



Blood Cancer Awareness Month 2023

Briefing guide

August 2023

Supporters



#ThinkMDS

Let's talk about blood cancer, let's think about MDS

Blood Cancer Awareness Month - MDS Alliance Campaign Strategy

September is Blood Cancer Awareness month

During the **Blood Cancer Awareness Month**, the MDS Alliance will be supporting the education and awareness of myelodysplastic syndromes (MDS), which are a rare group of blood cancers.

The MDS Alliance is running a 4-week campaign titled **#ThinkMDS**, which rests on three major pillars:

- **For Patients:** Patient education about noticing MDS symptoms, diagnosis and treatment options, and self-management of the disease
- **For Health Care Professionals (HCPs):** Reminding HCPs about MDS symptoms, the need for early diagnosis and referral to MDS specialists
- **For the General Public:** Raising awareness about MDS and the ways to help MDS patients - blood donation and registering as a stem cell donor

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Blood Cancer Awareness Month - MDS Alliance Resources and Timeline

The MDS Alliance has prepared the following information **materials** to be shared through social media (SM) channels.

- **11x** visuals to accompany each SM post
- **1x** foldable 4-page information brochure
- **5x** 1-page posters based on information in the brochure

These can be accessed and downloaded from the MDS Alliance website in a translatable form.

The MDS Alliance will follow the **timeline** below when sharing materials on SM

Week 1: Introducing MDS and its causes and types

Week 2: Focusing in on MDS symptoms and diagnosis

Week 3: Treatment and care for MDS patients

Week 4: How can the public help MDS patients

The hashtags will include **#ThinkMDS #OrderaBloodCount #ThisIsBloodCancer**

#ThinkMDS

Information brochure

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

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.





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.

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



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Page 1

WHAT IS MDS?

Myelodysplastic syndromes (MDS) are a rare group of bone marrow failure disorders that mostly occur after the age of 60 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



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!

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.




www.mds-alliance.org www.mds-alliance.org

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An informative brochure compiling all relevant information about MDS

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Week 1: Introducing MDS and its causes and types

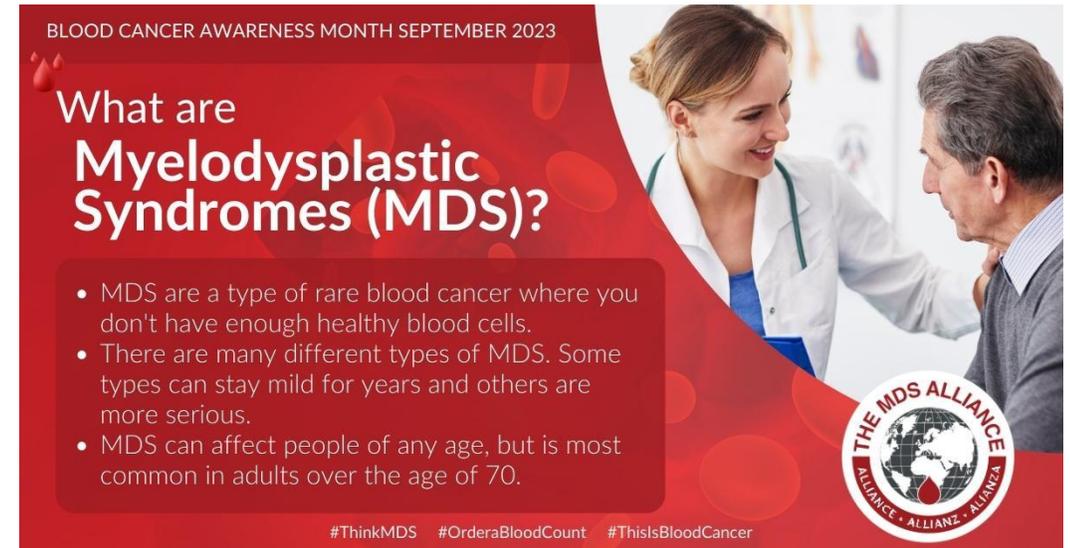
Using simple definitions and clear graphs so people understand **what MDS is, what causes it and what types of MDS exist**

Objectives

- Raise awareness of MDS in the general public
- Educate people on what MDS is and why it occurs
- Educate people about different types of MDS

Materials

- Visuals to enhance informative SM posts
- Posters to download, print and share in local communities



