

Understanding

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# Myelodysplastic Syndromes (MDS)

Caring for people with cancer

## Understanding

# Myelodysplastic Syndromes (MDS)

This booklet has information on:

- Treatment for myelodysplastic syndromes (MDS)
- Side-effects and how to manage them
- Coping with the emotional and practical side of cancer
- Financial and practical matters

### Useful numbers

Specialist nurse

Haematologist

Family doctor (GP)

Haematology day ward

Medical social worker

Emergency

Hospital records number (MRN)

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# Fast facts



## What is MDS?

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Myelodysplastic syndromes (MDS) are a group of diseases where the bone marrow doesn't make enough healthy blood cells. MDS is divided into 'risk groups'. These groups are low-risk, intermediate-risk or high-risk MDS.

## Can MDS be treated?

Page 25

Yes. The aim of treatment is to improve the number and type of blood cells in the bloodstream and to relieve symptoms. The type of treatment you're offered will depend on your type of MDS, your risk group and your general health.

## What treatment am I likely to have? Page 25

Depending on your risk group and symptoms you may not have treatment straight away. Other people may have blood transfusions or an injection of growth factor to increase the number of blood cells. Other treatments include chemotherapy and a stem cell transplant. You will need regular blood tests and check-ups.

## Will I be OK?

Page 16

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, such as your age, health, your type of MDS and your risk group. Everyone is different, so it's best to ask your consultant about your own situation.

## Are there side-effects of treatment? Page 39

Treatment for myelodysplastic syndromes can cause a number of side-effects. Read about the treatments (page xx) to learn more about their side-effects.

**There are treatments to help with most side-effects, so tell your doctor if you have any. Don't suffer in silence!**

## Clinical trials

Page 53

Clinical trials are when cancer patients get a new type of treatment to see if it works better than existing treatments. Ask your consultant if there are any trials suitable for you.

## We're here for you

Page 90

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

### Ways to get in touch

- Call our Cancer Nurseline on 1800 200 700
- Drop in to a Daffodil Centre
- Email us: [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

See page 90 for more about our services.

## Reading this booklet



This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference. If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Cancer Nurseline on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and care – they know your medical history and your individual circumstances.



Cancer Nurseline Freephone 1800 200 700

## Introduction and diagnosis

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## What are myelodysplastic syndromes?



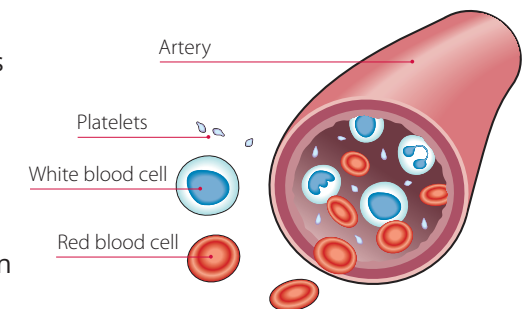
- MDS is a type of bone marrow failure. The bone marrow cannot make enough healthy red blood cells, white blood cells or platelets.
- Bone marrow is the soft spongy tissue that fills the centre of your long bones.

Myelodysplastic syndromes (MDS) are a group of diseases where the making of blood cells by the bone marrow is damaged. It is a type of cancer and sometimes may be referred to as bone marrow failure. 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.

### 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.

### MDS and your blood cells

As MDS can affect the production of white blood cells, red blood cells or platelets, people with MDS often have low blood counts. You may have just one type of blood cell affected. Or all 3 blood cells can be affected.

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. When all three blood cells are affected, it is called pancytopenia.

## 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:**
  - Tiredness and fatigue
  - Palpitations
  - Pale skin colour
  - Shortness of breath
- **Infections** that are frequent and difficult to treat
- **Bleeding**, often from the mouth or nose
- **Bruising or skin rash**

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

## How common is MDS?

MDS is a rare disease. In Ireland, less than 150 people are diagnosed per year. 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 tests will I have?



- Tests you may have include a full blood count, bone marrow tests and chromosome tests
- The tests will tell your medical team more about your MDS and help them to decide on the best treatment for you

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. They will ask you about your medical history to rule out other causes of low blood counts.

After being diagnosed with MDS, you may have more tests to find out about your cancer and your general health. Some of these tests will be used to find out exactly what type of MDS you have. Others may be used to monitor how well you are responding to treatment.

