



# MANAGEMENT FILE

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This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine. MEA membership costs £18 a year for people living in the UK/BFPO. For contact details, see foot of this page.

the ME association



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## A-Z OF SYMPTOM MANAGEMENT

### INTRODUCTION

With no effective drug treatment for the underlying causes of ME/CFS currently available, the medical management of this illness is very much aimed at trying to relieve the various disabling symptoms. This can involve the use of prescription-only and over-the-counter drugs, self-help strategies, and alternative and complementary therapies (ACMs) – sometimes involving all three.

The main purpose of this guidance is to summarise how these three approaches can be used to help manage some of the most common symptoms. It also includes symptoms that are not already covered in our symptom-specific information leaflets.

In the case of children and adolescents the symptom profile can be slightly different to adults in that gastro-intestinal symptoms (ie nausea, abdominal pain, changes in appetite leading to weight loss or weight gain) and headaches are more common. However, the basic principles of management are the same – although drug treatment will involve lower doses and some of the drugs that are used in adults may not be suitable or licensed for use in this age group.

People with severe ME/CFS often have more significant problems with cognitive dysfunction, pain, light and noise sensitivity. They may also have additional neurological symptoms including atypical seizures along with speech and swallowing problems.

ME/CFS can involve a wide range



PHOTO: COURTESY OF OUR 'REAL M.E.' CAMPAIGN

of symptoms. When a new symptom develops, don't assume that it's 'just another part of the illness' – check with your doctor as there may be another explanation. The same advice applies when an existing symptom is obviously getting worse, or changes in character, for no obvious reason.

When it comes to using prescription-only drugs, people with ME/CFS are often very sensitive to certain types of medication – especially those that act on chemical transmitter systems in the brain. So it's sensible to start with a low dose and gradually increase this over a period of time. If one drug isn't helping after a reasonable trial period, it may be worth trying a similar type of medication before concluding

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### KEY SYMPTOMS OF M.E.

- Post-exertional malaise
  - Activity-induced muscle fatigue
  - Cognitive dysfunction
  - Sleep problems
  - Ongoing flu-like symptoms including sore throats and tender glands
  - Orthostatic intolerance
- Other common symptoms include:*
- Pain – muscles, joints and nerves
  - Problems with balance and temperature control
  - Gastro-intestinal symptoms
  - Sensitivity to light and sound
  - Alcohol intolerance
  - Headaches

that this approach isn't going to help.

An additional and very useful source of information on symptom relief is our Management Report. This contains 'patient evidence' from over 4,000 people with ME/CFS and covers all three approaches to symptom management – along with information on which treatments help, and which ones do not. The report can be [downloaded free](#) from the ME Association website. Paper copies can be ordered using our [literature order form](#).

## ALLERGIES, INTOLERANCES AND SENSITIVITIES

Patient evidence indicates that some people with ME/CFS are more likely to develop allergic conditions, or experience a worsening of any pre-existing allergic condition. There is also some research evidence to support a link between ME/CFS and allergic disease.

Identifying and, wherever possible, avoiding any possible trigger factors for an allergy (e.g animal fur, plant pollens, drugs, foods) is obviously a key aspect of management. This could include the use of blood tests and skin tests that help to identify specific allergies.

There is no evidence from clinical trials to demonstrate that anti-allergy drugs, such as antihistamines or steroids, are of any general benefit in ME/CFS. However, drug treatments that are known to be safe and effective for specific allergic conditions, such as hay fever or allergic rhinitis, may well be helpful in controlling allergic symptoms.

If further help is required in either diagnosing or managing an allergic component to your ME/CFS you could ask your GP for a referral to an allergy specialist or clinic at a local hospital.

**Intolerances** to various foods can play an important part in triggering migraine-type headaches and exacerbating irritable bowel symptoms – both of which are more common in people with ME/CFS. The use of an exclusion diet, whereby different foods are carefully excluded, may be helpful here.

But do take professional advice from a dietitian before doing so.

