

# Living with myelofibrosis

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## Your simple Symptom Guide



**Get heard. Get help.**  
**Get involved in the conversation**  
**#MPNsymbols**

UK | March 2021 | 102695

This document was produced by Novartis Pharmaceuticals UK Limited, and developed in collaboration with MPN Voice and Leukaemia Care. It is intended for patients diagnosed with myelofibrosis and should not be considered an alternative to advice from a healthcare professional.

# What's this Symptom Guide all about?

Hello. Hopefully this Symptom Guide is useful to you. It's been developed with you in mind. With it, you can read an introduction to myelofibrosis (MF), a type of myeloproliferative neoplasm (MPN), and have a more detailed look at the main symptoms that can come with it, helping to understand your condition better.

Everyone's experience with MF is unique and sometimes the symptoms you're feeling can be difficult to explain. To help visualise what the reality of living with MF can look like, the symptoms have been illustrated in this Symptom Guide.

The Symptom Guide also provides information on resources that could help you keep track of your symptoms, to better understand what's going on with you. Having a record of your symptoms can help your doctor understand what's going on too.

Finding the words to tell your doctor or nurse the impact of your symptoms on your daily life can be difficult, but it means they can help you. That's the point of this Symptom Guide. To help you Get heard and Get help, and make sure you're getting the support you need. It might also make it easier for you to explain how you are feeling to family and friends, so they can better support you too.

**You don't have to suffer in silence. Get heard. Get help.**

# An introduction from MPN Voice

MPN Voice's mission is to provide clear and accurate information and emotional support to everyone who has been diagnosed with an MPN. Therefore, we were excited to be invited by Novartis to collaborate with them in the design and implementation of this Symptom Guide. They wanted to know what people with MPNs wanted and needed to help them feel more in control of their MPN.

We shared with Novartis that the majority of patients wanted to be believed when they reported their symptoms of fatigue, bone pain, confusion, itch and low mood. They also wanted to know if their blood counts had any relation to these symptoms. This highlighted the need for a way of recording these symptoms alongside test results in a way that would be easy for patients to do, and easy for medical teams to read.

Some people are more able than others to describe their symptoms and the impact on their daily life. For them, the Symptom Guide is more about recording details in one convenient place.

However, some people feel very intimidated by medical professionals and are unable to adequately describe their symptoms – how do you describe to a trained medical professional that the pain in your bone is actually right inside the bone and can't be 'rubbed better'? How do you describe fatigue so severe you can't even walk upstairs?

The diagrams in the Symptom Guide alongside the tracker will empower people to report these symptoms, to take away the anxiety of how to describe them, to not feel stupid! The Symptom Guide may also help people with MPNs who are in employment, helping to inform bosses and work colleagues about the symptom burden, the need for time off for hospital appointments, the need for adjustments to be made during periods of fatigue. The Symptom Guide aims to help put people in control of their MPN, rather than their MPN being in control of them.

# An MPN patient's perspective on the importance of understanding symptoms

*I was diagnosed with essential thrombocythaemia, also known as ET, in 2003. At that time there was very little information available, either printed or on the internet. All I knew was that I didn't feel very well, and that I had something that would never be cured; very scary knowledge.*

*Over the years my symptoms of fatigue, dizziness, bone pain and confusion have either been believed or completely dismissed, depending on the medical professional who I was talking to. Either my symptoms were part of my ET and therefore I had a reason for them, or they were nothing to do with it, so what was causing them? Fear, anxiety and frustration do not help these symptoms. Luckily on one of my trawls of the internet, I found MPN Voice, or MPN Support as it used to be called. What a difference having knowledge made to me and my family.*

Maz Campbell-Drew  
Patient living with an MPN

# MF at a glance

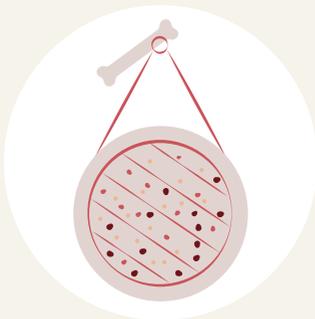
MF is part of a group of blood cancers called **myeloproliferative neoplasms or MPNs**, which all affect bone marrow. MF, together with two other MPNs called essential thrombocythaemia (ET) and polycythaemia vera (PV), make up most MPNs.

