

Myeloma

A guide for people with Myeloma and their support

This booklet has been written to help you and your support people understand more about Myeloma, which is sometimes called Multiple Myeloma.

We know you may be feeling anxious or overwhelmed if you or someone you care for has recently been diagnosed with Myeloma. Maybe you are discussing different treatment options with your treatment team or maybe you have started treatment. Whatever point you are at, this booklet will answer some of your questions and it may raise others, which you can jot down and discuss with your treatment team.

If you don't feel like reading this booklet from cover to cover, take a look at the list of contents and choose which parts to read now.. You can come back to read other parts later on. You may need more information, so towards the back of the booklet there is a list of useful resources. Your doctor or nurse might also give you some further reading. You can always call our Blood Cancer Support Coordinators to find out how we can help you.

You will come across quite a few medical terms in this booklet. Your treatment team will be happy to explain any terms you don't understand, so never be afraid to ask. Many of these words are defined in the text or in the Glossary at the end of this booklet.

Although we provide some information about treatments, this booklet does not recommend any particular form of treatment and you must discuss your circumstances and best treatment options with your haematologist.

We hope you find this information useful. We'd love to hear any feedback so we can make sure we best meet your information needs.

The Leukaemia Foundation acknowledges the traditional owners of country throughout Australia and recognises their continuing connection to land, sea and community. We pay our respects to their Elders past, present and emerging.

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Myeloma in brief

About Myeloma

Myeloma is a blood cancer that starts in the bone marrow in plasma cells. The bone marrow is where blood cells are made.

Normal plasma cells make antibodies called *immunoglobulins* that fight infection. In patients with Myeloma, the abnormal plasma cells release large amounts of an atypical immunoglobulin (called *paraprotein*) which cannot fight infections and may cause damage to the kidneys and other organs. The Myeloma cells crowd the bone marrow, causing bone weakness, pain, osteoporosis (lower bone density than normal), or fractures. Because of this crowding the bone marrow cannot make enough healthy blood cells.

Symptoms of Myeloma include bone pain, extreme tiredness, weakness, weight loss, infections, easily bruising and/or bleeding.

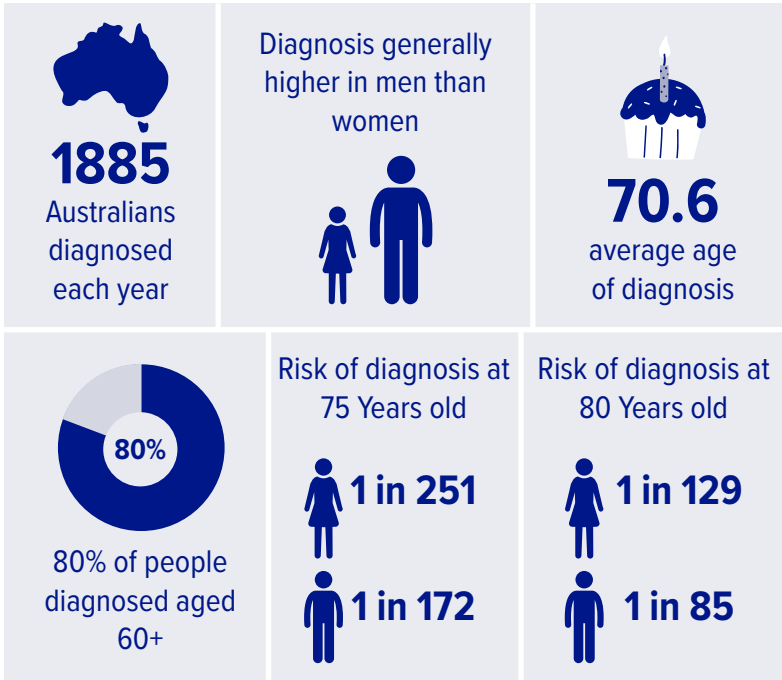
Myeloma is diagnosed using blood tests, urine tests and a bone marrow biopsy.

We don't know what causes Myeloma. There is usually a *mutation* in (change to) the genetic material of growing blood cells. There is no way to prevent Myeloma and you can't catch it or pass it on.



Scan to learn more about how the Leukaemia Foundation can provide you with additional support and the latest information about your blood cancer.

Who gets Myeloma?



What's the prognosis?

A prognosis is an estimate your haematologist will make of the likely course and outcome of your disease. Myeloma is divided into stages. Your haematologist will work out and let you know your stage when you are diagnosed.

Your haematologist will consider many factors when considering your prognosis. Some of these are your stage, the type of Myeloma you have, your age, your overall health and how you respond to treatment.

All about blood

What is blood?

Blood travels to all parts of the body, carrying oxygen and nutrients and removing waste products. It's made up of cells and plasma. Plasma is the straw-coloured liquid part of the blood that carries blood cells and other substances around your body.

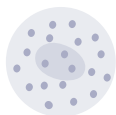
The main types of blood cells are red and white. Platelets are talked about like blood cells, but they are *fragments* of blood cells.

Platelets
Support blood clotting
to stop bleeding



Red Blood Cells

Carry oxygen for the body to produce energy



White Blood Cells

Form part of the immune system

Red blood cells

Red blood cells (also known as erythrocytes or RBCs) contain haemoglobin (Hb), which gives blood its red colour and carries oxygen from the lungs to all parts of the body.

Most blood cells in your total blood volume (40-45%) are red blood cells.

White blood cells

There are five types of white blood cells, also known as leukocytes or WBCs.

Although they make up only a small part (1%) of the blood, white blood cells protect us against and fight off infection. While all of them are important, you will hear the most about neutrophils and lymphocytes. Neutrophils fight bacteria and are especially important in recovering from chemotherapy.

Platelets

Platelets, also known as thrombocytes, are small pieces of cells. They help your blood clot or stick together; a process called *coagulation*.

Where and how is blood made?

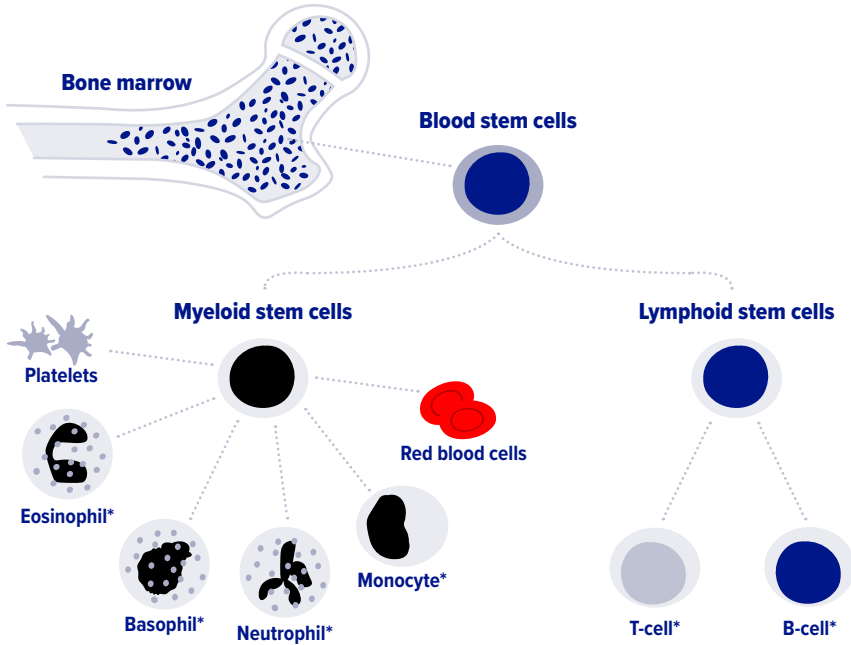
Bone marrow

Bone marrow is spongy tissue in the middle of certain bones. Most blood cells are made in your bone marrow. This process is called *haematopoiesis*.

In children, haematopoiesis takes place in the long bones, like the thighbone (femur). In adults, it's mostly in the spine (vertebrae) and hips, ribs, skull, and breastbone (sternum). You may have a bone marrow biopsy taken at the back of your hip (the iliac crest).

Think of blood production as a family tree. At the top of the tree are the blood stem cells, which are the youngest (most immature) blood-forming cells. They can make copies of themselves and new cells.

There are two types of progenitor cells that split the family tree: lymphoid cells and myeloid cells. Progenitor cells form blast cells.



Growth factors

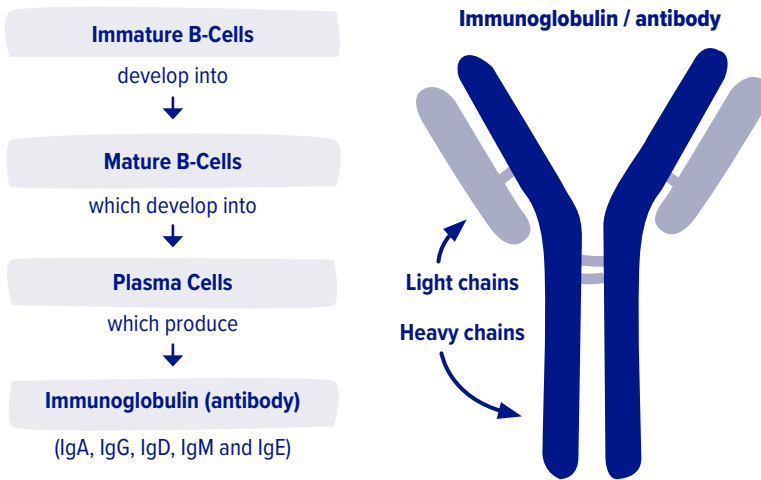
All normal blood cells live a short time: red blood cells for 80-100 days, neutrophils 8-14 days, and platelets 4-5 days. They then die off and are replaced by new cells from the bone marrow. This means that your bone marrow remains very busy throughout your life.

