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Aplastic Anemia & Myelodysplasia Association of Canada

Association canadienne de l'anémie aplasique et de la myélodysplasie

Myelodysplastic Syndromes (MDS)

AAMAC Educational Series

The Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC) is a federally incorporated and registered national not-for-profit charity guided by dedicated volunteer members of the Board of Directors and a distinguished team of medical advisors from across Canada. Our volunteer-run organization supports patients and caregivers across the country who are living with aplastic anemia (AA), myelodysplastic syndrome (also called MDS or myelodysplasia) and paroxysmal nocturnal hemoglobinuria (PNH). For more than 30 years, AAMAC has focused on education, advocacy, and research, and provides support for patients, and care partners across Canada who are dealing with AA, MDS and PNH.

This educational booklet is a comprehensive resource for Canadians who are living with MDS and their loved ones, to support the journey in navigating this disease from diagnosis to treatment and beyond.

CONTENTS

1 | ABOUT THE DISEASE

About Myelodysplastic Syndromes (MDS)

Myelodysplastic syndromes (MDS) are a set of various conditions that affect a person's blood and bone marrow and are considered a type of blood cancer.[1,2] MDS obstructs the process of making the blood cells (white blood cells, red blood cells, and/or platelets) that are developed inside the bone marrow. For a person living with MDS, their blood cells are unable to develop into a healthy shape and size or move from the bone marrow into the bloodstream.

The signs and symptoms of MDS differ based on the type of blood cells affected:

- **Red blood cells (RBCs)** are responsible for carrying oxygen from a person's lungs to cells throughout the body. Oxygen is carried on the hemoglobin (Hb) in the RBCs.
- **White blood cells (WBCs)** defend the body against germs
- **Platelets** support the clotting of blood and help stop bleeding

In Canada, approximately 5,900 new cases of MDS are diagnosed annually[3] with about 87,000 new cases detected every year globally, although this rare disease is often under-diagnosed.[4] While this is an extremely rare disorder in children and usually develops in adults over 60 years of age, it can occur in people of any age group including children. The incidence in this category is around four out of a million children.[5]

Determining the Severity of MDS

Physicians may analyze the number of **blasts** (immature WBCs) in a patient's bone marrow to determine the severity of their MDS. Healthy bone marrow has no more than five blasts out of 100 WBCs, yet people living with MDS may have a higher number of blasts in their bone marrow.

Some facts about blood cell measurements[6]

Below are the standard ranges of blood cell counts in adults:

Hemoglobin (the quantity of red cell pigment carrying oxygen)
- For men: 14 - 17 grams for every 100 millilitres of blood
- For women: 12 - 15 grams for every 100 millilitres of blood

Red blood cells (RBCs)
- For men: 4.5 - 6 million RBCs in every microliter of blood
- For women: 4 - 5 million RBCs in every microliter of blood

Hematocrit (the part of the blood made up of RBCs)
- For Men: 42% - 50%
- For women: 36% - 45%

Platelets
- 150,000 - 450,000 in every microliter of blood

White blood cells (WBCs)
- 4,500 - 11,000 in every microliter of blood

Differential (also referred to as diff)
- Refers to the part of blood made of the various kinds of WBCs
- The different kinds of white cells counted include neutrophils, lymphocytes, monocytes, eosinophils, and basophils
- Adults generally have lower than 1% basophils, 4% eosinophils, 5% monocytes, 30% lymphocytes and around 60% neutrophils

- Low risk* MDS is when there are less than five blasts out of 100 WBCs
- High risk* MDS is when the number is anywhere between five and 19 blasts out of 100 WBCs
- If there are over 10 blasts out of 100 WBCs, the person has **acute myelogenous leukemia (AML)** – another type of blood cancer

*Risk assessment in MDS is explained on Page 7 of this resource

Note: Approximately 30 percent of people living with MDS are expected to develop acute myeloid leukemia (AML)

Causes of MDS

Primary MDS: When the cause of a person's MDS is unknown, it is called **Primary MDS** or **de novo MDS**. This is quite common among MDS cases. Some factors that can increase the possibility of being diagnosed with Primary MDS include certain occupations or environmental exposure to specific substances like benzene, pesticides, fertilizers, and exhaust gases, among others.

Primary MDS is not inheritable and cannot be transmitted from one person to another. Anybody can be diagnosed with Primary MDS; however, the likelihood increases if a person is a Caucasian man over 60 years of age. The average age of diagnosis is 71.

Secondary MDS: Approximately one in 10 people develop MDS as a result of treatment received for various cancers. This is referred to as Secondary MDS or **treatment-related MDS** (t-MDS, related to prior chemotherapy or radiation therapy). Secondary MDS can be more severe and difficult to treat compared to Primary MDS.

Usually, Secondary MDS develops five to seven years after treatment for other cancers, although the possibility is less than 1%. This risk is higher for patients who have received several rounds of radiation therapy and chemotherapy or have undergone a bone marrow transplant.

People with cancer who are at a higher risk of being diagnosed with MDS also include those who have been treated for head and neck cancer, lung cancer, gastrointestinal cancer, prostate cancer, or breast cancer. In addition, people who have received treatment for blood or bone marrow disorders like multiple myeloma, chronic lymphocytic leukemia, or lymphoma are also at a higher risk.

Types of MDS[7]

The classification and subtypes of MDS can evolve over time as new research and understanding of the disease develop.

Myelodysplastic syndrome, in the recent past, has even been given a new name **myelodysplastic neoplasia** to clarify that

it is what is called a neoplasia (a new growth of cellular mass that is uncontrolled). That said, ***MDS*** the abbreviation, is still retained.

In 2022, the International Consensus Classification (ICC) and the World Health Organization (WHO) jointly released a revised edition of the classification for myeloid neoplasms.[8,9]

In this classification, MDS is classified or grouped under two categories: *MDS which is defined morphologically and MDS with defining genetic abnormalities*

MDS subtypes defined morphologically include[9]:

1. **MDS, hypoplastic (MDS-h) –** In this subtype, a patient's bone marrow cellularity is very low for their age (less than 30% if the patient is under 60 years of age, and less than 20% if they are over 60[10]
2. **MDS with low blasts (MDS-LB) –** In this particular form of MDS, there is an abnormally low count of blasts (immature cells) both in the bone marrow and the bloodstream[11]
3. **MDS with increased blasts (MDS-IB1) –** This subtype is defined by 5% to 9% blasts in the bone marrow or 2% to 4% blasts in the peripheral blood
4. **MDS with increased blasts (MDS-IB2) –** Patients have 10% to 19% blasts in the bone marrow or 5% to 19% blasts in the peripheral blood or Auer rods in this subtype
5. **MDS with fibrosis (MDS-f) –** Patients in this subtype also have increased blasts of 5% to 19% blasts in the bone marrow or 2% to 19% blasts in the peripheral blood

