

ME (MYALGIC ENCEPHALOMYELITIS)
INFORMATION SHEET

GENERAL BACKGROUND

ME (Myalgic Encephalomyelitis) is a serious, long-term neurological condition which affects around 200,000 in the UK. Approximately a quarter of those with the illness are severely affected, many becoming housebound and/or bed-bound for many years.

In Scotland the approximate number of sufferers could be as high as 20,000 (*based on published prevalence range of 0.2% to 0.4%).

CLASSIFICATION & CAUSE

ME has been classified by the World Health Organisation (ICD 10 G 93.3) as a neurological illness. The Chief Medical Officer's Report on the subject of CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalomyelitis) issued in January 2002 recognises that "CFS/ME is a real, serious and debilitating condition"; the CMO also stated that, "CFS/ME should be classed as a chronic condition with long term effects on health, alongside other illnesses such as multiple sclerosis and motor neurone disease".

A variety of causes have been suggested (immunological, endocrine, musculoskeletal, neurological etc.) but no single factor has been identified as the cause of this condition, which is known to affect all social classes, ages and ethnic groups, although there is often a viral trigger, probably associated with an enterovirus.

SYMPTOMS

Symptoms are numerous and extremely varied. However, the most common symptoms include:

- **Persistent/excessive exhaustion or fatigue** – is an essential symptom and varies in severity. Cognitive fatigue is also usually experienced.
- **Pain** – may include muscular pain, joint pain, headaches and neuropathic (nerve) pain.
- **Cognitive impairment** – for example reduced attention span, reported impairment of short-term memory, word-finding difficulties, inability to plan or organise thoughts, spatial disorientation and loss of powers of concentration.
- **Postexertional malaise** – the malaise that follows trivial exertion may comprise "flu-like" symptoms. This can be delayed, appearing 24 to 48 hours after physical or intellectual exertion.
- **Sleep disturbance** – in the early stages of the illness, excessive sleep is common. Sleep is usually unrefreshing in ME, and there may be frequent awakenings, or reversal of sleep patterns.
- **Recurrent sore throat** – with or without cervical lymphadenopathy.
- **Digestive disturbances** – nausea, difficulty with eating/swallowing, indigestion, bloating, abdominal cramps and alternating diarrhoea and constipation.
- **Intolerances** – these may include intolerance of some foods, some medication, multi chemical sensitivity and alcohol intolerance.
- **Other symptoms** – include altered temperature perception, dizziness, light-headedness, orthostatic tachycardia, postural hypotension and increased sensitivity to sensory stimuli, such as light and sound.
- **Emotional Disturbance** – reactive anxiety and depression due to having to cope with a chronic illness.

THE SEVERELY AFFECTED

Patients within this category are often house and/or bed-bound due to the effects of the condition. Both their physical and mental limitations are acute. They will often require the use of a wheelchair both within and outwith the house, because of difficulties with standing and walking. They can often experience problems sitting up (even fully supported), using their limbs to carry out everyday tasks, such as washing, toileting and turning themselves in bed. Effects on concentration can be catastrophic, leaving patients unable to hold a conversation, read, or listen to music – or only able to do so for a very short period. They may experience extreme pain and muscle weakness (not due to misuse or under-use) and transient paralysis – usually down the left side.

CARE AND MANAGEMENT OF THE CONDITION

LISTENING TO THE PATIENT: There has been in the past a great deal of misunderstanding about ME, but there is now a wider appreciation of the seriousness of the condition. With regard to moderate and severe ME, the level of disability and ill-health experienced is severe and complex. The degree of physical restriction may not be instantly apparent to the onlooker; the patient may look okay, despite being unable to walk to the toilet, sit up for more than a few minutes at a time, watch TV or go out in a wheelchair; so it is vital to listen to the person with the condition in order to support them fully with their complex individual care needs.

