

Understanding

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# Myelodysplastic Syndromes (MDS)

Caring for people with cancer

## Understanding

# Myelodysplastic Syndromes (MDS)

This booklet has been written to help you understand more about myelodysplastic syndromes (MDS). It has been prepared and checked by haematologists, cancer doctors, other relevant specialists, nurses and patients. The information is an agreed view on MDS, its diagnosis and management, and key aspects of living with it. Your hospital might have its own guidelines and practices not mentioned in this booklet. Your doctor or nurse will explain them to you in more detail.

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are important for you. You can also list below any contact names and information you may need.



Specialist nurse

Tel:

Haematologist

Tel:

Family doctor (GP)

Tel:

Medical social worker

Tel:

Haematology day ward

Tel:

Emergency number

Tel:

Pharmacist

Tel:

If you like, you can also add:

Your name

Address



This booklet has been produced by Nursing Services of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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## Introduction

This booklet has been written to help you understand more about myelodysplastic syndromes (MDS). It describes what they are and how they are diagnosed and treated and also the expected outcome (prognosis). The booklet is divided into four parts.

- **Part 1** gives an introduction to MDS, including symptoms, diagnosis and prognosis.
- **Part 2** looks at how MDS is treated and possible side-effects.
- **Part 3** discusses how you can cope with your feelings and the emotional effects of having MDS.
- **Part 4** gives information on further sources of help and support. This includes useful organisations, books, support groups and websites.

We hope this booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. We cannot advise you about which treatment to choose. This decision can only be made by you and your doctors when all your test results are ready.



### Reading this booklet

Remember you do not need to know everything about MDS straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the National Cancer Helpline on Freefone 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm. Or if you wish, you can visit a Daffodil Centre if one is located in your hospital. See page 52 for more about Daffodil Centres.

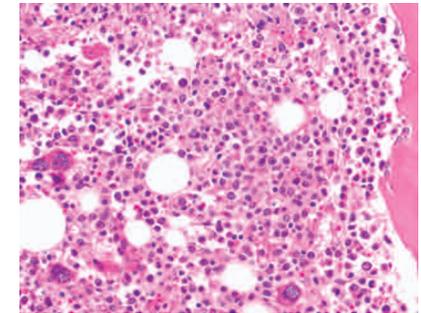


National Cancer Helpline Freefone 1800 200 700

## About MDS

### What are the myelodysplastic syndromes?

The myelodysplastic syndromes are a group of diseases where the bone marrow fails to make enough healthy blood cells. It is a type of bone marrow failure or cancer. In MDS, your bone marrow makes a large amount of faulty cells and many die before they reach your bloodstream. These faulty or abnormal blood cells are called 'dysplastic'. As a result, you do not have the right number of healthy blood cells in your bloodstream.



A bone marrow biopsy showing MDS cells in dark purple

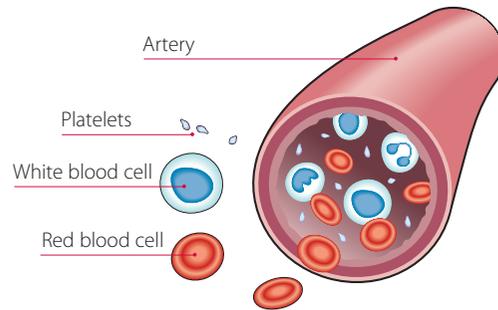
People with MDS often have low blood counts. If the red blood cells are low, it is called anaemia. A low white blood cell count is called leucopenia, while a low platelet count is called thrombocytopenia. You may have just one type of blood cell affected. Or you could have all three blood cells reduced. That is, red cells, platelets and white cells. When all three blood cells are affected, it is called pancytopenia.

As well as causing low blood counts, MDS can sometimes develop into a form of leukaemia over time. Usually this is acute myeloid leukaemia (AML). The risk of this occurring depends on the type of MDS you have, but most patients do not go on to develop leukaemia.

### Bone marrow

It can help to know what exactly your bone marrow does. All blood cells in a healthy person are made in the bone marrow. It is the soft spongy tissue that fills the centre of your long bones. The earliest and most basic type of cells in your bone marrow are called stem cells. They develop and mature into red blood cells, white blood cells and platelets.

- **Red blood cells** carry oxygen to all the tissues in your body.
- **White blood cells** are involved in fighting infection.
- **Platelets** are involved in blood clotting.



Once these blood cells are made, they leave your bone marrow and enter your bloodstream. Normally, the cells are made and replaced by your bone marrow when needed. The entire process is very well controlled.



### To sum up

- MDS is a type of bone marrow failure. The bone marrow cannot make enough healthy red blood cells, white blood cells or platelets.
- Bone marrow is the soft spongy tissue that fills the centre of your long bones.
- Some MDS patients may later develop leukaemia.

## What are the types of MDS?

Some types of MDS progress slowly, while others are more rapid. A classification system for the different types of MDS exists. It is based on the blood results, the appearance of the bone marrow and any chromosome changes found. The World Health Organization (WHO) classification of MDS is based on how the bone marrow looks and the number of leukaemia cells seen. These leukaemia cells are often called blasts. They refer to the youngest or most immature white blood cells. The number of blast cells is increased in some types of MDS and in leukaemia.

There are six types of MDS included in the WHO classification. You might also hear them referred to as subtypes. These are:

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

These names can sound confusing and be hard to understand. But your doctor will explain which type of MDS you have in more detail. Cytopenias refer to the number of cell types that are low in your blood. Refractory anaemia means you have low red cell counts. Dysplasia refers to when the size, shape or look of blood cells are abnormal. Ring sideroblasts are red blood cells with ring-shaped iron deposits in them. MDS with deletion 5q means part of chromosome 5 is missing. Normally there are 23 pairs of chromosomes in your body.

**CMML:** Chronic myelomonocytic leukaemia (CMML) is sometimes considered a type of MDS. In CMML, one specific type of white cell is raised in your blood. These are the monocytes. The WHO classification puts CMML into a different group but it is still closely related. See page 22 for more details.

### Low risk or high risk group

Sometimes it is easier to say if your type of MDS is high risk or low risk. The risk refers to your chance of developing acute myeloid leukaemia (AML) and how long you are expected to live.

**Low risk:** In this group, you have a 1 in 10 chance of developing AML. This includes the following types: RCUD, RCMD, RARS, MDS-U and the 5q-syndrome.

**High risk:** The risk of developing leukaemia is much higher in this group. This includes RAEB.

The treatment of low risk and high risk disease is often different. Your doctor may use the WHO classification to decide if your MDS is low risk or high risk, and also the International Prognostic Scoring System (IPSS). See page 12 for more details about IPSS.



## To sum up

- There are different types of MDS.
- MDS can be classified by the WHO system. This includes:
  - 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

## How common is MDS?

MDS is a rare disease. In Ireland, 147 people were diagnosed with it in 2010. It can be diagnosed at any age but is more common as people get older. MDS is very rare in children and uncommon in young adults. Children with MDS will generally be cared for by a children's specialist (paediatric haematologist). This booklet deals with the adult disease only.

## What causes MDS?

The cause of MDS is largely unknown. But there are certain things called risk factors that can increase your chance of developing the disease. These include:

- **Age:** The average age to develop MDS is about 70 years. About 9 out of 10 people are over the age of 50 at the time of diagnosis.
- **Gender:** Men are slightly more likely than women to get MDS.
- **Previous chemotherapy or radiotherapy:** About 1 in 10 patients with MDS will have received chemotherapy or radiotherapy for the treatment of other diseases in the past. This is often a long time before MDS happens. Damage to your bone marrow from these treatments is sometimes believed to have caused the MDS. This is usually called secondary MDS or therapy-related MDS.

- **Smoking:** Smoking might be linked to MDS. Also, the risk of developing AML is greater for smokers than for non-smokers.
- **Environmental factors:** Exposure to high levels of certain chemicals, particularly benzene, and radiation are both considered possible causes of MDS.
- **Inherited disorders:** In rare cases, MDS can be inherited or occurs because a rare blood disorder has been inherited. For example, Fanconi anaemia. This can make you more likely to get MDS. If you are a young person diagnosed with MDS, your doctor may test to see if you have any inherited conditions.

Remember MDS is not infectious and cannot be passed on to other people.

## What are the signs and symptoms of MDS?

Many MDS patients have no signs or symptoms and are diagnosed by chance after a routine blood test. If you do have symptoms, they can often vary from person to person and depend on which blood cells are affected. Most symptoms arise because the blood counts are low. About 8 out of 10 patients have anaemia, while about 2 in 10 have infections or bleeding. MDS symptoms include:

- |                         |  |
|-------------------------|--|
| ▪ Anaemia:              | ▪ Infection                              |
| ▪ Tiredness and fatigue | ▪ Bleeding, often from the mouth or nose |
| ▪ Palpitations          | ▪ Bruising or skin rash                  |
| ▪ Shortness of breath   |  |

Infections can occur anywhere in your body and are usually caused by bacteria or fungi.

## How is MDS diagnosed?

Low blood counts may be picked up by a simple test called a full blood count. If anything abnormal is seen on the blood count, you will be referred to a blood specialist. This doctor is called a haematologist. He or she will ask you about your medical history to rule out other causes of low blood counts.

The following tests are usually carried out as an outpatient. Some will find out exactly what type of MDS you have.

- Physical exam
- Full blood count
- Bone marrow tests
- Chromosome studies (cytogenetics)

**Physical exam:** You will be given a full physical exam. It is important for your haematologist to check your general health and also to check for any signs of disease. He or she will note any previous illnesses and treatment, and details about your lifestyle.

**Full blood count:** A full blood count (FBC) will be taken. This finds out the levels of the different types of cells in your blood. If anything abnormal is seen on the blood count, the laboratory will then examine the blood cells under the microscope. This is called a blood film exam.

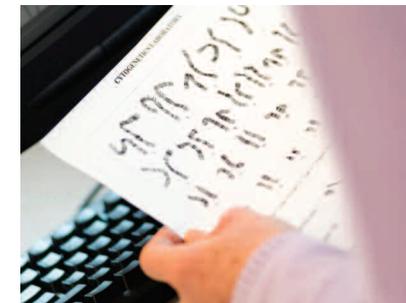
**Bone marrow tests:** A bone marrow test is usually needed to confirm the diagnosis of MDS. Bone marrow tests involve taking a tiny sample of your bone or bone marrow and looking at it under a microscope. The sample is taken from the inside of the bone, usually your hipbone. If a sample of bone marrow cells is taken, it is called an aspirate. If a tiny piece of bone or solid marrow is taken, it is a trephine biopsy. Both can be done at the same time.

