Irish Cancer Society

Understanding

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 side of cancer
- Practical and financial matters

Useful numbers

Specialist nurse

Haematologist

Family doctor (GP)

Haematology day ward

Medical social worker

Emergency

Medical records number (MRN)

Contents

Fast facts

What is MDS? Page 15

Myelodysplastic syndromes (MDS) are a group of blood cancers 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 37

Yes. The aim of treatment is to improve the number and type of blood cells in the bloodstream and to relieve symptoms. Fit patients with high-risk MDS might be offered a stem cell transplant (SCT). An SCT is the only treatment that can cure MDS. Other treatments are given to keep the disease under control and improve your quality of life.

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 53

Treatment depends mainly on your risk group and if you have symptoms. You may not have treatment straight away. This is known as watchful waiting. Or you may have blood transfusions or an injection of growth factor to increase the number of blood cells. Other treatments include targeted therapy drugs and a stem cell transplant. You will need regular blood tests and check-ups.

Will I be OK? Page 32

What is likely to happen to you (your prognosis) is sometimes difficult 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 53

Some treatments for MDS can cause several side-effects. Read about the treatments 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 70

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you.

Email: supportline@irishcancer.ie

We're here for you Page 111

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 Support Line on 1800 200 700
- Drop in to a Daffodil Centre.
  Email **daffodilcentreinfo@irishcancer.ie** to find your local Daffodil Centre.
- Email us: **supportline@irishcancer.ie**

See page 111 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 Support Line on **Freephone 1800 200 700**
- Visit a **Daffodil Centre**
- Email the nurses at **supportline@irishcancer.ie**

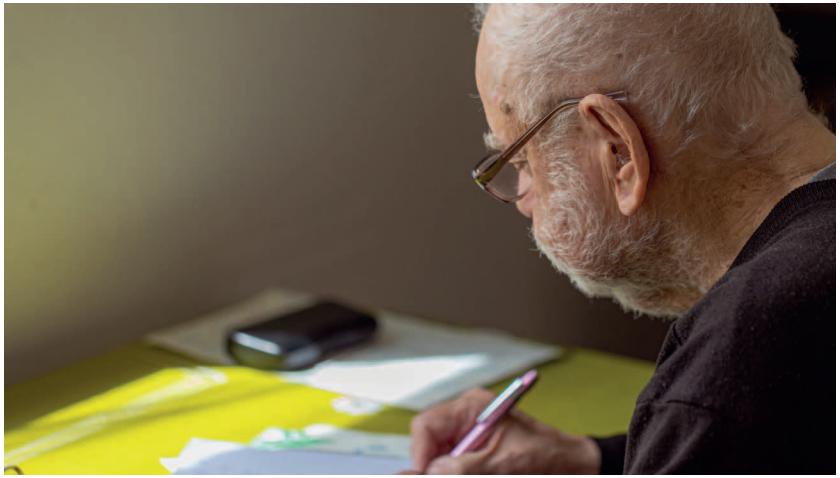
About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to your own team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

Preparing for your hospital appointments

Preparation is key to getting the most out of your hospital appointments. Being prepared also helps the doctors and nurses get the information they need to plan your care.



Before your appointment

- Write down a list of questions and things you would like to discuss.
- Know where you are going and plan your journey (build in extra time for unexpected delays, such as parking).
- Dress in warm comfortable clothes and shoes – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- Try to drink clear fluids (water or juice without pulp) if you are having a blood test and you aren't fasting. This can make it easier for the nurse or doctor to find a vein.
- Check with the hospital if it is okay to bring someone with you. Ask a friend or family member to go along for extra support.

What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- Your medical card, if you have one.
- Your private health insurance details, if you have insurance.
- The appointment letter from the hospital, if you got one.
- A referral letter or GP letter, if you got one.
- Your GP's name and contact details.
- Your medical history – remember, your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand.
- Your list of questions.
- A notebook and pen to take notes. (Some healthcare professionals/nurses may be happy for you to record the meeting, but make sure you ask for their permission first.)
- A list of your medications or the medication itself – ask your pharmacist to print off a list of your medications. Hand-written lists can be hard to read or inaccurate.
- Be aware of when your prescription is due, so you can ask for a prescription before you leave, if needed.
- Medications and any medical supplies you may need that day, in case you are delayed.
- A light snack and drink if you are likely to have to wait for some time. (Make sure you are not meant to be fasting – check with the hospital beforehand if you are not sure.)
- Your phone and your phone number.
- Contact details of the person to call in an emergency.
- Your glasses and hearing aid, if you use them.
- A book or something to listen to (including headphones) to pass the time while you wait.

Before leaving the appointment

- Make sure you feel satisfied that your questions were answered and that you have written down what you need to know.
- Make sure you know what will happen next.
- Ask for the name or number of someone you can contact in case you have further questions.
- Ensure you are booked in for your follow-up appointment before you leave, if required.

After the appointment

- Arrange any tests before your next appointment as soon as you can, for example, a blood test – if your healthcare professional has asked for it.

It's important to go to your appointments

If you can't go to your appointment, contact the hospital as soon as possible and ask them for a new appointment. Contact your GP if you have any trouble getting an appointment.

Questions to ask your doctor

Here is a list of questions that you might like to ask your doctor. There is also space on pages 125-126 for you to write down your own questions. Try not to be shy about asking questions. It is 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, for 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?

Introduction and diagnosis

What are myelodysplastic syndromes?

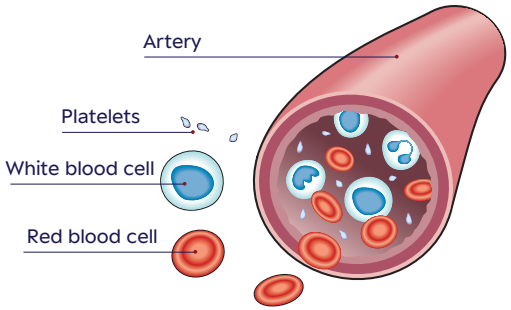
- MDS is a type of cancer where the bone marrow cannot make enough healthy red blood cells, white blood cells or platelets.
- Bone marrow is the soft spongy tissue that fills the centre of your long bones.

Myelodysplastic syndromes (MDS) are a group of diseases that affect the bone marrow's ability to make healthy blood cells. MDS is a type of cancer and sometimes may be referred to as bone marrow failure.

If you have MDS, your bone marrow makes a large number of faulty blood cells and many of these die before they reach your bloodstream. As a result, you do not have the correct number of healthy blood cells in your bloodstream. The faulty or abnormal blood cells are called 'dysplastic'.

With the high-risk type of MDS, there is an increased percentage of immature blood cells called blast cells in the blood. If the percentage of blast cells is between 10% and 20%, your disease is called MDS/AML. If the percentage of blast cells rises above 20%, it means MDS has transformed to a more aggressive cancer called acute myeloid leukaemia (AML).

