

# FOM Guide to Disease Management







Specially put together for Friends of Max by

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### **Editor's Note**

We are pleased to present this question - and answer booklet for patients with Chronic Myeloid Leukemia (CML). CML is a rare form of leukemia that requires constant care.

This booklet aims to provide patients and their families with a better understanding of the disease, its management, and treatment



options available. We have made every effort to ensure that the information presented here is accurate and up to date. However, it is important to note that medical knowledge is constantly evolving, and some of the information presented here may become outdated over time. It is also important to note that every patient is unique, and therefore, we strongly encourage you to discuss any questions or concerns you may have with your regular physician.

Finally, we would like to extend our thanks to all the patients who contributed to this booklet by sharing their experiences and insights. We hope this booklet serves as a useful resource for you and your loved ones as you navigate your journey with CML.

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## Contents

Know your CML	1
Treatment Protocol	3
Monitoring Tests of CML	4
Planning a Family	5
Diet & Nutrition	5
Treatment Free Remission (TFR)	6
Side Effects and its Management	7
CML in Children	8
CML in Elderly Patients	8
List of Commonly Used TKIs for the Treatment of CML	9
Advanced Stage of CML	9
Bone Marrow / Stem Cell Transplantation	10



#### Q.1 What is CML?

The full name of CML is "Chronic Myeloid Leukemia". "Chronic" refers to the fact that this disease progresses slowly over time, typically over the course of several years. "Myeloid" refers to the type of blood cell that is affected by cancer, specifically the white blood cells that originate from the bone marrow. Leukemia is the name given to cancers of the blood. CML is a type of blood cancer that is characterized by the abnormal growth and accumulation of these white blood cells in the body.

#### Q.2 What are the stages of CML?

Unlike solid cancers, blood cancers are generally not classified into stages because cancerous blood cells circulate throughout the body. However, CML is typically classified into two phases: the early (chronic) phase and the advanced phase, which can be further divided into Accelerated or Blast phases.

#### Q.3 Is CML contagious?

No, CML is not contagious, which means that it cannot be transmitted to family members or other close contacts. You can continue to live together and share meals without any risk of transmission. It is also safe for spouses to be together without any risk of transmitting the disease to each other. Children can play with you without any concern of contracting the disease.

#### Q.4 Is CML hereditary?

No, CML is not a hereditary disease. It is not passed down from parents to their children, and you cannot transmit it to your spouse or children.

#### Q.5 What age group is most affected by CML?

CML can affect people of any age, but it tends to be more common in India among individuals aged 30-40 years. In the western countries, it is more commonly diagnosed in people aged 50-60 years.

#### Q.6 What are the typical symptoms of CML?

In western countries, CML is often detected during routine annual health check-ups. However, in developing countries like India where routine health check-ups are not as common, most patients with CML present with nonspecific symptoms such as low-grade fever, malaise, or a feeling of heaviness in the left side of the abdomen (due to an enlarged spleen). Other symptoms may include fatigue, weakness, loss of appetite, and persistent weight loss lasting from weeks to months. These symptoms are not specific to CML and can be seen in many other illnesses, such as tuberculosis. The first indication of CML is often detected through a blood test called a complete blood count (CBC).

#### Q.7 How common is CML?

CML is relatively rare, with one case diagnosed in every 100,000 people. However, if all types of blood cancers are considered together, it is one of the most commonly diagnosed blood cancers among adults who seek medical care at hospitals.

#### Q.8 How do you diagnose CML?

A blood count is often the first indication that a patient may have CML. In most cases, white blood cell counts and platelet counts are elevated above the normal range. Upon examination of the body, an enlarged spleen is also commonly found in CML patients, with more than 80% of patients in India exhibiting this symptom. Following the blood count, a pathologist examines a blood film/bone marrow to look for the presence of a Philadelphia chromosome or a molecular test known as BCR-ABL. If either of these tests is positive, it confirms the diagnosis of CML.

#### Q.9 What is Philadelphia chromosome or BCR ABL?

The human body contains 23 pairs of chromosomes, which are normally arranged in a specific order. In some cases, a portion of chromosomes 9 and 22 can exchange places (known as a 9;22 translocation), resulting in the formation of a Philadelphia chromosome. This type of chromosome was first discovered by scientists in the city of Philadelphia, USA, hence the name. The Philadelphia chromosome produces a gene product called BCR-ABL. The presence of this gene can be detected using techniques such as Fluorescence in Situ Hybridization (FISH) or Polymerase Chain Reaction (PCR), both of which are highly sophisticated. The confirmation of the presence of the Philadelphia chromosome or BCR-ABL gene in blood or bone marrow confirms the diagnosis of CML.

