

Sleep

‘To equip people affected by CFS / ME with the skills for self-management towards a better quality of life’.



Pride in our older people's and adult community services

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Pemberton, S. (2009) Fighting Fatigue. London: Hammersmith Press

Sleep and CFS/ME

Introduction

Difficulty with sleep is common for people who have CFS/ME. Some people find that they are sleeping too much (Hypersomnia), while others find that they are not sleeping enough (Insomnia). If you experience problems with sleep there are several things you can do to help yourself.

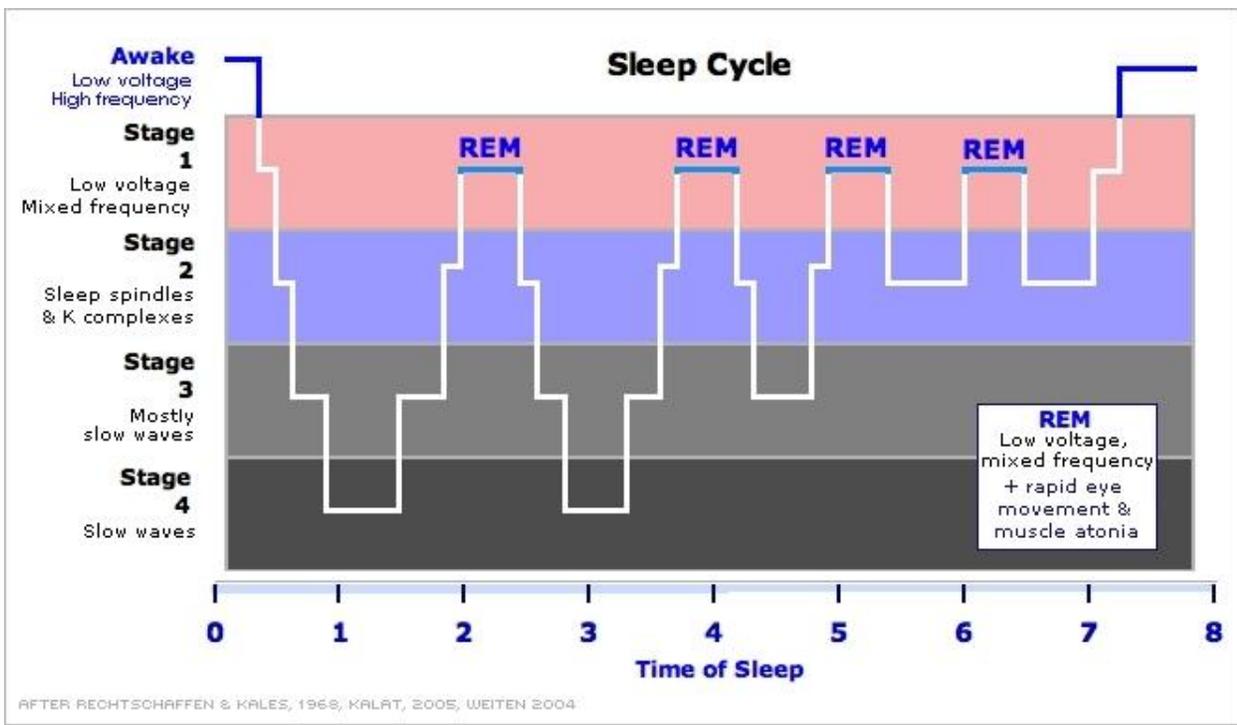


There is no such thing as an ideal amount of sleep. Some people need ten hours, while others only need five. An average night's sleep is around eight hours. Some people get very little sleep and do not feel any different; others sleep for long periods and feel fine. When the amount of sleep someone is getting is causing an increase in fatigue that is when it becomes a problem.

When people first become unwell with CFS/ME they often oversleep. Suggestions of what you might find helpful if you are oversleeping are covered first in this booklet. People who have had CFS/ME for a longer period of time often change from oversleeping to not being able to sleep enough, despite high fatigue levels. Suggestions that you might find helpful if you not sleeping enough will be covered in the second section. In order to manage your sleep better it is useful to understand the stages of sleep.

