

## SLEEP MANAGEMENT

Most people with Chronic Fatigue Syndrome (ME/CFS) have a sleep disorder, though many do not recognise this as such.

In the early stages of the illness there is often a need to sleep for very long periods of time, but as the illness progresses, there may be difficulties in falling asleep with restlessness throughout the night and early morning waking.

The body clock rhythm may also become disrupted, and the normal sleep/wake cycle can become reversed. The common cry however is that sleep is rarely refreshing and restorative.

In healthy people the body clock (circadian rhythm) is controlled by release of the hormone melatonin from the pineal gland. To keep this rhythm established and melatonin release regulated, the individual needs regular exposure to daylight during waking hours.

Also the body and mind become naturally fatigued as the day progresses, and sleep becomes a restorative essential to health and wellbeing. Sleep deprivation results in fatigue, anxiety, inefficiency, and total sleep deprivation has been shown to lead to death in animals.

Length of sleep required depends on a number of factors such as age, genetics, lifestyle etc. Very young babies need many hours of sleep, while the elderly often become anxious because they no longer sleep as long as when younger. The reality is that less sleep is required in the aged.

There is no set ideal time to be asleep. If you wake naturally and feel refreshed you know you have had enough. On average adults will sleep from 6 to 8 hours.

The normal sleep cycle consists of 4 main stages which will repeat themselves 2-3 times during the night, with each set of stages lasting about 90 minutes.

The average time taken to fall asleep is about 7 minutes. During this time you are in a state of "hypnagogic trance" when you are very hyper-alert in those few moments before falling asleep.

Then you go down systematically through the 4 sleep levels to achieve deep level 4 sleep in about an hour.

During level 4 sleep the body is very relaxed and releases the hormones and chemicals that have a restorative and healing effect.

Most bodily systems are under the control of these hormones. eg: growth hormone, cortisol etc. Without this stage of sleep the body cannot heal itself properly.

From level 4 there is often quite a rapid decrease in sleep depth up to level 1.

Level 1 is the stage of sleep known as REM (rapid eye movement) sleep and during this time you are dreaming, but you will only know you are dreaming if you happen to wake during the dream.

You can be woken easily during this phase as the sleep is shallow.

The eye movement is as if you are scanning the pages of a book.

During REM sleep there is restoration of the mind, which includes thinking, memory and emotion. After perhaps 10 minutes, the sleep deepening cycle begins all over again.

Most people wake after the third phase and the return to consciousness towards the end maybe more gradual. If however the alarm clock goes off during the final REM stage, you will feel as though you have been dreaming all night.

Normal sleep cycles maybe disturbed by environmental conditions such as temperature, noise, discomfort etc, and many illnesses, both physical and psychological are associated with lack of proper sleep, so that a vicious circle of non restoration and repair are established.

This certainly seems to be the pattern in ME/CFS. Most of those experienced in working with ME/CFS patients will say that until sleep is corrected, recovery is limited.

In ME/CFS there seems to be a flattening out of the normal sleep cycle with diminution of both REM and deep level 4 sleep.

This means that normal refreshment from sleep is rarely achieved either physically or mentally.

This helps to explain why some people with the illness seem to sleep on and on – often sleeping for 16 hours and still feeling no better.

It is as if the body and mind are crying out for those important restorative stages which are only happening minimally, so that subconsciously you just want to go on and on sleeping to achieve this.

## IMPROVING SLEEP IN ME/CFS

There are 5 main approaches to sleep management in this disorder.

1. Environmental
2. Lifestyle changes
3. Self help strategies
4. Symptom relief
5. Medication

**Environment:** Comfort, temperature, quiet and dark are all important factors. You can adapt to difficult environments, but you should look carefully at the setting for sleep and make it as fail safe as possible.

**Lifestyle changes:** include such things as looking at stress levels, establishing good routines, avoiding caffeine and alcohol late in the day, avoiding overexcitement or over-exercise towards bedtime etc. Regular daylight exposure outside during the day helps the body prepare for melatonin release at the right time.