Your doctor will give you a local anaesthetic to numb the area beforehand. The biopsy itself may be uncomfortable and can last up to 10 minutes, while the entire task can take about 30 minutes. Once the needle is in your bone cavity, a sample of your bone marrow is drawn into a syringe. Bone marrow looks like a red liquid similar to blood. A different kind of needle is used for the trephine biopsy.

When it is over, a small plaster is put on the area where the bone marrow has been taken. You may be asked to lie on your back for 10–15 minutes to stop any possible bleeding. You can take mild painkillers, like paracetamol, if you feel any discomfort later. The bone marrow sample is examined under a microscope to look for changes seen in MDS. Other tests are often needed on the bone marrow sample. This includes chromosome studies called cytogenetics. Marrow tests may be repeated later to check how well you are responding to treatment or to see how the disease is behaving.

>>> A bone marrow test is usually needed to confirm the diagnosis of MDS.

**Chromosome studies (cytogenetics):** Chromosome tests can find out the number and shape of the chromosomes in your bone marrow cells. In your body there are 23 pairs of chromosomes. These chromosomes contain the genetic information about the cells in your body. This information is sometimes also called the karyotype. The chromosomes in the bone marrow sample are compared to those in normal cells. In MDS, there may be some genetic changes in the marrow cells which help to confirm the diagnosis of MDS and also to predict the course of the disease (prognosis). Remember these chromosome changes occur when the disease develops and are only found in your bone marrow and blood cells, so they cannot be passed on to your children.



Cytogenetics

### Waiting for results

It may take a few weeks to get all your test results back. Your blood and bone marrow will be checked by both haematologists and doctors who specialise in studying cells and tissues. These doctors are called pathologists and can find out which type of MDS you have. Cytogenetic tests may take a little longer. Once all your tests are ready, your haematologist and you will decide what type of treatment you should have.

MDS can be a difficult diagnosis to make. Sometimes if your doctor is unsure if there is definite MDS, your blood counts will be watched for a few months, and the marrow test may then be repeated.

Naturally, waiting for results can be an anxious time for you. Do share your worries with a family member or close friend. Do call the National Cancer Helpline on 1800 200 700 if you have any queries or concerns, or visit a Daffodil Centre.

## What is the prognosis of MDS?

Prognosis means the expected outcome of MDS or how it will behave in the future. When deciding your treatment, your doctor may discuss many aspects of the disease with you. For example:

- The International Prognostic Scoring System (IPSS) or a revised version (R-IPSS)
- Your risk group
- Your age
- How the disease is affecting you
- Your general fitness

### International Prognostic Scoring System (IPSS)

Doctors have created a scoring system to help them understand how MDS is likely to behave over time. It is called the International Prognostic Scoring System. Together, the classification systems and the scoring system help your doctor know:

- How serious or severe your MDS is
- How likely you will develop AML or not
- How long you are likely to live
- What you can expect from MDS over time
- Which treatments are best for now, and when they should be changed.

The IPSS is based on three factors: the amount of blasts in your bone marrow, the number of cell types that are low in your blood, and the chromosome changes. Each factor gets a score. Together, the scores tell which risk groups you fall into. You can be put into one of four risk groups – two lower risk and two higher risk.

- **Low risk MDS:** These are the IPSS groups of **Low** or **Intermediate-1**.
- **High risk MDS:** These are the IPSS groups of **Intermediate-2** or **High**.

Do ask your doctor and nurse to explain the system if you find it difficult to understand. It can be confusing as there are many aspects to it. You can also call the National Cancer Helpline on 1800 200 700 for advice.

## Understanding the scoring system

Using the IPSS, you are given a score between 0 and 3. Scores of less than 1.5 are considered lower risk. Here are some of the definitions used.

### 1 Percentage of blasts in bone marrow

Blasts refer to the youngest or most immature white blood cells. In normal bone marrow, about 5 of every 100 white cells are blasts.

### 2 Cytogenetics

This deals with the genes in the bone marrow cells. Karyotype refers to the number and appearance of the chromosomes.

- **Good:** This means normal chromosomes, deletion of Y chromosome (-Y), del(5q), del(20q).
- **Poor:** This means complex (more than 3 chromosomal abnormalities), chromosome 7 abnormalities.
- **Intermediate:** This includes all other abnormalities.

### 3 Cytopenias

Cytopenias refer to the types of low blood counts. The haemoglobin in red blood cells is measured as well as the most common type of white blood cells called neutrophils.

- Haemoglobin – less than 10g/dl
- Neutrophils – less than  $1.8 \times 10^9/l$
- Platelets – less than  $100 \times 10^9/l$

Score	0	0.5	1	1.5	2
Marrow blast %	Less than 5	5-10		11-20	21-30
Karyotype	Good	Intermediate	Poor		
Cytopenias	0-1	2-3			

The individual scores are added together to give the IPSS score. The scores for the risk groups are as follows:

<b>Low</b>	0
<b>Intermediate-1</b>	0.5–1.0
<b>Intermediate-2</b>	1.5–2.0
<b>High</b>	greater than 2.5

Again, do ask your doctor and nurse to explain these scores. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.



### To sum up

- The cause of MDS is unknown. Certain factors like age, smoking, exposure to radiation, chemicals or previous chemotherapy drugs can increase your risk of getting it. Rarely, some inherited disorders may lead to MDS.
- Some symptoms of MDS are feeling tired, shortness of breath, infections or bruising.
- MDS is diagnosed by a physical exam, blood tests and bone marrow tests.
- There are different types of MDS. These include high risk and low risk groups.
- The expected outcome or prognosis for different types of MDS differs.
- The International Prognostic Scoring System is used to predict how MDS will behave over time.



## Treatment and side-effects

### How is MDS treated?

The course of MDS can vary from person to person and depend on which blood cells are affected. Treatment for MDS in Ireland is based on guidelines agreed by specialists and on the results of research worldwide. The main treatments available are:

- Supportive care
- Non-intensive treatment
- Intensive chemotherapy
- Stem cell transplant

Some patients with no symptoms may not need active treatment. In this case, you will have regular check-ups instead. This is often called a watch and wait approach.

**Supportive care:** This type of treatment controls the symptoms of MDS rather than curing it. For example, symptoms such as anaemia, infection and bleeding. No matter what type of MDS you have, you will still need supportive care if your blood counts are low. This will prevent you from becoming more ill. Red blood cells or platelets can be given by transfusion. Ways to prevent and treat infections are also very important. See page 18 for more details.

**Non-intensive treatment:** Non-intensive treatment means taking medication that may slow down the progress of MDS or improve your blood counts. See page 21 for more details.

**Intensive chemotherapy:** Chemotherapy is a treatment that can cure or control cancer. It is often called an intensive treatment when used to treat MDS. See page 22 for more details.

**Stem cell transplant:** The main treatment to possibly cure MDS is a stem cell or bone marrow transplant from another person. Unfortunately, only a small number of patients with MDS are suitable for this treatment. If you are suitable, you will be identified early so that a search for a donor can be started and a transplant considered. See page 29 for more details.

## Treatment planning

Once MDS has been diagnosed, you and your doctors will decide on which treatment is best for you. Before planning any treatment, your doctors will consider such things as:

- Your age
- Your type of MDS
- Your IPSS score
- Other health problems
- Your general health
- Your own wishes

If you have low risk MDS, the impact of the low blood counts on your quality of life will also be taken into account.

**Travelling for treatment:** Remember MDS is a rare disease. As a result, you will need to be assessed by specialist doctors such as haematologists. This means that you may have to travel to a different hospital for assessment and treatment. But it might be more convenient to have some treatments closer to home, for example, transfusions.

**Second opinion:** You might find it reassuring to have a second medical opinion before deciding on treatment. Your doctor can refer you to another specialist for a second opinion if you feel it would help.

## Giving consent for treatment

Before you start treatment your doctor will explain your treatment plan. He or she will tell you about the benefits and any side-effects that you can expect. You may be asked to sign a consent form saying you give permission for treatment to be given. In some cases you may give verbal permission. No medical treatment will be given without your consent. Ask as many questions as you like so that you understand what is involved. MDS is not a simple disease so do ask for more explanations if you are unsure. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

## Who will be involved in my care?

Some of the following health professionals may be involved in your care. Usually a team of cancer care doctors will decide your treatment.

<b>Haematologist</b>	A doctor who specialises in treating blood and bone marrow diseases.
<b>Clinical nurse specialist</b>	A highly trained nurse who gives support and information to cancer patients.
<b>Liaison oncology nurse</b>	A specially trained nurse who works in a cancer care unit. She or he can give support and reassure you and your family from diagnosis and throughout treatment.
<b>Dietitian</b>	An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.
<b>Medical social worker</b>	A person specially trained to help you and your family with all your social issues and practical needs. They are skilled in giving counselling and emotional support, especially to children and families at times of change. They can give advice on financial supports and services available to you when you go home.
<b>Psychologist</b>	A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.
<b>Counsellor</b>	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.



## To sum up

The main treatments available for MDS are:

- Supportive care
- Intensive chemotherapy
- Non-intensive treatment
- Stem cell transplant

## Supportive care

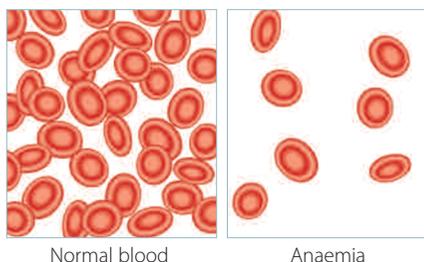
Supportive care aims to control the symptoms and problems caused by MDS and to improve your quality of life. It is not a cure for MDS as such. Even so, it is a very important part of your care no matter what other medical treatments you receive. Even if your MDS is at an advanced stage, many things can be done to make you more comfortable. The type of supportive care you need depends on which blood cells are affected and how low they are in number. Most patients with MDS will need blood transfusions at some stage. For example, if you are anaemic, you may get a blood transfusion or injections to try to increase the red blood cells.

Throughout your treatments, you will have blood tests regularly to check your blood count. You can use the diary at the back of the booklet to keep track of your results. Bone marrow tests may be needed from time to time to check the stage of your disease. Your doctors will let you know the results of all these tests. Depending on the results, your doctors may need to make changes to your treatment.

Supportive care can be given for the following symptoms:

- Anaemia
- Iron overload
- Low blood counts – using growth factors
- Low platelets
- Infection

**Anaemia:** Most people diagnosed with MDS are anaemic, though not all. Anaemia can cause symptoms such as tiredness and shortness of breath but it is not fatal. Because anaemia can affect your quality of life you might need transfusions or injections to help boost the making of red blood cells. How often you need transfusions can vary between patients. You might need one transfusion every few months or every couple of weeks. Once a course of transfusions has started, the interval between transfusions may get shorter over time.



