

SLEEP DISTURBANCE and Restless Legs Syndrome

Failing to have a good night's sleep isn't just frustrating – it can have a major effect on all aspects of your health. With various types of sleep disturbance being very common in ME/CFS, this is one aspect of the illness that cannot be ignored. Fortunately, there are a number of simple self-help solutions that can often be of help. And, in some cases, drug treatments have a role to play. This is our guide to getting a good night's sleep if you have ME.

WHY DO WE NEED TO SLEEP AND HOW MUCH SLEEP DO WE NEED?

Sleep has many different restorative functions but the most important one in relation to ME/CFS is the fact that the human brain – especially those parts where normal mental functioning takes place – needs a period of good solid sleep each and every night if it is going to perform effectively the next day.

How much sleep is required each night varies from individual to individual. Some people manage perfectly well on only a few hours each night – former Prime Minister Margaret Thatcher was a well known example – whereas others never feel refreshed unless they have a solid eight hours.

What does seem to be essential is having at least five hours of uninterrupted sleep each night.

WHAT HAPPENS DURING SLEEP AND HOW DOES THIS CHANGE IN ME/CFS?

A single night's sleep is composed of several stages during which we move

through alternating periods of deep sleep (called non-rapid eye movement/ non-REM sleep) into lighter periods of sleep (called rapid eye movement/REM or dream sleep).

A number of research studies have now looked at what may be happening to sleep patterns in ME/CFS. Abnormalities that have been identified so far include changes in what is called alpha non-REM sleep (ref: Moldofsky) and blunted slow wave activity in a twin study in response to a sleep challenge (ref: Armitage). While these studies all agree that there is a decrease in sleep efficiency, a consistent abnormality has yet to be identified.

One possibility is that the effect of an infection, along with the immune response that accompanies it, may be having an effect on sleep control mechanisms in the brain. As a result, the normal restorative pattern of REM and non-REM sleep no longer occurs.

WHAT TYPE OF SLEEP DISTURBANCES COMMONLY OCCUR IN ME/CFS?

Almost everyone with ME/CFS reports that they feel 'unrefreshed' or 'sleep deprived' – even after what appears to be a good night's sleep.

During the very early stages of the illness, especially when there has been an acute onset following an infection, excessive sleep requirements are often reported. This is known as hypersomnia and may result in someone sleeping for periods during the day as well as for much longer periods at night – say 12

hours or more.

As the illness becomes more chronic, this hypersomnia usually diminishes and is replaced by various other types of sleep disturbance. Difficulty in getting off to sleep and waking during the night are quite commonly reported.

Waking very early in the morning is another type of disturbance that sometimes occurs but this could also be an indicator of an unrecognised depressive component to your illness. Vivid dreams are also reported by some people with ME/CFS.

Significant sleep disturbance can be accompanied by cramp or 'restless legs' during the night. The MEA has a separate information leaflet covering the management of what doctors call 'restless legs syndrome'

Children with ME/CFS sometimes have a more unusual type of sleep disturbance whereby they are awake for long periods during the night and sleep during the day.

HOW SHOULD SLEEP DISTURBANCES BE INVESTIGATED?

It is always important to consider the possibility of primary sleep disorders such as sleep apnoea and narcolepsy because they are sometimes misdiagnosed as ME/ CFS.

- Sleep apnoea, where the normal breathing pattern is interrupted during the night, produces abnormal pauses in breathing or low breathing whilst asleep. This results in excessive daytime sleepiness. Sleep apnoea is more

common in people who are overweight – especially when they have a collar size of 17 or more, have enlarged tonsils or a blocked nose, or who snore. It can be diagnosed using an overnight sleep test called a polysomnogram.

- Narcolepsy causes sudden episodes of daytime sleepiness along with ‘sleep attacks’ – often following a meal. Narcolepsy is sometimes associated with hallucinations and cataplexy – where there is sudden loss of muscle tone whilst awake resulting in an inability to move.

The use of a sleep disorder assessment scale (eg Epworth sleep score) can also be helpful in the investigation of more significant sleep problems.

It should be noted that a number of drugs – both prescription and over-the-counter – can produce insomnia. So all current medication should be reviewed by your GP or pharmacist.

HOW SHOULD SLEEP DISORDERS BE MANAGED IN ME/CFS?

Management of sleep disturbance in ME/CFS will depend on what stage you are in the illness and what type of sleep disturbance you have.

Many doctors believe that an excessive sleep requirement early on in an infective illness like ME/CFS is the body’s way of telling you to slow down and rest. If you want to sleep for more time than you would normally require, there doesn’t seem any harm in doing so.

Later on, when there are problems with getting off to sleep or waking in the night, the basic management should always involve a range of simple self-help measures. The use of drugs and complementary therapies should also be considered.

