

Pain and M.E

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Pain is one of the worst symptoms, and often the worst symptom, for many people with ME/CFS, and it can be extremely disabling. The problem cannot be over-emphasised, and there is an urgent need for more support and research in this field. If pain is a major problem for you, then you will most likely already be your own expert, but still perhaps these notes could lead to something you have not tried before.

Many people with ME/CFS have found that **rest and sleep** are the best preventive measures, and the best treatment. If you don't sleep well, your body won't make the chemicals it needs to feel good or reduce pain. Try to sleep as much as possible during the worst times, and even though you may wake up feeling awful, you will feel the benefit later on. Not surprisingly, pain makes sleep difficult, so all methods should be tried to relieve pain in order to get to sleep.

Pain is a 'subjective' sensation, and what works for one person may not necessarily work for the next even though the diagnosis is the same. Various approaches to pain management are available, but as a first strategy, it is important to discuss pain with your GP, and to describe it carefully.

What kind of pain?

- Where is the pain? Muscles, joints, head, tummy? Make it clear to the doctor if you think this is a new pain, unrelated to your ME/CFS.
- How long have you had the pain?
- For how long does the pain stay with you? What makes it worse or better? Does it come and go?
- Describe the type of pain: Sharp, shooting pain, burning sensation, aching feeling, cramp-like, odd sensation like pins and needles or an electric shock?
- Does the pain bring other symptoms such as nausea or visual disturbance?
- Does the pain bring numbness?
- Does it come with twitching of the muscles, cramps or jerking movements?
- Do you find ordinary things painful, such as the bedclothes touching you at night?

Tell your doctor what you have tried so far, and how it has worked, or not worked.

Then, when trying new medications or remedies, it is a good idea to keep a simple diary to rate their effectiveness. Rate the pain on a scale of 0-10 (0 = no pain, 10 = worst pain) and also note any symptoms which you think are side-effects. This will help you to judge which pain relief works best for you.

Ways to manage and control pain

Medication

With any drug it is important to get the dose right and this sometimes takes a while, especially with ME/CFS where there is a **limited tolerance to drugs**. It is usually best to start with a very low dose and increase it gradually if it has no effect. Be aware that one of the effects could be a 'hung-over' feeling the next day. Some individuals simply cannot tolerate medication in sufficient doses to be effective against pain, and so other strategies should be tried in addition or instead (see later).

Over the Counter Medications

Paracetamol is worth a try for mild pain. It is generally well-tolerated, especially in low doses, but it may have little effect on moderate to severe pain. **Paracetamol overdose can be very dangerous** - read the instructions carefully and do not exceed the recommended dose. Be careful if you are taking other over-the-counter and prescription painkillers as they may also contain paracetamol (e.g. co-codamol, co-proxamol [which is now a restricted drug] and codydramol). Also, some over-the-counter preparations contain caffeine and other substances that may not be well tolerated by people with M.E.

Anti-Inflammatories

Non-steroidal anti-inflammatory drugs (NSAIDs) can be helpful if your pain is due to inflammation, such as **inflamed joints and period pain**. They include **aspirin, ibuprofen, diclofenic** and **naproxen**. However, NSAIDs are not usually helpful for the muscle pain experienced in M.E. Also, people with M.E. often experience side effects, such as gastrointestinal irritation, or allergic reactions (especially to aspirin). Aspirin should not be given to children under 16 years of age (unless supervised by a consultant).

*People who suffer from **asthma** should be aware that both aspirin and the NSAIDs may bring on an asthma attack in some people.*

Ibuprofen and **aspirin** can be bought from chemists, and soluble preparations may be useful as a gargle for **sore throats** (spit out afterwards to avoid too much getting into the bloodstream). NSAIDs are also available as **creams or gels** (worth trying for localised pain relief) which can be applied directly over the pain and consequently produce fewer side effects – over-the-counter examples of these are Ibugel and Proflex (both contain Ibuprofen) and Movelat. They are also available in **suppositories** for use at night to relieve morning stiffness. Some NSAIDs have a sustained release formula to prolong their action. Lower doses should be used to start with, and NSAIDs should never be taken on an empty stomach.

