Irish Cancer Society

Understanding

Acute lymphoblastic leukaemia (ALL)

Caring for people with cancer

Understanding

Acute lymphoblastic leukaemia (ALL)

This booklet has information on:

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

Useful numbers

Clinical nurse specialist

Advanced nurse practitioner (ANP)

Family doctor (GP)

Haematologist

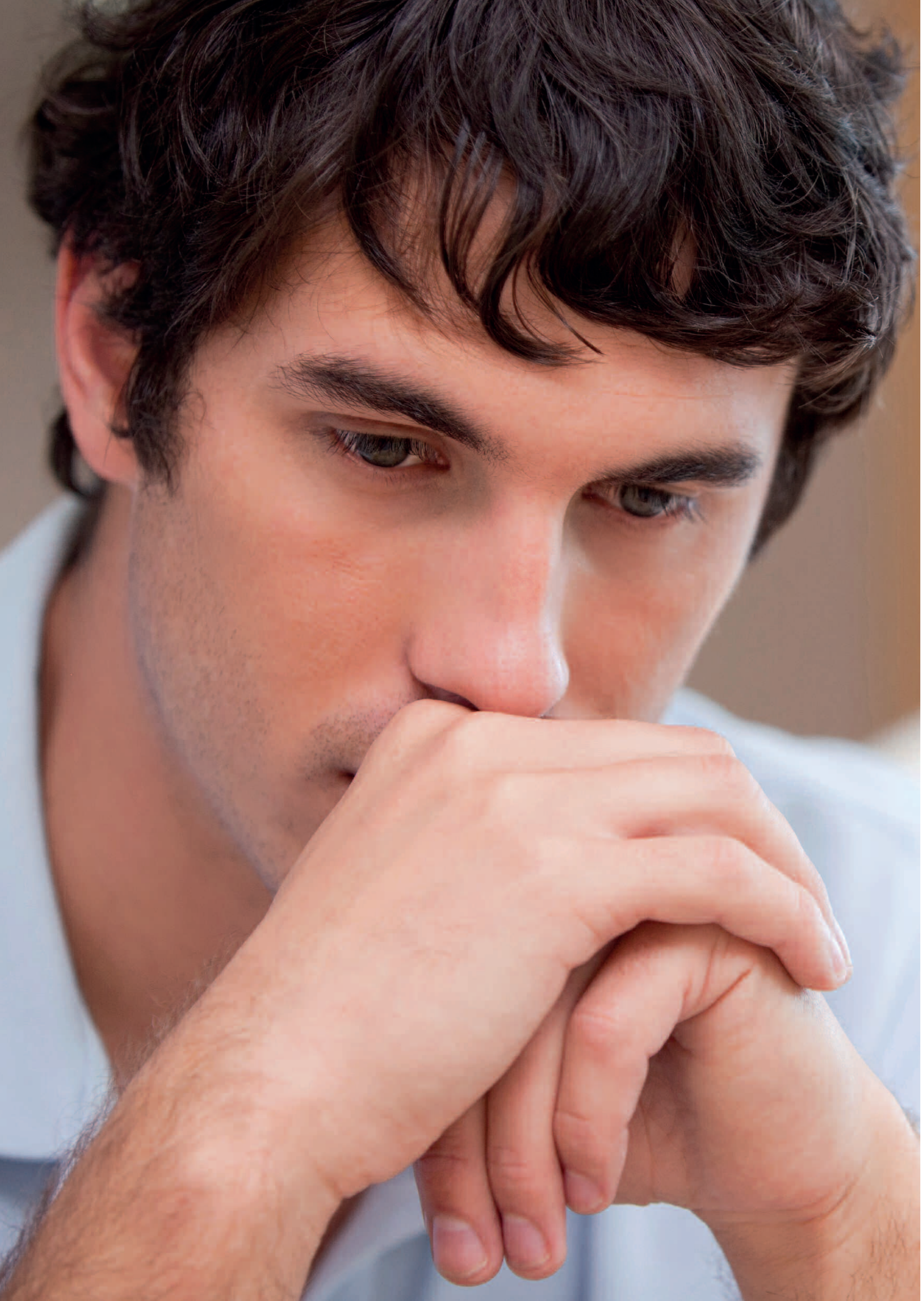
Medical social worker

Hospital day ward

Out-of-hours contact number

Emergency number for haematology team

Hospital records number (MRN)



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Fast facts

Can ALL be treated? Page 43

All stages of ALL can be treated. Your doctor will discuss with you what treatments will be of most benefit to you.

Will I be OK? Page 39

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

What treatment might I have? Page 59

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

How will my cancer treatment affect me? Page 59

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

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

Clinical trials Page 87

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

We're here for you Page 131

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

Ways to get in touch

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

See page 131 for more about our services.

Reading this booklet

This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

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

About our information

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

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

About acute lymphoblastic leukaemia (ALL)

What is leukaemia?

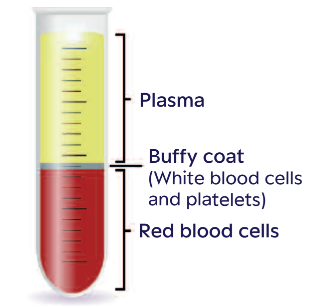
Leukaemia is a cancer that affects your blood. Your body has 3 main types of blood cells:

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

White blood cells are involved in fighting infection. Neutrophils are a type of white blood cell that protect you from infection; they are the most common type of white blood cell in your body. Lymphocytes are another type of white blood cell. They protect you from infection by making a substance called antibodies.

Platelets form clots, which stop you from bleeding.

What does blood look like?

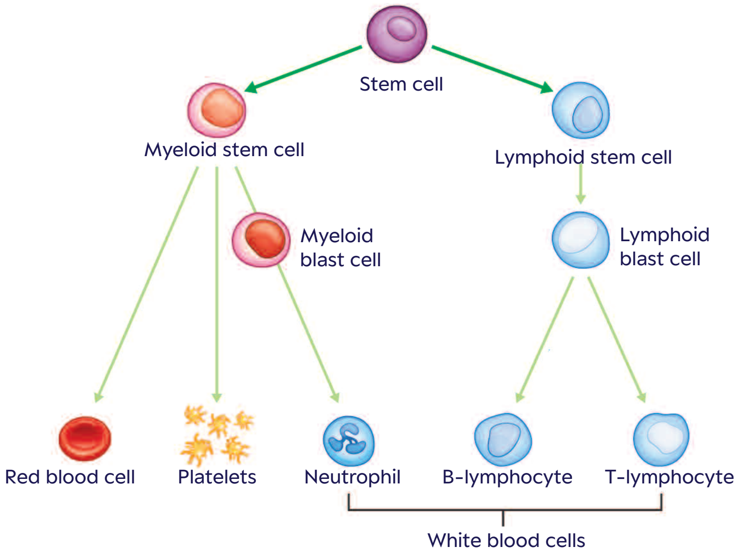


Blood has a liquid part (plasma) and circulating within that are tiny solid bits (cells). Every part of the body is made up of cells. In solid organs, like the liver or heart, cells are fixed in one place. But in the blood, cells flow around the body. This is what makes blood cancers different to cancers of solid organs.

If you were to look at blood in a test tube, blood cells would fall to the bottom of the tube because they are heavy. The plasma would settle on the top. The white blood cells and platelets are in an area known as the ‘buffy coat’. If you have leukaemia, you will have a lot more white blood cells so the buffy coat layer will be thicker and the red blood cells layer will be smaller because fewer good cells are being produced.

To understand leukaemia, it helps to understand a bit about how blood cells are made.

