Irish Cancer Society

Understanding

Acute myeloid leukaemia (AML)

Caring for people with cancer

Understanding

Acute myeloid leukaemia (AML)

This booklet has information on:

- Treatment for AML
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Clinical nurse specialist

Advanced nurse practitioner (ANP)

Family doctor (GP)

Haematologist

Medical oncologist

Radiation oncologist

Medical social worker

Hospital day ward

Out-of-hours contact number

Emergency number

Hospital records number (MRN)

Contents

Fast facts

Can AML be treated? Page 39

Yes. Treatment for acute myeloid leukaemia (AML) aims to destroy the leukaemia cells and allow the bone marrow to work normally again. When this happens, it is called remission. Some people stay in remission and the person is said to be cured. Treatment starts as soon as possible as AML is a fast-growing cancer.

Will I be OK? Page 36

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, such as the type of leukaemia you have, your age and general health. It's best to ask your consultant about your own situation.

What treatment might I have? Page 55

Depending on your age and general health you may have intensive chemotherapy, other types of drugs and maybe a stem cell transplant to put the disease into remission. If you are not suitable for intensive treatment, you will have low-dose chemotherapy or different drug therapies, perhaps as part of a clinical trial.

How will my cancer treatment affect me? Page 55

All treatments, particularly intensive chemotherapy, can cause side-effects. Read about the treatments to learn more about their possible side-effects.

There are treatments to help with most side-effects, so tell your doctor or nurse. Don't suffer in silence!

Clinical trials Page 81

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.

We're here for you Page 123

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 into a Daffodil Centre.
  Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 123 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 that 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 medical 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.

About acute myeloid leukaemia (AML)

What is leukaemia?

Leukaemia is a cancer that affects blood cells. To understand leukaemia, it helps to understand how blood cells are made.

About blood cells

Your body has 3 main types of blood cells:

Red blood cells carry oxygen to all the tissues in your body.

White blood cells are involved in fighting infection. Neutrophils are a type of white blood cell that protect you from infection; they are the most common type of white blood cell in your body.

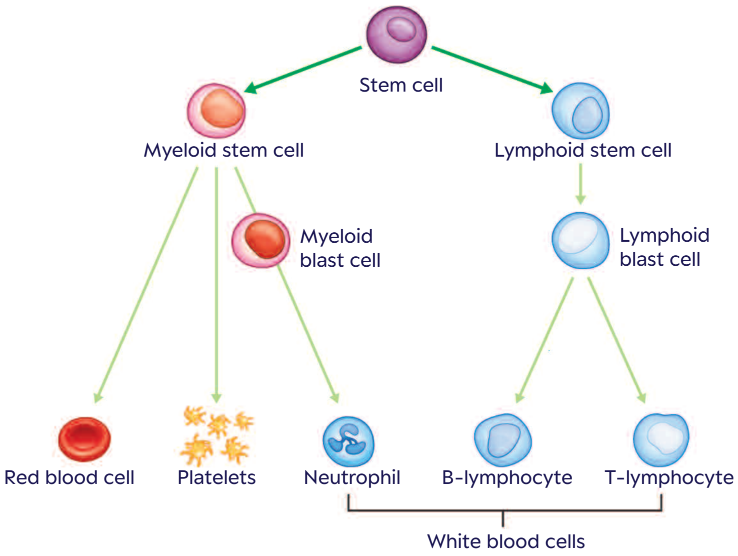
Platelets are involved in blood clotting.

New blood cells are made in your bone marrow. This is the soft spongy tissue that fills the centre of some of your bones. All blood cells come from cells known as stem cells. Stem cells split and develop into myeloid stem cells or lymphoid stem cells. They start out as immature cells (blast cells) and then they develop into different types of mature blood cells.

Lymphoid stem cells develop into lymphocytes (white blood cells that fight infection)

Myeloid stem cells go on to form red blood cells, platelets and other types of white cells.

As blood cells develop, they move out of the bone marrow and into your bloodstream, where they do different jobs, such as fighting infection (white cells), carrying oxygen (red cells) and clotting your blood so you don't lose too much blood (platelets). Your body is constantly producing enough cells to keep this process going.



Blood cancers happen when something goes wrong with the development of blood cells in your bone marrow. With leukaemia, blast cells are produced but they don't develop properly. Instead, the immature blast cells build up in your bone marrow and the number of healthy cells is reduced. You get sick because there aren't enough healthy blood cells to do their jobs in the body.

Types of leukaemia

There are 4 main types of leukaemia:

- Acute myeloid leukaemia (AML)
- Acute lymphoblastic leukaemia (ALL)
- Chronic myeloid leukaemia (CML)
- Chronic lymphocytic leukaemia (CLL)

Their names come from the type of cell affected by the leukaemia (myeloid blast cells or lymphoid blast cells) and from how quickly they develop (chronic or acute).

What do 'acute' and 'chronic' mean?

Acute and chronic refer to how quickly leukaemia develops.

Acute: The leukaemia develops very quickly, over days or weeks.

Chronic: The disease develops slowly, usually over months or years.

Each type of leukaemia has its own features and treatment. This booklet is about acute myeloid leukaemia (AML). For free booklets on the other types of leukaemia, contact our Support Line on 1800 200 700 or visit a Daffodil Centre.

What is acute myeloid leukaemia (AML)?

AML is an acute (fast-growing) blood cancer, which affects the myeloid cells. With AML, mutations (changes) in the genetic material in myeloid cells stop the immature myeloid cells (blast cells) from developing into healthy, mature blood cells. This results in a rapid build-up of blast cells in the bone marrow and a shortage of mature blood cells.

What are the types of AML?

The information from your tests (see page 27) will help to determine the exact type of AML you have. There are 2 main classification systems used by doctors to classify AML: the World Health Organization (WHO) and the International Consensus Classification (ICC). These divide AML into different groups based on genetics and other characteristics of leukaemia cells.

You're not likely to hear your doctor talk about these systems, but they can help your doctor to decide the best treatment for you, as some treatments are only used for certain types of AML.

AML risk groups

Your doctors may say that your leukaemia is 'favourable risk', 'intermediate risk' or 'adverse risk', based on the information they get from the tests you will have (see page 27). This is called risk grouping (or risk stratification). Your risk may change during your treatment.

Favourable risk: If you are suitable for intensive chemotherapy, your leukaemia is more likely to be cured and there's less chance of the cancer coming back (recurrence). Favourable-risk patients won't usually need a stem cell transplant unless their cancer recurs (comes back).

Intermediate risk: It is hard to predict how you will respond to treatment. You may or may not need a stem cell transplant.

Adverse risk: It may be difficult to get your leukaemia into remission or there's a high risk of the leukaemia coming back (recurrence), so if you are suitable, you will have very intensive treatment. You are likely to have a stem cell transplant if you are suitable for one.

If you are not suitable for intensive chemotherapy, other low-intensity chemotherapy options may be suitable for you. The current standard of care for patients not suitable for intensive chemotherapy is a combination of azacitidine and venetoclax (see page 62). Generally, this treatment cannot cure the leukaemia but can keep it in remission for a period of time.

Acute promyelocytic leukaemia (APL)

Acute promyelocytic leukaemia (APL) is a sub-type of AML. APL is treated differently to other forms of AML. It usually progresses very fast, however it has a very high cure rate and it responds well to certain non-chemotherapy drugs - all-trans retinoic acid (ATRA) and arsenic trioxide (ATO).

APL is divided into 2 risk groups – high risk and non-high risk – depending on the total white blood count during diagnosis. If you are in the non-high-risk group, you can be cured with the non-chemotherapy drugs, ATRA and ATO. If you have been diagnosed with high-risk APL, you might need some chemotherapy added to your treatment.

To find out more about APL, talk to a cancer nurse on our Support Line 1800 200 700 or visit your local Daffodil Centre.

What are the symptoms of AML?