Co-Codaprin is a combination of aspirin and codeine which can be bought over the counter. If you are using a combination pain killer, make sure you know what is in it and do not add on any more painkillers.

Cox-2 inhibitors, such as celecoxib, are a newer class of NSAID that were developed to minimise gastrointestinal side effects. Although they may not give much overall benefit

compared with standard NSAIDs, they may be more suitable for individuals with **gastro intestinal problems**.

NOTE: Concerns have been raised recently about the safety of, first the Cox-2 inhibitors, and now all the NSAIDs including Ibuprofen, for those at risk of heart disease or allergic reactions. The use of any of these must be discussed carefully with your doctor. Those already taking them should not stop, but should seek medical advice.

Codeine is a morphine derivative (opiate) which can be bought over the counter and is often combined with **paracetamol** and aspirin. It can be helpful to relieve **mild to moderate pain**, especially headaches.

Stronger Medications

Though most GPs are very unwilling to prescribe them, **opiate based painkillers** are usually effective for moderate to **severe pain that is deep, or internal in origin**. They include **codeine**, **morphine**, and **valium** and are derived from opiates found in the opium poppy, which are similar to the body's endorphin painkillers. Side effects may include nausea, dizziness, and drowsiness. Constipation is sometimes a problem. Regular use leads to tolerance (a need for increasing doses to achieve the same effect) and dependence (a reliance on the drug). However, addiction seems rare when these drugs are genuinely needed for pain control. Individual effects vary widely and depend on the particular drug used. They are best used only occasionally, as a last resort, taking a dose large enough to be effective, rather than a regular small dose, which would build up a habit. (There have been reports of morphine resistance occurring in people with ME/CFS but it is not known whether this is more common in people with ME/CFS.)

Some drugs which GPs prescribe for moderate to severe pain are dihydrocodeine (DF118), meptazinol (Meptid) and Tramadol (Zamadol, Zydol). **Tramadol** is a weak opioid-like drug which often helps people with ME/CFS in relieving both muscle and nerve pain.

Stronger opioid based painkillers are not generally used in the UK for relieving chronic M.E. type pain because of their addictive qualities. However, new developments mean that strong morphine-like drugs can be **delivered by skin patches** which release a steady amount over a three day period, with a lower incidence of side effects.

Rebound headaches (medication overuse headaches)

When pain medicine is taken daily, even if it's just an over-the-counter remedy, the body can gradually become accustomed to it. This may not be noticed until, for some reason, a day is missed. Then the pain medicine will wear off and the pain will return with a vengeance. This may be mistaken for an especially persistent headache, but the recurring pain actually is a symptom of medication withdrawal and can lead to dependence. For this reason codeine ideally should not be taken on more than 6 days a month, and paracetamol on more than 15 days a month. Frequent or regular use of pain medication (2 or 3 times per week) is more likely to cause this type of headache than taking the medication in clusters of several treatment days, separated by prolonged treatment-free intervals.



Antidepressants

Tricyclic antidepressants can be effective at suppressing **muscle pain** and also helping you to get to **sleep**. They include amitriptyline, lofepramine and nortriptyline. If taken for pain relief they should be used at a **much lower dose** than is usual for the management of depression (a typical daily dose for depression would be 100-150mg). At a low dose they can also have other benefits such as restoring better quality sleep and controlling some features of Irritable Bowel Syndrome. A starting dose of 5mg (half a 10mg tablet) is recommended. Starting on a 10mg or higher could cause unwanted side effects, although tolerance develops after a time and the dose has to be increased. Take the tablet before bedtime and increase the dose carefully up to 25g, according to its effect. Benefits may occur in a few days but it is worth carrying on for a few weeks before giving up on amitriptyline. Unfortunately the side effects on some people are too much (dry mouth, palpitations, weight gain). Alternatives drugs of this family are imipramine (Tofranil) and venlafaxine (Efexor) and lofepramine.

