MPN

Myeloproliferative neoplasms (MPN)

A guide for people with MPN and their support network

Leukaemia Foundation®

Developed by the Leukaemia Foundation in consultation with people living with a blood cancer, Leukaemia Foundation support staff, haematology nursing staff and/or Australian clinical haematologists. This content is provided for information purposes only and we urge you to always seek advice from a registered health care professional for diagnosis, treatment and answers to your medical questions, including the suitability of a particular therapy, service, product or treatment in your circumstances. The Leukaemia Foundation shall not bear any liability for any person relying on the materials contained in this booklet.

This booklet has been written to help you and your support people understand more about Myeloproliferative neoplasms (MPN).

This booklet has a list of contents, useful resources and a glossary. Your treatment team can answer further questions. You can also call our Leukaemia Foundation Healthcare Professionals on 1800 620 420.

You will meet many healthcare professionals working as a team to provide you with the best available treatment. You will need to have a regular GP throughout your treatment. In this booklet when we refer to 'your treatment team' we usually mean your haematologist and haematology nurses.

There is some information about treatments in this booklet, but it does not recommend any particular treatment. You must discuss your circumstances and treatment options with your haematologist.

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 and present.

The Leukaemia Foundation can provide you with additional support and the latest information about your blood cancer.

Booklets for Aboriginal and Torres Strait Islander patients and their families can be found on our website.

Access the Leukaemia Foundation online support service for practical and emotional information and resources.

Access MPN Your guide to best cancer care here.

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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, it may not work properly or may cause fibrosis (scarring) in the bone marrow.

Both bleeding and blood clots can occur in people with MPNs. Blood clots are one of the most serious complications of MPNs. A blood clot can block a blood vessel or artery, leading to a vascular or thrombotic events—such as a heart attack or stroke. These are medical emergencies and require urgent medical attention. The warning signs of blood clots are covered later in this booklet.

People with MPNs have a higher risk of arterial clots. Taking steps to manage other cardiovascular risk factors—like high blood pressure, high cholesterol, and diabetes—can help reduce this risk.

Myeloproliferative neoplasms are diagnosed using blood tests and often 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
- Bone pain
- Itching after showering (aquagenic pruritus)
- Visual disturbances
- Elevated risk of blood clots

In most cases we don't know what causes MPN. In most patients a mutation (alteration) in the genes of growing blood cells is identified. There is no way to prevent MPN and you can't catch it.

Who gets MPN?

1900
number of Australians diagnosed each year

74%
of people diagnosed are over 60

69
average age at diagnosis

Second opinion

If you are unsure about your diagnosis or treatment, you are entitled to seek a second opinion. 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.

You can also contact the MPN Alliance Australia which is a patient-led advocacy group who collaborate with the Leukaemia Foundation.

Visit the MPN Alliance Australia here

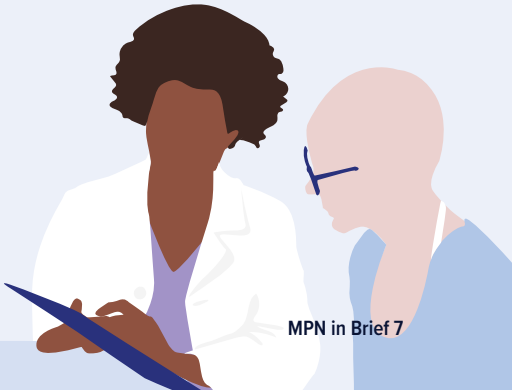
Access MPN Your guide to best cancer care here.

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:

- The risks of vascular or thrombotic (clotting) events.
- The risk of progression and transformation of the disease.

Your haematologist will take into account many factors when considering your prognosis. Some of these are the type of MPN you have, your age, and your overall health. MPNs are often a chronic blood cancer and patients may well have a close to normal life expectancy.



All about blood

What is blood?

Blood travels through the heart and blood vessels, carrying oxygen, nutrients and 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 cells. 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 the 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. They carry oxygen for the body to produce energy.

White blood cells

There are five types of white blood cells, also known as leukocytes or WBCs. They form part of the immune system. White blood cells are necessary to protect us against and fight off infection.

Platelets

Platelets, also known as thrombocytes, are small pieces of cells. They stick together when you are bleeding to help your blood clot, a process called coagulation.

Anaemia

Cause
Low RBCs or Hb

You might notice
Tiredness, weakness, pale skin, shortness of breath, heavy legs

Neutropenia

Cause
Low WBCs (neutrophils)

You might notice
More frequent infections

Leukopenia

Cause
Low WBCs

You might notice
More frequent infections

Leukocytosis

Cause
High WBCs

You might notice
Fever, weakness, dizziness, pain or tingling in arms, legs, or abdomen

Thrombocytopenia

Cause
Low platelets

You might notice
Bruising and bleeding, like nosebleeds

Thrombocytosis

Cause
High platelets

You might notice
No symptoms, headache, visual problems and dizziness

Pancytopenia

Cause
All three blood cell types are low

You might notice
A mix of symptoms

Polycythaemia (erythrocytosis)

Cause
High concentration of red cells in blood

You might notice
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, itching after showering (aquagenic pruritis), burning in hands and feet

Where and how is blood made?