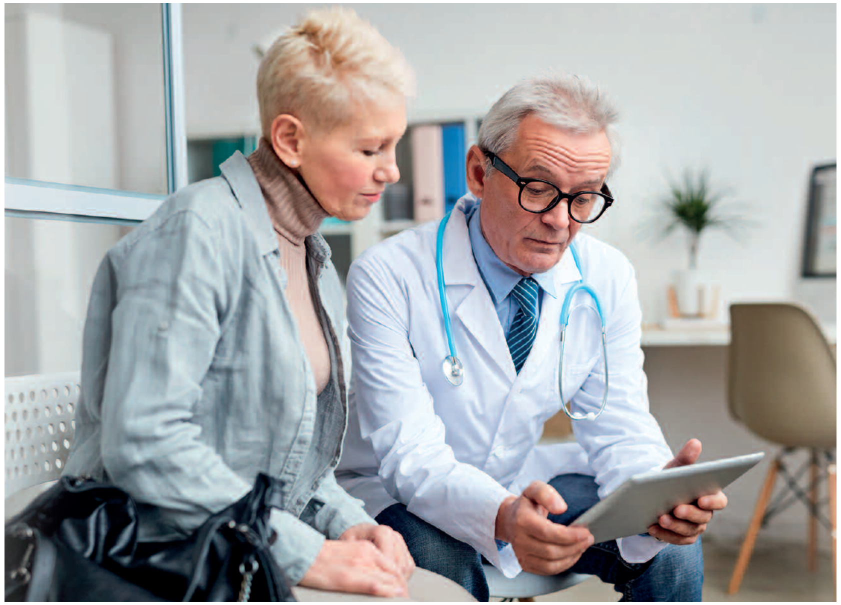
New blood cells are made inside your bones, in your bone marrow. This is the soft spongy tissue that fills the centre of some bones. All blood cells come from cells known as stem cells. These are like seeds that you might plant in your garden. They grow and produce different types of 'good' cells that help your blood to work properly. Stem cells split and develop into myeloid stem cells or lymphoid stem cells. They start out as immature cells (blast cells) and then they develop into different types of mature blood cells. Similar to a seed that grows into a plant with leaves and flowers – they look different but come from the same seed.



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

Myeloid stem cells go on to form red blood cells, platelets, neutrophils 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 bleed (platelets). Your bone marrow is constantly producing enough cells to keep this process going. A healthy marrow makes over 600 billion red, white and platelet cells every day.



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

Types of leukaemia

There are four main types of leukaemia:

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

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

What do 'acute' and 'chronic' mean?

Acute and chronic refer to how quickly leukaemia develops.

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

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

Each type of leukaemia has its own features and treatment. This booklet is about acute lymphoblastic leukaemia (ALL). For free booklets on the other types of leukaemia, contact our Support Line on 1800 200 700, visit a Daffodil Centre or download them from **www.cancer.ie**.

What is acute lymphoblastic leukaemia (ALL)?

Acute lymphoblastic leukaemia (ALL) is a fast-growing blood cancer, which affects the lymphoid blast cells (lymphoblasts). These are immature cells that give rise to lymphocyte white blood cells. Lymphocytes fight infection.

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

What are the types of ALL?

There are various types of ALL. Every patient with acute leukaemia needs specialised laboratory tests to show which type of ALL they have. These are cytogenetic, genetic and immunophenotyping tests (see page 14).

Different types of ALL respond to some types of treatment better than others, so knowing the type of ALL you have 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 – which fight infection in different ways:

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

Specialised tests to tell which leukaemia you have

Cytogenetics: This is a test that looks inside the deepest part of a cell, where that cell's instructions (DNA) are stored. The test looks at how the DNA is laid out and organised in chromosomes. This test detects big mistakes in the layout of the cell's genetic material.

Genetics: This test looks at the DNA deep inside the cell and even inside the chromosomes themselves. It can detect tiny mistakes that happen in the leukaemia stem cells as they divide rapidly. These changes are only in leukaemia cells and don't usually affect your family.

Immunophenotyping: This test looks outside of the cell – at the cell's coating (membrane). Every cell has a distinctive outside. Imagine a group of school children in uniform but each is wearing a differently coloured badge. These distinctive badges are called CD numbers and can help your haematologist to tell how many leukaemia cells are in your marrow and what type they are.

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.

If chromosome tests show that you have the Philadelphia chromosome, you can have a treatment that aims to block the action of the tyrosine kinase enzyme (see page 80). Your medical team will talk to you about this if you have Philadelphia positive ALL.

What are the symptoms of ALL?

Many of the symptoms of ALL are caused by the change to normal blood cell production. Each patient is different so you may not have all or any of the symptoms listed below. Symptoms can include:

- Big and small bruises on the skin, especially the legs. These tiny bruises can look like a rash. They are caused by a falling platelet count
- 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)
- Blood in your urine or stools (poo), or swollen or bleeding gums – caused by fewer platelets
- Aching bones and joints – caused by too many abnormal cells in your bone marrow
- Enlarged glands, for example in one or both armpits, groin or neck, or enlarged tonsils
- Enlarged spleen or liver – you may have a poor appetite, pain in your abdomen (tummy) or abdominal swelling
- Sepsis – this is a reaction to an infection. You may feel generally unwell, have a high or low temperature, or feel shivery. These symptoms require urgent action
- Loss of appetite

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

How common is ALL?

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

What caused my cancer?

We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. If you want to know more about why cancer happens or to learn about risk factors for leukaemia, see our website **www.cancer.ie** or talk to a cancer nurse. Call our Support Line on 1800 200 700 or visit a Daffodil Centre. Most people who get leukaemia have no obvious risk factors. Also, having a risk factor doesn’t mean you will get leukaemia.

What to expect in hospital

How long can I expect to be in hospital?

For most patients with ALL, their diagnosis is urgent and can come as a major shock to them and their GP. In most cases, the GP sends in a blood sample to a laboratory. When the scientists look at it and suspect ALL, they pass it on to a haematology doctor to review. That doctor will phone your GP.

If ALL is suspected, you will be offered a bed in hospital or a day ward appointment that day or the next day. It is likely that you will not be allowed home until your bone marrow is processed. Then you will have a chat with a senior haematology doctor and specialist haematology nurse.

After that, you may be allowed home for a day or two on medications or you may be kept in hospital.

Many patients with ALL need inpatient care for the first 4-5 weeks. In other words, you have to stay in hospital. After that, you will mostly be in and out of hospital for a further 4-5 months. Depending on treatment and side-effects, you may have short spells at home during these months, with day case visits every few days. Or you may need to stay in hospital for most of your care.

Your treatment

Treatment for ALL may take 2-3 years. In general, the first 6 months are mostly spent as an inpatient in a single room in hospital. Then over the next 1.5-2.5 years, you will be seen as a day case, attending the haematology ward.

After that, you will attend haematology outpatients or a late-effects clinic on an ongoing basis.

If you need a transplant (see page 84), this plan will change.

Tips for long stays in hospital

- Use headphones and an eye mask to block out sound and light.
- Use as much media as you can – phone, laptop or tablet, books and magazines. Watch shows and listen to music on streaming services.
- Ask someone to bring in your pillow, photos and anything else that will make the hospital room feel more like your own space.
- If you can have visitors, invite selected people to come and see you. Some may not realise you want them to visit you in hospital.
- Have video chats, watch shows or movies together or have a Zoom/Teams party.
- Make a visitor book or poster for visitors to sign and leave messages.
- Take pictures of people who visit.
- If you don't feel like talking to anyone, silence your phone or make a "Do not disturb" sign to let people know you're not up to visitors.