The Sleep Cycle

Sleep is divided into 5 stages. Stages 1,2,3,4, and Rapid Eye Movement (R.E.M.) sleep. In R.E.M. sleep the eyes of the sleeper move quickly and jerkily. It is also the stage of sleep in which people dream. R.E.M. is the lightest form of sleep. People descend through the stages of sleep from R.E.M. to stage 4, which is the deepest form of sleep.



During the night people move through the 5 stages of sleep a number of times in a pattern called the sleep cycle. One sleep cycle lasts roughly 90 minutes. In the first sleep cycle of the night the majority of the 90 minutes is spent in the deep stage of sleep (Stage 4). However in each cycle that follows more time is spent in R.E.M. and stage 2 sleep. A decreasing amount of time is spent in stage 4 (deep sleep).

The vast majority of deep sleep occurs within the first four hours of sleep. So in theory a healthy person who sleeps only 4 hours could get roughly the same amount of deep sleep as a person who sleeps for 12 hours a night (see graph). So when you have Chronic Fatigue Syndrome/ME you need to think about the sleep pattern you had before you were ill. You may have always been someone who needed more sleep or you may have functioned on less sleep. This may help when thinking about the sleep pattern you are aiming to achieve.

Are you sleeping too much?

When people have an acute illness, like an infection, the body may need more sleep to assist recovery. But with CFS/ME the fatigue and other symptoms are not improved by sleep, so although sleep may have been helpful at the beginning of your condition it may not be making any difference now.

It is not unusual for people suffering from CFS/ME to report that they sleep for twelve



or more hours, yet still feel fatigued and unrefreshed on waking. So with CFS/ME on the odd occasion when you also have an acute illness or are sleep deprived it is normal to 'catch up on sleep' by sleeping for longer than usual. However, some people with CFS/ME find that they regularly sleep much more than

they did prior to the condition.

Often people think that if they are tired they need sleep, but fatigue in Chronic Fatigue Syndrome is not improved by sleep. Therefore it is difficult for people to tell the difference between when they are tired due to lack of sleep and when they feel fatigued, which can be made worse by increased sleep.

The consequences of sleeping too much are:

- ❖ Increased need for more sleep
- ❖ The body getting used to excessive sleep and late waking
- ❖ Inability to concentrate properly
- ❖ Loss of motivation and energy whilst awake
- ❖ Reduced enjoyment and satisfaction in life



What can you practically do about oversleeping?

If you are sleeping too much, look at **GRADUALLY** reducing your amount of sleep by getting up earlier

or going to bed later. Sometimes just starting with half an hour less morning or evening (whatever feels manageable) and then every week add another half an hour. Maintain this reduction weekly until you are back to your normal (pre CFS) sleep pattern. Establishing a routine will help you gain more control over your symptoms.

Sleep Routine

Everybody has a biological clock, which regulates things like body temperature, activity levels and sleep. The example of jet lag demonstrates how our body's rhythm can be out of synch with that of our environment. In CFS/ME some people will be sleeping in the day and be awake at night. Others will be "cat napping" throughout the day.

"Cat-napping"

It is advised that people with CFS/ME avoid "cat napping" in the day if possible. "Cat-napping" can lead to people over sleeping or not being able to sleep at night. Also many people feel groggy after sleeping and take a while to come round, often feeling worse than they did before they went to sleep! It is important in CFS/ME for people to balance the demand for energy they are making on their body. This is difficult if their sleep routine is chaotic.

If you do not think you can manage to get through a whole day without sleeping, don't worry. Try to regulate your sleep in the day to a particular time e.g. 2 pm and for a regular length, e.g. 1 hour (An alarm clock may be needed to do this effectively). Once you have done this try to reduce the amount of time you sleep during in the day gradually over a few weeks, aiming to eventually (if possible) gain all your sleep at night.

