
Executive summary

Virtually everyone feels tired, or even exhausted, every now and again. We usually know why this has come about and the feeling wears off, either spontaneously or after a little extra rest. This is not the case with chronic fatigue syndrome (CFS). CFS patients feel perpetually tired and exhausted and also have a host of other physical complaints. CFS is also known as 'ME' (myalgic encephalomyelitis), a term that the Committee does not use since it erroneously implies the presence of an inflammation of the brain and spinal cord.

CFS is a controversial disorder. There are people both within and outside the world of medicine who believe that it does exist, and others who believe that it does not. This situation has given rise to major differences of opinion concerning the ability of CFS patients to work, and thus to their entitlement to social security benefit.

CFS is a genuine, severely incapacitating disorder. It is an established fact that CFS imposes limitations on an individual's personal, occupational and social functioning. The quality of life of CFS patients is lower than that of healthy people. The symptoms fluctuate, and this is unsettling for patients. They are forced to modify their activities, they no longer have the energy for social activities, working is often out of the question, contacts with colleagues gradually fall away, and their financial situation worsens. Not infrequently, they end up in social isolation.

Patients are reliant on help from others for their daily functioning. Onlookers do not always take their disorder seriously and dismissively suggest that 'it's probably psychological'. Patients expect their doctor to bring about an improvement in their condition,

but they are often told that the cause of these complaints is unknown and that there is no treatment. They hear stories (via the internet, a patients' organisation or those around them) about people who have had CFS for many years. They can easily get into a situation devoid of future prospects, which persists for many years. Spontaneous recovery is possible, but it is the exception rather than the rule. Such research as there is suggests that ten percent or less of adults with CFS recover spontaneously in the long term. For young patients, the prognosis is substantially better: the majority recover after a few months or a few years.

The internationally recognised case definition (CDC '94 criteria) is the standard.

Knowledge concerning the development and causes of CFS is inadequate, the symptoms are variable and not very specific, and there also are no straightforward diagnostic tests. One solution in instances of this type is a case definition (i.e. a consensus-based description of the disorder). The internationally recognised case definition of CFS is the one formulated by the US Centres for Disease Control (CDC) in 1994 (see panel). In order to

US Centres for Disease Control Case Definition of Chronic Fatigue Syndrome, 1994

Diagnostic criteria: At least 6 months of persistent or recurring fatigue for which no physical explanation has been found and which

- is of new onset, that is to say it has not been lifelong
- is not the result of ongoing exertion
- is not substantially alleviated by rest
- severely limits functioning

in combination with four or more of the following symptoms, persistent or regularly recurring over a period of six months and which must not have predated the fatigue:

- self-reported impairment in memory or concentration
- sore throat
- tender cervical lymph nodes
- muscle pain
- multijoint pains
- headache
- unrefreshing sleep
- post-exertional malaise lasting 24 hours or longer

Exclusionary criteria

- any medical condition that may explain the presence of chronic fatigue
- a psychotic, major or bipolar depressive disorder (but not an uncomplicated depression)
- dementia
- anorexia or bulimia nervosa
- alcohol abuse or the use of drugs
- severe obesity

broaden our understanding of the nature and course of the disorder, we recommend that the CDC-94 definition be applied by researchers and practitioners alike – which is not to say, however, that the research and treatment of chronic fatigue should be confined to those patients who satisfy the CDC-94 criteria.

Any case definition is a construct for the benefit of practitioners, with arbitrary elements and limitations. For example, the existence of criteria does not necessarily connote a disease (in the sense of a specific, well-defined pathological process) that corresponds to these criteria. That remains to be established. Limitations of the CDC definition lie in the fact that the symptom criteria have not been validated and that the definition was primarily formulated for scientific research purposes.

There are probably between 30,000 and 40,000 CFS patients in the Netherlands.

The Committee emphasises that this is no more than a rough estimate. Reliable epidemiological data concerning CFS are scarce. Variations in the applied case definitions and the fact that not all patients consult a general practitioner are to blame for this. The majority of the patients are adults, but the disorder also occurs in the young. Around three quarters of sufferers are women.

No prevalence figures are available for Belgium, France and Germany. Dutch data concerning CFS in people of different ethnic origin are likewise unavailable, nor is there any research into the question of whether CFS is more prevalent in certain occupations than in others.

