

This is to present the book:

FATIGUE IS THE WRONG WORD: Living with the invisible disease ME/CFS

Edited by Britt-Marie Thurén

Suppose there is a disease that is recognized by WHO and about which research is being done in countries with major research resources. Suppose new treatments for this disease are being tried out. Suppose Swedish citizens are being denied care for it. Suppose further that most of the time they do not even receive information about it from their doctors. Let us also suppose that they sometimes are denied sickness benefits from Social Security, when the disease makes it impossible for them to work. Is this not an outrageous way to treat people?

Well, there really is such a disease. Its official name is ME/CFS (abbreviation for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome), but in Swedish media it is usually called “kroniskt trötthetssyndrom”, which literally means: Chronic *Tiredness* Syndrome, using a word that tends to trivialize the deep fatigue it actually entails.

In order to create debate and describe how the disease works and how the people who suffer from it handle their situation, we have put together a book with personal narratives from nineteen patients. The book also includes two chapters written by two of Sweden’s few specialists on the illness, an overview of ongoing research and a summary of a survey.

In these pages, you will first find a summary of the introduction to the book. Then, as an example, there is an abbreviated version of one of the personal stories. Rose-Marie is representative, since she belongs neither among the sickest patients nor among the very light cases. Next, there are a few illustrative quotes from various other chapters, and finally the index.

SUMMARY OF THE INTRODUCTION

ME/CFS is usually set off by an aggressive infection, for instance mononucleosis, measles or the common flu. It can also develop gradually, but that is less common and it looks like the people to whom this happens have first been weakened in some other way, perhaps by stress. The usual case is that you feel as if you had a bad case of influenza from which you just never recover. You have a low-grade fever, your throat hurts, your body aches all over and above all you feel exhausted in a way you have never felt before. After some time you notice that you get worse, not better, when you try to "pull yourself together" and go back to work, exercise, and carry on with your social life. You also notice that you cannot think as clearly as you used to. You forget things and you might become temporarily confused. Not everyone but very many get serious bowel problems.

What usually happens next is that your doctor either pooh-poohs the whole thing as stress or depression, or else orders a whole lot of tests, which show nothing out of the ordinary. The people who are sick naturally worry about the dreadful way they are feeling and cannot accept that the doctors do not seem to understand that something serious is going on, that you really are ill in a way that has changed your life. If you are sent to a psychologist, you are usually quickly dismissed there, too. "You have no psychological problems," you are told. So you are back on Go, alone with your unrecognizable body.

A specialist was asked the common question if ME/CFS is not, after all, a kind of depression. True, it can be difficult to differentiate the two, since certain symptoms overlap. But not all. This specialist has a simple trick: He asks the patients what they would do if they were to recover the next day. A depressed person does not know, an ME/CFS patient starts writing lists!

Very often you are denied payments from Social Security. Some doctors refuse to sick list you, since none of the tests show anything wrong. Others realize that you really are ill but even so cannot formulate the kind of dead certain certifications that Swedish Social Security requires nowadays. And since most Swedish doctors have not had a chance to learn anything about ME/CFS, neither can they give you a correct diagnosis.

Compared to a neighboring country like Norway or important research countries like the United States or Japan, Sweden is underdeveloped when it comes to research on and care for the victims of this disease. The sick people who are forced, or force themselves, to return to work, almost always

take a turn for the worse and have to stop working anyway after a while, with or without economic benefits. Therefore, it is not uncommon that they become dependent on relatives. At first economically. And, if their health continues to deteriorate, also with the practicalities of every day life. Many cannot manage even simple housekeeping chores. Quite a few are housebound; little by little they lose the ability to leave their homes. Some are bed bound. On the other extreme, there are some who manage to work part time, at least if they are offered suitable conditions. They might for example be able to work full time on some days and part time on other days, if they are allowed to stay at home once in a while when the symptoms intensify.

Whether your case is light or severe, you recognize yourself in the lists of symptoms that are used for diagnosis.¹ The fatigue does not feel like being just tired but more like total exhaustion and it is not alleviated by rest. When you have exerted yourself in some way – for example if you have been forced to attend a training course for work or dared a trip, it might take several days to recover.

The label in FASS (the Swedish pharmaceutical manual) is Chronic Fatigue Syndrome (kroniskt trötthetssyndrom), but various other labels are also given. In the United States and various other countries the abbreviation CFS (Chronic Fatigue Syndrome) is the usual name, while English specialists and patients' associations prefer ME, so a compromise name is ME/CFS. The Swedish patients' association, RME, uses it.

The disease produces many symptoms aside from fatigue. Among the most common are a sore throat, aching muscles or joints, shortness of breath, fever or sensations of fever, dizziness, irregular sleep and waking up tired, not rested, hypersensitivity to drugs, swollen lymph glands. Many are also sensitive to bright lights, noise, heat and cold. It is as if anything that requires the body to make an extra effort becomes difficult to tolerate. The body is busy fighting the illness and cannot handle any extra load, so it reacts defensively, with exhaustion, as if to signal that it must be given a chance to do its job.

