

PAIN MANAGEMENT

COPING WITH PAIN IN ME/CFS

JULY 2023



PAIN MANAGEMENT IN ME/CFS

INTRODUCTION

Although a small but significant minority of people with ME/CFS experience little or no pain during the course of their illness, the majority – probably around 75% – do. When pain occurs, it can do so in several different forms and with varying degrees of severity.

Knowing what causes pain in any condition can obviously be very helpful in the way it is managed. However, in the case of ME/CFS, no significant research has been carried out into the cause. We therefore know very little about why some people with ME/CFS suffer severe and persistent pain and others have low levels of pain or no pain at all.

When it comes to pain management, the best we can do right now is to work on the basis that there may be faults in the way in which messages about pain from various parts of the body – muscle, joints, abdomen, etc – are transmitted up the spinal cord to centres in the brain that control how we respond to pain. Equally, it's also possible that the way in which these pain control centres in the brain dampen down pain is also at fault. And this is why, in addition to conventional pain-relieving drugs, doctors sometimes prescribe drugs that normally have other uses but affect chemical transmitter systems in the brain.

Despite pain being such an important part of ME/CFS, this is one symptom that tends to receive very little attention in medical descriptions of the illness. Consequently, pain is a key symptom that is often not managed very well by health professionals.

WHAT SORT OF PAIN OCCURS IN ME/CFS?

Muscle pain (myalgia) can be intermittent or continuous and/or be very similar to the sort of pain which occurs in fibromyalgia – an overlapping condition where there are localised tender points as well as more generalised muscle and joint pain. Muscle pain can also just occur, or be exacerbated, following exercise. Muscle pain is sometimes accompanied by visible twitching of the muscles (fasciculations), cramps or involuntary jerking movements (myoclonic jerks) of the limbs.

Joint pain (arthralgia) is less common than muscle pain and should not be accompanied by any swelling, redness or deformity of the affected joints. If it is, investigations should



Pain Management in ME/CFS 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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be carried out to exclude the possibility of a rheumatological disorder such as rheumatoid arthritis or lupus/Systemic Lupus Erythematosus (SLE).

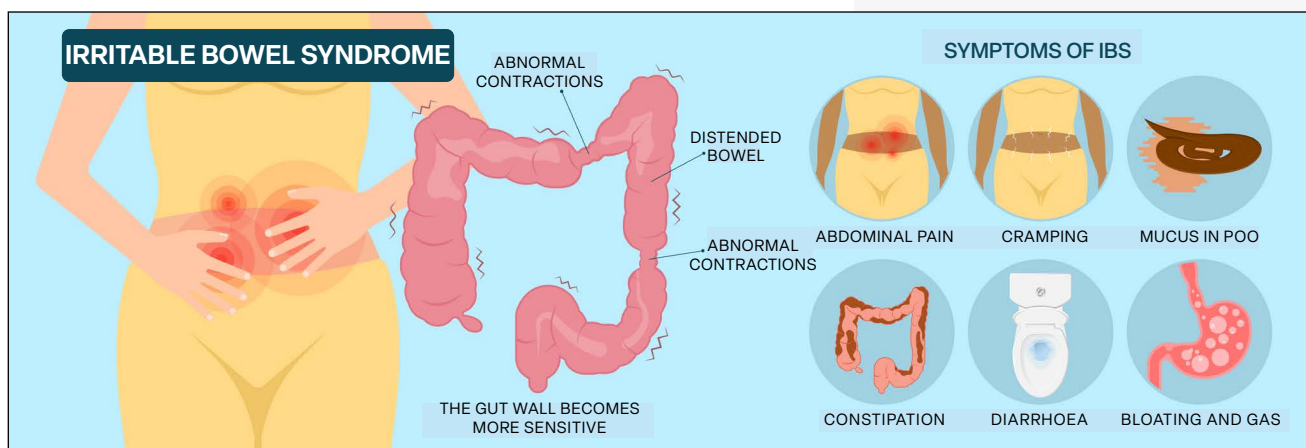
Nerve pain (neuropathic pain) is often described as a burning, searing, shooting, or stabbing sensation. Sometimes a painful response to a non-painful stimulus occurs – such as being unable to sleep because touching the bedclothes on the skin is unbearably painful. This type of neuropathic pain is known as allodynia.

