Irish Cancer Society

Understanding

Chronic myeloid leukaemia (CML)

Caring for people with cancer

Understanding

Chronic myeloid leukaemia (CML)

This booklet has information on:

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

Useful numbers

Specialist nurse

Haematologist

Medical oncologist

Family doctor (GP)

Medical social worker

Emergency

Hospital records number (MRN)

Contents

Fast facts

What is CML?

Page 12

CML is cancer of the blood-forming cells found in the bone marrow. It leads to an increase in white blood cells called granulocytes. It develops gradually in the early stages and progresses slowly over time.

Can CML be treated?

Page 35

The aim of treatment for CML is to put the disease into remission. Remission means leukaemia cells can no longer be detected in your body and you feel well. With the right treatment, many people with CML can lead a normal life. Life expectancy is near similar to people who do not have CML.

Will I be OK?

Page 33

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things and everyone's prognosis is different. Your doctor will advise you on what is likely to happen in your situation.

What kind of treatment will I have?

Page 51

Treatment with a targeted therapy drug called a tyrosine kinase inhibitor (TKI) is usually very effective at controlling the disease in the chronic phase. Chemotherapy and sometimes a bone marrow or stem cell transplant may also be used.

Clinical trials

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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

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

Ways to get in touch

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

See page 109 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 medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

About chronic myeloid leukaemia (CML)

What is leukaemia?

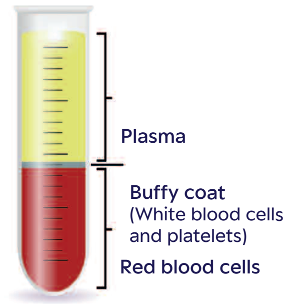
Leukaemia is a cancer that affects your blood. Your body has 3 main types of blood cells:

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

White blood cells are involved in fighting infection.

Platelets form clots, which stop you from bleeding.

What does blood look like?

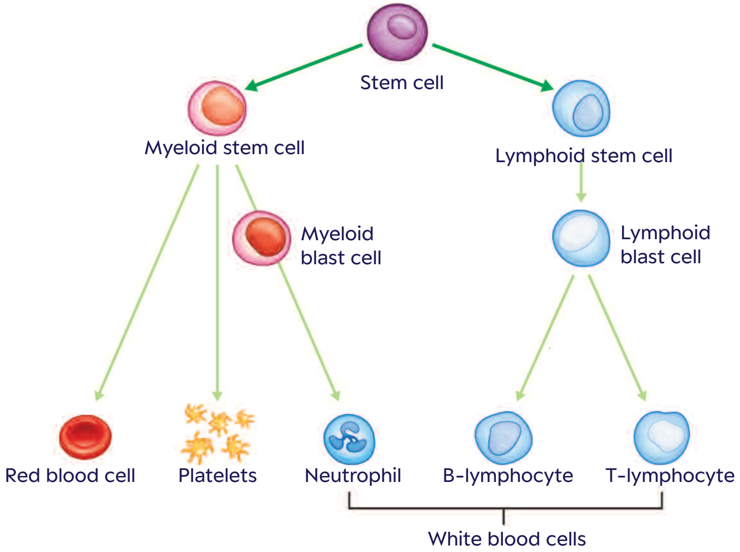


Blood has a liquid part (plasma) and circulating within that are tiny solid bits (cells). Every part of the body is made up of cells. In solid organs, like the liver or heart, cells are fixed in one place. But in the blood, cells flow around the body. This is what makes blood cancers different to cancers 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 (white blood cells that help the body to fight bacterial infections) and other types of white blood 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 blood cells to keep this process going. A healthy marrow makes over 600 billion red, white and platelet cells every day.

Patients with leukaemia have abnormal blood cells that grow out of control, filling up the bone marrow and preventing normal blood cells from being made. This changes the normal balance of good healthy cells in your blood. 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 lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML)

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

What do ‘acute’ and ‘chronic’ mean?

Acute and chronic refer to how quickly the leukaemia develops.

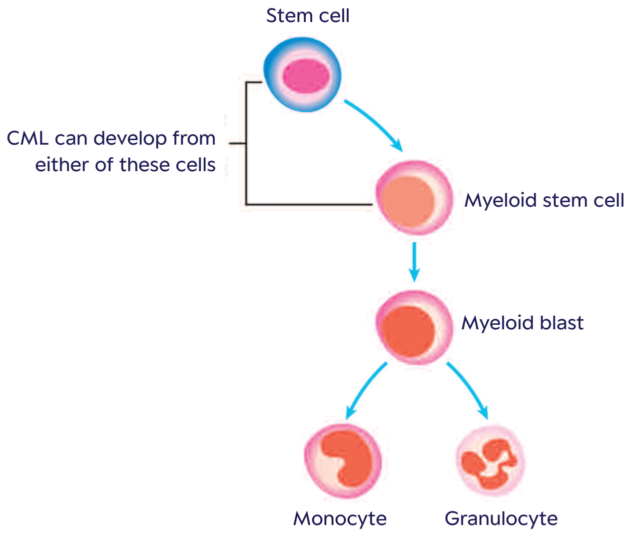
Acute: The leukaemia develops very quickly over days or weeks.

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

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

What is chronic myeloid leukaemia (CML)?

CML affects a group of blood cells known as myeloid cells. These cells begin as stem cells, before developing into immature myeloid cells (myeloid blasts) and eventually becoming fully-functioning mature blood cells.



