response to treatment.

Figure 05

Bone marrow biopsy



Lumbar puncture

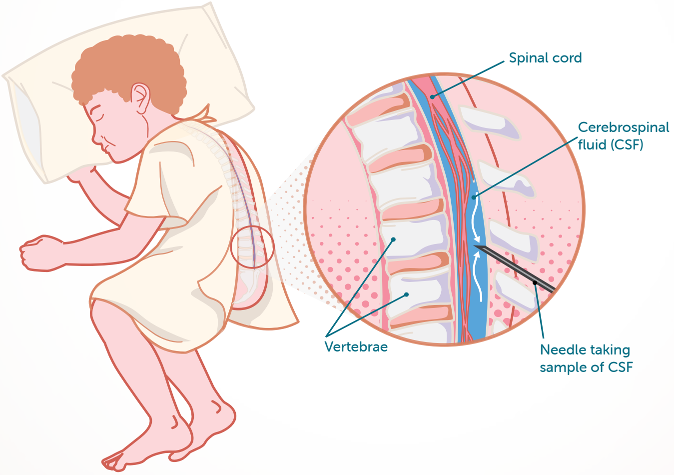
A lumbar puncture is a procedure where a small sample of the cerebrospinal fluid (CSF) that surrounds your brain and spinal cord is collected via a long thin needle in the lower back. The fluid is then examined in the laboratory to check for the presence of cancer cells within the central nervous system (CNS).

You will be asked to lie on your side in the foetal position to help keep your spine in the best position (see Figure 06). A local or general anaesthetic is used, just like in a bone marrow biopsy. You may be asked to lie flat for a short time after the procedure to help reduce the potential side effect of a headache.

Waiting around for tests can be both stressful and boring. Remember to ask beforehand how long the test will take and what to expect afterwards. You might like to take a book, some music or a friend for company and support.

Figure 06

Lumbar puncture



Other tests

There may be other tests that provide your health care team with information about your general health. Your health care team will let you know when you need to have these tests and what they are for.

Preparing for tests

Before you go for a test, ask your health care team how long the test will take, what the test involves and how you will feel afterwards. Things that you can do to help prepare for the test are:

- Plan your journey so that you arrive on time and do not have to rush.
- Find out about parking – your LBC Support Services Coordinator can help.
- Ask a support person to come with you.
- Ask for an interpreter if needed, your health care team at the hospital can organise this for you in advance.
- Take your favourite music on a device with headphones.
- Take something to read.

What health professionals will I meet after my diagnosis?

You may meet a range of health professionals who are part of your health care team. Each health professional is an expert in a different area. Working as a team, these health professionals will give you and your family/whānau the best treatment and support so that you can live as well as possible following a blood cancer diagnosis. Some of the health professionals you may meet include:

- **Adolescent and young adult (AYA) keyworker** – A specialised nurse or social worker who helps young people with their cancer journey.
- **Charge nurse** – A senior nurse in charge in an outpatient department, day unit or hospital ward.
- **Clinical nurse specialist** – A nurse with advanced skills in a specific area of cancer care. This person works closely with you and members of your health care team to help you manage the symptoms of your blood cancer and the side effects of treatment.
- **Consultant** – A specialised doctor who coordinates your health care (includes haematologists and oncologists).
- **Dietitian** – A dietitian can advise on what to eat and drink to minimise symptoms or side effects from your treatment. They may also prescribe supplements to make sure you are getting the calories and nutrients you need.
- **General practitioner (GP)** – A family and community doctor might already be involved with your blood cancer or blood condition diagnosis. They will be informed throughout your diagnosis and will work together with other health professionals to support you at home, in the community and after treatment.
- **Haematologist** – A doctor who specialises in the treatment of blood cancers or blood conditions. A haematologist or oncologist (see below) will be in charge of overseeing your treatment and follow-up.
- **Occupational therapist** – Helps you manage everyday activities and do the things you want and/or need to do.
- **Oncologist** – A doctor who specialises in cancer and cancer treatment. You may be under the care of an oncologist or a haematologist for your treatment.
- **Outpatient clinic nurse** – A nurse who gives you treatment as an outpatient or who works alongside a doctor in a clinic.
- **Pathologist** – A doctor who specialises in the laboratory diagnosis of disease and how disease is affecting the organs of the body.
- **Pharmacist** – Prepares and checks your medications. A pharmacist can advise you on how to take your medicine and the possible side effects and interactions with other medications.
- **Physiotherapist** – Specialises in maintaining and improving body movement and mobility. A physiotherapist (or physio) can help you regain independence and fitness.
- **Psychologist** – Specialises in helping you manage the emotional challenges of a a blood cancer or blood condition diagnosis, such as stress, anxiety and depression.
- **Registrar** – A doctor who is training to become a specialist. You may see a registrar in clinics, day units and ward. Registrars work very closely with senior specialists (haematologists and oncologists).
- **Social worker** – Helps you manage the practical and emotional impact of having a blood cancer diagnosis, such as advice about managing at home, employment and school.
- **Ward clerk** – Is often the first person you or your visitors will meet on the ward or day unit. Their job is to make sure everything runs smoothly on the ward, and can help you with booking and changing appointments.

Summary

Blood cells are made in the bone marrow and move around the body.

Blood cells do different jobs – red blood cells carry oxygen to body tissues, white blood cells are involved in your immune system, and platelets help with clotting to stop bleeding.

Problems in making or regulating blood cells can result in a blood cancer or blood condition.

There are lots of different health professionals you will meet, who are there to support you along the way.

You will need to have some tests to confirm or monitor your blood cancer or blood condition.

You did not cause your blood cancer or condition, you cannot catch it or give it to someone else.

Questions and notes

My treatment

Taku haumanutanga

How will my blood cancer be treated?

You might have chemotherapy (chemo), radiotherapy or a combination of both. Some people also have a stem cell transplant. Every blood cancer patient is different – the exact treatment you receive, the length of your treatment, and how it is administered is unique to you. It is very important that you follow your doctor’s advice and take all the medications for as long as you have been told to. More information on different types of cancer treatment can be found on pages 26-31.

Will I have to stay in hospital?

Your doctors may talk about the words ‘inpatient’ or ‘outpatient’. Inpatient means that you stay in hospital overnight. Outpatient means that you visit a day ward or outpatient department for treatment but you are able to go home afterwards. While there are times you may have to stay in hospital as an inpatient during treatment, how often and for how long depends on your type of cancer and treatment and how well you are.

Staying in hospital can be an adjustment. Some people hate hospitals, but others don’t really mind it at all. It can feel like there is less privacy, and it can be frustrating having different routines and being interrupted for tests and treatments. If you are feeling unhappy, talk to your doctors and nurses about this – you will not be the only person to feel this way. Your treatment team is there to help you through your treatment in the best way possible for you, and together you can create a plan that works.

Below are some tips that might help make your hospital stay a bit nicer:

- Wear your own clothes, and get dressed out of your pyjamas whenever you can.
- Bring your own pyjamas and slippers – they’re more comfortable than a hospital gown!
- Bring some beanies or scarves – hospital rooms can get cold, and lots of body heat is lost from your head (especially if you lose your hair).
- Keep in touch with school, university or work via emails, phone calls, texts and social media.
- Bring posters, pictures or photos to put up on the walls and make it feel like your own space. Ask your nurse if you can move any furniture around too, for a change of scenery.
- Bring headphones to listen to music – have a selection of relaxing and upbeat music that you like.
- Try some light reading – you might not feel like anything too heavy or serious, so magazines, comics, novels and audiobooks can be good options. Most libraries have a free app to borrow books from your phone, tablet or e-reader, to give you more options.
- Scrolling back through old photos and videos can make you feel good.
- Use scent warmers, diffusers or perfumes to make the room smell good (note: most hospitals will not allow flames or candles for fire safety reasons).
- Bring a notepad and pen to write down ideas, thoughts, questions and appointments.
- Bring a laptop or tablet if you have one – for games, streaming etc. Ask the ward clerk or nurses if there is WiFi available.
- Set a voicemail message on your phone for if you are too tired to speak or don’t want to answer.
- Creative hobbies like knitting, mindful colouring or scrapbooking can be a good way to pass the time.
- Bring your own pillow, duvet and blankets to make the room feel more like your own.
- Bring a stash of your favourite snacks to have between meals.

Which hospital will I be treated at?

Blood cancers often require specialist treatment, which can only be offered in some of the bigger towns and cities of New Zealand. This means that you may need to travel to the main centre nearest to where you live for your treatment. Or you may have shared care, which means you have some treatment at the specialist hospital and some at your local hospital. If you have to travel and stay away from home for treatment, you will be able to bring a support person with you, e.g. your mum, dad, partner or friend.

Your treatment centre will also help to organise accommodation for your support person, so they can stay close by. Currently there are no specialised wards for young adults in New Zealand, although there may be dedicated rooms in some of the wards in the hospitals.

Centre	Address	Phone
Whangarei Hospital	Hospital Road, Whangarei	09 430 4100
North Shore Hospital	Shakespeare Road, Takapuna, Auckland	09 486 8900
Auckland City Hospital	Park Road, Grafton, Auckland	09 367 0000
Starship Hospital	Park Road, Grafton, Auckland	09 367 0000
Middlemore Hospital	Hospital Road, Otahuhu, Auckland	09 276 0044
Waikato Hospital	Pembroke Street, Hamilton	07 839 8899
Thames Hospital	Mackay Street, Thames	07 868 0040
Tauranga Hospital	Cameron Road, Tauranga	07 579 8000
Rotorua Hospital	Pukeroa Street, Rotorua	07 348 1199
Hastings Hospital	Omahu Road, Hastings	06 878 8109
Whakatane Hospital	Stewart Street, Whakatane	07 306 0999
Palmerston North Hospital	Ruahine Street, Palmerston North	06 356 9169
Wellington Hospital	Riddiford Street, Newtown, Wellington	04 385 5999
Nelson Hospital	Tipahi Street, Nelson	03 546 1800
Christchurch Hospital	Riccarton Avenue, Christchurch	03 364 0640
Dunedin Hospital	Great King Street, Dunedin	03 474 0999
Invercargill Hospital	Kew Road, Invercargill	03 218 1949

Travel and accommodation support

National Travel Assistance (NTA)

The NTA Scheme may be able to cover some of your travel and accommodation costs if you meet their criteria. Their criteria is based on how far and often you have to travel to see your doctor or have treatment, or if you have a Community Services Card.

For full details on the NTA Scheme, including what you can and can't claim, visit the National Travel Assistance page on the Te Whatu Ora – Health New Zealand website (see the list of useful websites on page 83).

You can also see who is eligible for a Community Services Card on the Te Hiranga Tangata – Work and Income website. This can reduce costs of some doctor appointments, prescription fees and after-hours appointments.

If you are not eligible for the NTA Scheme, speak to your AYA keyworker, hospital social worker or LBC Support Services Coordinator about other support that is available. Some regions provide shuttle services, and there are non-government organisations (NGOs) such as LBC or the Cancer Society that may be able to help.

Accommodation

If you are travelling from out of town for treatment, you may be eligible for accommodation support via the NTA scheme (see above). You can also receive an allowance if you are staying with friends or family/whānau.

If you need accommodation, we recommend speaking to your hospital social worker, AYA keyworker or travel coordinator, who can tell you about the hospital accommodation options available.

If you are under the age of 18 and having treatment in Auckland, Wellington or Christchurch, you and your family/whānau may be able to stay at a Ronald McDonald House. Speak to your treatment team about getting a referral.

Informed consent

You will be asked to give your informed consent for all treatments or procedures suggested by a health professional in your health care team. Consent means that you agree. Informed consent means that you understand the information and accept the possible risks and benefits of the treatment or procedure. Informed consent also means that you have had other treatment or procedure options explained to you.

If you have any doubts or questions or need more information about a procedure or treatment, it is important you speak to your doctor or nurse again. It is very normal to have questions and no question is a silly question! You may need to sign a consent form (written consent), or you may just say you agree to a treatment or procedure (verbal consent).

If you are not able to give informed consent, a legal guardian, welfare guardian or person with enduring power of attorney can give consent on your behalf. Generally, a person over the age of 16 can give informed consent if the doctor feels they are able to do so. It is very normal to feel overwhelmed from all the information and questions. Sometimes it can feel like a lot of pressure on you to make a decision or give your consent. You can ask for your support person (close friend, parent or other family/whānau member) to be part of these conversations and decision-making. Your AYA keyworker or LBC Support Services Coordinator is also there to support you.

Your informed consent is also required if you agree to take part in a clinical trial. Clinical trials are explained on the following page.

Making treatment decisions

The treatment that your doctor will recommend depends on things like:

- Your diagnosis
- Your age
- Your general health
- How well your condition is likely to respond to treatment.

No two people are the same. To help you make the best treatment decision, your doctor will consider all the information available.

Many people feel overwhelmed when they are diagnosed with a blood condition. Waiting for test results and then making decisions about your treatment can be very stressful. Some people do not feel that they have enough information to make decisions, while other people feel that they have too much information. Some people feel that they are being rushed into making a decision. If treatment is recommended to start immediately, it can be difficult when you feel like you don't have time to consider all options and process the treatment information.

