

This leaflet explains how physiotherapy ('physio') can help young people with CFS/ME. It contains suggestions for improving how much activity you can manage and how to measure how well you are doing. If you have any questions, please call us. Our telephone number is 020 7813 8541.



Chronic fatigue syndrome and physiotherapy

Information for young people

Great Ormond Street Hospital for Children NHS Trust

CFS/ME and physio

Physiotherapists are interested in how you move and how much you move. For all daily activity, you need to have a level of fitness, endurance and strength. The physiotherapist will talk to you about how much activity you do each day, your daily routine, sleep patterns, what makes you better and worse. There are a number of different types of activity that will be discussed:

- **Formal Activity** – This refers to movement with a purpose and can sometimes be confused with exercise. An example of formal activity is walking the dog with your family or walking round a supermarket to do the shopping.
- **Informal Activity** – This refers to things you need to do for everyday activities. An example of informal activity is walking upstairs to your bedroom or going to the front door to pick up post.
- **Exercise** – This refers to activity that increases your heart rate, such as a specific exercise program.

Mental activity, such as school work, also counts towards your daily activity so will also be discussed.

Baseline activity and diary

It is necessary to discover how much you can do on a bad day, as well as on a good day. It is how much you can do day after day without making your symptoms worse. This is your 'baseline activity level' and can be used as the least amount to achieve every day.

You can work out your baseline activity level by keeping a diary for at least a week. You will need to record things like:

- whether you went to school
- your sleep routine
- things you did
- going out with friends or family
- talking on the telephone
- time on computer

By recording these things for a week or more, you will be able to see a pattern and workout your baseline activity level.

The diary can also show you changes in your baseline activity over time. As you begin to manage better with a particular level of activity, you will probably be able to do more. Each planned increase in activity will be worked out between you and your physiotherapist.

Routine is important

Young people with CFS/ME 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 (bust). Having a routine where you do the same things every day helps get rid of these boom and bust feelings. It also improves your mental and physical endurance.



Things to remember

- Try not to exceed the planned amount of activity or exercise, even if you are having a good day
- Have regular breaks between activities, not just at the end of the day
- Watching TV or using the computer can involve a lot of mental activity and may not be as restful as it seems
- Feeling strange or having different symptoms is normal when you start a new activity or exercise. Your skin may go red, you might feel tired, like jelly or stiff when you finish. This is quite normal. Delayed Onset Muscle Soreness (DOMS) is a common effect for all people when they increase their exercise or activity level.

What to do if you have a set back

- Do not stop completely – continue your exercise programme but go back to the previous level. You can contact your physio if you need some advice.
- Improve the quality of your rest time – build in some good relaxation time or use relaxation techniques
- Plan your day to ensure you avoid unnecessary over-activity.

If you have any questions,
please ring the CFS/ME team on 020 7813 8541.



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