# Fatigue and ME/CFS

## *The nature of fatigue in ME/CFS*

Including:

- Fatigue and fatiguability in ME/CFS
- What causes fatigue in ME/CFS
- Research into fatigue
- Medication and other treatments
- Self-help management
- Information from the NICE Guideline on ME/CFS

MAY 2026

**FATIGUE AND ME/CFS** was written by **Dr Charles Shepherd**, Trustee and Hon. Medical Adviser to The ME Association.

**DISCLAIMER**

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS or Long Covid.

# FATIGUE AND ME/CFS

## CONTENTS

## WHAT IS FATIGUE?

**Everyone gets fatigued or tired at times - it's a perfectly normal part of human life. And people will describe their fatigue in many different ways.**

Research into the subject of fatigue indicates that around 10% of the population have some degree of regular fatigue or tiredness. In fact, fatigue is a significant symptom in a quarter of all general practice consultations and it's one of the main problems in about 6% of GP consultations. But there are different types of mental and physical fatigue, and the unique type of fatigue described by people with ME/CFS is a key diagnostic feature of this illness.

So it's important to define what we mean by fatigue and fatiguability in ME/CFS and the way in which it differs from the chronic fatigue that occurs in a wide range of medical and psychiatric illnesses.

*There are different types of mental and physical fatigue, and the unique type of fatigue described by people with ME/CFS is a key diagnostic feature of this illness.*

## *The nature of fatigue in ME/CFS*

### FATIGUE AND FATIGUABILITY IN ME/CFS

**The key features of ME/CFS fatigue are:**

- New and definite onset, often following an acute infection – in other words the fatigue part of ME/CFS has not been a lifelong problem that has progressively become worse over time.
- Affects both physical and mental functioning – ie memory, concentration, information-processing
- Induced and exacerbated by physical activity.
- Often made worse by mental/cognitive activity.
- Results in an on-going inability to sustain physical and mental activities that could previously be achieved without any problem.
- Causes post-exertional malaise and flu-like symptoms after activity has ceased.
- Over-exertion beyond normally tolerated limits has a delayed impact which may be felt later in the day or the following day. This is then followed by a slow recovery period in physical and mental functioning. This may persist for days or weeks.

## FATIGUE AND FATIGUABILITY IN ME/CFS *(continued...)*

*ME/CFS is not the same as the 'healthy fatigue' that occurs after exercise and quickly resolves with rest. Neither is it the same as feeling 'tired all the time', or the lack of motivational fatigue that is found in depression and other psychiatric illnesses.*

- Made worse by alcohol, standing, stress and temperature extremes.
- Associated with unrefreshing sleep.
- May come with muscle pain.
- Causes a significant decrease in ability to take part in all aspects of daily life - home, social, work, etc.
- Often the most disabling symptom of ME/CFS.

ME/CFS is not the same as the 'healthy fatigue' that occurs after exercise and quickly resolves with rest. Neither is it the same as feeling 'tired all the time', or the lack of motivational fatigue that is found in depression and other psychiatric illnesses.

## WHAT CAUSES FATIGUE IN ME/CFS?

**The simple answer is that we just do not know.**

But the effect is that people with ME/ CFS have to function with an 'energy battery' that is smaller in size and less efficient than before they were ill. It's rather like putting a defective battery into a torch - it shines for a while at low intensity and then quickly fades away. After a period of rest and recharge, the torch will work again but only in the same inefficient way. Carry on repeating the exercise and the torch eventually fails completely.

From the scientific point of view, it seems likely that a number of different explanations may be interacting to cause this fatigue. They predominantly involve what doctors call central and peripheral fatigue.

Central fatigue refers to fatigue that is caused by a problem in the brain or nervous system - which explains why chronic fatigue can be a very significant symptom in neurological illnesses such as multiple sclerosis (MS), Parkinson's disease, post-polio syndrome and following a head injury.

Although not the same as ME/CFS fatigue, the fatigue experienced by many people with MS does have important similarities to ME/CFS fatigue (e.g. being made worse by heat). Similar pathological mechanisms may therefore be involved.