Chemicals in your blood, called *growth factors*, control blood cell formation. Different growth factors help make the blood stem cells in the bone marrow become different types of blood cells.

Some growth factors can be made in the laboratory (synthesised) and given to people to help treat blood disorders.

What are plasma cells and immunoglobulins?

Plasma cells are a type of white blood cell. They develop from mature B-lymphocytes (often called *B-cells*) in the bone marrow. Plasma cells help protect us against infection and disease. They produce substances that are proteins, called *immunoglobulins* (Igs). You may have heard their other name, *antibodies*. Plasma cells make immunoglobulins to target bacteria or viruses when we have infections.



Immunoglobulins are Y-shaped molecules. They're made up of two identical long pieces of protein (called *heavy chains*) and two identical short pieces of protein (called *light chains*).

There are two light chains: kappa (κ) and lambda (λ). There are five heavy chains, called A, G, D, M and E. The immunoglobulins are named by their heavy chain: IgA, IgG, IgD, IgM and IgE, where 'Ig' stands for 'immunoglobulin'.

Heavy chains can join to light chains. Examples are IgA/ κ or IgG/ λ .

All about Myeloma

What is Myeloma?

Myeloma is an uncommon type of blood cancer that starts in plasma cells in the bone marrow.

Plasma cells play an important role in our immune system. They make proteins called *immunoglobulins* (or *antibodies*) to help fight infection. Because of genetic changes, plasma cells become Myeloma cells.

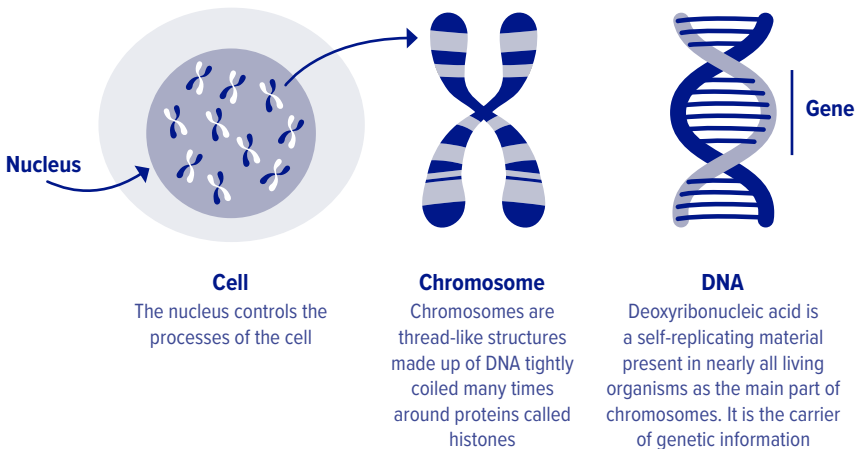
Myeloma cells make an abnormal protein, called a *monoclonal protein* (or *paraprotein*). Paraprotein can build up in the blood and the urine and may cause kidney damage and nerve problems with your hands and feet (*peripheral neuropathy*). It also reduces your immunity. As bones break down, they release calcium into your bloodstream. A higher-than-normal level of calcium in your blood is called *hypercalcaemia*. Hypercalcaemia can also cause kidney damage.

People with Myeloma may have a mass of Myeloma cells (a plasmacytoma) in only one part of the body. This is called **solitary plasmacytoma**. People with more than one plasmacytoma, who have Myeloma in more than one part of the body, have **Multiple Myeloma**.

How does Myeloma develop?

Myeloma affects how normal blood cells are made in your bone marrow. Normally stem cells make blast cells that become healthy blood cells.

Inside cells there are coded instructions that control how the cell should act. Chromosomes inside cells are long strands of DNA (deoxyribonucleic acid). Each section of DNA that holds the cell's instructions is called a *gene*.



In Myeloma, the DNA in early plasma cells in the bone marrow are damaged. The DNA damage is called an *acquired*, or *somatic mutation*. It starts with one damaged cell, which divides and creates a clone. A clone is a group of identical cells all with the same mutation. They divide to create more abnormal cells. This is why Myeloma is sometimes called *clonal*.

The bone marrow makes too many plasma cells which crowd the bone marrow. Because the bone marrow can't function properly, it can't make enough red blood cells, white blood cells and platelets.

This means that people with Myeloma have very active bone marrow, producing many cells, but can have a low number of healthy blood cells circulating in the bloodstream. Low numbers of blood cells are called *cytopenias*. One type of cytopenia is *anaemia*, which is where someone has low red blood cells.

Normally 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 M protein). It's found in the blood. People with Myeloma might make fewer-than-normal immunoglobulins too.

Light chains are a part of immunoglobulins. Sometimes in Myeloma too many light chains are produced. These light chains show up in the blood and sometimes in the urine.

Types of Myeloma

Myeloma is classified depending on where it is in your body. For most people Myeloma is found throughout the bone marrow in the body, which is why the disease is also called Multiple Myeloma.

Some people have Myeloma in only one site in the body outside the bone marrow. This is called a *solitary plasmacytoma*. You can find out more about this condition on our website, *Solitary Plasmacytoma*.

Myeloma is also classified by the type of immunoglobulin. The types are: IgG Myeloma, IgA Myeloma, light chain Myeloma (where the Myeloma cells make only kappa or lambda light chains), and IgM, IgD, IgE and non-secretory Myelomas (which has no paraprotein or excess light chains).

Very few people with Myeloma make little or no paraprotein. This is called *non-secretory Myeloma*.

Other conditions that affect plasma cells

Some people have an increased number of plasma cells in their bone marrow, but do not fit the criteria for a diagnosis of Multiple Myeloma.

Monoclonal gammopathy of undetermined significance (MGUS)

is a non-cancerous condition related to Myeloma. People with MGUS make paraprotein and/or excess light chains, but the number of plasma cells in their bone marrow is normal or only slightly higher than normal.

Smouldering, asymptomatic Myeloma or inactive Myeloma is a very early phase of Myeloma. There are no Myeloma symptoms, but a bone marrow biopsy shows signs of the disease. People diagnosed with smouldering Myeloma do not need treatment straight away but do need regular check-ups ('watch and wait').

In most cases, there is no specific cause of Myeloma. Gene mutations in cells happen all the time. Healthy cells have clever ways of stopping them from causing problems in the body. But the longer we live, the more chance we have of getting mutations that can escape these safeguards. That's why Myeloma is more common in older people.

Why a particular person at a particular time gets Myeloma is not really known. But some things (risk factors) give some people a higher risk of developing Myeloma.



You can find out more about these conditions on our website.

Known risk factors

Ageing because it's more common in older people. (Cancer Australia suggests the incidence rate for Multiple Myeloma is expected to increase with age, peaking at age group 80-84.)

A history of MGUS: everyone with Myeloma had MGUS, but not everyone with MGUS develops Myeloma.

Family history because people with a family member with Myeloma are slightly more likely to get it.

People with **autoimmune diseases** like lupus or pernicious anaemia may have a slightly increased risk. These conditions make the immune system attack healthy cells by mistake.

Exposure to high levels of some **environmental chemicals** like benzene and some pesticides

Previous **radiation therapy**, or accidental exposure to high levels of environmental irradiation.

Symptoms of Myeloma

The most common symptom of Myeloma is bone pain. You may have general symptoms, such as:

- fatigue (extreme tiredness not relieved by rest)
- feeling sick to the stomach (nausea) or vomiting
- lack of appetite
- weight loss
- thirst
- tingling or numb feeling in your hands

Bone pain

Most people with Myeloma (up to 90%) have bone pain when they're diagnosed. Usually, the pain is in the back or ribs. You feel it all the time, and it might be worse when you move.

Myeloma cells release substances that make other bone marrow cells (called *osteoclasts*) remove calcium from the bone. Over time, bones can become weak and thinner (this is called *osteoporosis*). X-rays may show areas in bone that look like holes (called *lytic lesions*).

Spinal cord compression

Sometimes a collection of Myeloma cells can develop in the bones of the spine (*vertebrae*). They can grow into the spinal canal and put pressure on the spinal cord. This is known as spinal cord compression.

If there is pressure on your spinal cord you may feel a tingling or pain in your legs or they may feel weaker than usual. Some people can have difficulty passing urine or opening their bowels. If you experience any of these symptoms, contact your treatment team right away.

You may have radiation therapy to help with bone pain or spinal cord compression pain. You can read more about radiation therapy later in this booklet.

High levels of calcium in the blood

High levels of calcium in your blood is called *hypercalcaemia*. When bone is damaged, the bone releases calcium into your blood. You may feel drowsy, sick (nausea), constipated, tired, thirsty or confused.

Low blood cell counts

Because Myeloma cells crowd the bone marrow, you may have lower-than-normal levels of red blood cells, white blood cells or platelets.

Anaemia is also very common in Myeloma. It's caused by low red blood cells. Red blood cells carry oxygen around your body.

You may have a low number of a type of white blood cells called *neutrophils* (called neutropenia) or low IgG (immunoglobulin G) (called *hypogammaglobulinaemia*). White blood cells support your immunity.

Thrombocytopenia is low platelet count. Platelets help control bleeding and help wounds to heal.

