

# MYELOMA

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A guide for patients,  
families & whānau



Vision to Cure. Mission to Care.

# INTRODUCTION

**This booklet has been written to help you and your family/whānau understand more about myeloma.**

If you or someone you know has been diagnosed with myeloma, you may be feeling anxious or a little overwhelmed. This is normal. Perhaps you have already started treatment or you are discussing treatment options with your doctor and your family. Whatever point you are at, we hope that the information contained in this booklet is useful

in answering some of your questions. It may raise other questions, which you should discuss with your health care team. It is not the intention of this booklet to recommend any particular form of treatment to you. You need to discuss your circumstances at all times with your doctor and treatment team.

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## Interpreter service

New Zealand's Code of Health and Disability states that everyone has the right to have an interpreter present when they go to a medical appointment. If a patient and their health care professional do not speak the same language, a family/whānau member or friend may assist. The hospital can organise a trained interpreter if needed. NZ Sign Language interpreters are also available.

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## Informed consent

If you are supporting a family/whānau member who needs language support at appointments, your doctor may ask an interpreter to join meetings where informed consent is required. Interpreters are specially trained to explain the information clearly.

# HOW TO USE THIS BOOKLET



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## Detailed information



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## Key points



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## Important information



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## More information available online

There are many resources available at [leukaemia.org.nz](http://leukaemia.org.nz) such as fact sheets, booklets and more. Most resources available on the Leukaemia & Blood Cancer New Zealand (LBC) website can be obtained in a printed version. Ask your LBC Support Services Coordinator if you would like information posted to you.

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## Space for your questions

There is space at the end of this booklet to write questions that you can ask next time you see a doctor, nurse or LBC Support Services Coordinator. They will be happy to answer your questions or explain something in more detail.

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## Glossary

On page 52 there is a glossary (word list). In the booklet you might come across words or phrases that you are not familiar with. The glossary gives you a short explanation of these words and phrases. A Dictionary of Terms booklet is also available from LBC.

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# WHAT IS MYELOMA?

**Myeloma is a type of blood cancer. Blood is made up of red blood cells, white blood cells and platelets. These are made in the bone marrow, which is the spongy tissue found in the centre of some bones in the body.**

Myeloma is a cancer of plasma cells, which are a type of white blood cell that form part of the immune system. Myeloma may also be called multiple myeloma or plasma cell myeloma.

Myeloma is a relatively rare disease, accounting for approximately 1.7% of all cancers and 15% of all blood and bone

marrow cancers. Each year in New Zealand approximately 400 people are diagnosed with myeloma.

Myeloma is more common in men than women and the majority of people diagnosed with myeloma are over the age of 50.

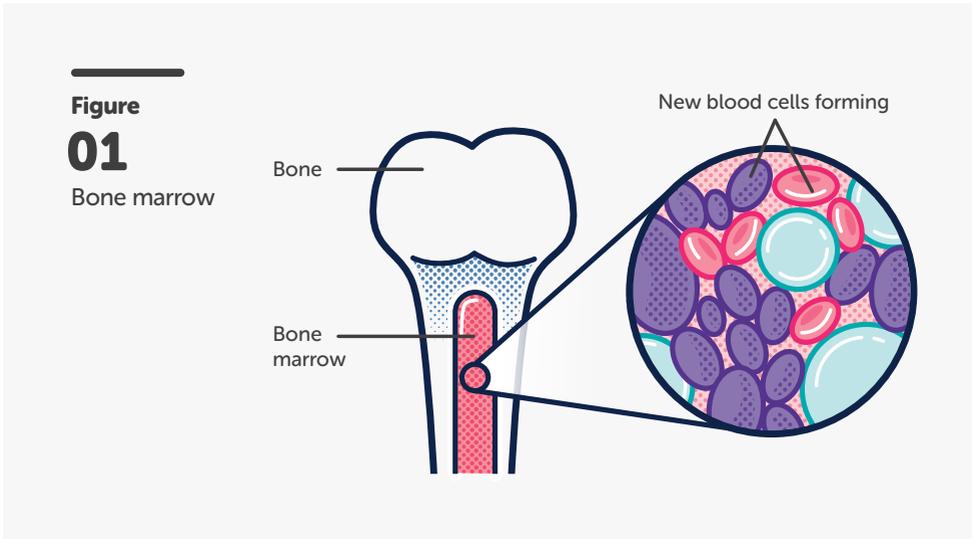


## Key points

- Myeloma is a type of blood cancer of the plasma cells.
- Myeloma may also be called multiple myeloma or plasma cell myeloma.

# BONE MARROW AND BLOOD STEM CELLS

Bone marrow is the spongy material inside your bones (see Figure 01).



**Figure 01**  
Bone marrow

In your bone marrow there are cells called blood stem cells. Blood stem cells create the new blood cells in your body.

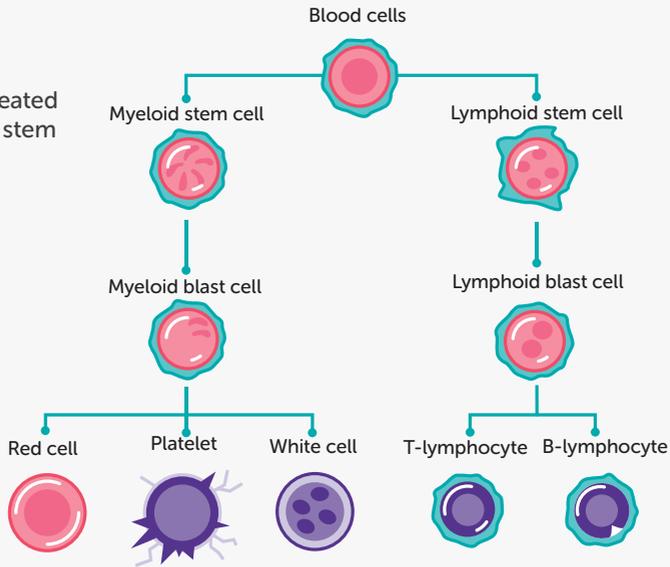
The two main functions of blood stem cells are to:

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

In Figure 02 you can see that the blood stem cell has divided to create a myeloid stem cell and a lymphoid stem cell. You can also see the blood cells that each of these cell groups create.

**Figure****02**

The cells created from blood stem cells



## Detailed information

- The medical term for blood stem cells is haematopoietic (he-ma-to-po-ee-tick) stem cells. When a blood stem cell matures into a blood cell, this is called haematopoiesis (he-ma-to-po-ee-sis). In adults, haematopoiesis occurs in the bone marrow of large bones such as the breastbone (sternum), thigh bone (femur) and hip bone (iliac crest).



## Key points

- Blood stem cells create new blood cells in your bone marrow.
- Blood stem cells mature and develop into functioning blood cells found in the bloodstream.
- Blood is made up of plasma and blood cells (red blood cells, white blood cells and platelets).

# YOUR BLOOD

**The red blood cells, platelets and white blood cells, created in your bone marrow, are released into your bloodstream so they can function around the body.**

Blood is made up of blood cells and plasma. The role of plasma and each type of blood cell is discussed in the next section.

## Red blood cells

Red blood cells transport oxygen from the lungs to all the cells in the body. A protein called haemoglobin (heem-a-glow-bin) in each red blood cell carries the oxygen throughout the body and also gives blood its red colour. A low level of haemoglobin in your body is called anaemia (a-nee-me-a).

## White blood cells

White blood cells fight infection. For example, if bacteria entered your bloodstream through a cut, the white blood cells would 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-fils) are the most common type of white blood cell. A low number of neutrophils in your body is called neutropenia (new-tra-pee-nee-a).

## Platelets

Platelets help your blood clot and prevent bleeding. For example, if you cut yourself, the platelets go to where the injury is, stick together and stop the bleeding. A low level of platelets in your body is called thrombocytopenia (throm-bo-sy-toe-pee-nee-a).

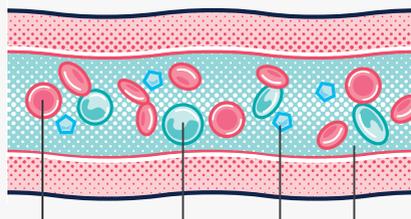
## Plasma

Plasma is a light-yellow coloured liquid in which blood cells travel around your body. Plasma cells develop from mature B-lymphocytes in the bone marrow. They play an important role in protecting the body against infection by producing immunoglobulins, which are also known as antibodies.

### Figure

# 03

Blood vessel and cells in your blood



Red blood cell White blood cell Platelet Plasma

## Immunoglobulins (antibodies)

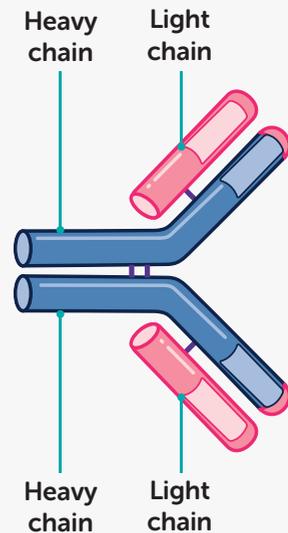
Proteins called immunoglobulins (imm-you-no-glob-you-lins) help protect the body against infection and disease.

Immunoglobulins (Ig for short) are produced by plasma cells in response to bacteria, viruses and other harmful substances that enter the body. Once released into the bloodstream, they circulate and attach to the harmful cells. This makes it easier for other white blood cells to recognise and destroy harmful organisms like bacteria or viruses and remove them from the body.

Immunoglobulins are Y-shaped structures made up of two heavy chains and two light chains (see Figure 04). There are five main families of immunoglobulins, which are named after the heavy chains that form an important part of their structure: IgA, IgD, IgE, IgG and IgM. There are two types of light chains: kappa ( $\kappa$ ) and lambda ( $\lambda$ ).

**Figure  
04**

Immunoglobulin structure



### Key points

- There are three main types of blood cells (red blood cells, white blood cells and platelets), each with an important role.
- Blood cells travel around your bloodstream in a light-yellow coloured liquid called plasma.
- Immunoglobulins (antibodies) are produced by plasma cells to protect the body from harmful substances.

# MYELOMA AND PLASMA CELL DISORDERS

**Myeloma is a form of plasma cell disorder, when plasma cells become abnormal and multiply without any proper order. These abnormal plasma cells (myeloma cells) release a type of antibody called paraprotein, which has no useful function.**

On one end of the plasma cell disorder spectrum is myeloma, where there are a significant amount of abnormal plasma cells growing uncontrollably and causing damage to the body. Excess myeloma cells can form collections known as tumours that accumulate in different parts of the body, most commonly in the bone marrow and on the surfaces of different bones in the body.

Myeloma cells may secrete chemicals that stimulate other bone marrow cells (osteoclasts) to remove calcium from the bone. As a result, bones can become weaker, more brittle and break more easily.

As myeloma cells multiply they can impact different areas of the body. They might crowd out the bone marrow and prevent it from making normal numbers of red blood cells, white blood cells and platelets. Myeloma cells can also interfere with the production of normal antibodies, increasing the risk of infection. Excess paraprotein in

the bloodstream can also cause damage to the kidneys. The signs and symptoms of myeloma are explained on page 10.

On the other end of the spectrum of plasma cell disorders is monoclonal gammopathy of undetermined significance, also known as MGUS. People with MGUS have a smaller amount of abnormal plasma cells, which are only growing slowly and not causing any obvious damage to the body. These people often do not require treatment and are managed with monitoring their blood through regular blood tests. Each year approximately 1% of people with MGUS will go on to develop myeloma.



**More information available online**



## Key points

- Myeloma is a form of plasma cell disorder where there are a significant amount of abnormal plasma cells causing damage to the body.
- Monoclonal gammopathy of undetermined significance (MGUS) is a plasma cell disorder where there are a smaller number of abnormal plasma cells and no damage to the body.