**Iron overload:** Most patients with MDS have enough iron, so taking iron tablets will not help your anaemia. These tablets should not be taken

unless prescribed. In fact, if you have frequent blood transfusions, you can build up excess iron in your body. This is true of most patients with MDS. Eventually, this excess iron can harm your liver and heart. Usually the levels of iron in your blood are checked regularly.

You might need treatment to prevent or treat the build-up of excess iron. This is called iron chelation. Iron chelation can be done in several ways and your doctor will advise you on the best way.

**Low blood counts – using growth factors:** Low blood counts can sometimes be improved by using growth factors. Growth factors are like natural hormones that boost your bone marrow to make blood cells. We all make these growth factors every day. For example, erythropoietin (EPO) is a growth factor that can increase the number of red blood cells, while G-CSF can increase the number of white blood cells. At present, some newer growth factors for platelets are being studied in MDS. They are not widely available because their long-term effects are not yet known. Not all patients are suitable for growth factors, as only a small number will respond to them. Your doctor will advise you about this.

### Giving growth factors

Growth factors are usually given as injections under your skin. Your nurse can discuss who will give these injections when you are at home. You may choose to give the injection yourself, or a relative, GP or public health nurse can do it instead.

Side-effects are usually quite mild. If you are receiving G-CSF to increase your white blood cells, you may get aching in your bones and muscles. This aching can usually be relieved by taking a mild painkiller. But do let your nurse or doctor know as they can prescribe the best medication for you. There are some possible serious side-effects but they are rare.

Erythropoietin is given to increase your red blood cells. Its side-effects include weakness, flu-like symptoms, tiredness, headache, joint pain, nausea, vomiting and chest pain. Your doctor and nurse will advise you about these beforehand and ways to relieve them. As with all injections given under the skin, your skin may get irritated at the injection site. Please tell your doctor or nurse if you experience this. Do rotate the injection sites and talk to your nurse or doctor about the best areas.

**Low platelets:** Low platelets are known as thrombocytopenia. About half of MDS patients will have a low platelet count at diagnosis. What platelets you do have might also work poorly. As a result, bruising and bleeding can be a serious problem.

If you have bleeding problems, you may get a transfusion of platelets. Because platelets last only a few days, they are usually only given if you have signs of bleeding. Drugs that can boost the platelet count may become available in the future if they are shown to be useful and safe in clinical trials. If you have low platelets, you should avoid aspirin and most anti-inflammatory medication. If in doubt, ask your doctors or nurses. A high temperature, meaning an infection in your body, can use up more of your platelets. If your temperature rises usually over 37.5°C (99.5°F) and you have an already low platelet count, you may need to go to hospital for a platelet transfusion.

**Infection:** With MDS, you may be at risk of developing infections. If infection does occur, it should be treated quickly with antibiotics. Do check your temperature at the same time each day when at home or if you are feeling unwell. Your nurse will give you more information about this and contact numbers you will need.

You might need to be admitted to hospital so that antibiotics can be given through a vein. Most specialist units will have a direct phone number to call for advice if you get a fever. If you develop any serious infections, you may need antibiotics quickly and perhaps injections to help make white blood cells.

**>>> Supportive care aims to control the symptoms and problems caused by MDS and to improve your quality of life.**

## Non-intensive treatment

The aim of non-intensive treatment is to slow down the progress of MDS. For example, if your blood counts are getting worse or if the disease is developing into leukaemia. It treats the disease with as few side-effects as possible, so your quality of life is not affected. These treatments will not cure MDS but may change the disease. Many of these treatments are new and often used as part of a clinical trial. See page 31 for more about clinical trials. You can receive these drugs as an outpatient or in the day ward. These treatments are sometimes called biological therapies. Two types deserve special mention.

### Epigenetic treatments

Epigenetic treatments try to change the behaviour of cancer cells by blocking chemical changes to DNA which can turn genes on or off. In this case, it can stop the bone marrow from making faulty blood cells. This treatment includes the drugs azacitidine and decitabine. They can improve how your bone marrow works and delay leukaemia from developing in some patients. If you have high risk MDS, they might increase how long you live. They are usually given as an injection under your skin. Side-effects include reduced blood counts, fever, nausea, constipation, diarrhoea, vomiting, leg swelling and pneumonia. Your doctor and nurse will advise you about these beforehand and ways to relieve them.

### Lenalidomide

Another drug sometimes used for the treatment of MDS is lenalidomide. It works by acting on your body's immune system to fight cancer. It is also known as immune modulation therapy. Lenalidomide is used for a subtype of MDS called the 5q minus syndrome. If you are in this group, you might be anaemic or need a transfusion. It is less useful in other subtypes of MDS.

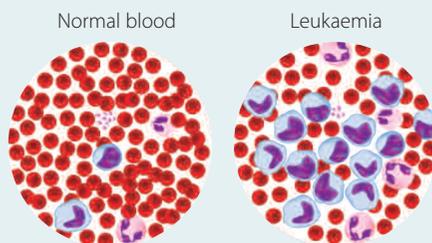
The drug can be taken orally as a capsule. Side-effects of lenalidomide include reduced white blood cells and platelets, blood-clotting problems, rash, itching, fatigue, diarrhoea and nausea. Because it causes birth defects, you must not get pregnant while taking the drug.

You will need to enter a special programme to receive this drug. Your doctor will explain more about this drug if you are suitable for it.

### Chronic myelomonocytic leukaemia (CMML)

This disorder is very like MDS.

CMML used to be known as a myelodysplastic syndrome, but is now separately classified by the WHO. CMML is usually treated with chemotherapy drugs that kill the leukaemia cells. This is done to control the high levels of white blood cells that occur in this condition. Drugs commonly used are hydroxyurea and azacitidine. Some patients with CMML will be suitable for a stem cell transplant if young and fit enough. See page 29 for more about stem cell transplants.



## Intensive chemotherapy

If you have high risk MDS, you may benefit from intensive chemotherapy. This is the same treatment as that used for acute leukaemia. Intensive chemotherapy uses high doses of drugs to try and clear the diseased cells from your bone marrow. Once the diseased cells are gone, it is called remission. This means that you will need to stay in hospital for about 4–6 weeks for each treatment block. A small number of people might stay in remission for a long time after intensive chemotherapy, although usually when a donor is available, a stem cell transplant will follow. Intensive chemotherapy is sometimes also used when preparing for a transplant. It can reduce the amount of MDS cells in your bone marrow before the transplant.

### How is chemotherapy given?

Chemotherapy is usually given into a vein or as a tablet. If given into a vein, it can be as an injection or through a drip (infusion). The chemotherapy drugs travel through your bloodstream to almost every part of your body. They are often given in cycles with a rest period

between treatments. The rest period allows your body to recover from the effects of the drugs. Your doctor will tell you how many cycles you need if the cancer is responding to treatment. You may be given a combination of drugs. Some drugs commonly used are idarubicin, cytarabine and fludarabine. These might be given as part of a clinical trial.

### Chemotherapy side-effects

The side-effects of chemotherapy can vary from person to person and depend on the type of drugs used. Your doctors and nurses will let you know what kind of side-effects to expect. Always tell your doctor or nurse if the side-effects of treatment are making you unwell. Chemotherapy usually affects the parts of your body where normal cells divide and grow quickly. This includes your bone marrow, mouth, digestive system, skin and hair. The side-effects may include:

- Bone marrow problems – anaemia, bleeding and bruising, infection
- Tiredness and fatigue
- Nausea and vomiting
- Loss of appetite
- Mouth or taste problems
- Diarrhoea
- Constipation
- Hair loss
- Skin and nail changes
- Changes in your nervous system – anxiety, headaches, dizziness
- Bladder or kidney changes
- Infertility
- Aching joints

**Bone marrow problems:** Because MDS is a disease of the bone marrow, treatment is aimed at your bone marrow. Your blood count will need to be checked regularly, as some treatments will cause low blood counts. You can use the diary at the back of the booklet to keep track of your results.

**Anaemia:** If the number of red blood cells in your blood is low, you may become tired and weak. Because the amount of oxygen being carried around your body is less, you may also become breathless. These are all symptoms of anaemia. You may also feel dizzy and light-headed and your muscles and joints can ache. A blood transfusion can be given if your red blood cells are low. This will help you feel more energetic and less breathless.

**Bleeding and bruising:** Bruising is caused by a reduced number of platelets. Platelets help your blood clot and stop bleeding when you cut yourself. You may suffer from nosebleeds or bleed more heavily than usual from minor cuts or grazes. Bleeding may develop under your skin, usually as blood spots on your legs, feet, trunk and arms. This is known as petechiae. Bleeding gums is also a common sign of low platelets. Do let your nurse or doctor know at once if you have this symptom. You may need a platelet transfusion to help reduce any bleeding or bruising. Also, use a soft toothbrush such as a child's toothbrush and an electric razor when shaving. In women, periods can be heavier and longer than usual during the first few cycles.

**Infection:** Infection is caused by fewer white blood cells. This is also called neutropenia and means that your body's immune system cannot fight infection. If you do not have enough white blood cells, even minor infections such as a cold or sore throat could make you ill. If your temperature goes above 37.5°C (99.5°F), or if you suddenly feel shivery or unwell, contact your doctor or the hospital immediately. You may need to go to hospital to get antibiotics through a vein.

You may be more at risk of picking up infections. Avoid crowds and close contact, such as hugging or kissing, with people who have colds or flu and other infections. This includes chickenpox, shingles or measles. Let your doctor know if you're in contact with these or any other infections. Wash your hands often during the day, especially before you eat and after going to the toilet. Be careful too about what you eat, given the risk of infection from raw, undercooked or contaminated food. Do talk to your doctor or nurse for more advice.

To reduce the risk of infection, growth factors may be used. These drugs encourage the growth of white cells. They are helpful if the number of white cells is low after treatment. The one most commonly used is called G-CSF (granulocyte-colony stimulating factor).

**Tiredness and fatigue:** Many people feel tired during chemotherapy. Ongoing tiredness not helped by rest is called fatigue. It can be a common symptom of MDS as well as due to treatment. You may find it hard to concentrate or make decisions. It can also be caused by the worry of having MDS and the added stress of treatment. Overall, you can feel very frustrated if you feel tired all the time.