- Get to know the night nurses well. They'll save you from insanity when you can't sleep.
- Find your release – art, knitting, reading, puzzles, games, crosswords, listening to music.
- Make plans for things you will do when you get out of hospital. It helps to have something to look forward to.
- If you don't have enough energy to read, try an audiobook or podcast.
- Get outside the hospital or ward when your team advises you that your white cell counts are near normal. If you are well enough, some fresh air can make a nice change. You may be encouraged to go home for a night between bouts of chemotherapy if your white cells are OK.
- If you are in school or college, ask your friends or teachers to bring things from there for you to do. This is also a nice way to keep in contact. (Anyone attending a children's hospital for cancer treatment can attend hospital school. They will be taught by fully trained teachers in classrooms in the hospital or at their bedside.)

Going home from hospital

If you have been in hospital for a long period, you may be really looking forward to going home. However, when the day comes, you may feel scared or anxious. This is completely normal. While you are in hospital, there is always someone to tell you what to do, when to wake up, what to eat and what treatments you will be having.

When you leave hospital, you might miss this routine. You might also miss people who understand your situation and the security of knowing you will be looked after if something goes wrong. You will usually have an appointment within a few days for a blood check and you can discuss how you feel with the haematology nurse when you return.

Re-adjusting to everyday life can be tough and people often need some support with this. Lean into your family, friends and community wherever you can. They are the ones who know you best.

Professional support will still be there for you after you leave the hospital, from your medical team, your GP and organisations like the Irish Cancer Society.

Preparing for your regular hospital appointments

After your inpatient care has finished, you will be expected to attend regular appointments as a day case for up to 2.5 years. Preparation is key to getting the most out of these hospital appointments. Being prepared also helps doctors and nurses get the information they need to look after you properly.

Before your appointment

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

What to take to your appointment

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

- Your list of questions
- A notebook and pen to take notes. (Some healthcare professionals may be happy for you to record the meeting, but make sure you ask for their permission before doing so)

- Always bring a list of your medications with you. Try to get as familiar as possible with the names of your medications. Your medical team may change your medications often so knowing what they are reduces the risk of mistakes being made. Let the team know if you have missed any doses
- Medications and any medical supplies you may need that day, in case you are delayed
- A light snack and drink if you are likely to have to wait for some time, if you are not fasting
- A book or something to listen to (including headphones) to pass the time while you wait

Before leaving the appointment

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

After the appointment

- Arrange any tests in advance of your next appointment as soon as you can, if your healthcare professional has asked for it

If you have to cancel your appointment

If you are unable to attend your appointment, contact the haematology day ward or haematology nurse in advance and they will arrange a new appointment for you.

Questions to ask your doctor

Here is a list of questions that you may wish to ask. Never be shy about asking questions. It is always better to ask than to worry.

What type of ALL do I have?

What treatment will I need?

Are there other treatment options?

How long will my treatment take?

Do I have to stay in hospital for my treatment?

Would I be suitable for a clinical trial?

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

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

How soon after treatment can I have sex?

Will I be able to have children?

How often will I need check-ups?

Diagnosis and tests

Being diagnosed with ALL

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

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

However you feel, you are not alone.

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

- Ask to speak to the haematology nurse specialist or the medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters.
- Talk to one of our cancer nurses in confidence – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our cancer nurses can put you in touch with a volunteer.
- Talk to other people affected by cancer. Join our online community at **www.cancer.ie/community**
- Go to your local cancer support centre. For more information, see page 138.

Telling people about your diagnosis

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

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

The nurses can also support you if you have children and aren't sure what to say to them. You could ask them for the booklet ***Talking to Children about Cancer***, which has practical advice about how to talk to children of different ages.

These booklets are also available on our website **www.cancer.ie**

What tests will I have?

- Tests you may have include blood and bone marrow tests. Scans may also be needed sometimes.
- The tests will be done rapidly. They will tell your medical team more about your cancer and help them to decide on the best treatment for you.

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

Blood tests

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

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

Normal blood cell counts

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

Central venous access devices

You will have regular blood tests, so it's likely you will have a tube inserted in a vein to make it less uncomfortable for you to have these tests and be given medications. These tubes are called a central line, a PICC line, or if you need a transplant, a Hickman line. See page 66 for more.

At the start of your treatment, you will need a daily blood test.

Blood film

Your haematologist may look at a blood sample under a microscope to determine the amount of leukaemia cells present. This is often called a blood film and is carried out in the haematology laboratory of the hospital. Your haematology consultant will work on the wards with you and in the laboratory with your samples.

Bone marrow tests

Bone marrow tests involve taking a tiny sample (biopsy) of your bone marrow and looking at it under a microscope. The sample is usually taken from your pelvis bone. If the sample of bone marrow cells is semi-liquid, it is called an aspirate. If a piece of solid bone marrow is taken, it is called a trephine biopsy. Both can be done at the same time.

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

When it is over, a small plaster is put on the area where the bone marrow has been taken. You may be asked to lie on your back for 10–15 minutes to stop any possible bleeding. Your team will prescribe you mild painkillers if you feel any discomfort later. Paracetamol should not be taken as it suppresses signs of infection. If you are having this test done as an outpatient – which is sometimes done between treatments – you will need someone to drive you home.

Lumbar puncture

This test involves passing a needle into the lower part of your back to take a sample of the fluid that surrounds your brain and spinal cord. This is called cerebrospinal fluid (CSF) and it will be checked for leukaemia cells. Your doctor will tell you if you need this test. If you have this test done as an outpatient, you will need someone to drive you home.

Specific tests on bone marrow

Chromosomes studies (cytogenetics)

Chromosome testing looks at how DNA is laid out and organised within a cell. DNA is a molecule that contains all of our genetic information. In chromosomes, DNA is twisted and coiled to protect it from damage. This test detects big mistakes in the layout of the cell's genetic material. For example, with ALL, sometimes there is an abnormal chromosome called the Philadelphia chromosome (see page 14).

These chromosomes are then compared to normal cells. Knowing about these changes helps your doctor to decide on the best treatment for you.

It is important to note that these gene changes/faults are not the same as genes passed through families. The changes are only in the leukaemia cells.

Tests can be done on your blood and/or bone marrow samples.

Genetic testing

Genetic testing of leukaemia cells is not the same as genetic tests carried out in normal body cells. Leukaemia is associated with mistakes in the genes. Some genetic changes in leukaemia cells tell us that the cells might be harder to treat and kill with normal therapy. If you are one of these patients, it might be clear that you would benefit from a transplant. Your haematology team will discuss this with you once your results are back.

Results of genetic and chromosomal testing can take up to 3 weeks to be reported.

Flow cytometry

Flow cytometry looks at the outside of the cells for the 'identity badges' or unique markers that tell scientists in the laboratory that leukaemia cells are present. This test can measure the number and percentage of cells in a blood or bone marrow sample. It can also measure cell characteristics such as size, shape and the presence of biomarkers on the cell surface. Cells are passed through a machine called a flow cytometer. This method can be used for immunophenotyping (which checks what kind of proteins or markers are on the surface of the leukaemia cells) or to check how you are responding to treatment.

This test can also be used when you are in remission – that is when there are very few cells left to see – to tell how deep the remission is. This is known as looking for minimal residual disease (MRD):

Minimal = hardly any

Residual = left over after treatment

Disease = acute leukaemia

Sometimes your team will refer to your ALL simply as 'the disease'. Even if you have other problems, such as an infection or drug side-effect, the disease is always the most important concern.

What is remission?