You may have symptoms from each of these groups because all your blood cell types can be affected by the disease (which is called *pancytopenia*).

Condition	Cause	You might notice
Anaemia	Low RBCs or Hb	Tiredness, weakness, pale skin, shortness of breath, heavy legs, difficulty concentrating, feeling lightheaded, rapid or irregular heartbeat
Neutropenia/ hypogammaglobulinaemia	Low WBCs (neutrophils)	More frequent or severe infections eg. Chest or skin, Fevers, shivering, chills, low blood pressure, mouth ulcers
Thrombocytopenia	Low platelets	Easy bruising and bleeding eg. nosebleeds, cuts that keep bleeding, coughing up blood, petechiae – tiny, unraised red blood spots under the skin, often starting on legs
Pancytopenia	All three blood cell types low	A mix of symptoms from all three conditions

Kidney damage

Myeloma causes kidney damage because of:

- damage by the paraprotein to the kidneys (leading sometimes to leaking of the K or L light chains into the urine, known as *Bence Jones protein*)
- higher-than-normal levels of calcium in your blood (*hypercalcaemia*).

Symptoms of kidney damage include fatigue (extreme tiredness not relieved by rest), mental confusion, and swollen ankles.

Hyperviscosity syndrome

For some patients, large numbers of Myeloma cells make the blood get thicker. It's called *hyperviscosity*. It makes blood flow to your brain slowly so you may have:

- headache
- dizziness
- confusion
- blurred vision.

These symptoms are similar to a stroke. It's important to contact your treatment team right away. You'll likely have a procedure called *plasmapheresis* in an outpatient unit. It removes protein from your blood and reverses the hyperviscosity quickly

How is Myeloma diagnosed?

Your haematologist will diagnose Myeloma by talking with you about how you are feeling and looking at samples of your blood and bone marrow. Some symptoms of Myeloma, like feeling tired and low or abnormal blood counts, are part of many conditions as well as side effects of some medications. Over recent years, the diagnosis and stage of Myeloma has become increasingly important to provide clinicians with all of the information they need to make the best treatment decisions for each patient. It is important for the clinician to understand the exact subtype classification (if applicable) and stage for treatment and prognostic decisions. You may need a few types of tests before the Myeloma and its stage is diagnosed.

Medical history and physical exam

First, your treatment team (usually your GP) will take a full medical history. They'll ask you to talk about past and present illnesses, health problems, infections and bleeding. They'll also need details of any old and new medicines you're taking, including prescribed and any over the counter medicines you take regularly.

Your doctor will also do a physical exam, to check your general health and your whole body for any signs of Myeloma. Then you'll have some blood tests.

Your GP will review your blood test results. If your GP thinks you may have Myeloma, next you will see a blood specialist called a haematologist. The haematologist will ask you to have some more tests to confirm that you have Myeloma.

Blood and urine tests

Full blood count

You'll be asked to have a simple blood test called a full blood count (FBC). This test measures the number of red cells, white cells and platelets in circulation. Your treatment team will give you a referral and tell you where to go to have it done. They will also tell you if you need to fast (not eat or drink) for a certain amount of time before you have the blood test. A pathologist (a blood specialist) will look at the blood cells under a microscope.

Blood chemistry tests

Blood chemistry tests measure the levels of different chemicals in your body. These blood tests are often taken at the same time as your FBC. Some substances that may be tested for Myeloma will be:

Substance tested	What it indicates
creatinine	Kidney function
electrolytes	Kidney function
blood urea nitrogen (BUN)	Kidney function
calcium	Bone destruction
uric acid	Kidney function
lactate dehydrogenase (LDH)	Blood cell damage
beta-2 microglobulin	Level of Myeloma in the body

Serum (blood) free light chains

The level of light chains (kappa or lambda) in your blood can reflect the amount of Myeloma in your body. The free light chains test measures the free light chains and calculates the kappa/lambda ratio.

Serum (blood) protein and urine electrophoresis and immunofixation These tests are carried out on your blood and your urine to measure the type and the amount of protein in them.

24-hour urine collection test

You may be asked to collect your urine over 24 hours at home. Your treatment team will give you the bottle with instructions and tell you where to take the bottle when you're done. Your urine will be tested for the Bence Jones protein.

Bone marrow biopsy

If your treatment team thinks you may have Myeloma based on your blood test results, the next step is a bone marrow test. This test is more complex than a blood test, but it won't involve a hospital stay. It will be done in your haematologist's rooms or in a day procedure clinic or outpatient ward in a hospital. You should bring a support person with you to keep you company while you wait and to help you home, as you won't be able to drive.

What does a bone marrow biopsy involve?

A bone marrow biopsy involves using a needle to enter the bone marrow most commonly in the back of the hip bone. This is an area where the bone is usually quite close to the skin and an area that can be easily accessed by the bone marrow needle. A small amount of liquid bone marrow is usually taken and placed onto slides that are examined in the laboratory. The liquid bone marrow is also sent for additional specialised tests. Usually, a small piece of the bone marrow is also taken and examined in the laboratory.

Is a bone marrow biopsy painful?

Having a bone marrow biopsy is sometimes painful. With the use of local anaesthetic before the bone marrow needle is inserted this pain is usually well tolerated. Often you will be given a form of pain preventer that you breathe in, or a small dose of sedative (under appropriate hospital conditions) to assist in the management of the discomfort.

What to expect after

You should try to rest for the day. If you have had sedation, then you must not drive a car or work for 24 hours, so you will need someone to take you home. You may not have any pain but if you do, take a paracetamol tablet. You can take off the dressing and shower 24 hours after the test

You may have to wait a few days for the results of the bone marrow biopsy.

Cytogenetic tests

Cytogenetic tests on the bone marrow are one type of genetic test. Their results give your treatment team information about the genetic make-up of your cells. They look at the structure of chromosomes in bone marrow cells to see if there is any gain, loss or switching of genetic material between chromosomes. Your haematologist will use the results to help work out which type of Myeloma you have and to plan your treatment.

FISH

Fluorescent in-situ hybridisation (or FISH) is a type of cytogenetic test your treatment team might mention. It can be done on either a blood or a bone marrow sample. The pathologist uses dyes to highlight parts of chromosomes to check if they are abnormal.

HLA Testing

Even though autologous stem cell transplant (where your own stem cells are harvested) is more common for Myeloma, some people may have an allogeneic stem cell transplant, where a donor donates compatible stem cells. HLA testing test for human leukocyte antigen. The test is also called tissue typing or histocompatibility testing. It tests which HLA genes someone has inherited if donors are suitable matches for an allogeneic transplant. You can read more about stem cell transplants later in this booklet and in our booklets, *Understanding Autologous Stem Cell Transplants* and *Understanding Allogeneic Stem Cell Transplants*.

X-rays and other bone imaging tests

X-rays – skeletal survey

If your haematologist suspects that you have Myeloma, you will have a full body X-ray. This is called a skeletal survey. It checks for bone damage caused by Myeloma. During a skeletal survey, X-rays are usually taken of your skull, spine (backbone), ribs, pelvis (hips), legs and arms. Areas of bone damage, called lytic lesions, may show up on standard X-rays.

CT Scans

You may have a whole-body low-dose CT instead of X-rays. It shows lytic lesions that may be missed on X-rays and has now become the most common technique to study the bone in Myeloma patients.

PET Scans

If you have a PET scan, you'll be given a substance that allows doctors to see if there's anything abnormal with your tissues or organs. This substance is known as a tracer and is radioactive, so abnormal areas show up as bright spots on the scan.

MRI Scans

Magnetic resonance imaging (MRI) uses a very strong magnet to make three dimensional (3D) images. It can show very early changes to your bones and gives more information than X-rays about how much bone damage you have.

Heart tests

Some medicines for Myeloma can cause heart problems. Before you start treatment, you might have an echocardiogram. This test takes pictures of your heart to check how well it pumps blood.

What happens next?

After diagnosis

When all your test results have been reviewed, you'll meet with your haematologist to discuss your Myeloma and treatment goals and options. Your haematologist will work out the stage of your Myeloma too. It's natural to feel scared, confused or sad. You'll hear a lot of information and it can be overwhelming.

Don't be afraid to ask your haematologist to repeat things and for some written information. It's helpful to bring someone along to the appointment as second pair of ears and to take notes.

Disease staging

The stage of your Myeloma shows how the disease is affecting your body. It helps with prognosis (estimating how slowly or quickly your Myeloma might develop) and treatment planning.

There are three stages of Myeloma: I, II and III. Stage I is the earliest stage, and Stage III is the advanced stage. Your haematologist will work out which stage you are at.

To work out your stage, your haematologist will look at some blood test results:

- the level of beta-2 microglobulin in your blood (which may be higher than normal)
- the level of albumin in your blood (which may be lower than normal)
- the level of lactate dehydrogenase (LDH) in your blood (which may be high)
- any abnormal chromosomes that show up in your FISH test.

The CRAB criteria are used to work out if you have active Myeloma that needs treatment:

C = increased calcium level

R = renal (kidney) problems

A = anaemia (lower-than-usual red blood cells)

B = bone changes (lytic lesions or bone loss).

If you have one or more of these CRAB symptoms, you'll need to start treatment. Other important factors your doctor will consider include the number of Myeloma cells in the bone marrow, or the level of abnormal protein in the blood.

