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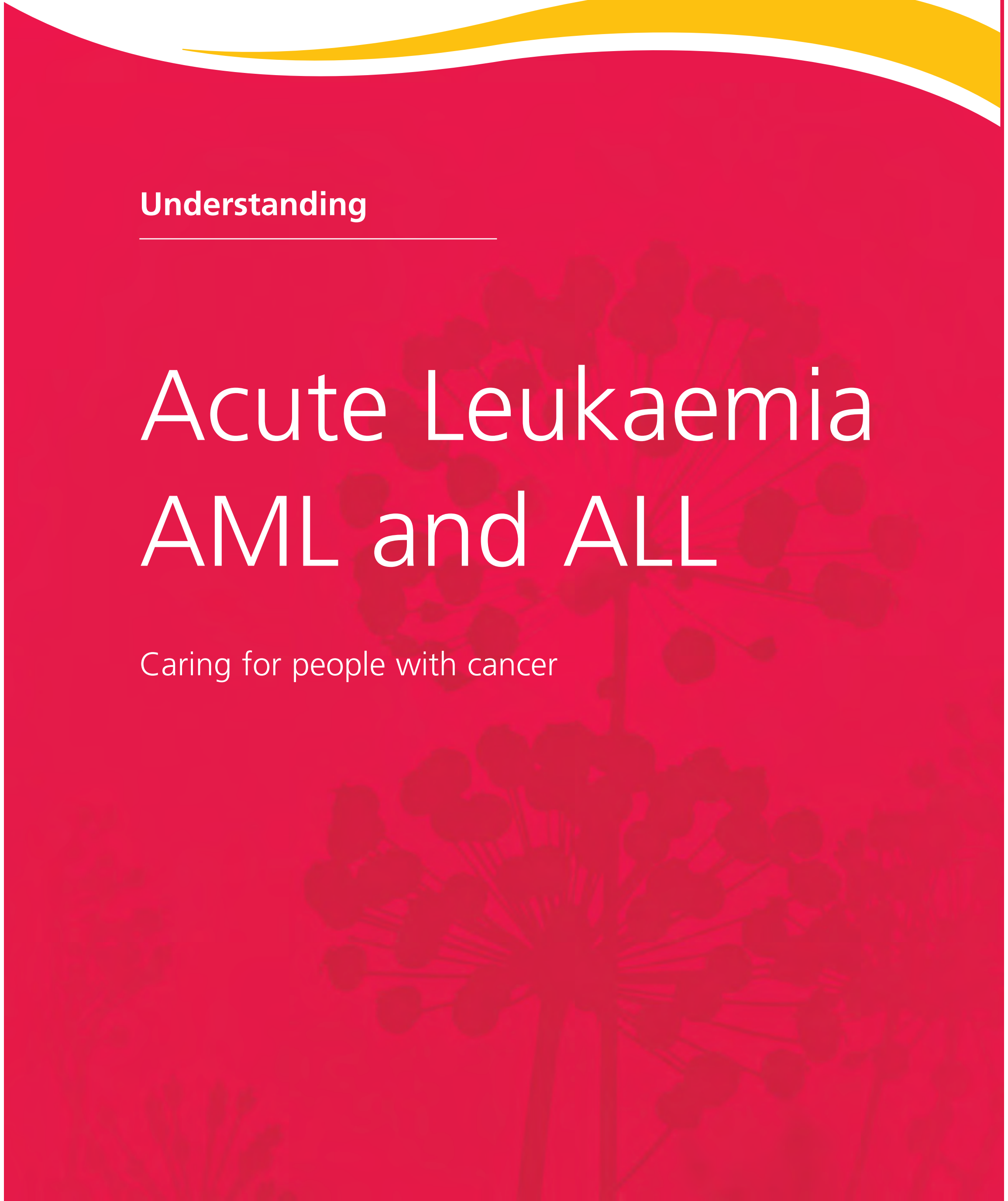

Understanding

Acute Leukaemia AML and ALL

Caring for people with cancer

Understanding

Acute Leukaemia

This booklet has been written to help you understand more about acute myeloid leukaemia (AML) and acute lymphoblastic leukaemia (ALL) in adults. It has been prepared and checked by haematologists, cancer doctors, nurses and patients. The information is an agreed view on these diseases, their treatment and how you may be affected.

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

	Name	Telephone
Specialist nurse		
Family doctor (GP)		
Haematologist		
Medical oncologist		
Radiation oncologist		
Medical social worker		
Hospital day ward		
Emergency number		

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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- *Cancer in Ireland 2013.* National Cancer Registry Ireland, 2013.
- *Guidelines on the Management of Acute Myeloid Leukaemia in Adults.* British Committee for Standards in Haematology, British Society for Haematology, 2006.
- Acute myeloblastic leukaemias in adult patients: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. ESMO Guidelines Working Group. *Annals of Oncology* 24 (suppl 6): vi138-vi143, 2013.
- *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology.* R Govindan (ed), 9th edn. Lippincott Williams and Wilkins, 2011.
- *Cancer Nursing: Principles and Practice.* CH Yarbro, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 2000.
- *The Chemotherapy Source Book.* M Perry. Lippincott Williams and Wilkins, 1997.

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Quick facts

Can AML and ALL be treated?

Page 35 ⏩

Yes. Treatment for acute leukaemia aims to destroy the leukaemia cells and allow the bone marrow to work normally again. This is called remission. Some people stay in remission and the person is said to be cured. Treatment starts as soon as possible, as AML and ALL are fast-growing cancers. **See page 15 for AML treatment and page 23 for ALL.**

What treatment am I likely to have?

Page 41 ⏩

Depending on your age and general health you may have intensive chemotherapy, other drugs and maybe a stem-cell transplant to put the disease into remission. You will normally stay in hospital for part of your treatment. 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.

You will also have supportive care to help you with any side-effects of your illness and treatment.

Will I be OK?

Page 34 ⏩

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

Are there side-effects from treatment?

Page 41 ⏩

All treatments, particularly intensive chemotherapy, can cause side-effects, but these are usually temporary. Read about the treatments to learn more about their side-effects.

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

Clinical trials

Page 55 ⏩

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

We're here for you

Page 84 ⏩

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

Ways to get in touch

- Call our Cancer Nurseline on 1800 200 700
- Drop into a Daffodil Centre
- Email us: cancernurseline@irishcancer.ie

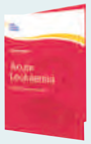
See page 84 for more about our services.

Introduction

This booklet has been written to help you understand more about acute myeloid leukaemia (AML) and acute lymphoblastic leukaemia (ALL) in adults.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care. The best choice for you will depend on your particular cancer and your individual circumstances.

Reading this booklet



Remember you do not need to know everything about your illness straight away. Read a section that you are interested in. Then read another section when you want to know more.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie. You can also visit a Daffodil Centre. See page 84 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.