In MF, the soft tissue in your bones that usually makes blood cells (your bone marrow) turns into scar tissue, which lowers the ability of the bone marrow to make new blood cells.

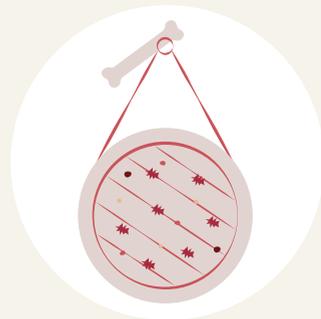
As a result, you can become anaemic (not having enough red blood cells). You may also develop thrombocytopenia (not enough platelets) or neutropenia (not enough white blood cells).

Your spleen and liver can make red blood cells, so they try to compensate for your bone marrow not working as it should. However, they can never fully compensate for your bone marrow not working correctly and both can become enlarged. Not having enough red blood cells and enlargement of the spleen can lead to some of the common symptoms of MF.

Cancer is a scary word, and you probably feel anxious or even frightened that your doctor says you have it. But try to remember that **every case of MF is different and how each person's body responds to treatment will vary**. Your doctor will give you advice and provide you with the treatment that works best with your individual circumstances.



*Healthy bone marrow produces most of the blood cells the body needs*



*MF causes scarring to the bone marrow, preventing it from producing enough blood cells*

# Recognising your symptoms

This Symptom Guide will take you through the common symptoms of MF.

It's important to be aware of the symptoms of MF, as some symptoms can be confused or masked by everyday life. For example, fatigue can range from feeling mild tiredness to an inability to do anything with your day. If a symptom such as fatigue interferes with your ability to live a normal life, you should ask for help. Don't feel guilty about it!

You don't have to suffer symptoms in silence and there are options to help control or alleviate them; Get heard, Get help. Your doctor is there to help you.



*"Like wearing concrete shoes up a flight of stairs"*

## General fatigue

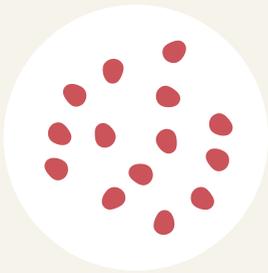
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/just so, so tired/

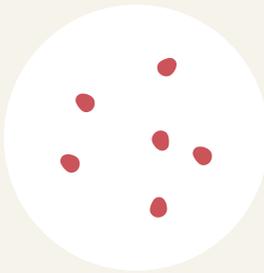
# Cause

Your condition causes your bone marrow (the soft tissue inside some of your bones) to produce fewer red blood cells, and can result in anaemia – a common contributing cause of fatigue. This means that your body can't transport oxygen as well, making it harder for your muscles to work.

Fatigue can be caused by any number of factors. Anaemia is just one of the possible causes. In any case, discuss your symptoms with your doctor to help evaluate your condition.



