Irish
Cancer
Society

Understanding

Chronic Myeloid Leukaemia (CML)

Caring for people with cancer

Understanding

Chronic myeloid leukaemia (CML)

This booklet has been written to help you to understand more about chronic myeloid leukaemia (CML). It has been prepared and checked by haematologists (specialists in diseases of the blood and bone marrow), nurses and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and key aspects of living with it.

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

	Name	Telephone
Specialist nurse		
Family doctor (GP)		
Haematologist		
Medical/oncology social worker		
Emergency		

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.

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The following sources were used in the publication of this booklet:
- *Recommendations for the management of chronic myeloid leukaemia.* British Society for Haematology.
- *A Strategy for Cancer Control in Ireland.* National Cancer Forum, 2006.
- *Cancer in Ireland: A Summary, 1994–2007.* National Cancer Registry Ireland, 2009.
- *Cancer Nursing: Principles and Practice.* CH Yarbro, MH Frogge, M Goodman & SL Groenwald, Jones and Bartlett, 2000.
- *Chronic Mylogenous Leukaemia, NCCN Guidelines for Patients.* Version 1 .2014
- *Chronic Mylogenous Leukaemia,* Tumor Board Review. R.F Todd, K.A Cooney, T.G Hayes, M Pritchett Mims & E. D Warden. Demos Medical 2015.
- *Tyrosine Kinase Inhibitors and Pregnancy,* E Abruzzeze, M. M Trawinska, A. P Perotti & P De Fabritiis. Mediterranean Journal of Haematology and infectious diseases, Apr 7 2014.
- *Leukaemia & Lymphoma Research E: beatingbloodcancers.org.uk*

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Introduction

This booklet has been written to help you understand more about chronic myeloid leukaemia (CML). CML causes your bone marrow to make abnormal white blood cells. The booklet is divided into four parts:

- **About CML** gives an introduction to CML, including causes and symptoms.
- **Treatment and side-effects** looks at the different treatments used and possible side-effects.
- **Coping and emotions** discusses your feelings and the emotional effects of having cancer.
- **Support resources** gives information on further sources of help and support. You will also find an easy-to-read explanation of words and terms used throughout the booklet.

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

Reading this booklet

Remember you do not need to know everything about CML straight away. Read a section about a particular item as it happens to you. Then when you want to know more, read another section. If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700. You can also visit a Daffodil Centre. See page 43 for more information about Daffodil Centres.

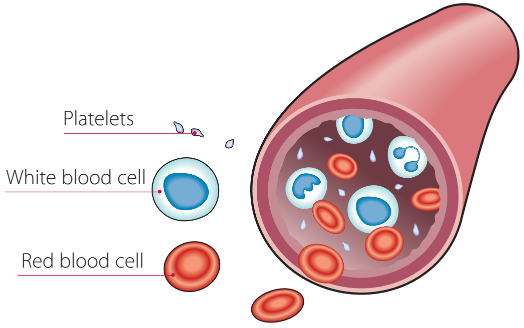
About CML

About blood cells

Your body produces 3 main types of blood cells:

- Red blood cells carry oxygen to all the tissues in your body.
- White blood cells are involved in fighting infection.
- Platelets are involved in blood clotting.

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.



Blood cells

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.

What is leukaemia?

Leukaemia is caused when your bone marrow makes too many white cells. Sometimes it is simply called blood cancer. Other cells such as red blood cells or platelets can be affected as well.

When leukaemia develops, immature blood cells (stem cells) continue to grow quickly but do not mature into white blood cells. These immature cells do not enter your blood stream. Instead they fill up your bone marrow and prevent normal blood cells from growing there.

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)

To understand the different types of leukaemia it can help to know more about white blood cells.

Leukaemia can affect:

Granulocyte white blood cells, which develop from myeloid stem cells. This is called myeloid leukaemia.

Lymphocyte white blood cells, which develop from lymphoid stem cells. This is called lymphocytic leukaemia.

White blood cells are an important part of your body's defence against disease (immune system). Different types of white blood cells fight infection in different ways. Myeloid cells are the body's quick defence against general infection. Lymphoid cells develop slowly. Lymphoid cells are more specific and target certain types of infection.

What do 'chronic' and 'acute' mean?