Peripheral fatigue is caused by a problem with the muscle itself. And, with exercise bringing on fatigue in ME/CFS, along with weakness and pain in the muscle, this suggests that there is a peripheral component to ME/CFS fatigue as well - at least in some people.

We also know that chronic fatigue can be a significant symptom in infectious and inflammatory conditions such as HIV, hepatitis C infection and rheumatoid arthritis.

To add to this complex picture, common ME/CFS symptoms such as unrefreshing sleep, pain, orthostatic intolerance (problems and symptoms relating to standing) and depression (where it occurs) will also cause significant levels of fatigue.

*We also know that chronic fatigue can be a significant symptom in infectious and inflammatory conditions such as HIV, hepatitis C infection and rheumatoid arthritis.*

## WHAT DO WE KNOW FROM RESEARCH INTO ME/CFS FATIGUE?

**With a strong possibility that central and peripheral components are both involved in ME/CFS fatigue, researchers have tried to find satisfactory explanations that could lead to effective forms of medical treatment. This research has involved brain scans, muscle biopsies and assessing the function of the autonomic nervous system (which controls heart rate and blood pressure responses).**

The good news is that some important clues are starting to emerge. The less good news is that none of these findings has so far led to the development of a drug that can reduce chronic fatigue in its broadest sense.

As far as the brain is concerned, changes in the levels of brain chemical transmitters (eg serotonin), decreased blood flow to the brain stem, and autonomic nervous system dysfunction are all possible explanations.

At a more scientific level, one attractive hypothesis is that a viral infection is followed by damage to a key part of the brain known as the ascending reticular activating system that includes the brain stem, basal ganglia and hypothalamus.

Research into muscle function in people with ME/CFS has found abnormalities in the way in which energy is produced by the mitochondria (the Duracell batteries within muscle cells) from glycogen and the way in which the waste product lactic acid is removed after exercise (which may cause muscle pain). These are abnormalities that cannot simply be explained by inactivity or deconditioning.

## WHAT DO WE KNOW FROM RESEARCH INTO ME/CFS FATIGUE? *(continued...)*

Another possibility is that autonomic nervous system dysfunction may be reducing blood supply and oxygenation of skeletal muscle.

Research into the chronic fatigue  that occurs in conditions such as arthritis, cancer, and HIV-AIDS suggests that persisting activation of the immune system, with production of immune chemicals called cytokines (which cause fatigue during acute infections), could well be relevant to ME/CFS as well.

## CAN ME/CFS FATIGUE BE TREATED WITH MEDICATION?

*Various medications have been used to try and reduce the chronic disabling fatigue that is found in various neurological conditions - in particular multiple sclerosis (MS).*

**Various medications have been used to try and reduce the chronic disabling fatigue that is found in various neurological conditions - in particular multiple sclerosis (MS).**

These include:

- **amantadine** - an antiviral medicine that also affects the level of the brain chemical transmitters, acetylcholine and dopamine. Amantadine has been shown in some trials to be effective in reducing central fatigue in MS
- **methylphenidate** – an amphetamine-like brain stimulant
- **modafinil** – another central stimulant drug that is an effective form of treatment for narcolepsy, the daytime sleeping disorder
- **injections of vitamin B12** – which most doctors are reluctant to use unless there is sound evidence of vitamin B12 deficiency

These medications have also been assessed in small clinical trials in ME/CFS but with conflicting or uncertain results. Consequently, they are not normally prescribed for people with ME/CFS.

Where fatigue is caused by a muscle problem, the list of possible medical interventions is much smaller or non-existent - especially when it comes to established muscle diseases such as muscular dystrophy. Despite all the claims for muscle energy supplements, there is no sound evidence that supplements such as carnitine, creatine, co-enzymne Q10, or magnesium are of any real benefit in reducing fatigue in ME/CFS.

### CAN ME/CFS FATIGUE BE TREATED WITH MEDICATION?

*(continued...)*

Other medications that have been tried or suggested for ME/CFS fatigue include low doses of hydrocortisone (to correct the lowered level of cortisol that may be present in ME/CFS), thyroxine (which should not be given to people with normal thyroid function tests) and drugs known as cytokine modulators that inhibit cytokine activity.

Antidepressants, while sometimes improving fatigue levels in people with depression, have not been shown to be an effective form of treatment for ME/CFS.