Your doctor will spend time with you and your family/whānau discussing what they feel is the best option for you. Ask as many questions as you need to, at any stage. You should feel that you have enough information to make the important decisions that you are facing.

Second opinion

You can ask for a second opinion. A second opinion is when you see a different haematologist or oncologist about your diagnosis and/or treatment. You can ask any member of your health care team, including your current specialist, about getting a second opinion.

Questions to ask your health care team

Before going to see your GP, specialist, or another member of your health care team, make a list of the questions you would like to ask. Some examples of questions you might like to ask can be found in the appendices on pages 82-83.

Bring a support person

We recommend that you bring a support person along to your appointments. Your support person can write down the answers to your questions, remind you of questions you want to ask and help you remember information. Your support person can be a close friend, parent or other family/whānau member and can change from appointment to appointment.

Prognosis

Prognosis means the likely course of a disease, i.e. how likely it is to be cured or controlled. Your prognosis will depend on many things. Your haematologist is the best person to give you a prognosis and tell you how well your blood cancer is likely to respond to treatment.

When doctors and other members of the health care team talk about prognosis, they might use the terms complete remission, partial remission, stable disease, relapse or refractory disease.

Here is what these terms mean:

- **Complete remission** – The treatment has successfully killed the cancer cells so they can no longer be detected in the blood or bone marrow, and there are no remaining enlarged lymph glands.
- **Partial remission** – The number of cancer cells has reduced, but there are still some cancer cells present in the blood, lymph nodes or bone marrow.
- **Stable disease** – The blood cancer has not improved or worsened with treatment.
- **Relapse** – The blood cancer has come back again. Some people's blood cancer may never relapse while others may have a higher chance of relapse.
- **Refractory disease** – The blood cancer is not responding to treatment (it is 'resistant' to treatment).

Clinical trials

Your doctor might ask you to take part in a clinical trial (also called research studies). Clinical trials help find out if a new treatment or different ways of giving treatment are better than treatments that are already available.

Taking part in a clinical trial is voluntary, which means that you do not have to take part in the trial if you do not want to. If you do not want to be part of the trial, your decision will be respected. You do not have to give a reason why you don't want to be part of the trial and there will be no change in the way you are treated by the hospital or health care team.

Make sure you understand the reasons for the trial and what is involved. You need to give informed consent for a clinical trial. Take time to talk through the trial with your haematologist or oncologist and other members of the health care team before signing the consent form.

Standard treatment

Standard treatment refers to common treatments for certain types and stages of blood cancer. They have been tried and tested (in clinical trials) and have proven to be safe and effective in those situations.

New therapies

There has been a lot of progress in the treatment of blood cancers. New drugs are being developed all the time. Your doctor will be aware of what new treatments are available and you should feel free to ask about your options.

What is chemotherapy?

Chemotherapy (often called chemo) literally means therapy with chemicals. Many chemotherapy drugs are also called cytotoxic (cell toxic) because they kill cells, especially ones that multiply quickly like cancer cells. Each drug affects the cancer cell in a different way, so usually a combination of two or more different chemotherapy drugs are given (combination therapy). How much, the timing and types of drugs used will vary depending on your blood cancer, your age, your general health, and the treatment protocol you will be following.

Chemotherapy is usually given in several cycles (or courses) with a rest period of a few weeks in between each cycle. This is to allow the body time to recover from the side effects of chemotherapy. For example, a typical chemotherapy regimen for acute myeloid leukaemia (AML) might involve 4-5 cycles of a combination of drugs, given over a period of about six months.

Most chemotherapy drugs travel around the body in the bloodstream, which means they can reach cancer cells anywhere in the body. Sometimes the chemotherapy drugs also kill healthy cells, which can lead to side effects. Side effects are discussed later in this section on page 28.

The names of different combinations of drugs are commonly made up of the first letters of the name of each of the drugs used. For example, someone with Hodgkin lymphoma may be having a combination of four chemotherapy drugs which are called Adriamycin, Bleomycin, Vinblastine and Dacarbazine. This combination of chemotherapy drugs will be abbreviated to ABVD.

How is chemotherapy given?

The different ways that chemotherapy is given are:

- Into a vein (intravenously or IV)
- As a tablet (orally)
- Into a muscle (by intramuscular injection)
- Under the skin (subcutaneously, sub-cut or SC)
- Into the spinal fluid via a hollow needle (intrathecally or IT).

If you are having several cycles of chemotherapy, your doctor may talk to you about having a central line (also called a central venous catheter or CVC), port or peripherally inserted central catheter (PICC) line inserted. These are special lines inserted through the skin into a large vein in your arm, neck or chest. Once your line is in place, chemotherapy and any other IV drugs can be given and blood tests can be taken from the line, without the need for frequent needles in your arms.

PICC line

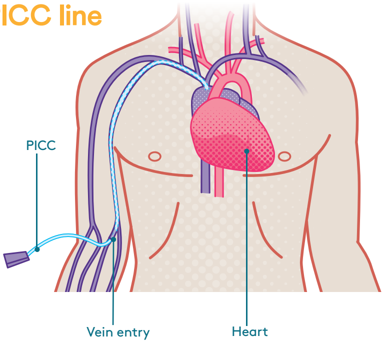
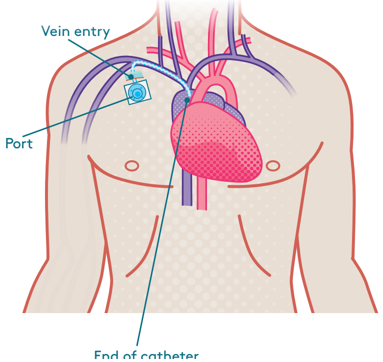


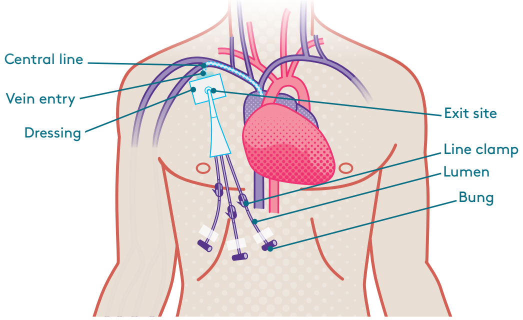
Figure
07

Central venous catheters

Port



Central line



What is central nervous system treatment and prophylaxis?

In some conditions like acute leukaemia and lymphoma, cancer cells are sometimes found in the central nervous system (CNS) – the brain and spinal cord. The blood supply to the CNS is separate from the blood supply to the rest of the body, so it can be difficult for standard treatments to reach cancer cells in these areas. In these cases, CNS treatment and prophylaxis (preventative protection) will be given at various stages throughout treatment. This usually involves injections of methotrexate and/or other chemotherapy drugs directly into the spinal fluid (called an intrathecal injection), through a lumbar puncture. Some types of intravenous chemotherapy, steroids and radiotherapy can also be used to provide protection for the CNS.

Side effects of chemotherapy

Healthy cells that multiply quickly in your body can also be killed or damaged during chemotherapy. Examples of these cells are those in your mouth, stomach, bowel, bone marrow and hair. The dead or damaged cells can cause side effects.

The side effects for each drug or drug combination are different. Most people will have some side effects, but some people do not. Side effects may vary depending on the dose of chemotherapy you are having. Most side effects of chemotherapy begin to go away when your treatment is finished.

When you receive chemotherapy, there are breaks during the treatment so that your body (the bone marrow in particular) has time to recover from the side effects of the chemotherapy. Side effects of treatment may be short term or long term (sometimes called 'late effects'). Short-term side effects should go away a few weeks after treatment finishes, once the damaged cells recover. Long term means that you may experience side effects for months after treatment.

Here is a list of the most common side effects of chemotherapy, in alphabetical order:

Anaemia (from a low red blood cell count)

- Bruising and bleeding (from a low platelet count)
- Constipation
- Diarrhoea
- Difficulty concentrating or remembering (chemo brain)
- Early menopause
- Fatigue (extreme tiredness)
- Fertility changes
- Hair loss (alopecia)
- Increased risk of infection (from a low white blood cell count)
- Low mood, anxiety or depression
- Nausea and vomiting
- Organ damage
- Pain
- Peripheral neuropathy
- Poor appetite and taste changes
- Skin changes
- Sore mouth (mucositis)
- Weight loss or gain.

These side effects, and what you can do if you have them, are discussed more on page 36.

What are steroids?

Corticosteroids (or steroids) such as prednisone (prednisolone) and dexamethasone are commonly used in blood cancer treatment. They work alongside chemotherapy drugs to kill lymphoma cells, make the chemotherapy drugs more effective, and reduce the risk of allergic reactions to some drugs. Steroids are usually taken as a tablet but can be given by IV/drip.

Steroid treatment commonly has side effects, these can be different for every person.

Below are some common side effects, and some suggestions for how to deal with them:

- Mood changes (mood swings, anxiety, irritability, tearfulness) – Ask your treatment team about what support is available and speak to your LBC Support Services Coordinator.
- Difficulty sleeping – Talk with your doctor about whether you can take the steroid at a different time. Some people find taking them in the morning helps, other people prefer to take them right before bed so they are asleep by the time the steroid starts working.
- Stomach pain – Take with food and speak to your treatment team if this continues, there may be medications you can take to help.
- High blood sugar – If you are diabetic, check your blood sugars more often. You may need to speak to your doctor about adjusting your insulin or other medications.
- Increased appetite and weight gain – This can be common with long-term steroid use. If you are concerned, ask your treatment team if you can speak to a dietitian.
- Muscle weakness – Steroids may cause muscle weakness or wasting in some people. Continue regular gentle exercise, you may also find it useful to see a physiotherapist.
- Increased risk of infection – Monitor for signs of infection such as a high temperature, swelling, red skin or unexplained pain, and speak to your doctor immediately.

What is radiotherapy?

Radiotherapy (also called radiation therapy) uses high-energy X-rays to kill cancer cells and shrink tumours. Radiotherapy is called a 'local therapy' because it only destroys cancer cells in the treated area (the radiation field).

Before you start radiotherapy

The radiation oncologist (doctor who specialises in treating people with radiotherapy) will calculate how much radiotherapy you need (the dose). You will have scans to work out the best position to be in, and the areas of your body that need to be treated will be marked with tiny ink dots on your skin using a special pen. Your doctor will treat the smallest area possible to avoid affecting the normal tissues.

During treatment

Radiotherapy is usually given in small doses (also known as fractions) in the radiotherapy department of the hospital. You usually do not need to be admitted to hospital for this treatment, but if you live far away you may need to organise to stay closer during this time. Your health care team can help you with this.

During radiotherapy you will be positioned on a table underneath the radiotherapy machine, which will give you the planned dose of radiation. Radiotherapy sessions are usually short (15–30 minutes), and you will need to stay perfectly still for a few minutes while the treatment is taking place. You will hear a buzzing sound as the machine moves around you. If necessary, important structures like your heart and lungs are shielded as much as possible to ensure that they are not affected by the treatment given. Radiotherapy is painless – you will not see or feel anything during the actual treatment. If you are feeling anxious, you might like to bring along some music to help you relax.

Radiotherapy treatment does not make you radioactive, as the radiation passes through your body. It is okay to interact with other people during and after your treatment.

After radiotherapy

There are some side effects from radiotherapy. These vary from person to person and can be short term or last for a while after treatment. **Side effects include:**

- Fatigue (see more about fatigue on page 44).
- Skin irritation – skin can become red, dry, painful or warm in the area that has been treated. Skin changes will be worst just after treatment has ended and should heal in 4–6 weeks. Stay out of the sun and avoid scented soaps and moisturisers, and skin products that contain metals during this time.
- Mouth pain.
- Parotitis – inflammation of the saliva glands in the mouth, which can cause a dry mouth and jaw pain.
- Feeling sick (nausea and vomiting).
- Bowel changes – gas/wind, loose stools, diarrhoea, bloating or cramping.
- Hair loss in the area of radiation treatment.

After your radiotherapy has finished, you may have scans to see how the blood cancer has responded. This will help your health care team make decisions about your treatment. If you have had radiotherapy to your mediastinum (chest) area, you may be advised to have earlier or more frequent mammograms, to monitor for breast cancer.

Excessive friction, heat or washing should be avoided on areas that have just been treated with radiotherapy. Your health care team in the radiotherapy department will be able to tell you the best way to care for your skin.

Immunotherapy and targeted therapy

Immunotherapy is the use of drugs to help a person's own immune system recognise and destroy cancer cells. Because this type of therapy specifically targets cancer cells, it doesn't usually damage normal cells and therefore causes less side effects. Side effects are generally mild and can be easily managed.

Targeted therapy is the term used to describe a group of drugs which target specific molecules that cancer cells need to survive and spread. Targeted therapies work in different ways to treat cancer.

What is a stem cell transplant?

