

SLEEP MANAGEMENT

INCLUDING RESTLESS
LEGS SYNDROME

FEBRUARY 2024



SLEEP MANAGEMENT (Including Restless Legs Syndrome)

INTRODUCTION

Failing to have a good night's sleep on a regular basis is likely to have an adverse effect on all aspects of your health. Various types of sleep disturbance occur in ME/CFS, especially waking up feeling unrefreshed. There are a number of simple self-help strategies that can be of help. In some cases drug treatments have a role to play as well. This is our guide to managing sleep disturbance in ME/CFS.

As there is a considerable amount of overlap between the core symptoms of Long Covid and ME/CFS, some parts of this information and guidance on sleep disturbance management will also be of help to people with Long Covid.

WHY DO WE NEED TO SLEEP? AND HOW MUCH SLEEP DO WE NEED?

Sleep has many different restorative functions. It helps with learning and memory and 'cleans the brain' of waste chemicals that build up in brain cells. The most important role in relation to ME/CFS is the fact that the human brain – especially those parts where normal mental functioning takes place – needs a period of good solid sleep each and every night if it is going to perform effectively the next day.

How much sleep is required each night varies from individual to individual. Some people manage perfectly well on only five or six hours each night – former Prime Minister Margaret Thatcher was a well-known example – whereas others never feel refreshed unless they have a solid eight or nine hours. The amount of sleep we require tends to become less in old age. And although quality of sleep is more important than length of sleep, having at least five hours of uninterrupted sleep each night is probably the minimum amount that is required.

WHAT HAPPENS DURING NORMAL SLEEP? HOW DOES THIS CHANGE IN ME/CFS?

Being awake or asleep is controlled by centres in the brain (such as the hypothalamus) along with chemicals and hormones known as neurotransmitters. This is your internal body clock. One sleep-inducing chemical of particular research interest at the moment is



Sleep Management was written by Dr Charles Shepherd, Trustee and Hon. Medical Adviser to The ME Association.

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DISCLAIMER

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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called adenosine, which steadily rises during the day and helps to induce sleep at night.

Normal sleep is composed of several different stages during which we move through alternating periods of increasingly deep sleep (called non-rapid eye movement/non-REM sleep) into lighter periods of sleep (called rapid eye movement/REM or dream sleep).

A number of research studies have now looked at what may be happening to these two sleep patterns in ME/CFS, including the quality of deep sleep. While many of these sleep research studies agree that there is a decrease in sleep efficiency, a consistent and significant abnormality has yet to be identified. The MEA Ramsay Research Fund has also funded research into sleep patterns in ME/CFS. The results of all these research studies are summarised and referenced in the MEA Clinical and Research guide (Purple Book).

One possible explanation is that the effect of an infection, along with the immune response that accompanies it, may be re-setting these sleep control mechanisms in the brain. As a result, the normal restorative pattern of REM and non-REM sleep no longer occurs.

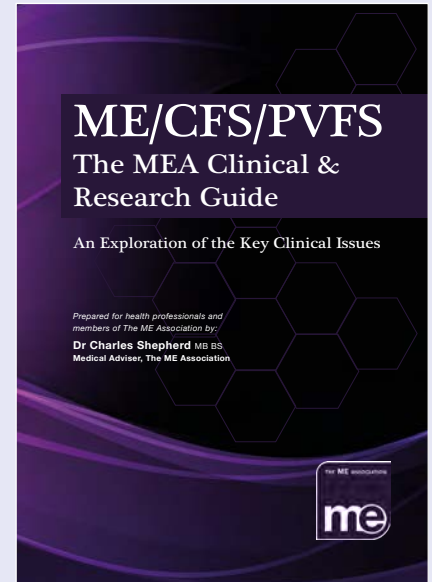
■ Academic review of research into sleep abnormalities in ME/CFS in the Journal of Clinical Sleep Medicine:

<http://tinyurl.com/bu7rnj6s>

WHAT TYPE OF SLEEP DISTURBANCES COMMONLY OCCUR IN ME/CFS?