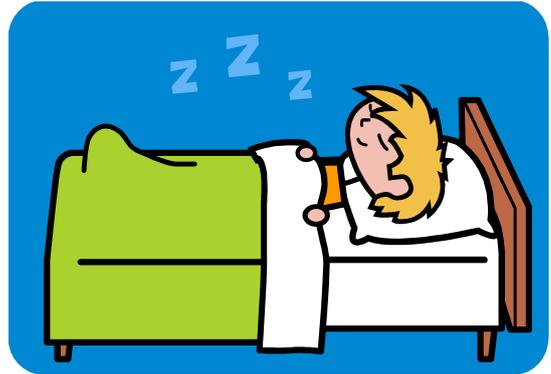
Some people find it helpful if they are used to "cat-napping" to gradually replace sleep during the day with rest. This allows them to help their body to recover when fatigued without disrupting their sleep pattern.

Do not worry!

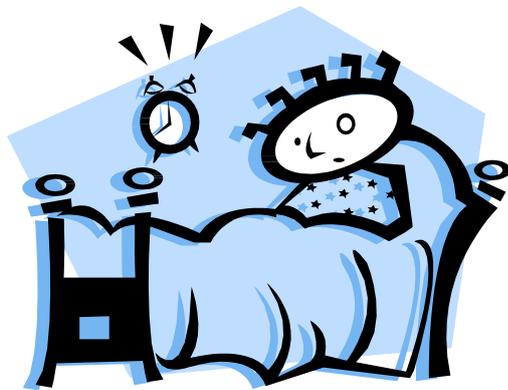
Initially the change to your sleeping pattern may make you feel worse and more fatigued. In the long term you should feel more energised. Another benefit of reducing your sleep is that you will have more time available for the activities you choose to do.

Quality not Quantity

Also applies to sleep. If you do not manage to stop "cat napping" or over sleeping completely don't worry, but do try to regulate your sleep to the same time each day and reduce it as much as possible. Remember, altering your sleep pattern is important, but is only one part of the jigsaw of recovering from Chronic Fatigue Syndrome.



Are you not sleeping enough?



Some people describe going to bed tired and then ending up "wired" the minute their head hits the pillow. Difficulty falling and staying asleep is common in CFS/ME. Don't panic if you're having trouble getting to sleep. One sleepless night has little effect on the body. Even if you have several bad nights, when you do fall asleep you will automatically catch up on

deep sleep.

Here are some tips to help you manage lack of sleep:

Wake up at a regular time

Establishing a regular sleep pattern is very important. The time that you wake helps to synchronise your body clock. Try not to vary the time you wake up by more than an hour, even across weekends.

Have a wind down period prior to sleep

Make sure you can stop work at least 30 mins before you go to bed and do something non-stressful e.g. read, have a bath or listening to music. Try not to watch T.V. just before you go to bed as this tends to encourage you to stay up “just a little bit longer” to see what happens next.

Use your bed only for sleep

Try to use your bedroom only for sleep. Activities such as reading, eating, watching T.V. and talking about problems should be done somewhere else. This is because these activities are associated with arousal and may interfere with you getting to sleep. These kinds of activities make you associate bed with wakefulness and alertness rather than drowsiness and sleep.

Do not stay in bed when you are not asleep

Once in bed, if you cannot get to sleep within approximately twenty minutes, it is suggested that you get up, leave the bedroom and do something relaxing. Preferably this should be something un-stimulating (the more boring the better). Return to bed only when you feel sleepy. Use this technique also if you wake in the night and can't get back to sleep. At first you may need to get out of bed a number of times before you finally fall asleep. The aim is that you begin to associate your bed with sleep not with stress or activity. **Still get up at the same time each morning, however long you have slept.** Routine and setting a consistent circadian rhythm is key.

