Myeloproliferative Neoplasms (MPN)

A guide for people with MPN and their support people

Leukaemia Foundation®

This booklet has been written to help you and your support people understand more about myeloproliferative neoplasms, most commonly called MPN. You can find more detailed information on the most common types of MPN in our fact sheets: Polycythaemia vera, Essential thrombocythaemia and Primary myelofibrosis.

We know you may be feeling anxious or overwhelmed if you or someone you care for has recently been diagnosed with MPN. 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 haematologist or nurse.

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 meet many different types of healthcare professionals who work as a team to provide you with the best treatment available. The people you'll most often see will be haematologists and haematology nurses, and you'll need a regular GP, but you'll also meet pathologists and allied health professionals, like dietitians. In this booklet, when we refer to 'your treatment team' we usually mean your haematologist and haematology nurses.

You will come across quite a few medical terms in this booklet. They are words that your treatment team will probably use and that you may not have heard before. They 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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MPN in brief

About MPN

Myeloproliferative neoplasms (MPN) are cancers that start in the bone marrow, where blood cells are made.

In MPN, the bone marrow makes too many of one or more types of blood cells (red blood cells, white blood cells and/or platelets). The increased numbers of blood cells produced by the bone marrow can affect the thickness of the blood, may not work properly or may precipitate fibrosis (scarring) in the bone marrow. There are six main types of MPN, diagnosed using blood tests and a bone marrow biopsy. Symptoms depend on which type of MPN you have. Common symptoms are: fatigue, weakness, weight loss, enlarged spleen (splenomegaly), bruising and bleeding, night sweats, and bone pain.

In most cases we don't know what causes MPN. In many patients an acquired driver mutation (alteration) in the genetic material of growing blood cells can be identified. There is no way to prevent MPN and you can't catch it or pass it on.

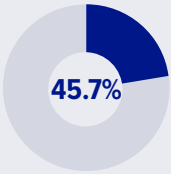
Scan to learn more about how the Leukaemia Foundation can provide you with additional support and the latest information about your blood cancer.

Who gets MPN

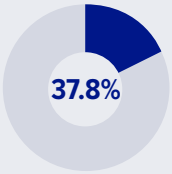
950
Australians diagnosed each year

Diagnosis generally higher in men than women

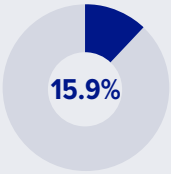
68
average age of diagnosis



45.7% of people diagnosed aged 70+



37.8% of people diagnosed aged 50-69



15.9% of people diagnosed aged 15-50

What's the prognosis?

The prognosis is an estimate your haematologist will make of the likely course and outcome of your disease. In MPN your haematologist will discuss the risks of complications from the disease, including the risks of vascular or thrombotic (clotting) events, and the risk of progression and transformation of the disease.

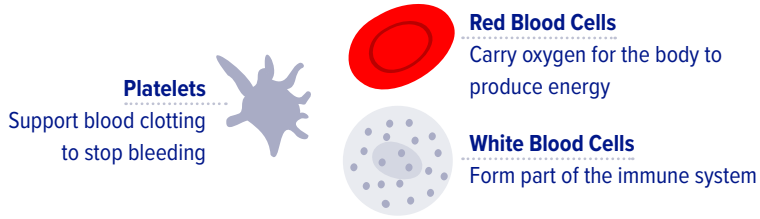
Your haematologist will consider many factors when considering your prognosis. Some of these are the type of MPN you have, your age, and your overall health.

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.



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. They help stop bleeding when you have an injury.