Nerve pain can be accompanied by other neurological symptoms such as pins and needles, sensations in the skin (known as paraesthesiae) or patches of numbness (hypoesthesiae).

Headaches are a common symptom in ME/CFS and may have a migrainous character to them. However, headaches can have many other causes. So if headaches occur as a new problem, or become more severe or persistent, you should have a check up with your GP. This aspect of pain is covered in our information leaflet on headaches.



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Irritable bowel syndrome (IBS) is fairly common in people who have ME/CFS and can cause cramp-like abdominal pain. This aspect of pain is covered in our information leaflet on IBS.

There is also a wide spectrum in the severity of pain reported in ME/CFS. At one end of the spectrum are people whose pain is only intermittent or mild. For others, pain is severe, constant and intrusive – as a result it forms the most disabling part of their illness.

Unrelieved pain is likely to impact on sleep and may lead to depression. Not surprisingly, this can then produce a vicious circle because disturbed sleep and/or depression will inevitably make the pain worse.

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Red flags

Pain can have many different causes. Just because you have ME/CFS and pain it doesn't always mean that the pain is being caused by ME/CFS.

If your pain is of new onset following a diagnosis, is becoming more persistent or severe, or is changing in character, then you should always see your GP.

It's also important to note that ME/CFS does not cause:

- bone pain
- joint pain that is accompanied by redness, heat, swelling or deformity
- chest pains

Although eye pain is sometimes reported by people with ME/CFS, any form of eye pain that is a new symptom, or is persistent or severe, must be checked by your GP – especially if it also involves a visual disturbance or reddening of the eye.

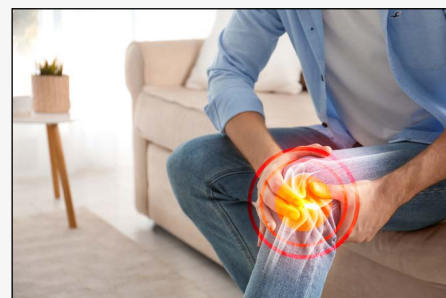
GENERAL PRINCIPLES OF PAIN MANAGEMENT

Mild or intermittent pain: The first option here is to try over-the-counter painkillers such as aspirin, ibuprofen or paracetamol. Heat will increase local blood flow and may help to reduce pain. So simple self-help measures include the use of locally applied heat in the form of a hot water bottle, a warm bath or heated pad. Gentle massage to the area using a cream such as Deep Heat or one based on a non-steroidal anti-inflammatory drug (eg ibuprofen) can also be helpful.

Moderate or more continuous pain: If simple self-help measures and over-the-counter pain-relieving drugs aren't helping, you ought to see your GP. Before doing so it's worth writing up a pain diary for the doctor to see. This should record what type of pain you are having, where it occurs, how often it occurs and how severe it is.

As far as prescription-only pain relieving drugs are concerned, there are a range of progressively stronger drugs that a doctor can choose from – something that is described as the 'analgesic ladder'.

Other options include the use of drugs such as amitriptyline and gabapentin. These are drugs that were not originally used for pain relief but are now known to have useful pain-relieving



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properties. Non-drug approaches such as a TENS machine and acupuncture are also worth considering.

Severe pain: Doctors are quite rightly cautious about prescribing stronger morphine/opiate-like painkillers to people with ME/CFS because of the risk of side-effects – including respiratory depression, sickness and changes in blood pressure – as well as the risk of addiction.

Many GPs find the management of severe pain a difficult subject to deal with and referral to a specialist or hospital pain clinic may be the only way of obtaining proper advice.



OVER-THE-COUNTER DRUG TREATMENTS

These are drugs that can be purchased in pharmacies and many other retail shops. The three commonly used ones are aspirin, ibuprofen and paracetamol.

These three drugs all have the potential to cause serious side-effects, especially if you exceed the daily dose limits. They may also be contra-indicated if you have other medical conditions such as asthma or if you take aspirin.

So do read the instructions on the packing before making use of any of these drugs, especially on a regular basis. You can also obtain information from your pharmacist, GP or internet sources such as the NHS.