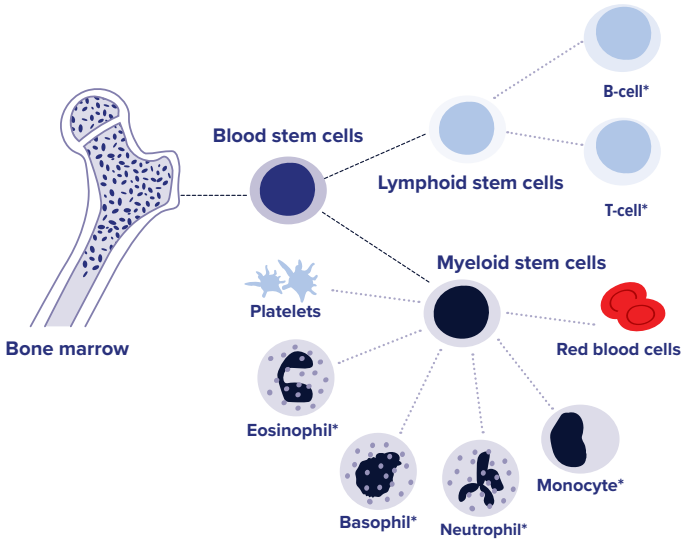
Bone marrow

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

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

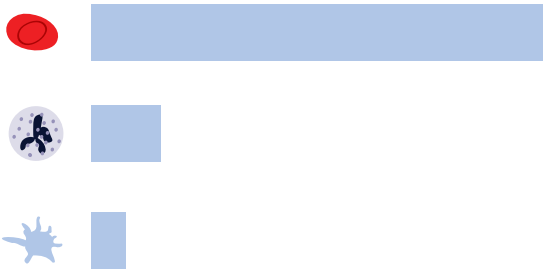
Think of blood production like a family tree. At the top of the tree are the blood stem cells, which are the youngest (most immature) blood-forming cells. They can make copies of themselves and new cells.

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

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.

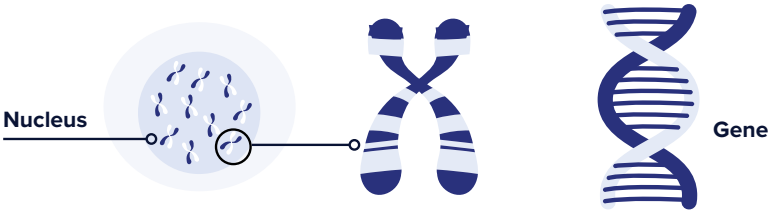
Chemicals in your blood, called growth factors, control blood cell formation. Different growth factors help make the blood stem cells in the bone marrow become different types of blood cells.

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 deoxyribonucleic acid (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. This results in the overproduction of blood cells. The DNA damage is an acquired mutation. The bone marrow also creates too many cytokines. Cytokines are substances like growth factors. People with MPNs may also have changes to the structure of the bone marrow.

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

MPN's are usually described according to the type of blood cell which is most affected. There are three main types of myeloproliferative neoplasms, these are sometimes referred to as 'Classic MPNs':

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. In some cases, one of these diseases may transform over time to another. While all MPNs have the potential to transform to AML, there is only a small risk that MPN will transform to AML.

Other types of myeloproliferative neoplasms include:

Chronic myeloid leukemia (CML) – can also be classified as an MPN. Information on CML can be found in the Leukaemia Foundation's CML booklet

Chronic neutrophilic leukaemia (CNL) – too many neutrophils (a type of white cell)

Chronic eosinophilic leukaemia (CEL) – too many eosinophils (another type of white cell)

Juvenile myelomonocytic leukaemia (JMML) – An uncommon childhood MPN.

Myeloproliferative neoplasm, not otherwise specified (MPN-NOS) – MPN that doesn't fit into any other subtype.

People with MPN often have very active bone marrow that produces too many cells. There may also be 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 transform into myelodysplastic syndromes (MDS) or acute myeloid leukaemia (AML). Myelofibrosis is the most likely type of MPN to progress to AML.

You can find more information in our AML and MDS booklets.

AML Booklet 

MDS Booklet 

Causes of MPN

In most cases, there is no specific cause of MPN. Gene mutations in cells happen all the time. MPN can start from changes in genes that happen very early in life, even before birth. These gene changes keep growing and evolving throughout life. 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

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

Known MPN risk factors

Ageing: 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.

Family: 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.

Genetic mutations that cause haemochromatosis may be a risk factor for being diagnosed with PV.

Types of MPN

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

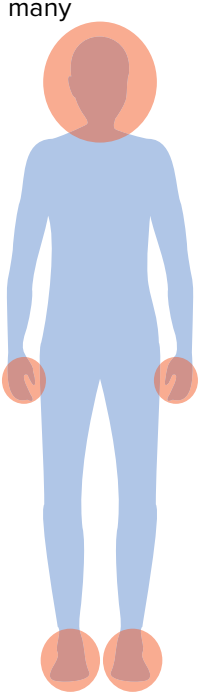
- Blood count results: the type and numbers of high blood cells (cytoses).
- Bone marrow results: which and how many types of blood cells in your bone marrow have abnormal size, shape or look (dysplasia), and if there is scarring within the bone marrow (fibrosis).
- Genetic mutations.

Your haematologist will determine which subtype you have, and the right treatment for you. Your type of MPN may change over time if 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. Post PV myelofibrosis is treated like primary myelofibrosis (PMF), there is a section on PMF later in this booklet. Very few cases of PV (just over 2% in the first ten years) transform into acute myeloid leukaemia (AML).



The high numbers of red blood cells circulating may cause a red face, or red palms on your hands, soles of feet, eyes and ear lobes.

Symptoms of PV including but not limited to:

- Headache
- Fatigue
- Dizziness
- Confusion or difficulty concentrating
- High blood pressure
- Discomfort in the abdomen
- Red skin – particularly in the face, hands and feet
- Itching after showering (aquagenic pruritis)
- Burning in hands and feet
- Weight loss
- Blood clots, including in the legs or lungs. Clots can also form in unusual places, such as within the abdomen.

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/phlebotomy or drawing to reduce blood volume),
- Oral blood thinning medication, and
- Cytoreductive (reduce blood cell counts) therapy.