Many of the symptoms of AML are caused by the change to normal blood cell production. You may not have all or any of the symptoms listed below. Symptoms of AML include:

- High temperatures or fevers, repeated infections. This is caused by fewer white blood cells
- Tiredness (fatigue), shortness of breath and weakness. This is caused by fewer red blood cells (anaemia)
- Blood in your gums, urine or stools (poo), unexplained bruising, tiny red spots on your skin, swollen gums. This is caused by fewer platelets
- Serious bleeding
- Aching bones and joints. This is caused by too many abnormal cells in your bone marrow
- Enlarged glands. For example, in one or both armpits, groin or neck
- Enlarged spleen or liver. You may have a poor appetite, pain in your abdomen (tummy) or abdominal swelling
- Sepsis. This is a reaction to an infection. You may feel generally unwell, have a high or low temperature, or feel shivery
- Loss of appetite
- Weight loss

Symptoms of AML can be vague and include lack of energy and a general inability to do the things you normally do. If you have symptoms that are troubling you, or new symptoms appear, tell your doctor.

How common is AML?

AML is a rare disease. About 150 people are diagnosed with it in Ireland each year. It is more common in people aged over 65.

What caused my cancer?

We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. If you want to know more about why cancer happens or to learn about risk factors for leukaemia, see our website **www.cancer.ie** or talk to a cancer nurse. Call our Support Line or visit a Daffodil Centre. Most people who get leukaemia have no obvious risk factors and having a risk factor doesn't mean you will get leukaemia.

Preparing for your hospital appointments

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 are not 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 before doing so)
- 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, if you are not fasting
- Your phone and your phone number
- 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 in advance of your next appointment as soon as you can, for example, a blood test, if your healthcare professional has asked for it.

If you have to cancel your appointment

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. If you don't go to your appointment or contact the hospital, you may have to return to your GP and go back on the waiting list for a new appointment.

Questions to ask your doctor

Here is a list of questions that you might like to ask your doctor. Never be shy about asking questions. It is always better to ask than to worry.

What type of AML do I have?

What type of treatment do I need?

Why is this treatment better for me?

How successful is this treatment for my leukaemia?

How long will my treatment take?

Do I have to stay in hospital for my treatment?

Would I be suitable for a clinical trial?

Will my blood cell count return to normal after treatment?

What side-effects or after-effects will I get?

Can some of the side-effects be controlled?

Is there anything I can do to help myself during treatment?

Do I need to use contraception during my treatment? What will happen if I, or my partner, get pregnant?

Should I eat special foods?

How will you know if the leukaemia is in remission?

Diagnosis and tests

Being diagnosed with AML

Hearing the words 'leukaemia' and 'cancer' 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 (haematology) liaison nurse or the medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters.
- Talk to one of our cancer nurses in confidence. Visit a Daffodil Centre or call our 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.
- Talk to other people affected by cancer. Join our online community at **www.cancer.ie/community**
- Go to your local cancer support centre. For more information, see page 130.

Telling people about your diagnosis

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

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can ask them 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 tests will I have?

- Tests you may have include blood and bone marrow tests. You may also have scans.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

The following tests give doctors more information about your cancer. Some tests may also be used to see how well you are responding to treatment.

Blood tests

A full blood count (FBC) will be taken. This finds out the levels of the different types of blood cells in your blood. Your blood will also be examined under a microscope, as leukaemia cells can sometimes be seen and the diagnosis confirmed. This is done by the haematologist.

Blood tests can also check how well your liver and kidneys are working. Your blood will also be screened for any infections, such as hepatitis and HIV, to make sure your treatment is safe for you.

Normal blood cell counts

Blood cell type	**Normal levels**
Haemoglobin	13-18g/dl (men)
	11.5-16.5 g/dl (women)
White blood cells (WBC)	4.0-11.0 x 10^9/l
Neutrophils	2.0-7.5 x 10^9/l
Lymphocytes	1.5-4.5 x 10^9/l
Basophils	up to 0.01 x 10^9/ (0-1% of WBC)
Platelets	150-400 x 10^9/l

Central venous access devices

You will have regular blood tests, so it's likely you will have a device inserted to make it easier for your doctors to take blood and give medications. For example, a central line or Hickman line. See page 64 for more information.

Blood film

Your doctor may look at a blood sample under a microscope in order to determine the amount of leukaemia cells present. This is often called a blood film and is usually carried out in the haematology laboratory of the hospital.

Bone marrow tests

Bone marrow tests involve taking a tiny sample (biopsy) of your bone marrow and looking at it under a microscope. The sample is usually taken from your pelvis bone. If the sample of bone marrow cells is semi-liquid, it is called an aspirate. If a piece of solid bone marrow is taken, it is called a trephine biopsy. Both can be done at the same time. Care has to be taken if you are on warfarin, apixaban, aspirin or any other drugs that thin your blood. Your doctor will advise you about this.

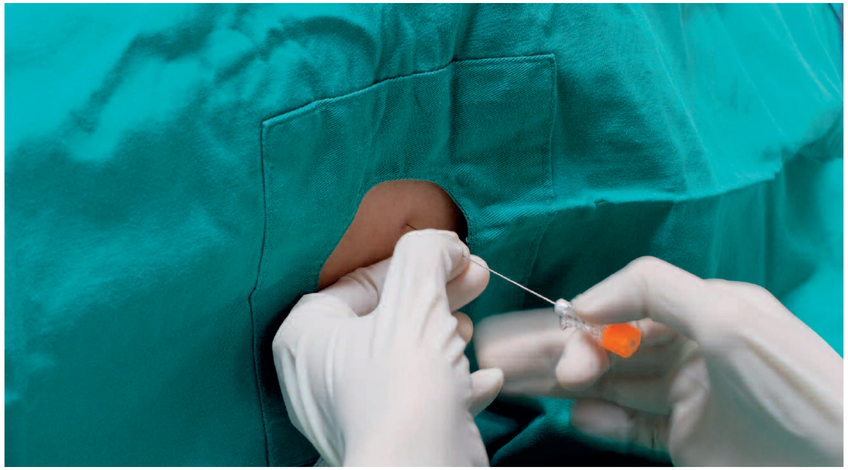
Your doctor will give you a local anaesthetic to numb the area beforehand. The biopsy itself may be uncomfortable and can last up to 10 minutes. The entire test can take about 30 minutes. Once the needle is put into your bone cavity, a sample of your bone marrow is drawn into a syringe. Bone marrow is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

When it is over, a small plaster is put on the area where the bone marrow has been taken. You may be asked to lie on your back for 10–15 minutes to stop any possible bleeding. You can take mild painkillers, like paracetamol, if you feel any discomfort later.

If you are having this test done as an outpatient, which is sometimes done between treatments, you will need someone to drive you home.

Lumbar puncture

This test involves passing a needle into the lower part of your back to take a sample of the fluid that surrounds your brain and spinal cord (cerebrospinal fluid). The fluid will be checked for leukaemia cells. Not everyone needs this test. Your doctor will tell you if you need it. If you have this test done as an outpatient, you will need someone to drive you home.



Specific tests on bone marrow

Immunophenotyping and flow cytometry

Immunophenotyping is a test that checks what kind of proteins or markers are on the surface of your leukaemia cells. Immunophenotyping can be used to determine what type of leukaemia you have. It can also help monitor your response after treatment. It can be performed on both a solid sample of your bone marrow (immunohistochemistry) and a liquid sample (flow cytometry).

Flow cytometry is the main type of immunophenotyping used to diagnose and monitor AML. It measures the number and percentage of different cells in a blood or bone marrow sample. It also measures cell characteristics such as size, shape and the presence of proteins (biomarkers) on the cell surface.

Cells are passed through a machine call a flow cytometer. This can be used for diagnosis or to check how you are responding to treatment.

Genetic testing

Genetic testing is the main tool used by doctors to classify AML into type and risk categories. It helps them to choose the best treatment for your disease and monitor your response to treatment.

Almost all AML patients will have some genetic abnormalities detectable in their leukaemia cells. It is important to note that these gene changes/faults are generally not the same as genes passed through families and are only present in the leukaemia cells.

