MDS UK
Supporting Patients with Bone Marrow Failure
www.mdspatientsupport.org.uk

Understanding Myelodysplastic Syndromes

Patient handbook

In collaboration with:

Leukaemia CARE
supporting a quality of life
Blood and Lymphatic cancers
Registered charity 259483 and SC039207

Bloodwise
Beating blood cancer since 1960

MDS UK
Supporting Patients with Bone Marrow Failure
www.mdspatientsupport.org.uk
to see how you can get involved

November 2016
Next planned review: November 2018
Version: 1

Useful information and contact details

Hospital Number: NHS Number:

Date of diagnosis:

My diagnosis / Type of MDS:

Cytogenetic results

Date	Details & chromosome affected	Good, Normal or Poor

	Name	Contact details
Consultant haematologist		
Specialist nurse		
GP		
Haematology day care unit		
Haematology inpatient ward		
Emergency contact number		

Introduction

Being diagnosed with myelodysplastic syndrome (MDS) can be a shock, particularly when you may never have heard of it.

This booklet has been written to help you understand more about MDS. It describes what they are, how they are diagnosed and treated and also the expected outcome (prognosis). It will also provide information on coping with the emotional impact of an MDS diagnosis.

For more information, your haematologist or clinical nurse specialist will be able to provide advice that is specific to your diagnosis.

This booklet has been written by 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; and peer reviewed by Professor David Bowen, Honorary Professor of Myeloid Leukaemia Studies and Consultant Haematologist St James's Institute of Oncology.

The booklet has also been reviewed by patients and we are grateful to Chris Dugmore and Claudia Richards for their valuable contribution.

Throughout this booklet you will see a number of quotations. These are the real experiences of MDS patients and will hopefully help you to understand your situation a bit better.

This booklet has been compiled by MDS UK Patient Support Group, Leukaemia CARE and Bloodwise in a joint collaboration. Although you are reading the version supplied by MDS UK Patient Support Group, all of the wording is the same in each organisation's booklet. This booklet does not endorse any specific product or brand – any names mentioned are for information only.

Acknowledgements and further thanks to:
The Irish Cancer Society for their permission to use information and images from their MDS booklet.

Contributing charities

About MDS UK

MDS UK Patient Support Group provides information, assistance and advice to patients and families affected by myelodysplastic syndromes. We offer a helpline, newsletter, website, chat forum and meeting groups nationwide to facilitate contact with other MDS patients and their families. Based at King's College Hospital, MDS UK is the only national support group solely dedicated to MDS.

About Leukaemia CARE

Leukaemia CARE is dedicated to providing information, support and advice to blood cancer patients, their carers and loved ones. Whether they need a listening ear from our 24-hour CARE Line team, a buddy to chat to who has been in a similar position, a visit to one of our support groups or good quality, trusted information about a diagnosis, treatment or side effects, we are here for them all.

About Bloodwise

Bloodwise is the UK's biggest blood cancer charity and we're here for every single person affected by blood cancer. Our world-class research has changed the world for patients, and we provide high quality patient services which are designed with and for people affected by all types of blood cancer. We offer support to patients, their family and friends: from facts to emotional support and practical advice – from the point of diagnosis through to a time when people are living with or beyond blood cancer.

In this booklet

Section 1

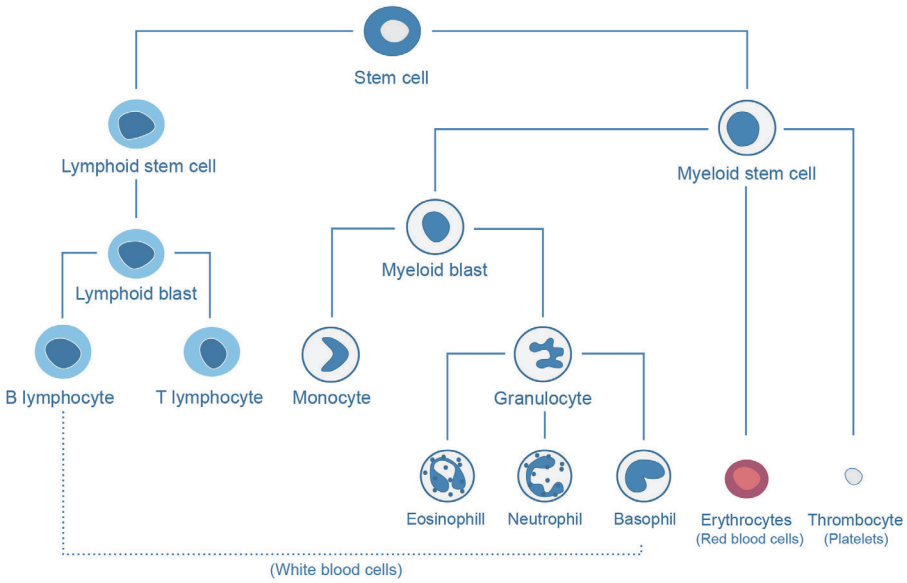
Myelodysplastic syndromes at a glance

What are myelodysplastic syndromes?

The myelodysplastic syndromes, or MDS for short, are a group of diseases in which the production of blood cells by the bone marrow is faulty. It is a type of cancer and sometimes may be referred to as bone marrow failure. The bone marrow is the factory where blood cells are made and it is here where the problem lies.

The bone marrow makes three main types of blood cells:

- red blood cells that carry oxygen around the body
- white blood cells that fight infections
- platelets that prevent bleeding



What causes MDS?

In MDS, the bone marrow is usually more active than normal, yet the cells it produces are not healthy (we refer to that as 'dysplastic') and many die either before they reach the bloodstream or shortly afterwards. This results in the number of blood cells in the bloodstream being reduced. In addition, those cells that are circulating in the blood do not work as well as they should. Some patients have just one type of blood cell that is low (such as red blood cells), however, sometimes MDS can cause a reduction in all the types of blood cells. This is called 'pancytopenia'.

Can MDS lead to any other conditions?

In addition to low blood counts, the myelodysplastic syndromes share a common tendency to develop into acute myeloid leukaemia (AML) over time. The risk of this occurring depends on the type of MDS, and some patients with early forms of the disease may never progress to AML.

You can find out more about AML in factsheets and booklets available from Bloodwise and Leukaemia CARE.

Is MDS a cancer?

MDS is a form of bone marrow cancer, although its progression into leukaemia does not always occur. It is included in the World Health Organisation Classification of Haemopoietic (blood and bone marrow) Tumours.

You do not need to learn everything about MDS at once.

Read a section of this booklet at a time, when you feel able.

Section 2
Who gets MDS and why?

MDS is a rare disease. It may be diagnosed at any age but it is very rare in childhood and young adults. This booklet deals with MDS occurring in adults.

The typical age for patients to develop MDS is around 75 years old. About 9 out of 10 patients are over 50 years at the time of diagnosis. Men are slightly more likely than women to be diagnosed with MDS.

The cause of MDS remains largely unknown, although there are many research groups around the world who are trying to improve our understanding of why it occurs and in whom. There are certain factors that may increase your chance of developing MDS and these include:

- Previous chemotherapy with or without radiotherapy – this treatment may have been given in the past usually for other cancers. It is thought that the treatment damages the bone marrow factory cells and may cause MDS in some patients. This is called secondary or therapy-related MDS, as it is secondary to the previous chemotherapy or radiotherapy.
- Inherited disorders – very rarely, MDS can be inherited or may develop from another rare blood disorder such as Fanconi anaemia. For this reason, young patients may be tested for any diseases that are linked to MDS. However for the vast majority of patients, MDS will not be passed down to children and is not an inherited genetic disease.
- Environmental factors – exposure to toxic chemicals such as benzene may marginally increase the risk of MDS, but such exposure is now uncommon.

MDS is not an infectious disease and it cannot be passed onto other people.

Section 3

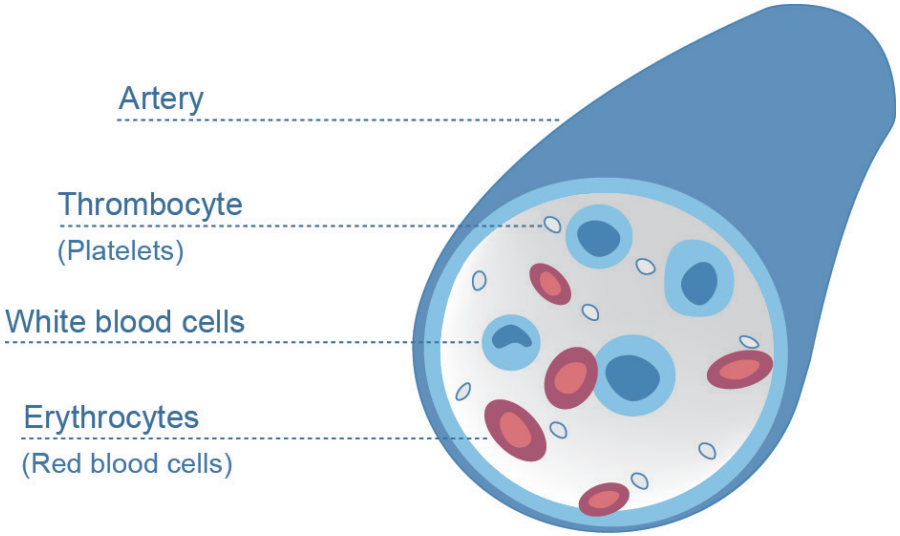
What are the signs and symptoms of MDS?

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

Symptoms vary from person to person and depend on which blood cells are low. About 8 in 10 patients have anaemia, whilst about 2 in 10 present to their doctor with infections or bleeding.

Anaemia is due to a lack of red cells (also referred to as a low haemoglobin), which may lead to fatigue and shortness of breath even on light exertion.

When your platelet count is low, you can suffer from easy bruising and bleeding. This can sometimes manifest itself as a rash on your skin. These are tiny bleedings under the skin called petechiae and often appear where clothes are tight fitted like around the ankles or waist. Nose or gum bleeds can also be a sign of a low platelet count.



Recurrent and persistent infections are another common symptom of MDS due to low white cell counts.

