



Chronic Fatigue Syndrome (CFS) / Myalgic Encephalopathy (ME) and Physiotherapy

Information for patients from the Children's and Young Person's
Integrated Therapy Team

This leaflet is for young adults with CFS/ME and their parents. It aims to help you understand the role of the physiotherapist and how they can help you with the symptoms of your chronic fatigue.



How does physiotherapy help people with CFS/ME?

The aim of physiotherapy is to provide support and advice on how to manage your symptoms of chronic fatigue, so that you can start getting back to doing all the things you used to enjoy such as meeting up with your friends, going on sleep overs, and playing sport again. Physiotherapy aims to help people make changes that make you feel physically better. It will also look at ways of maintaining these changes and dealing with any setbacks.

For all activities you need a certain level of strength, fitness, and endurance. Young people with CFS/ME can often struggle to maintain their usual levels of activities and exercise. Their strength and fitness are often reduced and they find taking part in their day to day activities tiring. Routine is the key to success and eliminating any boom and bust pattern is important to kick start this process.

What is boom and bust?

The reason you may have asked for help is that you can no longer do the daily activities and sports you used to be able to do. You may find on a 'good' day or week you are able to go to school, do your sports, and go out with your friends but then you have a bad day afterwards. This is called 'payback' and this common pattern is called boom and bust.

What will happen when I meet my physiotherapist?

Your physiotherapist will talk to you about how much activity you do each day. This will include talking about your daily routine, sleeping pattern, what makes you feel better, and what makes you feel worse.

There are different types of activity that will be discussed.

- **General activities** - things you do as part of daily life such as going to school and shopping, walking around the house, doing chores (such as taking out the bins or tidying your room), seeing friends.
- **Aerobic exercise** – this is an activity that increases your heart rate and makes you feel breathless. This is a good thing! Research has shown that a gradual increase in this type of activity can help people recover from CFS. It includes swimming, cycling, fast walking, or jogging as well as some light competitive sports.
- **Mental activities** - this refers to an activity that uses concentration and memory for example school work, being on your iPad and your phone!

How will my physiotherapy be planned?

Physiotherapy is planned individually and may include the following.

- **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 about how much you can do day after day without making your symptoms worse. This is your baseline activity level and it can be used to help you work out the amount of activity and exercise to try and achieve every day. It is about encouraging balance in your everyday life.

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

- Whether you went to school
- What your sleep routine was
- Did you go out with friends or family?
- Did you talk on your mobile?
- Did you spend time on your computer/ipad?

The diary can also show you changes in your baseline activity over time.

Your physiotherapist can help you to develop a daily structure and routine, and advise you on how to gradually build on your activity levels. 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.

- **Goal setting**

Your physiotherapist will help you to think about personal activities and goals and identify the different steps towards achieving them. Examples of physical goals are:

- Being able to get up at an agreed time, have a shower, and get dressed
- Getting back to walking the dog with the family (even if you only participate in part of the walk)
- Meeting up with friends for a hot chocolate
- Participating in the warm ups/playing 10 minutes of football at football training whilst gradually building up time levels
- Returning to an enjoyable hobby.

Goals provide the focus for therapy and can be used to help see how you are doing.

- **Relaxation/Breathing exercises**

Physiotherapists can help with strategies such as relaxation and breathing control to help you manage your symptoms.

- **School**

If you are having problems with school, we can work with the staff so they also understand what you need to do to get better and support you in different ways with your recovery.

Things to remember!

- Try not to exceed the planned amount of activity or exercise, even if you are having a good day as this could lead to the 'boom and bust cycle'.
- Have regular breaks between activities, not just at the end of the day.
- Watching TV, being on your ipad/computer and your mobile 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 may feel tired, your body and muscles may feel 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. As with all illnesses, physical and emotional factors affect recovery.
- After prolonged periods of inactivity, muscles decrease in size and this leads to a loss of fitness. In turn, this results in less strength and stamina for their usual activities. Poor diet and a change in sleep patterns also contribute to fatigue.
- Starting treatment needs a certain amount of commitment by you. For example between sessions you may be set tasks or 'homework' in the form of goals. These will be agreed between you and your physiotherapist. Carrying out these tasks is an important part of your treatment and good progress will not be made without it.
- It is also very important that you attend regularly if you are to achieve the maximum benefit.

What do I do if I have a set back?

Do not stop completely – continue your exercise programme but go back to the previous level. You can contact your physiotherapist if you need some advice.

See below for telephone numbers for The Rainbow Centre Ashford, The Beacon Folkestone, and Buckland Hospital Dover.

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| • Rainbow Centre, Ashford | Telephone: 01233 651927 |
| • The Beacon, Folkestone | Telephone: 01303 854461 |
| • Buckland Hospital, Dover | Telephone: 01304 222540 |

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 783145 or 01227 864314, or email ekh-tr.pals@nhs.net

Further patient leaflets are available via the East Kent Hospitals web site www.ekhufft.nhs.uk/patientinformation