Among the most handicapping symptoms is what is usually called brain fog – your memory fails, you find it difficult to concentrate and you may become confused.

¹ To be diagnosed with ME/CFS you have to show a certain set of symptoms. The most important ones are the persistent fatigue, the abnormal fatigability and the abnormally slow recovery after an exertion, but you should also have a number of neurological, immunological and other symptoms. A short version of the criteria can be found on EMEAs website www.euro-me.org

But worst of all is the fatigue. You do not just feel tired, you feel absolutely exhausted. In the stories in this book, the patients give various names to what they experience, and you can tell that the word fatigue actually simplifies the condition dangerously.

A few of us got the idea to write a book about what our lives look like. Two Swedish specialists have each contributed a chapter about the scientific aspects, but this book is not a medical text. We just wanted to describe a piece of reality – our reality – that does not conform with the promises of good health care and social security that are said to be fundamental for our society.

The stories are by both women and men, of all ages and all walks of life. Included are people with various degrees of severity of the disease as well as different experiences in the encounters with the care professions and Social Security bureaucrats. Being ill, we naturally wish to be better understood and better treated. But we also think it is important for information about how the illness expresses itself to reach the medical profession in order to avoid wrong treatment. The disease in itself plus the consequences of mistaken diagnoses and treatment are a source of great costs for both individuals and society.

We would like to see some debate on this!

FROM ONE OF THE STORIES: Rose-Marie Bergmark

I have been ill for seven years, oscillating between hope and desperation. During the first few years I did nothing but sleep, thinking that if only I got to rest long enough, I would get better again. When I began to realize that I would not improve in the short run, I started to console myself, thinking that by fall or next spring, I will certainly be back to normal and back at work. Now I take one day at a time, planning my days and activities. If I don't, I have to rest around the clock. There are days and weeks when I can barely get out of bed; I have to force myself to eat breakfast and take a shower. When I'm asked to do something, I don't function. I can't do anything unless I myself can judge how much time it will take and limit it.

I fell ill on December 27, 2001; I remember it well because we had been invited to the baptism of my husband's niece. I woke up that day with a fever of 39.5 and a severe flu that developed into

bronchitis. I was given antibiotics and the bronchitis disappeared, my fever went down to only about 38 degrees and that is where it has stayed since. I had a tremendous need of sleep. I slept twelve hours a night, and slept also during the day. If I just sat down on the couch I was asleep.

By mid-January I went back to work, even though I was not well; I worked until mid-March 2002, but then I couldn't go on; one day it was just impossible. For weeks I could hardly get out of bed. After that I was sent to the infection clinic at Gävle Hospital. During the month of June lots of tests were made, they showed nothing, I was healthy. My family doctor and infection specialist then decided that I should take it very easy during the summer, which was self-evident to me, as I still had no strength and no energy in my body.

There was no improvement. At the end of the summer, I was just as tired and exhausted as before. My family doctor then found that I was not depressed and not burnt out, so he diagnosed me with Chronic Fatigue Syndrome, ME. A sore throat and an aching head became permanent parts of my everyday life, even though I hadn't had any problems of that kind earlier. I was sent to a private company, *Stressmedicine AB*, where I had cognitive behavior therapy. This therapy helped me to understand my limits, learn to listen to my body and to always start from myself and what strength I have.

Today I sleep about eleven hours a night and still rest between two and three hours in the afternoon. My temperature stays around 38-38.5 degrees. In all I need to rest for three or four hours during the day, because otherwise I am drained of all strength. I don't function, I feel as though I were in a fog, more or less every day. I wake up feeling sick and as though I had the flu. My body vibrates with fatigue. After a shower and breakfast, I lie down to rest for 30 to 60 minutes, and after that I can usually do something for between fifteen minutes and one hour. Another rest and then try to do something again. During my "healthiest" time of the day, one of my priorities is to take walks. To feel that I am about to come down with a cold is common, as is the sore throat. Though I cover myself with a blanket or something when I rest in the afternoon, I still get strange shivers. It's as if my whole body trembles, from my feet all the way up to my head. Not always, but sometimes my head feels tender, it hurts to put it on the pillow; luckily an analgesic sometimes helps. Because I find it difficult to concentrate, it takes great effort to read for example a recipe or something like that. To bake a cake or cook a simple dish can be a big project for me.

The consequence of trying to do some kind of activity is that I get worse, either immediately or the next day. If for instance we are invited to our neighbors for dinner or a barbecue, or take a trip with the boat or go swimming or anything like that, then I have to accept that I will get worse afterwards for one to three days. If we take a stroll in town on a Saturday, we have to limit the time for it. When I have tried to do too much, I get a headache or migraine. I always have to take a rest in the afternoon, whatever we do. In spite of how I'm feeling, it's still so tempting to try a little bit more, just for a short while, we are having suuuch a good time. It's frustrating to be so sensitive to sounds; we have to choose the right restaurant; if my husband wants to turn on the car radio, I have ear plugs; if I want to have a cup of coffee somewhere I am careful to avoid places where there are for example small children or a lot of other noises.