Condition	Cause	You might notice
Anaemia	Low RBCs or Hb	Tiredness, weakness, pale skin, shortness of breath, heavy legs
Neutropenia	Low neutrophils (WBCs)	More frequent infections
Leukopenia	Low WBCs	More frequent infections
Leukocytosis	High WBCs	Fever, weakness, dizziness, pain or tingling in arms, legs, belly
Thrombocytopenia	Low platelets	Bruising and bleeding, like nosebleeds
Thrombocytosis	High platelets	No symptoms
Pancytopenia	All three types low	A mix of symptoms
Polycythaemia (erythrocytosis)	High concentration of red cells in blood	A variety of symptoms including but not limited to headache, tiredness, dizziness, confusion, high blood pressure, discomfort in the abdomen, red skin – particularly in the face, hands and feet.

Where and how is blood made?

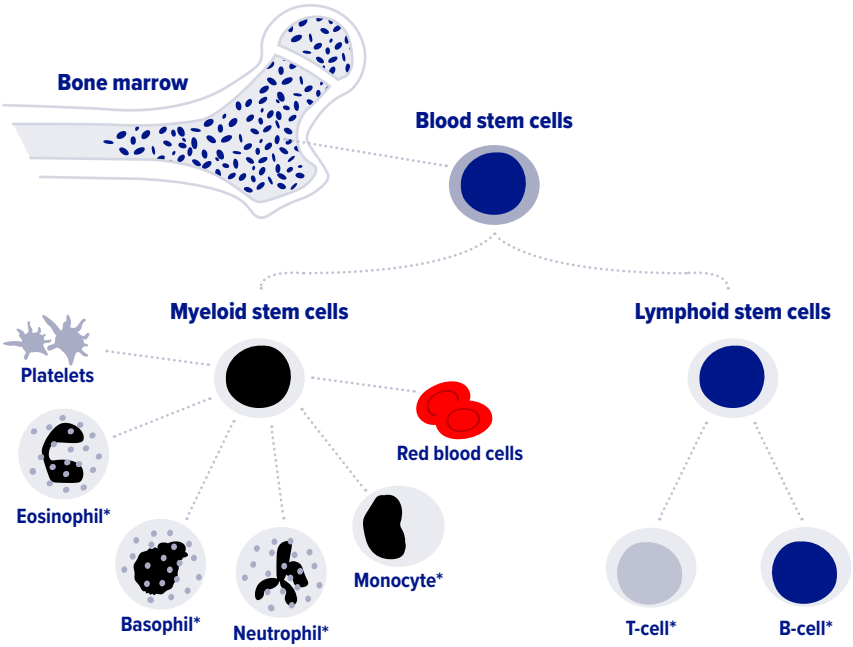
Bone marrow

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

In children, haematopiesis 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. At the bottom of the family tree are red blood cells, white blood cells*, and platelets.



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.

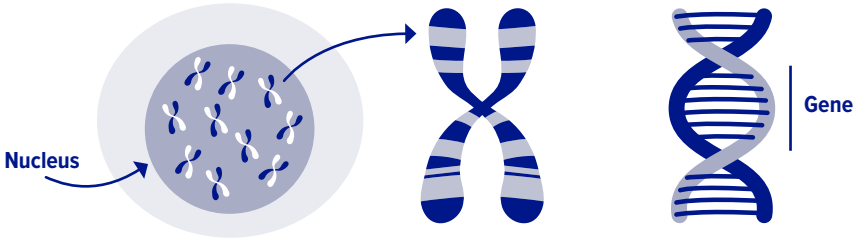
Chemicals in your blood, called *growth factors*, control blood cell formation. Different growth factors help make the blood stem cells in the bone marrow become different types of blood cells.

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

All about MPN

How does MPN develop?

Myeloproliferative neoplasms (MPN) are a group of diseases that affect how normal blood cells are made in your bone marrow. Inside cells there are coded instructions that control how the cell should act. Each section of DNA that holds the cell's instructions is called a gene.



Cell
The nucleus controls the processes of the cell

Chromosome
Chromosomes are thread-like structures made up of DNA tightly coiled many times around proteins called histones

DNA
Deoxyribonucleic acid is a self-replicating material present in nearly all living organisms as the main part of chromosomes. It is the carrier of genetic information

In MPN abnormalities develop in the DNA in stem cells in the bone marrow resulting in the overproduction of blood cells. The DNA damage is called an acquired mutation. The bone marrow also creates too many cytokines, which are substances like growth factors. As well as changes to stem cells, people with MPNs may have changes to the structure of the bone marrow (the bone marrow *microenvironment*).

