

MYELOFIBROSIS AND ME

A guide for people with myelofibrosis (MF)



Introduction

Being diagnosed with myelofibrosis (MF) can be a shock, particularly when you may never have heard of it.

If you have questions about MF – what causes it, who gets it, how it affects your body, what symptoms to expect and treatment options – this booklet covers the basics for you, but for more information talk to your Haematologist.

We have also included a specially designed Myeloproliferative Neoplasms (MPN) symptom tracker in this booklet so you can record how your symptoms are affecting you over time.

You can then use this to talk things through with your Haematologist at each appointment.

While we have tried to keep things simple, you might still come across some medical terms in this booklet that you are not familiar with. You can find an explanation of these terms in the Glossary at the back of this booklet.

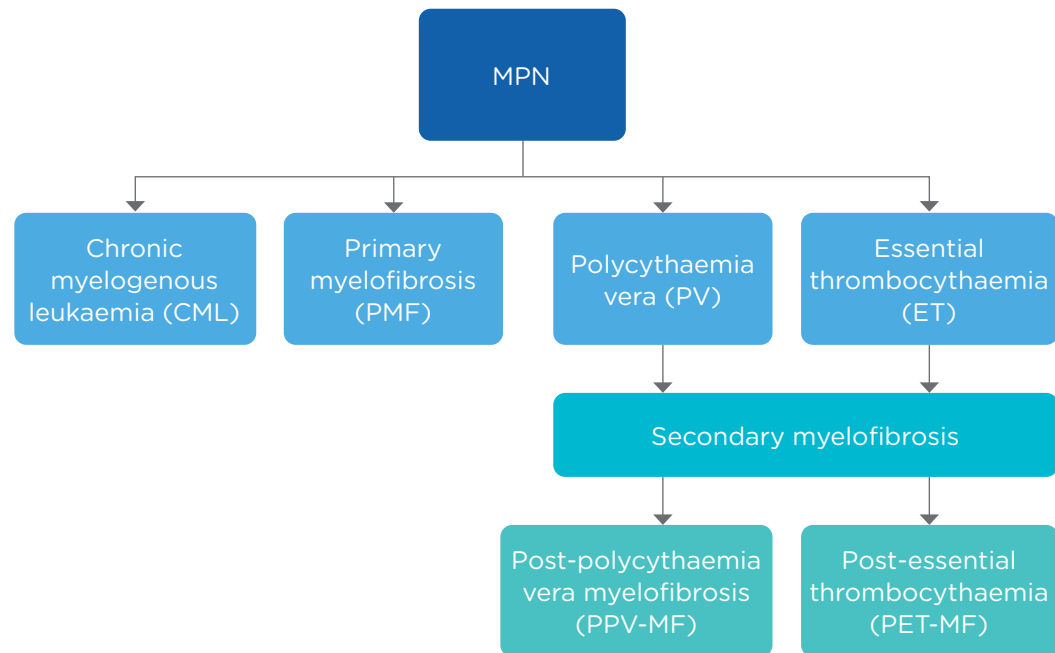
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What are MPNs?

Myeloproliferative neoplasms (MPNs) are a group of diseases in which the bone marrow makes too many red blood cells, white blood cells, or platelets. There are several types of MPNs.

Types of myeloproliferative neoplasms



What is MF?

Myelofibrosis (MF) is a disorder of the bone marrow. It happens when the marrow – the soft, fatty tissue inside your bones that produces blood cells – is replaced by fibrous (or scar) tissue. Scarring of the bone marrow means the marrow is not able to make enough blood cells, which leads to a set of symptoms that can have a significant impact on your quality of life.

If you have MF that occurs on its own, you have what’s known as ‘primary myelofibrosis’. This is most commonly seen in people over the age of 50. Or you may have previously been diagnosed with another bone marrow disorder such as essential thrombocythaemia (ET) or polycythaemia vera (PV). In this case your condition is known as post-essential thrombocythaemia MF or post-polycythaemia vera MF. ET, PV and MF are closely related diseases that belong to a group of conditions called myeloproliferative neoplasms (MPNs).

How common is MF?

MF is considered to be a rare disease. Generally, this means that it affects about

MF affects men and women in relatively equal numbers.

1 person in **100,000** per year.

