

I have lost faith in Danish public healthcare

The illness ME has cost me my career and my family's savings. Why won't the Danish public healthcare system acknowledge it?

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The second seizure-like episode was just getting underway. Once again I was losing contact with my muscles and the outside world began to spin. Even though I would rather not, my parents decided it was time to get me to the hospital. They were frightened.

My hands and jaws had started to shake uncontrollably. My temperature fell to 34.4 degrees centigrade. I was getting muscle cramps in my arms and legs. And I did not manage to speak in words of more than one syllable: "Mom... cold... help...".

I was awake and clear-headed but was only capable of observing my body's movements, not controlling them. It felt as if I were looking through a tiny crack in the wall of my prison cell, incapable of moving by my own free will.

We arrived at the hospital and my dad ran for help to get me out of the car, as by then I had lost all control over the larger muscles of my body.

At the arrival, I remember one of the nurses asking what had happened, to which my mother replied: "She has ME." The nurse said: "I have no idea what that is!"

Her reply triggered something primal in me. An anger, which I had kept inside for the then seven years I had suffered from this serious disease without ever meeting any doctor or other health professional who had taken it seriously or understood what this illness was all about.

This in spite of the fact that ME (Myalgic Encephalomyelitis) has been listed by the WHO (World Health Organization) as a neurological diagnosis since 1969. It is as common —some statistics claim even more common— as equally disabling illnesses such as multiple sclerosis or Parkinson's disease. Estimates point to the existence of about 14,000 ME patients in Denmark.

When the doctor on duty entered the ward, the first thing he asked me was whether I suffered from anxiety.

I answered him angrily and in my one-syllable words: “No... ME...”.

I did not have the energy to tell him that, in Denmark, ME is labeled as Chronic Fatigue Syndrome, a name which entails a stigma, fought by ME patients for over 30 years, because the label implicitly diminishes the serious character of the disease, including painful symptoms from mitochondrial, neuroendocrine, immunological, and metabolic dysfunctions. Those dysfunctions have been confirmed through biomedical research.

He looked bewildered, so my mother gave him a handout from the Danish ME Association explaining the disease.

The doctor took the handout and promised to read it, but he still asked me whether I had arrived at my diagnosis by means of Google search. I looked at him in puzzlement and said, very slowly in my newfound one-syllable language, that a medical specialist and two other doctors had given me this diagnosis. A diagnosis that it had indeed taken me six years to get.

Hospital staff kept me under observation for many hours but they did not know what to do, even though treatments exist to alleviate the symptoms of ME. However, I could muster neither the voice nor the energy to fight for those. Then I was sent home.

Numerous patients who suffer from this disabling disease have lived through this type of scenario all over the country: they seek help but often find themselves in situations where their own knowledge of their body and illness surpasses that of the health professionals who are supposed to help them. In effect, many people avoid seeking care.

An investigation of severely ill ME patients (around 25 percent of ME patients are estimated to fall into this category) by the Norwegian ME Association points to the fact that many patients have had such negative experiences with public health services that they no longer dare to reach out to them. Many open answers emphasised that “it is better not to get any help at all rather than a type of help which induces stress and relapses on the sufferer.” Even so, in Norway, conditions for ME patients are much better than in Denmark.

The worst (or best?) of all this was the fact that within the ME world, my visit to the hospital was among the most positive:

Neither myself nor my parents were met with suspicion by doctors thinking that ME does not exist or is not a physical illness, examples of which we have unfortunately seen many, including the case of Marie Louise from the island of Fanø, whom we could read about in the Politiken daily newspaper, or that of Karina Hansen, documented by the DR public broadcasting service in the documentary ‘Psykiatriens dilemma’ (‘The dilemma of psychiatry’).

Still, this hospital visit resides in me as a trauma. The experience of having to defend myself and my body, when in a state of barely being able to communicate, was excruciating. It is a trauma of not being seen or listened to.

For several weeks following this episode, my mother had to help me shower and cut my food into small pieces. My father had to help me sit in an office chair with wheels in order for me to get to the bathroom. I still had difficulties speaking and was suffering from excruciating pains, flu-like symptoms, feelings of being cold and sweaty at the same time, severe stomach cramps when eating, and a non-functioning brain.