The counting technique

When you get in to bed, as soon as your head hits the pillow, using the breathing technique (at the end of this booklet) using the out breath and then the in breath say “1” in your mind....then the next out breath and in breath say “2”...slowly and calming focusing on the breath and the number until you reach 10, then if you are not asleep, go back to 1 again and continue. The technique is effectively to bore the brain to sleep, offering it no stimulus or reason to stay awake. If your mind pulls you away, when you notice it has become distracted by thinking, just gently coax it back to the counting with the breath. If practiced enough it becomes a cue to the brain to fall asleep

Avoid napping during the day

It can be very tempting to take a nap in the day if you have not slept well the night before. However if you have insomnia and take a nap in the day you will be more likely to have another poor nights sleep. This is because you have taken your deep sleep in the day and you will be less tired and need less sleep at night. When you are tired, try to avoid daytime naps. If you want to increase your chances of sleeping for longer at night stick to regular sleep times, going to bed and waking up at the same time each day.

To reduce catnapping try to take your nap at the same time each day and for a regular time e.g. at 1 p.m. for 1 hour (you may need an alarm clock to do this). Then gradually reduce your daytime sleep, aiming to stop napping in the day altogether if possible.

Make your sleeping environment conducive to sleep

Noise

If your environment is too noisy it can be difficult to sleep. Try to sleep in the quietest bedroom in the house. If your bedroom is noisy close windows and doors to cut out noise from outside or wear earplugs.

Light

A light room will make it difficult to sleep. Make sure you have thick curtains that block out the streetlights and sunlight. Also make sure lights from the hall or electrical items like digital clocks are not shining in your eyes.

Comfort

Make sure you are not too hot or too cold in bed. Also try to make yourself as comfortable as possible before you try and go to sleep.

Take a snack

A light bedtime snack, such as a warm glass of milk or a banana will help some people get to sleep. These foods contain an amino acid called tryptophan, which is thought to be involved in the biochemical systems that induce sleep.



Avoid stimulants

Caffeine is in coffee, tea, cocoa, cola drinks and some over the counter medications. Consuming caffeine before bed or drinking too much during the day will increase feelings of wakefulness and make it more difficult to sleep. Any caffeine consumed after 4 pm will still have an effect by the time you go to bed.

Nicotine stimulates the nervous system by releasing adrenaline, which arouses the body and mind. Smoking prior to bedtime increases liveliness when you want to relax and sleep. Do not smoke for at least an hour before bedtime to allow the effects of nicotine to wear off.

Avoid excessive alcohol

As the body breaks down alcohol in your system, you tend to wake up more frequently and spend less time in the deeper stages of sleep. If you drink regularly to help you to sleep there is a risk that you will become dependent on alcohol, which will in fact rob you of quality sleep. Alcohol is not the solution to sleeping problems; so do not drink before you go to sleep.

Coping with worry and anxiety

Anxiety is a common cause of sleep disturbance. People can find themselves worrying about their problems when they would rather be asleep. Feelings of tension that accompany worrying thoughts make it difficult to fall asleep. People often start to worry about the fact they cannot sleep, which of course makes sleeping even harder.

Bed is not the place to think about things that distress you. Try to write down problems at night to deal with them in the morning. Try to set aside a time each day to think about the things that are happening in your life. Try to write down ways to resolve your problems. This may involve making difficult decisions about issues like work and family. However the uncertainty that accompanies difficult decisions is often much more unpleasant than living with the decision once it has been made.

Relaxation

When you are asleep your heart rate and breathing rate are slower than when you are awake. If you are stimulated e.g. by worry or excitement your heartbeat and

breathing rate is faster. If this is the case when you try to go to sleep it is very difficult for the body to reduce the heart and breathing level, from the high rate of stimulation to the low rate of sleep. Try the relaxation exercise at the back of this booklet as a way of calming your body down before you try to sleep.

Think of 3 things you are grateful for each night before sleep. It sets the scene and helps the brain to realise all is well and it can let go and sleep☺.



Medication

Using medication to help you to sleep can cause as many problems as it solves. While sleeping pills such as benzodiazepines can help people fall asleep and decrease anxiety in the short term, these benefits disappear if you use sedatives regularly. This is because if you take medication over a long period of time you become tolerant to the drug and it becomes ineffective. It can also be difficult to stop taking benzodiazepines after taking them for a long period due to the symptoms of anxiety and sleeplessness caused by stopping the medication.