Bone marrow



Blood cells are made in the bone marrow. Bone marrow is soft spongy tissue found inside our bones. The earliest and most basic type of cells in your bone marrow are called stem cells. These immature cells develop 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, which stops bleeding.

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.

MDS and your blood cells

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 cell types can be affected.

- **Anaemia:** A low red blood cell count
- **Leucopenia:** A low white blood cell count
- **Thrombocytopenia:** A low platelet count
- **Pancytopenia:** All 3 blood cell types are affected

What are the signs and symptoms of MDS?

Many people with MDS have no signs or symptoms and are diagnosed by chance after a routine blood test. If you do have symptoms, they depend on which blood cells are affected. Symptoms often vary from person to person. Most symptoms arise because the blood counts are low. MDS symptoms include:

- Anaemia
  - Tiredness and fatigue
  - Palpitations
  - Pale skin colour
  - Shortness of breath
  - Dizziness
- Infections that are frequent and difficult to treat. Infections can happen anywhere in your body and are usually caused by bacteria or fungi.
- Bleeding, often from the mouth or nose
- Bruising or skin rash

About 8 out of 10 patients have anaemia, while about 2 in 10 have infections or bleeding.

How common is MDS?

In Ireland, around 175 people are diagnosed with MDS each 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 usually 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 genetic 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 blood 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 what type of MDS you have and to decide on your treatment plan. Other tests may be used to monitor how well you are responding to treatment.

You will also have regular blood tests to monitor your disease. How often tests are needed is different for everyone. Always tell your healthcare team about any new symptoms or change in symptoms.

Tests you may have

Physical exam

You will be given a full physical exam. This is to give your haematologist information about your general health and to check for any signs of disease.

Full blood count

A full blood count (FBC) will be taken. An FBC counts the number of red blood cells, platelets and white blood cells in your blood sample. 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 a diagnosis of MDS. This is usually done by a specialist doctor or nurse. Bone marrow tests involve taking a tiny sample of your bone or the spongy tissue inside the bone (bone marrow) and looking at it under a microscope. The sample is taken from the inside of the bone, usually your pelvis ('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 called a trephine biopsy. Both can be done at the same time.

Your doctor will give you a local anaesthetic to numb the area beforehand. The biopsy itself may be uncomfortable and can last up to 10 minutes. The entire procedure 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. You may feel pressure while the sample is being taken.

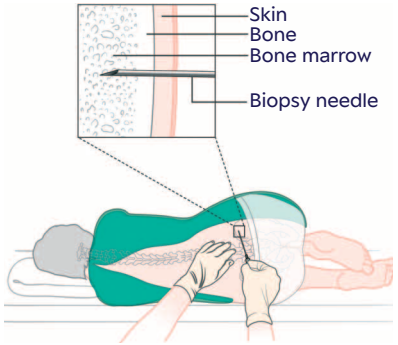
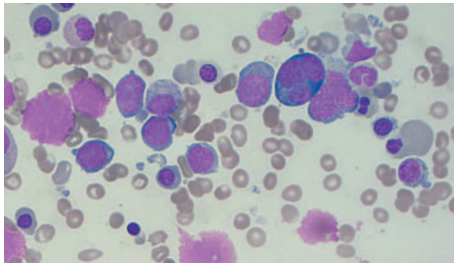


Image courtesy of Cancer Research UK/Wikimedia Commons

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 to 15 minutes to stop any possible bleeding. You can take mild painkillers, like paracetamol, if you feel any discomfort later.

The bone marrow sample is examined under a microscope to look for changes seen in MDS. Other tests are often needed on the bone marrow sample. This includes chromosome studies called cytogenetics.


MDS patient bone marrow aspirate showing abnormal blood cells.

Bone marrow tests may be repeated later to check how well you are responding to treatment or to see how the disease is behaving.

Bone marrow tests can:

- Confirm an MDS diagnosis
- See if your MDS has stayed the same, improved or worsened since the last exam

Genetic studies

Chromosomes are made up of genes, which control the activities of cells. These chromosomes contain the genetic information about the cells in your body.

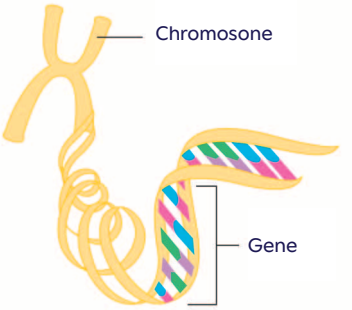


Image courtesy of Cancer Research UK/Wikimedia Commons

Tests on your blood or bone marrow samples can look for changes in your genes and in the number and shape of the chromosomes in your blood cells. These tests include:

- Karyotype testing, which looks at the number and shape of your chromosomes to see if there is anything unusual about them
- FISH (fluorescence in situ hybridization) testing, which looks for changes in selected genes in your chromosomes
- NGS tests (next generation sequencing tests), which look at the genetic profile of your cells

Your consultant can understand your disease better and suggest the best treatment for you, based on the detailed information from karyotyping, NGS and other genetic tests. If genetic changes are detected, you might have further tests to give your haematologist more information about your MDS.

Inherited gene changes

Usually, any genetic changes happen when MDS develops. They are only found in your bone marrow and blood cells, so they cannot be passed on to your children.

However, around 10 to 15 percent of people diagnosed with MDS have genetic changes that put them at higher risk of developing MDS. Sometimes these inherited cases are associated with other symptoms, such as a moderately low platelet count or inflammatory/autoimmune conditions.

If tests show that you have an inherited gene change, some of your family members may be offered testing to check if they also have gene changes that increase their risk of MDS. Your haematologist can arrange these tests or your family members may be referred to a genetics service.

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. They can find out which type of MDS you have. Genetic tests may take a little longer.

Once all your test results are ready, your haematologist and you will decide what type of treatment you should have.

MDS can sometimes be a difficult diagnosis to make. If your doctor is unsure, your blood counts will be watched for a few months, and the bone 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 Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a Cancer Nurse.

Being diagnosed with MDS

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
- **Angry** that this is happening to you

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/clinical nurse specialist (CNS) 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 Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our Cancer Nurses can put you in touch with a volunteer.
- Go to your local cancer support centre. For more information, see page 120.

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 of how to break the news or need a little time to adjust. 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 Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet ***Understanding the emotional effects of cancer***. It can help you find ways to talk about your cancer and to ask for the help and support you need.

What are the types of MDS?

- There are different types of MDS. The types describe how the MDS is affecting your blood, bone marrow and chromosomes/genes.
- Prognostic scoring systems are used to predict how your MDS will behave over time. For example, the IPSS-M Risk Calculator.

Tests can show how the MDS is affecting 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 – these are white blood cells that are immature (haven't developed properly).
- In other types your blood cells or chromosomes may be abnormal in some way.