However, a small number of AML patients might have abnormalities detectible in some genes that have been inherited and can be passed on to the next generation. These are called myeloid neoplasms with germline predisposition. They are found in up to 10% of all AML cases. If a gene that can be inherited was detected in your AML cells, your doctor may discuss doing further investigations into you and your direct family members, with their consent.

Cytogenetics

The 2 main tests used are chromosomal analysis (karyotyping) and fluorescent in situ hybridisation (FISH).

Chromosomes are made up of genes that control the activities of cells. Leukaemia is caused by mistakes in the genes. Chromosome tests can find out the number and shape of the chromosomes in your blood cells. Tests can be done on your blood and/or bone marrow samples. These chromosomes are then compared to normal cells.

With AML, there may be some particular genetic changes in the leukaemia cells. Knowing about these changes will help your doctor to decide on the best treatment for you.

Fluorescent in situ hybridisation (FISH) makes abnormal genes glow (fluoresce) so that the doctor can identify the particular type of genetic abnormality. A FISH test can help your doctor predict how your leukaemia might respond to a particular treatment. They can use this information to recommend the best option for you.

Molecular testing

Chromosome analysis and FISH are used to look at the larger structural defects in your chromosomes, while molecular tests are designed to look more precisely at the defects of certain genes. The 2 main techniques used for AML patients are polymerase chain reaction (PCR) and next generation sequencing (NGS):

- **Polymerase chain reaction (PCR):** This is a very sensitive test that can find even low levels of leukaemia cells in a test sample. It can find small levels of chromosome changes that other tests cannot find. The results of PCR tests are relatively fast to obtain. For these reasons, the test is often used to look for some particular genetic abnormalities that can change your initial treatment. They are also used to monitor the response of your disease to treatment. The PCR test can only look at a particular abnormality in one selected gene.
- **Next generation sequencing (NGS):** This is a powerful tool used in the diagnosis and management of AML. This advanced technology allows doctors to analyse multiple genetic changes in leukaemia cells, providing detailed information about mutations that may have caused the disease. By identifying specific genetic alterations, NGS helps confirm the diagnosis of AML, predicts how aggressive the leukaemia might be and guides treatment decisions. NGS can also uncover mutations that indicate how well a patient might respond to certain therapies. This helps to personalise treatment plans and improve outcomes. Unlike PCR, NGS is used to look at multiple genes at the same time. However, there is more work involved in this and results might take longer to come back.

Other tests

Depending on how well you are when you are diagnosed, your doctors may want to do additional tests. These tests aren’t always routine and some aren’t necessarily done before you start your treatment, so don’t worry if you don't have them.

Ultrasound

Ultrasound uses sound waves to produce pictures of the inside of your body. It only takes a few minutes and does not hurt. Some gel is first put on your skin and a device called a probe is passed over it. Ultrasound can be used to look at lymph nodes near the surface of the body. It can also be used to look inside your abdomen for enlarged lymph nodes or enlarged organs such as the liver, spleen and kidneys.

You may also have an echocardiogram (echo), which is an ultrasound of your heart. This can check your heart health and help your doctor to decide if intensive treatment may be suitable for you.

Blood-clotting tests

Some types of AML, like acute promyelocytic leukaemia (see page 13), can cause blood-clotting problems. Your doctor may decide to do a test to check how well your blood clots.

Chest X-ray

A chest X-ray uses high-energy rays to take pictures of the inside of your body. It can find out if you have a chest infection and the state of your general health.

CT scan (CAT scan)

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test.

You may also be given an injection or a special drink to help show up parts of your body on the scan. The injection may make you feel hot all over for a few minutes.

During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

MRI scan

This is a scan that uses magnetic energy and radio waves to create a picture of the tissues inside your body. MRI scans are sometimes used to check any irregularities seen on the CT scan.

You will need to complete a form before the test to ensure that it is safe for you to have an MRI scan. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. You cannot wear jewellery during the scan.

During the test you will lie inside a tunnel-like machine for around 40-60 minutes. The length of time depends on the number of images that are needed and the area of the body being scanned.

Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious.

An MRI can be noisy, but you will be given earplugs or headphones to wear. You might get an injection before the scan to show up certain parts of your body. It is important that you keep as still as possible during the scan.

Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

For most scans you will be alone in the treatment room, but the medical staff can still see you and hear you. If you need anything, just speak or raise your hand.

Waiting for test results

It usually takes 1-2 weeks for most of the test results to come back. 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.

Occasionally, some genetic tests might take 4-5 weeks to come back. Often, patients need to start treatment before these results are available. In such cases, your initial treatment will be decided on by your doctor without delay.

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.
- Make sure you are asking about your prognosis to meet your own information needs and not that of others.
- Get information on prognosis from your doctor. They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- 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.

If you feel upset or anxious about your prognosis, you can get support from family, friends or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treatment overview

How is AML treated?

- Many patients with AML will have inpatient chemotherapy treatment.
- Some patients will have chemotherapy treatment in a haematology day ward as an outpatient.
- Some patients may be suitable for a stem cell transplant.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

Because AML is a fast-growing cancer, treatment will start soon after you have been diagnosed.

In some cases, if your condition is stable, your doctor might decide to wait for all your test results to decide the best treatment for you. This can take a few weeks.

The aim of treatment is to reduce/eliminate the leukaemia cells from your blood and bone marrow to allow normal healthy cells to grow. The best treatment for you will depend on:

- Whether your doctor thinks there is a high risk your AML will return (recur) following standard treatment
- Your age and general health

You will normally stay in hospital for part of your treatment. Talk to your doctor about how long you will be expected to stay, as this can influence your decision on treatment. See page 55 for more about treating AML.

Chemotherapy

Chemotherapy is the main treatment for AML. It is given to destroy all the leukaemia cells and to make space in your bone marrow for healthy cells to grow again. There are 2 main types of chemotherapy regimens – intensive and non-intensive.

Intensive chemotherapy is harder to tolerate because it is more toxic, so it is suitable for younger and fitter patients. It is also more effective and has a higher success rate.

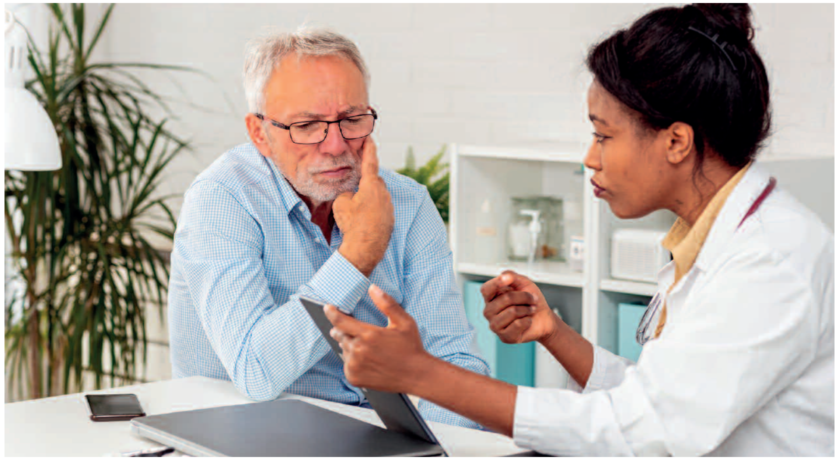
Chemotherapy drugs may be given in different doses and combinations. They are given through a drip (intravenous infusion) into a vein and this treatment usually lasts for 5-10 days. However, you will likely be admitted to hospital for around 4 weeks, as it will take time for your bone marrow to recover and start producing blood cells. Before your bone marrow starts working normally again, you will need supportive treatments such as blood transfusions.

After chemotherapy, most patients with AML go into remission. This means there are no signs of AML in your blood and bone marrow (see page 58). See page 57 for more information on chemotherapy.

Non-intensive chemotherapy is used to treat AML in older patients or in patients where high-intensity chemotherapy would be too toxic. A combination of azacitidine and venetoclax are most often used for these patients. See page 62 for more information on azacitidine and venetoclax

Targeted therapy

These are drugs that target certain parts of cancer cells that make them different from other cells. Some targeted therapy drugs are only effective in treating certain types of AML. They are often used in combination with chemotherapy. Your doctor or nurse will explain if they are suitable for you. See page 75 for more on targeted therapies.