Learn more about PV on our website here

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. Serious complications happen by blocking the flow of blood through the blood vessels. 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. Post ET myelofibrosis is treated like primary myelofibrosis (PMF), there is a section on PMF later in this booklet. Very few cases of ET transform into acute myeloid leukaemia (AML). 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:

- Fatigue
- Headaches
- Visual problems
- Abdominal discomfort
- Weight loss
- Tingling, numbness and/or burning in the hands and feet
- Blood clots - including in the legs or lungs. Clots can also form in unusual sites, such as within the abdomen.
- Bleeding - if platelets are very high

Preventing serious health conditions and relieving symptoms are the goals of treatment. **Treatment may include:**

- Oral blood thinning medication
- Cytoreductive (reduce blood cell counts) therapy

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

Primary myelofibrosis (PMF)

In primary myelofibrosis (PMF), chemicals released by high numbers of platelets and abnormal platelet-forming cells over-stimulate the bone marrow.

This results in the overgrowth of thick coarse fibres in the bone marrow, which replace normal bone marrow tissue. The normal bone marrow environment changes, preventing the production of adequate numbers of red cells, white cells, platelets.

There are two types of primary myelofibrosis (PMF) defined by the World Health Organization (WHO):

- Early/prefibrotic primary myelofibrosis
- Overt primary myelofibrosis

Your haematologist will discuss your PMF diagnosis with you including the type. PMF affects each person differently. It can progress at different speeds, follow different courses, and cause a range of symptoms that vary in how severe they are.

Over time, anaemia and low platelet counts are the result. The spleen and liver may also be affected and become enlarged. People with PMF have a 10-20% chance of progression to AML. Most people have anaemia as their only symptom on diagnosis.

Symptoms of PMF include:

- Pain or sense of fullness in the upper left abdomen
- Weight loss
- Fatigue
- Shortness of breath
- Bleeding or easily bruising
- Pallor
- Fever
- Night sweats
- Itchiness (especially after a warm bath or shower)
- Frequent infections
- Blood clots - including in the legs or lungs. Clots can also form in unusual sites, such as within the abdomen

Treatment goals for PMF are to improve symptoms, reduce enlarged spleen, and improve blood counts.

Treatment may include:

- Cytoreductive (reduce blood cell counts) therapy
- Other medicines such as JAK inhibitors
- Blood or platelet transfusions
- Rarely, splenectomy (surgery to remove the spleen)
- Stem cell transplant may be an option for younger patients.

You can read more about stem cell transplants on our website here

You can find more detailed information about PMF here

Chronic myeloid leukemia (CML)

Information on CML can be found in the Leukaemia Foundation's CML booklet

Chronic neutrophilic leukaemia (CNL)

CNL is a very rare disease, with on average one person diagnosed each year in Australia. 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. Within two years of initial diagnosis, CNL tends to progress to a more aggressive type of leukaemia. Currently, there is no standard therapy for CNL. Treatment options tend towards managing rather than curing the disease. However, there have been recent developments in the understanding of the genetic and molecular features of CNL. This research may 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

Chronic eosinophilic leukaemia (CEL)

In this extremely rare type of MPN, the bone marrow makes too many eosinophils (a type of white blood cell). They help fight infections and regulate allergic responses.

CEL is a slow-growing disease. As CEL advances, you may have symptoms such as:

- Shortness of breath from anaemia
- Bruising and bleeding from low platelets (thrombocytopenia)

There may be no early symptoms. 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 and what, if any, organs are being affected by the eosinophils. In the chronic phase, the goal is to use medications to stop CEL progressing.

This may include:

- Cytoreductive therapy
- Immunotherapy
- Corticosteroids to reduce inflammation or
- Targeted therapy

If CEL starts to progress, you may have other chemotherapy drugs, like those used for acute myeloid leukaemia (AML). Stem cell transplant may be an option in treating CEL. You can find more detail about these treatments later in the Stem Cell transplant section of this booklet or on our website.

Juvenile myelomonocytic leukaemia (JMML)

This is an uncommon MPN which occurs in early childhood. It may be linked with underlying health conditions like neurofibromatosis or Noonan syndrome. It often causes enlargement of the liver and spleen. Children with this condition are usually treated with a stem cell transplant.

Myeloproliferative neoplasm, not otherwise specified (MPN-NOS)

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)

This is a separate group of blood cancers that have features of both MPN and myelodysplastic syndromes (MDS). People with MDS/MPN cancers have both overproduction of and abnormal blood cells.

MDS/MPN subtypes:

- Chronic myelomonocytic leukaemia
- Myelodysplastic/myeloproliferative neoplasm with neutrophilia
- Myelodysplastic/myeloproliferative neoplasm with SF3B1 mutation and thrombocytosis
- Myelodysplastic/myeloproliferative neoplasm, not otherwise specified

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

Symptoms of MPN

The types of symptoms you will experience depend on:

- What type of MPN you have
- How severe your MPN is
- 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
- Abdominal pain or discomfort
- Difficulty concentrating
- Itchy skin
- Night sweats
- Pain in bones or joints
- Enlarged spleen (splenomegaly)
- Blood clots

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 feel full quickly 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 are a significant complication in MPN. Blood clots block blood vessels or arteries and are known as vascular or thrombotic events, such as heart attacks or strokes. They are serious and need urgent medical attention.

It is important to know the signs and symptoms of blood clots, these can vary depending on where the blood clot is.

You can find more detailed information about heart attack warning signs here

You can find more detailed information about signs of a stroke here

Deep vein thrombosis (DVT) is a blood clot in one of the deep veins in your body. They mostly occur in the legs, but they can occur anywhere in your body.

The most common symptoms of DVT are:

- Pain and/or swelling in the area, usually your calf or thigh. Less commonly, clots can form in your arm or unusual sites like in your abdomen.
- Redness and a warm feeling around the area of the blood clot.

