# Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Information for patients

NHS Lothian ME/CFS Service

Department of Clinical Psychology

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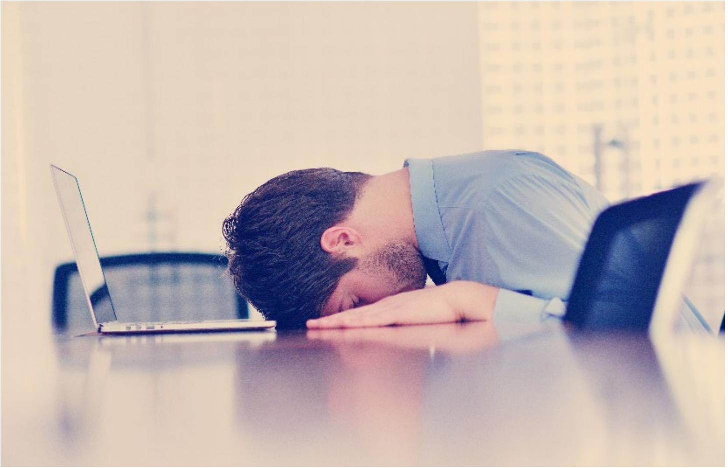
## What is ME/CFS/PVFS?

People with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome/ Post-Viral Fatigue Syndrome (ME/CFS/PVFS) experience extreme fatigue and vastly reduced energy levels.

ME/CFS/PVFS can have a significant effect on people’s lives and relationships. ME/CFS/PVFS can affect each person in different ways, and its severity can vary greatly.

The main symptom of ME/CFS/PVFS is **persistent and disabling fatigue** that lasts for at least 3 months and does not improve with rest. Other common symptoms can include:

- Unrefreshing sleep
- Difficulty with concentration and memory (often called "brain fog")
- Muscle and joint pain
- Headaches
- Sore throat
- Digestive problems (such as irritable bowel syndrome)
- Sensitivity to light, sound, or touch
- Post-exertional malaise (PEM) – worsening of symptoms after physical, mental, or emotional activity, which can last for hours or even days.



ME/CFS is a condition that can change over time and impact people for varying lengths of time. One day, a person may be able to do a task, but on another day, they may not be able to do the same task because their symptoms have increased.

This can be confusing for the person with ME/CFS as well as for their family, friends, and colleagues. Because the condition affects people in different ways, those with ME/CFS can often feel alone and unsupported.

Extra physical, cognitive, environmental, or emotional strain can affect recovery. It is important to remember that everyone experiences the condition differently. While there is no known cure for ME/CFS, many people with ME/CFS find ways to manage their symptoms and lead fulfilling lives.

## About the NHS Lothian ME/CFS Service

This service is available for individuals aged 16 or older who have been diagnosed with and accepted a diagnosis of ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) or PVFS (Post-Viral Fatigue Syndrome) and Long COVID (Post Covid Syndrome). This service is open to those living within Lothian. Our team is made up of specialists in Physiotherapy, Occupational Therapy, and Applied Psychology.

Referrals to our service are made by GP's or another medical consultant, who will complete a referral process which includes a series of blood screening investigations.

The Lothian ME/CFS service provides holistic, patient-centred support, recognizing the significant physical, emotional, and social impacts of ME/CFS/PVFS. We offer multi-disciplinary guidance to help individuals manage these challenges in their daily lives. All decisions about the therapy you receive are made jointly with you to develop a personalised plan to help you find a way to self-manage your condition. Our treatment approach is based on the updated NICE guidelines for ME/CFS (2021).

Areas of support may include:

- Understanding ME/CFS/PVFS
- Activity monitoring
- Learning activity management strategies such as pacing
- Identifying patterns which may add to difficulties
- Exploring environmental adjustments/aids
- Developing good sleep habits
- Learning relaxation and breathing strategies
- Managing brain fog
- Developing strategies to manage mood
- Exploring gentle movement
- Improving communication about ME/CFS
- Flare-up planning (strategies for managing worsening symptoms).

Like all self-management approaches, it can be useful to have some goals for working with the ME/CFS service and to be open to exploring different strategies.

## What will happen after I am referred to the ME/CFS service?

You will be notified by letter when you are on the ME/CFS service waiting list. When you reach the top of the waiting list, you will be contacted by telephone to arrange an appointment. If we are not able to contact you via telephone, an appointment will be sent to you via the post inviting you to attend an assessment appointment. We offer remote (Videocall and telephone) appointments, and face-to-face appointments. If you have a preference for how you are seen, you may highlight this once you are contacted for an initial assessment appointment. Face to face appointments take place at the Astley Ainslie Hospital in Edinburgh.

An initial assessment will be conducted with one of our specialist clinicians, who will seek to understand your current difficulties and your hopes/goals for your work with the service. The assessment will include finding out more about your difficulties with fatigue and other symptoms along with developing an understanding of how these symptoms impact your daily functioning, sleep, mood, relationships, and ability to work/engage with your usual activities.

In discussion with the clinician, and if there is mutual agreement at this stage to proceed, a programme designed for your needs will be developed. Work with the service will include looking at specific individual goals in keeping with your needs and hopes and will be reviewed regularly. Referral to other relevant therapies may be discussed if necessary. You may be offered one-to-one sessions or invited to attend an ME/CFS/PVFS group. These sessions may be conducted at the Astley Ainslie Hospital or by telephone/video call. The number of sessions will be agreed with your clinician.

## Other useful contacts

### Action for ME

Telephone: 0117 927 9551

Email: questions@actionforme.org.uk

Website: [www.actionforme.org.uk](http://www.actionforme.org.uk)

SCAN ME

### ME Association

Telephone: 0344 5765326

Email: meconnect@meassociation.org.uk

Website: [www.meassociation.org.uk](http://www.meassociation.org.uk)

SCAN ME

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