## Q.10 If the diagnosis is confirmed by a blood test, then why is a bone marrow test required?

As previously mentioned, CML has different phases, including chronic, accelerated, and blast phase. In some cases, the specific phase of CML may only be diagnosed through a bone marrow examination. In addition to the presence of the Philadelphia chromosome, other changes in the chromosomes may also be identified through bone marrow testing. Long-term untreated CML can also lead to changes in the bone marrow, such as myelofibrosis. All this information is useful for physicians in determining the appropriate treatment and predicting the future course of the disease.

#### Q.11 is CML curable?

As previously mentioned, CML has different phases, and the chronic phase of CML is considered functionally curable with available medications. However, there are several factors that may impact the likelihood of a successful cure, and not all patients achieve a complete cure. Even in cases where a patient is considered functionally cured, ongoing follow-up with a treating physician is necessary to monitor the disease and ensure that it does not recur.



#### Q.1 What are the treatments available for CML?

All phases of CML are primarily treated with targeted medicines called Tyrosine Kinase Inhibitors (TKIs). These TKIs are classified into three generations: first generation, second generation, and third generation. In certain situations, other medications such as chemotherapy or immune modulating drugs (interferon) may also be used. Additionally, bone marrow transplant (stem cell transplant) is an available treatment option reserved for a specific group of patients.

#### Q.2 What are the different TKIs?

TKI (Tyrosine kinase inhibitors) are first generation, second generation and third generation.

First Generation	Imatinib Mesylate
Second Generation	Dasatinib, Nilotinib, Bosutinib
Third Generation*	Ponatinib, Asciminib

<sup>\*</sup> not marketed in India at present (September, 2023)

#### Q.3 How does a doctor choose which medicine to give first?

Each CML patient may behave differently. The choice of TKI for CML treatment depends on various factors such as the stage of CML, age, gender, overall health condition of the patient, previous treatments, and any ongoing medications. The patient's ability to tolerate the side effects of the medication and financial considerations are also considered while selecting the TKI.

#### Q.4 What's the best time to take medicine?

Imatinib and Dasatinib can be taken with or without food, usually once a day, and at around the same time every day. Nilotinib should be taken on an empty stomach, at least two hours before or after a meal. Bosutinib should be taken with food, preferably a high-fat meal, once daily.

However, it's essential to follow your treating physician's instructions regarding the timing and dosage of these medications as they may vary based on the stage of the disease, other medications you may be taking and other individual health factors. It's also crucial to never alter the dosage or timing of these medications without consulting with your treating physician first, as it could potentially impact the effectiveness of the treatment.

#### Q.5 How long the medicines are continued?

At the time of diagnosis, all patients are advised to take these medicines lifelong. However, after regular monitoring of CML for a few years, medicines can be stopped in four out of ten patients (40%). However, there are strict criteria for stopping the medication. Even if the

treating physician stops the medicine, monthly check-ups are required for a few months, and then yearly follow-ups for life.

#### Q.6 Who are the patients whose medicine can be stopped?

Generally, patients who are diagnosed in early chronic phase CML and whose BCR ABL gene levels become undetectable by existing techniques or become very low (deep molecular response) and remain at this level for a few years can be the candidates for stopping the medicine. This approach is only considered for patients who have been on medication for more than five years and are in deep molecular response for at least two - three years. After stopping the medicine, CML may return in some patients and close monitoring of blood tests is required. However, the medicine cannot be stopped in CML patients who have an advanced phase of the disease (accelerated or blast phase).

#### Q.7 Can I take any other medicine while taking medicine for CML?

Generally, yes, if you are taking medicine for a short term, such as dental pain or a cough. However, if you are taking any other medicine for a long time, you must discuss it with your CML physician. It is especially important to mention if you are diagnosed with tuberculosis and are taking Imatinib. The dose of Imatinib may need to be increased if you are on antituberculosis medication.

## Q.8 Whether Imatinib can be stopped for any kind of surgery/operation or taking medicine for any other illness?

For minor problems, Imatinib does not require to be stopped. However, for major surgery specially related to neurosurgery, urological surgery, Imatinib or other TKI may temporarily be stopped before and after surgery generally for less than a week. Consult/involve your CML physician for any kind of major surgery or if you are diagnosed with an illness that requires prolong treatment.

