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INTRODUCTION

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

If you or someone you care for 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 different 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 doctor or specialist nurse.

You may not feel like reading this booklet from cover to cover. It might be more useful to look at the list of contents and read the parts that you think will be of most use at a particular point in time.

We have used some medical words and terms that you may not be familiar with. Their meaning is either explained in the text, in the glossary of terms at the back of this booklet or in the separate 'Dictionary of Terms' booklet.

Some people may require more information than is contained in this booklet. We have included some internet addresses that you might find useful. In addition, many of you will receive written information from the doctors and nurses at your treatment centre.

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.

We hope that you find this booklet useful. There is a feedback form in the back of this booklet, please feel free to fill this in and return it to us to assist in the production of future editions.

Acknowledgements

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Leukaemia & Blood Cancer New Zealand also gratefully acknowledges Dr Bart Baker (Palmerston North Hospital) and Dr Andrew Butler (Christchurch Hospital) for assistance with the development of this booklet.

Leukaemia & Blood Cancer New Zealand

Leukaemia & Blood Cancer New Zealand (LBC) is the only 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 manages the New Zealand Bone Marrow Donor Registry, which works towards finding matched volunteer donors from New Zealand or overseas for New Zealand patients who need a bone marrow or stem cell transplant and who do not have a family donor. The registry maintains information on New Zealand donors and has access to a worldwide database of over 18 million donors.

Patient Support

Leukaemia & Blood Cancer New Zealand's Support Services provide personalised support programmes for patients and their families. This can include regular visits, phone or email contact, as well as face to face education and support programmes and an online information forum. We also provide a toll free number for advice, empathy and support.

Research

Research plays a critical role in building a greater understanding of blood cancers and conditions. LBC supports and funds investigation into these conditions. Improved treatments for patients can lead to increased survival rates.

Information

We provide vital information to patients, families, health professionals and the community to improve understanding about blood cancers and conditions.



Awareness

We work to increase public knowledge of blood cancers and conditions. This is achieved through specifically focused campaigns for the public, health professionals and health agencies.

Advocacy

We represent the needs of patients and their families to the government, related agencies and other relevant organisations.

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, but you don't have to do it alone.



Call **0800 15 10 15** to speak to a local Support Services Coordinator or to find out more about the services offered by Leukaemia & Blood Cancer New Zealand. Alternatively, contact us via email by sending a message to info@leukaemia.org.nz or by visiting www.leukaemia.org.nz.

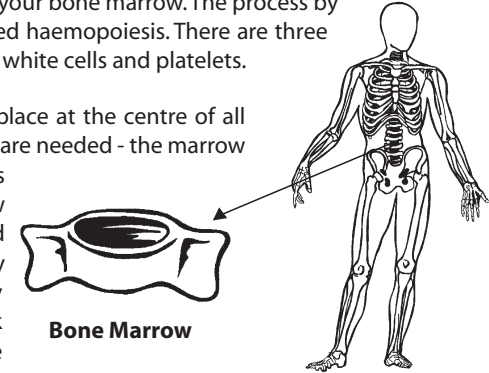
We welcome visitors to our offices in Auckland, Hamilton, Wellington and Christchurch. Please phone for an appointment.

BONE MARROW, STEM CELLS AND BLOOD CELL FORMATION

Bone marrow

Bone marrow is the spongy tissue that fills the cavities inside your bones. All of your blood cells are made in your bone marrow. The process by which blood cells are made is called haemopoiesis. There are three main types of blood cells; red cells, white cells and platelets.

As an infant, haemopoiesis takes place at the centre of all bones. As an adult, fewer new cells are needed - the marrow space in the arms and legs is replaced by fat, and active marrow is limited to the hips, ribs and breastbone (sternum). You may have had a bone marrow biopsy taken from the bone at the back of your hip (the iliac crest) or the breastbone.

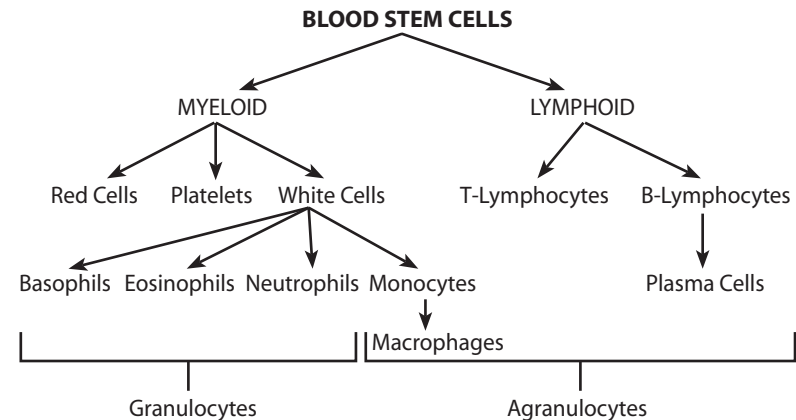


You might like to think of the bone marrow as the blood cell factory. The main workers at the factory are the blood stem cells. They are relatively few in number but are able, when stimulated, not only to replicate themselves, but also to grow and divide into slightly more mature stem cells called myeloid stem cells and lymphoid stem cells. These can multiply and mature further to produce all the circulating blood cells.

There are two main families of stem cells, which develop into the various types of blood cells:

Myeloid ('my-loid') stem cells develop into red cells, white cells (neutrophils, eosinophils, basophils and monocytes) and platelets.

Lymphoid ('lim-foid') stem cells develop into two other types of white blood cells called T-lymphocytes and B-lymphocytes.



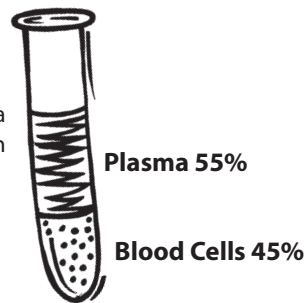
Growth factors and cytokines

All normal blood cells have a limited survival in circulation and need to be replaced on a continual basis. This means that the bone marrow remains a very active tissue throughout your life. Natural chemicals in your blood called growth factors or cytokines control the process of blood cell formation. Different growth factors stimulate the blood stem cells in the bone marrow to produce different types of blood cells.

Many growth factors can be made in the laboratory (synthesised) and are available for use in people with blood disorders. For example, granulocyte-colony stimulating factor (G-CSF) stimulates the production of white cells called neutrophils, while erythropoietin (EPO) stimulates the production of red cells. Unfortunately, drugs to stimulate platelet production have been less successful, but research is continuing in this area.

Blood

Blood consists of blood cells and plasma. Plasma is the straw coloured fluid part of the blood, which blood cells use to travel around your body.



Blood cells

RED CELLS AND HAEMOGLOBIN

Red cells contain haemoglobin (Hb), which transports oxygen from the lungs to all parts of the body. Haemoglobin also carries carbon dioxide to the lungs where it can be breathed out.

The normal haemoglobin range for a man is between 130 - 170 g/L

The normal haemoglobin range for a woman is between 120 - 160 g/L

Red cells are by far the most numerous blood cell and the proportion of the blood that is occupied by red cells is called the haematocrit. A low haematocrit suggests that the number of red cells in the blood is lower than normal.

The normal range of the haematocrit for a man is between 40 - 52%

The normal range of the haematocrit for a woman is between 36 - 46%

Anaemia is a condition caused by a reduction in the number of red cells, which in turn results in a low haemoglobin. Measuring either the haematocrit or the haemoglobin will provide information regarding the degree of anaemia.

If you are anaemic you will feel run down and weak. You may be pale and short of breath or you may tire easily because your body is not getting enough oxygen. In this situation a red cell transfusion may be given to restore the red cell numbers and therefore the haemoglobin to normal levels.

WHITE CELLS

White cells, also known as leucocytes, fight infection. There are different types of white cells which fight infection together and in different ways.

Granulocytes:

Neutrophils kill bacteria and fungi

Eosinophils kill parasites

Basophils work with neutrophils to fight infection

Agranulocytes:

T-lymphocytes kill viruses, parasites and cancer cells; produce cytokines

B-lymphocytes make antibodies which target microorganisms

Monocytes work with neutrophils and lymphocytes to fight infection; they also help with antibody production and act as scavengers to remove dead tissue. These cells are known as monocytes when they are found in the blood and macrophages when they migrate into body tissues to help fight infection

If your white cell count drops below normal you are at risk of infection.

