

DWP MEDICAL GUIDANCE – VERSION 10 (May 2007)

CHRONIC FATIGUE SYNDROME AND MYALGIC ENCEPHALOMYELITIS/ENCEPHALOPATHY

What is it? (Definition)

1. The term chronic fatigue syndrome (CFS) is used to describe an illness that is characterised by physical and mental fatigue and fatigability. A characteristic feature is fatigue/malaise that follows minimal exertion. People with CFS often describe the fatigue as being of a type and a scale beyond any other they have experienced. The illness may affect both physical and mental functioning, including cognitive function. Accompanying symptoms may include poor sleep, pain, poor concentration and memory, although this list is not exhaustive.
2. Chronic fatigue syndrome (CFS) is also known as myalgic encephalomyelitis (ME) and post-viral fatigue syndrome. There is some difference of opinion over whether ME is different from CFS; however, most authorities refer to the condition as CFS/ME.
3. The symptom of fatigue is a feeling that can sometimes be difficult to describe and to measure. It is a feeling of exceptional or abnormal tiredness or lack of energy in excess of that anticipated in response to current activity. Fatigability in CFS/ME is the overwhelming feeling of exceptional tiredness exacerbated by exertion. CFS/ME is identified by its symptoms and disabling effects, and by excluding other medical conditions that could explain them. There are no confirmatory abnormal findings on physical examination, nor is there any specific investigation such as an abnormal blood test that is diagnostic. This does not mean that CFS/ME is not a real illness, and all medical authorities now accept the illness as being a severe and valid condition.
4. A consensus definition of CFS/ME has been agreed by international experts for the purposes of research and includes the following:-

A complaint of:

Persistent or relapsing fatigue for 6 months or more that:

- Is of new or definite onset
- Is not the result of ongoing exertion
- Is not substantially alleviated by rest
- Results in a substantial reduction in previous levels of occupational, education, social or personal activities

Four or more of the following symptoms for 6 months or more:

- Impaired short term memory or concentration
- Sore throat
- Tender lymph nodes (neck or armpits)
- Muscle pain
- Pains in a number of joints (without arthritis)
- New headache
- Unrefreshing sleep
- Malaise after exercise lasting more than 24 hours

Other physical causes of fatigue such as anaemia, thyroid disease, sleep apnoea, malignancy, liver disease etc. are excluded.

Major mental health disorders are excluded, although as with other chronic conditions, people with CFS/ME may have conditions such as depression and generalised anxiety disorder occurring at the same time.

5. A number of other medical conditions such as fibromyalgia, irritable bowel disease, and migraine may also occur in people with CFS/ME. These have some symptoms in common with those described in CFS/ME.

How common is CFS/ME?

6. It is estimated that around 1 in 200 of the UK population have CFS/ME. It is predominantly a disease of young adults (commonest incidence between 25 to 50 years) and occurs in all socio-economic groups. It appears to be more common in women [female: male 2:1 or 3:2].

What is the cause?

7. A specific cause of CFS/ME has not as yet been identified. Possible causes of the condition have been the subject of much debate. It is likely that the term CFS/ME describes a spectrum of disorders in which physical and mental functioning are affected. In some cases infectious illnesses like glandular fever may trigger the onset of the condition. There is no evidence however that persistent infection is responsible for the continuation of the illness. Although the cause is not fully understood, changes associated with CFS/ME may include an altered stress hormone response, altered immune response, altered gene expression, sleep problems, alterations of mood, and coping strategies. Different factors are likely to be important in different people at different times.

What are the risks for developing and maintaining CFS/ME?

8. Although the cause of CFS/ME is unclear, certain factors may be important in its development. These are usefully divided into predisposing, triggering and maintaining factors. Some people may be predisposed to the condition, for example because of their genetic makeup, or gender. For example the condition is commoner in young women. An infectious disease such as glandular fever (infectious mononucleosis) or a major physical illness may trigger the condition. Other stressful life events or difficulties may precede development of CFS/ME, particularly if the stress is ongoing.. Finally some other factors may help to keep the illness going. For example, poor sleep, poor nutritional uptake, or a concurrent mood disorder.

