Myelodysplastic syndromes (MDS)

A Guide for Patients

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

A diagnosis of myelodysplastic syndromes (MDS) can be a shock, especially if you have never heard of it. We have written this booklet to help you understand more about MDS.

This booklet describes the various types of MDS, and how they are diagnosed and treated. We also include the expected outcome (prognosis) of the MDS subtypes, and how to cope with the emotional impact of MDS.

Your haematologist or clinical nurse specialist (CNS) will give you information or advice about your diagnosis.

In compiling this booklet (including previous editions) we are grateful to the following expert contributors:

- Dr Sally Killick, Consultant Haematologist
- Dr Dominic Culligan, Consultant Haematologist
- Philip Alexander, Counsellor and Cognitive Behaviour Psychotherapist
- Geke Ong and Janet Hayden, Clinical Nurse Specialists
- Professor David Bowen, Honorary Professor of Myeloid Leukaemia Studies and Consultant Haematologist at St James's Institute of Oncology
- Chris Dugmore and Claudia Richards, Patient Experts (MDS UK)

This booklet was also reviewed by patients reviewers, Peter Threader, Dave Jones and Alan Howarth.

We thank them all for their valuable contribution.

We have included several quotations from patients in this booklet to help you come to terms with your diagnosis. These quotations highlight the real experiences of MDS patients.

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Acknowledgements

MDS UK Patient Support Group and Leukaemia Care have collaborated in producing this booklet. There is no endorsement of any specific product or brand in the booklet. Names mentioned are for information only.

We acknowledge The Irish Cancer Society for allowing us to use information and images from their MDS booklet.

The Leukaemia & Lymphoma Northern Ireland charity have endorsed this booklet. It also funds research into the causes and cures of leukaemia, lymphoma and myeloma in Northern Ireland.

Throughout this booklet, you will see QR codes that will take you to webpages for further support. Open the camera app on your phone and hover it over the QR code to open the link (suitable for Android, iPhone 7 and above).

If you are not able to use QR codes and would like to be sent the relevant webpages as URLs, or you would like the list of references used for this booklet, please email **information@leukaemiacare.org.uk.**

In this booklet

Contributing charities

About Leukaemia Care

Leukaemia Care is the UK's leading leukaemia charity.

For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support. We are here for everyone affected by leukaemia and related blood cancer types – such as myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN). We believe in improving lives and being a force for change. To do this, we have to challenge the status quo and do things differently.

www.leukaemiacare.org.uk

About MDS UK

The MDS UK Patient Support Group (www.mdspatientsupport.org.uk) provides support and information for MDS and CMML patients, their families and caregivers through regular newsletters, dedicated website, chat forum, Facebook group, information leaflets and online patient meetings. Membership is free, join online via the website, or email membership@mdspatientsupport.org.uk, or call **020 7733 7558** during office hours.

For general, non-clinical advice please email info@mdspatientsupport.org.uk (please note, specific medical advice should be sought from your GP, Clinical Nurse Specialist or Haematology Department). MDS UK is the only UK-based support group solely dedicated to those with MDS and CMML.

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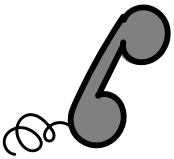
Our services



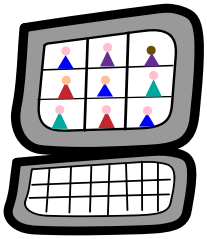
Helpline

Our helpline is available 9:00am - 5:00pm Monday - Friday. If you need someone to talk to, call **08088 010 444**.

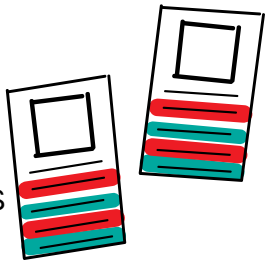
Alternatively, you can send a message via WhatsApp on **07500 068065** on weekdays 9:00am – 5:00pm.

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who have been affected by an MDS diagnosis. For more information about a support group local to your area, scan this QR code:



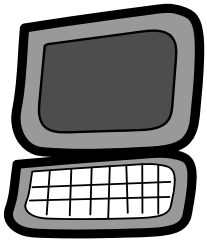
Buddy Support



We offer one-to-one phone support with volunteers who have had an MDS themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemiacare.org.uk**

Online Forum

Our HealthUnlocked online forum is a place for people to ask questions anonymously or to join in the discussion with other people affected by an MDS diagnosis. If you'd like to join, scan this QR code:



Webinars

Our webinars provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support. For information on upcoming webinars, scan this QR code:

Advocacy and Welfare

Our advocacy and welfare officers are here to help you find the support you need for many issues surrounding an MDS diagnosis. These include insurance, benefits and clinical trials. If you would like support from our advocacy or welfare officer, email **advocacy@leukaemiacare.org.uk** or call **08088 010 444**.

Patient magazine

Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe to our magazine, just scan this QR code:

Counselling Service

Our counselling service helps MDS patients and their loved ones access up to six sessions of counselling. To apply, scan this QR code:

Cost of Living Fund

This fund provides grants of up to £200 for essential living costs to patients and families affected by MDS. All applications must be made via the form which can be found by scanning this QR code:

Write a free will

Using our complimentary service, you can write a simple will so you know what happens to your estate when you die. Scan this QR code to start writing your free will today:

MDS Patient Pathway

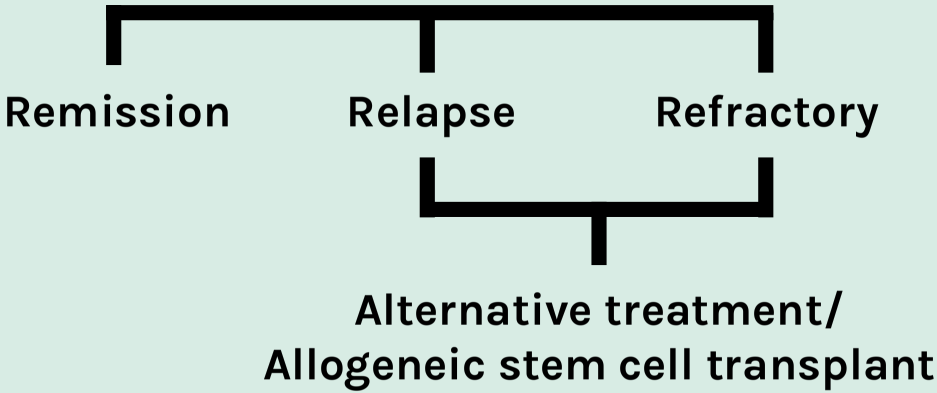
This flow chart represents the stages that an MDS patient might follow during the course of their illness. Each of the steps in this diagram are explained in the sections of the booklet.

1. Diagnosis

2. Active monitoring (minor or no symptoms)

3. Treatment

Front-line therapy
(increase in symptoms or new symptoms)



4. Living with MDS

5. Supportive care

6. End of life care

Patient story: Peter Threader

Peter was diagnosed with hypoplastic myelodysplasia (MDS) in early 2012, at the age of 63. On May 24th 2012, Peter received a stem cell transplant which saved his life. On the 11th year anniversary of his stem cell transplant, now 72, Peter tells his story.

Some 15 years ago I was diagnosed with haemochromatosis, an excess of iron in my blood. This was being managed at my local hospital in Stockport. Every three months I received a venesection: a quantity of blood was taken to help remove excess iron. Blood samples were tested after each visit but it wasn't until late 2011 that my platelet levels started dropping. This was closely monitored but the levels continued to drop and I eventually had a bone marrow biopsy. In February 2012, my local hospital confirmed I had bone marrow failure and I was referred within a week to the Christie Hospital in Manchester.

My wife and I realised this was probably something serious. We live only a few miles from the Christie Hospital. We knew it was the local cancer hospital and had friends who worked there. I didn't understand why I had no symptoms.

I was semi-retired, working as an assistant to a visually impaired criminal barrister. We had worked together for 10 years and I thoroughly enjoyed it. My wife and I have three grown up children all living away from home. We enjoyed a full and active social life, we went on holidays abroad and had frequent weekend breaks in the countryside.

All that was about to change. I had my first consultation at the Christie – further blood tests had confirmed lower levels of platelets and they had tested some bone marrow tissue. I was diagnosed with MDS, a blood disorder with bone marrow failure. I was told the condition was serious and there was only one cure: a stem cell transplant.