SSRIs (e.g. Prozac) may occasionally be used, but these are not generally recommended for people with ME/CFS. However on the basis of the possibility that it could help with pain and especially with sleep, then anecdotal evidence given to me suggests that the SSRI Sertraline (Lustral) is one of the appropriate SSRIs for people with M.E. Though many people now think that the possible benefits of taking these drugs are outweighed by the risks, which include suicidal thoughts, agitation, anorexia and insomnia.

Different drugs have different effects on symptoms and they also differ in their side effects. If you find that a drug is ineffective or cannot be tolerated, it is worth systematically trying others. Remember to take **careful note of the effects** of each medication that you try. Common side effects of some medications are dizziness, headache, and bowel disturbances – in other words, making your ME/CFS worse!

Anti-spasmodics

For a **neuropathic pain** (burning or piercing) a low dose of the anti-epileptic drug Neurontin (generic name = **gabapentin**) may be worth trying, though it has recently come to light [2006] that this medication may not be suitable for people with a history of eye disorders. Others are carbamazepine and sodium valproate. These have broad effects on nervous system functioning, including altering the pain threshold ('gating out' pain). Again, the starting dose should be low (e.g. 100mg at bedtime for a few days, to test the response).

Muscle relaxants and **anti-spasmodic drugs** may be useful for **muscle cramps, spasms, and twitching**, and these include **baclofen**, methocarbamol, and quinine. Again, very low doses should be used and these medications do need to be used with care as they can cause muscle weakness.

Anti-spasmodic drugs for **abdominal cramps** include **mebeverine**, **alverine**, and **buscopan**. **Peppermint oil capsules** can also be effective for treating abdominal cramps. Peppermint oil relaxes the intestine by preventing the entry of calcium (which is needed for muscle contraction) into intestinal smooth muscle cells.

For Headaches

For those who suffer from severe but infrequent **headaches and migraines**, 5-HT agonists or triptans such as sumatriptan (Imigran) may be useful, but frequent use can lead to 'rebound' attacks (see above). For severe, **frequent migrainous headaches**, cluster headaches and facial pain, drugs such as pizotifen, sodium valproate, and gabapentin can be helpful.

*People with ME/CFS are usually **more sensitive** to medication than healthy people and the golden rule is always to start with very low doses. Drugs often have different effects when used in combination with other remedies, and anyone using prescribed or over-the-counter medication should make sure that their GP knows what is being taken, **including herbal and other natural treatments.***

Pain Clinics

Pain relief is a specialist area of medicine and in serious cases a GP can refer a patient to a pain clinic. In Sheffield this could be either at the Royal Hallamshire Hospital or at the Northern General Hospital. For private patients in Sheffield, there is also a pain clinic at the Claremont Hospital. Pain clinics can involve anaesthetists, neurologists, physiotherapists and psychologists, and often an alternative approach such as acupuncture. At a pain clinic you might discuss the possibility of receiving **trigger point injections** whereby pain relief medication and muscle nutrient chemicals are delivered directly to the muscle fibre.

Natural and non-medical pain relief



Herbal and nutritional support

It is important to give your body the nutritional building blocks it needs to heal. People with ME/CFS should make sure that they are getting all the B vitamins, antioxidants, magnesium, zinc, selenium and protein that they need, from a varied wholefood diet, using supplements if necessary as a back-up. **Magnesium** is particularly important in the case of muscle pain, and Dr Sarah Myhill recommends taking as much of the supplement as possible without getting diarrhoea. Magnesium can also be absorbed through the skin by taking an **Epsom salts bath**, which some people find very helpful. (Epsom salts are magnesium sulphate; the amount to put in your bath would be around 600g of salts to a standard size bath of 60 litres).

There should also be enough Omega 3 fatty acids in the diet for there to be a correct balance of fatty acids in the body, since this will help to reduce the production of inflammatory hormones which worsen pain. It is thought that the Omega 3s are the ones most likely to be deficient in the modern diet. Natural sources of these are oily fish (mackerel, wild trout, herring, sardines, tuna and salmon), and also berries, leafy vegetables, flax seeds and oil, hemp seeds and oil, walnuts.

