

MPN TIME TO BE SEEN

**A GUIDE FOR UK PATIENTS LIVING WITH
MYELOPROLIFERATIVE NEOPLASMS (MPNS).**

GSK's patient educational campaign, MPN Time To Be Seen, is for UK patients diagnosed with myeloproliferative neoplasms (MPNs). It has been co-created with MPN Voice and is fully funded by GSK.

SCAN TO VIEW



CAMPAIGN
WEBPAGE

MPN
TIME
TO BE
SEEN

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WHAT IS 'MPN TIME TO BE SEEN?'

MPN Time to be Seen is GSK's patient educational campaign, co-created with MPN Voice, and is fully funded by GSK. The aim of the 'MPN Time to be Seen' campaign is to provide educational support for UK patients living with myeloproliferative neoplasms (MPNs) – a group of rare blood cancers. MPN affects 8 in every 100,000 people in the UK.ⁱ MPN Voice is a charity that provides information, emotional support and advocacy for people with myeloproliferative neoplasms (MPNs).

Typically, MPNs affect older adults, with an average onset age of 60 years old; however, they can also occur in younger adults.ⁱⁱ As MPNs are rare, many people aren't aware what they are when they are first diagnosed.ⁱⁱ This means living with MPNs may be difficult to explain to friends, family and employers. The MPN Time to be Seen campaign aims to provide you with the information to understand the cause, origin and nature of your condition, and to help you feel empowered to talk about it with loved ones, employers and healthcare professionals.



**Scan the QR code to to access the
MPN Time to be Seen webpage.**

WHAT ARE MPNs?

MPNs are a rare form of blood cancer that affects how blood cells are produced in our bodies.ⁱⁱⁱ

Every day, our bodies produce billions of blood cells in the bone marrow, where stem cells mature into red blood cells, white blood cells and platelets – each with specific functions in the body.^{iv} In MPNs, blood cell production becomes abnormal, leading to either an excess or deficiency of some blood cells.^v

The three most common types of MPNs are distinct blood cancers, each affecting blood cell levels differently.^v These are:

ESSENTIAL THROMBOCYTHAEMIA (ET)

ET is a rare chronic blood cancer characterised by an overproduction of platelets by the bone marrow, which can lead to an increased risk of blood clots and bleeding complications.^v ET is classified as a type of MPN and often requires ongoing monitoring and management for common symptoms, including fatigue and headaches.^{vi} ET accounts for approximately 25% of MPN cases.^v

POLYCYTHAEMIA VERA (PV)

PV is a rare blood cancer characterised by an overproduction of red blood cells in the bone marrow, leading to thickened blood and an increased risk of blood clots.^v It is a type of MPN and can also cause symptoms like fatigue, headaches and tingling or burning sensations.^{vii} It is the most common type of MPN, accounting for approximately 45% of all cases.^v

MYELOFIBROSIS (MF)

Myelofibrosis is a rare bone marrow cancer where the fibrous tissue replaces the bone marrow, leading to impaired blood cell production.^v This condition can lead to symptoms such as anaemia and fatigue, as well as signs like an enlarged spleen.^v In an estimated 10-20% of patients, myelofibrosis can potentially progress to Acute Myeloid Leukaemia (AML).^{viii,ix,x}

CAUSES AND RISK FACTORS

Unfortunately, current research has not yet discovered a specific cause of MPNs; however, it is generally accepted that many MPNs are related to genetic mutations in the Janus Kinase 2 (JAK2) gene.^{xi} Additionally, other genetic mutations, such as myeloproliferative leukaemia virus oncogene (MPL) and calreticulin (CALR), have been associated with MPNs, both of which can contribute to making JAK2 overactive.^{xii}

*“When I was
diagnosed at 17
years old, I’d never
heard of an MPN”*

Mary

(Mary is a patient
living with MPN)

The typical age of MPN diagnosis is after 60 years of age.ⁱⁱ
Patients experiences of MPN may differ depending on MPN
type, age and general health.



SYMPTOMS

The symptoms of MPNs can vary depending on the specific type and stage of the disease. Many symptoms can be hard to distinguish from other illnesses.

