



An overview of M.E.

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What is M.E.?

Myalgic Encephalomyelitis (M.E.) is a long-term (chronic) fluctuating illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems.

Defined by the World Health Organisation as neurological, M.E. affects an estimated 250,000 people in the UK, and around 17 million people worldwide.

Men, women and children of all ages and of all social and ethnic backgrounds can develop M.E., although it is most common in women aged 25-50.

What are the symptoms?

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

Severe and persistent fatigue or exhaustion most, or all of the time, is one of the main symptoms of M.E. This feels very different from ordinary tiredness.

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

The impact of this may be felt straightaway but it can typically take a day or two to kick in, and is not significantly improved by resting. This is a key feature of the way M.E. affects people, and is known as post-exertional malaise (sometimes called 'payback').

Other symptoms can include:

- flu-like symptoms (often called "general malaise" by doctors)
- recurrent sore throat, with or without swollen glands.
- pain in the joints and muscles
- sleep disturbance
- problems with concentration, thinking and memory ("brain fog"),
- Problems with the nervous system, such as poor temperature control and dizziness on standing or sitting up and hyper-sensitivity to light and sound

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

Research has found that early management of symptoms such as post exertional malaise is the most important factor in how the condition progresses (ie. how severe M.E. becomes). So it's really important to learn as much as you can about how the symptoms affect you, and what you can do to help manage them.

What causes M.E.?

We don't fully understand what causes the illness. There are likely to be a number of factors involved. It sometimes affects more than one family member. The reasons are being studied but it seems your genetic make-up can play a part, as can the influence of your environment.

There is evidence that certain infections can trigger M.E. Many are viruses but M.E. can be triggered by other types of infection. Many of the infections which trigger M.E. seem to be ordinary flu-like infections, from which some people don't recover in the normal way.

How is M.E. diagnosed?

There is no medical laboratory test currently available to detect M.E. Doctors diagnose the illness by assessing your medical history, recognising the typical symptom pattern of M.E. and conducting basic tests, for example on blood or urine samples, to rule out other conditions. Many illnesses can sound quite similar in their symptoms and excluding other conditions is a usual part of the process of reaching a diagnosis.

You may need to make several visits to your doctor before a final diagnosis is made. A provisional diagnosis should be made as early as possible.

NHS guidelines say a diagnosis should be made in adults if symptoms have lasted four months and other diagnoses have been excluded. In children or young people, diagnosis should be made (or confirmed by a paediatrician) after three months.

The earlier that your illness is recognised, the sooner you can begin to manage and treat your symptoms.

How is M.E. treated and managed?

There is no single pharmaceutical cure for M.E. but there are many approaches open to you and your doctor that can make a difference to how you feel and give you back control over your situation.

Guidelines for health professionals include:

- the National Institute for Health and Care Excellence (NICE) guideline www.nice.org.uk/guidance/CG53
- the Scottish Good Practice Statement on M.E./CFS www.show.scot.nhs.uk/GoodPracticeStatementonME-CFSforGeneralPractitioners.aspx

It is important to establish a relationship with your doctor so that you can discuss all the management approaches available, such as pacing (see below).

People with M.E. respond to treatment in different ways and what works for someone else may not be helpful for you. It is important to adopt one approach or make one change at a time, to find out what works for you.

You are the best judge of how you feel, so don't be afraid to discuss your treatment with your doctor, especially if you think it isn't working. Each different approach takes time to work, so be patient and don't expect results immediately.

Action for M.E.'s booklet *All about M.E. symptoms and management* offers more information about this (see p 8 for contact details).

What is pacing?

Learning to manage physical, mental and emotional activity and rest is referred to as pacing.

Pacing organises your day into sustainable activity and regular rest, helping you to avoid setbacks. It gives stability and a sense of control, making things more predictable and enhancing confidence. It can improve your ability to cope with the illness and your chances of recovery.

People with M.E. tell us and other patient charities that they find pacing helpful.

The NICE guideline says: "People with CFS/ME have reported pacing to be helpful in self-managing CFS/ME. However, healthcare professionals should advise people with CFS/ME that, at present, there is insufficient research evidence on the benefits or harm of pacing."