Each damaged stem cell divides and creates a clone. A clone is a group of identical cells all with the same mutation which is why MPN is sometimes called a clonal disorder.

Myeloproliferative neoplasms are usually described according to the type of blood cell which is most affected. There are three main types of myeloproliferative neoplasms –

- Polycythaemia vera (PV) – too many red cells
- Essential thrombocythaemia (ET) – too many platelets
- Myelofibrosis (MF) – bone marrow tissue is replaced by fibrous scar-like tissue

PV, ET and MF are closely related diseases, so it is not uncommon for people to have features of more than one of these diseases when they are first diagnosed, or during their illness. In some cases, one of these diseases may transform over time to another. All myeloproliferative neoplasms can transform into a type of leukaemia called acute myeloid leukaemia (AML). Less common types of myeloproliferative neoplasms include:

- Chronic neutrophilic leukaemia (CNL) – too many neutrophils (a type of white cell) in blood and bone marrow
- Chronic eosinophilic leukaemia, not otherwise specified (CEL/NOS) / hypereosinophilic syndrome – too many eosinophils (another type of white cell) in blood and bone marrow
- Myeloproliferative neoplasm– unclassifiable (MPN-U)

More information about these less common types of MPN can be found on our website

People with MPN often have very active bone marrow, producing many cells, but often 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. High numbers of blood cells are called cytoses. One type of cytosis is leukocytosis, where a person has high white blood cells.

Is MPN cancer?

MPN is a form of blood cancer.

MPNs can change (transform) into other conditions. Sometimes essential thrombocythaemia or polycythaemia vera can change to become another type of MPN, myelofibrosis. Some MPNs can change into myelodysplastic syndromes (MDS) and occasionally people with MPN may develop a fast-growing cancer called acute myeloid leukaemia (AML). This is called a 'progression' – so some people 'progress to' AML. Sometimes you might hear it described as 'transformation' to AML. Myelofibrosis is the most likely type of MPN to progress to AML.

You can find more information about AML in our booklet Understanding AML and more about MDS in our booklet Understanding MDS. There is also information on our website www.leukaemia.org.au

Causes of MPN

In most cases, there is no specific cause of MPN.

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 MPN is more common in older people.

3 key "driver" gene mutations in MPN:

- JAK2 (most common)
- CALR 1 or 2
- MPL (TPO)

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

Known risk factors

- Ageing because the risk of developing genetic mutations increases with age.
- Long-term exposure to high levels of benzene or very high doses of ionising radiation can affect bone marrow stem cells and the bone marrow microenvironment.
- Sometimes families have more than one member that has a certain type of MPN. This is called familial clustering. It is not very common. These family members usually have the same gene mutations.

Types of MPN

There are different types of MPN. The World Health Organization (WHO) defines the subtypes of MPN based on:

- Blood count results: the type and numbers of high blood cells (cytoses)
- Bone marrow results: which and how many types of blood cells in your bone marrow have abnormal size, shape or look (dysplasia)
- Genetic mutations.

Your haematologist will determine which subtype you have, and the right treatment for you.

Your type of MPN may change over time as your disease progresses or transforms.

Polycythaemia vera (PV)

In this type of MPN the bone marrow makes too many red cells. These cells build up in the bone marrow and in the bloodstream. The blood becomes thicker than normal. Many people with PV also make too many platelets and white blood cells.

The extra blood cells may settle in the spleen and make it swell (called splenomegaly). They can also cause bleeding problems and lead to clots forming in blood vessels. Clots increase the risk of stroke or heart attack.