You can find more detailed information about DVT here

Sometimes a blood clot travels from a deep vein to your lungs. This is called a pulmonary embolism (PE).

Symptoms of pulmonary embolism include:

- Shortness of breath
- Chest pain
- Coughing up blood
- Sweating
- Rapid heartbeat
- Feeling dizzy

You can find more detailed information about PE here

Your haematologist will discuss treatment with anti-coagulants if you have a blood clot. They will also discuss medications to reduce the risk of developing blood clots.

Control of risk factors like blood pressure, cholesterol and diabetes, maintaining a healthy weight, physical activity and not smoking can lower the risk of developing a clot. If you have symptoms of a blood clot you must seek medical attention straight away. You can read more about symptoms of each type of MPN in the symptoms of MPN section in this booklet.

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

Your treatment team will take a full medical history:

- Past and present illnesses
- Health problems
- Infections
- Clotting and bleeding
- Details of any medications you have taken, are taking or intend to take. These include prescribed and over the counter medications.
- Do a physical examination, to check your general health and any signs of MPN

Blood tests

Full blood count

You will 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 your blood. Your treatment team will give you a referral form 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. Your blood will be looked at under a microscope by a specialist haematologist.

Genetic blood tests

There are several important genes and gene mutations involved in MPN. People with variants in these genes have different treatment options and health outcomes. It is important to know which genetic variants you have.

The main types of genetic tests for MPN:

- Janus kinase 2 (JAK2) gene - looks for changes in the JAK2 gene. The JAK2 gene helps control how many blood cells your body makes.

- Calreticulin gene (CALR) - makes a protein called calreticulin. This protein helps new proteins form and keeps the right level of calcium in cells. The test looks for changes in this gene that may affect blood cell production.

- Myeloproliferative leukaemia gene (MPL) - helps your body make blood cells, especially platelets. This test checks for changes in that gene.

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 blood tests taken may include:

- Hepatitis and HIV tests: hepatitis B can become active again due to cancer or some of its treatments. HIV and hepatitis C may affect your treatment.
- Antibody testing: depending on the type of MPN you have and treatments you have received, you may have low or high levels of antibodies. Low antibody levels may increase your risk of infection.

Substance Tested	What it indicates
Iron studies	Iron levels in your blood and body
JAK2, CALR, MPL	Specific gene mutations
Liver function tests (LFT's)	Liver function
Uric acid	Cell breakdown and kidney function
Lactate dehydrogenase (LDH)	Blood cell damage
Erythropoietin (EPO)	EPO level which stimulates the bone marrow to produce RBCs

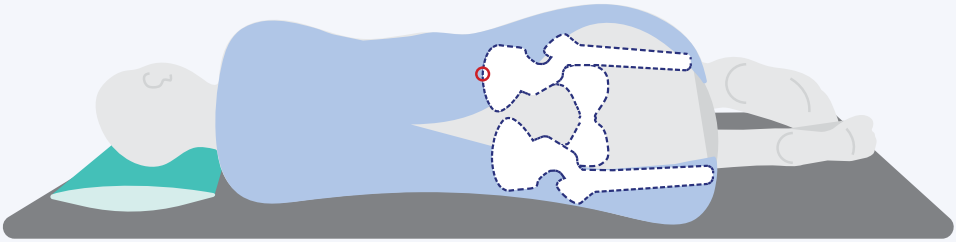
Bone marrow biopsy

If your treatment team thinks you may have MPN based on your blood test results, the next step may be a bone marrow biopsy. This test is more complex than a blood test, but it won't involve a hospital stay. This procedure is performed either in hospital, at your haematologist's rooms, in a day procedure unit or an outpatient clinic. It's a good idea to bring a support person with you. They can help you home if you are instructed not to drive afterwards.

What does a bone marrow biopsy involve?

A bone marrow biopsy involves using a needle to enter the bone marrow at the back of the hip (iliac crest). This is an area where the bone is usually close to the skin and can be easily accessed. A small amount of liquid bone marrow (aspirate) is usually taken and placed onto slides and into blood tubes. The liquid bone marrow is sent to the laboratory for examination and other specialised tests. Usually a small piece of the bone marrow (trephine) is also taken and examined in the laboratory.

The bone marrow is taken from the back of the hip bone, not from the spine.



Is a bone marrow biopsy painful?

A bone marrow biopsy can cause discomfort and/or pain. Local anaesthetic is injected into the skin and on the bone before the procedure to numb the area. You may also be given a form of pain preventer that you breathe in. On occasions a small dose of intravenous sedative may be required to manage discomfort. This is in the hospital setting, where you will be closely monitored.

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. If you have any pain or discomfort, you will be given instructions on what you can take. The dressing must remain in place for 24 hours after the procedure, or as advised by your treatment team. You will have to wait several days or weeks for the results of the bone marrow biopsy.

Molecular 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 to get these test results.

Polymerase chain reaction (PCR) – also called quantitative reverse transcriptase PCR (QPCR). This test evaluates DNA to look for known/specific gene mutations/sequence.

Next generation sequencing (NGS) – looks for multiple gene mutations across multiple samples at the same time. In MPN, an 'MPN gene panel' may be used to search for multiple mutations that are known to be associated with MPNs, which may help to determine disease prognosis.

Cytogenetic tests

Cytogenetic tests (also known as karyotype) are a genetic test performed on the bone marrow. The results provide information about the genetic make-up of your cells. These tests examine the structure of chromosomes (DNA) in your bone marrow cells. This determines if there are any gene mutations. The gene mutations are typically 'acquired'. This means they developed during your life, you were not born with them. These results help your haematologist diagnose which type of MPN you have, and your treatment plan.

