

# A review of the current knowledge status for Myalgic encephalomyelitis/chronic fatigue syndrome, ME/CFS

## Summary

Socialstyrelsen (National Board of Health and Welfare) has been tasked by the Government to review the knowledge status and examine the prerequisites for providing support to healthcare professionals through guidelines and insurance medicine decision support (FMB) with regard to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Patients with ME/CFS have autonomous, cognitive and immunological symptoms. Typical symptoms are tiredness or fatigue, influenza-like symptoms with a feeling of fever, general pain in joints and muscles, and disturbed sleep. The symptoms can be exacerbated by physical or mental exertion and the worsened state continues for more than 24 hours afterwards (post-exertional malaise, PEM).

Descriptions of this disorder have existed since the 1950s. There are many hypotheses about what causes ME/CFS but up to now it has not been possible to prove any of them. Research is being done but currently there are no biomarkers for diagnostics, nor any medical treatment. The prevalence of ME/CFS depends on what criteria have been used and how data have been gathered. The figure varies from 0.1 percent to 6.4 percent of the population.

When it comes to opinions regarding the cause of ME/CFS and its treatment, there are different standpoints: those who support a bio-medicinal view and those who support a biopsychosocial view. The question is whether the disorder should be explained purely through pathological biochemical and physiological findings, or whether mental and social factors must also be included in order to be able to explain certain medical problems.

ME/CFS is an exclusion diagnosis. There are no biomarkers. Instead, the diagnosis is made with the help of diagnosis criteria which are only used when other physical or mental causes of the symptoms have been excluded. There are several different diagnosis criteria which overlap one another in part and there is no international consensus about them. There are also different standpoints regarding what illnesses/disorders are to be excluded before the diagnosis is made, and what comorbidity may exist.

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Patient representatives have pointed out the need for equal healthcare, guidelines and specialist care for this group. Patients' experiences of healthcare vary both at individual level and according to geographical location in Sweden. Patients have also pointed out the need for more understanding treatment by healthcare professionals and for coordinated interventions.

An overview of qualitative studies from SBU (Swedish Agency for Health Technology Assessment and Assessment of Social Services) regarding how adult patients diagnosed with ME/CFS perceive the care they are given shows that diagnosis, advice and support are essential. The patients have described the journey to a diagnosis as being cumbersome and that they have had to fight in order to get help. They feel that people are not interested in their problems and that healthcare professionals at primary care level do not believe the illness exists.

Socialstyrelsen's dialogue with the healthcare professional groups in question has shown that there is a certain demand for national guidelines and insurance medicine decision support. However, specialists in general medicine seldom meet patients with ME/CFS, and no specific specialist field feels they have special responsibility for this patient group. This shows that these patients do not have any proper "home" in the healthcare system.

The systematic overview conducted by SBU indicates that the scientific supporting documentation for the interventions offered in the relevant studies is insufficient. In addition, Socialstyrelsen's survey shows that it is not possible to draw conclusions about the benefit of those interventions on the basis of proven experience since the prerequisites for consensus among clinical experts in this field are lacking. Therefore, Socialstyrelsen's assessment is that it is currently not possible to draw up national guidelines with general advice in this area, as requested by the healthcare sector.

Moreover, the basic preconditions for further work on insurance medicine decision support (FMB) for the diagnosis of ME/CFS do not exist. Socialstyrelsen emphasises that being on sick leave can be a correct intervention but no general recommendations can be given.

Considering the current situation as regards evidence, it is crucial that the interventions offered to each patient diagnosed with ME/CFS or similar symptoms must be individually adapted for the patient in question and evaluated. This patient group is in need of care measures to alleviate symptoms and improve quality of life. For the individual patient, different evidence-based interventions can be offered on the basis of the symptoms presented in the patient in question, for example, measures for pain or sleep disturbances. The care provider must be perceptive and take all aspects of the patient's medical problems and healthcare needs into account.

The systematic overview and the qualitative report from SBU and this review by Socialstyrelsen can provide the healthcare sector with an up-to-date picture of the knowledge status, and indicate the need for more interventions and research for this patient group. Socialstyrelsen's intention is to facilitate a dialogue between representatives for different professions in order to increase consensus in the long term.