Example of an SM post visual

Shout global – act local

#ThinkMDS

Week 2: Focusing in on symptoms and diagnosis

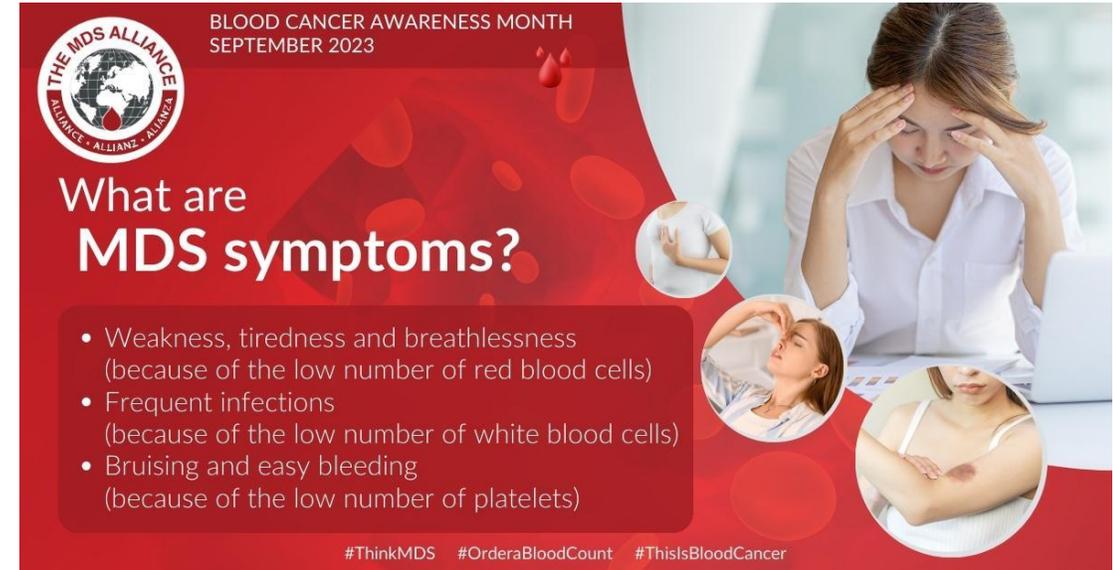
Using simple definitions and clear graphs to spread awareness about **symptoms, diagnosis** and the **importance of early detection**

Objectives

- To make patients and HCPs aware of early and common symptoms of MDS
- To educate the public about how MDS is diagnosed
- To remind about the importance of early diagnosis

Materials

- Visuals to enhance informative SM posts
- Posters to download, print and share in local communities



Example of an SM post visual

Week 3: Treatment and care options for MDS patients

Using simple definitions and clear graphs so people understand **how MDS can be treated.**

Objectives

- To inform patients about treatment and care options after MDS diagnosis
- To help patients manage their symptoms with appropriate lifestyle choices

Materials

- Visuals to enhance informative SM posts
- Posters to download, print and share in local communities



Example of an SM post visual

Shout global – act local

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Week 4: How can YOU help MDS patients?

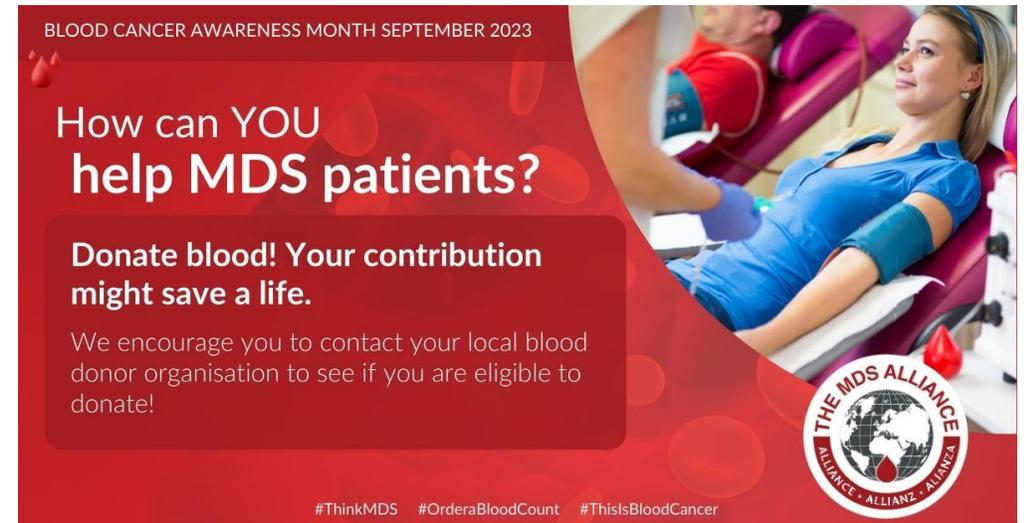
Using simple definitions and clear graphs so people understand **how the public can help MDS patients.**

Objectives

- Educate the public about blood donations and stem cell donor registries highlighting how big an impact these simple acts can have for MDS patients

Materials

- Visuals to enhance informative SM posts
- Posters to download, print and share in local communities



Example of an SM post visual

Shout global – act local

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Information posters

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.

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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 diagnosis, while others experience relatively few issues over several decades.

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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:

• Stay up to date with vaccinations (ask your doctor for recommendations)

• Get plenty of rest, getting as much rest as you can

• Connect with peers (ask your doctor for support group information)

• Stay active (ask your doctor for advice on what to do)

• Stay hydrated (ask your doctor for advice on what to do)

• Stay healthy (ask your doctor for advice on what to do)

• Stay informed (ask your doctor for advice on what to do)

• Stay safe (ask your doctor for advice on what to do)

• Stay calm (ask your doctor for advice on what to do)

• Stay positive (ask your doctor for advice on what to do)

• Stay hopeful (ask your doctor for advice on what to do)

• Stay strong (ask your doctor for advice on what to do)

• Stay brave (ask your doctor for advice on what to do)

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How can YOU get involved?



We encourage you to **get involved** and support the campaign on behalf of patients with blood cancer, globally!

You can show **your support** using social media and by downloading and printing posters to stick up in your local community

Customisation - live in September

Need to add your own message or logo? – Now you can customise these graphics with editable file options.

Using the Canva board - <https://www.canva.com/>



Like and share the social media posts on your social channels with the hashtag **#ThinkMDS** and tag **@MDSAlliance**



Read and share the posters on your social channels with the hashtag **#ThinkMDS**



Translate the posts into your local language and **disseminate** within your organisations

Download the graphics from the MDS Alliance website [here](#)
Edit the graphics directly in Canva [here](#)

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