



MDS World Awareness Day 2023

Briefing guide

25 October 2023

Supporters



#MDSWAD2023

Overview



All you need to know about MDS World Awareness Day



What are
Myelodysplastic
Syndromes
(MDS)?



Why are we
involved in a
world awareness
day?



Who
are we trying to
communicate
with?



The MDS World
Awareness Day
campaign details



How can you get
involved?

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What are Myelodysplastic Syndromes (MDS)



Myelodysplastic Syndromes (MDS) are an often unrecognised, rare group of blood cancers caused by the failure of the bone marrow to produce enough healthy blood cells.

- Also known as myelodysplastic neoplasms.
- There are many different types of MDS. Some types can stay mild for years and others are more serious.
- MDS can affect people of any age but is most common in adults over the age of 60.
- MDS can develop into acute myeloid leukemia (AML) in approximately 30% of patients.
- Treatment options depend on the subtype of MDS, the risk group, age, and general fitness. They include stem cell transplant, chemotherapy, and supportive care such as blood transfusions to control the symptoms of MDS.
- A stem cell transplant (SCT) is currently considered the only way to potentially cure MDS.

Why are we involved in the World Awareness Day?



The MDS Alliance represents over 40 patient advocacy groups worldwide. Our shared voice as a group with common causes and challenges allows us to support the education, resources and knowledge of **Myelodysplastic Syndromes** (MDS) globally and highlight the issues impacting the lives of those living with MDS.

MDS is **difficult to diagnose** - by raising awareness of MDS symptoms and encouraging those experiencing symptoms to take a blood test we aim to facilitate a timely diagnosis.

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Who are we speaking to and why?



During the 2023 MDS World Awareness Day we will be addressing all those who can notice the MDS symptoms before diagnosis - **members of the public who might be suffering with MDS** but also their **loved ones, family members and caregivers**.

Being aware of the first signs of MDS will help you to recognise that it is time to see your doctor and get a complete blood check. However, we may not always notice just how frequently we are feeling tired, or how quickly we get out of breath during activities that used to feel easy. That is why those around us also need to be vigilant and aware of the MDS symptoms.

A timely and accurate diagnosis is the first step to appropriate diseases management - the diagnosis can only begin once the symptoms are noticed and acted upon.

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MDS World Awareness Day 2023 – October 25



This **World Awareness Day**, we are sharing:

- Information about the **signs and symptoms of MDS** and highlighting that **getting a blood test**, with a full blood count analysis can confirm the diagnosis.
 - 4 x social media posts and graphics about MDS symptoms
 - Additional posts and visuals about the MDS WAD (Save the date, Tomorrow/Today is..., Thank you)
 - 4x information posters
 - An MDS WAD Twibbon campaign
- First-hand experience of **how MDS can impact one's life**
 - Short interviews with MDS patients and carers for MDS patients

The posting calendar, post graphics, posters and the twibbon can be accessed and downloaded [here](#).


The interviews will be available on the MDS Alliance website ahead of MDS WAD.

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Graphics for social media posts

On the day - awareness about MDS symptoms

MDS World Awareness Day
October 25




Does your partner
bruise easier
than normal?


Don't let them ignore it.

Bruising easily is one of the signs of MDS - myelodysplastic syndromes, a group of rare blood cancers. A healthcare provider can carry out a complete blood count to see if further action is required.

Get a #BloodCount



MDS World Awareness Day
October 25




Is your loved
one more
fatigued
than normal?

Don't let them ignore it.

Fatigue is one of the signs of MDS - myelodysplastic syndromes, a group of rare blood cancers. A healthcare provider can carry out a complete blood count to see if further action is required.

Get a #BloodCount



MDS World Awareness Day
October 25



Is a family
member more
breathless
than usual?


Don't let them put it down to ageing.

Feeling breathless after little exertion is one of the signs of MDS, a group of rare blood cancers. A healthcare provider can carry out a complete blood count to see if further action is required.

Get a #BloodCount



MDS World Awareness Day
October 25



Does your
loved one
feel weaker
than usual?

Don't let them ignore it.

Muscle weakness is one of the signs of MDS - myelodysplastic syndromes, a group of rare blood cancers. A healthcare provider can carry out a complete blood count to see if further action is required.

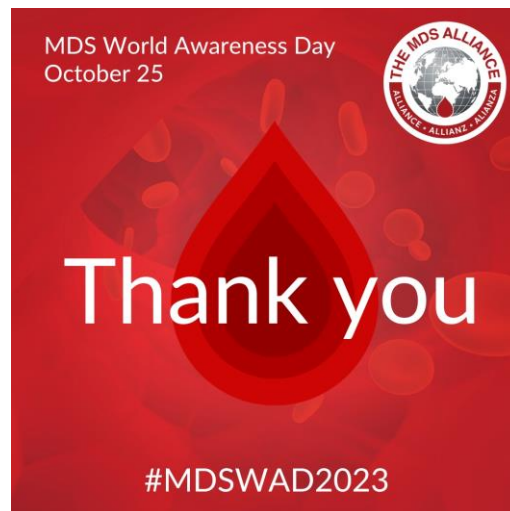
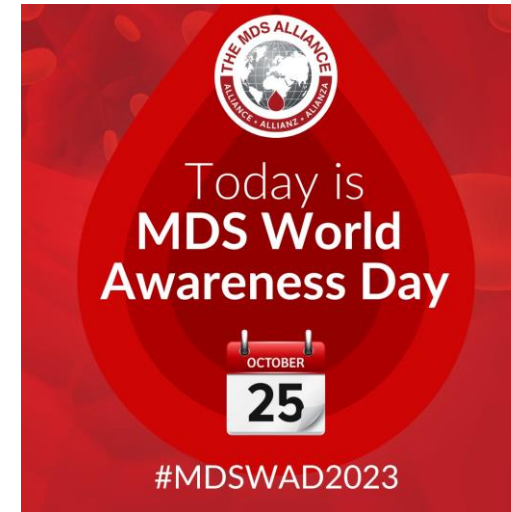
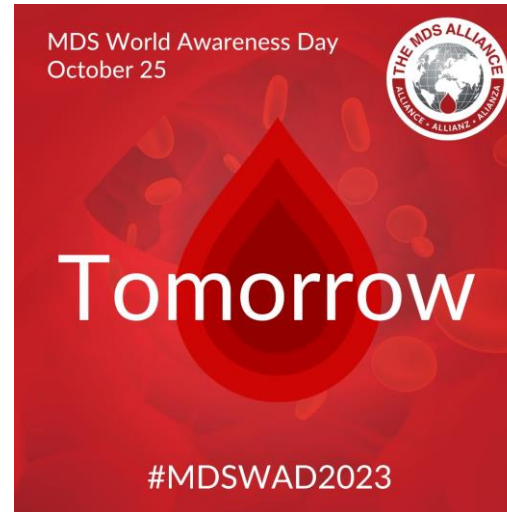
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Graphics for social media posts