Even so, there are ways to help. Treatment can sometimes help to relieve symptoms allowing you to get back to your normal routine. Ask your doctor what side-effects to expect before your treatment begins. If you are feeling very worried and find it hard to sleep at night, ask your doctor or nurse for advice. Also, talk to your family or close friends about your concerns. A booklet on fatigue is available called *Coping with Fatigue*. If you would like more information or a free copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download a copy from [www.cancer.ie](http://www.cancer.ie)



### Tips & Hints – fatigue



- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Wear clothes that are easy to put on and take off.
- Sit down when getting dressed or doing household jobs, such as ironing, etc.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.
- Ask for help at work or around the house, especially with cooking, housework or childcare.
- Make sure your bedroom is quiet and not too hot or cold.
- Go to bed each night at the same time. Each morning get up at the same time and do not lie in.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.
- Use relaxation techniques to get to sleep. For example, gentle exercise, relaxation CDs, etc.

**Nausea and vomiting:** Some chemotherapy drugs make you feel sick (nausea) or vomit. You will be given anti-sickness drugs along with your chemotherapy to help you. These drugs are called anti-emetics. Even so, you may experience some nausea and vomiting during the first few days after treatment. Your doctor will prescribe injections or medicine for you to take regularly. If you feel sick, flat fizzy drinks may help or nibbling on dry biscuits and toast.

**Loss of appetite:** Some chemotherapy drugs can reduce your appetite for a while. Do get early advice from a dietitian if this happens. A booklet called *Diet and Cancer* is available from the Irish Cancer Society and has helpful tips on boosting your appetite. Call the National Cancer Helpline on 1800 200 700 for a free copy or visit a Daffodil Centre. Download it from [www.cancer.ie](http://www.cancer.ie)

**Mouth or taste problems:** Some drugs can cause a dry, sore mouth that can lead to mouth ulcers. This can happen about 5 to 10 days after the drugs are given. It will gradually clear up but your doctor can prescribe mouthwashes to help in the meantime. If your white cell count is low, the ulcers may become infected. Cleaning your teeth regularly and gently with a soft toothbrush will help to keep your mouth clean. If your mouth is very sore, there are gels, creams or pastes available to reduce the soreness. Do ask your nurse for advice.

Your sense of taste may also change during treatment. Food may taste more salty, bitter or metallic. Normal taste will return once the treatment is over. It is worth trying various types of food and seeing which ones taste better. A booklet called *Diet and Cancer* has some helpful advice on how to manage taste changes. Call the National Cancer Helpline on 1800 200 700 for a free copy of the booklet.

**Diarrhoea:** Some chemotherapy drugs can affect the lining of your gut and may cause diarrhoea for a few days. Passing watery bowel motions more than three times a day is known as diarrhoea. You might also have cramping or abdominal pain. If this happens, drink lots of clear fluids (1½ to 2 litres a day) to replace the fluid you are losing. You should tell your doctor or nurse if you have diarrhoea for more than 24 hours. There are medicines that can stop this side-effect of treatment. Again, it might be useful to talk to a dietitian who can offer advice or support at this time.

››› Drink 1½ to 2 litres of fluid a day if you have diarrhoea or constipation.

**Constipation:** Chemotherapy might slow down your bowels and your regular bowel habit may change. You may have difficulty passing a bowel motion. This is known as constipation. If this happens, let your

doctor or nurse know as soon as possible. You may need to drink more clear fluids or take a laxative. In some cases, your doctor may have to adjust your treatment.

**Hair loss:** Some types of chemotherapy can cause temporary hair loss. This usually happens about 3 weeks after the start of treatment. You may lose all your body hair, including your eyelashes and eyebrows, but this can vary from person to person. You may experience tingling or sensitivity of your scalp just before your hair starts to fall out. This may last a day or so. Your hair will grow back once you have stopped treatment.

››› You may have tingling or sensitivity if your scalp before your hair starts to fall out.

It is natural to feel upset, angry or embarrassed at the thought of losing your hair. Don't be afraid to talk to your nurse or medical social worker about your feelings. They will help you to find ways to cope with your hair loss. If you like, you can get a wig or hairpiece when this happens, or you may prefer to wear a hat or scarf. Talk to your medical social worker or nurse if you would like a wig or hair piece. Arrange this before your hair starts to fall out, so that you can get a good colour match to your own hair.

In some cases it is possible to get financial assistance towards the cost of a wig. Ask your medical social worker or nurse for more information. If you have a medical card, you are entitled to 1–2 new or subsidised wigs every year. If you have private health insurance, for example with VHI, you are also covered for the cost of a wig. If you would like more details on hair loss, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for the factsheet, *Hair Loss and Cancer* or download it from [www.cancer.ie](http://www.cancer.ie)

**Skin and nail changes:** Some drugs can affect your skin. They may make it dry, itchy, discoloured or darker. It can be made worse by swimming, especially if there is chlorine in the water. Report any rashes or skin reactions to your doctor, who can prescribe something to relieve them. In general, your skin will improve once treatment is over. Chemotherapy drugs can also make your skin more sensitive to

sunlight, during and after treatment. It is best to stay out of the sun during the hottest part of the day. This is normally between 11am and 3pm. You can protect your skin from the sun by wearing a hat, covering your skin with loose clothing, and using a high skin protection factor (SPF) sunscreen.

Your nails might grow more slowly and you may notice white lines appearing across them. Sometimes the shape or colour of your nails may change too. They might become darker or paler. Your nails might also become more brittle and flaky. False nails or nail varnish can help to disguise white lines. These nail changes usually fade once treatment is over.

**Changes in your nervous system:** Some drugs can cause feelings of anxiety and restlessness, dizziness, sleeplessness or headaches. Some people also find it hard to concentrate or might have short-term memory loss. If you have any of these side-effects, do let your doctor or nurse know, as there are ways to relieve them. You may find it helpful to talk to a close relative or friend about your feelings. If not, ask your doctor to refer you to a counsellor or a psychologist.

**Bladder or kidney changes:** Some chemotherapy drugs may irritate your bladder and cause problems with your kidneys. For this reason, you must drink plenty of fluids. For example, 1½ to 2 litres a day. If you notice any pain, discomfort or blood on passing urine, tell your doctor at once.

**Infertility:** You may not be able to conceive or father a child due to the chemotherapy drugs. As a result, men may consider sperm banking and women may discuss options with their doctor. This should be done before treatment starts. However, do use contraception during treatment as the drugs may harm your baby if you do become pregnant. See page 32 for more details.

**Aching joints:** You may get joint pains if you are given growth factors such as G-CSF. These drugs can encourage the growth of cells within your bone marrow. This in turn may cause joint pains. Talk to your doctor or nurse if you experience this kind of pain.

## Other changes

Sometimes with MDS it can be very hard to tell if your symptoms are part of your illness or a side-effect of treatment. These symptoms can vary from time to time and be mild or severe. If you have symptoms that are troubling you or not listed above, do let your doctor or nurse know. There are ways to make your life easier and more comfortable.

If you would like more information about the side-effects of chemotherapy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet, *Understanding Chemotherapy*, or download it from [www.cancer.ie](http://www.cancer.ie)

## Stem cell transplant

A stem cell transplant offers the chance of curing MDS. It is also often known as a bone marrow transplant. There are two different types of transplant, depending on who donates the bone marrow or stem cells. In an allogeneic transplant, the stem cells are taken from a donor. Another name for this transplant is an allograft. In an autologous transplant, you are the donor. Your own stem cells are used in the transplant. This is called an autograft but it is rarely useful in MDS.

>>> A stem cell transplant offers the chance of curing MDS.

## Allogeneic transplant

In an allogeneic transplant, healthy bone marrow or stem cells are taken from another person whose tissue DNA is the same or almost the same as yours. This means the donor is HLA-compatible with you. The donor can be your brother or sister, or even a person not related to you.

Your brothers and sisters will have a blood test done to find out if they are a match with you. This usually happens in the same hospital that you are being treated in. If any of your siblings live abroad, your doctor will contact their local hospital to arrange for this test to be done. The results usually take a few weeks. If a sibling match has not

being found, there is a registry of unrelated donors that can be examined to see if there is a match. Your doctor will contact a transplant co-ordinator to arrange this.

The donor marrow or stem cells can be frozen and stored until you need them or, more often, they are given fresh. Your own bone marrow is first destroyed with high doses of chemotherapy with or without radiotherapy. The healthy marrow or stem cells from the donor are then given to you through a central line (drip). The cells then grow over a few weeks to replace your bone marrow that was destroyed.

### Who is suitable for stem cell transplants?

In the past, only younger patients were offered stem cell treatment. But now as medical knowledge has increased, more patients can be considered for transplant. By reducing the intensity of the treatment before the stem cell transplant, the side-effects are less. This approach is called a reduced-intensity conditioning (RIC) transplant.

Just over one-third of patients with MDS who receive this treatment may be free from the disease over many years. The disease may come back (relapse) in some cases. The treatment has many severe side-effects and some patients can become seriously ill from it. Your doctor will discuss this treatment option with you if you are suitable. It is suitable if you are fit enough for the treatment and where there is a good chance you will benefit from it.

If you would like more information, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.



Stem cells

National Cancer Helpline Freefone 1800 200 700



## Research – what is a clinical trial?



Research into new ways of treating MDS goes on all the time. Many patients take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use.

### Phases of research

There are many stages or phases involved when research is being done. If a treatment looks as if might be useful in treating MDS, it is given to patients in research studies called clinical trials. If early studies suggest that a new drug may be both safe and effective, more trials are done. These aim to:

- Improve how patients with MDS are managed
- Improve the blood counts and delay leukaemia developing
- Lessen the side-effects of treatment

### Taking part in clinical trials

Many patients with MDS take part in research studies. Do ask about trials available at your treatment centre. Or your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about MDS and new treatments. There is no need for worry as you will be carefully checked during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called informed consent. You will also need time to think about it and discuss it with your family or friends.

If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of MDS, your doctors may ask your permission to store some samples of your bone marrow or blood. For a copy of our factsheet on clinical trials, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download if from [www.cancer.ie](http://www.cancer.ie)

## Will treatment affect my sex life and fertility?

### Sex and sexuality

For some people sex is an important part of a relationship, while it is less so for others. During diagnosis and treatment you may lose the desire for sex. This is normal and there can be many reasons for it. Some aspects of treatment, such as losing your hair, may make you feel less sexually attractive. You may also feel too tired or perhaps not strong enough for the level of physical activity you are used to during sex. If your treatment is making you feel sick, then you may want to delay having sex until you feel better. Anxiety or stress about your illness may also play a part in losing your desire for sex.

**Time for sex:** There is no set time for you to be ready to have sex again. It varies from person to person and may take a while. Often it depends on how long it takes you to adjust to your illness and treatment. Most changes are usually short term.