♀ 1:1 ♂

That might explain why you probably haven’t heard of it, or met anyone with the condition before. MF is virtually unheard of in children and is very rare in young adults. It is most commonly diagnosed in patients between 60 and 70 years of age.

Is MF a type of cancer?

Cancer is a disease that occurs when normal cells grow in an uncontrolled way. Until recently there was some debate about whether MPNs such as MF should be described as cancers. This is because the word 'neoplasm' (new growth) is a term that has been used both for cancers (malignant neoplasms) and non-cancerous tumours (benign neoplasms).



Now, because MF is characterised by uncontrolled cell growth, most Haematologists and cancer organisations do classify it as a blood cancer. Whatever it's called, remember that the symptoms and prognosis can vary widely. Your Haematologist will advise you depending on your individual circumstances.

What causes MF?

As time goes on, we are learning more about MF and its causes. While the causes of MF are not fully understood, we do know that the disease causes an abnormal signal in the cells that make the red blood cells and platelets in your blood. Recent research found that about 50% of MF patients have a change (known as a mutation) in a gene that regulates blood cell production.

People are not born with these mutations but acquire them during their lives. These mutations may also be triggered by past exposure to ionising radiation or to some chemical substances such as benzene and toluene. It is also important to note that MF is rarely inherited. It is not passed on from parents to child, although some families do seem to develop the disease more readily than others.

MF is the gradual replacement of bone marrow by fibrosis. Bone marrow fibrosis is caused by mutations that genetically alter stem cells.



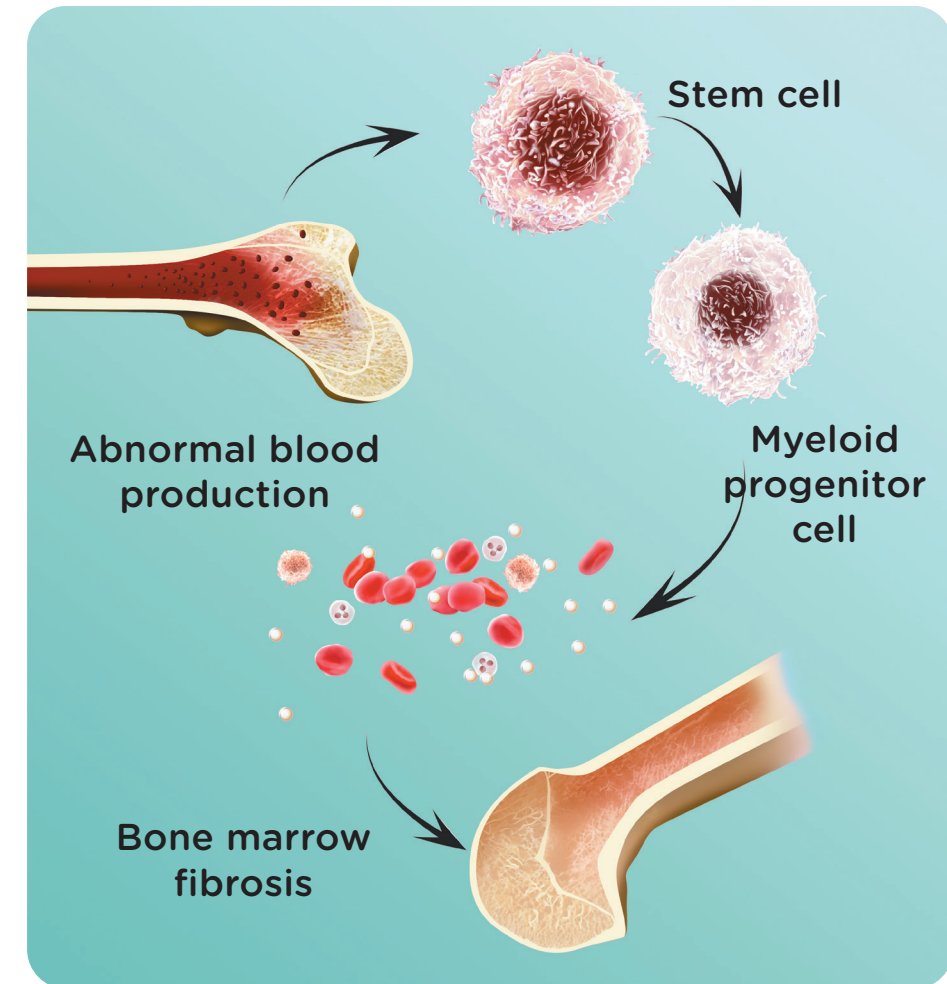
How does MF affect your body?