**Self help strategies:** Many people have found their own pet remedy or approach to getting a good night's sleep. Learning relaxation skills, listening to music, massage, warm baths etc all have a role. Soothing herbal drinks, aromatherapy (using lavender) and some herbal preparations (such as 5HTP and St John's Wort) can be useful.

However it is likely that herbs such as valerian and kava, while helping you get off to sleep may do nothing for the quality of the sleep and can even aggravate it. They may have the same effect as some sleeping pills or alcohol, which are not very helpful for those with ME/CFS and can leave you feeling hung over the next day.

**Symptom relief:** is vital to help achieve undisturbed night and involves dealing with pain, nausea, reflux, sinus problems etc and this gives you a better chance of doing well.

Simple approaches may work, such as having a nutritious snack at bedtime to "nourish" the tiny sleep regulating centre in the brain, and also provide calcium to prevent cramps. Magnesium and/or calcium supplements can also enhance sleep.

Many do wake in the night and this may be a need to empty the bladder or attend to a disturbed child. It is easier to get back to sleep if the time up is minimised and bright lights are not put on. You will then more easily fall back straight into the level of sleep from which you emerged and the cycle is less disrupted.

If you do have to be up for a long time, you will probably not fall asleep again until you reach the point in the next sleep cycle when you originally woke!

So you may as well read a good book for a while or do the ironing until you feel ready for sleep again.

**Medication:** most people with ME/CFS do need medication of some sort to help them re-establish a good sleeping pattern. Various approaches are tried:

**Benzodiazepines** - (halcion, zopiclone etc) the traditional sleeping pills - are not generally recommended except for short term use - they are addictive and do very little to improve sleep quality.

If a person is extremely stressed however, they may be useful as an emergency measure to break a bad phase. Sometimes they are used as muscle relaxants to relieve pain in ME/CFS and clonazepam is probably the most useful.

**Tricyclics** – (**amitriptyline, nortriptyline, dothiepin, doxepin**) old style antidepressants, but used in tiny non antidepressant doses.

They can give back quality to sleep and if taken about 5 hours before bedtime, there is minimal risk of hangover.

They have pain relieving and anti-allergy properties too. They are non addictive.

**Melatonin** – a sleep hormone - Used by shift workers, air crew etc to restore disrupted body rhythms –

This can be a useful adjunct in ME/CFS, though is not usually as good as a tricyclic.

The two drugs however can be combined successfully.

**Antihistamines** – traditionally used to treat allergies, but the older type have good sedating properties and can be very useful particularly for those with sinus problems.

They are non addictive but tiny doses should be used as they can last for 12 hours and leave you feeling thick headed.

**Orphenadrine** – a muscle relaxant – occasionally useful for muscle pain and night cramps.

**Quetiapine** – a drug used to treat mood disorders, but found to be extremely useful for sleep management in CFS.

Many people wonder how long they need to remain on medications such as tricyclics. It is important to continue until you feel the illness is over and when that time arrives, to reduce the dose slowly so that the body can adapt gradually. You will soon know if you are ready to come off, as with reduced dose, symptoms may return if you still need the drug.

The most important thing to remember is that a routine good sleep cycle must be established and maintained, medication should be taken very regularly and once you start to wake feeling refreshed, you know you are on the right track.

## **OTHER SLEEP DISORDERS**

There are a number of other health and sleep disorders which may complicate issues in CFS, or result in a mistaken diagnosis of CFS

Depression/Anxiety: Both are associated with sleep problems

Sleep apnoea: A tendency to stop breathing during sleep, and become restless or wake with a start, often accompanied by snoring.

Restless legs syndrome: A desire to constantly move the legs and be unable to get comfortable, or to relax properly

Narcolepsy: Easily falling asleep during the daytime, such as when driving, and a perceived need to sleep excessively

Acute/Chronic pain: Any illness with accompanying pain will cause sleep disturbance.

Menopause: Many women are constantly disturbed by hot flushes