

# CFS/ME

## Foundation Phase

### Workbook 2



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## Rest: ways of using rest, and how to get good quality rest

Rest can be used to both conserve the energy you have and to recover from expending energy. Quality, recuperative rest is not the same as sleeping or low-demand activity, such as reading or watching TV. Being able to rest effectively can shorten your rest periods and can enable you to do more

of the things you want to do. Long periods of rest can lead to a loss of fitness, so shorter, more effective rests can also stop you becoming weaker. Quality rest can involve learning relaxation methods such as progressive muscle relaxation, 'grounding', or relaxed breathing to relax body and mind.

Effective relaxation can then become part of your life, and how you manage your energy.

Here are some ways you can go about using rest. We would suggest you try these as an experiment - work out what works for you.

1. Plan your rests for the day: this helps you regulate your energy expenditure over the day and makes sure you do stop and rest. One advantage of having regular planned rest is that the body learns when it is rest time and goes into a deeper relaxation more efficiently.
2. If you have a high energy demanding activity in your day, plan to rest before you do the activity and afterwards too.
3. Once you have learnt a relaxation method, then try making an activity easier by using the method, for example using a breathing exercise while waiting in a shopping queue or sitting on the bus.

Try taking a quick "breather" every hour - 2 minutes or

even less of breathing exercise may help to reduce the energy drain. One way of thinking of this is to call it a "non smoking fag break!"

4. If you are watching TV, then try and do a relaxation method before you turn on the TV, or in breaks between programmes.

## Planning rest

When scheduling your day/week think about the following:

- When are your high level activities today / this week?
- Can you use rest before and after these high level activities?
- Can you use low level activities in addition to rest?
- Can you use relaxation techniques in addition to rest?
- When else can you use rest to help you with your activities?

## CFS/ME and Sleep

Most people with CFS/ME experience sleep difficulties. Some people will have difficulty falling asleep, or have broken sleep. Some people will have the opposite problem, and will sleep more than usual. This can reduce the quality of sleep, and leaves fewer hours awake to function. A sleep problem will usually add to the various other difficulties which already occur as a result of CFS/ME. Exhaustion and poor concentration are examples of this.

## **Can anything be done about sleep loss?**

CFS/ME may cause problems with sleep, but this is rarely the only reason why sleep is disturbed. The good news is that these other influences can be changed to improve sleep.

## **What is a normal good night's sleep?**

This varies from one person to the next, and changes as people get older. New born babies sleep for 18 out of 24 hours, young children up to 12 hours, young adults on average sleep for about 7 to 8 hours, whilst older people take even less, about 6 hours on average. So, how does your sleep compare with what you would expect to be getting? If you are concerned about this the next question is:-

## **What is the nature of the problem?**

Is there a problem getting off to sleep? Do you keep waking up throughout the night? Do you wake early and cannot get back to sleep again? Is it that despite having slept you don't feel you have slept well?

Do you feel the need to sleep longer in the morning, go to bed early, or sleep in the daytime? Over-sleeping can increase levels of fatigue, worsen concentration, and reduce motivation and enjoyment of life. It is important to work out what kind of disruption is taking place. This helps in deciding what changes might help.

## **What conditions are you trying to sleep in?**

Give some thought to how comfortable your bed is. Next, is the room helping? Temperature is important. It's hard to sleep when it's too warm as well as when it's too cold. Are there any noises disturbing you which 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. What is the ventilation like? Some prefer a window open but others find it too cold or a distraction. Try to get the conditions right to suit your needs.

## **Food and drink**

Going to bed after a big meal is usually a bad idea. Big meals do make people feel tired but digesting a large amount of food will keep many people awake. If on the other hand it has been a long time since your last meal, then hunger can keep you awake. If so, a light snack before bedtime may help.

A hot drink often helps as a way of settling down to go to sleep. However, drinks with caffeine or other stimulants in them are not a good idea. These include coffee, tea and chocolate. Caffeine 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. If you do have drinks with caffeine in, and you do have sleep difficulties, then it is worth cutting the caffeine level down. It can help simply to avoid caffeine in the six hours before bedtime. Some people need to avoid caffeine in the afternoon and evening altogether.

Alcohol is, in a sense a relaxant, (the opposite effect to caffeine). On the face of it a late drink might help you get off to sleep, hence the idea of a “nightcap”. However, there is some evidence to suggest that sleep which is affected by alcohol is less restful.

