MYELODYSPLASTIC SYNDROMES (MDS)

A guide for patients,
families & whānau

leukaemia & blood cancer
NEW ZEALAND
Vision to Cure. Mission to Care.

INTRODUCTION

This booklet has been written to help you and your family/whānau understand more about myelodysplastic syndromes (MDS).

If you or someone you know has been diagnosed with a myelodysplastic syndrome, you may be feeling anxious or overwhelmed. This is normal. Perhaps you have already started treatment, or you are discussing treatment options with your doctor and your family/whānau. Whatever point you are at, we hope that the information contained in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your health care team.

It is not the intention of this booklet to recommend any particular treatment to you. You need to discuss your circumstances with your doctor or treatment team.

Interpreter service

New Zealand's Code of Health and Disability states that everyone has the right to have an interpreter present when they go to a medical appointment. If a patient and their health care professional do not speak the same language, a family/whānau member or friend may assist. The hospital can organise a trained interpreter if needed, either in person or through a telephone interpreter service. NZ Sign Language interpreters are also available.

Informed consent

If you are supporting a family/whānau member who needs language support at appointments, your doctor may ask an interpreter to join meetings where informed consent is required. Interpreters are specially trained to explain medical information clearly.

HOW TO USE THIS BOOKLET

Detailed information

Key points

Important information

More information available online

There are many resources available at **leukaemia.org.nz** such as fact sheets, booklets and more. Most resources available on the Leukaemia & Blood Cancer New Zealand (LBC) website can be obtained in a printed version. Ask your LBC Support Services Coordinator if you would like information posted to you.

Space for your questions

There is space at the end of this booklet to write questions that you can ask next time you see a doctor, nurse or LBC Support Services Coordinator. They will be happy to answer your questions or explain something in more detail.

Glossary

On page 47 there is a glossary (word list).

In this booklet you might come across words or phrases that you are not familiar with. The glossary gives you a short explanation of these words and phrases.

A Dictionary of Terms is also available from the LBC website, or ask your LBC Support Services Coordinator for a printed version.

CONTENTS

WHAT ARE MYELODYSPLASTIC SYNDROMES?

Myelodysplastic syndromes (MDS or myelodysplasia) are a group of blood cancers which all affect, to a greater or lesser extent, the production of normal blood cells in the bone marrow.

MDS occurs because of a mutation (or abnormal change) in one or more of the genes that control the development of blood cells. These changes result in the abnormal growth of blood stem cells.

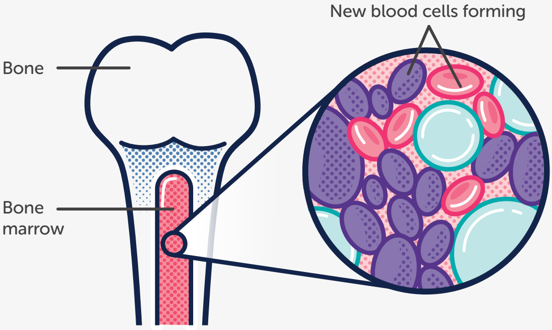
To fully understand MDS, it is helpful to learn about your bone marrow and the blood cells in your body.

BONE MARROW AND BLOOD STEM CELLS

Bone marrow is the spongy material inside your bones (see Figure 01).

Figure 01

Bone marrow



In your bone marrow there are cells called blood stem cells. Blood stem cells create the new blood cells in your body.

The two main functions of blood stem cells are to:

- Make exact copies of themselves
- Divide and make two different cell groups: myeloid (my-ill-oid) stem cells and lymphoid (lim-foid) stem cells.

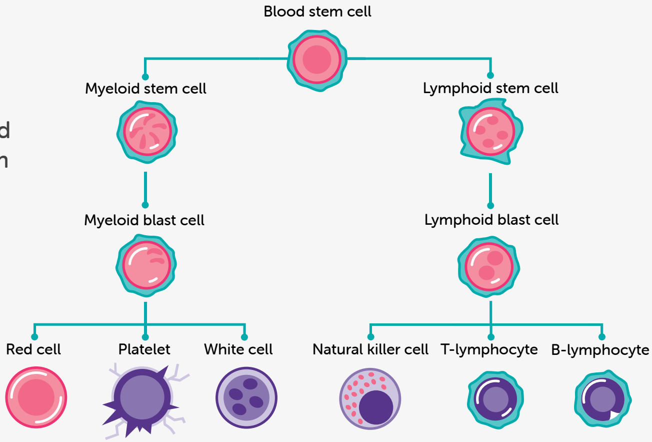
Myeloid and lymphoid stem cells create the blood cells for your body including white blood cells, red blood cells and platelets.

In Figure 02 (on the next page) you can see that the blood stem cell has divided to create a myeloid stem cell and a lymphoid stem cell. You can also see the blood cells that each of these cell groups create.

Figure

02

The cells created from blood stem cells



Detailed information

- The medical term for blood stem cells is haematopoietic (he-ma-toe-po-ee-tick) stem cells. When a blood stem cell matures into a blood cell, this is called haematopoiesis (he-ma-toe-po-ee-sis). In adults, haematopoiesis occurs in the bone marrow of large bones such as the breastbone (sternum), thigh bone (femur) and the hip bone (iliac crest).

Key points

- Blood stem cells in your bone marrow make exact copies of themselves, as well as divide to create myeloid and lymphoid stem cells. These cells create all the red blood cells, white blood cells and platelets for your body.
- MDS occurs when there is an abnormal change in the blood stem cell.

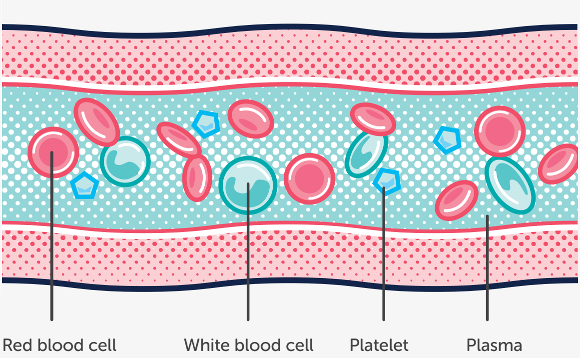
YOUR BLOOD

After being made in your bone marrow, the red blood cells, platelets and white blood cells are released into your bloodstream so they can function around the body.

Blood is made up of blood cells and plasma. A blood test measures the amount of each type of blood cell in your blood. Figure 03 shows the three main types of blood cells in the plasma. The role of plasma and each type of blood cell is discussed in the next section.

Figure 03

Blood vessel and cells in your blood



Plasma

Plasma is a light-yellow coloured liquid in which blood cells travel around your body.

Red blood cells

Red blood cells transport oxygen from the lungs to all the cells in the body. A protein called haemoglobin (heem-a-glow-bin) in each red blood cell carries the oxygen throughout the body and also gives blood its red colour. A low level of haemoglobin in your body is called anaemia (a-nee-me-a).

White blood cells

White blood cells fight infection. For example, if bacteria enter your bloodstream through a cut, the white blood cells attack and kill the bacteria cells before they divide and spread. If your white blood cell count is low, you are more at risk of getting an infection.

Neutrophils (new-tra-fils) are the most common type of white blood cell. A low number of neutrophils in your body is called neutropenia (new-tra-pee-nee-a).

Platelets

Platelets help your blood clot and prevent bleeding. For example, if you cut yourself, the platelets go to where the injury is, stick together and stop the bleeding.

A low level of platelets in your body is called thrombocytopenia (throm-bo-sy-toe-pee-nee-a) and can result in easy bruising and bleeding.

Detailed information

There are many different types of white blood cells, all with specific jobs to do.

Below is a list with the names of different types of white blood cells and what they do.

- **Neutrophils** (new-tra-fils)
  Kill bacteria and fungi.
- **Eosinophils** (ee-o-sin-o-fils)
  Kill parasites.
- **Basophils** (bay-so-fils)
  Work with neutrophils to fight infection.
- **T-lymphocytes** (T-lim-fo-sites) (T-cells)
  Kill viruses, parasites and cancer cells.
- **B-lymphocytes** (B-lim-fo-sites) (B-cells)
  Make antibodies which can target harmful microorganisms (germs).
- **Natural killer cells** (NK cells)
  Kill viruses and cancer cells.
- **Monocytes** (mono-sites)
  Work with neutrophils and lymphocytes to fight infection. They also help act as scavengers (cleaners) to remove dead tissue.
- **Macrophages** (mac-row-far-jes)
  Monocytes are known as macrophages when they move to body tissue to help fight infection there.

Key points

- There are three main types of blood cells (red blood cells, white blood cells and platelets), each with an important role.
- Blood cells travel around your bloodstream in a light-yellow coloured liquid called plasma.

MYELODYSPLASTIC SYNDROMES

In myelodysplastic syndromes (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.

This means that people with MDS usually have very active bone marrow but a low number of blood cells in their bloodstream. Low numbers of blood cells are called cytopenias (sy-toe-pee-nee-as). Without enough red blood cells, white blood cells and platelets you can become fatigued, bleed and/or bruise more easily, and are at more risk of getting infections.

The different types of MDS are discussed in more detail on page 15.

About 30% of people with MDS progress to acute myeloid leukaemia (AML). This is diagnosed by the percentage of immature blood stem cells (blast cells) they have in their bone marrow. Generally, we have between 2–5% of blast cells in our bone marrow. Someone with MDS will have more than 5% of blast cells in their bone marrow and someone with AML will have more than 20%.

There is a small group of people with MDS (10–15%) who have very low numbers of blood cells in their bone marrow. This is called hypoplastic myelodysplastic syndrome (MDS-h).

More information available online

See the Acute Myeloid Leukaemia (AML) booklet on the LBC website.

Detailed information

Inside our cells are coded instructions that control how the cell should act. Chromosomes carry DNA (deoxyribonucleic acid) in our cells. Each section of DNA is called a gene.

In MDS, the DNA in blood stem cells is damaged. Some of the genes that are needed to make healthy blood cells are turned off, which means the bone marrow doesn't make enough healthy blood cells. The DNA damage is called an acquired, or somatic, mutation.

Who gets MDS?

Approximately 225 people are diagnosed with MDS in New Zealand each year. The majority of people who are diagnosed with MDS are over 55 years old and it affects males slightly more than females. MDS can occasionally occur in children although this is rare.

In most cases, there is no specific cause of MDS. There is usually a change (mutation) to the genetic material of growing blood cells. Gene mutations in cells happen all the time. Healthy cells have clever ways of stopping them causing problems in the body. But the longer we live, the more chance we have of getting mutations that can escape these safeguards, so this disorder is increasingly common with age.

There is no way to prevent MDS and you can’t catch it or pass it on.

Why a particular person gets MDS is not really known. But there are some risk factors that give some people a higher chance of developing MDS.

The risk factors are:

- **Ageing** because the risk of developing genetic mutations increases with age.
- **Chemical exposure** to high levels of environmental chemicals, especially benzene and petroleum products.
- **Congenital disorders** such as Bloom syndrome, Trisomy 21 (Down syndrome), Fanconi anaemia, Diamond-Blackfan anaemia and neurofibromatosis. These conditions have unstable genes and are more at risk of developing mutations that cause MDS.
- **Previous chemotherapy or radiotherapy** is associated with an increased risk of MDS, which is called secondary MDS or treatment-related MDS.
- **Cigarette smoking** can increase your risk of MDS because of the chemicals in tobacco smoke.

Key points

- MDS occurs when abnormal blood stem cells are made in the bone marrow. These cells crowd the bone marrow, preventing the healthy blood cells from being made.
- People with MDS usually have active bone marrow but low numbers of blood cells in their bloodstream.
- Approximately 225 people are diagnosed with MDS in New Zealand each year.
- There is no way to prevent MDS and you can’t catch it or pass it on. There are some risk factors that give some people a higher chance of developing MDS.

