MANAGEMENT FILE

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the ME association

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HEADACHES AND ME/CFS

INTRODUCTION

Headaches are often reported by people with ME/CFS. They also form part of the symptom list for most diagnostic criteria for ME/CFS. But headaches can obviously have other causes – physical and psychological – as well.

WHAT CAUSES HEADACHES?

Doctors classify headaches as being **primary** where there is no obvious link to an underlying medical problem, or secondary where there is a clear link.

Primary headaches include:

Cluster headaches

An excruciatingly painful headache that causes intense pain around one eye. Cluster headaches are fairly rare and tend to occur in clusters for a month or two, sometimes around the same time each year. Ordinary painkillers don't tend to help – this type of headache normally requires a prescription-only treatment.

Migraine headaches

These tend to be recurrent, disabling and often prevent a person carrying on with normal daily life. The pain is often described as pounding or throbbing on one or both sides of the head. Other symptoms may include nausea and visual disturbances.

Tension headaches

These are the most common form of headache. Tension headaches are often described as a dull ache with constant pressure around the front, top and sides of the head – as if a rubber band has been stretched around it. Common causes include stress, depression, lack of proper sleep, skipping meals, not drinking enough fluid and alcohol.

Secondary headaches are caused by an existing medical problem. Some of these are serious, which is why you must see your doctor if you have severe or persistent headaches.

Common causes, which are normally self-limiting, include infections such as colds, flu and sinusitis. Examples of more persistent or serious causes include allergies, analgesic overuse, brain tumours, acute glaucoma, intra-cranial hypertension (where there is raised pressure in the brain and which has been suggested as a cause of ME/CFS) and brain infections such as meningitis.

Temporal arteritis should always be queried in elderly people who have a severe headache. Other symptoms include jaw pain when eating, blurred or double vision and/or a sore scalp. This type of headache is caused by inflammation in the large and medium arteries in the head and neck.

Temporal arteritis is a medical emergency that requires urgent treatment with high-dose steroids.

Headaches in women can be caused by hormonal problems – including taking the contraceptive pill, going through the menopause, pregnancy, and as part of period pain.

It's also worth noting that a headache is the most common symptom of carbon monoxide poisoning – a potentially fatal condition. Other symptoms include being/feeling sick, dizziness and stomach pain.

This should always be queried when there are other people in the house with similar symptoms; the headache disappears when away from home and returns when you come back; or a household pet is unwell.

WHAT CAUSES HEADACHES IN ME/CFS?

The simple answer is that we just don't know.

Although various abnormalities relating to brain and nervous system

function have been reported in the research literature, none of them provide a satisfactory explanation as to why some people with ME/CFS have headaches, and others do not.

What we do know from research is that there is a link between ME/CFS and migraine-type headaches *(reference 1)*. Where migraines or migraine-type headaches occur, this will influence the choice of drugs that might be used to both treat and prevent headaches occurring.

There is also a link between ME/CFS and temperomandibular joint (TMJ) disorders *(reference 2)* – where the joint between the lower jaw and base of the skull causes various types of facial pain. About 20% of people with TMJ disorders have headaches. If you suspect that you may have a TMJ problem, the best person to talk to is your dentist.

There has also been some research published from a neurology group at Addenbrooke's Hospital in Cambridge *(reference 3)* which indicates that an unquantified, but possibly substantial minority of patients with ME/CFS have what is called idiopathic intracranial hypertension.

WHEN TO SEE YOUR DOCTOR

If you have headaches at the start of your ME/CFS, this should always form part of the initial clinical assessment.

The doctor should ask about the location of the pain, severity, duration, exacerbating factors (e.g coughing, sneezing, exercising, change in posture, menstruation) and relieving factors – all of which will help to decide whether there is a need to investigate further and what sort of drug treatment is most likely to help.

If there are any other symptoms or signs suggesting that there could be another more serious explanation for your headaches, the doctor will arrange further tests, or refer you to a neurologist, or to a headache clinic at the hospital.

If headaches appear after ME/CFS has been diagnosed as a 'new symptom', this should always be discussed with your GP before you start self-treating with over-the-counter, painkilling drugs.

RED FLAG SYMPTOMS AND SIGNS

There are a number of 'red flag' symptoms and signs which indicate that a headache may have a more serious cause. If any of these occur, you must see your doctor for further advice:

- Sudden severe headache
- Red eye and haloes around lights – acute glaucoma
- Neurological symptoms or signs
- Coinciding with other new symptoms or signs.

IN CHILDREN

Headaches can also occur in children and adolescents with ME/CFS. Again, it's important to check with your doctor who will want to ask about:

- Where they occur
- How often they occur
- What makes them better (e.g sleep) or worse (e.g food, periods, stress)
- Are there any associated symptoms?
- Are headaches reported at school?