**Talking about sex:** You may find that talking to your partner can help. Your partner may have anxieties too and could be waiting for a sign that you are ready to discuss them. You can also talk to your nurse or doctor, if you are concerned about the matter. Sometimes people find it easier to discuss their feelings with someone they don't know, such as a medical social worker or counsellor. Your doctor can refer you to specialist counselling, if you think that would help. You can also call the National Cancer Helpline on 1800 200 700 for advice in confidence.

### Fertility

Some drugs used to treat MDS can cause infertility. This means that you may not be able to have a child in the future. The infertility can be temporary or permanent. This can depend on the type and dose of treatment given and your age at the time. Your doctor will explain this to you in more detail before starting your treatment. You may wish for your partner to be present when you talk to your doctor so he or she can discuss their concerns too.

**Contraception:** Treatment for MDS does not always cause infertility. As a result, it is important that you continue to use contraception during and after treatment. Pregnancy should be avoided as chemotherapy drugs and newer drugs like lenalidomide can cause birth defects. If you have received a bone marrow or stem cell transplant, you are likely to be permanently infertile afterwards. Do seek professional help if this side-effect will trouble you.

»»» Some drugs used to treat MDS can cause infertility.

**For men:** Chemotherapy drugs can lower the number of sperm cells and reduce how they move about. These changes can be temporary or permanent. The thought of infertility can often be difficult to come to terms with. If you are young, you may not have yet considered having children. Before starting treatment, do talk to your doctor about sperm banking. This involves freezing and storing your sperm for future use. It is done at the HARI Unit at the Rotunda Hospital in Dublin. In general, it does not take long and will not affect your treatment. For further information, talk to your doctors. You can also call the National Cancer Helpline on 1800 200 700 for more details and advice. It is important to use contraception with your partner during treatment and for a few months afterwards.

**For women:** Chemotherapy can cause damage to your ovaries. With treatment for MDS, you may find your periods become irregular or stop altogether. This is because chemotherapy affects the ovaries and reduces the amount of hormones they make. Your periods may return to normal after treatment so it is important to continue taking contraceptive precautions during and after treatment. Avoid getting pregnant as chemotherapy can cause birth defects.

If the risk of infertility is high, there are some options available. If you have a partner, it may be possible to store a fertilised egg. This involves freezing and storing your eggs for future use. It is carried out at the HARI Unit at the Rotunda Hospital in Dublin. However, it takes time and may not be an option if your MDS needs treatment immediately. In fact, your treatment for MDS will take priority.

Do discuss these options with your doctor. You can also call the National Cancer Helpline on 1800 200 700 for more details or visit a Daffodil Centre. See page 55 for details about contacting the HARI Unit for an information leaflet.

>>> Your own health will take priority over egg and sperm freezing.

### How can I cope with infertility?

Infertility may cause feelings of anger, sadness and loss of identity. It is important to talk openly to your partner or a friend about these feelings. If you are finding it hard to deal with infertility, it may help to talk to your nurse or doctor. If you cannot deal with any strong emotions you might have, your doctor may arrange for you to speak to a trained counsellor or specialist. Do seek professional help if infertility is likely to trouble you.

### What follow-up will I need?

After your treatment you will need to visit your doctor for regular check-ups. This is called follow-up. Your doctor will let you know how often you need to visit him or her at the outpatient clinic. Usually at these visits your doctor will check if your disease is stable or showing any signs of getting worse. At each outpatient visit, your doctor will examine you and blood tests may be done. If your disease is high-risk or you need active treatment or transfusions, you will need more frequent visits to the day ward.

If you are between visits and have a symptom or problem worrying you, do let your doctor know. An appointment can be arranged for you.

National Cancer Helpline Freefone 1800 200 700

## Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Some people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country you live in. In Ireland, cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted. You may hear about the following types of treatments or therapies.

### Conventional therapies

Conventional therapies are treatments that doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, hormone therapy and biological therapies. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

### Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Acupuncture
- Aromatherapy
- Gentle massage
- Hypnotherapy
- Meditation
- Music, art and dance therapy
- Nutrition therapy
- Reflexology
- Relaxation
- Shiatsu
- Visualisation
- Yoga

Many people find complementary therapies helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

### Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy,

megavitamin therapy and herbalism. The diet therapy can often be restrictive. This means it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition. Most doctors do not believe that such treatments can cure or control cancer, as there is no credible evidence available.



### If you decide to have complementary or alternative treatments...



Before you decide to change your treatment or add any methods of your own, do talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, do talk openly with your GP or haematologist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present in Ireland, this area is not fully regulated. Make sure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

## Coping and emotions

### How can I cope with my feelings?

There are many reactions when told you have cancer. Reactions can often differ from person to person too. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment. Or indeed it may not be until the later stages of your illness that your emotions hit hard.

#### Common reactions include:

- Shock and disbelief
- Fear and uncertainty
- Loss of control
- Sorrow and sadness
- Denial
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet that discusses them in detail is called *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy or visit a Daffodil Centre. Your medical social worker in the hospital is also available to support you.

#### Shock and disbelief

*'It can't be me.' 'Has there been a mistake?' 'Cancer happens to other people, not me.'*

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss the cancer with you, the news may not sink in for a while.

You may find yourself confused, asking the same questions over and over again. Or else you may accept the news calmly and say nothing because you cannot really believe what is happening to you.

### Fear and uncertainty

*'I'm going to die.'  
'Will it be painful?'  
'Will I become a  
different person?'*

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. No one knows how long anybody will live, but having MDS is likely to shorten your life. It can be very difficult to face an uncertain future and feel you are no longer in control. One way to reduce the stress of uncertainty is to make your plans day by day. Letting go of the past and not worrying about the future allows you to live fully in the present.

You may also have fears that your experience of cancer will change who you are or that people will reject or avoid you. For example, after some cancer treatments your body image may be different, and it will take some time for you and for others to adjust to your new look. You may also have practical worries and fears about the effect of your illness on your family, your finances, your job, and your lifestyle.

Do discuss your concerns with your doctor, nurse or medical social worker, as they can advise and help you. If living with uncertainty overwhelms you, it may help to talk to someone in a support group.

### Loss of control

*'I can't cope with  
this.' 'I'll never get  
through it.'*

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don't know enough about MDS at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident making any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also help you feel more in control of your illness.

### Sorrow and sadness

*'I used to be so  
healthy.' 'I had so  
many plans.' 'I've let  
my family down.'*

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body due to treatment. Depending on your type of MDS, your life may be affected by treatment. In this case, the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

### Denial

*'I'm fine, really.'  
'I don't have cancer.'*

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your cancer until you're ready.

### Anger

*'Why me? I always  
took care of my  
health.' 'Why did this  
happen now?'*

It is normal too to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you. Or if you have a religious belief, you may feel angry with God for

allowing cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot.

Your family and friends may not always be aware that your anger is really at your illness and not at them. It may be helpful to talk to them when you are calm, rather than feeling guilty or trying to bottle up your angry thoughts. Anger can sometimes affect your ability to think clearly. So if it persists and you are finding it hard to talk to your family, tell your nurse or doctor.

### Resentment

*'How can you talk, you don't have to deal with cancer.' 'How come I'm not getting better?'*

It is natural that you might be resentful and unhappy – even jealous – because you have cancer while other people are well. During the course of your illness similar feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker than you have. You may resent your healthy relatives or having to change your lifestyle in some way.

On the other hand, sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

**>>> Don't bottle up your feelings – express them.**

### Blame and guilt

*'I should've been more careful.' 'If only I had a more positive attitude, I wouldn't have got sick.'*

When diagnosed with a serious illness such as MDS, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming

yourself. Other times, people feel guilty because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don't torture yourself at this time.

Don't feel guilty if you can't keep a positive attitude, especially when you feel unwell. Low periods are to be expected. There is no evidence at all that your attitude will affect your health or cancer. Regret and guilt serve no useful purpose. Instead focus on what you can change or do to make you feel more in control of your illness.

### Withdrawal and isolation

*'I just need to be on my own.'*

It is true that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal to want to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for them, as they will want to share this difficult time with you. They may worry about you needlessly. Do let your family and friends know that you will talk to them once you are ready.

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand? Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)

## How can my family and friends help?

Your family and friends can support you through your cancer journey in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Others may gather up-to-date information on MDS to know what you can expect and what you are going through. Others again may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friends best.



### How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future.



Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may think you are not doing much by just listening. In fact, it is one of the best ways to help.

#### Be patient

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

*Lost for Words: How to Talk to Someone with Cancer* is a useful booklet written for relatives and friends of people with cancer. Call the National Cancer Helpline on 1800 200 700 for a free copy or visit a Daffodil Centre.

## How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as possible. If you have young children or grandchildren, continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives. Every family deals with cancer in its own way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or grandchildren or that you're letting them down. These are all natural feelings to have at this time.

### Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing for your children. It can put added pressures on your family and lead to confusion. Young children are very sensitive to stress and tension and if you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible, then someone else close to your children should break the news. How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent, grandparent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more.

It is best to prepare children for the side-effects of treatment before they happen and to answer their questions simply and honestly. For example, if you get hair loss due to treatment. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

## Coping with children's emotions

During your illness, your children may experience a range of emotions from fear, guilt and anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, young children may feel that they somehow are to blame. But by having an open honest approach, it may bring you a sense of relief too. Your family may also find new depths of love and inner strength that will boost your life together.

If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer: A Guide for Parents* gives practical advice for discussing cancer with children. If you would like a copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)



## Support resources

### Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards.

- Medical social worker
- Cancer nurse specialists
- Psycho-oncology services
- Family doctor (GP)
- Community welfare officer and community health services
- Support groups and cancer support centres
- Irish Cancer Society



**Medical social worker:** The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and give advice on practical and financial supports and services available when you go home.

**Haematology nurse specialists:** Some of the major cancer treatment hospitals have haematology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. The nurses along with other members of your medical team work together to meet your needs.

**Psycho-oncology services:** In some larger hospitals there are special units that provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

**GP (family doctor):** You may feel comfortable talking to your family doctor (GP) about your MDS too. He or she can discuss any of your queries and offer advice and support.

**Community health services:** There are various community health services available from your local health centre. These centres have

public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as financial problems or exceptional needs. More information on the services is available either from the medical social worker in your hospital before you go home or at your local health centre.

**Support groups:** Joining a support group can put you in touch with people who have been in a similar situation. For example, the MDS Support Group Ireland and Northern Ireland. They can give you practical advice about living with MDS. Cancer support centres are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet. Useful websites, including patient forums, are also listed. You can download the Irish Cancer Society's *Directory of Cancer Support Services* from [www.cancer.ie](http://www.cancer.ie)

**Irish Cancer Society:** The staff of the Cancer Information Service will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about your financial matters. For example, getting life insurance.