*Normal red blood cells*



*Reduced red blood cells*



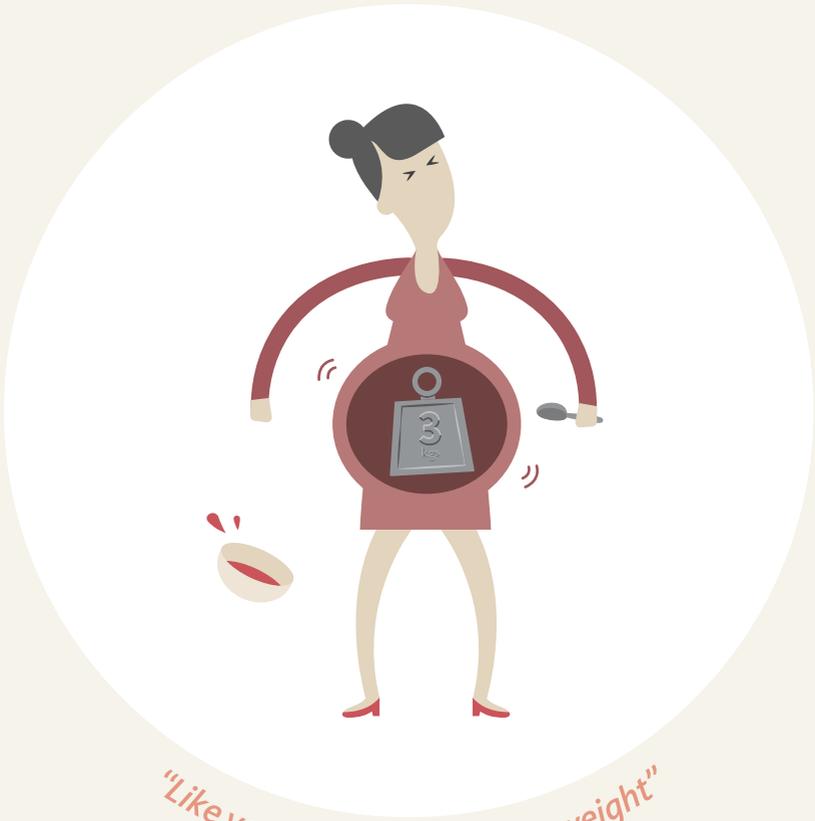
*Less oxygen available to your muscles*

## **IF I ACT**

Your doctor may check that the treatment you are receiving is working. Your doctor or a dietitian may also advise you on ways to make sure you get appropriate nutrition or therapies. Maintaining a healthy body via regular exercise and a balanced diet can help with fatigue.

## **IF I DON'T**

You may continue to feel tired and unable to complete everyday tasks, despite resting.



*"Like you've just eaten a 3kg weight"*

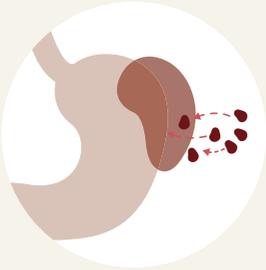
## Early satiety

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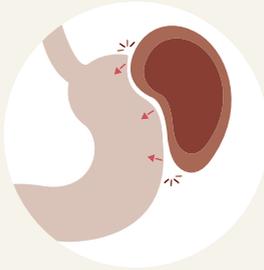
/full without eating much/

# Cause

Your condition may cause your spleen and liver to produce red blood cells; this causes the spleen to grow bigger and press on your stomach, reducing its size and making you feel full after only a small amount of food.