Within a few days I started the first of many platelet infusions. I was told the transfusions could only be maintained for a few months. I was advised to stop working and to stop all outside physical activities. The stem cell transplant process was fully explained to us, and a search would begin for a donor. We were warned that this was going to be a difficult few months ahead and that it could take 12 months for me to recover.

Within two weeks a donor with a perfect match had been found on the Anthony Nolan register. Preparations were made in earnest – there were more bone marrow biopsies, a heart check up as well as lung function and dental checks.

I was admitted to the haematology transplant unit on the 18th May 2012 ready to face at least a month in isolation. I stayed in an ensuite room with no open windows and with very strict hygiene rules for visitors which were limited to close family.

The first week was taken up with chemotherapy conditioning, a very intense treatment which got more unpleasant as the week progressed. I lost my appetite, was nauseous and had hair loss.

On transplant day, 24th May 2012, all went well. Two nursing staff sat with me whilst my donor cells were given through a transfusion. It was a painless process but at the same time an enormous event. My wife shared the experience with me. I had only been told my donor was a 25-year-old British male; he knew nothing about me but his generosity was about to save my life, an amazing thing for a stranger to do. I'm indebted to him and Anthony Nolan for their support.

Recovery for me was long and difficult. I suffered many infections and viruses and I was admitted back into hospital several times for treatment. Fatigue was a major problem for me but I had support and encouragement from my family and my transplant team. Together they all worked to get me better.

It did take me over a year to fully recover and return to normality, like being able to see and enjoy the company of my family and grandchildren and to resume holidays and outdoor activities such as walking.

Two years after my transplant I met my donor, a young man called David who lives in North Wales. It was my opportunity to thank him in person for saving my life. He was grateful to have had the opportunity to help me. We keep in touch and catch up when we can. The 24th of May marks our transplant anniversary and I tend to think of David a lot on this date.

Many people helped me get through the transplant process. I'm grateful to Leukaemia Care for their support; long before COVID-19 I joined their Manchester Haematology Support Group and attended the meetings at the Maggie's centre, Manchester. The meetings now continue both on Zoom and in-person and they are really interesting and informative, they also give you the opportunity to talk and share experiences with other members.

As Peter mentioned, receiving a diagnosis of something as rare as MDS and recovering from treatment can be difficult. Our buddy scheme offers one-to-one support and the opportunity to speak to someone in a similar situation to you. Email **support@leukaemiacare.org.uk** or call **08088 010 444** to find out more.

Glossary of medical terms

Acute Myeloid Leukaemia (AML)

AML is a cancer of the blood and bone marrow. It is characterised by an increase in the number of myeloid cells in the marrow that do not mature and interfere with the production of healthy blood cells.

Allogeneic stem cell transplant

A procedure where bone marrow stem cells are taken from a genetically matched donor and given to the patient through an intravenous line. The donor may be related or unrelated.

Anaemia

A medical condition in which the red blood cell (RBC) count is less than normal. For a normal blood result, RBC count should be approximately 4.0 to 5.9 $x10^{12}$/L (males) and 3.8 to 5.2 $x10^{12}$/L (females). The RBC count can vary slightly depending on your age, gender, health history and which laboratory is used. Your healthcare team should be able to interpret your test results for you.

Blast cell

An abnormal (dysplastic), immature blood cell found in the bone marrow or peripheral blood. As they are not mature, these cells are unable to fulfil their intended function. AML develops from these blast cells.

Blood transfusion

A procedure in which whole blood or one of its components is given to a person through an intravenous line into the bloodstream. A red blood cell transfusion or a platelet transfusion can help some patients with low blood counts.

Bone marrow

The soft blood-forming tissue that fills the cavities of bones and contains fat, immature and mature blood cells, including white blood cells, red blood cells, and platelets.

Chemotherapy

Therapy for cancer using chemicals that stop the growth of cells.

Clinical trial

A medical research study involving patients with the aim of improving treatments and their side effects. If you are eligible for a clinical trial you will always be asked for your consent before being enrolled.

Cytogenetics

The study of chromosomes (DNA), the part of the cell that contains genetic information. Some cytogenetic abnormalities are linked to different forms of MDS.

Fatigue

Extreme tiredness, which is not alleviated by sleep or rest. Fatigue can be acute and come on suddenly or it can be chronic and persistent.

Full blood count or FBC

A blood test that counts the number of different blood cells.

Genomics

The study of genes and their functions, which is increasingly important to refine the prognosis of the various subtypes of MDS. In future this information may also help to personalise MDS treatments.

Haemoglobin

A protein in the red blood cells. Haemoglobin picks up oxygen in the lungs and brings it to cells in all parts of the body. Normal haemoglobin counts are approximately 130 to 180g/L (males) and 115 to 165g/L (females).

Hickman line

Tunnelled central venous catheter placed under the skin for long term access (weeks to months). So called Hickman line after its trade name. It is suitable for patients who need numerous infusions of drugs, fluids, blood products, or total parenteral nutrition, as well routine blood sampling.

Measurable residual disease (previously minimal residual disease)

Presence of leukaemic cells below the threshold of detection when complete molecular remission has happened. It is important for treatment planning and prognosis.

Neutropenia

A condition in which the number of neutrophils (a type of white blood cell) in the bloodstream is decreased.

Neutrophil

A type of white blood cell that helps fight infection.

Platelet

A disc-shaped element in the blood that assists in blood clotting. During normal blood clotting, the platelets clump together (aggregate). Although platelets are often classed as blood cells, they are actually fragments of large bone marrow cells (megakaryocytes).

Platelet count

A normal platelet count in a healthy individual is between 150 to 450 $x10^9$/L of blood. In general, low platelet counts increase bleeding risks.

Red blood cell

A small blood cell that contains haemoglobin and carries oxygen and other substances to all the tissues of the body.

Refractory disease

MDS cells remain throughout treatment, or return within six months of treatment.

Relapse

MDS cells return in patients who have achieved remission for more than six months.

Response

A response occurs when a patient shows an improvement in clinical symptoms or on a predetermined response scale.

Response scale

Scale of level of responses defined prior to treatment in order to quantify the response.

Somatic mutations

Mutations that occur in any of the cells of the body except the reproductive cells (sperm and egg) and therefore are not passed on to children.

Stem cells

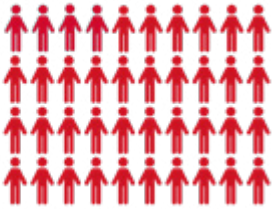
Cells that have the potential to develop into many different or specialised cell types.

White blood cell

One of the cells the body makes to help fight infections. There are several types of white blood cells. The two most common types are the lymphocytes and neutrophils. A normal white cell count is 4.0 to 11.0x10^9/L

Summary: What are myelodysplastic syndromes (MDS)?

- **Myelodysplastic syndromes (MDS)** are diseases of the bone marrow. MDS results in immature, abnormal blood cells. It is a type of cancer, but it is sometimes also called 'bone marrow failure'.
- Your haematology team should introduce you sensitively to the nature of MDS. They should provide you with the result of your **diagnosis tests** and explain your **subtype of MDS**.
- MDS is a rare disease with an incidence of about **4 cases per 100,000** population per year. The incidence of MDS increases with age especially in those **greater than 70 years of age**. In patients with MDS over the age of **80 years**, the incidence rises to **40 per 100,000** per year.



- Some patients with MDS are at risk of their MDS becoming acute myeloid leukaemia (AML).

"When I was diagnosed I was surprised; I had not heard of MDS before. But I also felt relieved; a reason why I was so fatigued."

What are myelodysplastic syndromes (MDS)?

MDS are disorders of the bone marrow, in which an excessive amount of immature, abnormal (or 'dysplastic') blood cells are produced. All types of MDS create an excessive amount of immature, abnormal blood cells. There are several types of MDS.

The bone marrow is the spongy substance found in the centre of some of your bones. It creates bone marrow stem cells which in turn become blood cells.

The bone marrow 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

The World Health Organization (WHO) Classification of Haematopoietic Tumours includes MDS. This means that MDS is a type of cancer. Sometimes it is also called 'bone marrow failure'.

Patients with MDS produce insufficient amounts of one, two or all types of blood cells. You can also make blood cells that do not work correctly. MDS can sometimes progress into AML, another blood cancer.