WHAT ARE THE SIGNS AND SYMPTOMS OF MDS?

Many people in the early stages of MDS have no symptoms at all, and it is discovered incidentally when they have a routine blood test. Most other people are diagnosed after seeing their doctor with various symptoms.

The types of symptoms that you experience depend on how severe the disease is and which type of blood cell is low (red blood cells, white blood cells and/or platelets).

Anaemia

Having a low haemoglobin level (because of a low number of red blood cells) can cause anaemia.

The symptoms of anaemia include:

- Lack of energy (lethargy)
- Feeling very tired all the time (fatigue)
- Shortness of breath, especially when exercising
- Dizziness
- Pale skin (pallor).

Bleeding and bruising

Having a low platelet count (thrombocytopenia) can mean it's harder for your blood to form clots to stop bleeding.

The symptoms of thrombocytopenia include:

- Bruising easily
- Minor cuts or wounds that take a long time to stop bleeding
- Frequent or severe nosebleeds or bleeding gums
- Unusually heavy periods
- Red or purple pinhead-sized spots on your skin called petechiae (pe-tee-kee-i).

Infections

Having a low number of white blood cells in your blood can put you at risk of getting an infection. Neutrophils are the most common type of white blood cell. A low number of neutrophils in your blood is called neutropenia.

Common signs and symptoms of infection include:

- Fever (high temperature of 38°C or above)
- Shivering or rigors
- Coughing up yellow or green phlegm
- Fatigue or extreme tiredness.

Many people with MDS have a combination of symptoms. This is because the production of all the blood cell types may be affected by the disease.

Key points

- The main signs and symptoms of MDS are caused by having low numbers of blood cells, which may include anaemia, bleeding and/or bruising and increased risk of infection.
- Some people have no symptoms of MDS when they're first diagnosed.

WHAT HEALTH PROFESSIONALS WILL I MEET AFTER MY DIAGNOSIS?

You may meet a range of health professionals who are part of your health care team.

Each health professional has a different area of expertise in cancer and cancer care. Working as a team, these health professionals will aim to give you and your family/whānau the best available treatment and support so that you can live as well as possible following a diagnosis of MDS.

Some of the health professionals you may meet, in alphabetical order:

- **Cancer coordinator** – A health professional who guides and supports patients and family/whānau, and is the main point of contact through different parts of the health system in their cancer journey.
- **Charge nurse** – A senior nurse in charge of an outpatient department, day unit or hospital ward.
- **Clinical nurse specialist (CNS)** – A nurse with advanced skills in a specific area of clinical care. This person works closely with you and other members of your health care team to coordinate treatment, and help you manage the symptoms of MDS and the side effects of treatment.
- **Dietitian** – A dietitian may advise you on what to eat and drink to minimise symptoms or side effects from MDS or your treatment. They may also prescribe supplements to make sure you are getting the calories and nutrients you need.
- **General practitioner (GP)** – A family and community doctor. You may be monitored by your GP if you have no symptoms and do not currently need treatment. They will work together with other health professionals to support you at home, in the community and after treatment. They can also refer you to a specialist if needed.
- **Haematologist** – A senior doctor who specialises in the treatment of blood cancers or blood conditions. A haematologist or oncologist (see below) usually oversees any treatment for MDS.
- **House officer** – A junior doctor in training. They work alongside registrars and specialists.
- **Occupational therapist** – Helps you manage everyday activities and achieve activities you want or need to do.
- **Oncologist** – A senior doctor who specialises in cancer and cancer treatment. An oncologist may look after a patient's condition that may have lead to treatment-related MDS, but isn't likely to manage the MDS itself.
- **Outpatient clinic nurse** – A nurse who gives you treatment as an outpatient or who works alongside a doctor in a clinic.
- **Pathologist** – A doctor who specialises in the laboratory (lab) diagnosis of disease and how disease is affecting the organs of the body.
- **Pharmacist** – Prepares and checks your drugs/medications. A pharmacist can advise you on how to take your medicine, possible side effects and interactions with other medications.

- **Physiotherapist** – Specialises in maintaining and improving body movement and mobility.
- **Psychologist** – Specialises in helping you manage any emotional challenges such as stress, anxiety and depression.
- **Registrar** – A doctor who is in training. You may see a registrar in clinics, day units and wards. Registrars works closely with senior specialists (haematologists or oncologists).
- **Social worker** – Helps you manage the practical and emotional impact of the condition and its treatment, such as advice about managing at home, employment or school.
- **Ward clerk** – Manages the administration on the ward, including scheduling admissions, and is the first point of contact for visitors.
- **Ward nurse** – A nurse who looks after you during a stay in hospital.

Other people you might meet or hear about are:

- **Palliative care team** – Doctors, nurses and other health care professionals whose roles include managing symptoms of MDS, helping improve quality of life and supporting people at the end of life.
- **Spiritual care and cultural support** – People who can support your individual cultural, spiritual or religious needs.
- **Non-governmental organisations (NGOs)** – Give emotional and practical support for those affected by cancer. Leukaemia & Blood Cancer New Zealand (LBC) is an NGO.
- **LBC Support Services Coordinator** – A professional who provides education as well as practical and emotional support. They can be contacted by calling 0800 15 10 15.

Meeting so many people can sometimes be confusing and overwhelming. It can be difficult to remember who does what job. If you are unsure, ask the person to remind you who they are and how they fit in to your health care team.

Key points

- Your health care team is made up of different health professionals who specialise in areas of cancer care.
- A haematologist is a senior doctor who specialises in the treatment of blood cancers or blood conditions and usually oversees treatment for MDS.

TESTS AND INVESTIGATIONS

Your doctor will diagnose MDS by talking with you about how you are feeling and looking at samples of your blood and bone marrow.

MDS affects everyone differently, so the types of tests you have may be different to what someone else has. Some symptoms of MDS, like feeling tired and having low or abnormal blood cell counts, are part of many conditions as well as side effects of some medications. Some of the tests and investigations you have are to rule out other blood cancers or blood conditions.

Physical examination and medical history

First, your health care team will take a full medical history. They will ask you about your past and present illnesses, health problems, infections and bleeding. They will also ask what medications you're taking, both over-the-counter medications and prescribed.

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 (FBC)

You will be asked to have a blood test called a full blood count (FBC) or complete blood count (CBC). Blood is taken from a vein in your arm and sent to a lab where the blood cells are counted, and a blood film is examined under the microscope.

This test measures the number of red blood cells, white blood cells and platelets, and looks at the blood cells' size and shape.

Normal blood test results for adults and children are shown below in Table 01.

An FBC is helpful for diagnosing MDS but a bone marrow biopsy is needed to make sure.

Table 01: Normal range for adults (local laboratory ranges may differ slightly)

	Adult men	Adult women
Haemoglobin (Hb)	130–175 (g/L)	115–155 (g/L)
Neutrophils	2.0–7.5 (x10^9/L)	2.0–7.5 (x10^9/L)
Platelets	150–400 (x10^9/L)	150–400 (x10^9/L)

Blood chemistry test

Blood chemistry tests measure the levels of different chemicals in your body. These tests may be done to rule out other causes of low blood counts, e.g. low iron, folate, vitamin B12, certain viral infections and abnormal kidney function.

Bone marrow biopsy

A bone marrow biopsy is a test where a doctor takes samples of your bone marrow and sends them to a lab to be looked at under a microscope. Bone marrow samples are usually taken from the back of your hip bone (the iliac crest) (see Figure 04).

A bone marrow biopsy can be done when you are staying overnight in hospital or as an outpatient (you visit the hospital for this purpose).

Your doctor might give you a drug that makes you feel relaxed and sleepy (a sedative) before the biopsy starts. You might also be given pain relief. Your doctor will give you a local anaesthetic. This is a small injection that is put into your skin where the biopsy is going to be done, to make the area numb.

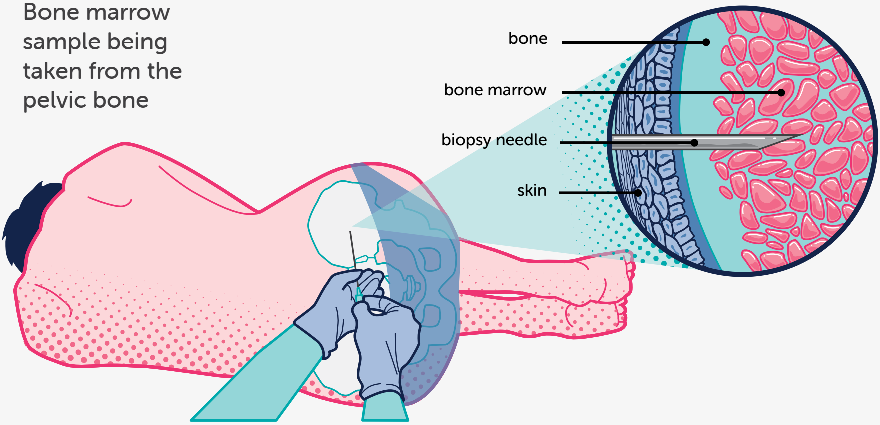
To do a bone marrow biopsy, your doctor inserts a long needle through your numbed skin into the bone and then into the bone marrow. Bone marrow has liquid and solid parts. A small sample of your bone marrow liquid is taken out. This is called bone marrow aspirate. A sample of the solid part of the bone marrow is also taken. This is called a bone marrow trephine (tre-fine).

Some people who have had a bone marrow biopsy say that it was painful and other people describe it as uncomfortable.

Figure

04

Bone marrow sample being taken from the pelvic bone



Everybody is different. We recommend that you bring a support person with you when you have a bone marrow biopsy. If you have a sedative, you will still feel a bit drowsy afterwards. Your support person can make sure you get home safely.

After the biopsy, your doctor or nurse will put a plaster or small dressing over the biopsy site. You may need paracetamol to help ease some discomfort in the area afterwards. Your doctor or nurse will talk to you about this.

The bone marrow aspirate and trephine samples are sent to a lab and examined under a microscope. Some samples may be sent for special tests, which may take longer to get results. You will then have an appointment with your haematologist to talk about the findings of your bone marrow biopsy. You may also have a bone marrow biopsy after you have started treatment for MDS to see how well you are responding to your treatment.

Cytogenetic and molecular tests

Cytogenetic (sy-toe-gen-et-ick) and molecular tests use the blood and bone marrow samples to see if the cells have differences (mutations) in their DNA compared to normal cells.

Below are the main types of cytogenetic tests used in MDS:

- **Chromosome analysis** – Chromosomes (organised structures of DNA) are examined under a microscope to see if there are any missing, extra or abnormal chromosomes.
- **Fluorescence in-situ hybridization (FISH)** – A test which 'paints' important genes so they can be seen under a microscope.
- **Polymerase chain reaction (PCR)** – A test which looks for changes in your DNA. It is often done at the same time as cytogenetic/FISH tests and can check for common mutations.

Detailed information

The results from the cytogenetic tests can take a couple of weeks and are often written in a shorthand form that describes which chromosome change is present.

For example:

- A minus sign (-) or the abbreviation 'del' is used to mean a deletion, e.g. if a copy of chromosome 7 is missing, it can be written as -7 or del(7). There are two parts to a chromosome (p and q) so if only part of chromosome 7 is missing it will be written as -7q or del(7q).
- A plus sign (+) is used when there is an addition (an extra copy of all or part of a chromosome), e.g. if chromosome 8 has been duplicated and there are too many copies of it within a cell, it is written as +8.
- The letter 't' is used to indicate a translocation, which means parts of two chromosomes have swapped places with each other, e.g. if chromosomes 8 and 21 have swapped, it would be written as t(8:21).