Venous Access for Treatments

Many Myeloma treatments are given directly into a vein (intravenously, or via IV). There are two broad ways to provide access to your bloodstream- 1) through the peripheral veins in your arms or 2) through a central vein in your chest. Most people will need both forms of intravenous access throughout their treatment, but some treatments can only be given through a line into a central vein. Your treatment team will discuss them with you before you start treatment so you can decide which is best for you.

Peripheral Intravenous Cannula

This is the most common way to access a peripheral vein. A cannula is a short, thin plastic tube. It has a thin needle that your nurse will put into a vein in your lower arm or the back of your hand. It will be held in place with a dressing. The cannula is connected to the lines that give you your treatment, often through a pump. Having a cannula inserted may hurt a little but once it's in you'll have no pain. It can stay in for a few days or be removed right after your treatment.

PICC Line

A PICC line is a long, thin silicone tube. It's put into a vein above where your elbow bends. A specialist nurse will insert it in an outpatient ward or a clinic. One end is fed up a vein in your arm into a large vein in your chest. The other end comes out around your elbow and can have one, two or three tubes (lumens). Treatment is given through the lumens. It will be taped with a dressing so it doesn't move. PICC lines can stay in for up to two years. Sometimes PICCs are called *central venous access device (CVADs)*.

Port

A port is a small medical device that is implanted under your skin in your chest, just above your heart. It's a thin, flexible silicone tube with a silicone disk on the end. The disk is the 'port'. When it heals, you can see and feel the port under your skin, but there are no external tubes. Your nurse will access the port each time you need blood tests or treatment with a short needle into the silicone disk. Ports can stay in for years and once healed, it requires little care from you. Ports are also called *infusaports* or *portacaths*.

Central line

A central line is a long, thin silicone tube. It's also called a Hickman[®] line, a central venous catheter (CVC), or a central venous access device (CVAD). One end of the tube sits in a large vein above your heart. The other end, which is capped, comes out of your chest. It often has one, two or three tubes (called lumens) coming off that line. Treatment is given through the lumens. A central line can stay in for years.

Multidisciplinary team meetings (MDTs)

Once all of your staging tests have been completed, your case may be presented at a multidisciplinary team meeting (MDT). Usually, an MDT will include a number of specialist haematologists, radiologists (X-ray and PET experts), radiation oncologists (radiotherapy experts) and pathologists. The pathologist will review the biopsy to ensure the diagnosis and subtype (if applicable) is accurate. In some cases, they may recommend more special tests are ordered on the existing biopsy. The radiologists will review all of the scans to help clarify the stage.

With all of the information double checked, the haematologists and radiation oncologists will suggest the best treatment options. This process ensures that initial diagnosis and staging are accurate. Having multiple experts discuss the same case ensures that the most up-to-date recommendations for treatment are put forward. A case may also be re-presented at an MDT during treatment (to ensure treatment responses are adequately monitored) or at a time of suspected Myeloma relapse.

Treatments & side effects

Your haematologist will recommend treatment based on:

- the stage of your Myeloma
- if you have symptoms
- whether you are suitable for a stem cell transplant
- your age
- your general health
- past treatment and how it went: any side effects or complications
- your risk of relapse, and your wishes.

There are a few kinds of treatment for Myeloma. Your treatment plan may include one or more of them:

1. supportive care controls symptoms of Myeloma, like pain
2. targeted therapies
3. chemotherapy
4. stem cell transplant which replaces bone marrow cells with new, healthy cells
5. radiation therapy
6. surgery.

Your treatment team will explain the treatments, their benefits and possible side effects. They might ask you to sign a consent form to agree to the treatment after you have thought about the options.

Treatment goals

There are a few treatment goals for Myeloma:

1. To slow the Myeloma's progress
2. To manage your symptoms
3. To achieve long periods of remission (where there are no signs of Myeloma or it's not causing any problems).
4. Don't be afraid to ask your haematologist to repeat things and ask for some written information. It's helpful to bring someone along to the appointment as second pair of ears and to take notes.

Your treatment team will explain the treatments, their benefits and possible side effects. They will ask you to sign a consent form to agree to the treatment after you have thought about the options.

Treatment responses

During and after treatment, your treatment team will order bone marrow and blood tests and scans to check how you are going. There are a few types of treatment responses defined by the International Myeloma Working Group:

Stringent complete response: No excess free light chains or paraprotein in blood or Bence Jones protein in urine, and a normal percentage of plasma cells in the bone marrow

Complete response: No sign of paraprotein in blood or Bence Jones protein in urine. Less than 5% of bone marrow cells are plasma cells

Very good partial response: Paraprotein in blood has decreased by more than 90%

Partial response: Paraprotein in blood has decreased by more than 50%, paraprotein in urine has decreased by more than 90% using a 24-hour urine collection

Progressive disease: Increase of more than 25% from lowest response value of paraprotein in blood, Bence Jones protein in urine, and/or percentage of plasma cells in bone marrow, and/or new bone lesions or increases in bone damage, and/or new hypercalcaemia

Stable disease: Not meeting any of the above criteria

Supportive care

Supportive care prevents and treats symptoms and side effects. It includes emotional and social support too. The goal is to improve symptoms of your Myeloma, but it doesn't treat the disease itself.

Pain relief

There are many types of medicine that can help with bone pain. Your treatment team will recommend the best type for you. It is important to take these medicines regularly. Don't wait until you have pain before you take them. The goals are to control the pain and keep you moving.

Drugs called bisphosphonates can help with bone pain. You can read more about them and how they treat osteopenia and osteoporosis later in this booklet.

Some people with Myeloma have radiation therapy for pain (this is called palliative care). You can read more about radiation therapy later in this booklet.

Blood transfusions

If you notice symptoms of anaemia tell your treatment team. You may need a transfusion.

Blood transfusions are slow infusions of blood into a vein (intravenously, or IV). Transfusions are usually given by a nurse in a clinic or in an outpatient ward of a hospital. Each bag of blood will take 60-120 minutes to transfuse.

Platelet transfusions

If you have symptoms of low platelets (thrombocytopenia), you may need a platelet transfusion. This is like a red blood cell transfusion, but you will be given a bag of platelets instead of packed red blood cells.

Growth factors

Growth factors are chemicals in your blood that help the bone marrow produce different types of blood cells. Some growth factors can be made in the lab and can be given as an injection. They are used to boost low blood counts.

In Australia, white blood cell growth factors are given. Neutrophils are white blood cells that help fight infections. A growth factor called granulocyte colony stimulating factor (usually called G-CSF) makes the bone marrow produce more neutrophils.

Growth factors don't usually cause any major side effects, but some people may have chills, headaches and bone pain after an injection.

Antibiotics

When your white blood cell count is low you have a higher risk of getting infections. If you do, it's important to be treated as soon as possible. Your treatment team will probably prescribe antibiotics, either in tablet form or given via 'drip' straight into your bloodstream (IV).

Antifungal and antiviral medicines

When you start chemo or if you are preparing for a stem cell transplant, you may be given antifungal and/or antiviral medicines. Because you are low in certain cell types, you have a higher risk of fungal or viral infections. These types of medicines will be taken to prevent infection. This is called prophylaxis, or you might hear the drugs referred to as prophylactics. They will usually be in tablet form and your treatment team will tell you how often and for how long you need to take them.

Vaccines

Vaccines are important for people with Myeloma because you have a higher risk of infection. Vaccines help prevent infections. Only some vaccines are safe, and these are called inactivated vaccines. You will need to check with your treatment team when to have them. You should not have any live vaccines.

Osteoporosis and osteopenia

Some people with Myeloma have a condition called osteoporosis. It affects the bones, causing loss of bone thickness. Bone thickness is often called bone density. Osteopenia is a stage of bone loss, where your bones are weaker than normal, but stronger than if you had osteoporosis. If you have osteoporosis, your treatment team might give you a medicine called a bisphosphonate. Bisphosphonates work by 'coating' the surface of your bones, protecting them from the damaging effects of Myeloma cells. They slow down bone loss. They also help with bone pain and lower the risk of bone fractures. They are given via drip (IV) in a clinic or outpatients unit.

If you're having bisphosphonates you should drink at least 2-3 litres of water each day. You'll need to avoid medicines that increase the risk of kidney damage, particularly prescribed or over the counter non-steroidal anti-inflammatory drugs (NSAIDs). Your treatment team will give you advice about what not to take.

Side effects of bisphosphonates

Bisphosphonates usually don't have many side effects. Some people will have:

- a headache
- flu-like symptoms, like a runny nose and aches and pains
- muscle aches, stiffness or joint pain.

If you feel achy, it's best to get up and move about as much as you can.

Osteonecrosis

Bisphosphonates can cause a serious condition called osteonecrosis of the jaw. It involves exposed parts of bone on the jaw, often where a tooth has been taken out or you've had dental work done at some stage before treatment. It happens because these drugs lower blood supply to the bone. You'll need to have a dental assessment and any dental treatment before you start bisphosphonates. You'll also need regular dental reviews while you have treatment.

Standard drug therapies

All about chemo

Chemotherapy medications (also called chemo), sometimes also called cytotoxic (which means 'cell killing') medications, make cancer cells stop growing. They either kill the cells or stop them from dividing. They also damage normal cells, but these cells can repair and recover.

Unlike supportive care, which treats symptoms, chemo treats the actual disease. Because of this it's often called disease modifying treatment.

Chemo can be given as tablets, injections, or infusions via a drip (IV). The type of chemo given depends on the type of cancer. It's common to be on more than one chemo drug at a time. Some people have chemo alongside other therapies like targeted therapy, immunotherapy, surgery or radiation therapy. You can take some tablet chemo at home and may have injections or IV chemo in a clinic, outpatient ward or as an inpatient in hospital.

