

# ME/Chronic Fatigue Syndrome

Updated 27/07/16

An estimated 250,000 people in the UK suffer from this illness of uncertain cause. It is known by a number of different names, including Myalgic Encephalomyelitis or Encephalopathy (ME), Chronic Fatigue Syndrome (CFS), Post-Viral Fatigue Syndrome (PVFS) and Chronic Fatigue Immune Dysfunction Syndrome (CFIDS). We will use the term ME/CFS in this factsheet.

Though there is some agreement on what can trigger ME/CFS, opinions are divided over what factors can cause it to become a chronic illness. There are two main schools of thought: either 'behavioural' or 'psychiatric' factors or 'physical' factors. Some argue that both of these could play a role, or that the term ME/CFS could cover a range of different conditions with similar symptoms. Whatever the cause, ME/CFS can have a significant impact on a person's physical and emotional health.

## What are the symptoms of ME/CFS?

For some people the symptoms of ME/CFS come on suddenly, while others experience a slow onset. Symptoms include severe and debilitating fatigue, painful muscles and joints, disordered sleep, digestive problems, poor memory and concentration. People may also be highly sensitive to light and sound. There are broadly four levels of severity that symptoms fall under:

- People who return to normal health after a period of time
- People who experience fluctuating symptoms, with good and bad periods (the majority fall into this category)
- People who remain severely affected and may require a great deal of support
- People whose condition continues to deteriorate (in this case it is especially important to rule out any other causes with comprehensive medical assessments)

ME/CFS can have a considerable impact on people's lives. They may need a lot of time to recover from any exertion, so everyday activities can be heavily disrupted.

### What treatments will help?

As previously mentioned, opinions differ on the root causes of ME/CFS. There is no 'cure' for the condition, but with the correct combination of treatments someone's quality of life can be improved. It is important that a specialist professional is consulted and is responsible for prescribing any treatments, particularly as ME/CFS shares symptoms with a number of other health conditions.

Treatment programmes for ME/CFS may include:

- Sleep management
- Short-term talking treatments, such as Cognitive Behavioural Therapy (CBT)
- Graded Exercise Therapy (GET) a programme of physical exercise that gradually increases in intensity
- Controlling symptoms through medication
- Living a healthy lifestyle, including reduction of stress and other potential triggers
- Pacing working out what are appropriate amounts of exertion and relaxation for you, ensuring that you do not overexert yourself (or underestimate what you are able to achieve)

It is likely that a combination of these treatments, and possibly others, will be needed. Always discuss your options with your doctor.

### Organisations that can provide support

Your first port of call if you are experiencing the symptoms of ME/CFS should be your GP. They can order tests to rule out any other health conditions or refer you to specialist services if they suspect you may have ME/CFS.

#### Hillingdon Chronic Fatigue Service

www.cnwl.nhs.uk/service/hillingdon-chronic-fatigue-service

Greenacres Centre, Hillingdon Hospital, Pield Heath Road, Middlesex, UB8 3NN Tel: 01895 279374 | Fax: 01895 279046 | Email: <a href="mailto:hillingdoncfsme.cnwl@nhs.net">hillingdoncfsme.cnwl@nhs.net</a>

Hillingdon Chronic Fatigue Service provides diagnosis, assessment and treatment for patients with mild to moderate ME/CFS. They accept referrals from GPs and other NHS professionals on behalf of patients within Harrow, Hillingdon, Hammersmith & Fulham, Kensington, Chelsea & Westminster, Brent, Ealing and Hounslow.

#### Action for ME

#### www.actionforme.org.uk

42 Temple Street, Keynsham, Bristol, BS31 1EH

Tel: 0117 927 9551 | Fax: 0117 986 1152 | Email: admin@actionforme.org.uk

Opening hours: Monday to Friday 9am to 5pm

Action for ME campaign for research and better treatment for people with ME/CFS. They also seek to support people affected by ME/CFS through providing advice and information. You can contact them for information and support via the details above.

#### The ME Association

#### www.meassociation.org.uk

Unit 7 Apollo Office Court, Radclive Road Gawcott, Buckingham, MK18 4DF

Tel: 0844 576 5326 | Email: meconnect@meassociation.org.uk

Helpline opening hours: every day, 10am-12pm, 2-4pm and 7-9pm

The ME Association is a national charity that funds and supports research and provides information and support, education and training. They provide ME Connect, a telephone and email helpline service for people with ME/CFS and those who live with or care for them; details are above.

Please call Mind in Harrow on 020 8426 0929 for a large print version of this factsheet or a summary translation.



Mind in Harrow's Mental Health Information Service is a part of SWiSH, a consortium of five local charities, offering the local Care Act Information & Advice Service for Harrow residents, funded by the Council. <a href="https://www.harrowca.org.uk">www.harrowca.org.uk</a>

## This factsheet was produced by Mind in Harrow

Mind in Harrow, First Floor, 132-134 College Road, Harrow, HA1 1BQ
T: 020 8426 0929 | E: <a href="mailto:info@mindinharrow.org.uk">info@mindinharrow.org.uk</a> | W: <a href="mailto:www.mindinharrow.org.uk">www.mindinharrow.org.uk</a> | Registered charity number 1067480