Almost everyone with ME/CFS reports that they feel unrefreshed or sleep deprived even after what appears to be a good night's sleep.

During the very early stages of ME/CFS, especially when there has been an acute onset following an infection, excessive sleep requirements are often reported. This is known as hypersomnia and may result in someone sleeping for periods during the day as well as for much longer periods at night – sometimes 12 hours or more.



ME ASSOCIATION ME/CFS/PVFS CLINICAL & RESEARCH GUIDE

The most comprehensive, evidence-based summary of ME/CFS/PVFS currently available. It contains everything that health professionals, patients, and the people who care for them need to know about this devastating neurological disease.

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



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As the illness becomes more chronic, hypersomnia usually diminishes and is replaced by other types of sleep disturbance. Difficulty in getting off to sleep and waking during the night are quite commonly reported.

Waking very early in the morning is another type of disturbance that sometimes occurs in ME/CFS. However, this could also be an indicator of an unrecognised depressive component to your illness. Vivid dreams are also reported by some people with ME/CFS.

Other symptoms of ME/CFS, especially pain, can have an adverse effect on sleep quality and poor sleep quality is likely to have an adverse effect on pain.

Significant sleep disturbance can be accompanied by cramps, myoclonic jerks or 'restless legs' - all of which can wake people up during the night.

Children and young people with ME/CFS sometimes have a more unusual type of sleep disturbance whereby they are awake for long periods during the night and sleep during the day.

HOW SHOULD SLEEP DISTURBANCES BE INVESTIGATED?

Where a more significant sleep disturbance occurs, it's important to consider the possibility of what are called primary sleep disorders such as sleep apnoea and narcolepsy because they are sometimes misdiagnosed as ME/CFS.

Sleep apnoea, where the normal breathing pattern is interrupted during the night, produces abnormal pauses in breathing or shallow breathing whilst asleep. This results in excessive daytime sleepiness or drowsiness. Sleep apnoea is more common in people who are overweight (especially when they have a collar size of 17 or more), have enlarged tonsils, a blocked nose, or who snore. It can be diagnosed using an overnight sleep test called a polysomnogram.

Narcolepsy causes sudden episodes of daytime sleepiness along with sleep attacks - often following a meal. Narcolepsy is sometimes associated with hallucinations and cataplexy - where there is sudden loss of muscle tone whilst awake resulting in an inability to move.

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The use of a sleep disorder assessment scale (e.g. Epworth sleep score) can be helpful in the investigation of more significant sleep problems. If a diagnosis of sleep apnoea seems possible this requires referral to a sleep disorder clinic.

It should be noted that a number of drugs – both prescription and over-the-counter – can produce insomnia. So all of your current medication and supplement use should be reviewed by your GP or pharmacist.

HOW SHOULD SLEEP DISORDERS BE MANAGED IN ME/CFS?

Management of sleep disturbance in ME/CFS will depend on what stage you are in the illness, what type of sleep disturbance you have, and the effect it is having on your ability to function during the day.

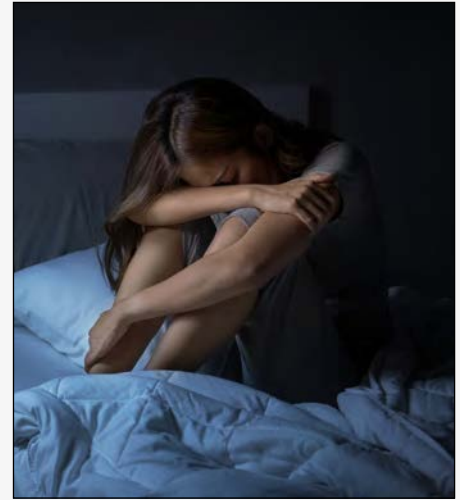
Many doctors (including myself) believe that an excessive sleep requirement early on in an infective illness like ME/CFS is the body's way of telling you to slow down and rest – just as it does with a sick animal. So if you want to sleep for more time than you would normally require, there doesn't appear to be any harm in doing so.

