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

Surgeon

Radiation therapist

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 25

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, CML often stays in the more stable, chronic phase.

Will I be OK?

With the right medication, many people with CML have no symptoms and can lead a normal life, but it's hard to predict exactly what will happen with your disease. The best thing to do is to talk to your consultant.

What kind of treatment will I have? Page 25

For CML in the more stable, chronic phase, treatment with a targeted therapy drug called a TKI (tyrosine kinase inhibitor) is usually very effective at controlling the disease. This may also be given for CML in the accelerated or blast phases. Chemotherapy and sometimes a bone marrow or stem cell transplant may also be used.

Are there side-effects from treatment?

Most treatments cause some side-effects. Read about the different treatments to learn more about their possible side-effects.

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

We're here for you Page 94

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

Ways to get in touch

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

See page 94 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**

We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and care – they know your medical history and your individual circumstances.

About CML

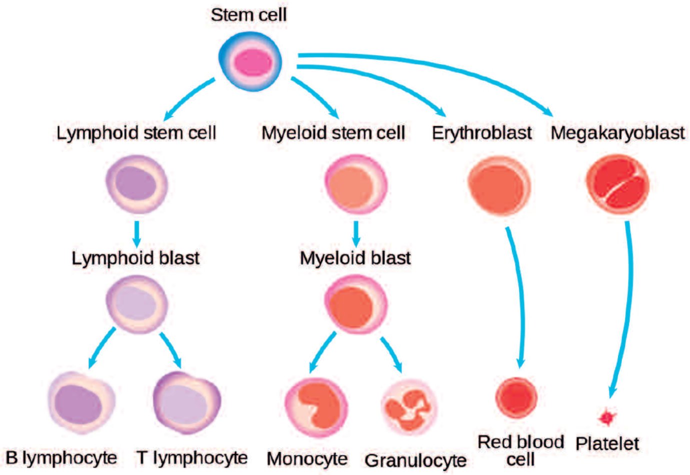
About CML

About blood cells

All types of blood cells are normally made by your bone marrow. Bone marrow is the soft spongy tissue that fills the centre of your long bones. For example, your hips and breast bone. The smallest and most immature type of cells found in your bone marrow are called stem cells. All blood cells start out as stem cells and develop into three main types of blood cells:

1. **Red blood cells** carry oxygen from your lungs to the rest of your body and carry carbon dioxide from the tissues back to the lungs. to all the tissues in your body.
2. **White blood cells** are involved in fighting infection. The 5 types are neutrophils, lymphocytes, basophils, monocytes and eosinophils.
3. **Platelet cells** are responsible for blood clotting.

Once these cells are made, they leave your bone marrow and enter your bloodstream. Normally, all the blood cells are made and replaced by your bone marrow when needed. The entire process is well controlled, but with leukaemia this control is lost.



Pictures courtesy of Cancer Research UK/Wikimedia Commons

What is leukaemia?

Leukaemia a blood cancer. When leukaemia develops, immature blood cells (stem cells) grow quickly but don't develop into mature white blood cells. These immature cells (blast cells) fill up your bone marrow instead of going into the blood. This prevents normal blood cells from growing in your bone marrow. This changes the normal balance of good healthy cells in your blood, which means:

- There aren't enough red cells or platelets in your blood to do their normal jobs.
- The white cells that are produced aren't fully developed, so they can't fight infection as they should.

Types of leukaemia

Leukaemia is a complex disease. There are many different types. There are four main types of leukaemia:

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

Leukaemia is described by:

The type of white blood cell affected

Granulocyte white blood cells develop from myeloid stem cells. Myeloid cells are the body's quick defence against general infection. When granulocyte cells are affected it is called myeloid leukaemia. CML affects the granulocyte white blood cells. CML can also be called chronic granulocytic leukaemia.

Lymphocyte white blood cells develop from lymphoid stem cells. Lymphoid cells develop slowly. Lymphoid cells are more specific and target certain types of infection. When lymphocyte cells are affected it is called lymphocytic leukaemia.

How quickly it develops

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

Chronic: The disease develops slowly, usually over months or years. Or it keeps coming back (recurring).

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

Each type of leukaemia has its own features and treatment. This booklet deals with CML only. For free booklets on the other types of leukaemia, contact our Support Line on 1800 200 700 or visit a Daffodil Centre.

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.

Having a risk factor doesn't mean you will definitely get CML.

What is chronic myeloid leukaemia (CML)?

CML is a type of leukaemia (cancer of the blood that starts in the bone marrow).