The doctor-patient relationship influences the course of fatigue complaints.

The outcome of such complaints as chronic fatigue is determined not only by doctors' instrumental actions, but also by their affective actions. It is important that doctors should take both the complaints and the patients seriously, invest in establishing a good relationship with them, allow them to express their emotions and explain the different aspects of fatigue.

Rigid preconceptions concerning physical and psychological causes put pressure on the doctor-patient relationship and obstruct research progress. Physical and psychological causes of CFS are frequently considered as polar opposites. A question that patient organisations are again and again confronted with is whether CFS is a neurological or a psychiatric disorder. This is, in fact, a spurious question. The neuroscientific research conducted in recent decades has revealed that psychology (e.g. behaviour) and biology (e.g. biochemical processes) are, as it were, two sides of the same coin. It is not a question of either one or the other, but of both together. Acceptance of this idea fosters the necessary common perspective on the part of the doctor and the patient, and offers researchers fresh insights into the causes of CFS.

Drawing a distinction between aetiology and pathophysiology lends clarity to discussions over the causes of CFS. Whereas aetiology is concerned with the cause of a disorder (i.e. what circumstances make a person develop CFS?), pathophysiology is concerned with the manner in which it arises (i.e. what biological disturbances are involved?). This distinction is crucial, however, when it comes to sorting out the large body of data, which vary in their level of abstraction and are derived from different fields of research, and translating findings into new hypotheses for research. It also provides a good starting point for discussions with patients.

The aetiology of CFS is influenced by a range of factors. Aetiological factors are commonly broken down into the following categories:

- *Predisposing factors.* Factors that make one individual more likely to develop CFS than another: familial (possibly genetic) factors, sex, learning history (experiences in early youth), personality, lifestyle and physical activity.
- *Precipitating factors.* Factors that can provoke CFS in susceptible individuals: acute stress, both physical stress (a serious injury, chronic sleep disturbances, an invasive surgical procedure or an infection) and situations of acute psychological stress.
- *Perpetuating factors.* Factors that impede recovery: physical inactivity, periodic over-activity, incorrect or unhelpful notions about the disorder, increased attention to physical sensations, inappropriate behaviour on the part of care providers, and social factors. Despite frequent claims to the contrary, chronic infections are not a perpetuating factor.

Models derived from the modern neurosciences form a good basis for pathophysiological research into CFS. CFS is one of the many syndromes with physically unexplained symptoms (other examples being fibromyalgia and irritable bowel syndrome). Pathophysiological research has hitherto focused mainly on those aspects that distinguish a given syndrome from other syndromes, though this approach has proved rather unproductive. The syndromes frequently occur in combination and display striking similarities. The pattern of symptoms associated with these conditions points to a disruption of control systems or of communication between control systems. Marked deviations in individual parameters are rare. The disruption appears to have its origins in the same basic pattern: a long-term and serious disturbance of the balance between emotional endurance and stress. Situations of chronic stress cause an imbalance of homeostatic mechanisms (e.g. energy balance and recovery processes) and alter sensitivity to pain and perception. Well-substantiated explanatory models derived from the modern neurosciences support this line of argument. These models afford an opportunity to bridge the gulf between somatic and psychological factors and form a sound basis for the development of new research hypotheses.

‘To stand still is to move back’ is the starting point in the management of fatigue complaints. Fatigue is, generally speaking, a signal to take things easier, but absolute rest is not beneficial and ultimately perpetuates the complaints. Patients with fatigue complaints should be advised to do whatever they still can, if necessary after having adjusted their work and/or working hours in consultation with either the occupational physician or – if the patient is unemployed – with other members of the household. Although a patient may well be (temporarily) unfit to perform his job, this need not mean that he is totally unfit for work. Fatigue frequently has an ‘everyday’ cause such as overwork or stress. Recovery is dependent on the patient facing up to these causes and actively addressing them. Rest by itself can reinforce avoidance tendencies, prolong sick leave and set in motion a process of social marginalisation.