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

Anaemia is the most commonly experienced symptom in MDS

Section 4

How are the myelodysplastic syndromes diagnosed?

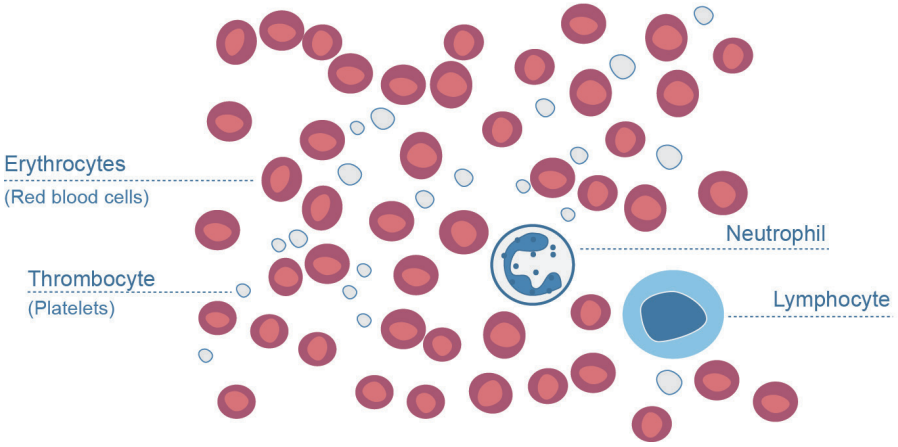
Full blood count

Low blood counts are picked up by a simple test called a full blood count (FBC). The laboratory performing the test will then examine the blood cells on a slide (called a blood film) under the microscope. If you are found to have changes on the blood film that suggest MDS, you will usually be referred to a blood specialist (haematologist). It is important to rule out other causes of a low blood count so the doctor will ask general health questions and give you a physical examination.

Bone marrow test

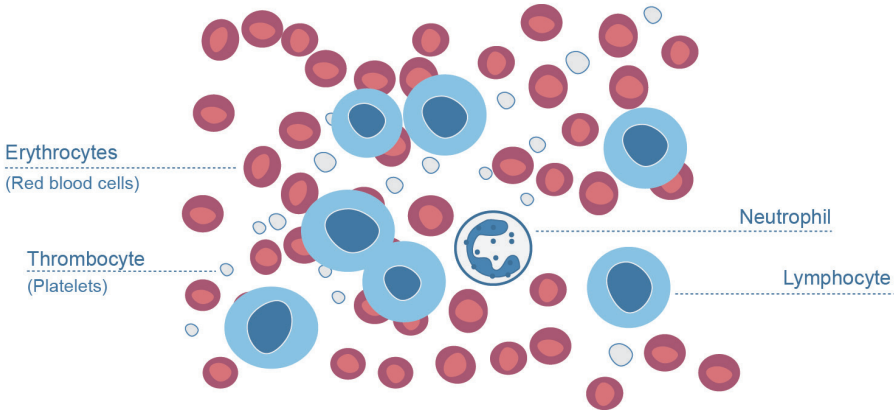
As MDS is a disease of the bone marrow, a bone marrow test is usually needed to diagnose the condition, or monitor response to treatment.

Normal blood film



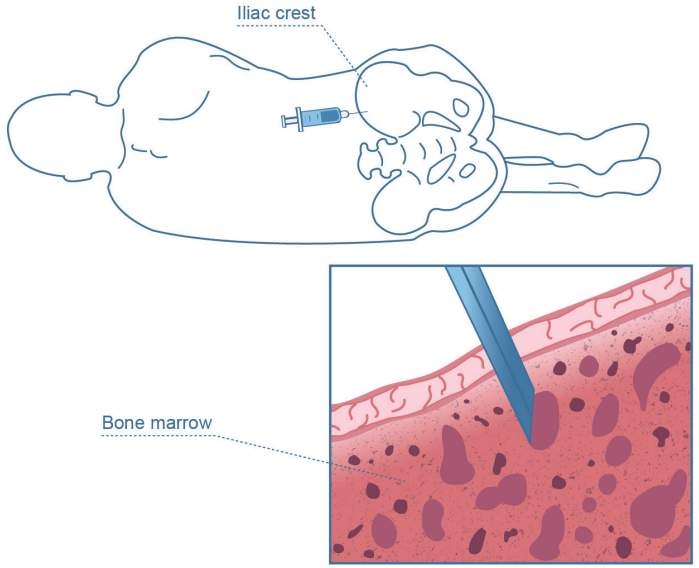
"I remember very little from when I was diagnosed as I was terrified and in shock."

Abnormal blood film



What does a bone marrow test involve?

This is usually performed as an outpatient when a small amount of bone and bone marrow are taken, generally from the pelvis (hip bone). The doctor will numb the area with local anaesthetic and a needle is inserted into the bone marrow cavity. A small liquid sample is taken followed by a biopsy.



The procedure usually takes around 20-30 minutes, but you should allow an hour of your time. It may be uncomfortable at the time, or later that evening, but simple paracetamol is usually enough to relieve the pain. You may be asked to lie on your back after the procedure for 10 minutes to reduce the risk of bleeding. A small dressing or plaster is applied to the site.

Why do I have to wait so long for the results?

Preparing the sample and analysing all the results can take two to three weeks. The bone marrow sample is processed in the laboratory and examined by a doctor under a microscope to look for changes seen in MDS. Additional tests are often requested on the bone marrow sample, which may help to make the diagnosis and provide information about how the disease will behave (prognosis).

These include cytogenetics (sometimes called a 'karyotype'), which is the study of the changes in the structure of the chromosomes in the affected cells. It is important to understand that these chromosome changes occur at the time the disease develops and are only in the bone marrow cells (so-called acquired changes) and are not passed on to family members (so-called inherited changes). Some centres are now also testing for 'molecular' changes. We are still learning what these changes may mean for MDS patients and this will become clearer in the near future.

In most cases of MDS, the typical features are present in the bone marrow and the diagnosis is straightforward. However, unlike most other diseases, there is currently no specific diagnostic test for MDS and so reaching a diagnosis can sometimes be challenging and take a little longer than expected. If there is doubt about whether or not you have MDS, your doctor may decide to monitor your blood counts and repeat the bone marrow test at a later stage.

Waiting for your test results may be an anxious time. Talk to your family and friends, or contact patient support organisations which can assist in different ways. They can help put you in touch with other patients over the phone, in person or through online forums.

A bone marrow sample may not be necessary in the case of some patients whose care is unlikely to be affected by the result, for example if the patient is not fit or suitable for any treatment.

You can read about the experiences of other people who are going through or have been through the same thing on the websites of patient support organisations. It is important at an early stage to get your support and information from recommended and reputable sources, as the internet can present misleading and unvetted facts.

You can find details of all the different support organisations in our Signposting chapter further on in the booklet.

"There is a lot of confusing and scary literature around, so talk with real people about it; it's really helpful."

Section 5

What are the types of MDS?

Your doctor will describe the type of MDS that you have, as they can behave differently. There is a generally accepted classification system for separating the different types of MDS. A 'classification' is broadly a means to describe the type of MDS that we see down the microscope. This system is based on the blood results, the appearance of the bone marrow and any chromosome changes found. The World Health Organization (WHO) has developed a regularly updated classification based on the appearance of the bone marrow and the number of leukaemia cells seen. These leukaemia cells are called blasts, which may be increased in some of the types of MDS.

There are six broad types of MDS included in the current classification (2008), these are:

- Refractory cytopenia with unilineage dysplasia (RCUD)
- Refractory anaemia with ring sideroblasts (RARS)
- Refractory cytopenia with multilineage dysplasia (RCMD)
- Refractory anaemia with excess blasts (RAEB)
- Myelodysplastic syndrome unclassified (MDS-U)
- MDS associated with del(5q), including the 5q- syndrome

The terminology used can be difficult to understand, so ask your doctor to explain which type of MDS you have. Low blood counts are called 'cytopenias', 'dysplasia' means that the bone marrow cells are abnormal in their appearance and 'sideroblasts' are young red cells that have a very distinctive ring of iron granules seen under the microscope. Del(5q) is a special type of MDS recognised by the fact that the chromosome tests show part of the chromosome five is missing.

Healthy, mature red blood cells

Abnormal, ('dysplastic') red blood cells

There are many types of MDS and this can be difficult to understand. Spend time talking to your doctor or nurse so you understand how your MDS will be treated. It's important that you know and understand your exact diagnosis. You could ask your treatment team to write it in the front of this booklet, so that you have it to hand.

What does high risk and low risk MDS mean?

It is often easier to consider whether the type of MDS you have falls into what is called a LOW risk group or a HIGH risk group. The 'risk' refers to your chance of developing acute myeloid leukaemia (AML) and your life expectancy (survival). In the low risk disease group a patient has about a 1 in 10 chance of progressing to AML. The low risk group includes RCUD, RARS, RCMD, MDS-U and the 5q- syndrome. In contrast, the risk of developing leukaemia is greater in the high risk disease group (RAEB). The separation into these groups is important as the treatment of patients with low risk and high risk disease can differ. Your doctor may use the WHO classification to decide whether your disease is low or high risk; although it is usually better to use the prognosis score (IPSS or IPSS-R) discussed further in the booklet.

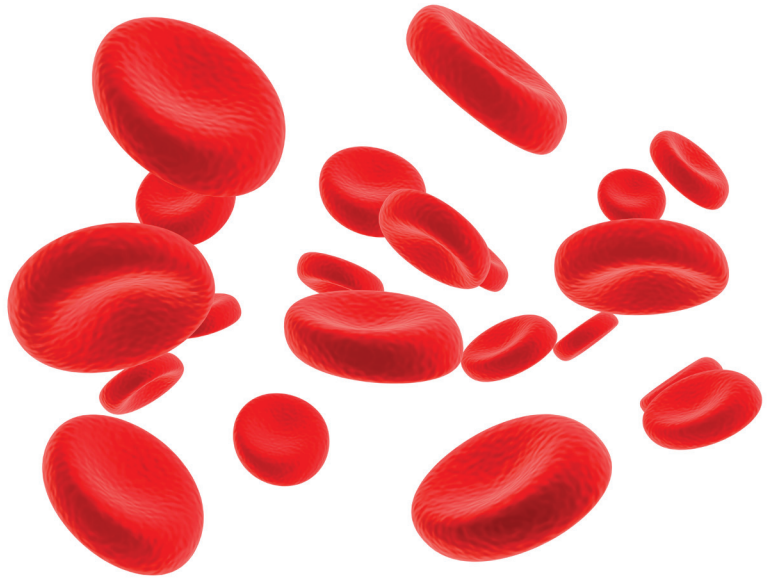
Why is Chronic Myelomonocytic Leukaemia (CMML) not included in the MDS classification?