MDS subtypes with defining genetic abnormalities include[9]:

1. **MDS with low blasts and isolated 5q deletion (MDS-5q) –** This is when RBCs are low in number, WBCs are maintained at a normal count, and platelets are higher than normal. In addition, there is a change in chromosome 5. This condition rarely leads to AML
2. **MDS with low blasts and SF3B1 mutation (MDS-SF3B1) –** In this subtype, the patient exhibits a low blast percentage in both, the bone marrow and blood, alongside a mutation present on the SF3B1 gene[11]
3. **MDS with biallelic TP53 inactivation (MDS-biTP53) –** In this subtype, the TP53 protein is inactive in the patient. [11] This protein functions as a tumour suppressor, thereby regulating cell division. Its role involves preventing cells from proliferating too rapidly or undergoing uncontrolled growth and division

2 | SIGNS & SYMPTOMS

Diagnosing MDS can be difficult since the signs and symptoms typically seen in patients could also be associated with other diseases. General signs and symptoms of MDS include:

- Shortness of breath during or after physical activity
- Infection
- Fatigue (tiredness)
- Dizziness
- Pale skin
- Increased risk of bleeding and bruising

Below are symptoms of MDS that are usually associated with deficiencies in the blood.

A **low count of hemoglobin** is referred to as **anemia**. People with a low RBC count may:

- Experience varying degrees of tiredness
- Have difficulty concentrating or staying alert
- Experience loss of weight and/or appetite
- Develop pale skin
- Have difficulty breathing
- Develop a rapid heartbeat or heart palpitations
- Dizziness and/or fainting
- Experience trouble climbing stairs or exercising

Anemia is usually one of the earliest symptoms of MDS. It is this symptom that generally alerts physicians of a need to look further into a patient's health. In the beginning, a person with MDS may experience mild or no symptoms at all. Usually, as the number of RBCs drop, more symptoms develop.

A **low overall count of white blood cells (WBCs)** is referred to as **leukopenia**. Generally, a low WBC count makes it harder for a person to fight bacterial infections. People with a low WBC count may:

- Get infections and fevers repeatedly and run a higher risk of becoming more ill with infections
- Experience bladder infections which lead to pain urinating or urinating more often
- Develop lung infections leading to breathing difficulties and coughing
- Severe coughing
- Shortness of breath
- Experience mouth sores
- Get a stuffy nose and sinus infections
- Experience skin infections, redness or swelling
- Experience sore throats
- Get patches in the mouth that are red or white
- Get diarrhea
- Experience vaginal itching or unusual vaginal discharge

A **low count of platelets** is referred to as **thrombocytopenia**. People with a low platelet count are likely to bleed or bruise more easily. They may:

- Bruising
- Experience heavier menstrual periods than normal
- Experience nose bleeds
- Notice flat and small red spots under their skin (called petechiae) due to bleeding
- Have bleeding gums after brushing their teeth and following dental work
- Experience hemorrhoids

There may not be any notable symptoms if the platelet count is not very low. In rare cases, the platelet count can drop to a point that leads to a concerning level of internal bleeding.

3 | IMPACT OF MDS ON QUALITY OF LIFE

A diagnosis of MDS can be very difficult for the person and their loved ones, bringing with it a significant impact on quality of life due to symptoms like fatigue and shortness of breath that can limit a person's participation in social and daily activities.

A 2022 study[12] conducted to understand the quality-of-life impact and mental health burden of people with MDS showed that 36% of the respondents reported 'concerning levels of depression and/or anxiety.' Dependence on transfusions, high-risk MDS, and functional impairment were also noted as contributors to a decline in mental health. The MDS patients in this study typically spent six hours at infusion centres and 60% of the participating patients reported some level of difficulty getting to the centre.

Caregivers in this study also reported a significant impact on their ability to plan for the future, including having feelings of uncertainty. Most caregivers (60%) reported significant distress and lower social, functional, and emotional well-being compared to patients.

A 2021 study[13] targeting health-related quality of life in patients with MDS pointed out that 'various studies have shown that the health-related quality of life of patients with lower or higher-risk MDS is significantly worse...' due to factors like the disease's impact on social functioning, role functioning, emotional issues, physical problems, fatigue, and shortness of breath, among others.

Considering the impact of the disease on mental health, it is important to connect with and use support systems including religious groups, friends and family, patient, or caregiver support groups, and professional counsellors to maintain optimal emotional health that may positively contribute towards improving quality of life.

For ***information about support groups and peer-to-peer support programs in Canada for people living with MDS***, *please contact the Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC) at info@aamac.ca or 1-888-840-0039.*

4 | DIAGNOSING MDS

Diagnostic Tests

Several tests may be used to confirm an MDS diagnosis.

1. **Bone Marrow Test –** **Bone marrow aspiration** and **bone marrow biopsy** are the two most common tests that are used to find out the quantity of abnormal blood cells in a person's bone marrow. Some tests that can be done on the marrow from a bone marrow biopsy include:

    a) **Microscopy –** This assesses what cells look like, if the marrow is empty or full, and if there are increased numbers of immature blast cells

    b) **Flow Cytometry –** This looks at patterns of surface markers on the cells

    c) **Cytogenetic Testing –** This assesses chromosomal abnormalities since some chromosome abnormalities are enough to diagnose MDS

    d) **Mutations Analysis –** This uses next-generation sequencing (NGS) to assess gene mutations. This is also called a myeloid panel.

2. **Blood Test –** A **complete blood count (CBC)** is a common test used for diagnosis. It is a comprehensive test that examines various components of the blood, including RBCs, WBCs, and platelets and supports monitoring of the disease. Its purpose is to identify issues with the bone marrow that can be the cause of low levels of various blood components and helps to assess the degree of blood cell breakdown. People with MDS generally have lower-than-normal numbers of **neutrophils** (a type of WBC), platelets and RBCs.

3. **Molecular Testing –** These tests can be done using either a blood or bone marrow sample to identify genetic mutations linked with MDS. Specific mutations are associated with varying prognoses—some indicating a more or less favourable prognosis. Medical professionals rely on the findings from molecular testing to guide treatment planning.

4. **Fluorescence in Situ Hybridization (FISH) –** This diagnostic procedure employs light and specialized probes to detect abnormalities in DNA within chromosomes. FISH analysis is performed using either a blood or bone marrow specimen.

5. **A Physical Examination –** Your physician will perform a physical examination to detect any indications of MDS. Their objective is to assess the severity of the condition and identify its underlying causes.

Making a Prognosis

A prognosis is a physician's best possible estimate of how a person will be affected by a disease and how they will respond to treatment. An MDS prognosis is impacted by several factors: the physician's familiarity with the patient's characteristics and history, and how MDS is presenting in a patient.