In-between MGUS and myeloma is a state known as smouldering myeloma. Smouldering myeloma may also be called indolent myeloma or asymptomatic myeloma. People with smouldering myeloma have a greater number of myeloma cells in the body than MGUS, but there is still no damage to the body. Historically, people with smouldering myeloma did not require treatment as there is no evidence of damage to the body. However, recent evidence has suggested that treatment may be indicated for those with high disease burden as the risk of developing damage to the body in the near future is high.

## What causes myeloma?

Many people who are diagnosed with myeloma ask the question: "Why me?" Naturally, they want to know what has happened or what they might have done to cause their cancer. Unfortunately, no one knows exactly what causes myeloma and how it may be prevented. It is thought to be caused by an interaction of both environmental and genetic factors through a complex process.

Like other types of blood cancers, myeloma is thought to develop when DNA is damaged during the development of a plasma cell. DNA is made up of genes, which contain the information that determines how your body grows, develops and functions. Most diseases are caused by a combination of different mutations (errors) that affect certain genes. Genetic errors are either inherited from our parent(s) or are acquired as a result of exposure to something in our environment.

We do know that myeloma is not contagious; you cannot 'catch' myeloma by being in contact with someone who has it. There is progress being made in understanding if and how inherited and acquired genetic errors cause myeloma.

Why these mutations occur in the first place remains unknown but there are likely to be a number of factors involved. There are certain environmental factors that may put someone at higher risk of developing myeloma. These include exposure to high doses of radiation and ongoing exposure to certain industrial or environmental chemicals. However, the exact cause or causes of myeloma remain unclear and are likely to be unique to each person.



## Key points

- Smouldering myeloma is a plasma cell disorder where the number of abnormal plasma cells is higher than someone with MGUS but there is still no damage to the body.
- The exact cause of myeloma is unknown although it is thought to be caused by a combination of environmental and genetic factors.
- Myeloma is not contagious.

## Types of myeloma

Traditionally, myeloma is subclassified according to the antibodies (immunoglobulins) that the abnormal plasma cells produce. The types of immunoglobulin that can be produced include IgG, IgA, and rarely IgD or IgE. For example, people with myeloma cells that produce IgG are known to have IgG myeloma. This abnormal antibody can often be detected in urine or blood (known as paraprotein, M-spike or M-protein).

Some people have myeloma cells that only produce part of the antibodies known as light chains, and these people are said to have light chain myeloma. The most common myeloma subtype is IgG myeloma, followed by IgA myeloma and light chain myeloma.

In some people, the amount of paraprotein or light chains produced is small or undetectable, and these patients are classified as having non-secretory myeloma or oligo-secretory myeloma.

With the advance in technology, more is known about the genetic abnormalities within the myeloma cells and the prognostic significance that this carries. Myeloma can also therefore be categorised according to the predominant genetic abnormalities detected. The significance of these genetic abnormalities and how it may affect treatment decisions is an ever-evolving topic, and it will be best for you to discuss this with your haematologist to obtain the most up-to-date information.

## Other plasma cell conditions

### AL amyloidosis

The term amyloidosis (a-mee-loid-o-sis) is used to describe a group of conditions where an abnormal protein called amyloid builds up in the body. One type of amyloidosis is called AL amyloidosis.

AL is the abbreviation for amyloid and light chain. Abnormal plasma cells in the bone marrow produce light chains that form amyloid proteins. The amyloid proteins can accumulate in tissues and organs, disrupting their function. Amyloid deposits can build up almost anywhere in the body.

### Plasmacytoma

Plasmacytoma (plas-mar-sy-toe-mar) is a mass of myeloma cells that can form in the bone, skin, muscle or elsewhere in the body. If it is only found in one location in the body, the condition is described as a solitary myeloma or solitary plasmacytoma.

A mass of myeloma cells outside the bone is called an extramedullary or soft tissue plasmacytoma.

A plasmacytoma can sometimes be successfully treated using radiotherapy alone but regular monitoring and follow-up is required in case it develops into myeloma.

**Plasma cell leukaemia**

Plasma cell leukaemia, also called plasma cell myeloma, is when a significant amount of abnormal plasma cells have left the bone marrow and are released into the bloodstream. This is unlike myeloma, where the majority remain in the bone marrow.

Plasma cell leukaemia is considered to be a more advanced form of myeloma and usually requires more intensive treatment and monitoring.

**POEMS syndrome**

POEMS syndrome is a rare type of plasma cell disorder that can affect multiple systems in the body, named after the five common features of the syndrome:

**P**olyneuropathy (damage to peripheral nerves)

**O**rganomegaly (abnormal enlargement of organs)

**E**ndocrinopathy (damage and change of function to the endocrine system, affecting hormones)

**M**onoclonal gammopathy (overproduction of abnormal plasma cells)

**S**kin changes (becoming harder and/or darker in places and more hair growth)

The most common symptoms are caused by the nerve damage (polyneuropathy) and can result in numbness and altered sensation in peripheral areas of the body (legs, arms, hands and feet).

Treatment for POEMS syndrome is different for everyone but usually involves chemotherapy and close monitoring by the health care team.



**More information  
available online**

## WHAT ARE THE SIGNS AND SYMPTOMS OF MYELOMA?

The signs and symptoms of myeloma can be different for everyone and depend on how advanced the disease is. In the earliest stages there may be no symptoms and myeloma may be detected by coincidence during a routine blood test. For others, they might have been experiencing symptoms for a period of time that have affected their daily living.

As mentioned earlier in this booklet, the normal blood cells in bone marrow and blood can get crowded out by the abnormal plasma cells and paraprotein that are being made. This can result in symptoms such as anaemia, bleeding or bruising and infections.

### Anaemia

Having a low haemoglobin level (because of a low number of red blood cells) can cause anaemia.

The symptoms of anaemia include:

- Lack of energy
- Feeling very tired all the time
- Weakness
- Dizziness
- Feeling unusually short of breath when doing exercise
- Pale skin

### Bleeding and bruising

Having a low platelet count (thrombocytopenia) can mean it's harder for your blood to form clots to stop bleeding.

The symptoms of thrombocytopenia include:

- Bruising easily
- Minor cuts or injuries that take a long time to stop bleeding
- Frequent or severe nose bleeds or bleeding gums
- Unusually heavy periods in women
- Red or purple pinhead-sized spots on your skin called petechiae (pe-tea-kee-eye)

### Infections

Having a low number of white blood cells in your blood can put you at risk of getting an infection.

Neutrophils are the most common type of white blood cell, and a low number of neutrophils in your blood is called neutropenia.

Common symptoms of infections include:

- Minor skin infections (redness/swelling/pus) that are slow to heal
- Urinary tract infections (UTI)
- Fever (high temperature)
- Sore throat or mouth infection



### Important information

- If you are neutropenic and have any signs of infection, including a high temperature of 38°C or over, you should ring your health care team immediately.

## Bone pain

The most common symptom of myeloma is bone pain. This is usually felt in the back or ribs and may be made worse by movement.

Bone pain is usually the result of gradual erosion of bone caused by a substance the myeloma cells produce. Over time bones can become weakened and thinned (osteoporosis) and holes (lytic lesions) may develop, increasing the risk of bone fracture (broken bone).

People with myeloma can experience bone fractures with very minor injuries or even without injury at all.

## Elevated blood calcium level

When bone tissue is damaged, calcium is released from the bone into the bloodstream. A large amount of calcium in the blood is called hypercalcaemia (hi-per-kal-see-mee-a).

Symptoms of hypercalcaemia may include:

- Feeling sick or nauseated
- Constipation
- Tiredness and fatigue
- Feeling thirsty
- Confusion



### Detailed information

The acronym CRAB is often used by doctors to describe the effect myeloma can have on different areas of the body:

- Calcium elevation (hypercalcaemia)
- Renal impairment and changes to kidney function
- Anaemia, or bone marrow failure
- Bone disease

## WHAT HEALTH PROFESSIONALS WILL I MEET FOLLOWING MY DIAGNOSIS OF MYELOMA?

You will meet a range of health professionals who are part of your health care team.

Each health professional has a different area of expertise in cancer and cancer care. 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 diagnosis of myeloma.

Some of the health professionals you will meet are, in alphabetical order:

- **Charge nurse** – A senior nurse in charge in the outpatient department or on the hospital ward.
- **Clinical nurse specialist (CNS)** – 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 and side effects of myeloma and treatment.
- **Dietitian** – A dietitian will advise on what to eat and drink to minimise symptoms or side effects from myeloma or your treatment. A dietitian may 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 diagnosis of myeloma. They will be informed throughout your diagnosis of myeloma 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 will be in charge of overseeing your treatment and follow-up.
- **Occupational therapist** – Helps you manage everyday activities and achieve activities you want or need to do.
- **Outpatient clinic nurse** – A nurse who gives you treatment as an outpatient or who works alongside a doctor in clinic.
- **Pharmacist** – Prepares and checks your medications. A pharmacist can advise you on how to take your medicine and the possible side effects.
- **Physiotherapist** – Specialises in maintaining and improving body movement and mobility. A physiotherapist (or physio) can help you regain independence and fitness following diagnosis and/or treatment of myeloma.
- **Psychologist** – Specialises in helping you manage the emotional challenges of myeloma, such as stress, anxiety and depression.
- **Registrar** – A doctor who is training to become a haematologist. You will often

see your registrar on the ward and in the clinic. Your registrar works very closely with your haematologist.

- **Social worker** – Helps you manage the practical and emotional impact of myeloma, such as advice about managing at home, employment or school.
- **Ward nurse** – A nurse who looks after you during your stay in hospital.

Other people you might hear about or meet are:

- **Palliative care team** – Doctors, nurses and other health care professionals whose roles include managing symptoms of myeloma, helping improve quality of life and supporting people at the end of life.
- **Spiritual care and cultural support** – People who can support your individual cultural, spiritual or religious needs.

- **Non-Governmental Organisation (NGO)** – Gives emotional and practical support for those affected by cancer, e.g. Leukaemia & Blood Cancer New Zealand.
- **Leukaemia & Blood Cancer New Zealand Support Services Coordinator:**
  - A professional who provides education as well as practical and emotional support.
  - Phone 0800 15 10 15

Meeting so many people can sometimes be confusing. It can be difficult to remember who does what job. If you are unsure, ask the person to remind you who they are and how they fit into your health care team.

# TESTS AND INVESTIGATIONS

**To find out if you have myeloma, your doctor will ask you to have some tests. Tests help your doctor make a diagnosis. Diagnosis means to find out what disease or condition a person has.**

Getting a diagnosis of myeloma can involve a number of different tests. Myeloma affects every person differently therefore results from the tests may vary from person to person.

## Blood test

A variety of blood tests are used to diagnose and monitor myeloma. Blood is taken from a vein in your arm and sent to a lab (laboratory) where it is looked at under a microscope.

Regular blood tests may be done to measure paraprotein and/or free light chain levels.

As discussed on page 5, some people with myeloma have an incomplete immunoglobulin structure therefore the excess light chains can be detected in the blood (called free light chains). For other people with myeloma, paraprotein can be tested in the blood. Paraprotein might also be known as monoclonal immunoglobulin, myeloma protein or M-protein.

The presence of paraprotein or free light chains is a strong indicator of myeloma and can be used as a measure throughout your diagnosis to see any changes in the levels.

**Other blood tests might include:**

### Full blood count

A full blood count (FBC) or complete blood count (CBC) measures the different levels of cells in your blood. The most important levels to monitor are red blood cells, white blood

cells (neutrophils) and platelets. There is a diagram with the normal ranges on page 17.

### Blood chemistry

These tests look at the levels of various substances in your blood that can indicate the presence of myeloma and what impact it is having on your body.