When there are problems with getting off to sleep or waking in the night, basic management should involve a range of simple self-help measures. The use of drugs and complementary therapies can also be considered.

SELF-HELP SLEEP STRATEGIES

These are some of the simple self-help measures that can often help to improve the quality and quantity of sleep once ME/CFS enters a more chronic stage:

- **Try to go to bed and get out of bed at roughly the same time each day.** This helps to maintain the normal sleep-wake cycle and the levels of neurotransmitters that help to control the internal body clock.
- **Try to avoid sleeping during the day.** Having periods of rest and relaxation during the day is fine but spending periods asleep can increase the risk of having fragmented and shallow sleep at night.



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■ **Use the bedroom for sleeping.** Your bedroom should be a quiet, dark and peaceful place with some fresh air coming in – not too hot or too cold – along with a comfortable bed and mattress. If you are bothered by external noise, try using earplugs.

■ **Deal with pain.** If you're woken at night by pain, consider taking a long-acting/sustained-release painkiller late at night. Your doctor or pharmacist can provide advice on the most suitable drug to use.

■ **Avoid alcohol, caffeine, chocolate for at least six hours before going to bed.** Caffeine slows down the rise of the chemical adenosine – one of the chemicals that helps to promote sleep. Note that decaffeinated drinks can contain small amounts of caffeine. Alcohol slows brain activity and some people mistakenly use it to help with sleep - but all alcohol does is create fragmented sleep. A glass of warm milk, which contains a sleep-inducing chemical called tryptophan, or a herbal tea, is a much better alternative.

■ **Start to relax in the hour or so before it's time to lie down and go to sleep.** This could include listening to relaxing music or doing some light reading. But try not to involve yourself in stimulating mental activity. If you find it difficult to relax, check out some of the relaxation techniques that are available.

■ **Possibly have a light snack before retiring.** An empty stomach can interfere with sleep but stick to a light snack - such as toast or some cereal - because a heavy meal shortly before bedtime will interfere with sleep.

■ **Have a warm bath in the evening.** Besides being very relaxing, a warm bath about 90 minutes before going to bed will raise the body temperature. The drop in temperature that follows getting out of a bath will help to make you feel sleepy. You can add a calming aromatic oil such as orange blossom to the bath water.

■ **Sleep should come naturally.** When it's time to go to sleep don't try too hard to do so – sleep will come when it's ready.

■ **If you can't get off to sleep.** Instead of counting sheep you could try simple mind games such as subtracting 7s from a high number or compiling an A-Z list of things like towns or countries. If you haven't relaxed properly in the hour before going to bed and have any muscle tension, learn how to relax individual muscle groups by tensing and relaxing them.



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■ **Don't take your worries to bed!** Above all, try not to go to bed and start worrying about things that you need to sort out or do. If this is a regular occurrence think about strategies that could help – such as writing them down during the day and try to prepare a plan. You could also keep a pen and paper by the bedside to write anything down that you need to remember the next day.

■ **Waking in the night.** If you wake up in the night and can't get back to sleep, it may be helpful to get out of bed, go to another room, and have some warm milk or make a cup of Chamomile tea.

■ **Use the morning sunlight to help reset your internal body clock.** If the sun is out, a short period outside in the sunlight when you wake up will help to re-set your biological clock. Remaining in daylight or good internal light will also help to maintain a normal circadian rhythm. This is the medical name given to all the physical, mental and behavioural changes that occur in a 24-hour cycle in response to changes in light and darkness. Bright lights should be avoided later in the evening.

OVER-THE-COUNTER REMEDIES

Go into any pharmacy and there's a bewildering range of sleep-inducing medications available. Some are OK but others are of dubious value and need to be used with care.

Antihistamines are sometimes used because of their sedating properties. The problem with these drugs is that they often remain in the body for long periods of time and may therefore make you feel drowsy the next day. They can also cause headaches and other side-effects. Examples include Nytol, Paxidorm (tablets and syrup) and Sominex. None of these drugs should be taken for long periods of time.

Herbal remedies are becoming increasingly popular, especially those containing valerian. This is a herb which needs to be used with care if you have ME/CFS as there are reports of valerian causing liver damage. There are other herbal remedies that don't include valerian.

