Your guide to

Fighting Fatigue in MPN

Fatigue is a big challenge for many patients with myeloproliferative neoplasm (MPN) and is the most common symptom across the three diseases of essential thrombocythaemia (ET), polycythaemia vera (PV) and myelofibrosis (MF).

How can fatigue affect you?

There can be many ways that fatigue might affect patients including:

- Lack of energy to do everyday things
- Not being able to work
- Not being able to have a full social life
- Forgetfulness
- Weakness
- Sleep disturbance
- Being more emotional
- Loss of sex drive
- Dizziness or light headedness
- Difficulty concentrating
- Difficulty speaking/thinking/making decisions

Why does fatigue occur?

The shortest answer is that we don't know. Probably there are several different factors for each patient; the disease itself, some complications related to having the disease, (including low mood, anxiety, stress), and complications of treatments for the disease (e.g. iron deficiency due to venesections, and side-effects of some drugs). In addition, it could be some basic every day things that apply to all humans not just those with MPN, for example poor diet, lack of exercise and not getting enough sleep.

Fatigue does not always correlate with blood counts or the stage of disease and it affects many patients from those with almost normal blood results to those with very normal ones as well as patients with very low risk disease to those with higher risk disease.

MPN voice

Coping with fatigue

These are tips from health professionals and other patients

- Talk about how you feel with your family, friends and healthcare team
- Keep a record of how you feel
- Plan your day and include some rest
- Ask for help if necessary
- Do not feel guilty
- Pace yourself
- Sleep is especially important (see later)
- Improve your fitness
- Exercise within your limits (see later)
- Eat a healthy diet and keep a record of what you eat and how you feel
- Keep hydrated
- Reduce your stress
- Set realistic goals

Focus on getting a good sleep!

- Try to keep to a regular routine at bedtime
- Aim for regular wake up times
- Try to avoid extremes of hot or cold
- Reduce light and noise in your bedroom
- Don't sleep for too long as this reduces the quality of sleep
- Use exercise to help you sleep deeper (more below)
- Avoid stimulants (coffee, alcohol, large meals etc) before bedtime
- Some exercises to help you sleep include using relaxation music or a routine, write a letter in your mind, re-live a favourite experience
- Consider a warm bath, perhaps using oils such as lavender
- If you do wake up and can't get back to sleep do something else, eg reading or watching TV, until you can sleep

Use relaxation and exercise

There is good evidence that physical activity such as gentle strengthening exercise and walking can help with the symptoms of fatigue. Being active can boost your appetite and give you more energy.

Set yourself some personal goals to plan some activity in your daily routine. Then monitor the effects of exercise, and remember to balance exercise and rest to allow your muscles to recover. Use relaxation techniques both physical and mental; consider complementary therapies such as mindfulness, meditation, aromatherapy and massage. Sometimes a limited number may be accessible through your local hospital or health centre.

Managing your work

Patients are protected by the Equality Act 2010 which protects against discrimination but also states that an employer should make reasonable adjustments to support employees, for example: changing hours, allowing more breaks, working from home etc.

Psychological effects of illness

Anxiety, depression, stress and tension can also contribute to fatigue. These are common and normal in patients living with a chronic disease especially at certain key points, for example at the time of diagnosis and if complications occur or when there is a change in condition or treatment.

Often these feelings get better with time but this is not always the case and you may need additional help which could vary from talking to others e.g. family or friends or via a support group as well as your healthcare team.

If you find that your mood is low and continues to be low most of the time, for example you are often tearful, you may have depression. You should discuss this with your GP and or healthcare team.

MPN Voice offers a 'buddy' programme for interested patients. Email buddies@mpnvoice.org.uk for more information.

MPN Voice
Registered under the auspices of Guy's and St Thomas' Foundation, MPN Voice provides patients and families affected by MPNs with a comprehensive range of disease and medication publications like this one. The website www.mpnvoice.org.uk provides access to an online community of MPN patients as well as the latest news and reports from leading healthcare professionals.

NHS 111
Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.
t: 111

NHS Choices
Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.
w: www.nhs.uk

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