### **Smoking and sleep**

Nicotine is a stimulant, like caffeine, and there is strong evidence that smokers usually don’t sleep as well as non-smokers. Happily, for those who give up smoking the evidence shows that they get off to sleep more easily within days of stopping. For those who don’t want to stop but are having problems getting off to sleep it is worth trying not to smoke in the three hours before bedtime. This will probably make sleeping worse to begin with as your body gets used to not having the nicotine, but you will quickly adjust, probably within three days.

### **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, taken in very low doses, about two hours before bedtime. Your GP can find advice about sleep and symptom management in a guide available from the British Association for CFS/ME called the “BACME Therapy and Symptom Management Guide”. You can find this at the bottom of the home page of the BACME website:[www.bacme.info](http://www.bacme.info)

### **Physical activity and sleep**

There are strong links between physical activity and good sleep. CFS/ME leads people to be less active during the day. This will make sleeping more difficult. On the other hand if you have been able to gradually increase the amount of activity you do in the day you may be already reaping one of the benefits: better sleep.

Brisk exercise taken late in the evening tends to liven people up when it would be better to wind down. Some people manage gentle exercise such as stretching in the evening without disrupting their sleep.

### **Emotions and sleep**

Some people will say that they do their worrying at night when everyone else is asleep. 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. Plan a time earlier in the day to think about your concerns, perhaps writing them down, as many people have found this process useful. Try to associate going to bed with going to sleep.

Some people will wake in the night and find they are unable to go back to sleep. If this is happening, and if you think that you are not restful and are likely to not drift off to sleep again afterwards then it’s probably better to get up. If you’re still weary then take rest in a chair instead.

## **The golden rule for good sleep: Establish a regular pattern**

It's possible to ignore most of the rules about sleeping and still manage all right. There are many who have a cup of tea and cigarette before going to bed, or who take the dog for a walk. They probably manage this because it is part of a regular habit of getting ready to go to bed. However being inconsistent with the time that you sleep is asking for trouble. You need a pattern. Taking care of this is by far the most important thing you can do. Getting up late one morning, and then early the next is disruptive to sleep. Your body needs a pattern. It needs to know when to expect to sleep and to wake. We can't change the time of sleep a lot and assume our bodies will adjust. This is basically what has gone wrong when someone flies to another part of the world and experiences "jet-lag". Another example is what is known as "Sunday Night Insomnia", when someone who has gone to bed late on Saturday night and got up late on Sunday morning then finds that they can't get off to sleep at the usual time on Sunday evening.

If you want to improve your sleep at night and you sleep in the day, make a plan to gradually reduce any daytime naps, because otherwise this will become part of your 24 hour pattern. Daytime sleep can reduce the quality of night-time sleep. This is because it changes the pattern of deep (restorative) sleep which we get in the night. The only exception to this is a daily "power nap" of 20-30 minutes which can help some people to reduce daytime sleepiness.

If you sleep for much more than eight hours, it might be worth trying to reduce your sleep, so that your sleep quality can increase. You will need to do this gradually, to allow your body to adjust. Most people find it is easier to set an alarm clock for a fixed time in the morning, and then slowly move the alarm clock earlier. There is nothing wrong with a 10 or 15-minute change per week, if you are making progress in the long-term. The reason for making the change in the morning is that our "body clock" is set when we first see daylight in the morning. Once the "body clock" is set, we will tend to feel naturally ready for sleep approximately 16 hours later. Opening the curtains a little can help with this process, but the sooner in the day that you can tolerate outdoor daylight the better.

During the initial phases of any sleep reduction program people often feel more tired, but this usually improves within two to three weeks. The rewards for this in the long-term are better sleep quality, and more hours in the day in which to balance activity and rest.

## Sleep summary

- Good sleep is about quality not quantity.
- Gradually reduce daytime sleep. Substitute with more rest periods.
- Aim for a regular bedtime, and more importantly, stick to a regular time to get up.
- A good balance between activity and rest during the day will help.
- During the evening, particularly just before bedtime, it helps to have a regular set of activities that help you to wind down. Take less exercise at this time of day, avoid stimulants such as coffee, and avoid other things that wind you up.
- If you wake in the night and can't get back to sleep straight away (20 minutes) get up! Try to relax and take rest instead. Only go back to bed when you have a good chance of falling asleep again.

