
Myelofibrosis (MF)

**A Guide for
Patients**

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Being diagnosed with myelofibrosis (MF) can be a shock, particularly when you may have never heard of it. If you have questions about MF – what causes it, who it affects, how it affects your body, what symptoms to expect and likely treatments – this booklet covers the basics for you.

You will also find useful advice about how to get the best from your haematologist, plus practical advice on how to help important people in your life understand such a rare condition. For more information talk to your haematologist or clinical nurse specialist.

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If you would like any information on the sources used for this booklet, please email communications@leukaemiacare.org.uk for a list of references.

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About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available 8:30am – 5:00pm Monday - Friday and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500068065** on weekdays 9:00am – 5:00pm.

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing **nurse@leukaemicare.org.uk** or over the phone on **08088 010 444**.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who

has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at **www.leukaemicare.org.uk/support-and-information/help-and-resources/information-booklets/**

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to **www.leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group/**

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some

way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemiacare.org.uk**

Online Forum

Our online forum, **www.healthunlocked.com/leukaemia-care**, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

Website

You can access up-to-date information on our website, **www.leukaemiacare.org.uk**.

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email **advocacy@leukaemiacare.org.uk**

Patient magazine

Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals: **www.leukaemiacare.org.uk/communication-preferences/**

What is myelofibrosis?

Myelofibrosis (MF) is a myeloproliferative neoplasm (MPN) characterised by excessive scar tissue. This forms in the bone marrow (soft, fatty tissue inside your bones) and prevents it from producing normal blood cells. MPNs are chronic disorders where the myeloid stem cells in the bone marrow make too many abnormal blood cells which do not function properly.

In the case of MF, the abnormal clonal blood stem cells in the bone marrow produce mature cells that reproduce quickly and occupy the bone marrow, causing the formation of scar tissue (fibrosis) and prolonged inflammation. Clonal describes a cell or organism descended from, and genetically identical, to a single common ancestor.

MF can occur on its own or following one of the MPNs, polycythaemia vera (PV) or essential thrombocythaemia (ET). Therefore, the two main types of MF are:

1. Primary myelofibrosis:
This type of MF occurs spontaneously.

2. Secondary myelofibrosis:
This occurs if you have been previously diagnosed with another MPN such as ET or PV.

Primary MF or MF secondary to PV or ET are very similar in terms of symptoms and treatment.

You can get copies of booklets on PV and ET by downloading them from our website at www.leukaemicare.org.uk or requesting a hard copy by emailing support@leukaemicare.org.uk, or calling our helpline on **08088 010 444**.

There has been some debate about whether or not MPNs are types of cancer. This is because the word 'neoplasm' (new growth) is a term used both for cancers (malignant neoplasms) and noncancerous tumours (benign neoplasms). Because in MF there is an uncontrolled increase in stem cells, most haematologists and cancer organisations do consider it and other MPNs

as blood cancers. Whatever it is called, the symptoms and prognosis for patients can vary widely. Your haematologist will advise you depending on your individual circumstances.

Who is affected by MF?

MF is a rare disease with an average incidence rate of 0.1 to 1 per 100,000 persons per year.

MF can affect anyone. However, it is virtually unheard of in children and very rare in young adults. It is most commonly diagnosed in patients between 60 and 70 years of age, with a median age at diagnosis of 64 years.

The incidence of MF is slightly higher in men than women, with incidences per 100,000 persons of 0.59 compared with 0.3, respectively. There is no significant difference between the incidences of MF in Europe, North America and Australasia. The incidences of MF by race is very similar, except for a noticeably higher incidence in those of Ashkenazi Jewish descent, where a family history is involved.

What causes MF?

While the exact cause of MF is not known, research has shown that about 80% of patients with MF have one of three main gene abnormalities, commonly referred to as mutations. These are:

- JAK2 (Janus Kinase 2)-V617F in about 50% of patients
- CALR (Calreticulin-R) in about 25% of patients
- MPL (Myeloproliferative Leukaemia virus gene MPL515L/K) in 5 to 10% of patients

Additionally, some 10% of patients do not have any of the gene mutations above and are known as 'triple-negative' MF patients. Patients who have triple-negative MF have a poor prognosis.

In the majority of cases, MF is not inherited and therefore cannot be passed on to your children, with the exception of MF in descendants from Ashkenazi Jews.

Some researchers believe MPNs may be triggered by past

What is myelofibrosis? (cont.)

exposure to ionising radiation (a type of radiation that has very high energy, like medical x-rays or nuclear fallout) or to some chemical substances such as benzene and toluene.

New genetic mutations that are associated with MF continue to be discovered and it is likely that, in most patients, the disease is caused by a combination of these mutations.

Factors that increase the risk of getting MF other than the presence of the JAK2, CALR and MPL mutations, are:

- Age: MF can affect anyone; however, it is most often diagnosed in people older than 50 years old.
- Another blood cell disorder such as ET or PV, in which MF can develop.
- Exposure to industrial chemicals such as toluene and benzene or very high levels of radiation.

What are stem cells?

Stem cells are the most basic cells in the body that have the ability to develop into any of the body's specialised cell types, from muscle cells to brain cells. They are found in many organs and tissues of the body and replenish any cells that have been lost or damaged. Blood stem cells (called haematopoietic stem cells) are found primarily in bone marrow. There, they have the potential to develop into mature blood cells, such as red cells, white cells and platelets.

What are the signs and symptoms of MF?

The essential features of MF are an enlarged spleen, fibrosis (scarring) in the bone marrow, anaemia (too few red blood cells), and symptoms such as fatigue, fever, night sweats and bone pain.

The bone marrow normally contains blood stem cells, that in time develop into mature blood cells such as:

- Red blood cells that carry oxygen to the tissues of your body
- White blood cells that fight infection and disease
- Platelets that help prevent bleeding by causing the blood to clot

However, in patients with MF, abnormal clonal stem cells take over the bone marrow, leading to chronic inflammation and fibrosis. This results in the bone marrow being unable to make enough normal blood cells to carry out their functions.

As MF prevents the bone marrow from producing normal blood cells, the spleen is obliged to take over producing blood cells, which causes its enlargement. These

changes may lead to some of the symptoms of MF.