CML is a slow-growing cancer of immature white blood cells (myeloid cells). These myeloid cells can be seen in the bone marrow and blood by the haematology doctor.

With the right medication, many people with CML have no symptoms and can lead a normal life.

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.

What is the Philadelphia chromosome?

You have 23 pairs of chromosomes in every cell in your body. Chromosomes carry genetic material (genes). The Philadelphia chromosome occurs when a piece of chromosome 9 breaks off and attaches to chromosome 22. It is called the Philadelphia chromosome because it was first described by a laboratory in Philadelphia. The Philadelphia chromosome is not inherited, so it is not passed from parent to child.

What are 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 process it controls.

What goes wrong with CML?

CML usually happens when the normal process of making new cells goes wrong, and a new abnormal gene called BCR-ABL1 is made. The Philadelphia chromosome is a specific genetic abnormality found only in CML. It happens when genetic material is swapped between chromosomes 9 and 22. Chromosome number 22 becomes shorter than normal. This shorter chromosome 22 is the Philadelphia chromosome. The changes in the chromosomes 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 and replaced. The gene produces a BCR-ABL protein (tyrokinase) that causes the bone marrow to produce too many immature or damaged white 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
- Swollen lymph nodes
- Bone pain
- Unexplained bruising or bleeding
- Headaches
- Sight changes
- Swelling of your spleen and/or tenderness on the left side of your abdomen, caused by 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 cancer. About 45 people are diagnosed with it in Ireland each year. It commonly affects adults between the ages of 40 and 60. The average age at diagnosis is 50. More men than women develop CML. It is very rare in children. There is no evidence CML runs in families.

Diagnosis and tests

Being diagnosed with CML

Even though CML can usually be well controlled by medication, hearing the words 'leukaemia' and 'cancer' can be a huge shock. After your diagnosis you may feel:

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

However you feel, you are not alone.

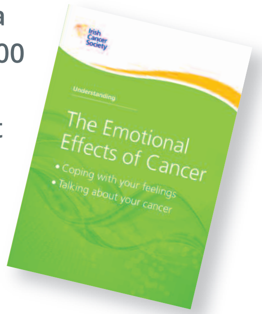
If you need to talk to someone, or if you want support or advice:

- Ask to speak to the cancer (oncology) liaison nurse 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 Survivor Support volunteer who has had a cancer diagnosis and really knows what you are going through. 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 100.

Telling people about your diagnosis

Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news. You may also to 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.


Irish Cancer Society
Understanding
The Emotional Effects of Cancer
• Coping with your feelings
• Talking about your cancer

What tests will I have?

- Tests you may have include blood tests, scans and bone marrow tests.
- 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 stage your cancer (see page 23).

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 blood tests to monitor your disease if you have CML. Ask your doctor if you don't understand what your blood test results mean.

Normal blood cell counts

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

Blood 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 semiliquid, it is called an aspirate. If a piece of solid bone marrow is taken, it is called a trephine biopsy. Both can be done at the same time. Care has to be taken if you are on warfarin, aspirin or any other drugs that thin your blood. Your doctor will advise you about this.

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

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

Chromosome studies (cytogenetics)

Chromosome tests can find out the number and shape of the chromosomes in your blood cells. This can tell your doctor if you have the Philadelphia chromosome, which can help with planning your treatment. These tests can be done on your blood or your bone marrow in a laboratory.

PCR (polymerase chain reaction) test

This is a very sensitive blood test that detects the amount of the abnormal BCR-ABL1 fusion gene in your blood. (See page 13 for more on the BCR-ABL1 gene.)

Immunophenotyping

Immunophenotyping is a test that checks what kind of proteins or markers are on the surface of the leukaemia cells to tell 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 doctor more information about how far your CML has developed and about your general health.

Heart function tests

ECG: Sensors are attached to your skin that can pick up the signals produced by your heart when it beats to give a recording of your heart rhythm and electrical activity.

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 pumping action, structure and muscle function.

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 this 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 first put on the area, which is then scanned to give more information about the cancer. It looks for any abnormal changes, for example, to your lymph glands or 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.

Waiting for test results

It usually takes 1-2 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.

Staging CML

- Staging describes which of the 3 phases of CML your CML is in.
- Knowing the phase helps your doctor to plan your treatment, as different phases need different treatments.

The tests you have after diagnosis are usually done to help the doctor to stage your CML. Staging CML means finding out which phase it is in. This helps your doctor to plan your treatment, as different phases need different treatments.