Supplements and herbs are reported to help pain. It is however important to remember that they may act in the body in a similar way to drugs, so can cause side effects and may interact with any other medication you are taking. For this reason you should tell your GP or specialist if you are taking any herbal or nutritional supplements, if other medication is being prescribed. Very little research has been done on the

effectiveness of these approaches. However, those that are supported by evidence include:

Feverfew for prevention and treatment of headaches and migraine. However, as with all herbs and nutrients, not all preparations and formulations have been found effective. Some people swear by chewing a leaf of feverfew, a common garden weed, as soon as they feel a headache coming on (you need to be SURE of the identification). **Butterbur** is also sometimes used for migraine type headaches, taken as a prepared tablet or tincture.

Willow bark is the original source of aspirin, but when the whole herb is used it has been found to be safer and even more effective than aspirin. It does not have adverse effects on the stomach lining.

Cherry fruit contains compounds which inhibit inflammation and it also has antioxidant properties. It can be bought as a supplement.

Essential fatty acids such as cod liver, evening primrose and starflower oils can be helpful for joint pains, period pains, breast pain (mastalgia) and some other inflammatory conditions. Really these should be part of a healthy diet in the form of fish oils or linseed.

Limited studies on the plant **Cat's claw** have found that it can be helpful for arthritis-related pain and inflammation. (In the form of Samento this is now being trialled amongst some people with ME/CFS for its other properties. Samento should never be taken without professional advice.)

Many non-drug measures exist that may improve pain, alone or in combination with painkillers and other drugs. However, not all these interventions are of proven benefit and some may have side effects.

Cannabis has been reported by many to be very effective in pain relief, and clinical trials are still taking place. **Cannabis is an illegal drug** but prosecution for possessing small amounts for medicinal purposes now seems fairly unlikely. Heavy use is now known to be connected with the onset of schizophrenia in young adults.

Nutrition Supplements

Glucosamine sulphate (sometimes combined with Chondroitin) often helps with bone and joint pains and can safely be used in conjunction with medical pain relief. This is widely available from health stores and chemist shops and there is now even a vegetarian form available from several companies, including Boots, and from Healthspan 0800 731 1277. Some nutritionists think that a superior form is glucosamine hydrochloride (not available in vegetarian form) which is available in health stores and from Higher Nature 01435 884668 www.highernature.co.uk.

TENS machine

Electromagnetic devices that emit electrical impulses or low-level electromagnetic fields have been found useful, and their use is supported by some evidence, in certain types of pain. For example, transcutaneous electrical nerve stimulation (**TENS**) is of proven benefit for lower back pain and might be helpful for other types of localised pain, although little research exists on its use by people with M.E.

One theory is that the application of a small current to the nerves interferes with the transmission of pain messages to the brain, and may also stimulate release of the body's endorphin painkillers. TENS and other such methods may become less effective over time and can have adverse effects, so seek professional advice before investing in such a device yourself if you are unsure. TENS may be available from your local physiotherapy department on the NHS and they can also be bought from many chemists. Prices start at about £30.00. They can also be bought online or via mail order from: <http://shop.glenmore.co.uk> tel: 1501 730000

Medicur is another small portable device for pain relief which releases gentle electromagnetic emissions to penetrate the affected areas. It doesn't need to be strapped on, like TENS, but is just held near to the affected part for three ten-minute treatments daily. It is different from the TENS machine and (like the TENS machines) is used in NHS hospitals, having certification as an approved medical device. It costs £168.95 but there is a money-back guarantee. Phone 08700 771 772, or visit www.snowdenhealthcare.co.uk.

Acupuncture

Acupuncture is used widely in Chinese medicine and more recently in western countries for pain relief. Needles, electrical stimulation, and other methods are used to stimulate certain 'acu-points', and this has the effect of prompting the release of endorphins and possibly other chemicals. The benefit of acupuncture in certain clinical situations is supported by some evidence. However, the effect varies depending on the nature of the pain and the types of acupuncture, but many people with ME/CFS do find it helps. Acupuncture is available on the NHS in some areas, in Sheffield for instance by GP referral to a pain clinic or to the Manor Clinic.