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What is leukaemia?

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

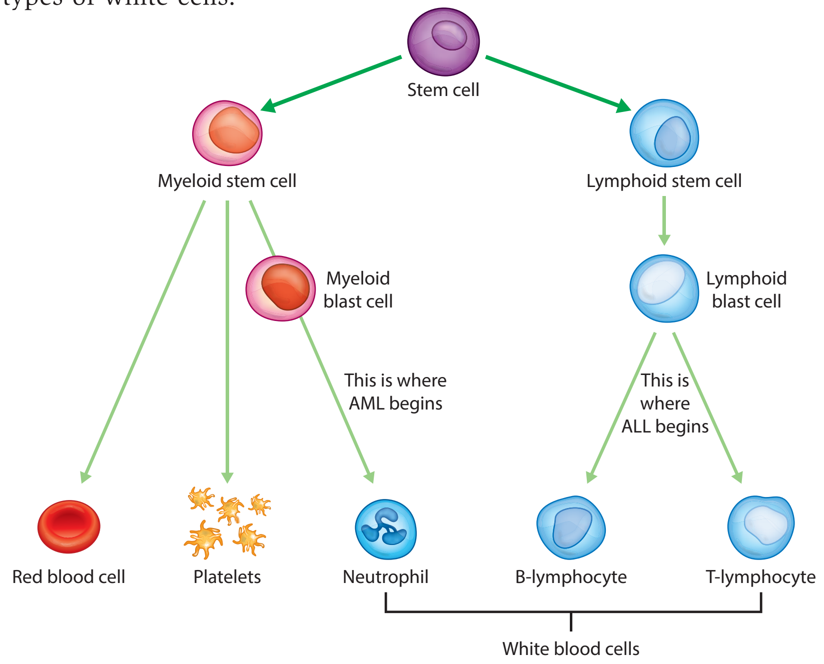
Blood cells

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.
- **Platelets** are involved in blood clotting.

New 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 a cell known as a stem cell. Stem cells then 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 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 four main types of leukaemia.

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

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 'chronic' and 'acute' mean?

'Chronic' and 'acute' refer to how quickly leukaemia develops.

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

Acute: The leukaemia develops very quickly over days and weeks.

Each type of leukaemia has its own features and treatment. This booklet is about the acute leukaemias – AML and ALL. For free booklets on the other types of leukaemia, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

To sum up

- All your blood cells are made in your bone marrow.
- Leukaemia is a cancer of your white blood cells, which protect you from infection.
- Myeloid cells are blast (immature) cells that develop into white blood cells, red blood cells and platelets.
- Lymphoid cells are blast (immature) cells that develop into white blood cells (T-cells and B-cells).
- When the blast cells in your bone marrow do not mature, they cannot make normal blood cells. This can lead to infection, bleeding and anaemia.
- Acute leukaemia develops very quickly over days and weeks.

About acute myeloid leukaemia (AML)

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What is AML?

AML is an acute (fast-growing) blood cancer, which affects the myeloid cells. With AML, immature myeloid cells called blast cells fill up your bone marrow and stop you making enough normal blood cells.

What are the symptoms of AML?

Many of the symptoms of AML are caused because the cancer cells affect your normal blood cell production.

AML has a number of different symptoms. Each patient is different so you may not have all or any of the symptoms listed below. Symptoms of AML include:

- High temperatures or fevers, repeated infections – Caused by fewer white blood cells
- Tiredness (fatigue), shortness of breath and weakness – Caused by fewer red blood cells (anaemia)
- Bleeding in your urine, gums or stools (poo), unexplained bruising, tiny red spots on your skin, swollen gums – Caused by fewer platelets
- Aching bones and joints – Caused by too many abnormal cells in your bone marrow
- Loss of appetite
- Weight loss

Symptoms of AML can be vague at first and appear like flu. Sometimes you can have no symptoms and the disease is picked up during a routine blood test.

>>> If you have symptoms that are troubling you, or new symptoms appear, tell your doctor.

How common is AML?

AML is a rare disease. Fewer than 200 people are diagnosed with it in Ireland each year. It is more common in older people.

What increases my risk of AML?

The exact cause of AML is unknown. But there are certain things called risk factors that can increase your chance of getting the disease:

- **Age:** AML occurs mainly in people over the age of 65.
- **Gender:** It is slightly more common in men than women.
- **Smoking:** Chemicals in cigarettes can increase your risk.
- **Radiation:** Exposure to high doses of radiation like in nuclear accidents can increase your risk. Hardly anyone is exposed to these levels of radiation in everyday life.
- **Exposure to gases and chemicals:** Benzene and other chemicals found in industry can increase your risk of AML.
- **Previous cancer treatments:** Certain types of chemotherapy and radiotherapy which are used to treat other cancers can lead to an increased risk of AML
- **Genetic disorders:** E.g. Down syndrome and Fanconi anaemia.
- **Blood disorders that affect the production of myeloid cells:** These include myelodysplastic syndromes (MDS) and myeloproliferative neoplasm (MPN).

Having a risk factor doesn't mean you will definitely get cancer. Sometimes people without any known risk factors develop cancer. AML doesn't normally run in families. AML is not infectious and cannot be passed on to other people.

What are the types of AML?

The information from your tests (see page 29) will help to determine the exact type of AML you have. There is a classification system used by doctors which was created by the World Health Organisation (WHO). This divides AML into different groups based on which cells have become abnormal and if the person has had previous chemotherapy or a blood disorder.

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

Low-risk and high-risk leukaemia

Your doctors may say that your leukaemia is ‘low risk’, ‘intermediate risk’ or ‘high risk’, based on the information they get from the tests you will have (see page 29). This is called ‘risk grouping’ (or ‘risk stratification’). Your risk may change during your treatment.

Low risk: Your leukaemia is likely to be cured and there’s less chance of the cancer coming back (relapse). Low-risk patients won’t usually need a stem cell transplant, unless they do relapse.

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

High risk: There’s a high risk of the leukaemia coming back (relapse) so you will have very intensive treatment. You are likely to have a stem cell transplant if you are suitable for one.

Acute promyelocytic leukaemia (APL)

Acute promyelocytic leukaemia (APL) is a sub-type of AML. APL is treated differently to other forms of AML, as it responds well to certain non-chemotherapy drugs, for example, all-trans retinoic acid (ATRA). APL is usually treated with a combination of drugs, which may include chemotherapy drugs. Call 1800 200 700 for more information or visit a Daffodil Centre.

To sum up

- AML is a cancer of the immature myeloid cells.
- There are many types of AML.
- Your AML may be low risk, intermediate risk or high risk. Your risk grouping will help doctors to decide on the best treatment for you.

How is AML treated?

Chemotherapy

Although each patient is treated on an individual basis, intensive chemotherapy treatment is usually appropriate if you’re under 65-70 years of age and have good medical fitness.