SELF-HELP SLEEP ARRANGEMENTS

These are some of the simple self-help measures that can often help to improve the quality and quantity of sleep once ME/CFS enters a more chronic stage:

- Aim to get up and go to bed at roughly the same time each day. This means trying to establish a reasonably regular pattern of waking up in the morning and going to bed at night.
- Avoid naps during the day. Having periods of rest and relaxation during the day is fine but spending even short periods asleep can result in fragmented and shallow sleep at night.
- Use the bedroom for sleeping. Make the bedroom a place for sleep with some fresh air coming in – bedrooms shouldn’t be too hot or too cold – along with a comfortable bed and mattress. If you are bothered by external noise, try using earplugs.
- Develop some sleep rituals before it’s time to lie down and go to sleep. These sort of cues could include listening to relaxing music or doing some light reading. But try not to involve yourself in stimulating mental activity. If you find it difficult to relax, check out some of the relaxation techniques that are available.
- Stay clear of alcohol, caffeine, chocolate and alcohol for at least four hours before going to bed. Alcohol slows brain activity and some people mistakenly use it to help with sleep - but all alcohol does is create fragmented sleep. A glass of warm milk, which contains a sleep-inducing chemical called tryptophan, or a herbal tea, is a much better alternative.
- Have a light snack before retiring. An empty stomach can interfere with sleep but stick to a light snack because a heavy meal shortly before bedtime will interfere with sleep.
- Have a warm bath. Besides being very relaxing, a warm bath about 90 minutes before going to bed will raise the body temperature. The drop in temperature that follows will help to make you feel sleepy. You can add a calming aromatic oil such as orange blossom to the bath water.
- Sleep should come naturally. When it’s time to go to sleep don’t try too hard to do so – sleep will come when it’s ready.
- Deal with pain. If you’re woken at night by pain, consider taking a long-acting painkiller late at night.
- Waking in the night. If you’ve woken in the night and can’t get back to sleep, it may be helpful to get out of bed, go to another room, and make a cup of tea.
- Use the morning sunlight to help set your biological clock. If the sun is out, a short period outside in the sunlight when you wake up will help to set your biological clock. Remaining in daylight or good internal light will also help to maintain a normal circadian rhythm. This is the physical, mental and behavioural changes that occur in a 24-hour cycle in response to changes in light and darkness. Bright lights should be avoided later in the evening.

OVER-THE-COUNTER REMEDIES

Go into any pharmacy and there’s a bewildering range of sleep-inducing medications available. Some are OK but others are of dubious value and need to be used with care.

- Antihistamines are sometimes used because of their sedating properties. The problem is that these drugs often remain in the body for long periods of time and may therefore make you feel drowsy the next day. They can also cause headaches and other side-effects. Examples include Nytol, Paxidorm (tablets and syrup) and Sominex.
- Herbal remedies are becoming increasingly popular, especially those containing valerian. This is a herb which needs to be used with care if you have ME/CFS as there are reports of valerian causing liver damage. There are other herbal remedies that don’t include valerian.

- Homoeopathic remedies can also be purchased over-the-counter and should be perfectly safe.

PRESCRIPTION-ONLY DRUGS

Doctors have, quite rightly, been criticised for dishing out sleeping pills far too readily with the result that some people with insomnia have become addicted. So doctors are generally rather reluctant to prescribe sleeping pills – unless there are good reasons for doing so.

However, there are several drugs which should be considered when failure to have a solid night's sleep has become a regular event.

- Tricyclic antidepressants such as amitriptyline have a sedating effect on the brain and may be helpful. When used to treat sleep disturbance in the absence of depression, amitriptyline is normally prescribed at a low dose of say 10mg or 25mg a few hours before going to bed. At this dose side-effects are usually less problematic. Alternative drugs to

amitriptyline include trimipramine. It should be noted that, while both the Chief Medical Officer's report on ME/CFS and the NICE Guideline on ME/CFS refer to the possible use of low dose tricyclic antidepressants to help treat insomnia, latest guidance from the British Association of Psychopharmacology advises against their use in insomnia.

- Short-acting hypnotics help people who have difficulty in getting off to sleep. As they are quickly eliminated from the body, they don't usually cause any 'hangover effect' the following morning – a problem that used to occur with other types of hypnotic drugs such as Mogadon (nitrazepam). Short-acting hypnotics are normally only prescribed for very short periods of time to help re-establish a normal onset of sleep. Drugs in this group are known as 'the three Zs': zaleplon/Sonata; zolpidem/Stilnoct; zopiclone/Zimovane. Zolpidem and zopiclone have a

short duration of action. Zaleplon is very short acting.

- Melatonin is a hormone that helps to regulate natural sleep rhythms and is frequently used by people to reduce the adverse effects of jet lag. Melatonin used to be available over-the-counter here in the UK but the government decided to restrict its availability because of concerns about side-effects. However, there is now a prescription-only preparation available called Circadin. Some doctors believe that melatonin can be helpful for both children and adults with ME/CFS who have more severe sleep disturbances and the possible use of melatonin (under specialist supervision) is referred to in the NICE guideline on ME/CFS – despite the relative lack of firm evidence from clinical trials (*refs: Van Heukelom, Williams*). Melatonin can also be obtained quite easily from internet suppliers but there are concerns about the quality and safety of such products.

A note about Circadin

Circadin – a prolonged-release preparation of melatonin – is licensed for the short-term treatment of what is called primary insomnia in people who are aged 55 or over. It can be prescribed for up to 13 weeks.

