

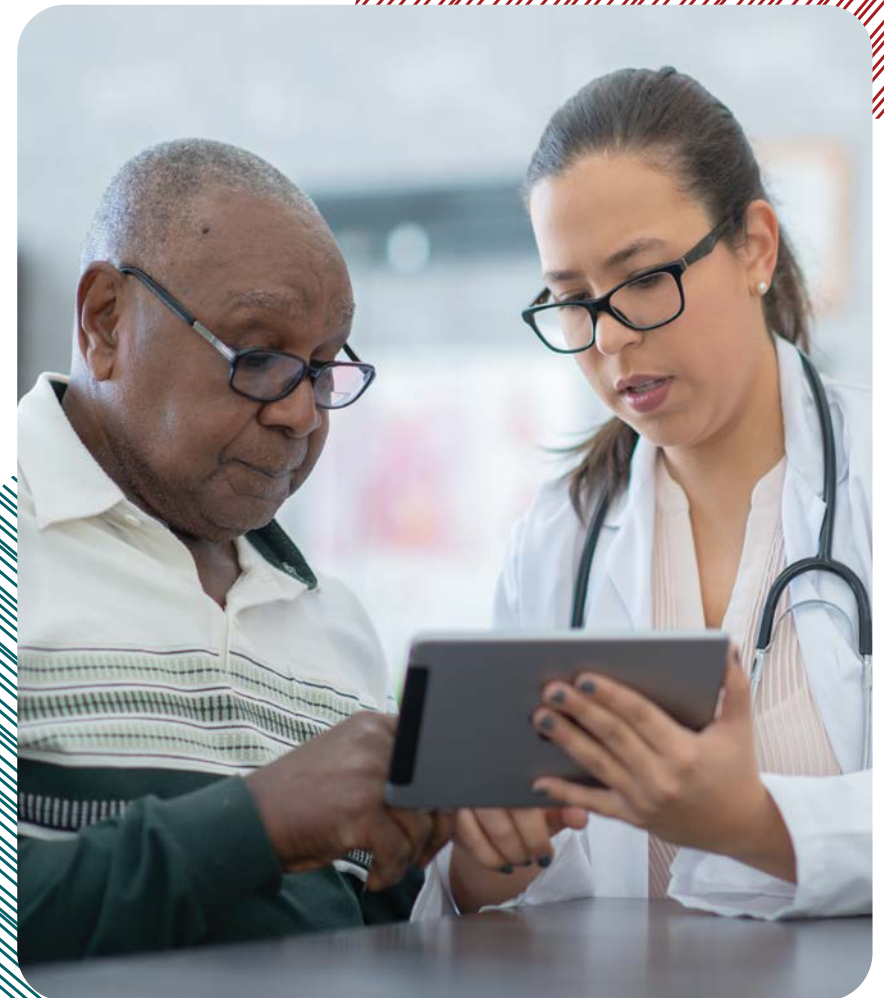
Understanding and managing
**myelodysplastic
syndromes (MDS)**



What is this booklet for?

This booklet was designed to answer some questions you may have about myelodysplastic syndromes. It summarizes the treatment options that are available in Canada. It can also serve as a starting point for discussions with your doctor, so that you can decide together what is best for you.

Once you have a better understanding of each treatment option, you can stay informed and take an active role in the treatment process for your MDS.

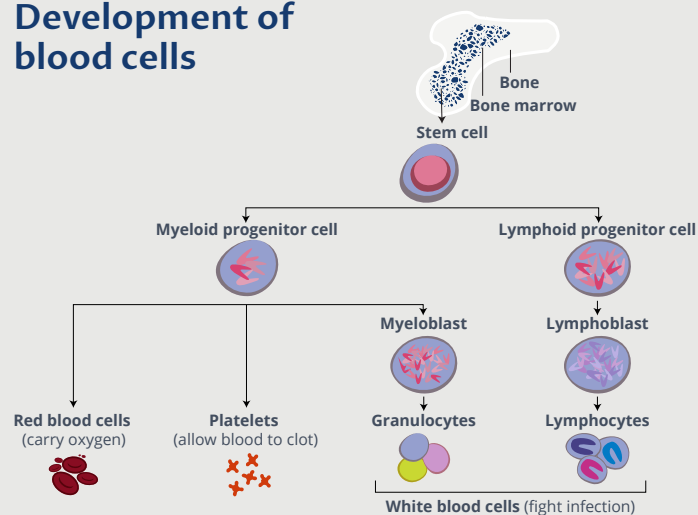


What are myelodysplastic syndromes?

Myelodysplastic syndromes are a group of cancers of the blood and bone marrow (the soft, spongy material inside your bones).