**Alcohol intolerance** is extremely common in ME/CFS, especially at the onset of the illness, and many doctors (myself included) would regard this as an important diagnostic marker. This is probably related to the way in which alcohol affects chemical transmitter systems in the brain. Alcohol should therefore be avoided during the early stages of ME/CFS. However, some people find their tolerance to alcohol slowly returns if their ME/CFS improves.

**Sensitivities** to some chemicals in the environment – eg perfumes, pesticides, chemical sprays – also appear to be more common, especially in people with severe ME/CFS. Identifying and avoiding trigger factors is the most important part of management here – as drug treatment options are very limited.

Finally, it's important to note that allergic reactions involve an abnormal immune response and that different mechanisms are involved in relation to food intolerance and chemical sensitivity.

## COGNITIVE DYSFUNCTION ('BRAIN FOG')

Cognitive dysfunction refers to problems with short-term 'working' memory, concentration, processing new information, retrieving information and attention span. For some people, cognitive dysfunction is one of the most disabling aspects of having ME/CFS.

Various explanations have been put forward as to why cognitive dysfunction occurs in ME/CFS. These include changes in the level of chemical transmitters that help to pass messages around the brain and alterations in blood flow to key parts of the brain.

Symptoms such as sleep disturbance and depression, where these occur, will also have a significant adverse effect on normal mental functioning and make cognitive dysfunction worse.

Equally, a number of other medical conditions that cause disabling fatigue (low thyroid gland function, for example) often cause cognitive dysfunction – so these need to be checked if cognitive dysfunction is deteriorating.

Cognitive dysfunction can improve over time as it does not seem to be caused by permanent damage to brain cells. A simple way to understand what may be going wrong is to compare the brain in someone with ME/CFS to a computer where the circuits are misbehaving and don't work properly all the time.

Unfortunately, none of the drugs that affect brain chemical transmitters or



increase blood flow to the brain – sometimes prescribed for other conditions where there are significant problems with mental functioning – appear to be of any value in treating cognitive dysfunction in ME/CFS.

One possible exception is the use of **antidepressants**, which may help where a depressive component is clearly contributing to problems with memory and concentration.

In relation to supplements there is a fatty acid supplement known as **eicosapentaenoic acid (EPA)** where some positive findings have been reported in ME/CFS from a very small preliminary study.

## COLD HANDS AND FEET

For details, please look at our [leaflet](#) covering the subject of Essential Fatty Acids and EPA in our website shop.

Claims have been made that the herbal remedy **gingko biloba** may improve memory in people with dementia. But there's no hard evidence that it helps memory problems in ME/CFS.

So managing this key aspect of ME/CFS is largely down to self-help strategies and applying the principles of good energy management/pacing to mental and emotional activities as well as to physical activities.

Self-help strategies such as pacing, delegating, doing things in small manageable chunks like reading or writing, employing distraction therapy – like switching activities when cognition becomes less manageable, and the use of written prompts to remind you to do things – can all be helpful.

Over time, things that were unachievable such as reading to the standard that was once taken for granted can become easier if you learn to use breaks and don't try to push beyond your limitations. Unfortunately, with a relapse, these activities and strategies may then have to be 're-learned'.

If cognitive problems are really disabling or deteriorating, it may be worth asking your GP for a referral to a psychologist who is interested in this type of problem.

If cognitive dysfunction is getting worse for no apparent reason, you do need to see your GP – who can check to make sure that there isn't another medical explanation that could even be treatable.

◆ We have a recently updated leaflet covering all aspects of [cognitive dysfunction](#) and [another one](#) that can be used to explain the effect of this to employers, schools, etc.

Problems with temperature control are an extremely common part of ME/CFS.

At one end of the spectrum this can involve an inability to tolerate high temperatures and hot environments. At the other end is an increased sensitivity to low temperatures – something that often produces cold hands and feet.

One possible explanation for poor temperature control is malfunction of a small thermostat-like gland in the brain called the hypothalamus. Reduced activity levels can also play a role in causing these type of circulation problems. In the case of cold hands and



feet, a part of the nervous system that controls the size of tiny blood vessels (the autonomic nervous system) also becomes super-sensitive to changes in temperature and causes over-constriction when the temperature falls.