The normal adult white cell count is between $4.0 - 11.0 \times 10^9/L$

Neutropenia is the term given to describe a lower than normal neutrophil count. If you have a neutrophil count of less than 1.0 ($1.0 \times 10^9/L$) you are considered to be neutropenic and at risk of developing frequent and sometimes severe infections.

The normal adult neutrophil count is between $2.0 - 7.5 \times 10^9/L$

PLATELETS

Platelets are disc-shaped fragments that circulate in the blood and play an important role in clot formation. They help to prevent bleeding. If a blood vessel is damaged (for example, by a cut) the platelets gather at the site of injury, stick together and form a plug to help stop the bleeding.

The normal adult platelet count is between $150 - 400 \times 10^9/L$

Thrombocytopenia is the term used to describe a reduction in the normal platelet count. If your platelet count is low, you are at higher risk of bleeding, and tend to bruise easily. Platelet transfusions are sometimes given to bring the platelet count back to a higher level. In certain situations, especially when patients are receiving some chemotherapy treatments, platelets may be transfused if the blood level falls below $10 \times 10^9/L$.

The normal blood counts provided here may differ slightly from the ones used at your treatment centre. You can ask for a copy of your blood results, which should include the normal values for each blood type.

WHAT IS MYELOMA?

Myeloma, also known as multiple myeloma or plasma cell myeloma, is a cancer of plasma cells (mature B-lymphocytes) that usually arises in the bone marrow. Myeloma develops when plasma cells undergo a cancerous (or malignant) change and become myeloma cells. These myeloma cells multiply without any proper order, forming 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 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.

Under normal conditions, plasma cells produce immunoglobulins (antibodies) that help protect the body from infection and disease. Myeloma cells produce an abnormal type of immunoglobulin called a paraprotein, (also known as monoclonal immunoglobulin, myeloma protein, or simply M protein). This can be detected in the blood.

As myeloma cells multiply, they crowd the bone marrow and prevent it from making normal numbers of red cells, white cells and platelets. Myeloma cells can also interfere with the production of normal antibodies. This can make people with myeloma anaemic, more susceptible to infections and to bleeding and bruising more easily. Excess immunoglobulin fragments can also cause damage to the kidneys.

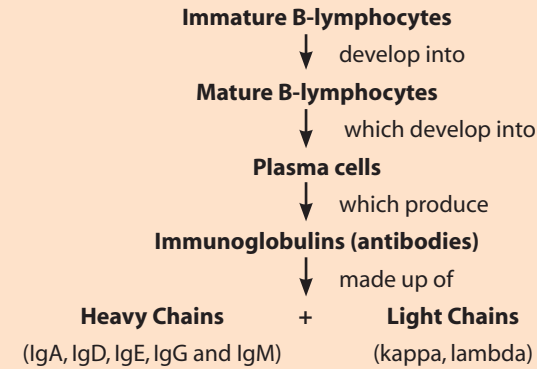
The myeloma type is described by which type of excess immunoglobulin is produced. Each immunoglobulin is made up of a combination of two 'heavy' chains and two 'light' chains. If excess heavy chains are produced it is termed heavy chain myeloma, and if excess light chains are produced it is called light chain myeloma.

What are plasma cells and immunoglobulins?

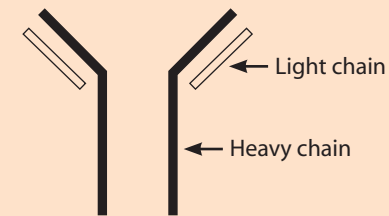
(Imm-you-no-glob-you-lins)

Plasma cells are a type of blood cell that develops from mature B-lymphocytes in the bone marrow. They play an important role in protecting the body against infection and disease by producing proteins called immunoglobulins (Ig), also known as antibodies.

Immunoglobulins (Ig) are produced by plasma cells in response to bacteria, viruses and other harmful substances which enter the body. Once released into the blood stream, they circulate and attach to the target for which they were originally made (the target antigen). This makes it easier for other white blood cells to destroy harmful organisms and other unwanted substances and remove them from the body.



Immunoglobulins are Y-shaped molecules made up of two heavy chains and two light chains (see below). There are five main families of immunoglobulins which are named after the heavy chains that form an important part of their structure. These are; IgA, IgD, IgE, IgG and IgM. There are two classes of light chains: kappa (κ) and lambda (λ).



HOW COMMON IS MYELOMA AND WHO GETS IT?

The majority of people diagnosed with myeloma are over the age of 50. Myeloma is rare under the age of 40 and it has not been reported in children or adolescents. It is more common in men than women.

Myeloma is a relatively rare disease, accounting for approximately 1% of all cancers and 10% of all blood and bone marrow cancers. Each year in New Zealand approximately 300 people are diagnosed with myeloma.

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.

We do know that it is not contagious; you cannot 'catch' myeloma by being in contact with someone who has it. We also know that in most cases people who are diagnosed with myeloma have no family history of the disease.

Like other types of blood cancers, myeloma is thought to arise from an acquired mutation (or change) in one or more of the genes that normally control the growth and development of blood cells. This change results in abnormal growth. The original mutation is preserved when the first affected cell divides and produces a 'clone' - that is a group of identical cells, all with the same defect, arising from a single cell. Acquired mutations in genes are gained during a person's lifetime and are not passed from one generation to the next (inherited).

Why these mutations occur in the first place remains unknown but there are likely to be a number of factors involved. There are certain factors that may put some people at a 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 unknown.

WHAT ARE THE SYMPTOMS OF MYELOMA?

The symptoms of myeloma 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.

Anaemia

Anaemia is a reduction in the number of red blood cells circulating in the blood. Haemoglobin is the red pigment in the red blood cells that makes blood red. A low haemoglobin level in the blood can cause symptoms of anaemia. These include a lack of energy, persistent tiredness and fatigue, weakness, dizziness, palpitations or feeling unusually short of breath when physically active. In addition, people with anaemia often have a pale complexion.

Bleeding or bruising

A low platelet count can cause bruising for no apparent reason. Some people experience frequent or severe nose bleeds, bleeding gums or excessive or prolonged bleeding following minor cuts or injury.

Excessive bleeding and bruising in myeloma can also be due to interference of the paraproteins with the blood clotting factors or very high levels of paraprotein causing hyperviscosity (increased thickness) of the blood.

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 the gradual erosion of bone caused by substances secreted by myeloma cells. Over time bones can become weakened and thinned (osteoporosis) and holes (lytic lesions) may develop increasing the risk of fracture (breaking of bone). Occasionally people with myeloma can experience bone fractures with very minor injuries or even without any injury at all.

Elevated blood calcium level

When bone tissue is damaged, calcium is released from the bone into the blood stream. An excess of calcium in the blood is called hypercalcaemia. If you have a higher than normal level of calcium in your blood you may feel nauseated, constipated, tired, thirsty or even confused.

Infections

People with myeloma are at risk of developing frequent or repeated infections. This is because their bone marrow may be unable to produce adequate numbers of white cells and because they may be unable to produce adequate amounts of normal antibodies. Common sites of infection include chest, urinary tract and skin.

Some of the symptoms described above may also be seen in other illnesses, including viral infections, people with these symptoms often don't have myeloma. However, it is important to see your doctor if you have any unusual symptoms, or symptoms that don't go away so that you can be examined and treated properly.

WHICH DOCTOR?

If your GP suspects that you might have myeloma you will be referred on to other specialist doctors for further tests and treatment. These may include the following:

Haematologist a doctor who specialises in the care of people with diseases of the blood, bone marrow and immune system.

Oncologist a doctor who specialises in the treatment of cancer. A medical oncologist specialises in chemotherapy. A radiation oncologist specialises in radiotherapy and a surgical oncologist specialises in surgery.



HOW IS MYELOMA DIAGNOSED?

Myeloma is diagnosed using information gathered from a number of different tests. These include a physical examination, blood and urine tests, bone marrow biopsy, x-rays and other specialised imaging tests. These tests provide important information about the extent of your myeloma, its likely prognosis and the best way to treat it. They also provide a baseline set of results regarding your disease and general health, and can be compared with later results to assess your response to treatment.

