

PACING

Activity and energy management for
people with ME/CFS and Long Covid

MAY 2023



PACING: Activity and Energy Management for people with ME/CFS and Long Covid

INTRODUCTION

Having ME/CFS means that you are no longer able to carry out most of the energy requiring activities that form part of normal everyday life in a way that you did before becoming ill. And it's not only physical activities that require energy – mental activity also requires a lot of energy.

In the absence of any effective drug treatment for ME/CFS, the most important aspect of living with this illness is finding a form of activity and energy management that suits your individual circumstances.

This information, which incorporates recommendations on activity and energy management from the new NICE guideline on ME/CFS, covers:

- Symptoms that relate to energy production and usage
- What is fatigue? Can fatigue be treated? What do we know about the cause of debilitating fatigue in ME/CFS?
- Pacing – a safe and effective form of activity and energy management
- Graded exercise therapy – a treatment that is not suitable for people with ME/CFS
- Further information

Debilitating fatigue is often a key symptom in Long Covid as well. So this information and guidance can also be helpful for people with Long Covid.



Pacing was written by Dr Charles Shepherd, Trustee and Hon. Medical Adviser to The ME Association, and Sue Mayes, Chartered Physiotherapist.

© The ME Association, 2023
All rights reserved.

Reproduction, in full or in part, is not allowed without the written permission of 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.

PACING: Activity and Energy Management for people with ME/CFS and Long Covid

ME/CFS SYMPTOMS THAT RELATE TO ENERGY USE AND PRODUCTION

The new NICE guideline on ME/CFS identifies four key diagnostic symptoms – all of which relate to energy use or production. All four symptoms should be present to confirm a diagnosis of ME/CFS.

■ **Debilitating fatigue** that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest. Most people find that their fatigue levels depend on the stage of their illness (where severity may be more pronounced in the early post-infection stage) as well as fluctuating from day and day and often throughout the day.

■ **Post-exertional malaise** (PEM) or symptom exacerbation occurs after activity and involves a worsening of symptoms such as cognitive dysfunction, nausea and pain. This is very different to the normal type of fatigue that healthy people experience after exercise. Post-exertional malaise:

- is often delayed in onset by hours or days
- is disproportionate to the activity
- has a prolonged recovery time that may last hours, days, weeks or longer.

■ **Unrefreshing sleep** and /or sleep disturbance, which may include:

- feeling exhausted, feeling flu-like and stiff on waking
- broken or shallow sleep, altered sleep pattern or hypersomnia.

■ **Cognitive difficulties** (sometimes described as 'brain fog'), which may include problems in finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking

ME/CFS SYMPTOMS

DEBILITATING EXHAUSTION: What does it feel like?



“DRAGGING MY BODY AROUND WITH HEAVY WEIGHTS ATTACHED”

“SINKING...DROWNING... BEING ENVELOPED BY LEADEN CEMENT”

“IT’S LIKE SOMEONE PULLED MY BATTERIES OUT”

“LIKE I HAVE A HANGOVER WITH REALLY BAD FLU AND JET LAG”

“AS IF MY BODY IS FULL OF WATER AND I AM SINKING”

Myalgic Encephalopathy/Encephalomyelitis
Chronic Fatigue Syndrome (ME/CFS)

COMMUNITY COMMENT

“Debilitating fatigue is an absolute exhaustion that is difficult to describe to anyone. And sadly, no one believes you”

SANDRA



PACING: Activity and Energy Management for people with ME/CFS and Long Covid

WHAT IS FATIGUE?

Fatigue is a description that many people with ME/CFS (and their doctors) dislike – as it implies everyday tiredness or being ‘tired all the time’, which is not the basic problem in ME/CFS.

Fatigue in ME/CFS is much more complicated and often has the following features:

- feeling flu-like, especially in the early days of the illness
- 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 affects normal mental functioning
- 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.

Can fatigue be treated with drugs?

Unfortunately the answer is no. Although there are drugs like amphetamines which stimulate the central nervous system, and may be used in conditions like narcolepsy that cause daytime fatigue, there are no drugs that have been shown to be safe and effective treatments for reducing fatigue levels in ME/CFS.