It should also be noted that a number of common medications - prescription and over-the-counter - can cause fatigue as a side-effect. These include antidepressants, antihistamines (for allergies), beta-blockers (for heart disease), and diuretics (water-losing tablets). So these sort of medications have to be used with much more care than usual in people with ME/CFS.

*Pacing refers to balancing rest and activity - both physical and mental - in order to cope with a very significant reduction in both size and efficiency of the human energy battery.*

## SELF-HELP MANAGEMENT

**With no effective drug treatment for what is normally the most debilitating symptom in ME/CFS, simple self-help measures remain the most effective forms of management:**

### Pacing

This refers to balancing rest and activity - both physical and mental - in order to cope with a very significant reduction in both size and efficiency of the human energy battery.

For most people, this means a radical change to the way in which they use up their available physical, mental and emotional energy during the day - especially avoiding any form of over-activity that is going to have to be paid for later.

The bottom line to successful energy management in ME/CFS is establishing a baseline of physical and mental activity which you feel comfortable with on a day-to-day basis. People also need to accept that progress is probably going to be gradual and erratic. To achieve this, it helps to split up the day into small and easily manageable chunks of physical or mental activity which are interspaced with periods of rest and relaxation.

## SELF-HELP MANAGEMENT *(continued...)*

### Avoid fatigue-inducers

**Try to avoid anything that is going to cause or increase your fatigue levels.**

Obvious ones include:

- Alcohol
- Dehydration
- Hot weather
- Heavy or irregular meals
- Stress

**So this means:**

- Making sure you drink plenty of non-caffeinated fluids, especially during hot weather, is important - especially if you have any orthostatic symptoms. Hot weather often produces a major increase in fatigue levels in ME/CFS - so keep cool with measures such as a fan and light cotton clothing.
- Avoiding heavy meals because they divert blood to the intestines and produce fatigue in healthy people. Stick to small regular meals that contain complex carbohydrates. This should help to maintain a steady level of blood sugar throughout the day.
- Learning how to relax through videos (for instance, on YouTube), relaxation classes or even something like gentle yoga classes - if stress is a factor.

*Hot weather often produces a major increase in fatigue levels in ME/CFS - so keep cool with measures such as a fan and light cotton clothing.*

### Sort out pain, sleep and orthostatic intolerance

Any kind of sleep disturbance - unrefreshing sleep, erratic sleep - or pain is going to exacerbate fatigue levels. Unfortunately, sleep problems and pain are two very common symptoms of ME/CFS. So it's important to do all you can, with the help of your doctor, to reduce pain levels and get a decent night's sleep. Equally, new research indicates that orthostatic intolerance, and the problems it causes, is strongly linked to the level of fatigue. This is an aspect of ME/CFS that also needs to be addressed.

### Help in the home

Work, social and family life require a great deal of physical, mental and emotional energy. While someone who normally spends their day at work should be able to go on sick leave, the same situation cannot always apply to those who are looking after a home and children on a full-time basis.

This may mean that people with ME/CFS are left with still trying to cope with domestic tasks while their partners are out at work. So it's important to look at all the practical and financial help that might be available from family, friends, social services (home helps, meals-on-wheels) and state benefits, e.g. Personal Independence Payment (PIP)*.

**Please note, this is Adult Disability Payment in Scotland and Disability Living Allowance in Northern Ireland.*

For people who are more severely affected there are various disability aids and adaptations that may be appropriate.

*It's important to look at all the practical and financial help that might be available from family, friends, social services (home helps, meals on wheels) and state benefits, e.g. Personal Independence Payment (PIP).*

### Keeping a diary

Keeping a simple daily diary may help you to identify things which either exacerbate or reduce fatigue levels.