**These include:**

- Creatinine, which is a chemical normally excreted in urine and is measured to assess how well your kidneys are functioning. High levels of creatinine may show some decreased function in the kidneys.
- Calcium is a mineral which is normally found in the blood. High levels may show that bone tissue is being damaged.
- Beta-2 microglobulin is a protein that is found on most cells in the body. In myeloma, high levels of beta-2 microglobulin can indicate a large amount of myeloma cells and the presence of kidney damage. This is an important indicator test for myeloma.

### Bone marrow biopsy

A bone marrow biopsy is a test where a doctor takes samples of your bone marrow and sends them to a lab to be looked at under a microscope. A sample of bone marrow is usually taken from the back of your hip bone (the 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 this purpose).

The doctor might give you a drug that makes you feel relaxed and sleepy (a sedative) before the biopsy starts. You might also be given pain relief. The doctor will give you a local anaesthetic. This is a small injection that is put into your skin where the biopsy is going to be done, to make the area numb.

To do a bone marrow biopsy the doctor puts a long 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).

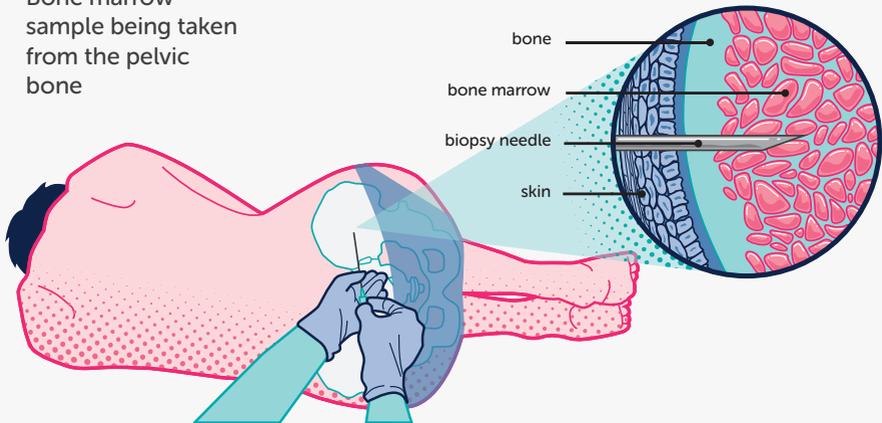
Some people who have had a bone marrow biopsy say that it was painful and other people describe it as uncomfortable. Everybody is different. We recommend that you bring a support person with you when you have a bone marrow biopsy. If you have a sedative, you will still feel a bit drowsy afterwards. Your 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.

## Figure

# 05

Bone marrow sample being taken from the pelvic bone



The bone marrow aspirate and trephine samples are sent to a lab and examined under a microscope. You will then have an appointment with your haematologist to talk about the findings of your bone marrow biopsy.

You may have other bone marrow biopsies done throughout your diagnosis of myeloma to monitor any change or response to treatment.

## X-rays and other imaging tests

Many people require x-rays or other imaging tests as part of being diagnosed with myeloma and also for ongoing 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.
- CT scan (computer-assisted tomography scan) or ultrasound may be used if there is concern about specific localised involvement or damage caused by myeloma.
- MRI scan (magnetic resonance imaging scan) may be used in diagnosis and monitoring of myeloma to detect early bone changes caused by disease. It can also be useful in rare cases where the myeloma is thought to be causing pressure on the spinal cord.
- A full-body x-ray or skeletal survey may be done to check for any evidence of bone damage caused by myeloma. X-rays are usually taken of your skull, spine (backbone), ribs, pelvis (hips), legs and arms.
- PET scan (positron emission tomography scan) uses a specialised type of intravenous contrast and CT scan technique to look for areas where there may be increased tissue

activity due to myeloma involvement. A PET scan is less commonly used in New Zealand. It may be clinically useful in some situations to identify whether residual disease is present in a particular part of the body.

Your haematologist will inform you of what tests they recommend you have and why. Everyone is different so tests may vary from person to person.

## MRD testing

MRD stands for minimal residual disease, which represents the smallest quantity of myeloma that current technology can detect. It aims to be able to detect one myeloma cell if present in 10,000 normal cells, whereas the standard microscope method of examination of your bone marrow can only reliably detect myeloma cells down to a level of one in 20.

MRD testing is a method of testing your blood and/or bone marrow to see if any myeloma cells can be detected. A sample is taken during a bone marrow biopsy procedure.

MRD negative refers to the fact that the amount of myeloma left in the body is so low that current technology is unable to detect it. MRD positive refers to the fact that although someone might be in remission there are still some myeloma cells detected in the bone marrow.

There is still research being done into how useful MRD testing is and how often it will be used in practice. Some studies have shown that people who are in complete remission and are also MRD negative have a longer time before relapse compared to people who are MRD positive. The significance of MRD is still being evaluated and researched in clinical trials. If you have any questions about MRD testing, you can ask your haematologist or health care team.

## 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 member 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 going to the test are:

- Plan your journey so 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.

## Normal blood test results

Table 1 gives you information about normal blood test results for adults. You may find this useful when you are having regular blood tests and want to compare your results with the normal range.

Please note that there may be small variations compared with the data used at your hospital or clinic.

Table 1

Normal range for adults:		
	Adult men	Adult women
Hb (g/L)	130-175	115-155
Neutrophils ( $\times 10^9/L$ )	2.0-7.5	2.0-7.5
Platelets ( $\times 10^9/L$ )	150-400	150-400



## Key points

The main tests for diagnosing myeloma are:

- Blood test
- Bone marrow biopsy

We recommend that you bring a support person when you have a bone marrow biopsy test. An interpreter can be arranged for your appointments, if needed.

# INFORMED CONSENT FOR TREATMENT AND PROCEDURES

**You will be asked to give your informed consent for all treatment 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. 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 someone is not able to give informed consent, a legal guardian, welfare guardian or person with enduring power of attorney can give consent on behalf of the patient.

Generally, a person over the age of 16 can give informed consent if the doctor feels they are able to do so.

Your informed consent is also required if you agree to take part in a clinical trial. Clinical trials are explained on page 20.



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## Key points

- Informed consent means that you understand the information around treatment or a procedure.
- Speak to your health care team if you have any doubts or need more information about treatment or a procedure.

# MAKING TREATMENT DECISIONS

There are two main goals of treating myeloma:

- **Destroy the myeloma cells using anti-myeloma treatments and stop any progression.**
- **Improve quality of life by treating the symptoms and complications associated with myeloma.**

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

- The type of myeloma you have.
- Your age.
- Your general health.
- How well your myeloma is likely to respond to treatment.

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

Many people feel overwhelmed when they are diagnosed with myeloma. 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 you are facing.

## Second opinion

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

## Questions to ask your health care team

Before going to see your haematologist, or another member of your health care team, make a list of the questions you would like to ask.

In Appendix A on page 56 there are some examples of questions you could ask your haematologist. You could write your questions and answers at the back of this booklet or in the LBC Haematology Patient Diary available from your LBC Support Services Coordinator.

## 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.

The LBC Haematology Patient Diary is useful for writing down your questions, making notes from appointments and recording details of treatment.

## Prognosis

Prognosis means the likely course of a disease, e.g. how likely it is for the disease to be controlled. Your prognosis will depend on many things. Your haematologist is the best person to give you a prognosis and how well your myeloma might respond to treatment. You might be given an estimated time of survival, which is usually based on previous research and can be very different for each person.

When doctors talk about prognosis they might use the terms; complete remission, partial remission, plateau phase, relapse, resistant/refractory or progression.

Here is what these terms mean:

- **Complete remission (CR)** – The treatment has been so successful that paraprotein or free light chains can no longer be detected in blood or urine using standard tests. The percentage of plasma cells in the bone marrow has returned to normal.
- **Partial response (PR)** – This indicates a good, but lesser response to treatment with persistent signs of myeloma in various tests.
- **Plateau phase/remission** – The progress of myeloma has been halted and the paraprotein level is stable. The myeloma is not getting any worse or better with treatment. The length of time that someone is in remission for varies from person to person, which is why regular check-ups and blood tests are done to detect this progression early.

- **Relapse** – The myeloma has reappeared, usually shown by a reappearance in the level of the paraprotein or new bone problems.
- **Resistant/refractory** – The myeloma is not responding to treatment.
- **Disease progression** – The myeloma is getting worse on or off treatment.

## Being on a clinical trial

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

Taking part in a clinical trial is voluntary, which means that you do not have to take part in the clinical 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 and other members of the health care team before signing the consent form.



**More information  
available online**

# TREATMENT FOR MYELOMA

**For people with myeloma, treatment is typically required at some point as delaying treatment can lead to further damage to the body.**

Chemotherapy is the main form of treatment for myeloma and it is usually given as a combination of two to three therapeutic drugs. It is important to note that the term 'chemotherapy' is often used loosely in this setting. Historically, chemotherapy refers to drugs that affect both normal and abnormal cells, but current novel agents used for myeloma, such as proteasome inhibitors and immunomodulatory drugs, have a more targeted effect on myeloma cells than normal cells.

For people who are younger and in good general health, the typical first-line treatment for myeloma is a combination treatment including at least one novel therapy. This is followed by autologous stem cell transplant in an attempt to eliminate as many of the myeloma cells as possible. Further combination treatment may also be given after transplant to suppress the disease and maintain remission. For people who are not a candidate for a stem cell transplant, they will also receive combination treatment involving novel therapies, and may or may not proceed with further maintenance treatment afterwards. Treatments will continue to evolve over time depending on drug development

and government funding, and therefore it is important for you to discuss this with your haematologist.

Unfortunately, despite recent advances in the management of myeloma, it remains an incurable condition. Patients can achieve a good remission with first-line treatment but will typically relapse or progress in the future. The time to relapse or progression can range from a matter of months to years. For people who relapse or progress, further treatment can be used to once again reduce the myeloma burden. In most instances, patients would receive a different combination of drugs to their previous treatment, although some drugs, e.g. dexamethasone, may be used again.

**The main treatment options for myeloma are:**

- Steroids
- Chemotherapy
- Novel therapy
- Radiotherapy
- Stem cell transplant

It is likely that a combination of these options is used to treat and manage your myeloma.



## Detailed information

- Combination treatment is when several different drugs and treatments are used to support each other in reducing myeloma in the body. The drugs work differently but when they are given together, they are more effective at killing the myeloma cells than if they were given by themselves. The aim is to attack the myeloma cells in different ways and increase the response or reduce the symptoms of myeloma.

For example, you might be having chemotherapy, steroids and a novel therapy at the same time to increase response to the myeloma cells.

### Common combination treatments for myeloma might include:

- Cyclophosphamide + bortezomib (Velcade) + dexamethasone (CyBorDex)
- Bortezomib (Velcade) + thalidomide + dexamethasone (VTD)
- Bortezomib (Velcade) + melphalan + prednisone (VMP)
- Cyclophosphamide + thalidomide + dexamethasone (CTD)
- Melphalan + prednisone + thalidomide
- Cyclophosphamide + lenalidomide + dexamethasone

## Steroids

Steroids are drugs which mimic different hormones in the body. There are several types of steroids and may be used as treatment or to manage symptoms or side effects. Steroids are often used in the treatment of myeloma and are known to be effective in killing myeloma cells.

Steroids can also enhance the activity and effectiveness of other treatments like chemotherapy, so are often used in combination with other drugs.

### What steroids are used to treat myeloma?

The two most common steroids that are prescribed to help treat myeloma are dexamethasone and prednisone.

Dexamethasone is usually given orally (in tablet form) and the dose will vary from person to person. Dexamethasone is very effective at killing myeloma cells.

Prednisone is also effective at killing myeloma cells and may have different side effects than dexamethasone for some people.