#### Q.9 Can I do my office or household work?

Yes, symptoms related to CML generally settle within four - six weeks. The enlarged spleen also regresses during this time. After this phase, you can resume any type of office or household work and engage in physical exercise.



#### Q.1 What are the important Monitoring Tests and their frequencies?

#### From diagnosis to three months

The initial monitoring of CML is carried out by complete blood count test and regression of spleen (if enlarged at diagnosis). The frequency of CBC is weekly or biweekly depending upon its report. Once the CBC is normalised then generally it is performed monthly.

#### After three months

After three months of starting TKI treatment, a test for BCR-ABL is performed along with a CBC. If the levels of BCR-ABL are decreasing gradually as defined by experts, then this test is generally repeated every six months. In addition, routine tests such as LFT, RFT, blood glucose, EKG, lipids, and chest X-ray are performed based on the type of TKI (Imatinib, Dasatinib, or Nilotinib) being used.



#### Q.1 Can a CML patient get married and start a family?

Getting married is a personal decision. A CML patient can get married and have a normal family life. However, it is important to inform the potential partner about the condition and its treatment. The partner should also be educated about the nature of the disease, the prognosis, and the potential side effects of the medication. Generally, chronic phase CML is considered a treatable cancer provided the patient is taking the medicine regularly and getting regular check-ups.

## Q.2 What issues to be considered for female and male patients to start a family while on treatment?

Male patients can start their family without any restrictions, as CML is not transmitted to their children. Female patients, on the other hand, require counselling and close monitoring before planning a pregnancy as TKIs can affect their pregnancy as well as their unborn babies and it may be necessary to stop the medication temporarily during pregnancy. The decision to start a family should be taken in consultation with their CML physician.

#### Q.3 Is breastfeeding allowed while on treatment?

Breastfeeding is not allowed if the patient is on treatment.



#### Q.1 What diet should I take? Are there any dietary precautions?

There are no specific dietary restrictions for individuals with CML, but it is important to follow healthy eating habits. You can attend social events and enjoy outside food but try to make healthy food choices. Smoking should be avoided as it can worsen the severity of CML. Alcohol consumption should also be limited to social occasions and moderation is key. If you have any other chronic illnesses such as high blood pressure or diabetes, it is important to follow the dietary precautions recommended for those conditions, such as reducing salt intake for hypertension or avoiding sugary foods for diabetes.

#### Q.2 How to boost immunity of a patient suffering from CML?

Patients with CML should focus on maintaining a healthy and balanced diet to boost their immunity. A diet rich in fruits, vegetables, whole grains, and lean proteins is recommended. Adequate hydration is also important.

There is no specific diet for CML patients, but they should avoid foods that are high in sugar, fat, and salt. Additionally, they should try to limit their intake of processed foods and alcohol.

In addition to a healthy diet, patients with CML can boost their immunity by practicing good hygiene, getting enough rest, managing stress, and engaging in regular exercise as tolerated. It is important to discuss any changes to diet or supplementation with a CML physician before making them.

As previously mentioned, if CML patient has additional illnesses (Diabetes, Hypertension, Renal failure, Lung disease or other such conditions), then dietary restrictions may be applied as applicable to other illnesses.

#### Q.3 Are there any additional protein supplements required?

Protein supplements may be helpful for some patients, but they should be used under the guidance of a healthcare provider or registered dietitian. Excessive protein intake can cause strain on the kidneys, so it is important to use these supplements in moderation.



#### Q.1 What is TFR?

TFR stands for Treatment-Free Remission in CML. It means stopping TKI treatment in patients who have achieved and maintained a deep molecular response for a certain period.

Not all CML patients are eligible for TFR, and the decision to stop treatment should be made in consultation with a CML specialist based on several factors, including the duration of treatment, the patient's response to treatment, and the presence of any comorbidities.

#### Q.2 Can I stop the medicine if my BCR-ABL report is negative?

If a patient achieves a negative BCR-ABL result, it does not necessarily mean that they can stop taking their medication. The decision to stop treatment should be based on specific criteria determined by a CML specialist.

## Q.3 What will be the frequency of testing for BCR-ABL if a patient is on TFR?

If a patient is on TFR, the frequency of testing for BCR-ABL depends on several factors, including the duration of TFR and the patient's individual risk of relapse. Typically, patients on TFR are monitored more frequently than those on active treatment.

