



Information, membership and administration

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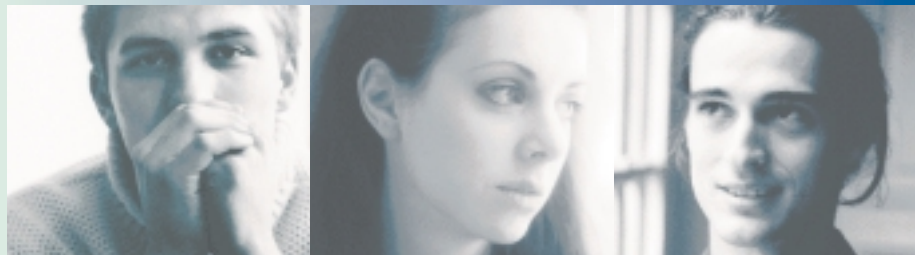
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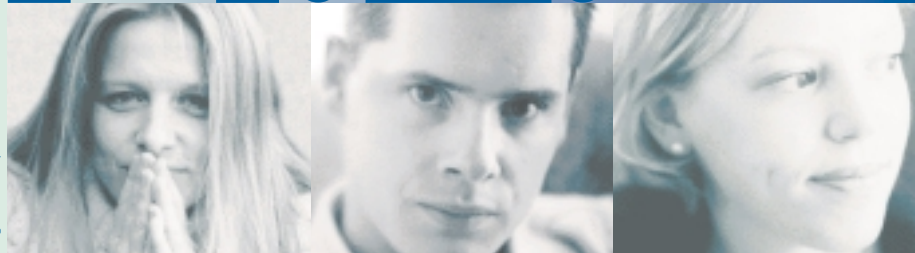
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in a nutshell



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What is M.E./CFS?

M.E. (myalgic encephalomyelitis) is a chronic illness that affects many body systems and their functions. The formal term used currently by the medical profession is Chronic Fatigue Syndrome (CFS). The changes seem particularly to affect the nervous system and immune system, but they also affect other body systems. The illness can cause profound exhaustion, muscle pain, problems with mental function such as memory loss and poor concentration, malaise and other symptoms.

Myalgic encephalomyelitis literally means muscle pain (myalgic) and inflammation of the brain and spinal cord (encephalomyelitis). However, the term is not accurate scientifically (there is no evidence of inflammation in the brain) or as a description of the illness (not everyone has muscle pain). A new name is needed once more is known about the illness. Some people have suggested that M.E.

could stand for myalgic encephalopathy, meaning muscle pain and an abnormality of brain function.

Some people consider that M.E. is distinct from CFS, or is a subgroup of it. Action for M.E. continues to use the term M.E. because many affected individuals prefer it, since the term CFS poorly describes those individuals in whom fatigue is not the most prominent symptom.

Who does it affect?

M.E. can affect men, women and children of all ages and backgrounds. It is estimated that there are over 150,000 people in the UK with M.E.; nearly two thirds of them are women. A recent study in the USA showed that about one in 250 people in the community have symptoms of CFS. Most people develop the illness between their early twenties and mid-forties. However M.E. does affect children and young people, generally those between the ages of 13 to 15 but sometimes children as young as five.

Symptoms

These are some of the symptoms commonly experienced by people with M.E. You may experience a combination of these. Do not panic at the length of the list - these are only possible symptoms and it doesn't follow that you will suffer from all of them.

- Persistent fatigue
- A general feeling of being unwell after normal physical or mental activity
- Painful or aching muscles or joints, headaches/migraines
- Problems related to thinking - reduced attention span, inability to plan and organise thoughts, loss of powers of concentration
- Sleep disturbance - unrefreshing sleep, not enough sleep or too much sleep
- Other nervous system symptoms - poor temperature control, increased sensitivity to light and sound
 - Recurrent sore throat
 - Digestive disturbances
 - Intolerances and increased sensitivity to alcohol, some foods, some medications, other substances

Causes

The cause of M.E. is not yet fully understood. Abnormalities have been found in the immune system and nervous system, including the functioning of the hypothalamus (a part of the brain that regulates basic functions like appetite, sleep and temperature control). More research is needed to understand the exact role of disruptions in these and other systems.

Some evidence exists on the factors that may make people more prone to developing M.E. (predisposing factors) and there is good evidence of factors that can trigger and maintain the illness. It is generally thought that an interplay of these factors contributes to the development of M.E.

Predisposing factors:

- gender - M.E. is more common in women than in men
- genetics - some studies have suggested M.E. may be more common in certain families

Triggering factors:

- infections
- immunisations
- life events
- physical injury
- environmental toxins

Maintaining factors:

- sleep difficulties
- mood disorders
- overactivity
- inactivity

Treatments

There is no treatment that can cure M.E. The limited understanding of the mechanisms underlying the illness adds to the problems of finding more effective and focused treatments. You may hear of 'miracle cures' through the press, various therapists, well-meaning friends, other patients or even some doctors, but be cautious and try to find out on what basis these claims are made.

Do not despair though because there is still plenty that can be done to increase your chances of recovery and to help you to feel less unwell, as the experiences of many of Action for M.E.'s members have shown. People with M.E. differ, sometimes greatly, in their response to treatments, so it is important to adopt one approach or make one change at a time, to find out what works for you. Although finding information yourself can be difficult in practice, or an energy drain, individuals who are informed about treatments and treatment options may get more benefit out of those treatments. Action for M.E. is here to help with diverse information needs.

We recommend that you discuss any approach with your doctor or other practitioner and ideally incorporate this into an overall individualised and flexible management plan to tackle your illness.

How can Action for M.E. help?

Action for M.E. is a national charity working to improve the lives of people with M.E. run by and for people with M.E. to give you, your family, friends and carers help and support.

We offer up to date, comprehensive information on M.E. treatment for patients and health professionals, to help you make informed choices based on experience, expert medical knowledge and research. Our quarterly magazine for members, *InterAction*, is for many, a real lifeline.

Over 150 local support groups across the UK give you the chance to meet up or contact other people with M.E. Finding support and new friendships in your own community can be a huge boost as you exchange information on what helps and what local support is available. Support groups also enable you to campaign locally to improve services and understanding of M.E.

Members of the charity have access to telephone helplines. A trained counsellor runs our counselling open line and can help you cope with the emotional difficulties of living with a long-term illness. Our welfare rights helpline gives expert advice and support on benefits.

We campaign on your behalf to ensure M.E. is recognised as a serious illness needing high quality research, better services and improved funding. We work with government, health professionals, the media and key opinion formers to bring about real change.