There are various self-help and practical measures that can help here, such as warming pads and the use of thermal clothing.

If symptoms become more persistent or unpleasant, or there are symptoms such as marked redness or swelling, check with your doctor because there are a number of drug treatments that help to open up the tiny blood vessels that may be worth trying.

◆ The MEA has a [leaflet](#) that provides detailed information on all aspects of the management of cold hands and feet

◆ The Raynauds and Scleroderma Association is a useful source of practical advice on management.

Website: [www.raynauds.org.uk](http://www.raynauds.org.uk)

Tel: 01270 872776

## DEPRESSION AND MENTAL HEALTH ISSUES

It's not always easy for a person with ME/CFS to realise and accept that they are moving from a very understandable state of being frustrated and fed up with this illness into what doctors would recognise as true clinical depression.

Symptoms that would point to clinical depression include loss of appetite and significant weight change, loss of interest in everyday activities (=anhedonia), early morning wakening, feelings of low self-esteem and worthlessness, being tearful or having suicidal thoughts/intentions. The latter symptom should always be taken seriously and normally indicates the need for professional help.

Depression, where it co-exists, needs treating. This means seeing your doctor. For mild to moderate depression, the options are counselling, cognitive

behaviour therapy and anti-depressant drugs.

While there is some limited evidence that a herbal remedy called St John's Wort can benefit people with mild depression, this is no longer recommended by doctors as it can cause side-effects and interact with a number of drugs

There are three main groups of anti-depressant drugs, along with a number of newer antidepressants – all of which can be useful in certain types of depression. In recent years the use of what are called tricyclic anti-depressants has declined while the use of selective serotonin reuptake inhibitor (SSRI) anti-depressants, which increase the level of a chemical called serotonin in the brain, has increased.

There's no ideal choice of anti-depressant drug in ME/CFS – this will

depend on your existing symptoms because some of the drug side-effects can be very similar to ME/CFS symptoms, whether you have any other medical problems, the severity of the depression you have, and whether there is any associated anxiety.

The two main groups of anti-depressant drugs (ie tricyclics and SSRIs) both have side-effects that can be problematic for people with ME/CFS.

In the case of SSRI drugs, patient evidence indicates that while some people with ME/CFS benefit from their use and don't have any problems with side-effects others react badly to this group – even at very low doses. This probably relates to the fact that serotonin status appears to be affected in ME/CFS – with those who have low levels of serotonin benefitting from SSRIs and those with high levels experiencing adverse effects.

Whatever drug is prescribed, it's often better (where possible) to start at a low dose and gradually increase this over a period of weeks. This is because people with ME/CFS are often very sensitive to drugs that act on the brain chemical transmitter systems that are involved in depression. Current thinking is that antidepressant therapy should normally be maintained for a period of time once the depression has cleared.

◆ The ME Association has a [leaflet](#) covering all aspects of depression and the use of antidepressant drugs in ME/CFS. There are also leaflets on [Anxiety and Panic Attacks](#) and [Managing your Emotions](#).

## EYE PROBLEMS

These can include problems with focusing – especially when coping with tiredness, vision and reading fatigue, and intolerance of bright lights (known as photophobia).

Dry eyes are sometimes reported. If this is the case, speak to your doctor about the regular use of eye drops called artificial tears. With dry eyes you will also need to be checked for Sjögren's syndrome – an autoimmune

## DIZZINESS AND PROBLEMS WITH BALANCE

**Experiencing dizziness**, or feeling faint, is fairly common in ME/CFS and may be related to problems with balance and/or changes in pulse rate and/or blood pressure when changing posture from lying to standing (*see the section on PoTS*).

However, dizziness and vertigo (which involves a spinning round sensation) can have other causes that are not related to ME/CFS, especially when this is associated with other symptoms such as hearing loss or headaches. If this is the case, you must see your doctor as it may require a specialist assessment and investigation.

**Balance problems**, which are often described as feelings of unsteadiness ('walking on rubber') or being dizzy, rather than actual spinning round or vertigo, are a very common symptom in ME/CFS.

