Myelodysplastic Syndromes (MDS)

A guide for people with MDS and their support people

Leukaemia Foundation®

This booklet has been written to help you and your support people understand more about myelodysplastic syndromes, also known as myelodysplasia, and most commonly called MDS.

We know you may be feeling anxious or overwhelmed if you or someone you care for has recently been diagnosed with MDS. 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 on 1800 620 420 to find out how we can help you.

You'll 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'll 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 recognise their continuing connection to land, sea and community. We pay our respects to their Elders past, present and emerging.

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MDS in brief

About MDS

Myelodysplastic syndromes (MDS) are cancers that start in the bone marrow, where blood cells are made.

In MDS, the bone marrow makes unhealthy blood stem cells. They are 'dysplastic', which means they are abnormally formed, and they don't grow or work as they should. Many of these abnormal blood cells die in the bone marrow or when they get to the bloodstream. The abnormal cells crowd the bone marrow, which then can't make enough healthy blood cells.

When healthy blood cells (red cells, white cells or platelets) are low, the body can't function how it should.

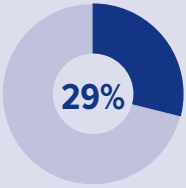
Symptoms of MDS include tiredness, weakness, weight loss, fever, infections, easily bruising and/or looking pale.

There are six types of MDS, diagnosed using blood tests and a bone marrow biopsy.

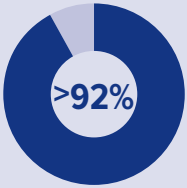
In most cases, we don't know what causes MDS. There is usually a mutation in (change to) the genetic material of growing blood cells. Sometimes people get MDS after other treatments. There is no way to prevent MDS and you can't catch it or pass it on.

Who gets MDS

1658
Australians diagnosed each year



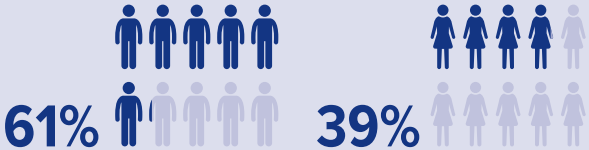
29% of people diagnosed aged 85+



>92% of people diagnosed aged 60+

77.5
average age of diagnosis

Percentage of males and females diagnosed



Approximately
7 children
are diagnosed per year

What's the prognosis?

A prognosis is an estimate your haematologist will make of the likely course and outcome of your disease. MDS is divided into 'risk groups'. Your prognosis depends on how high your risk is.

Your haematologist will take into account many factors when considering your prognosis. Some of these are the type of MDS you have, your age, and your overall health.

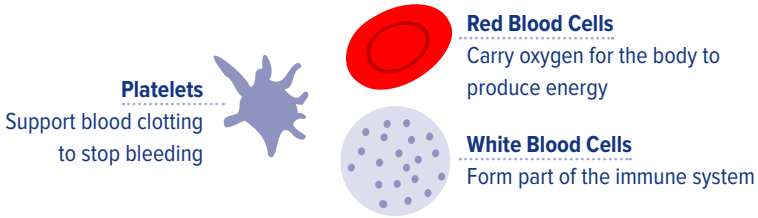
When you are diagnosed, your haematologist might use the International Prognostic Scoring System (IPSS, or IPSS-R). This helps predict the course of patients with MDS and the risk of MDS transforming to a more aggressive acute form of blood cancer, acute myeloid leukaemia (AML). It is useful to give you an idea about the disease risk, but it does not predict outcomes for individual patients.

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 from the bone marrow.



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.

White blood cells

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

White blood cells are necessary to protect us against and fight off infection.

Platelets

Platelets, also known as thrombocytes, are small pieces of bone marrow. They stick together to help your blood clot, a process called *coagulation*. They help stop bleeding when you have an injury.

Where and how is blood made?

