16. THE CHRONIC FATIGUE SYNDROME

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16.2 Introduction

16.2.1 There is a spectrum of conditions where the prominent symptoms are fatigue, both physical and psychological, which may affect both physical and psychological functioning. At one end are people whose clinical condition is indistinguishable from that of depressive illness. At the other are people with fatigue in the apparent absence of any readily identifiable psychiatric disorder.

16.2.2 A number of names, including post-viral fatigue syndrome and myalgic encephalomyelitis (ME), have been used to describe one of these conditions. More recently the term Chronic Fatigue Syndrome (CFS) has been universally adopted.

16.2.3 There is controversy over the causes of CFS. This is particularly over whether it has a physical basis (related to a persistent viral infection or disturbance of the immune system or some other cause), or is a purely psychological disorder, or is due to a combination of factors, such as occurs in other conditions [see Chapter 19]. Recent evidence (yet to be substantiated) suggested a functional disturbance in the brain. However, the significance of these findings is not yet clear.

16.3 Clinical Manifestations

16.3.1 There are some cases where the condition appears to follow a viral illness (e.g., influenza, glandular fever). There are no objective clinical or laboratory tests for CFS, and diagnosis can be difficult.

16.3.2 In some cases of CFS, subjectively prolonged recovery time and marked fluctuations of symptoms can be encountered. In severe cases, extreme physical and mental fatigue with prolonged recovery time and marked fluctuation in symptoms can be characteristic. However, neither prolonged recovery time after effort nor marked fluctuations are unique to CFS.

16.3.3 There is wide variation between individuals in the nature and severity of symptoms. These can include muscle pain and exhaustion when attending to

normal functions such as washing or dressing, and can be accompanied by a variety of symptoms affecting balance, concentration and sleep disturbance. In more severe cases the symptoms can persist for several years, and in a small minority of people there may be a state of total dependency.

16.4 Management

16.4.1 There is no specific drug treatment. Anti-depressants are helpful for clinical depression, and may be used in small doses as symptomatic treatment for those who have muscle pain and sleep disturbances. Cognitive behaviour therapy has been shown to promote recovery from CFS in some people. Among other things it aims to help people re-evaluate their understanding of the illness and to adopt more effective coping behaviours.

16.4.2 From the physical standpoint, the aim is to find and maintain the right balance between rest and activity (known as pacing). Reduced activity is important in the early phase of the illness and during a relapse. Following this, a baseline of sustainable physical and mental activity should be determined and every effort made to maintain and extend this. Careful pacing with gradually increasing physical and mental activity is the goal. Total rest is counterproductive and leads to a vicious circle of progressive muscle weakness and wasting.

16.4.3 A concerted approach to treatment is required, which should address physical, psychological, social and employment factors.

16.5 Care Needs

16.5.1 There may be wide day-to-day variation in the severity of symptoms. It is necessary to discover what a person can do on a bad day as well as on a good day, and to establish how often each type of day occurs. A satisfactory level of physical and mental activity is one which can be sustained day after day without leading to a prolonged increase in symptoms, and not the amount managed only on a good day.

16.5.2 Whilst attending to bodily functions may take longer than normal, the majority of people with CFS appear to manage these unaided most of the time. Matters such as food preparation, shopping and household tasks may appear to cause problems for people with CFS. In those who have been immobile for long periods, physical help from another person may be required. A few people may be bed or wheelchair bound and may need help with personal care and to transfer on and off toilets etc. In a minority there is severe disablement and a state of high dependency.

16.5.3 Objective studies of muscle function may fail to reveal abnormal fatigue or weakness. However, when muscle weakness is clinically evident, this may indicate secondary disuse atrophy (wasting), and be an indicator of likely care needs. Severe fatigue in the absence of any objective evidence of muscle wasting

or weakness does not necessarily imply a definite and exclusively psychological cause. Furthermore, in individual cases, causes for severe fatigue which have not yet been diagnosed may be present.

16.6 Mobility Considerations

16.6.1 The majority of those with CFS are mobile, although they may walk rather more slowly than normal. The difficulty in walking is the result of fatigue, but may also be, in part, due to muscle pain, loss of balance, or weakness of muscles resulting from disuse. Patterns of walking for which no neurological cause can be identified may be seen, even in the absence of muscle wasting or other specific cause of abnormal gait. Muscle symptoms adversely affecting mobility may continue beyond the actual period of exercise. Physical disability may be influenced by the psychological state of the person. In those with the severest disability there is an increased likelihood of treatable psychological disorders and mental health problems.

16.7 Duration of Need

16.7.1 There is wide variation in both severity and duration of the illness. In people who suffer from fatigue, muscle symptoms and a lack of well-being following a viral illness such as influenza or glandular fever, recovery can be expected within a few weeks or months. Of those with established CFS, the majority can be expected to show a substantial improvement over time. There are others in whom the symptoms of fatigue last for much longer and may pursue a relapsing course. The persistence of fatigue may occur both in severe and milder forms of the condition.

16.8 Further Evidence

16.8.1 A report, based on a home visit from an examining medical practitioner (EMP), may help in determining the care and mobility needs. The report should state whether the accepted criteria for the diagnosis of CFS have been met, identify the severity, variability and fluctuation of the condition and estimate the relative predominance of physical and psychological factors in the case. A report should request an explanation of any discrepancy between the examination findings and the information provided on the claim form. Indication of prognosis and details of past and present management and treatment should also be requested. A factual report from a GP, hospital or other relevant specialist may also be helpful.