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 or a very high platelet count. 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 your test results have been reviewed you will meet with your haematologist. Your MPN diagnosis including the subtype, and your treatment plan will be discussed. It is natural to feel scared, confused or sad. You will be given a lot of information, this can be overwhelming. You may feel relieved and reassured that your symptoms have been explained. Ask your haematologist if you need further details and for some written information. It is helpful to bring someone with you to the appointment - a second pair of ears, someone to take notes and ask questions for clarification.

Treatment goals in MPN:

- Lower high blood counts to reduce the risk of complications (e.g. clotting)
- Improve your symptoms
- Manage cardiovascular risk factors
- Help you live your best and longest life

Treatments and side effects

Your haematologist will recommend treatment based on:

- The type of MPN you have
- Your age
- Your general health
- Your prognosis
- Your wishes

There are four kinds of treatment for MPN. Your treatment plan may include managing cardiovascular risk factors and one or more of these treatments:

1. Active monitoring ('watch and wait') involves regular check-ups but no treatment (except low dose aspirin for many patients).

2. Standard therapies.

3. Supportive care controls symptoms of MPN, like low or high red blood cell counts.

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

You can find more information about the treatment of MPN on our website

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 MPNs can't be cured, but treatments can help control symptoms and improve quality of life. It is important to keep up to date with regular screening for other cancers like cervical, bowel, breast, prostate, lung, skin.

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'. Many MPN patients will be prescribed daily low dose aspirin during 'watch and wait'.

Standard 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 cytoreductive (cell number reducing) drugs available that work to reduce the over production of blood cells in the bone marrow. Your haematologist will recommend treatment depending on:

- Your type of MPN
- Your overall health
- The risk of your MPN causing blood clots
- The risk of your MPN transforming to leukaemia

Aspirin

Many people with MPN are prescribed 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.

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 donation, 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

Cytoreductive therapy (cell number reducing)

Hydroxycarbamide (Hydroxyurea)

Hydroxycarbamide (hydroxyurea) is a cytoreductive therapy that interferes with the growth and maturation of blood cells. It is used to treat some types of MPN. 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). 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

Pegylated Interferon

Pegylated interferon suppresses the production of blood cells via multiple and complex mechanisms. It can be useful in patients with various types of MPN with overactive bone marrow. It is the preferred therapy for people of child bearing age. It is a longer lasting immunotherapy medication which is administered by self-injection at home weekly or fortnightly, or even less frequently.

Your treatment team will show you how to inject it and how to reduce or manage any side effects. 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.

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.

Targeted therapy - JAK inhibitors ruxolitinib and momelotinib; and imatinib for CEL

Genes called Janus kinase 1 and 2 (JAK1 and JAK2) help control how many blood cells are made. A targeted therapy known as a 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 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:

- Headaches
- Low red blood cells (anaemia)
- Low platelets (thrombocytopenia)
- Dizziness

Momelotinib

Momelotinib is a protein kinase inhibitor, similar to Ruxolitinib. It is available for myelofibrosis (MF) with anaemia. It is used to reduce the size of the spleen, and relieve other symptoms related to the disease. It is a tablet taken daily at the same time each day. Its main side effects are:

- Low platelets, bleeding
- Dizziness
- Diarrhea
- Infections
- Nausea
- Tiredness

Imatinib

Imatinib is a type of protein kinase inhibitor tablet taken daily at the same time each day. Imatinib works by blocking signals a faulty gene, BCR-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 chronic eosinophilic leukaemia (CEL).

Supportive Care

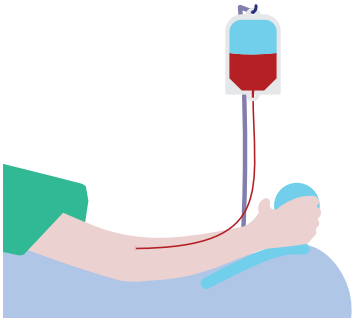
Supportive care prevents and treats symptoms and side effects. It includes emotional and social support too. The goal is to improve symptoms of your MPN, but it doesn't treat the disease itself.

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. A platelet transfusion usually takes 30 minutes. There are oral medications that can increase your blood clotting, these may be prescribed by your treatment team.

Blood transfusions

Blood transfusions are uncommon with MPN but you may need one if you have anaemia. You will have regular blood tests to monitor your haemoglobin. Your haemoglobin carries oxygen throughout the body. If your haemoglobin is low and you have fatigue, weakness, shortness of breath and dizziness, you may have anaemia.



Your treatment team will assess if you need a red blood cell transfusion. Transfusions are usually given by a nurse in an outpatient department. The nurse will insert a cannula into a vein in your arm or hand. Each bag of blood will take 60–120 minutes to transfuse.

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 laboratory. They are used to boost low blood counts.

Neutrophils are white blood cells that help fight infections. A growth factor called granulocyte colony-stimulating factor (G-CSF) makes the bone marrow produce more neutrophils. G-CSF is commonly given to people having chemotherapy. Growth factors are usually given as an injection under the skin (subcutaneous). You, a family member or friend can be taught to give the injections. The injections can be given at a local medical centre or outpatient department if preferred.

Some people experience flu-like symptoms while using G-CSF including mild to severe bone pain, fevers and chills, and headaches.

Antibiotics

When your white blood cell count is low you have a higher risk of infection. If you develop signs or symptoms of infection, it is important you are treated as soon as possible. Your treatment team will prescribe antibiotics, usually intravenous (IV). You will continue on antibiotics until the infection resolves and your white blood cell count recovers.

Vaccines

Vaccines are important for people with MPN because you have a higher risk of infection. Vaccines help prevent infections. Inactivated vaccines are the safest and you should not have any live vaccines. You will need to check with your treatment team for the best timing.

You can find out more on our website here

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. You will be monitored to help balance reducing cell numbers as a treatment goal and managing treatment related side effects.

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

If your platelets are low you can bruise and bleed more easily.

Your white blood cell count (neutrophils) may drop with your treatment. This puts you at a higher risk of developing an infection.