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

With ALL, there are different types of remission:

- **Haematological remission (complete remission).** This is an old term that was used before there were more modern sensitive techniques for finding small amounts of ALL. The term is still used and your haematologist can decide if you are in complete remission by looking at your bone marrow in the laboratory.
- **Minimal residual disease (MRD) negative remission.** Using flow cytometry, a very sensitive test that picks up tiny amounts of leukaemia, the test is negative and no tiny amounts of leukaemia are found.
- **MRD negative remission by molecular studies** (not needed for all patients). Using molecular studies, a molecular marker of your leukaemia, which was present when you were diagnosed, is now gone. Molecular tests can be even more sensitive than flow cytometry.

MRD negative remission by flow cytometry and MRD negative remission by molecular studies are 'deeper' types of remission than haematological remission. Your haematology team will want you to achieve one of these types of remission as well as haematological remission.

What if you are not in remission?

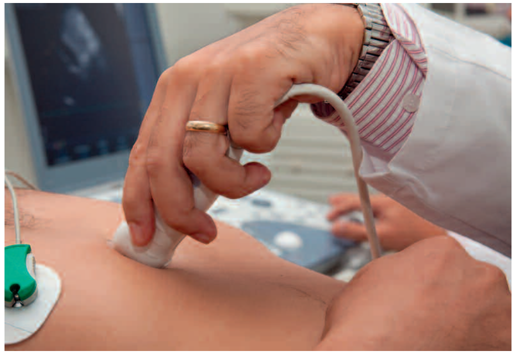
Sometimes after chemotherapy, the leukaemia cells are still present in your bone marrow. This is called refractory disease, but it can still be treated.

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

It is important to note that no single test on its own will give your medical team the whole picture. Your haematologist will interpret the different tests together – like putting the pieces of a jigsaw together – to see the whole picture.

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

Chest X-ray

A chest X-ray uses high-energy rays to take pictures of the inside of your body. It can find out if you have a chest infection or not and the state of your general health.

CT scan (CAT scan)

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine.

The scan is painless and takes between 10 and 30 minutes.

MRI scan

This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. With ALL, this test is most often done to look at the health of your brain. During the test you will lie inside a tunnel-like machine. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious.

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.

An MRI can be noisy, but you will be given earplugs/headphones to wear. You might get an injection into your veins before the scan to show up certain parts of your body.

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

Asking about your prognosis

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

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

Should I ask about my prognosis?

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

When you have ALL, the best time to have this conversation is 4-5 weeks after diagnosis, when the results of your first bone marrow test after a full course of treatment (induction) have come through.

Most patients are in remission at this time, but more detailed information may be available, for example, on minimal residual disease (see page 36).

If the information indicates that your risk of recurrence/relapse is higher than average, your haematology consultant will tell you this and may want to discuss changing therapy with you.

At this point also, it may be in your best interest to prepare for having a stem cell transplant. This discussion will be detailed so it's a good idea to have a family member or close friend with you for support.

General points to consider when thinking about talking to your haematologist about your prognosis:

- Think about how you will cope with the information and have a support plan in place if the news is bad or unexpected.
- Make sure you are asking questions that meet your own information needs and not that of others.
- Get information on prognosis from your haematology doctor. They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- Ask a friend or family member to be there. Make a list of the questions you would like to ask the doctor or nurse, as it is easy to forget what you want to say.
- Be careful with online information. It may be hard to understand or even incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- Accept that you will need some time to think about what you have been told. You may forget some things or there may be things you didn't understand. You may need to talk to your doctor or nurse again after you have thought about everything. ALL is a very complex cancer and it will take you time to understand it. This is normal.
- 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 Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treatment overview

How is ALL treated?

- Most patients with ALL will have chemotherapy treatment with multiple different drugs and immunotherapy. They may also have targeted therapy.
- Some patients may benefit from a stem cell transplant.
- A team of healthcare professionals, led by a consultant haematologist with expertise in ALL, will be looking after you (multidisciplinary team).

Because ALL is a fast-growing cancer, 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 outcome is remission (see page 36). The best treatment for you will depend on:

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

Treatment of ALL is divided into different phases:

- Pre-phase steroids
- Induction
- Intensification
- Consolidation
- Maintenance

Your haematologist will explain what is involved with each phase as it applies to you.

Treatment overview

Chemotherapy

Chemotherapy using many different drugs is the main treatment for ALL. Treatment starts with 'induction'. This is a 4-week cycle of chemotherapy, immunotherapy and steroids. This is often preceded by a few days of steroids (called 'pre-phase steroids').

Chemotherapy is given to destroy all the leukaemia cells and to make space in your bone marrow for healthy cells to grow again. After chemotherapy, over 95% of children and over 85% of adults achieve remission. This means there are no signs of ALL in your blood or bone marrow.

Further treatment is then given to maximise the chances of leukaemia not coming back. See page 61 for more information on chemotherapy for ALL.

Steroid therapy

Steroids may be given before and with chemotherapy, as well as for some time afterwards. Not only do steroids help to kill the leukaemia cells along with chemotherapy, they can also help to improve symptoms such as fatigue or nausea. See page 78 for more about steroids.

Targeted therapies

Sometimes targeted therapies are given to treat ALL. If you are found to have the Philadelphia chromosome (see page 14), you may be suitable for a type of targeted therapy drug known as a tyrosine kinase inhibitor (TKI). It can be used together with chemotherapy or given later if your ALL is no longer responding to chemotherapy. See page 80 for more details.

Immunotherapy

Immunotherapy helps your immune system to work better to fight cancer cells. Different types of immunotherapy treatments work in different ways. You might have immunotherapy on its own or with other cancer treatments. See page 82 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 84 for more about transplants.

Radiotherapy

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

Supportive care

Supportive care refers to essential extra treatments that are given to you to help with the symptoms of your leukaemia or the side-effects of anti-cancer treatments. For example, a blood transfusion to help with anaemia, antibiotics to help with infection or anti-sickness treatment to stop you feeling sick (nausea). For some patients, treatment may only be able to control your leukaemia rather than cure it. Supportive care can ease your symptoms and give you a better quality of life. See page 88 for more details.

Specialist cancer centres

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

Chemotherapy treatment for ALL

Planning treatment

Initial treatment for ALL tends to be the same all over the world. It usually starts within a day or two of diagnosis.

There are some patients who may choose to have less-intensive treatment. For example, patients who are very frail or who have lots of medical problems before a diagnosis of ALL may not benefit from aggressive inpatient treatment. Patients may be advised by their haematology team not to have induction treatment, or they may choose not to have it. This choice will usually result in a short survival, but may result in more time out of hospital with loved ones. Sometimes, more gentle outpatient treatment options can be offered in these circumstances.

Babies under 12 months and people with Down syndrome need special treatment planning and are not discussed in this booklet.

Deciding on treatment

Treatment usually needs to start very quickly.

Multidisciplinary team

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

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. If you do forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Second opinion

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

Accepting treatment

You have the right to find out what treatment options are available. You also have the right to accept or refuse treatment. If you want to refuse a particular treatment, let your doctor or nurse know your concerns first. The important thing is that you are fully aware of the benefits and risks.

Time to think

ALL is a fast-growing cancer, so treatment will start as soon as possible after diagnosis. This can be hard when you are coming to terms with your diagnosis. Talk to your consultant or specialist nurse if you're feeling overwhelmed or if you have any questions or worries.

Checking if your treatment is working well

Every time your haematology team does a bone marrow test or other assessment of your leukaemia, it could show:

- Your leukaemia is responding well to treatment and your treatment plan will continue as you expect.
- Your leukaemia is responding less well than the haematology team would like and your treatment may need to be changed.

Individual treatment

You may notice that other people with ALL are not getting the same treatment as you. However, their ALL may not be the same type as yours. Treatment decisions can also depend on any previous treatments you have had and your general health. Everyone’s treatment needs will be different. Ask your doctor about your treatment if you have any questions.