Chemotherapy drugs are 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.

Remission is when your bone marrow is producing blood cells normally and you have fewer than 5% of the immature leukaemia cells in your bone marrow. If your remission lasts indefinitely, you are said to be cured.

What are the stages of chemotherapy treatment for AML?
For AML chemotherapy is given in 2 stages:

1. **Induction:** The first step in your leukaemia treatment is an intense dosing of chemotherapy, which aims to get rid of all the leukaemia from your blood and bone marrow and quickly get your bone marrow working normally again (remission). This stage is called induction chemotherapy or remission induction.

   Induction usually involves two cycles of a combination of chemotherapy drugs. When the induction is over, a bone marrow test will be done to check if the leukaemia has gone into remission.

2. **Consolidation:** Once you have finished induction and you are in remission, you will start consolidation therapy.

   The aim of this phase is to reduce the risk of relapse. During consolidation you will usually have another two cycles of chemotherapy. Without these, there is a higher risk of your leukaemia coming back in the first year. You might also have a stem cell transplant (see page 53). If you do have a transplant, you might not have any further chemotherapy, or you might just have one more course.

How long does AML chemotherapy treatment last?
Intensive chemotherapy usually involves 3 or 4 courses or blocks 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. 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.

> ››› For AML there are 2 stages of chemotherapy treatment: induction and consolidation. Chemotherapy treatment usually starts as soon as possible.

For more information on chemotherapy, see pages 42–50.

Non intensive treatment
Non-intensive treatment involves low doses of chemotherapy or other drug treatments, for example, targeted therapies (see page 52). 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 older or have other medical problems. Azacitidine (Vidaza®) is an example of a drug used for non-intensive treatment.

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.

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 53 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet, *Understanding Radiotherapy*, or download one from **www.cancer.ie**

Supportive care

Supportive care means extra treatment that is given to help with the symptoms of your leukaemia or the side-effects of treatment. See page 56 for more information.

To sum up

- Most patients with AML with have chemotherapy treatment.
- For AML chemotherapy is usually given in 2 stages: Induction and consolidation.
- Patients who are not fit enough for intensive chemotherapy may have less intensive drug treatment to keep the cancer under control.
- Some patients may be suitable for a stem cell transplant.

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What are the types of ALL? 22

How is ALL treated? 23

What is acute lymphoblastic leukaemia (ALL)?

ALL is a fast-growing (acute) blood cancer, which affects the lymphoid blast cells (lymphoblasts). These are immature cells that give rise to lymphocyte white blood cells. Lymphocytes fight infection. There are 2 types of lymphocytes, which fight infection in different ways: T cells and B cells.

With ALL, immature lymphocytes called blast cells fill up your bone marrow and stop you making enough normal blood cells.

What are the symptoms of ALL?

Many of the symptoms of ALL are caused because the cancer cells affect your normal blood cell production.

ALL has a number of different symptoms. Each patient is different so you may not have all or any of the symptoms listed below. Symptoms of ALL include:

- High temperatures or fevers, repeated infections – caused by fewer white blood cells
- Tiredness (fatigue), shortness of breath and weakness – caused by fewer red blood cells (anaemia)
- Bleeding in your urine, gums or stools (poo), unexplained bruising, tiny red spots on your skin, swollen gums – caused by fewer platelets
- Aching bones and joints – caused by too many abnormal cells in your bone marrow
- Enlarged glands, for example in your armpit, groin or neck
- Enlarged spleen or liver
- Loss of appetite
- Weight loss

Symptoms of ALL can be vague at first and appear like flu. Sometimes you can have no symptoms and the disease is picked up during a routine blood test.

>>> If you have symptoms that are troubling you, or new symptoms appear, tell your doctor.

How common is ALL?

ALL is a rare disease. Fewer than 100 people are diagnosed with it in Ireland each year. It is more common in children and young people under 25 and people over 70 than in other adults.

What increases my risk of ALL?

The exact cause of ALL is unknown. But there are certain things called risk factors that can increase your chance of getting the disease:

- **Age:** ALL occurs mainly in children, people aged 15-25 and people over the age of 70.
- **Gender:** It is slightly more common in men than women.
- **Smoking:** Chemicals in cigarettes can increase your risk.
- **Radiation:** Exposure to high doses of radiation like in nuclear accidents can increase your risk. Hardly anyone is exposed to these levels of radiation in everyday life.
- **Exposure to gases and chemicals:** Benzene and other chemicals found in industry can increase your risk of ALL.
- **Previous cancer treatments:** Certain types of chemotherapy and radiotherapy which are used to treat other cancers can lead to an increased risk of ALL
- **Genetic disorders:** E.g. Down syndrome and Fanconi anaemia.
- **Infection:** Some types of infection may lead to ALL. For example, Epstein-Barr virus.

Having a risk factor doesn't mean you will definitely get cancer. Sometimes people without any known risk factors develop cancer. ALL doesn't normally run in families. ALL is not infectious and cannot be passed on to other people.

What are the types of ALL?

There are various different types of ALL. Cytogenetic and immunophenotyping tests (see page 31) can show which type you have. Different types respond better to different types of treatment, so knowing the type of ALL can help your doctor to plan the best treatment for you.

ALL affects immature lymphocyte cells. There are 2 types of lymphocytes: B-cells and T-cells.

B-cell ALL affects B-cell lymphocytes. This is the most common type of ALL.

T-cell ALL affects T-cell lymphocytes

ALL and the Philadelphia chromosome

Sometimes in ALL, part of one chromosome is moved to another chromosome, and a new one is formed. This is called the Philadelphia chromosome. This type of ALL is called **Philadelphia positive ALL**.

The Philadelphia chromosome makes a protein that in turn causes an enzyme called tyrosine kinase to make more leukaemia cells in your bone marrow. These chromosome changes occur when the disease develops and are not passed on through your family. They won't affect your children.

If chromosome tests show that you have the Philadelphia chromosome, you can have a treatment that aims block the action of the tyrosine kinase enzyme. Your medical team will talk to you about this if you have Philadelphia positive ALL (see page 52).

To sum up

- ALL is a cancer of the immature lymphoid blast cells (lymphoblasts).
- There are many types of ALL.

How is ALL treated?

Chemotherapy

Although each patient is treated on an individual basis, intensive chemotherapy treatment is normally appropriate if you're under 65-70 years of age and have good medical fitness.

Chemotherapy drugs are 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. With ALL, chemotherapy treatment usually starts as soon as possible.

What are the stages of chemotherapy treatment for ALL?
There are 3 main stages of chemotherapy for ALL:

1 Induction

The first phase of treatment for ALL is intensive chemotherapy using a combination of several different drugs, which aims to clear all the cancer cells from your blood and bone marrow (remission). This stage is called induction chemotherapy or remission induction.