For some people, very high doses of chemotherapy or radiotherapy are needed to treat their blood cancer. As a side effect of these treatments, normal bone marrow and bone marrow stem cells are also destroyed and need to be replaced. In these cases, a stem cell transplant is used (also called a bone marrow transplant, or peripheral blood stem cell transplant). If you have a stem cell transplant, you are given high-dose chemotherapy followed by stem cells through an IV/drip. The stem cells you are given may come from someone else (a donor), or they may be your own cells that were frozen before the high-dose chemotherapy.

There are two types of stem cell transplant:

- An autologous transplant involves collecting your own stem cells (usually from your bloodstream), storing them and then giving them back via IV/drip after you have received high doses of chemotherapy.
- An allogeneic transplant is where the stem cells are donated by another person. This could be a brother or sister, parent, or a matched unrelated donor. These donated stem cells replace your immune system with the immune system of the donor.

Having a stem cell transplant is a high-risk treatment option and a lot of things are taken into consideration before it is offered by your haematologist or oncologist.

More information is available online

Complementary therapies

Complementary therapies are not considered standard medical treatment, however many people find that they are helpful in coping with their treatment and recovery. **There are many different types of complementary therapies, including:**

- Yoga
- Exercise
- Meditation
- Prayer
- Acupuncture
- Relaxation
- Massage
- Homeopathy
- Visualisation
- Aromatherapy
- Reiki
- Art therapy
- Music therapy
- Tai chi.

Complementary therapies should 'complement' or assist with recommended medical treatment. They are not recommended as an alternative to medical treatment. It is important to realise that no complementary or alternative treatment has been proven to be effective against blood cancers and conditions.

It is also important to let your haematologist know if you are using any complementary or alternative therapies in case they interfere with the effectiveness of chemotherapy or other treatments you may be having.

Summary

Treatment for your blood cancer or blood condition can be as an inpatient (staying in hospital) or outpatient.

If you live far away from a main treatment centre, you may need to stay closer temporarily, and there are some support options available for this.

Some people like to use complementary therapies alongside their medical treatment to help with coping and recovery.

You (or your parents if you are under 16 years of age) will need to consent (agree) to any treatments, and have the right to be involved in the decision-making process for your treatment.

Your treatment will depend on a number of factors, and may involve chemotherapy, steroids, radiotherapy, immunotherapy or a stem cell transplant.

You'll find a glossary of terms at the back of this booklet if you need help along the way.

Questions and notes

Understanding side effects

Te whai mārama ki ngā mate āpiti

How will I be affected?

Your quality of life (how you feel, and your ability to do the things you want to do) is very important. The challenge is to treat your blood cancer or blood condition with the fewest possible side effects.

Chemotherapy and radiotherapy kill cells that grow quickly. This means they kill cancer cells, but they can also cause damage to fast-growing normal cells, including hair cells and cells in your mouth, stomach and bone marrow. When normal cells are damaged, this can cause side effects.

Radiotherapy side effects usually depend on the area of the body that is being treated, e.g. radiotherapy near the stomach is more likely to cause nausea and vomiting. Chemotherapy side effects can happen anywhere in the body, as the chemotherapy drugs are carried around in your blood. The side effects, and how bad they will be, are different for every person. Side effects can be horrible, but usually they don't last very long and will disappear with time.

Tell your doctor or nurse about any side effects that you have, because there are lots of treatments that can be given to make you feel better.

Reduced immunity

Chemotherapy (and sometimes radiotherapy) can temporarily affect the bone marrow's ability to produce enough white blood cells, platelets and red blood cells. As a result, your blood count (the number of white blood cells, platelets and red blood cells in your blood) will generally drop in the first few weeks of treatment. How long it takes for your bone marrow and blood counts to recover mainly depends on the type of chemotherapy you receive.

The point at which your white blood cell count is at its lowest (called the nadir) is usually expected 10–14 days after starting each cycle of your treatment. You will have a blood test to check your blood count.

At this stage you will be neutropenic, which means that your neutrophil count is low and you are more at risk of getting an infection. Neutrophils are important white blood cells that help us to fight infection.

While your white blood cell count is low, you should be extra careful to prevent infection. **Some things you can do include:**

- Washing hands before eating and after going to the toilet
- Showering daily
- Brushing teeth with a soft toothbrush after meals
- Avoiding crowds, e.g. malls, movie theatres, public transport, concerts
- Avoiding people with infections that are contagious, e.g. colds, flu, chickenpox
- Only eating food that has been properly prepared and cooked
- Get someone else to clean your pet's litter tray.

Your doctor and nurse will give you more information on how to reduce your risk of infection while your white blood cell count is low. If you do develop an infection you may experience a fever, with or without shivering/shaking. Infections while you are neutropenic are serious and need to be treated with antibiotics immediately.

It is important that you contact your doctor or the hospital for advice immediately (at any time of the day or night) if you are feeling very unwell, or if you experience any of the following:

- A temperature over 38°C and/or an episode of shivering (don't wait to see if it goes away)
- Bleeding or bruising, e.g. blood in your urine or faeces (poo), coughing up blood, bleeding gums or a persistent nosebleed
- Nausea or vomiting that prevents you from eating or drinking or taking your normal medications
- Diarrhoea, stomach cramps or constipation
- Coughing or shortness of breath
- The presence of a new rash or reddening of the skin which may be itchy
- A persistent headache
- A new pain or soreness anywhere
- You cut or otherwise injure yourself
- If you notice pain, swelling, redness or pus anywhere on your body.
- This might sound extreme, but a mild infection that would make someone with a healthy blood count feel a little off-colour can be life-threatening for someone who is neutropenic.

Should I have medicine if I feel unwell?

It is important that you do not use any drugs to bring your temperature down (e.g. paracetamol, ibuprofen) until you are reviewed by a doctor. This could mask an infection, which could lead to serious life-threatening complications. Do not take aspirin or ibuprofen in any form as this can increase the risk of bleeding if your platelet count is low. Always check with your doctor first before taking any over-the-counter medications.

What is GCSF?

You might be given a drug called granulocyte colony-stimulating factor (GCSF) to help increase your neutrophil count. This drug works by telling the bone marrow to make more neutrophils. GCSF is given as an injection, and the nurse will teach you, a family/whānau member or friend how to do this at home. There are not usually any major side effects, but some people experience aching bones.

Anaemia

Red blood cells contain haemoglobin (heem-a-glow-bin), which carries oxygen around your body. If your red blood cell count and haemoglobin levels drop, you may become anaemic.

When you are anaemic, you may look pale and feel more tired than usual. If your haemoglobin level is very low, your doctor may prescribe a blood transfusion via a drip/IV.

Bleeding and bruising

Platelets are blood cells which help clot the blood to stop bleeding. After treatment, your platelet count may drop – this is called thrombocytopenia (throm-bo-sy-toe-pee-nee-a). When your platelet count is very low you can bruise and bleed more easily.

Things that can help:

- Avoid food with sharp edges such as potato chips as these can cut your gums
- Use a soft tooth brush
- Don't floss your teeth
- Don't shave with a razor blade
- Move about carefully so you don't bump into things or trip
- Don't play contact sports such as rugby or hockey
- Wear protective gloves when doing work around the house or garden.

You may be given a platelet transfusion via drip/UV to reduce the risk of bleeding until your platelet count recovers.

Call the hospital straight away if you have:

- Nosebleeds
- Bleeding gums
- Tiny red or purple spots (petechia) on the skin that looks like a rash
- Heavier than normal menstruation bleeding.

Body image

Your body is going through some big changes right now. You probably feel different, and sometimes the person you see in the mirror looks different to what you are used to as well. Hair loss, skin changes, weight changes and fatigue can all change how you feel about yourself. This is very normal, and you are not the only one going through this right now. It is important to remember that most of these changes won't last very long and should resolve once your treatment is finished.

Hair loss (alopecia)

Hair loss is a very common side effect of chemotherapy and some forms of radiotherapy. This is because the drugs used to kill the blood cancer cells also kill other fast-growing cells such as hair cells. Many people lose all their hair. Others find their hair falls out in patches, thins on top, and the hair that remains is usually weak. Hair loss can also affect your eyebrows, eyelashes, arms, legs and genitals.

Hair usually starts to fall out within a couple of weeks of beginning treatment and tends to grow back 3–6 months after finishing. You may find your hair grows back differently to what it was before – it may be thicker, wavier or a different colour. You may experience itchiness or scalp tenderness while losing your hair.

Some tips for hair loss:

- Don't use hairdryers, straighteners or harsh chemicals on your hair, as this can make hair loss worse.
- Using a soft hairbrush and baby shampoo can help with itchiness or pain on your scalp.
- Pat your hair dry with a towel, rather than rubbing it.
- If you lose all your hair or decide to shave it, protect your head from the sun with a hat, scarf or wig. During treatment your skin is even more sensitive to sun damage.
- Take a beanie with you to hospital to keep warm in the air conditioning.

> **“If I could give myself one piece of advice, it would be to document the journey. Keep a diary and don't be afraid to take photos. I was devastated when I lost my hair and felt hideous for months. I know that sounds silly to some people but being a 21-year-old woman at the time, my hair meant a lot to me.**
>
> **Every time I looked in the mirror I was reminded of how sick I was and I couldn't escape it. Despite this, I wish I had taken lots of photos. Once you reach the end of your fight and even in the future years, you will be able to look at those photos and although they may have been the toughest moments of your life, it reminds you of how incredibly strong you are and how far you have come.”**
>
> Dani

If you are a citizen or usually live in New Zealand, the Ministry of Health has a wigs and hairpieces subsidy that you may be entitled to. How much you can get depends on your age, and whether your hair loss is permanent or temporary. You can use this money to purchase wigs, hats, head coverings, or other similar products. You will need a medical certificate from your specialist. You can get more information on the subsidy from your treatment team, LBC Support Services Coordinator or the Ministry of Health (see the list of useful websites on page 83).

! In summer, it is important to protect yourself against sunburn. Your skin will be more sensitive to the sun after chemotherapy so it's important to apply sunblock and cover up.

Skin and nails

Sometimes chemotherapy can cause changes to your skin and nails. Your skin may become dry or it might get more oily. It can also become red, sore, itchy and more sensitive. Your nails may become brittle and flaky. Ridges or lines may appear on your nails, and the skin around them can also become painful or swollen.

Washing with a soft cloth and warm water can be soothing – choose gentle or sensitive face washes and soaps.

If you shave, use an electric shaver rather than a razor, which can increase the risk of bleeding and infections if you cut yourself. You may need to avoid waxing and chemical hair removal while your skin is sensitive.

Makeup is usually okay to wear, but it is sensible to patch test your makeup to make sure your skin doesn't react to it. If you have radiotherapy, avoid wearing makeup in that area.

Weight loss

It is really common for your weight to change due to your blood cancer or its treatment. You may feel less hungry, or nauseous and you may lose weight. Losing a lot of weight can make you feel very exhausted with no energy (fatigued) which may make it harder to cope with the treatments. If you or haematologist are worried that you're losing too much weight, they may refer you to a dietitian who can help you come up with a plan

Other things that may help include:

- Eating foods high in calories (like ice cream, cheese, milkshakes) and proteins (like meat, eggs, nuts).
- Treat your eating like taking your medicines – part of your treatment plan to get better.
- Don't worry if there are only a few foods you like – eat lots of those.

The pressure of needing to eat and gain weight can be really challenging and bring up a range of emotions for you. Your health care team are there to support you so ask for extra help if you need.

Weight gain

Some treatments can cause constant hunger and weight gain. One type of drug that affects hunger and weight is steroids. Some people may be on big doses of steroids as part of their treatment plan. One of the side effects of steroids is constant hunger which can lead to weight gain. You may find these changes to your body upsetting or hard to manage. If you are worried about your weight changes, ask your doctors or nurses if you can speak to a dietitian and/or psychologist. They will talk to you about your concerns, and help you make any changes you need to.

Other tips that may help include:

- Focus on eating healthy food and snacks that are readily available
- Exercise regularly if you can
- Don't avoid eating because you're afraid of gaining weight. The nutrients from food are really important for your general health
- Wear clothes you feel comfortable in
- Talk to your family/whānau, friends or health care team if you're feeling upset.

Bowel changes

Diarrhoea

Chemotherapy and radiotherapy can cause some damage to the lining of your bowel (gut, intestines). This can lead to stomach cramps, wind, abdominal swelling and diarrhoea. You should tell your doctors or nurse if you experience any of these symptoms.

If you have diarrhoea, your health care team will do a test to see if you have an infection. After this, you will be given some medication to help stop the diarrhoea.

Things you can do to help:

- Take the drugs your doctor or nurse give you to stop the diarrhoea
- Use soft toilet paper
- Apply a barrier cream around your bottom to protect and soothe the skin
- Drink plenty of fluids – if you are unable to drink, tell your doctor or nurse as you may need to have a drip/IV
- Talk to a dietitian about changes you can make to your diet.

Call the hospital straight away if you have:

- More than 4 episodes of diarrhoea in a day.

Constipation

It is also important to tell your doctor or nurse if you are constipated or if you are feeling any discomfort or pain around your bottom (anus) when you are trying to move your bowels (poo).

