MANAGEMENT FILE

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the ME association

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GABAPENTIN – THIS IS AN OPTION FOR MODERATE TO SEVERE PAIN

BACKGROUND

Most people with ME/CFS experience pain. This can range from mild to severe and for some people pain is the most disabling aspect of their illness. The commonest type of pain affects the muscles (where it may be exercise induced) but it can also affect the joints (arthralgic pain) and nerves (neuropathic pain) where it is often described as burning, stabbing or searing and is sometimes accompanied by pain that is triggered by normally harmless stimuli such as touch (allodynia). The musculoskeletal pain of ME/CFS can be very similar to that reported by people with fibromyalgia.

WHAT CAUSES PAIN IN ME/CFS?

The cause of pain in ME/CFS is still uncertain and difficult to establish because there is no obvious painful injury that triggers it off and it may not even be present during the early stages of the illness. However, it may relate to the way in which messages about pain pass from the arms, legs and body via the spinal cord and brain stem to parts of the brain that are responsible for recognizing and responding to pain. It seems that the information about pain that passes to the brain via the nervous system is no longer being dealt with in a normal manner in ME/CFS. Consequently, the whole nervous system becomes over sensitive to pain and mechanisms that normally help to dampen down or modify pain are no longer functioning properly.

MANAGING PAIN IN ME/CFS

Management of pain in ME/CFS can be very frustrating for both patients and their doctors. Conventional over-the-counter painkillers such as aspirin, paracetamol and ibuprofen (Brufen) are often of limited or no real value when pain is more severe or persistent. Prescription-only pain–killers for moderate to severe pain (e.g amitriptyline – unlicensed indication, mild opiates) can also be of limited value.

One further option that may be worth discussing with your doctor when these drugs have been tried without any real benefit, and the pain is moderate to severe in character, is the use of a drug called gabapentin (trade name = Neurontin).

The rest of this Management File is about gabapentin. The MEA has a separate information sheet covering all aspects of pain management (drug and non-drug) in ME/CFS. We also have a leaflet covering the use of low dose amitriptyline – another prescription-only drug that some people find helpful.

WHAT IS GABAPENTIN?

Gabapentin is a drug normally used to treat epilepsy – where it stabilises and calms down electrical activity in the brain. It does so by mimicking the action of a brain chemical transmitter called GABA, which is a 'nerve-calming' chemical. However, it has also been found to be effective in relieving neuropathic/nerve pain. It is sometimes also used to treat migraine and trigeminal neuralgia (facial pain).

NEW PRESCRIBING GUIDANCE FOR GABAPENTIN

Due to growing concerns about misuse, the legal status of gabapentin (trade name = Neurontin) has changed and these changes came into effect in April 2019. This drug is now classified as a Class C Controlled Drug.

This means that there are additional restrictions on the way in which doctors are able to prescribe gabapentin.

Restrictions include prescriptions being limited to 30 days treatment and repeat prescriptions no longer being allowed.

And as a result, some doctors are likely to take a far more cautious view about prescribing gabapentin for pain relief in ME/CFS.

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

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HOW DOES GABAPENTIN ACT?

It appears that the drug acts on pain control mechanisms in the brain and/or spinal cord. The way in which it acts on chemical transmitters in the brain (neurotransmitters) remains uncertain but this may involve limiting the release of pain-communicating chemicals by nerve cells in the pain pathways of the brain and spinal cord and/or its 'nerve calming' role.

HOW IS GABAPENTIN USED FOR PAIN RELIEF?

The drug is available in 100mg and 300mg and 400mg capsules and 600mg and 800mg tablets. The British National Formulary (BNF) recommends starting with 300mg daily and progressively increasing the dose over a number of days. Anecdotal evidence suggests that in ME/CFS it may be worth trying a lower dose (100mg dose) to start with and working up more slowly – in view of the way in which people with ME/CFS can be more sensitive to drugs acting on brain chemical transmitter systems.

IS THERE ANY EVIDENCE THAT GABAPENTIN CAN RELIEVE PAIN IN OTHER CONDITIONS?

In addition to its use in neuropathic pain gabapentin has been assessed for relieving musculoskeletal pain in fibromyalgia – a condition with a considerable degree of overlap to ME/CFS. One clinical trial in fibromyalgia found that gabapentin reduced pain, fatigue and sleep disruption more effectively than a placebo. Gabapentin was generally well tolerated in this trial.