The reduced number of blood cells in your blood is the cause of the symptoms you experience. For example, a low number of mature red blood cells causes fatigue or shortness of breath.

As well as having low blood cell counts, MDS patients are at an increased risk of developing AML. AML is a type of leukaemia where patients have at least 20% of blast cells in the blood and bone marrow. 'Blast cells' are immature, abnormal cells that some MDS patients have in their bone marrow.

In some patients with MDS, the number of MDS blast cells increases with time. Your risk of developing AML depends on the type of MDS you have, but some patients may never progress to AML.

We have a dedicated booklet on acute myeloid leukaemia (AML) which gives you more information about this leukaemia type. Scan the QR code to order or download the booklet free of charge:

Who suffers from MDS?

MDS is a rare disease. In the UK there are about 4 cases per 100,000 population per year.

The typical age at which patients develop MDS is around 70 years old. Fewer than 10% of MDS patients are younger than 50 years. MDS may occur at any age but it is very rare in children and young adults. Men are more likely than women to be diagnosed with MDS, the ratio being 2:1.

This booklet deals with MDS occurring in adults.

What is the cause of MDS?

The cause of MDS is not known. Research groups are trying to improve our understanding of why it occurs and in whom. Several genetic mutations have often been observed in patients with MDS, but the exact mechanisms that result in the development of MDS still need explaining.

There are several conditions involving mutations in your bone marrow that can predict the development of MDS. These conditions occur by chance and patients with them do not display any symptoms. They are:

- **CHIP:** clonal haematopoiesis of indeterminate potential
- **CCUS:** clonal cytopenia of undetermined significance
- **ICUS:** idiopathic cytopenia of undetermined significance

These conditions may allow earlier diagnosis and monitoring for MDS. Take time to talk to your doctor or clinical nurse specialist about your MDS subtype so that you understand the treatment of your MDS. They will mention and explain CHIP, CCUS and ICUS, if they are relevant to you.

In MDS, the bone marrow is more active than normal, but the stem cells produce blood cells that are not healthy. They are abnormally-shaped and do not work as well as they should. Many die, either before they reach the bloodstream, or shortly afterwards. The medical term for these abnormally-shaped cells is 'dysplastic'.

Because of this, there is a decrease in the number of blood cells in the bloodstream. Some patients only have one type of blood cell that is low, which in the case of red blood cells results in anaemia. MDS causes a reduction in one or more types of blood cells.

MDS is not an infectious disease and you cannot pass it on to other people.

Genetic abnormalities in MDS

Chromosome abnormalities

Half of MDS patients have chromosomal abnormalities. Chromosomes 5 and 7 are the most common genetic abnormalities in MDS. The only genetic chromosomal abnormality defining MDS is the deletion of the long arm of chromosome 5. This is often abbreviated to deletion 5q or del 5q. Isolated deletion of the long arm of chromosome 5, together with clinical features of MDS, can lead to a diagnosis of MDS.

Mutation abnormalities

Some patients with MDS have a combination of gene mutations.

There are two types of mutations that occur in humans:

1. Inherited mutations are present in the egg or sperm cells. They pass to offspring during sexual reproduction. Because they start in the egg or sperm, every cell in the body contains this mutation.
2. Acquired (or somatic) mutations are not present from birth and occur during a person's lifetime. These mutations are only present in certain cells in the body unlike inherited mutations which occur in every cell in the body. You cannot pass these acquired mutations onto the next generation.

Both these types of mutations play a role in MDS. Research has shown that some people with MDS have both.

Inherited mutations

People with MDS do not inherit a mutated gene that is a direct cause of their MDS. However they inherit a gene mutation which results in a syndrome which means they are more likely to develop MDS. Examples of these inherited syndromes and their associated gene mutation are:

- **Fanconi anaemia (FA) syndrome:** Mutations in any of at least 23 *FA* genes
- **Diamond-Blackfan anaemia syndrome:** Mutation in *GATA1* gene
- **Mirage syndrome:** Loss-of-function mutation in the *SAMD9L* gene

In addition, 'familial MDS' has been reported but it is very rare. The actual reasons for MDS occurring randomly is not entirely understood. However, it is believed that some MDS cases are associated with predisposing germline mutations. Germline describes the germ cells. These are the egg and sperm cells that pass on their genes from one generation to the next (parents to children). This is in contrast to other cells of the body, which are known as somatic cells.

The familial MDS/AML predisposition syndromes are inherited disorders that considerably increase the lifetime risks of developing MDS and/or AML. Among them are the following familial inherited germlines associated with:

- Mutation in the *CEBPA* gene
- Mutation in the *DDX41* gene
- Mutation in the *GATA2* mutation
- Familial platelet disorders linked with the following mutations in:
  - *RUNX1* mutation
  - *ANKRD26* mutation
  - *ETV6* mutation

Acquired mutations

Acquired mutations such as *SF3B1*, *TET2* and *ASXL1* are the most common mutations found in MDS.

Work continues to understand how mutations lead to MDS. Artificial intelligence (AI) and machine learning are being used to understand MDS mutations.

- AI is the ability of computers to imitate problem solving or learning techniques.
- Machine learning is where computer systems learn from examples, data, and experience.

Risk factors for MDS

There are certain factors that may increase your chance of developing MDS. These include:

- Chemotherapy and radiotherapy for previous cancers can cause MDS in some patients. This is because chemotherapy and radiotherapy damage bone marrow. The medical term for this is 'secondary' or 'therapy-related' MDS.
- Very rarely, MDS may develop from another inherited rare blood disorder. Haematology teams perform tests on young MDS patients for any of these diseases.
- Exposure to toxic chemicals such as benzene may increase your risk of developing MDS.

What are the signs and symptoms of MDS?

Some MDS patients have no signs or symptoms, and diagnosis occurs by chance as a result of a routine blood test.

The signs and symptoms of MDS depend on which blood cells are in low numbers in your blood. About eight in 10 patients have anaemia, whilst about two in 10 have infections or bleeding.

Anaemia

Anaemia is the most common symptom in MDS. Anaemia is due to low numbers of red blood cells. This results in low levels of haemoglobin. Low levels of haemoglobin lead to fatigue and shortness of breath, even on light exertion.

Bruising and bleeding

When the number of platelets in your blood is low, you can suffer from easy bruising and bleeding. These bruises can sometimes appear as tiny bleeds under the skin called petechiae. They resemble a skin rash or red pin pricks. They often appear where clothes are tight-fitting like around the ankles or waist. Nose or gum bleeds can also be a sign of a low platelet count.

Infections

Infections are a common symptom of MDS as a result of low white blood cell counts. These infections may be recurrent or persistent.

Summary: How are myelodysplastic syndromes (MDS) diagnosed?

- To diagnose MDS, your haematologist will need to perform the following tests:
  - **Full blood count**
  - **Bone marrow test**
  - **Chromosome analysis** and **identification of gene mutations**
- A 2022 update of the MDS classification is nearly completed and will be published soon. For the purpose of this booklet we will still be referring to the **2016 classification**.
- The 2016 WHO Classification of Haematopoietic Tumours includes **six subtypes of MDS**.
- Your haematology team should tell you which subtype of MDS you have. If not, you should ask them. They will also tell you what it means for your treatment and prognosis, if you wish to know this.

How are myelodysplastic syndromes (MDS) diagnosed?

The diagnosis of MDS involves the results of following tests:

- Full blood count
- Bone marrow test
- Chromosome analysis and identification of gene mutations

Full blood count

A full blood count (FBC) measures the numbers and types of blood cells in a sample of blood. A review of the FBC results will show any low blood cell counts. Low cell counts can mean your bone marrow is not working as it should.

A microscope examination of your blood sample (blood film) also happens. This will reveal if you have changes in your blood cells that suggest MDS.

Bone marrow test

Because MDS is a disease of the bone marrow, a bone marrow test (aspiration or biopsy) may be helpful. This test will confirm your diagnosis and help check how you respond to treatment.

You will usually have a bone marrow test as an outpatient, without the need for an overnight stay.

A bone marrow test is usually done in the pelvic bone. Your haematology team will numb the area over the site of the bone marrow test with a local anaesthetic. Your haematologist inserts a needle, known as a cannula, into your bone marrow cavity. Then your haematologist takes a small sample of liquid bone marrow (aspiration), followed by some bone marrow (biopsy).

