

## *Solihull & South Birmingham ME Support Group*

Solihull & South Birmingham ME Support Group supports and represents people with ME, their families and carers. The group is run on a totally voluntary basis, without a regular funding stream and we rely on donations. We have approximately 110 members and have various mechanisms of engagement including, telephone; written; social media and website. Although our name states Solihull & South Birmingham - we have members as far apart as Staffordshire, the Black Country and the rest of Birmingham and West Midlands.

Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) is a serious, debilitating, complex, acquired illness with numerous symptoms. ME has been classified as a neurological disorder in the World Health Organisation's International Classification of Diseases since 1969.

ME is not the same as chronic fatigue.

It is estimated that up to 250,000 people in the UK have ME. ME can affect people of all age groups, social classes and ethnic groups.

The cause or causes are not known at this time. In many cases, onset is linked to a viral infection. Other triggers may include an operation or an accident, although some people experience a slow, insidious onset.

There is no diagnostic test for ME and there is currently no accepted cure and no universally effective treatment. Those treatments which have helped reduce particular symptoms in some people have unfortunately proved ineffective or even counterproductive in others. An early diagnosis, together with adequate rest during the acute phase and during any relapse, appear to bring the most significant improvement.

Diagnosis is usually done by tests excluding other illnesses and by clinical analysis of the symptoms.

This is very much hit and miss, as the diagnostic criteria used by the NHS (Fukuda) are too broad - the NHS itself has reported a differential diagnosis rate of about 30 - 40% of patients seen.

The patient groups favour the International Consensus Criteria (ICC) which are based on the Canadian Clinical Case Definition and are far more specific for ME.

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There are different levels of severity which are usually defined as: mild, moderate and severe.

In some the effects may be minimal but in a large number, lives are changed drastically: in the young, schooling and higher education can be severely disrupted; in the working population, employment becomes impossible for many. For all, social life and family life become restricted and in some cases severely strained. People may be housebound or confined to bed for months or years.

The indications are that a small percentage of people fully recover from ME, the majority may improve over time but do not fully recover, and another small but significant percentage of sufferers do not improve and remain severely affected.

### **The key features of ME are:**

- post exertional malaise following exercise.
- weakness and pain in the muscles after use.

### **ME is also characterised by:**

- the fluctuation of symptoms from day to day or within a day, together with remissions and flare-ups during a year.
- a tendency for the condition to persist for several years or more ie, to become chronic.

There are many and varied symptoms of ME, including muscle weakness, pain, headaches, cognitive dysfunction, immune deficiencies, sleep problems, multiple sensitivities, vascular/cardiac problems, dizziness, nausea, digestive problems etc.

All, or some, of these may change from hour to hour or day to day or week to week etc. and because of this, and the lack of any definite diagnostic tests for ME, the rest of the world may think that people with ME are 'making it up', malingering or doing this for attention. Nothing could be further from the truth. The majority of sufferers are previously well motivated and active people who would like nothing better than to return to how they were. They don't like being ill and feeling out of control of their lives.

It is worth noting that the disabling weakness and exhaustion a patient with ME experiences is so profound that the term "fatigue" is probably an insult.

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NHS diagnosis and treatment of ME/CFS is defined by the NICE Guidelines for CFS/ME. These guidelines are generally considered by patient groups to be not fit for purpose. However, there are some useful parts that patients can use to help them, such as that "the healthcare professional responsible for your care should make a care plan with you, which is looked at and kept up to date every time you see a healthcare professional about your CFS/ME."

The treatments recommended by NICE are cognitive behaviour therapy (CBT) and graded exercise therapy (GET). These therapies were recently underpinned by the PACE Trial research - costing £5million of tax payers money - which said that CBT and GET were moderately effective for people with ME. [This trial excluded anyone suffering from severe ME]. This research finding is contrary to several large surveys by national patient charities where patients reported that GET and to a lesser extent CBT had caused them harm.

Surveys by ME charities have consistently shown that the majority of people with ME. find that Pacing helps them to manage their illness. Pacing is a coping strategy that helps patients manage their available energy and to maintain a balance between rest and activity in order to avoid the over exertion which causes symptoms to get worse and can lead to a relapse.

In spite of some improvement over recent years, it is apparent that GPs still find ME a difficult illness to diagnose and treat. Many, although maybe sympathetic, admit they know nothing about ME and some, astonishingly, still say they do not believe in ME!

Specialist centres for ME are few and far between. There is a specialist centre in Birmingham at the Barberry, but it has limited resources. It is not consultant led but relies on triage system run by nurses and occupational therapists in order to prioritise the treatment options (if any) for the large number of patients who are referred to this service. They decide on who gets to see the consultant. Last year this service had a waiting time of over 12 months - considering the NICE guidelines acknowledge that early diagnosis and intervention give the best chance of recovery this was unacceptable. We have worked with the Barberry to try and improve things for ME patients and the waiting times have improved, but it appears that this service is underfunded and under resourced. It was also clear to us that there is very little help available for those patients who are severely affected and unable to access these services.

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For many years, ME has been a misunderstood and often misdiagnosed condition. Dismissal of people with the condition as malingers or hypochondriac, having depression or other fatigue-related conditions has resulted in a culture of skepticism among the medical community, and inspired discontent to outright rejection of the medical system among patients.

Poor understanding of the condition has resulted in many patients spending large amounts of money in desperation on drugs, specialists, programs and natural therapies that often promise much but deliver very little. The growth of so called 'fatigue clinics' and other such therapists offering 'cures' for ME is alarming and symptomatic of the lack of available support for people with ME in the NHS. We feel the NHS and local Commissioning Groups in particular should be aware of this and provide a greater level of support for patients with ME.

Patients would like to see a consultant who is experienced and knowledgeable about ME, more help with symptoms and a more 'joined up' service which provides support with benefits, welfare problems and access to practical help with care.

We feel that GPs generally are not well informed about ME and that it would be very helpful if there was some formal training available via the commissioning groups, working with the various patient forums.