Some of the common symptoms that people with MPNs experience include:^{xiii}

- ▶ Fatigue
- ▶ Headaches
- ▶ Difficulty concentrating
- ▶ Abdominal pain
- ▶ Night sweats
- ▶ Fever
- ▶ Weight loss
- ▶ Itching
- ▶ Bone pain

The above list does not cover all symptoms that MPN patients may experience.

SPEAKING TO YOUR HEALTHCARE PROFESSIONAL

PREPARING FOR YOUR APPOINTMENT

After being diagnosed with an MPN, you may be invited for regular appointments with your healthcare team to manage and monitor your condition. It is helpful to prepare in advance for these appointments as well as making note of any questions that you may wish to ask. You can use the space on page 16 to note down any questions you may have.

Your healthcare professional may ask about your symptoms and how they have been progressing over time. It's a good idea to have a think before your appointment and be ready to discuss with them:

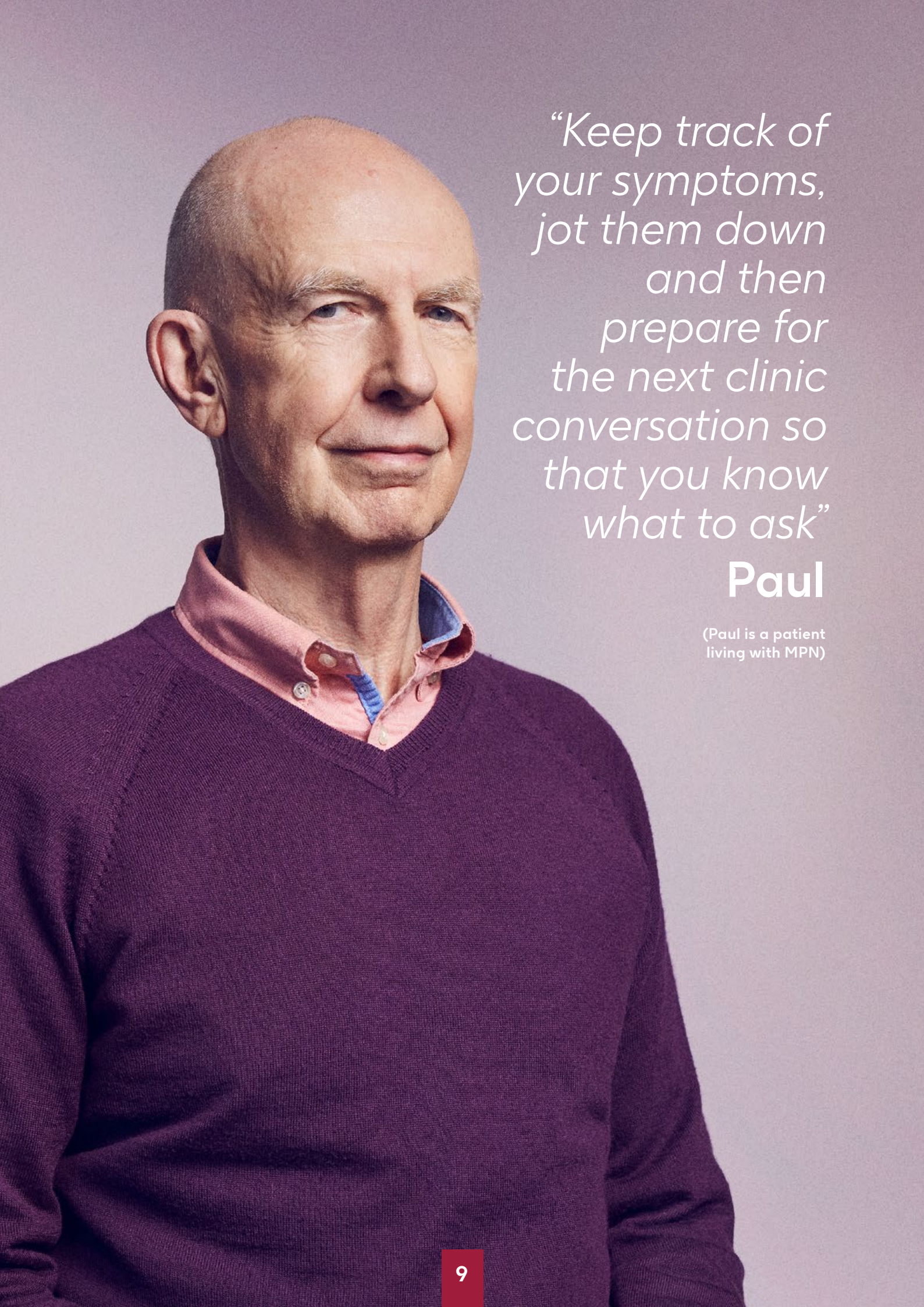
- ❑ **How long have you had the symptoms?**
- ❑ **Are they better, worse or have they stayed the same over time?**
- ❑ **Do they affect your daily activities?**