Doctors use this information to describe which type of MDS you have. This is called the subtype. Knowing what type of MDS you have helps your doctor to plan the best way to treat it and understand the likely course of your disease.

The system doctors use to describe the different types of MDS is called a classification system. The 2 main classification systems are the World Health Organisation (WHO)-HAEM5 system and the International Consensus Classification system.

Email: supportline@irishcancer.ie

WHO-HAEM5 classification system

- MDS with low blasts and isolated 5q deletion (MDS-5q)
- MDS with low blasts and SF3B1 mutation (MDS-SF3B1)
- MDS with biallelic TP53 inactivation (MDS-biTP53)
- MDS with low blasts (MDS-LB)
- MDS, hypoplastic b (MDS-h)
- MDS with increased blasts (MDS-IB)

International Consensus Classification

- MDS with mutated SF3B1 (MDSSF3B1)
- MDS with del(5q) (MDSdel (5q))
- MDS, NOS – without dysplasia
- MDS, NOS – with single lineage dysplasia
- MDS, NOS – with multi-lineage dysplasia
- MDS with excess blasts (MDS-EB)
- MDS/AML

Understanding MDS subtypes

The names of the different types of MDS can sound confusing and they can be hard to understand.

Numbers

The numbers, such as 5q, SF3B1, refer to **the particular chromosome or gene affected**.

Words

The words describe **the effect on blood cells or bone marrow.**
For example:

- Mutation: When a gene is changed, so it is abnormal
- Deletion (del): When part or all of a chromosome is missing
- Dysplasia: When there are abnormal cells
- Single lineage dysplasia: Only 1 cell type is abnormal
- Multi-lineage dysplasia: More than 1 cell type is abnormal
- Hypoplastic: With low cells in the bone marrow
- Blasts: Blood cells in the earliest stage of development that are abnormal. With MDS there can be too many of these cells in the blood or bone marrow, which can lead to a lower-than-normal number of healthy blood cells

Your doctor will explain which type of MDS you have.

Understanding your subtype

A good question to ask your doctor is: 'What does this mean for me, for my treatment and for how my MDS might progress?'

If you are confused or have more questions about your subtype, ask your doctor or specialist nurse. You can also speak to a nurse by calling our Support Line 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 people 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.

The treatment of low-risk and high-risk disease is often different. Your doctor may also use prognostic scoring calculators, such as the International Prognostic Scoring System – Molecular (IPSS-M Risk Calculator) to help them to decide if your MDS is low risk or high risk.

IPSS-M Risk Calculator

The IPSS-M is based on the following factors:

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

Each factor gets a score. Together, the scores tell which risk group you fall into. There are 6 risk groups:

1 Very low risk

2 Low risk

3 Moderate low risk

4 Moderate high risk

5 High risk

6 Very high risk

Ask your doctor and nurse to explain prognostic scoring. It can be confusing. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for advice.

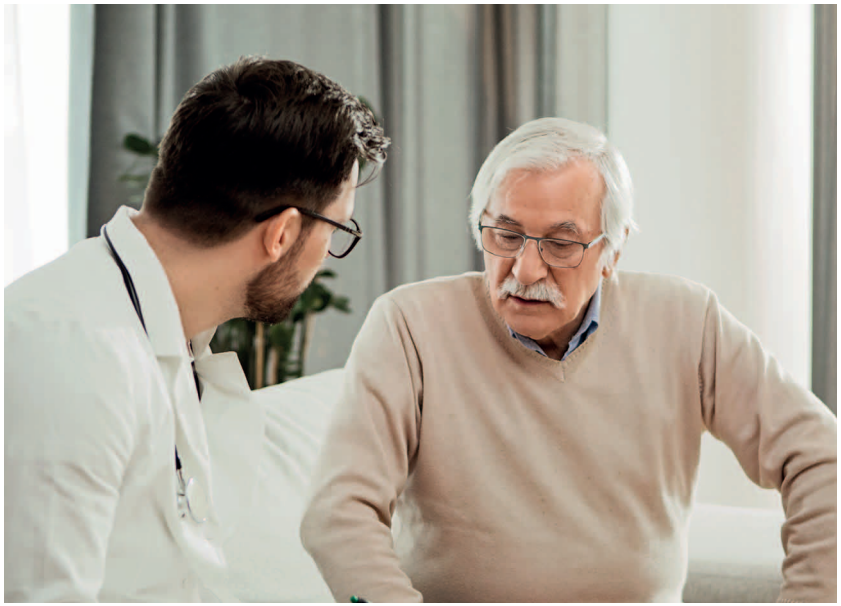
The subtype and risk profile of your MDS will give your doctor information about how your MDS might progress and which treatments might be best for you. Your doctor will also take into account other factors, such as other mutations not included in the IPSS-M, your age, your general health, your social support and your lifestyle.

If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. 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. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie to talk to a nurse.

Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.



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.

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 your 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.
- Ask a friend or family member to go with you, if you would like some support.
- Be careful with online information. It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- 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 or nurse again after you have thought about everything.

Treatment overview

How is MDS treated?

The main treatments available for MDS are:

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

You may also have treatment as part of a clinical trial, which is a research study looking at new treatments. 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-M score. See page 30 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, your medical team will monitor your condition. This is called 'watch and wait' or 'active monitoring'. You will have regular check-ups, including blood count checks. 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 55 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. You may also have non-intensive treatment as part of preparation for a stem cell transplant. See page 62 for more details.

Stem cell transplant

Transplants replace diseased cells with new healthy cells from a donor. This is the only treatment that can cure MDS. This treatment is usually only suitable for fit patients with high-risk MDS. Your doctor will check whether you are suitable as soon as possible after your diagnosis so that a search for a donor can be started and a transplant considered. See page 65 for more details.

Intensive chemotherapy

Intensive chemotherapy means having high doses of chemotherapy drugs. This is usually only done as part of the preparation for a stem cell transplant.

See page 68 for more details.

Specialist cancer centres

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

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. The haematologist will be your main treating doctor.

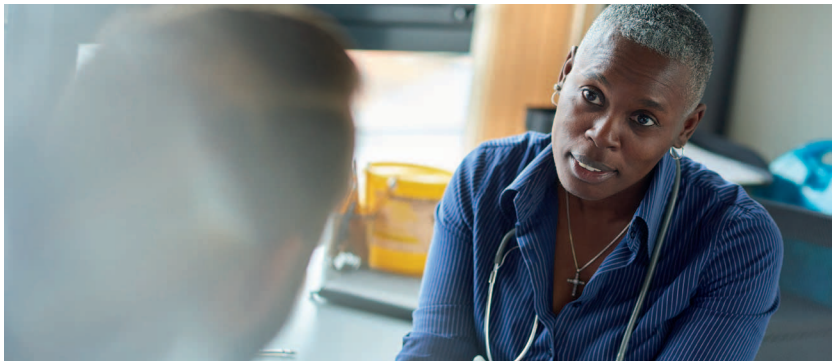
Pathologist: A specialised doctor who reads laboratory tests. This includes checking cells, tissues and organs to diagnose disease.