Symptoms of MF vary greatly between patients. While most patients are diagnosed having presented with some symptoms, others experience few or no symptoms at all in the early stages of MF. In fact, many patients are diagnosed after having tests for an unrelated condition.

Patients with MF may have any of the following symptoms or signs:

- Fatigue
- Sweats (predominantly at night)
- Itching (worse after baths or showers)
- Bone pain (arthralgia)
- Muscle pain (myalgia)
- Weight loss
- Fever
- Enlargement of the spleen which can cause abdominal pain, discomfort, loss of appetite and a feeling of filling up quickly during meals (sometimes referred to by doctors as 'early satiety').

How is MF diagnosed?

The diagnosis of MF will usually be made following a series of tests which may be done over a period of several visits to the haematology clinic. The current diagnosis of MF is based on the 2016 World Health Organisation criteria which takes into account clinical and laboratory features. The following tests are required to determine these criteria:

- **Full Blood Count** - This is a routine blood test which measures the number of red cells, different types of white cells and platelets in the blood. The blood is smeared on a microscope slide, allowing the blood cells to be examined under the microscope. In many patients with MF, this reveals the presence of immature stem cells in the blood that would normally only be seen in the bone marrow.
- **Bone marrow biopsy** - In most cases, a small sample of bone marrow is needed to be able to identify the abnormal myeloid stem cells and confirm the diagnosis of MF. The bone marrow sample can be taken from the hip bone under local

anaesthetic, using special biopsy needles: liquid bone marrow (aspirate) and/or a tiny core of bone marrow tissue (trephine).

- **Tests for gene mutations** - Blood tests may be performed to check for mutations in the patient's genes. The presence of genes such as JAK2, CALR and MPL are helpful for the diagnosis, and also provide information to determine the prognosis.
- **Abdominal ultrasound scan** - Often it will be easy for your haematologist to feel your enlarged spleen; however, an ultrasound might be done in patients with a spleen that is less enlarged. This will also help to look for liver enlargement or abnormalities of other organs.

For patients to be diagnosed with MF, they must meet all 3 major WHO criteria, and at least 1 minor criterion. The criteria are as follows:

Major criteria

- Rapid increase of abnormal megakaryocytes (large bone

marrow cell responsible for the production of platelets), accompanied by reticulin and/or collagen fibrosis. Reticulin is a type of fibre in connective tissue composed of a specialised collagen (type III). Reticular fibres crosslink to form a fine meshwork in the bone marrow.

- Not meeting the WHO criteria for any of the following conditions:
 - ET
 - PV
 - CML featuring the Philadelphia chromosome with the BCR-ABL1 gene
 - Myelodysplastic syndromes (MDS)
 - Other myeloid neoplasms
- Presence of the JAK2, CALR, or MPL mutations, or in the absence of these mutations, presence of another clonal marker, or absence of reactive MF. Reactive MF is fibrosis caused by infection, an autoimmune disorder, or other chronic inflammatory conditions.

Minor criteria

Presence of at least one of the following, on two consecutive occasions:

- Anaemia not caused by another condition
- White blood cell count greater than $11.0 \times 10^9/L$
- Enlarged spleen which can be felt on physical examination
- Lactate dehydrogenase (LDH) level increased above the upper normal limit (greater than 300 international units per litre [IU/L] depending on laboratory). LDH is an enzyme required during the process of turning sugar into energy for the cells of the body. High levels of LDH indicate some form of tissue damage.
- Presence of immature cells of myeloid origin and nucleated red cells in the circulating blood, with or without anaemia. This is called leukoerythroblastosis.

What is the treatment for MF?

Currently, the only possible cure for MF is an allogeneic stem cell transplant (Allo-SCT), which involves the transplantation of bone marrow stem cells from a suitable matching donor such as a sibling, parent or child. However, an Allo-SCT is really only suitable for young patients and those patients who can withstand the intensive chemotherapy required to prepare the bone marrow to receive the donor's cells.

Treatment options

While young fit patients with advanced MF may benefit from an allogeneic stem cell transplant, older patients with many symptoms and splenomegaly may gain greater benefit from targeted chemotherapy with a JAK mutation inhibitor such as ruxolitinib.

Experience of treating MF has shown it is possible to avoid the worsening of MF symptoms by using effective treatments such as ruxolitinib, interferon or hydroxyurea. Symptoms can be stabilised or even made to regress for many years. If symptoms remain present despite treatment, it is usually an indication that the MF is progressing or it is

becoming resistant to treatment.

Current drug treatment can improve the quality of life for patients with MF but it has not been shown to modify any of the characteristics of MF or prolong patient survival. Regular monitoring of symptoms will help track any progression of the MF and the efficacy of treatment.

Treatment is guided by the patient's risk level as determined by the prognostic scoring systems and any particularly bothersome symptoms such as anaemia or an enlarged spleen. Often patients with MF will require a combination of treatments.

Treatments according to prognostic scoring systems

Low risk

If patients with MF have no symptoms when first diagnosed (low risk; score=0), a 'watch and wait' approach is often recommended at first. Watch and wait usually involves regular check-ups and blood tests, as well as advice on how to maintain a healthy lifestyle.

An exception to this is if the

patients have been identified as having high risk mutations such as ASXL1 (Additional Sex Combs Like-1), SRSF2 (Serine and Arginine Rich Splicing Factor 2). It is very important to screen patients with no symptoms for these ASXL1 and SRSF2 mutations because they will have a poorer long-term prognosis, and if they are suitable for an ASCT, these patients will be encouraged to pursue an ASCT sooner rather than later.

There are other mutations in patients with MF, however, ASXL1 and SRSF2 are the most common (36% for ASXL1 and 18% for SRSF2) compared to other gene mutations that have incidences of around 1-5%.

Our booklet on Watch and Wait tells you all you need to know. You can get a copy by downloading it at www.leukaemiacare.org.uk, emailing support@leukaemiacare.org.uk or calling 08088 010 444.

Low-risk to intermediate-1 level

In patients with low-risk to

intermediate-1 level MF, the symptoms that need treating should be assessed and discussed between patient and haematologist. Treatment of a symptom that is distressing and limits the patient's quality of life is probably beneficial as long as it is effective and well-tolerated. In patients with low-risk to intermediate-1 level MF, the aim of treatment is to decrease the enlarged spleen, improve blood cell counts and relieve difficult symptoms such as anaemia, fatigue or muscle pain.