The procedure usually takes 20 to 30 minutes. It may be uncomfortable at the time, or later that day or evening, but paracetamol may help with any pain. After your bone marrow test, your haematologist may also ask you to lie on your back for

10 minutes to reduce the risk of bleeding. You may have to wait two to three weeks to get your bone marrow test results. This gives your haematologist enough time to analyse any changes that show MDS.

Chromosome analysis and identification of gene mutations

Looking for specific gene mutations is essential. The aim is to achieve a more precise diagnosis, and make your care more personalised. This is because changes to your DNA affect cells in different ways.

Waiting for your test results may be an anxious time. Talk to your family and friends, or contact patient support organisations. It is useful to speak to other patients either over the phone, in person or through online forums. You can read about other patients whose experience is similar to yours. Online meetings are particularly helpful for patients living in remote areas.

After all these tests, your haematologist will tell you which subtype of MDS you have. They should also say what it means for your treatment and prognosis.

2016 WHO classification of MDS

The World Health Organisation (WHO) has developed a classification for the different types of MDS. The most recent version of the classification was in 2016. An update of the MDS classification in 2022 has been completed and will be published soon. For the purpose of this booklet we will be referring to the 2016 classification.

The 2016 WHO classification system of MDS considers:

- Blood results
- Appearance of the bone marrow
- Number of blast cells
- Chromosome changes

There are six broad types of MDS included in the 2016 WHO classification of MDS. These are:

1. MDS with single lineage dysplasia (MDS-SLD)
2. MDS with multilineage dysplasia (MDS-MLD)
3. MDS with ring sideroblasts (MDS-RS)
4. MDS with excess blasts (MDS-EB); MDS-EB-1 and MDS-EB-2
5. MDS, unclassifiable (MDS-U)
6. MDS with isolated del(5q) or with one other abnormality

If you are looking for information on chronic myelomonocytic leukaemia (CMML), please see our separate booklet. Scan the QR code to order or download the booklet free of charge:

In the above MDS types:

- Dysplasia means that the bone marrow cells are abnormal in appearance.
- Sideroblast is the name for young red blood cells that have a distinctive ring of iron granules. You find sideroblasts by looking at red blood cells when seen under the microscope.
- MDS with isolated del(5q) means the chromosome tests show part of chromosome 5 is missing.

The 2022 new classification system is expected to be used more and more over time. This new classification is likely to indicate that some people previously considered as having MDS actually do not have MDS yet. Instead they will be classified as having a precursor condition for MDS and treated as being at increased risk for MDS.

If your doctor gives you a classification that is not in our list above, they may have used this new system. You should ask them to explain what this means for your MDS care and treatment.

High-risk and low-risk MDS

It is also helpful to classify MDS subtypes into **low-risk groups** or **high-risk groups**. The 'risk' is your chance of developing AML, and as a consequence a reduction in your life expectancy.

- In the low-risk disease group, a patient has about a 10% chance of progressing to AML. The low-risk groups include patients with:
  - MDS-SLD
  - MDS-MLD
  - MDS-RS
  - MDS-U
  - MDS with del(5q) either in isolation or with one other abnormality
- In the high-risk MDS group, patients have a much greater risk of developing AML. The high-risk group consists of only patients with:
  - MDS-EB

Your risk level is important because the subtypes have different treatments.

MDS specialists have designed scoring systems to predict how your MDS is likely to behave. Over time, these scoring systems have evolved to give very accurate estimations.

MDS doctors use the Revised International Prognostic Scoring System (IPSS-R) recommended by the British Society of Haematology. This replaces previous versions of the scoring system including the International Prognostic Scoring System (IPSS).

The IPSS-R is appropriate for the diagnosis and risk stratification of MDS, but not for use during the treatment to check a patient's progress.

Revised International Prognostic Scoring System (IPSS-R)

The British Society of Haematology guidelines for MDS recommend the use of the IPSS-R.

To work out the IPSS-R score, your haematologist will take all the following into account:

- Your blood count results at the time of diagnosis of your MDS
- The number of blasts in your bone marrow at diagnosis
- The chromosome test results from your bone marrow at diagnosis

Depending on your score, your IPSS-R risk will be one of the following:

- Very low
- Low
- Intermediate
- High
- Very high

More details are available at
www.mds-foundation.org/advanced-calculator/

Your doctor may use either of the following to decide whether your MDS is low-risk or high-risk:

- WHO classification of your MDS
- Your MDS prognosis score

Your risk score describes your expected risk of developing AML. It also predicts your expected survival time. It helps your doctor discuss with you the best treatment choices for you.

The risk group score gives an idea of the outcome for patients as a group. It gives a useful guide for a discussion about your future treatment options. It is not possible to give a precise outcome for any individual patient.

Molecular International Prognostic Scoring System for MDS (IPSS-M)

A new system for classifying MDS, known as IPSS-M, has been developed. This takes account of many more genetic mutations in its classifications system, to better predict your prognosis. This is unlikely to be a routine scoring system in the United Kingdom in the immediate future. This is because the genetic tests may not be available for everyone.

British Society of Haematology (BSH) MDS Guidelines

MDS experts have written guidelines for diagnosing and treating MDS. If you'd like to read the full guidelines, go to b-s-h.org.uk/guidelines and search 'myelodysplastic syndromes'. This will take you to two separate guidelines: one on diagnosis of MDS, and another one on management.

We used both these guidelines to write this booklet.

Haematologists follow these guidelines to determine your treatment. On occasion they may adapt them for your particular MDS subtype.

Summary: What is the treatment for MDS?

- Your treatment will depend on your **subtype of MDS**, and how your MDS behaves. MDS can vary from person to person within the same subtype of MDS.
- Your haematology team will follow the **British Society of Haematology MDS Guidelines** to choose your treatment. If they suggest a different treatment, they will discuss the reasons for this with you.

- Your local **multidisciplinary team (MDT) meeting** should also discuss your treatment and care.

"Having a blood transfusion is an amazing feeling. People around me could see the colour returning to my face. I had a shower and danced because at last it no longer hurt to stand and wash my hair. The relief was immediate."

What is the treatment for MDS?

Your local multidisciplinary team (MDT) should establish which treatment will be most appropriate.

Multidisciplinary team

An MDT team consists of:

- Haematologists
- Nurses
- Pathologists/laboratory specialists
- Stem cell transplant (SCT) specialists
- Other healthcare professionals

They will set up the best care plan for you, bearing in mind the unique features of your MDS.

Your MDT will discuss the treatment of your MDS at regular meetings. They may also ask for a secondary opinion from specialists outside of your MDT. This will help achieve an accurate diagnosis and the best form of treatment.

Treatment of MDS

The treatments selected for you will consider:

- Your type of your MDS
- Your own wishes
- Your age
- Your general wellbeing or fitness
- Your IPSS-R score

If you are unsure about any part of your treatment, please ask your haematologist. You can also ask for an additional opinion from an MDS specialist if you think that this would help you.

Active monitoring (Watch and Wait)

Not all patients have MDS symptoms that will 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'.

Treatment options for MDS

The following treatments for MDS are available and their order has been specified by our haematology specialist reviewer. In the following sections, we include details of all these treatments.

- **Non-intensive treatment** - Non-intensive treatment attempts to slow down the progression of your MDS and improve your blood counts. This includes hypomethylating agents such as azacitidine, and lenalidomide.
- **Intensive treatment** – Intensive treatment may be chemotherapy or an immunosuppressant such as azathioprine. If a matched donor can be found, a stem cell transplant (SCT) will be a good option for you.
- **Supportive care** – Supportive care can be added at any stage of your treatment. It is not used to treat your MDS, but just to reduce your MDS symptoms. It includes blood transfusions, growth factors and antibiotics, antifungals or antivirals.

Your MDT will explain the benefits and side effects of the treatments that may be available for you. If you agree to your treatment, you will need to sign a consent form (except for blood transfusions and erythropoiesis-stimulating agents, which do not require signed consent forms). Erythropoiesis is the production of red blood cells.

Your care plan will also include drugs to lessen any side effects of your treatment. This is an important part of your medical care.

In addition, your haematologist should let you know of any clinical trials for which you are eligible.

If an SCT is an option for you, your haematologist will let you know as soon as possible. This will allow a search for donors and the drafting of a schedule for your transplant at an early stage.