Immunotherapy

Immunotherapy helps your immune system to work better to fight cancer cells. Different types of immunotherapy treatments work in different ways. You might have immunotherapy with other cancer treatments. See page 77 for more details.

Stem cell transplant

A stem cell transplant may be offered as treatment for your cancer. The transplant will help to create healthy bone marrow that will in turn make healthy stem cells and normal blood cells. If your healthcare team thinks a transplant may be helpful to you, they will start to look for a suitable donor while you are having your chemotherapy treatment. See page 78 for more about transplants.

Radiotherapy

Radiotherapy is rarely used with AML. But it can be used to treat leukaemia cells that have spread to your brain and spinal cord. Radiotherapy can also prepare your bone marrow before a transplant. This is called total body irradiation (TBI). For more information, call our Support Line on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet, ***Understanding Radiotherapy***, or download it from **www.cancer.ie**

Supportive care

Supportive care means extra treatment that is given to help with the symptoms of your illness or the side-effects of treatment. For example, a blood transfusion to help with anaemia. If your illness is at an advanced stage, treatment may only be able to control it rather than cure it. Supportive care can ease symptoms and give you a better quality of life.

Specialist cancer centres

AML is a rare disease and is treated in specialist cancer centres in Ireland. The staff at these centres are experienced in managing patients with AML. As a result, you may be transferred to another hospital from the one where you received your diagnosis, depending on your diagnosis and your suggested treatment plan.

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 and specialist nurse. The team will meet to discuss your test results and your suggested treatment plan.

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. 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.

Second opinion

While you might find it reassuring to have another medical opinion to help you decide about your treatment, the reality is that because AML is a fast-growing cancer, it is essential that treatment begins as soon as possible. Be assured, your medical team will use the latest scientific information and best practice to develop your treatment plan.

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.

Time to think

AML is a fast-growing cancer, so treatment will start as soon as possible after diagnosis. This can be hard when you are coming to terms with your diagnosis. You may feel everything is happening too quickly.

You may feel under pressure to make a decision. Talk to your doctor or specialist nurse if you're feeling overwhelmed or if you have any questions or worries.

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 AML are not getting the same treatment as you. Their AML may not be the same type or at the same phase as yours. Treatment decisions can also depend on any previous treatments you have had and your general health. Everyone's treatment needs will be different. Ask your doctor about your treatment if you have any questions.

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 disorders of the blood and lymphatic system. They will be the main doctor looking after you during your AML treatment.

Advanced nurse practitioner (ANP): ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment.

Oncology or haematology liaison nurse/clinical nurse specialist (CNS): 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.

Radiation oncologist: A doctor who specialises in treating cancer patients using radiotherapy.

Radiation therapist: A person who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.

Pathologist: A doctor who examines any tissue samples taken and helps to reach a diagnosis.

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

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

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.

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

Pharmacists: Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. 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.

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

Community health services: This includes 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. See page 93 for more information on palliative care.

Waiting for treatment to start

Treatment for AML usually starts as soon as possible after diagnosis.

If you are waiting, even for a short time, while your treatment is being planned, you may worry that the cancer will spread during this time.

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.

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 before and when you start treatment to help you 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
- Reduce weight 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 better

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

Be active

If you are able, it can really help to be active before 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.

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 chemotherapy or radiotherapy work
- Quitting reduces your chance of further illnesses

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 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.

Other ways to help yourself

Get information about your cancer and treatment

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

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

Accept change in your life

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

Know that there will be ups and downs

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

Try to cope day by day

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

Plan ahead

Some people with a cancer diagnosis find it reassuring to organise medical and legal matters. See page 102 for more about planning ahead.

Types of treatment

Chemotherapy

- Chemotherapy uses drugs to kill cancer cells.
- Chemotherapy can cause a range of side-effects.
- Side-effects usually go after treatment ends.

Chemotherapy is the main treatment for AML. This drug treatment is given to destroy all the leukaemia cells and make space in your bone marrow for healthy cells to grow again. Usually, chemotherapy reduces the risk of the cancer coming back. After chemotherapy, most patients go into remission.

What is remission?

Remission means there is no evidence or signs of cancer in your body. There are different types of remission for AML, depending on the sensitivity of the test that has been used to detect your leukaemia cells.

Morphological remission: This is when your bone marrow is producing blood cells normally and you have fewer than 5% of the immature cells in your bone marrow. Your red blood cell, white blood cell and platelet counts have returned to normal or close to normal levels and there are no signs or symptoms of the disease.

Minimal residual disease (MRD): A very sensitive test, like flow cytometry, detects very small amounts of AML cells after treatment. Patients who do not have any detectable leukaemia cells and whose blood cells have recovered to normal levels are said to be in MRD negative remission. They have a high chance of being cured.

Sometimes after receiving chemotherapy the leukaemia cells are still present in your bone marrow. This is called refractory disease, but it can still be treated.

There is a chance that your illness will come back (recur). If this happens, you may have more chemotherapy, other types of drugs or a stem cell transplant.

Intensive or non-intensive treatment?

The most important decision about your chemotherapy treatment is whether you have intensive treatment or non-intensive treatment.

Intensive treatment

Intensive treatment involves strong chemotherapy with the aim of cure. Although each patient is treated on an individual basis, intensive chemotherapy treatment is usually appropriate if you're under 65 years old and have good medical fitness. Some older patients in good health may benefit from similar or slightly less intensive treatments, as older patients are more likely to have other medical problems, including diabetes, high blood pressure or heart disease.

Intensive chemotherapy for AML has 2 stages: induction and consolidation. Chemotherapy treatment usually starts as soon as possible after diagnosis.

What are the stages of intensive chemotherapy treatment for AML?

1 **Induction:** The first step in your leukaemia treatment is an intense dosing of chemotherapy, which aims to get rid of all the leukaemia cells from your blood and bone marrow and quickly get your bone marrow working normally again. This stage is called induction chemotherapy or remission induction. Induction usually involves 2 cycles of a combination of chemotherapy drugs. Typically, initial therapy requires a hospital stay of about 4 weeks. When the induction is over, a bone marrow test will be done to check if the leukaemia has gone into remission.

2 **Consolidation:** When you have finished induction and your blood counts are recovered, you will start consolidation therapy. The aim of this phase is to reduce the risk of recurrence. You will usually need 2-3 more cycles to complete the consolidation phase of treatment, but this can vary depending on the type of AML you have and the progress of the disease. Without these cycles, there is a higher risk of the leukaemia coming back in the first year. You might also have a stem cell transplant (see page 78). If you have a transplant, you might not have any further chemotherapy, or you might just have one more course.

How long does intensive chemotherapy treatment last?

Intensive chemotherapy usually involves 3 or 4 courses or cycles of treatment over a 4-6 month period. Each course lasts a number of days and it usually takes your blood count 3-4 weeks to recover. Your doctor or nurse will tell you about the schedule most suitable for you. You'll have most of your treatment as an inpatient in hospital, but nearly all patients will get to go home for a week or so between courses.

Maintenance and disease monitoring

Some patients, especially those whose disease was suitable for targeted therapies, might have maintenance treatment after finishing consolidation therapy or after a stem cell transplant. This treatment will usually be given in tablet form for 1-2 years, or sometimes longer.

Some patients will benefit from disease response monitoring after their treatment has finished. They will have regular blood or bone marrow tests for MRD detection. This is generally for a period of 2 years.

Non-intensive treatment

Non-intensive treatment involves low doses of chemotherapy or other drug treatments, for example, targeted therapies (see page 75). Non-intensive treatment can be less effective in guaranteeing long-term remission but it is easier on your body. This may be a better option if you are over 65 or have other medical problems.

There are lots of different options for non-intensive treatment. Your treatment and the way it is given will be tailored to your individual disease type and needs. Azacitidine and venetoclax are examples of drugs used for non-intensive treatment.

Azacitidine and venetoclax

This is a drug treatment that is used to treat AML in older patients and in patients where intensive chemotherapy would be too toxic.