CMML tends to behave in one of two ways; either like MDS or like the myeloproliferative neoplasms (MPN) where some of the blood counts are high rather than low. The WHO has therefore classified it separately to MDS, as one of the myelodysplastic/myeloproliferative neoplasms.

Most patients with CMML have a high white count and often an enlarged spleen. Treatment may be required including gentle chemotherapy with hydroxycarbamide or azacitidine.

A small number of younger patients may be suitable for a stem cell transplant; this should be discussed with your doctor. You can read more about transplants later in the booklet.

You can find out more about CMML in factsheets available from Bloodwise and Leukaemia CARE.



Section 6

What is the prognosis of MDS?

Prognosis refers to the expected outcome or survival from MDS and is therefore different from classification. Your prognosis can depend on many factors including those not related to MDS, such as your general fitness and age.

However, to allow your doctor to make the right treatment choices, MDS doctors and scientists around the world have designed a number of systems by which we can score how your MDS is likely to behave. Over time, these scoring systems have evolved to give more accurate estimations.

The most commonly used scoring systems are the International Prognostic Scoring System (IPSS) now largely superseded by the revised International Prognostic Scoring System (IPSS-R).

Can you explain the scoring systems in more detail?

The British MDS Guidelines recommend using the IPSS-R as a scoring system (see appendix).

The IPSS-R is calculated from:

- your blood count results at the time your MDS is diagnosed
- the number of blasts (leukaemia cells) in your bone marrow at diagnosis
- the chromosome test results from your bone marrow at diagnosis

The calculator adds together the individual scores to give a final score, and you are allocated to an IPSS-R risk group:

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

The risk describes the expected risk of developing acute myeloid leukaemia and survival. It helps your doctor make the best treatment choices for you. It is important to understand that the expected survival and outcome for each group refers to the information for all patients in that group as a collective. It is not possible to give a precise outcome figure for an individual patient but this information can be a useful framework for a discussion about the future and the options for treatment that may help.

As our understanding of the molecular changes seen in MDS increases, this may allow us to more accurately work out an individual patient's outcome and guide treatment further.

Doctors sometimes refer to 'low-risk' and high-risk' MDS. Low-risk refers to patients with IPSS Low and Intermediate-1, whilst high-risk is IPSS Intermediate-2 and High categories. The risk designation is more difficult with the IPSS-R with low risk certainly including Very Low and Low categories and high-risk including High and Very High categories. As yet we are not sure of the risk designation for IPSS-R Intermediate group.

UK MDS Forum and British Committee for Standards in Haematology MDS Guidelines

A group of expert haematologists, with a specialist interest in MDS, has prepared guidelines for the diagnosis and therapy of adult myelodysplastic syndromes.

These are updated periodically to reflect changes in medical practice. The content of the treatment section of this booklet is based on the BCSH guidelines, the full version of which can be found online at **www.bcshguidelines.com**.

It is important to understand that although guidelines represent the collected opinions of a group of experts based on best clinical practice from available evidence, they are only guidelines.

In most cases, a patient's treatment will be based on these but a doctor may decide that it is not in the best interests of a specific patient to be treated exactly, or even broadly, according to the guidelines. If this is the case for you, then your doctor will discuss the reasons for this.

The UK MDS Forum is an expert organisation open to those healthcare workers and scientists with an interest in MDS. The aim of the Forum is to increase the awareness of MDS through education and increase the access to clinical trials for patients with MDS across the UK.

Section 7

Treatment of MDS

How is MDS treated?

The way that MDS behaves varies from person to person, and on the type of MDS that you have. The types of MDS have been described in detail earlier in this booklet. Treatment is based on UK National Guidelines agreed by MDS specialists, and your care will be discussed in your local multidisciplinary team (MDT) meeting.

What is an MDT?

The diagnosis and treatment of all patients with MDS are reviewed by a group of haematologists in the area that you live. This is called a multidisciplinary team meeting. It allows your case to be discussed by many doctors and healthcare professionals in the Haematology clinical team. Occasionally, it is necessary to ask for another opinion outside of this group to help either with the diagnosis or to discuss the best form of treatment.

An MDT involves doctors, nurses and other healthcare professionals putting their heads together and deciding the best treatment specifically for you.

Treatment planning

Once the diagnosis of MDS has been made, you and your doctors will decide on the best treatment for you. The treatment that you are offered will depend on the type of MDS you have, your own wishes, your age, your general wellbeing or fitness and the IPSS-R score (see earlier section). Before your treatment starts, your doctor or nurse will explain the benefits and side effects of the chosen treatment so that your consent can be taken. It is likely that you will need to sign a consent form to agree to the treatment. If you are unsure about anything, do ask, as MDS is a complicated disease to understand.

The BCSH MDS guidelines recommend that all patients who are newly diagnosed with MDS are discussed with a regional or national expert in MDS, given that the disease is rare. You are entitled to ask your doctor if they have done this. The NHS also allows you to ask to see a regional or national expert in MDS if you think that this would help you.

Not all patients need active treatment, as some do not have any symptoms. If you are not starting treatment, you will have regular check-ups which is often referred to as 'watch and wait' – or 'active monitoring'.

> *"The challenge is predominately mental since it's very hard to accept that I have cancer but that it isn't being treated."*

Broadly speaking, treatment of MDS includes:

- supportive care – this aims to control the symptoms of MDS
- non-intensive treatment – this treatment tries to slow down the progression of MDS and improve your blood counts
- intensive chemotherapy – this involves giving high doses of chemotherapy in hospital
- stem cell transplant

Unfortunately most patients' MDS cannot be cured but MDS can usually be controlled and often improved.

The first question that your doctor will ask themselves is whether there is a treatment option that has a chance of curing the MDS. The only treatments that can possibly cure MDS are 1) a stem cell or bone marrow transplant from another person, or very rarely 2) intensive chemotherapy.

If a stem cell transplant is an option for you, you will be identified early so that a search for donors can be started and a transplant considered at an early stage.

What is a clinical trial?

Research into MDS continues worldwide to improve our knowledge of why MDS occurs, how individual types of MDS behave and how best to treat the condition. Today we benefit from the thousands of patients who have been part of clinical trials and research studies in the past. The word 'research', 'trial' or 'new drug' sometimes scares people, but rest assured, patients receiving new drugs in a trial are monitored very closely for side effects. Your doctor may discuss with you a clinical trial available at your hospital; however, you cannot be entered into a trial without your permission. It needs to be fully explained to you, and you need to have time to think about the treatment before deciding. This is called 'informed consent'. If you agree to be treated in a clinical trial, you can still change your mind at any point and come out of the trial. If you decide not to go into a clinical trial, you will be given the best-proven treatment available. We try to offer patients the opportunity to participate in clinical trials where possible so that we can improve our knowledge of MDS and make the treatment better for patients. Please ask if there are any clinical trials suitable for you available in your hospital or in the nearest specialist centre if you are interested to take part.

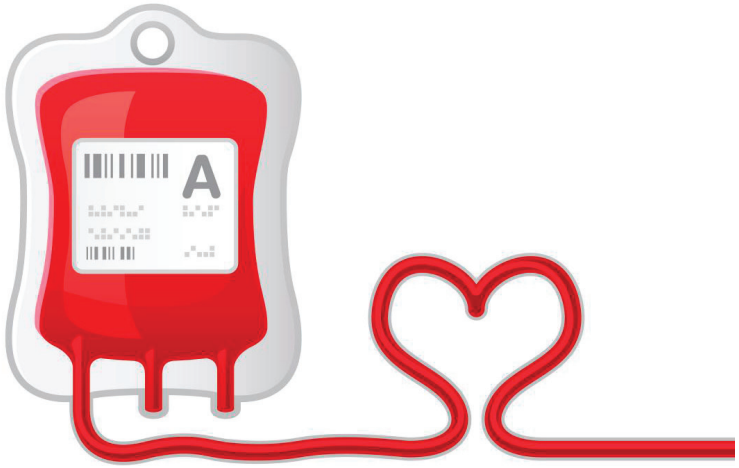
When you have a bone marrow test to diagnose MDS or monitor treatment, your doctor may ask your permission to store some of your blood or bone marrow for future research into the biology of MDS (what causes MDS). There will be an information sheet for you to read and informed consent will need to be taken. Remember to ask your research team if you have any questions.

Supportive care

All patients will need supportive care at some stage, either alone or to support the treatment that you are receiving. Supportive care is not directed at the underlying disease but rather at controlling the symptoms and complications caused by the disease. The nature and extent of supportive care needed depends on which blood cells are most affected and exactly how low their blood levels fall. Most patients will need blood transfusions at some stage.

a) Treating anaemia

Most patients (but not all) diagnosed with MDS are anaemic. Although the anaemia is usually not life threatening, it can cause symptoms such as tiredness and shortness of breath. Anaemia may affect your quality of life and if so it will need treatment. Some patients continue living with a normal or acceptable quality life despite anaemia and will not necessarily need treatment for the anaemia at that stage. The haemoglobin (Hb) level in your blood results will show your level of anaemia.



b) Blood transfusions

Blood transfusions are considered if you have symptoms from anaemia. There is no set haemoglobin level at which a blood transfusion is given, but your doctor will assess your symptoms and you will decide together. How often you have transfusions will vary between patients; some need transfusions every few months whilst others need one every couple of weeks. Usually, once you have started having regular blood transfusions, the length of time between transfusions will gradually get shorter. If you find that your symptoms of anaemia come back well before your next transfusion is due, contact your haematology team and discuss whether the interval between transfusions should be shorter, or the number of units of blood increased. This varies between patients.

