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FIGHTING CANCER – LIVING WITH IT

Chronic Myeloid Leukaemia

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Illustration 1

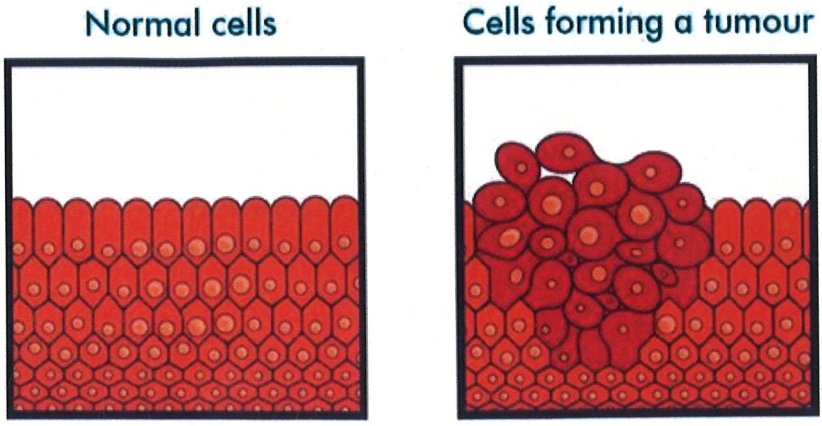


Illustration 2

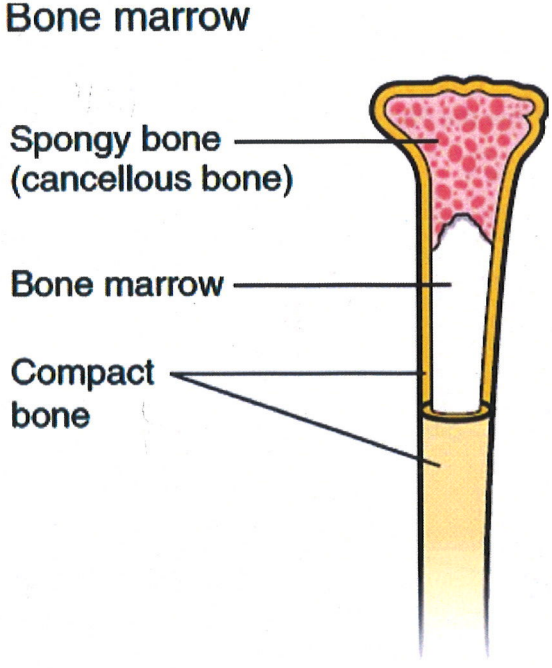


Illustration 3

How blood cells divide

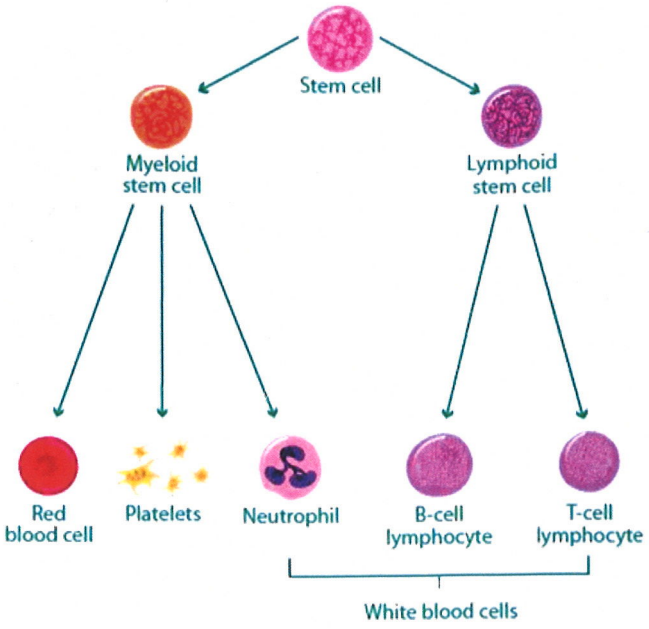
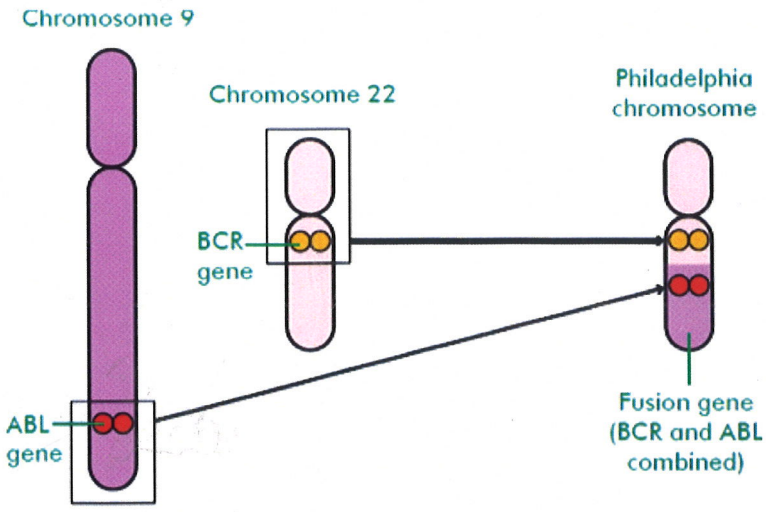


Illustration 4

How the Philadelphia chromosome develops



Contents

About this booklet

This booklet is about chronic myeloid leukaemia (CML). It is for anyone who has been diagnosed with CML. There is also information for carers, family members and friends.