You can use the space on page 15 to note and keep track of your symptoms. Write down anything you've tried to manage your symptoms, such as medications (including over the counter medicines or supplements).

DURING YOUR APPOINTMENT

1. It can be overwhelming to take in all the information at an appointment, so consider bringing a friend or family member for support, if you feel comfortable.
2. Be open about your concerns and share your written notes with your GP. You can also make notes throughout your appointments with your healthcare team on page 17.
3. If you don't understand any medical terms, don't hesitate to ask for clarification. A glossary has been included on page 14 of this guide with some common terms which you may find useful.
4. During appointments, your clinical team may request some blood tests. You have the right to ask why each test is needed. If you're afraid of needles, let your doctor or clinical team know so they can take extra care during the blood tests.
5. Before you leave your appointment, be sure to check:

- ❑ **Have you asked all your questions?**
- ❑ **Do you understand everything that has been discussed?**
- ❑ **What are the next steps in your care?**
- ❑ **Who will contact you next and when?**
- ❑ **How can you manage your symptoms until then?**
- ❑ **Who can you reach out to if your symptoms get worse?**
- ❑ **Do you know where you can find more information?**



*“Keep track of
your symptoms,
jot them down
and then
prepare for
the next clinic
conversation so
that you know
what to ask”*

Paul

(Paul is a patient
living with MPN)

SPEAKING TO YOUR SUPPORT NETWORK

Following an MPN diagnosis, it can be hard for your loved ones to know how best to support you. Taking time to think about what support you need and having conversations with loved ones to explain how you're feeling may help give them the guidance they need to support you better.

PREPARATION:

- ▶ Consider how living with MPNs has affected you emotionally, physically, and socially.
- ▶ Think about what kind of support or understanding you need from your family and friends.

SYMPTOM AWARENESS:

- ▶ Describe the symptoms you experience regularly and how they impact your life.

DISCUSS THE IMPACT OF MPNS ON YOUR DAILY LIFE:

- ▶ Share specific examples of how MPNs affect your daily routines, such as work, social activities and self-care.
- ▶ Explain whether your symptoms remain consistent each day or if they tend to vary.
- ▶ Let them know which areas of your life you would value their support with, and areas where you would rather stay independent.

ENCOURAGE THEM TO EDUCATE THEMSELVES:

- ▶ Don't be afraid to ask people to educate themselves on your condition. You can take your support network through this guide, as well as encourage them to visit the MPN Voice website to learn more about MPNs.
- ▶ Some people find it empowering to share the information they have learned and act as a 'teacher' for friends and family.
- ▶ MPNs are rare and complicated, and even the people who care for us can be confused by the medical terms and acronyms used by healthcare professionals. To help with this, you can refer to common terms in the Glossary on page 14.
- ▶ You may like to suggest they attend available support groups with you, such as the MPN Voice Patients' Forum, where they may be able to meet and share experiences with other people who are supporting their loved ones - please check on the MPN Voice website for upcoming forums. Otherwise, it may be helpful for them to attend a Clinical Nurse Specialist-led support group in your area (if available).

SPEAKING TO YOUR EMPLOYER

For people diagnosed with an MPN while they are in employment, explaining your symptoms to your employer (if you feel comfortable doing so) can feel stressful. Your employer may not have heard of MPNs, and the symptoms you have don't necessarily sound like cancer. Some people feel their employers aren't receptive to their needs while living with MPNs. Additionally, you can have these conversations with Occupational Health or your clinical team if appropriate.

