



ME/CFS

February 2020

your questions answered

ME, CFS AND PVFS – WHAT'S THE DIFFERENCE?

ME stands for myalgic encephalopathy or myalgic encephalomyelitis.

While there is no argument about the use of the word myalgic as a description of the muscle pain involved, encephalomyelitis – meaning inflammation in the brain and spinal cord – causes problems in the absence of good quality research evidence to support its use.

Encephalopathy has therefore been suggested as a less contentious term because it provides a more accurate description of the abnormalities involving blood flow, brain chemicals and hormones that are known to be present.

Chronic Fatigue Syndrome (CFS) is a name favoured by the medical profession because it makes no firm assumptions about cause.

Two major criticisms of CFS as a name are that it fails to reflect the severity and extent of the illness, and is often used as a convenient label for anyone with unexplained fatigue.

Post Viral Fatigue Syndrome (PVFS) was introduced in the 1980s as a description of an illness which can clearly be traced back to a viral infection.

Until there is international support for a new name, The MEA supports the combination term ME/CFS.

In the meantime, we wish to focus our energy on ensuring improved care across the board for people with ME/CFS and supporting research into the physical causes of the illness.

INTRODUCTION

Most doctors now accept that ME, sometimes referred to as chronic fatigue syndrome (CFS) or post viral fatigue syndrome (PVFS), is a genuine and disabling illness. The cause is still not clear, but research has identified a number of abnormalities that appear to be involved.

Guidance on diagnosis and management was published by the Chief Medical Officer in 2002, and by the National Institute for Health and Care Excellence (NICE) in 2007. However, controversy persists over the best way to manage the illness – in particular the role of cognitive behaviour therapy (CBT) and graded exercise therapy (GET). The ME Association (MEA) is currently involved in a thorough official review of the NICE guideline on ME/CFS.

The World Health Organisation classifies ME as a neurological disease, and this is recognised by the Department of Health as well. While this may not in itself affect the therapies offered, it may help in benefit or service provision disputes – especially in cases where the illness has been wrongly classified as a mental health condition.

The MEA believes that there has been a scandalous under-funding of research into the physical causes of the illness.

Although the NHS embarked almost two decades ago on the development of hospital-based services that are specially designed for people with ME/CFS, there is still a severe shortage of reliable referral services for ME/CFS in many parts of the UK.

WHO GETS ME/CFS/PVFS?

- Research suggests there may be up to 264,000 people with ME/CFS in the UK, of whom over 25,000 are children.
- Some 20-25% of people with ME/CFS are so severely affected that they become bedbound at some time in their lives, or they cannot leave their homes without personal assistance or without using wheelchairs or scooters.
- All age groups can be affected, although onset is rare below the age of seven or over the age of 60.

- The most common age of onset is between mid-teens and mid-forties.
- Women are more at risk than men.
- ME/CFS affects all social classes and races.

HOW DOES ME/CFS START?

ME/CFS often starts with a viral infection, sometimes involving the chest or digestive system. However, it can also occasionally develop after an accident, operation, vaccination, or exposure to pesticides. In about a quarter of cases, it develops gradually with no clear onset.

WHAT MARKS ME/CFS OUT FROM OTHER CAUSES OF CHRONIC FATIGUE?

The most characteristic feature of the illness, which makes it different from other causes of chronic fatigue, is exhaustion and malaise following minimal physical or mental activity – the full extent of which may not become apparent until 24 to 48 hours after the activity. Recovery may be prolonged: days, weeks or even months. Variability and fluctuation of symptoms is a second key indicator.

WHAT ARE THE OTHER MAIN SYMPTOMS?

- Muscle or nerve pain, and sometimes muscle twitching – often involving the eyelids.
- Problems with short-term memory, concentration and attention span. Doctors call this cognitive dysfunction. More colloquially, it's known as brain fog.
- Other cognitive problems such as a tendency to lose track of conversation in the middle of sentences, along with difficulty thinking of the correct word when speaking or writing and difficulty putting ideas into order.
- Constantly feeling unwell, with 'flu-like symptoms (eg sore throat, enlarged glands, joint pains) and problems with temperature control and night sweats.
- Sleep disturbance, especially waking unrefreshed. The disturbance can include sleeping for long periods, perhaps 12 to 18 hours at a stretch, inability to get to sleep, sleeping during the day while staying awake at night, dreams (sometimes nightmares), particularly memorable by their vivid colour.
- Alcohol intolerance, especially in the very early stages.

Other symptoms may include:

- Pain in one or more joints but without signs of swelling, redness or joint deformity.
- Feelings of unsteadiness when walking or standing. Some people

report feeling as though they are 'walking on rubber'.

- Sudden, unexplained mood swings.
- Headaches of a new type, pattern or severity.
- Sensations of tingling or numbness, or loss of sense of touch.
- Over-sensitivity to noise and/or light.
- Onset of drug and food intolerances.

HOW COMMON IS DEPRESSION IN ME/CFS?

As with any long-term medical condition, depression sometimes occurs. But there is no sound evidence to indicate that true clinical depression is more common in ME/CFS than in other chronic illnesses that affect so many aspects of a person's life. When depression occurs, it needs to be treated by a medical practitioner.

IS THERE A DIAGNOSTIC TEST OR A CURE FOR ME/CFS?

No, to both. The diagnosis has to be made from the typical pattern of symptoms, with the exclusion of other possible causes.

Anyone suspected of having ME/CFS should have a number of routine blood tests to identify other possible illnesses. More specialised investigations may be required if the diagnosis remains in doubt.

WHAT ARE THE CHANCES OF RECOVERY?