The booklet explains how CML is diagnosed and treated. It also has information about looking after yourself and getting support. We hope it helps you deal with some of the questions or feelings you may have.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

The blood and chronic myeloid leukaemia

What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing, making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

Please see Illustration 1 in the Illustration pages.

A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started

(the primary site) to other parts of the body. They can travel through the blood or lymphatic system. When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

What is leukaemia?

Leukaemia is a cancer of the white blood cells. People with leukaemia have abnormal white blood cells in their bone marrow. This usually means their white blood cell count is high. But in a few people with leukaemia, their white blood cell count is low.

The abnormal white blood cells are called leukaemia cells. They act differently from healthy white blood cells.

The four main types of leukaemia are:

- acute lymphoblastic (ALL)
- acute myeloid (AML)
- chronic myeloid (CML)
- chronic lymphocytic (CLL).

Each type of leukaemia is different. We have separate information about these different leukaemias.

The blood and bone marrow

To help you understand CML and its treatment, it can help to know more about your blood and blood cells.

Blood is made up of blood cells which float in a liquid called plasma. Blood cells are made in the bone marrow. The bone marrow is the spongy material found inside our bones. Most blood cells are made in the:

- back of the hips (pelvis)
- backbone (spine)
- breastbone (sternum).

The bone marrow usually makes billions of new blood cells every day to replace old and worn-out blood cells.

Please see illustration 2 in the Illustrations page

All blood cells are made from blood stem cells. These are blood cells at the earliest stage of their development. There are two types of blood stem cell:

- lymphoid stem cells, which make a type of white blood cell called lymphocytes
- myeloid stem cells, which make the other white blood cells such as neutrophils, red blood cells and platelets.

Blood cells go through different stages of development before they are ready to leave the bone marrow. All blood stem cells develop into immature cells (called blast cells). They then develop into mature, red blood cells, platelets or white blood cells.

Please see illustration 3 in the Illustrations page

When they are fully developed, they are released into the blood to carry out different functions:

- Red blood cells contain haemoglobin (Hb), which carries oxygen from your lungs to all the cells in your body.
- Platelets are very small cells that help blood to clot, and prevent bleeding and bruising.
- White blood cells fight and prevent infection. There are several types of white blood cell. The two most important types are neutrophils and lymphocytes.

The levels of these cells in your blood are measured in a blood test called a full blood count (FBC). The table below gives an idea of the normal ranges for certain blood cells in a healthy adult.

Type of cell	Levels found in a healthy person
Red blood cells (Hb)	130-180g/l (men)
	115-165g/l (women)
Platelets	150-400 x 109/1
White blood cells (WBC)	4.0-11.0 × 10/1
Neutrophils	2.0-7.5 x 109/1
Lymphocytes	1.5-4.5 x 109/1

These numbers can differ slightly between hospitals. Your doctor or nurse can tell you the normal ranges they use. The levels can also

vary between people based on their age, ethnic background or sex (male or female).

The numbers might look complicated when written down, but doctors and nurses talk about them in a way that is easy to understand. For example, you will hear them saying things like, 'Your haemoglobin is 140,' or, 'Your neutrophils are 4'.

Most people with CML quickly get used to these numbers and what they mean. But if you do not understand, you can always ask your healthcare team to explain in more detail.

Your doctors will look at how your blood test results change over time. This helps them know if you need treatment, and what type you should have.

Chronic myeloid leukaemia

CML is a cancer of the white blood cells. It develops when some white blood cells start behaving abnormally. It usually develops very slowly.

CML can affect people at any age, but it is more common as people get older. For many people, CML can be well controlled, and it will not shorten their life.

How CML develops

The information here explains how CML develops. It will help you understand the information about:

- having tests for CML
- treatment for CML.

The information is quite technical, so you might need to read it more than once. Don't worry if it is too much to take in. It is fine to skip it and come back to it another time.

Genes and chromosomes

All cells contain a set of instructions that tell them how to behave. These instructions are stored as genes. The genes are organised into structures called chromosomes. Most cells in the body contain 23 pairs of chromosomes.

The BCR-ABL1 gene

New cells are made when a cell divides into two cells. Before a cell divides, it makes a copy of all the instructions stored in the genes on the chromosomes. CML develops when something goes wrong during this copying process.

A gene called ABL1, which is on chromosome 9, gets stuck to a gene called BCR, which is on chromosome 22. When the ABL1gene sticks to the BCR gene, it creates a completely new abnormal gene called BCR-ABL1.

This new BCR-ABL1 gene makes a substance called tyrosine kinase. Too much tyrosine kinase causes the bone marrow to make too many white blood cells. It also stops these cells from developing into normal blood cells or dying when they should. These abnormal cells are the leukaemia cells.

The Philadelphia (Ph) chromosome

When the new BCR-ABL1 gene forms on chromosome 22, it changes how the chromosome looks. Doctors can see it when they look at the leukaemia cells under a microscope.

They call it the Philadelphia chromosome. Most people with CML have the Philadelphia chromosome in all their leukaemia cells. It is only in the leukaemia cells.

The Philadelphia chromosome is not inherited. You are not born with it, so you cannot pass it on to your children.