## Q.4 Possibility of relapse while on TFR, can patient be retreated with Imatinib?

There is a possibility of relapse while on TFR, and if a patient does relapse, they can be retreated with Imatinib or other TKIs depending on their specific circumstances.



## **Side Effects and its Management**

#### Q.1 What are the side effects of Imatinib?

The common side effects of Imatinib include nausea, vomiting, diarrhea, muscle cramps, muscle and joint pain, fatigue, and skin rash, face hypo/hyperpigmentation. However, the severity and frequency of side effects can vary from person to person.

Additionally, before attributing any side effect to Imatinib, inform your CML physician who may advice additional tests.

## Q.2 Is the change in skin colour or pigmentation a side-effect of Imatinib?

Yes, skin pigmentation changes are one of the rare side effects of Imatinib

#### Q.3 How does one maintain good hemoglobin levels while on treatment?

To maintain good hemoglobin levels while on treatment, it is important to eat a healthy diet rich in iron, folate, and vitamin B12. You may also need to take iron supplements as prescribed by your physician.

#### Q.4 How does one manage side effects like loose motion and vomiting?

If you are experiencing loose motion and vomiting after taking Glivec/Imatinib, it is recommended to consult your treating physician. They may adjust your medication or prescribe medication to manage your symptoms.

#### Q.5 How severe does long term use of Imatinib affect the muscles?

Long-term use of Imatinib may cause muscle cramps and muscle pain, but this is rare.

#### Q.6 Is weight loss a side effect of Imatinib?

Weight loss is not a common side effect of Imatinib, but it may occur in some patients.

## Q.7 Skin has thinned out a lot and easily get hurt. Is there any remedy for this?

Thinning of the skin is a rare side effect of Imatinib. To avoid further injury, it is recommended to protect the affected areas from trauma and injury.

## Q.8 Sensations of numbness and tingling in fingers of hand – Is this a side effect of Imatinib?

Numbness and tingling in fingers of hand are rare side effects of Imatinib. If you experience these symptoms, it is important to inform your treating physician.

#### Q.9 Will continuous use of Imatinib affect liver function?

Continuous use of Imatinib may cause mild liver damage in some patients, but it is rare. Regular monitoring of liver function is recommended.

## Q.10 Experiencing extreme tiredness, fluid build-up, joint pain – Are these the side effects of Imatinib?

Extreme tiredness, fluid build-up, and joint pain are rare side effects of Imatinib. If you experience these symptoms, it is recommended to consult your treating physician.

#### Q.11 What are the common or serious side-effects of Glivec/Imatinib?

While serious side effects of Glivec/Imatinib are rare, they can include liver damage, heart problems, and lung problems. If you experience any unusual symptoms or side effects, it is important to contact your treating physician immediately.



## **CML** in Pediatric Patients

In children, CML accounts for approximately two percent of all pediatric leukemias. The symptoms of CML in children are similar to those in adults and may include fatigue, weakness, fever, weight loss, and enlarged spleen or liver.

Treatment for CML in children is similar to that in adults and typically involves targeted therapy with medications such as Imatinib, Dasatinib, Nilotinib, or Bosutinib. Stem cell transplantation may also be considered in some cases. The dose of medications may vary based on the age and weight of the child.

While the prognosis for children with CML is generally good, regular monitoring and treatment are essential for managing the disease and minimizing its impact on the child's health and quality of life.



## **CML in Elderly Patients**

CML in the elderly population may present some unique challenges due to age-related changes in the body, including a higher prevalence of comorbidities, such as heart disease and diabetes, and reduced organ function. Additionally, the elderly population may have a higher risk of side effects associated with treatment.

The treatment of CML in the elderly is generally similar to that in younger individuals, with targeted therapy medications such as Imatinib, Dasatinib, Nilotinib, or Bosutinib being the first-line treatment options. However, in some cases, treatment may need to be modified to account for the patient's overall health and any comorbidities they may have.

Regular monitoring of the patient's blood cell counts and disease progression is essential. Treatment may need to be adjusted based on their response to therapy. The prognosis for elderly individuals with CML is generally good, with high survival rates reported in this population.

Overall, the management of CML in the elderly population requires a personalized approach that takes into account the patient's individual health status, preferences, and quality of life, as well as the potential benefits and risks of treatment.