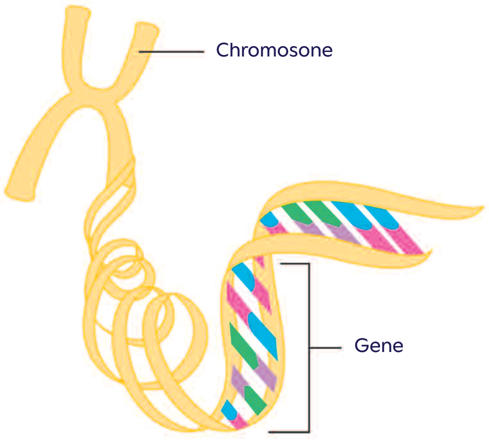
Myeloid cells include a type of white blood cell known as granulocytes. With CML, the body makes too many granulocytes. These fill up the bone marrow, preventing normal blood cells from being made.

Sometimes in CML, myeloid blasts also enter the bloodstream. Since they haven’t developed into mature blood cells yet, they stop the body fighting infection properly. However, this only happens in a small number of CML patients. Most are affected by too many granulocytes.

With the right medication, people with CML can lead a normal life. Life expectancy is near similar to people who do not have CML.

The Philadelphia chromosome

The changes to your blood caused by CML are nearly always because of an abnormal chromosome called the Philadelphia chromosome. More than 9 out of every 10 people with CML (95%) have the Philadelphia chromosome.



The Philadelphia chromosome is not inherited, so it is not passed from parent to child.

What is the Philadelphia chromosome?

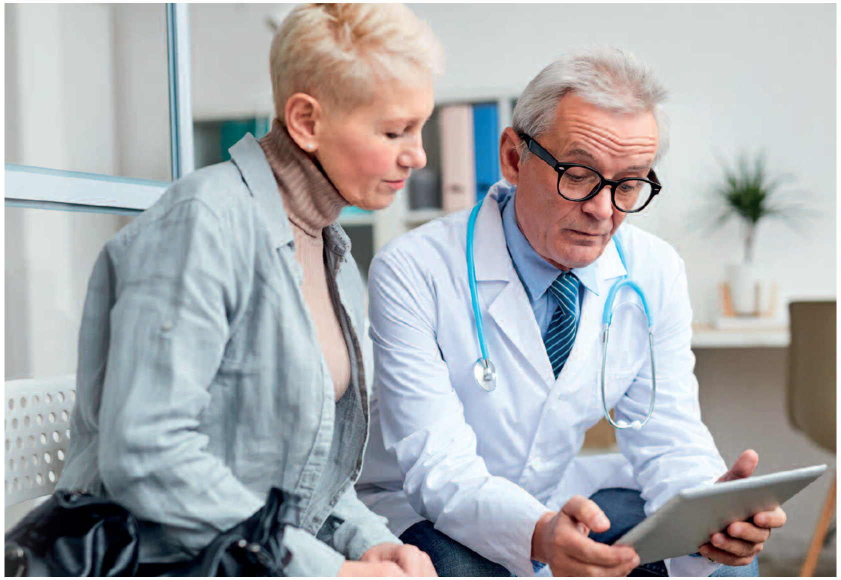
You have 23 pairs of chromosomes in every cell in your body. Chromosomes carry genetic material (genes).

Genes control the activity of different types of cells in your body. If a gene is abnormal, it can make things go wrong with the activities that it controls.

The Philadelphia chromosome is a specific genetic abnormality that is found in almost all cases of CML. It happens when genetic material is swapped between chromosomes 9 and 22. Chromosome 22 becomes shorter than normal. This shorter chromosome 22 is the Philadelphia chromosome. The changes in the chromosome result in an unwanted new gene called BCR-ABL1.

How does the abnormal gene BCR-ABL1 affect blood cell production?

The abnormal BCR-ABL1 gene changes the normal process of how blood cells are produced. The gene produces a BCR-ABL protein (tyrokinase) that causes the bone marrow to produce too many damaged white blood cells, also known as leukaemic cells. This causes the symptoms of CML.



What are the symptoms of CML?

The most common symptoms of CML include:

- Tiredness and looking pale
- Getting infections more often and recovering more slowly from infections
- Weight loss/loss of appetite
- Shortness of breath
- Anaemia (fewer red blood cells)
- Night sweats and fever
- Bone pain
- Unexplained bruising or bleeding
- Sight changes
- Abdominal discomfort or swelling due to an enlarged spleen

Treatment is usually very effective at keeping the symptoms of CML under control. If you do have any symptoms that are troubling you, let your doctor know.

How common is CML?

CML is a rare type of cancer. About 70 people are diagnosed with it in Ireland each year – this is around 15-20% of all leukaemia cases in adults. It commonly affects adults between the ages of 40 and 60. The average age at diagnosis is 50 and more men than women develop CML. It is very rare in children and there is no evidence that CML runs in families.

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 CML, see our website **www.cancer.ie** or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre. The majority of people who get CML have no obvious risk factors and having a risk factor doesn't mean you will definitely get CML.

Preparing for your hospital appointments

Preparing for your hospital appointments

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

Before your appointment

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

What to take to your appointment

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

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

Before leaving the appointment

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

After the appointment

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

If you have to cancel your appointment

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

Questions to ask your doctor

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

What tests will I have?

What phase is my CML at?

What symptoms should I watch for?

What are my treatment options?

What is the aim of my treatment?

How is the treatment given and how long will it last?

Do I have to stay in hospital for treatment?

