

PAIN -Coping with pain in ME

Although a small but significant minority of people with ME/CFS experience no pain at all during the course of their illness, the vast majority – probably around 80% – do. When pain occurs, it can do so in many different forms, and with varying degrees of severity.

Muscle pain can be continuous and/or be very similar to that which occurs in fibromyalgia – an overlapping condition where there are specific tender points as well as more generalised muscle and joint pain. Or muscle pain may just occur, or be exacerbated, following exercise. Muscle pain is sometimes accompanied by visible twitching of the muscles (doctors call these fasciculations), cramps or involuntary jerking movements of the limbs.

Joint pain is less common than muscle pain and should not be accompanied by swelling, redness or deformity. If it is, then investigations need to be carried out to exclude the presence of a rheumatological disorder such as lupus/SLE.

Nerve pain (known to doctors as 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 may be accompanied by other neurological symptoms such as

pins and needles sensations in the skin (known as paraesthesiae) or patches of numbness (hypoaesthesiae).

Headaches are very common and often have a migrainous character to them. This aspect of pain is covered in a separate Management File.

There is also a wide variety 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, their pain is severe, constant and intrusive – as a result it forms the most disabling part of their illness.

Unrelieved pain significantly impacts 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.

Despite pain being such an important part of ME/CFS, it is one symptom that tends to receive very little attention in descriptions of the illness which are read by doctors. While researching this review, I was disturbed to find that pain is hardly mentioned at all in three major medical books on the subject aimed at doctors.

RESEARCH INTO PAIN

Sadly, this is an area of almost total neglect – both from the point of view of cause and management. At the University of Glasgow, however, Dr Abhijit Chaudhuri and colleagues carried out research that aimed to give a better understanding of why pain

occurs in ME/CFS – results of which have been published (*reference: Exercise lowers the pain threshold in chronic fatigue syndrome. Pain, 2004; 109: 497-499*).

Until we understand more about the underlying cause of muscle, joint and nerve pain in ME/CFS, treatment is going to remain unsatisfactory.

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. Simple self-help measures include the use of locally applied heat in the form of a hot water bottle, a warm bath or one of the bags containing things like wheat that can be heated in a microwave. Gentle massage to the area using a cream such as Deep Heat or one based on a non-steroidal anti-inflammatory drug can also be helpful.

Moderate or more continuous pain

For a doctor to claim that 'nothing can be done' to help someone with moderate or more continuous pain is unacceptable – no matter what the cause. If you need medical help, it is worth writing up a pain diary for the doctor to see. This should record what type of pain you are having, where it occurs, and how severe it is.

As far as prescription-only drugs are concerned, there are a wide variety

of progressively stronger drugs to choose from – something that is often described by doctors as the analgesic ladder.

Other options include the use of amitriptyline and gabapentin – drugs which were not originally used for pain relief but are now known to have useful pain-relieving 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 – although the risk of addiction when used for pain is often exaggerated. 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.

SPECIFIC TREATMENTS

Mild analgesics

Aspirin remains an excellent anti-inflammatory drug – provided you can tolerate any side-effects, particularly stomach irritation. Some aspirin preparations work slowly, and these can be useful in relieving pain at night. But aspirin should no longer be given to children.

Ibuprofen and others in this group – which are known as non-steroidal inflammatory drugs (NSAIDs) – are also helpful in relieving mild to moderate muscle, joint and bone 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 the pain and consequently tend to produce less in the way of side-effects. Over-the-counter examples include Ibugel and Proflex (both containing ibuprofen) and

Movelat. As with aspirin, NSAIDs have to be used with caution by anyone with a history of stomach problems.

Paracetamol tends to be less effective in the control of muscle or joint pain but some people find it useful.

Some over-the-counter painkillers combine more than one drug and 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 add on any more individual painkillers.

Prescription-only analgesics: the analgesic ladder

For moderate to severe pain doctors can prescribe painkillers such as dihydrocodeine (DF118), meptazinol (Meptid), and tramadol (Zamadol, Zydol). These drugs tend to 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. Tramadol, which is a weak opioid-like drug, is quite often prescribed to people with ME/CFS as it seems to be quite helpful in relieving muscle and nerve pain.

For localised nerve pain another option is the use of capsaicin cream (Axsain). This is a relatively new pain reliever which 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.

Morphine, pethidine and other very strong painkillers come right at the top of the doctor's analgesic ladder. New developments mean that strong morphine-like drugs can be delivered by skin patches that release a steady amount over a period of about three days. As with other forms of locally applied pain relief, there appears to be a lower incidence of side-effects.

Other prescription-only drugs

Amitriptyline and gabapentin (Neurontin) are two drugs that are being increasingly used in the management of moderate to severe pain – even though their original use had nothing to do with pain relief.

Amitriptyline was one of the first drugs to treat depression but – at a very low dose (eg 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. An added bonus is that amitriptyline also causes sedation – so it can help with any sleep disturbance at the same time. Alternatives to amitriptyline include imipramine (Tofranil) and venlafaxine (Efexor).

NEW PRESCRIBING GUIDANCE FOR TWO DRUGS

Due to growing concerns about misuse, the legal status of gabapentin (trade name = Neurontin) and pregabalin (trade name = Lyrica) have changed and these changes came into effect in April 2019. These drugs are now classified as a Class C Controlled Drugs.

This means that 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, some doctors are likely to take a far more cautious view about prescribing either drug for pain relief in ME/CFS.

More information on these changes can be found in this MEA website statement: <https://tinyurl.com/y3gondvb>

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

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

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 (100mg or 300mg) and gradually increase this over a period of several weeks – depending on the response. Side-effects can include dizziness, headache, diarrhoea and weight gain, but the drug is usually well tolerated. Although other epilepsy drugs are used in pain relief, gabapentin is the only one so far to be issued with a product licence for this purpose.

Another drug normally used in the treatment of epilepsy, but now found to be effective in relieving neuropathic pain, is pregabalin/Lyrica. At present, we don't have much feedback on the use of this drug in people with ME/CFS.

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

Alternative and complementary approaches

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

One approach that does have a degree of solid scientific evidence to support its use is acupuncture – something that is certainly worth a

try for chronic headaches and localised pain. But do make sure that you find a reputable practitioner. Other approaches worth considering include osteopathy, aromatherapy, and even hypnosis.

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

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

Non-drug methods: TENS machines

A most effective 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 passed, 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.

If you find this approach helpful, it is worth buying your own machine from a chemist such as Boots.

Hospital pain clinics

When pain becomes a continuous and disabling part of your illness, 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 which tends to be run by anaesthetists along with help from neurologists, physiotherapists and psychologists.

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

FURTHER HELP WITH PAIN RELIEF

More information on pain and pain relief in ME/CFS can be found on pages 195 - 198 of *Living with ME* (Vermilion paperback, 1999; ISBN 0-09-181679-3).

Details of NHS pain relief clinics can be obtained by phoning your local hospital. Many hospitals also provide information on their pain clinics on their websites.

The British Acupuncture Council (tel: 0208 735 0400) has an on-line search facility at: www.acupuncture.org.uk to help you find a practitioner.

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 healthcare professional about any specific problem. We also recommend that the medical information provided by The MEA in this leaflet is, where appropriate, shown to and discussed with your doctor.



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