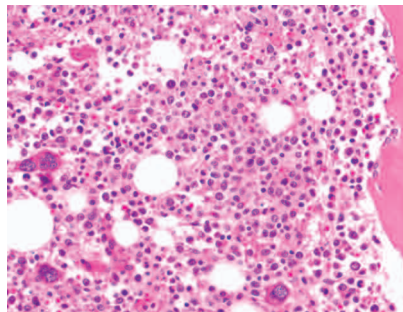
After a diagnosis of MDS, you will have regular blood testing to monitor your disease. How often you need testing is different for each patient. Always tell your healthcare team about any new symptoms or change in symptoms.

## Tests you may have include:

**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.

**Full blood count:** A full blood count (FBC) will be taken. A FBC counts the number of red blood cells, platelets and white blood cells. 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 analysis.

**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.



A bone marrow biopsy showing MDS cells in dark purple

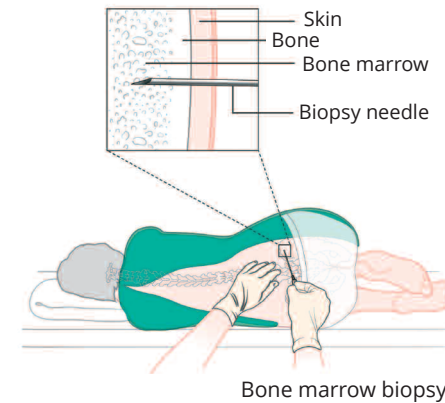


Image courtesy of Cancer Research UK/Wikimedia Commons

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 done for two main reasons:

- To confirm an MDS diagnosis
- To see if your MDS has stayed the same, improved or worsened since the last exam

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.

**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.

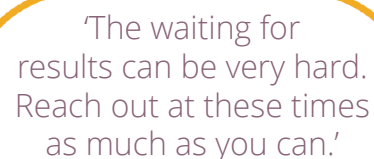
The chromosomes in the bone marrow sample are compared to those in normal cells. In MDS, there may be some genetic changes in the marrow cells which help to confirm the diagnosis of MDS and also to predict the course of the disease (prognosis). Remember these chromosome changes happen when the disease develops and are only found in your bone marrow and blood cells, so they cannot be passed on to your children.

## Waiting for test results

It usually takes 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, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.



'The waiting for results can be very hard. Reach out at these times as much as you can.'

## Types of MDS

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## What are the types of MDS?

- There are different types of MDS. These include high risk and low risk groups.
- The expected outcome or prognosis for MDS depends on the type you have.
- The Revised International Prognostic Scoring System is used to predict how MDS will behave over time.

The different types of MDS describe how it affects your blood cells and bone marrow and if there are any abnormal changes to your chromosomes. For example, in some types of MDS your blood will have a high number of blast cells, which are white blood cells which haven't developed properly. In other types your blood cells or chromosomes may be abnormal in some way.

The system doctors use to describe the different types of MDS is called a classification system. The most widely used classification system is the World Health Organisation (WHO) system.

In the WHO classification system, there are 6 main types, or subtypes, of MDS:

- 1 MDS with single lineage dysplasia (**MDS-SLD**)
- 2 MDS with multilineage dysplasia (**MDS-MLD**)
- 3 MDS with ring sideroblasts (**MDS-RS**)
- 4 MDS with isolated del (**5q**)
- 5 MDS with excess blasts (**MDS-EB**)
- 6 MDS unclassifiable (**MDS-U**)

## Understanding MDS subtypes

The name of the different MDS subtypes can sound confusing and be hard to understand.

- **Dysplasia** means 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.

Your doctor will explain which type of MDS you have. If you are confused or have more questions, don't be afraid to ask your doctor or specialist nurse. You can also speak to a nurse by calling our Cancer Nurseline on 1800 200 700 or by visiting a Daffodil Centre.



## Low risk or high risk MDS

In some people, MDS will develop into a type of cancer of the blood called acute myeloid leukaemia (AML). The risk of this happening depends on the type of MDS you have, but most patients do not go on to develop leukaemia.

High risk or low risk MDS 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: MDS-SLD, MDS-MLD, MDS-RS and the 5q-syndrome.

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

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 Revised International Prognostic Scoring System (IPSS).