Management of the condition should involve an individually-tailored care programme based upon the following:

- **EARLY RECOGNITION**
- **APPROPRIATE CLINICAL EVALUATION**
- **EFFECTIVE TREATMENT & FOLLOW-UP (appropriate to the severity of the condition)**
- **INTEGRATED COMMUNITY AND SOCIAL SUPPORT**

Both the Chief Medical Officer's Report (in England) and the Short Life Action Group Report (in Scotland) consider early recognition and diagnosis to be extremely important, but also recognise that patients who are severely affected, will require continuing and long-term care.

FORMS OF TREATMENT

Pacing: "pacing" of activities where the patient listens to his/her own body and fluctuating energy levels and plans daily activities in accordance with their own energy levels. This is a more suitable form of treatment than Graded Exercise Therapy, which is often considered as part of the management of ME. However, it has been shown from patient reporting that this (Graded Exercise) can be the most harmful form of therapy, which can hamper any improvement. (Patients may appear reluctant to exercise, but this is usually due to an inability to increase activity without relapse.)

Symptomatic Therapy: this is an important element in the management of ME. Most patients will experience many different symptoms associated with the condition and it is usually helpful to deal with these on an individual basis with appropriate therapeutic interventions.

Pain Management: Pain is one of the difficult symptoms for people with the condition. Although simple analgesics may suffice in some milder cases, they rarely have any effect on severely affected patients who may experience very high levels of pain. In such cases, anticonvulsants, such as gabapentin, may be beneficial to the patient for pain control.

Emotional Support: As with any chronic illness, anxiety and depression may be an additional complication that needs to be addressed. Anti-depressants may be necessary in some cases but they should not be given as a “blanket approach” to treat ME itself. Care, understanding and practical support for the patient (and their family) is usually much more beneficial.

Counselling and Cognitive Behaviour Therapy: CBT may be helpful to some patients if administered correctly by an appropriately trained and supervised therapist, who truly understands ME and the activity limitations imposed by the disease. However, we do not recommend this therapy to ME sufferers and we would consider one-to-one counselling with a therapist who understands the complexities of this illness to be a more beneficial form of treatment.

Issues of Disability with ME: People who are moderately or severely affected by ME invariably have mobility problems due to malaise, exhaustion, dizziness, pain, weakness etc. (for example, difficulty in standing, walking any distance, being wheeled in a wheelchair, or travelling in a vehicle). Aids such as walking frames, sticks and wheelchairs, either electric or manual (few can self-propel) may help to increase independence and mobility. Social Services and other care agencies play a vital role in enabling the individual to maintain some quality of life and to reduce the strain on the family. Adaptations within the home are also important in order to enable the person to live more comfortably (e.g. ramps, bathroom conversions, stair lifts, bedroom aids). Respite care provision should also be provided as part of the care package.

COMMUNITY & SOCIAL SUPPORT

As stated in the Short Life Action Group Report (Scotland): “The chronic and persistent nature of CFS/ME diminishes the patient’s ability to perform independently. There is often a substantial socio-economic impact relating to areas such as work, finance and education. This may result in a patient’s need to access state benefits, insurance policies or retirement on health grounds. Clear guidance from doctors regarding the diagnosis and the particular needs of patients to other agencies such as Social Work Departments and the Benefits Agency, will facilitate access to relevant support and services from these agencies. Particularly for housebound/bed-bound patients, integration of all aspects of health and social care services, aided by a care plan, is desirable: physiotherapy, occupational therapy, and disability provision, for instance. Such patients will also need help in accessing other services such as dentistry and optician services.”

CARE PROPOSALS

Many bed-bound or housebound patients are unable to attend GP surgeries or specialist outpatient clinics and, as a result, often become very isolated and “invisible” to the care services they so desperately need. Therefore, development of domiciliary services to meet the needs of the severely affected is crucial. Because of the severe nature of the condition, it is important that appropriate care be put in place in order to support the patient and their families. In some cases, patients may be too ill to fully manage their own affairs. Someone should be available to act as an advocate for the ill person where necessary; this could be an understanding friend, family member, or independent professional advocate. Advocates should always seek to put over the interests, wishes and views of the person they are representing. We feel that NHS Trusts should collaborate with Local Authorities and Patient-led Voluntary Organisations who often possess valuable knowledge about the condition. Models of such multi-disciplinary specialist services have already been set up in other parts of the UK.