For some people, PV does not change for long periods of time, often many years. PV can transform over time into another type of MPN called post-PV myelofibrosis. Very few cases of PV (just over 2% in the first ten years) transform into acute myeloid leukaemia. Because of the high numbers of red blood cells circulating, you may have a red face, red palms of hands, soles of feet, eyes and ear lobes.

The goals of treatment for PV are to reduce blood cells and reduce the risk of blood clots, as well as treating symptoms. Treatment may include venesection (bloodletting or drawing to reduce blood volume, oral blood thinning medication, and cytoreductive (reduce blood cell counts) therapy. You can find more detail about these treatments later in the Supportive care section of this booklet.

You can find more detailed information about PV on our website.

Essential thrombocythaemia (ET)

In this type of MPN the bone marrow makes too many platelets. Platelets are normally needed in the body to control bleeding. Too many platelets can lead to abnormal blood clotting which can cause serious complications by blocking the flow of blood through the blood vessels.

In addition to blood clotting (vascular and thrombotic events) some patients have abnormal bleeding and an enlarged spleen (called splenomegaly). Sometimes the liver may also be enlarged (hepatomegaly).

For most people, ET does not change for long periods of time, often many years. ET can transform over time into another type of MPN called post-ET myelofibrosis. Very few cases of ET transform into acute myeloid leukaemia.

You may have no symptoms when you are diagnosed with ET.

Many patients are under ‘watch and wait’, monitoring blood counts until they change.

Symptoms of ET include:

- tingling or burning in the hands and feet
- headache
- visual problems
- weakness
- dizziness
- weight loss.

Treatment goals for ET are to prevent serious health conditions and to relieve symptoms. Treatment may include oral blood thinning medication and cytoreductive (reduce blood cell counts) therapy. Plateletpheresis (removal of excess platelets in the blood) may be done to reduce platelet count. You can find more detail about these treatments in the Supportive care section later in this booklet.

You can find more detailed information about ET on our website.

Primary myelofibrosis (PM)

Primary myelofibrosis is a disorder in which normal bone marrow tissue is gradually replaced with a fibrous scar-like material. Over time, this leads to progressive bone marrow failure. Under normal conditions, the bone marrow provides a fine network of fibres on which the stem cells can divide and grow. Specialised cells in the bone marrow known as fibroblasts make these fibres. In myelofibrosis, chemicals released by high numbers of platelets and abnormal megakaryocytes (platelet forming cells) over-stimulate the fibroblasts. This results in the overgrowth of thick coarse fibres in the bone marrow, which gradually replace normal bone marrow tissue. Over time, this destroys the normal bone marrow environment, preventing the production of adequate numbers of red cells, white cells and platelets. This results in anaemia, low platelet counts and the production of blood cells in areas outside the bone marrow for example in the spleen and liver, which become enlarged as a result.

People with PM have a 10-20% chance of it progressing to acute myeloid leukaemia, higher than the other types of MPN.

Most people have no early symptoms. Many have symptoms of anaemia at diagnosis.

Symptoms of PM include:

- pain or sense of fullness in the upper left belly
- weight loss
- fatigue
- shortness of breath
- bleeding or easily bruising
- fever
- night sweats
- itchiness (especially after a warm bath or shower)
- flushed face.

Treatment goals for PM are to improve symptoms, reduce enlarged spleen, and improve blood counts. Treatment may include blood or platelet transfusions, cytoreductive (reduce blood cell counts) therapy, other medicines such as JAK inhibitors and rarely, splenectomy (surgery to remove the spleen). Stem cell transplant may be an option for younger patients.

You can find more detailed information about PM on our website.

Chronic neutrophilic leukaemia (CNL)

CNL is a very rare disease, where neutrophils (a type of white blood cell) are overproduced and accumulate in the peripheral blood and the bone marrow. Signs, symptoms and complications of CNL result from the overproduction of neutrophils.