They can sometimes be confirmed on a physical examination with tests that are designed to assess balance (eg a Romberg test) and the Fukuda test for vestibular function (the vestibular apparatus within the ear helps to

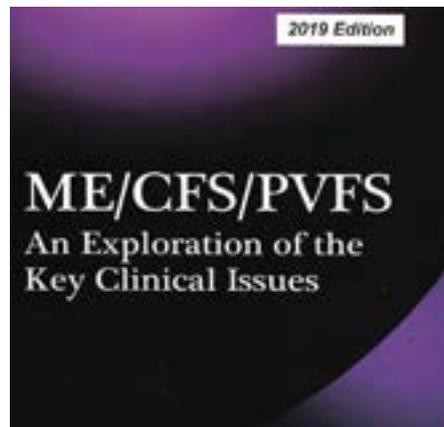
control balance). They can also be caused by dysfunction in the autonomic nervous system, a part of the nervous system which affects pulse and blood pressure control, especially when sudden unsteadiness occurs while changing posture from lying to standing (*see also the section on PoTS*).

There are several drugs available – including **cinnarizine / Stugeron** – that can sometimes help to relieve dizziness and balance problems. But they seem to be of very limited value in ME/CFS.

Where dizziness is related to a drop in blood pressure on standing (**ie postural hypotension**) there are self-help strategies and exercises that should help. There are also some drug treatments that may help if symptoms are more severe. *These are covered in more detail in the section on PoTS.*

Special exercises, known as Cawthorne-Cooksey exercises, have been designed for people suffering from certain types of dizziness and balance problems. They may be worth trying in some cases. If a balance problem is more severe or progressive, or is affecting your mobility, referral to an ear nose and throat (ENT) specialist could be discussed with your GP.

◆ Further information on balance problems, along with details of research that has been carried out in ME/CFS, can be found on pages 55-56 of *Living with ME* and in the clinical assessment section of the MEA clinical and research guide *ME/CFS/PVFS: An Exploration of the Key Clinical Issues*. n This can be [purchased here](#).



rheumatic illness that can cause disabling fatigue, joint pains, a dry mouth and dry eyes.

There is no evidence that ME/CFS is linked to any form of serious eye disease. However, if you are concerned about any form of eye symptom, do have it checked with either your doctor or an optician. Opticians can also advise on glasses and other ways of dealing with photophobia.

If there are any doubts about the

cause of an eye symptom, you can be referred to a hospital eye clinic / ophthalmologist for further assessment.

◆ Details of opticians who carry out home visits can be found by Googling 'Opticians, home visits'.  
◆ The MEA clinical and research guide has a more detailed review of eye symptoms, along with information on research into this aspect of ME/CFS.  
◆ Information on dry eye management can be found on [the MEA website](#).

# FATIGUE, ACTIVITY MANAGEMENT AND POST-EXERTIONAL MALAISE

Activity-induced fatigue and post-exertional malaise / symptom exacerbation are the cardinal symptoms of this illness.

Post-exertional malaise and symptom exacerbation, whereby undertaking activity beyond one's physical or mental limitations leads to an exacerbation of ME/CFS symptoms, is a highly characteristic and diagnostic feature of ME/CFS. The best way of preventing post-exertional malaise is through careful pacing of physical, mental and emotional activities.

The basics of pacing include:

- Aiming to establish a baseline of activities – physical, mental and emotional – that you are comfortable with and can cope with for most of the time
- Carrying out activities in small 'bit size' amounts with periods of rest or relaxation in between
- Alternating physical and mental activities throughout the day
- Gradually increasing activities in a very flexible manner when you feel capable of doing so
- Decreasing activity levels when symptom exacerbation or post-exertional malaise is occurring

The cause of fatigue in ME/CFS remains uncertain and probably involves complex factors affecting both the brain and muscle. Unfortunately, we don't yet have any drug treatment that has been shown to be effective in reducing fatigue levels, although a number of possible approaches are now being assessed.

The most important way of dealing with fatigue is taking the right approach to all aspects of energy management – in other words striking the right balance between activity and rest through the use of pacing.

