

FINANCIAL CONCERNS

The time away from work and the cost of travel for specialist care can be a significant burden. MPN Voice can offer advice and guidance on navigating insurance coverage, applying for financial assistance, and managing life costs effectively.

TRAVEL GUIDANCE

Travelling can be an exciting and happy time and most patients with well controlled MPNs can travel safely. Depending on your situation, travel may require additional planning, for example around medication. Talk to your doctor about any travel concerns and they can advise on necessary steps to take.

RELATIONSHIP CHALLENGES

At MPN Voice, we recognise that being diagnosed with a chronic illness can raise challenges for establishing and maintaining personal relationships. Communicating openly and honestly about your MPN and how you are feeling with partners, family, and friends is crucial.

FERTILITY

MPNs and their treatments can affect fertility in men and women. It is crucial to discuss these concerns with your doctor before starting treatment. They can advise on options like sperm or egg banking if desired.

PREGNANCY

If you plan to become pregnant, it is essential to talk to your doctor beforehand. MPNs can increase the risk of miscarriage both early and late in pregnancy. MPNs can also increase the risk of developing pre-eclampsia, a condition in which a woman develops high blood pressure during pregnancy. The good news is that having an MPN does not have to prevent you from having children, but it is important to be carefully monitored by your haematologist, obstetrician, and midwife who can watch for and manage any problems that may develop.

FUTURE PLANNING

You might have concerns about your future, including career goals, starting a family, and long-term health management. The network creates space for young patients to share their experiences and gain tailored support related to career development, life planning, navigating complex discussions with loved ones, and finding ways to manage your condition.

MPN VOICE'S YOUNG PATIENT NETWORK

We know that being diagnosed with an MPN under the age of 40 raises a unique set of questions and challenges. The network aims to connect you with others and signpost you towards relevant resources - helping you to navigate your journey and realise that you are not alone.

JOIN OUR *NETWORK*

Join the MPN Voice Young Patient Network to connect with others, access helpful resources, and participate in events designed specifically for you. We have a dedicated Facebook group for patients under the age of 40 which can help support you on your MPN journey.

SCAN TO JOIN THE YOUNG PATIENT NETWORK FACEBOOK GROUP



MPN voice
Young Patient Network



*Young People
and MPNs*

WWW.MPNVOICE.ORG.UK



SYMPTOMS

Some patients with MPNs do not experience any symptoms at all. However, MPNs can cause a range of symptoms. These include fatigue, bruising and bleeding, dizziness and ringing in the ears, headaches, coldness in the fingers or toes, redness or itching of the skin, blurred vision, joint pain, night sweats, weakness or shortness of breath, bone pain, and unexplained weight loss. It is important to keep track of what you are feeling and share your symptoms with your medical team.

INCREASED RISK OF BLOOD CLOTS

Thrombosis (blood clots) can be a serious complication of MPNs. They occur when blood clots block a vein or artery. You should seek immediate medical attention if you experience any of the following symptoms: pain, swelling, and redness in one leg; chest pain; unexplained shortness of breath or numbness on one side of your body. Clots are treated with blood thinning medication and managing your underlying MPN.

TREATMENT

If you have a low risk MPN, Aspirin or Clopidogrel (together with phlebotomy for those with PV) will reduce your risks of blood clots. If your MPN is higher risk, your haematologist may recommend treatments to manage overactive blood cell production. MPN Voice has leaflets about treatments like Interferon alpha, Hydroxycarbamide, and Anagrelide which you can read and download from the charity's website.

MENTAL HEALTH & WELLBEING

Living with a chronic illness and not knowing what the future may hold can lead to anxiety, depression, and feelings of isolation. The network understands this and has resources to help you, such as information on accessing mental health support, developing coping mechanisms, and building resilience. It also offers connections with other young people who are going through similar experiences and feelings.



PHYSICAL ACTIVITY

MPNs and their treatments can lead to symptoms and side effects, including fatigue, poor sleep, low mood, and weight changes. The good news is that physical activity can help in all these areas and boost your general wellbeing. Physical activity is defined as any movement that uses energy and often includes things we do without realising, such as walking, climbing the stairs, mowing the lawn, or cleaning the house. These activities can improve your fitness, strength, and balance. The recommendation is to do 5 x 30 minutes of moderate aerobic physical activity per week. It is important to build up slowly, so that you understand what you can manage and gradually improve your fitness.

DIET

The NHS Eatwell Guide outlines recommendations for eating a healthy balanced diet. It identifies the different types of foods and drinks you should consume - and in what proportions - every day or over a week. There are 5 main groups: fruit and vegetables; potatoes, bread, rice, pasta and other starchy carbohydrates; beans, pulses, fish, eggs, meat and other proteins; dairy and alternatives; oils and spreads. Consuming a variety of foods from each group will help you get the nutrients you need. For tasty recipes submitted by fellow patients, purchase a copy of the MPN Voice Recipe Book from Amazon.

EDUCATION & CAREER

Diagnosis at a young age can raise questions about and pose challenges for your education and career. Communicate with your teachers, lecturers, and employers about your condition and explore options like flexible work schedules, reduced course loads, and disability accommodations to help you stay on track with your studies and work.

WHAT ARE MPNS AND HOW DO THEY AFFECT YOUNG PEOPLE?

MPNs, or myeloproliferative neoplasms, are a group of rare blood cancers that affect how blood cells are produced in our bodies. There are three main types of MPNs called Essential Thrombocythaemia (ET), Polycythaemia Vera (PV), and Myelofibrosis (MF). Although MPNs are more common in older age groups, they can be diagnosed in children and young adults. The network aims to bring young patients together and help answer some of your questions.

SCAN TO READ THE YOUNG PEOPLE AND MPNS BLOG

Written by a young ET patient, the blog covers topics specific to young people and features helpful Q&As