*Spleen produces red blood cells*



*Spleen grows and presses on stomach*



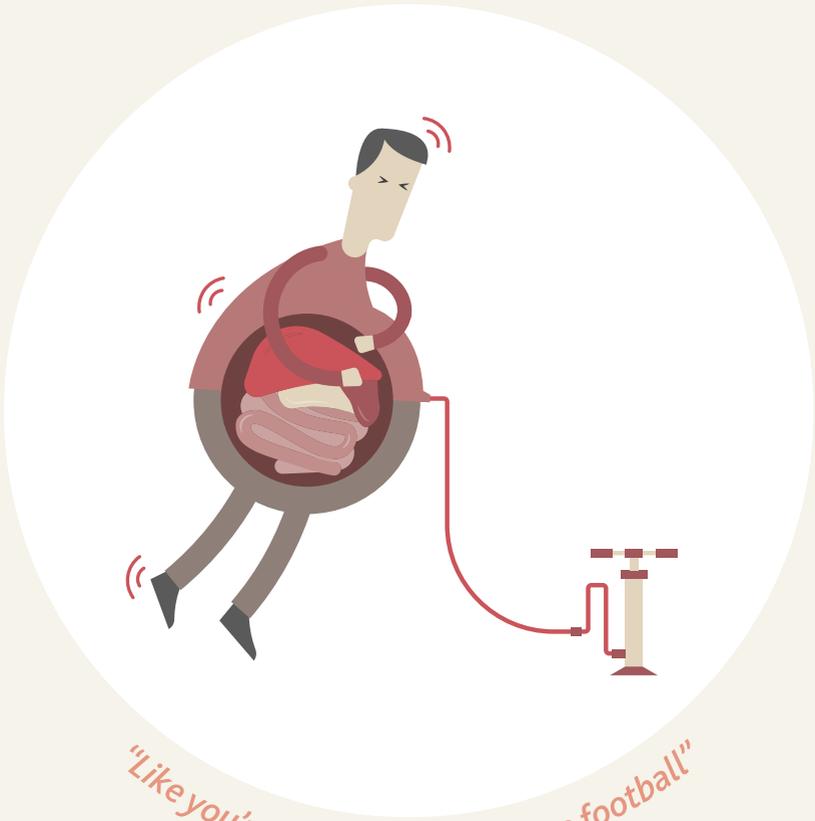
*You are full after smaller portions*

## **IF I ACT**

If your spleen or liver is enlarging while you are being treated, your doctor may recommend an alternative form of treatment.

## **IF I DON'T**

Not reporting this symptom may mean your health gets worse.



*"Like you've been blown up like a football"*

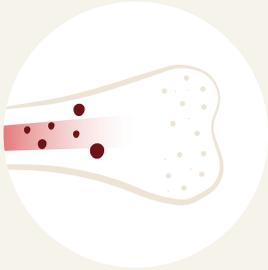
# Abdominal discomfort

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/an uncomfortable tummy/

# Cause

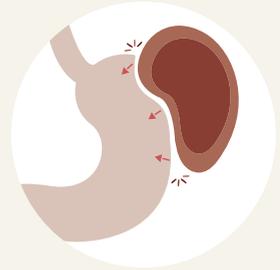
Your condition may cause organs other than your bone marrow (e.g. your spleen and liver) to produce red blood cells; if the spleen or liver start to produce red blood cells, they may become enlarged. This can put pressure on the stomach, leading to abdominal pain, discomfort or indigestion.



*Bone marrow usually produces red blood cells*



*Your disease can cause other organs to do this, which can make them become enlarged*



*Pressure on your stomach causes discomfort*

## **IF I ACT**

If your spleen or liver is enlarging while you are being treated, your doctor may recommend an alternative form of treatment.

## **IF I DON'T**

An enlarged spleen or liver will continue to be painful.



*"Like you could sleep for a week"*

## Inactivity/lethargy

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/don't feel like doing anything/low mood/

# Cause

Inactivity is feeling like you can't do anything. Lethargy is feeling low in mood. These are the feelings that come about because of the physical effect of fatigue in the body. Your mood can become low, and when you don't feel like doing anything, it's hard to stay active.



*Fatigue and low mood*



*Feeling like you can't do anything*



*Ending up being less active*

## **IF I ACT**

Your doctor may check that the treatment you are receiving is working, and may advise a change in treatment. They will also help you improve your mood by making small changes to your lifestyle (e.g. changing your diet or increasing your activity levels).

## **IF I DON'T**

You may continue to feel unproductive and unable to do everyday tasks.



*"Distracted by a million thoughts"*

# Concentration problems

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*/can't focus/*

# Cause

This symptom may be the result of your condition causing the release of cytokines (chemical messengers that help cells communicate), which can lead to inflammation in your brain. This inflammation is thought to affect small blood vessels called capillaries, and has been associated with difficulty thinking clearly and concentrating on things.