Things you can do to help:

- Drink plenty of water
- Eat more fibre such as cereals, fruit and vegetables
- Do some gentle exercise
- Talk to your doctor or nurse about getting some gentle stool softeners or laxatives
- Talk to a dietitian.

Difficulty concentrating or remembering (chemo brain)

Blood cancer and its treatment can sometimes make it harder to think clearly or remember things. You may hear some people describing this as chemo brain or chemo fog. How you are affected is different from person to person, but some people have trouble speaking, thinking, making decisions or concentrating.

It can even make you feel more emotional, and you might find yourself getting angry easier. For most people this is temporary, but some people experience this for longer.

More information is available online

Fatigue

Fatigue is extreme tiredness and is one of the most common side effects of blood cancer and many blood conditions. It can be related to your blood cancer, your treatment and/or other complications such as anaemia or infection. Fatigue can affect everyone differently. Some people may feel better after a few days, while others may feel fatigued for weeks or months.

Fatigue for people with blood cancers is not the same as normal tiredness. It can make simple activities such as showering or even walking around your home difficult. It will not be fixed by having more sleep. It can be hard watching other people out and doing things, when you don't have the energy to join in. Remember, fatigue is really common and should get better by itself with time.

> **"I found it so frustrating when I told my siblings that I was too tired to do something and they would say 'oh me too'. I felt like saying 'you have no idea!'"**
>
> Ben

More information is available online

You might find it helpful to keep a diary so you can work out if there is a pattern for your good and bad days – then you could plan to do more things when you are likely to have more energy. Having plenty of rest and a little light exercise each day might help to make you feel better as well. Getting out in the fresh air and doing some gentle exercise is important for your general feeling of well-being and it may also help to reduce your fatigue. It is important to listen to your body and rest when you are tired.

Nausea and vomiting

Some treatments, especially some types of chemotherapy, can make you feel sick (nausea) and vomit. However, there have been huge improvements in the availability of anti-sickness (antiemetic) drugs, so there are lots of things you can take to control this.

You will be given anti-sickness drugs before and for a few days after your chemotherapy treatment. You may find it helpful to take your regular anti-sickness medication an hour before eating. Some people also feel sick at just the thought of having their treatment, eating or even the smell of food. This is called anticipatory nausea. Some people find that thinking about the positive aspects of treatment (such as the chemotherapy destroying cancer cells) can help reduce anticipatory nausea.

You should tell your doctor or nurse if you think that the anti-sickness medication is not working or if you still feel sick. They might be able to give you a different medication, or a stronger dose.

Eating and sickness

Eating when you feel sick can be difficult, but an empty stomach can sometimes make nausea worse.

There are some things you can try to make it easier to eat:

- Drinking smoothies or milkshakes may be easier than eating solid food if you are feeling unwell
- Try cool or cold food such as jelly, ice cream and yoghurt
- Eat slowly and try not to watch other people eat
- Drinking flat ginger beer or soda water and eating dry toast may also help if you are feeling sick
- Get plenty of fresh air and avoid any strong or offensive smells
- Keep drinking water, even if you feel sick – you may find that you feel worse if you don't. Sucking on ice cubes or having an ice block might be easier than drinking
- Try sucking a lolly if you get a strange taste in your mouth from any of the drugs you are taking.

Nutrition and diet

Having enough nutritious food is important in helping your body to cope with your disease and treatment. Talk to your doctor or nurse if you have any questions about your diet or if you are considering making any big changes to the way you eat. A dietitian can advise you on planning a balanced diet that is right for you. If you are in hospital you may be able to store your own food and snacks, or have someone bring in your favourite foods.

When your immune system is low, you are at higher risk of getting very sick. You will need to be careful around eating some foods to reduce the chances of food poisoning. When you are in hospital, you may be placed on a 'low risk' or 'neutropenic' diet. The nurses or your dietitian will explain which foods you should avoid. The Ministry for Primary Industries (MPI) also has a guide to food safety for people with low immunity (see page 83 for website link to this booklet). When you are neutropenic you need to be very careful when preparing and cooking food. **Be sure to:**

- Always wash your hands before preparing or eating food
- Prepare food in a clean place
- Prepare raw chicken on a separate chopping board from other foods
- Wash fresh fruit and vegetables well
- Cook food well and makes sure it is very hot
- Make sure reheated food is very hot
- Eat food before its best before/use-by date
- Do not reheat food more than once.

Changes in taste and smell

Both chemotherapy and radiotherapy can cause changes to your sense of taste and smell. This is usually for a short time, but for some people it can last up to several months. You may find food and drink taste really bland – or just 'wrong'. This can be really disappointing.

Some people find that adding a little more sugar to sweet foods and salt to savoury foods can help. Others find spicy foods more enjoyable to eat. If you are thinking about using complementary supplements, e.g. vitamins or medicinal herbs, it is very important to talk to your doctor first because they can interfere with the effectiveness of chemotherapy or other treatment you are having.

More information is available online

Sore mouth (mucositis)

Chemotherapy and some kinds of radiotherapy can cause inflammation of the lining of your mouth and digestive system – this is called mucositis. It usually starts about a week after the treatment has finished and goes away once your blood count recovers – usually a couple of weeks later. It can be really uncomfortable and may cause ulcers or bleeding. Oral pain relief and other topical drugs (that can be applied to the sore area) can help. If the pain gets worse, stronger pain killers might be needed.

Sometimes your salivary glands can be affected, causing either a dry mouth or too much saliva. Small sips of drinks or sucking on ice cubes can be effective with a dry mouth, and some pharmacies sell a saliva substitute which can help.

Mouth care

It is important to keep your mouth as clean as possible while you are having treatment, to help prevent infection. It is especially important to do your mouth care regularly while your mouth is sore.

Your health care team will show you how to care for your mouth during this time, and may recommend a gentle mouthwash, soft toothbrush and mild toothpaste. Avoid mouthwashes you buy at the supermarket, as these are often too strong or may contain alcohol which will hurt your mouth. Use a lip balm regularly to prevent or treat cracked and sore lips.

Avoid using dental floss as this increases the risk of bleeding gums.

It is also helpful to let your doctor know if you have had any problems with your teeth or gums in the past as chemotherapy can sometimes cause old problems to flare up. Your doctor might recommend you see a dentist before starting treatment.

Sexual well-being

It is normal for your diagnosis and treatment to impact your body and sexual activity. Some of this information may not apply to you, but it is designed to cover some different ways your diagnosis can impact your sexual well-being (or health).

You can be intimate, and have sex during treatment, however there are some things you should know.

You may find you have less interest or comfort around having sex. Remember to only do what you are comfortable with and to talk with your sexual partner. Side effects can make having sex difficult (i.e. vaginal dryness), fatigue and mood changes can mean you are less interested. This is very normal and is not a reflection on you or your partner. It can be helpful to communicate with your partner and tell them how you feel. Some people prefer to focus on other ways of feeling close, such as cuddling, watching movies together or massages.

Always use a condom (or other physical barrier) during sex to protect your partner from chemotherapy exposure and to avoid catching sexually transmitted infections (STIs). Chemotherapy drugs can be in your bodily fluids, which includes saliva, vaginal fluid and semen (the fluid that contains sperm) for up to 7 days after you've finished chemotherapy. When using a condom it is important to use a water-based lubricant (lube) to reduce friction and risk of bleeding. Water-based lube can be bought at a supermarket, chemist or online.

If you have a low platelet count, this could increase your risk of bleeding, so avoid rough sex and use a water-based lubricant. If you do bleed after sex, tell your health care team. If the bleeding does not stop, contact the hospital straight away.

You won't spread your blood cancer to your partner by having sex. Blood cancers and conditions are not contagious and cannot be passed on to anyone else.

You should avoid getting pregnant (or getting your partner pregnant) while having treatment, as the drugs used to treat most blood cancers and blood conditions are toxic and can cause harm to the developing baby. You should use contraception (birth control) until your doctor tells you it is safe to try and have a baby. If you are pregnant when you are diagnosed or find out that you are pregnant while having treatment, it is important that you tell your health care team immediately. They will discuss various options with you, and whether any changes need to happen to your treatment plan.

If you have any questions about intimacy or sex, ask to speak with your nurse, doctor or AYA key worker. They are great people to ask your questions to as they have these conversations with patients everyday.

Menstruation

If you normally menstruate (get periods), you may find your periods stop or come at random times. You may be given a contraception pill to stop your periods. This prevents heavy bleeding and blood loss when your platelet count is low. It is best to use pads or a menstrual cup instead of tampons, as these can increase your risk of infection. Your health care team is available for you to ask any questions about your period or bleeding that you're concerned about. You may feel uncomfortable talking to your health care team about your periods but it is very important to let them know if you have any extra or heavy bleeding.

Some treatments may cause you to go into early menopause (when your periods stop due to hormone changes). If you have gone through menopause, you will not be able to have children without the assistance of fertility treatment (see below). Ask your doctor about whether your treatment is likely to cause early menopause or affect your fertility.

Fertility and cancer treatment

Your fertility is your ability to have a biological child – either to get pregnant, or to get someone else pregnant. Some types of treatment (such as chemotherapy and radiotherapy) can reduce your fertility, making it difficult to conceive or reproduce. Not all people who have a blood cancer or condition will be affected, other people may be affected temporarily or permanently. It may mean that in the future you might not be able to have a child when planned or you might need some help to have a baby (fertility treatment). It is important to discuss how your treatment will affect your fertility before you start your treatment. Not all treatments will cause infertility or make it harder to have children – so it's important to ask.

Before starting treatment, you should be asked if you want to freeze your sperm or eggs, or an embryo (fertilised egg). Unfortunately, not everyone will have the option of being referred to a fertility specialist before treatment starts. This is because some blood cancers and conditions (such as acute leukaemia and aggressive high-grade lymphoma) require treatment to start immediately and it is life-threatening if it is not. Your haematologist will explain this to you if this is the case. You may wish to speak to a fertility specialist even if you have already started treatment or are at a low risk of fertility problems after treatment. It might be possible to arrange a consultation over the phone. You can also talk with a fertility specialist about your options after you have finished treatment.

Freezing sperm

Freezing sperm (sperm banking) involves getting a sperm sample (by ejaculation) and freezing it using liquid nitrogen. The sample may be taken at a fertility clinic, or in some cases may happen on the ward. Sperm can usually be stored for up to 10 years, and you can request to store it for longer. The sperm sample can then be used later when you are ready to have a baby.

Egg freezing or ovarian tissue freezing

Egg freezing (oocyte cryopreservation) involves collecting and freezing some of your eggs until you are ready to use them. The process usually requires your ovaries to be stimulated by hormonal drugs in order to get lots of mature eggs. This process takes 10-14 days, so unfortunately may not be possible if your treatment needs to start urgently. It is funded by the government (will not cost you anything) if you are under 40 years old and do not have any other children.

To freeze ovarian tissue (ovarian cryopreservation), part of your ovary is removed by keyhole surgery and the tissue is frozen. There is funding available for this procedure if you are under 18 years and meet their eligibility criteria. A fertility specialist will discuss with you the details of how they may be able to transplant your ovarian tissue back into your body with the hope that the ovary starts functioning again and eggs can be collected. They can also discuss what funding options are available to you.

Embryo freezing

Embryo freezing (embryo cryopreservation) involves collecting eggs from your ovaries (usually after hormonal stimulation) and fertilising them with sperm. The embryos are frozen until you are ready to use them. This process may be an option if you are in a relationship with a male partner and he is willing to use his sperm, or if you have donor sperm. This process takes 10–14 days, which may not be an option if your treatment needs to start straight away.

IVF (in vitro fertilisation)

IVF is the process that uses collected sperm and eggs to make one or more embryos in a laboratory. When someone is ready to use a frozen embryo, the specialist doctor selects the embryo they consider has the best chance of a pregnancy to be transferred into the uterus.

Fertility and emotions

Finding out that your treatment could impact your fertility may make you feel upset, worried or angry. It is another area of your treatment that may seem uncertain and overwhelming. It is normal to feel a range of emotions and if you have a partner, they may also be experiencing the same.

It may be friends, family/whānau, a partner, a psychologist, your health care team or LBC Support Services Coordinator. Your health care team or fertility specialist can discuss your options further or answer any specific questions you have about your treatment and its potential effects on your fertility. It is a good idea to talk to someone who can listen and help you process these feelings.