Call the National Cancer Helpline on 1800 200 700 for information about any of the services outlined above or for support services in your area. Or if you prefer, you can also visit a Daffodil Centre.

>>> Remember that there are many people ready to help you.

## Health cover

Health cover falls into two groups – cover for medical card holders and cover for all other groups. Details of the following are given here:

- Hospital cover
- GP visit card
- Private healthcare cover
- Outpatient cover
- Drugs Payment Scheme (DPS)
- Benefits and allowances
- Medical card

At the end of this section there are also some useful telephone numbers and websites for further help.

### Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

### Outpatient cover

If you go to the outpatients or emergency department of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the emergency department first.

### Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You may have to pay a prescription charge of €2.50 per item up to a limit of €25 per family per month.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €500 or less (€900 for couples), you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card. But it will depend on your financial circumstances and how long your treatment is expected to last. In this case, your spouse and children will not be covered if your means are over the limit. If you wish to apply for a medical card, you can download an application form and apply online ([www.medicalcard.ie](http://www.medicalcard.ie)) or at your local health centre. LoCall 1890 252 919.

## GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at your hospital or your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online ([www.medicalcard.ie](http://www.medicalcard.ie)) or at your local health centre. LoCall 1890 252 919.

## Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office or local pharmacy.

## Private healthcare cover

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Laya Healthcare, AVIVA Health, GloHealth, and other schemes. They provide cover for day care or inpatient treatment and hospital outpatient treatment. Before attending hospital, do check the level of cover provided by your insurer, both for inpatient and outpatient services.

If you have private insurance, your tests might not get done as quickly as you would like. Your health insurer has to approve some tests in advance. For example, MRI and PET scans. Sometimes it might take 24–48 hours to get approval from your health insurer.

## Benefits and allowances

You or a family member may qualify for a number of benefits and allowances. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

More information is available in a booklet called *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. For a free copy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from [www.cancer.ie](http://www.cancer.ie)

Application forms for the benefits are available from social welfare offices or Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or LoCall 1890 927 770. You can also download the forms from [www.welfare.ie](http://www.welfare.ie) or [www.citizensinformation.ie](http://www.citizensinformation.ie)

## Appliances

If you have a medical card most appliances are free of charge or subsidised. For example, if you have hair loss due to chemotherapy, you are entitled to 1–2 free or subsidised new hairpieces every year. The subsidy will depend on the HSE area.

## Travel to hospital

You can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres, usually for patients with medical cards.

See page 54 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

## Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending.

For social welfare queries, contact:

### Dept of Social Protection – Information Service

Oisín House  
212–213 Pearse Street  
Dublin 2  
Tel: 1850 662 244

Leaflet line: 1890 202 325  
Email: [info@welfare.ie](mailto:info@welfare.ie)  
Website: [www.welfare.ie](http://www.welfare.ie)

If you have queries about health and social services, contact the HSE office in your area.

**HSE infoline:** 1850 24 1850 **Email:** [info@hse.ie](mailto:info@hse.ie) **Website:** [www.hse.ie](http://www.hse.ie)

Information is also available from your local Citizens Information Centre. A list of these centres is available from:

### Citizens Information

Tel: 0761 07 4000  
Email: [information@citizensinformation.ie](mailto:information@citizensinformation.ie)  
Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)



### If you have financial worries...



A diagnosis of MDS can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are unable to work or unemployed, this may cause even more stress. It may be hard for you to deal with MDS if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 53 for more details. You can also call the National Cancer Helpline on 1800 200 700 and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 55 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 61 for more information.

## Irish Cancer Society services

The Irish Cancer Society funds a range of support services that provide care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support groups
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets and factsheets
- Financial support
- Care to Drive transport project

### Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline 1800 200 700** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- The website **[www.cancer.ie](http://www.cancer.ie)** provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at **[helpline@irishcancer.ie](mailto:helpline@irishcancer.ie)**
- **Message Board** is a discussion space on our website (**[www.cancer.ie](http://www.cancer.ie)**) to share your stories, ideas and advice with others.
- The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on **Facebook** and follow us on **Twitter** (@IrishCancerSoc).

## Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

## Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See pages 56–59 for more details.

## Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to newly diagnosed patients. It can provide you and your relatives with information, advice and emotional support from time of diagnosis and for as long as is needed. All the volunteers have had a personal experience of cancer and understand the emotional and physical impacts of the disease. They are carefully selected after recovery and are trained to provide information and reassurance. The service is provided on a one-to-one basis and is confidential. If you would like to make contact with a volunteer, call the National Cancer Helpline on 1800 200 700.

## Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend

or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the National Cancer Helpline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

## Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

## Oncology liaison nurses

The Society funds some oncology liaison nurses who can give you and your family information as well as emotional and practical support. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

## Cancer information booklets and factsheets

These booklets provide information on all aspects of cancer and its treatment, while the factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. These booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from [www.cancer.ie](http://www.cancer.ie) or picked up at a Daffodil Centre.



## Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial help to patients in great need. You may be suitable for schemes such as Travel2Care or Financial Aid.

Travel2Care is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. The scheme can help with your travel costs if you have genuine financial hardship due to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking. If you are travelling to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

**Travel2Care:** If you would like to request this kind of help, contact your haematology nurse or the Irish Cancer Society at (01) 231 6643 / 231 6619 or email: [travel2care@irishcancer.ie](mailto:travel2care@irishcancer.ie)

**Financial Aid:** A special fund has been created to help families in financial hardship when faced with a cancer diagnosis. If this applies to you, contact the medical social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society at (01) 231 6619.

### Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their chemotherapy treatments using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 for more information.



If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700. See our website for more information: [www.cancer.ie](http://www.cancer.ie)

National Cancer Helpline Freefone 1800 200 700

## Useful organisations

### Irish Cancer Society

43/45 Northumberland Road  
Dublin 4  
Tel: 01 231 0500  
National Cancer Helpline:  
1800 200 700  
Email: [helpline@irishcancer.ie](mailto:helpline@irishcancer.ie)  
Website: [www.cancer.ie](http://www.cancer.ie)

### The Adelaide and Meath Hospital

**Department of Haematology**  
[MDS Centre of Excellence]  
Tallaght  
Dublin 24  
Tel: 01 414 3932 (Prof Helen Enright)

### MDS Support Group Ireland & Northern Ireland

Tel: 086 200 1402 (Sinead Mahon)  
Email: [mdsireland7@gmail.com](mailto:mdsireland7@gmail.com)

### The Carers Association

Market Square  
Tullamore  
Co Offaly  
Tel: 057 932 2920  
Freefone: 1800 240 724  
Email: [info@carersireland.com](mailto:info@carersireland.com)

### Citizens Information

Tel: 0761 07 4000  
Email: [information@citizensinformation.ie](mailto:information@citizensinformation.ie)  
Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)

### HARI: The National Fertility Centre

Rotunda Hospital  
Parnell Square  
Dublin 1  
Tel: 01 807 2732  
Email: [info@hari.ie](mailto:info@hari.ie)  
Website: [www.hari.ie](http://www.hari.ie)

### Irish Oncology and Haematology Social Workers Group

Website: [socialworkandcancer.com](http://socialworkandcancer.com)

### Irish Nutrition & Dietetic Institute

Ashgrove House  
Kill Avenue  
Dún Laoghaire  
Co Dublin  
Tel: 01 280 4839  
Email: [info@indi.ie](mailto:info@indi.ie)  
Website: [www.indi.ie](http://www.indi.ie)

### Money Advice and Budgeting Service (MABS)

Commercial House  
Westend Commercial Village  
Blanchardstown  
Dublin 15  
Tel: 01 812 9350  
Helpline: 0761 07 2000  
Email: [helpline@mabs.ie](mailto:helpline@mabs.ie)  
Website: [www.mabs.ie](http://www.mabs.ie)

### Health insurers

#### AVIVA Health

(formerly VIVAS Health)  
PO Box 764  
Togher  
Cork  
Tel: 1850 717 717  
Email: [info@avivahealth.ie](mailto:info@avivahealth.ie)  
Website: [www.avivahealth.ie](http://www.avivahealth.ie)

#### GloHealth

PO Box 12218  
Dublin 18  
Tel: 1890 781 781  
Email: [findoutmore@glohealth.ie](mailto:findoutmore@glohealth.ie)  
Website: [www.glohealth.ie](http://www.glohealth.ie)

#### Laya Healthcare (formerly Quinn)

Eastgate Road  
Eastgate Business Park  
Little Island  
Co Cork  
Tel: 021 202 2000  
LoCall: 1890 700 890  
Email: [info@layahealthcare.ie](mailto:info@layahealthcare.ie)  
Website: [www.layahealthcare.ie](http://www.layahealthcare.ie)

**Voluntary Health Insurance (VHI)**

IDA Business Park  
Purcellsinch  
Dublin Road  
Kilkenny  
CallSave: 1850 44 44 44  
Email: info@vhi.ie  
Website: www.vhi.ie

**National support groups**

**ARC Cancer Support Centres**  
Dublin and Cork (see pages 57 and 58).

**I've Got What?!**

[Support for young adults affected by cancer]  
c/o Cross Cause Charity Shop  
Blackrock  
Co Louth  
Tel: 086 339 5690

**Lakelands Area Retreat & Cancer Centre**

Multyfarnham  
Mullingar  
Co Westmeath  
Tel: 044 937 1971  
Callsave: 1850 719 719  
Email: info@larcc.ie  
Website: www.larcc.ie

**Connaught support groups & centres****Athenry Cancer Care**

Social Service Centre  
New Line  
Athenry  
Co Galway  
Tel: 091 844 319 / 087 412 8080

**Ballinasloe Cancer Support Centre**

Society Street  
Ballinasloe  
Co Galway  
Tel: 090 964 5574 / 087 945 2300  
Email: ballinasloecancer@yahoo.co.uk

**Cara Iorrais Cancer Support Centre**

2 Church Street  
Belmullet  
Co Mayo  
Tel: 097 20590  
Email: caraiorrais@gmail.com

**East Galway Cancer Support Centre**

The Family Centre  
John Dunne Avenue  
Ballinasloe  
Co Galway  
Tel: 087 984 5574 / 087 945 2300  
Website:  
www.eastgalwaycancersupport.com

**Gort Cancer Support Group**

The Hawthorn  
Ennis Road  
Gort  
Co Galway  
Tel: 086 312 4220  
Email: gcsupport@eircom.net  
Website: www.gortcs.ie

**Mayo Cancer Support Association**

Rock Rose House  
32 St Patrick's Avenue  
Castlebar  
Co Mayo  
Tel: 094 903 8407  
Email: info@mayocancer.ie  
Website: www.mayocancer.ie