Remission is when your bone marrow is producing blood cells normally and you have fewer than 5% of the immature leukaemia cells in your bone marrow.

Induction usually involves 2 cycles of chemotherapy treatment. During this phase, chemotherapy may be given into your spinal cord as well. This is called intrathecal therapy. See page 44 for more details.

The induction stage can last several weeks. Once your blood counts have recovered well enough, a bone marrow biopsy will be repeated. This can check how well your bone marrow is responding to the treatment and if remission has happened.

Minimal residue disease tests

Minimal residue disease means there are very few abnormal cells remaining in your body. Minimal residual disease (MRD) tests are very sensitive blood or bone marrow tests that can detect the number of leukaemia cells very precisely, even at very low levels. MRD tests are often used to test if your leukaemia is in remission.

2 Intensification

Once remission occurs, more courses of chemotherapy are usually given with a different combination of drugs. This is to clear any remaining leukaemia cells. The intensification phase may last several months. You will still need to stay in hospital during treatment, but you will probably have longer periods at home while your blood counts are good.

You will have to visit the outpatients department regularly to have your blood counts checked and be monitored for side-effects. If you have an infection or become ill at any stage, you will need to be admitted to hospital. During this time tests may be done to find a suitable stem cell donor, if your doctor thinks you will benefit from a stem cell transplant.

3 Maintenance

The third phase of treatment is called maintenance. The aim of this phase is to prevent relapse and usually involves low doses of chemotherapy and steroids.

This is far less intensive than the previous phases and treatment is given over a longer period of time. The chemotherapy drugs are often given in tablet form but you may have infusions into your veins. You will have a lumbar puncture every 3 months to check your response to treatment.

This stage of treatment typically lasts from 18 months to three years depending on whether you are female or male (treatment for females is generally shorter). You will be treated as an outpatient and see your doctor or nurse regularly in the hospital. It is unlikely that you will be have to stay overnight in hospital unless you get a relapse or develop an infection.

You may be able to go back to work and normal activities during the maintenance stage. Your specialist nurse and doctor will be able to advise you about what is safe for you.

How long does ALL chemotherapy treatment last?

Depending on how well you respond to treatment and your age and gender, the total length of time for all treatments can be up to 2 or 3 years if you do not need a transplant. In general, you will only need to spend long periods of time in hospital during the first two phases.

For ALL there are 3 stages of chemotherapy: induction, intensification and maintenance.

For more information on chemotherapy, see pages 42–50.

Steroid therapy

Steroids may also be given with chemotherapy and for some time afterwards. Not only do they help to kill the leukaemia cells along with chemotherapy, they can also help to improve symptoms such as fatigue or nausea. See page 51 for more about steroids.

Targeted therapies

Sometimes targeted therapies are given to treat ALL. If you are positive for the Philadelphia chromosome (see page 22), you may be suitable for a type of targeted therapy drug known as a tyrosine kinase inhibitor. It can be used together with chemotherapy or given later if your ALL is no longer responding to chemotherapy. See page 52 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. This will reduce the chance of ALL coming back.

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 53 for more about transplants.

Radiotherapy

Radiotherapy is rarely used with ALL. 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet, *Understanding Radiotherapy*, or download one from **www.cancer.ie**

Supportive care

Supportive care means extra treatment that is given to help with the symptoms of your leukaemia or the side-effects of treatment. See page 56 for more information.

To sum up

- Most patients with ALL with have chemotherapy treatment.
- For ALL chemotherapy is often given in 3 stages: Induction, intensification and maintenance.
- Steroids or targeted therapies may also be given.
- Some patients may be suitable for a stem cell transplant.

Diagnosis and tests

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Being diagnosed with acute leukaemia

Hearing the words ‘leukaemia’ and ‘cancer’ can be a huge shock.
You may be feeling:

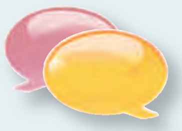
- Upset and overwhelmed by your emotions
- Confused by all the information being given to you
- Worried about what will happen next
- Scared about the future

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

- Ask to speak to the medical social worker or cancer liaison nurse 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 – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at cancernurseline@irishcancer.ie
- Talk to other people going through the same thing. Join our online community at **www.cancer.ie/community**

We hope this booklet will help you too. It has information on what to expect when you have been diagnosed with cancer. It also has tips on how to cope – practically, emotionally and financially. More helpful information is available on our website **www.cancer.ie**

Telling people about your diagnosis



It can be hard to tell other people the news that you have been diagnosed with cancer.

You may want to talk about your diagnosis, or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other people’s reactions when they hear the news. For example, they may fuss over you or be upset.

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet *Who Can Ever Understand?* This booklet 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?

You will have tests to give your healthcare team more information about:

- Your type of leukaemia
- How it might affect you
- How best to treat you

Some of the tests can be used to measure your response 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.

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/l (0-1% of WBC)
Platelets	150-400 x 10^9/l

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.

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 43 for more.

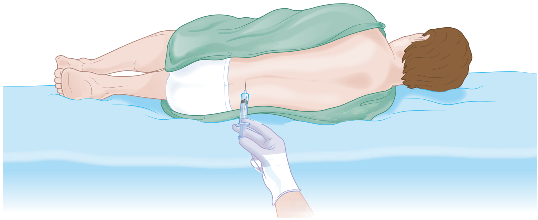
Bone marrow tests: These tests involve taking a tiny sample of your bone and bone marrow and looking at them under a microscope. The sample is taken from the inside of your bone, usually the hipbone. When a sample of bone marrow cells is taken, it is called an aspirate. When a tiny piece of bone or solid marrow is taken, it is a trephine biopsy. Both can be done at the same time.

This test gives your doctors more information about the structure of your bone marrow, the types of cells in your bone marrow and the number of cells in your bone marrow (too many or too few). A bone marrow test is very useful at this point because it can be used to compare your blood cells after treatment to see how well you have responded.

Before the test you will be given a local anaesthetic to numb the area. You will be asked to lie on your side with your knees tucked up to your chest. You will be helped to get into the right position for the doctors to get the best sample. A needle is passed through your skin into your bone marrow. A tiny sample of the bone and bone marrow is then taken. You will feel some discomfort during the test but it usually takes just 20–30 minutes to do.

You may be asked to lie on your back for 10–15 minutes to stop any possible bleeding. A small plaster is put on the area, which might feel tender and sore for a few days afterwards. You can take a mild painkiller for a day or two if needed.

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 (CSF). The fluid will be checked for leukaemia cells. Not every person will need this test. Your doctor will talk to you if you need it.



Specific tests on bone marrow

Chromosomes studies (cytogenetics): 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 either your blood and/or bone marrow samples. These chromosomes are then compared to normal cells. With AML and ALL, 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. For example, with ALL sometimes there is an abnormal chromosome called the Philadelphia chromosome (see page 22). It is important to note that these gene changes / faults are not the same as genes passed through families. The changes are only on your leukaemia cells.

