

MDS Alliance

An international umbrella organisation that aims to ensure MDS patients, regardless of where they live, have access to the best multi-professional care.

#ThinkMDS

WHAT IS MDS?

Myelodysplastic syndromes (MDS) are a rare group of bone marrow failure disorders that occur on average by age 70 and cause the body to stop producing a sufficient number of healthy, normal blood cells in the bone marrow. This results in low numbers of one or more types of cells in the blood and is considered a type of cancer.

The course of the disease can vary greatly: In some people, the disease worsens within a few months of diagnosis, while others experience relatively few issues over several decades.

WHAT ARE THE SYMPTOMS?

The symptoms of MDS can vary depending on the type and severity of the disorder, but some common symptoms include:

- Pallor
- Fatigue and feeling weak
- Shortness of breath
- Easy bruising/abnormal bleeding
- Petechiae or red spots on the skin
- Frequent infections
- Bone pain



If you want to find out more, please visit www.mds-alliance.org



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WHY EARLY DIAGNOSIS MATTERS

Since disease progression varies individually and there is still no cure for MDS other than transplantation of stem cells from a donor, treatment of myelodysplastic syndromes is mostly aimed at slowing down the disease, relieving symptoms and preventing complications. There are currently some drugs that can help slow the progression of the disease, improve patients' quality of life and prolong their lives.

General practitioners play a crucial role in the diagnosis and early referral of MDS patients, as they are often the first point of contact for patients in the health care system. It is therefore critical that they know and recognise the signs and symptoms of MDS.

If you repeatedly treat a patient with symptoms indicative of MDS, be mindful it might be MDS and do not hesitate to refer them to a specialist!



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HOW IS MDS DIAGNOSED?

MDS is usually diagnosed when a patient is evaluated for low blood counts, although some MDS patients may show an elevated white blood cell count, platelet count, or both. The defining feature of MDS is a bone marrow aspiration and biopsy showing heavy infiltration with abnormal-looking bone marrow cells. Molecular data may be analysed to determine the type and risk level of MDS.

MDS should be considered in any patient with unexplained cytopenias (low blood counts) or clinical findings related to anaemia (insufficient amount of healthy red blood cells), infection or bleeding/bruising, morphologic dysplasia of blood or bone marrow, or unexplained bone marrow failure.

HOW IS MDS TREATED?

Despite a high median age at diagnosis, it is essential to consider all viable treatment options. People over 75 years of age may be treated with low intensity therapy or supportive care. However, there is no absolute age limit beyond which high-intensity therapy or transplantation are no longer recommended.

There are different types of treatments available depending on the type and stage of MDS:

- Supportive medical care to relieve disease symptoms
- Blood transfusions
- Pharmacological therapy to slow down the progression of the disease
- Chemotherapy and bone marrow stem cell transplantation/allogeneic stem cell transplantation to eliminate cancer cells and inject healthy stem cells from a suitable donor.

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HOW CAN I TAKE CARE OF MYSELF?

It is important that MDS patients manage some parts of this condition themselves. Coping strategies may include:

- Learning as much as possible about MDS
- Reducing risk of infection and staying up to date with vaccinations
- Eating well and following food safety guidelines for people with cancer (here you will find a list of recommendations)
- Staying active and exercising
- Learning to manage fatigue (e.g. pacing yourself, getting as much rest as possible, avoiding alcohol)
- Getting psychological support
- Joining a (local) support group and connecting with peers
- Complementary approaches (make sure to talk to your doctor first), e.g. yoga, tai chi or meditation



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HOW CAN OTHERS SUPPORT PEOPLE WITH MDS?

DONATE BLOOD OR BONE MARROW. Your contribution might save a life.

During the Covid-19 pandemic, the already small number of donors has declined dramatically. For many people with MDS, this is a disaster: around 70% of all patients suffering from the rare blood cancer are anaemic and rely on blood transfusions to stay alive as their disease progresses.

Additionally, allogeneic stem cell transplantation is the most common type of transplantation for MDS. It involves using healthy hematopoietic cells donated by another person to replace unhealthy cells. These healthy cells can come from a family member, an unrelated donor, or umbilical cord blood.



Blood can be donated at any time at the local blood donation centre without registration. In stem cell transplantation, the donor - whether the stem cells are obtained from bone marrow or peripheral blood - is selected from a registry based on a detailed genetic match.



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