**Roscommon Cancer Support Group**

Vita House Family Centre  
Abbey Street  
Roscommon  
Tel: 090 662 5898  
Email: vitahouse@eircom.net

**Sligo Cancer Support Centre**

44 Wine Street  
Sligo  
Tel: 071 917 0399  
Email: scsc@eircom.net  
Website:  
www.sligocancersupportcentre.ie

**Tuam Cancer Care Centre**

Cricket Court  
Dunmore Road  
Tuam  
Co Galway  
Tel: 093 28522  
Email: support@tuamcancercare.ie  
Website: www.tuamcancercare.ie

**Leinster support groups & centres****ARC Cancer Support Centre**

ARC House  
65 Eccles Street  
Dublin 7  
Tel: 01 830 7333  
Email: info@arccancersupport.ie  
Website: www.arccancersupport.ie

**ARC Cancer Support Centre**

ARC House  
559 South Circular Road  
Dublin 8  
Tel: 01 707 8880  
Email: info@arccancersupport.ie  
Website: www.arccancersupport.ie

**Arklow Cancer Support Group**

25 Kingshill  
Arklow  
Co Wicklow  
Tel: 085 110 0066  
Email:  
arklowcancersupport@gmail.com

**Balbriggan Cancer Support Group**

Unit 23, Balbriggan Business Park  
Balbriggan  
Co Dublin  
Tel: 087 353 2872

**Bray Cancer Support & Information Centre**

36B Main Street  
Bray  
Co Wicklow  
Tel: 01 286 6966  
Email: info@braycancersupport.ie  
Website: www.braycancersupport.ie

**Cara Cancer Support Centre**

Mullavalley  
Louth Village  
Dundalk  
Co Louth  
Tel: 042 937 4905  
Mobile: 087 395 5335  
Email: info@ccscdundalk.ie  
Website: ccscdundalk.ie

**Cois Nore: Cancer Support Services Kilkenny**

8 Walkin Street  
Kilkenny  
Tel: 056 775 2222  
Email: coisnorekilkenny@gmail.com  
Website: www.kilkennycancersupport.ie

**Cuisle Centre**

Cancer Support Group  
Block Road  
Portlaoise  
Co Laois  
Tel: 057 868 1492  
Email: info@cuislecentre.com  
Website: www.cuislecentre.com

**Dóchas: Offaly Cancer Support**

Teach Dóchas  
Offaly Street  
Tullamore  
Co Offaly  
Tel: 057 932 8268  
Email: info@dochasoffaly.ie  
Website: www.dochasoffaly.ie

**Éist Cancer Support Centre Carlow**

The Waterfront  
Mill Lane  
Carlow  
Tel: 059 913 9684  
Mobile: 085 144 0510  
Email: info@eistcarlowcancersupport.ie  
Website: www.eistcarlowcancersupport.ie

**Gary Kelly Support Centre**

George's Street  
Drogheda  
Co Louth  
Tel: 041 980 5100 / 086 817 2473  
Email: services@gkcancersupport.com  
Website: www.gkcancersupport.com

**Greystones Cancer Support**

La Touche Place  
Greystones  
Co Wicklow  
Tel: 01 287 1601  
Email: info@greystonescancersupport.com  
Website:  
www.greystonescancersupport.com

**Haven Cancer Support and Therapy Group**

Haven House  
68 Hazelwood  
Gorey  
Co Wexford  
Tel: 053 942 0707 / 086 250 1452  
Email: info@thehavengroup.ie  
Website: www.thehavengroup.ie

**HOPE Cancer Support Centre**

22 Upper Weafer Street  
Enniscorthy  
Co Wexford  
Tel: 053 923 8555  
Email: mary@hopesupportcentre.ie  
Website: www.hopesupportcentre.ie

**Lakelands Area Retreat & Cancer Centre**

Ballinalack  
Mullingar  
Co Westmeath  
Tel: 044 937 1971  
Callsave: 1850 719 719  
Email: info@larcc.ie  
Website: www.larcc.ie

**Newbridge Cancer Support Group**

144 Allenvue Heights  
Newbridge  
Co Kildare  
Tel: 083 360 9898  
Email:  
newbridgecancerhealinghelp@gmail.com

**Rathdrum Cancer Support Centre**

34 Main Street  
Rathdrum  
Co Wicklow  
Tel: 087 292 8660  
Email: rathcan@gmail.com

**Tallaght Cancer Support Group**

Millbrook Lawns  
Tallaght  
Dublin 24  
Tel: 087 217 6486  
Email: ctallaght@yahoo.ie

**Wicklow Cancer Support Centre**

1 Morton's Lane  
Wicklow  
Tel: 0404 32696  
Email: wicklowcancersupport@gmail.com

**Munster support groups & centres****Cancer Information & Support Centre**

Mid-Western Regional Hospital  
Dooradoyle  
Co Limerick  
Tel: 061 485 163  
Website:  
www.midwesterncancercentre.ie

**CARE Cancer Support Centre**

14 Wellington Street  
Clonmel  
Co Tipperary  
Tel: 052 618 2667  
Email: cancersupport@eircom.net  
Website: www.cancercare.ie

**Cork ARC Cancer Support House**

Cliffdale  
5 O'Donovan Rossa Road  
Cork  
Tel: 021 427 6688  
Email: info@corkcancersupport.ie  
Website: www.corkcancersupport.ie

**Kerry Cancer Support Group**

124 Tralee Town House Apartments  
Maine Street  
Tralee  
Co Kerry  
Tel: 066 719 5560 / 087 230 8734  
Email: kerrycancersupport@eircom.net  
Website: www.kerrycancersupport.com

**Recovery Haven**

5 Haig's Terrace  
Tralee  
Co Kerry  
Tel: 066 719 2122  
Email: recoveryhaven@gmail.com  
Website: www.recoveryhavenkerry.org

**Sláinte an Chláir: Clare Cancer Support**

Tír Mhuire  
Kilnamona  
Ennis  
Co Clare  
Tel: 1850 211 630 / 087 691 2396  
Email: admin@clarecancersupport.com  
Website: www.clarecancersupport.com

**South Eastern Cancer Foundation**

Solas Centre  
7 Sealy Close  
Earlscourt  
Waterford  
Tel: 051 876 629  
Email: infosecf@eircom.net  
Website: www.secf.ie

**Suimhneas Cancer Support Centre**

2 Clonaslee  
Gortland Roe  
Nenagh  
Co Tipperary  
Tel: 067 37403  
Email:  
suaimhneascancersupport@eircom.net

**Suir Haven Cancer Support Centre**

Clongour Road  
Thurles  
Co Tipperary  
Tel: 0504 21197  
Email: suirhaven@gmail.com

**Youghal Cancer Support Group**

161 North Main Street  
Youghal  
Co Cork  
Tel: 024 92353 / 087 273 1121

**Ulster support groups & centres****Cancer Support and Social Club**

Tiernaleague  
Carndonagh  
Co Donegal  
Tel: 086 602 8993 / 087 763 4596

**Coiste Scaoil Saor ó Ailse**

Knockastoller  
Gweedore  
Letterkenny  
Co Donegal  
Tel: 083 121 7857  
Email: coiste.scaoil.saor@icloud.com  
Website: www.scaoilsaor.ie

**Crocus: Monaghan Cancer Support Centre**

The Wellness Centre  
19 The Grange  
Plantation Walk  
Monaghan  
Tel: 087 368 0965

**Cuan Cancer Social Support and Wellness Group**

2nd Floor, Cootehill Credit Union  
22-24 Market Street  
Cootehill  
Co Cavan  
Tel: 086 455 6632

**The Forge Cancer Support Group**

The Forge Family Resource Centre  
Pettigo  
Co Donegal  
Tel: 071 986 1924

**Living Beyond Cancer**

Oncology Day Services  
Letterkenny General Hospital  
Letterkenny  
Co Donegal  
Tel: 074 912 5888 (Bleep 674/734) /  
074 910 4477

**Support group & centres unaffiliated to Irish Cancer Society****Cancer Care West**

Inis Aoi bhinn  
University Hospital Galway  
Costello Road  
Galway  
Tel: 091 545 000  
Email: info@cancercarewest.ie  
Website: www.cancercarewest.ie

**Cúnamh: Bons Secours Cancer Support Group**

Bon Secours Hospital  
College Road  
Cork  
Tel: 021 480 1676  
Website: www.cunamh.ie

**Dundalk Cancer Support Group**

Philipstown  
Hackballscross  
Dundalk  
Co Louth  
Tel: 086 107 4257

**Good and New Cancer Drop In Centre**

Unit 1, Portlink Business Park  
Port Road  
Letterkenny  
Co Donegal  
Tel: 074 911 3437

**Killybegs Cancer Support Group**

Kille  
Kilcar  
Co Donegal  
Tel: 074 973 1292  
Email: riverbankdunne@eircom.net

**Solace: Donegal Cancer Support Centre**

St Joseph's Avenue  
Donegal Town  
Tel: 074 974 0837  
Email: solacedonegal@eircom.net

For other support groups or centres  
in your area, call 1800 200 700.