Men

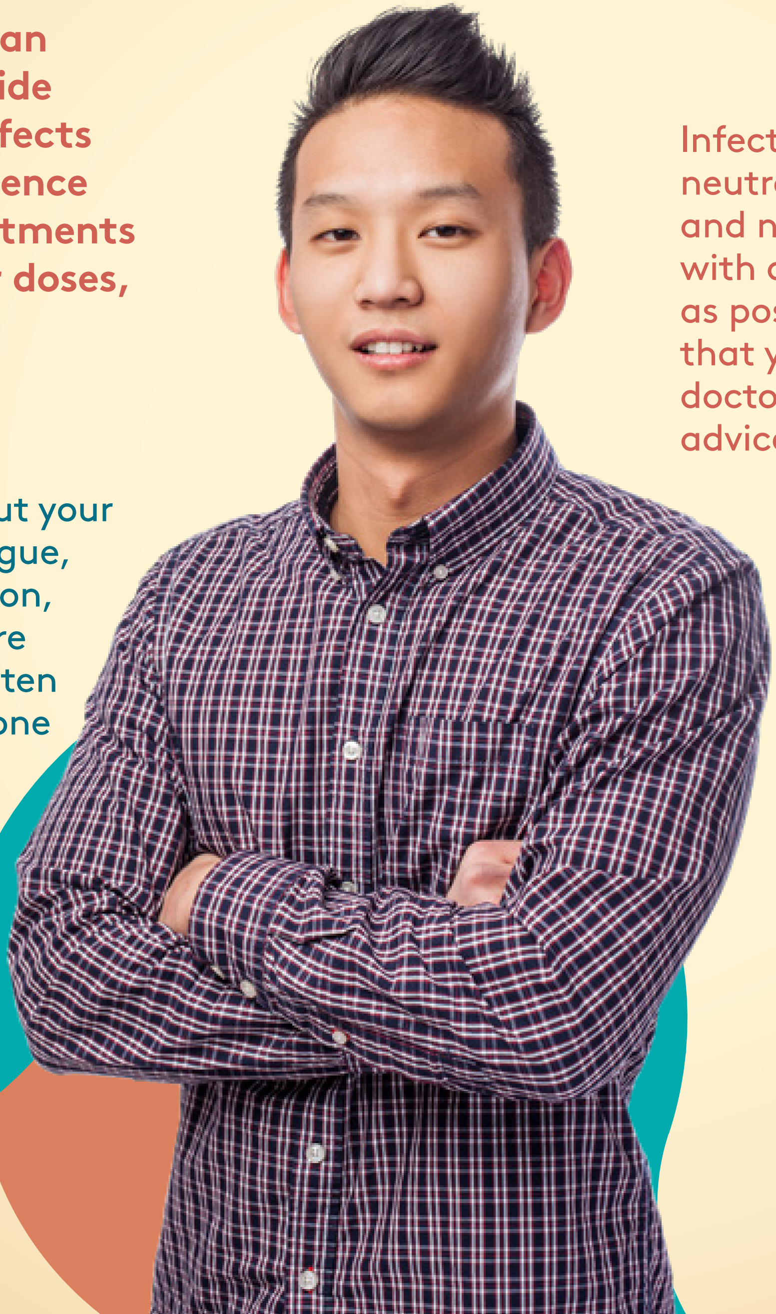
More information is available online

Women

Summary

Some treatments can cause unpleasant side effects – the side effects that you will experience depend on the treatments you have had, their doses, and how your body responds.

Keep talking to your treatment team about your side effects (e.g. fatigue, diarrhoea, constipation, nausea, vomiting, sore mouth) – there are often things that can be done to make them more manageable.



When you are neutropenic you should be extra careful to prevent infection

Infections while you are neutropenic can be serious and need to be treated with antibiotics as soon as possible. It is important that you contact your doctor or the hospital for advice immediately 24/7.

Your body is going through some big changes which can bring up a lot of different feelings. Hair loss, skin changes, weight changes and fatigue can all change how you feel about yourself.

When your platelet count is very low you can bruise and bleed more easily.

Some treatments can affect your fertility – ask your treatment team if this is likely to affect you, and any steps you can take to preserve your fertility.

It is normal for your diagnosis and treatment to impact your sexual activity. If you are having sex, you should use contraceptives to avoid pregnancy, and use condoms to protect your partner from exposure to the chemotherapy drugs.

Questions and notes

Life with cancer

Te ora tahi me te mate pukupuku

Feelings

There is no right or wrong way to feel throughout your diagnosis and treatment. Everyone is different, and your feelings and the way you cope with these feelings may not be the same as others going through the same experience.

Your feelings can change over time, and you will have good and bad days. When you are first told that you have a blood cancer you may be shocked or numb – as though it's all happening to someone else. Whatever your feelings are right now, give yourself the space and time to process them.

For many people, culture, language, religious or spiritual beliefs can be very important in helping you and family/whānau to cope with your diagnosis and treatment. Information regarding your diagnosis and treatment can be found in many different languages. Translators can be arranged, and your doctor or nurse can help organise any cultural or religious support you need. In New Zealand, most hospitals have kaiāwhina/kaumātua, Pacific health navigators and chaplaincy teams available to support you.

What if I'm feeling anxious?

Following your diagnosis with a blood cancer or blood condition, you might feel a bit unsettled, afraid or worried. You may have anxiety about your diagnosis and treatment and what it will mean for you and your family/whānau.

It can be especially scary when you are starting out and you have lots of questions – our brains tend to focus on the worst-case scenarios. Talk to your doctor and nurses, ask questions until you understand this new medical language and information. Remember that it takes time to absorb new information, so having someone you trust and who will be with you throughout your treatment journey may help.

Do not be afraid to ask the same questions again if you have forgotten what thas been said, or what things mean – your doctors and nurses understand that it is a lot of information to take on board all at once.

You may find that as your treatment progresses your anxiety lessens over time. If you are feeling very anxious or your anxiety is not improving, ask your treatment team about whether you can speak to a counsellor or a psychologist.

Organisations like LBC, CanTeen and the Cancer Society can also help support you with your anxiety.

What if I'm feeling emotional?

Having strong emotions, or having your moods swing from one to another (such as from anger to sadness to stress) is very normal. You are coming to terms with a new diagnosis, new treatments and big life changes. Medications such as steroids and sedatives can also affect how you feel.

There will be days when you are feeling positive and other days when you won't. Feeling this way is okay and normal. You don't need to make yourself 'look on the bright side' or 'think positively' if that's not how you are feeling right now. It is okay to feel how you feel. It can be helpful to focus on one step at a time, and one day at a time.

What if I feel out of control?

With so many big changes and new treatments, it can sometimes feel like you don't have much control over your life – either because other people are making decisions for you, or you don't feel that you can make the decisions you need to. This can make you feel vulnerable.

Focussing on the things you can control can help you feel more stable and confident in yourself. For example, you can decide how much to know about your diagnosis – you can find out lots of information with all the details, or you can choose not to know much about it at all. You can talk to your nurse about the timing of your treatment – can you have the drugs at a time of your choice? Even small choices, such as ice cream or no ice cream, can help – no matter how big or small the decision is, you have taken control.

> "Take each day as it comes, you may feel overwhelmed but you WILL get through it."
>
> Tanya

Loneliness

Having a blood cancer or blood condition can make you feel alone, even when you are surrounded by people. It might feel like no one really understands what you are going through. Some people might treat you differently because they don't know what to say or how to act around you. You might need to miss some school, university, work or social activities because of your treatment, and sometimes you might need to travel to another town or a city.

Talking to people about how you feel is really helpful. Some people find it helpful to give friends and family/whānau suggestions about how to feel more connected, such as a daily text, your own playlist, or notes you can stick up on the walls in your hospital room. You can also connect with others your age who are going through something similar.

LBC run in-person and online events, which are a good way to meet other people in the same boat. LBC also has private online forums, which are a great way to meet people locally and from around New Zealand having similar experiences. Talk to your LBC Support Services Coordinator about how to get involved with these.

If you are aged 13–24 years, you may also like to connect with CanTeen, an organisation which supports young adults with cancer and their siblings. It is a great way to meet other young adults with cancer around New Zealand and connect with them in person, or virtually via their CanTeen Connect app. There are also local and international websites and forums that you can join (see the list of useful websites on page 83).

Am I depressed?

It is normal to feel sad or down when something stressful or upsetting happens. Usually the feelings fade over time or get better when life improves. If things are improving but you still feel low, or the feeling lasts for more than two weeks, you may have depression.

The key signs of depression are:

- Constantly feeling hopeless, or having a low mood
- Not being interested or getting pleasure from things you used to enjoy.

Other possible signs of depression are:

- Feelings of anxiety
- Feeling restless or irritable
- Loss of energy or tiredness
- Feeling lonely or empty
- Sleeping too much or too little
- Losing or gaining weight
- Feeling bad about yourself, or things you've done
- Having difficulty concentrating
- Not feeling like having sex
- Thinking about death a lot
- Thinking of harming yourself.

If you are depressed, the best thing you can do for yourself is ask for help and support. It can help talking about how you feel with someone you trust, such as a friend or family/whānau member. There are options available, and people who can help you. Speak to your doctor, nurses, LBC Support Services Coordinator or call the **Depression Helpline on 0800 111 757** or text **4202**.

Coping strategies

A coping strategy is something you can do or think to help you deal with the hard things that come with having a blood cancer or blood condition. Having a range of coping strategies can help you feel more in control and feel better about how things are going. Everyone is different, so what works for someone else might not work for you – it is worth trying a few different things to see what you find most helpful.

Some helpful coping strategies are:

- Learning more about your illness – Some people feel more in control when they know what to expect. Tell your doctor how much or how little you want to know.
- Asking questions – Ask anything you want to know about your illness or treatment. Write the answers down so you can look at them later if you want to. Ask again if you forget, or still don't understand – it's okay to keep asking.
- Looking after yourself – Ask your nurse if there are parts of your care you can do yourself (e.g. taking your own medications, changing your own dressings, choosing your own foods).
- Talking – Telling someone how you are feeling is better than bottling it up. It can feel good to let it all out. Sometimes talking to someone less close to you (like a counsellor or your LBC Support Services Coordinator) is easier than talking to your close friends and family/whānau.
- Choose who you hang out with – Spend time with people who make you feel relaxed and good about yourself.
- Writing – Keep a journal or blog, or document your journey on social media. LBC has sticker journals available if you want to get started, ask your LBC Support Services Coordinator.
- Laughing – Watch something funny, spend time with people who make you laugh.
- Goal setting – Short-term and long-term goals can help keep a sense of perspective. Little goals are good too, such as finishing your book or TV series.
- Going somewhere different – Leaving your room, even just down the hallway, can be a much-needed change of scene.
- Napping – Being really tired can make life feel harder, and dealing with stress can be more difficult. Don't feel bad about taking a nap or having an early night if you need to.
- Exercising – Easy exercise like a walk or a gentle swim can be really helpful. Just check with your health care team first, and don't push yourself too hard.
- Mindfulness and meditation – This can be really helpful for stress management. There are lots of great resources online to get you started.
- Asking for help, and accepting it when it is offered – Life is easier with support, so see if there are people who can help you with study, shopping, cooking or getting rides.
- Support groups – These are a great way to connect with others, let out your emotions and fill your social tank. Ask your LBC Support Services Coordinator about what is available.

> **"There are very successful stories out there, don't be afraid, fight hard and you will become one of them. You would be surprised by how many lives you've touched and how inspirational you would be to other people, you got this!"**
>
> Carlos

Relationships

What do I tell my friends and family/whānau?

When you receive your diagnosis, you may find it difficult to tell your friends and family/whānau. Everyone reacts to big news in different ways, and the people closest to you may feel confused, stressed, angry or upset. They may not know what to do, or the best way to help you.

It is important to communicate with your family/whānau and friends about how you are feeling. Tell them how they can help you. Simple things such as watching a movie together can take your mind off your treatment and make life feel more normal. You don't have to talk about your diagnosis all the time if you don't want to. Remember, there is no right or wrong way to talk to your loved ones – you know them better than anyone else.

When you are used to your treatment pattern, you will have a good idea of which days you are likely to feel your best, and which days are not so good. Plan to do things with friends on the good days, and let yourself rest on the hard days.

Sometimes it can feel like your relationships with friends, family/whānau or your partner can change after your diagnosis. This might be because they don't know much about your cancer, or don't understand what you are going through. They might struggle to cope with their own feelings, or not know how to support you. There is support for your partner, friends and family/whānau so don't feel like you need to support them or 'stay strong' for them. Whatever you are feeling, it really helps to keep talking and listening to the people closest to you.

Who gets to make the decisions?

If you are over the age of 16, you can make your own decisions about your treatment and care.

If you are unable to make decisions for yourself, e.g. if you are unconscious, your next of kin will be involved in the decision making. Your next of kin may be your parents, guardians, or partner if you are married or in a civil union. An exception to this is for blood transfusions. If you need a blood transfusion and are unable to consent, your medical team can go ahead and give you a transfusion even if your next of kin is unavailable.

If you are younger than 16, your parents or legal guardians are the ones who make medical decisions for you. However, even if you are under 16, the law says you still have a right to know about your medical situation and have your opinions heard. Your health care team will take your views into account, and follow what you want to do, if they think it is reasonable.

Visit the YouthLaw Aotearoa website for advice on medical decision-making and your legal rights (see the list of useful websites on page 83).

Talking to children

You might have younger family/whānau members around you – brothers, sisters, cousins or your own children – who realise that something has changed. Children are often very aware when things are different, and it can be helpful to explain your diagnosis in simple language that they can understand.

Brothers and sisters, especially those younger than you, can find it very difficult to cope with your blood cancer diagnosis. It is normal for them to have lots of different feelings. They may feel afraid of what is going to happen or upset that you feel unwell. The attention that you need from the rest of your family/whānau can make siblings confused and resentful. Many families say that the experience of cancer really brings them closer and makes them realise how lucky they are to have each other.