The course of CNL varies. The disease can either develop slowly or it can progress rapidly. Within two years of initial diagnosis, CNL tends to progress to a more aggressive type of leukemia, usually acute myeloid leukemia (AML). Currently, there is no standard therapy for CNL and treatment options are geared towards managing rather than curing the disease. However, recent developments in the understanding of the genetic and molecular features of CNL may eventually have an impact on prognosis and outcome.

Symptoms of CNL vary and some people with CNL may not have early symptoms. Symptoms include:

- weight loss
- fatigue
- easy bruising
- bone pain
- night sweats
- enlarged spleen or liver

You can find more detailed information about CNL on our website

Chronic eosinophilic leukaemia, not otherwise specified (CEL-NOS)

In this rare type of MPN, the bone marrow makes too many eosinophils, a type of white blood cell normally involved in allergic responses. Higher than normal levels of eosinophils in the blood and bone marrow can lead to progressive symptoms and complications.

CEL-NOS is a slow-growing disease. As CEL-NOS advances, you may have symptoms related to low red blood cells (anaemia), such as shortness of breath. You may also have symptoms relating to low platelets (thrombocytopenia), such as bruising and bleeding.

There may be no early symptoms. Symptoms of CEL-NOS come about because eosinophils release their contents into nearby tissues and organs causing inflammation and organ damage. Symptoms are related to where the eosinophils are in the body.

They include:

- fever
- cough
- swelling around the eyes, lips, on hands and feet, or in your throat
- fatigue
- muscle pain
- itching
- diarrhoea

Treatment goals depend on the phase of CEL-NOS and what, if any, organs are being affected by the eosinophils. In the chronic phase, the goal is to use medications to stop CEL-NOS progressing. This may include cytoreductive therapy, immunotherapy, corticosteroids to reduce inflammation or occasionally targeted therapy. If CEL-NOS starts to progress, you may be given other chemotherapy drugs, like those used for acute myeloid leukaemia.

Stem cell transplant may be an option in treating CEL-NOS. You can find more detail about these treatments later in the Stem Cell transplant section of this booklet or on our website.

Myeloproliferative neoplasm, unclassifiable (MPN-U)

This type of MPN includes any cases that have features of MPN but don't fit into any other subtype. Symptoms, treatment goals and treatments vary depending on the features the person has.

Myelodysplastic/myeloproliferative neoplasms (MDS/MPN)

There is a separate group of blood cancers that have features of both MPN and myelodysplastic syndromes neoplasms (MDS - another WHO category of blood cancers).

People with MDS/MPN cancers have features of both overproduction of blood cells (proliferative) and abnormal (dysplastic) blood cells.

MDS/MPN subtypes:

- Chronic myelomonocytic leukaemia (CMML-1 and CMML-2)
- Atypical chronic myeloid leukaemia (aCML, BCR-ABL 1 negative)
- Myelodysplastic/myeloproliferative neoplasm unclassifiable (MDS/MPD-U)
- Myelodysplastic/myeloproliferative neoplasm with ring sideroblasts and thrombocytosis (MDS/MPN-RS-T)
- Juvenile myelomonocytic leukaemia (JMML)

You can find more information about the individual subtypes of MDS/MPN on our website.

Symptoms of MPN

The types of symptoms you will experience depend on:

1. what type of MPN you have
2. how severe your MPN is
3. which types of blood cells are high or low (red, white or platelets).

Symptoms people with all types of MPN can have:

- tiredness and fatigue not improved by rest
- weakness
- weight loss
- fever
- itchy skin
- night sweats
- pain in bones or joints
- enlarged spleen (splenomegaly)

Enlarged spleen (and liver)

Your spleen is located in the top left of your abdomen, under your rib cage. It stores blood cells but can also make them. In MPN where the bone marrow production of blood cells is reduced by

fibrosis (scarring) the spleen can start making blood cells and it may enlarge. When the spleen is enlarged (swollen), it is called splenomegaly.

If you have splenomegaly you may feel fullness, discomfort/pain in the upper left side of your abdomen and you may rapidly feel full when eating.