Intensive treatment involves high doses of chemotherapy to prepare your bone marrow for your transplant. Using stem cells from a donor, your SCT will replace your abnormal bone marrow cells with healthy ones. However, control of your MDS and improvement of your symptoms is possible until your SCT.

Non-intensive treatment

Non-intensive treatment can prevent your MDS from progressing. It may also be an option if your blood counts are low or falling. Non-intensive treatment aims to cause as few side effects as possible. It is usually given as an outpatient.

Hypomethylating agents

Hypomethylating agents alter the MDS cells at a DNA level. They cause a re-programming of the MDS cells. Hypomethylating agents, such as azacitidine or decitabine, improve your bone marrow function. They also slow down any progression of your MDS to AML.

MDS patients can receive azacitidine before and after their transplant. Hypomethylating agents are also used for high-risk MDS in patients who are not fit enough for an SCT.

Azacitidine is usually given as a subcutaneous injection. Side effects include:

- Mild nausea
- Diarrhoea/constipation
- Skin irritation at the injection site
- More infections (due to lowered white blood cell counts)
- Bleeding due to lowered platelet counts

Lenalidomide

Lenalidomide is a drug that affects how your immune system works. It changes the way in which cells divide and grow. Lenalidomide is available as an oral capsule.

On starting the treatment, the blood cell counts may fall until a response occurs. You may need transfusions of blood and/or platelets during this time. Some patients may also need treatment with granulocyte colony-stimulating factor (G-CSF). This increases the number of white blood cells in your body.

Lenalidomide is often recommended for MDS patients with deletion of part of chromosome 5 (del 5q). Lenalidomide is particularly effective in this subtype of MDS.

Side effects experienced with lenalidomide include:

- Rashes
- Fatigue
- Diarrhoea
- Small increased risk of blood clots

Intensive treatment

Intensive chemotherapy

If you have high-risk MDS, intensive chemotherapy such as azathioprine might be the best treatment for you. This treatment is the same as that used for AML. It intends to kill as many MDS cells as possible. Chemotherapy can cause severe side effects.

Intensive chemotherapy alone can treat a small proportion of patients. But, if you have a donor available, your MDT will discuss the benefits and risks of an SCT with you.

If an SCT is an option for you, your haematologist will let you know as soon as possible. This will allow a search for donors and the drafting of a schedule for your transplant at an early stage. We have more information on page 37.

Administration of intensive chemotherapy

Chemotherapy is delivered into your veins as an infusion over several weeks or months. Following each course of chemotherapy, there will be a rest period. A course of chemotherapy together with a rest period is called a cycle of treatment.

You may have a central venous catheter. This catheter tunnels under your skin and is fitted into a large vein for the intravenous infusion of your chemotherapy. This central venous catheter (sometimes called a Hickman line) offers long term access (weeks to months). This means you don't need to have many injections. The central venous catheter remains in place for the duration of your treatment.

The central venous catheter enables you to have:

- Repeated infusions of drugs
- Fluids
- Blood products
- Total parenteral nutrition
- Routine blood sampling

Common side effects with intensive chemotherapy

Chemotherapy for MDS kills the cancer cells in the bone marrow. This means your blood counts will fall after the chemotherapy and stay low for several weeks. Chemotherapy damages healthy bone marrow cells. However, your healthy cells recover faster than the MDS blast cells.

Intensive chemotherapy may cause serious, life-threatening side effects. The most common side effects are:

- Infections
- Bleeding
- Anaemia

Other side effects that you may experience are:

- Hair loss
- Nausea/vomiting
- Sore mouth
- Loss of appetite and taste
- Diarrhoea
- Skin and nail changes
- Infertility in younger patients

Immunosuppressive therapy

In a small number of patients with MDS, the number of bone marrow cells is very low. These patients can sometimes respond to immunosuppressant drugs. Examples of immunosuppressive drugs include anti-thymocyte globulin (ATG) or cyclosporine.

Stem cell transplants

An SCT may be able to cure your MDS. It replaces your abnormal bone marrow cells with healthy ones. The healthy cells usually come from a donor. The medical term for this is an allogeneic stem cell transplant (allo-SCT).

If an SCT is an option for you, your haematologist will let you know as soon as possible. This will allow a search for donors and the drafting of a schedule for your transplant at an early stage.

Intensive treatment involves high doses of chemotherapy to prepare your bone marrow for your transplant. Using stem cells from a donor, your SCT will replace your abnormal bone marrow cells with healthy ones. However, control of your MDS and improvement of your symptoms is possible until you can have your SCT.

An allo-SCT is the treatment of choice for most patients with MDS who have a matched donor (sibling or unrelated donor). If a matched donor cannot be found for you, your medical team will talk to you about other options. This may include a partially-matched transplant.

Age is no longer a barrier for proceeding to an allo-SCT. However, compared with younger patients, older patients have a higher incidence of comorbidities:

- Heart disease
- Diabetes
- Previous solid tumours

The comorbidity index of patients is based on the details of each comorbid condition. The most frequent comorbidities are:

- Lung impairment
- Heart disease
- A previous solid tumour
- Infections
- Liver impairment

Procedure for stem cell transplant

Your donor should have tissue DNA compatible with yours. Your donor may be a related (sibling or parent) or an unrelated donor. The donor will need a simple blood test to see if they are a full match to you. The results are usually available in two to three weeks.

You will receive high-dose chemotherapy to kill any remaining MDS cells. This happens before your transplant. This is called myeloablative conditioning.

Low-dose chemotherapy might be an option if you cannot tolerate high-dose chemotherapy. This is called reduced-intensity conditioning.

Donor cells are injected into your blood stream. This allows their migration to your bone marrow. Here, they form new blood cells to restore your bone marrow. After the allo-SCT, you will receive drugs to prevent rejection of the donated stem cells. You will need to stay in hospital for four to six weeks.

Common side effects of a stem cell transplant

Even though an allo-SCT can achieve a cure, it does cause considerable side effects. These include graft versus host disease (GvHD), bleeding and infections.

GvHD is a serious complication. It occurs when the donated marrow stem cells (graft) react against the cells of the patient receiving the stem cells (host).

The side effects from an allo-SCT can continue for several years after the transplant. Reduced-intensity conditioning may help reduce the severity of the side effects.

About one third of patients who receive reduced-intensity conditioning remain free from MDS over many years. There is always the possibility that the MDS may return (relapse).

It is important that your MDT has input to your decision to have an allo-SCT. You can also consult with a specialist centre to discuss the benefits and risks for you. Always try to take a family member or friend to the appointments.

For more information, we have a dedicated booklet on allogeneic stem cell transplants. Scan the QR code to order or download the booklet:

Supportive care

Supportive care can be used at any stage of your treatment. When you are first diagnosed, you may receive supportive care until you and your haematology team determine the best treatment for you. Supportive care is any medication/medical care that is not intended to treat your MDS. Supportive care includes blood transfusions, blood cell growth factors and antibiotics, antifungals or antivirals, if required.

Patients do not always require treatment as long as they are asymptomatic and most can be treated with supportive measures such as intermittent blood or platelet transfusions.

We have more details on supportive care on page 50.

Treatment outcome

There are several types of remission. It depends on how few of the MDS cells are left behind after treatment.

Complete **haematological** remission in MDS occurs when:

- Blood cell counts have returned to normal
- Less than 5% of blast cells are present in the bone marrow

Complete **molecular** remission happens when there are no MDS cells seen in the body at all. This is also called negative measurable residual disease (previously minimal residual disease).

Response can be described as an improvement in clinical symptoms or the achievement of a level on a pre-determined response scale.

Your haematologists will have agreed a response scale before the start of treatment. For example, if **complete haematological remission** in MDS requires *less than 5% of blast cells to be present in the bone marrow*, then it may be agreed prior to treatment that *a reduction of 50% of blast cells* will qualify as **partial haematological remission**. As such, you can respond to treatment without achieving complete remission.

MDS is often refractory to chemotherapy, but there has been some success with the use of hypomethylating agents (azacitidine or decitabine) and lenalidomide. After drug treatment, between 25% and 40% of patients with MDS can be refractory or relapse.

- Refractory disease occurs when MDS cells remain throughout treatment, or return within six months of treatment.
- Relapse occurs when MDS cells return in patients who have achieved remission for more than six months.

High-risk and some intermediate-risk MDS patients are often considered for stem cell transplants.

