Myelodysplastic syndromes (MDS)

Myelodysplastic syndromes (MDS) are diseases of the bone marrow. MDS is characterised by abnormal, immature blood cells that do not work properly. MDS is a type of cancer, but it is sometimes also called ‘bone marrow failure’. Here, we cover what MDS is, how it’s diagnosed, and what treatment you might have.

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About MDS

Myelodysplastic syndromes (MDS) are diseases of the bone marrow. MDS is characterised by abnormal, immature blood cells that do not work properly. MDS is a type of cancer, but it is sometimes also called ‘bone marrow failure’. There are several types of MDS.

The bone marrow is the spongy substance in the centre of some of your bones. It makes three main types of blood cells:

1. Red blood cells that carry oxygen around the body
2. White blood cells that fight infections
3. Platelets that prevent bleeding

If you have MDS, your bone marrow does not work properly and your levels of one or more types of blood cell will be low.

MDS is rare. The average age of people with MDS is 75. About 9 out of 10 people with MDS are diagnosed when they are over 50, but it can occasionally affect younger people.

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Cause of MDS

We do not know exactly what causes MDS. Scientists are trying to understand why it occurs and in whom. MDS is not infectious. It is important to know that getting MDS is not because of anything you have done.

- Scientists have found several gene changes in people with MDS. We do not know how these might lead to MDS. Some of the gene changes can be inherited. These gene changes do not pass on MDS directly but they can increase your chance of getting it in the future.
- MDS could possibly be related to having chemotherapy or radiotherapy in the past.

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Signs and symptoms of MDS

Some people with MDS have no signs or symptoms, and diagnosis occurs by chance because of a routine blood test.

Symptoms and signs of MDS depend on which blood cells are low:

- **A low red blood cell count** is called anaemia. About 8 out of 10 people with MDS have anaemia. It leads to fatigue and shortness of breath.
- **A low platelet count** can cause you to bruise or bleed more easily than usual. You may have a rash on your skin, unusual bruises, or bleeding from your nose or gums.
- **A low white blood cell count** means your body cannot fight infections as well as usual. You might get frequent infections, or infections that last a long time.

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Diagnosis of MDS

Your haematology team will carry out the following tests to diagnose MDS:

- Full blood count: This will show low blood cell counts because your bone marrow is not working as it should.
- Bone marrow test: This will confirm your diagnosis and help check how you are responding to treatment. It involves taking a sample of the spongy tissue from the

centre of one of your larger bones, usually your hip bone, under a local anaesthetic.
- Chromosome analysis and identification of gene mutations: This looks for genetic changes in your MDS cells. It uses a blood or bone marrow sample.

These tests help your haematology team work out which subtype of MDS you have. It also helps them choose the most suitable treatment for you.

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Treatment of MDS

Treatment of MDS can vary from person to person even with the same subtype of MDS. Your haematology team will recommend the most appropriate treatment based on:

- Your type of MDS
- Your preferences
- Your age
- Your general wellbeing or fitness
- Your chance of progressing to acute myeloid leukaemia (a faster-growing type of blood cancer)

Treatment options include:

Active monitoring (watch and wait)

Not all patients have MDS symptoms that need active treatment. If you are not having treatment, you will have regular check-ups. This is known as active monitoring or watch and wait.

Supportive care

You can benefit from supportive care at any time during your treatment. It involves any medication or medical care to improve your quality of life, rather than treat your MDS. Supportive care includes blood transfusions, growth factors (medicines to boost your blood cell counts), and medicines to prevent or treat infections. It helps control your symptoms of MDS.

Non-intensive treatment

Non-intensive treatment attempts to slow down the progression of your MDS and improve your blood counts. It includes medicines such as azacitidine and lenalidomide.

Intensive treatment

Intensive treatment aims to kill as many MDS cells as possible. It may be chemotherapy or an immunosuppressant such as azathioprine. Intensive treatment may also involve high doses of chemotherapy to prepare your bone marrow for a transplant.

Stem cell transplant

A stem cell transplant replaces your abnormal bone marrow cells with healthy stem cells, usually from a donor. It might be an option for you if you have a matched donor. However, it is a very intensive type of treatment and you have to be fit enough to cope with it.

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If your first treatment is not successful

If your treatment is not successful, your MDS may be described as refractory or relapsed.

- **Refractory MDS** is when MDS does not respond to treatment or comes back within 6 months of treatment.
- **Relapsed MDS** is when MDS comes back in people who responded to treatment for more than 6 months.

If you have relapsed or refractory MDS, your haematology team will talk to you about your treatment options.

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Prognosis of MDS

Prognosis describes the expected outcome and survival in people with a condition.

The prognosis for MDS varies according to your:

- MDS subtype
- Genetic changes

- Age
- General fitness

People with MDS have an increased chance of getting acute myeloid leukaemia (AML) over time. The chance of getting AML depends on your type of MDS. We have separate information on AML.

Your haematology team are best placed to talk to you about what they expect in your case because they know your individual circumstances.

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

Helpline and WhatsApp →

Help us improve our information

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