### Revised International Prognostic Scoring System (IPSS-R)

As well as the different types of MDS, doctors consider patients according to how the disease is most likely to develop. The system for grouping MDS according to likely outcome is called the Revised International Prognostic Scoring System (IPSS-R). The IPSS-R is based on the following factors:

- The number of cell types that are low in your blood (cytopenia)
- The amount of blasts (immature cells) in your blood and bone marrow
- Any chromosome changes (cytogenetics)

Each factor gets a score. Together, the scores tell which risk groups you fall into. There are 5 risk groups:

- |                 |                     |                  |
|-----------------|---------------------|------------------|
| 1 Very low risk | 3 Intermediate risk | 5 Very high risk |
| 2 Low risk      | 4 High risk         |                  |

You will find detailed charts describing the scoring system on page 100. Do ask your doctor and nurse to explain the system. It can be confusing as there are many aspects to it. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice.

### Asking about your prognosis



Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with MDS have questions about their prognosis.

## Should I ask about my prognosis?

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

It's not always easy for doctors to answer a question about life expectancy, as the answer is based on a 'typical' experience. In reality, experiences can vary a lot from person to person. What happens to you might be quite different from what the doctor expects.

If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.

- **Get information on prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Avoid looking online.** It can be hard to understand the information you find online without an expert like a doctor to help. The information may not really apply to your situation or to your particular cancer type.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie). Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

## Being diagnosed with MDS

Hearing that you have MDS can be a huge shock. You may be feeling:

- **Upset and overwhelmed** by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next

However you feel, you are not alone.

If you need to talk to someone, or if you want support or advice:

- Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters

- Talk to one of our cancer nurses in confidence – visit a Daffodil Centre or call our Cancer Nurseline on 1800 200 700. You can email the nurses at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)
- Speak to an Irish Cancer Society Survivor Support volunteer who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer.
- Talk to other people going through the same thing. Join our online community at [www.cancer.ie/community](http://www.cancer.ie/community)
- Go to your local cancer support centre. For more information, see page 96.

## Telling people about your diagnosis



Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset

If you would like to talk things over with a cancer nurse, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet *Who Can Ever Understand?* It can help you find ways to talk about your cancer and to ask for the help and support you need.

Cancer Nurseline Freephone 1800 200 700



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## How is MDS treated?



- The main treatments available for MDS are:
  - Supportive care
  - Non-intensive treatment
  - Intensive chemotherapy
  - Stem cell transplant
- Before you start any treatment, your doctor will explain the aims of the treatment to you

The best treatment for you will depend on:

- Your type of MDS
- Your IPSS-R score. See page 18 for more information.
- Your age
- How the disease is affecting you
- Your general fitness
- Your own wishes

### Watch and wait



You may not need active treatment if your MDS is not causing symptoms. In this case, you will have regular check-ups instead. If your disease changes, you can then start treatment.

## Supportive care

This type of treatment controls the symptoms of MDS rather than curing it. For example, symptoms such as anaemia, infection and bleeding. See page 39 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 43 for more details.

## Intensive chemotherapy

High doses of chemotherapy drugs to cure or control cancer. See page 45 for more details.

## Stem cell transplant

The main treatment to possibly cure MDS is a stem cell or bone marrow transplant from another person. Transplants replace diseased cells with new healthy cells from a donor. 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 51 for more details.

## Specialist cancer centres

MDS is treated in specialist cancer centres in Ireland. The staff at these centres have great expertise in managing patients with MDS. As a result, you may be transferred to another hospital from the one where you received your diagnosis.

'Always talk — if you are ever worried about anything just ask. Everyone is there to help you.'

## Deciding on treatment

### Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a haematologist, specialist nurse and oncologist (cancer doctor). The team will meet to discuss your test results and your suggested treatment plan.

Your doctor and nurse will discuss your treatment options with you. Do ask as many questions as you like. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.



### Time to think

When faced with a serious illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it's first explained to you.

## Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor will refer you to another specialist for a second opinion if you feel this would be helpful.

## Accepting treatment

You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse a particular treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

## Giving consent for treatment

Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Possible side-effects from treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

## Individual treatment

You may notice that other people with MDS are not getting the same treatment as you. Their MDS may not be the same type or in the same risk group as yours. Everyone's treatment needs will be different. Don't be afraid to ask your doctor about your treatment.

## Waiting for treatment to start

Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread during this time.

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works.

If you are worried, talk to your doctor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

You might like to make some lifestyle changes while you're waiting for treatment. This can help you prepare for your treatment and feel more in control. For more information, see page 32.

Cancer Nurseline Freephone 1800 200 700

## Who will be involved in my care?



Usually a team of health professionals will be involved in your treatment and care.