**Useful contacts outside  
Republic of Ireland****Action Cancer**

Action Cancer House  
1 Marlborough Park  
Belfast BT9 6XS  
Tel: 028 9080 3344  
Email: info@actioncancer.org  
Website: www.actioncancer.org

**American Cancer Society**

Website: www.cancer.org

**Aplastic Anaemia and MDS  
International Foundation (USA)**

Website: www.aamds.org

**Cancer Focus Northern Ireland**

40-44 Eglantine Avenue  
Belfast BT9 6DX  
Tel: 048 9066 3281  
Email: hello@cancerfocusni.org  
Website: www.cancerfocusni.org

**Cancer Research UK**

Tel: 0044 20 7242 0200  
Website: www.cancerhelp.org.uk

**King's College Hospital**

[MDS Centre of Excellence]  
Denmark Hill  
London SE5 9RS  
Tel: 0044 20 3299 3080 (Prof Ghulam Mufti)

**Macmillan Cancer Support (UK)**

Tel: 0044 20 7840 7840  
Email: cancerline@macmillan.org.uk  
Website: www.macmillan.org.uk

**Macmillan Support & Information Centre**

Belfast City Hospital Trust  
77-81 Lisburn Road  
Belfast BT9 7AB  
Tel: 028 9069 9202  
Email: cancerinfo@belfasttrust.hscni.net

**MDS UK Patient Support Group**

Haematology – Bessemer Wing  
King's College Hospital  
Denmark Hill  
London SE5 9RS  
Tel: 00 44 20 7733 7558  
Email: mds-uk@mds-foundation.org  
Website: www.mdspatientsupport.org.uk

**MDS Foundation (USA)**

Website: www.mds-foundation.org

**MDS Foundation (European Branch)**

King's College Hospital  
Denmark Hill  
London SE5 9RS  
Email: eupatientliaison@mds-foundation.org

**National Cancer Institute (US)**

Website: www.nci.nih.gov

**UK MDS Forum**

Website: www.ukmdsforum.org

## Helpful books

**Free booklets from the Irish Cancer Society:**

- *Understanding Stem Cell Collection*
- *Understanding Autologous Stem Cell Transplants*
- *Understanding Acute Myeloid Leukaemia*
- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *Coping with Fatigue*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*
- *Journey Journal: Keeping Track of Your Cancer Treatment*



*Anaemia, Blood Transfusions, Iron Overload, and Myelodysplastic Syndromes: A Handbook for Adult MDS Patients*  
MDS Foundation, 2011

*Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients*  
MDS Foundation, 2007

*Understanding Myelodysplastic Syndromes: A Patient Handbook*  
John Bennett (editor), 6th edn  
MDS Foundation, 2008

[Booklets from the MDS Foundation can be downloaded from [www.mds-foundation.org](http://www.mds-foundation.org)]

*100 Questions and Answers about Myelodysplastic Syndromes*  
Jason Gotlib & Lenn Fechter  
Jones & Bartlett Publishers, 2007  
ISBN 978-0763753337

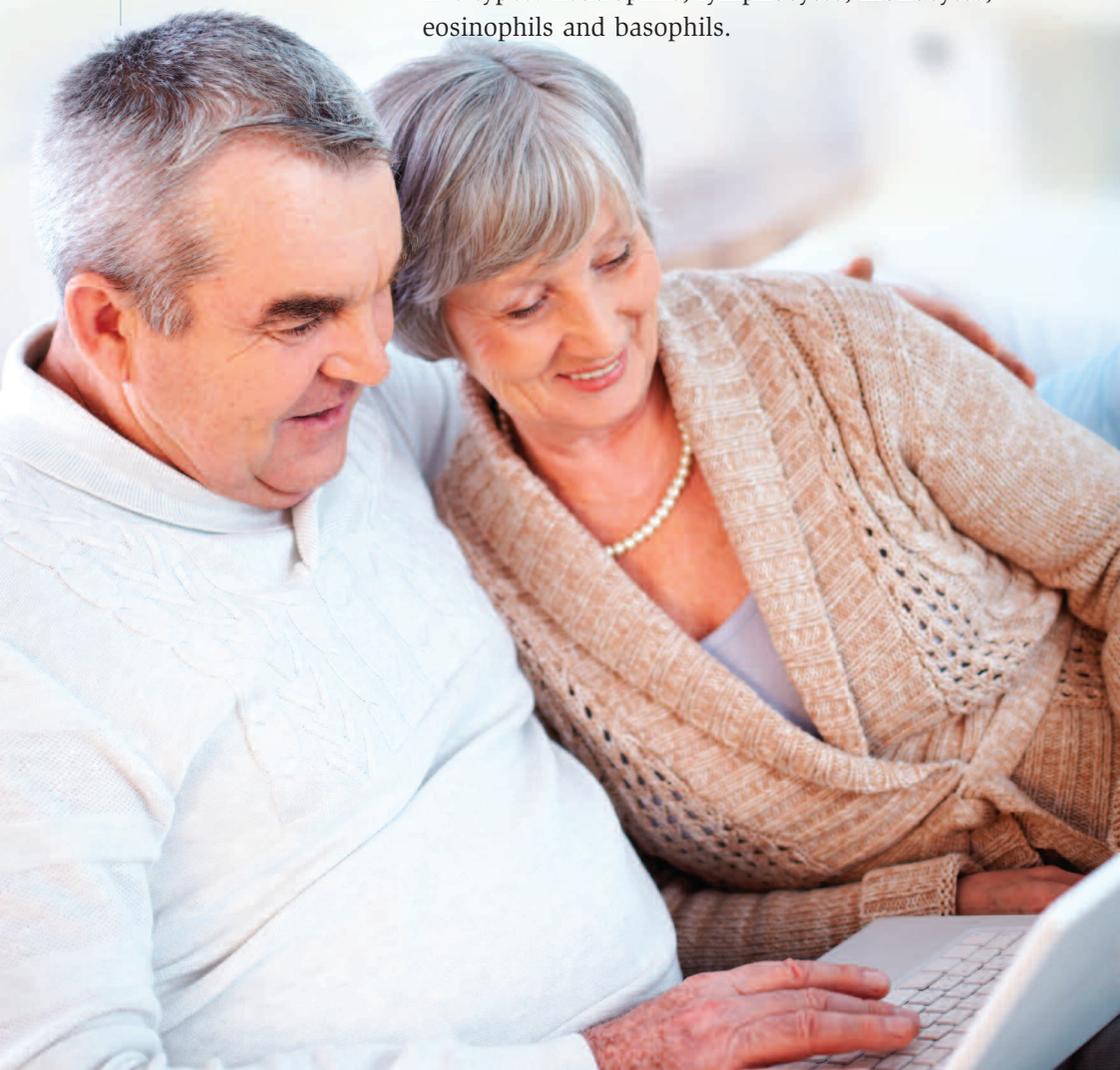
*101+ Square Meals*  
[Budget and nutrition]  
Norah Bourke et al  
MABS/HSE West/Paul  
Partnership/Limerick VEC/Safefood, 1998  
ISBN 187407514X  
[For more details, see [www.mabs.ie](http://www.mabs.ie)]

## What does that word mean?

<b>Anaemia</b>	Fewer red blood cells in your blood and a lack of haemoglobin. This can cause tiredness and breathlessness.
<b>Anti-emetic</b>	A tablet, injection or suppository given to stop you feeling sick or vomiting.
<b>Biopsy</b>	Removing a small amount of cells or tissue from your body to examine under a microscope.
<b>Blast cell</b>	Immature cells in bone marrow that develop into white cells called neutrophils or lymphocytes. The number of blast cells is increased in some types of MDS and in leukaemia.
<b>Bone marrow</b>	The soft spongy material found in the centre of your large bones. It makes red blood cells, white blood cells and platelets.
<b>Bone marrow aspirate or biopsy</b>	When a sample of marrow cells or bone is taken and looked at under a microscope.
<b>Central line</b>	A long, thin flexible tube put into a large vein usually in your upper chest to give medication and fluids.
<b>Chemotherapy</b>	The use of drugs to cure or control cancer.
<b>Chromosomes</b>	Tiny structures that contain the genetic information of the cells in your body.
<b>Cytogenetics</b>	Tests that look at the chromosomes of MDS cells.
<b>Cytopenia</b>	Low blood counts. A lack of red cells (anaemia), platelets (thrombocytopenia) or white cells (leucopenia).
<b>Fatigue</b>	Ongoing tiredness or exhaustion.
<b>Growth factors</b>	Medicines that can help to increase the number of red cells, white cells or platelets.

<b>Haematologist</b>	A doctor who specialises in treating patients with blood or bone marrow diseases.
<b>Haematology</b>	The study of blood and bone marrow.
<b>Immunophenotyping</b>	A test that checks what kind of proteins or markers are found on the surface of leukaemia cells.
<b>International Prognostic Scoring System (IPSS)</b>	An internationally agreed system based on your blood and bone marrow results to help predict how your type of MDS will behave in the future (prognosis).
<b>Iron chelation</b>	The use of medicines to get rid of excess iron from your body.
<b>Leukaemia</b>	Cancer of the white blood cells and bone marrow.
<b>Myelodysplasia</b>	A type of bone marrow failure with low blood counts. It is the same thing as myelodysplastic syndrome.
<b>Nausea</b>	Feeling sick or wanting to be sick.
<b>Neutropenia</b>	A lower than normal number of neutrophils in your blood.
<b>Neutrophils</b>	Important white cells that fight infection. They are the most common of the white blood cells.
<b>Petechiae</b>	Bleeding under your skin, usually on your legs, feet, trunk and arms, due to a low platelet count.
<b>Platelets</b>	Blood cells responsible for clotting.
<b>Prognosis</b>	The expected outcome or course of a disease. How it will behave in the future.
<b>Red blood cells</b>	Blood cells that carry oxygen to all parts of your body.

<b>Refractory anaemia</b>	A type of MDS with low red blood cells (anaemia).
<b>Ring sideroblast</b>	An abnormal-looking red cell in bone marrow found in some kinds of MDS.
<b>Stem cell</b>	The earliest cells found in bone marrow. They are responsible for making all blood cells.
<b>Thrombocytopenia</b>	A low platelet count.
<b>White blood cells</b>	Blood cells that help fight infection. There are five types: neutrophils, lymphocytes, monocytes, eosinophils and basophils.



## Questions to ask your doctor

Here is a list of questions that you might like to ask your doctor. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than to worry.

- How long will it take to get the test results?
- What type of MDS do I have?
- What is my prognosis?
- What treatment will I need?
- What is the goal of this treatment?
- Are there other treatment options?
- What side-effects will I get from the treatment?
- Would I be suitable for a clinical trial?
- Is there anything I can do to help myself during treatment?
- Can my symptoms be controlled?
- How will I know if the treatment is working?
- On average, how long does this treatment usually work?
- What happens if the treatment stops working?
- What problems should I report to you?
- How will this treatment affect my lifestyle?

## Your own questions

1 \_\_\_\_\_

Answer \_\_\_\_\_

2 \_\_\_\_\_

Answer \_\_\_\_\_

3 \_\_\_\_\_

Answer \_\_\_\_\_

4 \_\_\_\_\_

Answer \_\_\_\_\_

5 \_\_\_\_\_

Answer \_\_\_\_\_

## Blood results diary

Date	HB	WBC	Plts	Neut	Other







## Acknowledgements

We would like to extend a special word of thanks to Prof Helen Enright and the following for their invaluable contributions to this booklet:

Sinead Mahon, MDS Support Group Ireland and Northern Ireland

Michael H. Phillips, Illustrator

Shutterstock Images

## Would you like more information?

We hope this booklet has been of help to you. After reading it or at any time in the future, if you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700.

## Would you like to be a patient reviewer?



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**

If you would prefer to phone or write to us, see contact details below.

## Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, research and education. This includes patient information booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email: **fundraising@irishcancer.ie**

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4.

**Tel:** 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

**Irish Cancer Society**

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: [info@irishcancer.ie](mailto:info@irishcancer.ie)

W: [www.cancer.ie](http://www.cancer.ie)

National Cancer Helpline Freefone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