If you have young children in your life that are aged between 5–12 years, LBC has support programmes available to them. There are also picture books which can help explain conditions such as lymphoma or leukaemia, and treatments such as bone marrow transplant.

Speak to your LBC Support Services Coordinator for more information.

More information is available online

What about my partner?

An intimate relationship can be another important support when you are diagnosed and are having treatment. A boyfriend, girlfriend, partner or spouse can be a good person to talk to about hopes, fears and concerns. However, being diagnosed with a blood cancer or blood condition is a major life-changing event, for both you and your partner; it can take a lot of energy to keep a relationship going, especially if you haven't been together for very long.

Being diagnosed with a blood cancer or blood condition can take up a lot of time. There are lots of appointments and hospital visits, and there might be extra travel as well. This can mean you spend less time than normal with your partner, or that you are not able to do as many things together as you would like to.

It can be helpful to make the most of your time together – either with other family/whānau and friends, or on your own as a couple without other people. You can still build a strong, healthy relationship, even if you can't see each other in person as often. Staying connected by phone, video calls, texts, emails and social media can all help.

Living situations

Living alone with a blood cancer or blood condition

Living alone can be great – it gives you a sense of freedom and independence and means you can live the way you want to. However, living alone can get tricky if you are diagnosed with a blood cancer or blood condition. Being unwell can make you feel alone, and the practical side of living on your own (such as grocery shopping and cleaning) can be more difficult.

Feeling like you have to change your living situation on top of everything else can be overwhelming. Some people prefer to temporarily move home with family/whānau while they are having treatment and recovering. For others, this is not an option – if you are in this situation, there is support available to help you through your treatment. Ask your AYA keyworker, doctor or nurse if you can speak to a social worker who will be able to help you.

If you are living alone, it is important that you:

- Put together a list of emergency contacts in case you suddenly become unwell.
- Let friends, family/whānau and neighbours know about what could happen so if you call them in an emergency, they will know what to do and who to call.

Your doctors and nurses will also give you a list of 24-hour emergency contact numbers to use if you become unwell. It is okay to ask for help, and to accept help when it is offered – which can sometimes be difficult when you have previously lived so independently.

Some family/whānau members and friends may find it difficult to talk openly about your blood cancer or blood condition, but would be happy to help in more practical ways, such as doing your shopping, cleaning your house and driving you to doctors' appointments. Accepting help offered may make living alone easier and more manageable. Being independent is about finding the right balance between acknowledging when you need support and looking after yourself.

Living with others

Living at home

Living with your family/whānau can provide both emotional support and help with practical things like cooking, cleaning and transport. Having supportive people in your household can make it easier for you to focus on yourself, your treatment and getting well.

However, not having your own space or feeling like you have less independence can be challenging. It is normal for some parents to feel overprotective, or to be processing their own emotions. It can be really helpful to have open communication and be honest about what you need – whether it's a bit more help with day-to-day things, regular chats, or a bit of space and alone time.

Siblings can be a good source of support and entertainment when you are having treatment and recovering. However, they may struggle to cope with life changes or their emotions when it comes to your diagnosis. There is support available for siblings of people with blood cancer. If your sibling is 5–12 years old, speak to your LBC Support Services Coordinator about Kids Club support groups. If your sibling is 13–24 years old, CanTeen is another charity that can support them.

Flatting

Having flatmates can be helpful if you are diagnosed with a blood cancer, but treatment and cancer can also make flat life more complicated. Your flatmates may not be familiar with blood cancer or treatments, and they may need you to tell them what support you need from them.

The most important thing is to keep talking to your flatmates. You don't have to tell your flatmates all the details of your diagnosis if you don't want to, but you may want to tell them something – especially the parts that will affect them. You may need to follow a slightly different diet, and your flatmates may need to be extra careful about hand hygiene, avoiding infection and keeping themselves well. It is important you talk to your flatmates if you need them to do things differently.

Communicating about shared flat responsibilities such as rent, bills, grocery shopping and cleaning is important for keeping flat relationships happy and healthy. If your treatment means you can't do your usual household tasks such as cooking or cleaning, it is better to let your flatmates know as soon as possible, including how long you think it will last for. You may be able to make a plan together, such as picking up extra jobs on the days you feel well, or hiring a cleaner on occasions.

Treatment can be financially stressful, and sometimes it can be hard to pay rent and bills. If this is the case, speak to your AYA keyworker or social worker to see if there is any support available.

University halls/halls of residence

Living away from home in a hall of residence provides a combination of independent living and flatting. You get a bit more independence but with more people around you, which can feel less isolating – especially if you are in a new city. If your hall provides food, this can also be really helpful if you do not yet have the energy to cook for yourself every day.

It is up to you who you tell about your blood cancer diagnosis. You may want to let your residential adviser (RA) or hall manager know about what is going on so they can best support you, and help you with any special requirements (such as needing a special diet, or needing to take precautions against infection). It is a good idea to have at least one person who is aware of your diagnosis or treatment, in case you become unwell and need urgent medical care. Provide any roommates and your RA with a list of important contacts such as the hospital and your family/whānau.

It is also a good idea to enrol with a local GP or university health centre and let them know about your medical history, particularly if you are living in a different place to where you had your treatment.

Work and education

Secondary school

Your treatment is likely to change your daily routine. It can affect how much time or effort you can put into school or college work, and you may need to take some time off. If you need to put school on hold – that's okay. Someone will need to talk with your school about what is going on and any special requirements you may have. **This person can be:**

- You
- A family/whānau member or partner
- A specialised support nurse.

The person they talk to at the school can be a:
- School nurse, counsellor or pastoral care teacher
- Class or house teacher, or a teacher you feel comfortable with
- Dean or department head
- Personal tutor.

You can decide who you want to know about your illness. However, it is worth thinking about letting the people know who can help make your life easier at school. For example, if there is a rule about not wearing hats, it would be useful to let the teachers know why you would like to wear one. One of the most important things your school needs to know is that due to your cancer treatment your immune system may be low, making it easier for you to catch infections and harder to fight them off. You should stay away from school if any students have chickenpox, measles, shingles, the flu, Covid-19 or a bad cold.

You can discuss with your teachers/tutors a plan for your education while you are being treated for blood cancer. **There might be some options for getting your schoolwork done that work for you, including:**

- Being sent work to complete at home on your own
- Joining lessons virtually online
- Having a flexible timetable so you only have to go to school for the most important lessons, or when you feel that you are able to
- Enrolling in a regional health school. You may be eligible if you miss more than 10 days of school due to hospitalisation, or 40 days in a year – speak to your AYA keyworker about whether this is an option.

Throughout the entire treatment process, you are still part of your school, even if you are not there all the time. Your teachers should provide you with schoolwork if you feel up to doing it. School friends can provide a great support network and can often help if you need a hand with your studies.

If you miss a lot of school you may be asked to repeat the year, although this is avoided whenever possible. Keeping in regular communication with your school can help get you the support you need and identify any problems early.

University or polytechnic

Going to polytech or uni can be a big life change, particularly if you have just had treatment for blood cancer. Some people find they want to be closer to their family/whānau after their treatment and choose to study closer to home, while others see going away from home as a chance to regain independence. Either way, it doesn't have to be a scary time – it can be exciting too.

Treatment for a blood cancer or blood condition will change your day-to-day routine but that doesn't mean you will have to give everything up. University timetables are often flexible, and lots of the study can be done on your own and at your own pace. It is important to keep your tutors informed so that they can give you the best support possible. The student union and student disability services can also be good places to look for advice and support.

If you need a break from study, it is usually fairly easy to take a year off and pick your course up again the next year. Lots of students take a year off to travel overseas or spend a year working – so taking a year off for your health is often very achievable, and there will be others in a similar situation.

Work

It is hard to know before treatment starts how it will affect your job and your ability to work. Some people have no problem continuing to work full or part time, while others need to stop working altogether in order to focus on their treatment and recovery.

> **"I had to stop working – and that was a big shock! In the movies, people with cancer still work and do activities. But I had to isolate, and I couldn't even go to the mall or movies."**
>
> Maya

Often the biggest concerns for work are telling your employer that you have a blood cancer and worrying whether this will affect your job or pay. Most employers are supportive.

If you have any questions regarding employment issues, contact Employment New Zealand or the Citizens Advice Bureau (see the list of useful websites on page 83) – they will be able to advise and guide you through your concerns.

More information is available online

It can be helpful for you to talk to your employer about your blood cancer and treatments. You can explain how long you think it will last and what tasks you will be able to do. This will help them support you in taking time off or working more flexibly if this is possible. Letting your colleagues know what is happening can make it easier for them to support you too.

It can be helpful to keep in touch with colleagues from work and let them know how you are – a quick email or phone call can help keep you connected and make you feel part of the team.

If you are having issues with your employment or you have money problems, speak to your AYA keyworker or hospital social worker. You may be entitled to some supports and benefits. LBC has a great section on their website with detailed information about employment rights, flexible working entitlements and returning to work. Use the QR code above to access these resources online.

Summary

Having strong feelings and experiencing anxiety, loneliness or depression can be really common following a blood cancer diagnosis – there is help and support available to you if you need it.

Different coping strategies can be helpful to process and move through these feelings (see page 58).

Your relationships with family/whānau and friends may change following your diagnosis – keeping open communication is really important to ensure you continue to get the support you need.

Your support needs might be different based on your living situation – it can be helpful to check who is in your support network, and how your support needs can be met.

Diagnosis and treatments may have an impact on your work and/or study – check if it is possible to make changes to your schedule, or if you can take a break if you need to.

Questions and notes

Beyond cancer

Ki tua i te mate pukupuku

You might hear the word **'survivorship'** used to describe life with and after cancer. Survivorship means living with cancer. It starts when you are diagnosed and includes your treatment, recovery and life after treatment. When you are diagnosed, your health care team are focussed on treating your blood cancer or blood condition as well as possible, but they also want to make sure you have a good quality and enjoyment of life.

Everyone's experience is different. For some people, having a blood cancer or blood condition might be ongoing – with long-term treatment or management needed. Some might have side effects from their treatment which need ongoing management or regular check-ups, while others go into long-term remission without any major side effects. The mental, social, emotional and spiritual effects of a diagnosis and treatment can also last after treatment stops. Some people feel a bit anxious or isolated after stopping treatments or hospital visits – this is very normal.

Finding a new normal

It can be tough going back to 'normal life' after a big life change like a blood cancer diagnosis. You might feel pressure to go back to the way things were, but inside you might feel very different. You have had a lot of new experiences and have probably learnt more about yourself and what you want from life. It is okay to feel this way. Don't feel like you have to go back to the way things were or do the same things you used to do if they don't seem like 'you' anymore – try some new things!

Relationships with family/whānau and friends

You may find that your relationships with family/whānau and friends change once treatment is finished. Some people feel closer because of what they have been through together. Others find the relationships more difficult as they try and find a new normal together. It is important to understand that different people will react in different ways – and there is no correct way to react. The most important thing is to keep openly and honestly communicating with each other.

Dating

Dating can be difficult – with or without a blood condition! A blood cancer or blood condition can make things even more complicated, especially if you are struggling with body image, confidence or fear of relapse. If you are finding dating difficult, it is important to remember that you are not alone and many others with a blood cancer have felt this way. Talking to people you feel comfortable with and allowing time to recover from your blood cancer experience can be helpful.
Some things that can help are:

- Getting involved with activities to meet other people and to practice your social skills
- Attending support groups with other young adults to share advice and experiences
- Checking out the online support available from reputable websites (see list of useful websites on page 83)
- Counselling, and talking to your doctor or nurse or someone you feel comfortable with.

When should you tell someone you are dating that you have/had a blood cancer?

There is no perfect time to tell someone you have or have had a blood cancer or blood condition. It will depend on how you are feeling about your situation, and how comfortable you feel with that person. Some people prefer to talk about it straight away, as they consider it a big part of their lives. Others prefer to wait until they know someone better, or take a case-by-case approach and tell them when the moment feels right. Whatever you decide, it is always good to do what feels best to you.

How to tell someone that you have/had a blood cancer

It can be helpful to think about what you want to say ahead of time – being prepared may help you to feel more confident about the conversation. It is also a good idea to ensure you set aside enough time for your talk, so you can say as much or as little as you need to. Depending on your relationship, you might find that writing a letter helps you to think about what you would like to say. It can also give the other person time to respond to your letter.

Unfortunately, some people may react badly to your news. This may be upsetting, or make you feel as if you have done something wrong. It is important to remember that you haven't done anything wrong, and you cannot control other people's reactions. Some people may also surprise you and be more supportive and understanding than you were expecting.

Sexuality and relationships

Changes in body image and self-esteem can occur as a result of treatment and may impact relationships. Physical changes from the blood cancer or treatment can be difficult to come to terms with. You may also notice you want sex less often or are anxious about having sex. See page 47 for more information on sexual-wellbeing and page 59 on relationships.