Histopathologist: A doctor who examines tissues and cells under a microscope to diagnose diseases and guide treatment.

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. They give information and reassurance to you and your family from diagnosis and throughout treatment.

Pharmacist: A healthcare professional who dispenses chemotherapy and other cancer drugs. Pharmacists may be based in hospitals or in local pharmacies. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.



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.

Occupational therapist: A therapist who specialises in helping people who are ill or with disabilities learn to manage their condition and their daily activities, such as washing and dressing, housework, parenting, work and leisure activities.

Physiotherapist: A therapist who treats injury or illness with exercises and other physical treatments.

Medical social worker: A person trained to help you and your family with your emotional and practical needs. They can also give advice on social welfare benefits, practical supports and services available to you and financial and family matters.

Psycho-oncology team: These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

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

Community health services: These include family doctors, public health nurses (who can visit you at home), community welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Palliative care team: This team is experienced in managing pain and other physical symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care service is available in most hospitals. Palliative care teams also work in the community.

GP (family doctor): While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you. You can contact your GP about any worries you have or if you are finding it hard to cope.

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 histopathologist. 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.

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. You could also use the fill-in pages at the back of this booklet for your questions and answers.

If you do forget something or need more explanations, ask your specialist nurse or talk to one of our Cancer Nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

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 GP or treating doctor can 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, 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 and individual to them. Don't be afraid to ask your doctor about your treatment.

Email: supportline@irishcancer.ie

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 Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a Cancer Nurse.

While you're waiting for treatment, you might like to focus on your own health. This can help you prepare for your treatment and feel more in control.

Pre-treatment education workshops

Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on certain treatments, including what to expect and how to manage side-effects. You can also learn about different treatments by watching our patient education videos at **www.cancer.ie/video-library/patient-education-videos**

How can I help myself?

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 as well as possible.

Eat well

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

- Keep up your energy and strength
- Keep your weight stable and avoid muscle loss
- Tolerate your treatment better, so you can finish your course of treatment
- Cope better with side-effects of treatment
- Reduce your risk of infection and other complications
- Recover faster

Ask to talk to the dietitian at the hospital for advice on the best diet for you. We provide group online information sessions with an oncology dietitian, to support you to eat well during cancer treatment and beyond. You can also read our booklet ***Understanding diet and cancer***. For more information call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Stay active

If you are able, it can really help to be active before, during and after your treatment. Keeping up or increasing your activity levels 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 and may have information on exercise programmes and classes. Call our Support Line or visit a Daffodil Centre for information and support on how you can make exercise part of your everyday life. Ask about our free exercise classes, to build strength and fitness in a supportive environment.

Our Cancer Nurses can give you more information about preparing for treatment, including free booklets. They can also connect you to our supports and services. Call our Support Line on 1800 200 700 or visit a Daffodil Centre.

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 are likely to have fewer or less severe side-effects during cancer treatment. For example, chest infections.
- Smoking can reduce how well radiotherapy and some other anti-cancer treatments work.
- Quitting reduces your chance of further illness.

If you would like advice or support on quitting, call the HSE Quit Team on Freephone 1800 201 203, visit **www.QUIT.ie** or Freetext QUIT to 50100. Some hospitals have a stop-smoking service, with advisors who can help and support you.

Avoid alcohol

If you have MDS it's best to avoid alcohol. Alcohol can damage bone marrow and can affect how well the bone marrow works. This can further reduce your healthy blood cell counts. You can discuss this with your haematologist.

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. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

Involve your family and close friends

Don't keep any worries or 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

Activities 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. There is help and support available if you are finding it hard to cope – you can visit your nearest Daffodil Centre or Call our Support Line on 1800 200 700.

Try to cope day by day

Some people find it helpful to concentrate the present and on getting through each day of tests or treatment. That may help you to cope with your illness, especially if you are worrying a lot about the future.

There's more advice on coping with your feelings on pages 93-96, including supports to help such as free counselling and hospital-based psycho-oncology services.

Types of treatment

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 cell counts (neutropenia)
- Low platelets
- Infection

Even if your MDS is at an advanced stage, many things can be done to improve your symptoms.

You will have regular blood tests during treatment to check your blood count. You can use the diary at the back of this 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.

Most people diagnosed with MDS are anaemic. To improve your symptoms, you may need a blood transfusion or growth factors to increase the level of haemoglobin.

Blood transfusion

If you have a blood transfusion, you are given blood from someone else (a donor) into your vein. How often you need blood transfusions can vary. 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.

Growth factors

Growth factors increase certain blood cells in the bone marrow. For example, erythropoietin (EPO) stimulates the bone marrow to produce red blood cells.

Erythroid maturation agents

Erythroid maturation agents help your body make more healthy red blood cells by improving how they develop in the bone marrow. They can reduce the need for blood transfusions while improving energy levels. They can be particularly useful for people with SF3B1 mutated MDS. Like EPO, they are given as injections under your skin. Examples of erythroid maturation agents are luspatercept and elritercep.

Iron overload

When you have frequent blood transfusions, 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 them. 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 tell you if iron chelation is a suitable treatment for you.

Neutropenia (low white blood counts)

All white blood cells help the body to fight infection. Neutrophils are a type of white blood cell. When your 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 make 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 (subcutaneous injection). EPO is given weekly. G-CSF might be given more often. Your nurse can discuss who will give you 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.

As with all injections given under the skin, your skin may get irritated at the injection site. Tell your doctor or nurse if this happens. Rotate the injection sites so you don't inject in the same place every time and talk to your nurse or doctor about the best areas.

Side-effects from growth factors are usually quite mild. If you are having 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 let your nurse or doctor know, as they can prescribe the best medication for you. There are some possible serious side-effects of growth factors, but they are rare. Your doctor or nurse will explain about any possible side-effects.

Erythropoietin is given to increase your red blood cells. Its side-effects can include weakness, flu-like symptoms, tiredness, headache, joint pain, nausea, vomiting and chest pain. But most people don't have these side-effects.

Low platelets

Low platelets are known as thrombocytopenia. About half of people with MDS will have a low platelet count when they are diagnosed. 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, let your nurse or doctor know. They may give you a transfusion of platelets to help.

A platelet transfusion is when you are given platelets from a donor. It is given into a vein in your arm or through a temporary line, such as a Hickman line. Platelets are yellow and are stored in a small bag.

Because platelets last only a few days, they are usually only given if you have signs or risk of bleeding.

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 already have a low platelet count, you may need to go to hospital for a platelet transfusion.