The cytogenetic changes can help predict the likely course of MDS. Sometimes they can predict a better or poorer outcome.

Immunophenotyping

Immunophenotyping (im-u-no-fee-no-tie-ping) is also known as flow cytometry or cell marker studies. It is used to confirm a diagnosis of MDS and to separate it from other similar diseases. Flow cytometry uses lasers to detect special markers (called antigens, e.g. CD20) on the surface of abnormal cells in blood or bone marrow samples.

Other tests

You might need more blood tests or imaging tests when you are diagnosed with MDS and throughout your treatment.

Types of imaging tests may include:

- Chest X-ray
- Electrocardiogram (ECG)
- Echocardiogram (ECHO).

The results of your tests and investigations provide a baseline of your disease and general health. Your health care team can then compare later test results against the baseline to track any changes and how you are responding to treatment.

Preparing for tests

Before you go for a test, ask your health care team how long the test will take, what the test involves and how you will feel afterwards.

Things that you can do to help prepare for the test are:

- Plan your journey so that you arrive on time and do not have to rush.
- Find out about parking – your LBC Support Services Coordinator can help.
- Ask a support person to come with you.
- Ask for an interpreter if needed, your health care team at the hospital can organise this for you in advance.
- Take your favourite music on a device with headphones.
- Take something to read.

Key points

- A variety of tests and investigations are done to diagnose MDS and to rule out other blood cancers or blood conditions.
- Blood tests and bone marrow biopsies are used to examine the blood cells (including the number of blood cells, their shape and size).
- Cytogenetic and molecular tests can analyse the cell's DNA to see if/what mutations are present.
- Ask your health care team about upcoming tests and procedures so that you can prepare. We recommend you bring a support person to your appointments to help with driving, asking questions and listening to any information given by your health care team.

TYPES OF MDS

There are different types of MDS, also called subtypes. Some types are more severe than others.

The World Health Organization (WHO) has developed a classification for the different types of MDS, based on:

- The types of blood cells that are affected and how low those numbers are
- How many types of blood cells in your bone marrow are abnormal in size, shape or look (dysplasia)
- How many immature cells (blasts) you have in your bloodstream (peripheral blood) and bone marrow
- Any chromosome changes in your blood cells and the pattern of these changes.

Based on these factors, the WHO system has classified the following types of MDS:

- MDS with LB and SF3B1
- MDS with LB and del(5q)
- MDS with biallelic TP53
- MDS with low blasts
  - SLD
  - MLD
- MDS hypoplastic
- MDS – IB1 (blasts 5-9% BM)
- MDS – IB2 (blasts 10-19% PB/BM)
- MDS with fibrosis.

Abbreviations explained:
LB = low blasts
SLD = single lineage dysplasia
MLD = multilineage dysplasia
IB = increased blasts
EB = excess blasts
BM = bone marrow
PB = peripheral blood.

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Key points

- The World Health Organization (WHO) has classified MDS into different types.
- The types of MDS are generally based on which blood cells are affected, how many blast cells are in your bloodstream or bone marrow, how different (dysplastic) the cells in your bone marrow look and what chromosomal changes there are.

INFORMED CONSENT FOR TREATMENT AND PROCEDURES

You will be asked to give your informed consent for all treatments or procedures suggested by a health professional in your health care team.

Consent means that you agree. Informed consent means that you understand the information and accept the possible risks and benefits of the treatment or procedure. Informed consent also means that you have had other treatment or procedure options explained to you.

If you have any doubts or questions or need more information about a procedure or treatment, it is important you speak to your doctor or nurse again. You may need to sign a consent form (written consent) or you may just say you agree to treatment or a procedure (verbal consent).

If someone is not able to give informed consent, a legal guardian, welfare guardian or person with enduring power of attorney (EPOA) can give consent on behalf of the patient.

Generally, a person over the age of 16 can give informed consent if the doctor feels they are able to do so.

Your informed consent is also required if you agree to take part in a clinical trial. Clinical trials are explained on page 18.

Key points

- Informed consent means that you understand the information about a treatment or a procedure.
- Speak to your health care team if you have any doubts or need more information about a treatment or a procedure.

MAKING TREATMENT DECISIONS

The main goals of treating MDS is to:

- Manage your symptoms
- Prevent any complications
- To help you live as normal a life as possible.

No two people are the same. To help you make the best treatment decision, your doctor will consider all the information available.

Your haematologist will recommend treatment based on:

- The type of MDS you have
- Your age
- Your general health
- Your prognosis (see page 18 for information on prognosis)
- Your wishes.

Many people feel overwhelmed when they are diagnosed with MDS. Waiting for test results and discussing treatment options can be very stressful. Some people do not feel they have enough information to make decisions, while other people feel they can have too much information. Some people feel they are being rushed into making a decision. If treatment is recommended to start immediately, it can be difficult when you feel like you don't have time to consider all options and process the information.

Your doctor will spend time with you and your family/whānau discussing what they feel is the best option for you. Ask as many questions as you need to, at any stage. You should feel that you have enough information to make the important decisions you are facing.

Second opinion

You can ask for a second opinion. A second opinion is when you see a different haematologist about your diagnosis and/or treatment. You can ask any member of your health care team, including your current specialist, about getting a second opinion.

Questions to ask your health care team

Before going to see your GP or specialist, or another member of your health care team, make a list of the questions you would like to ask.

In the appendix on page 52 there are some examples of questions you could ask your GP or haematologist. You could write your questions and answers in the back of this booklet or in the LBC Haematology Patient Diary available from your LBC Support Services Coordinator. On page 13 of the Haematology Patient Diary there is also a list of suggested questions that you might like to ask your doctor.

Bring a support person

We recommend that you bring a support person along to your appointments. Your support person can write down the answers to your questions, remind you of questions you want to ask and help you remember information.

The LBC Haematology Patient Diary is useful for writing down your questions, making notes from appointments and recording details of treatment.

Prognosis

Prognosis means an estimate of the likely course of a disease. It provides a guide as to how long your MDS might be controlled or the likelihood that it will progress and get worse.

Your haematologist will consider many factors when making a prognosis. These may include the type of MDS you have, your age and your overall health.

A prognosis is useful to give you an idea about the disease risk, but it does not predict outcomes for individual patients.

When you are diagnosed, your haematologist might use the International Prognostic Scoring System (IPSS-R) or WHO prognostic scoring system (WPSS). These scoring systems help predict how your disease might progress and the risk of MDS transforming into a more aggressive form of blood cancer called acute myeloid leukaemia (AML). It is also used to inform treatment decisions.

Being in a clinical trial

Your doctor might ask you to take part in a clinical trial. Clinical trials are also called research studies. Clinical trials help find out if a new treatment or different ways of giving treatment are better than treatments that are already available. Participation in a clinical trial can provide an opportunity to access these latest treatments, or to use existing treatments for MDS in a new way.

Taking part in a clinical trial is voluntary, which means that you do not have to take part in the trial if you do not want to. If you do not want to be part of the trial, your decision will be respected. You do not have to give a reason why you don't want to be part of the trial and there will be no change in the way you are treated by the hospital or your health care team.

Make sure you understand the reasons for the trial and what is involved. You need to give informed consent for a clinical trial. Take time to talk through the trial with your haematologist and other members of the health care team before signing the consent form.

More information available online

See the Clinical Trials fact sheet on the LBC website.

Key points

- Your doctor will recommend a course of treatment to you, and will give you the opportunity to discuss your treatment and ask questions.
- You will be given information so that you can understand the risks and benefits of treatments and procedures. You will be asked to give your written or verbal consent for treatments and procedures.
- We recommend you bring a support person to your appointments if possible.
- Clinical trials (research studies) help find new treatments or aim to improve current treatments. Clinical trials are voluntary – you can choose whether or not you take part.

Detailed information

The IPSS-R system divides patients into five risk groups according to their bone marrow blast cell percentage, number of cytopenias (low number of blood cells) and chromosome changes or mutations in the bone marrow (cytogenetics). Firstly, your cytogenetic abnormalities are identified (see Table 03) then your blood cells in your bone marrow and bloodstream are measured (see Table 04). The prognostic variables in Table 04 give you a risk score, which puts you into one of the five risk groups (see Table 05).

Table 03: Cytogenetic risk groups

Cytogenic prognostic subgroups	Cytogenetic abnormalities
Very good	-Y, del(11g)
Good	Normal, del(5q), del(12p), del(20q), double including del(5q)
Intermediate	del(7q), +8, +19, +21, i(17q), any other single or double independent clones
Poor	-7, inv(3)/t(3q)/del(3q), double including -7/del(7q), complex: 3 abnormalities
Very poor	Complex: >3 abnormalities

Table 04: Prognostic variables and scores

Cytogenic risk groups	Very good	Good	Intermediate	Poor	Very poor
	0	1	2	3	4
Bone marrow blast (%)	≤2	>2–<5	5-10	>10	
	0	1	2	3	
Haemoglobin (g/L)	≥100	≤80-99	≤80		
	0	1	1.5		
Platelets (x10^9/L)	≥100	50–<100	<50		
	0	0.5	1		
Absolute neutrophil count (ANC) (x10^9/L)	≥0.8	<0.8			
	0	0.5			

Table 05: Risk scores and categories

Risk category	Risk score
Very Low	≤1.5
Low	>1.5–3
Intermediate	>3–4.5
High	>4.5–6
Very high	>6

TREATMENT FOR MDS

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

- Active monitoring
- Standard drug therapies
- Stem cell transplant
- Supportive care.

Each of these treatments will be discussed in the following pages.

Your health care team will explain the treatments, their benefits and possible side effects.

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

Active monitoring

Active monitoring, often called watch and wait, means that your disease does not need any treatment at that point in time. It does not necessarily mean that your disease is too advanced to treat, or that you are too old for treatment. Ongoing monitoring and regular checkups will likely include routine blood tests and physical examinations. The timing of doctor visits and tests might vary from person to person. This monitoring may be under the care of your GP.

While being monitored, it's recommended you remain active and maintain healthy habits. These include:

- Doing regular exercise
- Eating healthily
- Reducing stress levels
- Stopping smoking
- Stopping or limiting alcohol intake
- Using a high-factor sunscreen and wearing a hat while outdoors, to protect against skin cancers
- Having the influenza vaccine each year.

See page 45 for more on keeping in good health after your MDS diagnosis.

More information available online

See the Active Monitoring fact sheet on the LBC website.

Standard drug therapies

Your health care team might use the term 'standard treatment' or 'standard therapy'. This is a treatment plan that is commonly used to treat a certain type of disease.

The standard therapy for MDS includes:

- Chemotherapy
- Targeted therapy.

Chemotherapy

Chemotherapy is the main type of treatment for MDS. Chemotherapy is commonly called chemo or cytotoxic drugs.

Chemotherapy works by killing cells that multiply quickly, including cancer cells. Most chemotherapy drugs travel around the body in the bloodstream, which means they can reach cancer cells anywhere in the body. They stop cancer cells from dividing and reproducing. Normal cells that multiply quickly (such as hair follicles and cells on the inside of your mouth) can also be affected, causing side effects, but these cells usually recover. Side effects are discussed later in this section.

There are many different types of chemotherapy drugs and they can be administered (given to a patient) in a variety of ways.

The different ways that chemotherapy is given are:

- Into a vein (intravenously or IV)
- In a tablet (orally or PO [Latin for 'by mouth'])
- Into a muscle (by intramuscular injection or IM)
- Under the skin (by subcutaneous injection, subcut or SC)
- Into the spinal fluid via a hollow needle (by intrathecal injection or IT).

The main use of chemotherapy in treating MDS is to control a rising white blood cell count, and to prevent MDS from transforming into acute leukaemia. The amount (dose), timing and type of chemotherapy will depend on the type of MDS, your age and your health. Your haematologist may recommend you have low-intensity or high-intensity chemotherapy. These are both discussed in more detail below.