### Side effects of steroids

Side effects of steroids can be different for every person. It is important to know what some of the common side effects may be and to let your doctor know what symptoms you are experiencing and how severe they are.

### Common side effects include:

- Mood changes (mood swings, anxiety, irritability and tearfulness).
- Difficulty sleeping: you may have difficulty sleeping when taking steroids. Talk with your doctor about trialling different times during the day. Some people find the morning a good time to take their steroid tablets, as the effect of the steroids has lessened by bedtime. Alternatively, some people find it better to take them just before bed, so they are asleep by the time the full effect of the steroid is felt.
- Stomach pain: steroids can irritate or damage the lining of the stomach, which can result in pain or reflux. Inform your doctor or nurse if you are experiencing stomach pain as there may be some medications to prevent this.
- Increased blood sugar: steroids may increase the levels of sugar in the blood. If you are diabetic you may require more frequent monitoring or changes in your usual medications, so it is important to consult your doctor about this.
- Increased appetite: increased hunger is common while taking steroids. Weight gain may occur as a result of increased eating.

- Muscle weakness: steroids may cause muscle weakness and muscle wasting for some people. Regular, gentle exercise is important and input from a physiotherapist may be very useful.
- Increased risk of infection: like chemotherapy, steroids can suppress the immune system, making it easier to get infections. Signs of infection such as high temperature, swelling or red skin, and unexplained pain should be reported to your doctor immediately.

## Chemotherapy

Chemotherapy means therapy with chemicals and is often called 'chemo'. The term chemotherapy is also used loosely to describe the combination of drugs used to treat any cancer.

Chemotherapy is the name given to anti-cancer drugs (cytotoxic drugs) that work by stopping cancer cells dividing.

Each drug affects the cancer cells in different ways, which is why sometimes a combination of drugs is given.

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 cause side effects. Doses of chemotherapy can be different for each person. You might hear descriptions like low-dose chemotherapy, intensive chemotherapy or high-dose chemotherapy.

The different ways that chemotherapy is given are:

- Into a vein (intravenously/IV)
- In a tablet (orally)
- Into a muscle (intramuscular injection/IM)
- Under the skin (subcutaneous/sub-cut/SC)
- Into the spinal fluid via a hollow needle (intrathecal/IT)



### Detailed information

- Cyclophosphamide is the most common chemotherapy drug used to treat myeloma.
- Cyclophosphamide can be used to help treat myeloma and other cancers. It works by damaging the DNA within the myeloma cell which then dies. Cyclophosphamide can be given in different ways but in myeloma treatment it is usually as a tablet (pill). Tablets should be swallowed whole with water and it is important to keep drinking plenty of water during the day.
- Melphalan is another chemotherapy drug that works in a similar way to cyclophosphamide by damaging and killing cells in the body like myeloma cells. It is usually given as a tablet that you swallow. It is important to follow the instructions for taking melphalan as prescribed by your doctor.

## Side effects of chemotherapy

We mentioned earlier in this section that healthy cells that multiply quickly in your body can also be killed or damaged because of chemotherapy. Examples of these cells are those in your mouth, gut (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 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
- Bruising and bleeding
- Constipation
- Damage to organs
- Diarrhoea
- Difficulty concentrating or remembering ('chemo brain')
- Early menopause
- Fatigue (extreme tiredness)
- Fertility changes
- Hair loss
- Increased risk of infection
- Nausea and vomiting
- Pain
- Poor appetite and taste changes
- Skin changes
- Sore mouth (mucositis)

These side effects, and what you can do if you have them, are discussed in the section called 'Living with myeloma' on page 34.



### Key points

- There are many different types of chemotherapy and it can be given in a variety of different ways, e.g. as a tablet or via a drip (IV).
- Chemotherapy can be given in hospital, as an outpatient or at home, depending on the types of chemotherapy you are having and how well you are.

## Novel therapy

There are two types of novel therapies that are currently used in New Zealand and other countries for the treatment of myeloma:

- Proteasome inhibitors
- Immunomodulatory (im-mu-no-mod-you-lay-tor-ree) drugs

### Proteasome inhibitors

Proteasomes are large molecules that are present in all cells in the body. They can remove and breakdown unnecessary proteins that are no longer needed by the cell. Proteasome inhibitor drugs prevent this process from happening, which results in excess proteins being made until the high levels become toxic and kill the cell. The main proteasome inhibitor drug used in New Zealand for myeloma treatment is bortezomib (Velcade).

#### Bortezomib (Velcade)

Bortezomib (bor-tiz-o-mib) works by blocking the actions of proteasomes and can directly kill myeloma cells as well as alter how they grow and replicate in the body.

Bortezomib is usually given as an injection under the skin (subcutaneous). It can be given into a vein but this is less common.

#### Common side effects of bortezomib are:

- Bruising and/or bleeding
- Diarrhoea
- Fatigue (extreme tiredness)
- Nausea and/or vomiting
- Nerve damage (peripheral neuropathy)

## Immunomodulatory drugs

The primary action of immunomodulatory drugs (IMiDs) is to bind to a specific enzyme within the myeloma cells, causing it to induce destruction of several target proteins that are important for the survival of myeloma cells. IMiDs that are currently funded in New Zealand (as of December 2018) include thalidomide and lenalidomide, and are taken orally as a tablet. Specific precaution is needed with IMiDs as it can cause birth defects when pregnant women are exposed to it. Please discuss this with your haematologist as well as the potential side effects.

#### The two main immunomodulatory drugs used in myeloma treatment are:

- Thalidomide
- Lenalidomide

**Thalidomide** has been used since the late 1950s but was prescribed for morning sickness in pregnancy until it was found to cause severe birth defects. Thalidomide has been used since very cautiously but has been very effective in conditions related to the immune system. It is not fully understood why thalidomide acts against myeloma cells, but it has shown to directly kill myeloma cells as well as preventing the growth of new myeloma cells. It also boosts the immune response against myeloma cells.

Thalidomide is given orally (as a tablet) and the dose may vary from person to person depending on their disease and response to the drug.

**Lenalidomide** is a newer variation of thalidomide but works in a similar way. It is also given as a tablet. Some people may experience less side effects when taking lenalidomide compared with thalidomide.

Like other anti-myeloma treatments, immunomodulatory drugs are even more effective when given alongside other drugs that work differently to kill myeloma cells.

### Side effects of immunomodulatory drugs

Side effects can vary from person to person and can be minimal or more serious. It is important to let your health care team know about any symptoms you have.

Common side effects of thalidomide and lenalidomide are:

- Bruising and bleeding
  - Constipation
  - Damage to organs
  - Diarrhoea
  - Fatigue (extreme tiredness)
  - Increased risk of infection
  - Nausea and/or vomiting
  - Nerve damage (peripheral neuropathy)
  - Pain
  - Poor appetite and taste changes
  - Skin changes
- Anaemia
  - Birth defects
  - Blood clots or venous thromboembolic events (VTE)



### Detailed information

There is an increased risk of blood clots and venous thromboembolic events (VTE) when taking lenalidomide so it is important to be aware of some of the symptoms. The most common VTE is a deep vein thrombosis (DVT) that most often occurs in the legs. It is also possible to get a blood clot in the lungs, which is called a pulmonary embolism (PE).

Symptoms might include:

- Red, swollen or painful areas in your body, particularly in your calf (lower leg)
- Shortness of breath
- Chest pain



### Important information

- It is very important you tell your health care team if you are experiencing any symptoms that are affecting your quality of life.
- There are some practical tips for managing these different side effects later in this booklet under 'Living with myeloma' on page 34.

## Stem cell transplant

A stem cell transplant is when you have stem cells infused through a drip (IV) into your bloodstream after having high doses of chemotherapy and sometimes radiotherapy. When high-dose chemotherapy is given the stem cells are destroyed and cannot recover by themselves. This is why you are given 'new' stem cells to replace the ones that were destroyed.

A stem cell transplant may also be called a bone marrow transplant or a peripheral (perif-er-ral) blood stem cell transplant.

The stem cells you are given might be your own stem cells that were frozen before the high-dose treatment. You might be given stem cells from another person (donor) instead of your own but this is not as common for people with myeloma.

A stem cell transplant is not suitable for everyone. If your haematologist thinks a stem cell transplant is necessary or an option for you, they will discuss it with you in detail.

Stem cell transplants allow you to have much higher doses of chemotherapy. This may improve the chances of having a longer remission or keeping the myeloma away for as long as possible.

There are two main types of stem cell transplants:

- Autologous (or-tol-o-gus)
- Allogeneic (al-o-jen-ay-ic)

## Autologous stem cell transplant

An autologous stem cell transplant may also be called autograft transplant or high-dose treatment with stem cell support.

An autologous stem cell transplant is the most common type of stem cell transplant for people with myeloma. It will be discussed by your haematologist if it is an option for you.

You will be given initial treatment that is usually a combination of drugs to destroy the bulk of the myeloma. This is followed by collecting your healthy stem cells and freezing them. You then have high-dose chemotherapy and the frozen stem cells are defrosted and given back to you via a drip (like a blood transfusion).

The stem cell collection (also known as a stem cell harvest) involves having a drug called granulocyte-colony stimulating factor (G-CSF) that helps your body grow lots of stem cells for the collection. The collection is similar to giving blood, but you will have two IV lines that connect you to a big machine, which spins the stems cells out of your blood.



## Key points

- A stem cell transplant is a treatment option your haematologist might discuss with you if it is suitable.
- A stem cell transplant is when you are given high-dose chemotherapy followed by stem cells through a drip (IV).
- Stem cell transplants allow you to have much higher doses of treatment to improve chances of remission.

The aim of a stem cell transplant is to give you a long remission period and improve your quality of life.



### More information available online

## Allogeneic stem cell transplant

An allogeneic stem cell transplant is when the stem cells you are given are from a donor. The donor might be a sibling, or an unknown volunteer who has been genetically matched to you. Not all siblings are a genetic match for each other so blood tests need to be completed to check this.

An allogeneic stem cell transplant is not commonly used for people with myeloma. However, it may occasionally be a treatment option for some people. There can be less risks involved with an autologous stem cell transplant than an allogeneic stem cell transplant, because they are your own cells given back to you.

## Tandem stem cell transplant

Tandem transplant means having a second autologous stem cell transplant shortly after your initial one (usually within six months of each other).

There is some evidence from clinical trials to suggest that tandem transplants may improve long-term outcomes in some patients, like those with high-risk myeloma. If this is a recommended option for you, your haematologist will discuss it in more detail with you.

## Radiotherapy

Radiotherapy is the use of high-energy radiation to kill myeloma and other cancer cells. It damages the myeloma cells so they cannot continue to grow and multiply. Radiotherapy has been developed a lot over the years as technology has improved.

Radiotherapy is mainly used to relieve pain as a result of myeloma bone disease. As mentioned earlier on page 11, myeloma bone disease is a common feature of myeloma and it can cause a lot of pain.



### Key points

There are two main types of stem cell transplants:

- Allogeneic
- Autologous

Autologous stem cell transplant is when you have your own stem cells returned to you via a drip after having high doses of chemotherapy. This is the most common type of transplant for myeloma.

Radiotherapy is generally used to treat specific areas of myeloma bone disease if there is pain or other complications. Radiotherapy may also damage other healthy cells in the same area.

#### Radiotherapy may be used to:

- Relieve pain and kill myeloma cells in one area.
- Relieve pressure on the spinal cord if myeloma cells are pushing on this area.
- Treat an area where there is an accumulation of myeloma cells, which might get called a tumour of plasma cells (plasmacytoma).

#### What does radiotherapy involve?

Radiotherapy is given in the radiology department in larger hospitals. It is administered using a large machine positioned over the body and targets the exact area the doctor wants treated. Radiotherapy needs to be planned very carefully so there are usually some appointments with the doctor before receiving treatment. It is important that the exact target area of the body is measured through imaging scans like x-ray, CT or MRI. The radiation specialist then calculates the right dose, which is individual for each person.