Giving consent for treatment

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

- What the treatment is for
- The type and amount of treatment you will have
- The timing of tests which help the haematology team to assess if your treatment is working well
- The benefits and risks of the treatment
- Possible side-effects from treatment
- Any other treatments that may be available

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

Who will be involved in my care?

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

Haematologist: A doctor who specialises in disorders of the blood and lymphatic system.

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

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

Haematology liaison nurse/clinical nurse specialist: A specially trained nurse who works in a cancer care unit. They give information and reassurance to you and your family from diagnosis and throughout treatment.

Nurse transplant coordinator or CAR T-cell coordinator: If you need a stem cell transplant or CAR T-cell therapy, the nurse coordinator will work with you to manage tests and treatments in conjunction with the transplant centre.

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

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

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

GP (family doctor): While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you.

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

Occupational therapist (OT): A therapist who helps people to learn to manage their daily activities when faced with illness, injury, disability or challenging life circumstances.

Healthcare assistants: Healthcare workers who provide assistance, support and direct personal care to patients.

Pharmacists: Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

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

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

How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself before and when you start treatment. You will be in hospital for a while with ALL, but you may have periods of a few days at home in between courses of treatment. During this time, you should try to:

Eat well

Eat as well as you can. When you have cancer, this can help you to keep up your strength and muscle mass. It can also help you to:

- Feel stronger and maintain a healthy weight
- Cope better with the side-effects of treatment
- Reduce the risk of infection
- Recover

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

If you have a sore mouth or mouth ulcers, talk to your haematology nurse, who may recommend additional mouth care to help your symptoms. Attention to good mouth care throughout your treatment can help you to eat better. Don't eat crisps, toast or hard sweets while you are on chemotherapy for ALL as these may cause cuts in the soft lining of your mouth.

After treatment, your mouth may feel dry. Sucking a pineapple chunk or a few drops of lemon juice (provided your mouth is not sore) will help the saliva to flow.

Keep active

Keeping as active as you can has many benefits. It can help to:

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

You are likely to be spending time in a hospital isolation room. Some days you may feel well enough to do some gentle exercise. Some limb exercises can be done while in bed. You could ask for a referral to a physiotherapist to help you plan appropriate exercises while in hospital.

It's important to practise deep-breathing exercises to reduce your chance of developing a chest infection. Your physiotherapist may give you an 'incentive spirometer', which will encourage you to take deep breaths and exercise the base of your lungs.

There may be 'pedals' available on the ward so you can exercise your legs while sitting. Ask the nursing staff about this.

Many days, you may feel tired and have little energy. Don't be too hard on yourself – this is normal.

Quit smoking

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

- Non-smokers have fewer or less severe side-effects during cancer treatment
- Smoking can reduce how well chemotherapy and some other treatments work
- Not smoking reduces the risk of other illnesses

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203, visit **www.QUIT.ie** or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have a stop-smoking service, with advisors who can help and support you.

Other ways to help yourself

Prepare to cope with being in isolation in hospital

You may be in isolation in a room on your own with your own bathroom for some time. Allow your family to bring you in books, games or music that you might enjoy. Your concentration will not be normal while you are going through induction, so keep it light and entertaining. Think of things you like to do alone and see if these can be adapted to the hospital environment.

Get information about your cancer and treatment

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

Involve your family and close friends

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

Use your support network

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

Try relaxation and stress management techniques

Therapies like meditation or yoga can help you to cope with stress. ALL patients are too immunocompromised to join a group in the first 6-8 months of treatment. However, you may feel well enough to join an online group for this.

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.

Types of treatment

Chemotherapy

- Chemotherapy uses drugs to kill cancer cells.
- Chemotherapy is usually the main treatment for ALL.
- Chemotherapy can cause a range of side-effects.

Chemotherapy is typically the main treatment for ALL. It is given in structured batches called cycles. Chemotherapy drugs are given to destroy all the leukaemia cells and make space in your bone marrow for healthy cells to grow again. With ALL, chemotherapy treatment is given to bring about remission (see page 36).

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

Intensive treatment

Although each patient is treated on an individual basis, intensive chemotherapy treatment is usually appropriate if you're under 60 years old and have good medical fitness. Some older patients in good health may benefit from less-intensive treatments. This is because older patients are more likely to have other medical problems, such as diabetes, high blood pressure, high cholesterol levels or heart disease. As a result, they might not cope with treatment side-effects. Also, intensive chemotherapy has a lower success rate in older patients with ALL compared to younger patients.

Stages of chemotherapy treatment for ALL

There are 5 main stages of chemotherapy for ALL:

1. Pre-phase steroids

Steroids will start as soon as diagnosis is confirmed and continue until induction begins. This is usually a few days.

2. Induction

This 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 to achieve remission. This stage is called induction chemotherapy or remission induction.

Induction usually involves 2 cycles of chemotherapy treatment. During this phase, chemotherapy will be given into your spinal fluid as well. This is called intrathecal therapy. See page 68 for more details.

The induction stage can last 8 weeks in 2 phases. 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. If you are in remission, you may be encouraged to go home for a few days if you are well enough.

Minimal residual disease (MRD) tests

MRD tests are often used to test if the leukaemia is in deep remission (see page 36).

3. 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 and to protect your brain and spinal fluid from leukaemia. An intensification cycle lasts around 4 weeks and you may be able to be at home for some of this time.

You will have to visit the haematology day ward 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 quickly 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.

4. Consolidation

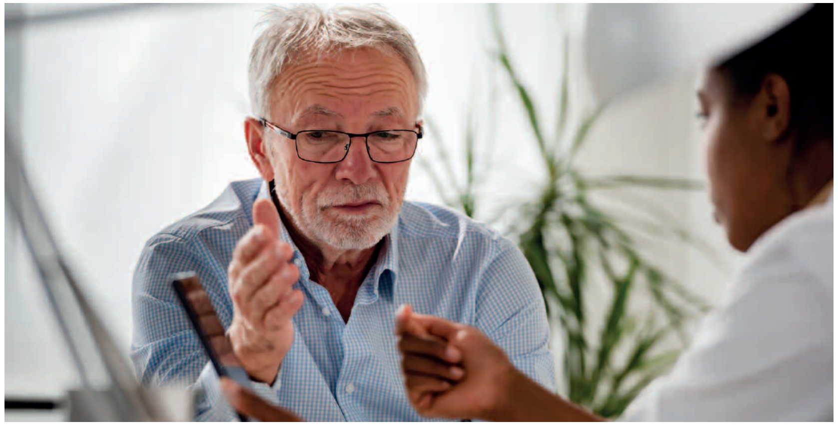
Normally, 4 cycles of consolidation are given. The 3rd cycle lasts around 6 weeks. The other cycles are around 4 weeks each.

5. Maintenance

The aim of maintenance is to prevent relapse/recurrence. It usually involves low doses of chemotherapy and steroids given in 3-monthly cycles. The chemotherapy is mostly given in tablet form, but once every 3 months, an intravenous injection and a lumbar puncture with chemotherapy will be given. These will not be done on the same day.

This is far less intensive than the previous phases and treatment is given over a longer period of time.

This stage of treatment typically lasts from 24 months to 3 years depending on your age and sex (treatment for females is generally shorter). You will be treated as an outpatient and will see your doctor or nurse regularly, usually weekly, in the hospital. It is unlikely that you will 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 advise you about what is safe for you.

How long does ALL chemotherapy treatment take?

Depending on how well you respond to treatment and your age and sex, 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 6 months.

How is my body prepared for chemotherapy?

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 kidney damage, gout or kidney stones, and can interfere with the flow of urine.