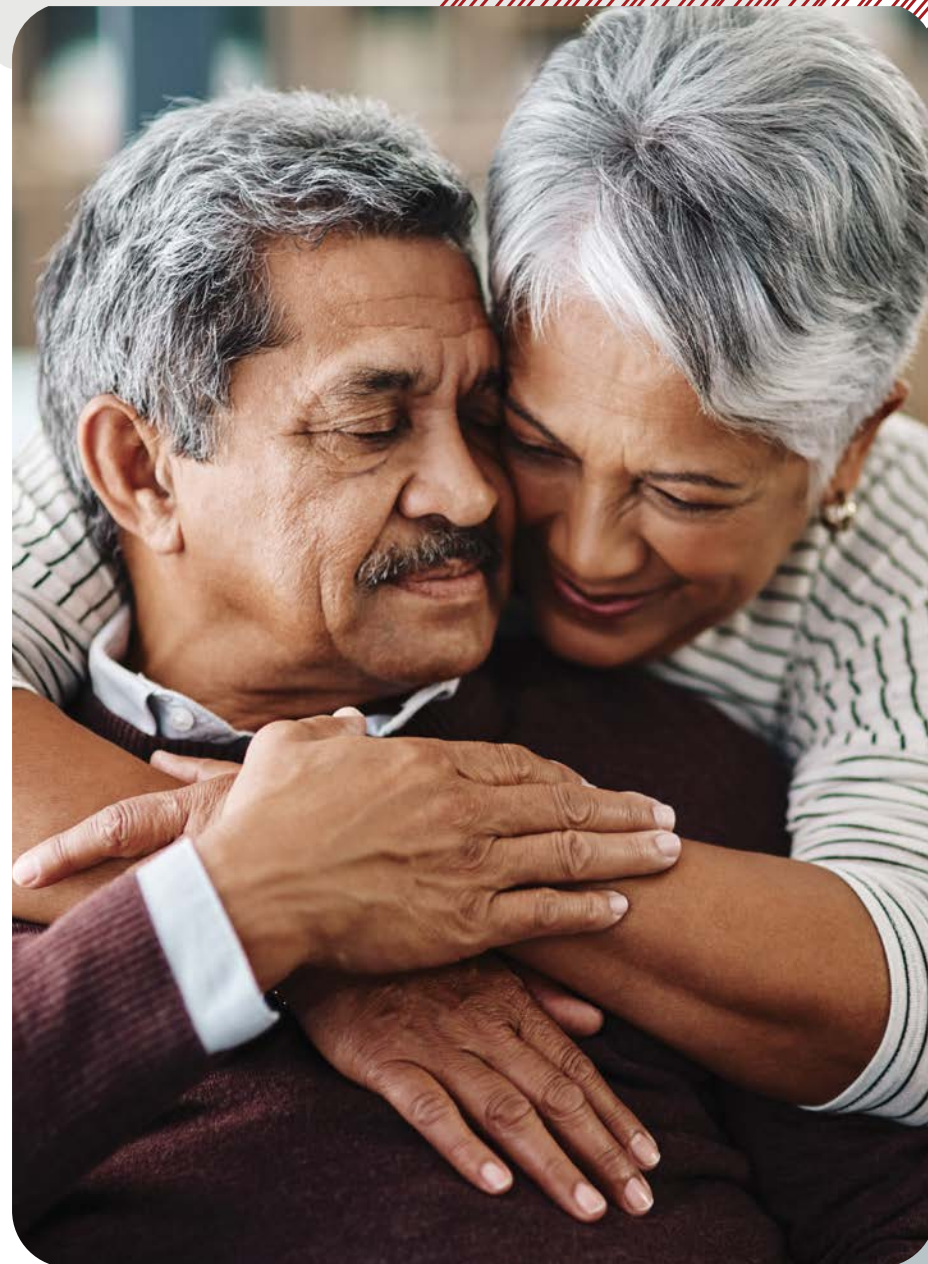
When you have an MDS, stem cells become damaged and abnormal (**mutate**), and your bone marrow does not produce enough healthy blood cells. This leads to having too many immature bone marrow cells, known as **blast cells**, which do not work the same way as healthy, mature blood cells.

Development of blood cells



Normally, blast cells make up less than 5% of the bone marrow. In someone with an MDS, blast cells make up 5%–19% of the bone marrow.

In Canada, it is estimated that **up to 5,900 new cases of MDS** are diagnosed each year.



What are the different types and subtypes of MDS?

There are several different MDS types and subtypes, which may progress very slowly or very quickly. To assess the severity of your disease, MDS can be categorized under different risk groups based on scoring systems.