As part of this treatment, you will need to take tablets and attend a haematology day ward or chemotherapy day ward for an injection every day for 1 week out of each month. This treatment is then repeated every month until it stops working.

You may experience nausea, diarrhoea and fatigue in the first few days of treatment. You may need to be admitted to hospital to manage infections or low blood counts during treatment, but most of the time, you will be able to have your treatment as an outpatient.

Where do I go for chemotherapy?

Chemotherapy is usually given in hospital. More than likely you will have to travel to a cancer centre for treatment.

How often will I have chemotherapy?

Chemotherapy is often given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of cycles can vary, depending on your cancer type and how well it is responding to treatment.

How is chemotherapy given?

Before chemotherapy starts, you will be given medication such as allopurinol or rasburicase to help your kidneys get rid of uric acid. Uric acid can build up in your kidneys when a lot of leukaemia cells are killed during chemotherapy. Without this medication, uric acid may cause gout or kidney stones, and can interfere with the flow of urine.

Drink plenty of fluid to protect your kidneys.

During the treatment cycles, many different chemotherapy drugs are used. There are a few ways to give these drugs. For example:

- By injection into a vein or by a drip infusion (intravenous)
- By injection into the fluid around your spinal cord (intrathecal)
- By mouth (oral), in the form of capsules or tablets

Most chemotherapy for AML is given into a vein (intravenously). Once in your bloodstream, the chemotherapy drugs can travel around your body. There are different ways to give the drugs directly into the vein. A cannula is a fine tube put into a vein in your arm or on the back of your hand. This is used as a short-term solution and will likely be removed in less than a week.

Central venous access devices

Chemotherapy will be given over a long period of time, so you will probably have a central venous access device fitted – a thin tube (line) which goes directly into a vein. This makes it easier and less painful to give chemotherapy and other drugs, antibiotics, and blood and platelet transfusions directly into your bloodstream. Blood samples can also be taken from the line too. This avoids you having repeated blood tests using a vein in your arm.

Central line

This is a thin flexible tube tunnelled through the skin in your chest and put into a large vein near your heart. It is usually used for a week or so, but it may be left in place for weeks if it does not become infected or blocked.

Hickman line

This is a thin flexible tube put into a vein in your neck and tunnelled through your chest. It exits above the breast and can have 3 or 4 different lines for accessing your bloodstream. It can be left in place for weeks, as long as it doesn't become infected or blocked.

PICC line (peripherally inserted central catheter)

This is a thin flexible tube put into a vein in your arm and tunnelled through your upper arm and chest until the tube lies in a vein near your heart. It may have 1, 2, or 3 lines for accessing your bloodstream. This is more long term and can stay in for weeks or months without complications.

Caring for central venous access devices

It is important to take good care of your device. You may experience some problems, such as:

Blockage

A blockage can be due to blood clotting where the tube enters your vein, like in a wound. The line will be maintained carefully to try to prevent it getting blocked.

Infection

An infection can cause fever, redness, pain or discharge around the tube, or swelling of one arm. Let the hospital know immediately – even out of hours – if you have these symptoms, as you may need antibiotics.

Tube falling out

In general it is hard for a line to fall out, as your skin will grow around it. If the line does come out, don't panic. Cover the area with a clean dressing and contact the hospital straight away. Before you go home, your nurse will show you how to care for your line and help prevent these complications. You will be told who to contact if you have problems during the day or at night. Keep all the parts of the line, if it falls out, and bring them to the hospital, as it may be repaired.

Intrathecal chemotherapy – injection into the spinal fluid

Chemotherapy is sometimes given into the fluid around your brain and spinal cord – known as the cerebrospinal fluid (CSF). This is called intrathecal chemotherapy. Intrathecal chemotherapy can be used to treat cancer that has spread to this area or to prevent cancer spreading to this area.

For this treatment, you lie on your side and hold onto your knees. Before placing a small needle into the spine in your lower back (lumbar puncture), your doctor will give you an injection to numb the area.

A small amount of spinal fluid will then be drawn off and the drug injected into your spine. This allows the drug to travel to your brain. When chemotherapy is given into the spinal fluid, you may get some headaches and dizziness or blurred vision. You must lie flat for 1–4 hours after the lumbar puncture to prevent these symptoms.
Tell your doctor or nurse if you have any symptoms.

If you have this treatment as an outpatient, you will need someone to drive you home.

By mouth

Many cancer drugs can be taken in tablet form. These include some chemotherapy drugs and targeted therapies. It can help if you eat or drink something before taking certain tablets. Your doctor or nurse will advise you about this. If you would like more details on how chemotherapy is given, contact our Support Line on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet ***Understanding chemotherapy and other cancer drugs*** or download it from **www.cancer.ie**

What drugs are used?

Your doctor will decide which drugs are best for you based on the type of AML you have, your age and your general health.

Chemotherapy drugs can be given alone or in combination. Examples of chemotherapy drugs used to treat AML are cytarabine, daunorubicin, idarubicin and fludarabine.

Understanding your drug treatment

It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you know the name of your chemotherapy drug, visit the Health Products Regulatory Authority's website at **www.hpra.ie** for more information about the drug and possible side-effects.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on 1800 200 700.

Will I get side-effects?

Side-effects happen because chemotherapy can affect both healthy cells and cancer cells. Side-effects often happen 10–14 days after chemotherapy.

It is likely you will have some side-effects. These can include anaemia and an increased risk of infection. These may happen if the chemotherapy reduces your number of red or white blood cells. Your blood count will be checked regularly to help monitor your condition.

After each treatment, your blood count will return to normal. But sometimes this may take longer than expected. As a result, your next cycle of treatment may be delayed to allow your bone marrow to recover. The side-effects vary from person to person and depend on the type of drugs used and the amount of chemotherapy given. Most side-effects can be helped by medication, so tell your doctor or nurse if you are having any problems. Usually the side-effects go away when the treatment ends or soon after.

What are the side-effects of chemotherapy?

Anaemia

If the number of red blood cells in your blood is low (anaemia), you may become tired and weak. Because the amount of oxygen being carried around your body is less, you may also become breathless. You might also feel dizzy and light-headed and your muscles and joints can ache. Once the chemotherapy is over, the tiredness will ease off gradually. But you may still feel tired for a year or more afterwards. A blood transfusion can be given if your red blood cells are low. This will help you to feel more energetic and less breathless.

Bleeding and bruising

Bruising is caused by a reduced number of platelet cells in your blood. This is called thrombocytopenia. Platelets help to make your blood clot and stop bleeding when you hurt yourself. You may suffer from nosebleeds or bleed more heavily than usual from minor cuts or grazes. Bleeding may develop under your skin, usually as blood spots on your legs, feet, trunk and arms. This is known as petechiae.

Bleeding gums is also a common sign of low platelets. In women, periods can be heavier and longer than usual during the first few cycles. Do let your nurse or doctor know at once if you have any bleeding or bruising, including any unusual vaginal bleeding. You may need a platelet transfusion to help reduce it. Also, use a soft toothbrush such as a child's toothbrush, use an electric razor when shaving and wear rubber gloves when doing household or gardening jobs, to protect yourself from cuts.

Infection

AML can affect your white blood cells, which fight infections. Having a low level of white blood cells is called neutropenia and means that your body's immune system cannot fight infections properly. If you don't have enough white blood cells, even minor infections such as a cold or sore throat could make you ill.

If your temperature goes above 38°C (100.4°F) or below 35°C (95°F) at home, or if you suddenly feel shivery or unwell, contact your doctor or the hospital immediately.

You may need to be admitted to hospital to receive antibiotics into a vein. Check with your nurse about how to take your temperature and when you should contact them if you have a high temperature. Most haematology units have a direct phone number to call for advice if your temperature is high.

Some hospitals have slightly different temperature guidelines so check these with your haematology department.

Remember, contact your doctor or hospital without delay if you think you have an infection. Sepsis (blood poisoning) can develop as the body reacts to an infection. Severe sepsis can require intensive care treatment.