The physician will also consider predictive factors that will affect how a patient will respond to specific treatments.

Some of the predictive and prognostic factors for MDS include:

1. **Quantity of Blasts in the Bone Marrow –** If blasts are present in a large percentage in the bone marrow, it usually indicates a less favourable prognosis.

2. **Changes in Chromosomes –** Changes in chromosome 7 generally indicate a prognosis that is not very favourable. Less than three changes constitute simple changes that are associated with a comparatively favourable prognosis. More than three constitute complex changes linked with a prognosis that is less favourable.

3. **Lower Number of Blood Cells –** A low number for more than one blood cell count (red blood cells, white blood cells or platelets) does not indicate a favourable prognosis.

4. **Gene Mutations –** The SF3B1 mutation in MDS cells, often seen in refractory anemia with ring sideroblasts (RARS), is associated with a more favourable prognosis. Whereas a TP53 mutation in MDS cells is associated with a less favourable prognosis.

5 | COMORBIDITIES OF MDS[14]

It is important to note that as with any disease, other **comorbid** conditions can exist in people living with MDS. It is important to speak to your physician about how to diagnose and manage them.

A research study published in 2011 looked at the occurrence of additional health conditions in individuals with MDS, as well as how these concurrent conditions relate to demographic and MDS-related factors. Additionally, the researchers devised the MDS-specific comorbidity index (MDS-CI). The use of this assessment tool, in conjunction with the Prognostic Scoring System based on the World Health Organization's classification (explained below), has the potential to improve the categorization of MDS patients according to their prognosis. This, in turn, may enable the development of more customized treatment approaches.[15]

In this study[15], the most commonly documented concurrent health condition was heart-related ailments, with a prevalence of 25% among patients. These cardiac issues encompassed various disorders such as arrhythmia, heart valve abnormalities, coronary artery disease, myocardial infarction (heart attack), congestive heart failure, and a reduced ejection fraction below 50%. Other comorbidities that were identified

- Hepatic disease (including fibrosis, chronic hepatitis, and persistent increase of bilirubin)
- Pulmonary disease (including shortness of breath and requiring oxygen)
- Cerebrovascular transient ischemic attack, hemorrhagic or ischemic cerebrovascular accident
- Rheumatological disease (including rheumatoid arthritis and systemic lupus erythematosus)
- Endocrinal disorders (including adrenal and thyroid disease)
- Obesity
- Psychiatric illnesses (like depression)
- Renal disease (including the need for renal transplant or dialysis)
- Gastrointestinal disorders (including Crohn's disease)

6 | PROGNOSTIC SCORING SYSTEMS OF MDS

MDS specialists (typically hematologists/oncologists) use the **IPSS-R (International Prognostic Scoring System – Revised)** to assess the prognosis of a patient with MDS before starting treatment. This scoring system is only a portion of the diagnosis and treatment decision-making process and should not be regarded as providing complete insight into a patient's future. It helps a physician determine a patient's risk which potentially indicates how quickly the disease will progress.

The IPSS-R assigns patient risk into five groups and the score is based on blood counts, marrow blast count and risk of cytogenetic abnormalities (irregularity in the number or structure of chromosomes[16]):

Risk Group	Points	% of Patients	Median Survival, Yr	Time Until 24% of Patients Develop AML, Yr
Very Low	<1.5	19%	8.8	Not Reached
Low	>1.5-3	38%	5.3	10.8
Intermediate	>3-4.5	20%	3.0	3.2
High	>4.5-6	13%	1.6	1.4
Very High	>6	10%	0.8	0.73

Some MDS specialists may still use the previous version of the International Prognostic Scoring System (IPSS) which is focused on three main variables for assessing MDS: cytopenias (low blood counts), blast percentages, and the degree and type of chromosomal abnormalities (karyotype).

As indicated above, the **IPSS-R** system considers various factors, including the proportion of blasts present in the bone marrow, the nature and scope of chromosomal alterations, and the levels of hemoglobin within red blood cells, platelets, and a specific type of white blood cell known as neutrophils.

The **Molecular International Prognostic Scoring System (IPSS-M)**, on the other hand, employs identical data as the IPSS-R system and additionally incorporates the outcomes of molecular testing. It can only be computed following the completion of **molecular testing** and the data put into a calculator categorizes the condition into one of six risk categories.

- Very low
- Low
- Moderate low
- Moderate high
- High
- Very high

Note: It is important to remember that prognostic systems are continuously evolving based on new research and a developing understanding of the disease. In this resource, we have tried to provide an overview of the current systems deployed for risk assessment of MDS.

7 | LIVING WITH MDS

Navigating Care

Preparing for Appointments: It's simple to overlook important questions during an in-person or virtual visit with your physician. Prior to an upcoming appointment, it is important to jot down questions and discuss these thoroughly with the hematologist/oncologist or their support team. It is also helpful to remember to carry a notepad for writing down the responses or, if allowed, record the session to review later. If possible, bring a trusted companion to the appointment to help ensure that all questions are answered.

Managing Medical Information: It is a good practice to keep your health information, including lab results and medical records, in a single location. Consider organizing and storing these documents in a notebook, on your computer, or in an online repository using a smartphone or tablet app to easily access and refer to them whenever needed.

The Treatment Plan: It is important to collaborate with your hematologist/oncologist in developing a treatment plan. This plan should consider the diagnosis, the current treatment options available, and the ultimate goal of treatment. Each person's treatment plan will be unique and tailored to factors such as age, blood count measurements, overall well-being, and other considerations. It is important to thoroughly review the treatment plan provided and ensure that you are comfortable with the approach. A well-crafted treatment plan should empower you, fostering a sense of control and optimism for the future.

Using Support Systems: Coping with MDS and navigating the treatment process can be challenging. People often experience fatigue, discomfort, or anxiety in this situation. This is why it is important to seek assistance. Consider whether family members or friends can help with tasks such as grocery shopping or providing transportation to and from medical appointments. You might be pleasantly surprised by the willingness of people to lend a helping hand when asked.

Consider scheduling a session with a counsellor or mental health professional. If possible, seek out someone who has a background in assisting people facing health challenges like MDS. Ask your physician about the availability of support networks for people coping with MDS. Becoming a part of a support group can offer valuable opportunities to exchange experiences and receive advice on effectively managing life with MDS. Interacting with people who genuinely comprehend your situation can have a significant impact on your overall quality of life.

*For more **information on MDS support groups in Canada**, please contact the Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC) at info@aamac.ca or 1-888-840-0039.*

Coping with Stress: Coping with a illness can lead to feelings of being overwhelmed, stressed or down. People often find themselves discontinuing activities they once enjoyed and withdrawing from social interactions. While medications and various treatments can alleviate symptoms and improve blood measures, they may not effectively address emotional well-being. This is why exploring mind-body therapies, which centre on reducing stress and enhancing the emotional state is strongly recommended. These therapeutic approaches can also provide relief from pain and enhance vitality. Consider whether treatments or practices such as meditation, deep breathing exercises, aromatherapy, yoga, tai chi, acupuncture, or massage therapy may be worth a try.