With every unit of blood you receive from a transfusion, you will receive an excess amount of iron. Over time this can accumulate in your body and could possibly cause damage to certain organs, like your heart or liver. Because blood transfusions are rich in iron, it is important that you do not take additional iron tablets unless your doctor prescribes them. There is still considerable uncertainty whether too much iron in your body is always harmful. The level of iron in your body should be checked regularly, especially when you are on a regular transfusion program and you may need treatment for the build-up of excess iron. This is called iron chelation. There is currently uncertainty about the benefits of removing iron. Whether you are offered iron chelation treatment or not will depend on the likely benefits versus the likely disadvantages in your individual case. This will be discussed with you before you make a decision to start iron chelation.

Desferal is a drug to treat the build up of excess iron and is given as a continuous subcutaneous injection under your skin by a pump. There are special teams that can teach you how to administer the drug at home. Exjade is another iron chelator and comes in tablet form, making it easier for patients with poor sight, problems of finger dexterity or a fear of needles. However, in most cases this is only available for patients who cannot manage subcutaneous Desferal or who have serious side effects on Desferal. Both treatments have certain side effects and often need to be continued for a long period of time to be effective. Your doctor can advise you which drug will be best in your situation. Don't hesitate to discuss your iron levels with your doctor at any time during your treatment.

"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."

c) Growth factors

Blood cell numbers can sometimes be increased by the use of growth factors. Growth factors are like natural 'hormones' that stimulate our blood production. We all make these growth factors every day. For example, erythropoietin (sometimes known as 'EPO') is a growth factor that increases red cell numbers. Granulocyte-colony stimulating factor (or 'GCSF') increases white cell numbers. Not all patients are suitable for this treatment, and only some MDS patients will respond. Your doctor can advise you on your suitability for growth factors.

Growth factors are given as an injection under the skin. The number of injections you will need will vary from patient to patient. A district nurse can give them at home, or you (or a family member) can learn how to give the injections yourself. The skin around the injection site may become irritated, so it is best to regularly change the injection site. Do talk to your nurses about this and also the common side effects that you may expect.

d) Platelet transfusions

About half of MDS patients will have a reduced platelet count at diagnosis (thrombocytopenia). The platelets may also function poorly and this means that bruising and bleeding can occasionally be a serious problem in MDS. Platelets can be transfused but because they only last about four days, they are usually only given if you have signs of bleeding. If you have low platelets, it is usually advisable to avoid blood-thinning agents and non-steroidal anti-inflammatory drugs. However this should be discussed with your doctor as there are exceptions where the benefit you will receive from these drugs outweighs the risks.

Most hospitals will not transfuse unless the platelet level drops below 10, and some hospitals will not routinely give platelet transfusion. When you have an infection, are on blood thinners or have suffered from bleeding, you might benefit from having platelets kept at a higher level (having a transfusion earlier than normal). Your doctor or nurse will inform you when this is necessary.

e) Antibiotics

It is important for you to understand that patients with MDS have a higher risk of developing infections. Antibiotics are not usually given to prevent infections as they cause side effects and may cause the bacteria to become resistant. If you do get an infection, this should be treated quickly with antibiotics, and you may need to be admitted into hospital so that the antibiotics can be given through a vein (intravenous). Most specialist units will have a direct phone number to call for advice in the event of a fever occurring.

Treatment extending beyond supportive care can be classed as low-intensity (or non-intensive), high-intensity or high-intensity with a stem cell transplant.

If you are feeling unwell, take your temperature. If it is raised, or you experience shivers, contact your specialist nurses at the hospital or helpline on the number you have been given.

Non-intensive treatment

Low intensity or non-intensive treatment aims to slow the progression of the disease. It may be considered if your blood counts are quite low or falling, or if there are signs that the disease is developing into leukaemia. The idea is to treat the disease with as few side effects as possible, thereby maintaining a good quality of life. These treatments will not cure MDS but may 'modify' the disease and are usually given as an outpatient. Some of the treatments are considered novel and therefore maybe used as part of a clinical trial.

a) Hypomethylating agents (HMA)

Hypomethylating agents work on the behaviour of cancer cells at the DNA level, which can turn genes on and off. In MDS, drugs such as azacitidine work to improve bone marrow function and slow the progression to leukaemia. They are currently used in high risk MDS patients (IPSS Intermediate-2 and High categories) who are not fit enough for a stem cell transplant. Azacitidine is usually given as an injection under the skin. Side effects can include:

- mild nausea
- diarrhoea or constipation
- skin irritation at the injection site
- becoming more prone to infections (due to lowered blood counts)

b) Lenalidomide

If you have a certain type of MDS called the 5q minus syndrome, or, MDS with deletion of 5q, you may be offered lenalidomide if you are anaemic. This is taken orally as a capsule and works in several ways to suppress the MDS cells, including by altering the immune system. Therefore it is often referred to as a type of immune modulation therapy. On starting the treatment, your blood counts fall before a response is seen. Other side effects can include:

- rashes
- fatigue
- diarrhoea
- a small increased risk of blood clots

As lenalidomide can cause birth defects, you must avoid getting pregnant whilst taking the drug.

c) Immunosuppressive therapy

In a small minority of patients with MDS, the number of the bone marrow cells is unusually low (termed hypoplastic). This is similar to a blood disease called aplastic anaemia. Patients can sometimes respond to drugs targeted at suppressing the immune system, such as anti-thymocyte globulin (ATG) or ciclosporin.

Intensive chemotherapy

If you have high risk MDS, you may benefit from intensive chemotherapy. It is the same treatment that is used to treat acute myeloid leukaemia and aims to kill a significant proportion of the diseased cells from your bone marrow to allow the bone marrow to work normally again (remission). The treatment has a high number of side effects so you need to stay in hospital for four to six weeks for each course.

A small proportion of people may be cured by intensive chemotherapy alone, although usually when a donor is available, a stem cell transplant will follow. Achieving remission, even if not able to cure the disease can improve your quality of life (often almost to normal quality) as long as the remission lasts.

How is intensive chemotherapy given?

Most chemotherapy is given as an infusion into a vein (intravenous), but sometimes as a tablet. It is given as a course or cycle of treatment, whereby a combination of chemotherapy is given over a number of days followed by a rest period. It is often easier for you to have a Hickman line inserted, which allows all the drugs to be given and blood tests to be taken. This is a line that is carefully inserted into a large vein and can stay in place for all your treatment.

The first course of intensive treatment is normally given in hospital but if your bone marrow is then in remission, subsequent treatment can often be started in an ambulatory care / day care unit, although you may have to come back into hospital once the blood counts drop to low levels.

What are the most common side effects from intensive chemotherapy?

The chemotherapy used in MDS is specially designed to kill the cancer cells from the bone marrow, so your blood counts will fall after the chemotherapy and remain low for a number of weeks. Healthy bone marrow cells are also 'stunned' in a type of 'friendly fire' but can recover better than the MDS cells if remission is achieved.

During this time there are serious, sometimes life-threatening side effects, the most common of which are:

- infections
- bleeding
- anaemia

Other side effects can include:

- hair loss
- nausea
- vomiting
- sore mouth
- diarrhoea
- loss of appetite and taste
- skin and nail changes
- infertility

Allogeneic stem cell transplant

A stem cell transplant, also known as a bone marrow transplant, offers the chance of curing the disease.

In an allogeneic transplant, healthy bone marrow or stem cells are taken from another person whose tissue DNA is identical or almost identical to yours. This means the donor is compatible with you. The bone marrow or stem cells are taken from a donor – either a family member (usually a sibling) or an unrelated donor. The donor has a simple blood test to see if they are matched to you – they do not need to have a bone marrow test. The results usually take two to three weeks to be ready.

In the past, only younger patients were offered this treatment, but as medical knowledge and experience has progressed, more patients can now be considered for a transplant. Reducing the intensity of the treatment before the transplant of donor stem cells means the side effects are less. This approach is called a reduced intensity conditioning (RIC) transplant. About one third of patients who receive this treatment are free of disease over many years but the disease may return (relapse).

The treatment has many side effects and it is important that the decision to have an allogeneic stem cell transplant is carefully thought through by your healthcare team and yourself. If you are suitable for a transplant, you will be referred to a specialist centre to discuss the benefits and risks of this treatment to you as an individual. Always try to take a family member or friend to the appointments.

You can find out more about stem cell transplants in 'The Seven Steps' booklet, available from Bloodwise and Anthony Nolan.

Follow-up

Once MDS has been diagnosed, your specialist will discuss treatment options and follow-up. For some patients, this will only mean infrequent outpatient visits to check if the disease is showing signs of progressing. Sometimes these check-ups can be shared with the GP. For those patients where the disease is thought to be high risk or for those who have received active treatment, the outpatient visits may be more frequent. This will be individually tailored to you.

Section 8

The psychological impact of MDS

This chapter is about the emotional impact of having MDS, which can be as significant as the physical impact of the illness. It will describe some of the thoughts and emotions that are possible and help you to understand why you might have these feelings. It includes some suggested coping strategies and ways in which you could help yourself.

It is important to emphasise that each person with MDS will cope in their own unique way. Not everything in this chapter will apply to you, but there are some common thoughts and feelings that you could be familiar with – and to some extent your relatives and carers too.

Your healthcare team should be considering your emotional needs, as well as your physical needs, and should regularly ask you about these.

Adjustment

People living with MDS sometimes experience a range of complex thoughts and intense feelings as they try to cope with the diagnosis, monitoring or treatment. This is often described as 'being on an emotional rollercoaster'. The formal term for these emotional ups and downs is adjustment.