CONCLUSION

We hope this information sheet helps to outline some aspects of care provision that may be required for people with severe ME. As with other serious chronic illnesses various agencies need to be involved in order to provide the maximum care provision possible. Many severely affected patients, because of the level and nature of the disability, will not necessarily be able to use existing services, so ways should be sought to enable them to access the care services they require.

The following extract is from a sufferer's own experience of living with severe ME:

ME AND MY PURE HELL

Before becoming ill with ME, I was fit and healthy. I was employed as a PE teacher who led a full and active sport and social life. I then suffered from a strange, debilitating virus and despite persistently returning to work, I eventually became so bad that I was unable to do so. (Incidentally, there was a cluster of cases of ME, affecting to various degrees, a number of pupils at the school.) I paid for tests to be undertaken privately and these proved that I was suffering from Post Viral Syndrome, following glandular fever. The NHS solution was that nothing could be done but it "would probably go away within two years" - which I refused to accept, and set out to find the solutions privately.

During the following three years, I continued to deteriorate until, I was reduced to crawling to the toilet, being carried downstairs and spending the day lying as still as possible due to severe agonising headaches. In addition, I suffered from terrible weakness, muscle aches, severe dizziness, blurred vision, sore throats, sweating and shivering, swollen glands, was highly light and noise sensitive and had digestive problems. I was barely able to sit up to eat, unable to watch TV or even converse for more than about five minutes.

Over the next three years, I made a very slow improvement to the stage where I was able to move about the house, go up and down the stairs and to occasionally go out with the use of a wheelchair, living independently (but with assistance for a couple of hours a day).

Unfortunately, I suffered a major relapse. My current state of health is that I am bed-bound, requiring a great deal of care, including transfer to a wheelchair for access to the toilet etc. As well as the above symptoms, the left hand side of my body suffers loss of sensation, pins and needles as well as pain and spasms.

Every day seems like an eternity and is spent enduring pain, feeling so ill, as if your blood had been poisoned, but worse still, is living with the frustrations of being trapped inside a malfunctioning body, unable to concentrate and needing assistance to do the most basic tasks. For months I suffered the humiliation of being unable to feed myself and struggled to push buttons on the telephone. I still need help to get to the toilet, to wash and dress etc. It is like the seasickness adage - first you feel so ill that you are afraid you are going to die and then it gets worse and you are afraid you are not going to die! I, and most other sufferers, have adopted a determined, positive and proactive attitude, which no doubt contributed to ME in the first place! Merely surviving these years of hell has been a far greater achievement than any of my academic qualifications, sporting achievements or job promotions.

Since becoming ill with ME, I have spent thousands of pounds, in vain, seeking a solution from many sources including ME consultants, acupuncture, osteopathy, homeopathy, herbal medicine, nutritional therapy, kinesiology, hypnotherapy, various healers, very many nutritional supplements, immunoglobulin, B12 and magnesium injections with little or no help from the NHS.

Governments, researchers and the medical profession in general need to realise that it is not just about saving lives but **QUALITY OF LIFE** and that with severe ME, this quality is zero. Society would not let animals go through such suffering and incapacity but ME sufferers are left to exist in a "**living death**" state for years; sustained only by the distant ray of hope of recovery and a positive attitude that keeps you fighting and thinking that it's got to get better soon even after years of disappointments.

Insult is added to injury by the fact that some people still believe a bit of graded exercise and some positive thinking is all that stops sufferers getting well. I used these methods to recover from an accident when I received 25% burns but with ME this form of "treatment" only results in deterioration rather than increasing your capacity! If only that was the answer I'd never have been in this hell. I'd have been well years ago enjoying the wonderful life I led before ME.