## List of Commonly Used TKIs for the Treatment of CML

Drug	Common Brand Name	Dose s	Common Brand Names
Imatinib	Glivec	400-800mg/day (1-2 times per day)	Nausea, vomiting, diarrhea, fatigue, muscle cramps, edema, rash, and skin hypo or hyperpigmentation
Dasatinib	Sprycel	50-140mg/day (1-2 times/day)	Nausea, vomiting, diarrhea, fatigue, muscle pain, headache, edema, rash, low blood counts, fluid buildup around the lungs (pleural effusion)
Nilotinib	Tasigna	600-800mg/day (1-2 times/day)	Nausea, vomiting, diarrhea, fatigue, muscle cramps, headache, rash, low blood counts, liver tests abnormalities, changes in lipids and ECG
Bosutinib	Bosulif	400-500mg/day (once daily)	Loose motions, nausea, vomiting, fatigue, rash, liver tests abnormalities, low blood counts



## **Advanced Stages of CML**

The advanced stage of CML consists of accelerated phase or blast phase of CML. The advanced phase consists of rapid growth and accumulation of immature white blood cells (blasts) in the bone marrow and bloodstream and rapid enlargement of spleen. The disease can also affect any other organ like lymph node, brain etc. The treatment of advanced phase requires aggressive therapy to control the disease and manage symptoms.

#### General principles

The accelerated phase is generally treated with a higher dose of TKIs. Closer monitoring of clinical symptoms as well as blood tests are required. In most situations, the CML physician will discuss the option of stem cell transplantation as the curative option if the patient is otherwise eligible.

Blast crisis of CML is the final stage of CML and it's an emergency. Even though the TKIs (Imatinib, Dasatinib, Nilotinib, Bosutinib) may be able to control the disease the effects of medications are temporary. Most CML physicians add chemotherapy to control this phase of the disease. Based on eligibility, stem cell transplantation is the only treatment that can give reasonable life for a long duration. In addition, these patients require supportive treatment such as blood and platelet transfusion, antibiotics to control infection and pain management. Treatment plans will vary depending on individual patient factors, such as age, overall health, and disease severity.



Stem cell transplantation (SCT) is also known as bone marrow transplantation. It's a medical procedure (no surgery is involved) that involves the transfer of healthy stem cells from a donor to a recipient. The goal of SCT is to replace damaged or diseased bone marrow with healthy stem cells, which can help to restore the production of normal blood cells in the body.

Stem cells are the basic building blocks of the blood and immune system, and they have the ability to develop into different types of blood cells, such as red blood cells, white blood cells and platelets. In SCT, the stem cells are typically collected from the bone marrow or blood of a healthy donor and are then infused into the recipient's bloodstream.

There are two main types of SCT: autologous and allogeneic. In autologous SCT, the patient's own stem cells are collected and stored before undergoing high-dose chemotherapy or radiation therapy. After the treatment, the stored stem cells are infused back into the patient's bloodstream to help restore the production of normal blood cells. This procedure is generally done for patients with lymphoma and myeloma (different type of blood cancers).

In allogeneic SCT, the stem cells are obtained from a donor who is a close genetic match to the recipient, such as a sibling or unrelated donor. The donor stem cells are infused into the recipient's bloodstream after undergoing a conditioning regimen of chemotherapy or radiation therapy, which aims to destroy any remaining cancer cells and suppress the immune system to prevent rejection of the donor cells.

The allogeneic SCT can treat and potentially cure advanced phase of CML. It's a high-risk medical procedure and hence reserved only for advanced phase of the disease. This procedure is available only at few places in India and generally carried out by a multidisciplinary team of healthcare providers.

### **Glossary of Commonly Used Terms**

Accelerated Phase - In the accelerated phase, the number of abnormal blast cells increase and grow faster. There are symptoms such as fatigue, fever, weight loss and an enlarged spleen. If untreated, accelerated phase will eventually transform to blast phase in CML.

**Allogeneic stem cell transplant** - Allogeneic stem cell transplantation involves the use of stem cells from someone other than the patient. The donated stem cells can come from either a person related or not related to the patient.

**Anemia** - Anemia occurs when there is not enough healthy red blood cells or hemoglobin to carry oxygen to the body's tissues.

**Antibiotics** - Antibiotics are drugs that fight bacterial infections in the body. They work by killing the bacteria or by impacting the ability of the bacteria to grow and multiply.