Intravenous chemo is given in cycles of treatment days. This means that you will have treatment for a certain number of days, followed by a set number of rest days. Chemo cycle times depend on the drug. The number of treatment days and the number of cycles can be different due to the drug or the disease being treated.

Combination therapy

Standard drug therapies for Myeloma include targeted therapy, chemotherapy and, in some cases, immunotherapy. When you start treatment, you'll most likely have a combination of these types of therapies.

Your haematologist will recommend your drug therapies depending on:

- your stage of Myeloma
- your overall health
- your age
- whether it is your first treatment or your Myeloma has come back after remission (relapsed), and
- whether you are preparing for a stem cell transplant. You can read more about stem cell transplants later in this booklet.

Targeted therapies

As we learn and understand more about the way Myeloma starts, we can utilise this information to help develop new treatments. Some of these treatments may directly target the mutations inside the Myeloma cells, whilst others may slow down their growth, or speed up the rate at which the Myeloma cells die.

Targeted therapies are now the main treatments used in Myeloma. The way these treatments are used can be complex, and your doctor will discuss the best options available for you. Also, many of these treatments are only available in clinical trials, and your treatment team may also discuss the option of participating in a clinical trial with you.

Monoclonal antibodies

Monoclonal antibodies are a type of immunotherapy. They work by attaching to specific cancer cells to tell the immune system to destroy those cells. They also make cancer cells grow more slowly.

Immunotherapies

Immunotherapies are sometimes called biologic therapies. They use a part of your immune system to fight cancer. In this case, antibodies are created in a lab. In your body, antibodies fight infection by targeting parts of cancer cells to change how they grow. Immunotherapies are given via drip (IV) or in tablet form.

Corticosteroids

During treatment you may be given drugs called corticosteroids or steroids for short. Steroids are drugs that act like your body's own hormones. They can help treat many types of cancer, and they can keep you from having nausea and vomiting after a round of chemo. They can also prevent allergic reactions to other drugs and blood products.

Common steroids are prednisolone and dexamethasone. They can be given in tablet form and/or via drip (intravenously). They help destroy cancer cells and reduce the risk of allergic reaction to some drugs.

Maintenance

Once you're in remission, you may have more drug therapy if your haematologist thinks it might help you stay in remission longer. Which drugs you will receive depends on if you are in remission following a stem cell transplant or after treatment with drug therapies.

Relapsed Myeloma

Often Myeloma comes back (relapses) after a period of remission. The treatment options will depend on your previous treatment, your age and overall health, and how long the Myeloma was in remission. The treatment goal is to achieve remission again. It may involve a similar combination of medicines or different drugs. A stem cell transplant may be an option too.

Hard-to-treat (resistant or refractory) Myeloma

Myeloma cells can become resistant to treatment over time. This means you don't see the changes you would expect after treatment.

If further treatment or a clinical trial is not an option, the treatment goal might change. You may receive supportive care, which treats any symptoms of Myeloma. It does not try to cure it.

Drug therapy side effects

Everyone gets different side effects with treatment. You may have no side effects, or one or more of them, and they may change over time.

Which side effects you have and how severe they are depends on:

- your stage of Myeloma
- your treatment type
- your overall health and wellbeing.



You can find more information on side effects and how to manage them on our website.

Changes in blood counts

Some treatments affect your bone marrow's ability to produce enough blood cells.

Low red blood cells cause anaemia. You may feel tired, short of breath, and look pale. Take it easy and contact your treatment team. You might need a blood transfusion.

If your platelets are low, you can bruise and bleed more easily. You may need a platelet transfusion.

Your white blood cell count (neutrophils) will drop within a week of your treatment. This puts you at a higher risk of developing an infection. You may be given G-CSF to help raise your neutrophils.

Feeling sick – nausea and vomiting

Nausea (feeling sick to your stomach) and vomiting are common side effects but you will be given medicine to prevent or manage them.

Keep an eye on your weight if you are eating less than usual. If you find it difficult to eat, talk to your treatment team. They can arrange for you to see a dietitian for some advice.

Sense of taste and smell

Changes to your sense of taste and smell can make you not enjoy food and drinks that you used to love. You might have a metallic taste in your mouth. These changes will pass when your treatment ends.

Mouth problems – mucositis

Your mouth or throat might become sore, or you might get ulcers. This is called mucositis. It is very important to keep your mouth clean by using an alcohol-free mouthwash, salty water or sodium bicarbonate in water.

Bowel changes

You might have cramping, wind, bloating, diarrhoea or constipation. You will be given medication to help. Tell your treatment team if you have diarrhoea, are constipated or if it's painful or hard to pass faeces if you have haemorrhoids. Sometimes making a few changes to what you eat can help too. Your treatment team can give you tips on food choices. You can read more about diet and nutrition later in this booklet and on our website.

Feeling tired and weak (fatigue), even after resting

Most people feel tired following chemo. It can be frustrating if you're used to keeping busy. You can find more on how to manage fatigue later in this booklet and on our website.

Bone, joint and muscle aches and pains

You may find you feel achy or sore, particularly in the morning. The pain may be because of your Myeloma, or it might be due to treatment. Talk to your treatment team if you have pain.

Chemo brain

You may find it difficult to concentrate ('foggy brain') or have trouble remembering things. Recovery will be different for everyone. There are no medicines to help with chemo brain but adaptive strategies can assist managing everyday life. Set up some ways to remember things, like writing them down. Talk to your support network too, so they know what's going on.

Hair loss (alopecia) and thinning

The thought of losing your hair is scary. Hair thinning or loss is a very common side effect of chemo although not all chemotherapy medication causes hair loss. You might lose your head hair, your eyebrows, and your eyelashes, but it's only temporary. Hair starts to fall out a few weeks after you start treatment and tends to grow back three to six months after it finishes.

You might find your scalp is itchy as you lose your hair, but this will pass. There are some great wraps, turbans and beanies available. Your nurse can give you information on where to find them, and about where to get wigs.

Tingling or numbness in fingers and toes (peripheral neuropathy)

Some drugs can affect your nerves, usually in your hands or feet. This is called peripheral neuropathy. Symptoms can start any time during treatment. Tell your treatment team if you feel tingling, numbness, burning or pins and needles in your fingers or toes. It might be hard to do up buttons or to grip things.

Skin issues

There are a few different skin changes you might have as a result of treatment. You may have a rash, or you may have soreness, redness or skin changes where you are having regular injections.

Sun sensitivity

Some drugs make you more prone to sunburn. You can go outside, but you will need to avoid direct sunlight.

Managing side effects

Potential side effects	What might help
Low red blood cells (anaemia)	<ul style="list-style-type: none">• you may be given a blood transfusion or recommended supplements
Low platelets	<ul style="list-style-type: none">• avoid sharp objects in your mouth like chop bones or potato chips• be careful not to cut or injure yourself• use a soft toothbrush• use an electric razor• wear gloves and closed shoes in the garden
Low white blood cells (neutrophils) – risk of infection	<ul style="list-style-type: none">• talk to your treatment team about vaccinations• avoid crowds• keep away from people who are sick and might be contagious (colds, flu, chicken pox)• eat food that has been properly prepared and freshly cooked• don't clean up pet faeces• wear gloves in the garden• don't swim in public pools, lakes or rivers
Feeling sick – nausea and vomiting	<ul style="list-style-type: none">• eat smaller meals more often during the day• try cool or cold food, like jelly• let someone else cook for you• drink ginger ale or soda water• avoid strong smells• you'll be given medicine to help
Change to taste	<ul style="list-style-type: none">• add a little more sugar to sweet foods• add a bit more salt to savoury foods• if you have a metallic taste, try rinsing your mouth

Mouth problems – mucositis	<ul style="list-style-type: none"> • use a soft toothbrush and mild toothpaste • brush every time after you eat • use salty water, sodium bicarbonate in water, or alcohol-free mouthwash • continue to floss but stop if your gums bleed
Bowel changes	<ul style="list-style-type: none"> • drink plenty of fluids • get some dietary advice from your treatment team • if you're constipated, don't strain • if you have haemorrhoids, do not push on them • tell your treatment team, you'll be given medicine to help
Skin problems (rashes, sensitivity)	<ul style="list-style-type: none"> • your treatment team will recommend body washes and cream that are safe to use • avoid soaps and perfumes on the affected area • take cooler showers or baths
Fatigue	<ul style="list-style-type: none"> • see later in this booklet for more information • rest or nap when needed • take regular gentle exercise
Bone, joint or muscle aches and pains	<ul style="list-style-type: none"> • talk to your treatment team • consider some gentle exercise, like walking a small distance every day • you may be given medicine to help
Chemo brain	<ul style="list-style-type: none"> • keep a notebook handy to write things down • ask your pharmacist to Webber-pak your medications • take regular gentle exercise • socialise – tell your loved ones what's going on

Hair loss and thinning	<ul style="list-style-type: none"> • prepare your family and friends • use a soft hairbrush and a mild baby shampoo • pat your hair dry gently with a towel • cut your hair shorter or have it shaved when you start chemo • use an electric shaver • avoid using heat or chemicals; don't dye or blow dry your hair • use sunscreen on your scalp
Sun sensitivity	<ul style="list-style-type: none"> • cover up with long sleeves and long pants • wear sunglasses and a hat or beanie to protect your scalp • talk to your nurse about which sunscreens are best to use • avoid sun exposure at high UV times of the day

Radiation therapy (radiotherapy)

Radiation therapy, also called *radiotherapy*, is a type of treatment that uses high energy X-rays to kill cancer cells and shrink tumours. Radiotherapy is a *local* therapy because it only destroys cancer cells in the area it treats.

