



Managing sleep

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ME and sleep

Sleep difficulties are one of the key symptoms of ME.

Some people will have difficulty falling asleep or have broken sleep. Some people will have the opposite problem and will sleep more than usual (known as hypersomnia). Others can experience reversed sleep cycles, sleeping more in the day and being awake at night or having insomnia.

This can reduce the quality of sleep, and leaves fewer hours awake to function.

Research shows that there are a number of “sleep phenotypes” in ME – which means that the type of sleep problem encountered varies from person to person and can change over the course of the illness.

It also means that what helps one person manage their sleep difficulties may not work for another.

Nevertheless, some basic sleep advice can be useful for some people.

What is the nature of the problem?

It is important to work out what kind of disruption is taking place.

You could use a diary to record your sleep pattern and gain more insight into the nature of the problems you are having. This helps you to decide what changes might help.

- Do you have a problem getting off to sleep?
- Is it that you keep waking up throughout the night?
- Is it that you wake early and cannot get back to sleep again?
- Is it that, despite having slept, you don't feel well-rested?
- Do you feel the need to sleep longer in the morning, go to bed early, or sleep in the daytime?

Your sleep environment

Make your bedroom “sleep-friendly”.

If possible, try to have a separate area to rest during the day so that you can create a different space for daytime rest and night-time sleep.

Advice is that the bedroom should be a relaxing environment, associated with sleeping (as opposed to having company, watching TV, etc).

There can be increased difficulties sleeping after using screens that emit blue light, such as TVs, laptops and mobile phones. Switching them off two hours before bedtime can be beneficial in getting off to sleep.

Bedrooms for sleep at night should be dark, quiet, tidy and ideally kept between 18° and 24°C.

Also make sure you have a supportive, comfortable mattress and pillows.

Useful tips:

- give some thought to how comfortable your bed is
- temperature is important: it's hard to sleep when it's too warm or too cold
- what is the ventilation like? Some prefer a window open but others find it too cold or a distraction
- are there any noises disturbing you that you could do something about? Some people are better able to sleep when there is a little noise going on in the background, and can't sleep when it's too quiet.

Preparing for sleep

Having good 'bedtime hygiene' can help - this is a routine that we do every evening before going to sleep so your body recognises it is time to wind down.

For example, turning off devices, listening to some gentle music, changing into night-time clothing.

Hot drinks can be soothing for some people, and we often associate hot milk with bedtime, so that can be a useful association to draw on.

However, drinks with stimulants in them are not a good idea. Caffeine – in tea and coffee – is a stimulant and is known to disturb sleep. This effect will last for several hours after drinking it.

The more caffeine you have in the day, the more likely it is to affect your sleep. It can help to simply to avoid caffeine six hours before bedtime.

Action for ME doctor, Robin Kerr, advises that people with concurrent autonomic dysfunction should avoid caffeine entirely.

Some people need to avoid caffeine in the afternoon and evening altogether.

While alcohol can help some people to fall asleep, many people find that it causes disruption later in the night so might be best avoided.

Emotions and sleep

Although you might say that there's nothing you can do when you're in bed to sort your anxieties out, it's sometimes hard not to worry anyway.

If you want time to think things through on your own, it can be better to do this earlier in the day, writing things down can be useful. It can help to have a pad and pen by your bed so you can catch any important thoughts or get worries down on paper so you can set them aside.

Just before bedtime, it can help to have a regular set of activities that help you to wind down.

Some find it helpful to write lists for the following day, do relaxation exercises, read a book or listen to relaxing music or talk radio.

The important thing is to do something that helps you wind down, so you are not feeling stressed at bedtime.

Remember, the key to self-management is learning what is helpful for you as an individual, and taking charge of any gradual changes, you make.

Medications and sleep

Different medications do have important effects on sleep.

If pain is disrupting your sleep, it might be worth discussing the pros and cons of different pain medication with your GP or a pharmacist.

Simple painkillers can help, but some people benefit from medications like Amitriptyline or Nortriptyline taken in very low doses, about two hours before bedtime.

NB. Note that some people experience side effects and find it difficult to stop taking these medications. You should consider all the implications carefully with your doctor first.



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