## THE 2021 NICE GUIDELINE ON ME/CFS

### 1.3 Advice for people with suspected ME/CFS

1.3.1 When ME/CFS is suspected, give people personalised advice about managing their symptoms. Also advise them:

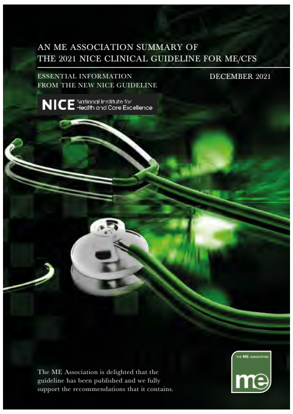
- not to use more energy than they perceive they have – they should manage their daily activity and not ‘push through’ their symptoms
- to rest and convalesce as needed (this might mean making changes to their daily routine, including work, school and other activities)

### Energy management

1.11.2 Discuss with people with ME/CFS the principles of energy management, the potential benefits and risks and what they should expect. Explain that it:

- is not curative
- is a self-management strategy led by the person themselves with support from a healthcare professional in an ME/CFS specialist team
- includes all types of activity (cognitive, physical, emotional and social) and takes into account overall level of activity
- helps people learn to use the amount of energy they have while reducing their risk of post-exertional malaise or worsening their symptoms by exceeding their limits
- recognises that each person has a different and fluctuating energy limit and they are experts in judging their own limits
- can include help from a healthcare professional to recognise when they are approaching their limit (children and young people in particular may find it harder to judge their limits and can overreach them)
- uses a flexible, tailored approach so that activity is never automatically increased but is maintained or adjusted (upwards after a period of stability or downwards when symptoms are worse)
- is a long-term approach – it can take weeks, months or sometimes even years to reach stabilisation or to increase tolerance or activity.

1.11.3 Help people with ME/CFS develop a plan for energy management as part of their care and support plan. Support them to establish realistic expectations and develop goals that are meaningful to them.



AN ME ASSOCIATION SUMMARY OF
THE 2021 NICE CLINICAL GUIDELINE FOR ME/CFS

ESSENTIAL INFORMATION
FROM THE NEW NICE GUIDELINE

DECEMBER 2021

NICE National Institute for Health and Care Excellence

The ME Association is delighted that the guideline has been published and we fully support the recommendations that it contains.

**NICE Guideline on ME/CFS: An ME Association Summary**

This booklet is recommended reading. It 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**

## THE 2021 NICE GUIDELINE ON ME/CFS *(continued...)*

Discuss and record the following in the plan along with anything else that is important to the person:

- cognitive activity
- mobility and other physical activity
- ability to undertake activities of daily living
- psychological, emotional and social demands, including family and sexual relationships
- rest and relaxation (both quality and duration)
- sleep quality and duration
- effect of environmental factors, including sensory stimulation.

1.11.4 Work with the person to establish an individual activity pattern within their current energy limits that minimises their symptoms. For example:

- agree a sustainable level of activity as the first step, which may mean reducing activity
- plan periods of rest and activity, and incorporate the need for pre-emptive rest
- alternate and vary between different types of activity and break activities into small chunks.

1.11.5 Agree how often to review the person's energy management plan with them and revise it if needed.

1.11.6 Advise people with ME/CFS how to manage flare-ups and relapses - see the section on managing flare-ups in symptoms and relapse:

**https://meassociation.org.uk/cjbj**

Also see the MEA's booklet, Relapses, Exacerbations & Flare-ups:

**https://meassociation.org.uk/42m**

1.11.7 Make self-monitoring of activity as easy as possible by taking advantage of any tools the person already uses, such as an activity tracker, phone heart-rate monitor, diary or the Visible app:

**https://meassociation.org.uk/lywl**

Explaining ME/CFS

*How to talk to other people about ME/CFS*

Introduction by ME Connect

Helping your GP to understand ME/CFS

What exactly is ME/CFS?

Disability Rating Scale

Meeting people in more formal situations

ME/CFS and your symptoms

SEPTEMBER 2024

### Explaining ME/CFS

The MEA's booklet, **Explaining ME/CFS**, has a useful section to record your symptoms, which can be helpful when describing symptoms to a healthcare professional.

**https://meassociation.org.uk/5t5e**

## THE 2021 NICE GUIDELINE ON ME/CFS *(continued...)*

1.11.8 Refer people with ME/CFS to a physiotherapist or occupational therapist working in an ME/CFS specialist team if they:

- have difficulties caused by reduced physical activity or mobility - also see the sections on physical functioning (1.12.5) and mobility and care for people with severe or very severe ME/CFS (1.12.6), or
- feel ready to progress their physical activity beyond their current activities of daily living (see the section on physical activity and exercise), or
- would like to incorporate a physical activity or exercise programme into managing their ME/CFS - see the section on incorporating physical activity and exercise (1.11.9).

