



# ME symptoms

Updated: March 2025

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# Symptoms

Everyone who experiences ME has a different pattern of illness, and symptoms and severity can fluctuate and change over time.

Some people find it useful to print the list symptom list below to take to their GP, highlighting those they experience along with any additional symptoms. Keeping an activity and/or symptom diary can also be useful.

## **ME is not “feeling tired.”**

In our [2024 Learn about ME webinar for GPs](#), Dr Nina Muirhead referred to research she undertook with medical students at Cardiff University.

They interviewed patients about their experience of ME going to their GP.

Not one of them said they had fatigue. Not one of them said they were tired. Most of them said they felt ill, or they couldn't go on.

In fact, most patients said they often underestimated how ill they felt to both their families and their doctors because they didn't want to sound like hypochondriacs.

## Four key symptoms

[Post-exertional malaise](#) is one of the four symptoms that must be present for a diagnosis of ME, according to the [2021 NICE guideline for ME/CFS](#).

The others are:

- debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional, or social exertion, and is not significantly relieved by rest
- unrefreshing sleep or sleep disturbance (or both), which may include:
  - feeling exhausted, feeling flu-like, and stiff on waking
  - broken or shallow sleep, altered sleep pattern, or hypersomnia
- Cognitive difficulties (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

## Other ME symptoms

While it's important to find out more about the range of symptoms experienced by different people with ME, it's also important to know that people with ME may only experience a few of them and at varying levels of severity.

Always get new symptoms checked by your doctor, as they may be unrelated to ME.

Women often find that symptoms worsen at different times in their menstrual cycle.

The NICE guideline for ME advises that healthcare professionals: "help people with ME/CFS develop a plan for energy management as part of their care and support plan. Support them to establish realistic expectations and develop goals that are meaningful to them." (Section 1.11.3)

Frustration, anxiety, low mood and depression are sometimes experienced by people with ME as a consequence of having to cope with the impact of the condition and its symptoms.

Some common symptoms of ME are as follows:

Feeling generally unwell, such as:

- having flu-like symptoms (often called "general malaise" by doctors)
- recurrent sore throat, with or without swollen glands.

Pain, such as:

- aching muscles or joints
- nerve pains or pins and needles
- headache or migraine
- twitching muscles or cramps
- abdominal pain (stomach or bowel problems)
- chest pain
- back pain.

If pain, especially muscle pain, is more of a problem than fatigue, fibromyalgia may be an issue.

- poor temperature control
- dizziness on standing or sitting up
- orthostatic intolerance (symptoms when standing upright which are relieved when reclining)
- hyper-sensitivity to light and sound
- sweating
- loss of balance
- poor circulation.

Digestive problems, such as:

- nausea
- loss of appetite
- indigestion
- excessive wind/bloating
- cramps
- alternating diarrhoea and constipation
- Irritable Bowel Syndrome (IBS).

Intolerance and increased sensitivity to:

- bright lights
- noise
- odours
- some foods (for example dairy or wheat)
- some medications
- alcohol.

During your illness you may experience periods of better health or well-being, but there may also be times when your health deteriorates.

Having a relapse or setback is not uncommon at some stage.

Relapses can be mild or severe and can happen for many reasons, but often because of trying to do too much. You will need to make changes in your daily routine to manage any setbacks.

Most importantly, you need to understand what is happening and to have a plan of what to do.

Some people say that they experience relapses throughout their illness but that over time they get shorter or less severe, thanks to learning ways to manage them better.

Just as a small step forward in your health doesn't guarantee that you will immediately get better, a relapse doesn't have to mean that the course of your illness is on a downward curve.



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