Action for M.E.'s booklet *Pacing for people with M.E.* offers more information about this (see p 8 for contact details).

When will I get better?

People with M.E. can vary enormously in their experience of the illness, and also how long their symptoms last.

Many people make good progress quite quickly, while others can remain ill for a number of years. Most people improve over time, especially with treatment. For many, the illness fluctuates, with periods of remission and relapse. A small minority are severely affected (bedbound or housebound) for a long time.

People often find that they don't go back completely to the way they felt before they became ill – but they do recover sufficiently and/or learn to manage their symptoms well enough to lead happy and fulfilling lives. This is similar to many other chronic illnesses.

Treatment (symptom management) can help by reducing symptoms and making the experience of illness much less unpleasant in the short term. More importantly, rehabilitative approaches that are suited to your level of severity can maximise the chances of recovery and the rate at which it happens, as well as reducing the risk of setbacks and relapses.

Hold on to hope, but be prepared in case the illness does last a long time.

Factors that can hold back recovery

M.E. can be an extremely frustrating illness, particularly as the intensity of the different symptoms can fluctuate.

On good days, you will naturally want to do more – but do too much and 24 hours or more later, you may find yourself in a relapse from which recovery will seem painfully slow. This pattern is called 'boom and bust.' If it becomes the norm it can be very distressing and it can undermine your confidence. There are also strong indications that this pattern can prolong the illness.

It is important to get to know your limits and to set yourself small, realistic goals for getting better. This may mean that initially you have to reduce your overall activity levels so that you can achieve a routine that you can sustain. You will achieve more by working within your limits and increasing activities very gradually, than by pushing the boundaries all the time. There are many small changes you can make on a daily basis that will improve your health in the long term.

The key to managing your illness is to 'pace' your physical and mental (including emotional) activity – to strike a balance between activity and rest and to make any changes in your routine small and gradual.

In the early stages of the illness in particular, adequate rest may be necessary and helpful. It is important to think about the quality of your rest, not just the quantity. Many people with M.E. find it difficult to relax and therefore do not get the full benefit from their rest periods.

Action for M.E.'s booklet *Newly diagnosed with M.E.* offers more information about this (see p 8 for contact details).

Relapses and setbacks

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. Don't be disheartened by these hiccups in your progress. Some people say that they experience relapses throughout their recovery but that over time they get shorter or less severe through 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. It could be just a blip!

Checklist for people with M.E.

1. Learn to manage your energy and physical, mental and emotional activities. Become an expert at managing your illness and stay in control.
2. Deal with the major symptoms that can take over your life, such as pain, sleep disturbance and low mood. Uncontrolled symptoms can get in the way of recovery. Your doctor can help you to manage these with medication. Other strategies can also be helpful, such as pacing your activities, relaxation techniques and complementary therapies.
3. Establish a relationship with your GP. This can take time and in some cases may be difficult, but the partnership between you and your GP can be crucial to stabilising your illness and enabling recovery.
4. Remember that people do recover from M.E. Learn to recognise and accept your illness and recovery is more likely to follow in time.
5. You are not alone. An estimated 250,000 people in the UK have this illness. To get information and support visit Action for M.E. online at www.actionforme.org.uk or call us on 0117 927 9551.

Useful contacts

Action for M.E.

Information, support and signposting for people with M.E. and their careers
General enquiries: 0117 927 9551 (Mon-Fri 9am-5pm)
Enquiries email: admin@actionforme.org.uk
Welfare Rights Line: 0800 138 6544122 8648 (free from landlines and mobiles;
times vary)
Online M.E. Centre: www.actionforme.org.uk

Association of Young People with M.E. (AYME)

Information, advice and support for people with M.E. under 26 and their families
Helpline: 08451 232389 (Mon-Fri 10am-2pm)
www.ayme.org.uk

Carers Trust

Help and advice for carers
Advice line: 0808 808 7777
Email: support@carers.org
www.carers.org



If you have found the information in this factsheet helpful, please consider making a donation to Action for M.E. at www.actionforme.org.uk or by calling 0117 927 9551. Thank you.

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