The ME Association does not recommend the use of graded exercise therapy (GET) – which is based on

the idea that symptoms and reduced mobility are largely maintained by inactivity and deconditioning.

Some people claim that supplements which are claimed to increase muscle energy performance, such as **carnitine**, **NADH / Enada** and **Co-enzyme Q10** are helpful. They may be worth a try if you can afford the expense but there is no sound evidence of benefit from clinical trials.

Co-enzyme Q10 is known as a coenzyme because it helps other enzymes in the body to carry out their normal functions. In relation to muscle fatigue, it is involved in energy-producing chemical pathways inside the mitochondria – parts of the cell where energy in the form of a chemical called ATP is produced. It also has anti-oxidant activity. So there are some theoretical reasons why CoQ10 might be helpful in ME/CFS.

However, despite all the claims being made for CoQ10, there is very little scientific evidence linking deficiency with disease. Neither is there much evidence of benefit in diseases where it is sometimes recommended such as heart failure, mitochondrial muscle diseases, and Parkinson's disease (where decreased levels have been found in the spinal fluid). The same situation currently applies to ME/CFS.

◆ We have a [single leaflet](#) covering energy and activity management and pacing. There are also separate leaflets on the [Management of Relapses, Exacerbations and Flare-Ups](#), the special [nature of fatigue](#) in ME/CFS and the use of [muscle energy supplements](#).

◆ Patient evidence on the use of pacing and graded exercise therapy can be found in our report on the safety and efficacy of these approaches to management. This report also carries an MEA position statement on the use of pacing and GET. Report Summary: <https://tinyurl.com/y3m3g96m>

## FLU-LIKE SYMPTOMS

Most people with ME/CFS will continue to feel as though they have an on-going infection and experience flu-like feelings – which can include sore throats, tender glands and temperature control problems.

The reason why this occurs remains uncertain. But it may be due to changes in immune system function – including what is called 'low level immune system activation' when the body still thinks it is fighting an infection and produces chemicals called cytokines. These are responsible for the flu-like symptoms that accompany any infection.

Unfortunately, there is no form of drug treatment that has been found to be effective at dampening down these symptoms in ME/CFS. So management here has to be based on carefully pacing your activities and reducing activity levels when flu-like symptoms are prominent.

## HEADACHES



Headaches are a well-recognised symptom in ME/CFS and are sometimes migrainous in nature. If so, ask your doctor if one of the drugs that are used to treat migraine attacks might be worth trying. If migraine-type headaches are more severe or frequent, a trial of one of the drugs that help to prevent migraine attacks could be considered.

As with irritable bowel syndrome, some people find that certain foods trigger headaches. So exclusion of groups of foods is another possible approach that could be discussed with your doctor.

### **Two important points to remember:**

Firstly, although headaches are a fairly common symptom in ME/CFS,

they do have other causes. So do check with your doctor if they are becoming more frequent or severe or changing in character.

Second is that using over-the-counter painkillers too often can make the problem worse rather than better. So if you are taking a lot of painkillers, check with your doctor or pharmacist.

◆ The MEA has [a leaflet](#) covering all aspects of headaches in ME/CFS – including information about ‘red flag’ symptoms which indicate that the situation must be re-assessed by a doctor.

## HEARING PROBLEMS

These can include tinnitus (abnormal ringing or buzzing sounds in the ear) and hyperacusis (increased sensitivity to loud noise).

If tinnitus is becoming persistent or disabling, talk your doctor about some of the self-help devices that can help to mask out the noise. If tinnitus is becoming worse or intrusive, you can ask for a referral to an ENT (ear nose and throat) clinic for further assessment and management.

◆ The British Tinnitus Association – [www.tinnitus.org.uk](http://www.tinnitus.org.uk) tel: 0800 018 0527 – has useful information on masking devices and other aids. For more details on hearing problems, see page 60 of *Living with ME*.

## IRRITABLE BOWEL SYMPTOMS

Irritable bowel-type symptoms are fairly common in ME/CFS. These can include bloating, stomach pains and cramps, diarrhoea or constipation. Weight loss and rectal bleeding are not part of irritable bowel syndrome. You must see your doctor if either of these symptoms are present.