Blood tests

Some tests provide information on your general health and how well your kidneys, liver and other vital organs are functioning. Other tests are specific to measuring your myeloma. They require a sample of your blood, which is usually taken from a small vein in your arm or hand.

- Full blood count (FBC) or complete blood count (CBC) is a simple blood test that measures the number of red cells, white cells and platelets in circulation and notes their size and shape. This helps to assess how well the bone marrow is functioning and whether or not normal blood cells are being affected by myeloma.
- Creatinine is a chemical normally excreted in urine and it is measured to assess how well your kidneys are functioning. High levels of creatinine indicate that the kidneys are not functioning as well as they should be, and this may be due to myeloma.
- High levels of blood calcium usually indicate that bone tissue is being damaged.
- Measuring the blood level of beta-2 microglobulin, a special protein found in myeloma, provides a useful indicator of the likely course of your disease (prognosis). High levels of beta-2 microglobulin indicate the presence of a large amount of myeloma cells, and/or the presence of kidney damage.
- The levels of other proteins like lactate dehydrogenase (LDH) and C-reactive protein (CRP) are also measured to assess the amount of myeloma in the body and how fast it is growing.

- Serum protein electrophoresis is carried out to measure the amount and type of paraprotein in your blood.
- Immunoglobulin (Ig) levels measure the total amount of immunoglobulins of various classes.
- Serum free light chains (SFLC) measures the excess level of immunoglobulin light chains.

Urine tests

Parts of the paraprotein known as 'light chains' or Bence-Jones protein may be filtered out of the blood in the kidneys and passed in the urine. Urine electrophoresis is a test used to measure the amount of protein in the urine. You may be asked to collect all of the urine you pass in a 24-hour period so that the amount of light chains you are passing during this period can be measured. This simply involves collecting all of the urine you pass during this period into a large container and returning it to the hospital the following day. Your doctor or nurse will supply you with a suitable container for this collection.

Bone marrow examination

If the results of your blood tests suggest that you might have myeloma, a small sample of bone marrow will need to be examined to help confirm the diagnosis and to provide important additional information about your disease. A bone marrow examination, or biopsy, involves taking a sample of bone marrow, usually from the back of the iliac crest (hip bone) or from the sternum (breast bone) and sending it to the laboratory for examination under the microscope.

Under normal conditions plasma cells make up less than 5% of all the cells in the bone marrow. In myeloma the number is over 10% and can be as high as 90%. As well as assessment of the number of plasma cells, the bone marrow may also be examined for changes in the chromosomes and genes of the myeloma cells. Such changes may be predictive factors for response to treatment and likely prognosis.

Following treatment, you may need another bone marrow examination to assess how well your disease is responding.

The bone marrow biopsy may be done in hospital or outpatient clinic under local anaesthesia or, in selected cases, under sedation. A pain-killer is given beforehand and the skin is numbed using a local anaesthetic; this is given as an injection under the skin. The injection takes a minute or two, and you should feel only a mild stinging sensation.

After allowing time for the local anaesthetic to work, a long thin needle is inserted through the skin and outer layer of bone into the bone marrow cavity. A syringe is attached to the end of the needle and a small sample of bone marrow blood is drawn out - this is called a 'bone marrow aspirate'. Then a slightly larger needle is used to obtain a small core of bone marrow which will provide more detailed information about the structure of the bone marrow and bone - this is known as a 'bone marrow trephine'.

If a sedative is used you might feel a bit drowsy afterwards, and it is advised that you take a family member or friend along who can drive you home. A small dressing or plaster over the biopsy site can be removed the next day and you should keep the area dry for 24 hours. There may be some mild bruising or discomfort, which usually is managed effectively by paracetamol. More serious complications such as bleeding or infection are very rare.

Cytogenetic, immunophenotyping and molecular genetic tests

During a diagnosis of myeloma, blood and bone marrow cells may be examined further in some cases (such as clinical trials) using special laboratory tests. These include immunophenotyping, cytogenetic and molecular tests. These tests provide more information about the exact type of disease, and the likely course of the disease.

Immunophenotyping ('im-u-no-feen-o-typing')

This test detects special markers, called antigens, found on the surface of blast cells to determine the exact subtype of myeloma you have.

Cytogenetic ('cy-to-gen-etic') tests

Cytogenetic tests provide information about the genetic make-up of the malignant cells, in other words, the structure and number of chromosomes present. Chromosomes are the structures that carry genes. Genes are collections of DNA, our body's blueprint for life. Certain cytogenetic changes, such as missing, extra or abnormal chromosomes help to confirm the specific subtype of myeloma you have, and its likely course.

Molecular tests

Molecular genetic tests (for example polymerase chain reaction or PCR tests and fluorescent in situ hybridization or FISH tests) are more sophisticated genetic tests that may give further useful information about the disease in some circumstances.

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.

- Chest x-ray to detect a chest infection or any other abnormalities
- Electrocardiogram (ECG) and echocardiogram to see how well your heart is working
- A full body x-ray or skeletal survey will 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.
- Occasionally a CT (computer assisted tomography) scan or ultrasound scan may be used to see if the myeloma cells have spread to areas outside the blood and bone marrow.

- A more specialised imaging test like an MRI (magnetic resonance imaging) may also be used 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. It is similar to having a CT (computerised axial tomography) scan.
- PET (positron emission tomography) scans use a specialised type of intravenous contrast and CT scan technique, but this is rarely required with myeloma.

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



STAGING

The stage of your myeloma refers to the extent of the disease in your body and is one of the factors used to predict the course of your disease, and the likely effect of potential treatments.

In recent years the International Myeloma Working Group (IMWG) developed the International Staging System (ISS) for myeloma based on the level of beta-2 microglobulin and albumin in the blood. There are three possible stages of myeloma, beginning with Stage I referring to early disease, through to Stage III referring to more advanced disease where a large amount of myeloma is detected in the body.

IMWG staging system for myeloma

Stage I

- Low levels of beta-2 microglobulin (<3.5 mg/L)
- Normal blood albumin level (> 35 g/L)

Stage II

- Moderate level of beta-2 microglobulin (3.5 mg/L to 5.5 mg/L)
- Reduced blood albumin level (< 35 g/L)

Stage III

- High level of beta-2 microglobulin (> 5.5 mg/L)

Besides the staging system above, the outcome of the disease and, sometimes, its treatment is also determined by the presence or absence of chromosome abnormalities in the myeloma cells. Certain cytogenetic abnormalities indicate what is termed "high risk" types of myeloma.

PROGNOSIS

A prognosis is an estimate of the likely course of a disease and the chances of curing or controlling it for a given time.

Your doctor is the best person to give you an accurate prognosis prediction, as he or she has the most information about your disease, treatments available and your general health to make this assessment.

Although there is currently no cure for myeloma, in most cases the progression of the disease can be halted for a period of time, and, unless serious irreversible complications of the disease have already occurred, you should be able to return to your normal activities during periods of remission. The development of new and improved treatments means that the outlook for people with myeloma is improving.

Commonly used prognostic terms

In myeloma, different levels of response (or remission) to treatment are recognised and the quality of response has been shown to indicate future prognosis.

Complete remission (CR) - The treatment has been so successful that paraprotein or excess light chains can no longer be detected in blood or urine using standard tests, and that the percentage of plasma cells in the bone marrow has returned to normal.

Very good partial response (VGPR) & partial response (PR) - Indicate a good, but lesser response to treatment than CR, with persistent signs of myeloma in various laboratory 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 any better with treatment. The length of time that the plateau (or remission) lasts varies from person to person and eventually the myeloma will reappear. Because of this, regular check ups continue in this phase so relapse is detected early and further treatment started before serious complications develop.

Relapse - The myeloma has reappeared, usually shown by a reappearance or increase in the level of the paraprotein or new bone problems.

Resistant/refractory disease - The myeloma is not responding to treatment.

Disease progression/relapse - The myeloma is getting worse on or off treatment.

TYPES OF MYELOMA

Myeloma is classified according to how the disease has affected the plasma cells in the bone marrow and blood. In the majority of cases myeloma is found in multiple bone marrow sites at diagnosis, which is why the disease is sometimes called multiple myeloma.

Myeloma can also be classified according to the type of immunoglobulin being secreted by the myeloma cells, and how it affects the body.