At present, there is no evidence that the new JAK inhibitor ruxolitinib can reverse bone marrow fibrosis but it may be effective for relieving symptoms of MF and reducing the size of the spleen in patients with low-risk to intermediate-1 level MF who required treatment.

Intermediate-2 or high-risk level

Patients with intermediate-2 or high-risk MF have the option of an ASCT, if applicable, or the JAK inhibitor ruxolitinib. Treatment for specific MF symptoms are

What is the treatment for MF? (cont.)

also available if required as for patients with low-risk to intermediate-1 level MF.

Allogeneic stem cell transplants (Allo-SCT)

Allo-SCT is currently the only treatment that can prolong survival or potentially cure MF. However, Allo-SCT in patients with MF is associated with at least a 50% rate of transplant related deaths or life-threatening side effects. Consequently, the risk of the Allo-SCT to patients must be justified in terms of their prognosis.

You will be individually assessed because ASCTs are usually only considered as an option for fit patients with advanced disease and who have a matched donor. If you are suitable for an Allo-SCT, you will first receive very high levels of chemotherapy or radiation therapy to kill all your abnormal myeloid stem cells in your bone marrow before receiving the healthy donor stem cells. This is why an Allo-SCT is more appropriate for young patients and those patients who can withstand the preliminary intense chemotherapy. Sometimes, for

weaker patients, less intense doses of chemotherapy to weaken their immune system enough to allow the donor stem cells to grow in their bone marrow are given. This is called reduced intensity conditioning. However, it has been shown that the Allo-SCT produces fewer effective results.

Apart from an Allo-SCT, all other treatments used in MF are aimed at improving quality of life by controlling symptoms, reducing the size of the spleen and improving the blood cell counts. Drug therapy can improve the quality of life for patients with MF but it cannot as yet modify the characteristics of the disease or prolong survival.

JAK Inhibitors

Ruxolitinib (Jakavi, Novartis Europharm Limited) is a JAK1/JAK2 inhibitor that works by blocking the JAK enzymes that send too many signals for the production and growth of cells. By blocking JAKs, ruxolitinib reduces the production of the abnormal myeloid stem cells in MF, thereby reducing the symptoms that they cause.

Ruxolitinib is approved for the

treatment of an enlarged spleen or symptoms in adult patients with primary MF, or secondary MF following PV or ET. It has also been recommended by the National Institute for Health and Care Excellence (NICE) for the treatment of enlarged spleen and symptoms in MF patients with intermediate-2 and high-risk disease.

In a study of patients with MF, ruxolitinib was compared with the best treatment available. Ruxolitinib reduced bone marrow fibrosis in 15.8% of patients and maintained the fibrosis stable in 32.2%. In addition, approximately one third of patients receiving ruxolitinib showed a reduction in the JAK2 mutations.

Although ruxolitinib can lessen the symptoms of MF, it does not modify the disease process or prevent the risk of transformation to AML. Several other JAK inhibitors, such as pacritinib, fedratinib and momelotinib, are currently under development in clinical trials. However, so far, none of these other JAK2 inhibitors have been shown to reverse bone marrow fibrosis.

Until the approval of fedratinib in the United States in August 2019, ruxolitinib was the only available JAK inhibitor for treatment of intermediate-2 or high-risk MF. However, fedratinib is not currently approved in the United Kingdom.

Because of ruxolitinib's mechanism of action, many patients with MF receiving it may develop anaemia as the haemoglobin levels of patients decrease over the first few months of treatment. Platelet counts can also be reduced. For these patients, the dose of ruxolitinib may need adjusting, particularly for those patients who already have anaemia. In addition, ruxolitinib is associated with increased risk of infections which can include shingles, hepatitis B reactivation and tuberculosis.

A recent review of the long-term outcome of treatment with ruxolitinib in patients with MF reported a high treatment discontinuation rate of 92% after a median period of 9.2 months. A 'ruxolitinib withdrawal syndrome' has also been described following discontinuation of treatment

What is the treatment for MF? (cont.)

with ruxolitinib. The syndrome is characterised by an acute recurrence of symptoms, an accelerated increase in the size of the spleen, worsening of low blood cell counts, and a septic shock-type syndrome caused with a drop in blood pressure.

Treatment for specific MF symptoms

Anaemia

When anaemia is the major symptom for patients with MF, it needs to be treated. Symptoms related to anaemia include excessive tiredness, weakness and shortness of breath. Generally, the use of hydroxyurea or ruxolitinib for anaemia associated with MF is ineffective and can sometimes be dangerous. Your haematologist may suggest some of the following more effective solutions:

Blood transfusion

A blood transfusion involves the transfer of red blood cells from a compatible donor into your body. This will quickly increase your red blood cell count and reduce symptoms of anaemia, often within 24-hours. Blood

transfusions are common and safe procedures and have only a very small risk of complications. However, if you receive a series of transfusions over a number of years, you may have an increased risk of iron overload.

Prior to the blood transfusion, the procedure will be explained to you and you will be required to sign a consent form. You will be sat or lying down during a blood transfusion. It normally takes less than four hours to receive a 500ml bag of blood. You can normally go home shortly after the transfusion, unless you feel unwell. Always tell the nurse if you feel hot, cold, shivery, as this might be a sign that you are having a reaction to the transfused blood.

Erythropoiesis-stimulating agents

Erythropoietin (EPO) is a growth factor protein normally made in the kidney, which stimulates the bone marrow to make red blood cells. It can also be developed in the laboratory as a medication to treat anaemia in a range of diseases, including MF.

Treatment with

erythropoiesis-stimulating agents (epoetin alfa, beta, theta and zeta, and darbepoetin alfa) are of limited value because they are ineffective in patients dependent on transfusions and may make an enlarged spleen in patients worse. A measurement of the EPO level before treatment will reveal which patients are likely to respond to treatment with erythropoiesis-stimulating agents. If the EPO level is high in patients with MF, then the likelihood of it working is very low.