In a person without MF...

...bone marrow (the soft, fatty tissue inside your bones) contains blood stem cells that in time develop into mature blood cells - red blood cells to carry oxygen to the tissues of your body; white blood cells to fight infection and disease; or platelets to help prevent bleeding by causing blood clots to form.

In someone with MF...

...abnormal stem cells take over the bone marrow, leading to fibrosis (scarring) and chronic inflammation. The consequence is that the marrow is not able to make enough normal blood cells. The spleen and then the liver try to compensate by producing red blood cells and sometimes, but not always, this causes the spleen to become enlarged (splenomegaly). Due to the inability of the bone marrow to make enough blood cells, MF patients often have low numbers of red blood cells (known as anaemia), white blood cells (known as neutropaenia) and/or platelets (known as thrombocytopenia). These changes lead to some of the symptoms of myelofibrosis. For example, anaemia may be associated with feelings of tiredness or shortness of breath; neutropaenia can lead to an increased risk of infections; and thrombocytopenia is associated with increased risk of bleeding and bruising.



What are the most common symptoms of MF?

While most patients are diagnosed having presented with symptoms, many people experience few or no symptoms at all in the early stages of MF. In fact, patients are often diagnosed after having tests for an unrelated condition. Regardless, not every person has the same combination of symptoms to the same degree of severity.

Fatigue



Inactivity



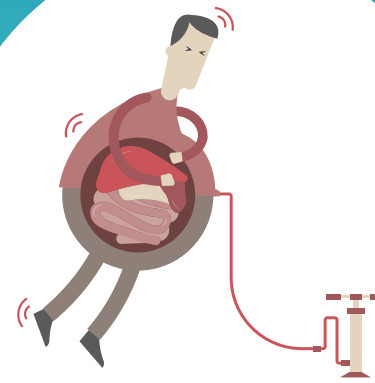
Bone pain



Itching



Abdominal discomfort



Problems with concentration

Fever



Unintentional weight loss



Night sweats



Filling up quickly when you eat (satiety)



What are the treatment options for MF?

Active surveillance

If you have no symptoms when you are diagnosed, your Haematologist may put you under active surveillance. This is a plan where your condition is watched closely but not treated unless there are changes in your test results or if you develop symptoms that show that your condition is getting worse. During active surveillance, certain exams and tests are done on a regular schedule.

Drug treatment

Your Haematologist will discuss your options. Some patients are treated with chemotherapy or targeted agents.

Radiation or splenectomy

Radiation or splenectomy may be considered in severe cases. Splenectomy is an operation to remove the spleen.

Bone marrow or stem cell transplant

The decision to transplant is difficult and your age, disease state, general health, and potential stem cell source, all have to be very closely assessed in order to evaluate if this is a viable option.



