

ME/CFS AND PVFS

YOUR QUESTIONS ANSWERED

OCTOBER 2022



## ME/CFS AND PVFS - YOUR QUESTIONS ANSWERED

### INTRODUCTION

Most doctors now accept that ME/CFS is a genuine and disabling illness.

The World Health Organisation in the authoritative International Classification of Diseases (ICD-11) considers Post-Viral Fatigue Syndrome (PVFS), Myalgic Encephalomyelitis (ME) (and Chronic Fatigue Syndrome (CFS)) as examples of neurological disease.

While this classification is recognised by the Department of Health. And while this classification may not affect the management of ME/CFS, it may help in benefit or service provision disputes – especially where ME/CFS has been wrongly classified as a mental health condition.

Although the precise cause is still not clear, research has identified a number of important abnormalities involving the brain, muscle and immune system. The ME Association (MEA) believes that there has been a scandalous under-funding of biomedical research into the cause and treatment of ME/CFS over many years.

Guidance on the diagnosis and management of ME/CFS was published by the Chief Medical Officer (CMO) in 2002, and by the National Institute for Health and Care Excellence (NICE) in October 2021.

Following publication of the CMO Working Group Report in 2002 the NHS in England embarked on the development of a network of hospital-based specialist referral services for people with ME/CFS. However, there is still a severe shortage of good quality referral services for ME/CFS in many parts of the UK, especially in Northern Ireland, Scotland and Wales. The MEA website has contact details for all the referral services throughout the UK and people have a right to choose which service they are referred to.

<https://meassociation.org.uk/nhs-me-cfs-specialist-services/>

### ME, CFS AND PVFS – WHAT IS THE DIFFERENCE?

ME stands for myalgic encephalopathy or myalgic encephalomyelitis. While there is no dispute about the use of the word myalgic as a description of the muscle pain that is often involved, encephalomyelitis – meaning widespread inflammation in the brain and spinal cord – causes problems in the absence of good quality research evidence to support its use.



**ME/CFS and PVFS - Your Questions Answered** was written by Dr Charles Shepherd, Trustee and Hon Medical Adviser to The ME Association.

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**DISCLAIMER:** Drug and medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your doctor. The ME Association recommends that you always consult your doctor or dentist about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor or dentist.



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The MEA therefore suggested Encephalopathy as a less contentious term because it provides a more accurate description of the research abnormalities that have been reported involving brain blood flow, brain chemical transmitters and hormones and problems with the autonomic nervous system – which helps to regulate pulse and blood pressure.

Chronic Fatigue Syndrome (CFS) is a name that is preferred by some doctors 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 has become a convenient label for anyone with unexplained chronic fatigue.

Post Viral Fatigue Syndrome (PVFS) was introduced in the 1980s as a description of an illness with ME/CFS-like symptoms that can be traced back to a viral infection.

While differences of opinion on the name of this disease remain, and some people are being diagnosed with CFS because their doctor will not use the name ME, the MEA uses the combination term ME/CFS.

### WHO GETS ME/CFS/PVFS?

Research suggests there are around 250,000 people with ME/CFS in the UK, of whom there may be 25,000 children and young people – where it is one of the most common causes of long term sickness absence from school.

Around 25% of people with ME/CFS are so severely affected that they become housebound or bedbound at some time in their illness.

- 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 the early twenties and mid-forties
- Women are more at risk than men in a ratio of about 4:1
- ME/CFS affects all social classes and ethnicities

### HOW DOES ME/CFS START?

ME/CFS often starts with a viral infection – although other types of infection can sometimes be the trigger. It can also occur after an accident, operation, vaccination, or exposure to pesticides. In about a quarter of cases, it develops gradually with no clear onset.