Menopause

Early menopause (hormonal changes that result in your periods stopping) is a potential side effect of some blood cancer treatments. Hormone replacement therapy may need to be considered to prevent side effects such as osteoporosis. See page 48 for more information on menopause.

Fatigue after treatment

Physical, mental or emotional fatigue after finishing treatment is really common. How long and how intense your fatigue is will vary but it is important to find ways to cope, such as through exercise and meditation. See page 44 for more information on fatigue.

More information is available online

Late effects

Late effects are health conditions that appear long after diagnosis and treatment – sometimes weeks, months or years later. These will vary depending on the type of blood cancer and treatments.

Discussing a care plan will ensure that any long-term effects are managed. It is good to know who to speak to if you have any medical concerns or think you are experiencing some late effects. Depending on how long it has been since finishing treatment, you might contact your haematologist or nurse specialist, or it might be better to go to your GP. Examples of some late effects are secondary cancers, heart complications, thyroid problems and difficulty with concentration and learning.

Keeping yourself healthy

Exercise

Keeping active is one of the best ways to help you feel better during your treatment. Blood cancers and their treatment affect people differently, and the amount of exercise you are able to do will depend on your condition, treatment and how your body responds to it. Gentle daily exercise (such as walking) is a great way to keep active and is better for you than sudden bursts of activity. When you are having treatment, your energy levels will probably go up and down – so listen to your body. **Some things to remember are:**

- Don't exercise if it's really hot – exercise in an air-conditioned room if you can
- Don't exercise if you have a fever
- If you have any shortness of breath, stop exercising immediately
- If you feel sick or dizzy, stop exercising immediately
- Only use good-quality exercise equipment to reduce the risk of injury.

Avoid doing any power lifting or heavy weights if your chemotherapy included anthracyclines. Anthracyclines are a group of very powerful chemotherapy drugs that can affect your heart. Ask your doctor whether this applies to you.

If your platelet count is low you will bleed and bruise easily, so sports where you are likely to get injured are not a good idea. If you want to take part in energetic sports such as rugby, soccer, netball, basketball or mountain biking, you should check with your doctor or nurse first.

You are likely to have a lower white blood cell count than normal, which means you are at more risk of getting infections. If you have a low white blood cell count, you may need to avoid swimming pools and spas as they pose a high risk of infection. You may also be advised not to swim if you have a central line in place. If you are unsure, check with your doctor or nurse. If you would like further information on exercising during cancer treatment, you can ask to be referred to a hospital or community physiotherapist.

Alcohol and drugs

If you usually consume alcohol or take recreational drugs, you will need to take a break from them during your treatment. This is because alcohol and drugs are broken down by your liver and kidneys, but so are chemotherapy and other treatment medications – so taking them together can cause damage and extra stress on your body. Some chemotherapy medication can interact with alcohol and drugs, which can make your side effects worse, and also create new ones.

Drugs can also mask serious symptoms and side effects of your treatment, such as brain complications, infection and pain. Smoking or inhaling any drug increases risk of fungal infections in your lungs, which can create serious complications with your treatment.

Drinking lots of alcohol, or drinking for a long time, is known to lower the body's immunity. This could mean a difficult and longer recovery, meaning more time in hospital. You will also likely have a lower tolerance for alcohol. Having the occasional glass of beer or wine might be okay, but this will vary from person to person – ask your doctor if it is safe for you to have any alcohol during your treatment.

It is always best to be open and honest with your doctor and health care team. Anything you tell them will be confidential. Your health is a priority and they will only have your health and safety in mind.

There is help available if you have been taking drugs or drinking lots of alcohol and you think it might be hard to stop. Speak to your doctor, nurse, AYA keyworker or GP, or the Alcohol Drug Helpline (0800 787 797 / alcoholdrughelp.org.nz) for more information and support.

> "I was so nervous telling my doctor that I used recreational drugs. I thought they would tell me off but they were so casual and helped me understand that it could interact with my chemo. To be honest it was a relief to get it off my chest!"
>
> Rachel

Smoking and vaping

Smoking causes damage to your lungs, mouth and throat, and also means your body gets less oxygen. This can lead to other health conditions and cancers such as emphysema (a lung condition), heart disease, stroke and lung cancer. Vaping can also cause lung damage. When you are diagnosed with a blood cancer or blood condition, it is a good opportunity to stop smoking to put your body in the best possible position for your treatment. It will be difficult, but there is a lot of help available. Speak to your doctor, nurse, AYA keyworker or GP, or visit Quitline (quit.org.nz or 0800 778 778) for more information and support.

All New Zealand hospital buildings and grounds are smoke free you will not be allowed to smoke or vape anywhere onsite. You may be able to leave for a short time to smoke if it is safe to do so, or your health care team can provide you with alternatives such as nicotine gum and patches.

Tattoos and piercings

It is safest to wait until after your treatment has completely finished before getting a new tattoo or piercing. **Both tattoos and piercings break the skin barrier, and therefore have a risk of:**

- Infection
- Bleeding
- Scarring
- Reactions, e.g. to the ink or metal used.

When your immune system is low (due to a blood cancer or treatment) it is harder for your body to fight infection and takes longer to heal from a wound, which increases the risk of infection further.

If you are planning on getting a new piercing or tattoo, your medical team will be able to tell you when the best time is, to minimise infection risk. It is important that any tattoos or piercings are done correctly and professionally, in a safe and clean environment with proper aftercare to reduce the risk of infection and other complications.

If you have existing tattoos and piercings, it is a good idea to let your medical team know ahead of any scans or procedures. Piercings will often need to be temporarily removed prior to a scan, and special precautions may need to be taken in the case of tattoos (e.g. ahead of an MRI).

Sun protection

Chemotherapy and radiotherapy cause changes to your skin, making it much more sensitive to the sun. **To protect your skin, it is a good idea to:**

- Cover your skin
- Stay in the shade when able
- Wear a sunhat and sunglasses
- Use at least an SPF 30+ sunblock when you go outside.

New Zealand sun is particularly strong, and you can burn even on a cloudy day, or in winter. It is also important that you do not use sunbeds to tan – the intense UV light will cause more damage to your skin.

Immunisations

After chemotherapy or a stem cell transplant, your doctor may advise you to get some of your childhood immunisations (vaccinations, injections) again. This is because the immunity that you gained from your childhood vaccines may be lost during treatment. Most people are also recommended to get a yearly flu vaccine and full Covid-19 vaccination after treatment. Check with your doctor to find out which immunisations you should get, and when you should get them.

What about travelling?

If you had plans to travel overseas or go on an OE, you may have had to put those plans on hold due to your diagnosis. Once you have finished your treatment, it is a good idea to talk to your doctor about the best time to begin planning to travel again. It is important that you attend any follow-up appointments and have any necessary tests once your treatment is finished – your doctor will be able to tell you when these are likely to be.

Depending on your blood cancer and treatment, you may need to choose where you will travel very carefully. If you want to travel to places that require vaccinations, it is best to discuss this with your doctor. There are some live vaccines which you should not have, such as yellow fever, typhoid and oral polio.

Will I be able to get insurance?

Having a blood cancer or blood condition can make it more difficult to get life or travel insurance because of your health history. You do need to tell your insurer about your condition and treatment when applying for insurance, otherwise the policy becomes void (doesn't count) and they will not have to pay any claims you make. Larger and more established insurance companies are more likely to be able to provide insurance for you but may cost more. Speak to your LBC Support Services Coordinator if you need more support regarding finding insurance.

Fear of relapse

It is normal to feel anxious or worried about your blood cancer coming back (relapse). This anxiety can get worse before a new scan or a follow-up appointment. The best thing you can do to reduce the chance of your cancer coming back is to follow the follow-up plan your health care team gave you when you were discharged, e.g. having recommended blood tests and going to clinic appointments. Your GP is also a good person to talk to if you have medical concerns but are no longer seeing the hospital team.

If you are having lots of anxiety, it can be helpful to talk to someone about it, such as a trusted friend or family/whānau member, a counsellor or your GP. Attending support groups can also be a really good way to get your feelings out in the open. It is important to recognise how you are feeling and be honest with yourself – you don't need to pretend you feel fine or hide your fear or anxiety

> **"I never even knew what a blood cancer was, let alone thinking I would have one. I kept making excuses for my symptoms and was in denial. And now that I've finished treatment and am in remission - every little symptom, I immediately think my cancer is back."**
>
> Luke

If cancer returns

Sometimes cancer can come back. This usually happens because a small number of cancer cells weren't completely removed or destroyed by the treatment. It doesn't mean you have done anything wrong, and it doesn't mean you weren't given the right treatment – it just means some of the cells managed to survive. When you are told about a cancer relapse, it is normal to feel a whole range of emotions such as anger, shock, guilt or fear – these are all very normal feelings. You might feel the same as you did when you were first diagnosed, or you might have some new emotions. It is okay to feel however you are feeling.

Just like when you were first diagnosed, your doctors will talk to you about your diagnosis, prognosis and treatment options. It is important to have these conversations with your health care team, so you can make the best decisions for you. **Some things you may want to consider are:**

- Your prognosis (how the disease is expected to progress)
- How treatment will affect your quality of life
- Long-term and short-term side effects
- How you tolerated treatment last time
- How you feel about having more treatment.

If treatment doesn't work

Sometimes, despite trying all the best treatments, some people cannot be cured. Being told your cancer is incurable or is not responding is awful and unfair. There is no wrong or right way to process this news, and there is no wrong or right way to feel about it. You are allowed to deal with this news however you need to.

It is really important to have people you trust who you can talk to. This may be friends or family/whānau, but sometimes it might be easier to talk to someone outside the family, like a counsellor. You only need to share the information you want to share, when you feel ready.

You may be referred to a service called palliative care. There are palliative care teams in the hospital and in the community. Palliative care is really important to get any symptoms under control, to help you enjoy the life you have left. They can also help support your mental and emotional well-being and support you through feelings of shock and grief.

It is important that you are as involved in the decisions around your care as you wish to be. You may have lots of questions – write them down, and don't be afraid to ask. Your doctors, nurses, AYA keyworker, social worker and family/whānau may be able to help you find the answers you need. **Examples of some questions you might have are:**

- Why did this happen?
- How do you know there are no more treatments?
- How long do I have to live?
- Can I get a second opinion?

Summary

It might take some time to adjust to the new 'normal' following treatment for a blood cancer or blood condition – don't feel pressured to slot right back into your old life.

Late effects are side effects that can appear months or years after treatment. If you are concerned about anything, speak to your health care team or your GP.

It is normal to feel some anxiety or fear about cancer returning – talking to a trusted person can be helpful.

Sometimes cancer does return – you may be offered further treatment if this is the case.

Sun protection, regular exercise, immunisations and limiting alcohol and drugs are all helpful in keeping healthy following treatment.

Sometimes there are no treatment options available – if this is the case, having trusted people you can talk to is really important. Ask your medical team any questions you have. You may also be referred to the palliative care team to help you manage any symptoms or emotions.

Questions and notes

Appendices Ngā Āpitihanga

Questions and tips for your hospital appointments

Being told you have a blood cancer or blood condition can come as a huge shock and be really upsetting. When you are processing all your emotions and new information in the moment, it can be hard to remember to ask the important questions you want the answers to.

The following tips can help you get the most out of your appointments:

- Bring a support person with you – another pair of ears is very helpful, not to mention company in the waiting room and help with driving and parking!
- Take a notebook and make notes
- Ask your doctor if they are happy for you to record the conversation on your phone or a recording device (it is important to ask first)
- Ask as many questions as you need to
- Write a list of questions before your appointment (and bring the list with you).

Questions to ask your doctor

- What kind of blood cancer or blood condition do I have?
- How does the blood cancer or blood condition affect my body?
- In your opinion, what is my prognosis?
- What are the pros and cons of treatment?
- What if I decide not to have treatment?
- Are there other treatment options for me to consider?
- How long will treatment take?
- How long will I be in hospital?
- Will this line of treatment affect my fertility? What can be done to protect it?
- Who will be in charge of my treatment and care?
- Do I have to stay in hospital for treatment?
- Will I be able to continue studying/working throughout treatment?
- Is there anything I can do to help me get better? Should I eat differently? Should I exercise?
- What are your thoughts about complementary therapies? Are there any you would advise against?
- Will drinking alcohol affect my treatment? Can I go to parties/out clubbing?
- Can I have sex with my partner? Are there any do's and don'ts?
- Can I be around animals and pets?
- Will I have any long-term effects from the cancer or treatment?
- If the treatment works, what are the chances that the cancer will return?
- Will my lifestyle be affected by my cancer experience?
- Will I be able to work full-time, have kids, travel etc?

Questions to ask your nurse

- What are the common side effects of the treatment? What can I do to reduce them?
- How are the drugs administered?
- Can my parent/sibling/partner stay with me if I have to be in hospital overnight?
- Will my friends be able to visit?
- Can I change the timing of my appointments and treatment?
- Who do I contact if I feel unwell?

Questions to ask your social worker

- Am I entitled to any government benefits?
- Are there any other support organisations I should be linked in with?
- Who can I speak to if I need to travel for treatment?