Aspirin is still an effective anti-inflammatory drug. However, its use has declined in recent years due to the risk of side-effects, particularly stomach irritation and bleeding. Some aspirin preparations work slowly, and these can be useful in relieving pain at night. Aspirin should not be given to children under the age of 16 because of the risk of developing a serious condition called Reye's Syndrome.

Ibuprofen (trade name = Brufen) and others in this group – which are known as non-steroidal anti-inflammatory drugs (NSAIDs) – are also helpful in relieving mild to moderate muscle and joint pain. They act by blocking the production of inflammatory chemicals known as prostaglandins. Some NSAIDs are also available – both on prescription and over-the counter – as creams or gels which can be applied directly over the site of localised pain and consequently tend to produce less in the way of side-effects. Over-the-counter examples include Ibuleve and Proflex (both containing ibuprofen), Movelat and Voltarol.



Read the instructions on the packing before making use of any over-the-counter drugs, especially if you use them on a regular basis.

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As with aspirin, oral NSAIDs have to be used with caution by anyone with a history of stomach problems. They can also cause more unusual side-effects such as irregular heart beats and there is now some research evidence to indicate that long-term use (i.e over one month) can increase the risk of other heart problems.

The NHS website states: Take ibuprofen tablets, capsules, granules or liquid with a meal or snack, or with a drink of milk. It will be less likely to upset your stomach. If you take it just after food, ibuprofen may take longer to start working.

Paracetamol tends to be less effective in the control of muscle or joint pain – because it doesn't have significant anti-inflammatory effects - but some people still find it useful. Long-term use has now been linked to increasing the risk of high blood pressure.

Some over-the-counter painkillers combine more than one pain-relieving drug and/or also add caffeine or codeine (which may cause constipation). If you are using one of these combination painkillers, do make sure you know what you are taking and do not take any more individual painkillers.

PRESCRIPTION-ONLY DRUG TREATMENTS

Over recent years there have been considerable changes to the way in which doctors use prescription-only drugs to treat moderate or more severe pain.

In the past, painkillers such as Co-codamol (codeine phosphate and paracetamol), dihydrocodeine (DF118), meptazinol (Meptid), and tramadol (Zamadol, Zydol) were quite widely prescribed for moderate pain. These drugs act on chemical transmitter systems in the brain and so 'dampen down' pathways which are involved in how the brain recognises and responds to pain found elsewhere in the body. However, due to increasing concerns about dependency and misuse, doctors are now being far more cautious about using them – especially those that are opioid-based like Tramadol.

Morphine, pethidine and other very strong painkillers come right at the top of the analgesic pain ladder and have the potential to cause serious side-effects and dependence. So these sort of very powerful pain-relieving drugs should only be prescribed under specialist supervision.



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Prescription-only drugs that are recommended by NICE as options for the management of neuropathic pain:

Amitriptyline, duloxetine (Cymbalta), gabapentin (Neurontin) and pregabalin (Lyrica) are four drugs that can be used in the management of moderate to severe neuropathic pain – even though their original use had nothing to do with pain relief.

Amitriptyline was one of the first drugs used to treat depression. However, at a very low dose (e.g. 10mg or 25mg), it has been found to be effective as a pain reliever as well. It is thought to work by partially blocking pain transmission in the spinal cord.

Benefits may occur in a few days but it is worth carrying on for a few weeks before concluding that amitriptyline is not going to help. Overall, extensive patient feedback to the MEA indicates that a significant number of people are helped by this drug. Amitriptyline also causes sedation – so it can help with any sleep disturbance at the same time. Alternatives to amitriptyline include **imipramine (Tofranil)**.

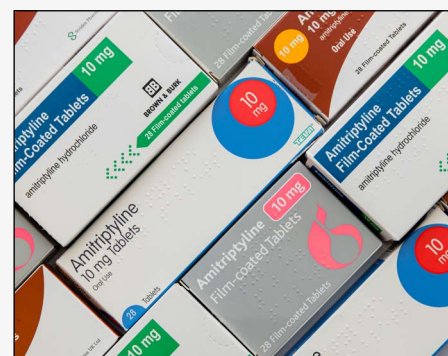
Unfortunately, some people with ME/CFS find that they cannot tolerate the side-effects (eg sedation, dry mouth, palpitations, weight gain) – even at a very low dose.