**Haematologist** a doctor who specialises in treating blood and bone marrow diseases.

**Pathologist** A specialised doctor who reads laboratory tests. This includes checking cells, tissues, and organs to diagnose disease

**Clinical nurse specialist** A highly trained nurse who gives support and information to cancer patients.

**Liaison oncology nurse** A specially trained nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment.

**GP (family doctor)** Your GP can be a great support to you. You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.

**Symptom management team** A group of highly trained health professionals who give supportive care to help prevent or relieve cancer symptoms. Their services are available both in the hospital and in the community

**Public health nurse** A nurse who is usually based in your local public health centre. They provide basic nursing care as well as advice and assistance to their patients. They also act as an important point of access for other community care services.



**Dietitian** An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.


**Medical social worker** A person trained to help you and your family with your social issues and practical needs. They can give counselling and emotional support. They can give advice on benefits and financial matters and on practical supports and services available to you when you go home.

**Psychologist** A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.

**Counsellor** a person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.



## How can I help myself?

- 
- Making healthy lifestyle changes may help you to cope better with treatment
  - Getting support, talking about your diagnosis and learning how to manage your feelings can make things easier for you

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel better.

### Lifestyle changes



#### Eat well

Eating well when you have cancer can help you feel better. It can help to:

- Make you feel stronger and help you to maintain a healthy weight

- Cope better with the side-effects of treatment
- Reduce the risk of infection
- Help your recovery

Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet *Diet and Cancer*. To get a copy, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or download it on our website [www.cancer.ie](http://www.cancer.ie)

#### Be active

Being active has many benefits. It can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues

Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. Be careful not to overdo it at the beginning, but build up gradually.

#### Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Non-smokers have fewer side-effects during cancer treatment
- Smoking can reduce how well chemotherapy or radiotherapy work

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100.



## Other ways to help yourself

### Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important.

### Involve your family and close friends

Don't keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

### Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.



## Try relaxation and stress management techniques

Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

### Accept change in your life

Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

### Know that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

### Try to cope day by day

Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

'So many kind and generous people asked me what I needed. I mostly had no idea! Specific questions helped, like: "I'm at the supermarket, can I bring you dinner?" or "I'm off tomorrow, can I call in at 3?"'



## Types of treatment

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## Supportive care



- Supportive care aims to control the symptoms and problems caused by MDS.
- The supportive treatment you need will depend on which type of MDS you have
- You might need a combination of treatments.

Supportive care aims to control the symptoms and problems caused by MDS and to improve your quality of life. It is a very important part of your care, no matter what other medical treatments you receive. Supportive care can be given for the following symptoms:

- Anaemia
- Iron overload
- Low white blood counts (neutropenia)
- Low platelets
- Infection

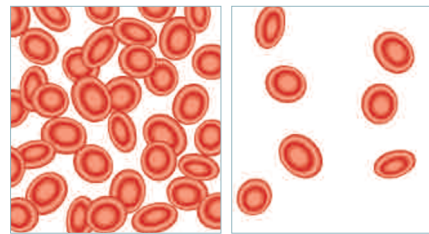
Even if your MDS is at an advanced stage, many things can be done to make you more comfortable.

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.

### Anaemia

Anaemia is when the number of red blood cells is lower than it should be. The haemoglobin (Hb) level in your blood results will show your level of anaemia. Anaemia can cause symptoms such as tiredness and shortness of breath but it is not fatal.

Most people diagnosed with MDS are anaemic. To improve your quality of life, you may need a blood transfusion or growth factors to increase the level of haemoglobin. A blood transfusion is when you are given blood from someone else



Normal blood

Anaemia

(a donor) into your vein. Growth factors are injections to increase certain blood cells in the bone marrow. For example, erythropoietin (EPO) stimulates the bone marrow to produce red blood cells.

How often you need blood 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

When you have frequent blood transfusion, you can build up excess iron in your body. Eventually, this excess iron can harm your liver and heart. It is important that you do not take iron tablets unless your doctor prescribes it. Your doctor will regularly check iron levels in your blood.

You might need treatment to prevent or treat the build-up of excess iron. This is called iron chelation. Your doctor will advise you if it is a suitable treatment for you.

### Neutropenia (low white blood counts)

All white blood cells help the body fight infection. Neutrophils are a type of white blood cell. When the neutrophil levels are low, you are more at risk of infection. A low level of neutrophils can be improved by injecting growth factors to stimulate the bone marrow to produce more white blood cells. For example, G-CSF.

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. But most patients don't experience any of these side-effects. 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. The platelets you have left 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

MDS can affect white blood cells, which fight infection. So 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.