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

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

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

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

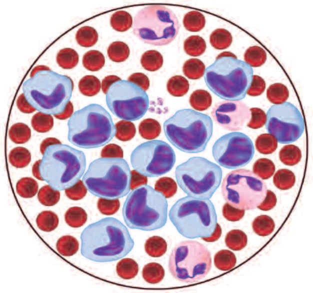
To sum up

- Leukaemia is a cancer of your white blood cells and bone marrow.
- Leukaemia cells can either develop rapidly (acute) or slowly (chronic).
- Leukaemia can affect granulocyte white blood cells (myeloid leukaemia) or lymphocyte white blood cells (lymphoblastic leukaemia).
- White blood cells protect your body against infection.

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.



Increased immature white blood cells in CML

How common is CML?

CML is a rare cancer. About 45 people are diagnosed with it in Ireland each year. It commonly affects middle-aged adults between the ages of 40 and 60 years. The average age at diagnosis is 50 years. It is more common in older people, and more men than women develop CML. It is very rare in children.

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.

What are genes? Genes control the activity of different types of cell 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, resulting in unwanted gene called BCR-ABL. 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 gene called BCR-ABL.

How does the abnormal gene BCR-ABL affect blood cell production? The abnormal BCR-ABL gene changes the normal process of how blood cells are produced and replaced. The gene produces a BCR-ABL protein that causes the bone marrow too produce too many immature or damaged white cells, also known as leukaemic cells. This causes the symptoms of CML.

What increases my risk of CML?

The exact cause of CML is unknown. But there are certain things called risk factors that can increase your chance of getting the disease. The majority of people who get CML have no obvious risk factors. Having a risk factor doesn't mean you will definitely get CML.

Risk factors for CML include:

- **Age:** CML usually occurs in people over the age of 45.
- **Exposure to chemicals:** Long-time exposure to the chemical benzene can increase your risk.
- **Previous cancer treatments:** If you have been treated with high doses of radiotherapy before, it can increase your risk.
- **Exposure to radiation:** If you are exposed to very high radiation levels like in a nuclear accident, it can increase your risk. This is unlikely to happen in Ireland.

Remember CML is not infectious and cannot be passed on to other people. Having CML does not increase the risk of anyone in your family getting CML.

What are the symptoms of CML?

CML develops very slowly so there may be no symptoms in the early stages. In fact, many people are diagnosed by accident, when they have a blood test that shows abnormal levels of white blood cells.

The most common symptoms of CML include:

- Tiredness and looking pale
- Weight loss
- Anaemia (fewer red blood cells)
- Night sweats and fever
- 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.

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
- **Scared** about the future

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

- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at cancernurseline@irishcancer.ie
- Ask to speak to the medical social worker or cancer liaison nurse at the hospital. They can help you and your family to understand CML and give you support
- Talk to other people going through the same thing. Join our online community at **http://www.cancer.ie/community**

Telling people about your diagnosis

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

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

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

To sum up

- CML is a cancer of the myeloid white blood cells. The abnormal cells stop normal blood cells developing.
- The cause of CML is unknown, but most people with CML have an abnormal chromosome called the Philadelphia chromosome. This Philadelphia chromosome is not inherited.
- CML develops very slowly, so there may be no symptoms in the early stages.
- Some symptoms include repeated infections, tiredness, anaemia, night sweats and swelling or pain in your spleen.

What tests will I have?

The following tests give doctors more information about your CML. Some of these tests may also be used to monitor your response to treatment.

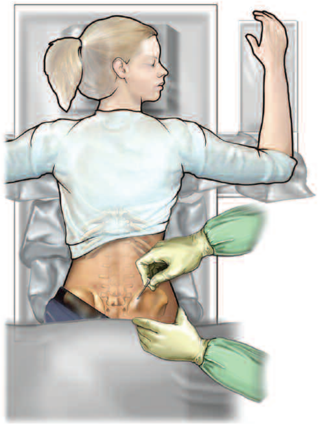
- Full blood count
- Blood film
- Bone marrow test
- Chromosome studies (cytogenetics)
- PCR (polymerase chain reaction) test
- Immunophenotyping

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 semi-liquid, it is called an aspirate. If a piece of solid bone marrow is taken, it is called a trephine biopsy. Both can be done at the same time. Care has to be taken that you are not on warfarin, aspirin or any other drugs that thin your blood. Your doctor will advise you about this and will tell you when it is safe to start taking blood thinning medication again after the biopsy.

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-ABL fusion gene in your blood. (See page 8 for more on the BCR-ABL gene)

Immunophenotyping: Immunophenotyping is a test that checks what kind of proteins or markers are on the surface of the cells. This test can be done on your blood or your bone marrow in a laboratory.

Other tests

You may have other tests to give your doctor more information about how far your CML has developed.