*Cytokines released*



*Inflammation happens*



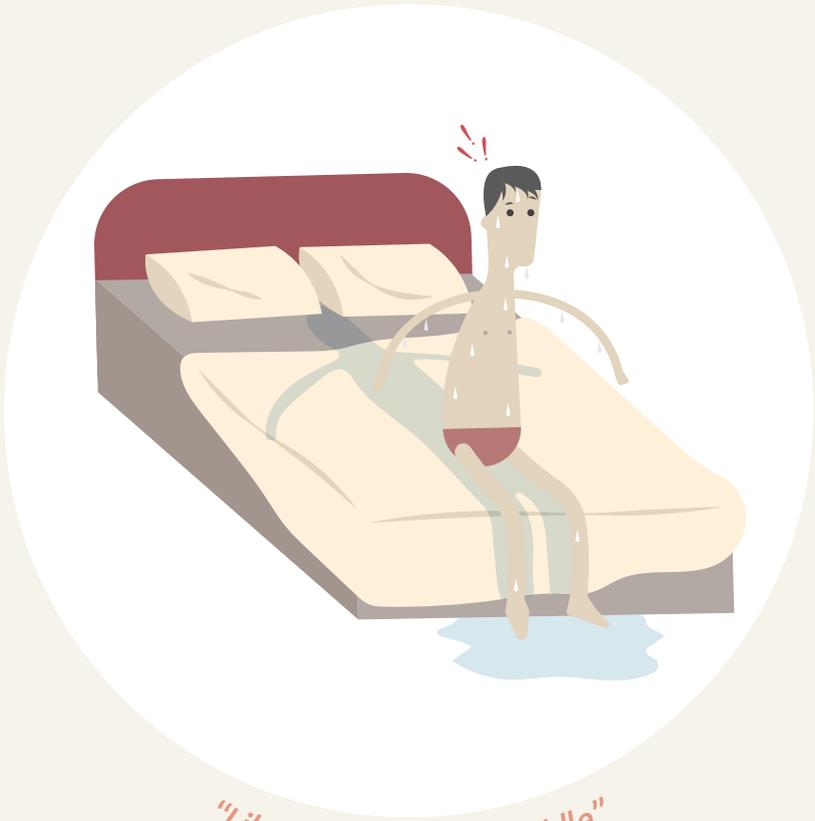
*Difficult to concentrate*

## **IF I ACT**

Your doctor may check that the treatment you are receiving is the best option for you and will advise you on how to help alleviate your symptoms.

## **IF I DON'T**

You may continue to find it difficult to concentrate.



*"Like waking up in a puddle"*

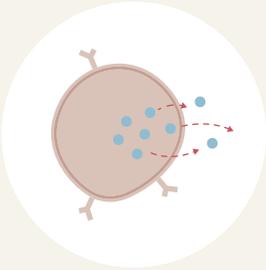
## Night sweats

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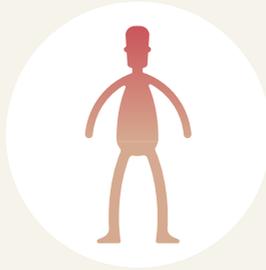
/waking up covered in sweat/

# Cause

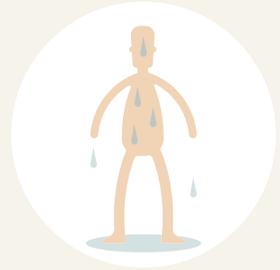
Your condition could cause the cells of your immune system to release cytokines that cause an inflammatory response in your body. This inflammation may cause you to sweat a lot during the night.