Doing other simple things that you love which make you smile could also be very meaningful. This could include taking up hobbies, enjoying nature, or other activities that may offer a welcome distraction.

IMPORTANT: *Before exploring mind-body therapies, consult with the hematologist/oncologist who oversees your treatment. Your healthcare facility may have dedicated professionals who can assist you in devising a customized plan tailored to your unique needs.*

Dealing with Fatigue: Coping with MDS can pose challenges in managing energy levels, with persistent fatigue often taking a toll. Fatigue is characterized by profound exhaustion and the depletion of our body's systems, manifesting as drowsiness, weariness, and physical, cognitive, and emotional weakness. Its effects are felt in many aspects of daily life, impacting mood, self-assurance, and emotional stability, and cannot be solely remedied with rest. To effectively address this, it is essential to identify activities that drain your energy and those that rejuvenate you, such as spending time with a close friend or taking a revitalizing walk. Energy conservation revolves around striking the right balance in this regard.

1. **Prioritize and schedule your time -** Evaluate your tasks and identify your top priorities. Avoid overloading your schedule, especially if it affects your concentration or memory. Utilize lists for shopping and maintain diaries or notepads for appointments
2. **Regulate your pace and positioning -** Plan regular rest breaks throughout the day. Acknowledge your accomplishments, seek assistance when needed, and don't hesitate to decline additional commitments. Organize your environment to minimize unnecessary bending or reaching
3. **Embrace relaxation techniques proactively -** Incorporate practices like visualization, breathing exercises, or meditation into your daily routine. These methods empower you to regain control and take charge of your situation.
4. **Address mental fatigue -** Understand that fatigue doesn't solely impact your physical well-being; it can also trigger feelings of anxiety, stress, and overwhelm. If comfortable, communicate your emotions to those around you to seek support and understanding.

Nutrition and Diet: Although diet has little impact on MDS symptoms, it is very important for one's overall health. Therefore, throughout the treatment process, diet could be helpful to avoid or address poor nutrition, prevent weight loss, and preserve lean body mass and muscle in addition to potentially helping negative effects like reduced appetite, queasiness, stomach upset, dry mouth, and changes in taste.

Being undernourished or having inadequate nutrition can significantly impact overall quality of life.

Myelodysplastic syndromes are often associated with symptoms like weakness, fatigue, disrupted sleep, and discomfort due to poor appetite and weight loss. You may be advised to follow a high-energy diet to address the shifting nutritional demands of your body during this period. Additionally, if you are going through chemotherapy, you may encounter complications that can negatively affect your nutritional status and your general well-being, such as mucositis (ulcers in the throat, mouth, or stomach).

Generally, people receiving treatment for cancer, including MDS, are advised to:

Get important nutrients including carbohydrates, fats, protein, and water

Ensure a well-balanced weight which for many people means preventing excessive weight loss or weight gain while ensuring an adequate daily calorie intake

IMPORTANT: *Before attempting weight loss during your treatment, seek guidance from your healthcare providers or ask for a recommendation from a dietician, if required.*

Exercise: People diagnosed with blood cancers like MDS should strive to minimize periods of inactivity and sedentary behaviour, aiming to resume their daily routines as soon as possible. There is compelling data which shows that engaging in exercise and physical activities can have a positive impact on:

- Fatigue, emotional distress, pain, depression, and anxiety
- Bone health, cardiovascular health, and cognitive function
- Overall health-related quality of life

IMPORTANT: *Before resuming or engaging in any exercise or physical activity, speak with your healthcare team.*

Relationships: Receiving treatment for a blood cancer, such as MDS, may have an impact on your role as a partner, parent, friend, or colleague, among other roles. Effective communication with family, friends, and caregivers is crucial. Articulating desires and requirements clearly to others enables them to offer more meaningful support.

Financial Planning: People living with diseases like MDS frequently describe a negative impact on their financial circumstances while undergoing treatment. Monthly expenses can escalate and might be due to an increase in travel expenses, childcare, and the need to take time off work for medical appointments. The household income could diminish if you or your caregiver need to stop work or reduce hours, either on a permanent or temporary basis, due to the diagnosis. To help reduce stress and worry, it is important to take the necessary steps to help manage the situation optimally.

Start by **evaluating your income and financial assets.** Questions to ask include:

- What kind of paid or unpaid medical leave is available to you and/or your caregiver?
- Can either you or your partner consider part-time employment?
- Do you have any Income Protection or any critical illness insurance, or is it integrated into a life insurance policy?
- Do you have access to existing funds or a mortgage-based line of credit, if needed?

Next, **make a list of any expenses that must be addressed in the near term.** If you don't already have one, create a budget that reflects the realities of managing finances while undergoing treatment.

You may wish to check if **getting life insurance** is possible at this stage if you didn't have it before your diagnosis.

- Certain private insurance companies may consider providing coverage to people who have previously experienced cancer. Eligibility hinges on the cancer type and its stage. It is advisable to consult with an insurance broker well-versed in securing coverage for people dealing with cancer. They can clarify the available choices and assist in selecting the most suitable option

If you are **incapable of meeting your usual mortgage obligations due to severe health issues**, it's vital that you promptly inform the appropriate institutions. Banks and similar financial entities usually offer specific accommodations for customers facing financial distress due to health-related challenges.

The Canadian Cancer Society **(CCS)** website provides **comprehensive information regarding financial assistance available to Canadians.**

- Explore various financial programs that can potentially be accessed by people living with MDS here
- Guidance on where to find help with financial planning is available on this page, along with a review of government assistance programs available to Canadians

The Canadian Cancer Survivor Network (**CCSN**) provides additional information on financial aid programs available to support people living with MDS and other forms of cancer

For more information, feel free to reach out to the
Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC)
at info@aamac.ca or 1-888-840-0039

Legal Planning: Maintaining an up-to-date will is one of the most effective ways to safeguard yourself and your family when dealing with a serious illness like MDS. A will provides formal directives regarding the management of finances, assets, and property upon death. It can also stipulate arrangements for the care of your children (those under 18) in the event of your passing. Additionally, you may wish to designate a guardian for your pets. When crafting a will, it's advisable to seek legal counsel to ensure the document's legality and validity.

If you had a will before your diagnosis, you might want to consider if it needs to be updated.

You also may wish to speak with your lawyer about preparing for circumstances when independent decision-making is no longer possible.