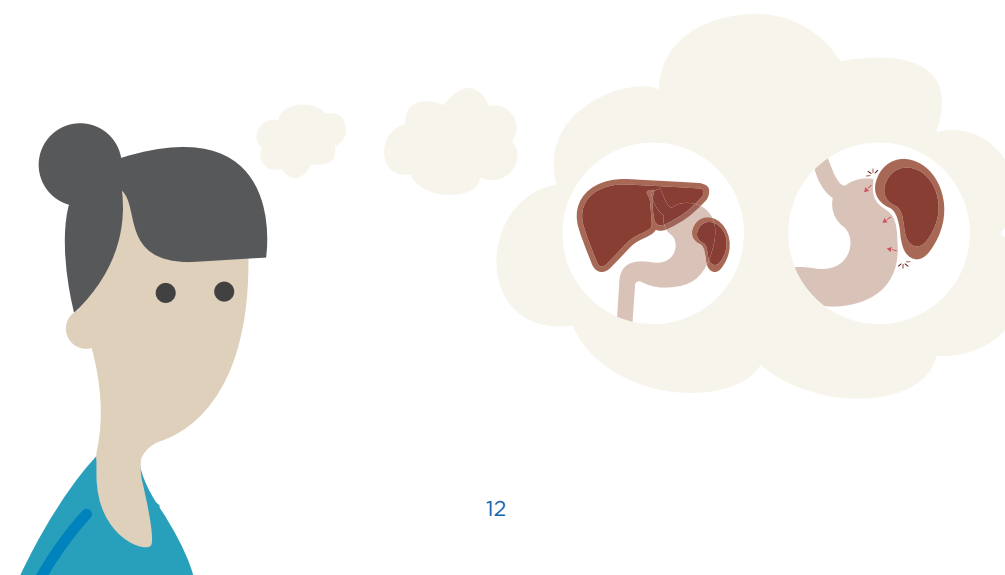
Talking to other people about MF

If you tell someone you've got diabetes or breast cancer, they'll probably have heard of it. As MF is a rare condition, it can be harder to explain.

This simple summary may help:

"I have a condition where my bone marrow is not working properly and this affects the number of blood cells it produces. This affects my body in several ways. For example, my spleen and liver have to work extra hard to produce blood cells and this can cause them to become bigger. It also makes me... [list your symptoms here e.g. feel tired, experience pain, etc.]"

"I have good days and bad days, and sometimes I may need... [explain what you need here e.g. a bit more support with my day-to-day activities; someone to talk to; someone to come to appointments, etc.]"

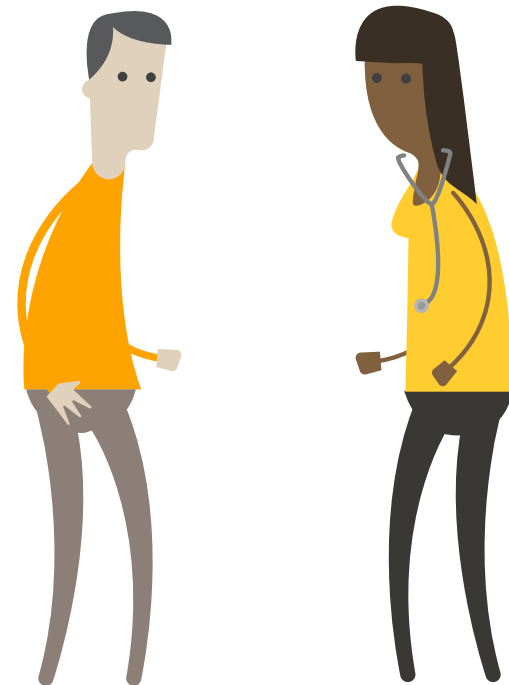


Talking to your Haematologist about MF

MF is a very rare condition and it's important to form a good working partnership with your Haematologist to make sure you get the best treatment possible.

Here are some tips to get you started:

- If it's your first consultation, take along a list of any medications you are taking and a list of any allergies that you have
- If you have a complicated medical history, take along a list of diagnoses, previous procedures and/or complications you have experienced
- It can be useful to repeat back what you have heard so that you can be sure that you have understood fully



The following key factors will help your Haematologist to work out your best treatment options:

- The number of abnormal red blood cells and white blood cells
- The number of blast cells in the blood (blast cells are cells which are in the early stages of development)
- Your age
- Certain genetic changes
- Symptoms such as fever, night sweats, or weight loss
- Health complications such as spleen and liver enlargement, gastrointestinal bleeding, infections and malnutrition



Questions to help you discuss your MF symptoms with your Haematologist:



Fatigue

- Do you still have the energy to perform daily activities?
- Has your level of fatigue led you to reduce your working hours?
- Has your level of fatigue interfered with your mood or social activities?



Night sweats

- Do your night sweats impair your ability to sleep?
- Have you missed work because you couldn't sleep comfortably?
- How often do you get through the night without having to change your garments or bed linens?
- Do you need to wash your face or body at night?



Fever

- How often does fever accompany your other MF symptoms?
- How often do you have a fever?
- When you have a fever, what is the temperature range?



Inactivity

- Are you able to exercise normally?
- Have you had to cancel any work engagements because you can't find the energy?
- Is your social life as active as you would like it to be?



Bone pain

- Does the pain in your bones keep you from getting a good night's sleep?
- Are you taking medication to control your bone pain?
- Does bone pain affect your mood?