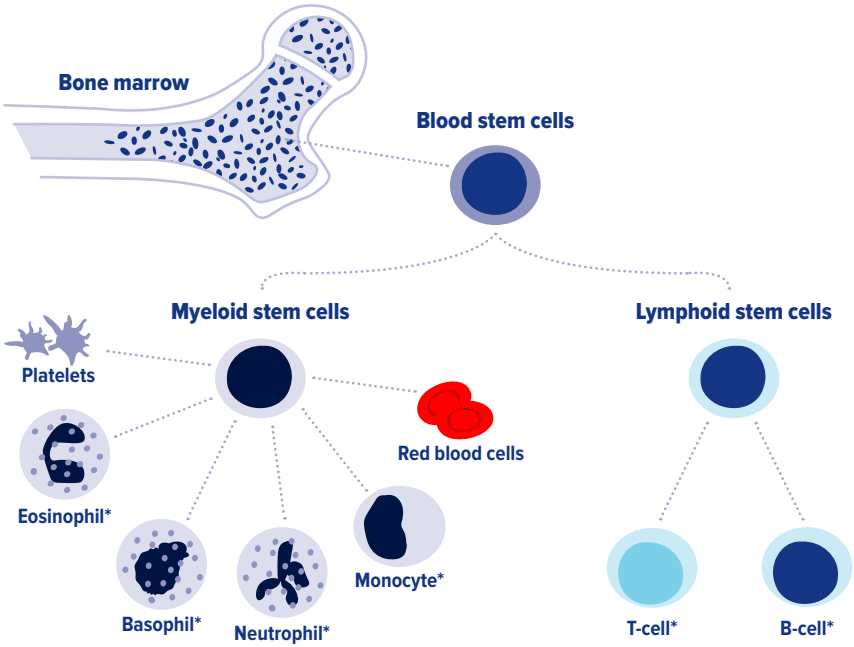
Bone marrow

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

In children, haemopoiesis takes place in the long bones, like the thigh bone (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 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 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.

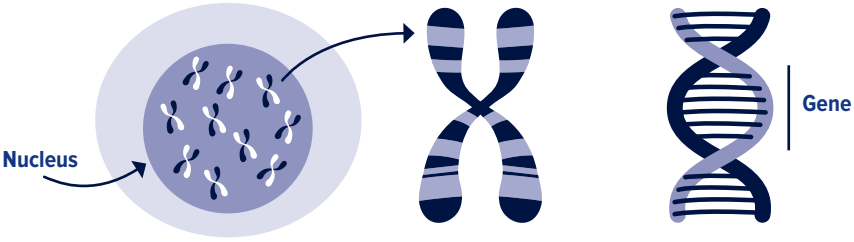
Chemicals in your blood called *growth factors* control blood cell formation. Different growth factors help make the blood stem cells in the bone marrow become different types of blood cells.

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

All about MDS

How does MDS develop?

Myelodysplastic syndromes (MDS) 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. Chromosomes inside cells are long strands of DNA (deoxyribonucleic acid). 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 MDS, the DNA in stem cells in the bone marrow is damaged. Some of the genes that are needed to make healthy blood cells are turned off. Because of this, the bone marrow doesn't make enough healthy blood cells. The DNA damage is called an *acquired*, or *somatic*, mutation. People with MDS may have more than one mutation in their bone marrow stem cells.

The blood cells that do survive:

- may be of poor quality
- may have an abnormal size or shape (are dysplastic)
- may be a lot of immature blood cells.

These cells can't function as they are meant to. They also crowd the bone marrow. This makes it hard for the bone marrow to create healthy blood cells.

This means that people with MDS often have very active bone marrow, producing many cells, but 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 numbers of red blood cells.

Is MDS cancer?

MDS is a form of blood cancer. It can get worse over time as more blast cells fill up the bone marrow and fewer healthy blood cells can be made.

Around one in three people with MDS may develop a fast-growing more severe 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. Your risk of progressing to AML depends on the type of MDS you have. You can find more information about AML in our booklet *Understanding AML* and on our website (leukaemia.org.au).

Causes of MDS

In most cases, there is no specific cause of MDS, which can be:

1. *primary*, or *de novo* – where there is no known cause; or
2. *secondary*, or *treatment-related* – where a person diagnosed with MDS has had prior chemotherapy and/or radiation therapy. Only 5-10% of people with MDS have treatment-related disease.

More than 40 different genetic mutations are connected to MDS. 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 MDS is more common in older people. Almost all people with MDS have at least one of these gene changes.

Why a particular person at a particular time gets MDS is not really known.

But some things (*risk factors*) give some people a higher risk of developing MDS, such as:

- **Ageing** because the risk of developing genetic mutations increases with age.
- Exposure to high levels of some environmental **chemicals**, especially benzene and petroleum products.
- Certain **disorders people have from birth** (*congenital* disorders) – such as Fanconi anaemia (see our website) and Diamond Blackfan anaemia (see our website) – involve unstable genes. They increase the risk of developing mutations that cause MDS.
- People treated in the past for cancer or other conditions with certain kinds of **chemotherapy** may develop *treatment-related* MDS. Combining the medications with radiation

therapy increases the risk of this type of MDS. Time between when the chemo was given and the average time for development of MDS is 3-5 years. The risk of developing MDS decreases after 10 years from treatment.
- Previous **radiation therapy**, or accidental exposure to high levels of environmental irradiation. Time between exposure and development of MDS may be up to 40 years.