Hints and tips: Avoiding infection

- **Avoid crowds and close contact with people who have colds or flu and other infections.** This includes chickenpox, shingles or measles. Let your doctor know if you are in contact with these or any other infections.
- **Wash your hands often during the day and apply an alcohol hand gel,** especially before you eat and after going to the toilet.
- **Avoid unpasteurised milk, soft cheeses, undercooked meat and poultry, and the skin of raw vegetables and fresh fruit.**
- **If your temperature is 38°C (100.4°F) or above or below 35°C (95°F) or if you suddenly feel shivery or unwell, even if your temperature is normal, contact your doctor or the hospital immediately.**
- **Ask your doctor about getting vaccinations** to protect you from infection before and after treatment.
- **Ask your doctor about seeing a dentist** before treatment starts.

Other possible side-effects

Fatigue

Fatigue is very common. It can make you feel tired and weak. For more information, see page 85.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). There are treatments that work well to prevent nausea and vomiting. Tell your doctor or nurse if they are not working well for you. Thinking or talking about the treatment can also make you feel sick. This is called anticipatory nausea. Tell your doctor or nurse if you have these side-effects.

Loss of appetite

It if often hard to eat well due to the cancer and effects of treatment. But do try to eat as well as you can to keep your strength up. Eat smaller amounts more often. Getting some fresh air and exercise may help to boost your appetite. For more information, see our booklet ***Understanding diet and cancer***. Call our Support Line for a copy or download it from **www.cancer.ie**

Mouth and throat problems

Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you. You will also be told how to look after your mouth during treatment to try to prevent mouth problems.

Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss from all over your body. This can be very distressing. It can affect your confidence and make you feel self-conscious about your cancer. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back 3-6 months after you stop chemotherapy.

Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements). Your doctor can give you medication to help, if needed.

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

Skin and nail changes

Skin may become dry, flaky and itchy. Rash is a common side-effect of leukaemia treatment. Cytarabine can often cause an inflamed, itchy skin rash on the back, trunk, legs and arms. This can sometimes be accompanied by a high fever and conjunctivitis (red eyes). Nails may become dark, yellow or brittle.

Peripheral neuropathy

Some drugs can affect your nerve endings. This is known as peripheral neuropathy. It’s important to tell your doctor if you have numbness or a tingling or burning sensation in your hands and feet.

Changes in kidney or liver function

Some drugs can irritate or damage kidney cells. Decreased urination, swelling of the hands or feet (oedema) or headaches are some of the signs of kidney damage. Yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Tell your doctor if you have these or any other changes in your body. Blood tests will check your kidney and liver function regularly.

Infertility and birth defects

Some of the drugs used may cause infertility (see page 89). It may be temporary or permanent. Chemotherapy can cause birth defects, so you should use contraception to avoid pregnancy until your doctor tells you it's safe to stop. See page 88 for more information.

Secondary cancers

Chemotherapy and radiotherapy can increase the risk of another cancer in the future. The most common secondary cancers are skin and blood cancers. The risk of this may depend on the treatment you receive. For more information on this risk, speak to your medical team.

Blood clots

Chemotherapy, staying in hospital and central lines can increase your risk of developing a blood clot. You may need treatment with blood thinners. It is important to tell your medical team if you notice any new limb swelling, swelling in the arm where you have a PICC line or any unexplained chest pain or shortness of breath.

Report any side-effects

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. You will be given details of who to contact before you start your treatment.

Growth factors

To reduce the risk of infection, growth factors may be used. These drugs encourage the growth of white blood cells. They are helpful if the number of white cells is low after chemotherapy. The two most commonly used ones are called G-CSF and GM-CSF, which are given as injections under the skin. You may need daily injections after chemotherapy until your white blood cells return to a normal level. You may get some side-effects from the injections like bone or joint pain. Let your doctor know if you feel unwell or have any side-effects.

For more information on the side-effects of chemotherapy or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website, **www.cancer.ie**, for tips on coping with different side-effects or to watch our patient education videos on chemotherapy.

Targeted therapies

- Targeted therapies target certain parts of cancer cells that make them different from other cells.
- Side-effects depend on the drugs being used and vary from person to person.

Targeted therapies are drugs that target certain parts of cancer cells that make them different from other cells. In other words, they take advantage of differences between normal cells and cancer cells.

Different targeted therapies work in different ways. Targeted therapies can work to:

- Block or turn off chemical signals that tell the cancer cells to grow and divide
- Change proteins within the cancer cells so the cells die
- Stop new blood vessels growing to feed the cancer cells
- Carry toxins to the cancer cells to kill these cells

Some drugs are given in tablet form. Others are given into a vein through a drip.

New targeted therapies

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be offered a targeted therapy as part of a clinical trial (see page 81). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

What are the side-effects?

Side-effects depend on the drugs being used and vary from person to person. Common side-effects can include fatigue, nausea, vomiting, dizziness and diarrhoea.

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you don't feel well or if you have any symptoms that are troubling you.

For more information on targeted therapies and their side-effects or to get a copy of our booklet, ***Understanding chemotherapy and other drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also watch our patient information videos that explain different types of treatment on **www.cancer.ie**

Immunotherapy

Immunotherapy helps your immune system to work better to fight cancer cells.

Your immune system protects you against disease and infection. Sometimes cancer cells find a way of hiding from the immune system. This allows cancer to develop or spread.

Different immunotherapy treatments work in different ways. Some help the immune system to attack the cancer directly. Others boost the immune system in a more general way.

Side-effects of immunotherapy

Because immunotherapy acts on the immune system, it can cause inflammation of any part of your body, for example, your eyes, liver or skin.

Depending on the drugs used, side-effects can include:

- Diarrhoea
- Liver problems
- Fatigue
- Skin rash
- Shortness of breath

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. For more information or for a copy of the booklet, ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also watch our patient education videos that explain different types of treatment on **www.cancer.ie**

New developments

New immunotherapies are being developed all the time and existing therapies are being used in new ways. You may also be given an immunotherapy as part of a clinical trial (see page 81). Ask your doctor if there are any immunotherapies available to treat your cancer or if there are any trials that are suitable for you.

Stem cell transplants

Your doctor may recommend a transplant:

- As a first treatment for adverse- or intermediate-risk AML
- If your AML returns after treatment (recurrence)

Stem cell transplants may not be suitable for everyone. It depends on a number of things such as:

- Your age and general health
- Whether a suitable donor is available
- The type of AML you have and the risk of it coming back.

How do transplants work?

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 usually come from a donor. This is called an allogeneic transplant. Stem cells are usually taken from the donor's blood, but they may also be taken from bone marrow.

You can also have a transplant using your own cells, but this is rarely used for AML. This type of transplant is called an autologous transplant.

How is an allogeneic (donor) transplant done?

In an allogeneic transplant, a patient receives healthy stem cells taken from another person.

You and the donor will have a blood test to see if you have the same tissue type. This means finding out about a group of proteins on the surface of white cells called human leukocyte antigen (HLA), to see if you are HLA compatible. The donor can be your brother or sister, or even a person not related to you (matched unrelated donor or MUD).

Your own bone marrow is first destroyed with high doses of chemotherapy, with or without radiotherapy. Then the healthy marrow or stem cells from the donor are given to you through a central line (drip). The cells then grow over a few weeks to replace the bone marrow that was destroyed.

> In an allogeneic transplant, healthy stem cells are taken from a donor and given to you.

