Myelodysplastic/ myeloproliferative neoplasms (MDS/MPNs)

Myelodysplastic/myeloproliferative neoplasms (MDS/MPNs) are rare types of blood cancer. Find out about the signs and symptoms of MDS/MPNs, tests to diagnose them and treatments you might have.

This information is about the rarer types of MDS/MPNs. We have separate information about chronic myelomonocytic leukaemia (CMML), which is the most common type of MDS/MPN.

Summary

- MDS/MPNs are rare types of blood cancer. There are four main types, which all behave differently.
- We do not know the exact cause of MDS/MPNs. It is not because of anything you have or have not done.
- They are diagnosed using blood tests and bone marrow tests.
- Treatment usually aims to control your condition and manage your symptoms. You might have:
    - Treatment as part of a clinical trial
    - Medicines to lower your blood cell counts
    - Treatment for anaemia
    - Medicines to prevent blood clots
    - Targeted medicines
    - A stem cell transplant
    - Supportive care
- Outcomes for MDS/MPNs vary from person to person. Your consultant is the best person to advise you on what they expect for you.
- **We are here for you if you need support.**

Download our factsheet about MDS/MPNs

What are MDS/MPNs?

Myelodysplastic/myeloproliferative neoplasms (MDS/MPNs) are rare types of blood cancer. They happen when cells in your bone marrow grow out of control and make:

- Too many of some types of blood cells
- Not enough of other types of blood cells
- Some abnormal blood cells that do not work properly

They get their name because they have features that overlap two more common groups of blood cancer:

- Myelodysplastic syndromes (MDS), where your bone marrow makes abnormal, immature blood cells. ‘Myelo’ means it’s to do with your bone marrow. ‘Dysplastic’ means it involves abnormal cell development.
- Myeloproliferative neoplasms (MPNs), where your bone marrow makes too many blood cells. ‘Myelo’ means it’s to do with your bone marrow. ‘Proliferative’ means growing or dividing quickly. ‘Neoplasm’ is a build up of cells that happens when they grow out of control.

You might also hear people call them MDS/MPN overlap syndromes or MDS/MPN crossovers.

There are different types of MDS/MPN. They can affect different blood cells.

More about blood cells

Blood cells grow and develop in the spongy centre of some of your larger bones. This is called bone marrow.

There are three main types of blood cell:

- Red blood cells carry oxygen around your body.
- White blood cells fight infections.
- Platelets help your blood clot.

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Types of MDS/MPN

There are different types of MDS/MPN, which affect different types of blood cells and behave differently. Their names are based on the main blood cells affected and the genetic changes in the cancer cells.

The main types are:

- **Chronic myelomonocytic leukaemia (CMML)**. This is the most common type. We have separate information about CMML.
- **MDS/MPN with neutrophilia**. This is where the main cells that grow out of control are neutrophils. Neutrophils are white blood cells that usually help fight infections. This form of MDS/MPN used to be called atypical chronic myeloid leukaemia (CML). But scientists now know that it is not related to CML and needs different treatment.
- **MDS/MPN with *SF3B1* mutation and thrombocytosis**. This is where the main cells that grow out of control are thrombocytes, or platelets. Platelets usually help your blood clot. The '*SF3B1*' part is named after a genetic change in the cancer cells that affects red blood cell production. This means you also do not make enough red blood cells, and the ones you make do not work properly. Another name for this condition is MDS/MPN with ring sideroblasts and thrombocytosis. This is named after the way some of the red blood cells look under a microscope.
- **MDS/MPN not otherwise specified**. This is the name for types of MDS/MPN that do not fit into any of the other categories.

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Who gets MDS/MPNs?

In the UK, around 900 people are diagnosed with an MDS/MPN each year. About 650 of these have CMML. The other types are very rare.

MDS/MPNs usually affect people over 65. They are slightly more common in men than women.

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What causes MDS/MPNs?

We do not know the exact cause of MDS/MPNs. It is not because of anything you have or have not done.