Hands-On treatments

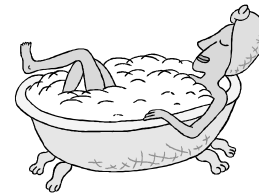
Self-help techniques such as **hot baths, massage, stretching, and hot or cold applications to painful areas** may be useful; all of these seem to work by generating nerve impulses that compete with pain signals.

Find out whether your pain responds to heat or to cool treatment, and then experiment with **EITHER** a hot water bottle wrapped in soft material, or a wheat bag, **OR** on the other hand with a cold damp face cloth or even a bag of frozen peas

Some people (including those with a wheat allergy) find an **electric heat pad** preferable to a wheat bag or hot water bottle. The Dreamland Heat Pad is available from ARGOS at the time of writing for £15.99.

At the most painful times, lie down with more than one hot water bottle or other source of heat over the worst affected parts, take your pain remedy, and **rest**.

A **warm bath** helps some people (too hot and it is exhausting for people with ME/CFS). Instead of rubbing yourself dry afterwards, wrap yourself in towels and lie on the bed. If a bath is too much for you, perhaps you can tolerate a footbath, which would also be a good way of using essential oils.



Essential oils can be used in conjunction with the above hands-on treatments, going carefully with them at first, using only a drop or two. Try **lavender, bergamot, clary sage, ylang ylang,** or **rosemary**. Put a couple of drops on a tissue inside your hot water bottle

or heat pad cover, or into your bath once you know that the oil does not cause a reaction with your ME/CFS.

Tiger balm is used as a rub for painful and aching muscles and it is worth trying a very gentle massage with a little of this. Deep Heat rub is another one to try. For headaches, you can also buy in health food shops an ointment called **4Head** which you rub gently into the temples.

Relaxation

Tensing the muscles makes pain worse. Many people have reported benefit from learning deep relaxation, sometimes incorporating visualisations and meditation. Our postal library has a selection of **relaxation tapes and cds** available for members to borrow. Yoga helps many people learn to relax (as long as the programme is suitable and preferably specifically designed for people with ME/CFS.)

Breathing

Gentle regular deep breathing is the basis of relaxation and a healthy pain-free body. Breathing is especially important for pain control, being the only part of the sympathetic nervous system over which we have some conscious control; calming the breathing has a marvellous effect on other parts of the sympathetic nervous system, which we can't of course consciously control. It is our 'gateway' to the parts of the nervous system which register pain.

In normal breathing, the in-breath is a muscular effort which takes less time than the relaxing out-breath. In stressed breathing, the in and out-breaths are quicker and of an almost equal duration. By becoming aware of our breathing, and sometimes counting with the breaths, we can **deepen and regularise our breathing** to one that has strong refreshing in-breaths and long luxurious out-breaths; this delivers the right amount of oxygen to our body cells and soothes and balances the nervous system with benefit to our other body systems and to our perception of pain. This is a way of breathing which with practice can become normal - not just something reserved for special times. It is of particular benefit to people with ME/CFS, where the body is under stress of various kinds.

Being comfortable

It can be helpful to experiment with **different positions** when in bed or sitting. Careful placing of cushions, foam wedges or rolled up towels can help to relieve painful and aching muscles and joints. It can also help to relieve and prevent pressure sores in people who are severely affected by M.E. and are very restricted in their movement.

Side lying - Use as many pillows under your head as required, keeping your neck straight rather than pushed sideways by pillows. To support the arm which is uppermost, put a doubled pillow underneath. A pillow is then placed along the length of the back and 'tucked in' a little underneath you. This prevents you from rolling backwards. One or two pillows are placed between the knees and this puts the hips and knees into a position of comfort and prevents the pelvis from rolling forwards.

Crook Lying - Lie on your back with your knees bent, use as many pillows to support your knees as you feel you need. This puts the lower back in a comfortable and well-supported position. Support your neck and head with one or two pillows. Place

each arm on a pillow giving support from behind the shoulder along the length of the arm, wrist and hand.