Front cover image is from The ME Association's Real ME Campaign

**ME/CFS is most often triggered by an infection - although other triggers have been reported.**



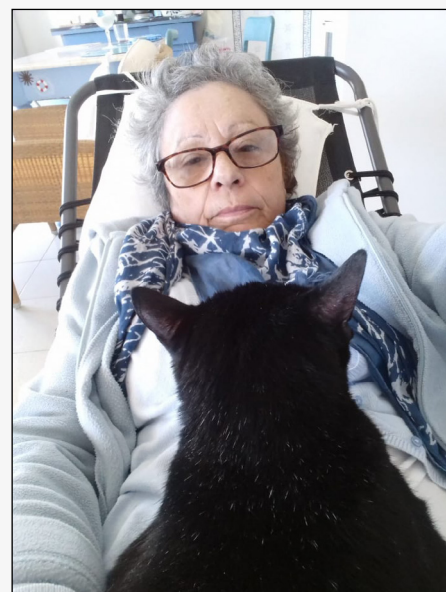
## ME/CFS AND PVFS - YOUR QUESTIONS ANSWERED

### WHAT DISTINGUISHES ME/CFS FROM OTHER CAUSES OF CHRONIC FATIGUE?

The most characteristic feature of ME/CFS, 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. This cardinal feature is called post-exertional malaise (PEM) - also known as Post-Exertional Symptom Exacerbation (PESE). 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 twitchings (fasciculations) – which may also involve the eyelids.
- Problems with short-term memory, concentration and attention span, and information processing. 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 - e.g., sore throat, enlarged glands.
- Problems with temperature control, including sensitivity to both heat and cold, and night sweats.
- Sleep disturbance, especially waking unrefreshed. The disturbance can include sleeping for long periods, perhaps 12 to 18 hours at a stretch (hypersomnia), inability to get to sleep, sleeping during the day while staying awake at night, and vivid dreams.
- Problems with the control of pulse and blood pressure leading to orthostatic intolerance (difficulty with remaining in an upright position) and postural orthostatic tachycardia syndrome (PoTS) – where the pulse rate increases on changing posture from lying to standing.
- Alcohol intolerance, especially in the very early stages.



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## ME/CFS AND PVFS - YOUR QUESTIONS ANSWERED

### CAN ME/CFS CAUSE OTHER SYMPTOMS?

Yes – ME/CFS can cause a wide range of other symptoms. These 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'.
- Headaches of a new type, pattern or severity.
- Sensations of tingling (paraesthesiae) or numbness, or loss of sense of touch.
- Over-sensitivity to noise and/or light.
- Onset of drug and food intolerances.

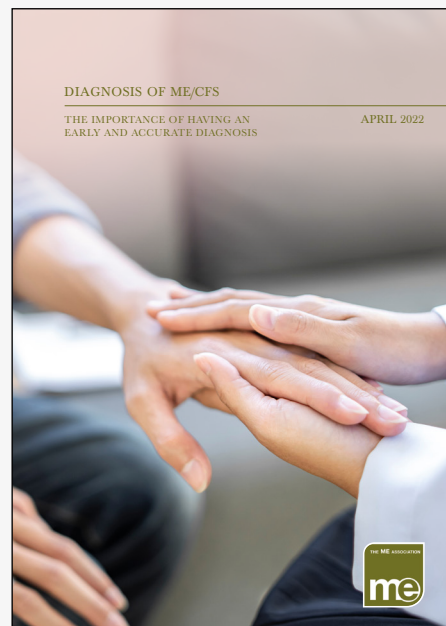
### HOW COMMON IS ANXIETY AND DEPRESSION IN ME/CFS?

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

What is termed emotional lability – involving unexplained changes in mood – can also occur.

### IS THERE A DIAGNOSTIC TEST FOR ME/CFS?

No. The diagnosis has to be made from the typical pattern of symptoms along with the exclusion of other possible causes of ME/CFS-like symptoms. This is done through a doctor taking a full clinical history, conducting a clinical examination and arranging various blood tests. More specialised investigations may be required if the diagnosis remains in doubt.