Please see illustration 4 in the Illustrations page

Risk factors and causes

It is not clear why people get CML. It is not linked to smoking, diet, exposure to chemicals or infections. It does not run in families. Like other cancers, CML is not infectious and cannot be passed on to other people.

There are some factors that might increase the risk of developing CML.

Age

CML can happen at any age. But it is more common as people get older.

Sex

CML is slightly more common in men than women, but the reason for this is not known.

Radiation exposure

Exposure to very high radiation levels increases the risk of developing CML. For example, these might be the high levels of radiation following a nuclear accident.

Research has found no link between the risk of developing CML and:

- living near nuclear power stations
- exposure to electro-magnetic fields
- living near high-voltage electricity cables
- household radon (naturally occurring gas).

Symptoms

CML develops slowly and many people don't have symptoms in the early stages. Sometimes CML is discovered by chance when a blood test is done before an operation or as part of a routine health check.

In the early stages of CML, any symptoms are usually mild and develop gradually. They can be confused with the symptoms of more common illnesses, such as flu.

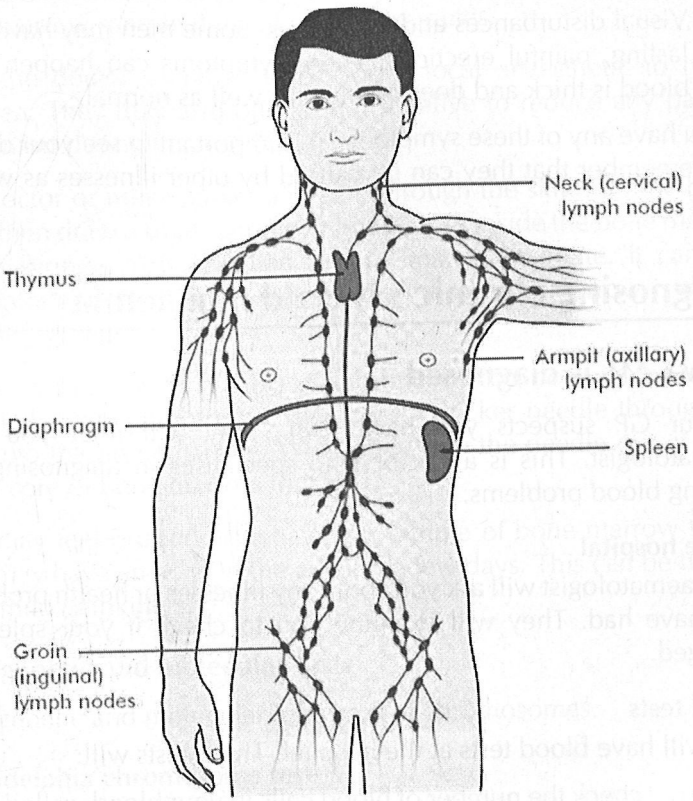
Common symptoms

If you do have symptoms, they may include the following:

- Feeling tired (fatigue).
- Weight loss.
- Heavy sweating at night.
- Feeling full or tender on the left side of your tummy (abdomen). This is caused by abnormal blood cells (leukaemia cells) collecting in the spleen, making it bigger. The spleen is part of the lymphatic system – see below. The spleen stores blood cells

and destroys old and damaged blood cells. The bone marrow and the lymph nodes (glands) are also part of the lymphatic system.

The spleen in the lymphatic system



Less common symptoms

Sometimes abnormal white blood cells (leukaemia cells) build up in the blood or bone marrow. This can make the blood thick, or mean the bone marrow cannot make enough healthy blood cells. These changes can cause the following symptoms:

- Bleeding or bruising, due to a lack of platelets in the blood. This may include bruising without any obvious cause, bleeding gums or nosebleeds. Women may bleed more heavily during their periods.

- Looking pale and feeling tired or breathless. This is caused bya lack of red blood cells in the blood (anaemia).
- Aching joints and bones. This can happen if there are too many leukaemia cells in the bone marrow. You may also get gout in some joints, for example your big toes.
- Visual disturbances and headaches. Some men may have long-lasting, painful erections. These symptoms can happen if the blood is thick and does not flow as well as normal.

If you have any of these symptoms, it is important to see your doctor. But remember that they can be caused by other illnesses as well as CML.

Diagnosing chronic myeloid leukaemia

How CML is diagnosed

If your GP suspects you have CML, they will refer you to a haematologist. This is a doctor who specialises in diagnosing and treating blood problems.

At the hospital

The haematologist will ask you about any illnesses or health problems you have had. They will examine you to check if your spleen is enlarged.

Blood tests

You will have blood tests at the hospital. These tests will:

- check the number of blood cells in your blood, called a full blood count (FBC)
- look for leukaemia cells.

If there are leukaemia cells in your blood, the haematologist will arrange more tests for you. These will find what type of leukaemia you have and what phase it is. This will help your doctors plan your treatment.

Bone marrow test

A bone marrow test is when a doctor or nurse takes a small sample

of bone marrow to test for abnormal white blood cells. They usually take the bone marrow from the back of the hip bone (pelvis). Rarely, they may take it from the breast bone (sternum).

A bone marrow test may be done on a ward or in an outpatient department. It takes about 20 to 30 minutes in total. Removing the bone marrow sample only takes a few minutes.

First, the doctor or nurse gives you a local anaesthetic to numb the area. They may also offer you a sedative to reduce any pain or discomfort during the test.

