

Oxford Health
NHS Foundation Trust



Oxfordshire CFS/ME Service

Chronic fatigue syndrome/ myalgic encephalomyelitis (CFS/ME)

What is CFS/ME?

People with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) experience extreme fatigue and vastly reduced energy levels. This can have a profound effect on their lives and on their families and loved ones. The fatigue is unlike usual fatigue and it does not resolve as normal following rest.

A range of the following symptoms can be present:

- severe fatigue, not alleviated by rest
- headaches
- flu-like symptoms
- muscle pain
- joint pain
- sleep problems
- digestive problems
- difficulty finding the right words
- problems with memory and concentration

CFS/ME is classified by the World Health Organisation as a neurological condition although its cause remains unclear. People affected are often highly motivated, hard working and caring for others. There can be a variety of triggers, both physical and emotional, and its pattern is characteristically that of a 'boom and bust' cycle with bursts of activity followed by prolonged periods of enforced rest. People are affected to different degrees; mild, moderate or severe and for varying lengths of time.

Will I get better?

When promptly diagnosed and managed people generally have good outcomes and achieve varying levels of recovery. Diagnosis can be made at four months for adults and at three months for children and young people. Even if you have had CFS/ME for some years there can be recovery, or at least an improvement, so you can take part in some normal everyday activities.

Who will make the diagnosis?

The diagnosis is made by looking at your history and carrying out blood tests to exclude other conditions. Your GP will usually make the initial diagnosis and may refer you to our service for a specialist opinion. You can be seen at home for this if necessary.

If you are under 16 your GP will refer you to a paediatrician. If you are over 14 years old you may also be referred to the Oxfordshire CFS/ME Service.

What is the treatment?

Some advice on managing your condition may be all that you need to help you. Initially it's helpful to restore balance to your day-to-day living. This is done by establishing a pattern and a level of activity and rest that is achievable for you on a daily basis. Starting with some gentle, regular, activities you can gradually begin to rebuild your stamina.

Your GP may supply management advice to you or may refer you to our service for specialist advice. You may be offered a place on our group course, Introduction to managing CFS/ME, which runs at various Oxfordshire locations throughout the year.

If you need additional help there are a number of group and individual programmes. We will recommend the best option for you, planning an individualised programme which will help you to understand the processes and effects of your condition, and provide you with a toolkit to:

- manage your energy levels
- manage your sleep
- learn relaxation techniques
- get back to some normal activities
- prepare yourself for return to work, college or school
- help you if you feel wound up or anxious
- help you if you feel low and lack motivation

What if I am severely affected?

We will tailor a programme to your current energy level. All we ask is that you are willing to explore different and possibly new options available to you, starting small and gently. We can contact you through home visits, telephone calls, Skype and audio files.

Who is in the team?

The Oxfordshire CFS/ME Service includes therapists and a GP who are all CFS/ME specialists. We can also refer people to CFS/ME clinicians at Talking Health, part of Oxford Health NHS Foundation Trust's TalkingSpace, for a programme cognitive behaviour therapy (CBT).

What happens to information about me?

All information is confidential and secure. Local NHS specialists for CFS/ME are in different teams and therefore information may be shared between services. With your consent, anonymous data from your initial meeting and your repeat 12-month follow up form will contribute to an NHS national data set which monitors for quality and good practice. If you would like to know more about this please ask one of the Oxfordshire CFS/ME Service.

"It really helps to accept what's happened and where you are now, have hope for the future and go forward with a stepping stone approach to recovery."

Encouragement from someone with CFS/ME who has engaged in one of our programmes.

Contact us

Oxfordshire CFS/ME Service

Windrush House

Windrush Industrial Estate

Witney

OX29 7DX

Telephone: 01993 848 266

Fax: 01865 425 133

Email: cfs@oxfordhealth.nhs.uk

Web: www.oxfordhealth.nhs.uk/cfs-me

Other useful contacts

Action for ME (AfME)

You can read and download useful information or order by telephone.

Telephone: 0845 123 2380

Helpline: 0845 123 2314

Web: www.actionforme.org.uk

Oxfordshire ME Group for Action (OMEGA)

4 Bursill Close

Headington

Oxford

OX3 8EW

Email: ltrl3@tiscali.co.uk

Web: www.ocva.org.uk/OMEGA

Association of Young People with ME (AYME)

10 Vermont Place

Tongwell

Milton Keynes

MK15 8JA

Telephone: 0845 123 2389

Web: www.ayme.org.uk

Information and resources on Mindfulness: Breathworks

16 - 20 Turner Street

Manchester M4 1DZ

Tel: 0161 834 1110

Email: info@breathworks.co.uk

Web: <http://www.breathworks-mindfulness.org.uk/>

Emergency service

NHS 111

NHS 111 is available 24 hours a day, 365 days a year for non-life threatening medical assistance. Calls are free from landlines and mobile phones.

Telephone: 111

Concerns and complaints

We aim to provide you with a high quality service at all times. However, if you have any concerns, complaints or comments about your experience of our service then please tell a member of the team or contact the PALS and complaints team on freephone 0800 328 7971.

If you need the information in another language or format please ask us

Nëse ky informacion ju nevojitet në një gjuhë apo format tjetër, ju lutem na kontaktoni

আপনি যদি এই তথ্যাদি অন্য কোন ভাষায় বা মাধ্যমে (ফরমেট) পেতে চান
তবে দয়া করে আমাদেরকে বলুন

ਜੇ તમને આ માહિતી બીજી ભાષામાં અથવા બીજા આકારમાં જોઈએ, તો કૃપા કરીને અમને પૂછો

यदि आपको यह जानकारी किसी दूसरी भाषा या आकार में चाहिए हो तो कृपया हम से पूछें

若您需要本信息的另一种语言或格式的版本文本，请与我们联系

ਜੇਕਰ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੀ ਦੂਜੀ ਭਾਸ਼ਾ ਜਾਂ ਆਕਾਰ ਵਿੱਚ ਚਾਹੀਦੀ ਹੋਵੇ ਤਾਂ ਕਿਰਪਾ ਕਰ ਕੇ ਸਾਨੂੰ ਪੁੱਛੋ

اگر آپ کو یہ معلومات کسی دوسری زبان میں یا کسی دوسرے طریقے سے درکار ہوں تو براہ کرم ہماری جم سے پوچھیں :-

Oxford Health NHS Foundation Trust

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Warneford Lane

Headington

Oxford

OX3 7JX

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The Oxfordshire CFS/ME Service is part of our Older People Directorate.

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