Homoeopathic remedies can also be purchased over-the-counter and should be perfectly safe.

Other strategies that can sometimes help include the use of a Light Box in the morning – especially if there are any features of seasonal affective disorder (SAD).



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PRESCRIPTION-ONLY DRUGS

Doctors have, quite rightly, been criticised for dishing out sleeping pills far too readily with the result that some people with insomnia have become addicted. So doctors have become increasingly reluctant to prescribe sleeping pills – unless there are really good reasons for doing so.

However, there are several drugs that could be considered when failure to have a solid night's sleep has become a regular event.

Tricyclic antidepressants such as amitriptyline have a sedating effect on the brain and may therefore be helpful. When used to treat sleep disturbance in the absence of depression, amitriptyline is normally prescribed at a low dose of say 10mg or possibly 25gm a few hours before going to bed. At this dose side-effects are usually less problematic. Alternative drugs to amitriptyline include trimipramine.

Short-acting hypnotics can help people who have difficulty in getting off to sleep. As they are quickly eliminated from the body, they don't usually cause any 'hangover effect' the following morning – a problem that used to occur with other types of longer acting hypnotic drugs such as Mogadon (nitrazepam). Short-acting hypnotics are not usually prescribed for more than a few weeks to help re-establish a normal onset of sleep. Drugs in this group are known as 'the three Zs': zaleplon/Sonata; zolpidem/Stilnoct; zopiclone/Zimovane. Zolpidem and zopiclone have a short duration of action. Zaleplon is very short acting.

Melatonin is a hormone that helps to regulate natural sleep rhythms and is frequently used by people to reduce the adverse effects of jet lag. Melatonin used to be available over-the-counter here in the UK but the Dept of Health decided to restrict its availability because of concerns about side-effects.

There is now a prescription-only preparation containing melatonin available from internet pharmacies through an on-line consultation.

There are very valid concerns about the quality and safety of other melatonin products that can be purchased via the internet from non-pharmacy sources. This is not a source of supply that we would recommend.

There is now a prescription-only preparation available called Circadin. Circadin is a prolonged-release preparation of melatonin and can also be obtained from internet pharmacies through an on-line consultation.



The MEA has an information leaflet that covers the use of low dose amitriptyline in the management of sleep disturbance and pain:

<https://meassociation.org.uk/xm4s>

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CIRCADIN

Circadin is a prolonged-release preparation of melatonin. Most adults aged 55 years old or older can take melatonin to help with short term sleep problems. Adults under the age of 55 and children with longer term sleep problems can take melatonin if a specialist recommends it. A primary sleep disorder is one where there is no underlying medical condition causing the sleep disturbance. Circadin can be prescribed for up to 13 weeks.

Circadin helps to restore a natural sleep rhythm by increasing the body's own level of this hormone at night.

The recommended initial dose is 2mg taken once a day 30 to 60 minutes before bedtime. Modified-release preparations should be taken with or after food. Immediate release preparations should be taken on an empty stomach.

There are a number of conditions where melatonin needs to be used with caution or not at all. These include susceptibility to seizures, liver and kidney disease, pregnancy, breastfeeding and trying to get pregnant. Another caution relates to autoimmune disease – which obviously needs to be considered in relation to ME/CFS. A number of drug interactions can also occur with drugs such as fluvoxamine and cimetidine and treatments for diabetes and high blood pressure.

As with any drug, melatonin can produce side-effects. Common side-effects include joint pain and increased risk of infection. Less common side-effects include anxiety, chest pain, dizziness, headaches, hypertension (increased blood pressure), nausea, night sweats, and weight gain. Rare side-effects include arthritis, memory loss, palpitations, paraesthesiae (abnormal skin sensations), and vertigo.

NICE guideline on prescribing melatonin:

<http://tinyurl.com/2v5r7ahh>

FURTHER INFORMATION

The Medical Matters library on the MEA website contains more detailed information on myoclonic jerks and vivid dreams.