Other conventional treatments

Other drugs that may improve anaemia in patients with MF include interferons such as interferon-alpha, immunomodulatory drugs such as thalidomide, steroids such as prednisolone, and androgens such as danazol.

Interferon-alpha is a drug made of purified derivative fractions of white blood cells. It boosts the body's natural immune system to fight cancer cells. In MF, interferon alpha suppresses the production of the abnormal myeloid stem cells and reduces the size of the spleen. Interferon-alpha has

flu-like side effects, nausea, headaches, depression, liver and thyroid inflammation and diarrhoea. Pegylated interferon, which is a slow-release weekly formulation, is often better tolerated with a lower rate of side effects. Pegylated interferon-alpha has been shown to improve anaemia completely in 63.5% of patients.

Thalidomide, lenalidomide and pomalidomide are immunomodulatory drugs that help the immune system dispose of the abnormal myeloid stem cells in MF, but they can also inhibit their growth. It is reported that thalidomide can achieve a modest improvement of anaemia in 20-60% of patient with MF. Side effects of these drugs include drowsiness, numbness/tingling of the hands and feet, and constipation. They are more easily tolerated when administered with prednisolone. However, most importantly, these drugs can cause birth defects, so they should not be given to pregnant women, and women who are sexually active must use effective contraception.

Prednisolone can be given as

What is the treatment for MF? (cont.)

a single treatment usually after failure of other therapies, or in combination with other therapies. As a single agent, it has been shown to improve anaemia temporarily in 40% of patients with MF. Prednisolone is usually more effective when in combination with other therapies such as the immunomodulatory drug thalidomide.

Danazol is a semi-synthetic male hormone (androgen) which has been shown to improve anaemia in 30% of patients. However, its use is often limited by its side effects of weight gain, male pattern hair growth and toxic effects on the liver. It is important to regularly monitor patients on danazol using liver tests, as well as screen for liver cancer, and prostate cancer in men.

Enlarged spleen

An enlarged spleen is a common symptom of MF, often leading to pain, discomfort and a feeling of fullness or a loss of appetite. Treatment options include the following:

Hydroxycarbamide

Hydroxycarbamide (also known

as hydroxyurea) is one of the most commonly used and the drug of choice for treating the symptoms of an enlarged spleen in patients with MF. It is an antimetabolite chemotherapy drug which interferes with the synthesis of the DNA of cells, and therefore prevents the growth or reproduction of the abnormal myeloid stem cells in the bone marrow.

Hydroxycarbamide has shown reductions of up 50% in the size of the spleen in approximately 40% of patients. This reduction lasts on average for 13 months. It can also be used to reduce the white blood cell and/or platelet counts and reduce the symptoms of MF.

Hydroxycarbamide can cause side effects, but generally these are mild. Side effects can include lowered resistance to infection, mouth or leg ulcers, anaemia, reduced white cell numbers, and diarrhoea or constipation. If hydroxycarbamide is used either alone or in combination with other chemotherapy drugs over a long period of time, it can potentially increase the chance of the MF developing into acute myeloid leukaemia (AML).

If you would like more information about AML, you can download our booklet from our website www.leukaemiacare.org.uk or request a copy by emailing support@leukaemiacare.org.uk, or call our helpline on 08088 010 444.

JAK inhibitors

Despite the fact that ruxolitinib has not been able to reverse bone marrow fibrosis or induce remissions in patients with MF, it can, however, lessen symptoms and reduce the size of the spleen.

In MF, the abnormal myeloid stem cells migrate to organs such as the spleen and the liver. Under normal conditions, the spleen normally fights infection by producing white blood cells and removes old or damaged blood cells. When bone marrow is prevented from producing normal blood cells by fibrosis, these organs, the spleen in particular, take over producing blood cells, which causes their enlargement.

For MF patients with an enlarged

spleen which is causing symptoms, and have not responded to treatment with hydroxycarbamide, ruxolitinib can be an effective alternative. In addition, ruxolitinib can also improve other symptoms of MF.

Other chemotherapy drugs

Other chemotherapy drugs such as melphalan, busulphan, cladribine and radioactive phosphorous (P32) have been used in patients with MF, but they are rarely used nowadays. They may, however, sometimes help when other medications are not working or are causing side effects. Your haematologist will explain the potential benefits and risks of these medications.

Splenectomy

A splenectomy is an operation to remove the spleen, which may be recommended for some patients if drug treatment has not been successful.

As the spleen becomes enlarged with the high number of cells it is producing and disposing of, it can cause patients severe abdominal pain. In addition, when body organs other than the bone

What is the treatment for MF? (cont.)

marrow try to make blood cells it can be very painful.

Splenectomy is usually considered to be required if the enlarged spleen is painful, causing complications and not responding to any other treatments. Other symptoms for which splenectomy in MF is considered relevant include very low levels of platelets and the need for frequent red blood cell transfusions.

Splenectomy is a major surgical procedure which carries significant risks of complications including infections, bleeding, blood clots and death; therefore, it should only be undertaken when the spleen is extremely large and drug treatment is not possible. A surgical oncologist who is a doctor specialising in cancer surgery will usually perform this procedure.

Radiotherapy

Radiotherapy, which is irradiation of the spleen using high-strength beams such as X-rays, is an option if splenectomy is not a viable solution. Performed in hospital, radiotherapy helps to reduce the size of the spleen,

and can also relieve other related symptoms, such as bone pain. The high-strength beams kill the abnormal myeloid stem cells. Radiotherapy provides temporary relief that lasts between three and six months; however, it may also result in prolonged episodes of anaemia, as well as lowering of the platelet and other white blood cell counts.

When body organs other than the spleen and liver, such as the vertebral column, lymph nodes, and the lining of the lung (known as pleura), try to make blood cells, it can be very painful. Lymph nodes are small nodules within the lymphatic system network that contain the antibody producing lymphocytes blood cells and the macrophage cells that digest dead cells. They are located mainly in the spleen but also in the neck, armpit and groin. Low-dose radiotherapy can be of benefit to these patients as well as those who have extremity bone pain.

