

## Patient information

# CFS – Recovering from CFS

## Recovering from Chronic Fatigue Syndrome

### Goal Setting

It is important both you and your team know and understand what areas in your life are most important to you. Goal setting allows you to focus on what you want to do and helps those around you support you in achieving this. Having a goal improves motivation and by monitoring your progress you can recognize in areas that help with your recovery, or those that have a negative impact.

Goals can be simple and short term and can lead to changes and improvements over a longer period. Your team will give you some questionnaires that will help them and you understand how you are feeling what you want to achieve and together you can set goals towards your recovery.

### Routine and Energy Management

Young People with CFS say they have good days and bad days. On a good day, they are often very busy (BOOM), but on the following days, their symptoms seem worse than normal and they don't do a lot (BUST). Having a routine where you do the same things every day helps get rid of this boom-and-bust pattern and helps to increase your daily activity.

Finding a baseline level of activity is the way all of us should balance our daily lives. When you have CFS, you have reduced activity levels and your energy stores are much lower, so finding that balance becomes even more important.

Activity is anything that stimulates the brain. It includes being on our phones and reading as well as physical activity such as baking, walking the dog or participating in sport. We all use different amounts of energy depending on the activity. Finding a consistent level of activity for each day stops this swinging from one extreme to another and starts the process towards recovery from chronic fatigue.

## Activity and Exercise

Remember we think of activity as anything that stimulates the brain. As you begin to manage your baseline level of activity, you will naturally want to and be able to do more. To begin with, your physiotherapist can help guide you with activity increases, however with time our aim is for you to be able to do this more independently.

Pacing is used to help with activity increases. It helps to stop the boom-and-bust pattern from reoccurring and maintains the balance of activity and rest.

**Before you increase your activities the two most important things to remember are:**

- You must be able to cope at your current level of activity every day.
- You need to make small increases each time (10%) and stay at this level until you are sure it doesn't impact on your other routines or exacerbate your symptoms.

Some people find it helpful to continue to record their activities each week, this allows you to monitor what you are doing and recognise what aspects of activity you can start to increase. For example, if you are reading for 30 minutes daily, you could increase this to 33 minutes. After 2 weeks, if this was successful, you could then increase it to 36 minutes a day or if you are achieving 3 hours of schoolwork successfully, 5 days a week, you could increase this to 3.5 hours a day. If this was successful for a few weeks, you could then increase a physical activity by 10% each day. Maintaining this pacing of activities will help you to continue with your recovery.

**Remember you are still trying to avoid boom and bust patterns.**

Some young people like to use exercise as a way of increasing their activity levels. This is great if it is important to you.

The most important things to remember are:

- You must start with baseline that is easily achievable. This is normally half the exercise that you could achieve on a good day.
- You should only increase the exercise slowly and you should still be able to participate in your other activities that day. This should not lead to a "Bust" in your activity levels.
- It is useful to continue to use a diary so you can document your progress.

If you want to use exercise as a part of your activity talk to your physiotherapist about this.

## Sleep

Sleeping problems are common in young people with CFS. Some issues are that you are getting too much sleep and or your body clock has changed, and you are sleeping more during the day and less at night. Trying to stop tiredness in CFS by sleeping more usually makes things worse rather than better.

With your physiotherapist you will work out how much sleep you are having in 24 hours, and plan together to reduce the amount and improve the quality of sleep you are having.

Initially you may feel worse as you are having less sleep but after a few weeks you should be sleeping better at night, less during the day and therefore feeling better. This will help you to give yourself the best chance of recovery.

**If you would like any information regarding access to the West Suffolk Hospital and its facilities, please visit the website for AccessAble (formerly DisabledGo)**  
**<https://www.accessable.co.uk>**