If a child has a more severe or sudden headache, or persisting headaches, other explanations must be considered. Red flag symptoms, where you must check with a doctor, include:

- Photophobia – sensitive to bright lights
- Neck stiffness
- Fever
- Non-blanching skin rash
- Weakness of arm or leg
- Changes in conscious level or behaviour.

Any headache that is accompanied by photophobia, neck stiffness or a rash could be due to meningitis – which is a medical emergency.

WHEN TO SEE YOUR PHARMACIST

When it comes to simple, over-the-counter (OTC) treatments for headaches, a good person to talk to is a pharmacist – who can advise on what sort of drug treatment may or may not be suitable and safe. The pharmacist can also advise on what sort of dose you should take and how much is safe to take on a regular basis.

Simple analgesics – such as aspirin, paracetamol and ibuprofen/Brufen – all have a role to play depending on individual preferences and sensitivities.

There's no need to buy expensive named brands – generic drugs are just as good.

Some OTC preparations contain additional ingredients such as caffeine but these may not be helpful if you have ME/CFS.

PRESCRIPTION–ONLY DRUGS

There are also a number of drugs that doctors can prescribe when headaches become more severe or persistent and do not respond to simple OTC remedies. Examples include a low dose of a sedating tricyclic antidepressant drug called amitriptyline, which may also help with pain and sleep disturbance in ME/CFS.

MIGRAINE HEADACHES AND ME/CFS

There are several OTC and prescription-only drugs for treating and preventing migraine attacks.

For acute attacks, simple OTC pain-killing drugs like aspirin, paracetamol or ibuprofen/Brufen may be sufficient. Dispersible or effervescent preparations are preferable because migraine slows down gut peristalsis (= movements) and decreases drug absorption during an attack.

If simple painkillers don't help, there are more powerful prescription-only drugs – especially a group known as the triptans (e.g almo/ele/frova/nara/riza/suma/zolmi - triptan) which act on

a chemical-transmitter system in the brain that seems to be involved in migraine attacks.

There are also drugs that will reduce sickness/nausea during an attack and compound preparations containing both a painkiller and an anti-sickness drug.

During an acute attack people often find that lying in a quiet dark room is one of the most helpful things you can do. Some people also find cooling – using a cold flannel or gel ice pack – helpful.

If you are having two or more migraine attacks per month, or have attacks that are becoming increasingly severe or prolonged, there are prescription-only drugs that can help to reduce the frequency of attacks.

Preventative drugs include low dose tricyclic antidepressants, gabapentin, pizotifen (limited value and causes weight gain), sodium valproate and beta-blockers such as propranolol (which are often poorly tolerated by people with ME/CFS).

Botulinum toxin is a further option for more severe migraine where these drugs have not been helpful.

Clonidine is no longer recommended for migraine prevention because it can aggravate depression and insomnia.

There is also some evidence to show that a popular herbal remedy called feverfew – a plant that comes from the daisy family – can help prevent attacks.

But do talk to your doctor or pharmacist before taking feverfew because it can have side-effects (abdominal pain, allergic reactions, nervousness, mouth ulcers); should not be taken during pregnancy; can interact with other drugs (eg blood-thinning tablets such as warfarin) and should not be taken with aspirin or ibuprofen (because it acts in a similar way). Feverfew should be discontinued gradually because abrupt cessation can cause a withdrawal syndrome.

If you have migraine-type headaches you need to look at possible trigger factors as well. These can include drugs (especially the contraceptive pill), foods such as citrus fruits and chocolate; caffeine intake; chemicals; stress; poor sleep and bright lights. An exclusion diet can help to identify 'culprit foods' – an pproach that should be carried out with the help of a dietician.

If migraine-type headaches aren't being well controlled, you could ask your GP to refer you to a hospital- based migraine clinic.

MEDICATION–INDUCED/ OVERUSE HEADACHES

One of the problems with taking regular analgesics, especially self-treating with OTC drugs for tension-type headaches, and for migraine attacks, is that frequent use of these drugs (eg for more than two days a week on a regular basis) can actually cause headaches – so people become trapped in a vicious circle.

This type of headache is often described as oppressive and tends to be worst first thing in the morning, or after exercise. It may turn into a constant dull headache with spells when it gets worse.

Medication-overuse headaches should be considered when headaches are present and are being treated for more than 10 days a month (for an opiate or triptan drug) or for 15 days or more a month (for other types of painkiller), or the headache has developed or worsened during medication use for headache.

Opiate-containing medications such as codeine cause the most frequent problems. Codeine, both on its own and in co-codamol (combined with paracetamol) are probably the worst culprits and are best avoided if possible. Non-steroidal inflammatory drugs like ibuprofen/Brufen are less likely to cause this type of headache. Although triptans are not classed as painkillers, and work in a different way, they can still cause a medication-induced headache.

Treatment involves devising a plan to reduce and stop painkiller use – but this has to be done in conjunction with your doctor.

So if you are self-treating using regular painkillers, it's worth having your medication reviewed at regular intervals by your GP or pharmacist.

REFERENCES:

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