

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management

Information for the public

Published: 29 October 2021

www.nice.org.uk

ME/CFS: the care you should expect

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) is a long-term condition that affects about 250,000 people in the UK. It can cause many different symptoms, which can be triggered or worsened by any kind of effort or activity. Symptoms include flu-like malaise, sleep difficulties, brain fog and a profound fatigue that is unlike normal tiredness. People may also experience chronic pain, headaches, nausea, digestive problems, and sensitivity to light, sound and other stimuli. Symptoms come and go and can change or worsen with little warning, causing distress and disrupting people's lives.

ME/CFS is different for everyone. It can range from a mild illness to a severely disabling one that leaves some people housebound or bedbound. Because it can look like many other illnesses, people often face uncertainty and delays in diagnosis. There are options that can help people manage their ME/CFS, but a therapy that helps one person may cause harm to another so a carefully tailored plan and specialist advice is always needed.

We have updated the 2007 version of this guideline using the best available research and working with people who are affected by ME/CFS and professionals who treat and support them. We want it to make a difference to all adults, children and young people with ME/CFS and their families and carers by:

- helping doctors recognise when someone's symptoms could be ME/CFS
- making it faster to get support once ME/CFS is suspected so people don't have to wait for help while other conditions are ruled out
- making sure people with ME/CFS have a confirmed diagnosis at 3 months
- helping everyone with ME/CFS get specialist support and care designed around their own particular needs
- making services more flexible to help people with ME/CFS get the care they need – for example by making home visits, offering shorter or longer appointments and planning any hospital stays around their needs.

Making decisions together

Decisions about care are best when they are made together. Your health and social care professionals should give you clear information, discuss all the possible options with you and listen carefully to your views and concerns. They should also:

- treat you with empathy and understanding and take time to build a supportive relationship with you and your family or carer
- help you make a plan to manage your ME/CFS that you have control of and can change as you need to
- ensure you understand the benefits and risks of different options so you can decide for yourself what is right for you
- provide support and information for your family or carer.

If you can't understand the information you are given, tell your healthcare professional.

Read more about [making decisions about your care](#).

Where can I find out more?

The [NHS website](#) has more information about ME/CFS.

The organisations below can give you more advice and support.

- [Action for ME](#), 0117 927 9551
- [#MEActionUK](#), uk@meaction.net
- [The ME Association](#), 0344 576 5326
- [The Young ME Sufferers Trust](#), 0845 003 9002
- [25% M.E. Group](#), 01292 318 611

NICE is not responsible for the content of these websites.

To share an experience of care you have received, contact your local [Healthwatch](#).

ISBN: 978-1-4731-4222-0