Types of MDS

There are different types of MDS, also called *subtypes*. Some types are more severe than others. People with mild MDS may have low numbers of red or white blood cells or platelets, but few or no other symptoms. In others, the lack of blood cells causes more symptoms.

The World Health Organization (WHO) has a system that defines the subtypes of MDS. The types are based on:

- which of your blood cells are affected: the type and numbers of low blood cell counts (cytopenias)
- which and how many types of blood cells in your bone marrow are abnormal in size, shape or look (dysplasia)
- how many immature (blast) cells you have in your blood and bone marrow
- if you have any chromosome changes in your blood cells and the pattern of these changes.

Your haematologist can tell you which subtype you have and make a recommendation about the right treatment for you.

Your subtype may change over time as your disease progresses.

You can find more information on each subtype in our MDS factsheets and on our website.

Myelodysplastic/myeloproliferative neoplasms (MDS/MPN)

There is a separate group of diseases that has features of both MDS and myeloproliferative neoplasms (MPN - another WHO category of blood cancers).

People with MDS/MPN diseases also have abnormal (dysplastic) blood cells, but they also have high numbers of at least one type of mature blood cell.

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

Symptoms of MDS

Many people in the early stages of MDS have no symptoms at all. It may be just be picked up during a routine blood test. Some visit their general practitioner (GP) because they have troubling symptoms.

The types of symptoms you experience depend on:

1. what type of MDS you have
2. how severe your MDS is
3. which type of blood cell is low (red, white or platelets).

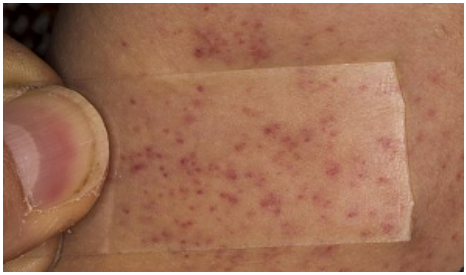
The most common symptoms are caused by low red blood cells (anaemia). Four out of five people with MDS have anaemia. Red blood cells are important for carry oxygen around your body.

One in two people with MDS have low white blood cells (neutropenia). White blood cells are necessary to support your immunity.

One in two people with MDS have low platelets (thrombocytopenia). Platelets help control bleeding and help wounds to heal.

You may have symptoms from each of these groups because all your blood cell types can be affected by the disease (which is called *pancytopenia*). About half of the people with MDS have pancytopenia when they are diagnosed.

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



Petechiae

How is MDS diagnosed?

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

Medical history and physical exam

First, your treatment team 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 old and new medicines you're 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 MDS, like unusual bruising.

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 circulation. Your treatment team will give you a referral and tell you where to go to have it done. They will also tell you if you need to fast (not eat or drink) for a certain amount of time before you have the blood test. A pathologist (blood specialist) will look at the blood cells under a microscope.

Blood chemistry tests

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

Substance tested	What it indicates
creatinine	Kidney function
electrolytes	Kidney function
blood urea nitrogen (BUN)	Kidney function
vitamin B12, folate	Specific vitamin deficiencies
uric acid	Cell breakdown
lactate dehydrogenase (LDH)	Blood cell damage

Bone marrow biopsy

If your treatment team thinks you may have MDS, based on your blood test results, the next step is a bone marrow test.

This is a test that involves taking a small sample of bone marrow through the back of the hip, which will be examined under a microscope to look for changes typical of MDS and any genetic abnormalities that form part of the disease. You may have to wait a few days for the results of the bone marrow test.

This test is more complex than a blood test but it won't involve a hospital stay. It will be done in your haematologist's rooms or in a day procedure clinic or outpatient ward in a hospital. You should bring a support person with you to keep you company while you wait and to help you home, as you 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 and where the needle is safely away from any vital organs.

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 afterwards

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, or as advised by your treatment team.

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

Special testing

Your haematologist might run additional special tests on your bone marrow biopsy. These tests help your haematologist work out your treatment options.

Cytogenetic tests

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

Other tests

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

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'll meet with your haematologist to discuss your MDS, treatment goals and options. It's natural to feel scared, confused or sad. You'll hear a lot of information and it can be overwhelming.