Fish analysis: A test called FISH analysis (fluorescence in situ hybridisation) makes abnormal genes glow (fluoresce) so that the doctor can identify the particular type of genetic abnormality. A FISH test can help your doctor to predict how your leukaemia might respond to a particular treatment, so he or she can recommend the best option for you.

Immunophenotyping: Immunophenotyping is a test that checks what kind of proteins or markers are on the surface of the leukaemia cells. Immunophenotyping can be used to diagnose what type of AML or ALL you have. For example, it can tell if the B-cells or T-cells are causing the problem with ALL. The result can affect what type of treatment you have.

Flow cytometry: Flow cytometry measures the number and percentage of cells in a blood sample and cell characteristics such as size, shape and the presence of biomarkers on the cell surface. Cells, usually from the bone marrow or blood, are passed through a machine called a flow cytometer. This method can be used for immunophenotyping or to check how you are responding to treatment.

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, can cause blood-clotting problems. Your doctor may decide to do a test to check how well your blood clots.

Chest X-ray: X-rays use high-energy rays to take pictures of the inside of your body to check your general health.

CT scan: This is a special type of X-ray that gives a detailed picture of the tissues inside your body. This test can help show if any lymph nodes or organs in your body are affected by the leukaemia.

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 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. Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary. The doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.

MRI scan: This is a scan that uses magnetic energy to build up a picture of the tissues inside your body, to show up any abnormal changes.

During the test you will lie inside a tunnel-like machine. Some people are afraid they may feel claustrophobic during the MRI scan. If you are anxious, contact the radiographer the day before. They may be able to give you medication to relax you on the day. An MRI can also be noisy, but you will be given earplugs to wear during it. You might get an injection before the scan to show up certain parts of your body. During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

PET scan: A PET scan looks at levels of activity in your cells to find out more about your cancer and to monitor treatment effects. A low dose of radioactive sugar is injected to your veins. This sugar can highlight where the cancer cells are. A little while after the injection you will have a scan.

During the scan you will lie on a table which moves through a scanning ring. You will be given instructions to follow before your scan like don't eat or drink and avoid sugar and caffeine. This will be given to you in detail in the hospital.

Waiting for results

It may take some time for all the test results to come back. Treatment may start while you are waiting for some test results.

If you are feeling anxious about your test results or starting treatment, it may help to talk things over with the specialist nurse or with a relative or close friend. You can also talk to one of our cancer nurses. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse in confidence.

To sum up

- Tests you may have after diagnosis include:
  - Blood tests
  - Bone marrow tests
  - Genetic tests
  - Scans
- These tests help your doctor to learn more about your cancer so that they can recommend the best treatment for you.

Asking about your prognosis

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

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

Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** He or she knows your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Avoid looking online.** It can be hard to understand the information you find online without an expert like a doctor to help. The information may not really apply to your situation or to your particular cancer type.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn’t understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie. 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

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How are acute leukaemias treated?

Because AML and ALL are fast-growing cancers, treatment will start soon after you have been diagnosed. 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 leukaemia will return (relapse) following standard treatment
- Your age and general health

>>> See page 15 for more about treating AML and page 23 for more about treating ALL.

Intensive or non-intensive treatment?

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

Intensive treatment involves strong chemotherapy with the aim of cure, and this approach is often split into different stages.

Non-intensive treatment usually involves gentler chemotherapy and possibly other drug therapies. For example, targeted therapies. The aim of this treatment is not to cure the leukaemia but to give you the best quality of life for as long as possible.

The biggest factor in determining your fitness for treatment is your age. Doctors are more cautious about giving intensive chemotherapy to people over 65 because your age can affect how well your body will respond to treatment or deal with the different drugs and their side-effects.

>>> Let your medical team know if there's anything you don't understand about your illness or treatment.

Supportive care

Supportive care means extra treatment given to help with the symptoms of your leukaemia or the side-effects of treatment. For example, a blood transfusion to help with anaemia or antibiotics to help with infection.

If your leukaemia is at an advanced stage, treatment may only be able to control it. Supportive care can ease your symptoms and give you a better quality of life. See page 56 for more details.

Where will I be treated?

AML and ALL are rare diseases. They need to be treated by specialist doctors (haematologists) in a recognised cancer centre. As a result, you may have your treatment at another hospital from the one where you received your diagnosis.

Deciding on treatment

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

Treatment options: Your doctor and nurse will explain your treatment options to you. Do ask as many questions as you like, no matter how small or trivial you think they are. All questions are important. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

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 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.

Acute leukaemias are fast-growing cancers, 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. Talk to your consultant 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, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- 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 are not getting the same treatment as you. Their leukaemia may not be the same type or at the same stage as yours. 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 treating blood and bone marrow diseases.

Haematology nurse specialist / Advanced nurse practitioner She or he gives information and reassurance to you and your family from diagnosis and throughout treatment.

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

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

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

Psycho-oncology team A group of specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

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

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

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

> ‘Confirm and clarify anything you have read with your medical team. They are on hand to address your unanswered questions and worries.’

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Chemotherapy

Chemotherapy is the main treatment for AML and ALL. With acute leukaemia there are usually different stages in the chemotherapy treatment.

››› See page 15 for more about AML chemotherapy stages and page 23 for ALL.

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. When you start treatment, you may need to spend a number of weeks in hospital. If you are well enough and the doctors are satisfied with your blood results, you will be allowed home before the next cycle begins.

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.

What is remission?

Remission is when there are no signs of leukaemia in your body. There are very few leukaemia cells left in your blood or bone marrow. If your remission lasts indefinitely, you are said to be 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 leukaemia will come back (relapse). If this happens, you may have more chemotherapy, other drugs or a stem cell transplant.

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
- By injection into the fluid around your spinal cord (intrathecal)
- By mouth, in the form of capsules or tablets

Most chemotherapy for AML and ALL is given into a vein. 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 or 2 lines for accessing your bloodstream. This is more long term and can stay in for weeks without complications.

››› Most chemotherapy is given into a vein.

Caring for central venous access devices

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

- Blockage
- Infection
- Tube falling out

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 at once 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.

Injection into spinal cord

Chemotherapy is sometimes given into the fluid around your brain and spinal cord. This can be done to treat cancer that has spread to this area or to prevent cancer spreading to this area. This is called intrathecal chemotherapy. 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 cord, you may get some headaches and dizziness or blurred vision. Tell your doctor or nurse if you get any of these symptoms. You must lie flat for 1–4 hours after the lumbar puncture to prevent these symptoms.

By mouth

Many cancer drugs can be taken in tablet form. These include steroids, antibiotics and chemotherapy. 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet *Understanding Chemotherapy* or download one from **www.cancer.ie**

> ‘Your team will prescribe you medications to get you through the side-effects.’