I was experiencing post-exertional malaise, or PEM, a symptom which is unique to ME patients.

PEM is the cardinal symptom of ME. If you are not experiencing PEM, then you do not have ME, according to internationally recognised criteria, also known as the Canada criteria. The Danish Health Authority still does not recognise these criteria in the same way that their Norwegian or Swedish counterparts do. That is absolutely unacceptable.

The worsening of symptoms entailed by PEM can take up to 72 hours following exertion to present themselves and, as such, are rarely witnessed by doctors or other health professionals.

The symptoms of PEM include activation of the immune system, flu-like symptoms, loss of thermoregulation, neuromuscular fatigue, burning pains, extreme vertigo, cramps and tremors, reduced cognitive function —such as losing the ability to speak or find words— and digestive problems. Common to all symptoms is the fact that they were not as severe prior to exertion. PEM is often described as a ‘disease within the disease’.

The features of PEM are confirmed in biomedical research. In the 10 June 2019 issue of the weekly Danish Medical Journal, a group of Danish researchers provided a summary of research on ME and PEM.

What triggers PEM varies greatly on an individual level and includes both physical as well as mental efforts.

For mild ME patients, PEM may be triggered by staying for too long at a birthday party. For those in the moderate category, it may be triggered by a trip to the doctor’s. For me, a severe ME patient, PEM is triggered by simply brushing my hair or by being in an upright position for two minutes, instead of the one minute I can usually tolerate. This opinion piece, which I have been writing intermittently during short sessions since 2017, has cost me innumerable episodes of PEM. For those in the very severe category, PEM may be triggered by simply turning over in bed or by the slightest touch.

PEM is serious. In my experience so far (which I share with many ME patients), every big 'crash' leads to a portion of my level of functioning being taken away from me, and each time I have to accept the ripping away of another chunk of my already constrained life.

Today, I can walk 5-10 metres before cramps render my muscles non-functional, or I get severe angina, or breathing becomes almost impossible.

I can take 300 to 900 steps daily. I can stand upright for about one minute at a time, and on certain days I completely lose the ability to walk or speak.

But despite this serious symptom, and despite an increasingly large pool of research showing physiological changes after exercise in ME patients, PEM is absent from all documents and web pages about ME from the Danish public health services. I have never met a doctor within the public healthcare system who had prior knowledge of the disease. This means that I and many other patients risk being offered help that makes us even worse.

If the authorities had opted to follow the lead of science, acknowledging the existence of PEM, they would also acknowledge the fact that Graded Exercise Therapy (which implies continuously increasing one's level of activity beyond what is normally tolerated), still the ME treatment of choice by the Danish Health Authority, has not only been ineffective but also harmful.

For decades, patients have complained about deterioration following Graded Exercise Therapy regimes. Patient studies from the ME Associations of Norway, the UK, and the Netherlands, conclude that among the more than 1,600 combined participants, between 53 and 74 percent experience a worsening of their illness following this 'treatment'.

Graded Exercise Therapy is based on research studies that include other 'fatigue syndromes' instead of strictly focusing on ME.

Both a report on ME from the Swedish government agency SBU (The Swedish Agency for Health Technology Assessment and Assessment of Social Services) and a revision of a Cochrane review on Graded Exercise Therapy concluded that no evidence exists of the efficiency of these treatments when using recent diagnostic criteria, such as the Canada criteria, and that evidence of side effects is lacking. Even when using outdated criteria, which do not include PEM, the effects are small.

In January 2018, Heidi Stensmyren, head of the Swedish Medical Association, was interviewed about the situation of ME patients in Sweden.

She acknowledged ME as a serious disease and made the case for more resources to be allocated to research, for new findings to be implemented more quickly, and for medical professionals to receive additional training based on new research.

The Swedish Medical Association in partnership with ME researchers now offer courses to help practitioners distinguish between ME (a neurological illness when diagnosed using the Canada criteria) and fatigue syndrome (a stress-related condition with chronic fatigue presenting as a symptom). This distinction does not exist in the Danish public healthcare system, resulting in misdiagnoses and mistreatment.

I dream of the day when Danish doctors publicly acknowledge ME as the serious and disabling disease it is. And when they say enough is enough and demand more resources for biomedical ME research and training.