Clinical features

9. The main symptoms are persistent mental and physical fatigue, tiredness or exhaustion that are characteristically made worse by activity. People often do not sleep well and find that sleep fails to refresh them. Often they feel symptoms more after physical or mental activity, even minor exertion within the home environment, and this effect is characteristically delayed until the next day or so, and is prolonged. Muscles and joints ache and are painful. Headaches, sore throat and tender lymph glands in the neck and armpits are described. People with the condition also report short-term memory loss and poor concentration. Their mood may fluctuate and they may be prone to feelings of anxiety. Hypersensitivity to everyday levels of noise and light are reported.

10. People with CFS/ME often describe variation in the level of symptoms and disability.

Symptoms of fatigue and pain may vary in their severity during the course of the day, or may be considerably worse for several days after undertaking unaccustomed levels of physical or mental activities, even if these involve relatively simple tasks. Patients may be able to undertake a task for a short period of time, but then be unable to sustain or repeat it..

11. Those whose symptoms are mild may continue to undertake a range of normal daily activities. Some people will be able to carry out their occupation but have to reduce their social activities. Those with more severe forms of the condition are unlikely to be able to continue at work or in education. Daily living activities, hobbies, interests and social interaction are also likely to be considerably reduced. In the most severe cases the individual may spend almost all of the day resting, or be bed-ridden. Some people may use a wheelchair outside to minimise the fatigue and symptoms such as joint/muscle pain, or problems with dizziness/balance, engendered by walking.

12. Between a quarter and a half of people with CFS/ME are in part-time or full time employment or education. When compared to people with other diseases like diabetes mellitus or arthritis seen in hospital clinics many people with CFS/ME are on average more disabled.

13. Physical examination is normal in most cases. Some people may have postural hypotension. (Normally blood pressure is lower when sitting or lying in bed, on standing up it rises. In some people, in particular the elderly, there is a lag phase - a time interval - during which the pressure rises to the higher level. This may be experienced as a sensation of dizziness or light headedness, and sometimes in the elderly leads to falls). Those who are the most chronically and severely disabled may have some observable generalised muscle wasting, most likely to be found in the lower limbs, although this is unusual.

Is CFS/ME a physical illness?

14. There has previously been much debate as to whether CFS/ME is a physical illness or not. Some researchers have put forward the argument that it is a purely psychological disorder, citing in evidence the high rate of co-morbid depression. Others are equally sure that it is purely physical, citing the abnormal hormonal tests found in some or the triggering of the illness by certain infections. Both views are oversimplifications. The reality is that the disability of CFS/ME involves both physical and mental incapacity and it is important to ensure full consideration is given to all the disabling effects of the illness and an accurate assessment of care and mobility needs is made."

15. For the purpose of DLA, however, the current law means that a claimant cannot be eligible for a higher rate of mobility unless his/her disability is considered "physical". For this purpose, CFS/ME is "physical".

Management

16. Several different approaches have been used to manage this condition. There is no cure and treatment is aimed at managing the effects of the illness to improve both physical and mental function. No one approach is effective in all cases.

17. Management starts with the diagnosis and an explanation of why a patient is still ill. An explanation that CFS/ME may be progressive in some patients, but is not life threatening is an important initial step. No specific drug treatments are available. A collaborative and concordant approach to managing the condition is used where doctor and patient discuss the different options with a view to reducing symptoms and disability. The aim of management is to enable the person to improve their quality of life by returning in a gradual way to usual

daily activities, education or work. It is helpful to address both the physical and mental effects of the illness, and to minimise the results of over exertion or prolonged inactivity, and revise a "boom and bust" pattern of activity. A variety of forms of management as described below may be tried, either individually or in combination. All involve establishing a sustainable baseline of activity as the first step.

Graded exercise therapy and graded activity therapy

18. Supervised and gradually increasing physical and cognitive activity will enable the majority of people to improve, and some to return to a normal level of functioning. This is likely to be undertaken with the help of an appropriately trained physiotherapist (using graded exercise therapy) or an occupational therapist (using life style management) often within a hospital or clinic setting. Caution is required since over-activity, or increasing at too fast a rate, may lead to relapses. Unsupervised or inappropriately supervised therapy can sometimes also cause relapses. Research suggests that this approach is helpful in the majority of adult ambulant patients.