Are there any vaccinations I should have before or after treatment?

Do I need other types of treatment?

What are the chances of my CML going into remission?

What side-effects can I expect? Will they last long?

Do I need to use contraception during my treatment?

Will treatment affect my chances of having children?

How often do I need check-ups and blood tests after treatment?

Why do I need to keep taking medicine when I feel well?

How will I know if my CML has come back?

Diagnosis and tests

Being diagnosed with CML

Hearing that you have 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

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

- Ask to speak to the haematology clinical 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 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 116.

However you feel, you are not alone.

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 or need a little time to adjust. You may also worry about how other people will react. For example, they may fuss over you or be upset.

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

What tests will I have?

- Tests you may have include blood tests, scans and a bone marrow aspiration (type of biopsy).
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

The following tests give doctors more information about your cancer. This can help them to find out what phase your cancer is in (see page 32). Some tests may also be used to see how well you are responding to treatment.

Full blood count

A full blood count (FBC) finds out the levels of the different types of blood cells in your blood. This test can also give your doctor an idea of your general health. This is an important test as CML affects the blood cells. You will have frequent full blood counts to monitor your disease if you have CML. These tests should be done before your clinic appointment, so that the results can be discussed at the appointment.

Blood film

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

Bone marrow tests

Bone marrow tests involve taking a tiny sample (biopsy) of your bone marrow and looking at it under a microscope. The sample is usually taken from your hip 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 help avoid a bleed. Your team can prescribe you mild painkillers if you feel any discomfort later. If you are having this test done as an outpatient, you will need someone to drive you home.

Chromosome 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. These tests detect big mistakes in the layout of the cell's genetic material. For example, they can tell your doctor if you have the Philadelphia chromosome (see page 13), which can help with planning your treatment.

It is important to note that these 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. This is often done in conjunction with other tests.

PCR (polymerase chain reaction) test

This is a very sensitive blood test that detects the amount of the abnormal BCR-ABL1 gene in your blood. The BCR-ABL1 gene is produced because of the Philadelphia chromosome (see page 13).

Immunophenotyping

Immunophenotyping is a test that checks what kind of proteins or markers are on the surface of the leukaemia cells. This tells doctors more about your CML. This test can be done on cells from your blood or your bone marrow.

Other tests

You may have other tests to give your medical team more information about your CML and about your general health.

Heart function tests

ECG: Sensors are attached to your skin and they can pick up the signals produced by your heart when it beats.

Echocardiogram ('echo' scan): This is a type of ultrasound that can produce a moving image of your heart at work and nearby blood vessels. It gives information about your heart's size and function, for example, how well the heart is pumping.

Other blood tests

Renal (kidney) profile: To see how well your kidneys are working.

Liver function test: To see how well your liver is working.

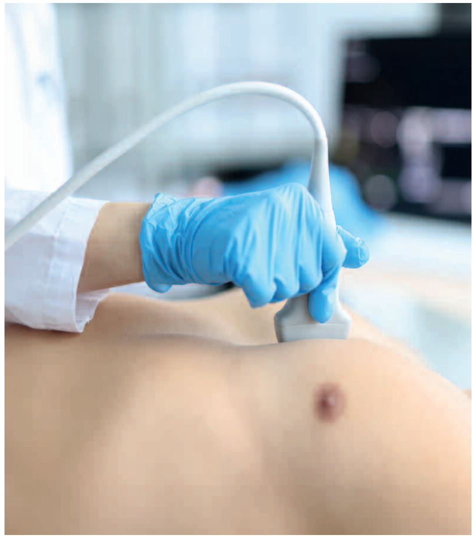
Infection screening: To test for HIV/hepatitis. Your medical team will discuss with you if you need this test.

Thyroid function test: To measure your thyroid hormone levels.

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.

Ultrasound scan



This is a scan that uses sound waves to look at organs and tissues in your body. It is done in the X-ray department of the hospital. The scan is painless and only takes a few minutes. Some gel is spread over your skin, over the area that the doctors are checking. A small device like a microphone is moved back and forth over your skin to take the scan.

The scanning device makes sound waves that are changed into pictures on a computer. These pictures show abnormal changes, such as changes in the size of the spleen.

CT scan (CAT scan)

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

Not everybody will need a CT scan.

Waiting for test results

You may have to wait for up to 4-6 weeks for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Phases of CML

- There are 3 phases of CML – chronic, accelerated and blast.
- Knowing the phase helps your doctor to plan your treatment, as different phases need different treatments.

With most types of cancer, your medical team uses all your test results to stage your cancer. Staging means finding out how big the cancer is and if it has spread to other parts of your body. CML is a bit different – the disease is described in phases rather than stages.

CML can present in 3 phases:

- **The chronic phase** (most common)
- **The accelerated phase** (much less common)
- **The blast phase** (rare)

The phases are mainly based on how many immature (blast) white blood cells are in your blood or bone marrow.

1. The chronic phase

Around 9 out of 10 people diagnosed with CML are in the chronic phase. In this phase, fewer than 10% of the blood cells in your bone marrow are blast cells and the disease develops very slowly.

You may only have mild symptoms or no symptoms at all during this phase. Treatment may keep your CML in the chronic phase for a long time – maybe even for your whole life if you keep taking your medication.

2. The accelerated phase

In this phase, there are more blast cells present – between 10% and 19% of the blood cells in your bone marrow are blast cells. You may develop new or more obvious symptoms if your CML enters this phase. For example, you may feel more tired than usual or you may lose weight. See page 15 for more about symptoms.

