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Photo: Einar Nilsen

Chronic fatigue syndrome – or myalgic encephalomyelitis, which is another name for this disorder – is a casteless disease. We do not know where it belongs, and few want to engage with it.

So many things we do not know

Kjersti Kirsner is caring for her 37-year-old journalism-trained son for the tenth consecutive year (1). Across the hall outside his darkened bedroom lies his 35-year-old sister. She too has spent long periods bedridden and completely intolerant of sound and light. The youngest son, 28 years old, can spend some time in the company of other people, but needs to use an electric wheelchair to conserve his energy. Three adult children in one and the same family have the same diagnosis – chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). To date, the health services have been unable to establish the reason for the siblings' illness or to help them recover, according to the *Aftenposten* daily (1). How is this possible?

The world is like clockwork, Descartes proposed (2). If we study the individual parts, we will be able to understand the workings of the entire machinery. Modern Western medicine has largely been shaped according to a similarly reductionist model. Today, many diseases can be explained at the molecular level. The various branches of medicine are becoming increasingly specialised. We have developed detailed classification systems for diagnostics and identification of diseases. How should we doctors react when a condition – despite all our efforts – cannot be unambiguously classified or explained? And how does this affect the patients, who in our highly specialised health services are at best provided with a controversial diagnosis based on exclusion of other conditions?

In an encounter with these patients, someone who tries to help will have to acknowledge his or her powerlessness. It will thus be tempting to refer the patient to yet another specialist. Many patients recount how nobody in the health service takes responsibility for following them up. Some experience being met with disbelief. Perhaps it is easier to doubt the patient's story when we are unable to fit together all the pieces of the puzzle? As doctors, we are used to the availability of solutions, and that our job is to find it. But are we sufficiently well equipped to deal with uncertainty and the absence of a final answer? The cleverness of doctors can be their Achilles heel, Erlend Hem wrote in an editorial in the Journal of the Norwegian Medical Association no. 21/2013 (3). Patients diagnosed with chronic fatigue syndrome/myalgic encephalomyelitis challenge our intellect, our professional self-image and our empathy.

The frontlines are clearly drawn up and tempers run high in the forums where this condition is discussed. The British psychiatrist Simon Wessely received death threats because of his opinions and research on it (4). Other researchers are winning accolades. The planned Norwegian multi-centre study on treatment of chronic fatigue syndrome/myalgic encephalomyelitis with rituximab has

triggered a crowd-funding effort under the auspices of the Norwegian ME association, as well as widespread engagement among patients, their next of kin and others nationwide (5). In a recent op-ed in *Aftenposten*, Henrik Vogt refers to this as «patient activism» (6). He believes that a struggle over the causes of the disease is unfolding. The hardest battles are fought by those who are in favour of a so-called biomedical disease model and those who emphasise biopsychosocial causes. In a research field where knowledge remains so scarce, we should welcome such controversy, since academic debate and disagreement are required to gain new insights. However, it is of no benefit to anybody to have an environment which is so conflict-ridden that many choose to shy away from it. Some years ago, when I entered the position of senior consultant at the CFS/ME centre at Oslo University Hospital, well-meaning colleagues warned me, saying that career-wise it would be a dead end.

Those of us who have worked with chronic fatigue syndrome/myalgic encephalomyelitis know that the disorder is real and that it is not «a matter of will». Many patients attempt almost any kind of therapy to regain the life they had before the illness. Some spend large amounts of money on alternative therapies. This notwithstanding, conflicts between the patient and the health services are most likely to occur with regard to the choice of treatment. This is a common occurrence in a field where belief, rather than knowledge, reigns. However, where belief rules, there should also be room for doubt. We need to take patients seriously when they tell us what kinds of therapies are helpful and what kinds are ineffective. At the same time, as doctors we cannot unconditionally endorse insufficiently documented forms of treatment that at worst may entail serious adverse effects, even though the patient may want to try them.

Chronic fatigue syndrome/myalgic encephalomyelitis may possibly be explained in terms of immunological mechanisms. It may be caused by disorders of the brain and the nervous system. We may be dealing with a systemic disease that nobody has yet understood fully. Or perhaps the answer lies somewhere beyond the limits of our imagination. Against this background it is essential for researchers – without any risk of personal harassment or censorship – to be able to present various hypotheses for scientific testing. We need to protect those who dare step into uncharted territory and devote time and effort to things that are poorly understood, not knowing where they will lead. More knowledge is the only route to the acceptance and understanding of chronic fatigue syndrome/myalgic encephalomyelitis that the patients require – and the treatment that they so sorely need. Scientific progress costs time and money – but we have no other alternative.

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References

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