There are a few treatment goals in MDS:

1. To manage your symptoms
2. To prevent any complications
3. To help you live as normal a life as possible.

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

Treatments and side effects

Your haematologist will recommend treatment based on:

- the type of MDS you have
- your age
- your general health
- your prognosis using the IPSS-R score, and
- your wishes.

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

1. **Active observation -** ('watch and wait') involves regular check-ups but no treatment
2. **Supportive care -** controls symptoms of MDS, like anaemia
3. **Standard drug therapies** - such as chemotherapy (or evolving targeted therapies)
4. **Stem cell transplant** - replaces bone marrow cells with new, healthy cells.

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

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

Watch and wait: active observation only

Many people don't need to start any treatment as they don't have any symptoms. Your haematologist may recommend regular check-ups to keep an eye on your health. Your GP may monitor your MDS 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 MDS, but it doesn't treat the disease itself.

Blood transfusions

Around 80% of people with MDS are anaemic. Up to half of them need regular blood transfusions to keep their red blood cell count high enough.

If you notice symptoms of anaemia, tell 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 use your CVAD, if you have one (*a device that gives access through a central vein in your chest*) or 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.

Iron overload

Normal red blood cells live for three months, but packed red blood cells have a shorter life. As time goes on, you may need more transfusions more often. Your treatment team might need to remove some iron from your blood. Iron is carried by red blood cells and can build up after many transfusions.

There are medications that can help with iron overload, called *iron chelators*. They come in tablet or injection form. Iron chelators are available on the PBS for patients with low-risk MDS.

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. Additionally an oral medication that increases your blood clotting may be used.

Growth factors

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

In Australia, white blood cell growth factors are given. Neutrophils are white blood cells that help fight infections. A growth factor called *granulocyte colony stimulating factor* (usually called G-CSF) makes the bone marrow produce more neutrophils. This is predominantly used when people are being treated with chemotherapy.

Antibiotics

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

Vaccines

Vaccines are important for people with MDS because you have a higher risk of infection. Vaccines help prevent infections. Only some vaccines are safe. They 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.

Chemotherapy

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

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

Chemo can be given as tablets, injections, or infusions via a drip (IV). The type of *chemo* given depends on the type of cancer. It's common to be on more than one chemo drug at a time. Some people have chemo alongside other therapies like targeted therapy or immunotherapy, this is referred to as a regimen or protocol.

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

In MDS, there are a few chemo drugs available. Your haematologist will recommend chemo depending on:

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

Low intensity chemo

Azacitidine Azacitidine is the main treatment for MDS. It is a low intensity chemo drug and is different to standard chemotherapy because it works on the genes that affect how

normal blood cells develop. Azacitidine may be given for people with intermediate II or high grade MDS. Your nurse will give it to you via a quick injection (needle) under the skin in a clinic or outpatient ward. You will have the injections either:

- for seven days in a row, or
- for five days in a row, then a weekend break, then the next two days.

You'll have these seven injections every four weeks (once a month).

Azacitidine takes up to six treatments (so six months) to work. You can continue to have it long-term.

High-intensity chemotherapy

Some people with MDS, who have a high risk of progressing to leukaemia may have the same chemo as people with AML. High-intensity chemo is higher doses of stronger medications that have stronger side effects. Sometimes it is called *high-dose* or *induction* chemo because its goal is to bring on (induce) *remission*.

This type of chemo is given in hospital via a drip (IV) over days or weeks because the side effects are more severe.

The goal of high-intensity chemo in MDS is complete remission. In MDS, remission means killing a large number of the unhealthy (dysplastic) cells from your bone marrow. Then, hopefully, the bone marrow can work normally.

Chemotherapy side effects

Chemotherapy, (also referred to as chemo) kills cells that multiply quickly, like the dysplastic cells that cause MDS. It also damages fast-growing normal cells. These include hair cells and cells that make up the tissues in your mouth, gut and bone marrow. You get chemo side effects because of the damage to the normal cells.

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

time. Your treatment team will have medicines and suggestions to help with side effects.

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

- your type of MDS
- the type of chemotherapy you are given
- your overall health and wellbeing.

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

Changes in blood counts

Chemo affects your bone marrow's ability to produce enough blood cells. Your red blood cells, white blood cells and platelets will usually drop within a week of treatment. They should then increase before your next cycle of chemo.

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) will drop within a week of your treatment. This puts you at a higher risk of developing an infection.

Feeling sick – nausea and vomiting

Nausea (feeling sick to your stomach) and vomiting are common side effects but you will be given medicine to prevent or manage them. If you do feel nauseous, even with medicine to help, do not hesitate to contact your treating team to ensure it is managed and you can continue eating and drinking.