Pruritis/itchy skin

Itchy skin is a common symptom of MF, and can often be worsened by exposure to water of any

kind or temperature. Before considering treatments, check with your GP or haematologist that there aren't any other causes for the itchy skin (such as thyroid problems or an iron deficiency). Also, think about if you have recently changed your soap or detergent and switch to a soap substitute if appropriate.

Antihistamines

Antihistamines or related drugs can be prescribed to relieve itching. Side effects can include a sore mouth as well as drowsiness or dizziness.

Phototherapy

This treatment involves exposing the skin to ultraviolet light regularly under medical supervision. It works as a temporary measure to ease generalised itching.

New treatments on the horizon

A number of new drugs including alternative JAK inhibitors, either used alone or in combination with other treatments, are being actively investigated for the treatment of MF.

The limitation of the use of ruxolitinib in patients with anaemia and low platelet levels has prompted the development of the second-generation JAK inhibitors which do not suppress the production of normal red blood cells and platelets in the bone marrow. Three of these second-generation JAK inhibitors, all of which inhibit JAK2, are in the process of being evaluated in clinical trials: pacritinib, momelotinib and fedratinib. Fedratinib was approved in the United States in 2019 for the treatment of adult patients with intermediate-2 or high-risk MF, and MF secondary to PV and ET including patients previously treated with ruxolitinib.

Promising new treatments which are being investigated include the telomerase inhibitor imetelstat and the anti-fibrosing agent PRM-151. However, these drugs are still in the early stages of development. It is clear from early results that imetelstat is active in patients with MF; however, its potential to suppress the bone marrow requires further assessment in clinical trials.

PRM-151 is a genetically

What is the treatment for MF? (cont.)

modified version of a protein called pentraxin-2 which has been developed to prevent and reduce fibrosis in the treatment of various fibrotic diseases, including MF. In patients with MF, it has already shown clinical benefit by reducing symptoms, decreasing the volume of the spleen and increasing haemoglobin levels and platelet counts.

Follow-up

Follow-up after treatment is an important part of your care. Follow-up for MF is often shared between the cancer specialists (oncologists), the blood specialists (haematologists) and your GP. Your healthcare team will work with you to decide on follow-up care to meet your needs.

What is the prognosis of MF?

Risk factors which will influence the prognosis of patients with MF should be evaluated by experienced haematologists. Your haematologist is the best person to advise you on your prognosis, based on your individual

circumstances. However, it is important to note that many MF patients can have a good quality of life, with some only experiencing a few symptoms.

Patients with MF have different risk factors that have been classified to create 'prognostic scoring systems' which help select the best treatment for patients.

Prognostic scoring systems

There are three main prognostic scoring systems:

1. International Prognostic Scoring System (IPSS)
 2. Dynamic International Prognostic Scoring System (DIPSS)
 3. DIPSS-Plus
- The IPSS is for use at the time of diagnosis, while DIPSS and DIPSS-Plus are for use during or after treatment. Prognostic scoring systems are being developed as the knowledge about MF increases. For example, DIPSS-Plus includes information about the mutations which help diagnose MF.

IPSS

The IPSS uses the following five independent factors for low survival:

- Age older than 65 years
- Haemoglobin less than 10g/dL
- White cell count greater than $>25.3 \times 10^9/L$
- Abnormal myeloid stem cells greater than 1% of blood cells
- Presence of symptoms
- Each risk factor counts as one point and the disease prognosis is determined as shown in Table 1.

Table 1: International Prognostic Scoring System (IPSS)

IPSS score	Risk
0	Low risk
1	Intermediate-1
2	Intermediate-2
3 or more	High-risk

DIPSS

The DIPSS uses the same risk factors as the IPSS except that haemoglobin less than 10g/dL is given two points, and the scores

indicate different prognostic risks as seen in Table 2.

Table 2: Dynamic International Prognostic Scoring System (DIPSS)

DIPSS score	Risk
0	Low risk
1 or 2	Intermediate-1
3 or 4	Intermediate-2
5 or 6	High-risk

DIPPS-Plus

The DIPPS-Plus score includes the same risk factor as DIPSS but adds the following three further risk factors:

- Platelet count less than $100 \times 10^9/L$
- Need for transfusion
- Presence of cytogenetic changes in the bone marrow. Cytogenetic changes are changes in the chromosomes that contain the genetic material.

DIPPS-Plus is therefore calculated using eight risk factors awarding one point for each but has a different scoring system as shown in Table 3.

What is the treatment for MF? (cont.)

Table 3: DIPSS-Plus

DIPSS score	Risk
0	Low risk
1	Intermediate-1
2 or 3	Intermediate-2
4 or more	High-risk

DIPSS-Plus, which includes information about mutations, the levels of platelets and dependence on transfusions has been shown to give a better prognosis for patients after their Allo-SCT compared with DIPSS. As more information is discovered about the mutations associated with particular groups of patients with MF, new prognostic scoring systems are developed such as the Genetically Inspired Prognostic Scoring System (GIPSS). Your haematologist will be able to tell you which of these new prognostic scoring systems are applicable for you.

Prognostic scoring systems can be used as guidance either at the time that the diagnosis of MF is made or at later points in the course of the disease.

Depending on the prognostic scoring systems used, median

survival for patients can be estimated as a guide. Using the IPSS which is used at the time of diagnosis of patients with MF, median survivals were estimated at 11.3 years for low risk, 7.9 years for intermediate-1 risk, 4.0 years for intermediate-2 risk and 2.3 years for high risk patients.

As mentioned previously the DISS-Plus includes details of mutations, the levels of platelets and dependence on transfusions, and therefore has been shown to give a better prognosis for patients since it is the most comprehensive. The DIPSS-Plus which is used during or after treatment of patients with MF estimated median survivals of 15.4 years for low risk, 6.5 years for intermediate-1 risk, 2.9 years for intermediate-2 risk and 1.3 years for high-risk patients.

Transformation to AML has been reported to occur in 8% to 23% of patients in the first 10 years. A number of mutations including ASXL1, EZH2 (Enhancer of Zeste Homolog 2), SRSF2 or IDH1/IDH2 (Isocitrate Dehydrogenase 1 and 2) have been linked to AML transformation and patients with these mutations have shorter

overall survivals compared with MF patients who do not have these gene mutations.