People with ME/CFS tend to fall into one of three broad groups:

- Those who manage to return to complete or nearly normal health – although this may take a long time.
- The majority tend to follow a fluctuating pattern with both good and bad periods of health. Relapses or flare-ups are often triggered by infections, operations, temperature extremes or stressful events.
- A significant minority, probably around a quarter, remain severely affected and require a great deal of

practical and social support.

Continued deterioration is unusual. When this occurs, a detailed medical review is advisable to exclude other conditions.

HOW CAN RECOVERY BE HELPED?

It is important to remain positive about the prospect of recovery. The period of illness varies from person to person and improvements in health can occur, even in people who have been ill for a long time.

Anecdotal reports suggest three things which improve prospects for recovery:

Early diagnosis – preferably within a few months of the onset of symptoms

Good management advice in the very early stages – especially about activity management and symptom control.

Age – younger people seem to make a better recovery than adults.

STABILISING THE ILLNESS

Anyone who was previously fit and active and who normally recovers from illness in a straightforward way will find that ME/CFS imposes restrictions on their way of life that can be very difficult to come to terms with.

While some benefit may be achieved using various treatments and therapies, inappropriate activity beyond a person's new and reduced limits (both physical and mental) may result in symptoms becoming worse. Exhausting fatigue or malaise, muscle pain, headaches, impaired concentration and poor memory are among the main symptoms which can easily be made worse.

If you suspect that you have ME/CFS, avoiding non-essential activity and taking additional rest while you await diagnosis could well be to your advantage. The illness, however, very often hits people so hard that bed rest can be the only option in the very early stages. For most people, some degree of gradual improvement will eventually

emerge, and it then becomes important to try and maintain this progress. It is important that this is not over-ambitious.

Anecdotal reports suggest that, in order to maintain some stability, it can be helpful to split activity into short periods with adequate rest/relaxation in between, rather than, say, doing everything in the morning and resting for the remainder of the day.

In the early stages, there often need to be periods of total rest, not just a relaxing activity. Use of a diary to record activity and its effects may help you manage your recovery.

MAINTAINING RECOVERY

A sudden and significant improvement in symptoms may create a false sense of security, so do not be tempted to do too much if you suddenly feel better for a short while. Sustained recovery is preferable to a roller-coaster ride of inappropriate activity and relapse.

IF RECOVERY SLOWS OR STOPS

Experience suggests a substantial proportion of people make a degree of recovery but then reach a point where their rate either starts to slow down, becomes sporadic or even stops – they reach a ‘glass ceiling’. The reasons for this remain uncertain.

RELAPSES

Relapses are common in ME/CFS and may occur through a variety of circumstances: exposure to other illness, sustained physical or mental activity unsuited to a person’s capacity at the time, incompatible treatments and therapies, emotional stress, vaccinations, anaesthetics and operations, etc.

So it may make sense to limit exposure to these situations, except where the consequences of doing so could make matters worse.

MEDICAL MANAGEMENT AND COMPLEMENTARY THERAPIES

At present, there is no effective drug treatment for ME/CFS – although a number of drugs are now being researched and assessed in clinical trials.

Doctors can, however, use drugs to help relieve symptoms – especially for pain relief, sleep problems, secondary depression, etc. People with ME/CFS are often sensitive to drugs that affect the nervous system, so low doses may need to be used to start with and then increased gradually.

The NICE guideline on ME/CFS recommends that cognitive behaviour therapy (CBT), and graded exercise therapy (GET) should be offered to everyone with mild or moderate ME/CFS. The ME Association have criticised this guidance on the grounds that existing research evidence is weak and not consistent.

In feedback from people with ME/CFS submitted to the Chief Medical Officer’s report and in our own 2010 Illness Management Survey in which over 4,500 people took part, significant numbers found that these treatments were either ineffective or – in the case of graded exercise – made their condition worse.

People with ME/CFS consistently report that a type of activity management known as pacing is the most appropriate and helpful approach to energy management.

Limitations of mainstream medicine lead many people to consider complementary therapies such as homeopathy and acupuncture. These are often only available on a private basis.

Training and regulation of these therapists is improving, but only slowly. So it is advisable to find a therapist who is registered with a reputable professional body for all the disciplines they practise, and who is suitably insured.

Dietary therapies are sometimes proposed. These may be quite restrictive and it is important to discuss them with

a properly qualified dietician – as the resulting deficiencies in nutrients may only add to your problems.

WHAT ABOUT BENEFIT ENTITLEMENT?

If your illness prevents you working or affects your ability to work full-time – or if it affects your ability to care for yourself or to get about – a range of incapacity and disability benefits, and income support benefits is available. However, qualification for benefit is not automatic.

Disability benefits are awarded according to a DWP decision-maker’s assessment of your condition, and the adjudicator may call for medical reports. Some benefits are means-tested, and so depend on your financial situation.

A poor quality application could adversely affect your chances of obtaining benefit. So, if you are unsure, it would be as well to get good advice before applying. You are permitted to have help filling in the forms and may be accompanied to any medical examination, if you so wish.

The most common benefits, and agencies which can advise on how to fill in the forms involved, are described in The MEA leaflet: *Benefits and Tax Credits*. We have our own guides to filling in the following forms: Universal Credit (UC), Employment and Support Allowance (ESA) and Personal Independence Payment (PIP). We also have a guide to the benefits appeals process, for those who have embarked on that prolonged and difficult journey. To see our full list of benefits and social care leaflets, visit: <https://tinyurl.com/yye6mksq>

FURTHER INFORMATION

To download material from our well-browsed library shelf of leaflets and booklets about diagnosis, symptoms, and illness management, visit: <https://tinyurl.com/y6ep8v6r>

Leaflets also be obtained by using the Order Form that goes out with our quarterly magazine or by viewing the same form which is held in a prominent position at our website: www.meassociation.org.uk