The doctor or nurse passes a needle through the skin into the bone. They then draw a small sample of liquid from inside the bone marrow into a syringe. This is called a bone marrow aspirate. It can feel uncomfortable for a few seconds when the liquid marrow is drawn into the syringe.

The doctor or nurse may also take a small core of bone marrow. This is called a trephine biopsy. They pass a thicker needle through the skin into the bone marrow. When they take the needle out, it has a small core of bone marrow in it.

You may feel bruised after having a sample of bone marrow taken. You may have an ache in the area for a few days. This can be helped with mild painkillers.

Cytogenetic and molecular tests

Cytogenetic and molecular tests look at chromosomes.

Philadelphia chromosome test

Doctors use the blood and bone marrow samples they have taken to look for the Philadelphia chromosome.

Polymerase chain reaction (PCR) test

This blood test looks for the BCR-ABL1 gene in the leukaemia cells. It is a very sensitive test, which can detect tiny amounts of leukaemia.

If you are diagnosed with CML, you will have regular PCR blood tests. Doctors use this test to check how well treatment is working.

Ultrasound scan

You might have an ultrasound scan to check the size of your spleen and liver. Ultrasound scans use sound-waves to build up a picture of the inside of the body. This is a painless test that only takes a few minutes.

Once you are lying comfortably on your back, the person doing the scan spreads a gel on the skin over the area they are scanning. Then they pass a small device that makes sound-waves over the area. A computer turns the sound-waves into a picture.

Phases of CML

CML develops slowly. There are three possible phases of CML:

- The chronic phase.
- The accelerated phase.
- The blast phase.

Most people are diagnosed when CML is in the chronic phase. Doctors know the phase of CML you are in from:

- the number of immature blood cells (blast cells) in your blood and bone marrow
- your symptoms.

Chronic phase

When CML is in the chronic phase, there may be no symptoms and most people lead a normal life. People usually have treatment by taking tablets at home. They have regular blood tests to check how well treatment is working.

For most people, the leukaemia can be well controlled for as long as they continue to take treatment.

In the chronic phase, less than 15 in 100 (15%) of the blood cells in the blood or bone marrow are blast cells.

Accelerated phase

In a small number of people, the leukaemia may progress from the

chronic phase to the accelerated phase. This can happen if the CML does not respond well to treatment. Sometimes people are diagnosed with CML in the accelerated phase.

In the accelerated phase, less than 2 in 10 blood cells in the blood or bone marrow (10 to 19%) are blast cells.

In this phase, there are more blast cells in the blood or bone marrow. You may also develop symptoms such as:

- tiredness
- weight loss
- bone pain
- sweating and a high temperature at night.

If you feel unwell or develop new symptoms, let your doctor know.

Blast phase

In some people, CML in the accelerated phase may transform into the blast phase. Rarely, people are diagnosed with CML in the blast phase. Or, the leukaemia progresses straight to the blast phase from the chronic phase.

The blast phase is like an acute leukaemia. In this phase, more than 2 in 10 blood cells in the blood or bone marrow (20%) are blast cells. The blast phase is sometimes called blast crisis.

Relapse

Relapse means the leukaemia cells have come back after a time in remission (where there are no signs of leukaemia cells). In CML, this is usually found using the PCR test.

Treating chronic myeloid leukaemia

Treatment overview

The aim of treatment is to put CML into remission and to maintain the remission. Remission means there are no signs of leukaemia cells in your blood or bone marrow, and you feel well. There are different levels of remission.

Treatments for CML are very effective, and remission can usually be maintained for many years. For many people, CML can be well controlled, and it will not shorten their life.

Most people with CML are treated with targeted therapies called tyrosine kinase inhibitors (TKIs). You take them as tablets or capsules every day. There are several TKIs for CML. If one TKI does not work, or stops working, your doctors can usually give you a different one.

You may have a very high level of white blood cells in your blood when you are first diagnosed. If this happens, you may be given chemotherapy tablets for a few days before starting TKI treatment.

Sometimes, your doctors may suggest chemotherapy followed by a stem cell transplant (sometimes called a bone marrow transplant). This might be if TKI treatment does not work, or if you are diagnosed in the blast phase. A stem cell transplant is an intensive treatment and it is not suitable for everyone.

Removing white blood cells from the blood (leukapheresis)

Some people have a very high number of white blood cells in their blood when they are diagnosed with CML. These cells can gather in the blood vessels and cause problems, such as headaches or blurred vision. Doctors can remove some white blood cells from the blood using a machine called a cell separator. This is called leukapheresis. It may also be used for women who are pregnant when they are diagnosed.

During leukapheresis, you lie on a bed or reclining chair with a small plastic tube (cannula) in a vein in each arm. Each cannula is connected to the cell separator by a tube. Blood goes from one of your arms through the tube into the cell separator. As the blood travels through the cell separator, the machine removes the white blood cells. The rest of your blood and blood cells are then returned to your body through the cannula in your other arm. This takes a few hours.

Leukapheresis is painless, but some people may find it uncomfortable having the cannula put in.

How your treatment is planned

There are guidelines for treating CML. Your treatment will be based on the guidelines but adapted to your situation.

A team of specialists will work with you to plan your treatment. This is called the multidisciplinary team (MDT).