It can be used in a few different ways to treat Myeloma. In some cases, single clumps of Myeloma cells (plasmacytomas) may be treated using only radiotherapy. Radiotherapy is also used to treat areas of bone that have become weak due to Myeloma (lytic lesions). It helps reduce bone pain and the risk of bone fractures.

Before you start radiotherapy, you'll meet with the radiation oncologist (specialist in treating people with radiotherapy). You'll discuss treatment options and goals, and you may have a physical examination.

Next, you'll have a *simulation* session. You'll have scans and your radiation oncologist and radiation therapists will work out what position you will be in for all your radiotherapy treatments. They'll also work out your dose of radiation. You may end up with small tattooed dots on your skin, which help guide the treatment.

During treatment

Radiotherapy: what to expect

Treatment is usually short: allow 15-30 minutes per treatment. Most of this time the treatment team will be setting you up for your session. You'll be alone in the treatment room, but your treatment team will be able to hear and see you. If you're feeling nervous you might like to bring along some music to help you relax.

You'll be positioned the way you were in your simulation session. The radiation machine will move around you to deliver the treatment and it'll make a buzzing sound. The radiation beam is on for only a couple of minutes. It's important to stay still while the treatment is taking place. If necessary, important structures like your heart and lungs will be shielded so they're not affected by the treatment. You don't see or feel anything during the actual treatment and it's painless.

You may have short (one or two treatments) or longer courses of radiotherapy depending on your needs. Longer courses are usually given in small doses (called fractions) every weekday (Monday to Friday) over a few weeks.

Side effects

Radiation therapy can cause side effects. The side effects vary from person to person. Some are short term, and some can last beyond treatment.

Side effects include:

- fatigue – extreme tiredness not relieved by rest. you can read more about it later in this booklet
- skin changes – your skin may become red, dry warm or sore where you are treated. Stay out of the sun. Skin changes will be worst just after your treatment end. They will usually start to heal four to six weeks after you finish radiotherapy
- mouth pain or soreness
- feeling sick (nausea and/or vomiting)
- bowel changes – wind, loose stools, diarrhoea, bloating, cramping
- hair loss – only in the area where you're having radiation.

Follow up

After your course of radiotherapy finishes, you may have scans. Then you'll see your radiation oncologist to discuss how your treatment went.

Surgery

Some people may need surgery to repair fractured bones or to help stabilise bones your treatment team thinks are likely to fracture.

Stem cell transplantation

Stem cell transplants are also called bone marrow transplant, or a hemopoietic cell transplant or HCT. This treatment is not available for everyone because there are very serious side effects, including a risk of dying.

Stem cell transplant involves having very high doses of chemotherapy before the transplant. The aim is to destroy the Myeloma cells in your bone marrow. These cells are then replaced with healthy stem cells.

The goal is to create an immune response called a graft-versus-Myeloma (GVM) effect. The new stem cells make their own immune cells. These immune cells kill any cancer cells that are left after you've had the high-dose chemotherapy.

Autologous stem cell transplant

Your own stem cells are collected when your Myeloma is stable or you are in remission. They're stored until after you've had chemo when they're returned to your bloodstream. Autologous transplants are more common in people with Myeloma than allogeneic transplants.

Allogeneic (donor) stem cell transplant

The healthy stem cells have to be donated. Usually, your brother or sister who has the same tissue type as yours is the donor. They will need a blood test to see if they are a match to you. If they are, they are called HLA identical matched donors.

Rarely, the stem cells can also come from someone who is not related but are HLA compatible.

Stem cell transplant side effects include:

- low blood counts
- all the same side effects as chemotherapy, but more severe
- graft-versus-host disease for allogeneic transplants, where the body rejects the donor's stem cells.

These side effects can go on for years after the stem cell transplant.

You can find out more about stem cell transplants in our booklets *Autologous Stem Cell Transplants* and *Allogeneic Stem Cell Transplants* and on our website.

Clinical trials

Clinical trials (also called research studies) test new treatments. They compare them against current treatments to see if the new treatment works better. They also check for the new treatment's side effects. Many clinical trials are randomised, which means some patients receive the new treatment and others the current standard of care treatment.

Clinical trials provide important information about how treatments can be improved. Sometimes people on clinical trials (called 'participants') have access to expensive new treatments that aren't on Australia's PBS. Clinical trials are an excellent opportunity to get access to world leading treatments that are often not available otherwise. Every clinical trial is reviewed by a human research ethics committee. They ensure that the research is appropriate, and that all patients receive the best available clinical care.

Your treatment team may suggest you join a clinical trial. Before you can start, you will need to give informed consent.

This shows that you understand the risks and benefits of the trial treatment.

Clinical trials are run through hospitals and clinics, just like other treatments. You will have a clinical trial nurse as part of your treatment team.

Clinical trial participation is purely voluntary. If you are offered a clinical trial, make sure you understand how your treatment will be different compared to what is generally given (standard of care treatments). Be sure to ask any questions you have before deciding whether to participate.

You can search current clinical trials at:

Australian Cancer Trials australiancancertrials.gov.au

ANZ Clinical Trials Registry: anzctr.org.au

Second opinion

If you feel unsure about your diagnosis or treatment, you are entitled to seek a second opinion from an independent doctor. This may be at the same hospital or clinic, or at a different location. If you feel overwhelmed, then you might benefit from speaking with someone at the Leukaemia Foundation, your GP or a counsellor for advice.

Complementary therapies

Complementary and alternative medicines (CAM) also known as Integrated therapies are not standard medical treatments. However, some people find that they help with side effects. These therapies should 'complement' or be done alongside medical treatment after consultation with your treatment team. No complementary or alternative treatment on its own can treat Myeloma. They may help with some symptoms or side effects.

Managing fatigue

Many people who have blood cancer treatment get fatigue. It's called cancer-related fatigue. It can be hard to describe to people who haven't felt it. It's more than being tired, it's different to normal everyday tiredness, and is often not resolved with sleep or rest. You will feel tired, but you may also feel weak and be sleepy, drowsy, impatient or confused. It's hard when you have no get-up-and-go, however, for most people fatigue should improve after you finish treatment.

Tips for managing fatigue

Fatigue is a side effect of your blood cancer or treatment so managing fatigue is an important part of your overall treatment and care. Make sure you talk to your treating team about it, they may suggest referral to a psychologist who specialise in sleep management. It's very important to explain how you feel to your carers and support people, and to let them know your priorities and discuss how they can help.

A positive sleep routine, pre-sleep relaxation techniques, napping if tired during the day for an hour or less, regular moderate exercise or movement, eating well, drinking plenty of water and avoiding use of electronic equipment such as computers late at night can be very helpful in improving sleep and reducing fatigue.

While you're managing your fatigue, you can jot down what time of day you have most energy and when you feel most tired. That will help you get into a routine and prioritise your energy. Play games, listen to or play music, read, catch up with friends and family. These things might seem difficult, but they will help distract you from the fatigue.

Fertility decisions

It may seem odd reading about fertility here, given the average age of most Myeloma patients. But some young people do get Myeloma, while others have younger partners.

Some types of treatment may affect your fertility, which is your ability to conceive a baby. It is important to talk to your treatment team about future fertility before you start treatment. If you are planning on having a child, there are steps you can take.

Make sure you understand:

- the fertility preservation processes
- success rates
- the risks
- side effects of fertility treatments
- any costs.

For men

Chemo can stop or lower your sperm production. It can reduce your sperm's ability to move. This can be temporary or permanent. It also affects the hormone testosterone.

The best way to preserve your fertility before treatment is by freezing a semen sample, which contains sperm. This is called *sperm cryopreservation*.

For women

Chemo can reduce your number of available eggs (ova) and can affect your hormones. Tell your treatment team right away if you are pregnant or think you may be.

There are several mainstream fertility *cryopreservation* (freezing) options for women. Egg and embryo freezing are common, less so ovarian tissue freezing. For some young women and their families, it may not be possible to pursue fertility options prior to cancer treatment. Having the opportunity for discussion about your future fertility is important.

Fertility Society of Australia: fertileysociety.com.au

Practical matters

Navigating the health system

The Australian health system may seem large, complicated, and stressful especially when you are also living with a blood cancer. Knowing a bit about how our health system works and who are key people in your care can make navigating the system much easier.

Key people in your health team

Haematologist - A specialist doctor trained in diseases of the blood including blood cancer who leads a team of doctors in your care.

Radiation oncologist - A doctor who specialises in treating cancer using radiotherapy.

Cancer care coordinator (CCC)/ Cancer nurse consultant (CNC) - Specialist cancer nurses who coordinate patient care and provide referrals to allied health professionals if needed.

Cancer nurse - A nurse in an outpatient clinic or cancer ward who supports, educates, and gives you your chemo treatment.

Palliative care physician - A doctor who specialises in controlling symptoms and improving quality of life in people with terminal illnesses and chronic health conditions.

Pharmacist - A health professional who prepares, dispenses medicines (drugs), and supports your understanding of how to manage your side effects with medication prescribed.

Accredited practising dietitian - A university-qualified professional with ongoing training and education programs, who helps to support your recovery and manage challenges in your diet.

Social worker - A health professional who specialises in emotional support, counselling, and advice about practical and financial matters.