And I dream of doctors and other health professionals receiving comprehensive and up-to-date information on both the scientific and phenomenological aspects of ME, allowing me and other ME patients to safely seek help.

But I have lost faith that this will ever take place in Denmark. I have lost faith in the Danish public healthcare system. I have felt safer avoiding this system.

My father, who had originally retired, had to find work again to raise funds for the treatments that help alleviate my symptoms.

At last and after much effort, I have succeeded —outside the boundaries of the public healthcare system— to arrange to have intravenous saline treatments given at home several times a week, and to receive medical advice via Skype from a private ME practitioner. These treatments allow me to at least walk to the bathroom on my own and speak normally, as well as helping to ease my hellish pains.

I dread the day when the money runs out or when our domestic solution no longer works.

This was not how I imagined living in a Danish welfare society.

Yes, we have taken one step forward in March 2019 when the Danish Parliament (Folketinget) unanimously decided to acknowledge ME as a physical illness, to remove it from the category of 'functional disorders', and to establish specialised treatment for ME.

But the motion received harsh criticism, particularly from the head of the Danish Medical Association, Andreas Rudkjøbing, who in the 16 August 2019 edition of the Dagens Medicin medical journal claimed the decision rested on "popular trends and gut feelings" that "affect patient safety", and that "patients pay the price." A completely different reaction to the patients' situations than that of his Swedish colleague.

What Rudkjøbing refers to as 'gut feelings' might include, among other things, a 2015 report by the American Institute of Medicine, which, based on the revision of more than 9,000 scientific papers on ME, concluded that ME "is a medical — not a psychiatric or psychological — illness".

Meanwhile, in an advisory report, the Health Council of the Netherlands revised the scientific literature on ME to conclude that ME is a "serious, chronic, multisystem disease" and that, due to a lack of research, no curative treatment is available, although medical treatments to alleviate symptoms are.

Also challenging Rudkjøbing's position is the fact that the Norwegian and Swedish public health agencies have long acknowledged ME as a biological illness and have established centres for specialised care. And biomedical research into ME is taking place at Stanford, Harvard, Columbia, Uppsala, Karolinska, Griffith, Charité, Norwich, London School of Hygiene and Tropical Medicine, Oslo and Haukeland University Hospitals, to name just a handful.

But nothing has come from the Danish parliamentary motion of March last year. ME patients continue to be referred to the five domestic Centres for Functional Disorders, which do not receive children with ME and that you have to be able to attend yourself. This excludes severe and very severe ME patients like myself and Marie Louise.

We cannot physically go there. And even if we could, what is on offer is not relevant. The Centres provide Graded Exercise Therapy, they are not staffed by ME specialists, and no alleviating medical treatments are available.

Due to the lack of progress from the Danish Health Authority, the Minister of Health has now been summoned to an open consultation at Parliament. I hope that this time around people will listen to organised ME patients and biomedical researchers working in the area, in order that new treatment offers that are in line with the latest research and are safe for ME patients be established.

Andreas Rudkjøbing, to you and all others who refuse to acknowledge ME as a serious, disabling, and physical illness, I say: we have already paid the price. We have paid the price for your view of ME as a psychosomatic disease, which has had a deterrent effect on the biomedical research meant to help us. We have paid the price with our quality of life.

According to a 2013-14 investigation by a team of independent Danish researchers, the health-related quality of life of ME patients in Denmark is lower than in the cases of multiple sclerosis, COPD, arthritis, AIDS, lung cancer, and schizophrenia.

I have paid with my once active life working with children's rights in Kenya and Egypt, which has now been exchanged for lying in a darkened room for 22-23 hours a day. I will soon be 38 years old and have to be cared for by my parents.

I have paid with my identity, once defined by a clever brain en route to a PhD position. I have paid with my own and my parents' savings to receive the type of domestic medical help I need.

Andreas Rudkjøbing, you say we should "let science rule from now on." I think so too. And we have to push for the financing of biomedical research and for new findings to be implemented quickly, like your Swedish colleague recommends.

At the same time, we must make sure to draw on the phenomenological knowledge that only ME patients possess. This type of knowledge is key to finding effective and safe solutions for those of us who live with ME.

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