CML can present in 3 phases. It usually presents in the **chronic phase**, less commonly in the **accelerated phase** and rarely in the **blast phase**. The phases refer to how many blast/leukaemia cells are in your bone marrow. The more abnormal cells there are, the more symptoms you will have. This is because the blast cells crowd the bone marrow, affecting your ability to produce normal white blood cells to fight infection.

1 The chronic (early) phase

Around 9 out of 10 people diagnosed with CML are in the chronic phase. In this phase the CML is developing very slowly. It can also be called a stable phase. Fewer than 1 in 10 (10%) of the blood cells in your bone marrow are blasts.

With medication (usually taking tablets at home), people with CML in the chronic phase usually live a normal life and have very few symptoms. Treatment may keep your CML in the chronic phase for a long time – maybe even for your whole life if you keep taking the medication.

2 The accelerated phase

In this phase, there are more immature blast cells present in your blood. Between 10% and 30% 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 14 for more about symptoms.

3 The blast phase

In this phase more than 30% of the blood cells in your bone marrow are blast cells and the blast cells may have spread to the blood and other organs. This phase is also called an acute phase or a blast crisis. This is when the leukaemia transforms 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, unusual bleeding such as bleeding gums and nosebleeds, and repeated infections.

With the right treatment, CML often stays in phase 1, the more stable, 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.

Treating CML

How is CML treated

- Targeted therapies, chemotherapy and sometimes stem cell transplants are used to treat CML.
- 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.

If you have a very high white blood cell count your haematologist consultant may decide that you need treatment for a time with a chemotherapy drug called hydroxyurea (Hydrea) to quickly reduce the number of white blood cells. This is because having too many white blood cells can damage small blood vessels and reduce blood flow to your brain, lungs and other parts of the body.

Chronic phase

Treatment with a targeted therapy drug called a tyrosine kinase inhibitor (TKI) is usually very effective at controlling the disease in the chronic phase. TKIs block the signal that leads to the production of leukaemia cells. TKIs are usually 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 stabilised so that it can be controlled better. You may be given TKIs or high-dose chemotherapy to reduce the high number of blast cells in your bone marrow. You may also have treatment to ease symptoms such as bone pain or a swollen spleen.

In a few cases a bone marrow or stem cell transplant may be recommended. Your haematology team will discuss the best option for you.

Relapse

Relapse 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 leukaemia cells to grow. See page 41 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 48 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 53 for more details.

Specialist cancer centres

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

Multidisciplinary team

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

Understanding your treatment

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

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

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.

You might like to make some lifestyle changes while you're waiting for treatment. This can help you prepare for your treatment and feel more in control. For more information, see page 35.

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.

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

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

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

Oncology or haematology liaison nurse / clinical nurse specialist: A specially trained nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment.

Medical social worker: A person trained to help you and your family with your social issues and practical needs. They can give counselling and emotional support. They can give advice on social welfare benefits and financial matters and on practical supports and services, available to you from the time of your diagnosis, right through to returning to work.

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

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

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

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

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

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

Community health services: This includes family doctors, public health nurses (who can visit you at home), 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 specially trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the ‘homecare team’ or the ‘hospice homecare team’. A specialist palliative care service is available in most general hospitals.

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 better.

Eat well

Eating well when you have cancer can help you to keep up your strength and muscle mass. This can help you to:

- Cope better with the side-effects of treatment
- Reduce the risk of infection
- Feel better in yourself

Ask to talk to the dietitian at the hospital for advice on the best diet for you, especially if you’re losing weight, have worries about your weight or you're finding it hard to eat well. You can also read our booklet ***Diet and Cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website **www.cancer.ie**

Be active

Being active has many benefits. It can help to:

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

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. Be careful not to overdo it at the beginning, but build up gradually.

Quit smoking

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

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

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Some hospitals have smoking cessation officers who can help and support you.

Other ways to help yourself

Get information about your cancer and treatment

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

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. You friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

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

Try relaxation and stress management techniques

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

Accept change in your life

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

Know that there will be ups and downs

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

Try to cope day by day

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

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. 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. Most people with CML have this abnormal gene. (See ‘Philadelphia chromosome’ on page 12 for more information.)

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. If you have a specific gene mutation you will be given a TKI to treat your particular type of CML. Examples of drugs used for CML include imatinib, nilotinib, dasatinib, bosutinib and ponatinib.

TKIs are normally 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 & 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 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.
- 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 damage an unborn baby. See page 61 for more.