Asymptomatic (also known as smouldering or indolent) myeloma is an early phase of myeloma, there are no symptoms but a bone marrow biopsy shows definite evidence of myeloma. People diagnosed with smouldering myeloma don't need treatment straight away but they do need to be monitored reasonably closely. Treatment is given at a later stage when the disease progresses, often after some months or years.

Symptomatic myeloma requires treatment because the disease has begun to cause symptoms or other problems. The complications that define symptomatic myeloma requiring treatment are summarized by the acronym "CRAB", shown in the box below.

The effect of myeloma on your body can be summarised by the acronym CRAB:

C – hypercalcaemia

R – renal impairment

A – anaemia, or bone marrow failure

B – bone disease

Heavy chain myeloma (IgA, IgD, IgE, IgG or, IgM) is measured by immunoglobulin levels. The most common type of myeloma is IgG myeloma representing between 50 – 60% of all cases. IgA myeloma represents about 20% of all cases.

Light chain myeloma (kappa or lambda) is measured by serum free light chains. Also known as Bence-Jones myeloma, where the immunoglobulin light chains only are produced, represents about 20% of cases.

Non-secretory myeloma is a rare type of myeloma where people do not secrete paraproteins in their blood or urine.

Related conditions

The following are conditions that are related to myeloma, as they also involve abnormal growth of plasma cells. Their treatment can be similar to that for myeloma, when treatment is required.

AMYLOIDOSIS

Amyloidosis is a condition in which plasma cells produce an abnormal protein called amyloid. This abnormal protein is broken down very slowly by the body, resulting in deposits of amyloid as it accumulates in the tissues and organs of the body, disrupting their function. Amyloid deposits can build up almost anywhere in the body.

Each patient has a different pattern of amyloid deposition, and organs such as the heart and kidneys are commonly affected.

MONOCLONAL GAMMOPATHY OF UNDETERMINED SIGNIFICANCE (MGUS)

MGUS is a non-cancerous condition related to myeloma. It also involves the production of paraprotein by plasma cells. MGUS doesn't cause any symptoms and it is usually picked up during a routine blood or urine test. People diagnosed with MGUS don't require any treatment apart from regular follow-up by their doctor, usually on a yearly basis to have their protein levels checked. Over time a small number of people with MGUS may go on to develop myeloma. For this reason, MGUS is often referred to as a "pre-malignant" condition but a change from MGUS to myeloma only occurs in approximately 1% of people with MGUS each year.

PLASMACYTOMA

A mass of myeloma cells is called a plasmacytoma and these can form in the bone, skin, muscle or elsewhere in the body. If only found in one site the condition is described as a solitary myeloma or solitary plasmacytoma. A mass of myeloma cells outside the bone is called an extra medullary or soft tissue plasmacytoma. Plasmacytomas can sometimes be successfully treated using radiotherapy alone but careful follow up is required since people with solitary plasmacytoma often go on to develop multiple myeloma.

PLASMA CELL LEUKAEMIA

Rarely, plasma cells can spill out of the bone marrow and are found in the blood in large numbers. This condition is called plasma cell leukaemia. It can occur occasionally when the disease is first picked up and it also occurs in people who have been treated for myeloma for some time. It is generally more difficult to treat than myeloma.

WALDENSTROMS MACROGLOBULINAEMIA (WM)

WM is a type of cancer that has features in common with myeloma and some types of lymphoma. It is also called lymphoplasmacytic lymphoma. The condition derives its name from a Swedish doctor called Waldenström, who described it in 1944.

WM affects a specific type of white blood cell called the B-lymphocyte. Some B-lymphocytes develop into plasma cells, which produce antibodies when foreign substances such as bacteria or viruses are detected in the body.

However, in WM, B-lymphocytes do not develop into mature plasma cells, but into a type of cancer cell known as a 'lymphoplasmacytoid' cell. These abnormal cells grow more quickly than normal cells would and can invade and build up in the bone marrow, spleen, and lymph glands. These cells also produce and release excessive amounts of the IgM protein into the blood. This disease is not usually associated with bone disease, kidney problems or high calcium levels in the same way that myeloma is.

TREATMENT OF MYELOMA

The treatment chosen for your disease depends on several factors including the stage of your myeloma, your general health and your age.

Information gathered from hundreds of other people around the world who have had the same disease helps to guide the doctor in recommending the best treatment for you.

Remember however that no two people are the same. In helping you to make the best treatment decision, your doctor will consider all the information available including the details of your particular situation.

Myeloma is generally regarded as a slow-growing disease. Some people with myeloma, particularly in the early stages of disease (smouldering myeloma), have few if any symptoms and do not necessarily need to be treated urgently. In these cases the doctor may recommend regular check-ups to carefully monitor your health.

When you do need treatment it may be used to control the growth of myeloma, to prolong a remission for as long as possible following treatment, and / or to prevent and reduce symptoms of this disease.

The aim here is to progressively reduce the amount of myeloma to as low a level as possible. This is usually indicated by a progressive reduction in the protein level. When there is no further reduction, the myeloma is said to have reached a 'plateau' and the person is regarded as being in remission or in the plateau phase of their disease.

Treatment for myeloma may involve the use of:

- Steroids
- Chemotherapy (intravenous or tablet form)
- Radiotherapy
- Stem cell transplant
- Novel therapies
 - Thalidomide/lenalidomide
 - Bortezomib
- Bone Support
 - Bisphosphonates

Standard therapy

Standard therapy refers to a type of treatment which is commonly used in particular types and stages of disease. It has been tried and tested (in clinical trials) and has proven to be safe and effective in a given situation.

Clinical trials

Your specialist doctor may ask you to consider taking part in a clinical trial (also called a research study). Clinical trials test new treatments, or existing treatments given in new ways to see if they work better. Clinical trials are important because they provide vital information about how to improve treatment by achieving better results with fewer side effects.

Participation in a trial may also involve giving blood or bone marrow samples in order to contribute to a better understanding of myeloma. Clinical trials often give people access to new therapies not yet funded by governments.

Taking part in a clinical trial is entirely voluntary and you are under no obligation to participate. If you are considering taking part in a clinical trial, make sure that you understand the reasons for the trial and what it involves for you. You should always take time to consider all the implications of a trial and discuss this thoroughly with your specialist doctor and other support people before giving your informed consent. Your specialist doctor can guide you in making the best decision for you.

Informed consent

Giving your informed consent means that you understand and accept the risks and benefits of a proposed procedure or treatment. It means that you feel you have adequate information to make such a decision.

Your informed consent is also required if you agree to take part in a clinical trial, or if information is being collected about you or some aspect of your care (data collection).

If you have any doubts or questions regarding any proposed procedure or treatment, please do not hesitate to talk to the doctor or nurse again.

Steroids

Cortico-steroids are hormones which are produced naturally by the body in the adrenal glands. Man-made steroids such as prednisone and dexamethasone are very important in the treatment of myeloma and are commonly used alone or in combination with chemotherapy in the treatment of myeloma.

Chemotherapy

Chemotherapy literally means therapy with chemicals. Many chemotherapy drugs are also called cytotoxics (cell toxic) because they kill cells, especially ones that multiply quickly like cancer cells.

Chemotherapy for myeloma often involves a combination of drugs (combination chemotherapy). These drugs act together and in different ways to destroy the myeloma cells. Each drug in a combination of drugs targets the cancer from a different angle, and also has different side effects. Therefore a combination of drugs is often more effective than a single drug in controlling your disease and the side effects are kept to a minimum.

Chemotherapy is usually given in several cycles (or courses) with a rest period of a few weeks between cycles. This is to allow the body to recover from the side effects of chemotherapy.

How is chemotherapy given?

There are many ways of giving chemotherapy. It is usually given through a vein in your arm or hand (intravenously or IV), or in tablet form (orally).

In most cases you don't need to be admitted for chemotherapy, which is usually given in the outpatients' department of the hospital. Sometimes, depending on the type of chemotherapy being given and your general health, you may need to be admitted to the ward for a short while.

Commonly used chemotherapy drugs to treat myeloma include:

- Melphalan
- Cyclophosphamide

The names of the different chemotherapy regimens used are commonly derived from the first letters of each of the drugs given. Many drugs have two names, one of which is the chemical name (e.g. bortezomib) while the other name is the trade name given the drug by the pharmaceutical company that manufactures it (e.g. Velcade). Some examples of combinations of chemotherapy drugs used to treat myeloma are listed below.