Lead-up & Thank you



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Information posters

MDS World Awareness Day
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Does your partner
bruise easier
than normal?

Bruising easily is one of the signs of MDS - myelodysplastic syndromes, a group of rare blood cancers.

In MDS, low levels of healthy blood cells can result in:

- Excessive bruising following minor injuries
- Nosebleeds
- Gum bleeds
- Pinpoint-sized red spots under the skin



A healthcare provider can carry out a complete blood count to see if further action is required. So, if your partner bruises easier than normal don't let them ignore it. Tell them to visit a healthcare provider to get a blood count.



Get a #BloodCount

MDS World Awareness Day
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Is your loved
one more
fatigued
than normal?

Fatigue is one of the signs of MDS - myelodysplastic syndromes, a group of rare blood cancers most seen in adults over the age of 70.

Fatigue, caused by low red blood cell counts, can result in patients reporting:

- Excessive tiredness
- Lack of energy
- Muscle weakness



These symptoms can be mistaken for general signs of ageing. A healthcare provider can carry out a complete blood count to see if further action is required. So, if your loved one reports feeling tired all the time and lacking in energy, don't let them put it down to ageing. Tell them to visit a healthcare provider to get a blood count.



Get a #BloodCount

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Is a family
member more
breathless
than usual?

Feeling breathless after little exertion is one of the signs of MDS - myelodysplastic syndromes, a group of rare blood cancers. In MDS, breathlessness is typically coupled with other signs of low red blood cell counts (anaemia), including:

- Excessive tiredness
- Dizziness
- Pale skin



These symptoms are generally common in older people, but they may be caused by MDS. A healthcare provider can carry out a complete blood count to see if further action is required. So, if your family member is regularly feeling breathless, don't let them put it down to ageing. Tell them to visit a healthcare provider to get a blood count.



Get a #BloodCount

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Does your
loved one
feel weaker
than usual?


Having too few red blood cells can lead to feeling tired, dizzy or weak. Muscle weakness is one of the signs of MDS, a group of rare blood cancers.

If you notice:

- Things are heavier than normal?
- Walking is harder than usual?
- A general lack of energy?



A healthcare provider can carry out a complete blood count to see if further action is required. So, if your loved one feels weaker than usual, don't let them ignore it. Tell them to visit a healthcare provider to get a blood count.

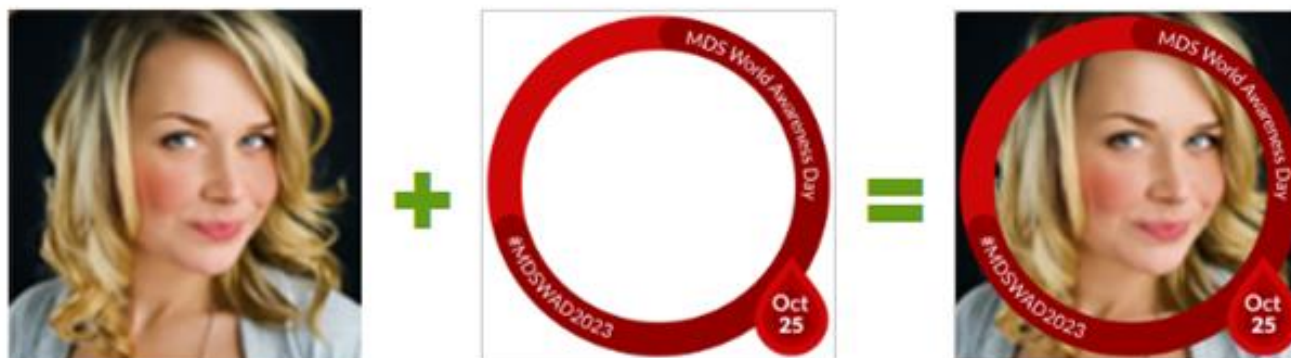


Get a #BloodCount

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MDS WAD Twibbon

Support this campaign by adding to your profile picture



Access the MDS WAD Twibbon campaign [here!](#)

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How can YOU get involved?



We encourage you to **get involved** and support the campaign on behalf of MDS patients globally!

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

Customisation

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 **#MDSWAD2023** and tag **@MDSAlliance**



Read and share the posters on your social channels with the hashtag **#MDSWAD2023**



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

Download all MDS WAD materials [here](#).

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Thank you to our sponsors



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Get in touch

If you would like more information or support from the MDS Alliance please contact the secretariat at:

secretariat@mds-alliance.org

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