Reference: Arnold LM et al. (2007) Gabapentin in the treatment of fibromyalgia: a randomised, double-blind, placebo-controlled, multicenter trial. *Arthritis Rheumatology*, 56, 1336 – 1344.

SIDE-EFFECTS

Results from studies where gabapentin has been used to treat nerve pain (in diabetic neuropathy and post-herpetic neuralgia) indicate that the drug is normally well tolerated. Feedback to the MEA Management Survey[1] from 248 people who had used gabapentin found that 56% found it to be an acceptable drug to use; 44% said it was not.

Side effects that are quite often reported in studies where gabapentin has been used in neuropathic pain include dizziness, drowsiness, headache, diarrhoea, confusion, nausea, ataxia (shaky movements and unsteady walking), peripheral oedema (fluid retention).

The British National Formulary lists a large number of potential side-effects. These include:

- dry mouth, dyspepsia, constipation, appetite change, weight gain
- hypertension, vasodilation
- dyspnoea (shortness of breath), cough, rhinitis
- tremor, paraesthesiae (abnormal sensory feelings – eg pins and needles)
- urinary incontinence,
- flu-like symptoms
- arthralgia, myalgia (joint and muscle pain)
- rash, purpura (bleeding into the skin) in legs/ankles, acne

Gabapentin can also cause anxiety, depression, mood swings, difficulty sleeping.

Occasionally, serious side effects have been reported. These include hepatitis, pancreatitis, movement disorders, blood glucose fluctuations in diabetes and suicidal intentions.

In practical terms this means taking care if you have to drive or operate machinery (as it can cause drowsiness and dizziness) and letting your doctor know if you have any adverse effects – such as skin rashes, mood changes or suicidal thoughts.

Your pharmacist will supply you with a leaflet covering side-effects in more detail. Please read it!

CAN GABAPENTIN BE USED IF TAKING OTHER DRUGS?

Absorption of gabapentin is reduced when taking aluminium or magnesium salts that are often found in antacids (indigestion remedies) – so antacids should not be taken at the same time as gabapentin, or in the two hours before a dose of gabapentin. So check with your pharmacist if you need to use a combination.

Otherwise, it does not normally cause problems with other drugs when use for pain relief.

OTHER PRECAUTIONS

Animal studies have not demonstrated impaired fertility or foetal harm with gabapentin. Even so, it should only be prescribed in pregnancy or when breast feeding where essential.

Gabapentin should not be withdrawn abruptly – because it can cause a withdrawal syndrome involving anxiety, sleep disturbance, nausea, pain and sweating. It should be tapered off over a period of at least one week. You doctor will tell you how to do this.

Gabapentin should be used with caution in the elderly, people with kidney problems/impairment and diabetes.

The capsules contain lactose and should not be taken by people with galactose intolerance or malabsorption.

FEEDBACK ON GABAPENTIN

Feedback to the MEA on the use of gabapentin indicates that it can be helpful in some cases, especially where there is nerve pain. Feedback from 248 people in our 2010 Management Survey, we reported that 11% had a good response; 27% had a moderate response; 11% had a poor/minimal response; 25% reported no change. However, 27% reported that it made them feel worse.

The Chief Medical Officer's report on ME/CFS also noted that gabapentin, along with other anticonvulsants, were

options that could be considered for more severe pain that has a neuropathic quality.

OTHER OPTIONS

Pregabalin (trade name = Lyrica) is a similar drug to gabapentin. Pregabalin has also been found to be helpful in treating fibromyalgia and the FDA in America has approved the use of pregabalin for fibromyalgia patients.

In the MEA Management Report, 146 people provided feedback on the use of this drug. 15% had a good response; 22% a moderate response; 10% a poor/minimal response; 23% reported no change; 29% said it made them feel worse.

The MEA Management Report – which contains a section on approaches to pain management that people with ME/CFS find helpful/unhelpful – can be downloaded from the MEA website or by using this TinyURL link: **http://tinyurl.com/czlpfnn**

Paper copies can be obtained using the Order Form in the centre pages of our quarterly *ME Essential* magazine.

Medical information contained in this leaflet is not intended to be used as a substitute for medical advice or treatment from your own doctor. The ME Association recommends that you always consult your own doctor or healthcare professional about any specific problem. We also recommend that any of the medical information provided by The MEA in this leaflet is, where appropriate, shown to and discussed with your doctor.