## Non-intensive treatment

- The aim of non-intensive treatment is to slow down the progress of MDS.
- It treats the disease with as few side-effects as possible, so your quality of life is not affected.
- Many of these treatments are new and often used as part of a clinical trial.

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, you may benefit from treatment. Non-intensive treatment aims to treat 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. They may be given as injections or tablets. See page 53 for more about clinical trials. You can receive these drugs as an outpatient or in the day ward. These treatments are often called targeted therapies. They include:

### Hypomethylating agents

Hypomethylating agents are drugs that affect the way certain genes inside a cell are controlled. Examples of this type of drug are 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. Side-effects include fever, nausea, constipation, diarrhoea, vomiting, leg swelling and pneumonia. Your doctor and nurse will talk to you about these beforehand and ways to relieve them. They will also closely monitor your blood counts.

If one of these treatments works well for you, your doctor may decide to keep you on it indefinitely.

## Lenalidomide

Lenalidomide 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.

For more information, please talk to your medical team or call our Cancer Nurseline on 1800 200 700 to speak to a nurse.

## New developments



New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 53). Ask your doctor if there are any targeted therapies available to treat your type of MDS or if there are any clinical trials that are suitable for you.



## Intensive chemotherapy



- If you have high risk MDS, you may benefit from intensive chemotherapy.
- Intensive chemotherapy uses high doses of drugs to try and clear the diseased cells from your bone marrow.
- The treatment has a high number of side-effects so you will need to stay in hospital for 4–6 weeks for each treatment block.
- Most side-effects can be helped by medication. Usually the side-effects go away when the treatment ends or soon after.

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.

The first step in your treatment is an intense dosing of chemotherapy, which aims to get rid of all the diseased cells from your blood and bone marrow (remission). This stage is called induction chemotherapy or remission induction. Induction usually involves two cycles of a combination of chemotherapy drugs. When the induction is over, a bone marrow test will be done to check if the MDS has gone into remission.

After induction, if you are in remission you may have 2 or 3 more cycles of less intense chemotherapy. This is to make sure that any remaining MDS cells are destroyed. This stage is called consolidation or intensification. 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?

Most chemotherapy is given as an infusion into a vein (intravenous), but sometimes as a tablet. It is given as a course or cycle of treatment, where a combination of chemotherapy is given over a number of days followed by a rest period. It is often easier for you to have a Hickman line inserted, which allows all the drugs to be given and blood tests to be taken. This is a line that is carefully inserted into a large vein and can stay in place for all your treatment. The first course of intensive treatment is normally given in hospital but if your bone marrow is then in remission, subsequent treatment can often be started in an ambulatory care/day care unit, although you may have to come back into hospital once the blood counts drop to low levels.

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. For example, cytarabine and daunorubicin. These might be given as part of a clinical trial.

### Understanding your drug treatment



It's important that you understand the medicine you have been given. Don't be afraid to ask your doctor or specialist nurse for more information about any drugs you are taking, what they are for and any possible side-effects. They may be able to give you a printed sheet to take home with you.

### What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

Most side-effects can be helped by medication. Usually the side-effects go away when the treatment ends or soon after. Side-effects may include:

#### 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

Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment.

#### Bleeding and bruising

Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

#### Infection

Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high temperature (above 37.5°C) or a low temperature below 35°C (95°F), having a cough, or pain passing urine. The haematology units will have a direct phone number to call for advice if your temperature is above 37.5°C (99.5°F) or below 35°C (95°F).

## Tips & Hints – infection



- 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 are 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.
- Avoid unpasteurised milk, soft cheeses, undercooked meat and poultry, and the skin of raw vegetables and fresh fruit.
- If your temperature goes above 37.5°C (99.5°F) or below 35°C (95°F) or if you suddenly feel shivery or unwell, even if your temperature is normal, contact your doctor or the hospital immediately.

### Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 57.

### Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.

### Mouth and throat problems

Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.

### Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss.

### Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

### Skin and nail changes

Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.

### Changes in kidney function

Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage.

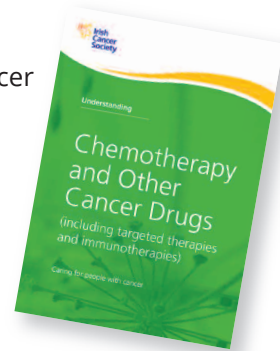
If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. They will tell you what to do.

‘Your team will give you medications to get you through the side-effects. Take them. Tell your doctor or nurse how you’re feeling and they will be able to help you.’