*Cytokines released  
by the immune system*



*Inflammatory response  
in the body*



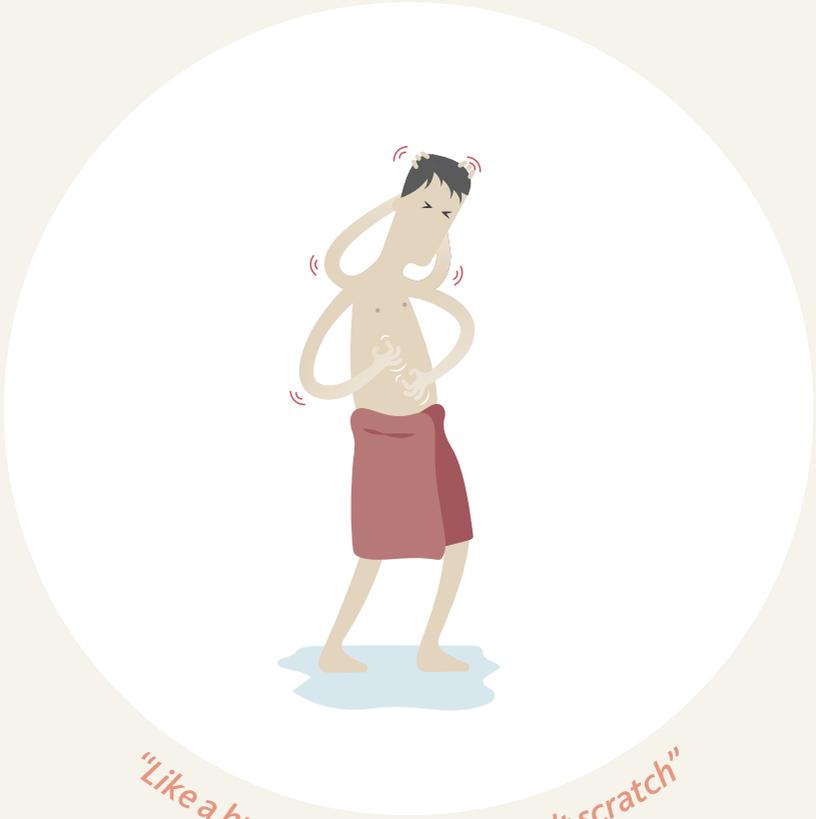
*Excess sweating  
at night*

## **IF I ACT**

Your doctor may check that the treatment you are receiving is working, and will help you with advice on ways to manage your night sweats.

## **IF I DON'T**

The night sweats may continue to make you feel uncomfortable, stopping you sleeping well – meaning you're tired during the day.



*"Like a hundred itches you can't scratch"*

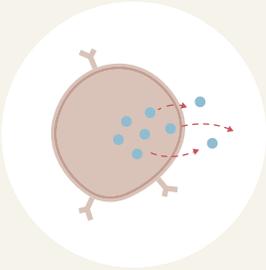
# Itching (pruritus)

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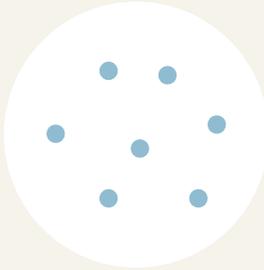
/very, very itchy/

# Cause

Your condition could cause the cells of your immune system to release cytokines that lead to an inflammatory response in your body. This inflammation may cause your skin to feel very itchy.



*Immune system*



*Cytokine molecules*



*Feeling the itch*

## ***IF I ACT***

Your doctor may check that the treatment you are receiving is working and can help you to manage or reduce your itching.

## ***IF I DON'T***

The pain may continue to cause you problems and impact your quality of life.



*"Like having your bones clamped in a vice"*

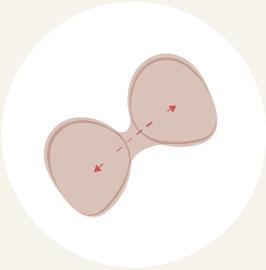
## Bone pains

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/bone, joint and body aches/

# Cause

Your condition may cause stem cells within your bones to multiply. This may stretch and stimulate the periosteum (the covering of the bone), which may be painful.



*Bone cells multiply*



*Periosteum is stretched*



*This leads to pain*

## ***IF I ACT***

Your doctor may check that the treatment you are receiving is working, and can talk to you and help you to manage your bone pain.

## ***IF I DON'T***

The pain may continue to cause you problems and impact your quality of life.