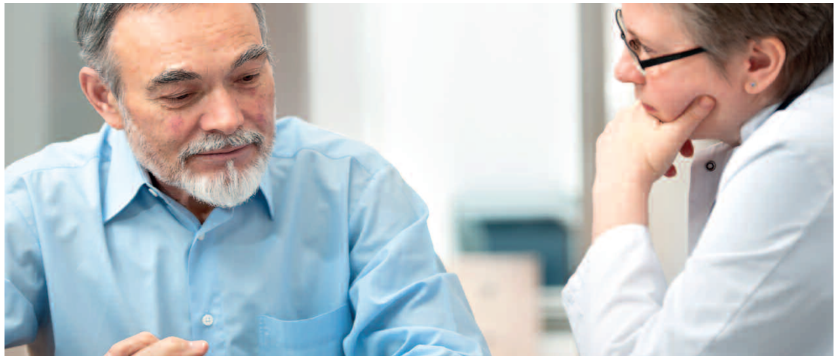
Stem cell transplants take place in special treatment units. You may spend up to 6 weeks in hospital. For 6-12 months after the transplant you may have to go to hospital very often, sometimes for a few days per week, for check-ups, antibiotics or blood transfusions. If your doctor thinks a transplant is suitable for you, they will discuss the treatment with you in detail. For more information or to order one of our booklets, ***Understanding allogenic stem cell transplants*** or ***Understanding autologous stem cell transplants***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Steroid therapy

Steroids are not part of the treatment of AML. However, people with acute leukaemia sometimes need steroids to treat the side-effects of chemotherapy. Steroids are usually given in tablet form but can also be given directly into your vein.

While receiving steroids, blood tests will be done regularly to check your blood sugar (glucose) levels. Tell your medical team if you are getting very thirsty or are passing more urine than usual. Blood sugar levels usually return to normal once treatment has stopped.

Rarely, steroids may cause episodes of extreme happiness, sadness and mood swings. Let your medical team know if this happens to you.



Hints and tips: Steroids

- Take steroids in the morning to try to avoid sleep problems.
- Take steroids with milk or food to prevent stomach upset.
- Talk to the hospital dietitian if you are putting on weight.
- Report any signs of infection to your medical team – a high temperature, cough, swelling or any inflammation.
- Take all tablets as instructed and don't stop taking steroids suddenly or without your doctor's advice.

Clinical trials

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

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

Because the drugs are still in trial, you'll be very closely monitored and may have extra tests and appointments.

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

More information

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

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

Managing side-effects and symptoms

How can I cope with fatigue?

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

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

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

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.
- **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 and drink plenty of fluids. Our booklet ***Understanding diet and cancer*** has tips to help.
- **Try to do some exercise** – ask your doctor for advice about the best exercise for you. They may also be able to recommend an exercise programme for you.
- **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 106).
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol 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. Have naps in the earlier part of the day.
- **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 call into 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 also be feeling tired from the effects of treatment and lose interest in sex as a result.

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

There is no set time for you to be ready to have sex again. It varies from person to person. But you may find it will be some time before you will feel well enough to have sex again after treatment.

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

For more information, see our booklet, ***Understanding sex, sexuality and cancer***. Call our Support Line to order a copy or download it from **www.cancer.ie**

Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. For example, 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. If you are of child-bearing age, you may be asked to have a pregnancy test prior to each cycle of 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.

It can sometimes happen that you are pregnant when diagnosed with AML. If you are pregnant, your haematologist will get the advice of your obstetrician as soon as possible. They will decide if and when it is safe for you to start treatment. You can also discuss what options are open to you at this time.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. They 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

Will treatment affect my fertility?

Some couples go on to have healthy babies after one or other partner has been treated for leukaemia. However, your fertility may be affected by some of the treatments, either temporarily or permanently.

Chemotherapy

Men and people assigned male at birth: Chemotherapy can cause infertility. It may be temporary or permanent. Even though doctors know that some chemotherapy drugs may cause infertility, it is very difficult to say if and when this will happen. You may be on treatment 2–3 months before your sperm count is reduced.

Women and people assigned female at birth: Some chemotherapy drugs can affect your ovaries. This means that your periods may stop during or for a few months after treatment. You may also be given medication to control your menstrual bleeding during treatment.

If your ovaries are affected, you may get hot flushes, a dry vagina or other symptoms of the menopause. If it is temporary, your periods may return to normal after a few months. This happens in about a third of those who have short-term infertility brought on by chemotherapy. In general, the younger you are, the more likely it is that your regular periods will return and that you will still be able to have children.

Stem cell transplants

If you have a stem cell transplant you are likely to be permanently infertile after treatment. Your doctor will talk to you about your options.

Discussing your options

Discuss any worries you have about infertility with your doctor before treatment starts. They will tell you if there are any options open to you.

You may want to have your eggs or sperm frozen for later use. However, treatment normally needs to start quickly with AML, so this may not be possible, especially for egg storage, which can take a few weeks.

Coping with infertility

Coping with infertility can bring feelings of sadness, anger and loss of identity. It can help to talk through your worries 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, yoga, acupuncture 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 illness 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 if you're using or considering using over-the-counter or herbal medications. 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**

Palliative care

Palliative care helps you to manage your symptoms and improve your quality of life. It also offers emotional support and comfort to patients and their families.

Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness.

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors.

Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer. You do not need health insurance. You can be given palliative care at home, in hospital or in a hospice.

For more information on palliative care, visit the Palliative Hub at **www.adultpalliativehub.com**. Talk to your doctor and nurse for more advice. If you do not feel well enough, your family can do so.

After treatment

What follow-up will I need?

After your cancer treatment has ended and you are in remission, you will still need to have regular check-ups. This is called follow-up. It is important for you to discuss any changes in your body or any new symptoms when you see the doctor. The doctor may order further tests. You will probably have more bone marrow tests to make sure you are still in remission.

At first, your follow-up visits will be quite often but these will become less frequent the longer you are well and free from disease. During the first year you may be checked every 1–2 months. After 5 years you will have yearly check-ups. Sometimes you may need to go to hospital if you get an infection, as your immune system takes time to recover. 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.

What if my AML comes back?

Sometimes the leukaemia cells return after being treated. This is called recurrence. With recurrence, the leukaemia cells can be found in either your blood, bone marrow, brain or spinal fluid. Recurrence can happen even after you respond well to treatment.

Sometimes, recurrence is detected at very low levels in your blood or bone marrow with MRD testing, before your blood count becomes abnormal.

Your cancer can recur:

- While receiving treatment or soon after finishing treatment
- Months or years after your treatment

While on treatment: The reason your cancer recurs while on treatment may be because the disease has become resistant to the drugs being used. This is known as primary refractory disease. In this case, other drugs that work well in leukaemia will be given to you. A stem cell transplant might also be considered as a treatment for some patients.

After treatment: It is not fully known why cancer recurs after finishing treatment. Recurrence can happen even after a good response to treatment. If your cancer does return, you might receive the same chemotherapy drugs you were first treated with, or a different treatment that may or may not include a stem cell transplant.

> Your doctor will advise you about the best course of treatment for you if your leukaemia comes back.

Living with AML

Be involved in your healthcare

- Learn about AML so you understand your treatment and know what to expect.
- Don't be afraid to ask questions. There are some questions you might like to ask on page 22.
- Keep all your appointments and take all your medications – ask your doctor or pharmacist if you have any questions about your medication.

- Let your doctor know straight away if you have any new symptoms or any symptoms that are bothering you.
- Don't feel like you have to wait until your next appointment if you have any health problems or worries.

Take care of your health

- You may still feel tired and lacking in energy for months after treatment. You may not feel ready to lead as active a life as you did before treatment. It is better not to fight these feelings but to allow your body the time it needs to recover.

- Take precautions to avoid infections. See page 71 for advice.
- Contact your doctor straight away if you have signs of infection, symptoms of AML (see page 14), or any other health problems.
- If you develop any problems such as bowel problems, you should contact your doctor as soon as possible.
- 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.
- Your skin will remain sensitive to the sun following chemotherapy and there can be an increased risk of developing skin cancer following treatment for AML. Wear protective clothing such as long sleeves and hats in the sun and always remember to wear sunscreen.
- Always tell doctors, dentists and other healthcare professionals that you have AML. If your white cell count or platelets are low it can increase your risk of bleeding or infection, so some procedures or treatments may not be suitable.

Vaccinations

It's important to have any vaccines recommended for you. For example, flu and pneumonia. You will probably be advised to get the flu vaccine every year and the pneumonia vaccine every 5 years. Leukaemia can weaken your immune system, so some vaccinations may not be suitable for you. Check with your doctor about which vaccinations are recommended for you and make sure you get them.