You will also be offered medication to reduce your chance of infection, reduce nausea and sickness, make you feel more comfortable and support your general health and wellbeing.

Drink plenty of fluid to protect your kidneys. You will be given fluid into your veins to make sure your body has enough.

How is chemotherapy given?

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

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

Most chemotherapy for ALL is given into a vein (intravenously). Once in your bloodstream, the chemotherapy drugs can travel around your body.

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 put in under the skin of your chest through your chest wall. It can have 3 or 4 different lines for accessing your bloodstream. It can be left in place for months, as long as it doesn't become infected or blocked.

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

Caring for central venous access devices

It is important to take good care of your device. Always keep your hands clean and don't handle the line unless you have been shown how to.

You may experience some problems, such as:

Blockage

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

Infection

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

Tube falling out

In general, it is hard for a line to fall out, as your skin will grow around it. If the line does come out, don't panic. Cover the area with a clean dressing and press hard to stop any blood flow. Contact the hospital straight away.

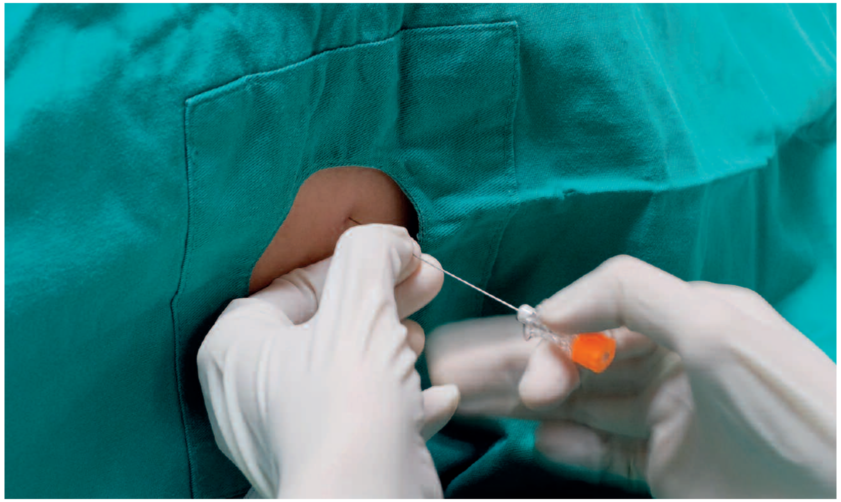
Minding your line at home

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.

Intrathecal chemotherapy – injection into the spinal fluid

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

For this treatment, you lie on your side and hold onto your knees. It can also be done with you seated, leaning over a table with your head on a pillow. Before placing a small needle into the spine in your lower back (lumbar puncture), your doctor will give you an injection to numb the area.



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

By mouth

Many drugs for ALL can be taken in tablet form. These include steroids, antibiotics, chemotherapy and targeted therapy. This is useful during maintenance therapy when you are an outpatient. It can help if you eat or drink something before taking certain tablets. Your doctor or nurse will advise you about this. If you would like more details on how chemotherapy is given, contact our Support Line on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet ***Understanding Chemotherapy and Other Cancer Drugs*** or download one from **www.cancer.ie**

Injection into muscle or under your skin

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.

Understanding your drug treatment

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

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

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

Will I get side-effects?

You will have some side-effects. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells. Side-effects can happen any time after chemotherapy.

An increased risk of infection, due to lower levels of white blood cells, is the biggest and most serious side-effect. Your team will discuss this with you and will start you on antibiotics if infection is suspected.

Other side-effects can include anaemia, which may happen if chemotherapy reduces the number of red blood cells. Bruising and bleeding can also happen because of reduced platelets. Your blood count will be checked every day to help monitor your condition.

After each treatment, your blood count will fall and then 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.

Side-effects vary from person to person and depend on the type of drugs used and the amount of chemotherapy given. Most minor side-effects like rash and nausea can be helped by medication, so tell your doctor or nurse if you are having any problems. Usually, the side-effects go away when the treatment ends, or soon after.

What are the side-effects of chemotherapy?

Anaemia

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

Bleeding and bruising

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

Bleeding gums is also a common sign of low platelets. In women and people assigned female at birth, periods can be heavier and longer than usual during the first few cycles. If you are young, you will be given medication to reduce your menstrual flow.

Let your nurse or doctor know at once if you have any bleeding or bruising, including any unusual vaginal bleeding. You may need a platelet transfusion to help reduce it. Also, use a soft toothbrush, such as a child's toothbrush, and an electric razor when shaving. When you are home, wear rubber gloves when doing household or gardening jobs, to protect yourself from cuts.

Infection

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 conditions such as a cold, a small cut or sore throat could make you very 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. This is the most important thing you can do to help yourself when you are being treated for ALL.

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

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

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

Hints and tips: Avoiding infection

- **Protect yourself against coronavirus by following public health guidelines.** Visit **www.hse.ie** for more information.
- **Avoid crowds and close contact**, such as hugging or kissing. Tell your family and friends not to visit you if they have colds, flu, rashes or other infections. This includes chickenpox, shingles or measles. Let your doctor know if you are in contact with these or any other infections.
- **Wash your hands often during the day**, and apply an alcohol hand gel, especially before you eat and after going to the toilet.
- **Avoid unpasteurised milk, soft cheeses, undercooked meat and poultry, and the skin of raw vegetables and fresh fruit.**
- **Take good care of the skin around your anal area and genitalia.** A wash of this area after opening your bowels and using a barrier, like petroleum jelly, can help to reduce sore or broken skin. This is most important when your white cell counts are low.
- **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.**
- **Ask your doctor about getting vaccinations to protect you** from infection after treatment is over. Some live vaccines may not be suitable for you.
- **When you go home, you will be prescribed one antibiotic and one antiviral medication** to reduce your chances of infection. You should continue taking these until your immune system is stronger.

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 93.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). Thinking or talking about the treatment can also make you feel sick. This is called anticipatory nausea. There are medications that work very 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 should come back once the treatment is over. Pineapple chunks can help stimulate saliva production and improve taste. Speak to the dietitian at the hospital or see our booklet ***Understanding Diet and Cancer*** for advice to help with loss of appetite.

Mouth and throat problems

Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you. Mouth care is very important from the first day of your ALL journey.

Hair loss (alopecia)

During intensive ALL therapy, you will have hair loss all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back after you stop chemotherapy. You may consider getting a wig, which is sometimes covered by private health insurance or with a medical card. You can check this with the medical social worker in the hospital. You can also talk to your specialist nurse about wig services that are available.

Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement/poo often enough) and diarrhoea (frequent loose or watery bowel movements/poo). If you have diarrhoea, take special care to clean and protect the skin around your anus.

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

Skin and nail changes

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

Peripheral neuropathy

Some drugs can affect your nerve endings. This is known as peripheral neuropathy. Tell your chemotherapy nurse or doctor if you have numbness or a tingling or burning sensation in your hands and feet.

Changes in kidney or liver function

Some drugs can irritate or damage kidney or liver 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. Yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Blood tests will be done to check your kidney and liver function before your chemotherapy treatment and daily while you are in hospital.

Infertility and birth defects

Some of the drugs used may cause infertility. It may be temporary or permanent. Chemotherapy can cause birth defects, so you should use contraception to avoid pregnancy until your doctor tells you it's safe to stop. See page 97 for more information.

Late effects

For some types of chemotherapy, side-effects can occur many years later. Although this is rare, some late side-effects can be serious.

You will have a small extra risk of heart attack, stroke and cancer having previously had ALL. You should ensure that you avail of any national screening programmes designed to pick up and prevent cancers. Your medical team will discuss these with you. When you no longer need the care of the haematology team, your GP will be asked to supervise care of your blood pressure, cholesterol and cardiovascular fitness to minimise the risk of heart attacks and stroke in the long term.