Discussion with Employer:

It is your choice as to whether or not to inform your employer that you have been diagnosed with MDS. Regardless, it is important to be aware of the criteria for short and long-term disability leave and other private health care coverage you may have through your employer.

While the majority of employers support employees dealing with an illness equitably and within the bounds of the law, certain employers may impose unwarranted and occasionally unlawful obstacles on their staff in such situations.

Concerns may arise regarding potential termination, lack of employment, reduced job status, rejection of advancement, denial of benefits, unwelcome reassignment, or unjust treatment by colleagues.

IMPORTANT: *Depending on your specific circumstances, it may be advisable to consult with an expert in employment law who is knowledgeable about employment rights for people coping with serious illness.*

Advocating for Yourself: It is important to remember that at any point in your journey with MDS, you could face a situation where you may need to advocate for yourself or your loved one. These opportunities may require you to communicate with decision-makers at various levels including your physician, the hospital where you or your loved one is treated, or the government to gain access to care and treatment.

A first step to addressing any roadblocks along the way may be discussing your situation with a support group where others may have lived through a similar experience and could potentially help you with useful advice. For assistance in navigating situations requiring advocacy for yourself or your loved one, you may also wish to contact the *Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC).*

8 | TREATMENT

The objective of treating MDS is to alleviate the symptoms of the disease, halt or slow the progression of MDS into AML, and enhance the patient's overall quality of life.

Your medical team will work with you to establish a treatment plan, which might involve addressing the symptoms or complications stemming from MDS, referred to as supportive therapy, such as low blood cell counts, as well as treatments that directly target the disease itself.

The table below indicates the priorities in the treatment of low and high-risk MDS.

Priorities in low-risk MDS

1	Improvement of cytonpenia(s) Less transfusions Less iron overload
2	Tolerability of a given treatment Quality of life
3	Delay disease progression Improve survival
4	Cure

Priorities in high-risk MDS

1	Delay disease progression Improve Survival Cure
2	Reduction of disease burden Improvement of cytopenia(s) Less transfusions
3	Tolerability of a given treatment
4	Quality of life

Source: Blood. Volume 133, Issue 10, 7 March 2019, Pages 1096-1107

Factors considered by a physician to determine a course of treatment for MDS include:

- A review of symptoms
- Age of the patient
- The patient's MDS subtype
- The patient's IPSS-R, IPSS-M or other risk score
- Other diseases or conditions present
- Availability of matching bone marrow

The main treatment options for MDS include:

- Observation with periodic blood counts
- Supportive therapy
  - Managing infections
  - Blood transfusions
  - Blood cell growth factors
  - Iron chelation therapy
- Allogeneic stem cell transplantation
- Drug therapy
- Chemotherapy
- New treatments currently being studied in clinical trials

Observation: Depending on the circumstances, immediate treatment may not be necessary for MDS patients. Employing a "watch-and-wait" strategy enables the physician to regularly assess the patient's condition and blood counts without starting drug therapy or other treatments until they become essential. These patients:

- Must see their physician periodically and get tested and examined regularly, as advised by the physician, and should inform them about any notable changes to their health
- Should be aware that starting treatment might be recommended if there is an indication of disease progression

Supportive Therapy

Managing Infections: A diminished count of white blood cells heightens the susceptibility to infections in patients. In certain instances, infections may occur frequently, and occasionally, they can be severe. Notify your doctor of any unexplained fever or signs of infection as antibiotics or antiviral medications may be necessary.

Blood Transfusion: A blood transfusion is a standard medical procedure. The majority of people with bone marrow failure disorders such as MDS and aplastic anemia will undergo at least one blood transfusion. During a blood transfusion, components of donated blood are introduced into the circulatory system intravenously to help boost diminished blood counts. Platelet transfusions may be required if a patient has bleeding problems because of a low count of platelets. Some side effects of a blood transfusion are:

- **Iron Overload -** Receiving frequent blood transfusions may result in an accumulation of excess iron in the body that can be life-threatening if not appropriately managed. MDS patients may also have iron overload in the absence of transfusions caused by an increase in gastrointestinal absorption of iron[17]. Speak to your hematologist to understand how to manage iron overload using medications known as iron chelators that remove the excess iron (see below).
- **Transfusion Reactions -** Platelet transfusions have a higher likelihood of triggering an allergic response, which can cause symptoms like chills and elevated body temperature. Blood transfusion may also lead to what is called a Hemolytic Transfusion Reaction. This is a complication where the red blood cells given to a patient are destroyed by their immune system. Its symptoms may include blood in urine, dizziness, or fainting, a flushed look on the skin, fever, back pain and more.[18]

Transfusion-associated circulatory overload or TACO is also a common reaction to transfusion where patients could develop pulmonary edema - referring to an unusual fluid build-up in the lungs – mainly due to a large overload of blood.[19]

Growth Factors: These are substances that regulate the growth, division, and survival of cells. Not having enough healthy blood cells causes most of the symptoms of MDS. Growth factors help return blood cell counts to normal.

- **Red Blood Cell Growth Factors: Erythropoietin** (also called EPO) is a growth factor produced by the kidneys which stimulates the bone marrow to produce an increased quantity of red blood cells. When there is a deficiency of red blood cells, specific medications can assist the bone marrow in generating more of them. These medications are referred to as erythropoiesis-stimulating agents (ESA) and are administered via injection. ESAs approved in Canada include epoetin alfa (Eprex®) and darbepoetin alfa (Aranesp®).

*Note: Surgery for other conditions **may** also decrease red blood cell (RBC) counts, requiring the use of EPO drugs. You may wish to ask your surgeon if a blood transfusion in advance of the surgery might help to prevent a further decrease in RBC and hemoglobin counts.*

- **White Blood Cell Growth Factors:** If you develop an infection due to low levels of WBCs, these medications can assist your bone marrow in producing more white cells. Research has indicated that incorporating these drugs into the treatment of people with bone marrow failure offers minimal or no significant benefit. Therefore, physicians typically suggest the short-term use of these medications to increase white cell counts before procedures, such as surgery or in the event of a severe infection. These medications are administered via skin injection and there are two types:
- **Granulocyte-colony stimulating factor (G-CSF)** is a hormone that stimulates the production of white blood cells. Some MDS patients who have low EPO levels may not experience enough benefit from an ESA medication alone, adding a G-CSF agent may enhance a patient's hemoglobin levels. G-CSF medications approved in Canada include filgrastim (Neupogen®) and pegfilgrastim (Neulasta®).
- **Granulocyte macrophage-colony stimulating factor (GM-CSF)** represents another type of growth factor. Sargramostim (Leukine®) is an example of a GM-CSF medication that is approved in Canada. These medications can support patients experiencing low neutrophil (white blood cell) levels who tend to develop infections.

