

# Myelofibrosis: Moving forward with myelofibrosis: Andrew's story



Andrew on his bike

Myelofibrosis (MF) is a complex blood cancer characterised by the buildup of excessive scar tissue – called “fibrosis” – in the bone marrow which negatively impacts the body’s normal production of healthy blood cells.<sup>1</sup> MF is one of a group of blood cancers known as myeloproliferative neoplasms (MPNs), in which the bone marrow makes too many red blood cells, white blood cells, or platelets.<sup>1</sup>

MF affects approximately 1 in 500,000 people worldwide.<sup>2</sup> Andrew is a MF patient living in Del Mar, CA. Alongside his wife, Andrew has spent much of his professional career advocating for cancer patients and care partners to feel empowered and to understand and navigate their disease.

## Andrew's journey to diagnosis

The symptoms of MF can appear similar to a variety of other conditions, and the journey to diagnosis is different for each patient.<sup>3</sup> While there has been progress in the treatment of MF in the last decade, patients are still in need of options that address the underlying symptoms of the disease.<sup>4</sup> Since MF is a complex cancer, it is important to ask the right questions and to seek a specialist who understands the disease and can help patients manage care.

Seventeen years after entering remission following treatment for chronic lymphocytic leukaemia (CLL), Andrew felt a pain in his leg. He knew his body was telling him something was wrong. Thankfully, he listened and visited his doctor who sent him straight to the emergency room. An ultrasound revealed a few deep vein thromboses (DVTs), blood clots that could have been fatal if they had reached his lungs.

Andrew participated in a clinical trial for an investigational medicine that had the potential to help prevent another DVT. Before the trial began, the doctors who reviewed Andrew’s screening tests told him there were irregularities in his laboratory results that would require additional testing. His haematologist conducted those tests and delivered Andrew’s MF diagnosis.

### Diagnosis

Several specialised tests and procedures may be used to diagnose myelofibrosis including<sup>5</sup>:

- Blood tests, including a FBC (full blood count)
- Imaging tests, such as X-rays and MRIs
- Bone marrow exams, such as biopsy and aspiration
- Genetic testing

“When you are told you have myelofibrosis, your first question is, what is that? You’re in shock when you learn it’s a complex condition, you don’t get it. Then the doctor explains that it’s a blood cancer distinguished by excessive scarring in your bone marrow, and you need the doctor to explain how that occurs, and what to expect,” said Andrew.

His wife and care partner, Esther, and three adult children provided support, and his haematologist connected him with a MF specialist. “For me, it made perfect sense to find out who the specialists were because the typical doctor may hardly ever see myelofibrosis in years of practice,” Andrew explained.

For Andrew, having a knowledgeable specialist has been extremely important, as MF affects individual patients differently.

## Living with MF

While some people may not notice any changes in the early stages of MF, the condition’s impact on the availability of normal blood cells may result in symptoms including anaemia, an enlarged spleen, and other constitutional symptoms such as fever, night sweats, itchy skin, and bone pain.<sup>2,3</sup> Nearly all MF patients will eventually develop anaemia, a condition in which the body does not produce enough healthy red blood cells and can cause life-altering fatigue, weakness and shortness of breath.<sup>3,6,7</sup>

### Each person experiences myelofibrosis differently

The symptoms of myelofibrosis can be different for each person, which means you may not experience all of them. Some of the key signs and symptoms are anaemia, enlarged spleen, low platelets and other symptoms.<sup>8</sup>

#### Anaemia

Having a low red blood cell count is called anaemia. Your doctor may call it low haemoglobin.

#### Anaemia can cause symptoms like:

- Tiredness/fatigue
- Weakness
- Shortness of breath
- Migraines

#### Enlarged spleen

Your spleen acts like a filter for your blood. Having an enlarged spleen is called splenomegaly.

#### Splenomegaly can cause symptoms like:

- Feeling full too fast
- Pain under the left ribs
- Severe abdominal discomfort

#### Low platelet count

Platelets are important to help your blood clot. Having a low platelet count is called thrombocytopenia.

#### Thrombocytopenia can cause symptoms like:

- Bleeding easily
- Bruising easily
- Bleeding for a long time when cut

#### Other symptoms

Myelofibrosis can cause different symptoms because it affects the body in many ways.

#### Other symptoms of myelofibrosis may include:

- Tiredness/fatigue
- Abdominal pain
- Itchy skin
- Night sweats
- Bone pain
- Weight loss

Since every day can be different, Andrew wakes up each morning and does what he refers to as a “systems check” of his body with input from Esther.

Esther describes Andrew’s experience with MF as “regularly uncertain” because the disease is so individualised that there is no typical journey. There are times when Andrew seems to have his normal energy, and others when he may be experiencing fatigue, or his spleen may be bothering him because it’s enlarged. Rarely are any two days the same, which makes managing MF an uncertain road, and can have a profound impact on quality of life.



Andrew and Esther, his wife and care partner



Individuals with MF can experience varying degrees of symptoms, and those with no current or mild symptoms can be monitored with regular health checkups and tests but may not need treatment. If symptoms – like anaemia and an enlarged spleen – become more serious, a specialist, haematologist, or oncologist may recommend therapies, over-the-counter medicines and other lifestyle measures to help manage the symptoms and blood transfusions may be required. Some patients may also have the option of receiving an allogeneic stem cell transplant, which is the only potential cure for MF, but carries significant risk.<sup>9</sup>

## The importance of self-advocacy

Andrew firmly believes in taking an active role in managing MF and moving forward in life, recommending that patients work with their healthcare team and community to find out how they can live their fullest life possible. It’s critical to identify and include care partners in learning about the disease, monitoring progression and creating a support system.

Living with MF means you should stay vigilant and listen to your body. If you think something feels off, speak with your doctor about finding a specialist.

#### References:

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