The same applies to all the iron, vitamin and mineral supplements that are sometimes advertised as treatments for fatigue.

There are, however, several self-management strategies that can help to reduce fatigue:

- having at least 6 hours of solid uninterrupted

sleep each night – because sleep is the most effective way of recharging human energy levels

- eating a well-balanced diet that contains all the main food groups and nutrients and avoiding ‘quick fix’ carbohydrates
- keeping well hydrated and avoiding caffeine and alcohol
- making sure that, as part of your medical assessment common conditions that can cause fatigue – such as anaemia and low thyroid function – are not present as well.

What causes debilitating fatigue in ME/CFS?

At a scientific level we don’t fully understand why people with ME/CFS experience such a sudden and dramatic fall in energy levels and why they are unable to undertake any form of strenuous physical activity, or sustain any form of physical or mental activity.

As this fatiguability affects both brain and muscle function, it’s possible that there are problems involving both the brain and muscle, and possibly the immune system.

We already know that there are numerous brain and inflammatory conditions – multiple sclerosis, Parkinson’s disease, rheumatoid arthritis for example – that cause debilitating fatigue and there are centres in the brain that are involved in the production of what is called central (brain) fatigue.

Acute infections often cause of fatigue as well. This is due to the production of immune system chemicals called cytokines. This type of fatigue often persists in conditions like hepatitis C and AIDS.

PACING: Activity and Energy Management for people with ME/CFS and Long Covid

We also know from research into ME/CFS that there are problems with the way in which battery-like structures called mitochondria, which are present throughout the body and are very important for muscle energy production, are not functioning correctly in ME/CFS.

Linking to the research into mitochondrial function, ME/CFS is rather like having a mobile phone with a malfunctioning battery. Just like a defective battery, your body's energy levels are no longer capable of charging up to full power. So they are quickly running out of power when you start using physical or mental energy during the day.

PACING

Basic principles

Pacing is a form of activity and energy management that aims to achieve the right balance between activity and rest. For people with ME/CFS it can make the difference between coping and feeling really ill.

Pacing should help you to gain better control and stabilization of your illness. It may also help with symptom control. Although each day is still going to be different, the aim of pacing is to try and produce a more stable situation and give your body the best chance for some degree of improvement.

The MEA has always recommended that pacing is the safest and most effective way of dealing with activity and energy management.

Pacing is a long-term approach that may need to be regularly modified over weeks, months, or even years.

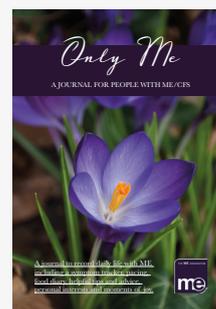
Practicalities

Pacing means learning new skills and recognising your limitations. This isn't always easy, especially at the very start of being ill. It may also involve a degree of trial and error before you master the art.

Activity and energy management has to be based on your own individual circumstances and learning to roughly judge how much energy you are likely to have on a day-to-day basis. This means taking three important factors into consideration:



Pacing is a long-term approach that may need to be modified over weeks, months, or even years.



Use a tracker to help you with your pacing. Try our 'Only Me' journal. It's a place to track symptoms, medication, appointments, pacing, food

diary and to record how you feel. It also features enjoyable activity ideas, tips, advice – and so much more. It is undated, so you can start it at any time!

<https://meassociation.org.uk/8wh8>



PACING: Activity and Energy Management for people with ME/CFS and Long Covid

- What stage you are in your illness: acute/early, stable, improving
- How severe your symptoms are: mild, moderate or severe
- To what extent your condition fluctuates

When ME/CFS is being suspected:

Stop >> Rest >> Pace!

The most important aspect of activity and energy management in the very early stages of any post-viral fatigue illness is good old-fashioned convalescence. Anecdotal evidence indicates that an adequate period of rest, possibly including some bed rest, is crucial. If bed rest is taken at this stage, try to include some periods when you sit in a chair or gently mobilise around the house.

Never try to exercise your way out of the very early stages of ME/CFS. This includes going back to school or employment before you are able to do so. An adequate period of rest in these crucial early stages is the most important way of helping to reduce the risk of developing a more persisting and severe form of ME/CFS.