Depending on what area of the body is being treated, you may need to have a mould or mask made. These are used to keep you still throughout the radiotherapy session.

It might feel similar to getting an x-ray. The radiation beam is invisible and is a painless procedure. There may be some side effects from radiotherapy, which we discuss in the next section. There may be noise and movement from the machines that are used.

#### Side effects of radiotherapy

Unfortunately, there can be side effects to radiotherapy, but this will vary from person to person.

#### Common side effects include:

- Pain and sensitive skin (might feel similar to sunburn)
- Tiredness and fatigue
- Nausea and/or vomiting
- Diarrhoea (if the abdomen or pelvic area is treated with radiotherapy)
- Loss of hair in the treated area



### Important information

- 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.



### Important information

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

## Bone support and bisphosphonate drugs

Myeloma bone disease is the most common complication of myeloma at diagnosis.

Myeloma bone disease can cause:

- Bone fracture
- Collapsed vertebrae (slipped disc)
- Spinal cord compression
- Bone thinning (osteopenia)
- Lytic lesions (holes in bones)
- Pain
- Hypercalcaemia (high calcium levels)

Bisphosphonate drugs can control further bone breakdown. If your haematologist thinks you might benefit from these drugs, they will be prescribed and usually given as an outpatient at the hospital.

Bisphosphonates are small molecules that bind to calcium and are taken up in the bone. They prevent bone breakdown by stopping one type of cell called osteoclasts. New drugs on the horizon



### Key points

There are two bisphosphonate drugs that are used in New Zealand, which are pamidronate disodium (Pamisol) and zoledronic acid (Zometa). They are given via a drip (IV), usually as an outpatient. Zometa can be administered in a shorter amount of time, but can put more stress on the kidneys, so this drug might not be offered to everyone.

Bisphosphonate drugs generally have minor side effects that may include:

- Fever
- Flu-like symptoms
- Vein irritation at the infusion site
- Nausea
- Reduced kidney function
- Risk of osteonecrosis of the jaw



### Important information

- Osteonecrosis of the jaw can be a serious complication when taking these drugs. It is a rare condition where the bones of the jaw become damaged, often after tooth extraction.
- As a precaution you should have regular dental checks, let your dentist know you are having bisphosphonate drugs, and let your haematologist know before you have any planned oral surgery or tooth extractions. It might be strongly recommended to postpone this for a period of time, for your own safety.

## New drugs on the horizon

There is currently a strong research interest in myeloma, and new drugs – whether a new generation of existing drugs or a new class of drugs altogether – are currently being developed. Some of these medications

include carfilzomib (a second-generation proteasome inhibitor), pomalidomide (a third-line immunomodulatory drug) and daratumumab (a novel monoclonal antibody that specifically targets and kills myeloma cells by binding to its surface marker).

It is beyond the scope of this booklet to discuss these new drugs in detail, as it is a rapidly developing field. Although many of these new drugs may not be funded by the Government, patients may be able to access them either through compassionate supply by the pharmaceutical companies or by enrolling in a clinical trial, depending on availability. It is important that you take time to discuss treatment options with your haematologist and family/whānau before making a decision.

If you would like more information about the latest drug information, please visit our website at [www.leukaemia.org.nz](http://www.leukaemia.org.nz).

## Treatment for relapsed disease

If your myeloma returns, another course of anti-myeloma treatment may be given to get the myeloma back under control. Your haematologist will talk to you about your options for treatment and will depend on many factors, including:

- How long after treatment did the relapse occur, e.g. months or years.
- How well the myeloma responded to the first treatment.
- How you coped physically with the treatment.
- Your age and general level of health.
- How you feel about future treatment.

## Complementary therapies

Complementary therapies can be very useful to help people feel better emotionally and physically. There are lots of different therapies and some people find it helpful to try more than one.

Examples of complementary therapies are:

- Relaxation
- Yoga
- Mindfulness techniques
- Massage
- Reiki
- Acupuncture
- Aromatherapy
- Homeopathy
- Reflexology
- Meditation
- Art therapy
- Music therapy
- Visualisation
- Tai chi

If you are not sure what some of these therapies are, ask a member of your health care team. If you plan to use complementary therapies, including any supplements, make sure they are a safe option for you by asking your haematologist first.

## Supportive care

Supportive care is important to help you cope with your diagnosis of myeloma, symptoms of myeloma and the impact of treatment.

Supportive care ensures that you have the best quality of life.

**Examples of supportive care include:**

- Being given blood products via a drip (a transfusion) to help with symptoms of low red blood cells or platelets.
- Being prescribed drugs to help manage side effects or symptoms, e.g. pain relief or antiemetics (drugs to stop you feeling sick).
- Being given antibiotics to help prevent or manage infections.
- Support from a dietitian, psychologist or chaplain.
- Practical support at home.
- Support for families/whānau who have to relocate for treatment.

**Supportive care is used in two situations:**

1. Supportive care helps a person receiving treatment, such as chemotherapy, manage difficult or overwhelming symptoms, e.g. pain or nausea.
2. Supportive care is a choice a person makes for managing symptoms of myeloma when they are not having chemotherapy or intensive treatment.

## **Palliative care**

The palliative care team is made up of doctors, nurses and other health care professionals who specialise in managing symptoms of myeloma. They aim to improve quality of life through support and services as you face a life-limiting illness. The palliative care team may be involved in providing you with supportive care.

Many people associate the word 'palliative' with end-of-life care. The palliative care team supports all people with myeloma.

The table on page 33 compares palliative supportive care and supportive care alongside treatments such as chemotherapy or a stem cell transplant. Supportive care is important regardless of whether you are receiving chemotherapy or not. It can help a person manage the symptoms of myeloma or the side effects of treatment.

Supportive care may start at diagnosis, during treatment, after treatment and at end of life. Family/whānau and friends can also receive supportive care.

Palliative supportive care	Supportive care alongside other treatments
<ul style="list-style-type: none"> <li>• You either have no chemotherapy or low-dose chemotherapy for myeloma symptoms.</li> <li>• Haematology team and palliative care team support the person to control myeloma symptoms, e.g. pain, nausea, anaemia or infection.</li> <li>• Emotional and practical support is given to ensure the best quality of life.</li> <li>• End-of-life wishes are supported.</li> <li>• End-of-life care is provided.</li> <li>• Support given in hospital, hospice, at home or as an outpatient.</li> </ul>	<ul style="list-style-type: none"> <li>• A treatment is given such as chemotherapy or stem cell transplant.</li> <li>• Health care team involves the palliative care team to support the person to control severe side effects of treatment or myeloma symptoms, e.g. pain, nausea or infection.</li> <li>• Emotional and practical support is given to ensure the best quality of life.</li> <li>• Support given in hospital, at home or as an outpatient.</li> </ul>



## Key points

- Supportive care helps people cope with their diagnosis of myeloma, the impact of symptoms and the side effects of treatment.
- Supportive care ensures you have the best quality of life.
- Palliative and end-of-life care provides people with support and services as they face a life-limiting illness.
- The palliative care team supports all people with myeloma regardless of whether or not they are receiving treatment.

# LIVING WITH MYELOMA

**There are a number of symptoms of myeloma or side effects of treatment. Some symptoms and side effects are more common than others.**

Each person's experience will be different. Some people feel very unwell, others have milder symptoms. If you are having intensive chemotherapy, your side effects may be more severe.

This section helps you manage the more common symptoms of myeloma and the side effects of treatment. Remember to report any side effects to your doctor or nurse. They can give you support or more information. Your LBC Support Services Coordinator can also give you support and information.

## Anaemia

A low red blood cell count is called anaemia. Anaemia was described on page 10.

If you have a low red blood cell count, you may have a blood transfusion via a drip (IV).

## Bruising and bleeding

When you have a low platelet count, you may bruise easily or bleed more than usual from minor cuts.

**Things you can do to help:**

- Use a soft toothbrush.
- Don't floss your teeth.
- Don't shave with a razor blade (men and women).
- 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 home or garden.
- Don't eat food with sharp edges, e.g. potato chips.
- Let your doctor or nurse know if you are constipated.

If you have a low platelet count, you might be given a platelet transfusion via a drip (IV) to help stop bruising and bleeding.



### Important information

Call the hospital straight away if you think your platelet count is low and you have:

- A nosebleed
- Bleeding gums
- Tiny red or purple spots on the skin that look like a rash

## Constipation

Constipation means that you cannot pass a bowel motion easily, usually because your bowel motions are hard. Tell your nurse or doctor if you are constipated or sore.

Hard bowel motions can damage the lining of your bowel and cause bleeding or infection.

**Things you can do to help:**

- Drink plenty of water.
- Eat more fibre such as cereals, raw fruit and vegetables while still sticking to your neutropenic diet if you are on one.
- Do some gentle exercise.
- Tell your doctor or nurse, as they can give you something to soften your bowel motions.
- Talk to a dietitian.

**Damage to organs**

Chemotherapy drugs can sometimes damage body organs such as heart, lung, liver or kidney. You will have regular tests to check that all your body organs are working properly.

**Important information**

- If you experience any chest or abdominal pain or are worried about any symptoms between your regular tests, you should contact your health care team as soon as possible.

**Diarrhoea**

Sometimes chemotherapy damages the lining of your bowel wall. This might cause diarrhoea (die-a-rea) (loose bowel movements) and other symptoms such as:

- Cramping (pains in the lower abdomen or gut)
- Abdominal swelling (swollen tummy/ lower gut)

If you have diarrhoea, your health care team may do a test to see if you have an infection.

**Things you can do to help:**

- Take the drugs that your doctor or nurse give you to stop the diarrhoea.
- Wipe your bottom with soft toilet paper or wipes.
- Apply a barrier cream around your bottom to protect and soothe the skin.
- Drink plenty of fluids.
- Eat less fibre, such as cereals, raw fruits and vegetables.

If you are unable to drink fluids, tell your doctor or nurse as you may need to have a drip (IV) of fluids so you don't become dehydrated.

**Important information**

- Call the hospital if you have more than four episodes of diarrhoea in a day.

**Difficulty concentrating or remembering ('chemo brain')**

Chemo brain can be a symptom of myeloma or a side effect of chemotherapy. It is also called mild cognitive impairment (MCI). It can also affect people with cancer who have not had chemotherapy. The exact cause of chemo brain is not known.

**The symptoms of chemo brain are:**

- Difficulty concentrating
- Difficulty remembering things, including finding the right word
- Feeling very tired

Chemo brain can be frustrating and can make everyday life difficult.

**Things you can do to help:**

- Keep a diary of your symptoms.
- Make lists, take notes and use sticky pads with reminders.
- Keep a calendar or diary.
- Do mental exercises such as crosswords and puzzles.
- Try to keep calm.
- Do some regular exercise.
- Get plenty of rest and sleep.
- Read short articles rather than books and watch episodes of programmes rather than films.

**Early menopause**

Some chemotherapy drugs can lower the amount of hormones that a woman's ovaries make. This can lead to early menopause and menopausal symptoms.

Menopause usually starts any time after 40 years of age when, due to hormonal changes, women's periods stop, and they can no longer have children.

Your doctor will be able to tell you if you are having the type of chemotherapy that might cause you to experience early menopause.

**Fatigue (extreme tiredness)**

**Extreme tiredness is very common for people with myeloma and after treatment.**

**Extreme tiredness can be caused by:**

- Myeloma itself
- Chemotherapy and other treatment
- Emotional stress
- Poor sleep
- Low blood counts
- Muscle loss
- Loss of appetite or dehydration

Extreme tiredness can have a huge impact on your life. If you have chemotherapy or other treatment, it can sometimes be several months before you feel your energy levels are back to normal. Some people feel tired for a year or more afterwards.

