CONDITION

Myelodysplastic syndrome

Myelodysplastic syndrome is a bone marrow condition that causes too few healthy blood cells.

WHAT IT IS
Bone marrow cancer causing abnormal, insufficient blood cells

BODY SYSTEM
Blood and bone marrow

MAIN SYMPTOMS
Fatigue, breathlessness, infections, easy bruising or bleeding

WHAT CAUSES IT
Acquired stem-cell DNA changes, sometimes after cancer treatment

HOW IT IS DIAGNOSED
Blood counts, bone marrow biopsy, chromosome and gene tests

MAIN TREATMENT
Monitoring, supportive care, medicines, or stem cell transplant

CAN IT BE CURED?
Sometimes - donor transplant can eradicate it

IS IT AN EMERGENCY?
Sometimes - fever, severe breathlessness, or uncontrolled bleeding

LONG-TERM OUTLOOK
Often manageable for years; higher-risk types can progress quickly

Overview

Myelodysplastic syndrome, usually called MDS, is a group of related conditions affecting the bone marrow. Bone marrow is the soft tissue inside certain bones where blood cells are made.

In MDS, a blood-forming stem cell develops abnormal DNA changes. It then produces blood cells that may not mature normally or survive for long enough. This can leave you with low numbers of healthy red blood cells, white blood cells, or platelets. These low counts are called cytopenias .

Red blood cells carry oxygen. White blood cells help fight infection. Platelets help blood clot after an injury. The effects of MDS therefore depend partly on which types of blood cell are low.

MDS is classed as a blood cancer because the abnormal cells grow from a changed group, or clone, of bone marrow cells. It is not contagious. It is also not the same as acute myeloid leukemia, or AML, although some forms of MDS can develop into AML.

There are several MDS subtypes. Some remain stable for years and mainly cause anemia, meaning too few red blood cells. Others affect several blood cell types or have a greater chance of progressing. Test results help the care team describe MDS as lower or higher risk and plan treatment.

Symptoms

MDS sometimes causes no symptoms at first. It may be found when a blood test done for another reason shows low blood cell counts.

Too few red blood cells can reduce the amount of oxygen reaching your tissues. Possible symptoms include:

Too few infection-fighting white blood cells, especially cells called neutrophils, may lead to frequent, severe, or slow-to-clear infections. Fever, chills, mouth ulcers, or a persistent cough can be signs of infection.

Too few platelets may cause easy bruising, frequent nosebleeds, bleeding gums, tiny red or purple skin spots, or bleeding that takes longer to stop. Some people notice heavier menstrual bleeding.

These symptoms have many possible causes and do not confirm MDS. Blood tests are needed to find out what is happening.

- Tiredness, weakness, dizziness, or headaches
- Breathlessness, especially during activity
- Pale skin or a noticeable heartbeat
- Chest discomfort in people with heart or lung conditions

Causes and risk factors

MDS develops when blood-forming stem cells acquire DNA changes. These changes alter how the cells grow and mature. In most people, it is not possible to identify one specific reason why this happened.

The likelihood of MDS rises with age. Other factors linked with a higher risk include:

MDS that appears after chemotherapy or radiation is called therapy-related MDS . It may occur years after the original cancer treatment. This does not mean the earlier treatment was inappropriate; those treatments may have been essential.

Most MDS is not inherited and cannot be passed to children. A small minority is linked to an inherited gene change. Genetic counseling may be considered when MDS develops unusually early, runs in a family, or occurs with other suggestive health problems.

- Previous chemotherapy or radiation treatment
- Long-term or substantial exposure to benzene or certain industrial chemicals
- Tobacco smoking
- Rare inherited conditions that affect bone marrow or DNA repair

Diagnosis

A complete blood count , or CBC, measures red blood cells, white blood cells, platelets, and hemoglobin. Hemoglobin is the oxygen-carrying protein in red blood cells. A blood smear allows the cells to be examined under a microscope.

Low counts alone do not confirm MDS. Nutritional deficiencies, medicines, alcohol, infections, autoimmune conditions, and kidney or liver problems can produce similar results. Tests may be used to check for these causes.

Confirming MDS usually requires a bone marrow aspiration and biopsy. During this procedure, a clinician takes liquid marrow and a small core of bone, most often from the back of the hip. Local anesthetic numbs the area, although pressure or brief pain can still occur.

Specialists examine the sample for:

Chromosome testing is called cytogenetic testing . Molecular testing looks for specific gene changes. These results can identify the MDS subtype, guide treatment, and help estimate its likely behavior.

Risk tools such as the Revised International Prognostic Scoring System or Molecular International Prognostic Scoring System combine blood counts, blast levels, chromosome findings, and sometimes gene changes. A risk group is a planning tool, not an exact prediction of what will happen to one person.

- Abnormally shaped or immature blood cells
- The percentage of very immature cells, called blasts
- Changes in the number or structure of chromosomes

- Gene mutations associated with MDS
- Other bone marrow conditions that could explain the results

Treatment and management

Treatment is based on the MDS subtype and risk group, the blood counts and symptoms, other health conditions, age, and personal priorities. A blood cancer specialist called a hematologist usually coordinates care.

If MDS is lower risk and is not causing significant symptoms, active monitoring may be appropriate. This means regular blood tests and appointments rather than starting treatment immediately. Treatment can be reconsidered if counts fall, symptoms develop, or the MDS changes.