> *"The diagnosis hit me like a ton of bricks. My emotions were on a rollercoaster"*

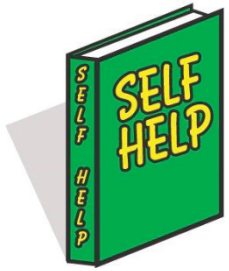
Adjustment is something every person will experience as they go through significant life events like divorce, bereavement or illness. It involves changes and losses of varying kinds, and includes both practical and mental adjustments. In the case of an illness these include:

- getting used to being monitored
- having medical appointments and treatments

- potential loss of – or reduction in – some physical capabilities which, in turn, could affect things like employment, or personal roles and relationships
- disruption to one's usual life patterns and routines
- questioning things normally taken for granted, like good health and future plans – perhaps making people more worried about things than usual

Given the losses and changes involved – which to some can feel frightening – and the need to adapt to and cope with something new, adjustment can be both stressful and distressing. The good news is, that while the emotional ups and downs of adjustment aren't always easy, human beings have evolved to be adaptable and to cope with life's difficulties.

What feelings might you experience and how can you help yourself?



This section describes many of the common emotions (and related thoughts) that people with MDS might experience. Following each description are some suggested coping strategies. These are drawn from evidence-based psychological practices, as well as feedback from patients about what has helped them. It is important to remember that not everyone will experience all of these feelings, but it is equally important to emphasise that if you have some – or all – of them, you are not alone and it does not mean that you are weak or mentally ill.

> *"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."*

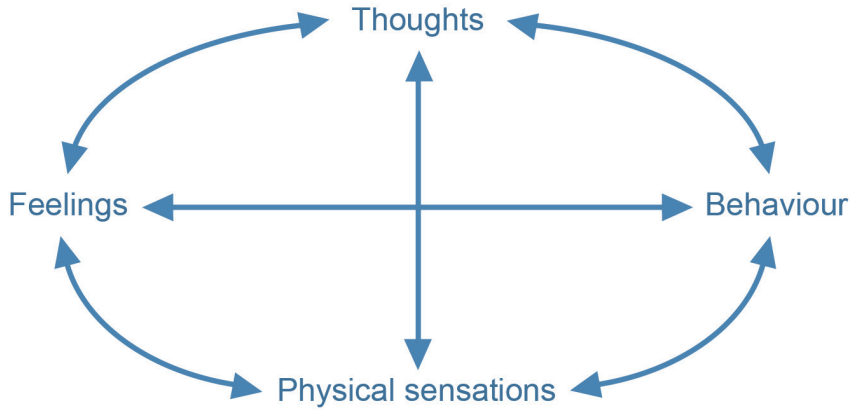
Coming to terms with your diagnosis

Although everyone is different, generally it is helpful to 'process' your thoughts and feelings, rather than ignore them. This means thinking about your diagnosis, including what it means to you and how you might cope. It means being aware of your feelings and being able to express them when you want to. It can be helpful to talk about your situation with other people, both professionals and those in your personal life. Writing thoughts and feelings down can help you to process them too. It is useful to strike a balance between thinking and talking about your situation, and having periods in which you focus on other, meaningful and enjoyable things instead.

> *"It's so important to stay positive, share what's going through your mind and know that you're not alone."*

There is a link between thoughts, feelings, physical feelings and behaviour

Before we move on, it is useful to explain that within every type of mood there are four elements: thoughts, feelings, physical sensations and behaviours (the actions we do, or don't do, to cope). Each of these elements interacts with and affects the other, like in this diagram:



It is hard to directly 'access' and change an emotion, whereas thoughts and behaviours and, to some extent, physical states, are more easily changed. This can help to improve emotional feelings. It is particularly effective to change negative thoughts and thinking patterns. In short, the way we think affects the way we feel.

Managing thoughts

Writing negative thoughts and worries down can be helpful. You will notice that some of them are 'valid' (this means understandable and acceptable) given your situation, but some of them are 'catastrophic' (meaning they predict the worst case scenario) or are very 'black and white' (meaning things are all good or all bad).

Here are some examples: "because of this illness, my life's ruined"; "I know the treatment won't work"; "nothing ever goes right for me"; "everything's awful"; "there's no hope"; "I must be a bad person".

Take a step back and ask yourself whether those thoughts are facts or opinions. Say to yourself "is there another way of looking at this?", or "is that actually what my medical team said to me?" Write down alternative, more helpful thoughts next to the original worries.

This is not the same as 'positive thinking', as you may have some valid concerns; it is about maintaining perspective, having a balanced view, and not getting too caught up in your thoughts.

> *"I think at the beginning I did bottle my feelings up too much, trying to stay strong for everyone else."*

Changing behaviour

Some types of behaviour make emotional distress worse. For example, when people avoid activity, socialising and exercise (even doing basic things like having a shower and getting dressed) they make depression worse, rather than better. And when people avoid situations that make them anxious, this tends to make the problem worse, rather than better.

Behavioural change, which includes engaging in enjoyable and meaningful activities, doing even a little exercise, moderating alcohol consumption, and connecting with other people will help your mood. Another helpful behaviour is 'pacing'. This means doing a consistent amount of activity on a regular basis, and not overextending yourself on a good day. This tends to result in people being so exhausted that they cannot function for a few days.

> *"I have accepted that first thing in the morning I am not going to leap out of bed; my whole body aches so I take it slowly. I feel human and am able to cope with almost anything. I still play golf a couple of times a week, and, being a competitive person I have to remind myself each time how lucky I am just to be out in the sunshine."*

Specific emotions and their coping strategies

Shock, disbelief, helplessness and feeling out of control

These feelings and sensations are common when people experience something outside of the realm of their normal experience, like a diagnosis of a serious illness. The situation can feel threatening and people wonder whether they can cope. These thoughts and feelings can be so overwhelming that people become shocked or numb as a means of protecting themselves. Some people describe a sense of unreality.

> *"There was a total overwhelming feeling of helplessness and being out of control of my everyday life. But I had to carry on regardless for everyone else."*

Coping strategies

- Time is needed for the information to sink in and to be 'processed.'
- It can be helpful to talk things through with others and to express feelings. This helps people to make sense of their situation and to think about how they will cope.
- Having access to the right information at this time is important. It can be difficult to take everything in, so it can be useful to write questions down that need answering or clarifying by the healthcare team.
- 'Grounding' techniques can be useful. These are simply things people can do to bring their awareness to the reality of the present moment, in other words to feel less detached or unreal. You can find more information on grounding techniques at **www.healthyplace.com**.

> *"At diagnosis I was shocked and upset. But I was determined to fight it and live a long life."*

Worry, anxiety and living with uncertainty

MDS often carries with it a degree of uncertainty which can lead to worry and anxiety. It is normal to experience fear about something which is threatening. The emotional response to fear is anxiety, or even panic. This tends to be driven by the physical response to fear, which is a release of adrenaline into the blood stream. This leads to many of the physical symptoms of anxiety like increased heart rate and dry mouth. The mental part of fear is worry. This is what people do as they try to predict and control things that might happen in the future. While it is normal for people to worry about their illness to some degree, excessive worry will lead to chronic anxiety and exhaustion.

> *"I was anxious a lot and focused on my diagnosis and what might happen to me. I didn't want to die."*

Coping strategies

- Managing the physiological part of anxiety is key. It helps to reduce the emotion of fear and to stop the pulse - and thoughts - from racing.
- To do this, it is necessary to reduce hyperventilation (over breathing) and excessive adrenaline production, which are always present in anxiety.
- Slow, controlled breathing is the most effective method. Practices like mindfulness and meditation can be useful, but there are a number of different breathing exercises that are helpful. For examples of these online, visit **www.getselfhelp.co.uk** and **www.patient.co.uk**.
- Reducing tension in the muscles is another means of alleviating anxiety.
- A widely-used technique is called 'progressive muscle relaxation'. This gets people to consciously tense and un-tense their muscles to induce relaxation.
- Notice your negative thoughts and worries and write them down to challenge them.
- Take gentle exercise.
- Various forms of distraction, or mental exercises like Sudoku, can help.

> *Living with uncertainty has been a phrase which I have often used in the past. But living with MDS tests it to extremes. In reality, it's very difficult to live when you are uncertain what the next few months or years have in store for you. Uncertainty breeds anxiety.*

Finally, a vital aspect of managing worry is to accept that some things you cannot know in advance or control.

Also, while it is possible to reduce some of the symptoms of anxiety, it is not possible to eliminate them altogether. As human beings we all live with a degree of anxiety.

A useful means of managing uncertainty is to focus on the 'here-and-now' – on the things you can change, and on the things that you find meaningful and enjoyable in the present moment.

Anger

It is common for people to feel angry that they have been diagnosed with a serious illness. For a number of reasons it can feel confusing, unfair, or that it is outside of their control – for example if the illness is rare, if they believe that they have a healthy lifestyle, if there's no history of similar illnesses in their family, or if they believe that they have already had too many problems in life to cope with. Sometimes it can be difficult to know what to do with feelings of anger or to understand what – or who – the anger is directed at. As a result anger can sometimes get directed at loved ones, or even towards oneself.

> *At diagnosis I felt distraught, devastated and angry. It was unfair. Why me?*

Coping strategies

- Although a sense of disbelief or injustice at being diagnosed with MDS is valid (and common), dwelling on the thoughts behind it tends to make the anger worse. Talk things through with others.
- Write down some of your thoughts and notice those that keep the anger going; try to change them or distance yourself from thoughts about things that have no explanation or cannot be changed.
- Use relaxation techniques, or exercise, for managing the physiological symptoms of anger (similar to those in anxiety, and also driven by adrenaline).
- 'Venting' anger at others tends to be self-defeating because it alienates people, rather than elicit feelings of compassion from them.
- Self-soothe. Treat yourself to things you enjoy; treat yourself with compassion.

Stress

We experience stress when we feel that we are under too much pressure or have too many demands being made of us and that we don't have the resources to cope. Understandably, people can feel like this at times when they are ill and they are trying to cope with the demands of treatment as well as with other concerns, for example financial, employment and relationships. The emotional symptoms of stress can include low mood, anxiety and irritability.