Thrombopoietin (TPO) agonists, such as eltrombopag and romiplostim, are occasionally used for MDS patients. They help your body produce more platelets to reduce the risk of bleeding in conditions where platelet counts are low. Some are taken as a tablet by mouth, others are given as a weekly injection under the skin. It depends on the medication.

If you are taking blood thinners or aspirin, tell your doctor or nurse, as these can increase your risk of bleeding when your platelet count is low. You may also be advised to avoid ibuprofen and some over-the-counter medicines which also increase the risk of bleeding. Always check with your medical team before taking them.

Infection

MDS can affect white blood cells, which fight infection, so you may be at risk of developing infections. If you do get an infection, it should be treated quickly with antibiotics. 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 have a high temperature. If you develop any serious infections, you may need antibiotics quickly and perhaps injections to help your body make more 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.
- Many of these treatments are new and they are 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 less affected by side-effects of treatment. These treatments will not cure MDS but they may help to slow it down and control it.

Many of these treatments are new and are often used as part of a clinical trial. They may be given as injections or tablets. See page 70 for more about clinical trials.

You can receive these drugs as an outpatient or in the day ward. These treatments are often drugs called targeted therapies. Treatments include:

Hypomethylating agents (HMA)

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 such as nausea, vomiting, constipation and diarrhoea may happen in 2 to 3 out of 10 patients. Other side-effects include injection-site reactions (redness/pain) and fatigue. Some people might also develop a low blood cell count. Your doctor and nurse will talk to you about possible side-effects 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 for a longer period of time.

Venetoclax with hypomethylating agents

Venetoclax, together with HMA, might be used to treat high-risk MDS or AML-MDS by helping to control the disease and prepare you for a stem cell transplant. Venetoclax works by targeting and helping to destroy abnormal blood cells. Azacitidine (an HMA) helps improve how your bone marrow produces healthy cells. This combination of drugs might be used to get the disease under better control before a stem cell transplant, improving the chances of a successful outcome. Venetoclax is taken as a tablet by mouth, and azacitidine is given as an injection or infusion. The 2 treatments are given in cycles, which are repeated regularly under close medical supervision.

Lenalidomide

Lenalidomide works by acting on your body's immune system to fight cancer. It is also called immune modulation therapy. It is given as capsules. Lenalidomide is used for a type of MDS called the 5q minus syndrome.

Targeted therapies

Targeted therapies are drugs that act on specific changes in abnormal blood cells to help control MDS. Examples include IDH inhibitors such as ivosidenib (IDH1) and enasidenib (IDH2), and in some cases JAK pathway inhibitors like ruxolitinib and FLT3 inhibitors like midostaurin or gilteritinib, which may be used depending on your individual disease features.

These treatments are not widely available for all people with MDS and are usually only suitable for people with certain genetic changes. This means they may only be offered through special access programmes or clinical trials. Your medical team will advise whether targeted therapy is appropriate and available for you.

Immunosuppressants

Immunosuppressants can sometimes help to improve blood counts. Usually they are offered to patients with hypoplastic MDS, a type of MDS with a low number of bone marrow cells. Examples of immunosuppressants are ATG and cyclosporine. For more information, talk to your medical team. You can also call our Support Line on 1800 200 700 to speak to a Cancer Nurse.

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 and so isn't suitable for everyone.

A stem cell transplant offers the chance of curing MDS. It is also known as a bone marrow transplant. A transplant works by destroying all the blood cells in your bone marrow and replacing them with healthy stem cells via a transfusion into your bloodstream. Stem cells are blood cells at their earliest stage of development that will grow into new healthy blood cells. The stem cells are taken from a donor. This is called an allogeneic transplant or allograft.

A stem cell transplant is only suitable for a small number of 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 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 people can be considered for transplant. Reducing the intensity of the treatment before the stem cell transplant reduces side-effects. This approach is called a reduced-intensity conditioning (RIC) transplant.

Just over 1 in 3 people with MDS who have this treatment may be free from the disease for many years. The disease may come back (relapse) in some cases. Stem cell transplant has many severe side-effects. Some people can become seriously ill from it.

Your doctor will discuss this treatment option with you if you are suitable. It may be suitable if you are fit enough for the treatment and if there is a good chance you will benefit from it.

If you would like more information, contact our Support Line on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of our booklet, ***Understanding allogeneic stem cell transplants***.

Intensive chemotherapy

Intensive chemotherapy uses high doses of drugs to try to clear the diseased cells from your bone marrow.

Intensive chemotherapy can be used in younger patients with high-risk MDS or MDS transformed to AML.

The treatment involves one or more cycles of intensive chemotherapy, which aims to get rid of the diseased cells from your blood and bone marrow.

Because the treatment has a lot of side-effects, you will stay in hospital for about 4 weeks while you are receiving chemotherapy.

What are the side-effects of chemotherapy?

With intensive chemotherapy, it is common to have side-effects. For example, anaemia, fatigue, nausea and vomiting and increased risk of infection. If you have any symptoms that are troubling you, let your doctor or nurse know. There are ways to make your life easier and more comfortable.

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 over time and be mild or severe. If you have any symptoms that are troubling you, let your doctor or nurse know.

To find out more about possible side-effects of chemotherapy, see our website **www.cancer.ie** or our booklet, ***Understanding chemotherapy and other cancer drugs***.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects.

People with cancer are sometimes asked to consider taking part in a clinical trial. You may get a new treatment instead of the standard treatment, or as well as the standard treatment. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using 2 treatments together.

If treatment is given as part of a clinical trial, you will be very closely monitored and may have extra tests and appointments.

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***. You can get a free copy by calling our Support Line on 1800 200 700 or by visiting a Daffodil Centre. It's also available to read or download on our website, **www.cancer.ie**

You can see a list of current cancer trials at **www.cancertrials.ie**

Palliative care

Palliative care aims to improve the quality of life of people with cancer and their families. 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 you deal with any MDS-related symptoms.

Palliative care can be given in a hospice or community hospital or in your own home. You can also attend a hospice for managing your symptoms. Hospices are places that specialise in symptom control and you can spend a day or 2 there receiving treatment.

Palliative care can be arranged by your GP, public health nurse or by the hospital. Palliative care is a free service for all people with advanced cancer. Palliative care teams work both in hospitals and in the community and sometimes visit patients at home. They may work along with your treating team. Ask 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 Support Line on 1800 200 700 or visit a Daffodil Centre to speak in confidence with a Cancer Nurse.

Managing side-effects and symptoms

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is very common with cancer. Usually fatigue starts to improve 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

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

- Ask your doctor about exercising. Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you. You can ask our nurses about our free exercise classes. Call our Support Line or visit a Daffodil Centre to talk to a nurse.
- Plan your days: Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- Ask for help at work or at home with any jobs that you find tiring.
- Try to eat a well-balanced diet. Eat little and often if your appetite is poor. Our booklet ***Understanding diet and cancer*** has tips to help.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 94).
- Have a good bedtime routine and try relaxation techniques if you are not sleeping well. Avoid alcohol and stimulants like caffeine in the evening and try not to use electronic devices for an hour before bedtime.
- Short naps (less than an hour) and rest periods can be helpful, as long as they don't stop you from sleeping at night.
- Try complementary therapies like meditation, acupuncture or massage, if your doctor says they're safe for you.

