

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

Activity, Rest and Sleep diary



The diary sheet available from us, is to help you use a graded activity program to record what you do each week. This will help as you gradually increase the amount you do. This leaflet tells you about graded activity, and how to use the diary sheet.

The Energy Management leaflet available from us will give you more information on this type of program.

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.

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Energy Management

You can use this approach to all activities in your life, and it can be used for anyone – no matter how severe their illness is.

We think of energy as anything that stimulates the brain or body, and includes watching television and talking on the phone, as well as more obvious physical activity.

A separate diary leaflet is available from us, with an hourly chart to record your activity on.

High Energy activity (red)

High Energy activity includes:

Physical

- walking and running
- PE and sport

and for the severely affected:

- sitting up
- brushing hair
- going to the toilet
- car journeys

Cognitive

- TV you are engaged in – stuff you like to watch and are following the story
- school work
- computer use
- chatting with a friend or neighbours



Emotional

- self talk – thinking a lot about what you have done/ should have done
- arguments
- worries

Low Energy Activity (yellow)

- watching TV your parents want to watch and that you are not engaged in – (who cares?)
- watching a favourite and well-loved DVD
- watching animals
- reading magazines, not books
- chopping food, not cooking
- getting ready for creative stuff, not actually doing anything creative
- colouring in, but not actually drawing anything original

Deep rest (green)

No physical, cognitive or emotional activity of any kind, but not sleep either.

- meditation
- yoga
- deep breathing
- use of structured relaxation techniques

How to use the diary

The diary goes from midnight to midnight and is colour coded according to activity.

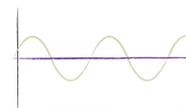
There are four different levels of activity.

Colour codes

-  High Energy Activity
-  Low Energy Activity
-  Rest/chill out time
-  Sleep

Decide on your baseline

- This is half of what you do on a good day – if you did **4 hours** of high energy activity on a good day and none on a bad day, your baseline would be **2 hours every day**.



Once you have started filling in blocks of colour, it is important that you keep a check on how your diary is looking, so **keep checking the following:**

- is my sleep anchored? (am I waking up at the same time EVERY day?)
- there should be NO blue blocks throughout the day – no day time sleeps
- is there the same amount of red every day
- the red should be in small blocks
- Rests: these should ideally be **5 minutes** every hour