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: This is a special type of X-ray that gives a detailed picture of the tissues inside your body. During the scan you will lie on a table which passes through a large doughnut-shaped machine. It is painless and takes between 10 and 30 minutes. You might be asked not to eat (fast) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparation for a CT scan can vary but the doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.

Waiting for results

It may take some time 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to one of our cancer nurses.

Staging CML

The tests that you have will help your 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.

There are three phases of CML. 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.

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, 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.

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 symptoms if your CML enters this phase. For example, you may feel more tired than usual or you may lose weight. See page 9 for more about symptoms.

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. 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 the more stable, chronic phase.

To sum up

- You may need tests like blood and bone marrow tests, chromosome studies (cytogenetics) and PCR tests and scans to give your doctor more information about your CML.
- There are 3 main phases to CML. The early, chronic phase, the accelerated phase and the blast phase.
- Most people with CML are in the chronic phase.
- With the right treatment, most people with chronic phase CML can live a normal life.

Treatment and side-effects

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.

How is CML treated?

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 a targeted therapy drug called a TKI (tyrosine kinase inhibitor) 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. The side-effects are usually quite mild. Once the disease is under control, 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.

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

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 19 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 23 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 25 for more details.

>>> A type of targeted therapy called a TKI is the usual treatment for CML. TKIs work very well for most people.

Deciding on treatment

Multidisciplinary team: A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, haematologists, oncologists, specialist nurses. They will meet to discuss your test results and your suggested treatment plan.

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

Time to think: When faced with a serious illness, it can be hard to decide what the right treatment is for you. 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 is first explained to you.

Second opinion: You might also find it reassuring to have another medical opinion to help you to decide about your treatment. Your doctor will 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 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.

Who will be involved in my care?

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

Haematologist	A doctor who specialises in treating blood and bone marrow diseases.
Haematology nurse specialist/ Advanced nurse practitioner	She or he gives information and reassurance to you and your family from diagnosis and throughout treatment
Dietitian	An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.
Medical social worker	A person specially trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits, and financial matters and on practical supports and services available to you when you go home.
GP (family doctor)	You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.

Psycho-oncology team	A group of specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.
Counsellor	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.
Community health services	These include family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Giving consent for treatment

Before you start any treatment, your doctor or nurse will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

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

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

Individual treatment

You may notice that other people with CML are not getting the same treatment as you. Their leukaemia may not be the same type or at the same stage as yours. Everyone's treatment needs will be different. Ask your doctor about your treatment if you have any questions.

To sum up

- The main treatment for CML is a type of targeted therapy (TKI).
- TKIs work very well for most people with CML.
- Chemotherapy may be given for CML in the acute or blast phase.
- Rarely your doctor may suggest a transplant to treat CML.
- A team of specialists will help you to decide which treatment is best for you.

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 gives rise to an unwanted gene called BCR-ABL. This gene gives rise to a protein which is a tyrosine kinase.

TKIs work by blocking the action of the BCR-ABL 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 7 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 (Glivec®), Nilotinib (Tasigna®), Dasatinib (Sprycel®) and Bosutinib (Bosulif®).

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.

Tips & Hints – 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 potassium include bananas and plain chocolate.
- Avoid grapefruit, pomegranate and Seville oranges. Chemicals in these fruits can stop TKIs from working properly.
- Ask your doctor about any other drugs 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 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.
- Use contraception if you are fertile and having sex. TKIs can damage an unborn baby. See page 27 for more.

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 will 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).

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 28.

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 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

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 fasting blood tests to check your blood sugar and cholesterol levels. Your doctors and nurses will tell you if you need these tests.

Tell your doctors and nurses straight away if you experience any of the above side-effects or others not listed above. 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.

>>> For more information on targeted therapies and their side-effects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 26). Your doctor will tell you if there are any clinical trials suitable for your cancer either at your own hospital or at another centre.

How does my doctor know my treatment is working?

You will have regular blood tests to check how well your treatment is working, such as the PCR test (see page 12). It may take some time for the results to come back. For more information on measuring your response to treatment, see page 30.

To sum up

- Most people with CML will be treated with a type of biological therapy called a tyrosine kinase inhibitor (TKI).
- TKIs are normally taken as a tablet.
- You will stay on TKIs permanently as long as they are working to control your CML. If you stop taking TKIs the effects of the CML may return.
- The side-effects of TKIs are usually mild. Side-effects include getting infections, fluid retention, tiredness (fatigue), irritated skin, headaches, sickness and diarrhoea.

Chemotherapy

Chemotherapy is a treatment using 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

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.

Chemotherapy is often given in cycles with a rest period between treatments to allow your body to recover and to let your blood count return to normal.