Some patients may also develop an enlarged liver, called hepatomegaly.

Blood clots and bleeds

Both bleeding and blood clots can be caused by MPNs. Blood clots block blood vessels or arteries and are known as vascular or thrombotic events. They are serious and need medical attention. You can read more about symptoms of each type of MPN in the symptoms of MPN section in this booklet and on our website www.leaukaemia.org.au

How is MPN Diagnosed?

A diagnosis of MPN is made on the basis of a person's symptoms, and the results of blood tests and a bone marrow biopsy. Some symptoms of MPN, like feeling tired, are part of many conditions. You may need a few types of tests before the MPN and your subtype is diagnosed.

Medical history and physical exam

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

Your doctor will also do a physical examination, to check your general health and your whole body for any signs of MPN. They will press on (palpate) your spleen if you have any upper left belly pain or discomfort to check if it is larger than normal (a symptom of some types of MPN called splenomegaly).

Full blood count

A full blood count (FBC) is an important diagnostic test for all patients suspected of having a MPN. 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 nurse will take a sample of blood from a vein in your arm. It is sent to a pathology laboratory where a haemato-pathologist (a blood specialist) will look at the blood cells under a microscope.

The pathologist looks for the number of red blood cells, white blood cells and platelets, and their size, shape and appearance. Your blood might be tested for other things to rule out other conditions.

Blood chemistry tests

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

Substance tested	What it indicates
Iron	Kidney function
JAK2, CALR, MPL	Specific gene mutations
Liver function tests (LFT's)	Liver function
Uric acid	Cell breakdown & kidney function
Lactate dehydrogenase (LDH)	Blood cell damage

All these tests help to rule out other health problems and to confirm your diagnosis.

Bone marrow biopsy

If your treatment team thinks you may have MPN 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. It's a good idea to bring a support person with you to keep you company while you wait and to help you home, as you may not 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. You may 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 for 7-10 days for the results of the bone marrow test.

Molecular genetic tests

Molecular genetic tests such as polymerase chain reaction (PCR) or next generation sequencing (NGS) look directly at the genetic sequence/code and help your haematologist work out which type of MPN you have. It may take a few weeks for these test results to come through.

Cytogenetic tests

Cytogenetic tests use the bone marrow aspirate. Their results give your treatment team information about the genetic make-up of your cells. They look at the cell's structure and any abnormalities in the chromosomes. You may also have cytogenetic tests after you have treatment to see how it is working

Other tests

You might need more blood tests and imaging tests (x-rays or scans) when you are diagnosed and throughout your treatment.

Coagulation tests are a type of blood test you might need if you have abnormal bleeding, a very high platelet count or an enlarged spleen (splenomegaly).

The results of your first blood and bone marrow tests provide a baseline of your disease and general health. Your treatment team can then compare later test results against the baseline to track how you are going.

What happens next?

After diagnosis

When all your test results have been reviewed, you will meet with your haematologist to discuss your MPN and treatment goals and options. It is natural to feel scared, confused or sad. You will hear a lot of information and it can be overwhelming.

Treatment goals in MPN:

- lower high blood counts to reduce the risk of complications (e.g. clotting)
- improve your symptoms and
- help you live your best and longest life.

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

Treatments and side effects

Your haematologist will recommend treatment based on:

- the type of MPN you have
- your age
- your general health
- your prognosis using the IPSS or another relevant score, and
- your wishes.

There are four kinds of treatment for MPN. Your treatment plan may include one or more of them:

1. Active monitoring ('watch and wait') involves regular check-ups but no treatment
2. Supportive care controls symptoms of MPN, like low or high red blood cell counts
3. Standard drug therapies

4. Stem cell transplant which replaces bone marrow cells with new, healthy cells.

You can find out more about treatments for the most common types of MPN - Polycythaemia vera, Essential thrombocythaemia, and Primary myelofibrosis on our website leukaemia.org.au.

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.

Unfortunately, most MPN can't be cured, but treatments can help control and improve it.

