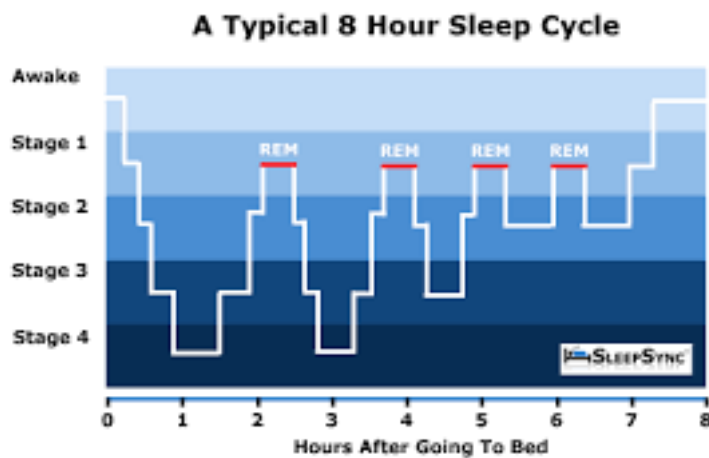


Sleep

"Most people with ME/CFS, FM have a sleep disorder, though they do not always recognise this. In the early stages of the illness you often need to sleep for very long periods of time (hypersomnia), but as it progresses you may experience difficulty falling asleep, restlessness through the night and early waking (insomnia). Your body clock may be disrupted and the normal sleep-wake cycle reversed. The common cry is that sleep is rarely refreshing or restorative.

Environmental conditions such as temperature, noise and discomfort may disturb normal sleep cycles... so that a vicious circle of non-restoration and non-repair begins. Most professionals who have worked with ME/CFS, FM patients will say that until you correct your sleep, efficient recovery is unlikely." Dr Valling 2012 (CFS/M.E Symptoms Diagnosis Management Chapter 23 Sleep pg 202)



Normal sleep in healthy people is created by the release of Melatonin from the pineal gland which control the body's circadian rhythms. People then move through the stages of sleep 1-4, which then repeat 2-4 times over a night. REM is the dreaming sleep which you can wake from easily as it is a shallow sleep, the eyes are moving and during this phase your mind is restored. Deep sleep is level 4 sleep and it when the body is restored with releases of hormones and chemicals to support the bodies health.

What happens when we have ME/CFS, FM is that our sleep cycle is often flattened out and we mainly experience light sleep, and often very little REM and level 4 sleep. Our brain's will often try to keep us sleeping for many hours in an effort to reach the different stages but to no avail. Also they have noticed in EEG's on PW ME/CFS that we have unusual brain waves (alpha wave intrusion) which cause restlessness or waking.

Steps to improving sleep for people living with ME/CFS, FM:

Environmental factors:

- make sure your room is dark
- bed/ mattress is comfortable for your body (Raise the bedhead for POTS or OI)
- room is a suitable temp (often cool air is more comfortable)
- have the right bedding that can be moved to suit your body temp
- is quite & undisturbed (that might mean not sharing a bed)
- it should also be a worry free calming space
- beds are for sleeping and sex, not offices or game or movie theatres.

Maintain regular sleeping routine:

- set a bedtime, wake time and stick to it. Try to observe normal circadian rhythms as much as possible
- stick to a pattern of behaviour for getting ready for bed
- reduce screen time prior to bed - even in the daytime
- have a wind down period prior to going to bed.
- Avoid naps after 3pm
- Spend time in natural daylight 15 minutes without sunglasses
- Try gentle restorative movement to help promote awake times
- Pace your activities in the day so you have a natural wind down to sleep.
- Avoid bright lights in the evening.

Foods and alcohol:

- Try not to eat a large meal before bed, try eating several hours earlier so that the bulk of the digesting is done by the time you go to bed. The digestive process can wake you up.
- Avoid caffeine after midday as it is a diuretic and it can be stimulating in some people.
- Avoid alcohol as it can cause early waking and hangover symptoms even in small amounts.
- Try eating a small amount of protein just before you go to bed to help with 3am waking which can be caused by the body having a drop in blood sugar levels.
- Don't drink too much water prior to bed.

Sleep and the brain:

- Try meditation during the day to help to teach the mind to slow down & relax.
- You cannot force your brain to sleep, reduce the pressure you put on yourself and instead try thinking that just resting in bed is enough, its ok not to sleep.
- Follow the breath. If you feel sleep is hiding from you try to follow the breath, eventually you will fall asleep. Counting can help too.
- You are not the best gauge for how much sleep you get. Don't look at a clock or try to count your hours, accept that you will sleep when you are tired and rest in-between.
- Use sleep CDs or apps that help you too relax and distract; Yoga Nidra, Sleep radio, Headspace sleep, music, meditations etc.
- Don't go to bed "tired and wired", use pacing and wind down time to make sure that you are in a calm place before you get into bed, even if that means you are up a bit later than normal.
- Make sure you are not sore. Use pain management, hot baths, massage etc to reduce pain as waking in the night from pain is often confusing. Have your plan for what you do if you wake sore in the night sorted before you go to bed and medications etc at the ready.
- If your head is busy try writing it down, journaling or write lists and then let it go.

Medications:

- Melatonin
- Magnesium
- Sedating tricyclics (e.g. amitriptyline, nortriptyline, doxepin, etc)

Every person will have their own ways to find sleep, be curious and interested in what works for you and what doesn't. Remember that your body needs to feel calm and relaxed in order to fall asleep so getting stressed and worried is not going to help. Its ok not too sleep – trust me on this one, resting eventually leads to sleep.