Itching

- Do you experience itching often?
- Has persistent itching limited your enjoyment with family and friends?
- Are you able to bathe with the same regularity as you used to?
- Do you require medication to control your pruritus?



Early satiety

- Do you experience any changes in appetite?
- Are meal times a cause of stress in your life?
- How often are you able to finish a regular-sized meal?



Abdominal discomfort or pain

- Does abdominal discomfort make it difficult to bend over to pick things up?
- Have you had to pare down your activities due to abdominal discomfort?
- Does abdominal pain keep you from accomplishing your daily activities?
- Does abdominal pain affect your mood?
- Do you require medication to control your abdominal pain?



Weight loss

- Has recent, unexplained weight loss left you feeling frail?
- Do you feel like you are receiving adequate nutrition?
- Have you had to go out and buy smaller-sized clothes because the old ones no longer fit properly?

Tracking your symptoms

It's important to monitor how you're feeling and what symptoms you're experiencing. This way, if you notice them changing or getting worse, you can tell your Haematologist and explain how they are affecting you on a day-to-day basis. You may want to consider using a pre-prepared form to measure and track your symptoms prior to each visit to your Haematologist.

MPN-10 Symptom Tracker

This MPN-10 tracker - developed by world-leading experts in the field - is a useful way of assessing your symptoms.

It will just take a few minutes to fill in every month.

- ✓ Fill in your name and the date - this will help you track your symptoms over time.
- ✓ Rate each symptom on a scale of 0 to 10, with 0 meaning you don't have that symptom and 10 meaning it is the worst imaginable.
- ✓ Make sure you fill in ALL the categories.
- ✓ Add up your results to get your total score.

Be sure to share your answers with your Haematologist or other Healthcare Professionals.

Example of a completed MPN-10 Tracker

MPN-10 Know your score

Name Date

Fill out the form below to track how your symptoms affect you.
 Circle a number that best describes your symptom from 1 to 10: 0 if absent and 10 being worst imaginable

Please rate your fatigue (weariness, tiredness) by circling a number that best describes your WORST level of fatigue during the past 24 hours

Fatigue

0 1 2 3 4 5 6 7 8 9 10
(ABSENT) (WORST IMAGINABLE)

Circle a number that describes how much difficulty you have had with each of the following symptoms during the past week

Filling up quickly when you eat (satiety)

0 1 2 3 4 5 6 7 8 9 10
(ABSENT) (WORST IMAGINABLE)

Abdominal discomfort

0 1 2 3 4 5 6 7 8 9 10
(ABSENT) (WORST IMAGINABLE)

Inactivity

0 1 2 3 4 5 6 7 8 9 10
(ABSENT) (WORST IMAGINABLE)

Problems with concentration - compared with before your diagnosis

0 1 2 3 4 5 6 7 8 9 10
(ABSENT) (WORST IMAGINABLE)

Night sweats

0 1 2 3 4 5 6 7 8 9 10
(ABSENT) (WORST IMAGINABLE)

Itching (pruritus)

0 1 2 3 4 5 6 7 8 9 10
(ABSENT) (WORST IMAGINABLE)

Bone pain (diffuse, not joint pain or arthritis)

0 1 2 3 4 5 6 7 8 9 10
(ABSENT) (WORST IMAGINABLE)

Fever (>37.8°C)

0 1 2 3 4 5 6 7 8 9 10
(ABSENT) (DAILY)

Unintentional weight loss in the last 6 months

0 1 2 3 4 5 6 7 8 9 10
(A LITTLE) (A LOT)

To help you and your doctor get a clear overall picture of how you are feeling, you can add up all of your scores to calculate your Total Symptom Score.

Total 45

Adapted from Emanuel R et al. J Clin Oncol 2012;30:4098-103.

What symptoms are tracked?



Fatigue



Early satiety



Abdominal discomfort



Fever/ high temp



Inactivity



Concentration problems



Night sweats



Itching



Weight loss



Bone pains



“If you notice your symptoms changing, getting better or worse, this tracker can help you tell your doctor and explain how they are affecting you on a day-to-day basis.”

Professor Claire Harrison, Consultant Haematologist, Guy's and St Thomas' Hospitals, London, UK

Tracking your score

Now that you've started monitoring your symptoms, you can keep track of how they change over time.