3. The blast phase

In this phase, more than 20% of the blood cells in your bone marrow are blast cells. These blast cells can also be found in the blood and in rare cases, can invade other organs.

This phase is also called an acute phase or a blast crisis. During this phase, your chronic leukaemia can transform into an acute leukaemia (usually acute myeloid leukaemia).

If your CML enters the blast phase, you will probably have more serious symptoms, such as pain in your tummy or bones, a swollen spleen, repeated infections and unusual bleeding, such as bleeding gums and nosebleeds.

> With the right treatment, CML often stays in the chronic phase.

Asking about your prognosis

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

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

Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

- Think 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 your prognosis from your doctor. They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- Ask a friend or family member to 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.
- Get emotional support if you need it. If you feel upset or anxious about your prognosis, you can get support from family, friends or your hospital team.

You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treating CML

How is CML treated?

- Targeted therapies known as tyrosine kinase inhibitors (TKIs) are the most common treatment for CML.
- Some patients may benefit from chemotherapy or a stem cell transplant.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

The aim of treatment for CML is to put the disease into remission. Remission means leukaemia cells can no longer be detected in your body and you feel well.

The type and amount of treatment you will need depends on which phase your CML is in, your general health and any symptoms you may have.

Chronic phase

Treatment with targeted therapy drugs called tyrosine kinase inhibitors (TKI) is usually very effective at controlling CML in the chronic phase.

The Philadelphia chromosome in CML produces an unwanted gene called BCR-ABL1 (see page 13). This gene gives rise to a protein called a tyrosine kinase. TKIs work by blocking the action of the BCR-ABL1 tyrosine kinase protein, which causes CML cells to grow and reproduce out of control.

TKIs are always given as tablets that you take at home. TKIs can often control the disease for many years and most people can live a normal life. You will have regular blood tests to check how well you are responding to treatment.

Accelerated phase

Your doctor may suggest different TKIs or chemotherapy, depending on your previous treatment, blood results, symptoms and overall health.

Blast (acute) phase

The aim of treatment is to get the disease under control and return it to the chronic phase. You may be given TKIs, chemotherapy and in some cases, a stem cell transplant. You may also have treatment to ease symptoms, such as bone pain or an enlarged spleen.

Recurrence

Recurrence means the leukaemia cells have come back after a time in remission. If this happens, you will have treatment to try to put it back into remission.

Types of treatment

Targeted therapies

Most people with CML will be treated with a type of targeted therapy called a tyrosine kinase inhibitor (TKI). TKIs work by blocking the tyrosine kinase protein, which helps the cancer cells to grow. See page 53 for more details.

Chemotherapy

This is the use of drugs to kill the cancer cells. Chemotherapy may be given on its own or with other treatments. See page 60 for more details.

Stem cell transplant

A stem cell transplant (or bone marrow transplant) is done in a very small number of cases. The idea of a transplant is that healthy stem cells can make new healthy blood cells in your bone marrow. Transplants are not suitable for everyone. See page 65 for more details.

Where will I be treated?

You may be transferred to another hospital from the one where you received your diagnosis, depending on your diagnosis and your suggested treatment plan. Currently in Ireland, any hospital that has a consultant haematologist can and will manage CML patients.

Multidisciplinary team

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

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything.

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

Time to think

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

Second opinion

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

Accepting treatment

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

Giving consent for treatment

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

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

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

Individual treatment

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

Waiting for treatment to start

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

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works. If you are worried, talk to your doctor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Pre-treatment workshops

Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on certain treatments, including what to expect and how to manage side-effects.

You might like to focus on your own health while you're waiting for treatment. This can help you prepare for your treatment and feel more in control. For more information, see page 45.

Who will be involved in my care?

Some of the following health professionals may be involved in your care.

Haematologist: A doctor who specialises in treating blood and bone marrow diseases, including blood cancers.

Medical oncologist: A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

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

Advanced nurse practitioner (ANP): ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment. In some hospitals, ANPs run Acute Oncology Clinics for people who need help with side-effects or other problems during their treatment. Ask your doctor or nurse if there is an Acute Oncology Clinic in your hospital.

Medical social worker: A person trained to help you and your family with social and practical issues and give you emotional support. 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 how to 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.

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.

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

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

Psychologist: A specialist who can talk to you and your family about how you can cope with your diagnosis.

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

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

How can I help myself?

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

Eat well

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

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

Ask to talk to the dietitian at the hospital for advice on the best diet for you. 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 from our website **www.cancer.ie**

Stay active

If you are able, it can really help to be active before, during and after your treatment. Keeping up or increasing your activity levels can help to:

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

Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you and may refer you to a physiotherapist to advise you about exercise.

Quit smoking

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

- Non-smokers are likely to have fewer or less severe side-effects during cancer treatment, such as chest infections
- Smoking can reduce how well radiotherapy and some other anti-cancer treatments work
- Not smoking reduces your chance of further illness

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.

Take care of your cardiovascular health

Cardiovascular health refers to your heart and blood vessels. Cardiovascular risk factors include type 2 diabetes, high blood pressure, obesity and high cholesterol. It is important to try to control these risk factors if you have CML. Your GP can help with this.

Take care of your teeth

It's a good idea to have a dental check-up before starting treatment. Treatment can increase your risk of infection, so it's best to have any fillings or other dental work done before you start. Tell your medical team about any planned dental treatment and tell your dentist about your diagnosis of CML.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you and tell you anything important. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE. Your doctor or nurse can also advise you on specific websites or support groups for patients diagnosed with CML. You can also speak to a cancer nurse by calling our Support Line on 1800 200 700.