Balancing risks and benefits

When you present with ALL, treatment is urgent. This is a fast-growing cancer and left untreated, you will not survive. While there may be side-effects from treatment in the short- and long-term, the only realistic choice is to go ahead with treatment.

Growth factors

To reduce the risk of infection, growth factors may be used. These drugs encourage the growth of white blood cells. They are helpful if the number of white cells is low after chemotherapy. The most commonly used is G-CSF which is 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.

Report any side-effects

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

For more information on the side-effects of chemotherapy or a copy of the booklet ***Understanding Chemotherapy and Other Cancer Drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website, **www.cancer.ie**, for tips on coping with different side-effects.

Steroid therapy

- Steroids can help some cancer drugs to work better.
- Steroids may be given while you are waiting for chemotherapy to start.

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 bone marrow cells. Examples of steroid drugs are prednisolone and dexamethasone. Steroids are given as part of your treatment for ALL. They 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, though not everyone will get side-effects. The more common side-effects that you will feel straight away include:

- Increased appetite and weight gain
- Increased blood pressure
- Stomach upset (acid reflux)
- Increased blood sugar – temporary diabetes
- Fluid retention
- Higher risk of infection, especially thrush

In the medium and long-term, they can cause:

- Sleeplessness
- Mood changes – irritability, anxiety, tearfulness, high spirits
- Bone changes including osteoporosis and bone breakdown (osteonecrosis), especially in the hip joints
- Cataracts

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 or nurse if you get very thirsty. Your nursing team will be monitoring how much urine you pass. 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 or nurse know.

There are prevention plans and treatments for all steroid side-effects. Remember – steroids kill the ALL cells directly and are a huge help for your treatment.

Hints and tips: Steroids

- **Take steroids in the morning** to try to avoid sleep problems.
- **Take steroids with milk or food** to prevent stomach upset.
- **Talk to the hospital dietitian if you are putting on weight.**
- **Report any signs of infection to your 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 14), 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®), dasatinib (Sprycel®) and ponatinib (Incyte®). 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 87 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, severe sunburn and skin cancers. It is best to use a high protection sunscreen – at least factor 30 – when outdoors. You might be more prone to infection, anaemia and bleeding as well. Avoid taking grapefruit, grapefruit juice, pomegranate and Seville oranges. Chemicals in these fruits can stop TKIs from working properly.

Immunotherapy

Immunotherapy helps your immune system to work better to fight cancer cells. Our immune system is often not good at recognising or clearing cancer cells from our body. Sometimes cancer cells find a way of hiding from the immune system, allowing cancer to develop or spread.

Immunotherapy treatments can change special immune cells to help them attack the cancer directly.

Types of immunotherapy

There are several types of immunotherapy for ALL

Monoclonal antibody therapy – Rituximab: Commonly used during induction for ALL.

Bispecific antibody therapy, also called bispecific T-cell engager (BiTE) – Blinatumomab: May be used early in treatment but also useful if the leukaemia comes back after treatment.

Antibody drug conjugate - Inotuzumab ozogamicin: Useful in relapse.

Your medical team will discuss your immunotherapy treatment with you. You can also find out more by searching 'immunotherapy' on **www.cancer.ie**

Side-effects of immunotherapy

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

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

- Reaction at the time of infusion (shivering, shaking, nausea)
- Diarrhoea
- Difficulty carrying out tasks or writing
- Skin rash
- Shortness of breath
- Altered levels of consciousness

These side-effects are usually short term. They are managed by the haematology team so that you can continue to receive the treatment.

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. These drugs are given initially while you are an inpatient and you will be monitored daily for any changes in how you feel. For more information or for a copy of the booklet ***Understanding Chemotherapy and Other Cancer Drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

New developments

New treatments are being developed all the time. For example, a type of immunotherapy called CAR T-cell therapy is now available in Ireland and may be an option in very rare cases. Some treatments are also given as part of a clinical trial (see page 87). You can ask your haematology consultant about new treatments and clinical trials.

Stem cell transplants

Your doctor may recommend a stem cell transplant:

- As a first treatment if your particular type of ALL has a high risk of coming back after treatment
- If your ALL returns after treatment (relapses/recurs)

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 ALL you have and the risk of it coming back

How do transplants work?

A transplant works by destroying all the blood cells in your bone marrow and replacing them with healthy stem cells via a transfusion into your bloodstream. Stem cells are blood cells at their earliest stage of development that will grow into new healthy blood cells. The stem cells usually come from a donor. The donor could be a brother or sister or someone you don't know. 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 Ireland, allogenic transplants are carried out by haematology consultants in St James's Hospital or Children's Health Ireland (CHI). In an allogeneic transplant, a patient receives healthy stem cells taken from another person into a vein. Unlike other transplants, no surgery is involved.

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. If the donor is not related to you but you still matched, this is known as matched unrelated donor (MUD)

Your own bone marrow is first destroyed with high doses of chemotherapy, with or without radiotherapy. Then the healthy marrow or stem cells from the donor are given to you through a central line (drip). The cells then find their way to your bone marrow and grow over a few weeks to replace the bone marrow that was destroyed. New red blood cells, white blood cells and platelets grow back. Most importantly, new lymphocytes grow back and give you a new immune system. Your new immune system recognises your leukaemia as different and will target it for destruction.

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

Stem cell transplants take place in special treatment units. You may spend up to 6 weeks in hospital. For around 100 days after the transplant, you may have to go to hospital very often for check-ups, sometimes a few days a week, for 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 Support Line on 1800 200 700 or visit a Daffodil Centre. You could also ask for one of our transplant booklets.

Clinical trials

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

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

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

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

ALL is one of the conditions in which trials have been ongoing for over 50 years, with each trial making things better for the next group of patients.

More information

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

Supportive care

You will be monitored very closely during your treatment. 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.
- You may need growth factor injections to help increase your white blood cell levels after chemotherapy (see page 77). 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 into a vein. You may be required to stay in hospital until your infection is gone.

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

Bone marrow and blood 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 resistant to treatment or at an advanced stage, you may be referred to the palliative care team. The palliative care team is very experienced in managing the symptoms of advanced cancer, including pain and psychological distress. Palliative care 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.

Managing side-effects and symptoms

How can I cope with fatigue?

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

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

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

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

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Plan your days.** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet ***Understanding Diet and Cancer*** has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 114).
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night. Try to have naps in the earlier part of the day.
- **Try complementary therapies** like meditation or massage, if your doctor says they are safe for you.

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

Will treatment affect my sex life?

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

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

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. But you may find it will be some time before you will feel well enough to have sex again after treatment. Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

Contraception

If you are having sex and you might be fertile, you should use a reliable method of contraception during and for some time after treatment. This is because some chemotherapy drugs and other cancer treatments may harm a developing baby, so it's important to avoid pregnancy at this time. If you are of child-bearing age, you may be asked to have a pregnancy test prior to each cycle of treatment.

Many specialists recommend that you wait for up to 2 years after treatment before trying to start a family or having more children. This time gives your body a chance to recover from the effects of the cancer and its treatment. Ask your doctor's advice about contraception or if you are thinking about having children.

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

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. They are well used to talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Will treatment affect my fertility?

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

Chemotherapy

Men and those assigned male at birth: Chemotherapy for ALL can cause infertility. It may be temporary or permanent. Even though doctors know that some chemotherapy drugs may cause infertility, it is very difficult to say if and when this will happen.