*"Feeling a little loose around the middle"*

## Weight loss

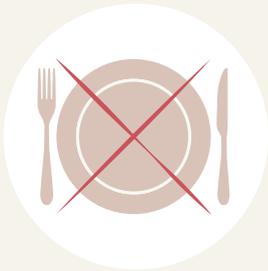
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/a noticeable drop in size/

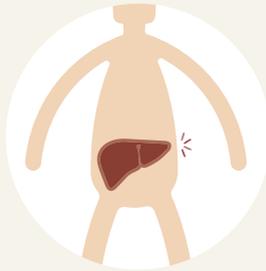
# Cause

Your condition may cause you to lose weight; this may be because you feel less hungry due to early satiety (feeling full after only a small amount of food) or abdominal pain, discomfort or indigestion caused by an enlarged spleen or liver.

It is important to note that not all weight loss is bad. Maintaining a healthy body weight as a result of regular exercise and a balanced diet is important. However, sudden or unintentional weight loss could be caused by your condition and should be discussed with your doctor.



*Less hungry due to early satiety*



*Discomfort of enlarged internal organs*



*Increased metabolism*

## **IF I ACT**

Your doctor may check that the treatment you are receiving is working and consider alternative therapies. Your doctor or a dietitian may also advise you on ways to make sure you get appropriate nutrition.

## **IF I DON'T**

You may continue to lose weight, which can affect your life.



*"Hot one minute, freezing the next"*

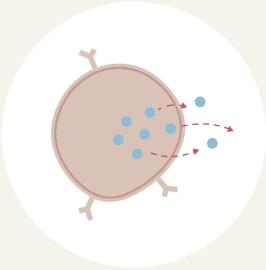
# Fever

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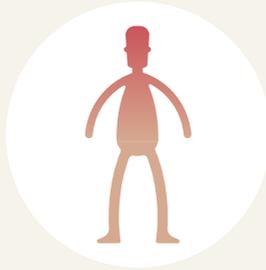
/covered in sweat/

# Cause

Your condition may cause the cells of your immune system to release cytokines that lead to an inflammatory response in your body. This inflammation may cause you to develop a fever.