What are the side-effects of chemotherapy?

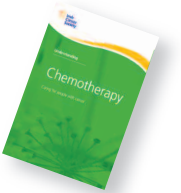
The side-effects of chemotherapy depend on the drugs you are given and can vary from person to person.

In most cases the side-effects go away when the treatment ends or soon after. With chemotherapy tablets the side-effects are usually mild.

Side-effects may include:

- Risk of infection
- Anaemia (reduced number of red blood cells)
- Increased bruising and bleeding
- Feeling sick (nausea)
- Sore or dry mouth
- Tiredness (fatigue)
- Hair loss

For more information on these side-effects and the different types of chemotherapy you can read our booklet *Understanding Chemotherapy*. You can read it on our website **www.cancer.ie** or get a free copy by calling our Cancer Nurseline on 1800 200 700 or by visiting a Daffodil Centre.



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. These studies are quite safe. See page 26 for more details about clinical trials.

To sum up

- Chemotherapy uses drugs to destroy cancer cells.
- The drugs can be given in tablet form, directly into a vein as an injection, or through an infusion (drip).
- For CML in the accelerated or blast phase you may have a combination of chemotherapy drugs, usually through a drip.
- The side-effects vary from person to person and depend on the drugs used.
- Most side-effects are well controlled with medication.

Transplants

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

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. Transplants are 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.

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

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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

To sum up

- A few patients with CML will need a stem cell transplant.
- The treatment destroys all the blood cells in your bone marrow and replaces them with stem cells to make healthy new blood cells.
- Usually the stem cells come from a donor. This could be a relative or someone unrelated to you.

Clinical trials

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

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.

When a drug is being used in a clinical trial it has already been carefully tested to make sure it is safe to use in a trial.

More information

If you are interested in taking part in a clinical trial or want more information, you can read our factsheet *Cancer and Clinical Trials*. It's available to read or download on our website, **www.cancer.ie**. You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

Will treatment affect my sex life and fertility?

Sex and sexuality

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

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

There is no set time for you to be ready to have sex again. It varies from person to person. Once you return to your usual routine your interest in sex should return too. You can also enjoy other forms of closeness, such as touching, caressing and holding each other.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this. It is quite safe for you to have sex again with your partner.

Contraception and fertility

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. Taking TKIs while pregnant has been linked to babies being born with abnormalities.

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.

If you were planning to start a family or have more children, talk to your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your eggs or sperm before treatment begins. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use.

Asking for advice

If you have any queries about how treatment may affect your sex life or your fertility, you can ask your doctor or nurse. Don't be put off by thinking the question is small or trivial or that you'll be embarrassed. Your doctor and nurse are well used to taking about these matters and will give you advice. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

How can I cope with fatigue?

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

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

- Tests and treatments
- Not eating well
- Low levels of red blood cells
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well

It is important to talk tell your doctor or nurse if fatigue is affecting you, so that they can help you.

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

Tips & Hints – fatigue

- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, 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.

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 go back to hospital for regular check-ups. At the start you will probably have check-ups every month and then every 3 months. It is important to always attend your follow-up appointments, even if you feel well and have no symptoms, as the tests you will have can spot any changes in your condition.

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. That way you won't forget what you wanted to say.

If you are between check-ups and have a symptom or problem that is worrying you, let your doctor or nurse know. Make an appointment to see him or her as soon as possible.

You may also need to go to hospital if you get an infection or develop a temperature, as your immune system takes 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 11–13 for more about these tests.

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

- **Your 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 (see page 11) 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.

- **Presence of the Philadelphia chromosome (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.
- **Presence of the abnormal BCR-ABL gene (molecular response)**
  A molecular response is based on the results of the PCR test, which looks for the BCR-ABL 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-ABL gene in your blood.
  - **Major molecular response (MMR):** A tiny amount of the BCR-ABL gene is found in your blood.

Living with CML

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.

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. It is best to get the flu vaccine each winter and the pneumonia vaccine every 5 years.

It is also important to take good care of your mouth, teeth or dentures, as they can be a source of infection. 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 pain, diarrhoea, bleeding or constipation, you should also contact your doctor as soon as possible.

Work and activities

Once you are on treatment and start to feel well there is no reason why you cannot return to work or study and carry on with your usual activities like socialising, sports and hobbies.

Holidays and insurance

You may decide to go on a holiday once your CML is being controlled. Check with your doctor first about any special precautions to take or vaccinations you may need. 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for more details.

Leading a healthy lifestyle

Many people want to make positive changes to their lives 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:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun

If you want more information or advice, call our Cancer Nurseline 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.

