

Supporting Young People with Chronic Fatigue

Sleep & Relaxation

ME/ PCFS Patient Information

This leaflet will give you some useful information and tips on how to help manage your sleep and rest routine. This will help you to give yourself the best chance of recovery.

Problems with sleep are very common in ME/ Chronic Fatigue Syndrome.

There are two things to tackle:

- Making sure you don't have too much sleep
- Getting your body clock back

How much should I sleep?

This varies for each person. Updated guidance for how much sleep you should get can be found at:

www.nhs.uk/Livewell/Childrenssleep/Pages/howmuchsleep.aspx

If you sleep just 1 hour more than this recommended amount, it will reduce the quality of your sleep and leave you feeling more tired. The more you over-sleep, the more damage this does to your sleep quality and the more tired you are likely to feel. We recommend trying to stick as close to the recommended sleep as possible.



Trying to stop tiredness in ME/ CFS by sleeping more usually makes things worse.

- You need to sleep no more than your friends
- At first you will feel much worse, because you will be having less sleep after a couple of weeks you should be sleeping better at night and most young people start to feel better



When should I sleep?

Day/ night reversal is common in young people with ME/ CFS and can add to your problems. If you do suffer from this, try to treat it like jet lag:

- Wake up **30 to 60 minutes** earlier each day until you're waking up between 7am and 8am
- The most important thing to set is your wake-up time, which should be anchored to the same time every day

It is important that your brain is given the right stimulation to tell it if it is day or night. Try to stay awake during the day so that you see daylight – this helps the brain get into the correct day/ night routine.

Can I rest during the day?

There are difference types of rest which people find helpful. Most rest doesn't involve sleeping and can include sitting quietly or **zoning out** whilst listening to restful music or a relaxation CD. If possible, this should **not** happen in your bedroom, to avoid the chance of falling asleep.

If you really need a sleep, make sure it is less than 30 minutes, before 3pm and in a light room with the curtains open. This is to stop you going into deep sleep, as this could disrupt your night-time sleep.

Sleep routine/ wind-down

This helps your brain get ready for sleep by giving it lots of signals to go to sleep.

For example, you might find that a warm bath relaxes you, or a warm drink might help you get off to sleep. Don't do things just before bed that send confusing signals and stimulate your brain, such as TV, computer games and certain books (e.g scary ones). In fact, there is some evidence that TV in the lead up to bedtime can be a bad idea even for people who don't have ME/ CFS.

- Try to do the same thing every evening your brain will learn to start getting ready for sleep
- Milk is helpful, but not hot chocolate as it is a stimulant
- Some people find the scent of lavender oil helps, or listening to gentle music
- Avoid anything with caffeine in the afternoon caffeine is a stimulant and is found in coffee, tea and soft drinks such as Coca Cola, Red Bull, Pepsi and in chocolate.

What if I can't get to sleep?

Wait 20 minutes and then get up, go out of the bedroom and perhaps get yourself a drink.

When you do this, you may need to repeat it a few times but after a few days you should find yourself getting off to sleep easier. Avoid tossing and turning.

The RUH, where you matter

You could also try some relaxation exercises:

Relaxation exercises

Spending some time relaxing before bed can help with getting to sleep. Here are some simple relaxation ideas you can try.

Controlled Breathing

The idea is to concentrate on your breathing. You can use this method anywhere and people won't even notice what you are doing!

Slowly draw in a deep breath, hold it for 5 seconds and then very slowly let it out. As you breathe, say to yourself "Relax!" Doing this a few times will help you feel calmer.

Empty your mind

Scan through your mind and see if there are any busy thoughts or worries. If there are, write them down and make a note to deal with them tomorrow. If something is really bothering you, plan to talk to someone you trust.

My Relaxing Place

Think about a special place that you find restful. Think about your dream place. It could be somewhere you have been, or a pretend place. Imagine a picture of it and make the picture as real as you can, think about:

- The noise of the waves crashing on the beach or the sound of the wind blowing in the trees.
- The smell of the sea or the scent of pine forests.
- The warm sun shining on your face or the wind blowing in your hair.

Physical Relaxation

When we are tense or worried, our muscles become tight. Practice tensing and relaxing different groups of muscles. Enjoy the feeling of being completely relaxed. There are many relaxation apps available, you might like to try one like "Mindshift CBT".

Further Information

Paediatric Specialist Fatigue Service

www.ruh.nhs.uk/cfs

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Please contact the Patient Advice and Liaison Service (PALS) if you require this leaflet in a different format or would like to feedback your experience of the hospital. Email ruhtr.pals@nhs.net or telephone 01225 825656 / 826319.

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