The MDT may include:

- haematologists – doctors who specialise in diagnosing and treating blood cancers and disorders
- specialist nurses – who give information and support
- pathologists – who advise on the type of leukaemia you have, as well as any chromosome changes
- radiologists – who specialise in understanding scans and x-rays
- pharmacists – who specialise in medicines.

It may also include other professionals, such as a:

- dietitian
- physiotherapist
- occupational therapist
- psychologist
- counsellor.

After the MDT meeting, your haematologist will talk to you about your treatment options.

The MDT will consider many factors when they talk to you about which treatments are likely to be best for you. These may include the phase of the leukaemia and your general health.

You may be invited to take part in a clinical trial of a new treatment for CML

Making decisions about treatment

If treatment has a good chance of putting the leukaemia into remission, you may find it easy to make your decision about having treatment. But sometimes it is more difficult. You may find it harder to decide what to do if a treatment has a smaller chance of working or a higher risk of serious side effects.

Talking through the benefits and risks with your doctor will help.

Giving your consent

Your doctor will explain the aims of your treatment before you have

it. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent. Before you are asked to sign the form, you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain it again. Some leukaemia treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

If you choose not to have treatment, you can have supportive (palliative) care, with medicines to control any symptoms.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Tyrosine kinase inhibitors (TKIs)

The main treatment for CML uses drugs called tyrosine kinase inhibitors (TKIs).

TKIs are a type of targeted therapy. They work by switching off (inhibiting) the tyrosine kinase made by the BCR-ABL1 gene in leukaemia cells. This slows or stops the bone marrow from making abnormal white blood cells. It also allows the leukaemia cells to mature and die.

The TKI drugs used to treat CML come as tablets. You keep taking them for as long as they are working. The three main TKI drugs currently used for CML are:

- imatinib
- nilotinib
- dasatinib.

Imatinib is the most commonly used TKI.

There are also some newer TKI drugs:

- ponatinib
- bosutinib.

Different drugs are used for different situations. Your haematologist will discuss which one is appropriate for you.

Although the TKIs are similar, they work in slightly different ways. This means they can have different side effects. To make sure the TKI you have is right for you, your doctor will think about:

- any health problems you have
- the possible side effects of the TKI.

If TKIs stop working for you, you may be referred to a specialist CML centre. Your haematologist will talk to you about this if it is needed.

Hepatitis B and C

Before you begin treatment with a TKI, you will have a blood test to check for hepatitis B and C (liver infections). This is because TKI treatment can make these infections active again. Your doctor or nurse will talk to you about this before the blood test.

Types of TKIs

Imatinib (Glivec®)

Imatinib is the most commonly used TKI for CML. It can be used in any phase.

Nilotinib (Tasigna®)

Nilotinib can be used as a first treatment in the chronic phase.

It can also be used in the chronic or accelerated phase if you can't have imatinib because of side effects or if it is not working to control the CML.

Dasatinib (Sprycel®)

Dasatinib can be used as a first treatment in the chronic phase. It can also be used in the chronic, accelerated or blast phase if imatinib is causing severe side effects or isn't working to control the CML.

Bosutinib (Bosulif®)

Bosutinib is a newer TKI. You might have bosutinib if other TKIs have stopped working or are not suitable for you.

Ponatinib (Iclusig®)

Ponatinib is a newer TKI. It may be used for people who have leukaemia cells with a particular gene change (mutation) called T3151. Only a few people with CML have this gene change in their leukaemia cells.

You may be offered ponatinib if you have tried other TKI treatments but:

- they have stopped working
- you had to stop taking them because of side effects.

Side effects of TKIs

The side effects of TKIs are usually mild and treatable. Side effects are

often more noticeable when you first start treatment, and they may improve with time.

If you have severe side effects, your doctor may ask you to stop taking the drug for a few days. After a short break, you may be able to start taking it again without having the same problems. Occasionally people need to stop treatment with the TKI they are taking because their side effects are too severe. If this happens, they will usually be offered a different TKI drug.

Sometimes a new side effect can develop many months after you started treatment. Always let your doctor know if you notice any new side effects or if your side effects get worse.

Each TKI can have slightly different side effects, so it is best to read specific information about the drug you are having.

Tiredness and feeling weak

This is a common side effect, but it's usually mild. Try to balance rest periods with regular gentle exercise. This can help reduce tiredness.

Feeling sick (nausea)

This is usually mild. Your doctor may prescribe anti-sickness drugs to prevent or reduce it. If you still feel sick, tell your doctor. They can prescribe another anti-sickness drug that may work better for you.

Diarrhoea

If you have diarrhoea, contact the hospital for advice. Try to drink at least 2 litres (3½ pints) of fluids every day. It can help to avoid:

- alcohol
- caffeine
- milk products
- high-fat foods
- high-fibre food.

Your nurse or doctor may give you anti-diarrhoea drugs to take at home. The diarrhoea can usually be controlled with these medicines. But it is very important to tell your doctor if it is severe, or if it continues.

Your doctor may ask you to stop taking your treatment. When the diarrhoea is better, they will tell you if you can start taking it again. Sometimes they reduce the dose.

Loss of appetite

A dietitian or specialist nurse can give you advice and tips on:

- boosting your appetite
- coping with eating difficulties
- maintaining your weight.

Headaches

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

Mood changes and problems sleeping

Treatment can affect your mood. It can also cause difficulty sleeping. Tell your doctor or nurse if you have any of these side effects.