**Things you can do to help:**

- Have a regular night-sleep routine.
- Have regular rest periods throughout the day.
- Don't try to do many things in a day, just do the important ones.
- Note the times in the day when you have the most energy and set goals to do your main activities at these times.
- Do some light exercises each day. This regular activity will improve your physical condition and make you feel good.
- Keep a diary so you can look back and see your improvements in energy levels over time.

In hospital your sleep can be very interrupted. Speak with your health care team if you are finding this is making you very tired during the day. Also speak with the team about emotional support if you are having trouble coping due to extreme tiredness.

LBC have a 'Managing cancer-related fatigue' fact sheet available on the LBC website or from an LBC Support Services Coordinator.



**More information  
available online**

## Fertility issues

Fertility means a person's ability to get pregnant or father a child. Infertility means that you may not be able to become pregnant or father a child. Intensive chemotherapy may cause infertility.

It is important that you discuss any questions or concerns you might have about your fertility with your health care team as soon as possible. There may be some things you can do before you start treatment that mean you might be able to have a baby, or father a child, in the future.

For some people, the possibility of losing their fertility can be very upsetting. There is practical and emotional support available. Talk to a member of your health care team. They will help you get the support you need.

## Hair loss

Hair loss is a common side effect of intensive chemotherapy, however it doesn't occur with every type of treatment. Hair loss usually happens over a number of days or weeks after you start treatment. You should start to feel and see new hair growing back six to twelve weeks after you finish treatment. For some people it might take longer.

Hair loss can happen on all parts of your body including your head, eyebrows, eye lashes, beard/moustache, underarms, pubic hair and legs. Your scalp may feel sensitive, sore or itchy when your hair is falling out.

### Things you can do to help:

- Pat your hair gently with a towel to dry it.
- Don't use heat, such as a hair dryer or straighteners.

- Don't use chemicals, such as hair dye.
- Use a soft brush. Some people find baby brushes are best.

### Shaving your head and head wear

Some people let their hair fall out naturally. Other people have their hair cut off in stages or shave it off before treatment begins as they find this easier than watching their hair fall out.

### Things you can do to help:

- Speak to other people who have had hair loss.
- Wear a wig, baseball cap, beanie or woolly hat, scarf or turban. This can make you feel more comfortable. In winter you will probably find it very cold without a head covering.
- In summer you are more prone to sunburn. Your skin is more sensitive to the sun after chemotherapy so it's important to ensure you apply sunblock and cover up.

As your hair grows back, you may find that it has changed. It may be curlier, thicker, a different colour or grow back unevenly. These changes do not always stay that way forever.

## Sex and fertility

Even though chemotherapy can cause infertility, it does not make all people infertile. Chemotherapy can affect a developing foetus, so use a condom when you have sex in the months before, during and after chemotherapy to avoid a pregnancy.



### Important information

- There needs to be extra caution around contraception (preventing pregnancy) when you are on IMiD treatment like thalidomide or lenalidomide. Getting pregnant while having these drugs can cause foetal damage and severe birth defects.
- Women of childbearing age must use an effective method of pregnancy prevention. Contraception must start four weeks before thalidomide/lenalidomide treatment and continue for the duration of treatment and for a period of four weeks afterwards.
- Medically supervised pregnancy tests are also performed regularly and monitored by your doctor and/or pharmacist.
- Thalidomide can be present in semen, so male patients must use condoms whenever they have sexual intercourse with a woman of childbearing potential.
- Women must not breastfeed while on thalidomide.

## Increased risk of infection

Some blood cancers and treatment cause your white blood cell count to drop, increasing risk of infection. Having a low white blood cell count can be very serious and even fatal if you do not see a doctor quickly for an assessment and antibiotics.

Your health care team will tell you if you have a low white blood cell count. They may use other names to describe this such as neutropenia, reduced or weakened immune system or immunocompromised.

Low white blood cells mean you are at risk of infection. Infections can be life-threatening.

## Food

Your doctor, nurse or dietitian will tell you what foods not to eat when you have a low white blood cell count. They may suggest you have a 'neutropenic' or 'clean' diet. This type of diet protects you from germs found in some foods and drinks. Your doctor or nurse will tell you when you can return to your usual diet. This will be when your white blood cell count has increased.

**You must be very careful when preparing and cooking food. You need to:**

- Always wash your hands before preparing or eating food.
- Tell your family/whānau and friends to wash their hands before preparing 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 make sure it is very hot.



## Important information

There are a number of things you can do to reduce your chance of getting an infection.

- Call the hospital if you have a temperature over 38°C.
- Don't wait to see if your temperature goes away.
- Make sure you have a thermometer at home and that you know how to check your temperature correctly.
- Don't take any drugs such as paracetamol to bring your temperature down before you see a doctor.

- Don't take aspirin or ibuprofen in any form. This can increase your risk of bleeding if your platelets are low. Always check with a doctor or nurse first.
- Ask a member of your health care team for the phone numbers of the hospital and write them here:
  - Monday to Friday (during office hours)  
ph.....
  - Evenings/nights/weekends  
ph.....

- Make sure reheated food is very hot.
- Eat food before its best before/use-by date.
- Don't reheat food more than once.

## Keeping yourself clean

When you have a low white blood cell count, you are more likely to get an infection from germs on your body. You need to:

- Have a bath or shower every day.
- Use a clean towel every day.
- Wash your hands after using the toilet and ask family/whānau members to do the same.
- Clean your teeth regularly; if your platelets are low, don't floss. See 'How and when to do mouth care' on page 44.
- Keep your central IV line clean and check for signs of infection such as redness, swelling, pus or pain.
- Use sanitary towels (pads) rather than tampons during your period.

## Other people

When you have a low white blood cell count, you are at a higher risk of getting an infection from other people. You need to:

- Stay away from people, including children, who are unwell, e.g. have colds, flu or other infections.
- Stay away from people who have been near others who have had chicken pox or measles.
- Stay away from crowded places such as buses, trains and busy shops.

If you live with children, talk to their school or preschool. They need to let you know of any infectious diseases in the school, e.g. chicken pox, measles, diarrhoea or vomiting.

Your haematologist will tell you if the people you live with need a flu vaccine to help protect you.

It is important that you keep up your usual social activities when you are able.

Touching, hugging and kissing your close family/whānau and friends is important. It is fine if they are well.

Talk to your health care team if you would like more information.

## Pets

**When you have a low white blood cell count, you may get an infection from pets.**

**You need to:**

- Always wash your hands after touching pets.
- Do not let a pet lick your face.
- Keep pets clean and treat them for worms and fleas.
- Keep pets away from areas where food is prepared.
- Don't touch the litter tray or dog/cat poo.

## Gardening

**Garden soil can cause infections in people with a low white blood cell count. You need to:**

- Wear gloves, as soil or potting mix can have harmful germs in it.
- Wash any cuts from gardening very thoroughly.
- Check cuts for signs of infection.
- Wear a mask to avoid breathing in particles.

## Mood changes, anxiety, depression or difficulty coping

After finding out you have myeloma, during treatment or after treatment, it can be common to have a low mood, feel anxious or depressed, or find it difficult to cope. There can be a lot of things that cause these feelings.

Some drugs, especially steroids, can change your mood and it may be hard for your family/whānau and friends to cope. Some people may get irritated easily, agitated or even aggressive.

**Things you can do to help:**

- Talk to someone you feel comfortable with about how you're feeling, e.g. family/whānau, a friend or an LBC Support Services Coordinator.
- Ask your health care team about a referral to a psychologist or counsellor.
- Set yourself daily achievable goals and bigger long-term goals.
- Make a list of things that make you feel better such as your favourite TV show, talking to someone on the phone or doing a hobby.
- Try to maintain your social circle by keeping in touch with friends and family/whānau.
- Try to spend time each day relaxing, e.g. meditation, listening to music.
- Exercise regularly.
- Try to keep a regular sleep pattern.
- Keep a diary. This can help you express how you feel without needing to talk to anyone.
- Cry if you need to.
- Try complementary therapies such as massage, aromatherapy or reflexology. Information on complementary therapies can be found on page 31–32.

It is important to tell a member of your health care team if you continue to have feelings of low mood, anxiety, depression or difficulty coping. They can make sure you get the support you need.

If you are experiencing any of these mood changes or your family/whānau have

commented that your mood has changed, it is important to tell a member of your health care team and get support.

## Feelings of isolation

A diagnosis of myeloma can also make you feel isolated or alone for a number of reasons, for example:

- Being unable to continue working, studying or doing the things you usually do.
- Symptoms and side effects, such as fatigue, or risk of infection, which make it hard to be with other people or attend social events.
- A lack of support from family/whānau or friends who may not know what to say or do.
- Financial difficulties that make it hard to maintain social activities or visit family/whānau and friends.

Feeling isolated can have an impact on your physical and mental well-being, therefore speak to your doctor, nurse, social worker or LBC Support Services Coordinator if you feel isolated or alone.

## Nausea, vomiting and dehydration

Some chemotherapy, especially high-dose chemotherapy, can make you feel sick (nausea) or be sick (vomiting). Feeling anxious can also cause nausea and vomiting.

There are drugs called 'antiemetics' that can help treat nausea and vomiting.

Different drugs work in different ways and you may have one or more types of antiemetic drugs to treat your nausea and/or vomiting. Antiemetic drugs are mainly given as a tablet,

an injection or as a skin patch. Tell your doctor or nurse if you still feel sick because they might be able to try a different antiemetic or give it to you in a different way.

Controlling your nausea and vomiting is important so you can keep up your food and drink intake. If you have bad nausea and vomiting and are unable to drink or keep fluid down, it is important you speak with your doctor or nurse to ensure you don't become dehydrated.

### Things you can do to help:

- Eat smaller meals or snacks, more frequently throughout the day.
- Don't eat foods with a strong smell or taste.
- Don't eat hot or fatty foods.
- Try ginger tea or ginger ale.

Complementary therapies such as relaxation, aromatherapy or massage might help some people.

## Pain

Some people may experience pain as a result of treatment, e.g. with mucositis or heartburn.

It is important to tell your health care team if you have pain. Your health care team will ask you about the pain, for example:

- What is the pain like, e.g. dull, sharp, burning?
- How bad is the pain on a scale of 0–10?
- What makes the pain worse and what makes it better?

Pain can be caused, or made worse, by your emotions or how you are coping with your diagnosis and treatment. This is called 'total pain'. Total pain can be psychological, social or spiritual. Examples of things that might cause total pain are anxiety, worries about your family/whānau or a crisis of faith. It is important that total pain is managed as well as physical pain. Ask your health care team for the support you need.

## Peripheral neuropathy

Peripheral neuropathy is the term used to describe damage to the nerves in the hands, feet, arms and legs. Some people might experience numbness, tingling, pain, hot or cold sensations, or increased sensitivity. This can be caused by the myeloma itself but more commonly from some of the drugs used to treat myeloma.

The best way to prevent peripheral neuropathy is to be aware of any changes and report symptoms to your doctor or nurse as soon as possible. The doctor might decide to reduce your drug dose or change you to a different drug with less side effects. There are some pain relief options that may be beneficial, but they don't always work for everyone.

### Things you can do to help:

- Take care of your hands and feet by wearing well-fitting, protective shoes. Keep hands and feet warm.
- Use caution when getting into baths and showers to make sure the water isn't too hot that it could burn your skin.
- Eat a well-balanced diet and try to include as many essential vitamins and minerals as possible.
- Reduce potential fall risks at home by clearing away clutter.
- Stop smoking as this can affect your peripheral blood flow.
- Use ice packs or hot water bottles to provide short-term relief of symptoms.