When ME/CFS is diagnosed:

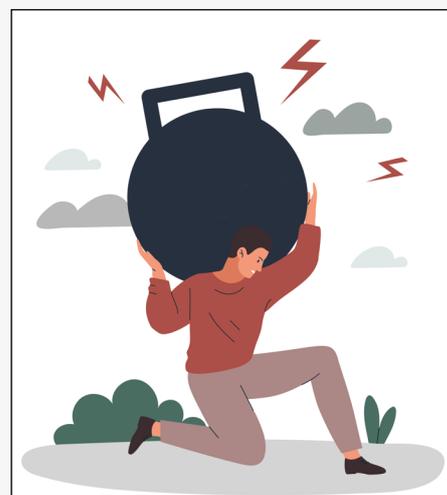
Stop >> Rest >> Pace!

- The first thing to do is find a comfortable baseline of activities – one that is not exacerbating symptoms or causing PEM. This is often lower than you think. Keep dropping your activity levels and increasing your resting until you feel you are living comfortably within your limitations and have better control over what you can and cannot do. This can take time and is likely to involve some trial and error.

- Think of your energy reserves – or energy envelope – like a battery. At the start of each day you are going to have a different amount of charge in your battery to last you through the day.

- The most effective way of using this limited amount of energy is to carry out physical and mental activities (such as computer work, doing mental puzzles or reading) in small manageable chunks throughout the day with longer periods of rest and relaxation in between.

- As well as switching between physical and mental activities during the day, it can also be helpful to change position from sitting to lying down.



Profound debilitating fatigue makes everyday tasks incredibly difficult, and can feel like you are carrying heavy a weight around day and night.

PACING: Activity and Energy Management for people with ME/CFS and Long Covid

- Do not to use more energy than you perceive you have and do not try to 'push through' your symptoms.
- Learn to recognise the feeling of 'doing too much' or sensing that you are getting close to this point. This is not just a feeling of tiredness. It can be a sensation of losing control, losing concentration or increasing fatigue.
- Aim to be prudent and still have some energy left at the end of the day.
- Rest is still very important but try to stick to resting and relaxation during the day because daytime sleeping can interfere with your ability to have at least five or six hours of solid sleep at night. Having a prolonged period of uninterrupted sleep at night is very important – even though you still wake up feeling unrefreshed.
- Just as you cannot exercise your way out of ME/CFS, total and prolonged bed rest is not the solution either.
- Feeling tired or stiff is a normal reaction to physical activity or exercise. However, in the case of ME/CFS these sort of symptoms indicate that you are not getting the balance right.
- Make use of aids and adaptations that may help with mobility, lifting and everyday household tasks. If your mobility is significantly reduced, the occasional or regular use of a wheelchair or mobility scooter is worth considering
- Plans for the day must be realistic, achievable, and sustainable. You may have to accept that progress can sometimes be two steps forward and one step backwards.
- Everyone with ME/CFS is different – so there has to be plenty of flexibility when it comes finding the approach that most suits your needs.
- Once you have achieved a degree of stability you can gradually and flexibly try to increase the amount of physical and/or mental activity you are doing.
- Remember that you used to use your willpower to keep going before being ill. Now you need to use your willpower to say stop!
- Don't fight the illness – stop when your body says so. And always stop an activity before you feel you are doing too much.



Learning how to pace activity (mental and physical) can be quite challenging, alongside finding ways to best manage symptoms; however, with time and practice most people find that pacing helps to create the right balance between activity and rest.



The ME Association has a leaflet that discusses common barriers to good management that may help you:

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

PACING: Activity and Energy Management for people with ME/CFS and Long Covid

Rest and relaxation

Resting and relaxation are skills to be learnt. You must give yourself permission to rest and relax and not feel any guilt. Remember you are ill.

There are different types of rest ranging from bed rest and sleep to relaxation:

- Complete rest when there is no outside stimulation. Turn off your phone and shut the door. Explain to others what you are doing.
- Reading or watching the television.
- Relaxation techniques with the help of tapes or books.