Changes in the way your heart works

Some TKI drugs can affect the way your heart works. Your doctor or nurse may organise some tests to check your heart before you start treatment. Tell your doctor straight away if:

- have pain or tightness in your chest
- feel breathless or dizzy
- feel your heart is beating too fast or too slowly
- feel that your heartbeat is irregular.

Keeping to a healthy weight and not smoking can help keep your heart healthy.

Fluid retention

This can affect different parts of the body. Your ankles may swell, or you may get swelling around the eyes. This often settles without needing treatment. If it doesn't settle, your doctor may prescribe a drug that makes you pass more urine (pee) – a diuretic to help get rid of some of the fluid.

Dasatinib can sometimes cause fluid to build up in the lining around

the lungs. This is called a pleural effusion. If this happens, your doctor may ask you to stop taking the dasatinib for a short time until the fluid goes away. Or they may prescribe medicine to help.

Tell your doctor if you:

- feel breathless
- have chest pain
- develop a cough.

Muscle, bone or joint pain

You may get some pain in your muscles, bones or joints. Your doctor can prescribe painkillers to help.

Skin changes

Your skin may become dry and itchy. Some people develop a skin rash. This is usually mild, but for some people it can be more severe.

Increasing the amount of fluids you drink can help with dryness and itching. Your doctor can also prescribe medicine or creams to help.

Constipation

If you are constipated, it usually helps to:

- drink plenty of fluids
- eat a high-fibre diet
- do regular, gentle exercise.

Sometimes you may need to take a medicine called a laxative. Your doctor can prescribe these.

Changes in the way your liver works

Some TKIs can affect the way your liver works. This is usually mild. Your doctor or nurse will take regular blood samples to check how well your liver is working.

Effect on blood cells

Sometimes TKIs can reduce the numbers of blood cells in your blood. Your blood count will be monitored regularly while you are having treatment. If your blood cell numbers fall too low, your doctor may stop your treatment for a few days to let them recover.

Risk of infection

TKIs can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia. You will have regular blood tests. If your white blood cell count is low, your doctor may delay your treatment for a short time.

Contact your doctor straight away if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have any symptoms of an infection

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

It is important to follow any specific advice your cancer treatment team gives you.

Rarely, some people are given injections of a growth factor called G-CSF. This can stimulate the bone marrow to make healthy white blood cells.

Bruising or bleeding

TKIs can reduce the number of platelets in your blood. Tell your doctor if you have any unexplained bruising or bleeding. This may include:

- nosebleeds
- bleeding gums
- blood spots or rashes on the skin.

They will advise you about this and explain any precautions you should take.

Anaemia (low number of red blood cells)

You may become anaemic. This can make you feel tired and

breathless. Tell your doctor or nurse if you feel like this. If your number of red blood cells becomes too low, you may need to have a blood transfusion. Rarely, some people are given injections of a growth factor called erythropoietin. This can help increase the numbers of red blood cells made by the bone marrow.

Fertility and pregnancy

Because TKIs are a newer type of drug, there is limited information available about becoming pregnant or getting someone pregnant while taking TKIs. But TKIs are not thought to affect your fertility (your ability to become pregnant or make someone pregnant).

If you may want to have children in the future, talk to your doctor about this as early as possible – before starting treatment if you can. They may refer you to a specialist CML unit or fertility expert. They can talk to you about the possible options for planning your treatment.

Women

Taking a TKI during pregnancy increases the risk of harm to a developing baby. Because of this, women are strongly advised to use contraception while being treated with a TKI.

If you think you may have become pregnant while taking a TKI, tell your doctor as soon as possible. This is because the highest risk to the baby is during the first few weeks of the pregnancy. Your doctor can talk to you about the possible options for planning your treatment and controlling the CML. They will aim to make things as safe as possible for you.

Men

Research has shown it may be safe for men to continue to take imatinib if they are trying to start a pregnancy. But there is less information about the newer TKI treatments. You should talk to your doctor before planning to have a baby. Their advice may be different depending on which TKI you are taking.

Monitoring response to treatment

When you first start treatment with a TKI, you will need to go to the clinic every 1 to 2 weeks. At these check-ups, your doctor will:

- ask about your general health
- ask about any new symptoms or side effects from treatment
- do blood tests to check the numbers of blood cells (FBC) and leukaemia cells (PCR test).

Sometimes they may also take a bone marrow sample. Your doctor can tell you how often you might need this.

These test results help your doctors know how well the treatment is working to control the leukaemia. They will also check for any side effects. They can make any changes if needed.

As time goes on, you will not need to see your doctors as often. Eventually, you may only need a check-up every 3 to 6 months.

Levels of response

The aim of treatment is to put CML into remission. In CML, remission means there are no signs of CML in your blood during a standard blood test. But this does not mean the leukaemia has completely gone. You will need to keep taking treatment to keep the leukaemia in remission. Because there are still leukaemia cells, doctors may use the word response instead of remission.

There are different levels of remission (response). These are based on the results of different tests that look for leukaemia cells as the leukaemia responds to treatment.

Your doctors will monitor your response to treatment regularly. This to check how well it is working for you. We explain the different levels of remission (response) below and on the next page.

Haematological response

This is the first level of response to treatment. It is measured with a full blood count (FBC).

When you first develop CML, the number of white blood cells in your blood is usually high. If there is a complete haematological response, it means:

- your full blood count has gone back to normal
- the doctors cannot see any leukaemia cells

- if your spleen was large before starting treatment, it has gone back to a normal size.