## Poor appetite and taste changes

You may not feel like eating and have taste changes. This may be because of the chemotherapy, medicines, the worry of having myeloma or doing less physical activity.

### Poor appetite

Having a poor appetite can be disappointing for people who usually enjoy eating. It is important to keep eating to help maintain your weight and energy levels. It is also important to drink plenty of water, especially if you are not eating very much.

It can be common for people to really feel like eating certain foods and then by the time it has been made, they cannot eat it. Choose meals that can be made quickly and are easy to eat.

If you are finding it difficult to eat, or are worried about your weight, ask to speak with a dietitian who will be able to advise you.

**Things you can do to help:**

- Eat small amounts of food as often as possible.
- Keep snacks handy such as nuts, cheese and dried fruit (as long as it is allowed if you are on a neutropenic diet).
- Add extra energy and protein to your diet by using full-fat products or supplements the dietitian has recommended.
- Eat what you feel like, you can return to your normal diet when your appetite returns.

**Taste changes**

You may find that your sense of taste changes or that the texture of food seems different. This may mean that you no longer enjoy food, all food tastes the same, or food has a metallic taste. Your sense of smell can also be affected.

**Things you can do to help:**

- Eat food cold as it often tastes better and smells less.
- Suck boiled sweets or drink fruit juice as they leave a pleasant taste in the mouth.
- Try different seasonings such as herbs and spices on your food.

If you are in hospital and don't feel like eating the hospital food, ask your charge nurse about suitable foods that family/whānau or friends can bring in for you.

LBC have an 'Eating well' fact sheet available on the LBC website or from an LBC Support Services Coordinator.



**More information  
available online**

**Skin changes**

Chemotherapy can affect your skin and nails. Your skin may become dry or more oily. Your skin can also become red, sore, itchy and more sensitive.

Nails may become brittle and flaky. Ridges or lines may appear on your nails and they can also become painful or swollen.

**Things that you can do to help:**

- Don't use soap, perfumed products or products that contain alcohol.
- Moisturise dry skin once a day, or more if needed.
- Use lip balm regularly.
- Don't scratch.
- Don't shave with a razor blade.
- Use oil-free moisturiser on oily skin.
- Use hand cream regularly.
- Use nail-strengthening cream.
- Wear gloves when doing chores.

**Sun protection**

After chemotherapy, you might find that the sun burns your skin much quicker than it used to.

**Things you can do to help:**

- Wear sunscreen with a high SPF and reapply regularly.
- Don't go outdoors, or stay in the shade during the hottest part of the day.
- Cover exposed skin with clothing.

You should do this for the rest of your life.

If you are having problems with your skin or nails and none of the above suggestions are helping, get support and advice from a member of your health care team or your LBC Support Services Coordinator.

## Sore mouth

A sore mouth is an uncomfortable side effect of chemotherapy. Chemotherapy causes damage to the cells in the lining of your mouth and digestive system. The medical name for this side effect is mucositis (mew-co-site-is).

You will usually notice symptoms of mucositis a couple of days after you start chemotherapy.

**The symptoms of mucositis can include any of the following:**

- Mild soreness of the mouth especially the insides of your cheeks, the sides and underneath of your tongue, and the back of your throat.
- Taste changes.
- White rough-feeling patches on the inside of your mouth.
- Red and inflamed patches on the inside of your mouth.
- Painful ulcers (sores) on the inside of your mouth.
- Difficulty or pain eating, drinking and taking tablets.
- Thick saliva (spit).
- Sore throat.
- Sore and cracked lips.

## Mouth care

Regular mouth care is important for comfort and to prevent infection, especially from mouth ulcers.

### When to do mouth care

You need to do mouth care five times a day: when you wake up, after meals and before bed. Doing mouth care can be painful, however it is very important to do it regularly and carefully. Mouth care reduces the risk of infection, especially from mouth ulcers.

### How to do mouth care:

- Brush your teeth with a soft or baby toothbrush or use a mouth sponge if a toothbrush is too painful.
- Rinse with mouthwash or with water, as instructed by your health care team.
- Use a lip balm or petroleum jelly (Vaseline) on your lips.
- Don't use dental floss as this increases the risk of bleeding gums.

### Things you can do to help:

- Suck ice cubes or ice blocks.
- Suck on hard-boiled lollies if your mouth is dry.
- Drink fizzy water.
- Spit your saliva into a bowl or if in hospital, ask the nurse how to use the suction.
- Your doctor may prescribe a saliva substitute.
- Don't eat citrus fruit, e.g. lemon, orange, mandarin or grapefruit.

## Managing mouth pain

Let your health care team know if your mouth is painful, especially if it stops you from eating. Your health care team can advise you on how to use pain relief, for example:

- Take painkillers regularly as directed.
- Take stronger painkillers 20 minutes before eating or mouth care as directed.
- Use a mouthwash with local anaesthetic to numb the pain.

Unfortunately, painkillers might not get rid of all the pain.

Sometimes mucositis can also affect the oesophagus (food pipe) and bowel (gut). This can cause discomfort, pain, indigestion and heartburn or diarrhoea. Tell your doctor or nurse if you have any of these symptoms. Mucositis should start to get better when your white cell count begins to increase.

## Contacting the hospital after-hours

Remember to ask your health care team for the hospital after-hours phone number.

If you are feeling unwell, ring the number and ask for advice, no matter what time it is. Your health care team and the hospital would rather you rang to discuss how you feel than not ring and feel worse. If in doubt, make the call. The emergency department at the closest hospital will always be open and their phone numbers can be found on page 59.



### Important information

#### When to contact your doctor or the hospital for help.

Contact your doctor, or the hospital, straight away (night or day) if you are feeling unwell or have any of these symptoms:

- Temperature of 38°C or over and/or shivering.
- Bleeding or bruising, e.g. blood in your urine, bowel motion, sputum (spit), bleeding gums or nosebleed.
- Nausea or vomiting that prevents you from eating or drinking or taking your normal medications.
- Diarrhoea, stomach cramps or severe constipation.
- Coughing or shortness of breath.
- New rash, reddening of the skin or itching.
- Headache that won't go away, confusion or blurry vision.
- New pain or soreness anywhere.
- Cut or injury.
- Pain, swelling, redness or pus anywhere on your body.

## Coping with isolation in hospital during chemotherapy or stem cell transplant

You may spend long periods of time in hospital at diagnosis, when having a stem cell transplant or other treatment. You may be in a shared room with other patients, a single room or in 'isolation'. Protective isolation means that you are in a hospital room by yourself and your main visitors should be restricted to family/whānau and close friends. This is to protect you from serious infections while your white blood cell count is low. This can be a difficult or challenging time. Being separated from family/whānau, especially children, can be hard for everyone. Each hospital has a policy around protective isolation, and they will tell you if you are allowed to leave your room and what precautions visitors should take, e.g. hand hygiene and wearing a mask.

### Things you can do to help:

- Set yourself daily goals. Your physio, occupational therapist or nurse could help you with this.
- Have special photos in your room.
- Maintain regular contact with family/whānau via phone and video conferencing.
- Shower and get dressed in day clothes each day.
- Do light exercise and relaxation.
- Write in a diary about your thoughts and feelings.
- Do activities you enjoy such as watching a favourite TV show, listening to music, games or puzzles, contacting friends and keeping up with world news and events.
- Ask your visitors to come throughout the day, not all at the same time.

Contact your LBC Support Services Coordinator if you need support while you are in isolation.

## Moving to a main-centre hospital for treatment

If your local hospital cannot provide the treatment you need, you may need to move to another hospital in a main centre.

A social worker can help you with information and practical support such as advice on how to get accommodation, transport and financial assistance.

Moving to another hospital for treatment can be stressful for you and your family/whānau.

Contact your LBC Support Services Coordinator to obtain a relocation booklet with practical information about moving to a main-centre hospital.

# RELATIONSHIPS

## Relationships with family/whānau and friends

A diagnosis of myeloma can have a positive and negative impact on relationships with family/whānau and friends.

### Relationships with your partner

A diagnosis and the treatment of myeloma can put a lot of strain on a relationship but some couples grow closer from going through this experience together. Good communication is essential to supporting your relationship, including sharing how you feel with your partner.

### Other things you can do to help:

- Planning activities together such as meals out. If you are in hospital and feel well enough, you and your partner could eat together and you could ask your nurse if it would be possible to have some time when no one comes into your room.
- Tell your partner how they can support you.
- Get support from a counsellor or psychologist. Ask your health care team or LBC Support Services Coordinator for more information or a referral.

There are other practical things you might want to discuss with your partner, such as setting up your partner, or another trustworthy person, to be your 'power of attorney'.

A power of attorney is where you give a person the authority to act on your behalf if you are not well enough.

You could complete an Advanced Care Plan (ACP) and discuss this with your partner. An

ACP gives you the opportunity to say what is important for you. Your doctor, nurse or LBC Support Services Coordinator can explain what an ACP is and how to get a copy of the booklet.

### Financial worries

A diagnosis of myeloma can cause money worries, perhaps through a drop in income or extra expenses. If you are working, keep in touch with your boss to discuss sick leave and your plans for returning to work. Information about your employment rights while undergoing cancer treatment can be found on the LBC website or by asking your Support Services Coordinator.



## More information available online

Ask your social worker for advice and support about money worries.

### Talking to your children and/or grandchildren

Helping children understand myeloma and how this will affect you can help them to cope with the changes and challenges.

You can encourage younger children in your treatment journey to use an LBC sticker diary/journal. Your children can record your treatments and write and share journal entries with you. Ask your LBC Support Services Coordinator if you would like one of these journals.

Counselling or psychological support is available if you are concerned about how your child or children are coping. Ask your health care team or LBC Support Services Coordinator for more information.

For preschool or school-age children, it is a good idea to speak with their teachers and let them know about your diagnosis and how this is affecting family/whānau routines and relationships.

LBC has a 'Supporting a child through a loved one's cancer diagnosis' fact sheet available on the LBC website or from an LBC Support Services Coordinator.



### More information available online

#### Talking to friends and colleagues

It can sometimes feel difficult to talk to friends and work colleagues about your diagnosis of myeloma. Friends and colleagues can also find it difficult to talk to you about myeloma. Sometimes people, without realising it, make comments that hurt you or suggestions that are unhelpful.

**Most people are very keen to offer support but just don't know how. Here are some suggestions to help you build your own support team:**

- Let people know what you need, e.g. a regular phone call, text or visit.
- Share how you are feeling and any worries you have with a good listener.
- Encourage people to read this booklet or speak to your LBC Support Services Coordinator to learn more about myeloma.

- Either you or a friend could make a list of practical things others can do to help. You might like to include tasks such as cooking meals, picking a child up from school or cleaning the house.

You may not always feel well enough to take individual phone calls or respond to texts. Some people find it helpful to have one person who updates friends and colleagues on how you are doing. That person can set up an email or social media group to share information.

#### Information for people supporting someone with myeloma

As the partner, family/whānau member or carer of someone with myeloma it is quite common to experience feelings of stress, anger, fear, anxiety or depression.

Speak with the health care team or LBC Support Services Coordinator if you are feeling this way. There is a lot of support available for you.

#### Other things you can do to help:

- Look after yourself by eating well, getting enough sleep, taking regular exercise and relaxing.
- Keep doing your normal social activities.
- Join a support group or see a counsellor.
- Write down a list of things that have helped you get through a tricky situation previously. Use these tips to assist you now. Some ideas might include talking to friends or writing a diary.

A diagnosis and the treatment of myeloma can put a lot of strain on a relationship. However, some people find that they feel closer as a result of what they go through together.

Remember, the health care team or LBC Support Services Coordinator are available to support you at any time throughout your loved one's diagnosis of myeloma.

## Sexual relationships

You cannot give cancer to another person when you have sex with them.