Patients who display a CALR mutation tend to be younger and have good prognosis with a median overall survival of 17.7 years. Patients with the JAK2 or MPL mutations have median survivals of around nine years. Patients with none of these mutations, also known as triple-negative, tend to have a shortened median survival of 3.2 years and are more prone to AML transformation. A JAK2 mutation is linked with an increased likelihood of blood clotting events (thrombosis).

New mutations that may influence the prognosis of MF are being discovered by researchers all the time, and are being added routinely to new prognostic scoring systems, but this is not yet part of standard practice.

You might find it useful to track your MPN10 score. This is based on marking the most common symptoms of MPNs out of 10 based on the severity you are experiencing. This might also be helpful for you when seeing your doctor for a check-up. For more information, go to: www.mpn10app.com.

Living with MF

After a diagnosis of MF, you may find that it affects you both physically and emotionally. This chapter will talk about both of these aspects.

Emotional impact of MF

Being told you have cancer can be very upsetting. Some of the symptoms of MF can be hard to cope with and, because of this, you may need emotional, as well as practical, support. Being diagnosed with a rare disease can affect the whole of you, not just your body, and it can impact you emotionally at any point of your journey. It is likely that you will experience a range of complex thoughts and emotions, some of which may feel strange or unfamiliar. It is important to know that these feelings are all valid and a normal response to your illness.

"There was a total overwhelming feeling of helplessness and being out of control of my normal everyday life. But I had to carry on regardless for everyone else."

Looking after you

Following a diagnosis of MF, you

may want to make changes to your lifestyle to try to stay as well as possible, after your diagnosis and during treatment. Do not try to change too much at once. Adopting a healthy way of living is about making small, manageable changes to your lifestyle.

A healthy lifestyle includes having a well-balanced diet and being physically active. With some of your side effects, the idea of getting out and being active may be the last thing you want to do, but it is important to try and stay as active as possible to make you feel better and reduce some of your symptoms or side effects.

One of the most commonly reported side effects of the treatment of MF is fatigue. This isn't normal tiredness and doesn't improve with sleep.

Some general tips on how to deal with fatigue include:

- Have a regular lifestyle – try going to bed and waking up at approximately the same time every day and try to avoid lying in.
- Take part in regular, gentle exercise to maintain your

fitness levels as much as possible.

- Reserve your energy for what you find important and build rest periods around those times.
- Before going to bed, avoid stimulants such as alcohol, coffee, tea or chocolate, or using laptops, tablets or mobile phones.
- Keep your bedroom quiet and at a comfortable temperature.
- Talk about your worries with family, friends, your doctor or nurse, or patient support groups.
- Discuss your fatigue with your doctor or nurse.

"Don't get me wrong, hard living with a chronic condition. I get tired a lot and have to be careful about picking up infections, as my immune system is lower than others. But all in all, I will not let it take over my life. I don't intend on fighting it; it will have to fight me."

You can find more information about living well with leukaemia at www.leukaemiacare.org.uk/support-and-information/information-about-bloodcancer/

living-well-withleukaemia/

If you're struggling to come to terms with your diagnosis and prognosis, you can speak to us on our helpline. Call us on **08088 010 444**.

Talking about MF

Talking to your haematologist

MF is a rare condition. It is important for you to develop a good working relationship with your haematologist, so you are given the best treatment possible for you.

The following gives advice on working well with your haematologist:

- If it is an initial consultation, take along a list of your current medications and doses, and a list of any allergies you may have
- If you have a complicated medical history, take a list of diagnoses, previous procedures and/or complications
- Make a list of questions to take to your appointment. This will help the discussion with your haematologist
- It can be useful to repeat back what you have heard so that you can be sure that you fully understood
- Note information down to help you remember what was said

- Be open when you discuss your symptoms and how you are coping. Good patient doctor communication tends to improve outcomes for patients

Other tips:

- Bring someone else along to your appointment – they can provide support, ask questions and take notes if required
- Do not be afraid to ask for a second opinion – most haematologists are happy for you to ask

You need to tell your haematologist if...

You're having any medical treatment or taking any products such as prescribed medicines, over the counter treatments or vitamins. It is important to understand that treatments, including complementary therapies, which are perfectly safe for most people, may not be safe if you are being treated for MF.

Remember, if you choose to start any form of complementary therapy outside of your medical treatment, discuss this with your haematology consultant or

clinical nurse specialist, prior to beginning it. It is important to understand the difference between complementary therapies, used alongside standard treatment, and alternative therapies, used instead of standard treatment. There is no evidence that any form of alternative therapy can treat MF.

Talking to other people

Telling people you have a rare condition like MF can be hard to explain. You might find it useful to let your close family and friends, as well as your employer know about your health condition. It might be easier to provide people with basic information and give them information leaflets about MF if they want to know more in-depth details.

"I made a conscious decision to be very open about my illness. Telling family was tough. But I encouraged people to ask questions."

It is probably best to focus conversations on the symptoms that you are experiencing, how the condition affects you and how you feel about it. Often

people misunderstand and, unfortunately, it will mostly fall to you to educate them as best as you can. Where possible, it is advisable to let people know what you find helpful and unhelpful, in terms of what others say and do. Often people make assumptions and do what they think helps. For example, saying you look well, recounting stories of others they know with a similar diagnosis, encouraging you to look ahead and stay positive is not always what people really want to hear.

In many ways, the more you communicate with them the better.

These points may help you:

- Explain that you have a condition that means your bone marrow does not function properly, and that this affects the number of blood cells it produces
- Explain your symptoms (maybe you are tired, or have a lot of pain)
- Explain what you need (maybe more help day-to-day, or someone to talk to)

Talking about ET (cont.)

You could also consider the following when telling people about your diagnosis:

- **Find out more** - Try to find out as much as you can about your condition from reliable internet sources, charitable organisations or your consultant haematologist. The more you know, the more you can share.
- **Have a print-out to hand** - It may help to have some information to hand to share with family and friends. This will take the pressure off you having to remember everything they may want to know.
- **Explain your needs** - Try and be clear about what your needs may be. Perhaps you need help with the weekly food shop, help with cooking dinner, or someone to drive you to and from appointments. You may find that friends and family are pleased that they can do something to help you.
- **Be open about how you feel** - Do not be afraid of opening up about how you feel, as people who care will want to help you

as best they can. Talk as and when you feel comfortable, so those around you will know when you need them most.