The ME Association has published a free to download booklet, **Diagnosing ME/CFS – The Importance of an Early & Accurate Diagnosis**. In this booklet we review the recommendations in the 2021 NICE Clinical Guideline. We examine the core symptoms and examine the need to consider a patient's clinical history, clinical investigations and blood tests, and other explanations for persistent symptoms:

<https://tinyurl.com/2cksmx7z>



## ME/CFS AND PVFS - YOUR QUESTIONS ANSWERED

### WHAT ARE THE CHANCES OF IMPROVEMENT AND RECOVERY OCCURRING?

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

- A minority return to complete or nearly normal health – although this may take a long time.
- The majority tend to follow a fluctuating pattern with relatively 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 at some stage and require a great deal of practical and social support.

Continued deterioration is unusual. When this occurs, a detailed medical review should always be carried out to exclude other conditions.

### HOW CAN IMPROVEMENT BE HELPED?

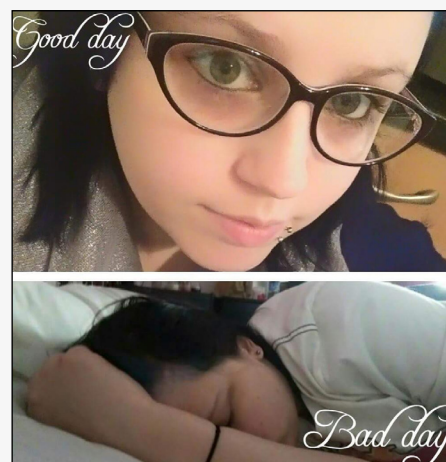
It is important to remain positive about the prospect of some degree of improvement occurring. Improvements in health can occur, even in people who have been ill for a long time.

Anecdotal reports suggest that there are three factors that help to facilitate improvement:

- Early diagnosis – preferably within three months of the onset of symptoms - as recommended in the new NICE guideline.
- Good management advice during the very early stages – especially activity and energy management, symptom control and curtailing unnecessary activities.
- Age – children and young people are more likely to make a significant degree of improvement and even full recovery if they are managed correctly.

#### 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 major restrictions on their way of life that can be very difficult to come to terms with.



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While some benefit is likely to be achieved with good overall management, 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 that 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 is therefore very advisable. The initial post-viral phase can be very debilitating - so a period of bed rest should also be considered in the early stages. For most people, some degree of gradual improvement will eventually emerge, and this progress will be hopefully maintained.

Patient evidence indicates that, in order to maintain some stability, it is helpful to split physical and mental 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 needs 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 improvement

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.

### When improvement slows or stops

Experience suggests a substantial proportion of people will make some degree of improvement over time but then reach a point where this either starts to slow down, becomes sporadic or even stops. At this stage you may be reaching a point which is sometimes termed the 'glass ceiling' and from which no further significant improvement occurs. The reasons for this remain uncertain.



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### Relapses

Relapses are common in ME/CFS and may occur through a variety of circumstances: exposure to other illness – especially new infections, 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 try and limit exposure to these situations, except where the consequences of doing so could make matters worse.

### WHAT ARE THE BASICS OF GOOD MEDICAL MANAGEMENT AND CAN ALTERNATIVE AND COMPLEMENTARY THERAPIES HELP?

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 prescribe drugs that may help relieve some of the main symptoms – especially for pain relief, sleep problems, and the depression caused by becoming chronically ill. People with ME/CFS are often sensitive to drugs that affect the nervous system. So low doses may be advisable to start with and then increased gradually.