Low-intensity chemotherapy

Some people with MDS may not be able to tolerate intense chemotherapy and their haematologist may recommend low-intensity chemotherapy.

Detailed information

Azacitidine

Azacitidine is a chemotherapy drug that is a type of hypomethylating agent (see Glossary on page 47). It may be a treatment option for people with high-risk MDS who are not eligible for a stem cell transplant.

Azacitidine is administered via subcut injection into your stomach, upper arm or thigh. Your first dose of azacitidine is usually given in an outpatient clinic at the hospital by a qualified nurse.

You will usually have the injections daily for seven days or seven injections within every 28 days. Then you have a rest period of 21 days. After this, you start another cycle of treatment in the same way. You usually have several cycles of treatment over a few months. You will have regular blood tests and be monitored by your health care team. If you have any questions or concerns, contact your health care team.

Side effects at the time of injection may include:

- Allergic reaction (feeling hot, shivering, itching, skin rash, headache, swelling in face or mouth, feeling wheezy or breathless, pain in your back, chest or stomach)
- Injection injury (redness, itching, bruising and/or swelling from the injection needle).

Your nurse will be monitoring you for these signs and symptoms immediately after your injection.

Common side effects of chemotherapy may include:

- Increased risk of infection
- Bruising and/or bleeding
- Anaemia
- Nausea and/or vomiting
- Diarrhoea or constipation
- Fatigue
- Headaches and/or dizziness
- Muscle or joint pain.

See 'Living with MDS' on page 28 for more information on managing side effects.

The aim of low-intensity chemotherapy is to control your MDS while avoiding severe side effects from chemotherapy and to help you maintain a good quality of life.

Low-intensity chemotherapy often means the dose (amount) of chemotherapy is reduced and it may be given in a different way (e.g. as a tablet or subcut injection).

People who have other health concerns may be recommended low-intensity chemotherapy because intense chemotherapy may cause severe side effects and cause more harm than good.

High-intensity chemotherapy
The goal of high-intensity chemotherapy 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.

Some people with MDS, who have a higher risk of their MDS transforming to acute leukaemia, may have high-intensity chemotherapy. Higher doses of stronger drugs can mean the side effects may be more severe. Sometimes it is called high-dose chemo or induction chemo because the goal is to induce remission.

High-intensity chemotherapy is given in the hospital (as an outpatient or inpatient) and is usually given as a combination of different drugs. Each drug works in different ways, and together they are more effective. High-intensity chemotherapy is usually given via an IV/drip over several cycles, with rest periods of 1-4 weeks between each dose. These rest periods allow your body time to recover from the side effects.

Side effects of chemotherapy

Healthy cells that multiply quickly in your body can also be killed or damaged because of chemotherapy. Examples of these cells are those in your mouth, stomach, bowel, bone marrow and hair. The dead or damaged cells can cause side effects.

The side effects for each drug or drug combination are different. Most people will have some side effects, but some people do not. Side effects may vary depending on the dose of chemotherapy you are having. Most side effects of chemotherapy begin to go away when your treatment is finished.

When you receive chemotherapy, there are breaks during the treatment so that your body (the bone marrow in particular) has time to recover from the side effects of the chemotherapy. Side effects of treatment may be short term or long term (sometimes called late effects). Short-term side effects should go away a few weeks after treatment finishes, once the damaged cells recover. Long term means that you may experience side effects for months after treatment. Some side effects may only start after treatment has finished, which is called late effects.

Here is a list of the most common side effects of chemotherapy, in alphabetical order:

- Anaemia (from a low red blood cell count)
- Bruising and bleeding (from a low platelet count)
- Constipation
- Diarrhoea
- Difficulty concentrating or remembering (chemo brain)
- Early menopause
- Fatigue (extreme tiredness)

- Fertility changes
- Hair loss (alopecia)
- Increased risk of infection (from a low white blood cell count)
- Low mood, anxiety or depression
- Nausea and vomiting
- Organ damage
- Pain
- Peripheral neuropathy
- Poor appetite and taste changes
- Skin changes
- Sore mouth (mucositis)
- Weight loss or gain.

These side effects, and what you can do if you have them, are discussed in the section called 'Living with MDS' on page 28.

Targeted therapy

Targeted therapies are drugs designed to treat cancer cells and minimise damage to normal healthy cells. There are many types of targeted therapies that work in a variety of ways to treat different cancers.

Detailed information

Lenalidomide

Lenalidomide is both a targeted drug and an immunotherapy drug. It is used to treat some very specific types of MDS, lymphoma and myeloma. Your haematologist will discuss with you if lenalidomide is a treatment option for you.

Lenalidomide works by blocking the development of new blood vessels which cancer cells need to grow. It also kills the growth of cancer cells and helps the immune system attack and destroy cancer cells.

Lenalidomide is given orally as a capsule. You usually take lenalidomide once a day for 21 days and then have seven days of not taking it. After this, you start taking it again in the same way.

Specific precaution is needed when taking lenalidomide as it can cause birth defects when pregnant women are exposed to it. Other important things to remember when taking lenalidomide are:

- Keep the capsules in the original package at room temperature, away from heat and direct sunlight
- Wear gloves when handling the capsules and wash your hands thoroughly afterwards
- Keep them out of sight and reach of children
- Don't chew or open capsules
- Take them at the same time each day with a glass of water.

Common side effects include:

- Risk of infection
- Brusing and/or bleeding
- Anaemia
- Skin changes
- Diarrhoea or constipation
- Sore mouth
- Nausea and/or vomiting
- Loss of appetite
- Fatigue
- Numb or tingling hands and/or feet (peripheral neuropathy)
- Effects on the heart, kidney and/or liver.

You will have regular blood tests and be monitored for side effects. If you have any questions or concerns, contact your doctor or other members of your health care

See 'Living with MDS' on page 28 for more information on managing side effects.

Stem cell transplant

A stem cell transplant (also called haematopoietic stem cell transplant or bone marrow transplant) may be recommended as further treatment.

A stem cell transplant is not suitable for everyone, and not everyone with MDS needs one. Your haematologist will weigh up the risks and side effects against the benefits of having a transplant.

If your haematologist thinks a stem cell transplant is necessary or a treatment option for you, they will discuss it with you in detail.

There are two main types of stem cell transplants – autologous and allogeneic.

Allogeneic stem cell transplant

An allogeneic stem cell transplant involves having high doses of chemotherapy in an attempt to completely destroy the abnormal stem cells in your bone marrow. These cells are then replaced with healthy stem cells that have been donated, usually by a sibling who has a similar tissue type as yours or a matched unrelated donor.

An allogeneic stem cell transplant is a high-risk treatment option and a lot of things are taken into consideration before it is offered by your haematologist.

Autologous stem cell transplant

An autologous stem cell transplant is when you have chemotherapy to kill off as many cancer cells as possible. You then have your own stem cells collected (called a stem cell harvest), which are given back to you via an IV/drip after more high-dose chemotherapy. This type of stem cell transplant is rarely used to treat MDS.

More information available online

See the LBC website for fact sheets on allogeneic stem cell transplants and autologous stem cell transplants.

Supportive care

Supportive care is important to help you cope with your diagnosis of MDS, symptoms of MDS and the impact of treatment. Supportive care ensures that you have the best quality of life.

Examples of supportive care include:

- Blood transfusions
- Growth factors
- Erythropoiesis stimulating agents (ESAs)
- Antibiotic, antimicrobial and antiviral treatments
- Vaccines
- Complementary therapies
- Palliative care.

Blood transfusions

The purpose of blood transfusions is to quickly increase the levels of healthy, functioning blood cells that are low because of treatment or the MDS itself. The two main types of blood transfusions are either red blood cells or platelets.

Most people with MDS have a low number of red blood cells (haemoglobin) and may need regular blood transfusions. Your haemoglobin is monitored through a blood test. The normal ranges of blood counts can be found in Table 01 on page 11.

Blood transfusions are generally administered at the hospital after a specific blood test is used to crossmatch the right blood. Blood transfusions are given through an intravenous (IV/drip) line and will take between 30 minutes to three hours. You will be closely monitored as there is a risk of having an allergic reaction while the transfusion is running. Monitoring will include you having your temperature, heart rate, respiratory rate, blood pressure and oxygen saturation levels measured. It is also important that you report any changes, like becoming breathless, itchy skin, rash or shaking (chills) to your nurse.

Growth factors

Growth factors are chemicals that help your bone marrow make more blood cells. They can be given to increase low blood counts. For example, if you have a low white blood cell count during treatment you may be given a growth factor (granulocyte colony-stimulating factor or G-CSF), which stimulates the body to produce more neutrophils. This is administered as a subcut injection.

Erythropoiesis stimulating agents (ESAs)

ESAs are a group of medications that improve haemoglobin levels. They may be a treatment option for people with low-risk MDS who have anaemia. They have the potential to reduce the frequency or need for red blood cell transfusions and may improve or maintain quality of life.

Erythropoietin (EPO) is a naturally occurring hormone produced in the kidneys in response to low levels of oxygen in the blood. It plays a vital role in promoting and controlling red blood cell production by the bone marrow.

A drug called Epoetin (EPREX®) mimics EPO and may be recommended for some people with MDS. It is administered by subcut injection.

Your haematologist will discuss ESAs in more detail if it is a treatment option for you.

Antibiotic, antimicrobial and antiviral treatments

You may be at higher risk of infection, due to either your MDS or treatment. If you get an infection, you may be given antibiotics, antivirals or other antimicrobials to help treat it. These are usually given as a tablet or via an IV/drip into your veins. You may also be given these treatments to prevent an infection – this is called prophylaxis.

Detailed information

Iron overload

Over time, repeated red blood cell transfusions can lead to a build-up of high levels of iron in the body. Your doctor will be monitoring your iron levels when you have your regular blood tests and will discuss with you if these levels are getting too high.

Vaccines

Vaccines help prevent infections. Some treatments can 'reset' your immune system, so you may need to have some vaccines you have already had again. Annual influenza vaccines, Covid-19 vaccination and the shingles vaccine (Shingrix) are safe and are recommended for most people with MDS. If your platelet count is very low (<30 x10^9/L), your doctor may recommend you have vaccines administered via subcut injection, to reduce risk of bleeding.

'Live' vaccines should usually be avoided by people with blood cancers such as MDS. Live vaccines include MMR, BCG, and yellow fever vaccines. If you have had an allogeneic stem cell transplant in the past year, or if you are still taking immune suppression medicines after a transplant, talk to your health care team about which vaccines they recommend for you, and when you should have them.

Complementary therapies

Complementary therapies can be very useful to help people feel better emotionally and physically. There are lots of different therapies and some people find it helpful to try more than one.

Examples of complementary therapies are:

- Acupuncture
- Aromatherapy
- Art therapy
- Homeopathy
- Journaling
- Massage
- Meditation
- Mindfulness techniques
- Music therapy
- Reflexology
- Reiki
- Relaxation
- Tai chi
- Visualisation
- Yoga.

If you are not sure what some of these therapies are, ask a member of your health care team. If you plan to use complementary therapies, including any supplements, make sure they are a safe option for you by asking your haematologist first.

Palliative care

As mentioned earlier in this booklet, the palliative care team is made up of doctors, nurses and other health care professionals who specialise in managing symptoms of MDS. They aim to improve quality of life through support and services as you face a life-limiting illness. The palliative care team may be involved in providing you with supportive care.

Many people associate the word 'palliative' with end-of-life care. Palliative care may start at diagnosis, during treatment, after treatment and at the end of life.

More information available online

See the Options for End-of-life Care fact sheet on the LBC website.