Irritable bowel syndrome (IBS) is not a condition that should be self-diagnosed and self-treated because there are a number of other conditions, such as coeliac disease and inflammatory bowel disease, that can cause fatigue and IBS-type symptoms.

Management includes the use of various drugs that can help to relieve

individual IBS symptoms – bloating, pain, change in bowel habit.

Food intolerance appears to play a role in some cases of IBS – so dietary modification/exclusion can sometimes help as well as a more specific diet such as the FODMAP diet. You can ask your GP for a referral to an NHS dietitian for help with this aspect.

◆ The MEA has [a leaflet](#) that covers all aspects of IBS, including the use of the FODMAP diet – along with a [separate leaflet](#) on diet and IBS.

## MENOPAUSE AND MENSTRUAL SYMPTOMS

The menopause has a number of symptoms – eg cognitive dysfunction, migraine type headaches, problems with temperature control – that overlap with ME/CFS.

So it's not surprising to find that many women experience an exacerbation of these symptoms, and sometimes their overall ME/CFS, during the menopause. In younger women there may also be a pre-menstrual exacerbation of symptoms. In both cases there is probably a link to changes in female hormone status – with declining levels of oestrogen being particularly important at and around the menopause.

Some form of hormone replacement therapy (HRT) can be helpful here and there are non-hormonal treatments that may help with individual symptoms that could be discussed with your doctor.

It's important to note that ME/CFS is not in itself a contra-indication to the use of HRT. However, some of the consequences of having ME/CFS, immobility in particular, will need to be considered when using HRT and may contra-indicate its use.

◆ The MEA has [a leaflet](#) covering the Menopause, Female Hormone Research and HRT. We have a [separate one](#) on Pre-Menstrual Symptom Exacerbation.

## MUSCLE SYMPTOMS AND RESTLESS LEGS

These symptoms are all too frequent in ME/CFS.

Muscle pain is sometimes accompa-

nied by visible twitchings (= fasciculations), cramps and spasms. Some people with ME/CFS also have ‘restless legs syndrome’. This is a fairly common complaint that may be associated with sleep disturbance, but can also be linked to iron deficiency anaemia.

Check with your doctor if you are having any of these problems because there are drugs, including muscle relaxants like **baclofen / Lioresal**, that can help to reduce unwanted muscle spasm if symptoms are becoming more disabling. However, muscle-relaxant drugs obviously need to be used with great caution in a condition where muscle fatigue and weakness is already present.

Simple stretching exercises might help if you are being woken at night by cramp in the leg muscles. Quinine may also be helpful for muscle cramps.

Complementary practitioners may recommend **magnesium supplements** for restless legs but their value in ME/CFS is not yet proven.

◆ Information on the management of restless legs is contained in [our leaflet](#) on sleep disturbance

## NAUSEA AND SICKNESS

Some people with ME/CFS experience nausea – possibly because of a disturbance in a part of the brain that normally keeps any feelings of sickness under control. Again, this is a symptom that you must not self-treat to start with. You do need to check with your doctor because there could be an explanation other than ME/CFS.

Self-help measures and complementary approaches, such as using products containing ginger or using acupressure bands (which are placed over a special point on the wrist), are worth trying.

Doctors can prescribe various drugs to relieve more persistent nausea and it is interesting to note that one of these drugs – **ondansetron / Zofran** – was reported to be of benefit in ME/CFS in one small clinical trial, possibly through its action on brain chemical transmitter systems.

◆ The MEA website has more detailed guidance on the drug and non-drug management of nausea and vomiting: <https://tinyurl.com/jlhoygh>

## ORTHOSTATIC INTOLERANCE

This refers to difficulty or an inability to remain upright and carry out physical and/or mental activities. Orthostatic Intolerance is one of the key diagnostic features of ME/CFS and affects almost everyone with this illness to some extent. Self-help measures include:

- Activity management advice on how to move from lying to standing; improving peripheral circulation; and physical counter manoeuvres – hand grip, muscle tensing
- Drinking plenty of decaffeinated fluids and avoiding alcohol
- Avoiding heavy meals and possibly changing to small low carbohydrate meals
- Cautious increase in salt intake
- Avoiding hot atmospheres
- Use of compression stockings to reduce pooling of blood in the legs

In more severe cases drug treatments may be considered.