## 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet, *Understanding Chemotherapy and other cancer drugs*, or download it from [www.cancer.ie](http://www.cancer.ie)



## Stem cell transplant

- A stem cell transplant offers the chance of curing MDS.
- Healthy bone marrow or stem cells are taken from another person who is compatible with you
- Your own bone marrow is destroyed with high doses of chemotherapy. The healthy stem cells from the donor are then given to you.
- This treatment has many side-effects.

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. But it is suitable for only a few patients with the disease.

### 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 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 been 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

## Clinical trials

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

Drugs that are used in a clinical trial have been carefully tested to make sure they are safe to use in a clinical trial.

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

### More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet *Cancer and Clinical Trials*. It's available to read or download on our website, [www.cancer.ie](http://www.cancer.ie). You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

You can see a list of current cancer trials at [www.cancertrials.ie](http://www.cancertrials.ie)



'Ask about drug trials, new combinations of drugs and research coming down the line.'

## Palliative care

Palliative care aims to improve the quality of life of patients and their families with cancer. As well as providing relief from pain, nausea and other symptoms, palliative care offers support and comfort to patients. It involves caring for their physical, emotional and spiritual needs in the best way possible. The palliative care team can work with your haematology team and family doctor (GP) to improve your quality of life. The palliative care team in your area might see you when you have just a few symptoms, but your own medical team will also help deal with any MDS-related symptoms.

Palliative care can be given in a hospice or community hospital or your own home. You can also attend a hospice for managing your symptoms. These days hospices are places that specialise in symptom control and you can spend a day or two there receiving treatment. Do talk to your doctor or nurse for more advice. Or if you do not feel well enough, your family can do so. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak in confidence with a specialist nurse.



## Managing side-effects and symptoms

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## How can I cope with fatigue?



- Fatigue means feeling extremely tired.
- There are things that can improve fatigue, depending on what's causing it.

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer. Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Fatigue when you have cancer can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

### What's causing the fatigue?



Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count a transfusion can make you feel better. If you are not eating well a dietitian may be able to give you some advice to help you.

## Hints and tips: Fatigue



- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage.

Our booklet *Coping with fatigue* has more advice. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre for a free copy. It's also on our website [www.cancer.ie](http://www.cancer.ie)

'You have to listen to your body. Nap if you need to and take things at your own pace. I find exercise great.'

## Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, counselling and acupuncture.

Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

## Integrative care



Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

## What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

## More information

To find out more about complementary therapies, you can talk to one of our cancer nurses - call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet *Understanding cancer and complementary therapies*, or download it from our website [www.cancer.ie](http://www.cancer.ie)



## Will treatment affect my sex life?

### Sex and sexuality

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result.

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.



There is no set time for you to be ready to have sex again. It varies from person to person.

Once you return to your usual routine your interest in sex should return too. You can also enjoy other forms of closeness, such as touching, caressing and holding each other.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

## Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy and some targeted therapies.

Many specialists recommend that you wait for up to 2 years after treatment before trying to start a family or having more children. This time gives your body a chance to recover from the effects of the cancer and its treatment.

Ask your doctor's advice about contraception or if you are thinking about having children after treatment.

## Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so there's no need to feel embarrassed. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)



## Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic if this is an option for you.

Dealing with infertility may not be easy, depending on your age and if you have already had children. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.





## After treatment

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## What follow-up will I need?

After your treatment you will still need to go back to the hospital for regular check-ups. This is called follow-up. At each outpatient visit, your doctor will examine you and you may have blood tests.

Your doctor will let you know how often you need to visit them at the outpatient clinic. If your disease is high-risk or you need active treatment or transfusions, you will need more frequent visits to the day ward.

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. Sometimes it helps to write down what you want to say before you see the doctor. That way you won't forget what you wanted to say.

If you are between check-ups and have a symptom or problem that is worrying you, tell your doctor or nurse. Make an appointment to see them as soon as possible.



## Leading a healthy lifestyle



Many people want to make positive changes to their lives after a diagnosis of MDS.

Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and recover faster
- Cope better with the side-effects of treatment
- Keep up your energy and strength

A healthy lifestyle includes:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun

If you want more information or advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also go to our website [www.cancer.ie](http://www.cancer.ie) for tips and publications on healthy living.