Useful websites and resources

Useful websites and resources

Leukaemia & Blood Cancer New Zealand (LBC)
www.leukaemia.org.nz

Alcohol Drug Helpline
www.alcoholdrughelp.org.nz

AYA Cancer Network Aotearoa
They have a great section of resources for young people.
www.ayacancernetwork.org.nz

Citizens Advice Bureau
www.cab.org.nz

Cancer Society NZ
www.cancer.org.nz

Canteen
CanTeen Connect app – they have a big range of supports and resources for young people.
www.canteen.org.nz

Depression and Anxiety
www.depression.org.nz

Employment NZ
www.employment.govt.nz

Look Good Feel Better NZ
www.lgfb.co.nz

Manatū Hauora Ministry of Health
www.moh.govt.nz

Ministry of Primary Industries
Booklet on food safety when you have low immunity
www.mpi.govt.nz/food-safety-home

National Travel Assistance Scheme Te Whatu Ora Health New Zealand
tewhatuora.govt.nz/our-health-system

Quitline
www.quitline.org.nz

Youth Law
www.youthlaw.co.nz

Youthline
www.youthline.co.nz

Glossary of terms

Alopecia. Hair loss, which can occur temporarily following treatments for blood cancer and conditions such as chemotherapy.

Anaemia. A reduction in the haemoglobin level in the blood. Haemoglobin normally carries oxygen to all the body's tissues. Anaemia causes tiredness, paleness and sometimes shortness of breath.

Antibiotics. Drugs that kill or stop the growth of bacteria, e.g. penicillin.

Antibodies. Naturally produced substances in the blood, made by white blood cells called B-lymphocytes or B-cells. Antibodies target antigens on foreign or abnormal cells such as bacteria, viruses and some cancer cells to destroy them.

Antiemetic. A drug which prevents or reduces feelings of sickness (anti-sickness) or vomiting.

Antigen. A substance that can stimulate white blood cells to get rid of the antigen or attack it directly. This is called an immune response. Also see Immune system in this glossary.

Anxiety. An ongoing worry or concern that doesn't go away. Feelings of worry that a person does not seem to be able to control or seem greater than they should be for a situation.

Biopsy. A small sample of fresh tissue, e.g. lymph node or bone marrow, removed for testing in a laboratory, to establish the exact diagnosis or to monitor treatment response.

Blood count. Also called a full blood count (FBC) or complete blood count (CBC). A routine blood test that measures the number and types of cells circulating in the blood.

B-lymphocyte. A type of white blood cell that produces antibodies to fight infection. Also called a B-cell.

Bone marrow. The tissue found at the centre of many flat or big bones of the body. The bone marrow contains stem cells from which all blood cells are made.

Bowel. Also known as intestines or guts. After your stomach has finished with the food you eat it goes into your small bowel, which absorbs nutrients that the body needs. What is left after this moves into your large bowel and eventually moves out of your body as waste, known as a bowel motion or poo.

Cancer. A malignant disease where abnormal cells grow, divide and accumulate uncontrollably and can invade other tissues from the original site where the cancer started. Cancer cells can grow and multiply to form a lump or swelling (a tumour). Not all tumours are due to cancer; tumours that are not cancer are called non-malignant or benign tumours.

Cannula. A plastic tube that is inserted into a vein (intravenously or IV) to allow fluid to enter the bloodstream.

Central line. Also known as a central venous catheter (CVC) or central venous access device (CVAD). A tube passed through the large veins of the arm, neck, chest or groin and into the central blood circulation. It can be used to take blood samples, or give IV fluids, blood and medications including chemotherapy.

Chemotherapy. Single drugs or combinations of drugs used to kill and prevent the growth and division of cancer cells. Although aimed at cancer cells, chemotherapy can also affect rapidly dividing normal cells and this is responsible for some common side effects including hair loss (alopecia) and a sore mouth (mucositis). Most of the side effects of chemotherapy are usually temporary and reversible.

Chromosomes. Your body is made up of cells. Inside most cells are chromosomes which, under a microscope, look like threads. These threads contain hundreds to thousands of genes. Genes determine things like what colour your hair and eyes are and how your body develops. You have 23 pairs of chromosomes and you get half from your mother and the other half from your father.

Chronic. An illness or disease that persists for a long time or is constantly recurring (coming back).

Complementary therapies. Therapies used alongside your medical treatment that can help you feel better or help you cope with your diagnosis and treatment, e.g. massage, yoga.

Complete remission. Anti-cancer treatment has been successful and so much of the disease has been destroyed that it can no longer be detected using current technology.

CT scan, also known as a CAT scan (computerised axial tomography). A specialised scan that produces detailed 3D images of cross sections of the body.

Cure. This means that there is no evidence of disease and no sign of the disease reappearing, even many years later.

Cytogenetic tests. Tests commonly carried out on samples of blood and bone marrow to detect chromosomal abnormalities (things that are wrong with the chromosomes) associated with disease. This information helps in the diagnosis and selection of the best treatment.

Digestive system. The system in your body that deals with food. Starts at your mouth and ends at your bottom. Turns food and fluids into fuel for your body.

Disease progression. This means that the disease is getting worse despite treatment.

DNA (deoxyribonucleic acid. The cell's hereditary material which contains instructions for development, growth and reproduction. DNA is located in nearly every cell of the human body. DNA is found in chromosomes.

Foetus. An unborn child.

Genes. Genes are made up of DNA. Each chromosome contains many genes. Every person has two copies of each gene, one inherited from each parent.

Genetic analysis. Blood tests screening parts of your genetic code (chromosome and molecular tests) to identify the genetic features of your blood cancer and help you plan your treatment.

Granulocyte colony-stimulating factor (GCSF). A growth hormone given to stimulate the bone marrow to produce certain types of blood cells. It is often used to treat neutropenia, or before a stem cell harvest for a stem cell transplant.

Haematologist. A doctor who specialises in the diagnosis and treatment of diseases of the blood, bone marrow and immune system.

Haematopoiesis (or haemopoiesis). The processes involved in blood cell formation.

Immature. Not fully developed, e.g. a cell that is immature is still at a baby stage. It will mature (or develop) over time to an adult stage.

Immune suppression. The use of drugs to reduce the function of the immune system.

Immune system. The body's defence system against infection and disease.

Immunocompromised. When the function of the immune system is reduced.

Immunoglobulin. See Antibodies in this glossary.

Immunophenotyping. A specialised laboratory test used to detect markers on the surface of cells. These markers identify the origin of the cell.

Incurable. A disease or illness that is unable to be completely removed or treated. Unable to be cured.

Laparoscopy. An operation done through a small keyhole incision in the skin, often assisted by camera views. The spleen and gallbladder are often removed using this technique.

Leukaemia. Cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal and immature blood cells. These cells crowd the bone marrow and spill out into the bloodstream.

Leukaemic cells. Abnormal cells which multiply in an uncontrolled manner, crowding out the bone marrow and preventing it from producing normal blood cells. These abnormal cells also spill out into the bloodstream and can build up in other organs.

Lumbar puncture. A procedure for taking a sample of the fluid that surrounds your brain and spinal cord to look for leukaemia or lymphoma cells, using a long thin needle inserted into your lower back/spine. A local anaesthetic is given to numb the area.

Lymph nodes or glands. Small structures found throughout the body, e.g. in the neck, groin, armpit, chest and abdomen, which contain both mature and immature lymphocytes. There are hundreds of lymph nodes throughout the body.

Lymphatic system. A large network of vessels that carries a fluid called lymph through almost all tissues in the body. Lymph moves through the body in a similar way to blood. The lymphatic system is part of the immune system.

Lymphocytes. Specialised white blood cells involved in defending the body against disease and infection. There are three types of lymphocytes: B-lymphocytes (B-cells), T-lymphocytes (T-cells) and natural killer cells (NK cells).

Lymphoid. Term used to describe a pathway of maturation of blood cells in the bone marrow. White blood cells (B-lymphocytes and T-lymphocytes) are derived from the lymphoid stem cell line.

Lymphoma. A cancer characterised by the uncontrolled multiplying of lymphocytes. Lymphoma cells can be found in lymph glands, spleen and other tissues. It can spread to involve the bone marrow and blood and then look like leukaemia. There are many different subtypes of lymphoma, classified in two main categories: Hodgkin lymphoma and non-Hodgkin lymphoma.

Malignancy. See Cancer in this glossary.

Markers. A gene or DNA sequence with a known physical location, and where it has come from. In genetics, markers act as chromosomal landmarks. They are used to trace or identify a specific region of a gene on a chromosome.

Menopause. The time in a woman's life when her period stops and she is no longer able to have children. Hormones produced by the ovaries decrease after menopause. Also see Ovaries in this glossary.

Mucositis. An inflammation of the lining of the mouth, throat or gut.

Myeloid. A term used to describe a pathway of maturation of blood cells in the bone marrow. Red blood cells, white blood cells (neutrophils, eosinophils, basophils and monocytes) and platelets are derived from the myeloid stem cell line.

Neutropenia. A low number of circulating neutrophils, an important type of white blood cell. Neutropenia is associated with an increased risk of infection.

Neutrophils. Neutrophils are the most common type of white blood cell. They are needed to fight effectively against infection.

Oncologist. General term used for a specialist doctor who treats cancer, e.g. medical, radiation, surgical oncologist.

Ovaries. Small organs that produce and then release eggs into a woman's reproductive system and produce female hormones.

Partial remission. The tumour shrinks to less than half its original size after treatment. In people with leukaemia, this means that the proportion of blast cells in the bone marrow has been reduced following treatment, but not necessarily below 5%. There are still some leukaemic cells present.

Petechiae. Tiny purple or red spots on the skin caused by bleeding into the skin. They commonly appear in clusters and may look like a rash. They are usually flat to the touch and don't lose their colour when you press on them.

Plasma. A light-yellow coloured fluid in the blood that carries blood cells, nutrients, hormones and proteins to different parts of the body.

Platelets. Type of blood cells produced in the bone marrow that circulate in the blood, involved in clotting and the control of bleeding.

Power of attorney. One person gives another person permission to act on their behalf, such as making decisions about their health or operating their bank account. You usually see a lawyer to arrange this.

Prognosis. An estimate of the likely course of a disease.

Psychological. Relating to your mental and emotional well-being.

Radiotherapy. Also known as radiation therapy, it involves the use of high-energy X-rays to kill cancer cells and shrink tumours.

Red blood cells. Cells that transport oxygen from the lungs to all the cells in the body.

Relapse. The return of the original disease.

Resistant or refractory disease. This means that the disease is not responding to treatment.

Rigors. A chill (feeling cold), usually with shivering, at the onset of having a high fever (temperature).

Spleen. An organ that accumulates lymphocytes, acts as a reservoir for red blood cells for emergencies, and destroys red blood cells, white blood cells and platelets at the end of their lifespan. The spleen is found high in the abdomen on the left-hand side. It is often enlarged in diseases of the blood or bone marrow.

Splenomegaly. Enlargement of the spleen.

Stable disease. When a disease is stable, it is not getting any worse or any better with treatment.

Staging. A description of how far a lymphoma has spread. Stage 1 disease is localised whereas stage 4 disease has spread beyond the lymphatic system. Staging is not as relevant to leukaemias.

Stem cells. Primitive cells that can give rise to more than one cell type. There are many different types of stem cells in the body. Bone marrow (blood) stem cells have the ability to grow and produce all the different blood cells including red blood cells, white blood cells and platelets.

Stem cell transplant. Also known as bone marrow transplant, haemopoietic stem cell transplant or peripheral blood stem cell transplant.

Supplements. Tablets or liquids you take as well as the food you eat. Supplements include vitamins, minerals, herbs and other plants.

T-lymphocyte. A type of white blood cell involved in controlling immune reactions. Also called a T-cell.

Tumour. An abnormal mass of cells which may be non-malignant (benign) or malignant (cancerous).

Ultrasound. Pictures of the body's internal organs built up from the interpretation of reflected sound waves.

Urinary tract infection (UTI). An infection in any of the parts of your body that make or store urine or take urine out of your body, e.g. bladder or kidneys.

White blood cells. Specialised cells of the immune system that protect the body against infection. There are five main types of white blood cells: neutrophils, eosinophils, basophils, monocytes and lymphocytes.

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Leukaemia & Blood Cancer New Zealand

LBC is the leading organisation in New Zealand dedicated to supporting patients and their families/whānau living with leukaemia, lymphoma, myeloma, MPNs and related blood conditions.

Since 1977, our work has been made possible through our fundraising events and the generous support we receive from individuals, companies, trusts and grants.

LBC is committed to improving the quality of life for patients and their families/whānau living with these blood cancers and conditions by providing patient support services, investing in and supporting research, providing information, raising awareness and advocating on behalf of patients.

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LINDSAY
FOUNDATION

Support Services
0800 15 10 15

Support Services Centres

Auckland
Hamilton
Wellington
Christchurch
Dunedin

Telephone	09 638 3556
Email	info@leukaemia.org.nz

National Office

6 Claude Road, Epsom, Auckland 1023
PO Box 99182, Newmarket, Auckland 1149

leukaemia.org.nz

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