People with MDS/MPNs develop genetic changes in bone marrow cells called stem cells. Stem cells usually make all the blood cells your body needs. The genetic changes mean they don't work properly.

Most of these changes happen by chance during your lifetime, generally as you get older. You did not get them from your parents and you cannot pass them to any children you have. In most cases we do not know why these genetic changes occur.

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Signs and symptoms of MDS/MPNs

Depending on the type of MDS/MPN you have, you might have:

- Low levels of red blood cells
- Low levels of white blood cells
- High levels of white blood cells
- Low levels of platelets
- High levels of platelets
- A swollen spleen or liver

These can cause different symptoms. You might get some of these symptoms but not others:

Feeling exhausted for no reason.

Feeling out of breath easily.

Bruising easily.

Bleeding when you wouldn’t usually, like bleeding gums or nosebleeds.

Infections that last a long time or keep coming back.

Feeling full quickly when you eat.

Tummy pain or bloating.

Fever.

Losing weight without trying to.

Skin problems, like a rash, or red patches or bumps on your skin. On black or brown skin, these can be harder to see and might look purple, red or darker.

Itching.

Bone pain.

Blood clots. These most commonly happen in your leg, which can cause pain, swelling and redness. In black or brown skin, this can be harder to see but it might look darker or discoloured.

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Diagnosis of MDS/MPNs

You'll have blood tests and bone marrow tests to diagnose MDS/MPNs. The samples go to the lab for specialist testing.

It can be difficult waiting for tests and test results. Our Helpline is here for you if you need support.

Blood tests

You will have blood tests to:

- Measure your numbers of red blood cells, white blood cells and platelets. This is done using a standard blood test called a full blood count. If you have an MDS/MPN, you'll have high levels of some blood cells and low levels of others. The cells that are affected help your medical team work out what type of MDS/MPN you have.
- See how your blood cells look under a microscope. Abnormal cells look different from healthy cells.
- Check your clotting.
- Check how well your liver and kidneys are working
- Measure the levels of some chemicals in your blood

Bone marrow tests

If your haematology team think you might have MDS/MPN, they may do a bone marrow test to confirm it. It's also called a bone marrow biopsy or bone marrow aspiration.

It involves taking a sample of your bone marrow, usually from the back of your pelvis, with a local anaesthetic. Some people may have a sedative too.

Lab tests

Your doctor will send your samples to the lab for specialist tests. These look for changes in the genes or chromosomes of cancer cells.

The results can rule out other blood cancers and help your doctor work out the type of MDS/MPN you have. They can also help them decide on the most suitable treatment for you.

Other tests you might have

You might have an ultrasound or CT scan to check for a swollen spleen or liver. Depending on your symptoms, you might have other tests or scans.

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Treatment for MDS/MPNs

This section does not cover treatment for CMML. We have separate information about CMML.

Because MDS/MPNs are rare, it is difficult for researchers to carry out trials to work out the best treatment for them. So, at the moment, most approaches are based on treatments that work for MDS or MPNs.

Treatment usually aims to control your condition and manage your symptoms. Most treatments do not cure it.

Your haematology team will recommend the most suitable option for you. They will base this on many factors, including:

- Your symptoms and blood test results
- Your overall fitness
- Any other medical conditions you have
- Your preference on how you wish to be treated

They will explain what they recommend and what you can expect from it. This might include:

Treatment as part of a clinical trial

Your haematology team may ask if you'd like to take part in a clinical trial, if there is one suitable for you. This is where new treatments, or different ways of using existing treatments, are tested to find out if they are better than standard treatments. For example, a clinical trial might test a treatment already used in another blood cancer, to find out if it works well in people with MDS/MPNs.

If there is a clinical trial suitable for you, your team should explain what it involves and the risks and benefits of it. It is your choice whether to take part.

Medicines to lower blood cell counts

If you have a high level of white blood cells or platelets, you might have medicine to lower it. This can also help shrink your spleen, if it is swollen.