Stem cell transplantation

Stem cell transplants (also called bone marrow transplant) 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 which can cause complications. Many people with MPNs will have targeted therapies to try to reduce spleen size. These work in most patients hence the need for splenectomy (removal of the spleen) is rare.

Clinical trials

Clinical trials, or research studies, test new treatments.
Your haematologist may suggest you join a clinical trial. Results from clinical trials compare new or combination therapy to current treatments. Results also report any side effects of the new treatment. Many clinical trials are randomised. This means some patients receive the new treatment and others the current treatment. Clinical trials provide important information about how treatments can be improved. In Australia some clinical trials may provide access to expensive new treatments not available on the Pharmaceutical Benefits Scheme (PBS).

For a clinical trial you will need to:

Understand the risks and benefits of the trial.

Understand how your treatment will be different compared to current treatment.

Ask any questions you have before deciding whether to participate in the trial.

Give your informed consent to participate in the clinical trial.

Clinical trials are run through hospitals and clinics. A clinical trial nurse will be part of your treatment team.
Clinical trial participation is purely voluntary.

You can search current clinical trials at the following websites.

Australian Cancer Trials:
australiancancertrials.gov.au

ANZ Clinical Trials Registry:
anzctr.org.au

Patients and Carers – Clin Trial Refer:
clintrialrefer.org.au/for-patients-and-carers/

Complementary therapies

Complementary and alternative medicines are not standard medical treatments. Some people find that they help with side effects and symptoms. No complementary or alternative treatment on its own can treat blood cancer. Tell your treatment team what complementary or alternative medicines you plan to take.

Go to our online ‘Complementary therapies’ learn module to find out more.

“Meditate” and “Use breathing techniques.”

Top tips from people with blood cancer

Visit ‘A mindful moment’ to ground and calm yourself.

Managing fatigue

Many people who have blood cancer treatment get fatigue. It's called cancer-related fatigue (CRF). 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, this may improve when your MPN is well managed in conjunction with your treatment team.

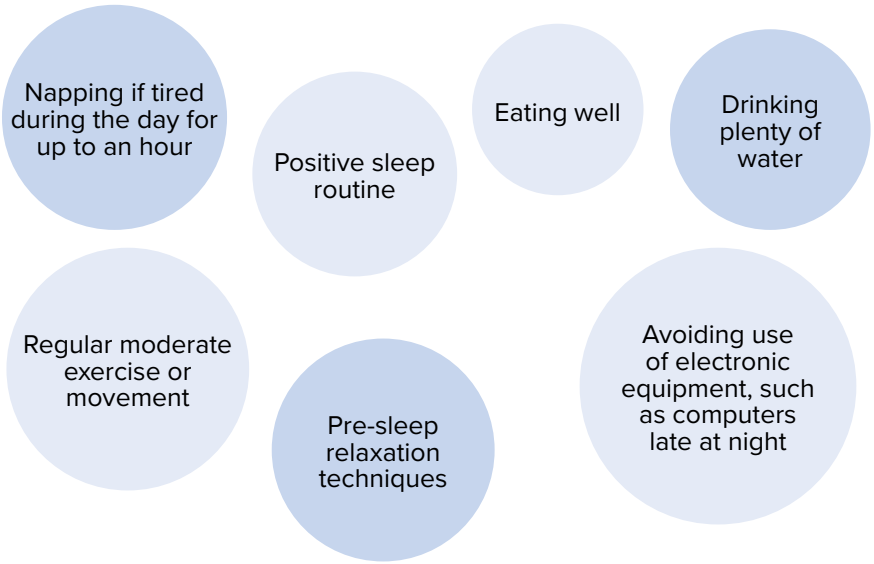
"Cancer-related fatigue (CRF) is not the same as being tired."

Top tips from people with blood cancer

Tips for managing fatigue

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

Tips to manage fatigue include:



“Recognise your limits, physical/cognitive/emotional/social.”

Top tips from people with blood cancer

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.

“Know when you are at your most productive and do important tasks then.”

Top tips from people with blood cancer

Go to our online ‘Cancer-related fatigue’ learn module or website to find out more.

Fertility decisions

Your treatment team will advise if your treatment for MPN will affect your fertility, which is your ability to conceive a baby. It is important that you discuss your plans in advance with your treatment team, before attempting to conceive or father a child. You should also inform your treatment team as soon as you find out that you or your partner is pregnant. Certain medications, such as aspirin and interferon, can be safely continued in pregnancy. However, some medications are not considered safe in pregnancy and should be discontinued.

Patients with MPNs are at higher risk of pregnancy-associated complications and will require closer monitoring in pregnancy. However, many patients with MPN are able to have a successful pregnancy.

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 the key people are 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.

Occupational therapist – A health professional who helps maintain or improve your quality of life using different techniques and equipment. Occupational Therapists help develop, recover, improve and/or maintain the skills needed for daily living, community participation and vocational pursuits.

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 support your understanding of how to manage your side effects with medication prescribed.

Accredited practising dietitian – A university-qualified professional with ongoing training and education who helps to support your recovery and manage challenges in your diet. Dietitians provide you with personal support to help with your health and wellbeing. They provide expert nutrition and dietary advice, advice to understand how to improve your nutritional health, and help to understand how nutrition affects the body.

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

Physiotherapist/Exercise physiologist – A health professional who specialises 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

	Contact name	Phone number and/or email	Comments
Emergency			
GP			
Haematologist			
CNC/CCC			
Chemo day unit			
Pharmacist			
Dietitian			
Social worker			
Psychologist			
Occupational therapist			
Physiotherapist			

You can find out more about navigating the healthcare system as a cancer patient and the wide range of health professionals here.

The new normal – what is it?

