

WHAT IS ME?

Myalgic Encephalomyelitis/Encephalopathy (ME) is a chronic, fluctuating illness, often referred to as Chronic Fatigue Syndrome (CFS) and sometimes as Post Viral Fatigue Syndrome (PVFS). National and international debate is ongoing as to the appropriate terminology but for the purposes of this Statement we will use the composite ME/CFS, the term recommended by the Scottish Public Health Network in the recent Scottish Needs Assessment.

ME/CFS is a common ailment, or range of ailments, which causes significant ill health and disability in people of all ages. It has some characteristic features but is highly variable – including its duration and severity – and lacks specific features leading to an indisputable diagnosis. There is widespread acceptance amongst the medical profession that ME/CFS is a real and disabling illness. The World Health Organisation classifies ME (and PVFS) as a disease of the central nervous system. Although CFS does not have a similar distinct clinical classification it can be linked to ME.

The NHS has recognised that the physical symptoms can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis, congestive heart failure and other chronic conditions and that the illness places a substantial burden on people with the condition, their families and carers, and on society.

Prognosis is extremely variable. Many patients have a fluctuating course of illness with some setbacks. Patients can often be helped by the use of quite straightforward treatments and many patients do improve to some degree over a period of time. However, health and functioning rarely return completely to the individual's previous healthy levels; most of those who feel recovered stabilise at a level of functioning lower than that before the illness. Overall, there is a wide variation in duration of illness, with some people recovering in less than two years, while others remain ill for longer.

People experience ME/CFS as a range of symptoms and it is therefore necessary to adopt a holistic approach to treatment and care. Empathetic listening is vital by health professionals. A working diagnosis is better than none and allows active management to begin. GPs should usually be able to manage most people with ME/CFS, similar to other chronic conditions. Being seen by specialists, for diagnosis or development of a management plan, may help where problems are complex, severe or prolonged.

SYMPTOMS

The core symptom is profound and debilitating fatigue that almost always has a physical and mental effect.

Key symptoms:

Exercise-induced muscle fatigue

Post-exertional malaise

Cognitive dysfunction: problems with short-term memory, concentration and memory span

Pain that is often persistent and difficult to control. Pain is often mechanical (musculoskeletal) but can also be rheumatic, neuropathic or myalgic

Sleep disturbance (e.g. insomnia, early morning wakening, unrefreshing sleep, disturbed sleep/wake cycle)

A general feeling of ongoing malaise

Orthostatic intolerance (difficulties in movement or uncomfortable at rest)

Other symptoms:

Difficult to maintain lifestyle and activity (disequilibrium)

Autonomic dysfunction

Disturbed thermoregulation, night sweats and heat sensitivity

Sensory disturbances

Hypersensitivity, tinnitus and/or photophobia

Headaches of new type, pattern or severity

Arthralgia (joint pain) but not including swelling, redness or joint deformity

Irritable bowel-type symptoms (e.g. nausea, loss of appetite, indigestion, excessive wind, bloating, abdominal cramps, alternating diarrhoea and constipation, food intolerance)

Muscle pain

Alcohol intolerance, drug and chemical sensitivities

Recurrent sore throats and tender lymph nodes

INVESTIGATIONS

As the crucial tool in diagnosis is the clinical history, sufficient time should be allowed for people to give an account of their illness experience.

Screening tests should be undertaken to exclude other conditions; additional tests may be needed to evaluate specific symptoms or features.

Blood screening

Urinalysis

Blood pressure (both lying and standing)

ECG (heart trace, in adults)

If symptoms suggest that any of the following are likely appropriate investigations should be carried out.

Adrenal insufficiency

Anaemia

Chronic infection

Coeliac disease

Immunodeficiency

Malignancy

Mood disorders

Multiple sclerosis

Myasthenia gravis

Primary sleep disorder

Rheumatic diseases

Somatisation disorder

Thyroid disease

Dependent on symptoms, examples of further tests include:

Neurological tests

Chest x-ray

Infectious disease screen

MRI scan

Muscle biopsy

Epworth sleepiness score

Rheumatology and autoantibody screen

Serum tests from further blood samples

Other causes of chronic fatigue must be considered where the history is atypical.

TREATMENT

A number of consultations are often required to establish a positive diagnosis and to agree and monitor chosen treatments. The symptoms of ME/CFS fluctuate in their severity and nature over time. Holistic approaches in treating the symptoms of ME/CFS are more effective.

It is particularly important to:

acknowledge and accept the reality and impact of ME/CFS and its symptoms

share decision-making about treatment options with health professionals

try to find explanations and possible causes, nature and course of the illness, together with possible treatments (benefits/risks), as outlined in this guide, taking account of age and other underlying health condition.

At present there is no single treatment that has been shown to be consistently effective in alleviating the underlying disease process. Particular approaches have been found to be potentially beneficial in modifying this illness. A variety of drug treatments have been advocated for people with ME/CFS, but few have been subjected to well organised, randomised controlled trials (RCTs).