Involve your family and close friends

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

Use your support network

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

Try relaxation and stress management techniques

Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups – online and in person - to help you learn these techniques.

Accept change in your life

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

Know that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope (see page 93).

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

Targeted therapies – TKIs

The main treatment for CML is a type of targeted therapy called a tyrosine kinase inhibitor (TKI). The Philadelphia chromosome in CML produces an unwanted gene called BCR-ABL1 (see page 13). This gene gives rise to a protein called a tyrosine kinase.

TKIs work by blocking the action of the BCR-ABL1 tyrosine kinase protein, which causes CML (granulocytic) cells to grow and reproduce out of control. Most people with CML have this abnormal gene.

Nearly everyone with CML will be treated with a TKI. If your CML doesn’t respond to one type of TKI, you will usually be given a different type. Examples of drugs used for CML include imatinib, nilotinib, dasatinib, bosutinib, ponatinib and asciminib.

TKIs are taken as a tablet, once or twice a day, depending on the drug used. You will stay on TKIs permanently as long as they are working to control your CML, even if your blood tests are normal and you feel well. If you stop taking TKIs, the effects of the CML may return.

Hints and tips: Taking TKIs

- **Take your medication exactly as your doctor recommends.** Don't stop taking your tablets, even if you no longer have any signs of CML.
- **If you find it hard to remember to take your tablets, plan ways to help you remember.** For example, keep your pills somewhere where you will see them, set a reminder on your mobile phone or use a 7-day pill container.
- **TKIs can cause muscle cramps. Eating more calcium- and magnesium-rich foods may help.** Calcium is found in dairy products. Good sources of magnesium include leafy green vegetables, wholegrains, beans, nuts and fish.
- **Avoid grapefruit, pomegranate and Seville oranges.** Chemicals in these fruits can stop TKIs from working properly.
- **Ask your doctor, pharmacist or clinical nurse specialist about any other drugs, herbs and supplements** that may stop your TKIs from working well or that may harm your health when you are taking TKIs.
- **When you are prescribed any new medications, ask your doctor or pharmacist to check whether they might interact with your CML medication.**
- **Look after your skin to try to avoid rashes.** Moisturise your skin with a product recommended by your healthcare team and protect your skin from the sun. Avoid products that dry out or irritate the skin, such as soaps or perfumed products.
- **Always tell your doctor or nurse if you feel unwell or have any symptoms that are troubling you.** It may be useful to keep track of any side-effects and symptoms in a notebook or on your phone. That way you will be able to remember them when talking to your doctor or nurse.
- **If you find it hard to swallow the capsules get advice from your medical team on how to take them safely.**
- **Don't breastfeed while taking TKIs,** as the drug may pass into your milk.
- **Use contraception if you are fertile and having sex.** TKIs can harm an unborn baby. See page 76 for more. Tell your medical team if there is any chance you are pregnant.

Tell your doctor about any prescribed or over-the-counter medicines you're taking, as well as any herbs, supplements or vitamins. Some may interact with your TKIs and stop them working properly.

What are the side-effects of TKIs?

Any side-effects you get will depend on the drugs being used and will vary from person to person. Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. You should also be given written information on the drug to take home with you.

Side-effects of TKIs include:

Risk of infection

TKIs can make you more likely to get infections. You will be asked to watch out for signs of infection at all times and contact your doctor or the haematology ward if you have signs of infection. These signs include feeling shivery and unwell, having a high temperature or feeling suddenly unwell, even if your temperature is normal, having a cough, or pain passing urine. Do check your temperature if you are feeling unwell. Your hospital team will give you temperature guidelines to follow. Most haematology units have a direct phone number to call if you have signs of infection. You should always call if you are feeling unwell in any way. You can call at any time – including during the night, at weekends and on bank holidays.

Hints and tips: Avoiding infection

- **Avoid crowds and close contact,** such as hugging or kissing, with people who have colds or flu and other infections. This includes chickenpox, shingles and measles.
- **Let your doctor know if you are in contact with these infections.**
- **Wash your hands often during the day,** especially before you eat and after going to the toilet.
- **Avoid unpasteurised milk, soft cheeses, undercooked meat and poultry, and the skin of raw vegetables and fresh fruit.**
- **If you have a high temperature, or if you suddenly feel shivery or unwell, even if your temperature is normal, contact your doctor or the hospital immediately.**

Fluid retention

You may gain weight or you may feel breathless if fluid collects around your lungs. Tell your doctor if you are putting on weight due to fluid retention.

Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 71.

Skin changes

You may develop an itchy rash. Your doctor can prescribe creams to help with this.

Nausea

Some drugs may cause nausea (feeling sick), but this tends to be mild. Usually, you will be given a prescription from the hospital for anti-sickness medications before you start your treatment.

Diarrhoea

Diarrhoea is passing frequent bowel motions (poo) that are soft, loose and watery. Drink plenty of water and let your doctor know if it lasts for more than 24 hours.

Headaches

Let your doctor know if you have headaches. Your doctor can advise you which painkillers to take.

Muscle, bone and joint pain

Your doctor can prescribe painkillers to ease this.

Anaemia

Anaemia is when you have a low number of red blood cells. This can make you feel tired and breathless. A blood transfusion can be given if your red blood cells are low. This will help you to feel more energetic and less breathless. You may also be given an injection of a drug called erythropoietin to increase the level of your red blood cells.