Our booklet, ***Coping with fatigue,*** has more advice. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy. It's also on our website **www.cancer.ie**

Will treatment affect my sex life?

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 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. Touching and holding each other can help you to stay physically close.

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. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again. You can also ask the nurses for a copy of our booklet, ***Understanding sex, sexuality and cancer***, or download it from **www.cancer.ie**

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

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. Some chemotherapy and other cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment.

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 try not to feel embarrassed. You can also call our Support Line 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 supportline@irishcancer.ie

Our booklet, ***Understanding sex, sexuality and cancer***, can be viewed or downloaded on **www.cancer.ie**

Will treatment affect my fertility?

Your fertility may be affected by some treatments. This could mean 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. They 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 for advice, counselling and support if this is an option for you.

Dealing with infertility 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 Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a Cancer Nurse.

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 aromatherapy.

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. Tell them also if you're using or considering using over-the-counter or herbal medications or supplements. 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?

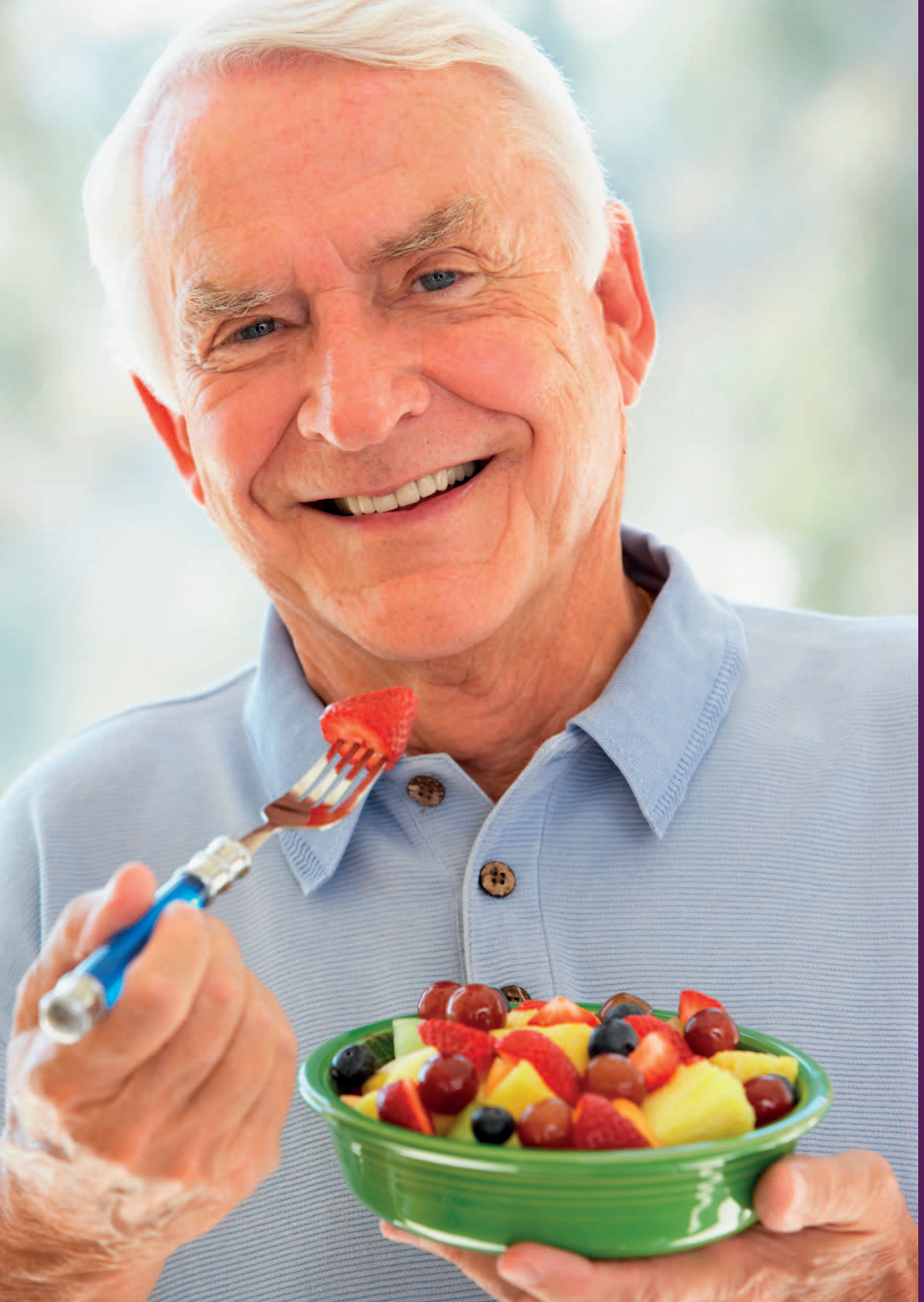
Complementary therapies are used **together with** standard medical treatment.

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 Support Line 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**



After treatment

What follow-up will I need?

After your treatment you will still need to have regular checkups. This is called follow-up. At each 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. It can help to write down what you want to say before you see the doctor, so you don't forget anything.

It's important to attend your follow-up appointments so your doctor can check for signs of the cancer coming back (recurrence) and help with any side-effects that you may have. They can also check for signs of new side-effects that may develop. It is better to be aware of these as early as possible so that suitable treatment can be given.

If you are between check-ups and have a symptom or problem that is worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment, if necessary.

If you become suddenly unwell and can't contact your specialist nurse or hospital team, go to your GP or the emergency department at the hospital.

Living with MDS

Take care of your health

Watch out for any signs or symptoms of infection or other problems. Contact the hospital if you have any signs of infection. These include feeling shivery and unwell, having a high or low temperature, having a cough or sore throat, or pain passing urine. We have tips on avoiding infection - search 'Increased risk of infection' at www.cancer.ie

Have regular dental and eye check-ups. Take good care of your mouth, teeth or dentures, as they can be a source of infection. Check with your haematologist before having dental treatment and let your doctor or nurse know if you have any discomfort or pain in your mouth.

If you develop any bowel problems such as ongoing abdominal (tummy) pain, diarrhoea, bleeding or constipation, you should also contact your doctor as soon as possible.

You will probably be advised to get the flu vaccine each winter and the pneumonia vaccine every 5 years, as well as regular Covid booster vaccines. Some vaccinations may not be suitable for you if your immune system is low. For example, live vaccines. Ask your doctor about any vaccinations you should have and make sure you get them.