People with ME/CFS are often sensitive to the side-effects of drugs, particularly anti-depressants, anaesthetics and some others designed to reduce symptoms such as vertigo/dizziness. Consequently, it is normally desirable to commence at a low dose, followed by gradual increases over a couple of weeks, when it comes to the use of antidepressant medication in particular.

SYMPTOMATIC TREATMENTS

Pain Relief

Simple painkillers should be tried first including anti-inflammatory such as aspirin and ibuprofen.

Should these prove ineffective, sometimes amitriptyline 10mg to 25mg at night can be tried if approved by your GP. Medication such as gabapentin may be tried if the pain is neuropathic (nerve tissue involvement) in type, starting with a low dose of 100mg and gradually increasing. If there is a history of severe muscle spasm, anti-spasmodics such as baclofen can be used.

Physical treatments such as transcutaneous electrical nerve stimulation (TENS) machine or acupuncture can also be tried.

Sleep Disturbance

The importance of a good sleep pattern should not be underestimated. Sleep hygiene should be looked at initially detailing avoiding caffeine and setting a routine for going to bed and getting up, a warm bath before going to bed and an equitable temperature for the bedroom. The bedroom should be a “worry free zone”. Day-time napping should be replaced with rest/relaxation periods.

If medication is required then use of amitriptyline, or similar medication should be tried. A hypnotic, such as diazepam, should only be used if there are problems with initiation of sleep and only short term.

Headache

If migrainous in nature, standard treatments for migraine should be tried.

If frequent, then prevention medication, such as amitriptyline or pizotifen could be of value.

Abdominal Symptoms

People with ME/CFS often suffer from symptoms of irritable bowel syndrome. This can be treated using the conventional medication such as ispaghula husk and antispasmodics.

Mood Disorders

For patients with co-existent clinical depression, pharmacological treatment with an antidepressant is appropriate. It should be noted that there is overlap between antidepressant side effects and ME/CFS symptoms. Therefore it is advised that treatment be started in a low dose and gradually increased over a period of several weeks.

When appropriate anxiety management or psychotherapy can be extremely helpful.

OTHER TREATMENTS

The following treatments have a varying rate of success and in some cases have been harmful to individuals. If, after careful planning, they are recommended, their use by individuals must be regularly and carefully monitored.

Activity management or pacing, is a way of managing the reduced “energy envelope” of people with ME/CFS. Gaining the balance between activity and rest can be difficult. It will vary from patient to

patient and also during the course of the illness in any patient. It is important to avoid periods of “boom and bust” in energy expenditure. This energy expenditure is physical and mental. Graded exercise therapy makes use of an exercise programme involving a progressive increase in aerobic exercise on a day to day basis.

Activity Management is an approach that is customised to the needs of the person with ME/CFS. It is based on an understanding that all activities have physical, emotional and cognitive components and on identification of those components.

Pacing is largely a self-management technique with the underlying approach being to establish sustainable activity levels. A consistent baseline of activity (mental as well as physical) should be established that avoids delayed setbacks. A diary may help to establish patterns of activity. This is widely considered by patients to be the most helpful intervention.

Graded Exercise Therapy (GET) is delivered by a suitably trained GET therapist with experience in ME/CFS ideally on a one-to-one basis. GET is intended to restore some physical fitness which has declined due to inactivity imposed by ME/CFS.

Cognitive Behaviour Therapy (CBT) is a psychological intervention usually undertaken on a one-to-one basis. The essence of the treatment is to examine difficulties as they relate to events in an individual's life and identify patterns of expectation that may be unhelpful to coping with being unwell for a prolonged time. CBT can be used, as in other chronic physical medical conditions, as a tool to aid people develop better ways of coping with symptoms such as fatigue, pain, sleep disturbance. This is particularly useful when there is a super-added depression or psychological distress.

Pacing, Graded Exercise and CBT as specific treatments for ME/CFS

In England, there are special clinics which offer these therapies as specific treatments for ME. There has been much concern expressed about the evidence base for these treatments. In Scotland, these treatments are being evaluated in the PACE trial, which is at present underway in Edinburgh. It would be prudent, therefore, to await the evaluation of the publication of the report of the PACE trial before making any further pronouncements on the specific place of these therapies. The report on the PACE trial is scheduled to be published by 2010.

WELFARE BENEFITS

People with ME/CFS are as potentially disabled as those with other chronic conditions and are therefore entitled to apply to the Department of Works and Pensions for the full range of sickness and disability benefits. In order to qualify for these benefits the claimant has to provide sufficient written medical evidence to support the claim. The GP's input is therefore essential for a claim to succeed. ME/CFS is a fluctuating condition for most people with the illness and this aspect needs to be taken into account by medical practitioners when assisting with Welfare Benefits applications. It may be that a referral to a specialist will be necessary to help clarify the level of disability and/or confirm the diagnosis.

More information about benefit applications and appeal procedures can be found through Action for ME or the ME Association.