Bruising and bleeding

Tell your doctor if you have any unexplained bruising or bleeding, such as nosebleeds or bleeding gums. You will need a blood test to make sure that your blood is clotting properly.

Constipation

If you find it painful or hard to pass a bowel motion (poo), you may be constipated. Drinking plenty of fluids, eating a high-fibre diet and taking gentle exercise usually helps to relieve constipation. Sometimes you may need to take medicine (laxatives). Talk to your nurse or doctor about this.

Other side-effects

Other common side-effects include cold or flu symptoms like a fever, runny nose or sore throat.

Rarely, some targeted therapies can cause issues such as an irregular heartbeat, high blood sugar, a build-up of fluid around the heart and lungs, hair loss and high cholesterol levels. Longer-term side-effects may include heart problems and problems with blood vessels.

Not everyone will get these side-effects. It varies from person to person and also depends on the drug being used and the dose. You will be monitored carefully during your treatment to watch out for any problems. As well as your routine blood tests, you may need to have additional blood tests to check your blood sugar and cholesterol levels. Your doctors and nurses will tell you if you need these tests.

Report any side-effects

Tell your doctors and nurses straight away if you experience these or any other side-effects. There are many ways to relieve them and make you feel better. It is important that you look after your general health when you are taking TKIs by eating healthy foods, keeping a healthy weight and not smoking.

Chemotherapy

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

Chemotherapy is a treatment that uses drugs to kill cancer cells. Although TKIs are the standard treatment for most people with CML, chemotherapy is sometimes given:

- If TKIs are not effective or are not suitable
- To control symptoms when you are first diagnosed
- To try to stabilise blast-phase CML
- As a high-dose treatment before a transplant

You might also receive your chemotherapy as part of a clinical trial. Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. See page 67 for more about clinical trials.

How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. For example, you might have a few days of treatment every week for 3 weeks and then a week off. This rest period allows your body time to recover from the side-effects of treatment. The number of treatments and cycles can vary, depending on your cancer type and how well you respond to treatment.

How is chemotherapy given?

Chemotherapy for CML is given in tablet form in the chronic phase. For CML in the accelerated or blast phase, you may have a combination of chemotherapy drugs, usually through a drip.

What kinds of drugs are used?

There are several chemotherapy drugs used to treat CML. Your doctor or nurse will discuss your treatment with you. Chemotherapy drugs can be used on their own or in combination with each other.

Hints and tips: Understanding your drug treatment

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

If you know the name of your drug, you can visit the Health Products Regulatory Authority's website at **www.hpra.ie** for 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.

What are the side-effects of chemotherapy?

Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

The side-effects of chemotherapy vary from person to person. Some people have fewer side-effects than others. The type of side-effects you might get and how severe they are mainly depends on the amount of chemotherapy you have and the drugs used. Ask your doctor or nurse if you're worried about side-effects or have any questions.

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

- **Fatigue:** Fatigue is very common. It can make you feel tired and weak. For more information see page 71.
- **Nausea and vomiting:** Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). There are treatments that work well to prevent nausea and vomiting. Tell your doctor or nurse if they are not working well for you. Thinking or talking about treatment can also make you feel sick. This is called anticipatory nausea. Tell your doctor or nurse if you have these side-effects.
- **Risk of infection:** Chemotherapy drugs make you more likely to get infections. You will be given a number to call for advice if you have signs of infection. If you are an inpatient, you will be monitored for signs of infection. These signs include feeling shivery and unwell, having a high or low temperature, having a cough or sore throat, or pain passing urine.
- **Anaemia:** Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment. You may need a blood transfusion to treat your anaemia.

- **Bleeding and bruising:** Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums. You may need a platelet transfusion.
- **Mouth and throat problems:** Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.

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

- **Constipation and diarrhoea:** Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements). Your doctor can give you medication to help, if needed.
- **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. It's important to tell your doctor if you have numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

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

- **Allergy:** On rare occasions, people can have a reaction to certain chemotherapy drugs. Reactions can include rash, itching, low blood pressure and shortness of breath.
- **Blood clots:** Chemotherapy and having cancer can both increase your risk of developing blood clots. A blood clot may cause pain, redness and swelling in your leg, or breathlessness and chest pain. Contact your hospital immediately if you have any of these symptoms, as blood clots can be serious. Usually they are treated with medication to thin your blood.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. You will be given contact 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.

Transplants

Transplants are mainly used when CML does not respond well to the various TKIs or becomes resistant to them, although they may also be used for a patient who is still taking TKIs.

A transplant may be suggested at any phase of CML. A transplant is a very intensive treatment, so it is not suitable for every patient.

How do transplants work?

A transplant works by destroying all the blood cells in your bone marrow using high doses of chemotherapy, with or without radiotherapy. These blood cells are then replaced with healthy stem cells, which are given to you through a central line (drip).

Stem cells are blood cells at their earliest stage of development that will grow into new healthy blood cells. The stem cells are usually taken from a donor. This is called an allogeneic transplant.

The stem cells grow over a few weeks to replace the blood cells that were destroyed.

Stem cell transplants take place in special treatment units only. You may spend up to 6 weeks in hospital. For 6 to 12 months after the transplant, you may have to go to hospital very often for check-ups, antibiotics or blood transfusions.

Your doctor will discuss this treatment with you if they think it is needed or suitable for you. For more information, contact our Support Line on 1800 200 700 or visit a Daffodil Centre.

