

We are a specialist NHS service that seeks to meet the needs of people who have a diagnosis of Myalgic Encephalomyelitis (ME) also referred to as Chronic Fatigue Syndrome (CFS).

We offer an outpatient service throughout Suffolk and Norfolk. This is via face to face appointments, email and telephone and in a small number of cases, home visits.

What do we provide?

We provide assessment, diagnosis, management, advice, education and support for people who have a diagnosis of ME/CFS. The team comprises of G.P's with specialist interest (GPwSI) and knowledge of ME/CFS and Specialist Occupational Therapists (OT) who are supported by administrative staff.

What is Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?

The condition has been called by a variety of names including Chronic Fatigue Syndrome (CFS), Myalgic Encephalomyelitis (ME) and Post-Viral Fatigue Syndrome (PVFS). We use the term ME/CFS.

The main symptom of ME/CFS is a feeling of unusual and excessive tiredness that is characteristically made much worse after any activity. The fatigue is usually both physical and mental. The fatigue would be of new onset rather than life long. It impacts on the person's life to the extent that they have to cut down significantly on what they do day to day. This together with other symptoms such as un-refreshing sleep, swollen lymph glands, new headaches, muscle and joint pain and others, are used as a basis for giving a diagnosis.

It is important that other medical conditions that can cause significant fatigue are excluded before the diagnosis of ME/CFS is made.

ME/CFS is different from a more short-lived fatigue that may occur after many common illnesses especially viral infections. A diagnosis of ME/CFS is only made by the service after a person has had the symptoms for at least six months as an adult or three months in children.

How is ME/CFS treated?

There is no specific single medical treatment for ME/CFS and although many different treatments have been suggested few have been thoroughly tested.

There is now good evidence for management strategies such as activity management, which enable people to control and improve their fatigue levels. This is done by addressing how energy is used and managing other factors which impact upon fatigue. Also it is useful to use strategies to control debilitating symptoms.

We believe in patients being central to the therapy process and we focus on supporting patients to apply strategies which they can use to help themselves. We seek to work with you to help you achieve improvement in your condition and establish and maintain a quality of life.

How can I access the service?

People can be referred to the service by their GP or a hospital based health professional involved in their care.

There is no test to tell whether someone has ME/CFS. Therefore, the diagnosis is largely dependent on the history of the symptoms and exclusion of other illnesses. We make sure that other illnesses have been excluded by the GP or other health professional involved in the patient's care, which means individuals undergoing some routine investigations, usually blood tests, before first coming to the service.

When we receive the referral we will contact you. We send out a pre-clinic questionnaire for completion, and upon its return you will be offered an initial appointment with either a GPwSI or a Specialist OT.

For your longer term support and follow up visits you will be allocated a Specialist OT with whom you will be able to arrange appointments at the locations listed below and/or via a method such a phone or email if this is more convenient for you.

Area Covered/Service delivery

The ME/CFS service covers the whole of Norfolk and Suffolk. If you are unsure if our service covers your area please contact us.

The Suffolk and Norfolk ME/CFS Service is provided by East Coast Community Healthcare CIC and we are also commissioned by NHS Suffolk and NHS Norfolk. The service is currently based at Kirkley Mill and we run outpatient clinics at Great Yarmouth, Lowestoft, Reydon, Norwich, Aylsham, Kings Lynn and Stowmarket. If your first appointment is with one of our GPwSI's you will be asked to attend a clinic at either Great Yarmouth, Stowmarket or Norwich. Your follow up appointments will be at one of the above and

can also be done via email and phone. The method of your follow up appointments will be something you can discuss with your specialist OT at your initial appointment.

Our service operates:
Monday to Friday, 8.30 am to 4.30 pm.

Further advice and information

ME/CFS Service
Norfolk and Suffolk ME/CFS Service
Kirkley Mill Health Centre
Clifton Road
Lowestoft
NR33 0HF

Tel: 01493 809977

Compliments, comments, concerns or complaints

PALS, Patient Advice and Liaison Service
PALS may be the best starting point if you have a question or concern about the NHS. If you would like to find an NHS dentist, know where your nearest doctor is or talk through a problem you have had with a service, you can contact the PALS service.

To contact PALS:
Call 01502 445 447
Monday to Friday, 8am – 4.00pm
Email:
patientliaison@ecchcic.nhs.uk

Or write to:
PALS
Hamilton House
Battery Green Road
Lowestoft
Suffolk

If you would like this leaflet in large print, audio cassette, Braille or in a different language please contact Katrina McGill on 01493 334 137 or gyw-pct.csenquiries@nhs.net



Jei šios publikacijos kopija noretumete gauti savo kalba prašome susisiekti su Katrina McGill telefono numeriu: 01493 334 137.

Jezeli chcieliby Panstwo otrzymac niniejsza publikacje w tłumaczeniu na jezyk polski, prosimy o kontakt z Katrina McGill pod numerem telefonu: 01493 334 137

Pokud byste chteli kopi této publikace ve Vašem jazyce, prosím kontaktujte Katrina McGill ovou na telefonním čísle 01493 334 137

Bu yayinin kendi dilinizde bir nüshasını isterseniz, lütfen 01493 334 137 nolu telefondan Katrina McGill ile temasa geçiniz

Se pretender uma cópia desta publicação no seu idioma, por favor contacte Katrina McGill no número 01493 334 137



Adult Services

Norfolk and Suffolk Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) Service

Information for patients

*Being treated with dignity and respect
is the right of every patient*

Produced by East Coast Community Healthcare C.I.C
Community Services 2011©

Issue date: 27/07/2012