Openness is essential when assessing fitness for work. This is important in order to avoid (where possible) the many misconceptions and differences of opinion that surround CFS patients’ fitness for work. One such misconception is the belief that the diagnosis and the cause of a disorder are what determine a person’s entitlement to absence from work or to receive social security benefit. It is the responsibility of occupational physicians and insurance physicians to explain that manifestations and consequences of illness are what matters, and that the assessment of fitness for work hinges on three issues:

- *General functioning:* Someone who, as a result of disease or infirmity, generally speaking cannot function is also unable to work. If he is, in fact, able to function to some extent, then certain forms of work will also soon be possible.
- *Consistency:* of reduced fitness for work can only be said to apply where there is a logical and consistent relationship between illness, limitations and a decline in work participation. If that is not the case, then there is no incapacity due to illness.
- *Problem analysis:* People’s stress load is only partly determined by working conditions. In addition to the medical aspects, an insight into the psychosocial context plays an essential role when forming an opinion on an individual’s fitness for work.

Proper patient care requires guidelines for the diagnosis and support of patients with fatigue complaints. There is great variation in the diagnosis and support of patients with fatigue complaints (and especially those with CFS). This applies both to the procedures followed by general practitioners as well as to those adopted by occupational and insurance physicians. Patients have a right to uniform treatment and procedures. The Committee explains the broad principles to be applied with fatigue complaints (and especially CFS). Translating these into policy guidelines is a matter for the Netherlands Society of General Medical Practitioners (NHG), the Institute for Healthcare (CBO), the Association for Medical Services in Industry (NVvAB), and the

Association for Insurance Medicine (NVVG). First of all, however, it is imperative that they should come together to agree on a common set of basic principles and on collaboration in this area.

Special attention is required for CFS in young people. Youngsters with CFS are frequently no longer able to follow a standard school curriculum, do homework, cycle or walk normal distances, or take part in sports and other social activities. CFS threatens normal, age-appropriate development, such as the pursuit of autonomy and identity, and separation from one's parents.

Doctors are advised against making the diagnosis of CFS before a child reaches the age of 10, since the presentation of symptoms at that age is, to a great extent, dependent on the way in which they are interpreted by the parents. Non-functional attributions by the parents can stand in the way of the youngster's recovery. It is therefore advisable to separately speak with the patient and the parents. This also fosters a feeling of autonomy in the youngster.

Cognitive behavioural therapy (CBT) is an effective treatment. There is no shortage of treatments for CFS – especially on the internet – but few have been tested for efficacy. The systematic reviews that have been conducted of interventions for CFS reveal CBT to be an effective treatment.

CBT has been successfully applied in several places to patients with CFS. The therapeutic effect has proved to be long-lasting and no deterioration has been shown to occur as a result of this therapy. However, CBT is not a panacea. The therapy is intensive, makes great demands on the patient and has a success rate of around 70%. Success means that the patient is restored to a more or less normal level of functioning. However, many successfully treated patients will no longer return to their former level of functioning, but have learned to adapt to the constraints imposed by their illness. Some people experience this as a loss that they must accept. Self-efficacy is an essential element in CBT. It is extremely important to motivate patients to undergo the therapy. CBT is inextricably bound up with a gradual stepping-up of physical activity ('graded exercise training', GET). Whether GET is effective without any form of CBT is being investigated at this moment in the UK.

The patient population is diverse and not everyone benefits from CBT according to the current protocol. The development of additional, less intensive variants of CBT will make it possible to bring supply more into line with demand.

Treatment capacity needs to be expanded. CBT for CFS patients is only available on a formal basis in Nijmegen, and there are around 300 patients on the waiting list. In order to provide proper patient care, treatment capacity needs to be expanded, for exam-

ple by establishing centres along the lines of the Nijmegen model or centres for the research and treatment of stress-related conditions. One problem hampering efforts to scale up this capacity is the fact that very few psychologists possess the requisite expertise. More attention needs to be given in the training of psychologists to the use of behavioural therapy to treat physical complaints (not only for the treatment of patients with CFS but for all patients with physically unexplained complaints).

Sound scientific research into CFS requires a multidisciplinary approach. Large gaps exist in our knowledge of CFS. Countless unresolved questions require new scientific research. The search for a single, specific cause of CFS has proved fruitless and will probably not lead to an explanation of the range of symptoms and associated phenomena. If we are to succeed in actually expanding our understanding of the causes and the treatment of CFS, then a multidisciplinary approach will be required in which the interrelationships between the various factors are studied.