Injection into muscle

Some chemotherapy drugs may be given by injection directly into your muscle. The most common one given in this way is asparaginase, which is used to treat ALL. Your nurses will give this to you.

What drugs are used?

Your doctor will decide which drugs are best for you, based on your type of AML or ALL, your age and your general health. Chemotherapy drugs can be given alone or in combination. Examples of chemotherapy drugs used to treat AML and ALL are cytarabine, daunorubicin, and cyclophosphamide.

Hints and tips: Understanding your drug treatment

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

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Cancer Nurseline 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.

You are likely to have a range of side-effects, including side-effects linked to chemotherapy's effect on your blood cells, such as anaemia and an increased risk of infection. Your blood count will be checked regularly to help watch 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, you may become tired and weak. Because the amount of oxygen being carried around your body is less, you may also become breathless. These are all symptoms of anaemia. You 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.

››› Take plenty of rests and breaks if you are feeling tired or fatigued.

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 vaginal bleeding. You may need a platelet transfusion to help reduce it. Also, use a soft toothbrush such as a child's toothbrush and an electric razor when shaving and wear rubber gloves when doing household or gardening jobs, to protect yourself from cuts.

Infection: AML and ALL 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 37.5°C (99.5°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. Do check with your nurse about how to take your temperature or 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.

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.

Tips & Hints – infection

- Avoid crowds and close contact, such as hugging or kissing, with people who have colds or flu and other infections. This includes chickenpox, shingles or measles.
- Let your doctor know if you are in contact with these or any other infections.
- Wash your hands often during the day, especially before you eat and after going to the toilet. You could also carry an antibacterial handrub to use when you're out and about.
- Avoid unpasteurised milk, soft cheeses, undercooked meat and poultry, and the skin of raw vegetables and fresh fruit.
- If your temperature goes above 37.5°C (99.5°F) or below 35°C (95°F) or if you suddenly feel shivery or unwell, even if your temperature is normal, contact your doctor or the hospital immediately.

Other possible side-effects

- **Fatigue:** Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 64.
- **Nausea and vomiting:** Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.
- **Loss of appetite:** Some chemotherapy drugs can reduce your appetite for a while. Your sense of taste may also change during treatment, which can also affect your appetite. Food may taste more salty, bitter or metallic, or you may lose your sense of taste. Normal taste will come back once the treatment is over. Speak to the dietitian at the hospital or see our booklet *Diet and Cancer* for advice to help with these problems.
- **Mouth problems:** Chemotherapy can cause mouth problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.
- **Constipation or diarrhoea:** Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements). There is medication to help with these side-effects.

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

- **Hair loss (alopecia):** Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Your nurse can give you information about any possible hair loss and a list of wig providers.
- **Skin and nail changes:** Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle. Your skin may also become more sensitive to sunlight during and after treatment, so you should be careful to protect your skin.
- **Changes in hearing:** Some drugs make you unable to hear high-pitched sounds. They can also cause a continuous sound in your ears called tinnitus. These buzzing or ringing sounds can be very distressing. Let your doctor know if there is any change in your hearing.
- **Nerve changes (peripheral neuropathy):** Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy. Tell your doctor or nurse if this happens, as some changes may need to be made to your treatment.

This side-effect is almost always temporary and usually goes away after treatment stops, although it may take several months or even years. Occasionally the changes may be permanent.

- **Changes in nervous system:** Some drugs can cause headaches and anxiety or make you feel restless and dizzy. Or you might find it hard to sleep or concentrate or have short-term memory loss. If you have any of these side-effects, let your doctor or nurse know, as medication can often ease them. It can help to talk to a close relative or friend about your feelings too. If this is not possible, ask your doctor to refer you to a counsellor or a psychologist.
- **Kidney changes:** Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage. If you notice any pain, discomfort or blood in your urine, tell your doctor at once. The chemotherapy drug doxorubicin can turn urine red for 1–2 days after receiving it. This is harmless and nothing to worry about.
- **Infertility:** Changes to your fertility may be temporary or permanent. See page 67 for more details on infertility.

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

For more information on the side-effects of chemotherapy or a copy of the booklet *Understanding Chemotherapy,* call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read, order or download the booklet from our website **www.cancer.ie**

To sum up

- Chemotherapy is a treatment using drugs to kill leukaemia cells.
- The drugs can be given directly into a vein as an injection or through an infusion (drip) or in tablet form.
- The side-effects vary depending on the drugs used.
- Most side-effects are well controlled with medication.

Steroid therapy

Steroids are often used with chemotherapy. Or you may be given steroids straight away while waiting for chemotherapy to start. Steroids are natural hormones made in your body. But they can kill leukaemia cells while having little effect on normal cells. Examples of the drugs are prednisolone and dexamethasone. Steroids are usually part of the first treatment for ALL and may be continued throughout your treatment. They may also be given as part of treatment for AML. Steroids are usually given in tablet form, but can be given directly into your vein too.

What are the side-effects?

In high doses steroids can have several side-effects. But not everyone will experience the same ones. The more common side-effects include:

- Increased appetite and weight gain
- Increased blood pressure
- Osteoporosis
- Stomach upset
- Increased blood sugar – diabetes
- Fluid retention
- Higher risk of infection, especially thrush
- Sleeplessness
- Mood changes – irritability, anxiety, tearfulness, high spirits

Blood sugars: While receiving steroids or the chemotherapy drug asparaginase, blood tests will be done regularly to check your blood sugar levels. Tell your doctor if you get very thirsty or if you are passing more urine than usual. Your blood sugars usually return to normal once treatment has stopped.

Mood and emotional changes: Occasionally steroids may cause you to have episodes of extreme happiness, sadness and mood swings. These are rare but if they occur, let your doctor know.

Tips & Hints – 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 doctor and nurse – a high temperature, cough, swelling or any inflammation.
- Take all tablets as instructed and don't stop talking steroids suddenly or without your doctor's advice.

Targeted therapies

Targeted therapies can be used alone or with chemotherapy. Targeted therapies can stop cancer growing or spreading by targeting specific proteins and gene mutations that help the cancer to grow. For example, targeted therapy drugs called tyrosine kinase inhibitors (TKIs) can be used with ALL.

TKIs work by blocking an enzyme called tyrosine kinase, which makes the leukaemia cells grow and divide more quickly. TKIs are usually given to those who have the Philadelphia chromosome (see page 22), as the Philadelphia chromosome causes your body to produce tyrosine kinase.

Targeted therapies can be used alone or with chemotherapy. Examples of TKIs include imatinib (Glivec®) and dasatinib (Sprycel®). New drug treatments are being developed all the time. Some new drugs may be available to you as part of a clinical trial. Ask your consultant about this. See page 55 for more about clinical trials.

What are the side-effects?