VMP	Velcade, Melphalan, and Prednisone
CyBorDex	Cyclophosphamide, Bortezomab and Dexamethasone
CTD	Cyclophosphamide, Thalidomide and Dexamethasone
MPT	Melphalan, Prednisone and Thalidomide
Cy/Dex	Cyclophosphamide and Dexamethasone

Radiotherapy

Radiotherapy (also known as radiation therapy) uses high energy x-rays to kill cancer cells and shrink tumours. Radiotherapy is regarded as local therapy because it only destroys cancer cells in the treated area. The radiation field is the area of the body which is being treated. Common radiation fields in myeloma include the spine, ribs, pelvis and shoulder areas.

What is involved in radiotherapy?

Before you start radiotherapy, a radiation oncologist (a doctor who specialises in treating people with radiotherapy) will carefully calculate the correct dose of radiation therapy for you. The areas of your body that need to be treated will be marked with tiny ink dots on your skin using a special indelible pen.

Radiotherapy is usually given in small doses (also known as fractions) in the radiotherapy department of the hospital. Myeloma is generally quite sensitive to radiotherapy and usually only a single fraction is required. Rarely several fractions given over consecutive days are also used. You do not need to be admitted to hospital for this treatment, but if you live far away you may need to organise some accommodation for this time. The social worker or nurses can assist you with this.

When you are having radiotherapy you usually lie on a table underneath the radiotherapy machine which delivers the planned dose of radiation. Important structures such as your heart and lungs are shielded as much as possible to ensure that they are not affected by the treatment given. Radiotherapy is painless - in fact you do not see or feel anything during the actual treatment. You will need to stay perfectly still for a few minutes while the treatment is taking place. You might like to bring along some music to help you relax.

Stem cell transplant (peripheral blood stem cell or bone marrow transplant)

AUTOLOGOUS

An autologous transplant uses bone marrow or blood stem cells from yourself. They are collected from your blood after mobilisation chemotherapy and kept frozen in preservative. Your stem cells are thawed and returned via an intravenous infusion some weeks after you receive high dose chemotherapy which empties your marrow of stem cells.

ALLOGENEIC

An allogeneic transplant uses donated bone marrow or blood stem cells from another person. This treatment carries significant risks and is generally only considered for selected younger patients for whom a suitably matched donor can be found. In older patients, the considerable risks and problems caused by this form of treatment make it an unacceptable option.

A stem cell transplant is usually only discussed with you if your doctor feels that it will benefit you.

There are separate booklets about autologous and allogeneic transplants available from Leukaemia & Blood Cancer New Zealand.

Novel therapies

THALIDOMIDE/LENALIDAMIDE

Thalidomide was a drug developed in the 1950's. It was used as a sedative and to treat nausea and vomiting associated with early pregnancy. It caused severe birth defects in the babies of the mothers who had taken it and, as a result, the use of thalidomide was banned for a long time. Because of this, its use is now governed by very strict regulations. Your doctor will explain this process with you.

In the late 1990's thalidomide was found to be an effective anti-myeloma drug and over the last 10 years has become part of routine treatment for patients with this disease. Thalidomide works in a number of ways to interfere with the growth and survival of myeloma cells and is more effective when combined with steroids and/or chemotherapy.

While thalidomide is not strictly speaking a chemotherapy drug, it does have side effects which have to be carefully monitored. These include sleepiness, constipation, increased tendency to form blood clots and nerve damage leading to numbness and tingling, particularly in the fingers and toes. It is important to tell your doctor if you experience symptoms as the dose of thalidomide may need to be reduced or stopped.

Lenalidomide is a modified form of thalidomide. It has been trialled mostly in patients with relapsed myeloma and is effective for many people when the usual chemotherapy drugs, or even thalidomide, are no longer effective. The common side effects of lenalidomide include a reduction in blood counts, cramps, and blood clots. As lenalidomide is related to thalidomide, it is also thought to cause birth defects, and so is not appropriate for pregnant women.

Both thalidomide and lenalidomide are oral tablets.

BORTEZOMIB (VELCADE®)

Bortezomib is the first of a new class of anti-myeloma drugs called proteasome inhibitors. Following successful trials in relapsed myeloma they are now being used more often in first-line treatment.

Bortezomib has a number of side effects, the most common being nausea, vomiting, diarrhoea, low platelet count and nerve damage. It is given as an intravenous infusion.

Supportive therapies

Bisphosphonates are drugs used to treat and prevent osteoporosis. They work by preventing bone destruction which helps reduce bone pain, the risk of bone fractures and hypercalcaemia (excess calcium in your blood).

A very rare, but serious, side effect of bisphosphonate therapy is damage to the jaw bone (osteonecrosis of the jaw). To reduce the possibility of this side effect you should pay careful attention to your dental hygiene. Your doctor may recommend a dental check-up prior to beginning therapy and you should inform your dentist if you have ever had bisphosphonates. Osteonecrosis of the jaw is also associated with dental work such as teeth removal. Contact and inform your treating doctor before having any dental work.

HOW DO I KNOW IF TREATMENT IS WORKING?

There is usually a strong relationship between the paraprotein level in the blood and the amount of myeloma in the body. Changes in these levels can indicate response to treatment or disease progression. It is important to realise that very small changes may not mean anything, and the results of other tests such as a blood count, kidney function tests and blood calcium levels will also be taken into consideration. Occasionally, another bone marrow biopsy and more x-rays of the bones will be needed to get a better picture of your condition.

Palliative care

When the decision is made not to continue with anti-cancer treatment (e.g chemotherapy) for your myeloma, there are still many other options which can be used to support your quality of life and comfort for some time. Palliative care is aimed at relieving symptoms and/or pain you might be experiencing as a result of your disease, or treatment, rather than trying to control it. Palliative care does not mean the withdrawal of all treatment and you will continue to receive supportive treatments (e.g transfusions, antibiotics, pain relief), as required.

COMMON SIDE EFFECTS

Side effects of steroids

The side effects of steroids depend on duration and dose. Common side effects include increased appetite, feeling more restless than usual, and difficulty sleeping.

Steroids can also cause a rise in blood sugar. Diabetics need to more closely monitor their blood glucose and may need to increase their diabetes medication while on steroids. Some people who are not normally diabetic also experience raised blood sugars and need to have diabetic treatment while undergoing steroid treatment. Most of the side effects of steroids are temporary and should pass once treatment finishes.

Long term use may cause some other effects such as fluid retention and an increased susceptibility to infections. Aching joints such as the hips and knees have also been reported. Tell your doctor or nurses about any side effects you may experience as they can be managed.

Side effects of chemotherapy

Chemotherapy kills cells that multiply quickly, such as cancer cells. It also causes damage to fast-growing normal cells such as hair, mouth, gut and bone marrow. The side effects of chemotherapy occur as a result of this damage.

The type of side effects and their severity vary from person to person depending on the type of chemotherapy used and how an individual responds to it. There is no doubt that side effects can be very unpleasant at times but it's good to remember that most of them are temporary and reversible. It is important that you report any side effects you are experiencing to your nurse or doctor because many of them can be treated successfully, reducing any unnecessary discomfort for you.

EFFECTS ON THE BONE MARROW

As mentioned previously, all of your white cells, platelets and red cells are made in your bone marrow. Chemotherapy temporarily affects the bone marrow's ability to produce adequate numbers of these cells. As a result, your blood count (the number of white cells, platelets and red cells circulating in your blood) will generally fall within a couple of weeks of treatment. The length of time it takes for your bone marrow and blood counts to recover mainly depends on the type of chemotherapy given.

The point at which your white cell count is at its lowest is called the nadir. This is usually expected 10 to 14 days after having your chemotherapy, during which time you will be at a higher risk of developing an infection. At this stage you may be neutropenic, which means that your neutrophil count is low. Neutrophils are important white blood cells that help us to fight infection. While your white blood cell count is low you should take sensible precautions to help prevent infection.

These include avoiding crowds, avoiding people with infections which are contagious (for example colds, flu, chicken pox) and only eating food which has been properly prepared and cooked.

Your doctor and nurse will advise you on how to reduce your risk of infection while your white cell count is low.