Supportive care treats the effects of low blood counts. It may include red blood cell transfusions for anemia, platelet transfusions for bleeding or very low platelet counts, and prompt treatment of infections. People receiving many red blood cell transfusions can build up excess iron. Selected people may be offered treatment to remove some of this iron.

Growth-factor medicines can encourage bone marrow to make particular blood cells. Erythropoiesis-stimulating agents may improve anemia in some lower-risk cases. Other medicines, including luspatercept, may be considered for certain forms of transfusion-dependent anemia. White blood cell growth factors are used in selected situations rather than for everyone.

Treatment may also target the abnormal marrow cells:

An allogeneic stem cell transplant replaces abnormal marrow with blood-forming stem cells from a donor. It is the only treatment with the potential to cure MDS, but it can cause serious complications and MDS can still return. Suitability depends on more than age alone. Overall health, MDS risk, donor availability, and your preferences all matter.

- Azacitidine or decitabine can slow abnormal cell growth and improve blood counts in some people
- Lenalidomide can be particularly helpful for eligible people with a chromosome change called deletion 5q
- Immunosuppressive treatment may help a small, carefully selected group
- Intensive chemotherapy may be used for some higher-risk cases
- Clinical trials may provide access to treatments being studied

Complications

Anemia can limit activity and place extra strain on the heart, particularly when it is severe or when heart disease is already present. Low white blood cell counts increase the chance that infections will become serious. Low platelets can lead to significant bleeding.

Repeated transfusions can cause iron overload or, less often, transfusion reactions. Treatments may also temporarily lower blood counts before improvement occurs.

Some MDS progresses to acute myeloid leukemia. This is more likely with certain chromosome or gene changes and a higher proportion of blasts. Many people with lower-risk MDS do not develop leukemia.

Prevention

Most cases of MDS cannot be prevented because the DNA changes usually arise without a clear avoidable cause. Inherited susceptibility also cannot be prevented.

Not smoking and following workplace protections around benzene and other hazardous chemicals may reduce avoidable exposure, but these steps cannot guarantee prevention. The possibility of therapy-related MDS is considered when cancer treatment is planned, but necessary chemotherapy or radiation should not be stopped or avoided without discussing the benefits and risks with the cancer team.

There is no screening test recommended for the general population. People with known inherited bone marrow conditions may be offered planned monitoring.

Living with it and what to expect

The course of MDS differs widely. Some lower-risk forms change little over several years. Others gradually cause more fatigue, infections, bleeding, or need for transfusions. Higher-risk forms can worsen more quickly or progress to AML.

Follow-up commonly includes blood counts, symptom reviews, and checks for treatment side effects. A repeat bone marrow biopsy may be needed if blood counts change unexpectedly, blasts appear in the blood, or a treatment decision requires updated information.

Treatment goals can also change. Early care may focus on reducing symptoms and transfusions. If MDS becomes more active, disease-modifying treatment or transplant may be considered.

Many people continue work, exercise, travel, and family activities, although plans may need to account for fatigue, appointments, or infection risk. Gentle, regular activity can help maintain strength if it feels safe. Balance activity with rest rather than pushing through severe fatigue.

Tell the care team about emotional strain, financial concerns, or problems managing appointments and transfusions. Support from specialist nurses, counselors, social workers, and patient groups can be useful over the months or years of care.

When to get medical help

Contact your usual care team for routine advice if fatigue, bruising, breathlessness, or infection frequency is gradually increasing. Also report new medication side effects or symptoms that interfere with daily activities. These changes may mean blood counts should be checked sooner.

Seek urgent same-day medical advice for:

Follow any fever or infection plan provided by your hematology team. Infection can become serious quickly when white blood cell counts are very low.

Call emergency services for severe trouble breathing, chest pain, fainting, confusion, signs of a stroke, or heavy uncontrolled bleeding. These symptoms require emergency assessment whether or not MDS is the cause.

- Fever, chills, or feeling suddenly unwell, especially with low neutrophils
- New shortness of breath at rest
- Bleeding that is difficult to stop
- Black stools, blood in urine, or vomiting blood
- A rapidly spreading rash of red or purple spots

Common questions

Is MDS the same as leukemia?

No. MDS and leukemia are related bone marrow cancers, but they are not the same condition. In MDS, abnormal blood formation and low counts are central features. Some MDS can progress to acute myeloid leukemia, while many lower-risk cases never do.

Can MDS be cured?

Sometimes. A donor stem cell transplant offers the only established possibility of cure. It is not

suitable for everyone because it carries substantial risks, and relapse can still occur. Other treatments aim to control MDS, improve blood counts, reduce symptoms, and delay progression.

How quickly does MDS progress?

There is no single timeline. Some lower-risk forms remain stable for years, while higher-risk forms may change over months. Blood counts, blast percentage, chromosomes, gene changes, and response to treatment provide more useful information than the name MDS alone.

Is MDS always terminal?

No. The outlook ranges from long-term, manageable low blood counts to aggressive disease that shortens life. Risk test results and overall health help put the diagnosis into context, but they cannot predict an exact outcome for an individual.

Does MDS cause pain?

MDS itself does not usually cause ongoing pain. Anemia may cause headaches or chest discomfort, and infections can be painful. A bone marrow biopsy can cause temporary soreness. New or persistent pain should be assessed rather than assumed to be from MDS.

What does lower-risk MDS mean?

Lower risk means test findings suggest slower progression and a lower chance of developing AML in the near term. It does not mean there are no health effects. Anemia, infections, bleeding, or dependence on transfusions can still require treatment.

Sources

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