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RESTLESS LEGS SYNDROME

INTRODUCTION

Restless legs syndrome (RLS) is under-recognised, under-diagnosed, under-treated and thoroughly unpleasant!

Often described as a ‘medical black hole’, restless legs were first described by English physician Sir Thomas Willis in 1672. The term restless legs syndrome (RLS) was introduced in the 1940s by a Swedish neurologist called Dr Karl Ekbom. So it is also known as called the Willis-Ekbom Syndrome.

HOW COMMON IS RLS?

RLS is a common and often quite distressing condition with a middle age and female bias. It can affect children and adolescents as well – where it may be misdiagnosed as ‘growing pains’. Some research suggests that up to about 10% of the adult population describe some degree of symptoms with about 3% having moderate to severe symptoms. Yet many people remain undiagnosed and untreated.

WHAT ARE THE SYMPTOMS?

A variety of leg symptoms occur – normally in association with some kind of sleep disturbance and daytime fatigue. People with RLS describe unpleasant symptoms or sensations in their legs, normally below the knees. It can occasionally affect the arms as well.

Common descriptions include: electrical sensations, throbbing, pulling, creeping or crawling, or having ‘fizzy water inside your blood vessels’. The symptoms tend to appear during a period of inactivity, rest or lying down in the evening, as well as in bed at night. So the symptoms often delay the onset of normal sleep and then interrupt sleep throughout the night.

There is a constant urge to move the legs. So it becomes almost impossible to get comfortable and sleep soundly at night. Involuntary jerking or twitching movements may also occur – doctors call this periodic limb movement of sleep (PLMS).



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The overall disturbance, and the constant need to move the legs, means that people with RLS often get up and walk around the bedroom or house.

Not surprisingly, people with RLS often feel sleepy and tired the next day – which obviously does not help if you already have ME/CFS.

Overall, the disruption to normal life varies from mild to severe. The symptoms tend to be persistent but they may remit and relapse.

WHAT CAUSES RLS?

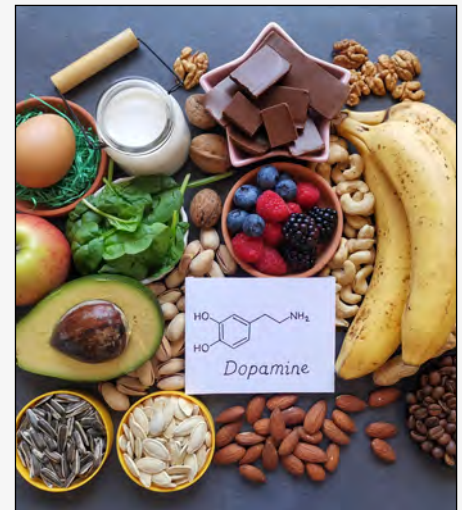
Recent research into RLS has found that there is a genetic basis with linkages to several chromosomes. This may explain why RLS is sometimes more common among members of the same family.

RLS is linked to problems in the central nervous system – including neuronal circuits that involve a part of the brain known as the basal ganglia and the chemical transmitter dopamine. Dopamine levels naturally fall towards the end of the day and this may help to explain why symptoms often occur in the evening or at night. The autonomic nervous system also appears to be involved. Some of these abnormalities also occur in ME/CFS.

There is also an important association with iron status and a link to iron-deficiency anaemia in some people with RLS has long been recognised. Most RLS patients have a normal ferritin level (ferritin = an iron-protein complex used to store iron in the body) but for some unknown reason they may have reduced concentrations of ferritin and transferrin in their cerebrospinal fluid. So there appears to be something rather strange going on in the brain as to how it absorbs and handles iron. RLS is also more common in people with diabetes, kidney disease, migraine, Parkinson's disease, rheumatic disorders and pregnancy during the last trimester.

CAN RLS BE TREATED?

Firstly, with RLS being associated with a number of medical conditions, it's important to have a blood test checked for ferritin and iron-deficiency anaemia – if not already done as part of an ME/CFS assessment. Do not treat yourself with iron supplements.