Low-risk patients may be managed with supportive measures such as blood cell transfusions or blood cell growth factors. Low-risk patients may also be offered treatment with systemic agents.

Clinical trials

Research into MDS occurs worldwide to improve the knowledge of MDS. Taking part in a clinical trial may mean you help people diagnosed with MDS in the future. Your doctor may discuss with you a clinical trial available at your hospital. You will be asked for your consent before entering into a trial. You will receive details of the trial and you will have plenty of time to consider taking part. You will have to sign an 'informed consent' form before taking part.

Taking part in a clinical trial may also benefit you as a patient. A clinical trial can allow you to access the latest treatments. These may turn out to be more effective for you or have fewer side effects than your current treatment.

You can change your mind and leave a clinical trial at any point in time. If you decide not to enter a clinical trial, you will still receive the best treatment available for you.

Details of clinical trials are accessible through your consultant or you can contact Leukaemia Care's advocacy officers who will be able to provide you with more information on clinical trials that are available for MDS. You can email them at advocacy@leukaemiacare.org.uk, message them on WhatsApp at **07500 068 065** or call the helpline at **08088 010 444**. Areas of research in MDS include gene mutations, new drugs and drug combinations.

MDS UK also keeps a list of current clinical trials at mdspatientsupport.org.uk/what-is-mds/current-trials/. You can contact MDS UK on **0207 733 7558** if you have any general questions about clinical trials.

Follow-up care

Your MDT who coordinated your treatment plan will follow-up through outpatient visits.

Outpatient visits for patients with low-risk MDS will be infrequent.

Outpatient visits may be more frequent in patients with high-risk MDS. Those who are still on active treatment will also have more regular appointments.

What is the prognosis of MDS?

Prognosis describes the expected outcome and survival in patients with MDS. It is not the same as MDS classification. The prognosis for patients varies with their genetic mutations, age and general fitness.

Your genetic mutations play a considerable role in determining your prognosis. A mutation can be positive as well as negative.

- Mutations occur in various types of genes. The most commonly mutated groups of genes in MDS are the splicing factor mutations, the most common of which is *SF3B*.
- The *SF3B1*-mutant MDS predicts a good prognosis.
- Mutations that forecast a poor prognosis are the somatic mutations in the genes *TP53*, *EZH2*, *ETV6*, *RUNX1*, *ASXL1*, and *SRSF2*. Research into these genes is ongoing.

A diagnosis of MDS can be a lot to take in, especially when it comes to treatment options and prognosis. If you think you may benefit from counselling, we can help you access up to six sessions. Scan the QR code to fill in a form:

Summary: Living well with MDS

- **A diagnosis of MDS can be a shock.** How people behave in response to their diagnosis can vary. You may need a lot of time and help from your haematology team to adjust to your situation and feelings.
- You may experience a range of emotions when you receive your diagnosis of MDS. Talk to family and friends about how you feel. Let them know what you find helpful and unhelpful. Even if you are able to control your emotions by taking a practical approach, **a diagnosis of MDS is a major life event that takes getting used to**.
- Physical symptoms can affect you, whether you are having treatment or not. If these affect your day-to-day activities, you should seek help. Many symptoms are responsive to treatment.

- **Speak with your doctor or clinical nurse specialist** if you are finding it hard to deal with your symptoms. They can offer you support to relieve your symptoms and maintain your quality of life.
- **You may like to let your employer know about your diagnosis**. Support with any work adjustments or time off you may need is available.

"The emotions that went through my body cannot be explained – there was anger, worry, fear and sadness. But the overwhelming one was determination that we would get through this."

Living well with MDS

Your diagnosis of MDS will have implications for your daily life. Knowing in advance what to expect might help with some of the stress or worries.

Knowing the complications of MDS helps you recognise when to seek medical attention or support. It can also help you feel more in control.

Reducing the risk of infections

Patients with MDS may be more vulnerable to infections. This is because their white blood cell levels are not only low, but the cells are also dysplastic.

You should seek medical attention immediately if you feel unwell or have a fever. If you are too unwell to leave the house, call an ambulance to get you to hospital.

Patients who have an infection and low levels of neutrophils can deteriorate in a short space of time. They should receive intravenous antibiotics as soon as possible.

If you are feeling unwell, check your temperature. If you have an increased temperature or shivers, you should contact your CNS at the hospital. Most specialist units will have a direct phone number to call for advice in the event of a fever. A fever is a temperature above 38°C.

Advice for MDS patients to avoid infections include:

- Good hand hygiene is the best way to avoid catching bacterial infections.
- Lots of hand gels are available, but normal hand washing with water and soap is very effective. Hand washing is important:
  - After using the toilet
  - When preparing food and before you eat
  - After gardening or touching animals
- Try to avoid people who are unwell and ask your friends and family not to visit when they have cold or flu symptoms or gastroenteritis or COVID-19.

Granulocyte colony stimulating factor (G-CSF)

Injections of G-CSF can stimulate the growth of white blood cells in the bone marrow. It is available as a subcutaneous injection. These injections may give you pain in the bones and muscles. The pain responds to painkillers, like paracetamol.

Anti-infective medications

Anti-infective is a term to describe any medicine that can stop or kill infectious organisms. Anti-infective medications include the following:

- Antibiotic drugs
- Antifungal medicines (creams, sprays, pessaries and capsules)
- Antimalarial drugs
- Antitubercular medications
- Antiviral medicines (tablets, liquid, inhaled powders or intravenous solutions)

Antibiotics are not usually given to prevent infections. This is because antibiotics can cause side effects. Overuse of antibiotics may also make bacteria become resistant to the antibiotics. However, if you do get an infection, you should get prompt treatment with antibiotics. If the infection gets worse, you will need intravenous antibiotics in hospital.

If you are planning to travel, ask your doctor if you should take any anti-infective medications with you. This may help to avoid any problems while abroad.

For information about travelling for people with lowered immune systems, scan the QR code to read guidance from the National Travel Health Network and Centre:

COVID-19 advice

Patients diagnosed with MDS have a lowered immune system. Because of this, they are at increased risk of serious illness if they contract COVID-19.

The latest COVID-19 advice for people with MDS is on the Leukaemia Care and MDS UK websites.

Scan this QR code to access Leukaemia Care's information:

Scan this QR code to access MDS UK's information:

Fatigue

Fatigue or lack of energy can have a serious impact on your quality of life. For MDS patients who have anaemia, a blood transfusion can relieve fatigue for a period of time. In some cases, this may be for a few weeks, and for others it may last longer. At first, this treatment for MDS can make your fatigue worse. If your blood cell levels recover, your fatigue may improve over time.

Adjusting your lifestyle to your energy levels can be difficult. Some general tips on how to deal with fatigue include:

- Have a regular sleep routine. Try going to bed and waking up approximately the same time every day, and try to avoid lying in.
- Use ready-made meals if cooking is too tiring, so you keep your energy for eating.
- Wear clothes that are easy to put on and take off.
- Keep your energy for important activities. Make sure to build in rest periods around those times.
- There is no specific guidance regarding exercise and MDS. As long as your energy levels allow, you can be as active as you like. If you have low levels of platelets, you should avoid contact sports. Low platelets may cause serious bleeding.

Emotional impact of MDS

The emotional impact of MDS can be as great as its physical impact. Each person with MDS will cope in their own way. Not all these emotions will apply to you, but some may be familiar. Many of these emotions will be relevant to your family and friends.

Adjustment

Coping with your diagnosis and treatment of MDS can result in complex thoughts and intense feelings. This is often described as 'being on an emotional rollercoaster'. The formal term for dealing with these emotional ups and downs is called 'adjustment'.

Adjustment in the case of MDS includes:

- Getting used to the monitoring of your MDS
- Having medical appointments and treatments
- Losing, or experiencing a reduction, in physical abilities
- Experiencing a disruption to your usual life patterns and routines
- Questioning things taken for granted, like good health and future plans

Coming to terms with a diagnosis of MDS

It is generally helpful to address your thoughts and feelings rather than to ignore them. It is important to achieve a balance between thinking about your MDS and periods when trying to carry on with your life.

Managing thoughts

Writing down negative thoughts and worries can be helpful. You will notice that some of them are understandable in view of your situation. Other thoughts are more like worst-case scenarios. They are often the result of catastrophic thinking, or very 'black and white' (i.e. all good or all bad).

