

Children & Young People's Specialist ME/CFS & Post Covid Service

Sheffield Children's Hospital, Western Bank, Sheffield S10 2TH

ME/CFS & Post Covid Service Overview

The ME/CFS Service at Sheffield Children's is a specialist regional team, and consists of a doctor (consultant paediatrician), occupational therapists, and a clinical psychologist. The Service is currently based at the Michael Carlisle Centre in Nether Edge, Sheffield.

The service aims to help young people and their families manage the impact of Myalgic Encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS) and post viral fatigue on daily life and to support them to do the things they want. This may involve changes to usual routines and ways of doing things and we encourage young people to be involved in the sessions and to follow the programme as best they can with our support and guidance.

ME/CFS is a complex condition with a wide range of symptoms, the most common being persistent fatigue. Other common problems include:

- Feeling unrefreshed after rest or sleep
- Taking a longer time to recover after activities
- Disruption to daily life, including education, socialising and sports or other interests
- Problems with memory, concentration and processing information
- Aches and pains
- Dizziness
- Mood changes and anxiety as a result of living with persistent fatigue

Our team provides a comprehensive ME/CFS and Post Covid service for children and young people requiring support. We aim to help you and your family explore the following areas:

- **Routine** – Young people with ME/CFS often say they have good and bad days. On a good day, most people tend to do more, but on the following days, their symptoms seem worse than normal. We call this a boom-and-bust cycle which we know can hold back or slow down recovery. Having a routine where activities are broken down into achievable chunks across the week can help people move away from the boom-and-bust pattern.
- **Sleep** – Difficulties getting to sleep or staying asleep can have a big impact on doing activities the next day. This may then affect a young person's mood and motivation. We can explore techniques that help establish a healthier sleeping pattern.
- **Activity and exercise** – It is normal to struggle to get back to activities after being unwell for a while. Young people commonly report that their limbs feel weak or heavy and are worried about making their symptoms worse by increasing activities. We can help you put a plan together around how to improve what you can do each day.

- **Emotional Wellbeing** – The ME/CFS Team are experienced in talking about and helping young people with mood changes because of living with chronic fatigue and pain. These are common and understandable feelings which usually improve as young people learn to manage their energy. However, in some cases these feelings become overwhelming and can get in the way of recovery. Our psychologist offers individual sessions either following the clinic assessment or at the request of the occupational therapists.
- **Education** – School or college is a normal part of everyday life for most young people. The ME/CFS team will work with you, your family and your local school and health teams to get the most out of your education.
- **Medication** – Medication is rarely used in helping young people manage persistent fatigue. Specific concerns should be discussed with a paediatrician or GP.

Clinic

Your first appointment will be with a doctor, an occupational therapist and/or a psychologist. The appointment lasts for an hour, sometimes a little longer, with a short break in the middle.

During the appointment we will ask you and your family about your medical history, symptoms and the impact fatigue has on your daily life. We may also ask about your family situation, school, and activities that you are interested in, as all of this will help us to make a plan with you. The doctor will discuss with you whether you have a diagnosis of ME/CFS and talk to you about treatment options.

We see children and young people up to the age of 18 from Sheffield, Barnsley, Rotherham, Doncaster, and North Derbyshire. We also see young people from further away if they do not have a fatigue service near them. If you are under 16 and have unexplained fatigue which has been present for three months or more, you need to be referred to us by your consultant paediatrician with the relevant tests and investigations. Please see the referral guidance for more information.

If you are aged 16-18 years, your GP can refer you directly.