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Secondly, a drug review is useful because a number of drugs can sometimes make RLS worse. These include antidepressants (especially high doses of tricyclics such as amitriptyline), antihistamines (in over-the-counter cold remedies), anti-sickness drugs (especially metoclopramide/Maxolon) and calcium channel blockers.

Mild RLS can sometimes be relieved with simple self-help steps such as cutting out caffeine (in tea, coffee, cola, etc), alcohol, tobacco, going to bed a bit later, having a deep massage, and stretching/relaxation exercises.

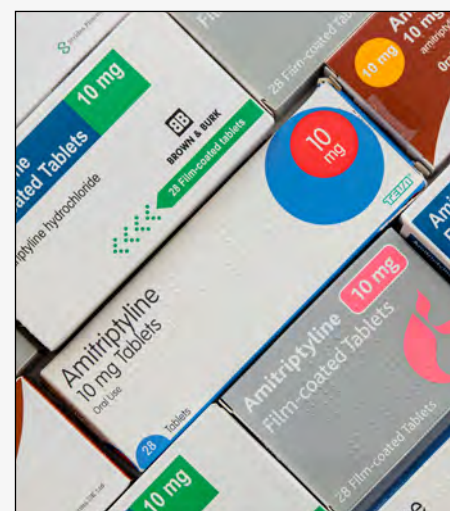
During an attack it may be helpful to massage your legs, apply a hot compress or have a hot bath, or go for a short walk or leg stretch.

Drugs that are normally used to treat Parkinson's disease may help because at low doses they increase the level of dopamine in the brain. They are the treatment of choice for moderate to severe symptoms. But their use has to be balanced with the fact that they can cause unpleasant side-effects.

Other drugs that may be helpful in more severe cases include opioid painkillers such as tramadol, anti-epileptic painkillers such as gabapentin/Neurontin or pregabalin/Lyrica and the short-acting hypnotic drugs that are referred to in the MEA sleep information leaflet.

More information and support can be obtained from the Restless Legs Syndrome UK:

<https://www.rls-uk.org>



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HOW WE CAN HELP

■ **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. 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. We will provide you with a regular ME Essential magazine which is simply the best magazine available. It will keep you informed of developments, it shares personal stories and the latest medical information, with an Ask the Doctor feature in every issue.

To become a member, please see the following link:

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

■ **SUPPORT:** Support is available from ME Connect, our telephone helpline, email, and social media private messaging service (see last page for details). It can be very helpful to speak with a trained member of the team at a time when you need it most and we can find the most relevant information for your situation.

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the largest range of literature covering all aspects of life with ME/CFS and Long Covid. We can show you how to recognise and manage symptoms, to 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 biomedical research through our dedicated Ramsay Research Fund, which has invested over £1m in recent years. We fund all the basic running costs for the ME Biobank - which collects and stores blood samples for research into ME/CFS - and fund post-mortem research into ME/CFS at the Manchester Brain Bank.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations from 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.”



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■ **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.

THE ME ASSOCIATION LITERATURE

The ME Association has the largest selection of free literature on ME/CFS and Long Covid in the UK. We cover:

- Awareness and Fundraising
- Benefits
- Carers and Social Care
- Diagnosis
- Diet and Nutrition
- Education and Employment
- Insurance and Travel
- Medical Management
- Mental Health
- Symptoms
- Template letters
- Vitamins and Supplements

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

All of our literature, excluding books and other goods, are now free to download.

“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.”



THE ME ASSOCIATION

me



Freephone

0808 801 0484

For opening hours visit:

meassociation.org.uk/me-connect

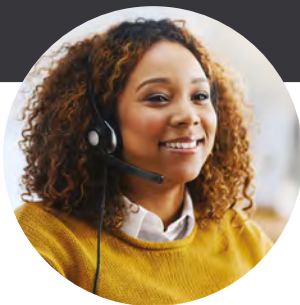
ME CONNECT

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

Contact ME Connect

3 WAYS TO GET IN TOUCH:

by phone, email or
social media private message



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.



SAFE ENVIRONMENT

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

We're here for you!



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