

CFS/ME Service

Family Services Information Leaflet



Who are we?

We are a team consisting of a Paediatrician, Occupational Therapists and Physiotherapists who have a special interest in CFS/ME and who have training in Health Coaching, Cognitive Behavioural Therapy and Graded Exercise Therapy. The care we provide is in line with NICE guidelines.

Where do we work?

We provide a service to all children aged up to 19 years in full time education, with a GP in the Cambridgeshire and Peterborough area.

How can my child be referred?

Your child will be referred to our services by your GP or a Paediatrician.

If your referral is accepted you will receive a general advice leaflet, pre-clinic questionnaire and an appointment date in the post.

Where will the clinic be?

Our monthly multi-disciplinary team clinics are run mainly at the Oak Tree Centre in Huntingdon.

What will happen at the first appointment?

Your child will be seen by our Paediatrician, and one or more of the other members of the specialist team. We may ask to see your child / young person separately. If a diagnosis of CFS/ME is confirmed, we will discuss a plan of intervention with you and your child, including medication if appropriate.

The information you bring with you including the completed questionnaire will form the basis of the consultation.

During this appointment we will also begin a discussion with you and your child about how to manage CFS/ME symptoms. Usually there will be a next appointment in which this can be explored further. A key therapist will be identified (Occupational Therapist or Physiotherapist).

How is a diagnosis of CFS/ME made?

A diagnosis of CFS/ME may be made by our Paediatrician on the basis of your child's symptoms and their severity. All the appropriate medical investigations need to have been carried out to make sure your child doesn't have any other illnesses, which may be the cause of their symptoms. If it is thought other tests need doing, your child will be referred to the appropriate service. Even without a diagnosis of CFS/ME we can discuss fatigue management with you and your child at the initial appointment.

What happens next?

For long term management we use a Health Coaching approach. This means that we aim to help you and your child to set their own goals to manage their health. We will then ask you and your child to agree a goal plan. The idea is for you and your child to be actively involved in managing the condition and improving your child's quality of life. While we are there to support you and your child, we expect you to make your own decisions (with our help) regarding wellbeing and how to achieve this.

Interventions could be any of the following or a combination of them:

- Specialist advice on how to manage energy and activity levels (Graded Activity Management)
- Advice to school and college to ensure a realistic time table is achieved
- Advice on sleep and pain management
- General dietary advice
- Physiotherapy assessment

- Advice on Graded Exercise Therapy (GET) if appropriate
- Specific assessments and advice on Handwriting and fine motor skills if appropriate
- Possible housing adaptations and/or equipment
- A block of Cognitive Behaviour Therapy will be offered if this is felt this may be useful
- Referral to other services, for example CAMH, Dietitian, etc.

What can I do as a parent/carer to support my child?

Your role as parent/carer is very important to help your child to be actively involved in the intervention programme and set goals.

The aim of working with you and your child is to help you manage the illness and improve your family's quality of life.

At times parents/carers need individual support for themselves.

What written communication can I expect to receive from your service?

You, the GP and your child's school will receive a letter after the initial clinic appointment from the Paediatrician, with information regarding the condition and an agreed management plan.

When will my child be discharged from your service?

The episode of care will end when you and your child are managing the symptoms and on the road to recovery. The episode of care will also be closed if it is felt that you are not ready or not able to fully engage with the plan that we agreed.

Can my child be re-referred?

Yes, your child can be re-referred at any time. We will take self referrals for this as well. We can continue to provide letters of support (e.g. for school/university), even if your child is no longer on our caseload.

Will my child be referred on to Adult Services?

If they still require input from a CFS/ME service after this, they can be referred by their GP to the Adult Service based in Peterborough after discharge from our service.

Signposting

<https://www.actionforme.org.uk/>

<http://www.cambscommunityservices.nhs.uk/what-we-do/children-young-people-health-services-cambridgeshire/specialist-services/children's-chronic-fatigue-service>

For further information about this service contact:

CFS/ME Service for Children and Young People
The Peacock Centre
Brookfields Campus
351 Mill Road
Cambridge
CB1 3DF

Tel: 01223 218064

Email: CCS-TR.cfsmeenquiries@nhs.net

If you require this information in a different format such as in large print or on audio tape, or in a different language please contact the service on the details above.

If you have any compliments about this service or suggestions for improvements, contact our Patient Advice and Liaison Service on 0300 131 1000 (charges may apply depending on your network) or email: ccs-tr.pals@nhs.net.

For free, confidential health advice and information 24 hours a day, 365 days a year please contact NHS 111.