Most people get a complete haematological response (CHR) within 3 months of starting a TKI.

Although your blood counts are normal, there may still be leukaemia cells that cannot be detected by a full blood count.

Cytogenetic response

This is the next level of response. It refers to the amount of Philadelphia chromosome in the blood and bone marrow. As treatment starts working, the number of Philadelphia chromosome-positive (Ph+) cells in the blood and bone marrow goes down.

It takes longer to get a cytogenetic response than a haematological response. It can take many months. A complete cytogenetic response (CCyR) means there are no Ph+ cells detected in the bone marrow sample.

Molecular response

Even after you have a cytogenetic response, there can still be leukaemia cells in your blood and bone marrow. Because there may only be 1 leukaemia cell among 1000s of normal blood cells, a very sensitive test is needed to find the leukaemia cells. This test is called a polymerase chain reaction (PCR) test.

There are different levels of molecular response:

- **MR3,** or major molecular response (MMR) – this means there is less than 1 leukaemia cell in every 1000 white blood cells.
- **MR4,** or deep molecular response (DMR) – this means there is less than 1 leukaemia cell in every 10,000 white blood cells.
- **MR4.5** – this means there is less than 1 leukaemia cell in every 32,500 white blood cells.
- **MR5** – this means there is less than 1 leukaemia cell in every 100,000 white blood cells.

Continuing with treatment

You will need to keep taking the TKI for as long as it is controlling the

leukaemia. This is important even if your PCR tests do not show any signs of leukaemia.

Regularly missing a dose of TKI can affect how well the CML responds to treatment. Research has shown that missing as few as 3 doses a month lowers your chances of getting the best response to treatment.

The following tips may help you to remember to take your treatment every day:

- Take your tablets at the same time each day.
- Set a daily reminder on your mobile phone.
- Put your tablets in a place where you will see them every day (but keep them out of sight and reach of children).
- Mark off each dose you take on a calendar.
- Keep a supply of tablets with you when you travel, and take your medicine in your carry-on luggage when you fly.

Your prescriptions will be organised through the hospital, so you may have to go there to collect the tablets each time you need more. Tell your doctor, nurse or pharmacist if it is difficult for you to get to the hospital.

Treatment free remission

Trials are being done to see whether it may be safe to stop TKI treatment if someone has had a deep molecular remission (MR4) for a long time. This is called treatment free remission.

Your doctor can tell you more about this.

Chemotherapy for CML

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy or damage leukaemia cells. It works by disrupting the way leukaemia cells grow and divide. Chemotherapy is only very occasionally used for CML.

Chemotherapy tablets

Some people may be given a type of gentle chemotherapy if their number of white blood cells is very high when they are first diagnosed

with CML. This may be while their doctors are waiting for test results to confirm that the CML is likely to respond to a TKI.

The most commonly used chemotherapy drug for CML is hydroxycarbamide. You take this as tablets. Your doctor, nurse or pharmacist will tell you how many tablets to take. Your doctors will usually change your treatment to a TKI when they have your test results.

Combination chemotherapy

Combination chemotherapy is occasionally used if CML is in the blast phase. This usually involves a combination of three or four drugs given into a vein (intravenously).

People who are treated with a stem cell transplant usually have intensive chemotherapy as preparation for the transplant.

Your doctor will tell you about the chemotherapy drugs and their possible side effects.

Side effects of chemotherapy

If you are taking a single chemotherapy tablet, the side effects are usually mild. Treatment with a combination of two or more chemotherapy drugs may cause more troublesome side effects.

People with CML rarely have chemotherapy, so we have not given much detail on the side effects in this booklet. Your doctor or nurse will tell you about what to expect.

The more common side effects of chemotherapy include:

- feeling sick
- risk of infection, because of a lower number of white blood cells
- bruising and bleeding, because of a low number of platelets
- a sore mouth
- anaemia (a low number of red blood cells)
- changes to your bowel habits (constipation or diarrhoea)
- tiredness (fatigue)
- hair loss

- numb or tingling hands or feet
- changes to fertility.

Stem cell transplants

A stem cell transplant may be used if:

- the CML is in the blast phase
- treatment with TKIs is not controlling the CML.

If your doctor thinks a stem cell transplant may be appropriate for you, they will discuss it with you in more detail. Stem cell transplants are only done in specialist cancer treatment centres. A stem cell transplant may cure some people with leukaemia, or put the leukaemia into remission.

A stem cell transplant allows you to have much higher doses of chemotherapy than usual. You may also have radiotherapy (high-energy rays) to the whole body.

If you have a stem cell transplant for CML, you will usually have stem cells from someone else who is a match for you (a donor). This is called a donor stem cell transplant or an allogeneic stem cell transplant.

Interferon alpha

Interferon alpha is a protein that the body normally makes during viral infections, such as flu. Scientists can make this protein in the laboratory, so it can be used as a treatment.

If other treatments haven't worked, occasionally some people are given interferon alpha in the chronic phase. Doctors may also use it for women who need treatment and are pregnant or want to become pregnant.

You have interferon alpha as an injection under the skin using a very fine needle. You or a relative or friend can be taught how to give these injections so you can have them at home.

Side effects

Interferon alpha can cause various side effects. Some are similar to the symptoms of flu. They include:

- chills
- fever
- depression
- weight loss
- feeling sick
- headaches
- aching in the back, joints and muscles
- tiredness.