Treatment for relapsed disease

If the MDS returns after treatment, your haematologist will talk to you about your options for treatment. They could include any of the treatment options discussed in this section and will depend on many factors, including:

- The time between when you finished initial treatment and when your relapse occurred (e.g. months or years).
- How well the MDS responded to your initial treatment.
- How you coped with the treatment.
- Your age and general level of health.
- If there is a donor available for an allogeneic stem cell transplant.
- How you feel about further treatment.

Key points

- Treatment for MDS can include a combination of active monitoring, chemotherapy drugs, targeted therapy and supportive care.
- Stem cell transplants allow you to have much higher doses of chemotherapy to improve your chances of remission. The two main types of stem cell transplants are autologous and allogeneic.
- Supportive care includes blood transfusions, vaccines, complementary therapies and other medications to support your body.

LIVING WITH MDS

There are a number of symptoms of MDS or side effects of treatment. Some are more common than others.

Each person's experience will be different. Some people feel very unwell, while others have milder or no symptoms. Side effects can be unpleasant, but most of them are temporary and reversible. If you are having intensive chemotherapy, your side effects may be more severe.

This section helps you manage the more common symptoms of MDS and the side effects of treatment. They are listed below in alphabetical order.

Remember to report any side effects to your doctor or nurse. Your LBC Support Services Coordinator can give you support and more information.

Anaemia

A low red blood cell count is called anaemia. Anaemia is described in more detail on page 8.

If you have a low red blood cell count, you may be given red blood cells via IV/drip, which is called a blood transfusion.

Bruising and bleeding

You may bruise easily, or bleed more than usual from minor cuts if you have a low platelet count (thrombocytopenia), or as a side effect of some medicines. Symptoms of thrombocytopenia are described on page 8.

Things you can do to help or prevent bruising and bleeding include:

- Use a soft toothbrush.
- Don't floss your teeth.
- Don't shave with a razor blade.
- Move about carefully so you don't bump into things or trip.
- Don't play contact sports such as rugby or hockey.
- Wear protective gloves when doing work around the home or garden.
- Don't eat food with sharp edges, e.g. potato chips.
- Let your doctor or nurse know if you are constipated.

If you have a very low platelet count, you might be given a transfusion of platelets via IV/drip to help stop bruising and bleeding.

Important information

Call the hospital straight away if you have:

- Nosebleeds
- Bleeding gums
- Unusually heavy menstrual bleeding (period)
- Tiny red or purple spots on the skin that look like a rash (petechiae).

Constipation

Constipation means that you cannot pass a bowel motion easily – usually because your bowel motions are hard. Tell your nurse or doctor if you are constipated or sore.

Hard bowel motions can damage the lining of your bowel and cause bleeding or infection.

Things you can do to help:

- Drink plenty of water.
- Eat more fibre such as cereals, raw fruit and vegetables (ensure they are cleaned well).
- Do some gentle exercise.
- Tell your doctor or nurse, as they can give you medications to soften your bowel motions.
- Talk to a dietitian.

Diarrhoea

Sometimes treatment (e.g. chemotherapy) damages the lining of your bowel wall.

This might cause diarrhoea (die-a-rea) (loose bowel movements) and other symptoms such as:

- Cramping (pains in the lower abdomen or gut)
- Abdominal swelling (swollen tummy).

If you have diarrhoea, your health care team will do a test to see if you have an infection.

Things you can do to help:

- Take the drugs that your doctor or nurse give you to stop the diarrhoea.
- Wipe your bottom with soft toilet paper or flushable wipes.
- Apply a barrier cream around your bottom to protect and soothe the skin.
- Drink plenty of fluids.
- If you are unable to drink fluids, tell your doctor or nurse as you may need to have a drip/IV.
- Eat less fibre, such as cereals, raw fruits and vegetables.

Important information

Call the hospital if you have more than four episodes of diarrhoea in a day.

Difficulty concentrating or remembering (chemo brain)

Chemo brain is another symptom of MDS or side effect of treatment such as chemotherapy.

Chemo brain is also called mild cognitive impairment. It can also affect people with cancer who have not had chemotherapy. The exact cause of chemo brain is not known.

The symptoms of chemo brain are:

- Difficulty concentrating
- Difficulty remembering things, including finding the right word
- Feeling very tired.

Chemo brain can be frustrating and it can make everyday life difficult. Some things you can do to help are:

- Keep a diary of your symptoms.
- Make lists, take notes, and use sticky pads or your phone for reminders.
- Keep a calendar or diary.
- Do mental exercises such as crosswords and puzzles.
- Try to keep calm.
- Do some regular exercise.
- Get plenty of rest and sleep.
- Read short articles rather than books and watch episodes of programmes rather than films.

More information available online

See the Chemo Brain fact sheet on the LBC website.

Difficulty eating or drinking

You may find it harder than usual to eat or drink due to the effects of MDS or your treatment. Sometimes people can lose weight as a result. Having small, frequent meals or snacks and sipping fluid throughout the day can make it easier to get enough nutrients in.

Speak to your health care team if you have pain or nausea that is stopping you from eating and ask to speak to a dietitian for further support.

More information available online

See the Eating Well fact sheet on the LBC website.

Early menopause

Some chemotherapy drugs can lower the amount of hormones that the ovaries make. This can lead to early menopause and menopausal symptoms.

Menopause usually starts any time after 40 years of age when, due to hormonal changes, women's periods stop and they can no longer have children.

Your doctor will be able to tell you if you are having a type of chemotherapy that might cause you to experience early menopause.

Fatigue (extreme tiredness)

Fatigue is very common for people with MDS or having treatment.

Fatigue can be caused by:

- MDS itself
- Chemotherapy and targeted therapies
- Emotional stress
- Poor sleep
- Low blood counts (especially anaemia caused by a low red blood cell count)
- Muscle loss
- Loss of appetite or dehydration.

Fatigue can have a huge impact on your life. If you have chemotherapy, it can sometimes be several months before you feel your energy levels are back to normal. Some people feel tired for a year or more afterwards.

Things you can do to help:

- Have a regular night sleep routine.
- Have regular rest periods throughout the day.
- Don't try to do too many things in a day, just do the important things.
- Note the times in the day when you have the most energy and set goals to do your main activities at these times.
- Do some light exercise each day.
- Keep a diary so you can look back and see your improvements in energy levels over time.

Talk to your health care team if you are struggling to cope with your fatigue.

More information available online

See the Managing Cancer-related Fatigue fact sheet on the LBC website.

Feelings of isolation

A diagnosis of MDS can make you feel isolated or alone for a number of reasons, including:

- Being unable to continue working, studying or doing the things you usually do.
- Symptoms and side effects (such as fatigue or risk of infection) can make it hard to be with other people or attend social events.
- A lack of support from family/whānau or friends who may not know what to say or do.
- Financial difficulties can make it hard to maintain social activities or visit family/whānau and friends.

Feeling isolated can have an impact on your physical and mental well-being. It is important to speak to your doctor, nurse, social worker or LBC Support Services Coordinator if you feel isolated or alone.

Fertility

Fertility is a person's ability to get pregnant or father a child. Infertility means that you may not be able to become pregnant or father a child. Some chemotherapy drugs may cause infertility.

It is important that you ask any questions or discuss concerns you might have about your fertility with your doctor as soon as possible. There may be some things you can do before you start treatment that mean you might be able to have a baby or father a child in the future.

For some people, the possibility of losing their fertility can be very upsetting. There is practical and emotional support available. Talk to a member of your health care team, who will help you get the support you need.

Chemotherapy can affect a developing foetus, so use a condom when you have sex during and after chemotherapy to avoid a pregnancy. More information on contraception, sex and relationships can be found on page 43.

More information available online

LBC has a Fertility fact sheet for both men and women available on the LBC website.

Hair loss (alopecia)

Hair loss can be a side effect of certain chemotherapy drugs. Your doctor will let you know if the treatment you're having will cause hair loss.

Hair loss is typically only temporary and usually occurs three to six weeks after you begin treatment. You should start to feel and see new hair growing back six to 12 weeks after you finish treatment, although the colour and/or texture may be different. Each person is different and some might take longer for their hair to fall out or grow back.

Hair loss can happen on all parts of your body including your head, eyebrows, eyelashes, beard or moustache, underarms, pubic hair and legs. You may experience hair thinning, or it may fall out completely. Your scalp may feel sensitive, sore or itchy when your hair is falling out.

Things you can do to help:

- Pat your hair gently with a towel to dry it.
- Don't use heat, such as a hair dryer or straighteners.
- Don't use chemicals, such as hair dye.
- Use a soft brush – some people find baby brushes are best.

Unfortunately, there is nothing you can do to prevent your hair from falling out. Stopping brushing or washing your hair will not stop your hair from falling out.

Emotional support

Some people find losing their hair upsetting. Hair, including facial hair, can be an important part of a person's identity. It is important to acknowledge how you feel about hair loss. If you are struggling with hair loss, talk to your health care team. They can give you information and support.

Other people's reactions to your hair loss can sometimes be difficult to cope with. It can be helpful for you to talk to them about it first. Children will generally cope well if you talk to them about your hair loss and explain why it happens.

There is support for family/whānau members who are struggling to cope with your hair loss. Talk to your health care team to find out about the support available to them.

Shaving your head and head wear

Some people let their hair fall out naturally. Other people have their hair cut off in stages or shave it off before treatment begins as they find this easier than watching their hair fall out.

Things you can do that can help:

- Speak to other people who have experienced hair loss.
- Wear a wig, cap, beanie or woolly hat, scarf or turban. This can make you feel more comfortable. In winter you will probably find it very cold without a head covering.
- In summer you are more prone to sunburn. Your skin is more sensitive to the sun after chemotherapy so it's important to apply sun block and wear a hat.

Increased risk of infection

MDS itself, and treatments for MDS, including chemotherapy and targeted therapies, can increase the risk of infection.

If you are receiving chemotherapy, you may be at risk of a very low white blood cell count (neutropenia). If this is the case, your health care team will tell you what to do if you develop a fever or other symptoms of infection.

Infections during chemotherapy can be very serious and even fatal if you do not seek medical advice quickly for an assessment and antibiotics.

You may also be prescribed preventative (prophylactic) antibiotics to prevent infection, especially during and after some types of treatment.

Even if you are not receiving chemotherapy, and do not have a low white blood cell count, you should consider yourself at increased risk of infection due to having MDS. The most common infections in people with MDS are chest infections (including pneumonia), skin infections (including cellulitis and shingles) and urinary tract infections (UTIs, including kidney and bladder infections). You should promptly see a doctor if you develop a fever or other symptoms of an infection, as you are more likely to need antibiotic or antiviral treatment than someone who does not have MDS.

You may also be prescribed preventative (prophylactic) antibiotics to prevent infection, especially during and after some types of intensive treatment.

You should ask your doctor about what vaccines they recommend you have, to minimise risk of certain infections. See page 26 for more information on vaccines.

See page 8 for common signs of infection.

There are a number of things you can do to reduce your chance of getting an infection. These are as follows:

Avoiding food-related infections

You need to be careful when preparing and cooking food.

Be sure to:

- Always wash your hands before preparing or eating food.
- Tell your family/whānau to wash their hands before preparing food.
- Prepare food in a clean place.
- Prepare raw meat on a separate chopping board from other foods.
- Wash fresh fruit and vegetables well.
- Cook food well and makes sure it is very hot.
- Make sure reheated food is very hot.
- Eat food before its best before/use-by date.
- Do not reheat food more than once.