**Incorporating physical activity and exercise**

1.11.9 Do not advise people with ME/CFS to undertake exercise that is not part of a programme overseen by an ME/CFS specialist team, such as telling them to go to the gym or exercise more, because this may worsen their symptoms.

1.11.10 Only consider a personalised physical activity or exercise programme for people with ME/CFS who:

- feel ready to progress their physical activity beyond their current activities of daily living or
- would like to incorporate physical activity or exercise into managing their ME/CFS.

1.11.11 Tell people about the risks and benefits of physical activity and exercise programmes. Explain that some people with ME/CFS have found that they can make their symptoms worse, for some people it makes no difference and others find them helpful.

*1.11.11 Tell people about the risks and benefits of physical activity and exercise programmes. Explain that some people with ME/CFS have found that they can make their symptoms worse, for some people it makes no difference and others find them helpful.*

1.11.12 If a physical activity or exercise programme is offered, it should be overseen by a physiotherapist in an ME/CFS specialist team.

1.11.13 If a person with ME/CFS takes up the offer of a personalised physical activity or exercise programme, agree a programme with them that involves the following and review it regularly:

- establishing their physical activity baseline at a level that does not worsen their symptoms
- initially reducing physical activity to be below their baseline level
- maintaining this successfully for a period of time before attempting to increase it

## THE 2021 NICE GUIDELINE ON ME/CFS *(continued...)*

- making flexible adjustments to their physical activity (up or down as needed) to help them gradually improve their physical abilities while staying within their energy limits

- recognising a flare-up or relapse early and outlining how to manage it.

1.11.14 Do **not** offer people with ME/CFS:

- any therapy based on physical activity or exercise as a cure for ME/CFS

- generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses

- any programme that does not follow the approach in recommendation

1.11.13 or that uses fixed incremental increases in physical activity or exercise, for example, graded exercise therapy.

> *An individualised approach that should be taken for people with ME/CFS who choose to undertake a physical activity or exercise programme is described in recommendations 1.11.10 to 1.11.13.*

### Graded exercise therapy definition

**Note: GET should *never* be an option.**

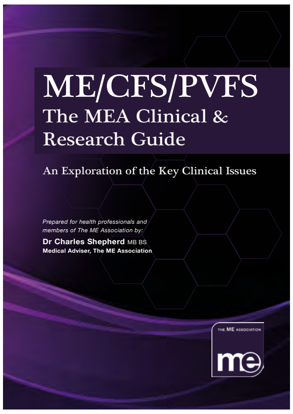
Graded exercise therapy is a term used in varying ways by different services supporting people with ME/CFS.

In this guideline, graded exercise therapy is defined as first establishing an individual’s baseline of achievable exercise or physical activity, then making fixed incremental increases in the time spent being physically active. This definition of graded exercise therapy reflects the descriptions given in the evidence that was reviewed, and it is this approach that the guideline says should not be undertaken.

An individualised approach that should be taken for people with ME/CFS who choose to undertake a physical activity or exercise programme is described in recommendations 1.11.10 to 1.11.13.

- physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories as perpetuating ME/CFS.

## FURTHER INFORMATION



Use this QR code to link to the MEA's Clinical and Research Guide, **ME/CFS/PVFS: An Exploration of the Key Clinical Issues (The Purple Book).**

■ The MEA leaflet on **Muscle Energy Supplements** contains detailed information on carnitine, creatine, co-enzyme Q10, etc:

**https://meassociation.org.uk/14ae**

■ Section 7:3 of **ME/CFS/PVFS: An Exploration of the Key Clinical Issues** summarises the results of clinical trials into the use of amantadine, hydrocortisone, methylphenidate and modafinil in ME/CFS. It also summarises research findings into various supplements.