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 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 temperature above 37.5°C (99.5°F) 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. Most haematology units have a direct phone number to call for advice if your temperature is above 37.5°C (99.5°F).

Hints & 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 or measles.**
- **Let your doctor know if you are in contact with these or any other infections.**
- **Wash your hands often during the day, especially before you eat and after going to the toilet.**
- **Avoid unpasteurised milk, soft cheeses, undercooked meat and poultry, and the skin of raw vegetables and fresh fruit.**
- **If your temperature goes above 37.5°C (99.5°F), or if you suddenly feel shivery or unwell, even if your temperature is normal, contact your doctor or the hospital immediately.**
- **Most haematology units have a direct phone number to call for advice if your temperature is above 37.5°C (99.5°F).**

Fluid retention

You may gain weight or you may feel breathless if the 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 57.

Skin changes

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

Nausea / vomiting

Some drugs may cause nausea (feeling sick), but it is usually mild. Your doctor can prescribe anti-sickness drugs to prevent this.

Diarrhoea

Diarrhoea is passing frequent bowel motions 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 a drug called erythropoietin.

Bruising and bleeding

Tell your doctor if you have any unexplained bruising or bleeding, such as nosebleeds or bleeding gums.

Constipation

If you find it painful or hard to pass a bowel motion, 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 medicines (laxatives).

Other side-effects

Other common side effects include skin rashes and itching, breathlessness, cold or flu symptoms like a fever, runny nose or sore throat, constipation.

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. The doctor who specialises in chemotherapy for CML is a haematologist.

Although TKIs are the standard treatment for most people with CML, chemotherapy is sometimes given:

- If TKIs are not effective or 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 find out if the drugs can improve the treatment results. See page 54 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 it is responding to treatment.

How is chemotherapy given?

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

Usually your treatment will be given in the chemotherapy day care unit.

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.

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 and a number to call if you need advice or feel unwell while you're at home.

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?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. With chemotherapy tablets the side-effects are usually mild. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

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

Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 57.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.

Infection

Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high or low temperature, having a cough, 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.

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.

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. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back after you stop chemo.

Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

Skin and nail changes

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

Peripheral neuropathy

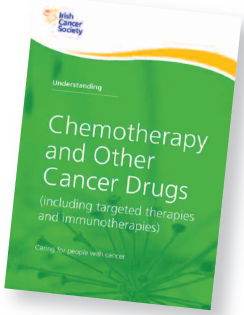
Some drugs can affect your nerve endings. Tell your doctor if you have numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

Changes in kidney function

Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of kidney damage.

If you 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.



Irish Cancer Society
Understanding
Chemotherapy and Other Cancer Drugs
(including targeted therapies and immunotherapies)
Caring for people with cancer

Transplants

Transplants are mainly used when CML does not respond well to the various TKIs or becomes resistant to them, although they may 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 and replacing them with healthy stem cells via a transfusion into your bloodstream. Stem cells are blood cells at their earliest stage of development that will grow into new healthy blood cells. The stem cells are usually taken from a donor. This is called an allogeneic transplant.

How is an allogeneic transplant done?

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

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

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

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

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.

Cancer and Clinical Trials

Cancer Nurseline 1800 200 700

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 a very common symptom of cancer. Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

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

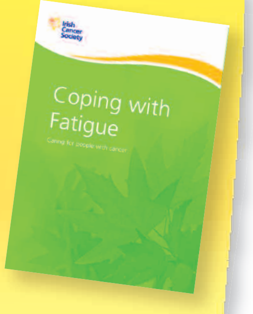
- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

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

Hints & Tips – Fatigue

- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage, if your doctor says they're safe for you.

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



Cancer and complementary therapies

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

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

It's very important to talk to your doctor if you're thinking of using complementary therapies. 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 treating 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?

CML can affect how you feel about sex and your relationships. Coming to terms with the fact that you have CML 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, caressing 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. He or she may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

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

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. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy and some targeted therapies.

Taking TKIs while pregnant has been linked to babies being born with abnormalities, so it's important to use a reliable method of contraception, to avoid pregnancy.

Because people with CML will most likely need to take TKIs permanently it will affect any plans you had to start a family or have more children (see page 62)

Ask your doctor's advice about contraception or if you were thinking about having children.

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

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 there's no need to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Will treatment affect my fertility?

It isn't safe to get pregnant while taking TKIs, the most common treatment for CML. Other treatments can also affect your fertility, either temporarily or permanently.