Work and activities

Once you are on treatment and start to feel well, you should talk to your doctor about returning to work or study and carrying on with your usual activities like socialising, sports and hobbies. If you stopped working during treatment, you might want to take your return to work slowly, by working part-time or reduced hours.

Living a healthy lifestyle

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

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

Holidays and insurance

You may decide to go on a holiday once your AML is under control.

If you are planning a holiday, ask your doctor about any special precautions you need to take or vaccinations you should have before you go. It’s best to have travel insurance too. We have information on travel insurance on our website, **www.cancer.ie**

You can also contact our Support Line on 1800 200 700 or visit a Daffodil Centre for more details.

Planning ahead

Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead is useful for everyone, whether they have an illness or not.

Planning ahead might include:

- Thinking about how you feel about different types of medical treatment, including if you want to stop treatment at any stage or carry on for as long as possible.
- Writing an advance care directive. This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- Picking someone to make medical decisions for you if you are not well enough.
- Making a will.
- Sorting out financial affairs.
- Talking about what you want to your family, friends, carers and healthcare providers.

Who can help me plan?

Think Ahead is a planning pack with different sections and easy-to-read forms. You can fill in your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at **www.hospicefoundation.ie**

Coping and emotions

How can I cope with my feelings?

There are many different reactions to getting a cancer diagnosis. There is no right or wrong way to feel and there is no set time to have any particular emotion. 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.

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

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.

> 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.

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.

The Irish Cancer Society funds professional one-to-one counselling through many local cancer support centres. To find out more about counselling, call our Support Line on Freephone 1800 200 700, email the nurses at supportline@irishcancer.ie or visit a Daffodil Centre.

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

Ways to get emotional support

Find out about 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 130 for more about cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people who are 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 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. Visit **www.cancer.ie/community** to join the Irish Cancer Society online community.

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

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

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

Peer Support

Peer Support is the Irish Cancer Society's 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 1800 200 700 or contact your nearest Daffodil Centre.

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

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 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.

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 to you find ways to talk about your cancer and to ask for the help and support you need.

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 do certain things or 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.

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.

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 them, 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 drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. The Irish Cancer Society funds free one-to-one counselling for family members and friends remotely and through many local cancer support centres. Talk to your GP or see page 106.

Find out about support for carers

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

> "The emotional support I got made a huge difference to me."

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**

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 has a section 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 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.

Irish Cancer Society Welfare and Supports Team

We provide appropriate supports and advice for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis/returning to work**
- **Housing and homelessness issues**

We can tell you about the public services, community supports and legal entitlements that might help you and your family.

We can also act as advocates for patients and their families who may need extra support after a diagnosis. This might include having an Irish Cancer Society Welfare Officer present when discussing your diagnosis with your employer or at meetings with your financial provider to help them understand your diagnosis.

To be referred, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre. Our nurses will chat with you and confirm if a discussion with one of our Welfare Officers or other supports might help you.

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

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

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

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

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

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

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

Benefits and allowances

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

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

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0818 074 000
- Department of Employment Affairs and 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 photocopy completed forms before posting them.

If you have money problems

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

Call the MABS Helpline 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 127 for more details of our Volunteer Driver Service and the Travel2Care fund.

You can also call our Support Line 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 **Managing money** 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 Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Irish Cancer Society services

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

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Support in your area
- Transport Service
- Night Nursing
- Publications and website information
- Welfare and Supports Team (see page 120)

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am-5pm.

The Support Line service also offers video calls for those who want a face-to-face chat with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.

Our cancer nurses are available Monday to Friday to take video calls on the Microsoft Teams platform. To avail of this service, please go to **https://www.cancer.ie/Support-Line-Video-Form**

You can also email us at any time on supportline@irishcancer.ie or visit our Online Community at **www.cancer.ie**

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide face-to-face advice, support and information to anyone affected by cancer. The service is free and confidential.

This is a walk-in service; you do not need an appointment. For opening hours and contact details of your nearest Daffodil Centre, go to **www.cancer.ie** and search 'Daffodil Centres'.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone. Just call in if you want to talk or need information on any aspect of cancer including:

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

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Support Line and Daffodil Centre nurses in your own language through our Telephone Interpreting Service.

If you would like to speak to us using the Telephone Interpreting Service, call our Support Line on Freephone 1800 200 700, Monday to Friday 9am-5pm, or contact your nearest Daffodil Centre.

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.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers 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.

For more information on Peer Support, search 'peer support' at **www.cancer.ie**

Patient Education

At our free patient education workshops, our cancer nurses provide tailored information before and after cancer treatment.

The workshops take place in person in one of our 13 Daffodil Centres nationwide, or online. To register for a place at one of our patient education workshops, call our Support Line on 1800 200 700, contact your nearest Daffodil Centre or email patienteducation@irishcancer.ie

Counselling

The Society funds professional one-to-one counselling for those who have been affected by a cancer diagnosis. Counselling is available for the person who has been diagnosed, family members and close friends. The services we provide are:

- Remote counselling nationwide, by telephone or video call.
- In-person counselling sessions in cancer support centres around the country.

For more information, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them.

For more information about what's available near you, visit **www.cancer.ie/local-support**, contact your nearest Daffodil Centre or call our Support Line on 1800 200 700.

Transport Service

We provide patient travel and financial grants for patients in need who are in cancer treatment.

- The Irish Cancer Society Volunteer Driver Service is available mainly to patients undergoing 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 radiotherapy patients attending University Hospital Cork and the Bon Secours Hospital, Cork for treatment.
- **Travel2Care** is a fund for patients who are having difficulty getting to and from their diagnostic test appointments or cancer treatments. Patients can apply for the fund if they are travelling over 50km one way to a national designated cancer centre or approved satellite centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these services please contact your hospital healthcare professional, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Night Nursing

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

For more information, please contact the healthcare professional who is looking after your loved one.

> “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.”

Email: supportline@irishcancer.ie

Publications and website information

We provide information on a range of topics including cancer types, treatments and 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 Freephone our Support Line or call into your nearest Daffodil Centre for a free copy of any of our publications.Local cancer support services

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

- **Visit us at www.cancer.ie**
- **Call our Support Line on Freephone 1800 200 700**
- **Email our Support Line at supportline@irishcancer.ie**
- **Contact your nearest Daffodil Centre**
- **Follow us on:**
  - **Facebook**
  - **X**
  - **Instagram**
  - **LinkedIn**

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients, 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.

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie** and search 'Find support'.

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

What does that word mean?

Allogeneic The use of another person's tissue. For example, when healthy stem cells are taken from another person for a transplant.

Alopecia Loss of hair. No hair where you normally have hair.

Anaemia When there are fewer red blood cells in your blood. This can cause tiredness and shortness of breath.

Autologous The use of a person's own tissue. For example, when cells are taken from your bone marrow or blood.

Biopsy Removing a small amount of tissue from your body and looking at it under a microscope to see if leukaemia cells are present.

Blast cell Immature myeloid cells that fill up your bone marrow and prevent normal blood cells from being made.

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

Bone marrow aspirate When a sample of bone marrow cells or bone aspirate or biopsy 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.

Chemotherapy Treatment that uses 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 leukaemia cells.

Growth factors Medicines that help increase the number of red cells, white cells or platelets in your blood.

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

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

Intravenous Into a vein.

Leukaemia Cancer of the white blood cells and blood marrow.

Lymphocytes A type of white blood cell that helps fight infection.

Neutropenia Fewer white blood cells called neutrophils in your body. As a result, you develop infections easily.

Neutrophils Important white blood cells that fight infection.

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

Platelets Blood cells responsible for clotting.

Prognosis The likely outcome or course of a disease.

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

Relapse When the leukaemia returns after treatment.

Remission When there are no signs of leukaemia in your blood and bone marrow.

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

Thrombocytopaenia When there are fewer platelets in your blood. This can cause you to bleed and bruise easily.

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

Notes/Questions

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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 especially thank the people who generously shared their personal experiences of cancer throughout this booklet. We also acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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First published by the Irish Cancer Society in 2003.

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 Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

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

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

Raise money

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

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

Did you like this booklet?

We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre

Irish Cancer Society

www.cancer.ie