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

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

Stem cell transplants

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

Discussing your options

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

SIMS IVF Clinic provides a service for cancer patients where eggs or sperm can be frozen for later use. However, treatment normally needs to start quickly with ALL, so this may not be possible, especially for egg storage, which can take a few weeks. The ability to produce a good sperm sample can also be reduced if you have ALL.

Coping with infertility

Coping with infertility can bring feelings of sadness, anger and loss of identity. It can help to talk through your worries with someone who is a good listener or with a professional counsellor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

Cancer and complementary therapies

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

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

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your diagnosis. Haematologists generally advise patients not to take any complementary therapies while undergoing intensive therapy for ALL.

Integrative care

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

What's the difference between complementary and alternative therapies?

Complementary therapies are used together with standard medical treatment.

Alternative therapies are used instead of standard medical care.

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

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet ***Understanding Cancer and Complementary Therapies***, or download it from our website **www.cancer.ie**

After treatment

What follow-up will I need?

After your cancer treatment has ended and you are in remission, you will still need to have regular check-ups. 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. At each visit, you will have a full blood count done to make sure your counts are normal. The doctor may order further tests. You will probably have more bone marrow tests to make sure you are still in remission.

At first, your follow-up visits will be quite often but these will become less frequent the longer you are well and free from disease. During the first year you may be checked every 1–2 months. After 5 years you will have yearly check-ups. Sometimes you may need to go to hospital if you get an infection, as your immune system takes time to recover. If you are between check-ups and have a symptom or problem that is worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment if necessary.

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

What if the ALL relapses (recurs)?

Sometimes the leukaemia cells return after being treated. This is called a relapse or recurrence. 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, any cytogenetic or genetic changes in your ALL cells, your age and your response to your first treatment. You can relapse:

- While 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, new treatment options are available and will be discussed with you. Sometimes, similar chemotherapy drugs to the ones you were first treated with will be used. More treatment may or may not include a stem cell transplant.

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

Living with ALL

Be involved in your healthcare

- Learn about ALL so you understand your treatment and know what to expect.
- Don't be afraid to ask questions.
- 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. Ring the haematology team.

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 73 for advice.
- Contact your doctor straight away if you have signs of infection, symptoms of ALL or any other health problems.
- If you develop any problems such as bowel problems, or you find a lump somewhere, 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.
- Attend any national screening programmes that you are eligible for (BreastCheck, CervicalCheck, BowelScreen).
- If you are over 50, have your heart health checked regularly.
- Your skin will remain sensitive to the sun following chemotherapy and there can be an increased risk of developing skin cancer following treatment for ALL. Wear protective clothing such as long sleeves and hats in the sun and always remember to wear factor 50 sunscreen.
- Always tell doctors, dentists and other healthcare professionals that you have ALL. If your white cell count or platelets are low, it can increase your risk of bleeding or infection, so some procedures or treatments may not be suitable.

Vaccinations

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

Living a healthy lifestyle

Many people want to focus on living healthily after a cancer diagnosis. Having a healthy lifestyle is important as it 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 wellbeing. 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.

If you want more information or advice, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website **www.cancer.ie** for tips and publications on healthy living.

Mind your mental health

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

- **Try to manage 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 99 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 114 for more information.
- Having the support of loved ones, healthcare professionals and other people going through a similar illness can also make a big difference. See page 115 for more about getting support.

Work and activities

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

Holidays and insurance

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

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

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

Planning ahead

Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time.

Planning ahead is useful for everyone, whether they have an illness or not.

Planning ahead might include:

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

Who can help me plan?

Think Ahead is a planning booklet with easy-to-read forms to fill in 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

How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer. You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

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

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

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

Anxiety and depression

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

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

Counselling

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

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

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

Ways to get emotional support

Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 138 for more about cancer support services.

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

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

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

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

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

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

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

Peer Support

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

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

Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what’s important in life. Or it opened up new experiences and relationships. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

You and your family

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

Further information and support

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

Changing relationships

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

Supporting someone with cancer

Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support them, practically or emotionally. You might also be struggling with your own feelings and responsibilities. Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one’s illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website **www.cancer.ie** or call our Support Line for free copies of our cancer information booklets.

Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. The Irish Cancer Society funds one-to-one counselling for friends and family members remotely or in person at many local cancer support centres. Talk to your GP or see page 114.

Find out about support for carers

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

How to talk to someone with cancer

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

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet ***Caring for Someone with Cancer***. The booklet has a section on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre or download it at **www.cancer.ie**

Support for you

Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

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

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

Free copies are available from our Daffodil Centres and our Support Line, or download it from our website **www.cancer.ie**

Support resources

Money matters

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

A diagnosis of cancer often means that you will have extra expenses, such as 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.

Practical and financial solutions from the Irish Cancer Society

We provide individualised financial support and practical solutions for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis**

We can tell you about public services, community supports and legal entitlements that might help you and your family. We can also act as advocates for patients and their families who may need extra support after a diagnosis. This might include having a Practical and Financial Officer present when discussing your diagnosis with your employer or at meetings with your financial provider to help them understand your diagnosis.

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

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Medicines
- Medical aids and equipment (appliances), like wigs

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

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

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

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

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

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

Benefits and allowances

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

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

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0818 074 000
- Department of Employment Affairs and Social Protection – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to keep a copy of completed forms, so take a photo or photocopy them before posting.

If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0818 072 000 for information.

If you are finding it hard to cope financially, contact the medical social worker in your 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 135 for more details on our **Transport Service** and the **Travel2Care** fund.

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

Money and finances

Go to **www.cancer.ie** and see our **Managing money** page for information on:

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

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Irish Cancer Society services

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

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Support in your area
- Transport Service
- Night nursing
- Publications and website information
- Practical and financial solutions (see page 128)

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am-5pm. You can also email us any time on supportline@irishcancer.ie or visit our Online Community at **www.cancer.ie/community**

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

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

One of our nursing team will then email you with the time for your video call. The email will also have instructions on how to use Microsoft Teams on your phone, tablet or computer.

Daffodil Centres

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

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

Who can use the Daffodil Centres?

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

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

Telephone Interpreting Service

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

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

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

We will connect you to an interpreter. The interpreter will help you to speak to us in your own language

Peer Support

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

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre. For more information on Peer Support, search 'peer support' at **www.cancer.ie**

Patient Education

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

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

Counselling

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

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

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

Support in your area

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

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

Transport Service

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

- Transport is available to patients having chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for patients having radiotherapy treatment at University Hospital Cork and Bons Secours Hospital, Cork.
- Travel2Care is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatment. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre or satellite centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these supports, please contact your hospital healthcare professional, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Night Nursing

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

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

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

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

Publications and website information

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

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

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

Local cancer support services

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

- **Professional counselling.** The Irish Cancer Society funds one-to-one counselling remotely and through many local support services
- **Support groups,** often led by professionals like social workers, counsellors, psychologists or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques,** such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and aromatherapy
- **Specialist services** such as prosthesis or wig fitting and lymphoedema services, such as education, exercise, self-management and manual lymph drainage
- **Mind and body sessions,** for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

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

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

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 to you.

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 with a view to using them for treatment.

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 blood 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.

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.

Genetic tests Tests that look at the changes in the blood cancer cell deep inside the leukaemia cell. These tests don't answer questions on whether leukaemia is inherited. They are designed to look for possible drug targets and provide information on whether the ALL can be cured.

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 bone marrow.

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

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/recurrence When the leukaemia returns after treatment.

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

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

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

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

Notes/Questions

Notes/Questions

Acknowledgments

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

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Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit **www.cancer.ie** if you want to get involved.

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

Did you like this booklet?

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

Our cancer nurses are here for you:

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

Irish Cancer Society

www.cancer.ie