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# M.E. SUPPORT NORFOLK



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Myalgic Encephalomyelitis has been categorised as a neurological disorder by the World Health Organisation (at ICD-10 G93.3) since 1969.

*M.E. Support-Norfolk* (the initials in our name stand for Myalgic Encephalomyelitis) has adopted the 'Canadian Guidelines' definition of M.E. - available at:

[http://www.ahmf.org/me\\_cfs\\_overview.pdf](http://www.ahmf.org/me_cfs_overview.pdf)

The group has been in existence for over thirty years now, having originally begun as a local branch of one of the national M.E. charities and since 2000, when our current name was adopted, has been an independent support group. (Members pay an annual subscription

but we do rely on donations to keep afloat.) We have our own library of books, videotapes, DVDs and audiobooks for members to borrow. Most of these are naturally M.E.-related, but some are purely for enjoyment! Members also receive our monthly newsletter *MEMO*.

Regular informal monthly support meetings are held in Norwich, sometimes with presentations on topics such as nutrition and complementary therapies, and individual members also host their own occasional get-togethers as well as organising various events throughout the year.

*M.E. Support-Norfolk*, in line with the World Health Organisation, recognises Myalgic Encephalomyelitis as a neurological disease. We are therefore interested in biomedical research and treatments and do not seek to promote 'biopsychosocial', psychological or psychiatric approaches to dealing with M.E.

The WHO does not have a classification for 'myalgic encephalopathy' and we do not promote this name as an alternative for Myalgic Encephalomyelitis. We do not accept 'chronic fatigue syndrome' as being another name for M.E., nor do we

agree that M.E. is an illness 'characterised by fatigue'. While we recognise that any severe long term illness can induce fatigue as well as anxiety, despair or even depression in patients, in line with the experience of hundreds, if not thousands, of patients we do not accept that cognitive behavioural therapy (CBT) or graded exercise therapy (GET) - or equivalent 'treatments' under other names - actually address the illness itself.

## **Our Aims and Objectives:**

to provide information and support to people with M.E., their carers, families and friends;

to raise awareness of M.E. locally within the media, health care organisations and the general public;

to campaign for more recognition, research and better care and benefits for people with M.E.

## **Enquiries & Helpline**

**07823 - 407966**

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mesnorfolk@btinternet.com

[www.mesupportnorfolk.co.uk](http://www.mesupportnorfolk.co.uk)

## What is Myalgic Encephalomyelitis?

One way of answering this question is to clarify what M.E. is not - and it is *not* "being tired all the time".

M.E. is sometimes confused with 'chronic fatigue syndrome', a condition whose main symptom is fatigue, or lack of energy.

Fatigue is not so much a symptom but a *consequence* of having M.E., a disease which affects virtually all the bodily systems. Sufferers struggle to get through each day with simple tasks normally taken for granted, such as washing, dressing, preparing meals etc. Such activities, *when achievable*, leave patients utterly debilitated, in increased pain and feeling even more ill. Indeed, many sufferers are so badly affected by M.E. they are incapable of any independent living at all and are permanently bedbound, some having to be tube-fed in a soundproofed, darkened room.

Something often forgotten when it comes to diseases like M.E. is that it is not just a matter of being disabled by it; sufferers *feel ill constantly*, which, of course, affects every aspect of their daily existence, making interaction with the

world very difficult, if not impossible, for much of the time.

One of the major symptoms of M.E. is pain, ('myalgic' refers to muscle pain) which can be so bad that it becomes overwhelming and patients literally cannot even think. Although any type of exertion can exacerbate it, especially in the muscles, pain can appear anywhere in the body (head, joints, soft tissue, nerves) at any time, and normal analgesics don't usually help to relieve it.

The brain itself is affected (evidence is now emerging of the scarring of the brain tissue which occurs with Multiple Sclerosis, a related disease), leading to what is known in medical parlance as cognitive dysfunction and in common language as 'brain fog': sufferers have difficulty in finding words and experience problems with thinking straight or speaking.

A further consequence of M.E. is that balance and coordination can be so badly affected that mobility is seriously restricted. All of this, naturally, can lead to psychological and/or emotional problems, which also have to be overcome, as if the physical damage alone wasn't difficult enough to deal with.

## What causes M.E.?

One could ask, what causes a broken leg? No single cause of M.E. has been identified, although it is evident that in many cases the disease has been preceded by a viral or bacterial infection. Current thinking is that it is the result of a 'hit-and-run' infection, which leaves long term damage in its wake.

## What about treatment?

At the moment there is no cure, and therefore no effective medical treatment, for M.E. The most sufferers can do for themselves for the time being is to learn to cope and manage as best as possible within an impoverished, disabling and restricted lifestyle.

But there *is* hope: medical research is slowly making progress in identifying what is actually wrong with the various parts of the body affected. The next step will be to find ways of repairing that damage. Not so long ago MS was referred to as 'hysterical paralysis' and the tremors produced by Parkinson's also dismissed as being of a psychological origin. But the world is catching up at long last with the reality and nature of neurological diseases, including M.E.