Coping strategies

- Relaxation techniques (controlled breathing, progressive muscle relaxation) and/or exercise to manage the physical, adrenaline-fuelled aspects of stress (which are the same as those in anxiety and anger).
- Notice the negative thoughts which contribute to anxiety, tension and irritability, producing adrenaline as they arise: "this is unbearable", "I can't cope".
- Challenge negative thoughts by writing them down and coming up with more helpful ones e.g. "although this is difficult, I can cope (especially with support)".
- Plan, prioritise, break things down into manageable 'chunks' (writing this out is helpful).
- Pace yourself, rather than doing too much or trying to cope with everything at once.
- Take breaks, and 'time out'.
- Ask for help and support.
- Maintain a 'here and now' focus on things that are enjoyable and meaningful to you.
- Useful online resources include:
  www.helpguide.org
  www.getselfhelp.co.uk
  www.nhs.uk/conditions/stress-anxiety-depression

Guilt and blame

Although becoming ill is never anyone's fault, it is common for people to experience feelings of guilt and blame about their illness. For example people might question whether they became ill because of something they did, or their 'lifestyle'. Some people might think that they are a burden on other people because they need their help, or because they are not functioning as they once were. Although these thoughts are common, they are not valid. They can be part of people's attempts to find meaning in the situation, but what they do is to make people feel bad and distressed about themselves.

> *"At diagnosis, I felt terror, grief, shock, depression, helplessness."*

Coping strategies

- Write guilt and blame thoughts down and try to come up with more balanced and rational thoughts.
- Don't dwell on these negative thoughts.
- Think about what you would say to a close friend or loved one if they were having these thoughts and feelings – and apply this to yourself.
- Make a conscious effort to be more compassionate towards yourself.
- Do some things which are comforting and soothing.

Sadness, low mood, hopelessness and despair

It is natural and normal for people to experience feelings of intense sadness at times when they are ill. Sometimes it can feel that things aren't going well or that they will never be the same again. Some days people can feel very down, but usually these feelings are temporary and people tend to say that they have 'good days and bad days'.

Depression is when people feel persistently sad and hopeless for two weeks or more – and when these feelings are combined with having no interest or pleasure in life, having disrupted sleep and appetite, feeling worthless, and people thinking they would be better off dead.

To some extent, sadness, low mood and clinical depression sit along a continuum. At one end, sadness tends to be an appropriate response to a specific situation, which fluctuates and gradually diminishes over time. In the middle, people can have 'down days' or 'feel blue'. At the other end of the spectrum, depression (often called clinical depression) is more severe and persistent, and it affects the whole of your life and stops you from functioning.

Dwelling on negative thoughts is one of the things that makes low mood much worse and keeps it going. Often the thoughts are self-critical and hopeless in nature; they are nearly always 'black and white' or catastrophic. It can be hard to 'see' or believe anything positive about life, but all too easy to notice and believe negative things. As with the other emotions, writing down negative thoughts and trying to change them can be helpful, as well as talking things through with others. This helps people to gain some perspective and to feel less hopeless.

> *"Cancer is such a tough experience and you can easily be filled with very depressing or scary thoughts. Doing something positive is a very good thing."*

The other thing that helps depression is doing more and engaging with others. This helps to increase a sense of pleasure and reward from life.

> *"The support of my family and local community kept me going and talking with them helped me to offload."*

Coping strategies

- Activate yourself as much as possible; do more, rather than less. Take gentle exercise and don't stay in bed or on the sofa.
- Connect with other people.
- Consciously plan and schedule activities, social time and pleasurable things.
- Try to 'capture' negative thoughts and come up with more helpful and balanced thoughts.
- Remember to ask yourself: "is this a fact or an opinion?"; "what's the evidence?"; "is there another way of seeing this?"; "what would I say to my best friend or partner if they thought this?"
- Useful online resources:
  www.getselfhelp.com
  www.nhs.uk/Conditions/stress-anxiety-depression
  www.helpguide.org/articles/depression/dealing-with-depression

Please note: It is often helpful to seek support if you are sad or low in mood, but it is essential to do so if you are depressed, especially if you are feeling suicidal. If you are feeling depressed, talk to your GP and to your healthcare team so that they can organise formal support for you. Talking therapies can help, and medication if necessary.

Grief

Grief is what people experience when they are mourning people, things, or aspects of ourselves that they have lost. Grief includes most of the emotions described above, especially sadness, as well as a kind of yearning for what has been lost (in other words, you wish you could have it back). In the case of illness this might include previous roles and responsibilities, previously enjoyed activities, fertility, certain freedoms and choices, health and vitality. As grief is a normal response to loss, it cannot be rationalised away. Loss is something that people can learn to live with – and cope with – over time, especially as they adapt to their changed circumstances and engage with other aspects of life.

Coping strategies

- Although grief is a normal process, a preoccupation with certain types of negative thoughts and beliefs, e.g. "I cannot cope without X, my life isn't worth living now", will make it worse and keep it going.
- It can help to write down and challenge thoughts like this.
- Especially helpful for grief is for people to be able to talk about their feelings and about what, or who, has been lost. For a while, many people who are grieving need to be able to 'tell their stories' again and again.

Summary

A diagnosis of MDS affects the whole of you, not just your body and the complex mixture of thoughts and feelings associated with a diagnosis of MDS is common and legitimate. Although they can be unpleasant, they are a normal response to a major life event. Emotional distress of varying kinds can be experienced at any point in your 'journey' but it is important to remember there is support out there and ways in which you can help yourself.

Section 9
Living with MDS

A diagnosis of MDS will have implications for your daily life. Knowing in advance what to expect might alleviate some of the stress or worries around it.

Information about the disease and possible complications can help you recognise when to seek medical attention or ask for further support. It also can give you the feeling that you are more in control.

This chapter will discuss some of the implications a diagnosis of MDS can have on your daily life and provide advice how to deal with certain issues.

Hospital visits

A diagnosis of MDS will inevitably involve regular hospital visits. The frequency of these can vary greatly depending on the severity of the symptoms and the progression of the disease. Patients with low risk disease might only need monitoring every few months or even yearly, while others might need weekly checks. Your doctor or nurse will guide you in how often visits and blood tests will be needed.

All patients diagnosed with MDS have the right to be referred to a Centre of Excellence for MDS (further details are at the back of this booklet). These are academic hospitals with expertise of this rare disease and availability of new drugs via clinical trials. You can ask your doctor if you would benefit from a referral to a Centre of Excellence or ask for an additional opinion when you have questions about your treatment or disease management.

The National Institute for Clinical Excellence (NICE) guidance, published in 2003, promotes that all haemato-oncology patients should have a designated clinical nurse specialist (CNS) who is available throughout their disease pathway to provide support and information. If you have not been introduced to a CNS, ask your doctor if there is one available in the hospital where you are treated and request the contact details.

Blood results

Most patients will learn to keep a record of their visits and blood results and specially designed diaries or apps for your mobile phone are available to record these results. This can be valuable information, especially if you are under the care of more than one hospital or department. Knowing your own blood levels can help you understand why you have certain symptoms and what to do in those situations. You can ask your nurse or doctor to explain the results to you.

The most useful levels to know are:

- Your Hb or haemoglobin (contained in red blood cells) – carries oxygen around your body and are an indicator whether you are anaemic or not.
- Your platelet count (or thrombocytes) – when these are low you can be prone to bruising or bleeding.
- Your white cell count – these are cells that fight infections.
- Your neutrophil count – these cells are part of the white cells in your blood. Neutrophils are the first line defence when there is a bacterial infection. When these cells are low, you are neutropenic, which can make you more susceptible to infections.

Infection and reducing the risk of infection

When you are neutropenic (low levels of neutrophils) and you feel unwell or feverish at home, it is very important to immediately seek medical attention at your nearest hospital. If you are alone or too unwell to leave the house, call an ambulance so that they can bring you in. Patients with the combination of an infection and neutropenia can deteriorate rapidly and should be started on intravenous antibiotics as soon as possible. If you don't have a thermometer, it is advisable to buy one so that you can measure your temperature when you are at home.

Call your hospital team if your temperature goes above 38°C.

Most patients with MDS will be more susceptible to infections. Infections can occur more frequently and also last longer than normal. Patients receiving treatment for their MDS will be more vulnerable and they will start on drugs to prevent infections.

Good hand hygiene is the best way to prevent catching bacterial infections. There are lots of gels for sale but normal hand washing with water and soap is just as effective. In particular, make sure that you wash your hands after using the toilet, when preparing food, before you eat, after gardening and 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.

Normal food hygiene rules apply when you have MDS. When you are on treatment and especially when your neutrophil level drops, you may be asked to avoid certain foods. This varies per hospital. Ask your doctor or nurse for instructions for your specific situation and get general advice from the patient support organisations in this booklet.

When you are planning to travel, ask your doctor if you should bring or start a course of antibiotics to prevent any infections. Especially if you have experienced picking up infections easily, this may help avoid any problems while abroad.

Avoiding infections is not always possible. It is useful to have a thermometer in the house in case you develop a fever so that you can check and inform your doctor or nurse. They can advise you better if they have an accurate temperature level. Most hospitals will have emergency contact details in case you become unwell at home. Ask your doctor or nurse about the arrangements in your local hospital.

If your neutrophil count is low and you have regular infections, you may benefit from injections that can boost your neutrophil levels. GCSF (granulocyte colony stimulating factor) is a drug that can be given under the

skin. It is a hormone that is normally produced in the body and stimulates the growth of white cells in the bone marrow. The injections can cause pain in the bones and muscles which can usually be relieved by taking a mild painkiller, like paracetamol. You can be taught to take these injections yourself, or alternatively a family member, GP or nurse can do it instead.

Nutrition and exercise

Eating well and maintaining a healthy weight will give you more strength and energy. A healthy diet includes:

- lots of fruit and vegetables
- a good proportion of carbohydrates (bread, rice, pasta, potatoes)
- some protein rich foods (meat, poultry, fish, nuts, eggs, pulses)
- some dairy products
- low proportion of foods that are high in salt, fat or sugar
- plenty of water, juices, sugar-free drinks, a little tea and coffee

You are unlikely to benefit from an increase in iron rich foods as most patients with MDS will have normal or high levels of ferritin (a protein that stores iron) levels. There are many theories about specific diets and cancer available. Always discuss with your nurse or doctor before starting a strict diet.