Some of these side effects can be reduced by taking a mild painkiller, such as paracetamol, before the injection. Your doctor can give you more advice.

The side effects are most noticeable with the first one or two injections, and they usually wear off after that. But the tiredness may continue.

Research – clinical trials

Leukaemia research trials are carried out to try to find new and better treatments for leukaemia. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how leukaemia treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about leukaemia and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. Some treatments that look promising at first are later found not to be as good as existing treatments. Or they have side effects that outweigh the benefits. This is something for you to keep in mind.

If you decide not to take part in a trial, your decision will be respected. You do not have to give a reason. But it can help to tell the staff your concerns so they can give you the best advice. There will be no change in the way you are treated by the hospital staff. You will still be offered the standard treatment for your situation.

Blood samples

You may be asked for your permission to use some of your samples for research into leukaemia. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of leukaemia and its treatment, which will hopefully improve the outlook for future patients.

Living with chronic myeloid leukaemia

Most people with CML live a normal life-span. To help you stay as well as possible, you may want to make changes to your lifestyle. Even if you had a healthy lifestyle before your diagnosis, you may want to focus more on making the most of your health.

A healthy lifestyle doesn't have to be difficult or expensive. It is about making small changes to the way you live. This will improve your health and sense of well-being. It will also lower your risk of getting other illnesses and some other cancers.

A healthy lifestyle includes:

- having a well-balanced diet
- being physically active
- reducing stress
- being involved in your healthcare.

When planning changes, you need to take any side effects of treatment into account. Try not to do too much, too soon.

Eat well and keep to a healthy weight

A well-balanced diet should include:

- plenty of fresh fruit and vegetables – aim to eat at least five portions a day
- foods high in fibre, such as beans and cereals
- plenty of water or other non-alcoholic drinks.

You should also try to reduce your intake of:

- red meat and animal fats
- alcohol
- salted, pickled and smoked foods.

Our booklet Dietary advice for cancer patients has more information.

Stop smoking

If you smoke, speak to your doctor or call a stop-smoking helpline for further advice. They can tell you where your local stop-smoking service is.

Reduce stress

There are different ways of reducing stress, and they will vary from person to person. Try to take some time for yourself to do something you find relaxing. You might decide to take up a new hobby or exercise. You could try learning relaxation techniques or try a complementary therapy like massage.

Some people find it helpful to talk about their feelings or have contact with other people who have been through a similar experience. Others find it helpful to write a journal or blog.

Get physically active

Physical activity can improve your sense of well-being and help build up your energy levels. It reduces the risk of heart disease, strokes, diabetes and bone thinning (osteoporosis). Physical activity doesn't have to be very strenuous. You can start gently and build up the amount you do.

You can read more about exercise and its benefits in our booklet Physical activity and cancer treatment.

Get involved in your healthcare

This includes taking your medicines as prescribed and always going to your hospital appointments. If you have any problems or notice any new symptoms between your appointments, let your doctor know as soon as possible.

Understanding more about CML and its treatment can also help you cope. It means you can discuss treatment, tests and check-ups with your doctors and nurses, and be involved in making decisions. This can make you feel more confident and give you back a feeling of control.

Self-help and support groups

Talking about your feelings can help reduce stress, anxiety and isolation. There are lots of different ways to communicate, and they can all help people feel less alone.

Self-help or support groups offer a chance to talk to other people who may be in a similar situation and facing the same challenges as you. Joining a group can be helpful if you live alone or don't feel able to talk about your feelings with the people around you.

Not everyone finds it easy to talk in a group, so it might not be for you. Try going along to see what the group is like before you decide.

Your feelings and relationships

Your feelings

Relationships

Talking to children

What you can do

If you are a relative or friend

JASCAP has a range of booklets listed below with detailed information on the above subjects.

JASCAP has a series of booklets on the following topics relating emotional aspects of cancer.

Talking about cancer

Talking to children and teenagers when an adult has cancer Talking with someone who has cancer

Making or changing your Will When Cancer Returns

Looking after someone with cancer

JASCAP has a series of booklets on the following topics relating physical aspects of cancer.

Dietary advice for cancer patients

Eating Hints Before During and After Cancer Treatment Cancer and your sex life

Cancer pain

Control of common cancer symptoms

Other symptoms and side effects of cancer and its treatments Life After Cancer Treatment

Side effects of cancer treatment Coping with fatigue

Physical activity and cancer treatment

Please also note that all these booklets (PLUS this booklet itself), in various Indian languages are available on our website www.jascap.org for free download.

Work and financial support

Financial help and benefits

The hospital social worker will help you in identifying sources for financial assistance and guide you the procedures for obtaining such help.

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

JASCAP is a charitable trust that provides information various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

JASCAP is registered under the Societies Registration Act, 1860 No. 1359/1996 G.B.B.S.D, Mumbai and under the Bombay Public Trusts Act 1950 No. 18751 (Mumbai). Donations to JASCAP qualify for deduction u/s 80G (1) of the Income Tax Act 1961 vide Certificate No. DIT (E)/BC/80G/1383/96-97 dated 28.2.97 subsequently renewed.

Contact: **Mr. Prabhakar Rao or Ms. Neera Rao**

JASCAP: We need your help

We hope that you found this booklet useful

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by cheque or D/D payable in Mumbai in favour of "JASCAP".

Important

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