Cancer and complementary therapies

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

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

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

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

If you decide to have complementary or alternative treatments…

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

More information

If you want to know more about the different complementary and alternative therapies read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website **www.cancer.ie**

Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have CML. Shock, fear and uncertainty, sorrow, denial, anger and withdrawal are all common reactions. Reactions can differ from person to person. There is no right or wrong way to feel and there is also no set time to have one particular emotion or not. Fortunately for most people, having CML will not affect their lives too much, as it can usually be managed effectively. Understanding CML, its phases and the different treatments may make it easier to cope with your diagnosis.

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

Anxiety and depression

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

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

Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support and help you to make decisions and cope better.

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

Ways to get support

Find out about cancer support services in your area. There are lots of local cancer support services that provide a range of helpful services such as counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 45 for more about cancer support services.

Get online support. There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community.

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

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

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

Coping with a CML diagnosis

Everyone experiences cancer in a different way. And how each person copes with CML varies too. There is no right or wrong way to cope, only your way.

Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

Use your support network. Most people with CML lead a normal life, but there may be times when you need extra support. Don't be afraid to ask for help from those who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

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

Gather information about CML and treatment. Understanding CML and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. Don’t be afraid to ask your medical team to answer any questions you have and explain anything you don’t understand.

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

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.

Try complementary therapies. Complementary therapies are treatments like yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 32 for more information on complementary therapies.

Accept change in your life. Accept that it may take time to adjust to having CML and being on treatment.

Know that there will be ups and downs. Sometimes people feel they have to be brave or positive all the time, but it is normal to have bad days. Get help if you are finding it hard to cope.

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

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

Positive emotions

After being diagnosed with CML you may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what is important in life for you.

How can my family and friends help?

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

Tips & Hints for carers

- **Information:** Find out as much information as possible about CML, especially its symptoms, treatment and side-effects. Talk to the doctor and nurses and call our Cancer Nurseline if you need more information.
- **Healthcare:** Support your loved one by making sure they take their medication every day and attend all appointments. Ask them about how they are feeling and encourage them to talk to their healthcare team if they have any symptoms or worries.
- **Emergencies:** Find out who to call if you are particularly worried or in an emergency situation and make sure you know the phone number to call.
- **Caring for yourself:** Many cancer support services offer help for friends and family of people with cancer. If you need any support or want to talk to someone, call our Cancer Nurseline on 1800 200 700 or contact your local cancer support centre.

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 want most is a good listener.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline and 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**

Talking to children and teenagers

It can be hard to know the best way to talk to your children and explain CML without frightening them too much. Although many people live a normal life with CML, the words leukaemia and cancer can be very scary. You may worry about the emotional impact your illness will have on your children, especially older children, who may already be struggling with the difficult changes that adolescence can bring. These are all natural feelings to have at this time.

Saying nothing

You may feel it is best not to tell your children anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

How to tell your children

It is best that you or your partner tell your children about your CML. How you discuss your illness and treatment with them will depend on their age and character. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.

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

Further information and support

If you want more advice and support, you can ask your nurse or medical social worker. Or call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

Support resources

Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like medication, travel, heating, car parking and childcare costs. If you are not able to 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.

Health cover

Health cover means the amount you pay for the medical care you receive. Things you might have to pay for include:

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

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

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

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

If you do not have a medical card you will have to pay some of the cost of your care and medication.

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

Benefits and allowances

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

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

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 07 4000
- Department of Social Protection – Tel: 1850 662 244

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

If you have financial difficulties

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some help towards travel costs. See page 44 for more details of our Volunteer Driving Service and the Travel2Care fund.

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

More information

For more information please see our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

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

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

For a free copy of the booklet, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. The booklet is also available on our website: **www.cancer.ie**

Irish Cancer Society Services

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

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

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

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

- Our **Daffodil Centres.** Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Survivor Support.** Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 45 for more information.

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

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

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

Local cancer support services

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

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

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

Helpful books

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

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue

Coping and emotions

Understanding the Emotional Effects of Cancer

Lost for Words: How to Talk to Someone with Cancer

Who Can Ever Understand? Taking About Your Cancer

Talking to Children about Cancer: A Guide for Parents

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

Managing the Financial Impact of Cancer. A Guide for Patients and their Families.

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.
Radiotherapy	A treatment of cancer using high-energy X-rays.
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. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than to worry.

- What 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?
- 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?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

Notes

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 is like to organise or take part in a fundraising event

Raise money

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

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

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

Did you like this booklet?

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

More information and support

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

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E: info@irishcancer.ie
W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700
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