Watch and wait: Active monitoring only

Many people may not need to start any treatment as they don't have any symptoms and are not at high risk of complications. Your haematologist may recommend regular check-ups to keep an eye on your health. Your GP may monitor your MPN with blood tests as part of your active follow up. How often will depend on any changes in your blood counts and your general health. This is called 'watch and wait'.

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 MPN, but it doesn't treat the disease itself.

Blood transfusions

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

Blood transfusions are slow injections 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. The nurse will insert a 'drip' (a cannula), a plastic tube, into a vein in your arm. The cannula connects to a bag of blood (called packed red blood cells). Each bag of blood will take 60-120 minutes to transfuse.

Venesection (also known as phlebotomy or bloodletting)

If your blood tests show high numbers of red blood cells (judged by a high haematocrit on your FBC), you may need a procedure called venesection. Venesection involves removing a set amount of blood from your bloodstream. Like a blood transfusion, a nurse in an outpatient ward or a clinic will put a needle (a cannula) into your arm. This will be attached to a bag and a weight measure. Blood will drip from your vein to the bag.

Usually 450-500mL of blood is taken and it will take about 30 minutes. It is important to drink lots of water before and after venesection. Tell your nurse if you feel dizzy or lightheaded during the procedure.

Plateletpheresis

If your blood test shows that your platelet count is very high (thrombocytosis) it can be dangerous. Your platelets may need to be reduced quickly to prevent complications. Excess platelets can be removed from your bloodstream using a procedure known as plateletpheresis.

This usually takes place in an outpatients ward or day hospital and takes about two hours.

Platelet transfusions

If you have symptoms of low platelets (thrombocytopenia), you may need a platelet transfusion. This is similar to 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. 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. This is predominantly used when people are being treated with chemotherapy.

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

Antibiotics

If 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 usually prescribe antibiotics, either in tablet form or given via 'drip' straight into your bloodstream (IV).

Vaccines

Vaccines are important for people with MPN 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. .

Standard drug therapies

Your treatment team might use the term 'standard of care' or 'standard therapy'. This is a treatment that is commonly used by medical experts for a certain type of disease.

In MPN, there are a few chemo/ cytoreductive (cell number reducing) drugs available that work to reduce the over production of blood cells in the bone marrow.

Your haematologist will recommend chemo depending on:

- your type of MPN
- your overall health and
- whether your MPN has a lower or higher risk of transforming to leukaemia.

Cytoreductive therapy (cell number reducing)

Hydroxycarbamide/ Hydroxyurea

The main drug used for treating some types of MPN is hydroxycarbamide (hydroxyurea). It is a cytoreductive (cell number reducing) therapy that interferes with the growth and maturation of blood cells. It reduces the number of blood cells caused by MPN crowding your blood stream and slowing the flow. It is a capsule you take every day to reduce the risk of blood clots (thrombosis) and scarring in the bone marrow. How long you take it for and how often you take it depends on your type of MPN. Your treatment team will advise what is best for you.

Some potential side effects are low red blood cells (anaemia), low white blood cells (leukopenia), nausea and vomiting, and constipation or diarrhoea.

Antiplatelet therapy

Aspirin

Many people with MPN take low doses of an oral blood thinning medication such as aspirin every day. Aspirin reduces the stickiness of platelets, making them less likely to stick to each other and the blood vessel wall. It does not alter the number of platelets or other blood cells but reduces your risk of developing blood clots.

Immunotherapy

Interferon

Interferon suppresses the production of blood cells via multiple and complex mechanisms which is why it can be useful in patients with various types of MPN with overactive bone marrows.

Most patients are treated with pegylated interferon, a longer lasting immunotherapy medication which is administered by self-injection at home on a weekly or fortnightly basis. Your treatment team will show you how to inject it safely and how to reduce/manage side effects from this therapy.

The most common side effects are flu-like symptoms, such as fever, chills, headache. You may also have aches and pains, nausea, and lack of appetite.