Living a healthy lifestyle

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

- Feel better
- Heal and recover faster
- Cope better with any side-effects
- Keep up your energy and strength
- Reduce your risk of further illness

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun

If you want more information or advice, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website **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:

- 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. Try complementary therapies and relaxation techniques like yoga, meditation, mindfulness or aromatherapy. See page 80 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 94 for more information.
- Having the support of loved ones, healthcare professionals and other people going through a similar illness can also make a big difference. See page 95 for more about getting support.

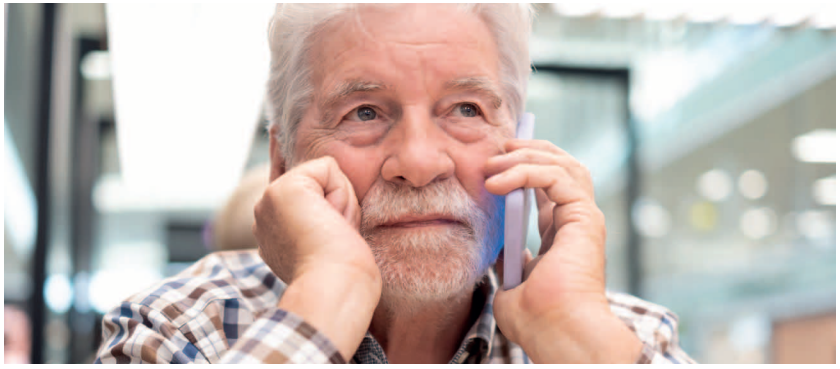
After-treatment workshops

You might like to join our **Life and Cancer – Enhancing Survivorship (LACES)** programme when you have completed treatment or have commenced maintenance therapy. This workshop covers topics such as diet, exercise, wellbeing, finance and self-management and gives information on support and services to help you. Call our Support Line or visit a Daffodil Centre for details or ask your specialist nurse or doctor to refer you to a LACES workshop.

Your feelings 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 with 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**

You can also call our Support Line or visit a Daffodil Centre to talk to a Cancer Nurse in confidence. See page 95 for other ways to get emotional support.

Coping and emotions

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 Support Line 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 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. We fund professional one-to-one counselling, remotely and at many local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email our Cancer Nurses at supportline@irishcancer.ie

> "Counselling has helped me with every part of my life. I feel I have a future now."

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 120 for more about cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people who are in a similar situation and facing similar 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 if they are available at your hospital.

Get online support: Special websites called online communities let you write questions, share stories, and give and receive advice and support.

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 Support Line on 1800 200 700 or drop into a Daffodil Centre.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Positive feelings

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 that 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."

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

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 ***Understanding the emotional effects of cancer*** can help you to find ways to talk about your cancer and to ask for the help and support you need.

Further information and support

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.

Changing relationships

You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, ask another family member or friend to talk to them.

Talking to children and teenagers

Saying nothing

If you have children, you may feel it's best not to tell them 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.

Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a copy of the booklet. Our Cancer Nurses can also support you if you have children and aren't sure what to say to them.

Supporting someone with cancer

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** or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or visit 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. The Irish Cancer Society funds professional one-to-one counselling for friends and family members, remotely and at many local cancer support centres. Talk to your GP or see page 94.

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 Support Line on 1800 200 700. Ask for a copy of our booklet ***Caring for 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**

Support for you

Our Cancer Nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@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 Support Line, or download it from our website **www.cancer.ie**

Support resources

Money matters

- If you have cancer, you may not be able to work for a time. You may also have extra expenses.
- You may have to pay for some of your cancer treatment.
- You might be entitled to certain social welfare payments.
- There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as 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 your illness if you are worried about money.

Our Welfare and Supports Service

Cancer can create additional challenges. Our Welfare and Supports team can help. We can advise on benefits, social welfare entitlements, public services, medical card applications, community support, legal entitlements, housing and mortgages, childcare or talking to your workplace about your diagnosis.

For more information or to be referred to our Welfare and Supports Service, visit **www.cancer.ie/welfare-and-supports**, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

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
- Medical aids and equipment (appliances), like wigs and incontinence products

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 and 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: 0818 074 000
- **Department of Social Protection** – Tel: 0818 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 keep a copy of completed forms, so take a photo or photocopy them before posting them.

If you have money problems

If you are in debt or worried about getting into 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 on 0818 072 000 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 117 for more details of our Transport Service and the Travel2Care fund.

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

Money and finances

Go to **www.cancer.ie** and see our **Welfare and support** page for information on:

- 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

Our website has lots of information on government supports for people who are unwell and their carers. Our Welfare and Supports Service may also be able to help (see page 108).

Irish Cancer Society services

We provide a range of cancer support services for people with cancer, at home and in hospital, including:

- **Support Line**
- **Daffodil Centres**
- **Telephone Interpreting Service**
- **Patient Education**
- **Peer Support**
- **Eating well information sessions**
- **Exercise information and support**
- **Counselling**
- **Transport Service**
- **Welfare and Supports Service** (see page 108)
- **Publications and online information**
- **Night Nursing**

Support Line Freephone 1800 200 700

Our Cancer Nurses offer confidential advice, support and information for anyone affected by cancer. Our Support Line is open Mon to Fri 9am – 5pm. Email us on supportline@irishcancer.ie

The Support Line also offers video calls. From the comfort of your own home, you can meet a Cancer Nurse virtually. To avail of this service, offered on the Microsoft Teams platform, visit **www.cancer.ie/Support-Line-Video-Calls** One of our nursing team will email you with the time for your video call and instructions on how to access Microsoft Teams on your phone, tablet or computer.

Daffodil Centres

Our Daffodil Centres, located in 13 hospitals nationwide, are staffed by Cancer Nurses and trained volunteers who provide face-to-face advice, support and information for anyone affected by cancer. This service is free and confidential. This is a walk-in service; you do not need an appointment.

To see your nearest Daffodil Centre, contact details and opening hours visit **www.cancer.ie/daffodil-centres**

What information is available?

Our Cancer Nurses provide free and easy-to-understand information on:

- Screening, cancer prevention and early detection
- Cancer types
- Tests and investigations used to diagnose cancer
- Cancer treatments and side-effects
- Local cancer support services
- Life after cancer treatment
- Financial and practical supports
- End-of-life services

Our Cancer Nurses can also give you more information or refer you to any of our supports and services.

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Cancer Nurses in your own language through our Telephone Interpreting Service. To use the service:

- Tell us in English the language you would like.
- You will be put on hold while we connect with an interpreter. You may be on hold for a few minutes. Don't worry, we will come back to you.
- We will connect you to an interpreter.
- The interpreter will help you to speak to us in your own language.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit **www.cancer.ie/our-services**

Patient Education

We offer free group sessions (online and in person) and video resources that provide information to guide you through and beyond cancer treatment.