PREPARATION:

- ▣ In the same way as your friends and family, think about what kind of support or understanding you need from your workplace.

BACKGROUND:

- ▣ Provide an overview of your diagnosis and its impact on your daily life, to the extent you feel comfortable.
- ▣ If your employer is not aware of MPNs and if they are happy to learn more, you could refer them to MPN Voice.

DISCUSS HOW YOUR CONDITION AFFECTS YOUR WORK:

- ▣ Clearly communicate any challenges you face at work due to your condition, such as needing flexible hours, more breaks, or adjustments to your workload.
- ▣ Emphasise what you can still do and your commitment to maintaining your productivity and contributions to the team.

OPEN COMMUNICATION:

- ▣ To the extent that you feel comfortable, talk about any anticipated changes in your condition or treatment that might affect your work in the future, and how to prepare for them.



“I was worried speaking about my diagnosis would affect my career, but I regret not being open sooner. Be transparent and honest - you have rights.”

Mary

(Mary is a patient living with MPN)

TOP TIPS FOR LIVING WITH MPNS



“My advice for someone who is newly diagnosed, if they don’t feel like they have anyone to discuss it with, is to get in touch with MPN Voice and consider using the MPN buddy programme where they can talk to someone living with the same diagnosis as them. I’m a buddy myself.”*

Paul

(Paul is a patient living with MPN)

* The MPN Buddy Programme is run by MPN Voice and is independent of GSK.

“I’d recommend finding other people with your condition because you’ll meet people who are ahead of you in their journey. They can share tips, they can encourage you and they can help take away that fear”

Alisia

(Alisia is a patient living with MPN)



“Do your research and don’t let it define you!”

Mary

(Mary is a patient living with MPN)

GLOSSARY

There are various MPN types as well as associated acronyms. To help navigate this, refer to the list below:

1. ACUTE MYELOID LEUKAEMIA (AML):^{xiii} A quickly progressive, malignant disease where there are too many immature blood cells forming in the blood and the bone marrow.

2. CALRETICULIN (CALR):^{xvii} A protein involved in various cellular functions. Mutations in the CALR gene are found in some patients with MPNs and disrupt cell signalling, leading to abnormal blood cell production.

3. CHRONIC MYELOID LEUKAEMIA (CML):^{xiv} A rare type of cancer affecting the bone marrow and white blood cells.

4. ESSENTIAL THROMBOCYTHAEMIA (ET):^v A rare blood cancer characterised by an overproduction of platelets in the bone marrow, which if uncontrolled, can lead to an increased risk of blood clots and bleeding complications.

5. HYPEREOSINOPHILIC SYNDROME (HES):^{xv} A group of disorders characterised by persistently high levels of eosinophils in the blood, which can cause damage to the heart, lungs, skin and nervous system.

6. JAK2 V617F:^{xvi} A mutation in the Janus Kinase 2 (JAK2) gene, which plays a critical role in controlling cell production, particularly in the blood cells.

7. MYELOFIBROSIS (MF):^v A rare bone marrow cancer where fibrous tissue gradually replaces the bone marrow, leading to decreased blood cell production, anaemia and an enlarged spleen. It can progress to acute myeloid leukaemia (AML).

8. MYELOPROLIFERATIVE LEUKAEMIA VIRUS ONCOGENE (MPL):^{xiii} The MPL gene, located on chromosome 1p34, encodes the TPO-R MPL receptor, which signals through JAK2 and plays a key role in megakaryopoiesis.

9. POLYCYTHAEMIA VERA (PV):^v A type of blood cancer in which the bone marrow produces too many red blood cells. If uncontrolled this causes the blood to thicken and may increase the risk of clotting, strokes and other cardiovascular issues.

10. STEM CELLS:^{iv} Undifferentiated cells that have the ability to develop into different types of specialised cell types.

SYMPTOM TRACKER

A series of 20 horizontal dotted lines for tracking symptoms.

MY QUESTIONS

A series of 18 horizontal dotted lines for writing.

MY NOTES

A series of horizontal dotted lines for writing notes.

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