Add up the ratings for each of your individual symptoms to find your overall symptom score. This can be charted on the tracker on page 35-36.

You can take this booklet along to your appointments so that you can share your results, and use them to help explain how you've been feeling. The pattern you build up will also help your Haematologist to better understand how your current treatment plan is working.



Try to complete the form prior to each visit with your Haematologist

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Inactivity

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Problems with concentration – compared with before your diagnosis

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Night sweats

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Fever (>37.8°C)

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Date

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Total

Tracking my symptom score

EXAMPLE

TOTAL SYMPTOMS SCORE	DAY	01																	
	MONTH	SEPT																	
	96-100																		
	91-95																		
	86-90																		
	81-85																		
	76-80																		
	71-75																		
	66-70	X																	
	61-65																		
	56-60																		
	51-55																		
	46-50																		
	41-45																		
	36-40																		
	31-35																		
	26-30																		
	21-25																		
	16-20																		
	11-15																		
6-10																			
0-5																			

Where can you find more support?

It's always good to meet and chat to other people with myelofibrosis who might be experiencing similar symptoms and feelings to you.

The Leukaemia Foundation is dedicated to ensuring every Australian with blood cancer gets access to trusted information, best-practice treatment and essential supportive care to improve their quality of life. To learn more about the many services they provide, including emotional and practical support, call **1800 620 420** or visit www.leukaemia.org.au

MPN Alliance Australia is a patient-led advocacy group that collaborates with the Leukaemia Foundation towards the common goal of achieving better outcomes for Australian patients with MPNs. MPN Alliance Australia shares information and links to helpful resources, organisations and support services for the benefit of patients and their families. You can read more about MPN Alliance Australia at www.mpnallianceaustralia.org.au

For more information, visit the Novartis website at www.livingwithmf.com.au

Notes

Getting more copies

Ask your Haematologist or nurse for more printed copies of this information guide. You can also download the MPN-10 tracker from www.livingwithmf.com.au

Glossary

A

Abdomen

The abdomen is the part of the body that lies below the rib cage and diaphragm and above the hip bones. Organs in the abdomen include the stomach, small intestine, colon, liver, gallbladder, spleen, and pancreas.

Abdominal pain

Pain that is felt in the abdomen (above).

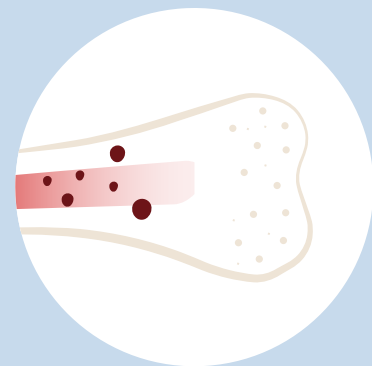
Acute myeloid leukaemia

(also known as acute myelogenous leukaemia)

A malignant disease that develops when there are too many immature blood-forming cells in the blood and bone marrow. This affects the development of white blood cells that fight infections. The “acute” in its name represents its ability to progress rapidly.

Anaemia

A medical condition in which the red blood cell count or haemoglobin is less than normal.



B

Blood cells

See red blood cells (RBC), white blood cells (WBC) and platelets.

Blood clot (or thrombus, or thrombosis)

Blood that has been converted from a liquid to a solid state; also called a thrombus. A blood clot is stationary within a vessel or the heart. If it moves through the bloodstream, it is called an embolus.

Blood transfusion

The transfer of blood or blood components from one person (the donor) into the bloodstream of another person (the recipient). Often used to replace blood cells or blood products lost through bleeding, or used when your body can't make blood properly because of an illness such as some MPNs.

Bone marrow

The soft, blood-forming tissue that fills your bone cavities. It contains fat and blood cells, including white blood cells and platelets.

Bone marrow transplant (BMT)

A procedure in which bone marrow that is diseased or damaged is replaced with healthy bone marrow. The bone marrow to be replaced may be deliberately destroyed by high doses of chemotherapy and/or radiation therapy. The replacement marrow may be the patient's own marrow or it may come from a donor.

C

Chemotherapy

Therapy for cancer using chemicals that stop the growth of cells.