Life is not the same as it was before a blood cancer diagnosis. Frequent appointments and regular follow up appointments can be tiring and stressful. Everyday life changes for you and the people around you. Things that were once important don't matter as much. 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 as good a life as possible.

Changes you may face include:

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

It is important to seek information and support. Accepting help to manage challenges that arise throughout your cancer experience isn't always easy. Having this support can enable you to have a high quality of life while living with a blood cancer. 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 differently.

You can find out more about living well with blood cancer on our website.

Go to our online learn module, 'Transition to a new normal' to learn more.

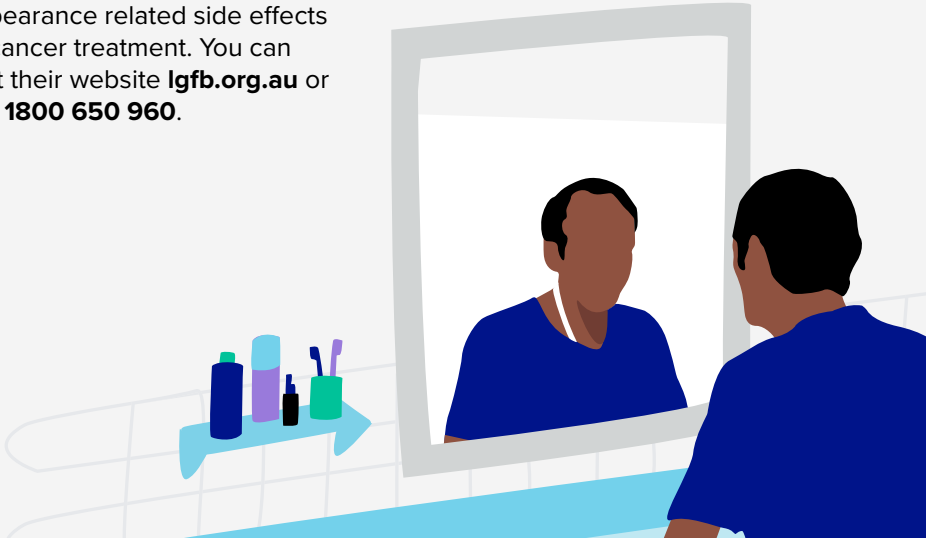
"Need to practise and build up skills over time – multi-tasking/moving/travel/work."

Top tips from people with blood cancer

Body image

You may not always look like a patient with cancer. Your physical appearance may improve. In the meantime, do things that make you feel good about yourself. This might include enjoying time with friends, regular exercise and relaxing.

Look Good...Feel Better is a free community service for people with cancer. The program focuses on how to manage the appearance related side effects of cancer treatment. You can visit their website **lgfb.org.au** or call **1800 650 960**.



Diet and nutrition

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

General nutrition recommendations for people living with blood cancer:

Maintain a healthy weight. For many people, this means avoiding weight loss by getting enough kilojoules every day. For people who are obese, this may mean losing weight, get advice from your treatment team.

Get essential nutrients. These include protein, carbohydrates, fats, vitamins, minerals 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 treatment team may refer you to a dietitian. Community dietitians are also available. Your GP can arrange this through a care plan if your private health insurance doesn't cover it.

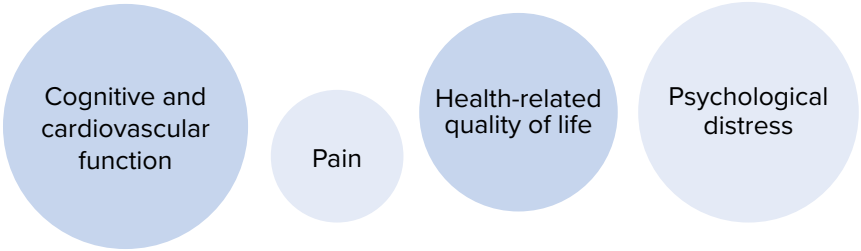
You can find more information about eating well on our website.

Physical activity

It is common to experience a physical and/or psychological drop in function. This is called deconditioning. Having cancer doesn't mean you can't be physically active. Avoid inactivity and sedentary behaviour as much as possible.

What are the benefits of exercise/physical activity?

Strong evidence has shown that exercise and physical activity improves outcomes for people with cancer for:



Anxiety and depression

Cancer-related fatigue

Bone health

"Doing something is better than nothing"

Top tips from people with blood cancer

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

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

You can find out more about exercise and blood cancer on our website.

Visit our Online Blood Cancer Support Service here

Mental health and emotional wellbeing

Your emotional health is a very important aspect of overall wellbeing. Many people being treated for blood cancer experience a range of feelings. 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
- Feeling isolated or lonely

Worrying about treatment, its success and side effects can impact your mental health. Changes in your physical, lifestyle, and family dynamics can also impact your wellbeing. Seeking help from your treatment 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 Healthcare Professionals 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

Having a blood cancer can affect your role as a parent, a friend, a partner, and a workmate .

You and the people in your life will cope in different ways. Encourage open communication between yourself, family and friends. Effective communication with family, children, friends, and carers 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 resources and other organisations that can assist with support and information.

The Leukaemia Foundation's Healthcare Professionals can assist you, your carer or family in identifying who can help with different issues and how to contact them (1800 620 420 or support@leukaemia.org.au).

For information for carers go to our online 'Carers' learn module.

Carers Australia: **carersaustralia.com.au**

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

Canteen: **canteen.org.au**

Redkite: **redkite.org.au**

Relationships Australia: **relationships.org.au**

Sexuality and sexual activity

It is likely the experience of the treatment will have some impact on how you feel about yourself. Skin changes, weight gain or weight loss and fatigue can all interfere with feeling attractive. You may experience a decrease in libido, which is your body's sexual urge or desire. It may take some time for things to return to 'normal'. It is safe to have sex as soon as you feel like it, but there are some precautions you need to take. Check with your treatment team if your MPN drugs may harm a developing baby. Treatment with Interferon for MPN is not harmful in pregnancy. If it is recommended not to become pregnant then condoms (with a spermicidal gel) provide good contraceptive protection. This also protects against infection or irritation.