For most people, TKIs work very well to control their disease and so a transplant is not necessary.

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 get a new trial drug. Or you may be given existing treatments used in different ways. For example, you may be given a different dose of a drug or you may be given 2 treatments together.

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

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

More information

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

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

Managing side-effects and symptoms

How can I cope with fatigue?

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

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

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

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

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Plan your days:** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. 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 92).
- **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 complementary therapies** like acupuncture or yoga, if your doctor says they're safe for you.

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

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, acupuncture, aromatherapy and yoga.

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

It's very important to talk to your doctor if you're thinking of using complementary therapies. Tell them also if you're using or considering using over-the-counter or herbal medications. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

Integrative care

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

What's the difference between complementary and alternative therapies?

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

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

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

More information

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

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. You can also get a copy of our booklet, ***Understanding sex, sexuality and cancer***. Call our Support Line, visit a Daffodil Centre or download it from **www.cancer.ie**

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

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

Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. Some chemotherapy and other cancer drugs may harm a developing baby.

If you are only taking TKIs, women and people assigned female at birth are advised to avoid pregnancy because TKIs have been linked to babies being born with abnormalities. Men and people assigned male at birth can continue to take TKIs when trying to have a baby as this will not harm the baby.

Because people with CML will most likely need to take TKIs permanently, it will affect any plans you have to start a family or have more children (see page 77). Ask your doctor's advice about contraception or if you are thinking about having children.

Asking for advice

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

Talk to your doctor about contraception if you're sexually active.

Will treatment affect my fertility?

The most common treatment for CML is TKIs. It isn't safe for women and people assigned female at birth to get pregnant while taking TKIs because they can harm the baby. Men and people assigned male at birth can continue to take TKIs when trying to have a baby.

Other treatments can also affect fertility in both men and women, either temporarily or permanently.

Discuss any worries you have about fertility with your doctor before treatment starts. They can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

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

After treatment

What follow-up will I need?

Once you are in remission, you can begin to return to your everyday life as soon as possible. Your treatment with TKIs will continue and you will still need to have regular check-ups. This is called follow-up.

For the first year, you will likely have your bloods checked every month for the first 3 months and then every 3 months. After 1 year, if your response is excellent, you will likely be checked every 6 months.

It's important to go to your follow-up appointments, even if you feel well and have no symptoms. The tests you will have can tell your doctor how well you are responding to treatment and spot any changes in your condition. Your doctor can also check for signs of the cancer coming back and new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that suitable treatment can be given.

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

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.

You may also need to go to hospital if you get an infection, as your immune system will take time to recover.

How will I know if my treatment is working?

At your follow-up appointments, your doctor will examine you and do blood tests. Other tests such as bone marrow and cytogenetic tests can be arranged if needed.

The tests will show how well your treatment is working. Depending on the results of your tests, sometimes the doctor will give you a different drug or change your dosage.

Ways to measure response to treatment

Full blood count (haematologic response)

A haematologic response is based on the effect of treatment on your blood cells.

- Complete haematologic response (CHR): Your full blood count is normal and no leukaemia (blast) cells can be detected in the blood. Your spleen is a normal size.
- Partial haematologic response: There has been some improvement in your blood count, but there are still signs or symptoms of CML. The spleen may be enlarged. Most people get a haematological response within 3 months of starting treatment with TKIs.

Cytogenetic tests (cytogenetic response)

A cytogenetic response is based on a more sensitive test that measures the amount of cells in your bone marrow that have the Philadelphia chromosome (Ph+ cells). If no Ph+ cells are found, it is called a complete cytogenetic response.

Molecular tests (molecular response)

A molecular response is based on the results of a PCR test, which looks for the BCR-ABL1 gene in the blood or bone marrow. This is a very sensitive test that can detect one leukaemia cell in up to 10,000 normal blood cells.

- Complete molecular response (CMR): The PCR test cannot detect any BCR-ABL1 gene in your blood.
- Major molecular response (MMR): A tiny amount of the BCR-ABL1 gene is found in your blood.

What if the CML comes back (recurs)?

If the CML starts to cause symptoms again after remission, this is called recurrence. CML can still be treated after recurrence to try to put it back into remission.

Living with CML

Be involved in your healthcare

- Learn about CML so you understand your treatment and know what to expect.
- Don't be afraid to ask questions. There are some questions you might like to ask on page 22.
- Keep all your appointments.
- 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. Get a name and number from the hospital so you know who to contact if you have any worries or questions.

Take your medication

If you are on TKIs it is very important to keep taking them, even if you are in remission and feel well. If you stop taking your medication or miss even one or two doses you may relapse. This means your body will start to produce leukaemia cells again and you may develop symptoms. Ask your doctor or pharmacist if you have any questions about your medication.

Take care of your health

Watch out for any signs of infection or other problems and contact the hospital straight away if you have any symptoms that are troubling you. Some people may experience pneumonia or other lung problems. You may find that you have excess mucus, coughing, pain, blocked sinuses or a mild cold. See page 56 for advice on avoiding infections.

If you need treatment for another medical condition, tell the person treating you that you have CML and about any medication you’re taking.

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

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

Vaccinations

You will probably be advised to get certain vaccines, such as the flu vaccine and the pneumococcal vaccine. Some vaccinations may not be suitable for you if your immune system is low. For example, live vaccines. Ask your doctor about any vaccinations you should have and make sure you get them.