## Mind your mental health

Living with MDS and coping with any symptoms can be stressful. The following may help:

- **Try to avoid additional stress wherever possible.** Spend time with your friends and family. Make time to relax and do the things that you enjoy.
- **Use stress-management techniques if you do feel stressed.** Try complementary therapies and relaxation techniques like yoga, meditation, mindfulness or aromatherapy. See page 59 for more about complementary therapies.
- **Give yourself time to get back to normal.** Once you feel better you may have financial or practical matters to sort out. Try not to let these overwhelm you and take one task at a time.
- **Counselling or a short course of medication may also help you,** if you are finding it hard to cope. See page 74 for more information.
- **Having the support of loved ones, healthcare professionals and other people going through the same thing** can also make a big difference. See page 75 for more about getting support.



## Life after treatment

It can take some time to adjust to life after cancer treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

**Fear of cancer coming back** and worrying about every small symptom

**Loneliness** without the company and support of your medical team and fellow patients

**Stress** at having to deal things that may have been on hold during your treatment, such as your finances, going back to work and family issues.

**Isolation or guilt** if your family and friends expect you to get back to normal before you are ready

**Anxiety and self-doubt** about sexual and romantic relationships

**Anger** at what has happened and the effect on you and your loved ones

### Depression or sadness

There is more about how to cope with these feelings and adjusting to life after cancer on our website [www.cancer.ie/coping/life-after-cancer-treatment](http://www.cancer.ie/coping/life-after-cancer-treatment)

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 75 for other ways to get support.

'You're not on your own. There are many services and people to help you.'

## Coping and emotions

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## How can I cope with my feelings?



Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment.

*A cancer diagnosis can be hard on you - mentally and emotionally. Give yourself time and space to deal with your emotions, and get help if you need it.*

A helpful booklet that discusses in detail how you may be feeling is called *Understanding the Emotional Effects of Cancer*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy.

### Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of antidepressants or anti-anxiety medication can work well. Professional counselling can also be very helpful.

**It's not a sign of failure to ask for help or to feel unable to cope on your own.**

### Counselling

If you're feeling very distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

Free one-to-one counselling is available at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

A list of counsellors funded by the Irish Cancer Society is available at [www.cancer.ie](http://www.cancer.ie)

## Ways to get emotional support



### Find out about cancer support services in your area:

Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 96 for more about cancer support services.

**Join a support or educational group:** Many people find it very reassuring to talk to other people who are in a similar situation and facing the same challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

### Ask about psycho-oncology services at the hospital:

Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

**Get online support:** Special websites called online communities let you write questions, share stories, and give and receive advice and support. Visit [www.cancer.ie/community](http://www.cancer.ie/community) to join the Irish Cancer Society online community.

**Talk things through:** It can be a great weight off your mind to share your feelings and worries. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

**Seek spiritual support:** For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

If you need more information or help with finding support, call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.

## Survivor Support



Survivor Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has dealt with a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

'Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better'

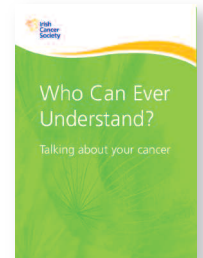
In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

'I am very happy and content ... even though I have to live with this.'

## You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet *Who Can Ever Understand?* can help to you find ways to talk about your cancer and to ask for the help and support you need.



If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to Children about Cancer*, which has practical advice about how to talk to children of different ages.



## Talking to children and teenagers

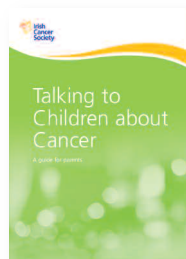
Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, or feel guilty that you can't do activities with your children, or that you're letting them down. You may also worry about the emotional impact your illness will have on your children, especially older children, who may already be struggling with the difficult changes that adolescence can bring. These are all natural feelings to have at this time.

### Saying nothing

You may feel it's best not to tell your children anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

### How to tell your children

It's best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.



The booklet is available free of charge from Daffodil Centres or by calling the Cancer Nurseline. It's also available on our website [www.cancer.ie](http://www.cancer.ie).

### Further information and support

If you want more advice and support, you can ask your nurse or medical social worker. Or call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

## Supporting someone with cancer

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## Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

### Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website [www.cancer.ie](http://www.cancer.ie) or call our Cancer Nurseline for a free copy of our publications.

### Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

### Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

### Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members at our affiliated cancer support centres. Talk to your GP or see page 74.

### Find out about support for carers

Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

## How to talk to someone with cancer



When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline on 1800 200 700. Ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer*. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at [www.cancer.ie](http://www.cancer.ie)



## Support for you



Our cancer nurses are there to support you. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie) for confidential support, advice and information.