Chemotherapy Education is for cancer patients who are due to have chemotherapy. The aim of the session is to guide the patient through the treatment from beginning to end: what chemotherapy is, how it is given, managing side-effects and available supports.

Our after-treatment education workshop is called **Life and Cancer – Enhancing Survivorship (LACES).** It was developed in partnership with the National Cancer Control Programme. LACES aims to improve the quality of patients' lives after active treatment has ended.

Patient education sessions are led by our Cancer Nurses. Sessions take place online or in person in our 13 Daffodil Centres nationwide.

We also have pre-treatment video resources that you can watch in your own time. For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre, visit **www.cancer.ie/our-services** or email patienteducation@irishcancer.ie

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. If you have a cancer diagnosis, you can be connected with a Peer Support volunteer who has had a similar cancer experience. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be connected to a Peer Support volunteer, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre. More information on Peer Support is available at **www.cancer.ie/our-services**

Eating well information sessions

We provide group online information sessions with an Oncology Dietitian on the important role nutrition has for people with cancer. Using evidence-based specialist advice, we can support you to eat well during cancer treatments and beyond.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit **www.cancer.ie/our-services**

Exercise information and support

Exercise before, during and after treatment can improve quality of life. We provide information and support on how you can make exercise part of your everyday life. We also offer free exercise classes to help people with cancer to improve fatigue, quality of life, reduce anxiety and build strength and fitness in a fun and supportive environment.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit **www.cancer.ie/our-services**

Counselling

We fund professional one-to-one counselling for anyone affected by cancer – the person diagnosed with cancer, family members and close friends. Counselling sessions are available remotely (over the telephone/online) or in person in certain cancer support centres around the country.

For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit **www.cancer.ie/our-services**

Transport Service

We provide transport and limited financial grants for patients in need who are in cancer treatment.

Transport is available to patients having chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments. We have recently opened a pilot service for patients having radiotherapy treatment at University Hospital Cork and Bons Secours Hospital, Cork.

Travel2Care is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatment. Patients can apply for this fund if they travel over 50 kilometres one way to a national designated cancer centre or satellite centre. Travel2Care is made available by the National Cancer Control Programme (NCCP).

To access this support, please contact your hospital healthcare professional. For more information call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or visit **www.cancer.ie/our-services**

Publications and online information

We provide information on a range of topics, including early detection of cancer, cancer types, treatments, side-effects and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can also call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre for free copies of any of our publications.

Night Nursing

We provide end-of-life care for cancer patients in their own homes. We offer up to 10 nights of care free of charge for each patient. Our service supports patients to remain at home for the last days of their lives, surrounded by their families and loved ones. This is a unique service in Ireland, providing night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

To access this service please contact the healthcare professional looking after your loved one. For more information visit **www.cancer.ie/our-services**

> We were really lost when we brought Mammy home from the hospital and the night nurse's support was invaluable. She provided such practical and emotional support.

> Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us.

To find out more about the Irish Cancer Society's services and programmes:

Visit us at www.cancer.ie

Speak with one of our Cancer Nurses:

- **Call our Support Line on Freephone 1800 200 700**
- **Visit one of our 13 Daffodil Centres in hospitals nationwide**

Email the nurses at supportline@irishcancer.ie

Follow us on:

- **Facebook @IrishCancerSociety**
- **X @IrishCancerSoc**
- **Instagram @irishcancersociety**
- **LinkedIn @irish-cancer-society**

Local cancer support centres

Local cancer support centres have a range of services for cancer patients, their partners, families and carers, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds one-to-one counselling through many local support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists or cancer nurses
- **Special exercise programmes**
- **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 lymphoedema services, such as education, exercise, self-management 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.

Visit **www.hse.ie** to find a cancer support centre in your area or visit **www.cancer.ie** and search '**local cancer support centres**'.
Our Cancer Nurses can also help you to find support and services. Call our Support Line or visit a Daffodil Centre to talk to a nurse.

Email: supportline@irishcancer.ie

What does that word mean?

Anaemia: Fewer red blood cells in your blood and a lack of haemoglobin. This can cause tiredness and breathlessness.

Anti-emetic: A tablet, injection or suppository given to stop you feeling sick or vomiting.

Biopsy: Removing a small amount of cells or tissue from your body to examine under a microscope.

Blast cells: 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.

Bone marrow: The soft spongy material found in the centre of your large bones. It makes red blood cells, white blood cells and platelets.

Bone marrow aspirate or biopsy: When a sample of marrow cells or bone is taken and looked at under a microscope.

Cells: The building blocks that make up your body. They are tiny and can only be seen under a microscope.

Central line: A long, thin flexible tube put into a large vein, usually in your upper chest, to give medication and fluids.

Chemotherapy: The use of drugs to cure or control cancer.

Chromosomes: Tiny structures that contain the genetic information of the cells in your body.

Cytogenetics: Tests that look at the chromosomes of MDS cells.

Cytopenia: Low blood counts. A lack of red cells (anaemia), platelets (thrombocytopenia) or white cells (leucopenia).

Fatigue: Ongoing tiredness or exhaustion.

Growth factors: Medicines that can help to increase the number of red cells, white cells or platelets.

Haematologist: A doctor who specialises in treating patients with blood or bone marrow diseases.

Haematology: The study of blood and bone marrow.

Immunophenotyping: A test that checks what kind of proteins or markers are found on the surface of leukaemia cells.

International Prognostic Scoring System (IPSS): 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).

Iron chelation: The use of medicines to get rid of excess iron from your body.

Leukaemia: Cancer of the white blood cells and bone marrow.

Myelodysplasia: A type of bone marrow failure with low blood counts. It is the same thing as myelodysplastic syndromes.

Nausea: Feeling sick.

Neutropenia: A lower-than-normal number of neutrophils in your blood.

Neutrophils: Important white cells that fight infection. They are the most common of the white blood cells.

Petechiae: Bleeding under your skin, usually on your legs, feet, trunk and arms, due to a low platelet count after cancer treatment.

Platelets: Blood cells responsible for clotting.

Prognosis: The expected outcome or course of a disease. How it will behave in the future.

Red blood cells: Blood cells that carry oxygen to all parts of your body.

Refractory anaemia: A type of MDS with low red blood cells (anaemia).

Ring sideroblast: An abnormal-looking red cell in bone marrow found in some kinds of MDS.

Stem cell: The earliest cells found in bone marrow. They are responsible for making all blood cells.

Thrombocytopenia: A low platelet count.

White blood cells: Blood cells that help fight infection. There are 5 types: neutrophils, lymphocytes, monocytes, eosinophils and basophils.

Blood results diary

Date	HB	WBC	Plts	Neut	Other

Blood results diary

Date	HB	WBC	Plts	Neut	Other

Notes/Questions

Notes/Questions

Acknowledgments

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 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:

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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! Visit **www.cancer.ie** if you want to get involved.

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 Peer 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

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We would love to hear your comments or suggestions.
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