Although in general a healthy diet is advised, for some people this may be difficult, especially when you have had chemotherapy or a transplant as your appetite may be strongly affected. Foods that previously tasted nice may not now and you may find that you lose weight. Nutrition is very important in this situation as this is the source for your body to rebuild itself. If your weight loss is more than 5% of your normal body weight, it is important that special measures are put in place to support you. A referral to a dietician is usually the first step, who will then advise and guide you further.

There is no specific guidance with regards to exercise and MDS. As long as your energy levels allow, you can be as active as you like to be. If your platelets are low, however, you will have to be careful with falls or bumps as these may cause serious bleeding.

In general the more active you remain before, during and after treatment, the easier you will recover after having treatment. Some hospitals will provide exercise programs for patients during and after treatment. Ask your nurse or doctor if you want more information about this.

Fatigue

Fatigue is one of the most widely reported side effects of low haemoglobin levels. Fatigue or lack of energy can seriously impact on your quality of life. A blood transfusion can improve fatigue temporarily – for some it may be a few weeks, for others it may last longer. Treatment for MDS can initially make your fatigue worse but if the treatment is effective and your blood levels recover, fatigue levels can improve over time.

When you feel fatigued you may find it hard to concentrate or make decisions. The worries of having MDS and dealing with treatment can also add to the feeling of being tired all the time.

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

- have a regular lifestyle – try going to bed and waking up approximately the same time every day and try to avoid lying in.
- take part in regular, gentle exercise to maintain your fitness levels as much as possible.
- keep energy for eating. Use ready-made meals if cooking is too tiring.
- wear clothes that are easy to put on and take off.
- sit down on a plastic chair for showers, or washing your hair.
- sit down when doing certain jobs, like ironing or cooking.
- reserve your energy for what you find important and build rest periods around those times.
- avoid stimulants before going to bed such as alcohol, coffee, tea or chocolate, or using laptops, tablets or mobile phones.
- keep your bedroom quiet and at a comfortable temperature.
- ask for help from family and friends.
- talk about your worries with family, friends or your doctor or nurse, or patient support groups.
- discuss your fatigue with your doctor or nurse.

Patient support organisations have booklets, factsheets and videos on managing fatigue. You can find contact details at the back of this booklet. Macmillan Cancer Support has also produced a booklet about fatigue. You can download this at **be.macmillan.org.uk**

Sexuality and fertility

For some people, sex is an important part of their lives; for others it might be less so. A diagnosis of MDS can impact on your sex life in several ways. For example, you may feel more fatigued and want to reserve your energy for other activities; the treatment sometimes requires you to be admitted and as a consequence separates you from your partner; you may feel less attractive due to hair loss, skin changes or reduction in weight; or perhaps worries can make you feel less interested in sex. Treatment with chemotherapy can also make sex more difficult as it can cause changes in the mucous membranes resulting in dryness and painful intercourse for women and men can experience erectile problems.

If you are in a sexual relationship it may help to talk to your partner about the changes you are experiencing and how you are feeling. Your partner may struggle with the subject as well and wait for a sign that you are ready to talk about it. Alternatively, you may want to talk to your GP or nurse who may be able to put you in touch with a sexuality expert or counsellor.

Certain treatments for MDS can have consequences for your fertility and during some of the treatments you will be asked to take measures to prevent a pregnancy. Lenalidomide is a drug that is NICE approved for a specific group of MDS patients. It can cause birth defects and you will be asked to use contraception during and after this treatment. The same applies for patients that are treated with chemotherapy drugs. Most patients will be permanently infertile after an allogeneic transplant.

Men have the option to freeze their sperm before starting their treatment. If treatment does not need to be started urgently, women also have the option of freezing their eggs. The medical team should discuss these options with you when treatment is required. Do not hesitate to raise these issues yourself if you feel this is important to you.

Changes in sex life and possible infertility may cause a range of difficult feelings. Do speak with someone close to you or your doctor, nurse or counsellor when

this is negatively affecting you and ask for professional support when you feel you need this.

Work and finances

MDS and its treatment can sometimes lead to difficulties relating to your work life. Sometimes it leads to temporary sick leave or reduction in working hours but it can also mean that you have to stop work altogether. This will most likely have financial consequences for you and your family.

Your consultant can guide you in these decisions and either the hospital or your GP can arrange letters to confirm your situation to your employer. It is often worth taking time to explain MDS to your employer, as it is likely they will never have heard of the disease.

Macmillan Cancer Support has published a booklet about financial support when diagnosed with cancer. They can also give you personal advice over the phone via their helpline and you can discuss which benefits you are eligible for. Some Macmillan centres can arrange face to face meetings with a benefits advisor. Please visit the Macmillan website for more information. They can also provide financial assistance in the form of grants – ask your nurse in the hospital how to apply (see contact details for Macmillan at end of this booklet).

As MDS is regarded as a cancer diagnosis you will also be entitled to apply for a medical exemption certificate which means that you are entitled to free NHS prescriptions. Your GP or specialist nurse at the hospital can provide you with the details how to apply for this. Most hospitals will also have special arrangements for patients on benefits to claim their travel expenses back.

Extra support at home

You may find that the MDS or the consequences of the treatment impacts on your independence at home. Most patients will have family or friends who can step in when certain tasks or activities need to be taken over. But not everyone will have this kind of support at home.

Speak to your GP when you need additional help at home. They can arrange a social worker to assess your situation and the support that needs to be arranged.

When you are in hospital, an occupational therapist can assess your abilities and discuss the support and other resources that you need at home. Support arranged from hospital can normally be arranged very quickly, but can take some time if arranged via a GP.

Palliative care

Some treatments for MDS can cause symptoms that require more than the normal interventions. The palliative care team can provide additional advice and support when symptoms are not easily controlled. Symptoms such as nausea and vomiting, breathlessness and pain are examples of symptoms regularly dealt with by this specialist team. Their input can be temporary or for a longer period of time, in hospital but also in the community.

Some medical treatments can be fairly aggressive and call for equally aggressive palliative approaches to your care. Treatments provided by your palliative care team can help you tolerate the side effects of these treatments. An improved understanding of your treatment choices will help you have more control over your care.

Not all treatments, sadly, are successful and sometimes patients have to be told that the disease is too progressive for any treatment to control it. Discussions around end of life will then be initiated. That conversation will most likely be started by your medical team. Most hospitals will have palliative care teams that have experience in dealing with end of life and related symptom control. Alternatively you can be referred to a community palliative care team connected to your local hospice. Additional support can be organised either at home, at the hospital or at a hospice in accordance with the wishes of the patient and carers.

Impact of MDS on partners or carers

As with all cancer diagnoses, MDS may also have an impact on other members of the family. As MDS is often diagnosed in the elderly, there may be other health issues in the family that require attention.

An initial diagnosis will inevitably cause feelings of concern and anxiety and may cause disruption to the normal life of partners and carers as well. All emotions mentioned in the booklet about psychological support, may very well also apply to the rest of the family or close friends.

It sometimes happens that the information needs of the patient and the partner differ, where one wants to know more than the other. This can lead to feelings of frustration, misunderstanding or anger. Coping mechanisms may differ too and cause similar feelings.

The support of the partner or carers is very important. Carers who wish to find out more on the disease can contact the organisations involved in this booklet, or Macmillan, who all recognise the important role a carer has in looking after someone with MDS. Carers can also attend support groups in confidence and ask any questions that may help them better understand the needs and care of the person with MDS. Support groups can also help with advice when the need for information differs between carer and patient.

If the burden for caring for someone is too much, respite can be arranged via carers associations. Details of these groups can be found at the back of this booklet.

Section 10
Signposting and useful contacts

There are a number of UK centres with a specialist interest in treating patients with MDS, some of which are recognised as Centres of Excellence.

You can request to be referred to these specialists for an additional opinion and a referral request can be made via your GP or your local haematologist. These referrals are particularly helpful for the more complex MDS cases.

Please note that additional opinions are sought by many patients across the UK. These are perfectly reasonable requests, given that MDS is a rare and complex disease. Although all haematologists will be familiar with the condition, not all of them will have the specific expertise found in specialist centres. After you are seen at a specialist centre for your additional opinion, you will still be treated at your local hospital and your local haematologist will work together with the specialist to provide you with optimal care.

A specialist centre will also provide you with a dedicated Clinical Nurse Specialist – whom you will be able to consult between appointments if necessary.

The specialist centres include:

England

King's College Hospital, London
Professor Ghulam Mufti

St James's Institute of Oncology, St. James's University Hospital, Leeds
Professor David Bowen

Royal Bournemouth Hospital, Bournemouth
Dr Sally Killick

Queen Elizabeth Hospital, Birmingham
Professor Charles Craddock
Dr Manoj Raghavan

Brighton and Sussex University Hospital, Brighton
Dr Tim Chevassut
Dr Christopher Dalley

MRC Laboratory, Addenbrookes NHS Trust, Cambridge
Professor Alan Warren

University of Oxford Cancer and Haematology Centre, Oxford
Professor Paresh Vyas

Christie Hospital, Manchester
Dr Mike Dennis

Newcastle Centre for Cancer Care
Dr Gail Jones

Nottingham University Hospital
Dr Emma Das-Gupta

Great Western Hospitals NHS Foundation Trust, Reading
Dr Alex Sternberg

Royal Cornwall Hospitals Trust, Truro
Dr Anton Kruger

Worcestershire Acute Hospitals NHS Trust and Birmingham NHS Foundation Trust
Dr Juliet Mills

St Bartholomew's Hospital, London
Professor Jamie Cavenagh

Northampton General Hospital
Dr Jane Parker

Scotland

Aberdeen Royal Infirmary
Dr Dominic Culligan

Beatson West of Scotland Cancer Centre
Dr Mark Drummond

Wales

University Hospital of Wales, Cardiff
Dr Jonathan Kell

Ireland

Adelaide and Meath Hospital, Dublin
Dr Helen Enright

Other signposting

UK patient organisations and support groups

MDS UK (see author information at beginning of this booklet)

020 7733 7558 Mon-Fri 9.30-18.00
www.mdspatientsupport.org.uk (website and forum)
mds-uk@mds-foundation.org

Leukaemia CARE (see author information at beginning of this booklet)

08088 010 444 (Freephone 24 hours a day)
www.leukaemiacare.org.uk
care@leukaemiacare.org.uk