The most common options are:

- Chemotherapy medicines such as hydroxycarbamide capsules. This is less intensive than many other types of chemotherapy. You do not usually have to stay in hospital to have it.
- A medicine called peginterferon-alfa-2a. This might sometimes be used to lower platelet levels in people with MDS/MPN with SF3B1 mutation and thrombocytosis. You have it as an injection under your skin, usually in your tummy, thigh or upper arm. Your team might teach you how to do it yourself at home.

Your doctor might suggest a different medicine to help lower your blood counts. They will tell you what they recommend and how you have it.

If you also have anaemia, medicines that lower your blood cell counts can make it worse. Your medical team will try to balance the need to treat anaemia against the risk of high blood cell counts.

Treatment for anaemia

Anaemia means your red blood cell count is too low. If you have it, your doctor might recommend:

- Blood transfusions, where you have donated blood through a drip into a vein.
- Injections of a medicine called EPO, which stimulates your body to make red blood cells.
- Injections of a medicine called luspatercept, which encourages immature blood cells to develop into healthy red blood cells. Luspatercept is not available on the NHS.

Medicines to prevent blood clots

If you have a high level of platelets, you are at risk of getting blood clots. These can be serious. You may need treatment to prevent them.

This might include:

- Medicines to lower your blood cell counts (see above)
- An antiplatelet medicine like low-dose aspirin or clopidogrel, to help thin your blood

Targeted medicines

Rarely, depending on the genetic changes in your cancer cells, your doctor might recommend a targeted medicine. This is a treatment designed to block a specific protein in your cancer cells.

Targeted medicines they might suggest include:

- Ruxolitinib
- Venetoclax

These come as tablets that you take at home. They are not approved to treat MDS/MPNs, but your medical team might use them off-label. This is when a doctor prescribes a medicine that's approved for one condition to treat a different condition.

A stem cell transplant

If your MDS/MPN is aggressive or does not respond well to other treatments, your haematology team might suggest a stem cell transplant.

Stem cell transplants have the potential to cure MDS/MPNs, but they are very intensive. They are only suitable for people young and fit enough to have them, so may not be an option for most people with MDS/MPNs.

Your haematology team will let you know if a stem cell transplant is an option for you. They will discuss it with you and answer any questions you have.

Supportive care

Supportive care is treatment to help with the effects of MDS/MPNs. It does not treat the cancer directly, but it aims to help you feel better and improve your quality of life.

Supportive care is used alongside other treatments for MDS/MPNs. It might include:

- Medicines to relieve symptoms
- Medicines to prevent or treat infections
- Medicines to prevent or treat side effects
- Psychological support
- Support from a dietician or nutritionist
- Support with exercise or physiotherapy
- Social support

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Outcomes of MDS/MPNs

Outcomes for MDS/MPNs vary from person to person. They depend on many different factors, such as:

- The exact type of MDS/MPN you have
- The genetic changes in your cancer cells
- Your age
- Your blood test results

> **Your consultant is the best person to advise you on what they expect for you. They can take account of your individual circumstances and test results.**

We have separate information on overall outcomes for people with MDS/MPNs, if you want to know this. Remember that these are averages. They cannot tell you what will happen to you.

Transformation of MDS/MPNs

Sometimes MDS/MPNs can develop into a faster-growing blood cancer called acute myeloid leukaemia (AML). The medical term for this is transformation.

The risk of MDS/MPN transforming varies from person to person. It also depends on the type of MDS/MPN you have and the genetic changes in your cancer cells.

- In general, transformation happens in up to 4 in every 10 people with MDS/MPN within 5 years of diagnosis. So it does not happen to more than 6 in every 10 people.
- Transformation is less common in people who have MDS/MPN with SF3B1 mutation and thrombocytosis.

There is a lot of overlap between symptoms of MDS/MPN and symptoms of AML. If your condition transforms, symptoms you are already experiencing might get worse.

Your haematology team will regularly check you for signs and symptoms of transformation. If it happens, you will need treatment for AML.

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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 →

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