Medication can change the natural sleep cycle, which can negatively affect your quality of sleep. For example if the medication means you get more R.E.M. sleep than deep sleep you may dream more, but wake up feeling less refreshed. The effect on the sleep cycle varies between different types of medication.

Some people with CFS/ME find that sleeping tablets can add to their fatigue making them feel 'groggy' in the mornings. It is preferable to try some of the other techniques mentioned in this hand-out to help you to sleep. However some people with CFS/ME do find medication useful in helping them to sleep. GP's working in CFS/ME services tend to prescribe tricyclic antidepressants for example amitriptyline, to people with persistent lack of sleep. This is at a low dose that would be ineffective in treating depression, but can help people to sleep without making them feel too 'groggy' in the morning.

Adjusting your sleep pattern?

Some people with CFS/ME may be getting enough sleep, but getting their sleep mainly in the day rather than at night, for example sleeping from 4 am to 1 pm. If this is the case and you want to change it start by regulating the time you get up i.e. always get up at 1 pm (you may need an alarm clock to help you with this). Then gradually move the time you get up back half an hour at a time e.g. get up at 12.30 p.m. Gradually start to go to bed earlier as you should start to feel tired earlier. Continue this process until you are going to sleep and waking up at the time you want. This process may increase fatigue levels slightly to begin with, but if you stick with it should help you to adjust your sleep pattern with the minimum shock to the system.

Don't worry if your sleep routine is not perfect, any improvement in your sleep routine can be beneficial. Remember it is only part of the treatment of CFS/ME and improvement in sleep routine will be more effective alongside other measures e.g. graded activity, exercise diet, stress management etc..

Sleep Checklist

Below is a list of the techniques contained in this booklet. The columns on the left allow you to tick off the techniques you have tried and record if you have found them helpful. For most people it is a combination of factors, which can help to improve their sleep.

- Sleep Diary
- Sleeping too much?
- Gradually reducing amount of sleep by getting up earlier
- Not cat napping
- Limiting cat napping
- Gradually reducing cat napping
- Not Sleeping enough?
- Waking up at a regular time
- The counting technique
- Having a sleep wind down period
- Using your bed only for sleep
- Not staying in bed when you are not asleep
- Avoiding napping during the day
- Making your environment more conducive to sleep
- Avoiding stimulants
- Avoiding excessive alcohol
- Coping with worry and anxiety
- Relaxation and 3 things you are grateful for.

Abdominal Breathing Technique

Follow These Steps

- ❖ Breathe out through your mouth and let your shoulders drop right down.
- ❖ Concentrate on your stomach and let the muscles of your stomach relax.
- ❖ Take as slow a breath as you can in through your nose and push stomach muscles gently outwards.
- ❖ Hold the breath for two seconds, with your stomach as relaxed as you can.

- ❖ Now let the breath go making sure you breathe all the air out of your lungs and breathe out through your mouth.
- ❖ Let your stomach fall gently down again with the out breath.

How to test that you are doing the technique right

It is very easy to take a deep breath in but this can offer make your muscles more tense if you are not breathing in the correct way.

Therefore the most important element of this breathing is concentrating on letting your stomach to relax, to allow the diaphragm to drop into the abdomen and therefore allowing the chest to expand.

To test that you are doing the technique correctly, place a hand on your stomach just below your ribs, this hand should gently rise when you breathe in and fall down as you breathe out.

Apps

- Sleep Apps – (Pzizz and Sleepstation) - <https://apps.beta.nhs.uk/category/sleep/>

Useful Resources

- Every Mind Matters (guide to help improve sleep) - <https://www.nhs.uk/oneyou/for-your-mind/sleep/>

Adult CFS / ME Service

Tel: 0330 7260077

Press 2 for Huntingdon area

Press 3 for East Cambs and Fenland area

Press 4 for Peterborough area

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Email: cpm-tr.cfsme@nhs.net

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HQ Elizabeth House, Fulbourn Hospital, Cambridge CB21 5EF
T 01223 219400 F 01480 398501 www.cpft.nhs.uk



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