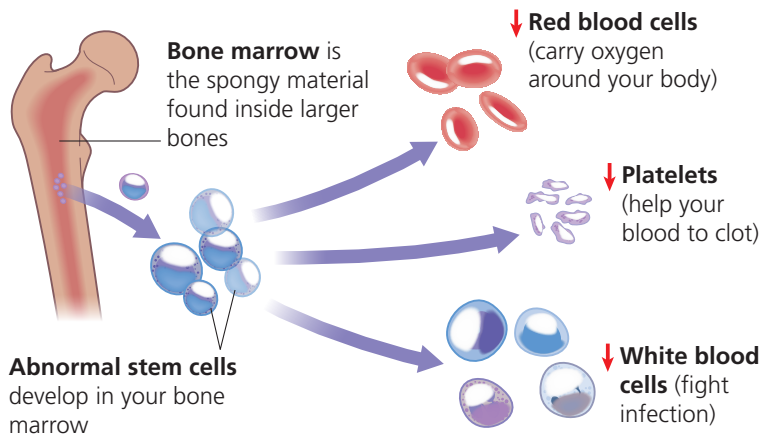


# What is myelodysplastic syndrome?

Myelodysplastic syndrome (MDS) is a rare blood condition. It is most often diagnosed in people over 65 and more often in men than women. There are several different types of MDS, affecting one or more of the different types of blood cell. MDS can sometimes run in families but most people don't have a family history.

MDS can be **primary** or **secondary**. Most people have primary MDS, which means there is no obvious cause. Secondary MDS develops as a result of previous chemotherapy or radiotherapy.

## Blood cells are made in the bone marrow



'Myelo' means bone marrow and 'dysplastic' means abnormal growth. So MDS means there are abnormal blood cells developing in your bone marrow. These don't work as well as they should and don't live for long in your circulation. So you may have:

- **Too few red blood cells**
- **Too few platelets**
- **Too few white blood cells**

The type of blood cells affected depends on the type of MDS you have. There are around seven different types.



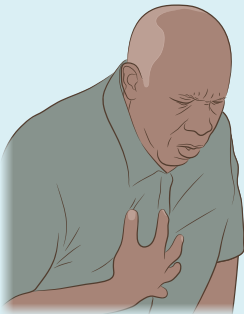
**Ask your doctor**

My MDS is .....

## How will MDS affect me?

Some people don't have any symptoms. For others, having too few normal blood cells may cause...

**Anemia**, which can make you feel tired and breathless. This is the most common symptom.

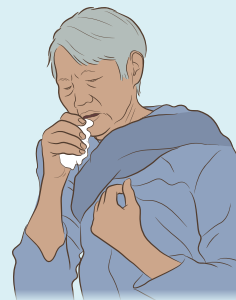


↓ Red blood cells

**Fatigue**. You may feel extremely tired, even if you are not anemic.



**More frequent infections** or infections that are difficult to shift, resulting in fever, cough or headache.



↓ White blood cells

**Abnormal bleeding**, such as nose bleeds, bleeding gums, bruising or a skin rash of red blood spots called petechiae.



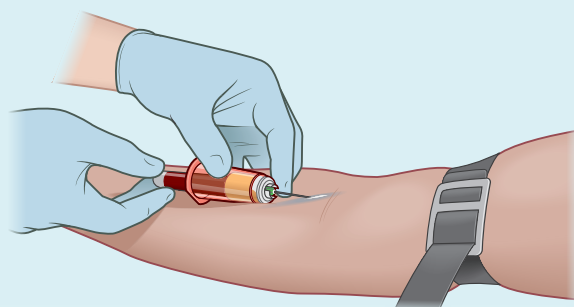
↓ Platelets

## Transformation to leukemia

In some people, MDS can transform into leukemia. The risk of transformation varies depending on the type of MDS you have. It is best to discuss this with your doctor.

## What tests will I need to have?

After you are diagnosed, you will need...



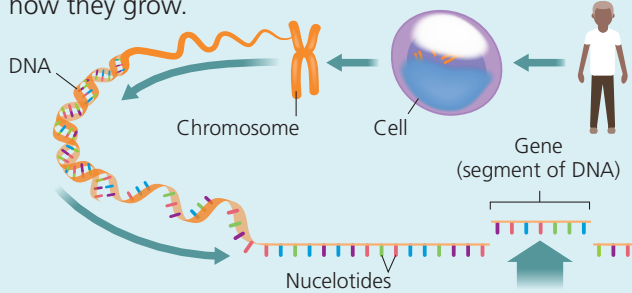
**Regular blood tests** to measure your blood cell counts. People with no symptoms may be diagnosed by chance after a routine blood test.