These drugs have some mild side-effects. Sometimes they can cause nausea and diarrhoea, fatigue, leg aches, muscle cramps, skin rashes and swelling of fingers, eyelids, face or lower legs. But these can be treated easily. Your skin may become more sensitive to sunlight when taking the drugs. As a result, you can develop skin rashes, itching, redness or severe sunburn. It is best to use a high protection sunscreen when outdoors. You might be more prone to infection, anaemia and bleeding as well. Avoid taking grapefruit juice with these drugs.

To sum up

- Targeted therapies attack specific molecules that help cancer to grow or spread.
- Some side-effects include nausea and diarrhoea, fatigue, leg aches, muscle cramps, and skin rashes.

Stem cell transplants

Your doctor may recommend a transplant:

- As a first treatment for high-risk (very fast growing) leukaemia
- If your leukaemia returns after treatment (relapse)

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

You can also have a transplant using your own cells, but this is less common. 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 cells called human leukocyte antigen (HLA). If you are HLA compatible it means you and the donor have similar proteins and there is more chance that the transplant will be successful. The donor can be your brother or sister, or even a person not related to you.

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 only. 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 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 call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You could also ask for one of our transplant booklets.

> 'Always talk. If you are ever worried about anything, just ask. Everyone is there to help you.'

To sum up

- A stem cell transplant works by collecting stem cells from a donor or from your own bloodstream and using them to grow new healthy blood cells in your body after you have had very high doses of chemotherapy.
- A stem cell transplant may be an option if you have high-risk leukaemia or if your first treatment fails.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer.

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

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

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching acute leukaemia. Your doctor can advise you about this.

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 Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

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

Supportive care

You will be monitored very closely during your treatment. It is likely that you will be given supportive care to help with the treatment side-effects and symptoms of your cancer. For example:

- You may need to have transfusions of blood and platelets to keep normal levels in your blood.
- You may be given tablets to help prevent infections while your immune system is more vulnerable. Your doctor will speak to you about this if you need it.
- You may need growth factor injections to help increase your white blood cell levels after chemotherapy (see page 48). This is because if your white blood cell count is low, you are at risk of developing serious infections. You can still get infections despite these injections.
- If you develop an infection you will be started on antibiotics through the vein. You may be required to stay in hospital until your infection is gone.

There are lots of medications used to help treat other side-effects of treatments. Make sure you tell your doctor and nurse about any new symptoms.

If your disease is at an advanced stage there are many things that can be done to make you comfortable.

Bone marrow tests will also be done regularly to check for leukaemia cells. Your doctors will let you know all these results. Depending on the results of these tests, your doctor may need to make changes to your treatment.

Palliative care

If your leukaemia is at an advanced stage you may be referred to the palliative care team.

The palliative care team are experts in managing the symptoms of advanced cancer, such as breathlessness, pain and nausea.

Palliative care 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 earlier in your illness, to help to manage your symptoms and improve your quality of life.

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 medical insurance.

After treatment

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What follow-up do I need?

Once treatment is over and you are in remission, you will still need to visit your doctor at the outpatient clinic regularly. These check-ups are 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 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 you have a symptom or problem that worries you, let your doctor know. Make an appointment to see him or her as soon as possible.

What if the leukaemia relapses?

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

Your doctor can decide if you have a low, moderate or high risk of relapsing. This is based on your white cell count at diagnosis and your response to your first treatment.

You can relapse:

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

While on treatment: The reason you relapse while on treatment may be because the disease has become resistant to the drugs being used. This is known as 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 patients relapse after finishing treatment. A relapse can happen even after a good response to treatment. If you do relapse, you might receive the same chemotherapy drugs you were first treated with, as you responded well to them. More treatment 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 acute leukaemia

Here are some things you can do to feel more in control, avoid unnecessary complications and stay as well as possible.

Leading a healthy lifestyle

Many people want to make positive changes to their lives after a diagnosis of AML or ALL. A healthy lifestyle can help you to:

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

A healthy lifestyle includes:

- Exercising
- Staying at a healthy weight
- Not smoking
- Avoiding alcohol

Exercising is a great way to boost your mood and sense of well-being. Exercise can also improve your energy levels if you are feeling very tired. Talk to your doctor or nurse about which activity will suit you best.

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 48 for advice.
- Contact your doctor straight away if you have signs of infection, symptoms of AML or ALL (see page 12/20), 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.
- Always tell doctors, dentists and other healthcare professionals that you have acute leukaemia. 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.

Vaccines

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. For example, live vaccines. Check with your doctor about which vaccinations are recommended for you and make sure you get them.

Be involved in your healthcare

- Learn about your illness and treatment options so that you can make informed decisions and know what to expect.
- Don't be afraid to ask questions. There are some questions you might like to ask on page 90.
- 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.

Mind your mental health

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

- Try to avoid additional stress wherever possible. Spend time with your friends and family. Make time to relax and do the things that you enjoy.
- Use stress-management techniques if you do feel stressed. Try complementary therapies and relaxation techniques like yoga, meditation, mindfulness or aromatherapy. See page 68 for more about complementary therapies.
- Give yourself time to get back to normal. Once you feel better you may have financial or practical matters to sort out. Try not to let these overwhelm you and take one task at a time.
- Counselling or a short course of medication may also help you, if you are finding it hard to cope. See page 72 for more information.
- Having the support of loved ones, healthcare professionals and other people going through the same thing can also make a big difference. See page 73 for more about getting support.

Work and activities

It can take at least a year for you to get over the effects of treatment. If you feel well, there is no reason why you cannot return to work or study and carry 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. 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for more details.

> ‘It’s OK to be gentle with yourself. It can be hard to sit back if you’ve been active all your life, but give yourself that time.’

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer.

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

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.

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.

Tips & Hints – fatigue

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

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy.

Will treatment affect my sex life?

Sex and sexuality

It is unlikely that treatment will affect your ability to have sex, but having 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 and lose interest in sex as a result. If your platelets or white cell counts are low or if you have a stem cell transplant, ask your doctor or specialist nurse for advice.

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

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

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

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

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

Pregnancy and contraception

If you are having sex, you must use a reliable method of contraception throughout your treatment and for some time afterwards. When you have finished treatment there are blood tests that can show if you are fertile or not. Many doctors believe it is better not to try to start a family for 2 years after your chemotherapy ends. This gives you a chance to recover from the effects of treatment and by then the likelihood of the disease coming back is much less. Talk to your doctor or nurse if you need more information. They will answer your questions in more detail.

It can sometimes happen that you are pregnant when diagnosed with acute leukaemia. 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.

››› Use a reliable method of contraception during treatment and for a time afterwards.

Asking for advice

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

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: Chemotherapy can cause infertility in men. 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: 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 women who have short-term infertility brought on by chemotherapy. In general the younger you are, the more likely your regular periods will return and the more likely it is 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.

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

Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use. However, treatment normally needs to start quickly with acute leukaemia, so this may not be possible, especially for egg storage, which can take a few weeks.