*Cytokines released by the immune system*



*Inflammatory response in the body*



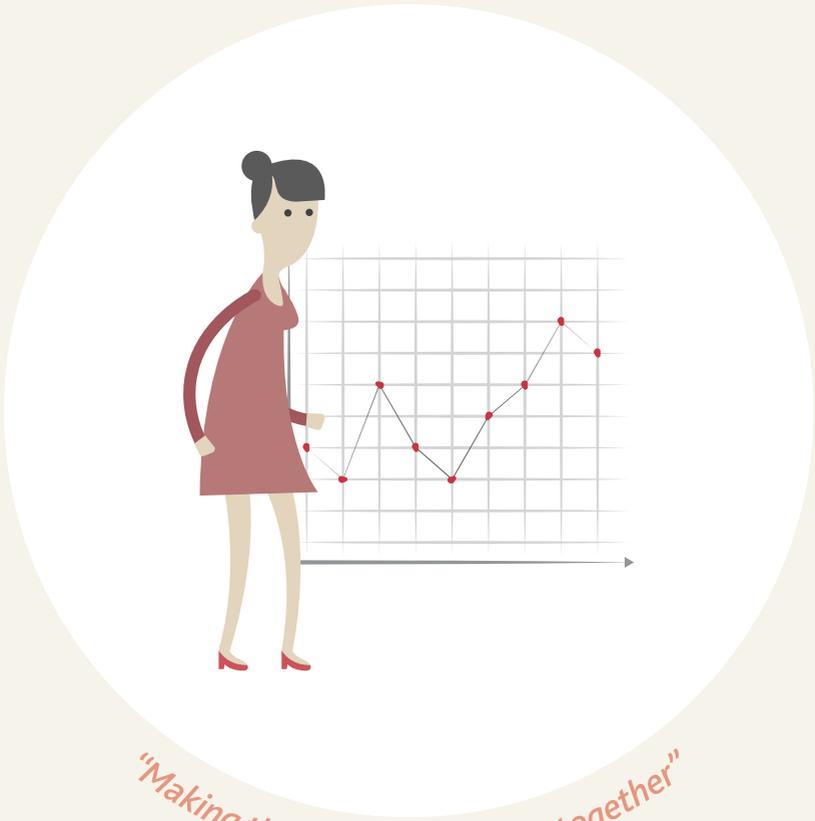
*Fever develops*

## ***IF I ACT***

Your doctor may check that the treatment you are receiving is working, and may advise you on how to manage fevers.

## ***IF I DON'T***

The fevers may continue to affect your life unmanaged.



*"Making the most of your time together"*

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Preparing for your next appointment  
with your doctor or nurse

# Tips for Getting heard and Getting help

The time with your doctor and nurse can just fly by. You want to be sure you've asked them all the questions you wanted to and told them what they need to know so they can offer you the treatment and support that's right for you. Taking some time to think about what you want to tell or ask your doctor or nurse before each appointment can help you get the most out of your time with them.

Here are some tips to consider before your next appointment:

## TRACK

changes in your symptoms between appointments using the specially created MPN10 Tracker form. This can also be done online at the [MPN Tracker website](#). For more information, see page 29.

## TAKE

your completed MPN10 Tracker form and your questions with you when you go to your appointment – don't forget a notebook and a pen so you can write down any answers.

## ASK

a family member or friend to go with you to appointments for moral support. They can also take notes or even ask questions that may not have occurred to you.

## REMEMBER

that MF is a variable condition and there will be highs and lows. It's important to be prepared for these, and to try to work through any issues with your doctor or nurse as they arise.

## EXPLORE

the additional information available to you, by reading online and speaking to your doctor or nurse.

## CONNECT

with others. There are other people living with MF out there who are experiencing similar symptoms to you. Sometimes it's good to connect to someone who gets it. Get involved in the conversation #MPNsymbols.

# Track your MF symptoms in the way that suits you

It's important to monitor your symptoms so that you and your doctor can keep track of your MPN. If you notice that your symptoms are changing, getting worse or you're feeling more and more unwell, it's really important to let your healthcare team know. Keeping a record of your symptoms can help you and your doctor understand how your symptoms affect your life and how they change over time. By understanding what is going on, your doctor can help you, so that you don't have to suffer your symptoms in silence.

## Knowing your score with MPN10

MPN10 is a tool designed by world-leading experts to help you keep track of your MPN symptoms. Follow the steps below to get started and stay on top of your MPN.

### STEP 1:

Go to [mpntracker.com/en-gb](https://mpntracker.com/en-gb) and select if you want to monitor symptoms for MF using the buttons at the top of the page.

### STEP 2:

Use the sliders to rate the severity of each symptom from 0 (absent) to 10 (worst imaginable) and press save.

The screenshot shows the MPN Tracker symptom tracking interface. It features ten sliders for rating symptom severity from 0 to 10. The symptoms are: Tiredness, Night events, Early satiety (full or quickly - after eating), Pruritus (itching), Abdominal discomfort, Bone pain (aching/stabbing pain in joints), Headache, Fever (night or day), Problems with concentration (trouble with tasks or memory), and Unintentional weight loss (in the last 6 months). Below the sliders, it displays 'your score 41 / 100' and a 'Save symptoms' button.

### STEP 3:

Download your results and take them with you to your doctor, so they can see how your MPN affects you.



### STEP 4:

Now that you've started monitoring your symptoms, you can keep track of how they change over time. Try to track your symptoms on the same day each week to build up a pattern, which will help you and your doctor better understand your symptoms and how they are affecting you over time.

MPN Voice:  
Tel: 07934 689 354  
[www.mpnvoice.org.uk](http://www.mpnvoice.org.uk)

Leukaemia Care:  
Tel: 08088 010 444  
[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

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