Physiotherapist/Exercise physiologist - Health professionals who specialise in treating and rehabilitating patients through physical means.

Psychologist - A health professional who specialises in providing emotional support and difficulties such as anxiety, distress, and depression.

Record your important contact details here:

	Contact name	Phone	Comment
Emergency			
GP			
Haematologist			
CNC/CCC			
Chemo Day Unit			
Pharmacist			
Dietitian			
Social worker			
Psychologist			

Useful website: <https://patients.cancer.nsw.gov.au/diagnosis/navigating-the-health-system>

The new normal – what is it?

For many people, the start of treatment signals changes to life that include the day-to-day managing of a multitude of new activities and changes around treating and monitoring of your blood cancer. Frequent appointments with your health care team and regular follow up can be tiring and stressful for all.

Life is not exactly the same as it was before the blood cancer diagnosis. Everyday life changes for you and the people around you. Things that were once important may no longer be so, or things that weren't important before, now take greater priority.

In essence, a 'new normal' is about living with your blood cancer, creating and maintaining your new normal to live as good a life as possible while facing changes such as and not limited to:

- Physical/mental/spiritual
- Emotional/relationships/identity/sexuality
- Financial, ability to work/return to productivity

Seeking information, tools, and support, and accepting help to manage challenges that arise throughout a person's cancer experience is very important. Having this support can enable individuals to have a high quality of life throughout their blood cancer journey. It is also important to remember that dealing with the diagnosis and treatment of blood cancer is a big life change and everyone handles it and is affected differently.

Diet and nutrition

During treatment nutritional goals are designed to prevent or reverse malnutrition, avoiding weight loss (preserving lean body mass/ muscle) and to minimise side effects, such as decreased appetite, nausea, diarrhoea, dry mouth, and taste changes.

Being underweight or malnourished can have a negative effect on your overall quality of life. Poor appetite and weight loss are associated with symptoms such as weakness, fatigue, difficulty sleeping, and pain.

It is likely you will be encouraged to eat a high-energy diet to meet the changing metabolic demands of your body during this time. During chemo treatment you may experience complications that negatively affect your nutrition and hence your overall wellbeing, such as mucositis (ulcers in the mouth/throat and/or stomach).

You may be given drugs called corticosteroids, as part of your treatment. Steroids can cause weight gain through increased appetite stimulation and fluid retention (oedema) in your limbs, abdomen, and face.

General nutrition recommendations for people receiving cancer treatment:

- **Maintain a healthy weight.** For many people, this means avoiding weight loss by getting enough calories every day. For people who are obese, this may mean losing weight. It's important to get advice from your health care team before you try to lose weight during treatment.
- **Get essential nutrients.** These include protein, carbohydrates, fats, and water.

You can make an appointment to see a hospital dietitian as an outpatient or ask to see one if you are an inpatient. Your treating team may refer you to a dietitian. Community dietitians are also available, and your GP can arrange this through a care plan if your private health insurance doesn't cover it.

Exercise/physical activity

With any blood cancer treatment, it is common to experience deconditioning; a physical and/or psychological drop in function. Having cancer doesn't mean you can't be physically active.

People with blood cancer should attempt to avoid inactivity and sedentary behaviour as much as possible and return to normal daily activities as soon as possible following diagnosis.

What are the benefits of exercise/physical activity?

Strong evidence is available to show that exercise and physical activity improves outcomes for people with cancer across a range of dimensions including:

- cancer-related fatigue, pain, psychological distress, anxiety, depression
- in-bone health, cognitive, and cardiovascular function
- Health-related quality of life.

Exercise can be tailored to the individual and often around activities of daily living. Before you commence any exercise program it is important to speak with your treatment team first to make sure it is safe to do so and to see who is best placed to help you.

Information on exercise in cancer can be found on the Clinical Oncology Society of Australia (COSA) website: cosa.org.au

Please see our website for more detailed information and videos that may be helpful www.leukamia.org.au

Specific information for older people on exercising with chronic illness and some advice about healthy eating is available from the Australian Government "Choose Health: Be Active A physical activity guide for older Australians"

Mental health and emotions

Your emotional health is a very important aspect of overall wellbeing. Many people being treated for blood cancer experience a range of feelings and it is not uncommon to feel low, depressed, or anxious.

Feeling sad is a normal response to a cancer diagnosis as is worrying about the future. Feelings can be challenging and may include anxiety, grief, guilt, uncertainty, anger, spiritual distress, fear, and feeling isolated or lonely. Worrying about treatment, its success and side effects, or changes in your physical, lifestyle, and family dynamics can also impact your mental health.

Seeking help from your healthcare team is important. They and/or your GP can refer you to someone who can help, such as a psychologist who specialises in blood cancer. The Leukaemia Foundation's Blood Cancer Support Coordinators can also help you to work through what you are feeling and provide information on who might assist you in your local area.

Visit leukaemia.org.au or call 1800 620 420.

Relationships/carers/family and friends

Undergoing treatment for a blood cancer can affect your role as a parent, partner, friend, and workmate, to name a few. You and all the people in your life will cope differently. Be open with your communication and encourage family and friends to be open with you.

Communicating effectively with family, children, friends, and a carer is essential. Being clear with others about what you want and need allows them to be of greater support. Together you can work as a team to manage and solve problems as they arise.

There are many allied healthcare staff and not-for-profit organisations that can assist with support and information.

The Leukaemia Foundation is one of them and can assist you, your carer or family in identifying who can help with different issues and how to contact them.

Carers Australia: carersaustralia.com.au

Carer Gateway (Australian Government): carergateway.gov.au

Canteen: canteen.org.au

Redkite: redkite.org.au

Work/finances/legal matters

Finances

People with blood cancer often report a negative impact on their financial situation during treatment. Monthly costs can increase and may be influenced by financial considerations such as travel, childcare, and taking time off work for appointments. Your household income may be reduced due to you or your carer having to stop work, or reduce hours permanently or temporarily, as a result of your diagnosis.

A financial stocktake

When you become aware that you may lose your income or suffer a reduced income as a result of the ill health of you or an immediate family member, the first step should be to run a quick 'financial stocktake'.

First, assess what income you can expect or what financial resources you have available. Possibilities may include:

- Are you or your partner able to work part-time?
- Do you have sick leave or long service leave?
- Do you have income protection or trauma insurance, either as a stand-alone policy or part of a life policy?
- Do you have money in the bank or a line of credit against your mortgage which can be drawn against?

The second step involves checking on important expenses which need paying in the immediate future. Put together a brief budget if you don't have one.

Seeking help

Financial advice around budgeting and what financial assistance is available to you can be discussed with a number of sources. Your local Leukaemia Foundation Blood Cancer Support Coordinator can help point you in the right direction.

A few key other options to consider are:

Centrelink

If you expect to lose all or most of your income or your partner's income, the first organisation to contact is Centrelink. The earlier you make an application, the sooner you may receive some relief payments. If you have employment to return to, this will affect the basis of your benefit. Your partner may also be eligible for a Carer Payment or Carer Allowance, so be sure to enquire about this.

Centrelink online account (*sign in through myGov for instructions*): centrelink.gov.au

Financial institutions

If you are unable to make your regular payments on your mortgage as a result of serious ill health, it is important that you let the relevant organisations know as soon as possible. Most banks and other financial organisations have special arrangements for customers in financial hardship as a result of ill health.

Other sources of help

Do not hesitate to discuss your financial circumstances with your treatment centre social worker or your private insurer. They may be able to assist with advice on deferring payments. Some of your household accounts may also have hardship support programs (like energy providers). It may be possible to access some money from

your superannuation fund to help with emergency payments. Don't forget to check if your superannuation has income replacement insurance as one of its features. If you are not sure, give their helpline a call.

Moneysmart: moneysmart.gov.au

National Debt Helpline: ndh.org.au or phone 1800 007 007

Legal matters

This information applies equally to all members of the community, not just those who have a blood cancer or their carer. The best time to get your affairs in order is when you are in good health. Here we consider some of the most common legal documents you should have and where to get help.

Enduring Power of Attorney/Enduring Guardian

There may be circumstances when a person loses the capacity to make decisions for themselves. You can sign a legal document which allows you to choose a trusted person to make decisions on your behalf.

An Enduring Power of Attorney (EPOA) is a document that allows your trusted person the power to sign documents on your behalf, make personal, administrative and, if you choose, financial decisions.

An Enduring Guardian (EG) is another document where your trusted person can make decisions on your behalf regarding your health matters such as medical treatment, care, and protection, even if this decision overrides your wishes.

Australian Guardianship and Administration council: agac.org.au

Wills

It is very important to have specialist legal advice when preparing your Will. There are many questions and options your legal adviser will discuss with you which may not be immediately apparent. This is particularly important when you have dependent family members and you need to determine who will be responsible for them in the event of your death.

If you die without leaving a valid Will, you leave what is known as 'intestacy'. Although you may feel your affairs are very simple and your immediate family will receive your assets, this is not necessarily true. Should you die intestate, distribution of your estate will be determined by a formula set down in legislation. If you already have a Will, you need to consider if it is still current.

Advance Health Directive

This is a document you may complete to clearly indicate your wishes as to medical treatments you may or may not wish to receive in the event of a serious illness or accident. Although this is a lengthy document, it is simple to complete as it mainly consists of a series of optional questions. There are also sections where you make comments in your own words. While this form can be completed on your own, you may wish to discuss it with your family, and you are also required to have a doctor sign the form to certify that you understand the contents of the document.