Dealing with infertility

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

Cancer and complementary therapies

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

Complementary therapies: Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of complementary therapies are yoga, meditation, aromatherapy and massage.

Standard treatment: Standard or conventional cancer treatments include chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

Alternative therapies: Alternative therapies are generally treatments that are used **instead of** standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

If you decide to have complementary or alternative treatments…

Before you decide to change your treatment or add any methods of your own, talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects.

More information

To find out more about the different complementary and alternative therapies, read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. To get a copy call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website **www.cancer.ie**

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.**
- **Talking about what you want** to your family, friends, carers and healthcare providers.

Who can help me plan?

Think Ahead is an easy-to-use planning booklet to record your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at **www.hospicefoundation.ie**

Coping and emotions

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How can I cope with my feelings?

People react in different ways when they hear that they have acute leukaemia. There is no right or wrong way to feel and you'll probably have different feelings at different times.

Common reactions include:

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

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

Anxiety and depression

Sometimes a cancer diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it's important to get help. It's not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. Medical social workers can also offer support to you and your family.

If you are finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can work well. Professional counselling can also be very helpful.

Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. 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.

Counselling is available free of charge at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at cancernurseline@irishcancer.ie. A list of counsellors funded by the Irish Cancer Society is available at **www.cancer.ie**

Ways to get emotional support

Find out about cancer support services in your area: There are lots of local cancer support services that 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 86 for more about cancer support services.

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

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

Get one-to-one support: The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a cancer diagnosis and who can give you emotional and practical support.

Get online support: There are special websites called online communities where people with cancer can 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 concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

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

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

> ‘I thought I wasn’t ready, but … I have never looked back. Counselling has helped me with every part of my life.’

Coping with a diagnosis of leukaemia

Everyone experiences cancer in a different way. There is no right or wrong way to cope with cancer, only your way.

Here are some things that can help you to feel more involved and more in control of your illness. They can boost your self-esteem and well-being, which may make it easier for you to cope.

How can I help myself?

Use your support network: Doing things for yourself can help to make you feel more in control, but be realistic about what you can manage by yourself. Don't be afraid to ask for help from those who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Involve your family and close friends: Don’t keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. If you’re feeling alone, you can also talk in confidence to one of our cancer nurses by calling our Cancer Nurseline or visiting a Daffodil Centre.

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.

Express yourself: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.

Practical planning: It’s very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it can give you the chance to plan and deal with any practical concerns or worries you may have in your personal life. See page 69 for more information on planning ahead, or look at our advanced cancer web pages on our website **www.cancer.ie.** You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support.

Positive emotions

A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what’s important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.

You and your family

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

How can my family and friends help?

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

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.

The booklet is available free of charge from Daffodil Centres or by calling the Cancer Nurseline. It’s also available on our website **www.cancer.ie**.

Advice for carers

Caring for someone with cancer 78

How to talk to someone with cancer 78

Looking after yourself as a carer 79

Caring for someone with cancer

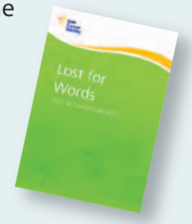
Coping with both the practical and emotional issues of a cancer diagnosis can be hard. Here are some things that can help to make life a little easier

- **Information:** Find out as much information as possible about acute leukaemia, especially its symptoms, treatment and side-effects, as well as the emotional effects it can cause. Talk to the doctor and nurses and call our Cancer Nurseline if you need more information.
- **Healthcare:** Support your loved one by making sure they take any medication every day and attend all appointments. Ask them about how they are feeling and encourage them to talk to their healthcare team if they have any symptoms or worries.
- **Emergencies:** Find out who to call if you are particularly worried or in an emergency situation and make sure you know the phone number to call.

How to talk to someone with cancer

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

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline on 1800 200 700. Ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer.* The booklet gives advice on talking to someone with cancer. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at **www.cancer.ie**



Looking after yourself

It can be difficult to find time for yourself if you're busy caring for someone with cancer, but it's important to look after yourself, too, and get help if you need it.

Share worries: You may feel tired with all the worry and extra work. It can also be very difficult as you try to adapt to a new way of life. Make sure you share your worries with someone else. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence. Stay in touch with your own friends and get out when you can, even if you don't always feel like it.

Take regular breaks: If your partner or friend is anxious or depressed, try to take a break each day, even if it's just a walk to the shops. Ideally, try to organise a longer break as well, such as an evening out with friends or a trip to the cinema each week. If you have young children, organise for your family or a babysitter to mind them for an hour or two, if possible.

Have little treats: If you don't want to take a break, then at least give yourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.

If you find it difficult to cope, get help: Talk through your feelings and frustrations with a friend or your GP. Your GP can suggest other services and sources of help.

Look after your own health: See your GP sooner rather than later if you have any health concerns of your own.

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

Support for you

Our cancer nurses are there to support you as a carer. If you need any support or want to talk to someone, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre to speak to a cancer nurse in confidence. You can also email the nurses at cancernurseline@irishcancer.ie Ask for a copy of our booklet, *Caring for Someone with Cancer,* or download it from our website **www.cancer.ie**

Many cancer support services offer help for friends and family of people with cancer, too. See page 86 for more about support services.

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Coping with the financial impact of cancer

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

Medical expenses

Medical expenses that you might have to pay include:

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

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

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70 years old, 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 do not 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.

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

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

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

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

If you have financial difficulties

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 85 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

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

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

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

Irish Cancer Society services

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

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

- Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at **www.cancer.ie**

  For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie
- Our **Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
- **Support in your area**. We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 86 for more information.

- **Patient travel and financial support services**. We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
  - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
  - **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

  To access either of these services please contact your hospital healthcare professional.
- **Irish Cancer Society Night Nursing**. We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- Our **publications and website information**. We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website **www.cancer.ie** or call our Cancer Nurseline for a free copy of our publications.

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

Local cancer support services

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

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

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

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

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: **www.cancer.ie**.

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue

Coping and emotions

Understanding the Emotional Effects of Cancer

Lost for Words: How to Talk to Someone with Cancer

Who Can Ever Understand? Taking About Your Cancer

Talking to Children about Cancer: A Guide for Parents

A Time to Care: Caring for Someone Seriously Ill at Home

Caring for Someone with Cancer

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	The 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 or biopsy	When a sample of bone marrow cells or bone is taken and looked at under a microscope.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
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 five types: neutrophils, eosinophils, basophils, monocytes and lymphocyte

Questions to ask your doctor

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

- What type of leukaemia 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?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

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

Did you like this booklet?

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

More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.

Irish Cancer Society
43/45 Northumberland Road, Dublin 4

T: 01 231 0500
E: info@irishcancer.ie
W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700
Email: cancernurseline@irishcancer.ie

Find us on Facebook
Follow us on Twitter: @IrishCancerSoc

The National Cancer Charity

Irish
Cancer
Society