Just as you cannot exercise your way out of ME/CFS, total and prolonged bed rest is not the solution either. It is also possible to overdo the resting, particularly when you are fearful of doing too much and causing a relapse. Learning how to pace will help you to achieve the right individual balance between activity and rest.

Activity and exercise

Physical activity is different to exercise. Physical activity is any muscle movement relating to normal daily living that requires the production of energy.

Exercise is a planned, structured and intentional movement that aims to maintain or to improve strength or cardiovascular fitness.

Planning your tasks ahead

It's helpful to plan ahead and, depending how you feel at the start of the day, deciding what sort of physical and mental activities you might be able to do.

For more complicated tasks think about how you can split these down into smaller components. A good example here would be splitting the various tasks that are involved into preparing an evening meal into separate items throughout the day:

- plan what needs doing, check the fridge, and other ingredients
- prepare some of the ingredients and lay the table
- cook anything that can be reheated later
- heat the meal and enjoy!



COMMUNITY COMMENT

“Pacing is HARD. Keeping routine to a clock takes discipline. I do ok but not as strict as I’d like to be some days. We are human. I find when you have a little energy it feels weird to go back to bed and rest because you don’t feel like you need it... *but you do.*”

LIZZIE



PACING: Activity and Energy Management for people with ME/CFS and Long Covid

■ leave the table clearing and washing up till later – or for someone else to do!

And do make use of any labour-saving devices and services – such as online shopping and grocery deliveries.

Reviewing your priorities

- Remember you are ill – put yourself and your health first
- Is the physical or mental activity really necessary? Can you put it off? Does it have to be completed in one go?
- Learn to say no and to ask for help
- Try to include things that provide enjoyment
- Make a sensible and realistic plan which allows for last minute changes to be made.

Try to still enjoy your life!

You need to accept that you are ill. But you still need some enjoyment.

So your plan for the day should contain some activities that are there only for you. They should be a priority and not added on the end of the list if you have spare capacity.

If you have a big event coming up, you may feel anxious about whether you can cope and what effect this will have on you.

- Make a sensible and realistic plan and stick to it.
- Explain to people about your limitations. Hopefully, they will understand and be helpful.
- Do not try to hide your problems.
- Plan your travel and timetable well in advance and be prepared to alter it if necessary.
- Find a suitable place where you can be restful and quiet. Have a rest before you feel tired.

If you overdo things, do not worry. You have already proved that you can gain control by pacing and you will succeed again.



Plans for the day must be realistic, achievable and sustainable. Once you have achieved a degree of stability you can gradually try to increase the amount of physical and/or mental activity you are doing.

PACING: Activity and Energy Management for people with ME/CFS and Long Covid

Aids to pacing

Most people find that 'listening to their body' is the most helpful way of pacing. However, keeping a daily activity and symptom-monitoring diary can help to show up where mistakes are being made.

Activity monitoring – whereby you use an activity tracker (which records your number of daily steps) or a heart-rate monitor (to monitor a rise in pulse rate) can also be helpful.

Physios 4 ME carried out a survey of nearly 500 people with ME/CFS to assess the value of heart-rate monitoring. They concluded:

Although there are limitations, HRM has many benefits including helping PwME to understand and manage their PEM and support them to increase their activities, including work. There is a need for more research and education of healthcare professionals in the safe use of HRM.

<https://content.iospress.com/articles/work/wor220512>

Severe and very severe ME/CFS

If you have severe or very severe ME/CFS any increase in physical activity will have to be carried out in very small amounts, preferably with the help of a health professional who fully understands the complexities of this disease.

Problems that can be associated with prolonged immobility or bed rest – e.g. osteoporosis (thinning of the bones), pressure sores – will have to be taken into consideration as well.

Please note that the new NICE guideline on ME/CFS has a very detailed and helpful section covering the care and management of people with severe and very severe ME/CFS. The guideline emphasizes that people with severe ME/CFS will have extreme weakness and severely decreased movement and sensitivity to touch. Consequently, any physical contact must be carried out with care.



