

15 oktober 2019

Report Survey Summary 'Zorg voor ME' ('Care for ME')

August 2016

Read the report 'Zorg voor ME' <https://www.me-cfsvereniging.nl/sites/default/files/documenten/Rapport%20Zorg%20voor%20ME.pdf>

Healthcare for ME-patients in the Netherlands is in bad shape. This has been demonstrated in the report 'Care for ME' which was presented on 12 September 2016 to Dianda Veldman, president of the Dutch Federation of Patients in Utrecht. The Dutch ME/cfs Association wrote the report to call for attention for the extremely problematic situation of the care for this chronic illness.

The care for ME is ranked by Dutch patients with an average score of 2.3 out of 10. An astonishing low score that is - as indicated by a large-scale survey - largely due to a lack of knowledge about the illness with physicians and a lack of effective treatments.

Inexpert physicians

The experiences with general practitioners and specialists are often very bad. Two-thirds of the patients experience a huge lack of expertise in the field of ME with general practitioners and specialists. Moreover, it often takes a long time before the diagnosis is being made. Almost half of the patients had to wait more than four years to get diagnosed.

Sickening treatments

As least as shocking are the effects of the standard treatments: Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET). For 52% of the patients, CBT has had a negative effect on their health. Combined with GET this was the case for 63%.

Summary

The ME/cfs Association is a Dutch patient association that serves the interests of patients with Myalgic Encephalomyelitis (ME). This illness, also called chronic fatigue syndrome or CFS, is a severe, chronic and complex multi-systemic illness, that often drastically impairs the life and activities of patients. The members of the association often report that they experience huge problems. These are caused by the debilitating nature of the illness itself, but also by the way care for ME patients is provided in the Netherlands.

These signals have led the Dutch ME/cfs Association to research the experiences with healthcare in the Netherlands by means of a survey. The survey was distributed by email in 2015 among more than 400 members of the Dutch ME/cfs Association. In addition it was distributed through the association's website and Facebook. A total of 842 people have responded, of which eventually 629 met the selection criteria of the 2015 report Beyond Myalgic Encephalomyelitis; an IOM report on defining an illness by the Institute of Medicine (IOM).

ME is a seriously debilitating condition, as is shown by the survey. Two-thirds of the respondents are, as a consequence of ME, mostly confined to their homes or even bedridden. Fatigue is definitely not the only symptom. Also, complaints about Post-exertional Malaise (PEM), non-refreshing sleep, cognitive impairments, orthostatic intolerance, pain in muscles or joints, sensitivity to stimuli and gastrointestinal complaints, cause large functional impairments and a high disease burden.

The outcomes of the survey shows that respondents are highly dissatisfied with healthcare. They rate healthcare for ME in the Netherlands with only a 2.3 on a scale from 0 to 10. The opinions on general practitioners and general specialists are predominantly negative. The vast majority, 80% of the patients, had to wait more than a year to before they got diagnosed. More than 40% had to wait even more than four years. The majority of the patients experience a lack of expertise in general practitioners and specialists.

The treatments that are most regularly offered, i.e. cognitive behaviour therapy (CBT) and the combination of CBT and graded exercise therapy (GET), have had a negative to very negative effect on the health of the majority of patients. Only a very limited group benefitted, respectively 11% and 3%.

The results of the survey show a significantly higher appreciation for physicians that are specialised in ME/CFS. 70% of the patients is positive about their expertise and 38% indicates the treatment has had a positive effect on their health. There are only a limited number of these specialised physicians in the Netherlands. Therefore patients have to travel far to see a specialised physician, while their ability to travel is limited or they are even not able to travel at all.

In the field of participating in the labor process, the invalidating nature of the illness becomes clear again. Of the respondents that had a job before they became ill, 60% worked more than 32 hours a week. At the time of completing the survey, the vast majority of respondents were not working.

If the respondents were still working, they did not work for more than eight hours a week. Still less than half of them received a disability benefit. There is no relationship between the severity of the illness and receiving a benefit. The financial situation of a lot of respondents has deteriorated.

From the reactions to the open question 'Do you have wishes regarding healthcare for ME in the Netherlands?' it becomes clear that the call for acknowledging ME as a biomedical illness is strong. There is a need for researching the cause of ME and for effective treatments.

Furthermore respondents indicate that there is a need for more knowledge and expertise with physicians and specialists. There is demand for an approach that is not based on psychological treatment. A lot of respondents ask explicitly to abolish CBT as a treatment method for ME. Respondents also experience a lack of financial support and practical help.