Important information

- Make sure you have a thermometer at home and you know how to check your temperature correctly.
- All people with MDS are at increased risk of infection. You should seek medical advice immediately if you develop a fever or other symptoms of infection. Infections can get worse very quickly if left untreated.
- If you are currently receiving chemotherapy or if you have been told you are at risk of, or have, neutropenia, you should contact your hospital immediately if you have a temperature over 38°C. Do not wait to see if your temperature goes away as you could get worse very quickly. Your health care team will provide you with instructions and/or emergency telephone numbers if you are in this risk group.
- Don't take any drugs such as paracetamol to bring your temperature down before you talk with a doctor.
- Be cautious about using aspirin or ibuprofen in any form. These drugs can increase your risk of bleeding if your platelet count is low. Always check with a doctor or nurse first.
- Ask a member of your health care team for the phone numbers of the hospital and write them here:

  Monday to Friday (during office hours) ph...

  Evenings/nights/weekends ph...

Avoiding viral infections

People with MDS may be at increased risk of viral infections.

If possible, you should:

- Try to avoid people, including children, who are currently unwell with a cold, flu or another infection.
- Try to avoid people who have, or have been near others who have, active chicken pox, shingles or measles.
- Try to avoid people who currently have Covid-19, who have recently had Covid-19 and are still symptomatic and/or returning positive tests, or are currently isolating due to Covid-19 exposure.

It is important that you maintain your usual social activities when you are able. Touching, hugging and kissing your close family/whānau and friends is important. It is fine if they are well.

Pets

You need to:

- Wash your hands after touching pets.
- Avoid letting a pet lick your face.
- Keep pets clean and treat them for worms and fleas.
- Keep pets away from areas where food is prepared.
- Wash your hands carefully if you touch a litter tray or animal poo.

Gardening

Garden soil can cause infections in people with a low white blood cell count.

You need to:

- Wear gloves, as soil or potting mix can have harmful germs in it.
- Thoroughly wash any cuts you receive from gardening.
- Check cuts for signs of infection.
- Wear a mask when working with manure, compost or soil to avoid breathing in particles.

Talk to your health care team if you would like more information about preventing or treating infection.

Low mood, anxiety, depression or difficulty coping

It can be common to have a low mood, feel anxious or depressed, or find it difficult to cope after diagnosis with MDS or during treatment. There can be a lot of things that cause these feelings.

Things you can do to help:

- Talk about how you're feeling with someone you feel comfortable with, e.g. family/whānau, a friend or an LBC Support Services Coordinator.
- Ask your health care team about a referral to a psychologist or counsellor.
- Set yourself daily achievable goals and bigger long-term goals.
- Make a list of things that make you feel better such as your favourite TV show, talking to someone on the phone or doing a hobby.
- Try to keep socialising by staying in touch with friends and family/whānau.
- Try to spend time each day relaxing, e.g. meditating, listening to music.
- Exercise regularly.
- Try to keep a regular sleep pattern.
- Keep a diary. This can help you express how you feel without needing to talk to anyone.
- Cry if you need to.

- Try complementary therapies such as massage, aromatherapy or reflexology. Information on complementary therapies can be found on page 26.

It is important to tell a member of your health care team if you continue to have feelings of low mood, anxiety, depression or difficulty coping. They can help you get the support you need.

Nausea, vomiting and dehydration

Some chemotherapy can make you feel sick (nausea) or be sick (vomiting). Feeling anxious can also cause nausea and vomiting.

There are drugs (medicines) called antiemetics which can help treat nausea and vomiting. Different antiemetic drugs work in different ways and you may have one or more types to treat your nausea and/or vomiting. Antiemetic drugs are mainly given as a tablet, an injection or as a skin patch.

Tell your doctor or nurse if you still feel sick because they might be able to try a different antiemetic or give it to you in a different way.

Controlling your nausea and vomiting is important so you can keep eating and drinking enough to fuel your body. If you have nausea and vomiting and are unable to drink or keep fluid down, it is important you speak with your doctor or nurse to make sure you don't become dehydrated.

Things you can do to help:

- Eat smaller meals or snacks, more frequently throughout the day.
- Don't eat foods with a strong smell or taste.
- Don't eat hot or fatty foods.
- Try fizzy drinks.
- Try ginger tea or ginger ale.

Complementary therapies such as relaxation, aromatherapy or massage might help some people.

Organ damage

Sometimes chemotherapy can cause damage to cells in organs such as your kidneys, liver, heart and lungs. This damage can be temporary (short term) or less likely, permanent.

Some types of chemotherapy are more likely to cause organ damage than others. Examples include doxorubicin (which can cause heart damage), cyclophosphamide (heart damage), methotrexate (kidney damage) and vincristine (damage to nerve ends). Your treatment team will be able to give you more information about whether organ damage is a likely side effect of the chemotherapy you are having.

Things you can do to help:

- Have all recommended blood tests – these are often used to monitor organ function, so your treatment team can see if damage is occurring.
- Ask your health care team if there are any follow-up checks and/or tests you should have after you have finished treatment (such as regular heart checks or lung function tests).

Pain

Some people may experience pain as a result of MDS or its treatment, e.g. with mucositis (sore mouth) or heartburn.

It is important to tell your health care team if you have pain.

Your health care team will ask you about the pain, for example:

- What the pain feels like, e.g. dull, sharp, burning?
- How bad is the pain?
- What makes the pain worse and what makes it better?

Pain can be caused, or made worse, by your emotions or how you are coping with your diagnosis and treatment. This is called 'total pain'. Total pain can be psychological, social and/or spiritual. Examples of things that might contribute to total pain are anxiety, worries about your family/whānau or a crisis of faith. It is important that total pain is managed as well as physical pain. Ask your health care team for the support you need.

Peripheral neuropathy

Peripheral neuropathy is the term used to describe damage to the nerves in the hands, feet, arms and legs. Some people might experience numbness, tingling, pain, hot or cold sensations, or increased sensitivity. This can be caused by some of the drugs used to treat MDS.

The best way to manage peripheral neuropathy is to be aware of any changes and report symptoms to your doctor or nurse as soon as possible. Your doctor might decide to reduce your drug dose or change you to a different drug with less side effects. There are some pain relief options that may be beneficial, but they don't always work for everyone.

Things you can do to help:

- Take care of your feet by wearing covered shoes. Keep hands and feet warm.
- Use caution when getting into baths and showers to make sure the water isn't too hot that it could burn your skin.
- Eat a well-balanced diet and try to include as many essential vitamins and minerals as possible.
- Reduce potential fall risks at home by clearing away clutter.
- Stop smoking as this can affect your peripheral blood flow.
- Use ice packs or hot-water bottles to provide short-term relief of symptoms.

Poor appetite and taste changes

You may not feel like eating, and you may experience taste changes. This may be because of the chemotherapy, other drugs, the worry of having MDS, or doing less physical activity.

Low appetite

Having a low appetite (not feeling like eating) can be disappointing for people who usually enjoy eating. It is important to keep eating to help maintain your weight and energy levels. It is also important to drink plenty of fluids, especially if you are not eating very much.

It can be common for people to really feel like eating certain foods but then by the time it has been made, they cannot eat it. Choose meals that can be made quickly and are easy to eat. If you are finding it difficult to eat, or are worried about your weight, ask to speak with a dietitian who will be able to advise you.

Things you can do to help:

- Eat small amounts of food as often as possible.
- Keep snacks handy such as nuts, cheese and dried fruit.

- Add extra energy and protein to your diet by using full-fat products or nutritional supplements.
- Eat what you feel like – you can return to your normal diet when your appetite returns.

Taste changes

Your sense of taste may change or the texture of food may seem different. This may mean that you no longer enjoy food, that all food tastes the same, or food has a metallic taste. Your sense of smell can also be affected.

Things you can do to help:

- Choose cold foods as they often taste better and smell less.
- Suck boiled sweets or drink fruit juice, as they leave a nicer taste in the mouth.
- Try different seasonings such as herbs and spices on your food.

If you are in hospital and don't feel like eating the hospital food, ask your nurse about suitable foods that family/whānau or friends can bring in for you.

More information available online

See the Eating Well fact sheet on the LBC website.

Skin and nail changes

Chemotherapy can affect your skin and nails. Your skin may become dry or oily, and can also become red, sore, itchy and more sensitive. Nails may become brittle and flaky. Ridges or lines may appear on your nails and they can also become painful or swollen.

Things you can do to help:

- Don't use soap and perfumed products, or products that contain alcohol.
- Moisturise dry skin once a day, or more if needed.
- Use lip balm regularly.
- Don't scratch.
- Don't shave with razor blades.
- Use oil-free moisturiser on oily skin.
- Use hand cream regularly.
- Use nail-strengthening cream.
- Wear gloves when doing chores.

Sun protection

After chemotherapy, you might find that the sun burns your skin much quicker than it used to.

Things you can do to help:

- Wear sunscreen with a high sun protection factor (SPF) and reapply regularly.
- Don't go outdoors during the hottest part of the day.
- Cover exposed skin with clothing.

You should protect your skin from the sun for the rest of your life.

If you are having problems with your skin or nails and none of the above suggestions are helping, get support and advice from a member of your health care team or your LBC Support Services Coordinator.

Sore mouth (mucositis)

A sore mouth can be an uncomfortable side effect of chemotherapy. Chemotherapy can cause damage to the cells in the lining of your mouth and digestive system. The medical name for this side effect is mucositis (mew-co-site-is).

You will usually notice symptoms of mucositis a couple of days after you start chemotherapy.

The symptoms of mucositis can include any of the following:

- Mild soreness of the mouth, especially the insides of your cheeks, the sides and underneath of your tongue and the back of your throat.
- Taste changes.
- White, rough-feeling patches on the inside of your mouth.
- Red and inflamed patches on the inside of your mouth.
- Painful ulcers (sores) on the inside of your mouth.
- Difficulty or pain eating, drinking and taking tablets.
- Thick saliva (spit).
- Sore throat.
- Sore and cracked lips.

Mouth care

Regular mouth care is important for comfort and to prevent infection, especially from mouth ulcers.

It is recommended that you do mouth care five times a day: when you wake up, after each meal and before bed. Doing mouth care can be painful, however it is very important to do it regularly and carefully. Mouth care reduces the risk of infection, especially from mouth ulcers.

How to do mouth care:

- Brush your teeth with a soft or baby toothbrush, or use a mouth sponge if a toothbrush is too painful.
- Rinse with mouthwash or water, as instructed by your health care team.
- Use a lip balm or petroleum jelly (Vaseline) on your lips.
- Don’t use dental floss as this increases the risk of bleeding gums.

Things you can do to help:

- Suck on ice cubes or ice blocks.
- Suck on hard-boiled lollies if your mouth is dry.
- Drink fizzy water.
- Spit your saliva into a bowl. If you are in hospital, ask the nurse how to use the suction.
- Your doctor may prescribe a saliva substitute.
- Avoid acidic foods if they are causing you pain, e.g. lemon, orange, mandarin, grapefruit, tomato.

Managing mouth pain

Let your health care team know if your mouth is painful, especially if it stops you from eating.

Your health care team can advise you on how to use pain relief, for example:

- Take painkillers regularly as directed.
- Take stronger painkillers 20 minutes before eating or doing mouth care.
- Use a mouthwash with local anaesthetic to numb the pain.

Unfortunately, painkillers might not get rid of all the pain.

Sometimes mucositis can also affect the oesophagus (food pipe) and bowel (gut). This can cause discomfort, pain, indigestion and heartburn or diarrhoea. Tell your doctor or nurse if you have any of these symptoms. Mucositis should start to get better when your white blood cell count begins to increase.

Contacting the hospital after-hours

If you are feeling unwell, ring the hospital contact number you were given and ask for advice, no matter what time it is. Your health care team and the hospital would prefer that you ring to discuss how you feel, rather than not ring and feel worse. If in doubt, make the call. The emergency department (ED) at the closest hospital will always be open. A list of haematology centres in New Zealand can be found on page 55.

It can also be useful to keep a letter from your doctor that has important information about your diagnosis and treatment and take it with you to the ED or hospital. This is especially useful if you are going on holiday and have to go to a different hospital.