KEY POINTS SUMMARY

- You are ill. Make allowances for yourself.
- Do not feel guilty.
- Find a stable baseline before trying to increase your activities.
- Break up any physical or mental activity into small manageable chunks.
- Switch to other types of activities or have a proper rest before you feel tired.
- Feel your confidence grow as you gain control of your life.

PACING: Activity and Energy Management for people with ME/CFS and Long Covid

When improvement is occurring

If you are making progress and your condition has stabilized, or is steadily improving, you may want to move onto some form of more regular, longer lasting or energetic physical activity. You could, for example, steadily increase the distance you are walking each day, or do some gentle swimming in a warm pool. Another form of gentle muscle-stretching exercise that may be suitable is yoga.

Any form of increased physical activity or exercise still has to be done in a gradual and flexible way. A sudden return to any form of more vigorous physical activity is not recommended.

A return to school, college or work must be carried out in a flexible and gradual manner. ME/CFS is an illness that can be covered by the 2010 Equality Act – which means that employers have to consider making suitable adjustments to hours and duties to help someone with a disability return or remain in work.

Exacerbations, Flare ups and Relapses

Flare-ups and exacerbations are still going to occur – especially when you have a trigger such as a new infection. If your symptoms are infective in nature – ie feeling flu-like, having a sore throat and enlarged glands, a raised temperature – then a short period of bed rest may be advisable. This should be followed by a period of convalescence and a very gradual return to where you were before.

- Drop your activity levels, but do not go right back to the beginning unless really necessary.
- Reset your baseline.
- Do not increase activity until you feel stable.
- Learn from the experience.

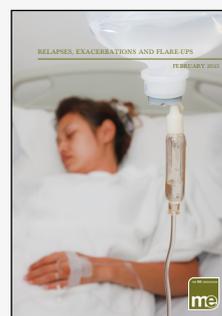
The MEA has a new information leaflet covering Relapses, Exacerbations and Flare-ups:

<https://meassociation.org.uk/mo56>



The MEA has an information booklet covering all aspects of Employment and ME/CFS:

<https://meassociation.org.uk/vo36>



The MEA has a new information leaflet covering Relapses, Exacerbations and Flare-ups:

<https://meassociation.org.uk/mo56>

PACING: Activity and Energy Management for people with ME/CFS and Long Covid

When pacing isn't working

If you can't get your activity management under reasonable control you should discuss the situation with your GP and ask for further help – possibly by referral to a local ME/CFS service.

If your overall condition is deteriorating you must speak to your GP – who should carry out a full medical assessment to make sure that there isn't another so far undiagnosed medical problem.

Professional help with pacing

Pacing is a self-help management strategy. However, if you can find a nurse, occupational therapist, or physiotherapist who understands ME/CFS, then they should be able to provide appropriate information and guidance. All the ME/CFS referral services should have an occupational therapist and physiotherapist who knows about pacing and can provide appropriate information and guidance. The MEA website has a directory of all the UK specialist referral services. ■

GRADED EXERCISE THERAPY (GET)

Graded exercise therapy (GET) used to be the form of activity management that was recommended in the old (2007) NICE guideline on ME/CFS. This was based on the flawed scientific theory that reductions in physical activity were caused by abnormal illness beliefs and behaviours and deconditioning. In other words there was no actual disease present. So it was safe to progressively increase activity and exercise and gradually return to normal.

Having reviewed all the research evidence and clinical trials for GET, the NICE guideline committee concluded that there was evidence of significant harm from GET and there was no sound evidence of benefit. Consequently, GET is no longer recommended as a treatment for ME/CFS by NICE and health professionals should not be prescribing it.

Further information

NICE guideline on ME/CFS: <https://tinyurl.com/yu6x3cf4>

MEA guide to NICE guideline on ME/CFS: <https://tinyurl.com/yc3mevwr>

BECOME A MEMBER



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/8cjm>



The MEA website shop:

The ME Association has the largest selection of ME/CFS advice leaflets in the UK on: Medical Management; Mental Health; Diet & Nutrition; General Information; Fundraising Leaflets; Benefits & Social Care; 'To Whom It May Concern' letters; and leaflets written by ME Connect: <https://meassociation.org.uk/shop>