Duloxetine (Cymbalta) is another antidepressant drug which increases the levels of serotonin and noradrenaline in the brain. It has been found to help with pain relief as well, including the pain of fibromyalgia. A 2023 Cochrane Review on the use of antidepressant drugs for pain relief concluded that, while the evidence for use of antidepressant drugs was poor, this was the most effective drug for pain management. However, patient feedback to the MEA indicates that some people with ME/CFS do not tolerate this drug, so it does need to be used with caution.

MEA website report:

<https://tinyurl.com/mtet9uh2>

Gabapentin (Neurontin) was originally developed to treat epilepsy but has now been found to have considerable benefits in the treatment of nerve pain, along with muscle pain to a lesser extent.



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Gabapentin works by increasing the level of a brain chemical transmitter called gamma amino butyric acid. With gabapentin, the usual approach is to start with a very low dose at night (100mg) and gradually increasing over a period of several weeks – depending on the response.

Side-effects can include dizziness, headache, diarrhoea and weight gain. Although other epilepsy drugs are used in pain relief, gabapentin is the only one so far to be issued with a product license for this purpose.

Pregabalin (Lyrica) is another drug normally used in the treatment of epilepsy, but has also been found to be effective in relieving neuropathic pain.

Due to growing concerns about misuse, the legal status of gabapentin and pregabalin were changed in April 2019. These drugs are now classified as Class C Controlled Drugs under the 1971 Misuse of Drugs Act. This means there are additional restrictions on the way in which doctors are able to prescribe gabapentin and pregabalin. Restrictions include prescriptions being limited to 30 days treatment and repeat prescriptions no longer being allowed. As a result, most doctors are taking a far more cautious view about prescribing either drug for pain relief in ME/CFS.



The Medicines and Healthcare Products Regulatory Authority (MHRA), which monitors drug safety

here in the UK, has issued warnings about the use of both gabapentin and pregabalin during pregnancy. So if there is any possibility that you may become pregnant, this is something you need to raise with your doctor if these drugs are being considered.

If muscle pain is accompanied by cramps, spasms or painful leg movements, it may be worth considering the use of a muscle relaxant drug such as **baclofen (Lioresal)**. The drawback here is that, although pain and spasm may be reduced, this sort of drug can also increase weakness in the muscles.

For localised nerve pain another option is the use of **capsaicin cream (Axsain)**. This is a relatively new pain reliever that comes from an unusual plant source: chillies. Capsaicin is thought to act by depleting a chemical involved in pain production – substance P – in the nerve endings.



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ALTERNATIVE AND COMPLEMENTARY APPROACHES

All kinds of alternative treatments, especially electronic devices and magnets, are claimed to reduce pain. However, very few have been assessed in proper clinical trials to determine if they really do work. So do take care before spending large amounts of money.

Acupuncture is one approach that does have a degree of scientific evidence to support its use. So this is something that may be worth a try for chronic headaches and localised pain. But do make sure that you find a reputable practitioner. Other approaches that could be considered include osteopathy, aromatherapy, and even hypnosis.

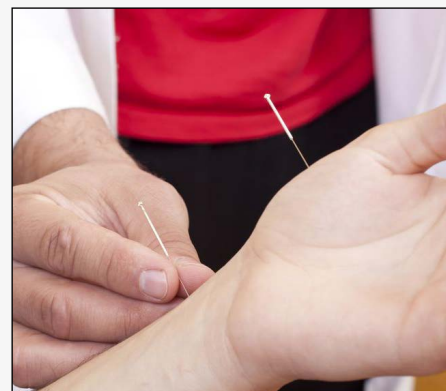
Cannabis: Some people with ME/CFS report that **cannabis** is a very effective method of pain relief and clinical trials are taking place to see if the active chemicals in this plant (cannabinoids) have genuine pain-relieving properties. It is important to remember that cannabis remains an illegal drug – although police prosecution for possessing small quantities of cannabis for medicinal purposes now seems far less likely.