Cognitive behavioural therapy

19. Cognitive behaviour therapy (CBT) is used in CFS/ME to help people to examine their interpretation of symptoms such as fatigue or muscle pain, which they may perceive as damaging to their bodies, and as a result avoid activities that appear to precipitate them. People are encouraged to view such symptoms as reversible physical and psychological processes rather than evidence of a fixed or progressive disease process, by trying out a mutually agreed programme of graded activities, which help to challenge these beliefs. Understanding the illness, addressing fears and where appropriate reinterpreting the disabling symptoms allows the person to make a gradual improvement in their level of functioning and well being. Sleep is improved and mutually agreed graded increases in activity become possible over some weeks or months. Research suggests that this approach is helpful in the majority of adult and adolescent outpatients.

Pacing

20. Pacing is a lifestyle management approach in which the person with CFS/ME is encouraged to live within the limits of their illness and energy levels carefully balancing their activity and rest, as well as balancing different activities. When possible, activity is increased gradually, but readjusted in the event of symptom exacerbation. Patient group feedback is favourable and a research study is underway to look at the efficiency of the treatment.

Medication

21. Antidepressants may be very helpful in treatment of co-morbid conditions such as depression or insomnia. They can elevate mood or relieve anxiety in standard doses (eg. sertraline, citalopram) or improve sleep and relieve pain in low doses (e.g. amitriptyline, trimipramine). However, antidepressants can have side effects when used at the standard dose required to treat depression; and these side effects may need to be taken into account. Simple analgesics and non steroidal anti-inflammatory drugs are also used to alleviate persistent pain.

Course of illness and prognosis

22. People with mild illness may recover spontaneously, or with some general advice or a limited treatment programme over the course of the following six months. These people are

likely to be treated in a general practice setting.

23. People with established CFS/ME of moderate severity lasting one to two years or more are likely to need a more extensive management programme, as described above, lasting 6 to 12 months or more. Most people who are able to attend hospital for treatment are likely to make a significant improvement with appropriate management.. Some people will recover fully, but others will not achieve their previous level of functioning. Some may not improve. Those who recover may be at risk of recurrence. Those who improve are at risk of relapse. In many patients, disability and quality of life can be improved, sometimes to a significant extent..

24. Severe cases are less likely to recover completely or benefit substantially from a management programme.

25. Indicators of a good prognosis

- Male sex
- A definite history of an acute viral illness like glandular fever at the onset
- Mild disability and few symptoms
- Clinical features showing a pattern of evolution towards functional recovery
- Early diagnosis aimed at eliminating associated physical disorders and/or identifying psychiatric illness, along with other complicating psychological or social factors
- A management approach which may encompass physical, psychological and social elements that allows a stepwise approach to functional improvement, using rehabilitation

26. Indicators of a poor prognosis

- Onset of symptoms without any clear precipitating factor
- Clinical features characterised by severe and unremitting symptoms
- Severe and persistent disability
- A management approach that overemphasises the importance of either complete rest or which advocates a rapid return to pre-illness levels of physical activity.
- Those with comorbid significant medical conditions or mood disorders
- A complex background of adverse psychological and social factors

Functional restrictions

27. The disabling effects of CFS/ME in individuals is variable (see para 9). The following describes the typical problems a with daily living activities for the majority of the time.

28. Mild condition

The person would normally to be able to wash, dress, bathe, use the toilet, get up and downstairs without difficulty. The ability to plan a meal is not impaired and the tasks involving in preparing and cooking food are unlikely to be restricted in any way. The ability to walk long distances may be reduced, but the person is likely to be able to walk short distances on an unrestricted basis most of the time. Their judgment, thought processes and means of communicating are not affected to the extent that they would be unable to find their way around in familiar and unfamiliar places.

29. Moderate condition

Those with a moderate level of disability would be expected to be able to manage some

personal care and preparation of food without help from another most of the time. Tasks may take longer than normal and may need to be followed by a period of rest. Although the level of fatigue and symptom severity may vary during the day or from day to day, the ability to maintain personal hygiene and nutrition is likely to be unimpaired. The ability to walk more than 100 metres consistently may be restricted in moderate cases, but severe restriction of walking is unlikely.

30. Severe condition

People with a severe level of disability, who spend most of the day in bed or otherwise immobile, and who may have clinically evident muscle wasting, may well need help with personal care and preparing food. Such claimants may be severely restricted in their ability to walk. There may a requirement for supervision either at home or out of doors as a result of significant cognitive impairment, but it would be uncommon.