Discuss any worries you have about infertility with your doctor before treatment starts. They can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this may be 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 normal life. But your treatment with TKIs will continue and you will still need to have regular check-ups. This is called follow-up. At the start you will probably have check-ups every month and then every 3 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. Sometimes it helps to write down what you want to say before you see the doctor, so you don't forget anything.

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. See pages 19-21 for more about these tests.

The tests will show how well your treatment is working. Your doctor will look at how much the number of blast cells in your blood has reduced and the number of cells with the Philadelphia chromosome or the BCR-ABL1 gene.

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

Blood tests (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 the 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 (relapse)?

If the CML starts to cause symptoms again after remission, this is called relapse. CML can still be treated after a relapse 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 104.
- 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 45 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 the flu vaccine each winter and the pneumonia vaccine every 5 years. 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
- Protecting yourself from the sun and checking your skin for any changes
- Having all the recommended cancer screening tests, such 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 59 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 78 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 78 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.

Coping and emotions

How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

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

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

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

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

Anxiety and depression

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

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

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

Counselling

If you're feeling very distressed or finding it hard to cope, a trained counsellor 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.

Free one-to-one counselling is available at some local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

A list of counsellors funded by the Irish Cancer Society is available at **www.cancer.ie**

Ways to get emotional support

Find out about cancer support services in your area: 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 100 for more about cancer support services.

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

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

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

Survivor Support: Survivor Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has dealt with a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

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

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

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

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

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

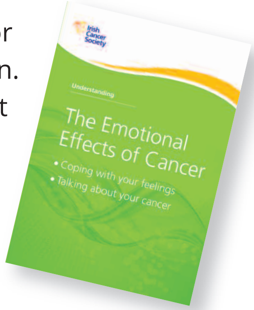
Positive feelings

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 go out.

Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel.

If you find it hard, ask another family member or friend to talk to them.

Further information and support

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

Supporting someone with cancer

Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

Learn about cancer

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

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or 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. Free one-to-one counselling is available to friends and family members at our affiliated cancer support centres. Talk to your GP or see page 78.

Find out about support for carers

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

How to talk to someone with cancer

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

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

Support for you

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

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

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

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

Support resources

Coping with the financial impact of cancer

- 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, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- 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: 0761 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

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

If you have 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 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 97 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.

More information

Go to **www.cancer.ie/publications** and check out our booklet, ***Managing the Financial Impact of Cancer***. This explains:

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

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

Irish Cancer Society services

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

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

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information.

The Support Line is open Monday–Friday, 9am to 5pm.

You can email us at any time on **supportline@irishcancer.ie** or visit our online community at **www.cancer.ie**

For the deaf community, our Support Line is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

Daffodil Centres

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

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. 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

You can email **daffodilcentreinfo@irishcancer.ie** or visit **www.cancer.ie** to find your local Daffodil Centre.

Survivor Support

Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

Support in your area

We work with cancer support groups and centres and the National Cancer Control Programme to ensure cancer patients and their families have access to high-quality, confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country. For information about what's available near you, call our Support Line on 1800 200 700 or go to **www.cancer.ie** and search 'Find support'.

Patient travel and financial support services

We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is mainly for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional.

Irish Cancer Society Night Nursing

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

The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website **www.cancer.ie** or call our Support Line for free copies of our publications.

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

Local cancer support services

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

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling in many affiliated support services)

- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation

- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions,** for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

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

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at **www.cancer.ie/cancer-information-and-support/cancer-support/find-support**

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 immature blood cells present.
Bone marrow	The soft spongy material found in your large bones. It makes three types of blood cells: red blood cells, white blood cells and platelets.
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 abnormal blood or bone marrow.
Haematology	The study of blood and bone marrow.
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 sudden infections.
Platelets	Blood cells responsible for clotting.
Red blood cell	Blood cells that carry oxygen to every cell in your body.
Relapse	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-ABL) so that your body can produce healthy white blood cells.
White blood cell	Blood cells responsible for fighting infection.

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?

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.

LEUKAEMIA ADVISERS
Dr Su Maung, Consultant Haematologist
Liz Karimi, Haematology Clinical Nurse Specialist

CONTRIBUTOR
Caroline Miller, Support Line Nurse

EDITOR
Sarah Lane

The following sources were used in the publication of this booklet:

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Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

Contact our Support Line on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

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

Irish Cancer Society
43/45 Northumberland Road, Dublin 4

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

Support Line Freephone 1800 200 700
Email: supportline@irishcancer.ie

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