# What treatment will I need to have?

Your treatment will depend on the type of MDS you have and the results of gene tests on the MDS cells. It may also depend on your age and general health and fitness.

## Genes and MDS

MDS happens because of changes to chromosomes or changes in genes within chromosomes. Your genes are the instruction manual for everything your cells do and how they grow.

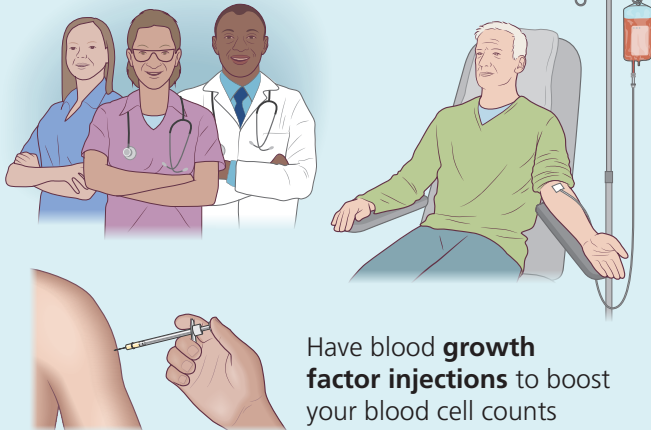


Your doctors will send some of your MDS cells for gene testing. This is called molecular profiling. It can show the type of MDS you have, the treatment you need, and whether your MDS is likely to be controlled with treatment or develop into acute myeloid leukemia.

## If you have lower-risk MDS, you may...

Be **monitored** by your doctors if you have no symptoms

Have **transfusions** to top up red blood cells and platelets to treat symptoms



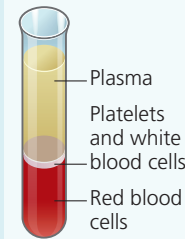
Have blood **growth factor injections** to boost your blood cell counts

## Questions to ask your doctor(s)

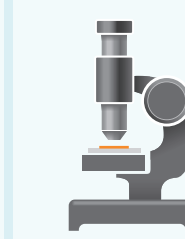
- What type of MDS do I have? Is it low or high risk?
- Have you done gene testing on the MDS cells?
- How does this affect the type of treatment I need?
- What is the aim of my treatment?
- What are the possible short- and long-term side effects of my treatment?
- How will you know if the treatment is working?
- Will I be in hospital for treatment?
- How long will I need to have treatment for?

## Your MDS score

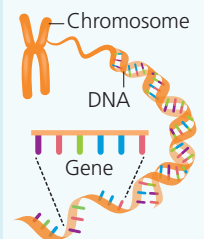
Your doctors will use an internationally agreed **prognostic scoring system** to find out how your MDS is likely to behave. The scoring system looks at:



Your blood cell count when you were diagnosed



What your bone marrow cells look like under a microscope



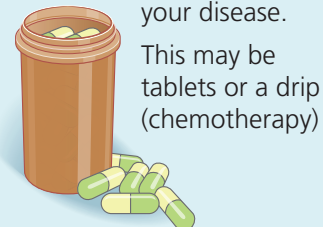
The results of gene tests on your MDS cells



Your **prognostic score** may be anything from very low risk to very high risk. If you have high-risk MDS, there is an increased chance you could develop acute myeloid leukemia, so it is treated more intensively than moderate- or low-risk MDS.

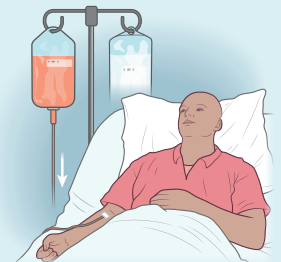
## If you have higher-risk MDS, you may need...

**Treatment** to control your disease.



This may be tablets or a drip (chemotherapy)

**Donor stem cells**



Chemotherapy followed by a stem cell transplant to try to cure MDS and lower the risk of future leukemia

**Treatment side effects** depend on the treatment you're having.

- Allergic reactions to transfusions or growth factor injections
- Aches and pains
- Sickness, diarrhea or constipation
- Fatigue
- Increased risk of infection
- Abnormal bruising or bleeding
- Hair loss

Your healthcare team can give you medications to help with many of these.