Take a step back and ask yourself whether these thoughts are real facts or only gut reactions. Write down alternative, more helpful thoughts next to the original worries.

Feelings you may experience

This section includes many of the emotions and thoughts that people with MDS have expressed. You may not experience all these feelings, but if you do, you are not alone. It is not a sign of weakness, but a normal reaction to your situation. It does not mean you have mental health issues.

Shock, disbelief, helplessness and a feeling that you have lost control

These feelings are normal when receiving a diagnosis of MDS. You might find the situation threatening and wonder how you can cope.

Worry, anxiety and living with uncertainty

MDS often carries with it a degree of uncertainty which can make you anxious and leads to worrying. The emotional response to your fear is anxiety, or even panic. This may lead to physical symptoms of anxiety such as an increased heart rate and dry mouth. A useful means of managing uncertainty is to focus on the 'here and now'.

Anger

Anger is common when diagnosed with MDS. It can be confusing, feel unfair or outside of your control. It can be difficult to know how to deal with your anger or understand who you are angry with. Sometimes you may direct your anger at loved ones, or even at yourself.

Stress

Everyone feels under stress when there is too much pressure or when they are dealing with too many demands.

Sources of stress for you may be:

- Trying to cope with your MDS
- Demands of treatment
- Financial issues
- Employment
- Relationships

The emotional symptoms of stress can include low mood, anxiety and irritability.

Sadness, low mood, hopelessness and despair

Feeling sad at your diagnosis of MDS is natural. Sometimes it can feel that things aren't going well or that they will never be the same again. Some days you can feel down, but these feelings are usually temporary. You will tend to have 'good days' and 'bad days'.

Depression

If you feel sad and hopeless for two weeks or more, you may have depression. You may also notice the following symptoms:

- A lack of interest or pleasure in life
- Disrupted sleep and appetite
- Feeling worthless
- Thinking you would be better off dead

If you think you may be depressed, contact your GP. They can help you access the support and treatment you need.

If you are in crisis, the NHS has urgent mental health helplines that offer 24-hour advice and support. Scan the QR code for details:

Dwelling on negative thoughts is one of the things that makes your low mood worse and keeps it going.

One thing that helps depression is keeping active and engaging with others. This helps to increase a sense of pleasure and reward from life. Bearing in mind that patients with MDS have a higher risk of infection, especially during COVID-19 and peak flu seasons, you can connect with other patients through online forums and meetings, as well as read about patients whose experiences are similar to yours.

Talk to your clinical nurse specialist who will be able to give you independent advice.

Summary: Supportive care

- Supportive care describes any medication/medical care that is not intended to treat your MDS. Supportive care **improves your quality of life**.
- **Supportive care is available at any time** during your MDS treatment. The main goal of supportive care is to help relieve symptoms from your MDS and the side effects of your treatment.
- **Palliative care** is the care of people living with serious illnesses, such as MDS. It helps relieve the symptoms and stress of a serious illness. **It is not only used at the end of life.**
- Some healthcare teams use supportive care and palliative care to mean the same thing. In this booklet, we avoid the term palliative care on its own. This is to help you tell the difference between supportive care and end-of-life care. **End-of-life care is not the only type of palliative care.**
- For MDS, **supportive palliative care is very common**. Haematologists use treatments to **replace red blood cells or platelets**. This can happen either alongside treatment for the cause of the MDS, or instead of it.
- You may also receive:
  - **Growth factors** to stimulate blood cell production and increase your blood cell levels.
  - **Iron chelation treatment** to prevent iron overload from having red blood cell transfusions.

Supportive care

What is supportive care?

Supportive care is used to prevent or treat side effects of treatment. Supportive care can also treat the symptoms of cancer itself.

Palliative care is specialised care for people living with serious illnesses. It provides patients with relief from the symptoms and stress of a serious illness, irrespective of the diagnosis.

There is a misconception that palliative care only applies to people at the end of their life. Therefore we use the terms supportive care and end-of-life care, to tell the difference.

In patients with MDS, supportive care treats the symptoms of MDS. It also helps reduce the side effects caused by treatment. Supportive care can also provide relief of non-physical problems related to your MDS. This might include psychological or spiritual issues.

Supportive care also includes:

- Advice on reducing your susceptibility to infections
- Awareness of the side effects of treatment so you can report them early
- Blood transfusions (red cells or platelets)
- Antibiotic, antifungal or antiviral treatment. Most common treatments are:
    - Trimethoprim/sulfamethoxazole (cotrimoxazole) for pneumocystis pneumonia (PCP) prophylaxis
    - Aciclovir to prevent viral infections

All patients will need supportive care at some stage during their MDS. Supportive care may be the only long-term treatment required. You may also have supportive care only if you are unable to have other treatments, for example, due to frailty.

The nature and extent of the supportive care offered depends on:

- Which of your blood cells are affected
- How low your blood cell levels have dropped

Supportive care may be provided by a palliative care team. The palliative care team can provide advice and support when symptoms of MDS are not controlled. Symptoms such as nausea and vomiting, breathlessness and pain are symptoms that the palliative care team can deal with. The help provided by the palliative care team can be temporary, for a longer period of time in hospital, and also in the community.

Some medical treatments for your MDS can be very aggressive. The supportive treatment provided by your palliative care team can help you tolerate the side effects of these hard-hitting treatments.

Blood or red cell transfusions

The majority of patients with MDS will need a blood transfusion at some stage due to anaemia. Your haemoglobin levels will reveal your degree of anaemia. If you have low haemoglobin levels, you may suffer from tiredness and shortness of breath. These symptoms can affect your quality of life.

- Some patients with anaemia have a good quality of life and do not need treatment.
- Other patients will need blood transfusions to improve their symptoms.
- Being dependent on red cell transfusions is generally associated with a decrease in 'overall survival' and 'leukaemia-free survival' in patients with MDS.

Some clinicians follow a hospital policy for red cell transfusion dependent on symptoms. Other clinicians only start red cell transfusions when haemoglobin reaches a certain level. This results in individual treatments for each MDS patient.

The frequency of transfusions will vary between patients. For some, it is every few months, whilst for others the frequency is every couple of weeks. The length of time between transfusions generally shortens over time with regular transfusions.

Contact your haematology team if your anaemia symptoms come back before your next transfusion is due. They can determine whether the interval between your transfusions should be shorter. They may also increase the number of units of blood you have each time.

Platelet transfusions

About half of the patients with MDS show a reduced platelet count at diagnosis. Because the platelet count is reduced and the platelets do not function well, bruising and bleeding can occur.

If your platelet count is low, you should avoid taking:

- Blood-thinning agents such as: aspirin, warfarin, clopidogrel or rivaroxaban
- Non-steroidal anti-inflammatory drugs such as: ibuprofen, naproxen or diclofenac

These drugs will increase bleeding. There are occasions when the benefit of taking these drugs can outweigh the risks. You should always discuss with your doctors first.

Platelet transfusions might help to keep your platelet count at a higher level.

Your blood platelet levels can be low if:

- You have an infection
- You are on blood thinners or have suffered a bleeding event

Antifibrinolytic drugs (tranexamic acid) and thrombopoietin receptor agonists (eltrombopag) increase platelet production. This helps prevent bleeding from the mucous membranes in patients with MDS.

Growth factors

The use of growth factors can sometimes increase blood cell levels in people with low blood counts. Growth factors are like natural ‘hormones’ that stimulate blood production. Everyone makes growth factors in their bodies.

Growth factor injections are given under the skin (subcutaneous). The number of injections of growth factors will vary from patient to patient. A district nurse can give you these injections, or you can learn how to give the injections yourself. The skin around the injection site may become inflamed or irritated. To avoid this, it is best to change the injection site on a regular basis.

Types of growth factors include:

Erythropoiesis-stimulating agents

Erythropoietin (Epo) is a growth factor that has the potential to increase the number of red blood cells in some MDS patients. Epo is potentially beneficial for patients with very low/low/intermediate MDS and an IPSS-R risk score of up to 3.5. These patients must also have symptomatic anaemia with a haemoglobin <100g/L. and a serum Epo of <500IU/L. Patients with high-risk MDS can also show a good response to Epo therapy.