Bloodwise (see author information at beginning of this booklet)

020 7504 2200
www.bloodwise.org.uk

MPD Voice

Provides support specifically for those with myeloproliferative disorders
www.mpdvoice.org.uk/contact-us
info@mpdvoice.org.uk

Macmillan

Provides a helpline, information on all types of cancer, financial advice and travel insurance recommendations.
0808 808 00 00
www.macmillan.org.uk

Delete Blood Cancer

Their key mission is to provide a suitable donor for every person in need of a blood stem cell donation.
020 8747 5620
www.deletebloodcancer.org.uk

Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families.
www.maggiescentres.org

Anthony Nolan

Provides information specifically to patients, families and stem cell donors regarding stem cell transplantation and donation.
0303 303 0303
www.anthonynolan.org
info@anthonynolan.org

International patient organisations and support groups

MDS Support Group Ireland (& Northern Ireland)
Group set up specifically for patients in Ireland (and Northern Ireland), to organise regular meetings and have contacts to other patients and families. Affiliated to and supported by both MDS UK and MDS Foundation.
www.mdsireland.com
086 200 1402
mdsireland7@gmail.com

MDS Foundation
International information and support group based in the USA. Provides further information on MDS – and contact to American MDS patients via a chat forum.
www.mds-foundation.org
patientliaison@mds-foundation.org

Aplastic Anaemia and MDS International Foundation
International organisation based in the USA, supporting patients and families living with aplastic anaemia, myelodysplastic syndromes (MDS), paroxysmal nocturnal haemoglobinuria (PNH), and related bone marrow failure diseases.
www.aamds.org
help@AAMDS.org

Financial assistance and benefits advice

Macmillan Support Line
0808 808 00 00

Your local Citizens Advice Bureau
www.adviceguide.org.uk

Turn2us
0808 802 2000
www.turn2us.org.uk

Travel insurance

Whilst it can often be difficult to get travel insurance if you have a pre-existing medical condition such as MDS, you can still go on holiday. Fact sheets and information about travel insurance and recommended insurance providers are available from MDS UK and Leukaemia CARE.

For carers

Carers UK
0808 808 7777
www.carersuk.org
info@carersuk.org

Carers Trust
0844 800 4361
www.carers.org
support@carers.org

International prognostic scoring system

The International Prognostic Scoring System (IPSS) was developed by analysing information on almost 1,000 MDS patients, who mostly received only supportive care, and determining which factors best predicted disease progression and outcome. This was then used to create a scoring system based on percentage of blasts in the bone marrow, cytogenetics and the number of cell types affected in the circulating blood. The IPSS is now only used to decide whether patients are suitable for certain treatments that were developed in the IPSS era (1995-2012). Since 2012, all discussions with patients about prognosis should be based on the IPSS-R (see below)

Definitions used in the IPSS

Karyotype

- Good – normal, deletion of Y chromosome, del(5q), del(20q)
- Poor – complex (more than 3 abnormalities), chromosome 7 abnormalities
- Intermediate – all other abnormalities

Cytopenias

- Haemoglobin – less than 100g/l (or 10g/dl)
- Neutrophils – less than 1.8 x 10^9/l
- Platelets – less than 100 x 10^9/l

IPSS score table

Score	0	0.5	1	1.5	2
Bone marrow blasts %	<5	5-10		11-20	21-30
Karyotype	Good	Intermediate	Poor		
Cytopenias	0/1	2/3			

The individual scores for bone marrow blast percentage, karyotype and cytopenias are added together to give the IPSS score. The scores for the risk groups are as follows:

Low 0

INT-1 0.5-1.0

INT-2 1.5-2.0

High >2.5

The Revised IPSS (IPSS-R)

This scoring system has used the data gathered from patients in the IPSS to further categorise patients into more defined risk groups from over 7,000 untreated patients with MDS. The score now has five categories which allow a more accurate idea of expected outcome.

Both scoring systems should only be used at diagnosis and not during the course of the disease.

IPSS-R Cytogenetic Prognostic Subgroups

Very good	-Y, del(11q)
Good	Normal, del(5q), del(12p), del(20q), double including del(5q)
Intermediate	del(7q), +8, +19, i(17q), any other single or double independent clones
Poor	-7, inv(3)/t(3q), double including -7/del(7q), complex: 3 abnormalities
Very Poor	Complex: >3 abnormalities

IPSS-R Prognostic Score Values

Prognostic variable	0	0.5	1	1.5	2	3	4
Cytogenetics	Very Good		Good		Intermediate	Poor	Very Poor
Bone marrow blast %	≤2		>2-<5		5-10	>10	
Haemoglobin concentration (g/l)	≥100		80-<100	<80			
Platelet count (x 109/l)	≥100	50-<100	<50				
Neutrophil count (x 109/l)	≥0.8	<0.8					

IPSS-R Prognostic Risk Categories/Scores and Clinical Outcomes

RISK CATEGORY	RISK SCORE	SURVIVAL (median – years)	25% AML evolution (median – years)
Very Low	≤1.5	8.8	NR
Low	>1.5-3	5.3	10.8
Intermediate	>3-4.5	3.0	3.2
High	>4.5-6	1.6	1.4
Very High	>6	0.8	0.73

Your own questions

Question 1:

Answer

Question 2:

Answer

Question 3:

Answer

Question 4:

Answer

Question 5:

Answer

Blood results diary and energy/fatigue levels

Date	HB	WBC	Plts	Neut	Other	Transfusion? Yes/No	Fatigue level 1-None to 6-Extreme

Blood results diary and energy/fatigue levels

Date	HB	WBC	Plts	Neut	Other	Transfusion? Yes/No	Fatigue level 1-None to 6-Extreme

Symptom diary (for example Fatigue, pain, headache etc)

Just tick boxes every day according to level of symptom

Symptom:	

Tick the days on which you have a transfusion, treatment or a special event, to notice the effect across the whole week or month.

Transfusion or treatment day	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Levels \ Days	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Extreme																												
Severe																												
Moderate																												
Some																												
Mild																												
None																												

Symptom:	

Tick the days on which you have a transfusion, treatment or a special event, to notice the effect across the whole week or month.

Transfusion or treatment date?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Levels \ Days	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
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Levels \ Days	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
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Transfusion or treatment date?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Levels / Days	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
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Transfusion or treatment date?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Levels / Days	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
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Transfusion or treatment date?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Levels / Days	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Extreme																												
Severe																												
Moderate																												
Some																												
Mild																												
None																												

List of MDS UK resources (online and paper versions)

- Newsletter
- Leaflets for patients
- Factsheet - Managing Fatigue
- Factsheet - Clinical Trials
- Factsheet - Travel Insurance
- Factsheet - Nutrition
- MDS Factsheet for GP's
- Waiting room posters
- 100 Questions & Answers on MDS (book only)

Getting in touch with other MDS patients and families

If you would like to speak directly to others affected by MDS and exchange experiences, MDS UK offers four options:

- MDS online chat forum on our MDS UK website
- MDS UK Community Facebook page
- Telephone Buddy system – for those without internet access – call us to arrange
- Local MDS UK group meetings – see our Events webpage or call us

MDS Information for general public

- MP Information "MP Rarer Cancer Toolkit"
- Leaflet "What is MDS"

Would you like more information or speak on the phone to someone?

We hope this booklet is helping you. If you would like more information, now or in the future, our dedicated MDS UK Helpline is available Mon-Fri (9.30-18.00). Please don't hesitate to call with any questions, issues or concerns you may have.

Would you like to help with suggestions?

If you have suggestions on how this booklet or any of our information materials could be improved, or for useful new resources for patients, families, friends, carers, colleagues and employers - not forgetting clinical staff members - please do get in touch with us (see contact details on back page).

Can you help with any financial support?

MDS UK relies entirely on voluntary contributions from the public, corporate donations, grants from the pharmaceutical industry and legacies.

If you are able to support us in any way - by making a donation, organising a fundraising event, donating raffle prizes, etc - please call us or email us on fundraising@mdspatientsupport.org.uk

MDS UK
Supporting Patients with Bone Marrow Failure
www.mdspatientsupport.org.uk

FRSB give with confidence

MDS UK is a registered member of the FundRaising Standards Board

Notes

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Glossary of 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 (a brother, sister, or unrelated donor) and given to the patient through an intravenous (IV) line.

Anaemia
A medical condition in which the red blood cell count or haemoglobin is less than normal.

Blood transfusion
A procedure in which whole blood or one of its components is given to a person through an intravenous (IV) 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. You will always be informed if your treatment is part of a trial.

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

Fatigue
Extreme tiredness, which is not alleviated by sleep or rest.

Full blood count or FBC
A blood test that counts the number of different blood cells.

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.

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 150,000 and 450,000 per microlitre of blood. In general, low platelet counts increase bleeding risks.

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.

Understanding Myelodysplastic Syndromes

The printing of this MDS UK booklet version has been made possible thanks to the combined donations from our patients, corporate supporters and pharmaceutical sponsors. None of the supporters or sponsors were involved in the development of the content of this booklet.

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Tel: 0330 010 0004 Email: sales@evolutiondc.co.uk
Web: www.evolutionprintmanagement.com

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Thank you for this extra work in our collaboration.

MDS UK
Supporting Patients with Bone Marrow Failure
www.mdspatientsupport.org.uk

MDS UK Patient Support Group

Haematology - Bessemer Wing
King's College Hospital - London SE5 9RS

Rare Diseases require a special level of support.
MDS is a complex form of bone marrow failure.

We provide a dedicated service to help and guide you:

Support, Information, Awareness and Campaigns for those affected by Myelodysplastic Syndromes.

MDS UK is the only nationwide charity dedicated to Myelodysplastic Syndromes.

Helpline:	**020 733 7558 (Mon-Fri)**
Email:	**info@mdspatientsupport.org.uk**
Web:	**www.mdspatientsupport.org.uk**
Facebook:	**MDS UK Patient Support Group** **MDS UK Community**
Twitter:	**@MDS_UK** **@HelpforMDS**

www.mdspatientsupport.org.uk

Charity No. 1145214 Company Reg No. 7818480