**https://meassociation.org.uk/pbme**

■ The practical approach to balancing activity with rest is described in the MEA information leaflet, **Pacing: Activity and Energy Management:**

**https://meassociation.org.uk/h8qj**

■ The management of orthostatic intolerance, pain, sleep disturbance and stress are covered in four separate MEA information leaflets.

Orthostatic Intolerance:

**https://meassociation.org.uk/geo2**

Pain Management:

**https://meassociation.org.uk/je48**

Sleep Management:

**https://meassociation.org.uk/wr86**

Stress & How to Handle it:

**https://meassociation.org.uk/2h22**

:

## TERMS USED IN THIS GUIDELINE

### Activity

Any effort that uses energy, which includes cognitive, emotional and social activity as well as physical activity. Different activities combine and interact to cause a cumulative impact for the person.

### Care and support plan

The personalised collaborative care and support plan is developed by the ME/CFS specialist team based on a holistic assessment. It is the basis for other assessments and plans in areas such as social care, energy management, physical activity, physical functioning and mobility, cognitive behavioural therapy and dietary management.

### Carers

In this guideline, a carer refers to someone who provides unpaid care and support to a family member, partner or friend with ME/CFS. This is distinct from care workers who are employed to provide support.

### Children and young people

In this guideline, children and young people are aged under 18 (adults are 18 and above).

### Energy limit

The amount of energy a person has to do all activities without triggering an increase or worsening of their symptoms.

### Energy management

A self-management strategy that involves a person with ME/CFS managing their activities to stay within their energy limit, with support from a healthcare professional.

### Exercise

Exercise is planned, structured, repetitive and purposeful activity focused on improvement or maintenance of one or more components of physical fitness. Exercise is a subcategory of physical activity.

### Fatigue

Fatigue in ME/CFS typically has the following components:

- feeling flu-like, especially in the early days of the illness
- restlessness or feeling ‘wired but tired’
- low energy or a lack of physical energy to start or finish activities of daily living and the sensation of being ‘physically drained’
- cognitive fatigue that worsens existing difficulties
- rapid loss of muscle strength or stamina after starting an activity, causing for example, sudden weakness, clumsiness, lack of coordination, and being unable to repeat physical effort consistently.

### Flare-up

A worsening of symptoms, more than would be accounted for by normal day-to-day variation, that affects the person’s ability to perform their usual activities. Flare-ups may occur spontaneously or be triggered by another illness, overexertion or other triggers. Flare-ups usually occur as part of post-exertional malaise but it is possible for other symptoms, such as pain, to flare-up without post-exertional malaise. The worsening of symptoms is transient and flare-ups typically resolve after a few days, either spontaneously or in response to temporary changes in energy management or a change in treatment. A relapse lasts longer than a flare-up.

## TERMS USED IN THIS GUIDELINE *(continued...)*

### Graded exercise therapy

**Note: GET should *never* be an option and should be avoided.**

In this guideline, graded exercise therapy is defined as establishing a baseline of achievable exercise or physical activity and then making fixed incremental increases in the time spent being physically active. It is a therapy based on the deconditioning and exercise avoidance theories of ME/CFS. These theories assume that ME/CFS is perpetuated by reversible physiological changes of deconditioning and avoidance of activity. These changes result in the deconditioning being maintained and an increased perception of effort, leading to further inactivity. This definition of graded exercise therapy reflects the descriptions of it included in evidence review G: non-pharmacological management of ME/CFS and evidence review H: appendices for the management of ME/CFS.

### ME/CFS specialist team

These teams consist of a range of healthcare professionals with expertise 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, dietitians, and clinical or counselling psychologists. Children and young people are likely to be cared for under local or regional paediatric teams that have experience working with children and young people with ME/CFS in collaboration with ME/CFS specialist centres.

### Orthostatic intolerance

A clinical condition in which symptoms such as light-headedness, near-fainting or fainting, impaired concentration, headaches, dimming or blurring of vision, forceful beating of the heart, palpitations, tremulousness and chest pain occur or worsen on standing up and are improved (although not necessarily resolved) by sitting or lying down. Orthostatic intolerance may include postural orthostatic tachycardia syndrome (POTS), which is a significant rise in pulse rate when moving from lying to standing, and postural hypotension, which is a significant fall in blood pressure when moving from lying to standing. People with severe orthostatic intolerance may find they are unable to sit up for any length of time.