If you do develop an infection you may experience a fever which may or may not be accompanied by an episode of shivering, where you shake uncontrollably. Infections while you are neutropenic can be quite serious and need to be treated with antibiotics as soon as possible.

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

- a temperature of 38°C or over and / or an episode of shivering
- bleeding or bruising, for example blood in your urine, faeces, sputum, bleeding gums or a persistent nose bleed
- nausea or vomiting that prevents you from eating or drinking or taking your normal medications
- diarrhoea, stomach cramps or constipation
- coughing or shortness of breath
- the presence of a new rash, reddening of the skin, itching
- a persistent headache
- a new pain or soreness anywhere
- if you cut or otherwise injure yourself
- if you notice pain, swelling, redness or pus anywhere on your body

Sometimes your doctor may decide to use a growth factor such as G-CSF to help the recovery of your neutrophil count. This drug works by stimulating the bone marrow to increase the production of neutrophils. G-CSF is given as an injection under the skin (subcutaneous). This is quite a simple procedure and the nurse will teach you or a family member (or friend) to do this at home. Major side effects are uncommon, but occasionally aching bones may occur.

Your platelet count may also be affected and you may become thrombocytopenic (a reduction in the number of platelets circulating in the blood). When your platelet count is very low you can bruise and bleed more easily. During this time it is helpful to avoid sharp objects in your mouth such as potato chips as these can cut your gums. Using a soft tooth brush also helps to protect your gums. In some cases a transfusion of platelets is given to reduce the risk of bleeding until the platelet count recovers.

If your red blood cell count and haemoglobin levels drop you may become anaemic. When you are anaemic you feel more tired and lethargic than usual. If your haemoglobin level is very low, your doctor may prescribe a blood transfusion.

NAUSEA AND VOMITING

Nausea and vomiting are often associated with chemotherapy and some forms of radiotherapy. Due to significant improvements in anti-sickness (antiemetic) drugs, nausea and vomiting are now generally very well controlled. You will be given anti-sickness drugs before and for a few days after your chemotherapy treatment. Be sure to tell the nurses and doctors if you think that the antiemetics are not working for you and you still feel sick. There are many different types of antiemetics that can be tried. A mild sedative may also be used to help stop you feeling sick. This will help you to relax but it might make you a little sleepy.

Some people find that eating smaller meals more frequently during the day, rather than a few large meals, helps to reduce nausea and vomiting. Many find that eating cool or cold food is more palatable, for example jelly or custard. Drinking ginger ale or soda water and eating dry toast may also help if you are feeling sick. Getting plenty of fresh air, avoiding strong or offensive smells and taking the prescribed anti-sickness drugs as recommended by the nurse and doctor should also help.

CHANGES IN TASTE AND SMELL

Both chemotherapy and radiation therapy can cause changes to your sense of taste and smell. This is usually temporary but in some cases it lasts up to several months. During this time you may not be able to enjoy the foods and drinks that you used to love and this can be very disappointing. Some people find that adding a little more sugar to sweet foods and salt to savoury foods can help.

MUCOSITIS

Mucositis, or inflammation of the lining of the mouth and throat, is a common and uncomfortable side effect of chemotherapy and some forms of radiotherapy. It usually starts about a week after the treatment has finished and goes away once your blood count recovers, usually a couple of weeks later. During this time your mouth and throat could get quite sore. Soluble paracetamol and other topical drugs (ones which can be applied to the sore area) can help. If the pain becomes more severe, stronger pain relief might be needed.

It is important to keep your mouth as clean as possible while you are having treatment to help prevent infection. Your nurse will show you how to care for your mouth during this time. This may include using a soft toothbrush and mild toothpaste. Avoid commercial mouthwashes, like the ones you can buy at the supermarket. These are often too strong, or they may contain alcohol which will hurt your mouth. It is particularly important to do your mouth care regularly while your mouth is sore.

BOWEL CHANGES

Chemotherapy and radiotherapy can cause some damage to the lining of your bowel wall. This can lead to cramping, wind, abdominal swelling and diarrhoea. Be sure to tell the nurses and doctors if you experience any of these symptoms. If you develop diarrhoea, a specimen may be required from you to ensure that the diarrhoea is not the result of an infection. After this you may be given some medication to help stop the diarrhoea and/or the discomfort you may be feeling.

It is also important to tell the nurse or doctor if you are constipated or if you are feeling any discomfort or tenderness around your bottom (anus) when you are trying to move your bowels. You may need a gentle laxative to help soften your stool.

HAIR LOSS

For most of us, the thought of losing our hair is very frightening. Hair loss is unfortunately a very common side effect of chemotherapy and some forms of radiotherapy. It is, however, usually only temporary. The hair starts to fall out within a couple of weeks of treatment and tends to grow back three to six months later. In the meantime there are lots of things that you can do to make yourself feel more comfortable.

Avoiding the use of heat or chemicals and only using a soft hairbrush and a mild baby shampoo can help reduce the itchiness and scalp tenderness which can occur while you are losing your hair. When drying your hair, pat it gently rather than rubbing it with a towel. Some people find it better to simply have a short hair cut when they notice that their hair is starting to fall out.



You need to avoid direct sunlight on your exposed head (wear a hat) because chemotherapy and radiotherapy makes your skin even more vulnerable to the damaging effects of the sun (i.e. sunburn and skin cancers). Remember that without your hair, your head can get quite cold, so a beanie might be useful, especially if you are in an air-conditioned environment like a hospital. Hair can also be lost from your eyebrows, eyelashes, arms and legs.

Look Good, Feel Better is a free community service that runs programs on how to manage the appearance-related side effects of cancer treatments. The beauty therapists who run these programs give useful advice and demonstrations on how to manage hair loss including the use of hats, wigs, scarves or turbans. You might like to find out more or register for a workshop, call 0800 865 432.

FATIGUE

Most people experience some degree of tiredness in the days and weeks following chemotherapy and radiotherapy. Having plenty of rest and a little light exercise each day may help to make you feel better during this time. Getting out into the fresh air and doing some gentle exercise is important for your general feeling of wellbeing and it also may help to reduce your fatigue. It is also important to listen to your body and rest when you are tired.

Side effects of radiotherapy

Radiotherapy can cause similar side effects to those caused by chemotherapy including nausea and vomiting, hair loss and fatigue. These are described above.

In general the type of side effects seen with radiotherapy depends on the area of the body which has been treated. For example, radiotherapy to the abdomen is more likely to cause nausea and vomiting while hair loss is usually confined to the areas of the body being treated.

SKIN REACTIONS

Radiotherapy can cause a reddening of the skin which may also flake and become itchy. The staff at the radiotherapy department will advise you on how to care for your skin while you are having treatment. Gentle washing (avoiding perfumed products like scented soaps) and drying (patting rather than rubbing) is often recommended. You should also avoid any creams or moisturisers that contain traces of metals. Check with the radiotherapy department staff if you are unsure. Also, it is best to avoid direct sunlight on any area of skin that has received radiotherapy, even after the therapy has finished. This is because radiotherapy makes your skin more vulnerable to the damaging effects of the sun (i.e. sunburn and skin cancers).

PAROTITIS

Parotitis is an inflammation of the saliva-producing glands in the mouth which can occur if these glands are within the treatment field used. These include the parotid or submandibular glands, which are situated at the top of the jaw line, in front of the ears. Parotitis causes dryness of the mouth and jaw pain, which usually settles down within a few days, once the inflammation subsides.

SUPPORTIVE CARE

Supportive care plays an important role in the treatment of many people living with myeloma. This involves making every effort to improve your quality of life, by relieving any symptoms you might have and by preventing and treating any side effects that arise from your disease or treatment. Blood transfusions, antibiotics, and for some people, complementary therapies, are all important elements of supportive care.

Complementary therapies

Complementary therapies are therapies which are not considered standard medical therapies. Many people find that they are helpful in coping with their treatment and recovery from disease. There are many different types of complementary therapies. These include yoga, exercise, meditation, prayer, acupuncture, relaxation and herbal and vitamin supplements.

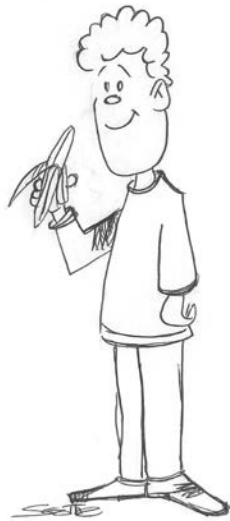
Complementary therapies should 'complement' or assist with recommended medical treatment. They are not recommended as an alternative to medical treatment. It is important to realise that no complementary or alternative treatment alone has proven to be effective against myeloma.