Cannabidoil (CBD) products are being heavily promoted for pain relief and can be purchased over-the-counter in health shops and over the internet. Although there is some evidence to support their use, there haven't been any clinical trials to demonstrate safety and effectiveness in people with ME/CFS. So our advice is to use with care.

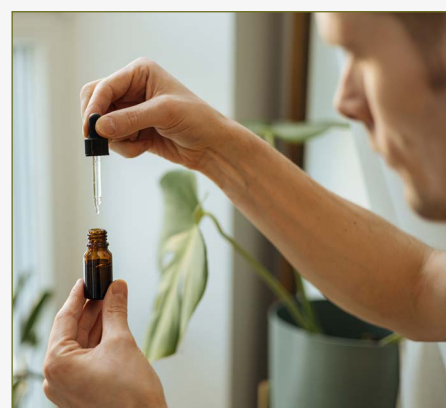
Evening primrose oil has also been shown to be effective in the relief of some types of joint pain.

NON-DRUG METHODS

TENS machines: One form of non-drug pain relief is the use of a transcutaneous electrical nerve stimulation (TENS) machine. Treatment involves applying small padded electrodes onto the skin directly over the site of chronic pain. A small current is then applied, which is thought to stimulate the production of endorphins – the body's own natural form of painkiller. TENS machines can be hired out from some hospital pain-relief clinics and GP surgeries.



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If you find this approach helpful, it is probably worth checking internet reviews of the popular makes and buying your own machine from a chemist such as Boots.

HOSPITAL PAIN CLINICS

When pain becomes a continuous and disabling part of your illness, and is largely unrelieved by any form of treatment, it is worth asking your GP for a referral to an NHS pain clinic. Most large district general hospitals now have a specific pain clinic that tends to be run by anaesthetists along with help from neurologists, physiotherapists and psychologists. This means the management is likely to involve self-help measures, drugs and psychological support – possibly in the form of CBT.

An increasing number of pain clinics are also offering alternative approaches such as acupuncture as part of their multidisciplinary approach.



NICE GUIDELINES ON ME/CFS AND MANAGEMENT OF NEUROPATHIC PAIN

The new (2021) NICE guideline on ME/CFS only contains a very brief summary on pain management in sections 1.12.12 – 1.12.14 and refers doctors to the NICE guideline on neuropathic pain. It is important to note that the ME/CFS guideline does not refer doctors to the NICE guideline on the management of chronic primary pain, which is where there is no obvious cause for the pain. This guideline recommends exercise and CBT but does not recommend the use of commonly used pain medications such as NSAIDs and paracetamol. It does however recommend that consideration can be given to the use of an antidepressant such as amitriptyline.

There are some important and helpful recommendations in the NICE guideline on neuropathic pain (NG 173) on the general

management of pain – as well as a list of drugs that that should only be considered if advised by a specialist. These are as follows:

1.1.1 When agreeing a treatment plan with the person, take into account their concerns and expectations, and discuss:

- the severity of the pain, and its impact on lifestyle, daily activities (including sleep disturbance) and participation.
- the underlying cause of the pain and whether this condition has deteriorated.
- why a particular pharmacological treatment is being offered.
- the benefits and possible adverse effects of pharmacological treatments, taking into account any physical or psychological problems, and concurrent medications.

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NICE GUIDELINES ON ME/CFS AND MANAGEMENT OF NEUROPATHIC PAIN

- the importance of dosage titration and the titration process, providing the person with individualised information and advice.
- coping strategies for pain and for possible adverse effects of treatment.
- non-pharmacological treatments, for example, physical and psychological therapies (which may be offered through a rehabilitation service) and surgery (which may be offered through specialist services).

1.1.2 Consider referring the person to a specialist pain service specialist at any stage, including at initial presentation and at the regular clinical reviews if:

- they have severe pain or
- their pain significantly limits their lifestyle, daily activities (including sleep disturbance) and participation, or
- their underlying health condition has deteriorated.

1.1.3 Continue existing treatments for people whose neuropathic pain is already effectively managed, taking into account the need for regular clinical reviews.

1.1.4 When introducing a new treatment, take into account any overlap with the old treatments to avoid deterioration in pain control.

1.1.5 After starting or changing a treatment, carry out an early clinical review of dosage titration, tolerability and adverse effects to assess the suitability of the chosen treatment.

