

This leaflet explains about chronic fatigue syndrome and how the CFS/ME team at Great Ormond Street Hospital can help. If you have any questions, please call us. Our telephone number is 020 7813 8541.



What is chronic fatigue syndrome?

Information for young people

Great Ormond Street Hospital for Children NHS Trust

What can we do to make things better?

What is chronic fatigue syndrome?

Chronic fatigue syndrome (CFS) can also be called Myalgic Encephalomyelitis (ME). The Chief Medical Officer recommends it be referred to as CFS/ME. No one knows why it happens or what causes CFS/ME. Your doctors will have checked that there is no other explanation for your symptoms.

People diagnosed with CFS/ME have some common complaints and symptoms:

- **Fatigue**
- **Sleep problems**
- **Nausea**
- **Dizziness**
- **Headache**
- **Forgetfulness**
- **Poor concentration**
- **Mood changes**
- **Joint pain**
- **Muscle aches**

The CFS/ME team at GOSH is made up of various people. This includes a nurse consultant, social worker, physiotherapist, doctor and secretary. Each person plays a different part in helping you to become better and more able to manage the symptoms of CFS/ME.

Your first clinic appointment will be with the nurse consultant and another member of the team. You will have plenty of opportunity to ask questions. Some people find it helps to write a list of questions before each appointment to remind them. When you are sent the appointment by the hospital there will be more details about what will happen.

We have a rehabilitation programme at GOSH. It works best if you, your family and our staff work together to help you manage your symptoms. Our experience is that many young people benefit from taking part in a rehabilitation programme, and our research supports this.

The team will help you decide if the Rehabilitation Programme is suitable for you. If it is, they will arrange appointments with other members of the team. Some young people may not feel ready to take part in a rehabilitation program, so they will be offered regular appointments to give them advice and support on living with CFS/ME.

What does it involve?

■ Routine: avoiding boom and bust

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.

■ Sleep

Not getting enough sleep can affect how much activity you can do. This part of the rehabilitation programme tries to help you improve the quality of sleep. This means you are more able to take part in activities.

■ Activity & exercise

Everyone finds it difficult to get back to normal activities when they have been ill for a while. This may be because your muscles have become weak and you may have become unfit. Some people are frightened of making their symptoms worse by doing particular activities. The physiotherapist will help you put together a plan of how to improve what you can do each day.

■ Returning to school

School is a normal part of everyday life. The CFS/ME team will work with you, your family and your local school and health teams to plan your return to school. Some people find that having lessons at home is a good start.

■ Medication

While there is no medication to cure CFS/ME, it is sometimes possible to help with the symptoms such as poor sleep.

■ Working with families

It can be helpful to discuss your feelings with the team and other staff. Being ill can have an effect on the whole family, so it may help your parents, brothers and sisters to talk about their feelings too.

Who else can help?

There is a support organisation for young people with CFS/ME:

Association for Young People with ME (AYME)

Telephone: 08451 23 23 89
(Monday to Friday
from 10am to 2pm)

Web: www.ayme.org.uk

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

Further reading

A report of the CFS/ME Working Group: report to the Chief Medical Officer of an Independent Working Group – published 2002.

Web: Available from the Chief Medical Officer's web page www.dh.gov.uk/AboutUs/MinistersAndDepartmentLeaders/ChiefMedicalOfficer/fs/en

Young person's guide to CFS/ME

– Royal College of Paediatricians and Child Health (RCPCH)

Web:

www.rcpch.ac.uk/publications/recent_publications/Latest%20news/Leaflet.pdf

They have also produced a guideline for managing children and young people with CFS/ME. It was written after looking at all the published research on CFS/ME.

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Compiled by the Chronic Fatigue team in collaboration with the Child and Family Information Group.

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www.goshfamilies.nhs.uk

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