The decoding myelofibrosis dictionary

Most people have never heard of myelofibrosis until they, or a loved one, are diagnosed. It's perfectly understandable not to grasp the intricate medical terminology, and online searches can often lead to more confusion than clarity. Our aim is that this "Decoding Myelofibrosis Dictionary" can demystify these terms, empowering you with knowledge. By understanding the nuances of myelofibrosis and its symptoms, you can better self-advocate for your care and engage in more confident conversations with your healthcare team.

Myeloproliferative neoplasms (MPNs)

These are a family of blood cancers within which myelofibrosis (MF) sits, where bone marrow makes too many red blood cells, white blood cells, or platelets.

Other MPNs include polycythaemia vera (PV) and essential thrombocythaemia (ET) which can both progress to MF, known as secondary MF

Myelofibrosis (MF)

A chronic blood cancer where there is an excessive build-up of scar tissue in the bone marrow, impacting the normal production of blood cells. This is caused by a mutation or a change in the growth of cells, which is why this is classed as a cancer.

This can cause symptoms such as:

'Myelo' – means blood cell
'Fibrosis' – means scar tissue or fibrous tissue in the bone marrow

Anaemia

If you have too few red blood cells, you have anaemia (your doctor may call it low haemoglobin). Red blood cells carry oxygen from our lungs to our tissues, and if you have too little oxygen, that can make you feel very tired, so fatigue or tiredness is a very common symptom. It can make you feel breathless and sometimes give you muscle pain.

Nearly all patients with MF will become anaemic over time.

Splenomegaly

Or an enlarged spleen, occurs in patients with myelofibrosis because when the bone marrow becomes more scarred, the spleen starts to take over production of blood cells, making it enlarged. This can cause physical discomfort under your ribs or abdomen, feeling full too fast and can cause interference with everyday tasks like tying your shoelaces, bending down to play with your grandchildren or doing housework.

Constitutional symptoms

Other symptoms of myelofibrosis which can include bad itching (medical term, pruritus) where sometimes tasks like taking a shower are difficult, extreme weight loss that can cause physical pain, and sweating at night, impacting sleep.

Thrombocytopenia

Simply means low platelet count. Thrombocytes, or "platelets," are important to help your blood clot, and as myelofibrosis progresses, patients often have lower platelet counts which may cause bruising and bleeding.

Neutropenia

Refers to a low count of neutrophils, which are one of five different types of white blood cells that are important for fighting off infections. Myelofibrosis can lead to a low neutrophil count and can increase the risk of infection.

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Bone marrow

The soft matter inside the bones where blood cells are made.

Extramedullary haematopoiesis (EMH)

The production of blood cells outside the bone marrow and is a known complication of myelofibrosis. This is typically associated with splenomegaly (enlarged spleen).

Cytopenia

Too few of a certain type of blood cell, including anaemia (too few red blood cells), thrombocytopenia (too few platelets) and neutropenia (too few white blood cells).

"Cytosis" is its opposite

Cytokines

Type of protein that plays a crucial role in regulating inflammation and the development of blood cells. The underlying genetic mutations in myelofibrosis lead to a dysfunctional state where cells produce and respond abnormally to cytokines, which directly contribute to the cancer progression and symptoms.

Allogeneic stem cell transplant

The only potentially curative treatment for myelofibrosis, where healthy stem cells are transferred from a donor to a patient. This treatment comes with significant risk, as prior to the infusion the patient receives chemotherapy and/or radiation therapy to eradicate diseased bone marrow. Serious complications may include:

Graft-versus-host disease (GVHD)

When the donor's new stem cells attack healthy cells in the recipient. Signs and symptoms of acute GVHD most often affect the skin (rashes), gastrointestinal tract (diarrhoea), or liver. Some symptoms may be mild, and some can be severe and even life-threatening.

Increased risk of infection

As a result from the chemotherapy, radiation, and the stem cell treatment itself, these therapies weaken the immune system as they lower white blood cell counts.

Janus kinase (JAK)

A family of proteins (JAK1, JAK2, JAK3, and TYK2) that acts as important messengers inside our cells, helping to control the growth of blood cells and regulate the immune system. In myelofibrosis, a common change or mutation in the JAK2 gene causes these proteins to become overactive. Finding this specific mutation is an important "biomarker" that helps doctors diagnose myelofibrosis and guide treatment decisions, though some patients may have other genetic mutations.

Bonus term: **Driver mutations** – specific genetic changes in your blood cells that are believed to drive or cause the myelofibrosis.

JAK inhibitors

A treatment option for myelofibrosis used to control general symptoms and those associated with the spleen. JAK inhibitors may reduce the size of the spleen and reduce the severity of symptoms, improving quality of life.

Red blood cell transfusion

A procedure to manage anaemia where blood from a donor is transfused into your blood through an intravenous (IV) line placed into a vein.

"Watch and Wait"

While this term might be unsettling, this is a standard management approach where clinicians closely monitor your myelofibrosis with regular checkups and blood tests without active treatment. Rather than thinking of it as "doing nothing," it is "carefully observing."

Prognosis

The trajectory or outcome of your cancer. Your prognosis also might be affected by other factors, such as age and general health. Your healthcare team uses these factors to help you understand the seriousness of your condition.

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