Leading a healthy lifestyle

Many people want to live a healthy life after a diagnosis of CML. Having a healthy lifestyle is important as it can help you to:

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

A healthy lifestyle includes:

- Avoiding alcohol
- Checking your skin for any changes and protecting yourself from the sun by wearing sunscreen (at least factor 30+).
- Having all the recommended cancer screening tests, such as bowel cancer screening
- Exercising
- Taking vitamin supplements as advised by your doctor, if blood tests show you have a deficiency
- Staying at a healthy weight
- Not smoking

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

The uncertainty of living with CML and coping with any symptoms can be stressful. The following may help:

- Try to avoid additional stress wherever possible. Spend time with your friends and family. Make time to relax and do the things that you enjoy.
- Use stress-management techniques if you do feel stressed. Try complementary therapies and relaxation techniques like yoga, meditation, mindfulness or aromatherapy. See page 73 for more about complementary therapies.
- Counselling or a short course of medication may also help you, if you are finding it hard to cope. See page 92 for more information.
- Having the support of loved ones, healthcare professionals and other people going through a similar diagnosis can also make a big difference. See page 93 for more about getting support.

Work and activities

Once you are on treatment and start to feel well, you should talk to your doctor about returning to work or study and carrying on with your usual activities like socialising, sports and hobbies.

Holidays and insurance

You may decide to go on a holiday once your CML 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 is 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.

After-treatment workshops

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

Coping and emotions

How can I cope with my feelings?

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

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

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

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

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

Anxiety and depression

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

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

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

Counselling

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

The Irish Cancer Society funds free 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, email the nurses at supportline@irishcancer.ie or visit a Daffodil Centre.

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

Ways to get emotional support

Find out about support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 116 for more about local cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people with cancer 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 healthcare team can refer you to psycho-oncology services if they're available at your hospital.

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

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

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

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

Peer Support

Peer Support is the Irish Cancer Society's free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. To be referred to a Peer Support volunteer, call 1800 200 700 or contact your nearest Daffodil Centre.

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

Positive feelings

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

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

You and your family

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

Changing relationships

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

Further information and support

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

Supporting someone with cancer

How you can help

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 free one-to-one counselling for friends and family members remotely and through many local cancer support centres. Talk to your GP or see page 92.

Find out about support for carers

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

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

Support for you

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

Our booklet, ***Caring for someone with cancer***, has lots of information on:

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

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

How to talk to someone with cancer

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

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

Support resources

Money matters

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

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

Irish Cancer Society Welfare and Supports Team

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

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

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

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

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

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

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

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

Benefits and allowances

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

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

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

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to 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 your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 113 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

Money and finances

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

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

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

Irish Cancer Society services

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

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Support in your area
- Transport Service
- Night Nursing
- Publications and website information
- Welfare and Supports Team services (see page 106)

Support Line Freephone 1800 200 700

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

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

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

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

Daffodil Centres

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

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

Who can use the Daffodil Centres?

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

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

Telephone Interpreting Service

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

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

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

We will connect you to an interpreter.

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

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers 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 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 1800 200 700.

Transport Service

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

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

Night Nursing

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

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

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

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

Publications and website information

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

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 (formerly Twitter)
  Instagram

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

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

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

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

What does that word mean?

Anaemia: A decrease in the number of your red blood cells. It can cause fatigue, breathlessness and pale skin.

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

Blast cells: Immature blood cells.

Blood film: A test that involves a blood sample. The sample is examined by your haematologist under a microscope to determine the amount of leukaemia cells present.

Bone marrow: The soft spongy material found in the centre of most bones. All of the body's blood cells are made in the bone marrow.

Bone marrow aspirate: A test that involves removing a small amount of bone marrow fluid and cells from your bone and looking at it under a microscope.

Bone marrow biopsy: A test that involves removing solid bone marrow from your bone and looking at it under a microscope.

Chemotherapy: Treatment using drugs to cure or control cancer.

Chromosome: Strands of genetic material called DNA that carry the instructions that tell cells how to grow and reproduce.

Cytogenetics: Tests that look at the number and shape of the chromosomes in your blood cells.

Fatigue: Ongoing tiredness often not helped by rest.

Growth factors: Drugs that encourage the growth of white blood cells in your bone marrow and which reduce the risk of infection.

Granulocyte: A type of white blood cell that helps to fight infection.

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

Haematology: The study of blood and blood disorders.

Immunophenotyping: Tests that check what kind of proteins or markers are on the surface of leukaemia cells.

Leukaemia: Cancer of the white blood cells.

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

Nausea: Feeling sick or wanting to be sick.

Neutropenia: A reduced number of white blood cells called neutrophils. It can put you at risk of serious infection.

Platelets: Blood cells responsible for clotting.

Red blood cell: Blood cells that carry oxygen to every cell in your body.

Recurrence: When disease returns following a stable/remission phase.

Stem cell transplant: A treatment where you receive high doses of chemotherapy to kill off all the blood cells and leukaemia cells in your bone marrow. You then receive stem cells donated from a suitable donor, which can make new healthy blood cells in your bone marrow.

Tyrosine kinase inhibitors (TKIs): Drugs that stop the action of the abnormal gene, BCR-ABL1, so that your body can produce healthy white blood cells.

White blood cell: Blood cells responsible for fighting infection.

Notes/Questions

Notes/Questions

Notes/Questions

Notes/Questions

Acknowledgments

This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave 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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Published in Ireland by the Irish Cancer Society.

The Irish Cancer Society is a registered charity, number CHY5863.

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