◆ The ME Association has [a leaflet](#) that covers the cause and management of the symptoms of Orthostatic Intolerance.

## PAIN

Most people with ME/CFS have pain in varying degrees of severity – either continuously, or at some stage in their illness. However, some have no pain at all.

ME/CFS pain can affect muscles, joints, or nerves (= neuropathic pain) where it may be described as burning, searing or stabbing in quality. When pain becomes more persistent or severe, over-the-counter pain-relievers such as **aspirin, paracetamol and ibuprofen / Brufen** tend to be of limited value only.

Fortunately, doctors now have access to a wide range of drugs that can often be matched to different types and severities of pain. They can also be

## POSTURAL HYPOTENSION – POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (PoTS) – ORTHOSTATIC INTOLERANCE – FEELING FAINT – HYPOGLYCAEMIA

**Postural hypotension** is a term used by doctors to describe what happens when people experience symptoms of low blood pressure – in particular feeling faint or dizzy – when changing position from lying or sitting to standing up.

**PoTS** refers to symptoms that are related to a sudden rise in pulse rate (tachycardia) when moving from lying to standing.

**Orthostatic intolerance** is the medical term for finding it difficult or impossible to remain in an upright / standing position for long periods.

All of these problems are quite common in ME/CFS and are caused by a malfunction in the autonomic nervous system – a part of the nervous system that sends messages from the brain to control blood pressure and heart rate.

**Feeling faint, or fainting**, is something that should always be discussed with your doctor, who will probably want to carry out some investigations to make sure there are no other explanations. One investigation that should always be checked in people who have low blood

pressure symptoms is the serum cortisol level. This is to exclude a rare but potentially life threatening condition called **Addison's disease** – where very low levels of cortisol can produce a number of ME/CFS-like symptoms.

You might also be referred to hospital for what is called a tilt table test. This measures changes in blood pressure and pulse rate during changes in posture.

Simple measures – such as making sure that you drink enough water and carry out some simple exercises before standing up – can often help. There are also drug treatments (eg **beta blockers** to slow the pulse rate), **fludrocortisone** (to increase fluid in the blood) and **midodrine** (to increase blood pressure) that might be considered when PoTS symptoms are more severe.

Another cause of feeling faint is hypoglycaemia – a low level of blood sugar. If necessary, this can be checked for with blood tests.

◆ The MEA has a leaflet covering [orthostatic intolerance](#) and another on the [management of PoTS](#).

given in a variety of ways – including skin patches that deliver a steady supply of painkiller over a prolonged period of time and creams which can be applied to a localised area of pain.

In the case of ME/CFS, approaches such as the use of a low dose of **amitriptyline** (a sedating anti-depressant) or a drug such as **gabapentin / Neurontin** or **pregabalin / Lyrica**, which were developed as a treatment for epilepsy, can be helpful in some cases. Another possible option is **duloxetine (Cymbalta)**.

Complementary approaches, **acupuncture** in particular, are also worth considering. Another non-drug

option here is the use of a **TENS machine** (for more localised pain).

If pain relief remains inadequate, you should ask your GP about being referred to a pain clinic at your local hospital.

◆ The MEA has [a leaflet](#) covering pain management in general as well as other leaflets covering all the commonly used pain-relieving drugs: [amitriptyline](#), [gabapentin](#), [pregabalin](#) and [duloxetine](#).

## SENSORY SYMPTOMS

People with ME/CFS may experience a variety of sensory symptoms.

Dislike of bright lights (photophobia) and loud noise (hyperacusis) have already been covered. Sensory

disturbances can also be felt in the skin as patches of numbness, increased sensitivity to touch or pain, or abnormal sensations such as 'pins and needles'.