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

Sense of taste and smell

Changes to your sense of taste and smell can stop you from enjoying food and drinks that you used to love. You might have a metallic taste in your mouth. These changes will pass when your treatment ends.

Mouth problems – mucositis

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

Bowel changes

Chemo can damage the lining of your bowel wall. You might then have cramping, wind, bloating and diarrhoea. You will be given medication to help. Tell your treatment team if you have diarrhoea, are constipated or if it's painful or hard to pass faeces and you have haemorrhoids. Your treatment team can give you tips on food choices. You can read more about diet and nutrition later in this booklet and on our website.

Feeling tired and weak (fatigue), even after resting

Most people feel tired following chemo. It can be frustrating if you're used to keeping busy. You can find more on how to manage fatigue on page 30 of this booklet and on our website.

Chemo brain

You may find it difficult to concentrate ('foggy brain') or have trouble remembering things. It can take up to a year after treatment finishes to recover. There are no medicines to help with chemo brain and in some cases changes can be permanent. You can set up some ways to remember things, like writing them down. Talk to your support network too, so they know what's going on.

Hair loss (*alopecia*) and thinning

The thought of losing your hair is scary. Hair thinning or loss is a very common side effect of chemo. This occurs uncommonly with the main type of MDS medication. You might lose your head hair, your eyebrows, and your eyelashes, but it's only temporary. Hair starts to fall out a few weeks after you start treatment and tends to grow back three to six months after it finishes.You might find your scalp is itchy as you lose your hair, but this will pass. There are some great wraps, turbans and beanies available. Your nurse can give you information on where to find them, and about where to get wigs.

Tingling or numbness in fingers and toes (*peripheral neuropathy*)

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

Sun sensitivity

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

Managing chemo side effects

Potential side effects	What might help
Low red blood cells (anaemia)	you may be given a blood transfusion or recommended supplements
Low platelets	• avoid sharp objects in your mouth like chop bones or potato chips • be careful not to cut or injure yourself • use a soft toothbrush • use an electric razor • wear gloves and closed shoes in the garden

Low white blood cells (neutrophils) – risk of infection	• talk to your treatment team about vaccinations • avoid crowds • keep away from people who are sick and might be contagious (colds, flu, chicken pox) • eat food that has been properly prepared and freshly cooked • don't clean up pet faeces • wear gloves in the garden • don't swim in public pools, lakes or rivers
Feeling sick – nausea and vomiting	• eat smaller meals more often during the day • try cool or cold food like jelly • let someone else cook for you • drink ginger ale or soda water • avoid strong smells • you'll be given medicine to help
Change to taste	• add a little more sugar to sweet foods • add a bit more salt to savoury foods • if you have a metallic taste, try rinsing your mouth out
Mouth problems – mucositis	• use a soft toothbrush and mild toothpaste • brush every time you eat • use salty water, sodium bicarbonate in water or alcohol-free mouthwash • continue to floss but stop if your gums bleed
Bowel changes	• drink plenty of fluids • get some diet advice from your treatment team • if you're constipated, don't strain • if you have haemorrhoids don't push on them, tell your treatment team, you'll be given medicine to help
Fatigue	• see page 30 in this booklet for more info • rest or nap when needed • take regular gentle exercise

Chemo brain	• keep a notebook handy to write things down • ask your pharmacist to Webster pack your medications • take regular gentle exercise • socialise – tell your loved ones what's going on
Hair loss and thinning	• prepare your family and friends • use a soft hairbrush and a mild baby shampoo • pat your hair dry gently with a towel • cut your hair shorter or have it shaved when you start chemo • use an electric shaver • avoid using heat or chemicals – don't dye or blow dry your hair • use sunscreen on your scalp
Sun sensitivity	• cover up with long sleeves and long pants • wear sunglasses and a hat or a beanie to protect your scalp • talk to your nurse about which sunscreens are best to use • avoid sun exposure at high UV times of the day

Targeted therapy

Targeted therapy such as lenalidomide, is a medicine given to some people with MDS with isolated del(5q) who are anaemic and need frequent blood transfusions. It works by boosting your immune system, so it's sometimes called an *immune-modulating* drug. It also helps stop cancer cells from multiplying. Its goal is to decrease the need for blood transfusions.

Stem cell transplantation

Stem cell transplants (also called *bone marrow transplant*, or a *haemopoietic cell transplant* or *HCT*) are the only potential cure for MDS. This treatment has very serious side effects. Your haematologist will work out if you need and can have a stem cell transplant.