**Antibodies** - An antibody is a protein produced by the body's immune system when it detects harmful substances called antigens.

**Antituberculosis drugs** - Drugs that work against tuberculosis (a contagious bacterial infection that usually affects the lungs and other body parts).

**Autologous** - An Autologous stem cell transplant uses healthy blood stem cells from the patient's own body to replace the diseased bone marrow.

**Blast cells** - When a patient has leukemia, abnormal immature white blood cells (called blasts) multiply severely, filling up the bone marrow, and preventing production of other cells important for survival, namely red blood cells and platelets.

**Blast Phase** - Also known as the blast crisis. It is the third and final stage of CML. Fortunately, the incidence of blast crisis has diminished markedly in the BCR-ABL tyrosine kinase inhibitor (TKI) era. BCR-ABL - The BCR-ABL fusion gene is seen in patients with certain types of leukemia, a cancer of the white blood cells. BCR-ABL is found in almost all patients with chronic myeloid leukemia (CML). The swapping of DNA between the chromosomes (9 and 22) leads to the formation of a new gene (an oncogene) called BCR-ABL. This gene then produces the BCR-ABL protein, which is the type of protein called the tyrosine kinase. This protein causes abnormal WBCs to grow and divide out of control.

Bone Marrow - Bone marrow is a spongy substance found in the centre of the bones. It manufactures bone marrow stem cells and other substances, which in turn produce blood cells. Each type of blood cell made by the bone marrow has an important function. For example: Red blood cells carry oxygen to tissues in the body.

**CBC** - CBC stands for "Complete Blood Count". It is a blood test that's used to look at the number and morphology of cells circulating in the blood like the red blood cells, white blood cells and platelets. It has a wide range of applications. Example: anemia (low RBCs).

**Chemotherapy** - Chemotherapy is a type of cancer treatment that uses one or more drugs to kill fast-growing cancer cells and to stop them from dividing rapidly. Chemotherapy may be given to cure the disease or prolong the life and reduce the symptoms. Chemotherapy may be given orally or via injection or infusion. It may also be given alone or with other treatments, such as surgery or radiation therapy.

**Chromosomes** - Chromosomes are the threadlike structures found inside the nucleus of a cell. Chromosomes are made up of DNA that serve to carry the genomic information from one cell to another. Each cell normally contains 23 pairs of chromosomes.

**Comorbidities** - Comorbidities refer to the existence of more than one disease or condition

within the body at the same time. Comorbidities are usually long-term, or chronic. They may or may not interact with each other. Example: Diabetes Mellitus Hypertension and other such conditions.

Molecular Response - Molecular response is based on how much of the BCR-ABL gene (which is found in abnormal WBCs) can be detected by the PCR test. This test can be done on either the blood or bone marrow. A complete molecular response (CMR) means that the PCR test does not find the BCR-ABL gene.

**FISH** - FISH stands for fluorescence in situ hybridisation. It is a test in molecular biology that looks for specific DNA sequence on a chromosome. In CML, It is used to confirm the presence of BCR-ABL1 fusion gene on chromosome 22.

Hemoglobin - Hemoglobin is a protein contained in red blood cells that is responsible for delivery of oxygen to the tissues. To ensure adequate tissue oxygenation, a sufficient hemoglobin level must be maintained. Hemoglobin count in blood can be detected through CBC test.

**Hyperpigmentation** - Hyperpigmentation is a common skin condition affecting people of all skin types. It is usually a harmless condition in which patches of skin become darker than the surrounding area. It occurs when special cells in the skin produces excess of the pigment called melanin, the pigment that gives skin its color.

**Immune System** - The immune system is a complex network of organs, cells and proteins that defends the body against infections and other diseases, whilst protecting the body's own cells.

**LFT** - The full form of LFT is "Liver Function Tests" - a group of blood tests that can help to show how well the patient's liver is working.

**RFT** - The full form of RFT is "Renal Function Tests" - a group of tests performed to evaluate the function of the kidneys. It helps diagnose inflammation, infection or damage in the kidneys.

**Edema** - Edema is the swelling caused by excess fluid build-up in body tissues. It is more common likely to show up in the legs and feet but can affect the brain, lungs, and other organs also.

**ECG** - The ECG is a simple test that can be used to check the heart's rhythm and electrical activity. Sensors are attached to the surface of the skin to detect the electrical signals produced by the heart each time it beats.