Iron Chelation Therapy: Iron overload is evaluated through periodic blood tests to measure the amount of iron in the blood (Serum transferrin saturation test and Serum ferritin test) conducted multiple times annually. If recommended by a physician, there are a number of iron chelation therapies (oral, subcutaneous, or intravenous) approved in Canada that have been proven to address iron overload in patients with MDS and other bone marrow disorders, including deferasirox (Exjade®, Jadenu®), and deferoxamine (Desferal®).

Iron chelation therapy can potentially lead to an increased risk of impaired colour vision and hearing loss. Patients taking these treatments should undergo periodic vision assessments conducted by an ophthalmologist and hearing evaluations conducted by an audiologist.

Treatments for MDS

Stem Cell Transplantation: In this procedure, healthy stem cells from a donor completely substitute all the patient's bone marrow stem cells. This remains the sole treatment capable of providing the potential for complete recovery from MDS. Nevertheless, it brings with it substantial risks and challenges including finding a compatible donor which is essential for transplantation. It may be a suggested therapeutic route for younger patients who are in reasonably good physical condition.

To obtain a more thorough understanding of stem cell transplantation, speak with your hematologist/oncologist. Due to the risk of bone marrow transplantation, there is an extensive assessment of the patient and the disease severity to determine if someone is eligible for bone marrow transplants. It is important to understand the potential for complications, occurrences of treatment ineffectiveness, and even the risk of death.

What to Expect: Stem cell transplantation is a significant medical intervention. It involves hospitalization and a series of treatments, including chemotherapy, immune suppression therapy, and possibly radiation, aimed at eliminating a major portion of your existing bone marrow to create space and reduce the risk of rejection for the incoming donor cells. Throughout this period, you must remain hospitalized to safeguard against potential infections, and the duration of hospitalization can vary, ranging from as brief as a week to potentially more than a month.

Your physician will introduce the healthy stem cells from your donor into your bloodstream through an infusion process resembling a blood transfusion. The compatible donor can be a family member (such as a sibling) or an unrelated donor. In situations where a perfect match is unavailable, a half-match (haploidentical match) may be considered a viable option for several patients following appropriate pre-transplant preparation.

If successful, these newly introduced, healthy donor stem cells will migrate to your bone marrow and initiate the process of self-replication, a phase known as engraftment, which may extend for up to one month. Your medical team will closely monitor your blood cell counts to ensure the proper functioning of the new cells. In the event of a successful outcome, the newly established healthy cells will assume control, generating all the required red blood cells, white blood cells, and platelets.

Risks and Side Effects: Stem cell transplants entail significant risks, and it is important to engage in a comprehensive discussion about them with your physician. The treatment may lead to side effects stemming from chemotherapy and radiation, which can include gastrointestinal issues such as nausea and diarrhea, hair loss, and in rare cases, organ damage. Serious infections may also arise, necessitating blood transfusions due to severely depleted blood cell levels.

In certain instances, the transplanted cells may initiate an immune response against the recipient's body, resulting in a condition known as **graft-versus-host disease (GVHD)**, which can pose a life-threatening risk. The symptoms of GVHD can vary from mild, such as a temporary skin rash, to severe, including persistent diarrhea with damage to the intestinal walls. It is important to note that GVHD can manifest even when you are receiving medications (such as cyclosporine or others) intended to prevent its occurrence. The likelihood of GVHD is higher if you are of advanced age, if your donor is not related to you, or if there is not a perfect match between you and the donor.

Chemotherapy: This treatment employs cytotoxic medications to eliminate cancer cells. Cytotoxic signifies that these drugs are toxic to all cells throughout your body. While these drugs effectively eradicate cancer cells, they can also inflict damage on healthy cells. Chemotherapy may also address the symptoms associated with MDS and hinder or delay the progression of MDS into AML. Below are some common chemotherapy drugs used in treating MDS:

- decitabine and cedazuridine combination therapy (Inqovi) (oral)
- decitabine (Demylocan) (IV)
- azacitidine (SQ)

Drug therapy: Other drugs that could be prescribed[20] to address or prevent issues stemming from diminished blood counts in MDS patients include luspatercept (Reblozyl®), eltrombopag (Revolade®) and lenalidomide (Revlimid®)

Anti-thymocyte globulin and cyclosporin might be used to treat a rare subtype of MDS characterized by a severely depleted blood cell count within the bone marrow.

Note: *Prior to beginning a new therapy, it is advised that patients review the product monograph and discuss with their physician the pros and cons of taking the medication. The product monograph will include possible side effects, risk factors and other information to consider when beginning a new medication.*

Clinical Trials

Clinical trial research studies involve human participants to evaluate the safety and impact of a specific treatment. Results from clinical trials could be used for the approval of treatments for Canadians or in order to compare against established approaches to treating a disease. You can visit the Government of Canada website to learn about clinical trials in greater detail.

Visit the Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC) clinical trials page for updates on the latest clinical trials for MDS and speak with your physician about any clinical trials that you may be eligible for.

9 | VACCINATIONS

Vaccinations are important for people with MDS because they are more susceptible to infection due to low immunity. Non-live vaccinations, alternatively known as inactivated vaccines (such as influenza, pneumonia, and the novel shingles vaccine), are considered safe for MDS patients. On the other hand, live vaccines should typically be avoided. If you plan to travel to a distant or exotic destination, consult with your physician or an infectious disease specialist.

