



25% M.E. Group
Support for Severe M.E.

A PATIENT'S PERSPECTIVE

Information Leaflet for Professionals Caring for People with Severe M.E.
(Myalgic Encephalomyelitis)

25% M.E. Group
21 Church Street,
TROON, Ayrshire KA10 6HT
Charity No: SC034265

Tel: 01292 318611
Email: enquiry@25megroup.org

Website: www.25megroup.org

PATRON: Dr Byron M Hyde MD
MEDICAL ADVISOR: Dr N Speight MA, MB, B Chir, FRCP, FRCPC, DCH
SCIENTIFIC ADVISORS: Dr Vance Spence PhD
Prof M Hooper PhD. B.Pharm. C.Chem. MRIC

SOME FACTS ABOUT SEVERE M.E.

It is important for professionals and carers to remember that this illness can be made worse with physical activity, talking, trying to concentrate or indeed any kind of stimulation or exertion.

Unfortunately this is not widely understood and the misconceptions surrounding this illness can cause additional physical and emotional suffering for those with M.E.

Researchers have demonstrated numerous abnormalities of the immune, muscular, cardiovascular, and central nervous systems. The emerging picture is of a multi-system disease with a strong component of immune and neurological dysfunction. The World Health Organisation recognises M.E. as a neurological illness.

Myalgic Encephalomyelitis (M.E.) describes an illness characterised by a combination of muscle pain (myalgia), and neurological and cognitive symptoms such as memory loss and concentration difficulties (hence 'encephalomyelitis').

As with any illness, the symptoms and disability which results will be experienced differently by each individual. Symptoms can vary in severity and commonly include chronic pain and lack of stamina / weakness of the muscles and limbs, acute hypersensitivity to stimuli such as light and noise, cognitive and memory problems, vocal/muscular limitations, multi-joint pain, and severe migraine type headaches.

These are real physical symptoms, which also cause severe distress to the person suffering from them.

The vast majority of severely affected sufferers are virtually housebound or bedbound due to the effects of the disease.

This means their physical and mental limitations are very acute. Commonly the person will require to use a wheelchair to get around, help with transferring from seat to seat within and out with the home, and may have problems with sitting up, using their arms and hands for even simple tasks like doing up buttons on clothing, and have difficulties toileting and bathing themselves. Some very severely affected patients are unable to do any of these tasks because of very severe pain and muscle weakness (not due to misuse or under use) and even transient paralysis - normally down left side. This can leave the person unable even to swallow, or to turn themselves in bed.

SO HOW CAN YOU HELP SEVERE M.E. SUFFERERS?

- People with severe M.E. are asking for no more than other ill people. They need professionals to be aware of the devastating disabling effects of the illness, and its varied symptoms.
- Even severe debility may not be instantly apparent – for example a sufferer may be able to walk to the toilet when required, but unable to sit up in bed for more than a few minutes, watch TV or go out even in a wheelchair, and they may find that they expend most of their energy on something as simple as eating.
- M.E sufferers are happy to arrange for information to be given to any health care or social services professional, if this will help alleviate the current trend of being met with scepticism and disbelief.
- Sufferers need people to respect their experience and knowledge of their own illness. They want to get better - to regain what they have lost. Sadly, complete recovery is rare. Meanwhile the patients are the only ones who know where their limitations lie, and how much they can do without exacerbation.
- Conspicuous deterioration of symptoms after exertion or stimulus –often apparently trivial– is a key feature of this illness. In particular there is a body of research demonstrating abnormal response to exercise and many members of the 25% ME Group have only become severely affected after attempting this. It is important to be aware of the danger of steering patients towards an approach that is highly likely to cause more harm than good.

Please be a responsible professional and carer - to do this you need to listen to what is being said to you by the M.E. patient.

A FINAL MESSAGE

Most importantly, **please listen to the person with M.E.** There can be harmful consequences for M.E. patients when they are encouraged to push on through the symptoms.

Thank you for your time, please feel free to contact us at the 25% M.E. Group for more information or to use our service as a resource.

If you have any questions, opinions or general concerns that you wish to be addressed, we are more than happy to hear from you. Should you wish to make any comments or submit your views please do so using the form below and return to the address provided on the front of this leaflet. Or you can contact us by e-mail at: enquiry@25megroup.org

Thank you for reading this and for seeking to care for this person.