



# What is ME?

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# What is ME?

Myalgic Encephalomyelitis (ME), sometimes referred to and diagnosed as Chronic Fatigue Syndrome (CFS), is a chronic, fluctuating disease, causing symptoms such as post-exertional malaise (PEM), sleep problems, and problems with thinking and memory (brain fog).

There are an estimated 1.3 million people in the UK with ME or ME-like symptoms (see “How many people have ME?” below), including post-exertional malaise, (the hallmark symptom of ME) which is the worsening of symptoms after any physical, mental, or emotional exertion, even when only small amounts of energy are used.

While there are key symptoms that must be present for an ME diagnosis, not everyone with ME experiences the same set of symptoms, and the illness can vary enormously, including how long symptoms last.

It is not clear why some people get ME while others recover; some fully and others to a degree.

Sadly the majority of people with ME remain ill for decades. A small proportion do recover fully, and others to a degree, however it is not clear why this happens.

This is why Action for ME believes we need services to support people living with ME now, and research to find effective treatments.

People who get ME may be vulnerable genetically, or their recovery after an infection could be affected by, for example, over-exertion, trying to return to work too soon, or experiencing major stresses.

Some people find that they don't go back completely to the way they felt before they became ill, but they do recover sufficiently to lead happy and fulfilling lives.

This is similar to many other chronic illnesses.

There is still some disagreement and confusion among professionals about how to manage ME. This means that people with ME often have to be particularly self-reliant.

The most important thing is to understand how to manage your energy, so that you stop, rest and recharge your battery before your energy is used up.

This can be particularly challenging when you are first diagnosed, so we offer resources to [support with this](#).

# Degrees of severity

The [National Institute for Health and Care Excellence \(NICE\)](#) acknowledges that the physical symptoms of ME can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions.

Other research shows that people with ME score lower overall on health-related quality of life tests than most other chronic conditions (Hvidberg et al, 2015) [\[LINK\]](#)

The [October 2021 NICE guideline for ME/CFS](#) describes four levels of severity of ME/CFS, making it clear that "individual symptoms vary widely in severity and people may have some symptoms more severely than others. The definitions below provide a guide to the level of impact of symptoms on everyday functioning."

- People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off and use the weekend to cope with the rest of the week.
- People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.
- People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.
- People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

Even in its so-called mildest form, ME can have a significant impact on an individual's life, and not just on their health.

A lack of understanding and awareness about ME means patients can experience disbelief, and even discrimination, from friends, family, health and social care professionals and employers. We are here to help.

# Chronic Fatigue Syndrome (CFS)

Within the NHS, a diagnosis of chronic fatigue syndrome (CFS) or CFS/ME is often given. This can make it confusing for many.

In February 2015, the Institute of Medicine in the United States recommended changing the name to systemic exertion intolerance disease, or SEID. This has not been universally adopted.

Action for ME uses the terms ME, CFS and ME/CFS because we do not wish to withhold support from those who have been given a diagnosis of CFS, as opposed to ME.

We recognise that it is quite possible that ME/CFS may be an umbrella term for a number of illnesses.

Therefore, it is critical that there is more biomedical research to further investigate and validate our understanding and increase knowledge of the different sub-groups (phenotypes) of ME and/or CFS.

## What causes ME?

The causes of ME are still being investigated. Emerging evidence indicates there are likely to be a number of factors involved, including neurological and immunological elements, and there may be a number of different types or sub-groups of the illness.

There is evidence that certain infections can trigger the illness. Many are viruses but ME may be triggered in other ways.

Common viral triggers include glandular fever (caused by the Epstein-Barr virus or Covid-19 (caused by the SARS-CoV-2 virus).

Non-viral triggers can include toxoplasma, brucella, salmonella, tuberculosis, Q fever, and Lyme disease.

However, there is no clear evidence that ME is a form of persistent, chronic infection. It may be a consequence of infection.

One big outstanding question is whether emotional stressors can be a trigger. Studies are not clear, some suggesting a link and others not. It is very unlikely that stressful life events, such as bereavement, can trigger ME on their own.

Often it isn't possible to find out exactly what caused your illness – but with the right support you can still improve your symptoms.

## Potential sub-groups

There is growing evidence from experts in the field of ME that sub-groups exist within ME, on the basis that individuals within these sub-groups differ in terms of their illness experience and the course their illness follows over time.

The likelihood of multiple sub-groups within ME most probably explains the huge variation observed by doctors in the progression of the illness and underlines the difficulty of making a prognosis.

The experience of doctors specialising in ME is that some people recover completely (the rate is higher for young people) and that other people improve, often significantly, over time.

However, some remain very ill, often bedbound and/or housebound for many years.

Identification of sub-groups will, it is hoped, will help doctors to improve and personalise treatments for managing the symptoms of ME.

## How many people have ME in the UK?

There are an estimated 1.3 million people in the UK with ME or ME-like symptoms, including post-exertional malaise: the hallmark symptom of ME.

The figures vary greatly because of issues with misdiagnosis and recording (coding) of diagnosis.

Additionally, there are different criteria across different countries, and this can impact on the accurate collection of data.

Because we are unable to identify the exact number of people diagnosed with ME (incidence data), we use prevalence data which is an estimate.

More research is needed to provide more accurate data which will inform policy and commissioning.

NHS England state there are 250,000 people in the UK with ME/CFS, but this figure is an estimate, and it is a very old one.

Action for ME believes this figure is significantly below the real figure.

A recent preprint by [Samms & Ponting \(2024\)](#) used hospital data to estimate a lifetime prevalence of 0.6%, or 390,000 people in the UK.

This is the highest estimate to date with an evidence base. However, it excludes anyone who hasn't been admitted to hospital as well as those whose diagnosis have been recorded differently from the ICD code G93.3 (the code used to record a diagnosis of ME).

It will also include some with long Covid seen in outpatients if they received the same ICD code for their diagnosis.

This study is awaiting peer review by other scientists. Once received, this may inform the numbers currently being used.

Other studies may have higher estimates, but they are based on people with ME self-selecting or self-reporting of ME (i.e. with no evidence of diagnosis).

Other charities are using a range of figures [up to 700,000 \(#MEAction\)](#).

Improvements in diagnosis and recording of diagnosis are essential as this will enable us to have more accurate data and will give clinicians and policy makers a better understanding of the level of need.

## ME and long Covid

Numbers for people with long Covid fluctuate.

Research by [Davis et al. \(2023\)](#) identified that around 50% of people with long Covid have symptoms that directly mirror ME, including the key-defining symptom of ME, post-exertional malaise.

Using figures produced in 2023 for people with long Covid, this would mean that there are around 1.1m people with the condition.

## What does this all mean?

If you add in the estimates of people with ME to the estimates of people with long Covid who have symptoms that mirror ME, including post-exertional malaise, you reach the 1.3m estimate figure of people in the UK with ME, or ME-like symptoms.





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