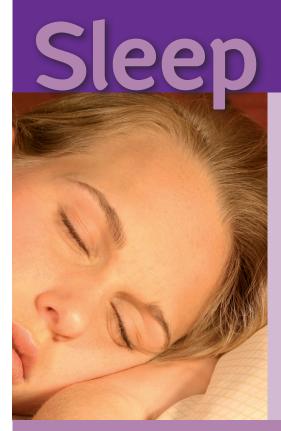
Dealing with Chronic Fatigue (CFS/ME) in Young People



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

There are two things to tackle:

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

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.

This is one of a series of information leaflets on managing CFS/ME in children and young people. These are also available on our website at www.rnhrd.nhs.uk.

For more information on our service, please contact Heather Hill on **01225 473425** at the Specialist Paediatric Chronic Fatigue/ME Service, Royal National Hospital for Rheumatic Diseases (NHS Foundation Trust), Upper Borough Walls, Bath BA1 1RL.









How much should I sleep?

Research suggests that it is possible to have too much sleep.

Refreshing sleep has lots of REM – or Rapid Eye Movement – sleep. But if you sleep more than normal, you get less and less refreshing sleep, and more and more poor quality sleep that still leaves you feeling tired.

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

- You need to sleep no more than your friends, and possibly, slightly less
- 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 CFS/ME, and adds to your problems.

So try and avoid it. If you do suffer from day night reversal, then treat it like jet laq.

- 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

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



Can I rest during the day?

There are different 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. This should not be in your bedroom, if possible.

If you really need a sleep, make sure that it is less than 40 minutes before 3pm, otherwise your night time sleep will be disrupted.

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 <u>warm</u> <u>bath</u> relaxes you, and a <u>warm drink</u> 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 (like 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 CFS/ME!

- Try and do the same thing every evening, and your brain will learn to start getting ready to sleep
- Milk is helpful, but not hot chocolate, as it is a stimulant
- Some people find 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, soft drinks such as Coca Cola, Red Bull, Pepsi and chocolate

If I can't get to sleep

Get up, go out of the bedroom, and try the sleep routine/wind down again.

- Avoid tossing and turning in bed as this teaches your brain that the bed is a place not to sleep
- Avoid stimulating things such as the TV