Coping with isolation while in hospital

There may be periods of time that you have to stay in hospital. This may be for treatment, a complication or monitoring. If you are on treatment and have a low white blood cell count, you might be in a single room, which may be referred to as ‘protective isolation’.

Important information

When to contact your doctor or the hospital for help.

Contact your doctor or the hospital straight away (night or day) if you are feeling unwell or have any of these symptoms:

- A temperature of 38°C or over and/or shivering.
- Bleeding or bruising, e.g. blood in your urine, bowel motion or sputum (spit), bleeding gums or a nosebleed.
- Nausea or vomiting that prevents you from eating or drinking or taking your normal medications.
- Diarrhoea, stomach cramps or severe constipation.
- Coughing or shortness of breath.
- A new rash, reddening of the skin or itching.
- A headache that won’t go away, confusion or blurry vision.
- A new pain or soreness anywhere.
- A cut or injury.
- Pain, swelling, redness or pus anywhere on your body.

Isolation means that you are in a hospital room by yourself and visitors may be limited. This is to protect you from serious infections while your white blood cell count is very low. Being separated from family/whānau can be a challenging time for everyone, especially children. Each hospital has a policy around protective isolation, and they will tell you if you are allowed to leave your room, who is allowed to visit, and what precautions visitors should take – such as hand hygiene and wearing a mask.

Things you can do to help:

- Set yourself daily goals. Your physio, occupational therapist or nurse could help you with this.
- Have special photos in your room.
- Maintain regular contact with family/whānau via phone and video calling.
- Shower and get dressed in day clothes each day.
- Do light exercise and relaxation.
- Write in a diary about your thoughts and feelings.
- Do things you enjoy such as watching favourite TV shows, listening to music, playing games or doing puzzles, contacting friends, and keeping up with world news and events.
- Ask your visitors to come at different times throughout the day.

Contact your LBC Support Services Coordinator if you need support while you are in isolation.

Moving to a main centre hospital for treatment

If your local hospital cannot provide the treatment you require, you may need to move to another hospital in a main centre.

A social worker can help you with information and practical support such as advice on how to get accommodation, transport and financial assistance.

Moving to another hospital for treatment can be stressful for you and your family/whānau.

Contact your LBC Support Services Coordinator to obtain a relocation booklet with practical information about moving to a main centre hospital.

RELATIONSHIPS

A diagnosis of MDS can have both positive and negative impacts on relationships with your partner, family/whānau and friends.

Relationship with your partner

A diagnosis and the treatment of MDS can put a lot of strain on a relationship, but some couples grow closer as they go through this experience together. Good communication is essential to supporting your relationship, including sharing how you feel with your partner.

Other things you can do to help:

- Plan activities together such as meals out. If you are in hospital and feel well enough, you and your partner could eat together and you could ask your nurse if it would be possible to have some time when no one comes into your room.
- Tell your partner how they can support you.
- Get support from a counsellor or psychologist. Ask your health care team or LBC Support Services Coordinator for more information or a referral.

There are other practical things you might want to discuss with your partner, such as setting up your partner, or another trustworthy person, to be your 'power of attorney'. A power of attorney is where you give a person the authority to act on your behalf if you are not well enough to do so yourself.

You could complete an Advanced Care Plan (ACP) and discuss this with your partner. An ACP gives you the opportunity to say what is important to you. Your doctor, nurse or LBC Support Services Coordinator can explain what an ACP is and how to get a copy of the booklet.

Talking to your children

Helping children to understand MDS and how this will affect them can help them to cope with the changes and challenges of your diagnosis and treatment.

You can encourage younger children in your treatment journey to use an LBC sticker journal. Your children can record your treatments and write and share journal entries with you. Ask your LBC Support Services Coordinator for more information about the LBC sticker journal.

Counselling or psychological support is available if you are concerned about how your child or children are coping. Ask your health care team or LBC Support Services Coordinator for more information.

For pre-school or school-age children, it is a good idea to speak with their teachers to let them know about your diagnosis and how this is affecting family/whānau routines and relationships.

Regular LBC Kids' Club events are held throughout the country and online to support children who have a loved one diagnosed with a blood cancer. These sessions are run by trained facilitators who are experienced in supporting children through these situations. Contact your LBC Support Services Coordinator for more information.

More information available online

See the Supporting a Child Through a Loved One's Cancer Diagnosis fact sheet on the LBC website.

Talking to friends and colleagues

It can sometimes feel difficult to talk to friends and work colleagues about your MDS diagnosis, and they may also find it difficult to discuss with you. Sometimes people, without realising it, make comments that can be hurtful or make suggestions that are unhelpful.

Most people are very keen to offer support but just don't know how.

Here are some suggestions to help you build your own support team:

- Let people know what you need – such as a regular phone call, text or visit.
- Share how you are feeling and any worries you have with someone who is a good listener.
- Encourage people to read this booklet or speak to an LBC Support Services Coordinator to learn more about MDS.
- Either you or a friend could make a list of practical tasks others can do to help you. You might like to include things like cooking meals, picking a child up from school or cleaning the house.

You may not always feel well enough to take individual phone calls or respond to texts. Some people find it helpful to have one person who updates friends and colleagues on how you are doing. That person can set up an email or social media group to share information.

It can be difficult for some friends and family to understand that you don't suddenly 'get better' or 'are cured' from MDS. Your journey with MDS may look different to other types of cancer and other people with MDS. You also may have periods of time when you are quite unwell, or when your condition is well managed and you can continue to work and socialise as you normally would have before your diagnosis.

Try and find a support network to help you feel validated and cared for. This might be a variety of people like close friends, family/ whānau, colleagues, counsellor/ psychologist and/or LBC support Services Coordinator.

Financial worries

A diagnosis of MDS can cause money worries, maybe due to earning less or having to spend more. If you are working, keep in touch with your employer to discuss sick leave and your plans for returning to work. Information about your employment rights while undergoing cancer treatment can be found on the LBC website or by asking your LBC Support Services Coordinator.

Ask a social worker for advice and support about money worries.

More information available online

See the Blood cancer and your job section of the LBC website.

Sexual relationships

People who receive a diagnosis of MDS and have treatment can experience changes in their sex life.

The reasons for this can include:

- Extreme tiredness
- The side effects of treatment, e.g. nausea
- Changes in mood, e.g. anxiety
- Changes to body image, e.g. due to hair loss, weight change
- Changes to libido
- Vaginal dryness or difficulty getting an erection.

It is important to talk to your partner about sex and how your diagnosis and treatment are making you feel. If you are having problems with sex and it is affecting your relationship, or you are worried about starting a new relationship, speak with someone in your health care team. They can give you more information or refer you to someone who can help.

You cannot give cancer to another person when you have sex with them.

Contraception

It is recommended that you do not try to get pregnant while on some treatments for MDS. This is because some drugs may harm a developing baby. It is important to use contraception (such as condoms, the pill etc) during treatment and for several months afterwards.

If you are having or recently finished treatment, always use a condom when having sex. Even if you are beyond childbearing age or no longer need birth control, it is still important to use condoms until after your treatment has finished, for two main reasons:

1. To protect yourself from getting an infection. A low white blood cell count puts you at a higher risk of infection.
2. To protect your sexual partner while you are having chemotherapy. Chemotherapy drugs are secreted (come out) from your body via your urine, bowel motions and sperm and vaginal secretions. The small amounts of chemotherapy that come out this way can cause irritation (a rash or itching) to your partner's skin.

Talk to your health care team if you have any questions about contraception or getting pregnant.

Sex when you have a low platelet count

Speak with your doctor or nurse about having sex if your platelet count is low as you may need to be careful due to the risk of bleeding. It is often a good idea to use a lubricating gel (lube) such as KY Jelly.

New relationships

Some people feel worried about starting a new relationship following a diagnosis of MDS. It can be difficult to know what to say. Being open and honest about your experience will make it easier for you. Talk to your friends, family/whānau or health care team if you have concerns about what to say.

Information for people supporting someone with MDS

As the partner, parent, friend or carer of someone with MDS, it is quite common to experience feelings of stress, anger, fear, anxiety or depression. Speak with your health care team or LBC Support Services

Coordinator if you are feeling this way. There is a lot of support available to you, including an online forum to meet other people in similar situations.

Other things you can do:

- Look after yourself by eating well, getting enough sleep, doing regular exercise and relaxing.
- Keep doing your normal social activities.
- Join a support group and/or see a counsellor.
- Write down a list of things that have helped you get through a tricky situation previously. Some ideas might include talking to friends or writing in a diary. Use these tips to assist you now.

A diagnosis and the treatment of MDS can put a lot of strain on a relationship. However, some people find that they feel closer because of what they go through together.

Remember that your health care team and LBC Support Services Coordinator are there to support you at any time throughout your diagnosis, treatment and beyond.

KEEPING IN GOOD HEALTH AFTER YOUR MDS DIAGNOSIS

After a diagnosis of MDS, it is important to look after your health. When you feel well enough, regular exercise and eating a variety of healthy foods are very important.

The following health changes can reduce complications from your treatment or any long-term side effects:

- Stop smoking
- Protect your skin from the sun
- Stop drinking alcohol, or reduce the amount you are having.

Your health care team is available to help you to keep well:

- A physiotherapist can advise you about the exercise that is right for you.
- A dietitian can give you advice about eating well, especially if your treatment is making you feel sick or you have taste changes.
- Ask your doctor or nurse about support to help you stop smoking and stop or reduce drinking alcohol.

Contact your LBC Support Services Coordinator if you would like more information about exercise options in your area.

THE FUTURE

A diagnosis of MDS can affect many areas of your life such as work, your emotions, relationships and finances.

For some people, a diagnosis of MDS can mark a turning point in their lives. For others, a diagnosis means they feel their life has been put 'on hold'. The length of time it takes to recover emotionally and physically from an MDS diagnosis or treatment is different for everyone. Getting back to your previous routine of work or childcare, for example, may be a goal, or it may not be what you want any more. You may need to make a few adjustments to your life.

Your health care team and LBC Support Services Coordinator can help you manage:

- Day-to-day practical problems including work, travel and travel insurance.
- Relationships and communication with your partner, family/whānau, friends and colleagues.
- The emotional effects of MDS and treatment, including fear of relapse and feeling uncertain about the future.

There is a lot of support available to help you and those around you cope. Some people find it helpful to speak to someone else who has been diagnosed with MDS, or their support person. Your nurse, specialist or LBC Support Services Coordinator may be able to put you in contact with someone you can talk to.

Travelling overseas

If you are thinking of travelling overseas, speak to your doctor before making any bookings to check if they have any concerns about you travelling. It can sometimes be difficult to get travel insurance when you have been diagnosed with cancer. Speak with your LBC Support Services Coordinator, who will be able to help you.

After treatment

Once your treatment has finished, you will have regular check-ups with your haematologist and health care team. You will also be encouraged to go back to see your GP. Your health care team will send regular letters to your GP to tell them about your progress and what needs to be followed up, e.g. blood tests and vaccines. If your GP has any questions, they are able to contact your haematologist for advice. See page 26 for more information on vaccines.

GLOSSARY

Alopecia – Hair loss, which can occur temporarily following treatments for MDS such as chemotherapy.

Anaemia – A reduction in the haemoglobin level in the blood. Haemoglobin normally carries oxygen to all the body's tissues. Anaemia causes tiredness, paleness and sometimes shortness of breath.

Antibiotics – Drugs that kill or stop the growth of bacteria, e.g. penicillin.

Antibodies – Naturally produced substances in the blood, made by white blood cells, called B-lymphocytes or B-cells. Antibodies target antigens on foreign or abnormal substances such as bacteria, viruses and some cancer cells and cause their destruction.