It is also important to let your doctor or nurse know if you are using any complementary or alternative therapies in case they interact with chemotherapy or other treatments you may be having.

Nutrition

A healthy and nutritious diet is important in helping your body to cope with your condition, and its treatment. Talk to your doctor or nurse if you have any questions about your diet or if you are considering making any radical changes to the way you eat. You may wish to see a nutritionist or dietician who can advise you on planning a balanced and nutritious diet.

If you are thinking about using herbs or vitamins it is very important to talk this over with your doctor first. Some of these substances can interfere with the effectiveness of chemotherapy or other treatments you are having.



REPRODUCTIVE HEALTH

Fertility

Fertility is the ability to produce a child. In males, fertility means having enough healthy sperm to get a female pregnant. In females, fertility is the ability to become pregnant.

Some types of treatment may cause a temporary or permanent reduction in your fertility. It is very important that you discuss any questions or concerns you might have regarding your future fertility with your doctor, if possible before you commence treatment.

In women, some types of chemotherapy and radiotherapy can cause varying degrees of damage to the normal functioning of the ovaries. In some cases this leads to menopause (change of life) earlier than expected. In men sperm production can be impaired for a while but the production of new sperm may become normal again in the future.

There are some options for preserving your fertility, if necessary, while you are having treatment. These are described below.

Protecting your fertility - Men

Sperm banking is a relatively simple procedure whereby the man donates semen, which is then stored at a very low temperature (cryopreserved), with the intention of using it to achieve a pregnancy in the future. You should discuss sperm banking with your doctor before starting any treatment that might impact on your fertility. In some cases, however, people are not suitable for sperm banking when they are first diagnosed because they are too unwell and therefore unable to produce the sperm in sufficient quantity or quality.

If possible, semen should be donated on more than one occasion. It is important to realise that there are many factors that can affect the quality and quantity of sperm collected in a semen donation and its viability after it is thawed out. There is no guarantee that you and your partner will be able to achieve a pregnancy and healthy baby in the future. You should raise any concerns you have with your doctor who can best advise you on your fertility options.

The use of donor sperm might be another option for you and your partner. The sperm is donated from another male to achieve a pregnancy.

Protecting your fertility - Women

There are several approaches that may be used to protect a woman's fertility. These are outlined below.

Embryo storage - this involves collecting your eggs, usually after taking drugs to stimulate your ovaries to produce a number of eggs, so that more than one egg can be collected. This process takes at least several weeks and this can be a problem if your treatment needs to start immediately. Once the eggs are collected they are then fertilised with your partner's sperm and stored to be used at a later date. Your unfertilised eggs can also be collected and stored in a similar manner (egg storage).

Ovarian tissue storage - this is still a fairly new approach to protecting your fertility and to date there is very little experience with this technique in New Zealand. It involves the removal and storage at a very low temperature of some ovarian tissue (cryopreservation). It is hoped that at a later date the eggs contained in this tissue can be matured, fertilised and used to achieve a pregnancy.

To date, these first two approaches have unfortunately shown little success in cancer patients.

Donor eggs - the use of donor eggs might be another option for you and your partner. These eggs could be fertilised using your partner's sperm and used in an attempt to achieve a pregnancy in the future.

It is important to understand that these methods are still quite experimental and for many reasons achieving a pregnancy and subsequently a baby is not guaranteed by using any of them. In addition, some are time consuming and costly while others may simply not be acceptable to you or your partner.

Because of the need to start treatment without delay and the problems associated with the cancer itself, it is often not possible to collect eggs or ovarian tissue prior to the first cycle of chemotherapy.

Early menopause

Some cancer treatments can affect the normal functioning of the ovaries. This can sometimes lead to infertility and an earlier than expected onset of menopause, even at a young age. The onset of menopause in these circumstances can be sudden and, understandably, very distressing.

Hormone changes can lead to many of the classic symptoms of menopause including menstrual changes, hot flushes, sweating, dry skin, vaginal dryness and itchiness, headache and other aches and pains. Some women experience decreased sexual drive, anxiety and even depressive symptoms during this time.

It is important that you discuss any changes to your periods with your doctor or nurse. He or she may be able to advise you or refer you to a specialist doctor (a gynaecologist) or clinic that can suggest appropriate steps to take to reduce your symptoms.

Menstruation

Cancer treatment can affect your menstrual cycle; you may find your periods stop or become irregular. You may be prescribed a birth control pill to stop your periods. This prevents heavy bleeding and blood loss when your platelets are low. If you are having chemotherapy, it is best to use pads instead of tampons if you are menstruating as this will reduce the risk of infections. Always let your doctor know if you are having your period.

BODY IMAGE, SEXUALITY AND SEXUAL ACTIVITY

It is likely that the diagnosis and treatment of myeloma will have some impact on how you feel about yourself as a man or a woman and as a 'sexual being'. Hair loss, skin changes and fatigue can all interfere with feeling attractive.

During treatment you may experience a decrease in libido, which is your body's sexual urge or desire, sometimes without there being any obvious reason. It may take some time for things to return to 'normal'. It is perfectly OK and safe to have sex while you are on treatment or shortly afterwards if you wish to, but there are some precautions you need to take.

It is usually recommended that you or your partner do not become pregnant as some of the treatments given might harm a developing baby. As such, you need to ensure that you or your partner uses a suitable form of contraception. Condoms (with a spermicidal gel) offer good contraceptive protection as well as protection against infection or irritation. Your partner may be worried that sex might in some way harm you. This is not likely as long as your partner is free from any infections and the sex is relatively gentle. Finally, if you are experiencing vaginal dryness, a lubricant can be helpful. This will help prevent irritation. Using a condom is also important to protect your partner from chemotherapy drugs that can be excreted in body fluids in the first few days after they are administered.



If you have any questions or concerns regarding sexual activity and contraception don't hesitate to discuss these with your doctor or nurse, or ask for a referral to a doctor or health professional who specialises in sexual issues.

MAKING TREATMENT DECISIONS

Many people feel overwhelmed when they are diagnosed with myeloma. In addition to this, waiting for test results and then having to make decisions about proceeding with the recommended treatment can be very stressful. Some people do not feel that they have enough information to make such decisions while others feel overwhelmed by the amount of information they are given. It is important that you feel you have enough information about your illness and all of the treatment options available, so that you can make your own decisions about which treatment to have.

Before going to see your specialist doctor (haematologist or oncologist) make a list of the questions you want to ask. It may be useful to keep a notebook with you and write questions down as you think of them, as often questions are forgotten between appointments.

Sometimes it is hard to remember everything the doctor has said. It may help to bring a family member or a friend along who can write down the answers to your questions or prompt you to ask others, to be an extra set of ears, or to simply be there to support you.

Your doctor will spend time with you and your family discussing what he or she feels is the best option for you. Feel free to ask as many questions as you need to, at any stage. You are involved in making important decisions regarding your wellbeing. You should feel that you have enough information to do this and that the decisions made are in your best interests. Remember, you can always request a second opinion if you feel this is necessary.

The Haematology Patient Diary, available from Leukaemia & Blood Cancer New Zealand, may be useful for recording details of treatment and making notes from clinic appointments.

Interpreting services

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



INFORMATION AND SUPPORT

People cope with a diagnosis of myeloma in different ways, and there is no right, wrong or standard reaction. For some people, the diagnosis can trigger any number of emotional responses ranging from denial to devastation. It is not uncommon to feel angry, helpless and confused. It is natural for people to feel fear for their own lives or that of a loved one.

It is worth remembering that information can often help to take away the fear of the unknown. It is a good idea for you and your family to speak directly to your doctor regarding any questions you might have about your disease or treatment. It can also be helpful to talk to other health professionals including social workers or nurses who have been specially educated to take care of people with haematological diseases. Some people find it useful to talk with other patients and family members who understand the complexity of feelings and the kinds of issues that come up for people living with blood cancers and conditions.

Many people are concerned about the social and financial impact of the diagnosis and treatment on their families. Normal family routines are often disrupted and other members of the family may suddenly have to fulfil roles they are not familiar with, for example, cooking, cleaning, and taking care of children.