## CFS/ME and Stress

Stress is a normal reaction to the challenges we face in life. A certain amount of stress is necessary to keep us all going; without it, we would feel bored and listless. However, continued stress over a long period of time can be exhausting, and if your energy levels are low due to CFS/ME, the additional drain on energy because of stress is a particular problem.

People differ both in the way that they react to stress and the extent to which they are aware of their own stress levels. Below are some of the possible effects that stress may have; it may affect us physically, emotionally and in the way that we behave.

Physical Changes	Emotional effects	Other people notice
Heart racing	Tense	"Short fuse"
Sweating	Frustrated	Always rushing
Breathing faster	Afraid	Loss of humour
Queasy stomach	Irritable/angry	Impatience
Trembling	Tiredness	Don't listen
Dry throat	Fear or dread	Sudden mood change
Muscle tension	Argumentative	

Other effects: Poor concentration, Memory problems, Difficulties making decisions

All of the reactions above are normal. When we face a physically threatening situation these responses help the

body prepare itself for action.

This is known as the “Fight or Flight” response because the body prepares itself to fight, or run away from dangerous situations. This is a helpful, instinctive response. When the dangerous situation is over, the body can begin to recover.

In modern society, a lot of the things that create stress are not dangerous situations where we can physically fight or run away from something. For example, financial worries or family problems can make us feel under stress. In these situations stress levels may rise and remain quite high, and after a while we may begin to feel the effects of this. Over a long period of time stress can make us feel exhausted and unwell. Some of the symptoms of chronic stress are the same as those of CFS/ME. How can we know which is which?

### **Managing CFS/ME and stress**

Long term illness can cause its’ own worries. Worrying can trigger the stress response, and muscles then become tense. Changes in muscle tension can be quite subtle, and it is difficult to be aware of it happening. This increased tension can worsen fatigue, and aggravate any pain, leading to more stress and worry: a “vicious circle”.

**We also tend to put ourselves under stress by doing some of the following things;**

- Taking on more than we can do
- Not saying “No” to people
- Not being satisfied with what we have achieved
- Not having enough relaxing things to do

Being aware of some of these things can be useful. There are positive management strategies for stress, and for the symptoms of stress.

### **Reducing stress through relaxation**

Most people already have things they tend to do when they feel quite stressed - there are lots of possible ways of tackling it. For example, some people listen to music, talk with a friend, or go for a walk. Regular exercise can also help to reduce tension in the muscles, and give a feeling of wellbeing. Sometimes your usual methods of handling stress may become less effective when stress rises beyond a certain point. It is useful during these times to have some specific methods of dealing with it.

It can be useful to become aware of the signs of increased tension and stress so we can spot them at an early stage, and manage the stress differently. Listening to a relaxation is one way of beginning to become more aware. Learning to relax means that you can reduce muscle tension and break out of the vicious cycle of fatigue, stress and tension, which can be worsened when living with CFS/ME.

Relaxation is different from watching TV or reading a book; these activities may be tiring in their own right. When practising relaxation you need to find somewhere quiet and warm, where you can find a comfortable position and you will not be interrupted.

At the beginning relaxation may be frustrating if you find it difficult to concentrate or feel it is not working. It is a skill, and is likely to take a bit of practice. Remember that there are different forms of relaxation, to meet individual preferences. It is worth seeing the initial stages as an investment of time, which can pay dividends in the medium and long term. Daily practise will give the best results.

You can download relaxation recordings from our website: [www.nbt.nhs.uk/relaxation](http://www.nbt.nhs.uk/relaxation). Start by listening to the guidance, then if you are happy with the instructions, try the method yourself. You may need to practice each method several times to learn how to relax. If you are not making progress with these recordings, please discuss this with your CFS/ME clinician.

Finally, be aware of any effects of stress upon your sleep, or upon your ability to use rest. If you notice that you are awake at night feeling stressed about not sleeping, you can try using your relaxation skills to help. Clock watching at night is a common mistake: it can increase stress levels and make it harder to sleep. Can you use relaxation methods to help you to sleep, or to help you to rest more effectively? You may also benefit from learning meditation, which is different from relaxation. You can discuss this option with your clinician if you are interested.

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If you or the individual you are caring for need support reading this leaflet please ask a member of staff for advice

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