1.1.6 Carry out regular clinical reviews to assess and monitor the effectiveness of the treatment. Each review should include an assessment of:

- pain control.
- impact on lifestyle, daily activities (including sleep disturbance) and participation.
- physical and psychological wellbeing.
- adverse effects.
- continued need for treatment.

1.1.7 When withdrawing or switching treatment, taper the withdrawal regimen to take account of dosage and any discontinuation symptoms.

1.1.8 Offer a choice of amitriptyline, duloxetine, gabapentin or pregabalin as initial treatment for neuropathic pain.

1.1.9 If the initial treatment is not effective or is not tolerated, offer one of the remaining 3 drugs, and consider switching again if the second and third drugs tried are also not effective or not tolerated.



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NICE GUIDELINES ON ME/CFS AND MANAGEMENT OF NEUROPATHIC PAIN

1.1.10 Consider tramadol only if acute rescue therapy is needed .

1.1.11 Consider capsaicin cream for people with localised neuropathic pain who wish to avoid, or who cannot tolerate, oral treatments.

1.1.12 Do not start the following to treat neuropathic pain in non-specialist settings, unless advised by a specialist to do so:

- cannabis sativa extract
- capsaicin patch
- lacosamide
- lamotrigine

- levetiracetam
- morphine
- oxcarbazepine
- topiramate
- tramadol (this is referring to long-term use; see recommendation 1.1.10 for short-term use)
- venlafaxine

NICE guideline on ME/CFS (NG 206):

<https://tinyurl.com/2p9jabdh>

NICE guideline on Neuropathic Pain (NG 173):

<https://tinyurl.com/235pavcb>

10 FURTHER INFORMATION

■ Details of NHS pain relief clinics can be obtained by phoning your local hospital. Most hospitals also provide information on their pain management services and clinics on their websites.

■ The British Acupuncture Council (tel: 020 8735 0400) has an on-line search facility at: www.acupuncture.org.uk to help you find a practitioner.

The MEA has information leaflets covering the use of specific pain relieving drugs:

Amitriptyline:

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

Duloxetine/Cymbalta:

<https://meassociation.org.uk/rwn0>

Gabapentin/Neurontin:

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

Pregabalin/Lyrica:

<https://meassociation.org.uk/65wi>

Evening Primrose Oil:

<https://meassociation.org.uk/klh2>



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BECOME A MEMBER

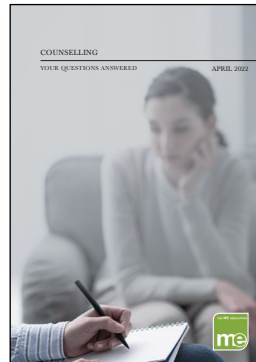
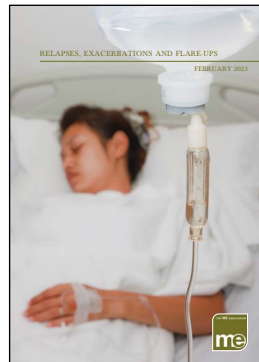
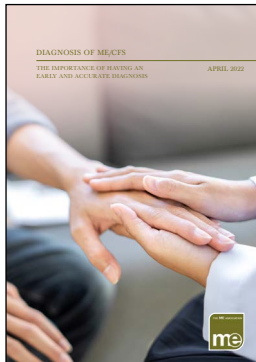
For a small subscription you can receive quarterly issues of **ME Essential** magazine, keep updated with the latest information on ME/CFS and with stories from other members of the charity.

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>



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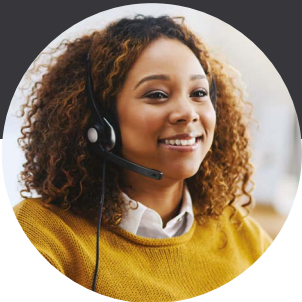
The Support and Information Service
for people affected by ME/CFS/PVFS
and Long Covid

3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message



Freephone
0800 538 5200

Monday to Friday 10am - 6pm
(Late night until 9pm on Thursdays)
Saturday & Sunday
10am - 12 noon & 7pm - 9pm



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.

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