### Physical activity

Any bodily movement produced by skeletal muscles that results in energy expenditure. It should not be confused with exercise. Physical activity in daily life can be categorised into occupational, sports, conditioning, household or other activities, and can be done during leisure time, to get around or as part of a person's work. See World Health Organization advice on physical activity. Physical activity has a health benefit for most people and many conditions but, in people with ME/CFS, physical activity may make their symptoms worsen.

## TERMS USED IN THIS GUIDELINE *(continued...)*

### Physical functioning and mobility

The process of incorporating into daily activities a level of movement that helps to maintain joint and muscle flexibility without worsening symptoms of ME/CFS. This aims to support people to have as much independence as possible in their activities, ranging from personal hygiene to activities of daily living, working and social interaction. Such movement is undertaken within the person's energy limits and avoids pushing through their boundaries of tolerance.

### Post-exertional malaise

The worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity, or activity that could previously be tolerated. Symptoms can typically worsen 12 to 48 hours after activity and last for days or even weeks, sometimes leading to a relapse. Post-exertional malaise may also be referred to as post-exertional symptom exacerbation.

### Relapse

A sustained and marked exacerbation of symptoms lasting longer than a flare-up and needing a substantial and sustained adjustment to the person's energy management. It may not be clear in the early stages of a symptom exacerbation whether it is a flare-up or a relapse. Relapses can lead to a long-term reduction in the person's energy limits.

### Special interest in ME/CFS

A special interest in ME/CFS refers to a healthcare professional who is not working in an ME/CFS specialist team service but has knowledge and experience in this area.

### Therapy blueprint

This summarises the therapy and provides a basis for future independent self-management. The blueprint may include the therapy formulation, strategies that have been helpful, 'warning signs' and triggers of flare-ups and how to manage them, and goals for the future. It is important that the therapy blueprint is led by the person themselves and is in their own words, supported by guidance from the therapist.

### Unrefreshing sleep

Unrefreshing sleep means sleep that is non-restorative. Even after a full night's sleep, people do not feel refreshed. People with ME/CFS often report waking up exhausted and feeling as if they have not slept at all, no matter how long they were asleep.

## THE ME ASSOCIATION

*Changing attitudes and improving lives...*

■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign effectively and fund medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today**.

■ **SUPPORT:** ME Connect is the charity's support and information service. We listen and we understand. All our staff and volunteers have knowledge and understanding of these medical conditions. We provide a personalised service and we're here when you need us most. You can contact us via our telephone support line (this is a freephone number) or by email. Please see back page for more details. To view the ME Connect telephone support line opening hours, please visit: **https://www.meassociation.org.uk/me-connect**

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of free literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £2m in medical research in the last 10 years.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine called ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations of the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

> *"Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful."*

EMPLOYMENT ISSUES

*What you need to know about your employment rights*

Including:
The Law and Disability
Returning to Employment
Reasonable Adjustments
Employment and Sickness
National Insurance and State Pension
Ill-health Early Retirement
Income protection
Insurance
Termination of Employment
Community Comments

FEBRUARY 2024

*"The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research."*

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Tel: 01280 818963

Email: admin@meassociation.org.uk

Registered Charity
Number 801279

## THE ME ASSOCIATION

*Changing attitudes and improving lives...*

■ **LOBBYING:** We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can make a direct donation via the website.

### WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guideline reproduced in full in an easy-to-use database.

### MEDICAL MATTERS

Medical Matters is an easy-to-use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions: https://meassociation.org.uk/medm

### NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic, then we can help. We have listed all secondary care referral services in an easy-to-use database.

THE ME ASSOCIATION

# ME CONNECT

The Support and
Information Service for
people affected
by ME/CFS/PVFS
and Long Covid

## Freephone
## 0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect

Contact ME Connect
HOW TO GET IN TOUCH:
by phone or email

### HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.

### VITAL SUPPORT

We are here to help you reach an informed decision.

*We're here for you!*

### SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

✉ meconnect@meassociation.org.uk

X.com/meassociation

facebook.com/meassociation

instagram.com/meassociation

meassociation.org.uk