



Getting an ME diagnosis

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Getting an ME diagnosis

Scientists have not yet found biological abnormalities in ME that are specific enough to be used as a diagnostic test (even though abnormalities in the brain and the immune system show very clearly that this is a serious, systemic illness).

Simple physical or mental activities, or combinations of activities, can leave people with ME feeling utterly debilitated. They can also experience an increase in other symptoms.

A doctor should assess medical history, recognise the typical symptom pattern of ME and conduct basic tests, for example on blood or urine samples, to rule out other conditions. Several visits to the doctor might be needed.

Many illnesses can sound quite similar in their symptoms and excluding other conditions is an essential part of the process to inform a diagnosis.

The earlier the illness is recognised, the sooner symptom management and support can begin.

Unfortunately, we know that some people experience significant delays to diagnosis, as some GPs lack confidence when it comes to diagnosing and managing ME. You can signpost them to [medical education resources](#) that can help.

Some people with ME find it helps to keep a diary of their symptoms so that they can take this to their GP. This can be really useful in communicating how your health fluctuates and identifying possible triggers.

Once you have a diagnosis of ME your GP may be able to refer you to an ME specialist (subject to availability in your area) who can offer options for managing your symptoms.

If you are struggling to get a diagnosis, our Healthcare Services doctors may be able to help. They are very experienced in assessing and diagnosing ME, and creating individualised management plans.

Medically Unexplained Symptoms

We understand that a small number of people with ME are being challenged by their healthcare professional as to the validity of their ME diagnosis. Instead, they being told that they have Medically Unexplained Symptoms.

If you are concerned that your ME diagnosis is not being acknowledged or validated, please contact us for information and support.

Official UK guidelines

The [2021 NICE guideline for ME](#) sets out evidence-based recommendations for health and care in England and Wales, including:

- the time in which a diagnosis should be made
- the assessments and investigations that must be carried out
- the right of all patients to have shared decision making
- the need for individualised, person-centred programmes of symptoms management and support for people with ME.

According to the guideline, ME should be suspected if:

- a person has had a specific set of persistent symptoms for a minimum of six weeks in adults and four weeks in children and young people **and**
- the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels **and**
- symptoms are not explained by another condition.

This specific set of symptoms can be found on page 12 of the guideline, as follows (all should be present for a diagnosis of ME):

- **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.

- **Post-exertional malaise** after activity in which the worsening of symptoms:
 - is often delayed in onset by hours or days
 - is disproportionate to the activity
 - has a prolonged recovery time that may last hours, days, weeks or longer
- **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.

An ME diagnosis can only be confirmed after three months of persistent symptoms, according to the NICE guideline.

The [2010 Scottish Good Practice Statement \(SGPS\) on ME](#) provides GPs with guidance on the differential diagnosis and clinical management of patients with ME.

It recommends making a formal positive diagnosis three-four months into the illness, based on symptom pattern, and excluding other conditions as appropriate.

This document was updated following the publication of the 2021 NICE guideline to highlight new information.

There is no official guideline (not any specialist healthcare services for ME) in Northern Ireland, though some doctors choose to use the NICE guideline.

The support group [Hope 4 M.E. and Fibro](#) is a great resource for information and support in Northern Ireland.



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