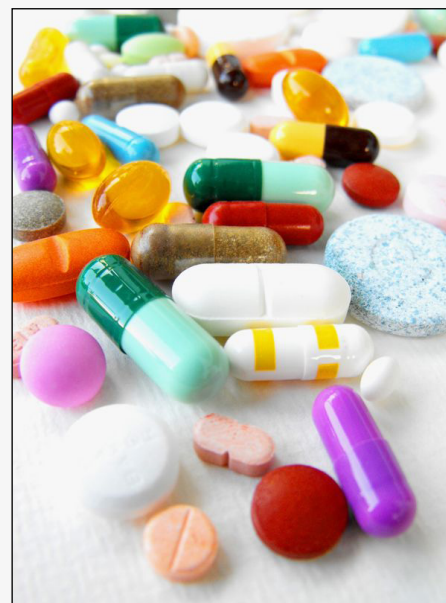
People with ME/CFS consistently report that a type of activity and energy management known as Pacing is the most appropriate and helpful approach to energy management.

The new NICE Guideline on ME/CFS recommends that graded exercise therapy (GET) should no longer be offered.

Limitations of mainstream medicine lead many people to consider complementary therapies such as homeopathy and acupuncture. These are normally only available on a private basis. However, people should be aware that there are parts of the alternative and complementary health sector that make unproven claims for the effectiveness of the treatments they are selling.

Training and regulation of complementary therapies and 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 practice, 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



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

■ The MEA has information leaflets covering all the main symptoms and their management, including activity management and Pacing. We also have information covering alternative and complementary therapies and nutritional management (see opposite).

### WHAT ABOUT SICKNESS AND DISABILITY BENEFIT ENTITLEMENT?

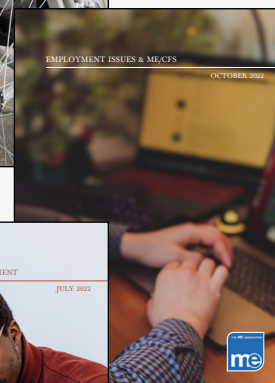
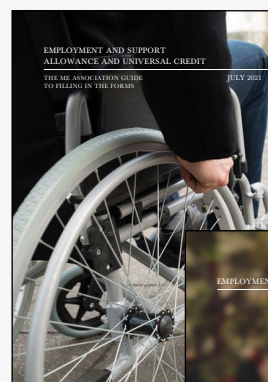
If your illness prevents you working or affects your ability to work full-time – or if it affects your ability to care for yourself or to get about – a range of sickness and disability benefits, and income support benefits is available from the Department of Work and Pensions (DWP). However, qualification for benefit is not automatic.

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

A poor quality application could adversely affect your chances of obtaining benefit. So, if you are unsure, do obtain 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 completing applications for: Universal Credit (UC), Employment and Support Allowance (ESA), Personal Independence Payment (PIP) and Carer's Allowance. We also have a guide to the benefits appeals process, for those who have embarked on that prolonged and difficult journey. There is a full list of DWP benefit and social care leaflets on the MEA website.

The MEA also has information for people who are having difficulty in obtaining insurance-based benefits such as income protection policies (see opposite).



The range of MEA literature can be found in the online shop:

<https://meassociation.org.uk/me-association-shop>



## ME/CFS AND PVFS - YOUR QUESTIONS ANSWERED

### Key recommendations from the new NICE Clinical Guideline on how ME/CFS should be diagnosed and managed

1. Early recognition of people who have ME/CFS symptoms (which often follow an acute infection) in primary care.
2. GPs should provide appropriate management advice whilst a diagnosis is being suspected and made.
3. GPs should aim to confirm a diagnosis of ME/CFS in primary care no later than three months from the onset of symptoms in both adults and children.
4. At this point the GP should be able to refer the person on to a specialist centre where there is a multidisciplinary team that can confirm the diagnosis (as there is a high rate of misdiagnosis of ME/CFS in primary care), provide expert help on all aspects of management, and prepare an individual care and support plan.