Granulocyte colony stimulating factor (G-CSF)

G-CSF is a growth factor that increases the numbers of white blood cells. It is useful in patients with low-risk MDS to prevent recurring infections. In patients with high-risk MDS treated with azacitidine and lenalidomide, combined administration of G-CSF and antibiotics can improve symptoms.

Iron chelation treatment

With every blood transfusion you have, you may be at risk of an iron overload. This is because red blood cells have a rich iron content. An iron overload may damage your organs, such as your heart or liver.

Your haematology team will check the level of iron in your body at regular intervals if you are having transfusions. Iron chelation can be prescribed if its benefits outweigh its disadvantages. Iron chelation drugs bind to the iron in your body. They are passed out through the urine or stools. Your MDT will discuss the pros and cons of iron chelation administration with you, if you decide to have iron chelation.

Only prolonged iron chelation administration will be effective.

End of life care

Your MDT will let you know if end-of-life care is needed. End-of-life care may last days, months or years.

There are no specific guidelines about what your MDT will do if they can no longer treat your MDS. You will be managed according to general good practice for anyone who has a terminal diagnosis of a cancer. Your healthcare team will treat you according to how you feel over time and your individual wishes.

End-of-life care helps patients live the remainder of their lives as well and comfortably as possible. The aim is to ensure a good quality of life, and then, when the time comes, to die with dignity.

Most hospitals have palliative care teams. They have experience in dealing with end-of-life and related symptoms. If your local hospital does not have a palliative care team, you may have access to a community palliative care team. Further support at home or a hospice is available.

Your MDT will talk over your wishes for future care. They will also provide support to your family, carers and loved ones. You can decide where you receive end-of-life care, either at home, in a care home or a hospice. The same choices apply when it comes to where a patient wishes to spend their final days.

For more information about end of life, including how to talk about it, plan for it, and record your wishes, scan the QR code to take you to the Compassion in Dying website:

MDS Specialist Centres and useful organisations

MDS Centres of Excellence are UK centres with a specialist interest in treating patients with MDS. Under NHS rules, you are free to seek a referral to the hospital of your choice. You can make the referral request through your GP or your local haematologist.

If you feel that your care is not sufficient for your needs, you can also ask for a referral. These referrals are particularly useful in complex cases of MDS.

Generally, you should expect your haematologist to provide you with the following:

- Your subtype of MDS
- Your IPSS or IPSS-R score
- A regional MDT meeting to discuss and confirm your diagnosis
- A discussion covering a monitoring/treatment plan
- A mention of the availability of clinical trials
- Regular reviews with potential further biopsy if circumstances change
- Details of a Clinical Nurse Specialist
- Information materials and details of support groups

Haematologists in the MDS Specialist Centres have extensive experience of treating MDS patients. They will work with your local haematologist to offer you the best possible care and advice.

If you request a second opinion at a different MDS Specialist Centre, you will still receive treatment at your local hospital. Your haematologist and the specialist at the Specialist Centre will work together to provide you with the best care, known as ‘shared care’.

Specialist Centres

The details of these specialist centres are available at mdspatientsupport.org.uk/what-is-mds/specialists-centres/

UK patient organisations and support groups

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

Leukaemia Care

Helpline: 08088 010 444 (Monday to Friday, 9:00am to 5:00pm)
WhatsApp: 07500 068065 (Monday to Friday, 9:00am to 5:00pm)
www.leukaemiacare.org.uk
support@leukaemiacare.org.uk

MDS UK

020 7733 7558 (Monday to Friday, 9:00am to 5:00pm)
www.mdspatientsupport.org.uk
info@mdspatientsupport.org.uk

MPN Voice

Provides specific support for those with myeloproliferative neoplasms.

07934 689 354 (Monday to Friday, 8:00am to 5:00pm)
www.mpnvoice.org.uk
info@mpnvoice.org.uk

MDS-Europe

The MDS-RIGHT website in Europe is a host for MDS blogs, international patient resources and interactive MDS guidelines for the diagnosis and management of MDS.

www.mds-europe.org

Anthony Nolan

This charity provides specific information to patients, families and stem cell donors about stem cell transplantation and donation.

0303 303 0303

www.anthonynolan.org

info@anthonynolan.org

Blood Cancer UK

Leading charity into the research of blood cancers.

0808 2080 888

www.bloodcancer.org.uk

Young Lives vs Cancer

This charity helps children and young people (0-25 years) and their families find the strength to face their cancer.

www.younglivesvscancer.org.uk

DKMS

This charity maintains the largest network of stem cell donor databases in the world. It is also involved in the research and science in the area of stem cell donation and transplantation.

www.dkms.org.uk

Macmillan

Provides free practical, medical and financial support for people facing cancer.

0808 808 0000

www.macmillan.org.uk

Maggie's Centres

Offers free practical, emotional and social support to people with cancer and their loved ones.

0300 123 1801

www.maggiescentres.org

Financial help and benefits advice

Citizens Advice

Offers advice on benefits and financial assistance.

0800 144 8848 (England); 0800 702 2020 (Wales)

www.citizensadvice.org.uk

Turn2us

A national charity providing practical help to people who are struggling financially.

0808 802 2000

www.turn2us.org.uk

Macmillan

Provides free practical, medical and financial support for people facing cancer.

0808 808 0000

www.macmillan.org.uk

Travel insurance

You are able to get travel insurance and go on holiday even if you have a pre existing medical condition such as MDS.

MDS UK and Leukaemia Care have information about travel insurance and recommended insurance providers.

For carers

Carers UK

A charity that provides information, advice and support to help make life better for carers.

0808 808 7777

www.carersuk.org

info@carersuk.org

Carers Trust

A charity that works to transform the lives of unpaid carers through collaboration, influence, evidence and innovation.

0300 772 9600

www.carers.org

support@carers.org

How you can help us

If you've been affected by MDS, sharing your story can help others going through a similar situation and help the public to better understand.

Scan the QR to share your story:

Alternatively, you can email our Communications team at communications@leukaemiacare.org.uk.

We are continually working to make sure our information is up to date and includes everything you need to help feel supported and empowered to advocate for yourself. With this, it is important for us to listen to any feedback you might have about our MDS booklet.

After ordering one of our booklets online, please consider leaving a review. Your feedback helps us provide better information.

Alternatively, you can email our Information team at information@leukaemiacare.org.uk, call our office line on **01905 755 977** or write a letter to our Head Office at **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**.

If we've helped you - here's how you can give back

Fundraising is at the core of what we do here at Leukaemia care, and without it we wouldn't be able to provide the support we do.

Fundraising isn't all about running a marathon, and there are plenty of ways to give thanks and show your support.

You could:

- Ask your local shop or workplace to host a collection tin
- Ask your place of work about charity of the year partnerships or grants
- Take on one of our more accessible walking challenges
- Host a quiz night or get your friends together for a catch-up and a meal
- Host a bake sale at work or school, or even a coffee morning with friends
- Share information about the activities we have going on to get friends and family joining in
- Stream online from the comfort of your own home

However, if you can run a marathon or want to do a thrilling skydive, we've got you covered!

Whatever you want to do, we can support you to raise money for Leukaemia Care. Get in touch with the fundraising team by email fundraising@leukaemiacare.org.uk or calling **08088 010 444**.

You can find out more about how to get involved by scanning the QR code.

Plenty of ways to give

There are so many ways you can give in support of those affected by a leukaemia diagnosis, the possibilities are endless - find one that fits you and let's get giving!

By bank transfer

You can transfer the funds straight from your account to ours. Our bank details are:

Sort code: **20-98-61**

Account number: **80823805**

Account name: **Leukaemia Care**

By cheque

Please make your cheque payable to Leukaemia Care, and then pop it in the post to: **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**

Online

Simply pop onto our website at www.leukaemiacare.org.uk/donate to pay your money in. Remember to include your activity name to help us know it's you paying in.

By phone

You can call us to pay by debit or credit card over the phone. Simply call 0**1905 755977**.

You can also make a donation by scanning the QR code.

Leukaemia Care is the UK's leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

Every year, 10,000 people are diagnosed with leukaemia in the UK. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**
(free from landlines and all major mobile networks)

WhatsApp: **07500 068065**

Office Line: **01905 755977**

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

Leukaemia Care is registered as a charity in England and Wales (no. 1183890) and Scotland (no. SC049802).

Company number: 11911752 (England and Wales).

Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity

Trusted Information Creator
Patient Information Forum