Glossary

Acute Leukaemia

Leukaemia which progresses rapidly and is generally aggressive. There are two types: acute lymphoblastic leukaemia and acute myeloid leukaemia.

Acute Lymphoblastic Leukaemia (ALL)

Leukaemia in which lymphocytes start multiplying uncontrollably in the bone marrow, resulting in high numbers of abnormal, immature lymphocytes.

Acute Myeloid Leukaemia (AML)

Rapid and aggressive cancer of the myeloid cells in the bone marrow.

Allogeneic Stem Cell Transplant (Allo-SCT)

Transplant of stem cells from a matching donor.

Amino Acids

Organic molecules which are the building blocks for making proteins.

Anaemia

Condition where the number of red blood cells are reduced. Red

blood cells contain haemoglobin and transport oxygen to body cells. This may be due to a lack of iron, leukaemia, or sickle cell disease.

Antibody

Large Y-shaped protein produced by B-cell lymphocytes in response to a specific antigen, such as a bacteria, virus, or a foreign substance in the blood. The antibodies neutralise the bacteria and viruses.

Antigen

Toxin or other foreign substance which induces an immune response in the body, especially the production of antibodies.

Blast Cells (Blasts)

Immature cells found in the bone marrow which are not fully developed. Up to 5% of the cells found in the bone marrow are blast cells. Patients with leukaemia have a much higher number of immature, abnormal cells called blasts cells.

Blood Cancer

Cancer of blood cells from the bone marrow or lymphatic

Glossary (cont.)

system. There are three main types of blood cancer:

- Leukaemia begins in the bone marrow and is classified according to the type of blood cell it affects (either myeloid or lymphoid) and whether it grows quickly (acute) or slowly (chronic).
- Lymphoma starts in the lymphocyte white blood cells within the lymphatic system.
- Myeloma is a cancer of the plasma cells and starts in the bone marrow. Plasma cells are a type of white blood cell that makes antibodies.

Blood Cells

Cells present in the blood and bone marrow which include red blood cells, white blood cells and platelets. These three types of blood cell make up 45% of the blood volume, with the remaining 55% being plasma, the liquid component of blood.

Bone Marrow

Soft blood-forming tissue that fills the cavities of bones and contains fat, immature and mature blood cells, including

white blood cells, red blood cells and platelets.

Bone Marrow Aspirate

Bone marrow aspirates consist of taking a sample of the liquid part of the soft tissue bone marrow inside your bones using a syringe. They are crucial to establish a diagnosis of leukaemia and may be performed at stages during treatment to monitor progress.

Bone Marrow Biopsy

Bone marrow biopsy involves the collection of a sample of bone marrow from the hip bone, generally under local anaesthesia. A bone marrow surgical instrument with a cylindrical blade, called trephine, is used to remove a one to two-centimetre core of bone marrow in one piece.

Bone Marrow Failure

Term used when the bone marrow is unable to keep up with the body's need for white and red blood cells and platelets.

Calreticulin (CALR)

Soluble protein which is known to be involved in many body cell processes including regulation of calcium, cell adhesion and gene

expression. Mutations in CALR are common in ET and MF.

Chemotherapy

Drugs that work in different ways to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing.

Chromosomes

Thread-like structures which carry the genes, and are located in the nuclei of every cell in the body. There are 46 chromosomes (23 pairs) in humans.

Clinical Trial

Trial designed and planned to determine a specific answer or aim; for example, whether treatment A is better than treatment B. The study will be conducted in patients who meet particular inclusion criteria, and the results are collected and analysed to provide an answer.

ClinicalTrials.gov

ClinicalTrials.gov is a database of trials and includes details of approximately 276,190 research studies in 205 countries.

Clonal

Refers to an organism descended

from, and genetically identical, to a single common ancestor.

Complete remission

Complete remission has occurred when:

- Blood cell counts have returned to normal
- Less than 5% of abnormal, leukaemia cells are still present in the bone marrow

Corticosteroids (Steroids)

Hormones normally produced by the adrenal glands which are two small glands found above the kidneys. Corticosteroids reduce inflammation (redness and swelling) and the activity of the immune system. They are used for inflammatory conditions such as asthma and eczema and autoimmune diseases such as rheumatoid arthritis.

Cytoplasm

Jelly-like fluid in a cell that houses all the constituents it requires for survival and reproduction

Dendritic Cells

Dendritic cells are white blood cells that capture toxins or other foreign substances and present

Glossary (cont.)

them to the T-cell lymphocytes for destruction. A dendritic cell has a branched appearance resembling a tree, hence its name.

DNA (Deoxyribonucleic Acid)

Thread-like chain of amino acids found in the nucleus of each cell in the body which carries genetic instructions used in the growth, development and functioning of the individual's cells.

Eosinophil

Type of white blood cell which has a protective immunity role against parasites and allergens.

Essential Thrombocythaemia (ET)

Increased production in the bone marrow of the platelets by the megakaryocytes, which are the platelet-forming cells. The condition leads to abnormal blood clotting or bleeding.

Fatigue

Tiredness and weakness rendering the patient unable to work or perform usual activities.

Genes

Genes are made up of DNA which

stores the genetic information required to make human proteins.

Granulocytes

Group of white blood cells, which have granular bodies in their cytoplasm. They include the neutrophils, eosinophils and basophils white blood cells, all of which protect the body from bacteria, allergens and inflammation.

Haematology

Branch of medicine which studies the cause, prognosis, treatment, and prevention of diseases related to blood.

Haemoglobin

Red protein contained within the red blood cells and responsible for transporting oxygen to the tissues of the body.

Immunotherapy

Treatment that uses the body's own immune system to fight the cancer.

Incidence

Number of new cases of disease which can be reported as an incidence rate or a risk.

Interferons

Naturally occurring body proteins that send signals to interfere with the ability of viruses to multiply.

Irradiation

Particles or rays falling on to a surface (radiation wave on the surface of the skin).

JAK Gene

Janus Kinase gene which manages signals from cytokines.