Circadin helps to restore a natural sleep rhythm by increasing the body's own level of this hormone at night.

The recommended dose is 2mg taken once a day one to two hours before bedtime and after food. Circadin is not recommended for use in children under the age of 18.

There are a number of conditions

where this drug needs to be used with caution or not at all.

One of those listed is autoimmune disease – which obviously needs to be considered in relation to ME/CFS. A number of drug interactions can also occur with drugs such as fluvoxamine and cimetidine.

The most common side effects to be reported are drowsiness, headache, nasopharyngitis, back pain and arthralgia (joint pain). Less common side-effects include abnormal liver function tests and palpitations.

Circadin information website:
www.sleepwelllivewell.co.uk

Medical information contained in this leaflet is not intended to be 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 problems.

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.

Restless Legs Syndrome

We all know it's under-recognised, under-diagnosed, under-treated and thoroughly unpleasant!



INTRODUCTION

Recently, Dr Shepherd was at a medical conference devoted to the research and management of sleep disorders. There were presentations from a number of international sleep disorder experts – one of which was about the often neglected subject of restless legs syndrome. With restless legs sometimes being reported by people with ME/CFS as part of their sleep disturbance, this is a chance to review what we know about the restless legs syndrome.

HISTORY

Often described as a 'medical black hole', restless legs were first described by English physician Sir Thomas Willis in 1672. The term restless legs syndrome (RLS) was introduced in the 1940s by a Swedish neurologist called Dr Karl Ekbom. So it is also known as called Ekbom's Syndrome.

EPIDEMIOLOGY

RLS is a common and often quite distressing condition with a female bias. It can affect children and adolescents as well – where it may be misdiagnosed as 'growing pains'. Some research suggests that up to about 10% of the adult population describe some degree of symptoms with about 3% having moderate to severe symptoms. Yet many people remain undiagnosed and untreated.

SYMPTOMS

A variety of leg symptoms occur – normally in association with some kind of sleep disturbance and daytime fatigue. People with RLS describe unpleasant symptoms or sensations in their legs, normally below the knees. Common descriptions include "antsy", electrical, throbbing, pulling, creeping or crawling. The symptoms tend to appear during a period of inactivity, rest or lying down in the evening, as well as in bed at night. So the symptoms often

delay the onset of normal sleep and then interrupt sleep throughout the night.

There is a constant urge to move the legs so it becomes almost impossible to get comfortable and sleep soundly at night. Involuntary jerking or twitching movements may also occur – doctors call this periodic limb movement of sleep/PLMS.

The overall disturbance, and the constant need to move the legs, means that people with RLS often get up and walk to the kitchen (to make a cup of tea) or bathroom (where cooling the leg/s in a cold bath may help).

Not surprisingly, people with RLS often feel sleepy and tired the next day – which obviously does not help if you already have ME/CFS.

Overall, the disruption to normal life varies from mild to severe. The symptoms tend to be persistent but they may remit and relapse.

WHAT CAUSES RLS?

Recent research into RLS has found that there is a genetic basis with linkages to several chromosomes. This may explain why RLS is sometimes more common among members of the same family.

RLS is linked to problems in the central nervous system – including neuronal circuits that involve a part of the brain known as the basal ganglia and the chemical transmitter dopamine. The autonomic nervous system also appears to be involved. Some of these abnormalities also occur in ME/CFS.

There is also an important association with iron status and a link to iron deficiency anaemia in some people with RLS has long been recognised. Most RLS patients have a normal ferritin level (ferritin = an iron-protein complex used to store iron in the body) but for some unknown reason they have reduced concentrations of ferritin and transferin in their cerebrospinal fluid. So there

appears to be something rather strange going on in the brain as to how it absorbs and handles iron. RLS is also more common in diabetes, kidney disease, migraine, Parkinson's disease, rheumatic disorders and pregnancy during the last trimester.

TREATMENT

Firstly, with RLS being associated with a number of medical conditions, it's important to have a blood test checked for ferritin and iron deficiency, anaemia, etc – if not already done as part of an ME/CFS assessment.

Secondly, a drug review is useful because a number of drugs can sometimes make RLS worse. These include antidepressants (especially high doses of tricyclics such as amitriptyline), antihistamines (in over-the-counter cold remedies), anti-sickness drugs (especially metoclopramide/Maxolon) and calcium channel blockers.

Mild RLS can sometimes be relieved with simple self-help steps such as cutting out caffeine (in tea, coffee, cola, etc), alcohol, tobacco, going to bed a bit later, having a deep massage, and stretching/relaxation exercises.

Drugs that are normally used for Parkinson's disease may help because at low doses they increase the level of dopamine in the brain. They are the treatment of choice for moderate to severe symptoms. But their use has to be balanced with the fact that they can cause unpleasant side-effects.

Other drugs that may be helpful in more severe cases include anti-epileptics (eg gabapentin or pregabalin), benzodiazepines (clonazepam) and opioid pain killers.

● *Do you have restless legs as part of your ME/CFS? If so, please let us know what treatments – drugs and self-help – have helped and what treatments have not helped.*