

# ME/CFS

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## Executive summary

Health Council of the Netherlands



ME/CFS is a serious chronic disease that substantially limits the activities and quality of life of people suffering from it. Patients with ME/CFS have been campaigning for recognition and better treatment of their condition for years. In response to a citizens' initiative, the Lower House asked the Health Council to provide insight into what is scientifically known about the disease and what developments are to be expected. The ME/CFS Committee investigated this subject. This committee consisted of experts from various fields and patient representatives. Different views on ME/CFS were represented.

### **The disease: symptoms, pathogenesis and diagnosis**

People with ME/CFS suffer from a substantial reduction in the ability to engage in pre-illness levels of social and personal activities, which lasts longer than six months. They suffer from severe fatigue that is not caused by exertion and is not substantially alleviated by rest. Minor physical or mental effort can already exacerbate

the complaints. Almost all patients have a disturbed sleep. Neurocognitive problems (concentration, memory, comprehension) and orthostatic intolerance (such as dizziness, nausea, headache, weakness) are also common. In addition, pain, fever and enhanced sensitivity are symptoms that may occur.

The committee notes that little is known with certainty about the pathogenesis of the disease. Various body systems can be involved, such as the immune system, metabolic system, cardiovascular system, central nervous system, neuroendocrine system, microbiome and genome. Therefore, it is called a 'multisystem disease'. It is unclear how these systems interact in the development of ME/CFS. There may also be several diseases that fall under ME/CFS.

The diagnosis of ME/CFS is made based on symptoms. There is no agreement in the scientific literature on the criteria that should

apply. The committee believes that the diagnostic criteria proposed in 2015 by the Institute of Medicine (currently: National Academy of Medicine) provide for the time being a good tool for practitioners.

As with the pathogenesis, there is little to say with certainty about the prevalence and the course of the disease. Presumably, there are 30,000 to 40,000 patients in the Netherlands with ME/CFS, most of whom are female. Their chance of spontaneous recovery is low.

### **Treatment of ME/CFS**

Treatment of ME/CFS cannot be aimed at addressing the causes of the disease, due to lack of knowledge. However, sometimes it is possible to relieve the symptoms of the disease. It is important for the physician and patient to explore the options together. For example, patients may benefit from medicines such as sleeping pills, analgesics and agents that positively influence intestinal motility. The



majority of the committee believes that cognitive behavioural therapy (CBT) can also be considered as an option for treatment. Four members take a different view. They indicate that many patients with ME/CFS have negative experiences with the therapy and object to the form of CBT for ME/CFS applied in the Netherlands.

### ME/CFS in practice

Many physicians have preconceptions about ME/CFS and about the patients who suffer from it. They are inclined to suggest that the disease is psychological. As a result, patients do not experience empathy from their physicians and feel that they are not taken seriously, which does not improve their health and reinforces their social isolation. A survey from the Dutch ME/cfs Association reveals that 75% of the patients rate the quality of care as highly inadequate. Patients also frequently experience problems in the assessment of claims on income, care and other provisions because the limitations of their

functional capabilities are not recognised. This is partly due to misinterpretation of the rules. Sometimes patients are found to be fit for work because an insurance physician believes that no physical abnormality can be proven or an unequivocal diagnosis cannot be made. However, according to the applicable rules, these are not good reasons to disregard someone's limitations. The point is that there is a consistent set of impairments, limitations and disabilities. The committee reiterates that ME/CFS is a serious disease that, by definition, generally leads to substantial restrictions on functional possibilities. Furthermore, the committee believes that patients must be free to decide whether to have CBT – or, in the Netherlands not or hardly used as a self-standing treatment for ME/CFS, graded exercise therapy (GET) – as part of their treatment. Not choosing for CBT or GET may not lead to the judgement that the patient misses his chance of recovery or is to blame for not cooperating in his/her recovery.

### Conclusions and recommendations

Scientific research on ME/CFS is needed to serve patients better. Meanwhile, it is essential that ME/CFS is a diagnosis that is made in practice, that patients' disease symptoms are taken seriously and treated as well as possible. Their functional limitations must also be fully recognised in the assessment of claims on income and other provisions.

The committee recommends the following.

- The Minister of Health, Welfare and Sport should commission ZonMw for a long-term, substantial research programme on ME/CFS. The research would primarily focus on substantiation of the diagnosis, pathogenesis and treatment of ME/CFS.
- Those responsible for training and further education of healthcare providers should ensure that education and training highlight the serious, chronic, multisystem disease ME/CFS and what healthcare providers can do for patients with this disease.



- The Federation of University Medical Centres and the healthcare insurers should designate a few university medical centres that – in collaboration with patient representatives, other hospitals, GPs, rehabilitation centres, sleep centres and other healthcare providers in the region – will open an outpatient clinic for ME/CFS, with associated healthcare networks and research groups.
- Medical disability assessors within the context of private and social disability insurance, the Social Support and Provision Act and the Long-term Care Act should recognise that ME/CFS is a serious disease that is accompanied by substantial functional limitations, and they should not regard a patient's decision to forego CBT or GET as inadequate recovery behaviour.



The Health Council of the Netherlands, established in 1902, is an independent scientific advisory body. Its remit is “to advise the government and Parliament on the current level of knowledge with respect to public health issues and health (services) research...” (Section 22, Health Act).

The Health Council receives most requests for advice from the Ministers of Health, Welfare and Sport, Infrastructure and Water Management, Social Affairs and Employment, and Agriculture, Nature and Food Quality. The Council can publish advisory reports on its own initiative. It usually does this in order to ask attention for developments or trends that are thought to be relevant to government policy.

Most Health Council reports are prepared by multidisciplinary committees of Dutch or, sometimes, foreign experts, appointed in a personal capacity. The reports are available to the public.

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