Lactate Dehydrogenase

Enzyme that is required during the process of turning glucose (sugar) into energy for the body cells. Lactate dehydrogenase is released during tissue damage, and it is therefore a useful marker for common injuries and disease such as heart failure or muscle injury.

Lymph Nodes

Components of the lymphatic system (part of the body's immune system) that contain lymphocytes which produce antibodies and macrophage cells which digest dead cells. Lymph nodes are swollen with cell fragments in the event of

infection or cancer. They are located mainly in the spleen but also in the neck, armpit and groin.

Lymphocytes

Lymphocytes are a type of white blood cell that are vitally important to the immune response. There are three types of lymphocytes: B-cells, T-cells and natural killer (NK)-cells. B-cells produce antibodies that seek out invading organisms. T-cells destroy the organisms that have been labelled by the B-cells, as well as internal cells that have become cancerous. NK-cells attack cancer cells and viruses.

Lymphoid

Relates to lymphocyte white blood cells.

Macrophage

Type of white blood cell that submerges and digests cellular debris, foreign substances, microbes, cancer cells, and anything else that does not have the type of proteins specific to healthy body cells on its surface.

Megakaryocyte

Large cell in the bone marrow

Glossary (cont.)

which produces the platelets in the blood to prevent bleeding.

Monocyte

White blood cell that attacks invading organisms and helps combat infections.

Mutation (Gene)

Permanent alteration in the DNA sequence of a gene, so that it differs from what is found in most people.

Myeloblasts or Myeloid Blasts

Name given to blast cells in the myeloid cell line. These cells originate in the bone marrow and eventually become the following white blood cells: neutrophils, monocytes, macrophages, basophils, and eosinophils.

Myeloid cells also give to the red blood cells and platelets.

Myelodysplastic Syndromes (MDS), also called

Myelodysplasia

Myelodysplastic disorders occur when the bone marrow does not make enough normal blood cells. The blood cells made are not fully developed and not able to

work normally. These blood cells include red blood cells which supply oxygen to the body's tissues, white blood cells which fight infection and platelets which help blood clot.

Myelofibrosis

Reactive and reversible process which occurs with many cancerous and non-cancerous diseases of the bone marrow.

Myeloid

Relates to bone marrow.

Myeloproliferative Neoplasms (MPNs)

Disease of the bone marrow in which excess cells are produced.

Neoplasm

Medical term for cancer, meaning literally a new and abnormal growth of tissue anywhere in the body.

Neutrophils

White blood cells involved in fighting inflammation and infection specifically bacterial infections.

Philadelphia Chromosome, also called Breakpoint Cluster Region-Abelson Murine Leukaemia Viral proto-oncogene 1 (BCR-ABL1)

Abnormal chromosome fusion gene due to a swapping over and fusion of sections of DNA between chromosomes 9 (ABL1) and 22 (BCR), resulting in a new fusion gene BCR-ABL1. This gene causes overproduction of myeloid cells. It is found in all patients with chronic myeloid leukaemia and some patients with acute lymphoblastic leukaemia.

Plasma Cell

Type of white blood cell that produces antibodies and is derived from B-cells. It is an ovoid (egg-shaped) cell with an off-centre nucleus.

Platelets

One of the types of blood cells which help to stop bleeding.

Polycythaemia Vera (PV)

Chronic increased production of red blood cells, white blood cells and platelets in the bone marrow.

When the increased production is only of the red blood cells, the condition is erythrocytosis.

Prognosis

Indication of how well a patient is expected to respond to treatment based on their individual characteristics at the time of diagnosis or other timepoint in the disease.

Proliferation

Rapid increase, for example in the number of cells.

Radiation Treatment

Cancer treatment that uses high doses of radiation to kill cancer cells and shrink tumours.

Red Blood Cells

Small blood cells that contain haemoglobin and carry oxygen and other substances to all tissues of the body.

Spleen

Largest organ of the lymphatic system whose function is to help clear the body of toxins, waste and other unwanted materials. The spleen is located under the ribs

Glossary (cont.)

on the left of the abdomen.

Splenectomy

Removal of the spleen.

Stem Cell

Most basic cell in the body that has the ability to develop into any of the body's specialised cell types, from muscle cells to brain cells. However, what makes these stem cells reproduce uncontrollably, as in cancer, is thought to be linked to chromosome abnormalities.

Stem Cell Transplant

Transplant of stem cells derived from part of the same individual or a donor.

Targeted Therapy

Drugs that specifically interrupt the leukaemia cells from growing in the body. However, these drugs do not also harm the body's healthy cells the way conventional drugs do.

Watch and Wait

Management approach for slow growing blood cancers. Also called active monitoring, the Watch and Wait approach is the current

standard of care for patients with slow growing blood cancers who do not have any symptoms. Treatment is usually started either once symptoms appear or when test results suggest the blood cancer is progressing.

White Blood Cells

White blood cells are one of the types of cells found in the blood and bone marrow, along with red blood cells and platelets. White blood cells create an immune response against both infectious disease and foreign invaders. Granulocyte white blood cells include the neutrophils (protect against bacterial infections and inflammation), eosinophils (protect against parasites and allergens) and basophils (create the inflammatory reactions during an immune response). Other white blood cells include the lymphocytes (recognise bacteria, viruses and toxins, to which they produce antibodies) and monocytes (clear infection products from the body).

Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

Leukaemia Care

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer.

We provide emotional support through a range of support services including a helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our help line for any medical queries relating to your diagnosis.

Helpline: **08088 010 444**
www.leukaemicare.org.uk
support@leukaemicare.org.uk

Blood Cancer UK

Blood Cancer UK is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

0808 2080 888
www.bloodcancer.org.uk

Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

0808 800 4040
www.cancerresearchuk.org

Macmillan

Macmillan provides free practical, medical and financial support for people facing cancer.

0808 808 0000
www.macmillan.org.uk

Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

0300 123 1801
www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
www.adviceguide.org.uk

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemicare.org.uk

support@leukaemicare.org.uk

Leukaemia Care,
One Birch Court,
Blackpole East,
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Leukaemia Care is registered as a charity in England and Wales (no.1183890) and Scotland (no. SC049802).
Company number: 11911752 (England and Wales).
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Leukaemia Care
YOUR Blood Cancer Charity