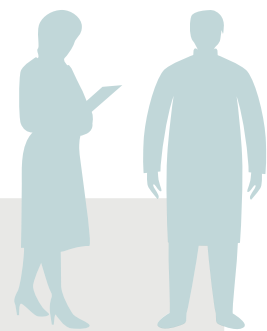
Types and subtypes

There are **two types of MDS**:

1. Primary (no cause can be identified)
 2. Secondary (treatment-related and less common)
- Most people diagnosed with MDS have primary MDS.

There are **six subtypes of MDS** according to the current guidelines created by the World Health Organization (WHO). Subtypes are based on blood and bone marrow test results, and include:

1. MDS with single lineage dysplasia (MDS-SLD)
2. MDS with ring sideroblasts (MDS-RS)
 - Single lineage dysplasia (MDS-RS-SLD)
 - Multilineage dysplasia (MDS-RS-MLD)
3. MDS with multilineage dysplasia (MDS-MLD)
4. MDS with excess blasts (MDS-EB)
 - MDS with excess blasts-1 (MDS-EB1)
 - MDS with excess blasts-2 (MDS-EB2)
5. MDS with isolated del(5q)
6. MDS unclassifiable



Scoring systems and risk groups

To assess the severity of your disease, doctors may also use the **International Prognostic Scoring System (IPSS)** and the **IPSS-Revised (IPSS-R)**.

IPSS	IPSS-R
<p>The risk tells the doctor how quickly the disease will progress into one of four categories:</p> <ul style="list-style-type: none">• Low• Intermediate-1• Intermediate-2• High	<p>Doctors also use this recent update to the IPSS to help assign individuals with MDS into one of five risk groups:</p> <ul style="list-style-type: none">• Very low• Low• Intermediate• High• Very high

Identifying the type, subtype and risk level of your MDS is an **important step in planning your treatment.**

What are the possible tests for MDS?



Medical history and physical exam

The doctor reviews any past illnesses, injuries, and symptoms. They also examine your lungs, heart, and other organs.



Blood tests

A complete blood count (CBC) is a common blood test that measures the number of red blood cells, white blood cells, and platelets in the blood. With an MDS, one or more of these numbers will be low.



Bone marrow tests

There are two tests used most commonly to find the percentage of abnormal blood cells in the bone marrow: **bone marrow aspiration** and **bone marrow biopsy**. These two tests are usually done at the same time and look at bone marrow cells for anything unusual in your chromosomes or genes.



Molecular tests

These tests can be done on either a sample of blood or bone marrow to look for mutations in genes that are associated with an MDS. Certain mutations are linked with either a better or a worse outcome.



Cytogenetic testing (karyotyping)

This test examines your blood or bone marrow samples under a microscope to see any changes in chromosomes that are specific to MDS.

Fluorescence *in situ* hybridization (FISH)

FISH is a test that uses light and probes to identify damaged DNA in chromosomes. This test is done using a blood or bone marrow sample.

DNA is the material that carries all the information about how our bodies look and function. Each piece of information is carried on a different section of the DNA and these sections are called "genes." Genes tell a cell how to make a specific protein, which is used by the cell to grow and survive. DNA is organized into tightly coiled thread-like bundles called "chromosomes" that contain thousands of genes. Some changes called "mutations," can happen in your genes.

With a diagnosis, your doctor can determine the right treatment for you. Your test results can help your doctor predict how your MDS will likely progress and how you may respond to treatment.

What treatment options are available for MDS?

Myelodysplastic syndromes are manageable with treatment, although not everyone needs treatment right away. Treatment is usually focused on relieving symptoms, improving blood counts, and preventing progression. Treatments can be used alone or together.

If you are **low risk**, your cancer is more likely to progress slowly, and can often be stable for many years. You will likely undergo a period of active surveillance.

If you are **high risk**, your cancer tends to progress quickly and there is a higher risk of developing acute myeloid leukemia (AML). You will likely undergo chemotherapy treatments, or other therapies.

Now let's take a closer look at the available MDS treatment options.