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

Allogeneic (donor) stem cell transplant

The healthy stem cells have to be donated. Usually your brother or sister who has the same tissue type as yours is the donor. They just need a blood test to see if they are a match to you. If they are, they are called *HLA matched donors*. The stem cells also can come from someone who is not related but is a match.

The goal of stem cell transplant is twofold. First, to create an immune response called a *graft-versus-host* (GVH) effect. The donated stem cells make their own immune cells and these create a new immune system. These immune cells kill any cancer cells that are left after you've had the high-dose chemotherapy.

Second, to restore normal blood cell growth with healthy donated stem cells after 'conditioning' chemo destroys your abnormal cancerous stem cells.

Stem cell transplant side effects include:

- low blood counts
- all the same side effects as chemo, but more severe
- graft-versus-host disease.

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

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

Clinical trials

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

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

Your haematologist 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 **australiancancertrials.gov.au** and the ANZ Clinical Trials Registry: **anzctr.org.au**

Second opinion

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

Complementary therapies

Complementary and alternative medicines (CAM) also known as integrated therapies are not standard medical treatments. However, some people find that they help with side effects.

These therapies should 'complement' or be done alongside medical treatment. No complementary or alternative treatment on its own can treat MDS. They may help with some symptoms or side effects.

Managing fatigue

Many people who have blood cancer treatment get fatigue. It's called cancer-related fatigue. It can be hard to describe to people who haven't felt it. It's more than being tired, 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 specialises in sleep management. It's very important to explain how you feel to your carers and support people, and to let them know your priorities and discuss how they can help.

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

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

Fertility decisions

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

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

Make sure you understand:

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

For men

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

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

For women

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

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

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 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.

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 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 includes 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 living with your blood cancer and maintaining your new normal to live as good a life as possible while facing changes such as:

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

Seeking support and accepting help to manage challenges that arise throughout a person's cancer experience is very important.

Having this support enables individuals to have a high quality of life throughout their blood cancer journey.

Diet and nutrition

During treatment, nutritional goals are to prevent or reverse malnutrition, avoiding weight loss (preserving lean body mass/ muscle) and 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/stomach).

You may be given drugs, called *corticosteroids* or *steroids* for short, 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 you don't have private health insurance or insurance that covers dietitians.

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
- 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: leukaemia.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** at health.gov.au

Mental health & emotions

Your emotional health is 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 Blood Cancer Support Coordinators and Grief Counsellors can also help you to work through what you are feeling and provide information on who might assist you in your local area.

Call us on 1800 620 420 or visit leukaemia.org.au

Relationships/carers/family & friends

Undergoing treatment for a blood cancer can affect your role as a parent, partner, friend, or work mate, 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 health care 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 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: my.gov.au): 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 (including 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 will 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 have the option of appointing an enduring power of attorney purely for financial matters and signing documents on your behalf. The same or a different person can be appointed as your Enduing Guardian (EG).

An Enduring Power of Attorney (EPOA) is a legal document giving someone else, who you nominate, the power to sign documents on your behalf or make personal, administrative and, if you choose, financial decisions on your behalf.

An EG has the power to make decisions regarding the person's health matters, care and protection, even if this decision overrides that adult's 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: *advancedcareplanning.org.au 1300 208 582.*

Getting help

Help with legal matters is available from several sources including:

- Solicitors
- Trustee companies
- The Public Trustee in your local state.

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.
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.
de novo MDS	Also called primary MDS, where there is no known cause.
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.
immune system	The body's defence system against infection and disease.
immunotherapy	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.

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 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.
primary MDS	Also called de novo MDS. MDS where there is no known cause.
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.
secondary MDS	Also called treatment-related MDS. MDS caused by earlier treatment.
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).
syndrome	A group of medical symptoms and signs. Myelodysplastic syndrome involves fatigue due to **anaemia**, increased risk of infections, and increased bruising.
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.

treatment-related MDS	Also called secondary MDS. MDS caused by previous treatment.
white blood cells	Also called leukocytes or WBCs. Blood cells made in the bone marrow and found in the blood and lymph tissue. They help the body fight infection and are part of the **immune system**. Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).

Useful websites

Leukaemia Foundation:	leukaemia.org.au
MDS Foundation:	mds-foundation.org
AA MDS International Foundation:	aamds.org
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
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 MDS 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 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®

GPO BOX 9954, BRISBANE QLD 4001
1800 620 420
leukaemia.org.au