If you have a psychological or psychiatric condition, please inform your doctor and don't hesitate to request additional support from a mental health professional.

There is a variety of assistance available to help ease the emotional and financial strain created by a diagnosis of a blood cancer or condition. Support Services staff at Leukaemia & Blood Cancer New Zealand are available to provide you and your family with information and support to help you cope during this time. Contact details for Leukaemia & Blood Cancer New Zealand are provided on the back of this booklet.



USEFUL INTERNET ADDRESSES

The value of the internet is widely recognised; however, not all the information available may be accurate and up to date. For this reason, we have selected some of the key sites that people living with myeloma might find useful.

With the exception of our own websites, Leukaemia & Blood Cancer New Zealand does not maintain these listed sites. We have only suggested sites we believe may offer credible and responsible information, but we cannot guarantee the information on them is correct, up to date or evidence based medical information.

Leukaemia & Blood Cancer New Zealand

www.leukaemia.org.nz

Cancer Society of New Zealand

www.cancernz.org.nz

Leukaemia Foundation of Australia

www.leukaemia.org.au

American Cancer Society

www.cancer.org

MacMillan Cancer Support (A UK cancer information site)

www.macmillan.org.uk

Leukaemia & Lymphoma Research (UK)

www.llresearch.org.uk

National Cancer Institute (USA)

www.cancer.gov/cancerinfo

MyelomaUK (formally International Myeloma Foundation UK)

www.myeloma.org.uk

The International Myeloma Foundation (US)

www.myeloma.org

The Multiple Myeloma Research Foundation

www.multiplemyeloma.org

GLOSSARY OF TERMS

Alopecia

Hair loss. This is a side effect of some kinds of chemotherapy and radiotherapy. It is usually temporary.

Anaemia

Deficiency of red blood cells which results in a reduced level of the oxygen carrying pigment haemoglobin in the blood. Causes pale skin, tiredness and other symptoms such as shortness of breath.

Antibodies

Naturally produced proteins in the blood which form an important part of the body's defence system against infection. Antibodies target antigens on other substances such as bacteria, viruses and some cancer cells and cause their destruction. When the body is exposed to these agents, antibodies are produced by cells known as plasma cells, which are derived from lymphocytes.

Anti-emetic

A drug which prevents or alleviates nausea and vomiting that can sometimes be a side effect of chemotherapy.

Antigen

A substance, usually on the surface of a foreign body such as a virus or bacteria that stimulates the cells of the body's immune system to react against it by producing antibodies.

B cell (B lymphocyte)

A type of white cell normally involved in the production of antibodies to combat infection. The fully mature B lymphocyte is often called a plasma cell. Tumours of mature B lymphocytes include myeloma and Waldenstroms macroglobulinaemia.

Bence-Jones protein (BJP)

A protein found in the urine of many patients with myeloma. BJP is the light chain part of the antibody produced by the myeloma cells. It can be used to help in the diagnosis of the disease and may be measured in the urine to monitor treatment. BJP is a small molecule that can potentially damage the kidneys.

Beta-2 (β 2) microglobulin

A protein found on the surface of many cells including white blood cells. A very high level of beta-2 microglobulin in the blood at diagnosis of myeloma may indicate a more advanced disease and a poorer diagnosis.

Bisphosphonates

Medication used to treat and prevent high calcium levels as well as bone disease in myeloma. Bisphosphonates are very useful in strengthening bones to prevent fractures and pain. Also used in the treatment of osteoporosis.

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.

Bone marrow

The tissue found within the hollow cavities of most of the bones of the body. Active or red bone marrow contains stem cells from which all blood cells are made and in adults this is found mainly in the bones making up the axial skeleton – hips, ribs, spine, skull and breastbone (sternum). The other bones contain inactive or (yellow) fatty marrow, which consists mostly of fat cells.

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 which can be inserted into a vein, usually in the hand or arm, to allow fluid to enter the blood circulation.

Central venous catheter (CVC)

Also known as a central venous line (CVL). A line or tube passed through the large veins of the arm, neck, chest or groin and into the central blood circulation. It can be used for taking samples of blood, giving intravenous fluids, blood, chemotherapy and other drugs without the need for repeated needle punctures.

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 nowadays largely preventable with modern anti-nausea medication. Most side effects are temporary and reversible.

C-reactive protein (CRP)

A protein released by the liver in response to inflammation in the body. Levels of CRP may be elevated in advanced myeloma.

Creatinine

A waste product of muscle breakdown normally excreted by the kidneys. The level of creatinine in the blood will be raised if the kidneys are not functioning properly.

Haemopoiesis (or Haematopoiesis)

The processes involved in blood cell formation.

Haematologist

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

Hickman catheter

A type of central venous catheter used for patients undergoing intensive treatment, such as bone marrow or peripheral blood cell transplant. It may have single or multiple tubes (called lumens).

High dose therapy

The use of higher than normal doses of chemotherapy to kill off resistant and/or residual (left over) cancer cells that have survived standard-dose therapy. Often used in conjunction with a stem cell transplant.

Hypercalcaemia

Abnormally high levels of calcium in the blood.

Hyperviscosity

Increased viscosity (thickness) of the blood, usually caused by a build up of paraprotein in the blood. Blood flow becomes more sluggish, and the blood supply to various parts of the body, including the brain and eyes, may be affected. Symptoms include confusion, drowsiness, impaired vision and retinal bleeds.

Immune system

The cells and tissues that make up the body's defence mechanism against infection and disease.

Immunocompromised

When someone has lowered immune function.

Immunoglobulins

Proteins produced by plasma cells which function as antibodies and play an important role in protecting the body against infection and disease.

Lymphocytes

Specialised white blood 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.

Malignancy

A term applied to tumours characterised by uncontrolled growth and division of cells (see cancer).

Mucositis

Inflammation of the lining of the mouth and throat, which also can extend to the lining of the whole of the gastro-intestinal tract (stomach and intestines). Often occurs after high dose chemotherapy.

Myeloma

Also called multiple myeloma or plasma cell myeloma. Myeloma is a cancer that usually arises in the bone marrow when mature B-lymphocytes known as plasma cells, undergo a malignant change.

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, especially bacterial and fungal infection.

Oncologist

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

Paraprotein

Also called monoclonal immunoglobulin, myeloma protein, or M protein. Paraprotein is the abnormal protein produced by myeloma cells.

Pathologist

A doctor who specialises in the laboratory diagnosis of disease, and how disease is affecting the organs of the body.

Peripherally inserted central venous catheter (PICC)

A type of central venous catheter which is inserted into a large vein in the arm.

Plasma cells

Mature B-lymphocytes that have become activated in response to bacteria, viruses and other substances in the body. Plasma cells secrete antibodies that help protect the body from infection and disease.

Plasmacytoma

Isolated mass of myeloma cells.

Plasmapheresis

A procedure that uses a special machine called a 'cell separator' to remove the straw-coloured fluid part of the blood (plasma) while returning the rest of the blood and a suitable plasma substitute to the patient.

Plateau

When myeloma is stable it is not getting any worse or any better with treatment.

Prognosis

An estimate of the likely course of a disease.

Radiotherapy (radiation therapy)

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

Disease that is not responding to treatment.

Remission (or complete remission)

When there is no evidence of disease detectable in the body. Note this is not always equivalent to a cure as relapse may still occur since we are sometimes unable to detect very low levels of disease.

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 cell in the body. Bone marrow stem cells have the ability to grow and produce all the different blood cells including red cells, white cells and platelets.

Spinal cord compression

Injury to the spinal cord caused by mechanical pressure usually caused by collapsed or protruding spinal bones, or tumours on or near spinal bones. Spinal cord compression is accompanied by weakness or paralysis in parts of the body below the level of the spinal cord injury.

Stage

The extent or spread of cancer in the body.

Staging

An assessment of the extent or spread of cancer in the body.

T Cell (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).

White blood cells

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

X-ray

A form of radiation used to produce images of the body.

Please refer to the Dictionary of Terms booklet for further definitions.



5. What did you like most about this booklet?

6. What did you like least about this booklet?

7. Any other comments?

Thank you for helping us review this booklet. We will record your feedback and consider it when this booklet is reviewed for the next edition.

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