Once again, this is a symptom that needs to be discussed with your doctor because conditions such as diabetes and vitamin B12 deficiency / pernicious anaemia can cause this type of sensory disturbance in the nerves that feed information back to the brain.

When it comes to treatment, vitamins are often recommended but this approach is unlikely to help unless there is an obvious vitamin deficiency – which does not appear to be the case in ME/CFS.

Some types of prescription-only medication (eg **amitriptyline**) may help if symptoms are more severe.

## SLEEP DISTURBANCE

In the very early stages of ME/CFS people often require excessive amounts of sleep – this is known as hypersomnia. Later on, this type of sleep disturbance tends to be replaced with problems in getting off to sleep and frequent waking during the night.

A minority of people develop a reversal of normal sleep patterns – being awake at night and asleep during the day. Sleep disturbance can also be accompanied by restless legs and jerking movements (= myoclonic jerks).

Whatever type of sleep disturbance occurs, people with ME/CFS nearly always report that they wake up feeling unrefreshed – even after what appears to have been a good night's sleep.

We all need at least five to six hours of uninterrupted sleep each night and there are several strategies that can help to achieve this.

A short course of a rapid-acting non-benzodiazepam sleeping tablet (eg **zopiclone**) may be useful if getting off to sleep is a problem. A small dose of **amitriptyline** is an option when sleep is interrupted or erratic, especially if pain is also a problem.

Early morning wakening suggests that

there may be a depressive component that probably needs treating with antidepressants.

Although not licensed for use in ME/CFS, **melatonin** (the drug that is used to reduce jet lag) could be considered where sleep disturbance is more severe or there is a reversal of normal sleeping and waking times.

There are a number of specific sleep disorders like narcolepsy (sudden episodes of daytime sleepiness) and sleep apnoea (an obstructive breathing disorder) that can produce an ME/CFS-like illness. These are described in more detail in the clinical assessment section of the MEA clinical and research guide.

If there is any doubt over the diagnosis, or a sleep problem is more severe, you can ask your doctor for a referral to a hospital-based sleep clinic.

Self-help measures are a very important form of management for most types of sleep disturbance. These include:

- Avoiding caffeine containing stimulants in the evening
- Avoiding heavy meals in the mid to late evening
- Having a warm bath an hour or so before going to bed

## WEIGHT CHANGE

There is no research evidence to indicate that the underlying disease process in ME/CFS causes weight loss or weight gain. However, some people do lose weight and many others gain weight.

In the case of weight loss, this can be linked to changes in diet or nausea causing loss of appetite. Unexplained weight loss is a 'red flag' symptom that always requires medical assessment to rule out conditions such as an over-active thyroid function, or Addison's disease.

Weight gain in ME/CFS can be related to not adjusting calorie intake to a more sedentary lifestyle. But it can also be caused by medical conditions such as an underactive thyroid gland. Drugs used

- Making sure that the bedroom is relaxing and not too hot or cold
- Where possible, trying to establish a regular routine for waking up, getting up, and going to bed at roughly the same times

These self-help strategies are summarised in more detail in our [leaflet](#) on sleep management, which also covers restless legs syndrome and melatonin.

## SORE THROATS AND ENLARGED GLANDS

Some people with ME/CFS frequently have sore throats and enlarged glands in the neck – possibly due to on-going immune system activation.

Acute sore throats are normally caused by viral infections – so antibiotics are not usually prescribed.

Simple self-help approaches such as drinking plenty of warm fluids (eg a glycerine, honey and lemon mixture), sucking soft pastilles, and using a throat spray if this helps, are the most effective forms of treatment.

When sore throats are more frequent and involve tonsillitis as well, removal of the tonsils may need to be considered. Any persistent swelling of a lymph gland, or group of lymph glands, needs to be checked by your doctor.

to treat pain or depression in ME/CFS (eg gabapentin) can cause weight gain.

◆ The management of weight loss and weight gain has been covered by items in our membership magazine from our professional adviser on diet and nutrition. As mentioned earlier, we also have a [separate leaflet](#) on nutrition and ME/CFS.

**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.**