Our booklet, *Caring for Someone with Cancer* has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring



Free copies are available from our Daffodil Centres and our Cancer Nurseline, or download it from our website [www.cancer.ie](http://www.cancer.ie)

Cancer Nurseline Freephone 1800 200 700



## Support resources

Coping with the financial impact of cancer	87
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## Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

### Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

**If you have a medical card**, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP visit card.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

**If you don't have a medical card** you will have to pay some of the cost of your care and medication.

**If you have health insurance** the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment to check you're covered.

## Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 074 000
- Department of Employment Affairs and Social Protection – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.



## If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 93 for more details of our Volunteer Driver Service and the Travel2Care fund.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

## More information

For more information go to [www.cancer.ie/publications](http://www.cancer.ie/publications) and check out our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

- **Medical costs and help available**
- **Benefits and allowances that you or your family may qualify for**
- **Travel services**
- **Ways to cope with the cost of cancer**



The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

Cancer Nurseline Freephone 1800 200 700

## Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Cancer Nurseline
- Patient travel and financial support services
- Daffodil Centres
- Night nursing
- Survivor Support
- Publications and website information
- Support in your area

### Cancer Nurseline Freephone 1800 200 700

Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information.

You can also email us on [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie) or visit our Online Community at [www.cancer.ie](http://www.cancer.ie)

For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: [remote@slis.ie](mailto:remote@slis.ie)



## Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide.

The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.



### Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

You can email [daffodilcentreinfo@irishcancer.ie](mailto:daffodilcentreinfo@irishcancer.ie) or visit [www.cancer.ie](http://www.cancer.ie) to find your local Daffodil Centre.

## Survivor Support



Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

### Support in your area

We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 96 for more information.

Email: [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

## Patient travel and financial support services



We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
- **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional.

## Irish Cancer Society Night Nursing



We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

Email: [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

## Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website [www.cancer.ie](http://www.cancer.ie) or call our Cancer Nurseline for a free copy of our publications



If you would like more information on any of our services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

## Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's Strides for Life walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at <http://www.cancer.ie/support/support-in-your-area/directory>

## 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 after cancer treatment.
<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



## Revised International Prognostic Scoring System (IPSS-R)

The Revised International Prognostic Scoring System (IPSS-R) gives each patient a score to help their doctor understand how quickly their MDS is progressing and what is likely to happen to their disease over time. For more information see page 18. The below charts describe the scoring system. Ask your doctor and nurse to explain the system. It can be confusing as there are many aspects to it. You can also call our Cancer Nurseline on 1800 200 700 for advice.

### IPSS-R Cytogenetic Score

Prognostic subgroups	Cytogenetic Abnormalities
Very Good	-Y, del(11q)
Good	Normal, del(5q), del(12p), del(20q), double incl. del(5q)
Intermediate	del(7q), +8, +19, i(17q), any other single or double independent clones
Poor	-7, inv(3)/t(3q), del3q, double including -7/del(7q), Complex: 3 abnormalities
Very Poor	Complex: > 3 abnormalities

### IPSS-R Prognostic Score

Prognostic score	0	0.5	1.0	1.5	2	3	4
Cytogenetics	Very Good		Good		Intermediate	Poor	Very Poor
Bone marrow blasts (%)	≤2	—	>2-≤5		5-10	> 10	—
Haemoglobin	≥10	—	8-≤10	< 8	—	—	—
Platelets	≥100	50- <100	< 50	—	—	—	—
Neutrophil count (ANC)	≥0.8	< 0.8	—	—	—	—	—

## IPSS-R prognostic risk categories

Risk Category	Risk Score
Very Low	≤ 1.5
Low	> 1.5-3
Intermediate	> 3-4.5
High	> 4.5-6
Very High	> 6



## 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?
-

Blood results diary

Date	HB	WBC	Plts	Neut	Other

Blood results diary

Date	HB	WBC	Plts	Neut	Other

Blood results diary

Date	HB	WBC	Plts	Neut	Other

Blood results diary

Date	HB	WBC	Plts	Neut	Other



## Your own questions

## About this booklet

This booklet has been produced by 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. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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The following sources were used in the publication of this booklet:

- *National Cancer Strategy 2017-2026*, National Cancer Control Programme
- *Cancer in Ireland 1994-2016 with estimates for 2016-2018: Annual report of the National Cancer Registry* (2018)
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- *The Chemotherapy Source Book*, M Perry, Lippincott Williams and Wilkins, 5th Ed (2012).

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## Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

### Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

### Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

### Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

### Did you like this booklet?

We would love to hear your comments or suggestions. Please email [reviewers@irishcancer.ie](mailto:reviewers@irishcancer.ie)

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