Antiemetic – A drug which prevents or reduces feelings of nausea (anti-sickness) or vomiting.

Antigen – A substance that can stimulate white blood cells to get rid of an antigen or attack it directly. This is called an immune response. Also see Immune system in this glossary.

Antimicrobial – A drug or substance that destroys or inhibits the growth of microorganisms.

Antiviral – A drug or substance that fights against viruses and inhibits their growth. Antiviral drugs can be used to treat a viral infection or prevent a viral infection from developing.

Anxiety – An ongoing worry or concern that doesn't go away. Feelings of worry that a person does not seem to be able to control or seem greater than they should be for a situation.

Biopsy – A small sample of fresh tissue, e.g. lymph node or bone marrow, removed for testing under a microscope in a laboratory, to establish the exact diagnosis or to monitor treatment response.

Blasts – Immature stem cells, normally making up no more than 5% of cells in the bone marrow. Blast cells are not normally found in healthy peripheral blood.

Blood count – Also called a full blood count (FBC) or complete blood count (CBC). A routine blood test that measures the number and types of cells circulating in the blood.

B-lymphocyte – A type of white blood cell normally involved in the production of antibodies to combat infection. Also called B-cells.

Bone marrow – The tissue found at the centre of many flat or big bones of the body. The bone marrow contains stem cells from which all blood cells are made.

Bowel – Also known as intestines or guts. After your stomach has finished with the food you eat it goes into your small bowel, which absorbs nutrients that the body needs. What is left after this moves into your large bowel and eventually moves out of your body as waste, known as a bowel motion or, as it is commonly known, poo.

Cancer – A malignant disease characterised by uncontrolled growth, division, accumulation and invasion into other tissues of abnormal cells from the original site where the cancer started. Cancer cells can grow and multiply to the extent that they eventually form a lump or swelling. This is a mass of cancer cells known as a tumour. Not all tumours are due to cancer; in which case they are referred to as non-malignant or benign tumours.

Cannula – A plastic tube that is inserted into a vein (intravenously or IV) to allow fluid to enter the bloodstream.

Chemotherapy – Single drugs or combinations of drugs which may be used to kill and prevent the growth and division of cancer cells. Although aimed at cancer cells, chemotherapy can also affect rapidly dividing normal cells and this is responsible for some unwanted side effects. Most of the side effects of chemotherapy are usually temporary and reversible.

Chromosomes – Your body is made up of cells. Inside most cells are chromosomes which, under a microscope, look like threads. These threads contain hundreds to thousands of genes. Genes determine things like what colour your hair and eyes are and how your body develops. You have 23 pairs of chromosomes and you get half from your mother and the other half from your father.

Chronic – An illness or disease that persists for a long time or is constantly recurring.

Complementary therapies – Therapies used alongside your medical treatment that help you feel better or help you cope with your diagnosis and treatment, e.g. massage, yoga.

Complete remission – Anti-cancer treatment has been successful and so much of the disease has been destroyed that it can no longer be detected using current technology.

Cure – This means that there is no evidence of disease and no sign of the disease reappearing, even many years later.

Cytogenetic tests – Cytogenetic tests are commonly carried out on samples of blood and bone marrow to detect chromosomal abnormalities (things that are wrong with the chromosomes) associated with disease. This information helps in the diagnosis and selection of the best treatment.

Depression – A group of conditions associated with the lowering of a person's mood or loss of interest in activities.

Digestive system – The system in your body that deals with food. Starts at your mouth and ends at your bottom. Turns food and fluids into fuel for your body.

DNA (deoxyribonucleic acid) – The cell's hereditary material which contains instructions for development, growth and reproduction. DNA is located in nearly every cell of the human body. DNA is found in chromosomes.

Foetus – An unborn child.

G-CSF (granulocyte colony-stimulating factor) – A growth hormone given to stimulate the bone marrow to produce certain types of blood cells. It is often used to treat neutropenia, or before a stem cell harvest for a stem cell transplant.

Genes – Genes are made up of DNA. Each chromosome contains many genes. Every person has two copies of each gene, one inherited from each parent.

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

Haematopoiesis (or haemopoiesis) – The processes involved in blood cell formation.

Heartburn – A painful burning feeling in your chest or throat caused when stomach acid backs up into your esophagus (the tube that carries food from your mouth to your stomach).

Immature – Not fully developed, e.g. a cell that is immature is still at a baby stage. It will mature (or develop) over time to an adult stage.

Immune suppression – The use of drugs to reduce the function of the immune system.

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

Immunocompromised – When the function of the immune system is reduced.

Immunophenotyping – Specialised laboratory test used to detect markers on the surface of cells. These markers identify the origin of the cell.

Leukaemia – Cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal and immature blood cells. These cells crowd the bone marrow and spill out into the bloodstream.

Lymphocytes – Specialised white cells involved in defending the body against disease and infection. There are two types of lymphocytes: B-lymphocytes and T-lymphocytes. They are also called B-cells and T-cells.

Lymphoid – Term used to describe a pathway of maturation of blood cells in the bone marrow. White blood cells (B-lymphocytes and T-lymphocytes) are derived from the lymphoid stem cell line.

Malignancy – See cancer.

Markers – A gene or DNA sequence with a known physical location, and where it has come from. In genetics, markers act as chromosomal landmarks. They are used to trace or identify a specific region of a gene or chromosome.

Menopause – The time in a woman's life when her period stops and she is no longer able to have children. Hormones produced by the ovaries decrease after menopause. Also see Ovaries.

Mucositis – An inflammation of the lining of the mouth, throat or gut.

Myeloid – A term used to describe a pathway of maturation of blood cells in the bone marrow. Red blood cells, white blood cells (neutrophils, eosinophils, basophils and monocytes) and platelets are derived from the myeloid stem cell line.

Neutropenia – A reduction in the number of circulating neutrophils, an important type of white blood cell. Neutropenia is associated with an increased risk of infection.

Neutrophils – Neutrophils are the most common type of white blood cell. They are needed to mount an effective fight against infection.

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

Ovaries – Small organs that produce and then release eggs into a women's reproductive system, and produce female hormones.

Plasma – A light-yellow coloured fluid in the blood. This fluid carries blood cells, nutrients, hormones and proteins to different parts of the body.

Platelets – Type of blood cells produced in the bone marrow that circulate in the blood, involved in clotting and the control of bleeding.

Petechiae – Tiny purple or red spots on the skin caused by bleeding into the skin. They commonly appear in clusters and may look like a rash. They are usually flat to the touch and don't lose their colour when you press on them.

Power of attorney – One person gives another person permission to act on their behalf, such as making decisions about their health or operating their bank account. You usually go to see a lawyer to arrange this.

Prognosis – An estimate of the likely course of a disease.

Psychological – Concerning your mental and emotional well-being.

Radiotherapy (radiation therapy) – The use of high-energy X-rays to kill cancer cells and shrink tumours.

Relapse – The return of the original disease.

Red blood cells – Transport oxygen from the lungs to all the cells in the body.

Rigors – A chill (feeling cold), usually with shivering, at the onset of having a high fever (temperature).

Standard therapy – The most effective and safest therapy currently being used.

Stem cells – Stem cells are primitive blood cells that can give rise to more than one cell type. There are many different types of stem cells in the body. Bone marrow (blood) stem cells have the ability to grow and produce all the different blood cells including red cells, white cells and platelets.

Stem cell transplant (haemopoietic or blood stem cell transplant) – The general name given to bone marrow and peripheral blood stem cell transplants. These transplants are used to support the use of high-dose chemotherapy and/or radiotherapy in the treatment of a wide range of blood cancers and other diseases.

Supplements – Tablets or liquids you take as well as the food you eat. Supplements include vitamins, minerals, herbs or other plants.

T-lymphocyte – A type of white blood cell involved in controlling immune reactions. Also called T-cells.

Tumour – An abnormal mass of cells which may be non-malignant (benign) or malignant (cancerous).

Ultrasound – Pictures of the body's internal organs built up from the interpretation of reflected sound waves.

Urinary tract infection – A urinary tract infection (UTI) is an infection in any of the parts of your body which make or store urine or take urine out of your body, e.g. bladder or kidneys.

Vaccine – A substance used to help the immune system develop immunity from a particular infectious disease. It is usually produced from an inactivated or weakened form of the disease. A vaccination is the administration of this substance.

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

A Dictionary of Terms is also available from the LBC website, or ask your LBC Support Services Coordinator for a printed version.

APPENDIX

The following are sample questions to ask your doctor when considering treatment options for MDS.

Place a tick alongside the questions you would like to ask. You could add your own questions in the space provided. Record the answers to your chosen questions in your Haematology Patient Diary or on the 'Questions and notes' page that follows.

- ☐ Which doctor will be managing my MDS?
- ☐ How often do I need to have a blood test? Will my GP or haematologist review my blood tests and who will contact me with the results?
- ☐ What exactly does the treatment involve? How long will the entire treatment take?
- ☐ What are the alternatives to this treatment?
- ☐ How ill might I feel before, during and after treatment?
- ☐ What are the potential side effects, how long might they last and how serious are they?
- ☐ Why are you recommending this treatment for me?
- ☐ If the MDS comes back (relapses), what are the options for me?
- ☐ How can I prepare myself for starting treatment?
- ☐ Is there anything I can do to help my general health?
- ☐ How do I arrange an appointment if I develop new symptoms?
- ☐ What should I do if I develop an infection during the night or at the weekend?

QUESTIONS AND NOTES

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Leukaemia & Blood Cancer New Zealand

LBC is the leading organisation in New Zealand dedicated to supporting patients and their families/whānau living with leukaemia, lymphoma, myeloma and related blood conditions. Since 1977, our work has been made possible through our fundraising events and the generous support we receive from individuals, companies, trusts and grants.

LBC is committed to improving the quality of life for patients and their families/whānau living with these blood cancers and conditions by providing patient support services, investing in and supporting research, providing information, raising awareness and advocating on behalf of patients and their families/whānau.

Pub Charity Limited

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HAEMATOLOGY CENTRES IN NZ

Centre	Address	Phone
Whangarei Hospital	Hospital Road, Whangarei	09 430 4100
North Shore Hospital	Shakespeare Road, Takapuna, Auckland	09 486 8900
Auckland City Hospital	Park Road, Grafton, Auckland	09 367 0000
Starship Hospital	Park Road, Grafton, Auckland	09 367 0000
Middlemore Hospital	Hospital Road, Otahuhu, Auckland	09 276 0044
Waikato Hospital	Pembroke Street, Hamilton	07 839 8899
Thames Hospital	Mackay Street, Thames	07 868 0040
Tauranga Hospital	Cameron Road, Tauranga	07 579 8000
Rotorua Hospital	Pukeroa Street, Rotorua	07 348 1199
Hastings Hospital	Omahu Road, Hastings	06 878 8109
Whakatane Hospital	Stewart Street, Whakatane	07 306 0999
Palmerston North Hospital	Ruahine Street, Palmerston North	06 356 9169
Wellington Hospital	Riddiford Street, Newtown, Wellington	04 385 5999
Nelson Hospital	Tipahi Street, Nelson	03 546 1800
Christchurch Hospital	Riccarton Avenue, Christchurch	03 364 0640
Dunedin Hospital	Great King Street, Dunedin	03 474 0999
Invercargill Hospital	Kew Road, Invercargill	03 218 1949

Contacting us

Leukaemia & Blood Cancer New Zealand provides services and support throughout New Zealand. Every person's experience of living with a blood cancer or condition is different. Our Support Services Coordinators are here to help.

Freephone 0800 15 10 15
Telephone 09 638 3556
Email info@leukaemia.org.nz

National Office
6 Claude Road, Epsom 1023
PO Box 99182, Newmarket 1149
Auckland, New Zealand

leukaemia.org.nz

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