Chronic

A chronic condition is one that lasts 3 months or more. MPNs are considered chronic conditions.

Complete blood cell count (CBC)

A set of values that represent the different components of blood. It is possible to take blood counts for each element of the blood, e.g., WBCs, RBCs, and platelets.

E

Embolus

Something that travels through the bloodstream, lodges in a blood vessel and blocks it, such as a detached blood clot, a clump of bacteria, and foreign material such as air.

Erythropoietin

A growth factor produced by the kidney that promotes the formation of red blood cells by the bone marrow.

Essential thrombocythaemia (ET)

A rare acquired myeloproliferative neoplasm (MPN) characterised by a sustained elevation of platelet numbers with a tendency for thrombosis and haemorrhage.

F

Fatigue

Feelings of weariness and tiredness. Occurs when you have reduced capacity for work and other activities. Fatigue can be acute and come on suddenly or be chronic and persistent.

Fever

Technically any body temperature above 37°C. In practice a person is usually not considered to have a fever until their temperature is above 38°C.

H

Haematocrit

The ratio of the volume of red cells to the volume of whole blood.

Haematologist

A doctor who is trained in blood diseases.

Haematology

The diagnosis, treatment and prevention of diseases of the blood and bone marrow.

Haemoglobin

The protein molecule in red blood cells that carries oxygen from the lungs to the body's tissues and returns carbon dioxide from the tissues to the lungs.

Hepatomegaly

An enlarged liver.

L

Liver

An organ in the upper abdomen that aids in digestion and removes waste products and worn-out cells from the blood.

M

MPL

MPL is a gene that is involved in the growth of platelets.

Myelofibrosis (MF)

Fibrosis or scarring of the bone marrow. It is characterised by significant anaemia and an enlarged spleen.

Myeloproliferative neoplasms (MPNs)

MPNs are cancers of the blood and bone marrow. Four main types of MPNs make up around 95% of all MPNs: MF, ET, PV and chronic myeloid leukaemia (CML).

N

Neutropaenia

A condition in which the number of neutrophils (a type of white blood cell) in the bloodstream is decreased.

Night sweats

Severe hot flushes that occur at night and result in a drenching sweat.

P

Platelet (thrombocyte)

A disc-shaped element in the blood that assists in blood clotting. During normal blood clotting, the platelets clump together (or aggregate). Although they are often classed as blood cells, they are actually fragments of large bone marrow cells.

Platelet count

The number of platelets (see above) in a volume of blood, usually expressed as platelets per cubic millimetre of whole blood. Normal platelet counts are in the range of 150,000 to 400,000 per microlitre.

Polycythaemia vera (PV)

A myeloproliferative neoplasm resulting from overproduction of RBCs.

Pruritus

Another word for itching. It can result from drug reaction, food allergy, kidney or liver disease, cancers, parasites, ageing or dry skin, contact skin reactions, and unknown reasons.

R

Radiotherapy (or radiation)

The treatment of disease with ionizing radiation. High-energy rays are used to damage cancer cells and stop them from growing and dividing.

Red blood cell (or erythrocyte)

The blood cell that carries oxygen. Red cells contain haemoglobin, which permits them to transport oxygen (and carbon dioxide).

S

Spleen

An organ located in the upper left part of the abdomen near the stomach. The spleen produces lymphocytes (a type of white blood cell), filters blood, serves as a reservoir for blood, and destroys old blood cells. The spleen can also supplement the bone marrow in the production of blood cells in certain situations (as with MPNs). This can sometimes lead to an enlarged spleen (splenomegaly). An operation to remove the spleen is called a splenectomy.

Splenomegaly

Enlargement of the spleen.

Stem cells

Stem cells are cells that have the potential to develop into many different or specialised cell types.

T

Thrombocytopenia

An abnormally high number of platelets in the blood (see platelet count).

Thrombocytopenia

A lower than normal number of platelets in the blood, typically below 150×10^9 per litre.

Thrombosis

When a blood clot forms in a blood vessel, which can be any vein or artery. The clot itself is termed a thrombus (see blood clot).

W

White blood cell (leukocyte)

Cells the body makes to help fight infections. There are several types— the two most common are lymphocytes and neutrophils.

Novartis would like to acknowledge the Myelofibrosis Advisory Council for their assistance in compiling this booklet.

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