Targeted therapy

Genes called Janus kinase 1 and 2 (JAK1 and JAK2) help control how many blood cells are made. The body makes too many blood cells when these genes are damaged. A targeted therapy known as protein kinase inhibitor works by blocking the signals a faulty gene sends. This helps reduce the number of extra blood cells being made. It is called a targeted therapy because it targets the cancer cells but doesn't harm normal cells.

Ruxolitinib

Ruxolitinib is a type of protein kinase inhibitor and is a tablet you will take at the same time each day. It is available in Australia for myelofibrosis either primary or following PV or ET and is used to improve splenomegaly and symptoms. You can continue taking this medicine for as long as it keeps working.

Its main side effects are low red blood cells (anaemia), low platelets (thrombocytopenia) and dizziness.

Imatinib

Imatinib is different type of protein kinase inhibitor tablet also taken daily at the same time each day. Imatinib works by blocking signals a faulty gene (BCR) and ABL1, sends to control how many blood cells are made. This helps reduce the number of extra blood cells being made. This medication may be used in treating the MPN subtype CEL.

Anagrelide

Anagrelide hydrochloride is a medicine that reduces high platelet counts by reducing the production of platelets. This decreases the risks related to clotting. It is a capsule you take at home. Anagrelide treatment for MPN is uncommon as it is currently not funded on the Pharmaceutical Benefits scheme.

Drug treatment side effects

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

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

- your type of MPN
- your drug treatment
- your overall health and wellbeing.

Changes in blood counts

Drug treatment can affect your bone marrow's ability to produce enough blood cells. Your treatment team will monitor the balance between reducing cell numbers as a treatment goal and managing treatment related side effects.

Low circulating red blood cells causes 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 to help your levels recover.

If your platelets are low you can bruise and bleed more easily. If you notice these signs please let your treatment team know.

When your white blood cell count (neutrophils) is too low, you are at a higher risk of developing an infection. You may have chemotherapy (either in tablet form or intravenously) and/or immunotherapy. Often you may have both treatments together; 'chemo-immunotherapy'. Sometimes treatment with immunotherapy continues after the chemotherapy stops (this is called *maintenance therapy*).

Stem cell transplantation

Stem cell transplants (also called bone marrow transplant, or a hemopoietic cell transplant or HCT) are the only potential cure for some types of MPN.

Stem cell transplant is only suitable for a very small number of MPN patients. Your haematologist will discuss if this is an option for you.

Surgery – splenectomy

Some people with MPN have a very enlarged spleen (splenomegaly). Surgery to remove the spleen (called splenectomy) has been used to stop symptoms of splenomegaly. Massive splenomegaly can be dangerous.

Splenectomy can cause complications, so many people with MPNs will be given targeted therapies to try to reduce spleen size. These work in most patients hence the need for splenectomy is rare these days.

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 valuable information about how treatments can be improved. Sometimes people on clinical trials (called 'participants') have access to expensive new treatments that are not on Australia's PBS.

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 in 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 www.australiancancertrials.gov.au and the ANZ Clinical Trials Registry www.anzctr.org.au.chemotherapy.

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.

Complimentary 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.

Complementary therapies (CAM) or Integrated therapies should 'complement' or be done alongside medical treatment after consultation with your treatment teamNo complementary or alternative treatment on its own can treat MPN. They may help with some symptoms or side effects.

Information on CAM can be found on the Clinical Oncology Society of Australia (COSA) website Include Link

https://www.cosa.org.au/media/1133/cosa_cam-position-statement_final_new-logo.pdf

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, its 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

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

Drug treatment 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 three mainstream fertility preservation 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 https://www.fertilitysociety.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: 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 themself. 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 *clotting*. 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 *partial* (a reduction in some or many symptoms) or *complete* (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

MPN Alliance:	mpnallianceaustralia.org.au
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
Lymphoma Australia:	lymphoma.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 MPN 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?

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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