**People who receive a diagnosis of myeloma and have treatment can experience changes in their sex life. The reasons for this include:**

- Extreme tiredness (fatigue)
- The side effects of treatment, e.g. nausea
- Changes in mood, e.g. anxiety
- Changes to your body image, due to hair loss, weight change
- Changes to your libido
- Vaginal dryness or difficulty getting an erection

After your treatment, your sex life should start to return to how it was before your diagnosis.

It is important to talk to your partner about sex and how your diagnosis and treatment are making you feel. If you are having problems with sex and it is affecting your relationship, or you are worried about starting a new relationship, speak with someone in your health care team. They can give you more information or refer you to someone who can help.

### Contraception

If you are having treatment for myeloma, you should always use a condom when having sex.

Even if you are beyond childbearing age or no longer need birth control, it is still important to use condoms if you are on any treatment for myeloma. The two main reasons for this are:

1. To protect yourself from getting an infection. Your low white blood cell count puts you at a higher risk of infection.
2. To protect your sexual partner while you are having chemotherapy. Chemotherapy drugs are secreted (come out) from your body via your urine, your bowel motions and other body secretions such as sperm and vaginal secretions. The small amounts of chemotherapy can cause irritation (a rash or itching) to your partner's skin.

If you are having sex and also receiving treatment for myeloma then there is a high risk of damage to an unborn child, so the appropriate contraception is essential.

For more information around precautions and contraception, see section 'Sex and Fertility' on page 38.

### Sex when you have a low platelet count

Speak with your doctor or nurse about sex if your platelet count is low as you may need to be careful due to the risk of bleeding. It is often a good idea for women to use a lubricating jelly ('lube') such as KY Jelly.

### New relationships

Some people feel worried about starting a new relationship following a diagnosis of myeloma. It can be difficult to know what to say. Being open and honest about your experience will make it easier for you. Talk to your friends, family/whānau or your health care team if you have concerns about what to say.

Contact your LBC Support Services Coordinator if you would like more information about sexual relationships or new relationships.

# KEEPING IN GOOD HEALTH AFTER YOUR MYELOMA DIAGNOSIS

**After a diagnosis of myeloma, it is important to look after your health. When you feel well enough, regular exercise and eating healthy food are very important.**

So that you do not have complications from your treatment, or long-term side effects, the following health changes should be made immediately:

- Stop smoking
- Protect your skin from the sun
- Stop drinking alcohol (or cut down)

Your health care team can advise you on how to keep well. The physiotherapist can advise you about the exercise that is right for you. The dietitian can advise you about eating well, especially if your treatment is making you feel sick or you have taste changes.

Ask your doctor or nurse about support to help you stop smoking and reducing or stopping alcohol.

Contact your LBC Support Services Coordinator if you would like more information about exercise options in your area.

# THE FUTURE

**A diagnosis of myeloma can affect many areas of your life such as work or school, your emotions, relationships and finances.**

For some people, a diagnosis of myeloma can mark a turning point in their life. For other people a diagnosis means they feel their life has been put 'on hold'. The length of time it may take you to recover emotionally and physically from a myeloma diagnosis or treatment is different for everyone.

Getting back to your previous routine of work, school or childcare, for example, may be a goal or may not be what you want anymore. You may need to make a few adjustments to your life.

**Your health care team and LBC Support Services Coordinator can help you manage:**

- Day-to-day practical problems including work, travel and travel insurance.
- Relationships and communication with family/whānau, friends and colleagues.
- Emotional effects of myeloma and treatment including fear of relapse and feeling uncertain about the future.

There is a lot of support available to help you and your family/whānau cope.

**Speaking to someone who has already experienced a myeloma diagnosis and treatment**

Some people find it helpful to speak to someone else who has been diagnosed with myeloma, or their support person. Your nurse, haematologist or LBC Support Services Coordinator may be able to put you in contact with someone you can talk to.

## Travelling overseas

If you are thinking of going overseas, speak to your haematologist before making any bookings to check if they have any concerns about you travelling.

It can sometimes be difficult to get travel insurance when you have been diagnosed with cancer. Speak with your LBC Support Services Coordinator who will be able to help you find information about travel insurance.

## After treatment

Once your treatment has finished, you will have regular check-ups with your haematologist and health care team. You will also be encouraged to go back to see your general practitioner (GP). Your health care team will send regular letters to your GP to tell them about your progress and what needs to be followed up, e.g. blood tests and vaccinations. If your GP has any questions, they are able to contact your haematologist for advice.

# GLOSSARY

**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.

**Antibodies** – Naturally produced substances in the blood, made by B-lymphocytes (or B-cells). When an antigen binds to the surface of a B-cell it stimulates it to divide and mature. The mature B-cells, called plasma cells, secrete millions of antibodies into the bloodstream. An antibody is also called immunoglobulin.

**Antiemetic** – A drug that prevents or reduces feelings of sickness (anti-sickness).

**Antigens** – An antigen 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' later in this glossary.

**Anxiety** – An ongoing worry or concern about something 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.

**Blast cells** – Immature blood cells normally found in the bone marrow.

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

**B-lymphocyte** – A type of white cell normally involved in the production of antibodies to combat infection.

**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 as it is commonly known, poo.

**Cancer** – A malignant disease characterised by uncontrolled growth, division, accumulation and invasion into other tissues of abnormal cells from the original site where the cancer started. Cancer cells can grow and multiply to the extent that they eventually form a lump or swelling. This is a mass of cancer cells known as a tumour. Not all tumours are due to cancer; in which case they are referred to as non-malignant or benign tumours.

**Cannula** – A plastic tube that can be inserted into a vein to allow fluid to enter the bloodstream.

**Cardiovascular disease** – Heart and blood vessel disease, e.g. heart attack or stroke.

**Chemotherapy** – Single drugs or combinations of drugs which may be 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 and a sore mouth (mucositis). Nausea and

vomiting are also common but are nowadays largely preventable with modern antiemetic medication. 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.

**Complementary therapies** – Therapies used alongside your medical treatment that 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 or CAT scan** – A specialised x-ray or imaging technique that produces a series of detailed three-dimensional (3D) images of cross sections of the body.

**Cytogenetic tests** – Cytogenetic tests are 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.

**Echocardiogram (echo)** – A special ultrasound scan of the heart.

**Electrocardiogram (ECG)** – Recording of the electrical activity of the heart.

**Foetus** – An unborn child.

**Growth factors** – A complex family of proteins produced by the body to control the production and maturation of blood cells by the bone marrow. Some are now available as drugs as a result of genetic engineering and may be used to stimulate normal blood cell production following chemotherapy or before collecting stem cells prior to an autologous stem cell transplant, e.g. G-CSF (granulocyte-colony stimulating factor).

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

**Haemopoiesis (or haematopoiesis)** – The processes involved in blood cell formation.

**High-dose chemotherapy** – The use of higher than normal doses of chemotherapy to kill off resistant and leftover cancer cells.

**Immature** – Not fully developed. For example, 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.

**Immunoglobulin** (see Antibodies).

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

**Localised disease** – Disease that is confined to a small area or areas.

**Lymphocytes** – Specialised white cells involved in defending the body against disease and infection. There are two types of lymphocytes: B-lymphocytes and T-lymphocytes. They are also called B-cells and T-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.

**Magnetic resonance imaging (MRI)** – A scan used to look inside your body using magnetic fields and radio waves.

**Malignancy** (see Cancer).

**Menopause** – The time in women's lives when their periods stop, and they are no longer able to have children. Hormones produced by the ovaries decrease after menopause (also see Ovaries later in this glossary).

**Monoclonal gammopathy of undetermined significance (MGUS)** – A benign (non-cancerous) condition where there is an increased amount of abnormal protein in the blood and/or urine.

**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 reduction in the 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 mount an effective fight against infection.

**Oncologist** – General term used for a specialist doctor who treats cancer by different means, e.g. medical, radiation, surgical oncologist.

**Osteoclasts** – Cells that are responsible for breaking down and absorbing bone. Bone is constantly being broken down and restructured. Osteoblasts are responsible for developing new bone.

**Osteoporosis** – A condition where bones become brittle and fragile and can break more easily.

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

**Paraprotein** – An antibody (immunoglobulin) that occurs in plasma cell disorders. Paraprotein levels can be monitored through a blood test.

**Partial remission** – The tumour and/or myeloma cells shrink to less than half their original size after treatment. This indicates a good, but lesser response to treatment with persistent signs of myeloma in various tests.

**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 go to see a lawyer to arrange this.

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

**Psychological** – Concerning your mental and emotional well-being.

**Radiotherapy** – The use of high-energy x-rays to kill cancer cells and shrink tumours.

**Relapse** – The return of the original disease.

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

**Stable disease** – When the disease is stable it is not getting any worse or any better with treatment.

**Standard therapy** – The most effective and safest therapy currently being used.

**Stem cells** – Stem cells are primitive blood 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 cells, white cells and platelets.

**Stem cell transplant (haematopoietic or blood stem cell transplant)** – The general name given to bone marrow and peripheral blood stem cell transplants. These transplants are used to support the use of high-dose chemotherapy and/or radiotherapy in the treatment of a wide range of cancers including leukaemia, lymphoma, myeloma and other diseases.

**Subtype** – A smaller group of something that belongs to a more general or bigger group. For example, different subtypes of myeloma include IgG myeloma, IgA myeloma or non-secretory myeloma.

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

**T-lymphocyte** – A type of white cell involved in controlling immune reactions.

**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** – A urinary tract infection (UTI) is an infection in any of the parts of your body which make or store urine or take urine out of your body, e.g. bladder or kidneys.

**White 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.

# APPENDIX A

**The following are sample questions to ask your doctor when considering treatment options for myeloma.**

Place a tick alongside the questions you would like to ask. You could add your own questions in the space provided. Record the answers to your chosen questions in your Haematology Patient Diary or on the 'Questions and notes page' that follows.

- What is the expected outcome of this treatment for me?
- What exactly does the treatment involve? How long will the entire treatment take? What are the alternatives to this treatment?
- How ill might I feel before, during and after treatment?
- What are the potential side effects, how long might they last and how serious are they? Why are you recommending this treatment for me?
- If the myeloma comes back (relapses), what are the options for me?
- Which doctor will be looking after me while I am having this treatment? How can I prepare myself for treatment?

# QUESTIONS & NOTES

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# ACKNOWLEDGEMENTS

**Leukaemia & Blood Cancer (LBC) New Zealand would like to thank everybody who has helped in the development of this booklet: those who have experienced myeloma, their personal supporters, health care team members and LBC staff.**

## **Leukaemia & Blood Cancer New Zealand**

Leukaemia & Blood Cancer New Zealand (LBC) is the leading organisation in New Zealand dedicated to supporting patients and their families living with leukaemia, lymphoma, myeloma 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. We do not receive government funding.

LBC is committed to improving the quality of life for patients and their families 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 and their families.

## HAEMATOLOGY CENTRES IN NZ

Centre	Address	Phone
Whangarei Hospital	Hospital Road, Whangarei	(09) 430 4100
North Shore Hospital	Shakespeare Road, Takapuna	(09) 486 8900
Auckland City Hospital	Park Road, Grafton	(09) 367 0000
Starship Hospital	Park Road, Grafton	(09) 367 0000
Middlemore Hospital	Hospital Road, Otahuhu	(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	(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

## Contacting us

Leukaemia & Blood Cancer New Zealand provides services and support throughout New Zealand. Every person's experience of living with a blood cancer or condition is different. Living with leukaemia, lymphoma, myeloma or a related blood condition is not easy, and our Support Services Coordinators are here to help.

**Freephone** 0800 15 10 15

**Telephone** 09 638 3556

**Facsimile** 09 638 3557

**Email** [info@leukaemia.org.nz](mailto:info@leukaemia.org.nz)

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