Body treatments

Physiotherapy may be beneficial as it can help to keep your joints and muscles moving and help prevent muscle weakness and joint stiffness. This in turn can help to reduce pain. Physiotherapy may be available on the NHS depending on your specific circumstances but we recommend that it **must be given by a practitioner who knows about the specific needs of someone with ME/CFS**. If a neurophysiotherapist can be found, that may be preferable. An inexperienced physiotherapist or massage therapist can cause even more pain and soreness by giving more than the extremely gentle treatment that is required. Deep massage is after all a passive exercise for the muscles and can have the same effect as active exercise on someone with ME/CFS.

A gentle **massage** from a therapist or family member can be very helpful and soothing. The best massage for pain is a gentle stroking ('effleurage') over the affected area and for people with ME/CFS this usually must be **VERY gentle**. Self-massage is also possible, as with the natural instinct is to rub over a painful area. **Reflexology** is one of the most relaxing treatments available and it has a good track record in helping people who experience chronic pain.

There are also **acupressure points** on the surface of the body which may control certain pain pathways. A headache may be eased by thumb pressing between the eyebrows for 15 seconds. Pressing up and under the base of the skull with the thumbs is also helpful.

Coping with pain

Cognitive Behavioural Therapy (CBT) can help individuals cope better and adjust to living with a chronic health problem such as M.E. Studies have shown positive results in some people well enough to attend an outpatient clinic. The effect of CBT on pain in M.E. is not yet well researched, although the technique is used widely for many forms of chronic pain, and trials suggest that it can be very effective.

We recommend that CBT be administered by an appropriately trained therapist who has experience of caring for people with M.E.

Triggers

Listen to your body. Rest if it hurts! Wherever possible, avoid things that you know will make you feel worse – these may include stress, hunger, coffee, alcohol, certain foods, bright light, noise, and exercise.

Other people



Pain can make you tired, sad, irritable and difficult for others to live with. Explain this to your family and friends so that they realise that they are not to blame for your being short tempered and unhappy. At the same time, don't feel guilty about your pain. The pain is not your fault. People in pain are often disbelieved, especially when there is no obvious cause for the pain. Sometimes it can help friends and family to

understand if you give them something to read about your illness, or if you take them along to a support group meeting or conference.

One of the best things that other people can do for you is to arrange for you to have the time for the **rest and recuperation** that is needed by all those who suffer from chronic pain.

Sleep

Chronic pain sufferers frequently have insomnia, which can be profound. It is vital to achieve good quality sleep because it is in sleep that much of the body's healing and repair takes place. A very low dose tricyclic anti-depressant such as amitriptyline or nortriptyline (see above) can improve sleep quality and is non-addictive. Take it about five hours before bedtime to ensure maximum benefit and avoid any hangover effects.

Take all the sensible measures you can for a good night's sleep, including relaxation before bedtime and making a comfortable bedroom atmosphere. Don't eat a heavy meal before bedtime, but don't go to bed hungry either. Don't take essential oil or vitamin supplements at night because these are 'energising' – take minerals at night, especially magnesium, for their relaxing and restorative properties. It is particularly important to make the bedroom completely dark. Even if you wear an eye mask, the scalp is translucent and so the brain is aware of daylight and produces 'wake-up' hormones when there is natural or artificial light.

Do all you can to achieve a good night's sleep, even if it means using herbal or medical means. Discuss with your doctor, herbalist or therapist how you can break the vicious pain / insomnia cycle.

Resources

On Line: www.painsupport.co.uk is very much worth a visit. It covers just about all the orthodox medical and the complementary treatments available and is an organisation which anyone affected by chronic pain (also carers) can join on-line, receive email updates and make contact with others. There are many other websites with information about pain relief which you can find by following links from this site and the one mentioned below.

By post: Pain Concern, PO Box 13256, Haddington, East Lothian EH41 4YD www.painconcern.org.uk has lots of information to send for, and a Listening Ear service, as well as internet services. Phone 01620 822572.

The British Acupuncture Society can help you find a qualified acupuncturist www.acupuncture.org.uk phone 020 8735 0400.

Books

Natural Pain Relief – a Practical Handbook of Self-Help by Jan Sadler (CW Daniel Books 2001, £9.99) Jan Sadler has also produced tapes and cds on relaxation and pain relief strategies, all of which are recommended.