# Royal United Hospitals Bath

# 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

Rest/chill out time

Low Energy Activity

Sleep

Once you've started filling in blocks of colour, it is important that you keep a check on how your diary is looking:

- Is my sleep anchored? (am I waking up at the same time every day?)
- There should be NO blue blocks during the day no napping
- There should be the same amount of red each day
- The red should be in small blocks
- Rests: Ideally 5 minutes every hour.

Other ways of monitoring your activities

- ActiveME iPhone App our app is available in the App Store
- Coloured wristbands move from one hand to the other when you've "used" an hour of activity
- Coloured marbles move from one pocket to another
- Be Creative! What ideas work for you?

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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 <u>ruh-tr.PatientAdviceandLiaisonService@nhs.net</u> or telephone 01225 825656.

Further information can be found at our website: www.ruh.nhs.uk/cfs

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# **Energy Management**

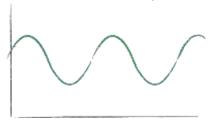


Energy Management is the way all of us should balance our daily activity. It is especially useful if you have CFS/ME as your energy stores are much lower, and therefore balance becomes more important. This leaflet will explain how to monitor and record your daily activities, including how to fill in the Activity, Rest and Sleep Diary.

# **Boom-Bust Cycle**

Most people tend to do a lot when they feel good and not very much when they feel unwell.

This can lead to big swings in activity, and if you have CFS/ME you may find that you over-do it one day (boom), and have a bad day (bust) another. The recovery time is often called 'payback'.



**Energy Management** helps to stop this swinging from one extreme to another so that you can start the process towards recovery.



#### What is energy?

We all use up different amounts of energy, depending on the activity we are involved in.

Activity is anything that stimulates the brain and includes watching TV and talking on the phone, as well as more obvious physical activity.

#### **High Energy Activity (red)**

#### Physical

- walking and running
- PE, sport, dance

#### and, for the severely affected:

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

#### Cognitive

- TV you are engaged in -
- things you like to watch and
- following the story
- school work
- computer use
- chatting to friends or neighbours

#### Emotional

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

## Low Energy Activity (yellow)

- watching TV that you are not engaged in
- scrolling through your phone
- watching a favourite and wellloved DVD, series or repeats
- playing with pets
- reading magazines, not books
- chopping food, not cooking
- colouring in, but not actually drawing anything original

## Deep Rest (green)

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

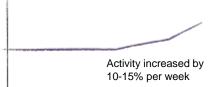
- meditation
- relaxation exercises
- yoga
- deep breathing
- use of structured relaxation techniques
- mindfulness techniques

## How do I go about Energy Management?

 Before you start Energy Management you need to keep a record of your activity levels. You then need to decide on the **baseline** – this is half of what you do on a good day. For example, 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.

# When can I increase my activity levels?

When you have managed **2** weeks of the same activity daily, you can start to increase by 10% a week. We will review this with you in your appointments.



The Activity, Rest and Sleep diary, available from us, is somewhere for you to record your daily activities. Doing this will help you increase your activity gradually, so that you avoid the boom-bust cycle.

See over the page for how to fill in the diary, and some other ways of recording your activities.