

## What are PVFS, CFS & ME?

Post Viral Fatigue Syndrome (PVFS), Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (ME) are different names for what is possibly the same illness. Its cause is currently unknown, but the World Health Organisation states that it is a neurological illness.

At least 80 people in Lochaber have PVFS/ CFS/ ME at any one time. The illness can be very debilitating, but with early diagnosis and careful management the outlook is improved.

Most people have experienced a bad dose of flu and know that recovery to normal energy levels can take a month or two. When post viral exhaustion is severe, with a substantial reduction in activity and recovery taking more than 3-4 months, the cause may be PVFS/ CFS / ME. It is important that your doctor does blood tests to exclude other potential causes of the fatigue – especially Lyme disease, coeliac disease, underactive thyroid and autoimmune disease. There is no specific test for PVFS/ CFS/ ME - diagnosis is made by excluding other possible causes of the symptoms. Not all GPs accept PVFS/ CFS/ ME as an organic illness – if you are having problems please contact the Support Network as our members can recommend knowledgeable local GPs.

Common symptoms can include:

- Persistent fluctuating or continual exhaustion or 'fatigue'
- Feeling generally unwell or having flu-like symptoms (often called "general malaise" by doctors)
- Recurrent sore throat, with or without swollen glands
- Cognitive dysfunction: inability to concentrate & problems with thinking & memory ("brain fog/thick head")
- Pain (can also be Fibromyalgia)
- Sleep disturbance
- Poor immune function (getting lots of viruses)
- Feeling faint on standing up
- Problems with the nervous system
- Digestive problems (which can also be Irritable Bowel Syndrome)
- Intolerance and increased sensitivity, for example to noise, light or odours
- Post-exertional malaise (feeling ill after physical or mental activity)

It's common for people with PVFS/ CFS/ ME to look normal.

The severity of symptoms varies from person to person, and over time. Please see our leaflet on Mild, Moderate, Severe and Very Severe PVFS/ CFS/ ME for more info.

There is currently no cure, and while some people find they benefit from complementary therapies, others do not. Your GP may advise management by Pacing, Graded Exercise Therapy (GET), Cognitive Behavioural Therapy (CBT) or any combination of the three. "Pacing" is staying within one's energy limits and balancing bouts of activity and rest to minimise symptoms. GET is a process of slowly and carefully increasing the amount of exercise done in one go. GET is controversial, with many patient groups reporting that it can cause bad relapses while scientific evidence reports that it is safe

for people with mild-moderate illness. However, a large scientific trial (White et al., 2010)<sup>1</sup> that found GET and CBT to be safe and moderately effective has been accused of significant bias (<http://evaluatingpace.phoenixrising.me/homepageanim.html>). Cognitive behavioural therapy (CBT) can help people cope with having a chronic illness and is helpful if people are suffering from depression as well as PVFS/ CFS/ ME – though for some sufferers, cognitive dysfunction may be so great that they cannot attempt CBT. For more info on approaches that can help ME, see Action for ME's website: <http://www.actionforme.org.uk/get-informed/about-me/treatment>

There is no scientific evidence on how best to treat severe and very severe PVFS/ CFS/ ME. Many people, at all levels of severity, find listening to relaxation or meditation tapes useful.

The duration of the illness varies from person to person. Sometimes people recover within a year, for other people it takes longer to achieve recovery/remission. Others recover to the point where they can lead a fulfilling life, even if they have to manage their activity levels differently to the way they did when they were healthy. Sadly some people never recover.

There are currently no specialist services for people in Lochaber who have PVFS/ CFS/ ME. One of the Support Network's aims is to persuade NHS Highland to provide us with specialist services.

The aims of Lochaber PVFS/ CFS/ ME Support Network are to:

- Allow people whose lives are affected by PVFS/ CFS/ ME (both those with the illness and their carers, families and friends) to support one another;
- Raise awareness of the illness locally among the public and the medical profession
- Campaign for specialist services to be provided by NHS Highland

We aim to include the severely affected and people who don't/can't use the internet – even if you're too ill to go out we welcome contact via phone and text. Contact details are below.

We meet regularly for a cuppa and a chat – please get in touch for up to date details.

Membership is free.

To join or find out more, e-mail [m.e.lochaber@googlemail.com](mailto:m.e.lochaber@googlemail.com)

Or leave a voice or text message on the Support Network's mobile:  
07786 590 450.

Or find us on Facebook: Google 'Lochaber M.E.'

Web site: [www.me-lochaber.org.uk](http://www.me-lochaber.org.uk)

<sup>1</sup> White et al. (2011) Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. The Lancet, Volume 377, Issue 9768, Pages 823 - 836, doi:10.1016/S0140-6736(11)60096-2