**Leukemia** - Leukemia is a cancer of the body's blood-forming tissues, including the bone marrow and the lymphatic system. Leukemia involves white blood cells. There are various types of leukemia. Some forms of leukemia are more common in children. Other forms of leukemia occur mostly in adults.

**Lymphoma** - Lymphoma is a group of cancers of the lymphocytes, a type of white blood cells. The uncontrolled growth of lymphocytes occur in the blood or lymph nodes.

**Malaise** - A general feeling of discomfort, illness or lack of well-being often indicative of or accompanying the onset of an illness.

**Myelofibrosis** - This is an uncommon type of blood cancer that disrupts the body's normal production of blood cells. Myelofibrosis causes extensive scarring in the bone marrow, leading to severe anemia that can cause excessive weakness and fatigue.

**Myeloma** - Myeloma also called multiple myeloma, is a cancer of the plasma cells, a type of white blood cells that make antibodies which protect us from infection. In myeloma, cells grow in excess, crowding out the normal cells in the bone marrow that make red blood cells, platelets, and other white blood cells. Myeloma also affects bones, kidneys and many other organs.

**Nausea** - Nausea is a sensation of discomfort in the upper abdomen, accompanied by an urge to vomit. This can be a side effect associated with several medications or a symptom of disease or other disorders in the body.

Pathologist - A pathologist is a medical healthcare provider who examines body tissues under a microscope. He or she is also responsible for performing laboratory tests. A pathologist helps other healthcare providers reach diagnoses and is an important member of the treatment team.

**PCR** - The full form of PCR is "Polymerase Chain Reaction". It is a technology used for quick and easy amplification of DNA sequences in genes. This method is used in the field of molecular biology for DNA analysis.

**Platelet** - Platelets are tiny, disc-shaped cells that are found in the blood. They help form blood clots to stop bleeding and help wounds heal.

**Pleural effusion** - Pleural effusion is the development of fluid between the layers of tissue that line the lungs and chest cavity.

Philadelphia chromosome - A gene formed when pieces of chromosomes 9 and 22 break and exchange places. The ABL gene from chromosome 9 translocates to the BCR gene on chromosome 22 to form the BCR-ABL fusion gene. The changed chromosome 22 with the fusion gene on it is called the Philadelphia chromosome.

**Prognosis** - A prognosis is the prospect of recovering from an injury or disease, or a prediction of the normal course and outcome of a medical condition.

**Red cell** - A type of blood cell that carries oxygen to all parts of the body. Red blood cells are made in the bone marrow. In healthy people, red cells make up almost half of the blood.

**Relapse** - The return of a disease or the signs and symptoms of a disease after a period of improvement is called a relapse.

**Remission** - In Remission signifies the absence of signs and symptoms of the disease and a period of time when the disease is not causing any health problems.

**Stem cell** - These are cells with the potential to develop into many different types of cells- namely: red cells, white cells and platelets in the body. They serve as a repair system for the body. There are two main types of stem cells: embryonic stem cells and adult stem cells.

**Solid Tumors** - These are tumors of the solid organs in the body like lungs, breast, oral cavity, stomach, colon and so on. Solid tumors may be benign(not cancerous), or malignant (cancerous). Solid tumors are called sarcomas or carcinomas. Leukemias (cancers of the blood) are not part of solid tumors.

**Spleen** - The spleen is an organ that is part of the lymphatic system. It is located on the left side of the abdomen near the stomach. It functions as a blood filter and destroys old or abnormal blood cells. It also produces lymphocytes and helps fight infections.

**Tyrosine kinase inhibitor (TKI)** - Tyrosine kinase inhibitors (TKIs) are a type of targeted therapy which identify and attack specific types of cancer cells while causing less damage to normal cells. They come as pills and are taken orally. In CML, TKIs target the abnormal BCR ABL protein and block its function, causing the abnormal white blood cells to die.

**Treatment-free remission (TFR)** - When a patient who has discontinued TKI therapy maintains a major molecular response (MMR) and does not need to restart therapy, he is said to have achieved TFR.

**Trauma** - A disturbing event or injury to the body resulting in an adverse impact on someone's physical, emotional or social wellbeing.

White Blood Cells - These cells are formed in the bone marrow and circulate in the blood and lymph nodes. They are a part of our body's immune system and protect us from infections.

## Important Links to Access More Information

www.cmlsupport.org.uk

www.cmladvocates.net

www.cml-foundation.org

www.themaxfoundation.org

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## Notes



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