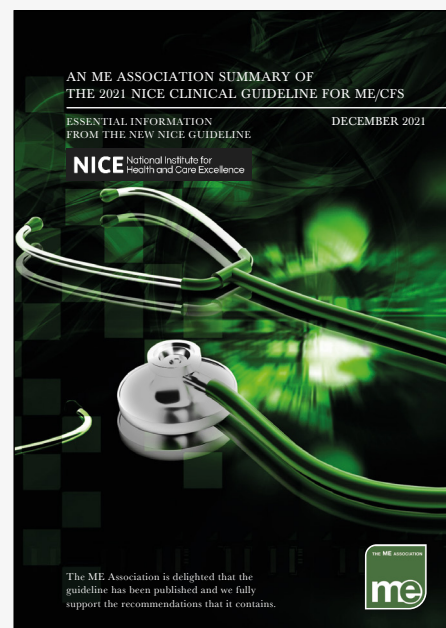
The NICE guideline (in 1.4 Diagnosis - Box 3,) provides specific guidance on the composition of the multidisciplinary specialist team:

Specialist teams consist of a range of healthcare professionals with training and experience in assessing, diagnosing, treating and managing ME/CFS. They commonly have medically trained clinicians from a variety of specialisms (including rheumatology, rehabilitation medicine, endocrinology, infectious diseases, neurology, immunology, general practice and paediatrics) as well as access to other healthcare professionals specialising in ME/CFS. These may include physiotherapists, exercise physiologists, occupational therapists, dieticians, and clinical or counselling psychologists.

Children and young people are likely to be cared for under local or regional paediatric teams that have experience of working with children and young people with ME/CFS in collaboration with ME/CFS specialist centres.

5. The specialist team should also provide management guidance for people who are housebound with severe or very severe ME/CFS.
6. There should be a separate service for children and young people with ME/CFS.
7. Specialist services should provide information and guidance on relapses, education, employment and nutrition.

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### MEA guide to the new NICE guideline on ME/CFS

The MEA has produced a free to download booklet, **An ME Association Summary of the NICE Clinical Guideline on ME/CFS**, which lets you know what to expect from the NHS and social care services with regard to symptom recognition, diagnosis, management, referral, and ongoing care and support:

<https://meassociation.org.uk/9d0l>



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8. Following referral to a specialist team, future management and follow up may continue in secondary care, primary care, or in a mixture of both.

9. All health professionals who are involved in the management of people with ME/CFS should be properly trained in ME/CFS and be aware of the recommendations in the new NICE guideline.

## FURTHER INFORMATION

### Medical Matters

Medical Matters, the ME Association's online resource, features questions asked by Members of the ME Association on health-related topics.

Dr Charles Shepherd and the ME Association's other advisers answer these questions by sharing their expert knowledge.

Medical Matters is based on the popular 'Ask the Doctor' series in ME Essential magazine.

It is a free resource that supplements the detailed information contained in the full range of literature that can be found in the website shop.

<https://meassociation.org.uk/medical-matters/>

### Social Media

We have a very active Facebook page with information and discussions on all aspects of management of ME/CFS:

 [/meassociation](https://www.facebook.com/meassociation)

You can also connect with us on other social media platforms:

 [/meassociation](https://www.instagram.com/meassociation)

 [/MEAssociation](https://twitter.com/MEAssociation)

 [/me-association](https://www.linkedin.com/company/me-association)

 [/MEAssociationUKCharity](https://www.youtube.com/MEAssociationUKCharity)



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### BECOME A MEMBER OF THE ME ASSOCIATION

For a small subscription you can receive quarterly issues of **ME Essential** magazine, keep updated with the latest information on ME/CFS and with stories from other members of the charity.

You don't have to be personally affected by ME/CFS to join the ME Association. Membership is available to carers, family members, and anyone with a professional interest in the condition.

Visit our website to find out more:

<https://meassociation.org.uk/mea-membership>



### THE ME ASSOCIATION WEBSITE SHOP

The ME Association has the largest range of information covering all aspects of living with ME/CFS. Topics include:

**Awareness, Carers and Social Care, Covid-19 and Long Covid, Diagnosis, Diet and Nutrition, Education, Employment, Management, Mental Health, Symptoms.**

Literature can be downloaded and you can place an order for goods and clothing:

<https://meassociation.org.uk/shop>