Advance Care Planning Australia: advancecareplanning.org.au or phone 1300 208 582.

Getting help

Help with legal matters is available from several sources including:

- Solicitors
- Trustee companies
- The Public Trustee in your state
- Australian Guardianship and Administration Council

More information & help

Glossary

You can find any **bold** terms in the definitions also defined in this glossary.

anaemia	A lower-than-normal number of red blood cells in the blood. It causes tiredness, paleness, and sometimes shortness of breath.
baseline	A first measurement of a condition taken early on, used to compare over time to look for changes.
biotherapy	A type of treatment that uses substances made from living organisms to treat disease. These substances may occur naturally in the body or may be made in the laboratory.
blast cells	Immature blood cells normally in the bone marrow in small numbers.
bone marrow	Soft, sponge-like tissue in the centre of most bones. It contains stem cells that make all blood cells.
bone marrow biopsy	Also called a bone marrow aspirate, bone marrow trephine or BMAT. The removal of a small sample of bone marrow . This is sent to the lab for a pathologist to look at under a microscope.
bone marrow aspirate	A sample of bone marrow fluid.
bone marrow transplant	Also called a stem cell transplant . A procedure where a patient is given healthy stem cells to replace their own damaged stem cells. The healthy stem cells may come from the bone marrow of the patient or a donor. There are three types: autologous (using a patient's own stem cells that were collected from the marrow and saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stem cells donated by an identical twin).
bone marrow trephine	A sample of bone marrow tissue.
cancer	Diseases where some of the body's cells become faulty, begin to multiply out of control, can invade and damage the area around them, and can also spread to other parts of the body to cause further damage.

chemotherapy	The use of drugs to treat cancer.
chromosome	Part of a cell that contains genetic information.
coagulation	Process of changing from a liquid blood to a solid. Also called <i>clotting</i> . Platelets help with coagulation.
cytogenetic tests	The study of the structure of chromosomes . These tests are carried out on samples of blood and bone marrow . The results help with diagnosis and getting the most appropriate treatment.
cytopenia	Where there is a lower-than-normal number of a type of blood cell in the blood.
dysplasia	Also called dysplastic cells. A change in size, shape, and arrangement of normal cells seen under a microscope.
erythrocytes	Also called red blood cells. A type of blood cell made in the bone marrow and found in the blood. Haemoglobin makes these cells red in colour.
full blood count	Also called FBC or complete blood count. A routine blood test that measures the number and type of cells, and the haemoglobin and haematocrit in the blood.
growth factors	Proteins that control cell division and cell survival. Some are made in the lab and used as treatments, such as G-CSF.
haematocrit	The amount of blood that is made up of red blood cells .
haematologist	A doctor who specialises in diagnosing and treating blood disorders.
haemoglobin	A protein inside red blood cells that carries oxygen around the body.
haemopoiesis	The formation of new blood cells.
hypogammaglobulinaemia	A problem with the immune system in which not enough gamma globulins are produced in the blood. This results in a lower antibody count, which impairs the immune system, increasing risk of infection.
immune system	The body's defence system against infection and disease.

immunotherapy	Immunotherapy, sometimes called biological therapy, is a type of cancer treatment that works by boosting a person's own immune system to fight the cancer. Immunotherapy is currently approved in Australia for some types of cancers and is also being trialled for other cancers.
leukaemia	Cancer that begins in blood-forming tissue, such as the bone marrow . It causes large numbers of abnormal blood cells to be made and to enter the bloodstream.
leukocytes	Also called white blood cells. These blood cells are made in the bone marrow and found in the blood and lymph tissue. They help the body fight infection and are part of the immune system . Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).
megakaryocytes	Very large bone marrow cells that break apart to form platelets .
mutation	A harmful change in 'normal' DNA (the building blocks of all cells).
neutropenia	A lower-than-normal number of neutrophils in the blood. It increases the risk of infection.
neutrophils	The most common type of white blood cell . They help fight infection.
pancytopenia	Where there are lower-than-normal numbers of a type of all blood cells and platelets in the blood.
pathology	The study of diseases to understand their nature and their cause. A specialist in this field is called a pathologist . In cancer, histopathology/histology involves examining tissue under a microscope. Haematopathology involves blood and lymph.
petechiae	Tiny, unraised, round red spots under the skin caused by bleeding.
platelets	Also called thrombocytes. Tiny pieces of cells (megakaryocytes) found in the blood and spleen. They help form blood clots (coagulation) to slow or stop bleeding and to help wounds heal.
prognosis	An estimate of the likely course and outcome of a disease.
purpura	Bleeding and bruising under the skin.

radiotherapy (radiation therapy)	Uses high-energy radiation from X-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells or injure them so they can't grow or multiply.
red blood cell	Also called an erythrocyte or RBC. A type of blood cell made in the bone marrow and found in the blood. Haemoglobin makes these cells red in colour.
relapse	Return of the original disease after it has improved for a time.
remission	Where the signs and symptoms of cancer decrease or disappear. Remission can be <i>partial</i> (a reduction in some or many symptoms) or <i>complete</i> (all symptoms have disappeared). Remission is not the same as a cure. Even in complete remission cancer cells may still be in the body.
rigor	Also called a chill. Feeling cold with shivering or shaking and looking pale, but with a high temperature. A symptom of infection.
stem cells	Young (immature) blood cells that can develop into more than one type of cell. Bone marrow stem cells grow and produce red blood cells, white blood cells and platelets .
stem cell transplant	Also called a SCT or bone marrow transplant. A procedure where a patient is given healthy stem cells to replace their own damaged stem cells. The healthy stem cells may come from the bone marrow of the patient or a donor. There are three types: autologous (using a patient's own stem cells that were collected from the marrow and saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stem cells donated by an identical twin).
thrombocytes	Also called platelets. Tiny pieces of cells (megakaryocytes) found in the blood and spleen. They help form blood clots (coagulation) to slow or stop bleeding and to help wounds heal.
thrombocytopenia	A lower-than-normal number of platelets in the blood. It causes bruising and bleeding.
white blood cells	Also called leukocytes or WBCs. Blood cells made in the bone marrow and found in the blood and lymph tissue. They help the body fight infection and are part of the immune system . Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).

Useful websites

Leukaemia Foundation:	leukaemia.org.au
Australian Cancer Trials:	australiancancertrials.gov.au
Australian New Zealand Clinical Trials Registry:	anzctr.org.au
eviQ Cancer Treatments Online:	eviq.org.au
Australian Red Cross Blood Service:	mytransfusion.com.au
Pharmaceutical Benefits Scheme:	pbs.gov.au
Myeloma Australia:	myeloma.org.au
ClinTrial Refer:	clintrial.org.au

Question builder

- Who will be my main contacts? How do I best contact you/ them?
- What can I do to avoid infections?
- Can I have the flu shot and other vaccinations?
- Is it safe to take my supplements or vitamins?
- Can I eat normally, is there anything I need to avoid or special diets that will help me?
- Can I exercise and what is the best frequency and type for me?
- Are there any clinical trials for my type of Myeloma and am I eligible?
- Could this treatment affect my sex life? If so, how and for how long?
- Will my treatment send me into menopause?
- Where can I or my loved ones get any other support?

How you can help

The Leukaemia Foundation ensures every Australian with blood cancer gets access to the trusted information, best-practice treatment, and essential care they need. With no ongoing government funding, we rely on the generosity of the community to help support all Australians living with blood cancer.

We understand that everyone's personal situation is different, so below are some of the ways you and your family may like to get involved.

Give

Your donations help provide free support services to Australians affected by blood cancer, (like financial and practical assistance, education, counselling and accommodation), and drive some of Australia's most important—and life-saving—cancer research.

Become a Lifeblood Hero

With your regular monthly gift, you can be there every step of every day in every way, for people living with blood cancer. Your ongoing support helps ensure everyone everywhere has access to the life-saving treatment and support they need.

Leave a gift in your Will

After taking care of your loved ones, a gift in your Will is a direct and valuable way of helping transform the future for Australians with blood cancer allowing your support to live on as a lasting legacy.

Fundraise

Get involved in World's Greatest Shave, plan a special Light the Night or celebrate your Best-Birthday-Ever! You can even create your own personal fundraising initiative that is completely unique.

Volunteer

Our wonderful volunteers are a crucial part of our success—helping at our signature fundraising events, maintaining our accommodation centres or providing support with specialised skills.

Become a Leukaemia Foundation Member

You can make a difference to the future of blood cancer by joining a networked community who care about people living with blood cancer. Members are the lifeblood of the Leukaemia Foundation and play an important role in shaping the future of the organisation.

Partner with us

There are many ways your business can help people with blood cancer. Together, we can create a bespoke partnership that aligns with your organisation's objectives and corporate social responsibility.

Give blood, marrow and tissue

Stem cell transplants and blood donations save the lives of many people facing many blood cancer. Visit donateblood.com.au to register today.

**To find out more contact us today supporters@leukaemia.org.au
1800 620 420**

The Leukaemia Foundation gratefully acknowledges those who assisted in the development of this information: Leukaemia Foundation Blood Cancer Support Coordinators, nursing staff, clinical haematologists, and bone marrow transplant physicians representing the various states and territories of Australia.


The Leukaemia Foundation values feedback. If you would like to make suggestions or tell us about your experience in using this booklet, please contact us via email: info@leukaemia.org.au or phone us on **1800 620 420**.

**Leukaemia
Foundation[®]**

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 The Leukaemia Foundation cares about our environment.
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