10 | DISEASE MANAGEMENT

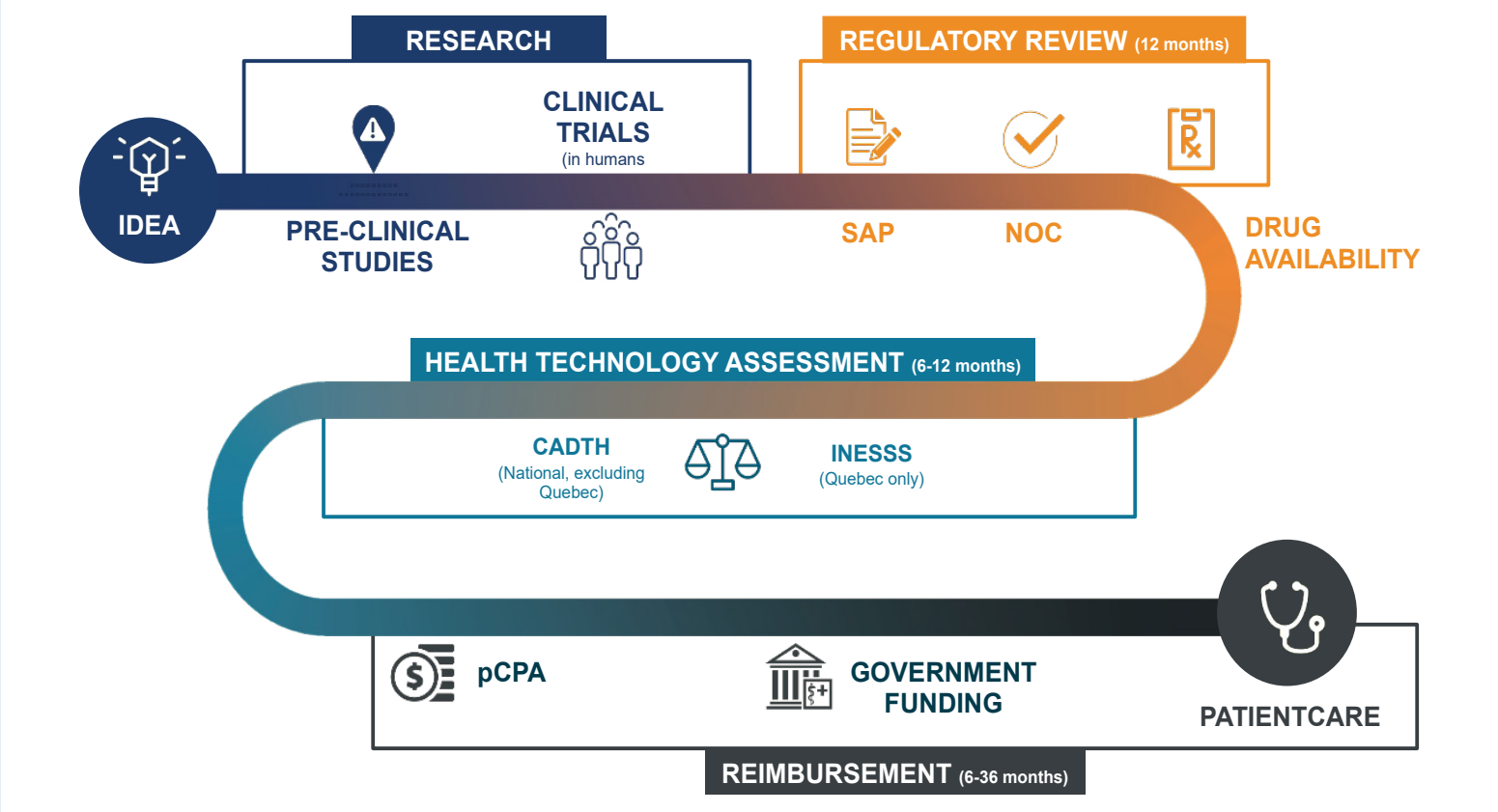
In order to take ownership of managing your MDS by tracking your symptoms and progress with treatments, try using the following resources from the **Aplastic Anemia and Myelodysplastic Association of Canada (AAMAC)** and **the Aplastic Anemia and MDS International Foundation (AAMDSIF):**

1. Patient Tracker
2. Appointment Tracker
3. Blood Transfusion Record
4. Symptom Tracker
5. Platelet Transfusion Record
6. My Health Care Team
7. Emergency Room Card

Living with a disease like MDS brings various challenges, and you will have good days and not-so-good days. As you go through your journey with MDS, you will find that knowledge combined with the right support from health care experts, family and friends will make all the difference to your well-being and quality of life.

11 | ACCESS TO TREATMENTS IN CANADA

Processes Involved in the Approval and Public Funding of Treatments in Canada



Source: EVERSANA

Regulatory Review

For a medication to be available to Canadians, Health Canada (a department of the Government of Canada) must first approve it for safety, efficacy and quality. As part of the regulatory review process, Health Canada examines various scientific data, including clinical trial studies, to assess the potential benefits and risks of the medication. Once approved, the treatment will be issued with a **Drug Identification Number (DIN)** and a **Notice of Compliance (NOC)**. The NOC then allows a pharmaceutical company to market and sell that drug in Canada, as well as qualified healthcare professionals to prescribe the treatment.

For more information, visit the Health Canada Drug and Health Products *page.*

Special Access Program

In cases of severe or life-threatening illnesses, when conventional treatments have proven ineffective, are unsuitable, unavailable, or offer limited choices, a physician may make an application on behalf of a patient **for a medication that**

has not yet been approved by Health Canada. Application is made to the Special Access Program (SAP) within Health Canada's Therapeutic Products Program. If approved, the SAP then authorizes the release of the drug to the physician, who in turn administers it to the patient. It is important to note that while a successful SAP application allows a non-approved medication to be brought into the country, it does not address who is required to pay for treatment.

For more information, visit the Health Canada Special Access Programs: Overview *page.*

Health Technology Assessment (HTA)

Health Technology Assessment (HTA) is the process whereby a health technology or treatment is assessed to determine the value of that technology and how it should be used in a health system. In Canada, we have two HTA bodies – the Canadian Agency for Drugs and Technologies in Health (CADTH) and the Institut national d'excellence en santé et en services sociaux (INESSS).

CADTH

CADTH is the national agency (excluding Quebec) that makes recommendations to the public drug plans in Canada as to whether or not a particular medication should be publicly funded. They do so through what is called a Reimbursement Review, which is a comprehensive assessment of the clinical effectiveness and cost-effectiveness, as well as patient and clinician perspectives, of a treatment. While these reviews are non-binding on the public drug plans, they do help to guide the ultimate reimbursement decisions of the federal, provincial, and territorial governments.

For more information, visit the CADTH *website.*

INESSS

INESSS is the provincial agency in Quebec that makes recommendations to the Minister of Health and Social Services as to whether or not a particular medication should be publicly funded. Assessments by INESSS focus on therapeutic value, cost-effectiveness (compared with other drug options), unmet need and the impacts of a listing on the public health budget. While also non-binding, INESSS recommendations play a critical role in guiding the final drug funding decisions of the Government of Quebec.

For more information, visit the INESSS *website.*

Drug Reimbursement

The final step to accessing treatments in Canada through public funding consists of two parts: the pan-Canadian Pharmaceutical Alliance (pCPA) and Product Listing Agreements (PLAs).

The pCPA conducts joint federal, provincial, and territorial negotiations in which member jurisdictions engage drug manufacturers to determine if a particular drug will be publicly funded, at what cost, and with which reimbursement criteria. If a negotiation is successful, a Letter of Intent (LOI) is issued. A drug company then takes that LOI to each of the public drug plans in Canada and uses it as the basis for finalizing a PLA – a legally binding agreement that will trigger publicly funded access to that treatment in the jurisdiction.

For more information, visit the pCPA *website.*

PATIENT AND CLINICIAN INPUT: A vital part of the CADTH and INESSS review processes is patient, caregiver, and clinician input. Both CADTH and INESSS post calls for input from patient organizations and clinician groups (for INESSS, individual members of the public can also submit input) when conducting reimbursement reviews. Patient and clinician groups are encouraged to share their experiences and perspectives on the disease, existing treatments, including the drug under review, as well as insights into unmet needs the drug under review addresses. The combined input from patients, caregivers and clinicians serves to inform the review processes at the two agencies.

The Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC) provides input into HTA reviews for treatments in aplastic anemia, myelodysplastic syndromes, and paroxysmal nocturnal hemoglobinuria.

For more information, visit the CADTH Patient Group Input and Feedback *page.*

For more information, visit the CADTH Clinician Group Input and Feedback *page.*

For more information, visit the INESSS Public Input *page.*

Formal and Informal Advocacy to Support Access to Treatment

Numerous patient organizations, like AAMAC, across the country advocate on behalf of their communities around issues such as access to treatment. Many provide opportunities for people to share their experiences and opinions as treatments make their way through the approval and reimbursement processes across Canada. Such engagement can be divided between formal and informal advocacy opportunities.

As part of the structured drug approval and public reimbursement processes, the only formal opportunities for input from patients, caregivers and physicians are within CADTH and INESSS. Beyond formal advocacy, individuals and the groups or organizations who represent them can make their voices heard around an issue related to access to treatment in a variety of ways. Some examples of informal advocacy include meetings with elected officials and bureaucrats, letter-writing campaigns, petitions, and social media campaigns.

For more information about advocating for access to treatment, please contact the Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC) at info@aamac.ca or 1-888-840-0039.

12 | ACKNOWLEDGEMENTS

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13 | APPENDIX

Being diagnosed with a complex disease like MDS can be overwhelming and the learning curve can be steep. Below are some points to help you prepare for medical appointments and to ask your physician if they are not addressed during your appointment.

Note: *These lists are compiled from resources by AAMAC and AAMDSIF*

Points to address with your physician about diagnostic tests for MDS[21]:

1 What types of tests will be conducted to diagnose my disease?

2 What should I be expecting from the test/s?

3 Where will the tests be performed?

4 What's the typical turnaround time for receiving the test outcomes?

5 What is the frequency of necessary testing?

6 How will the results be conveyed to me?

Points to address with your physician following a diagnosis[22,23]:

1 How sure are you about the diagnosis of MDS?

2 Can you explain what MDS is? How is it different from leukemia?

3 Could this diagnosis potentially be something other than MDS?

4 Will you be the primary doctor responsible for treating my MDS, or will other specialists be involved in my care?

5 Do I need any other tests before we can decide on treatment? e.g., cytogenetic testing, a gene mutation profile.

6 Will further tests be required, and can you explain the types of tests to me? How frequently will I need a bone marrow biopsy?

7 Do I need to see any other types of doctors?

8 How can I contact you if I have any questions or concerns?

9 What type of MDS am I dealing with? Is it classified as Low Risk or High Risk? What does the IPSS-R (or IPSS) score indicate?

10 What is my prognosis? How does it compare with the average lifespan of this condition?

11 Are there other factors that could affect my outlook or treatment options?

12 Is there a risk of developing acute myeloid leukemia (AML)?

13 What factors contributed to my diagnosis?

14 What approach will be used to monitor my condition?

15 What treatments are available to me and are any of them curative?

16 How will MDS affect my overall quality of life?

17 Am I able to travel by plane, both within Canada and internationally?

18 Are there any dietary restrictions I should be aware of? Can dietary choices influence my condition?

19 Do you have or can you direct me to any additional resources about MDS (and AML)?

20 Can I have a printout of my blood results?

21 Where can I get information about MDS, what support groups are there?

Points to address with your physician before starting treatment[24,25]:

1 How much experience do you have treating MDS?

2 Are you part of a multidisciplinary team (MDT) or do you have access to an MDT with access to a recognized MDS expert?

3 What is the objective of my treatment?

4 Do we need to treat the MDS right away?

5 Which treatment, if any, do you recommend, and why?

6 What treatment choices do I have? What is the expected duration of my treatment?

7 What is the duration of blood transfusion treatment? What are the associated adverse effects? What is Iron overload and what should I expect?

8 What are the potential risks, advantages, and adverse effects associated with my treatment options? When are side effects likely to happen? Are any of these long-term?

9 What should I do to be ready for treatment?

10 How long will treatment last? What will it be like? Does it hurt? Where will it be done?

11 What are the risks or side effects of the treatments that you recommend? How long are they likely to last?

12 When can I anticipate observing a treatment response?

13 How will the treatment be administered?

14 Will treatment affect my daily activities?

15 How will my progress be tracked during the course of my treatment and afterward?

16 What is the outlook for my survival?

17 How do genetic mutations impact treatment choices?

18 What alternatives are available to me if the treatment proves ineffective?

19 Are there any clinical trials that I should contemplate participating in? Should I consider this before deciding on a standard treatment?

20 What travelling is involved? I am, (or I am not) able to travel far for a clinical trial.

21 Will I be treated any differently if I enrol in a clinical trial?

Points to address with your physician during treatment[26,27]:

1 How will we know if the treatment is working?

2 What type of follow-up will I need during and after treatment?

3 Is there anything I can do to help manage side effects?

4 What symptoms or side effects should I tell you about right away?

5 How can I reach a health professional with knowledge of MDS on nights, holidays, or weekends?

6 What if blood transfusions and ESA treatment prove ineffective? What steps are taken next? (if you are receiving blood transfusions)

7 What steps should be taken if my private insurance declines to cover the treatment? Is it accessible through public funding in my province?

8 My caregivers are facing significant challenges in supporting me and managing our household. What assistance or resources are available for them?

9 Can you suggest a mental health professional I can see if I (or my spouse/partner) start to feel overwhelmed, depressed, or distressed?

10 What are the indicators of disease relapse? How would we address a relapse?

11 How frequently should I anticipate follow-up examinations and tests?

12 In the event of AML development, what is the prognosis? What treatment avenues are available? Is lifelong monitoring necessary?

13 What vaccines should I get at this stage?

14 Do I need to change what I eat during treatment?

15 Are there any limits on what I can do?

16 Should I exercise? What should I do, and how often? At what point can I return to regular activities like physical exercise and employment?

17 Am I consistently categorized as immunocompromised in the absence of a transplant?

18 Are there specific supplements I should consider to support my immune system?

19 Is ongoing monitoring necessary throughout my life for other bone marrow failure conditions such as aplastic anemia and/or PNH?

20 Where can I find more information and support?

Top tips[28]

1 Take a pen and paper and write your questions down

2 A detailed summary is usually documented by the physician at every medical visit. While recording the consultation should not be necessary, if the physician is unable to provide this, with their permission, you can sometimes electronically record the consultation if you feel you cannot take all the information down

3 We recommend you attend most consultations with a family member or friend, as it can be difficult to remember all that is said in a conversation

4 When necessary, a health professional may also be available to go through the main aspects of the consultation again with you

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