Treatment options for MDS

Treatment option	Active surveillance
What it does	<ul style="list-style-type: none">• This option involves monitoring your blood cell counts• It delays treatment until the disease progresses
What it entails	Individuals in active surveillance protocols: <ul style="list-style-type: none">• Need to continue to see their doctor regularly• Should undergo regular tests and exams, as advised• Tell their doctor about any changes or symptoms• Understand that if there are signs that their MDS is progressing, treatment may become necessary

Treatment option	Supportive care
What it does	<ul style="list-style-type: none">• Supportive care aims to relieve the symptoms of an MDS and the side effects of treatment
What it entails	This treatment option can include: <ul style="list-style-type: none">• Blood transfusions• Iron chelation, a process that removes excess iron from your body• Blood cell growth factor therapy to stimulate the making of more blood cells• Infection management

Treatment options for MDS

Treatment option	Drug therapy
What it does	<p>There are various types of drug therapy which may be used to slow progression of MDS.</p> <ul style="list-style-type: none"> • Chemotherapy is used to kill and destroy cancer cells • Additional drug therapy may be used to treat or prevent problems caused by low blood counts
What it entails	<p>Drug therapies may be taken by mouth (orally) or given as injections and each option may have a different treatment duration. Some treatments may be taken at home while others may require a visit to a hospital or clinic.</p> <ul style="list-style-type: none"> • Chemotherapy drugs to treat MDS may include: <ul style="list-style-type: none"> - Cytarabin, idarubicin, topotecan, fludarabine, daunorubicin, mitoxantrone, decitabine, decitabine and cedazuridine • Additional drug therapies may include: <ul style="list-style-type: none"> - Deferoxamin, lenalidomide, antithymocyte globulin, azacitidine, luspatercept, antibiotics

Treatment option	Allogeneic stem cell transplantation (ASCT)
What it does	<ul style="list-style-type: none"> • Transfers a healthy person's (donor) stem cells to your body to slow the growth of the disease • It is the only option for a possible cure for people with myelodysplastic syndromes
What it entails	<ul style="list-style-type: none"> • This can be a high-risk procedure, and many people cannot safely receive this treatment option

Joining a clinical trial can be a good option for you. A clinical trial is a type of research that studies a test or treatment in people. It gives people access to healthcare options that otherwise wouldn't be available. Ask your medical team if there is an open clinical trial that is right for you.

What else should you know about your MDS treatment?

Treatment side effects

- When you begin your treatment for an MDS, you may experience mild to severe side effects, depending on your age, overall health, and treatment plan. Most side effects should disappear once your treatment ends.
- New drugs and therapies are available that can help control side effects, such as nausea.
- You may experience **chemotherapy-related side effects**, including:
 - Diarrhea or constipation
 - Nausea
 - Rashes
 - Increased risk for infections
 - Changes to your blood counts
- **Long-term side effects** are common and may last for months or years after you complete your treatment. Some examples are:
 - Chronic fatigue
 - Problems concentrating (chemo brain)
- **Late effects** are medical problems that do not show up until years after treatment ends. See your doctor to get follow-up care for possible early detection of heart disease and secondary cancers.

Speak to your doctor if you are experiencing side effects.

With an MDS, it is very important to watch out for signs of infection, as your immune system can be low. Try keeping a good thermometer on hand and, if you develop a fever, call your doctor or go to the emergency room.



What questions should you ask your doctor?



Being an active participant in your cancer care can give you and your family a greater sense of control. One way to achieve this is by building a relationship with your medical team based on open communication.

Consider bringing this list of questions to your next doctor's appointment.

Diagnosis

- What type and subtype of MDS do I have? From what type of cell did it form? Is this cancer common?
- What is the severity of my disease?
- Will I need to have other tests before we can decide on treatment?
- What tests do you recommend for me?
- Where will the tests take place? How long will the tests take?
- How do I prepare for testing? How will the test be done? What can I expect?

General treatment

- Should I start treatment now? Why or why not?
- What should I do to be ready for treatment?
- How do my age, health, and other factors affect my options?
- What are my treatment options?
- Which one do you recommend for me? Why?
- What is the treatment frequency?
- How often will you test my blood or bone marrow to see how treatment is working?
- What should be avoided or taken with caution while receiving treatment?



Side effects of treatment

- What are the possible risks or side effects of my treatment? How serious are they and what should I report right away?
- How can I manage the side effects?

Other considerations

- Can treatments be taken at home?
- How will treatment affect my daily activities?
- What if I miss a treatment?
- Are there any limits on what I can do?
- Should I still take the other medications I am on?
- Is it okay to continue with the supplements I am currently taking?
- What costs will I encounter?
- In cases of emergency, how can I reach your office on nights, holidays, or weekends?

Be sure to write down any questions you have that are not on this list. For instance, you might want information about how you'll feel so that you can plan your work schedule. Or you may want to ask about qualifying for clinical trials.

What resource is available to you?



Visit our website to learn more about myelodysplastic syndromes and their treatment.

bloodcancers.ca

For more information, never hesitate to contact us. We're here to help you!

1 833 222-4884

info@bloodcancers.ca

Please download the LLS Health Manager™ app by visiting

bloodcancers.ca/health-manager-app

You can use this app to note down any questions that you may have to bring to your next doctor's appointment.



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