Partners are sometimes afraid that sex might harm the patient. This is unlikely, as long as the partner is free from infections and the sex is gentle. This is especially important if your platelet count is low. If you experience vaginal dryness and irritation the use of lubricants is helpful.

If you have questions or concerns about sexual activity and contraception talk to your treatment team. You may ask for a referral to a doctor or health professional who specialises in sexuality.

Find out more about sexual health during and after a blood cancer diagnosis here.

"Pay attention to emotional fatigue in relationships – adjust expectation/social commitment/ hours of care given"

Top tips from people with blood cancer

Work, finances and legal matters

Finances

People with blood cancer often report a negative impact on their financial situation. Monthly costs can increase for items such as travel, childcare and, taking time off work for appointments. Your household income may reduce due to you or your carer having to stop work temporarily.

A financial stocktake

A good first step is 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 insurance policy, or through a superannuation policy?

Do you have money in the bank or a line of credit against your mortgage which you can access?

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

To find out more visit our website.

Seeking help

Financial advice around budgeting and what financial assistance is available to you can be discussed with a number of sources.

The Leukaemia Foundation's Healthcare Professionals can help point you in the right direction (1800 620 420 or support@leukaemia.org.au).

A few key other options to consider are:

Centrelink

If you expect your income to reduce, the first organisation to contact is Centrelink. The earlier you make an application, the sooner you could receive 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

It is important that you let organisations know as soon as possible if you think you will have financial difficulties. Banks and other financial organisations have special arrangements for customers in financial hardship because of ill health.

Other sources of help

Discuss your financial circumstances with a social worker or your private insurer. They may be able to assist with advice on deferring payments.

- Many providers have hardship support programs (like energy providers).
- State governments have hardship programs available.
- 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. If you are not sure, give their helpline a call.

To find out more go to:
Money smart: moneysmart.gov.au
National Debt Helpline: ndh.org.au or phone 1800 007 007

Getting back to work

The decision about when to return to work is a very personal one. It will depend on how well you are feeling, the type of work you do, and your personal and financial circumstances.

On return to work some people may go back part-time, increasing their hours when they feel up to it. Discuss timeframes for returning to work with your doctor.

"Make a plan with your workplace"
Top tips from people with blood cancer

Find out more about returning to work or study on our website.

Discover more on our online learn module, 'Return to work'.

Legal matters

This information applies 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 are 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. 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. They also can make personal and administrative decisions, and if you choose, financial decisions.

An Enduring Guardian (EG) is a trusted person who can make decisions on your behalf regarding your health including medical treatment, care and protection (even if this decision is against your wishes).
An Enduring Guardian (EG) requires another legal document.
To find out more visit the Australian Guardianship and Administration council at agac.org.au

Wills

It is very important to have specialist legal advice when preparing your Will. Intestacy is the condition of your estate if you die without a valid Will. Intestacy laws set out the way in which an estate will be distributed when there's no Will. This process is very specific and may not reflect your personal wishes. You will need to determine who will be responsible for your dependents in the event of your death. Even if your affairs are very simple and your immediate family will receive your assets, you need a Will. If you already have a Will, you need to consider if it is still current.

Advance Health Directive

This is a document that states your wishes about medical treatments. It indicates those you may or may not wish to receive in the event of a serious illness or accident. Although lengthy, it is simple to complete as it 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.
A doctor must 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, and the Australian Guardianship and Administration Council.

To find out more about putting your personal affairs in order, visit our website.

And our online learn module, 'Financial and legal matters'.

More information and 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.

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 and 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.

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.

Bone marrow aspirate – a procedure that takes 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.

Haematopoiesis – the formation of new blood cells.

Immune system – the body's defence system against infection and disease.

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.

Leukocytes – also called white blood cells that 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 tissue.

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

Leukaemia Foundation

Australian Cancer Trials

eviQ Cancer Treatments Online

Pharmaceutical Benefits Scheme

ClinTrial Refer

MPN Alliance Australia

Question builder

Who will be my main contacts?
How do I best contact them?

What can I do to avoid infections?

Can I have a flu shot and other vaccinations?

Is it safe to take my supplements and/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?

Where can I or my loved ones get any other support?

The Leukaemia Foundation would like to extend our sincere gratitude to Dr. Renee Eslick, Consultant Haematologist, and MPN Alliance Australia for their invaluable contribution in reviewing the content of this booklet. Their expert insights and guidance - generously contributed without compensation - have ensured the medical accuracy of the information provided for patients and their families. This resource was last reviewed and updated in June 2025.

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.

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Achieving excellence in blood cancer supportive care

At the Leukaemia Foundation, patient safety and quality care are at the heart of everything we do.

We are proud to have voluntarily achieved accreditation against the National Safety and Quality Primary and Community Healthcare Standards.

This significant milestone underscores our unwavering commitment to providing the highest standard of care for people living with blood cancer, reflecting our dedication as a not-for-profit organisation to support patients and their families throughout their experience with blood cancer.

Quality Innovation Performance
ACCREDITED

Why are these standards important?

Patient safety: They ensure that healthcare providers have the systems in place to prevent and manage risks, ensuring patient safety.

Quality assurance: These standards promote continuous improvement in care delivery, helping organisations maintain high-quality services.

Equity in healthcare: They emphasise the importance of delivering culturally safe and inclusive care, ensuring that all patients, regardless of their background, receive the care they need.

Consumer engagement: The standards encourage healthcare providers to engage with patients and communities, placing their needs at the centre of care.

Visit https://www.safetyandquality.gov.au for more information.