One just has to accept that the brain doesn't function as it used to. I feel foggy almost all the time, and if I have a bad day or if I get too tired, the brain short-circuits. I have changed mentally – I can't discuss things like I used to, can't carry on a conversation like before, I lose my train of thought, I can't find words or names. Before I got sick, I enjoyed driving a lot. Now I am careful not to drive any further than ten kilometers. I used to drive at least 500 kilometers a week, now I have to be careful, I know I am a very bad driver when I am tired.

Can anyone understand what it's like not to have the strength to read a book? That even this is something you have to plan if you want to understand what you are reading? People who don't know anything about this illness tend to believe that just because you stay at home, you read books, clean house, keep yourself busy and have a good time. That is not what it's like.

In 2007 I had a new experience, that of not being believed by Social Security. A Social Security doctor determined that my family doctor's statement was not medically proven. So Social Security booked a meeting with the employment service, and suddenly I was unemployed and belonged to them. I had been ill for five years and now I was supposed to be in good health, without any rehabilitation or training. I was defined as jobless for eight hours a day and for a while I was paid unemployment benefits. After some tests, the employment service declared that I was too ill to work. The feeling of having fallen in between categories is terrible, there is no firm ground to stand on, no human dignity. I'm left out in the cold.

During this time I got into touch with a professor, one of the few doctors in Sweden with any experience of this disease. It was wonderful to meet a doctor who knew what I was talking about

and recognized the symptoms. I appealed the decision of the Social Security to the regional court and won the case. It took fifteen months. Nothing could be done about the decision, since the Social Security doctors don't see the patients. They just follow the rules. My opponent in the regional court was a Social Security lawyer. My lawyer asked me questions about my illness, and I described how it had affected me and what my life is like today. Since the court decision, I have had fifty percent permanent and fifty percent temporary sick benefits, and now, in late 2008, I have been given full time permanent sick benefits.

FROM THE STORIES

"Then suddenly, in a single day, I fell ill with total exhaustion. I felt sick, constantly dizzy, and I barely had the strength to stand up. There was a constant buzz in my head and I was oversensitive to all sounds. I could for example not tolerate the sound of water from the faucet, TV, music or small talk. (---). It felt as if I could not get enough oxygen when breathing, and my pulse was extremely slow. (---). The most minimal physical effort caused me pain and I felt as if I would faint from exhaustion. It was a scary feeling. To cook my own food was next to impossible. I became totally dependent on help from other people. It felt as if my body was overstrained all the time and in a constant state of emergency." (*Tanja*)

"The way healthy people feel during the very worst days of flu is how I feel all the time. You know, the way you feel when your body spends all its energy to fight a vicious infection. You can't move. You lie in your bed, everything hurts, your head buzzes, your joints and muscles ache, there is not an ounce of energy to be summoned." (*Anne Örtegren*)

"I can no longer read books, watch a movie, do needlework or even carry out the simplest chore in the house. I depend totally on my husband who has to care for the children, do the shopping and go to his job. (---) I could for the life of me never have imagined that it was possible to be this sick and suffer to this extent." (*Eva*)

"You look better, says the doctor. Sure, the late summer tan helps. But I don't feel better, no, not at all. Keep struggling. Manage to take the steps I need to get home to silence and my bed. (---) The interest from people around me is mild, to say the least, when I say that I have an illness called Chronic Fatigue Syndrome. "A misleading name", I add immediately, knowing that I will lose their interest any second. Tired, is all they hear. Who the heck isn't tired? Is that a disease? (---) Saw the

doctor again. (---) Then he said, "What do you need such a diagnosis for?" Is that what the profession says to patients with chronic diseases, such as Parkinson's? "What do you need such a diagnosis for?" (*Ingela Wiman*)

"None of the meetings with doctors of all the different specialties where I was sent resulted in anything. On paper I was the healthiest of persons. I felt caught in a Kafkaesque nightmare and was very confused – but also a bit ashamed of taking up the time of all these busy doctors with something that was obviously there inside of me but never showed up in any tests. Besides I felt pressed to produce answers to the storms of questions the doctors asked. I adopted the role of accused, rather than victim. At home, I never said more than a few short words to my family. Mostly I just nodded or shook my head. All my energy was spent on concentrating during the visits with doctors, and afterwards there were several days with bursting headache and a worsened general condition." (*Xenia*)

"On bad days I can hardly do anything, my neck is stiff and my throat sore, I get easily nauseous and feel terribly tired. Sometimes I lie flat on the bed thinking: If you can't stand, you sit; if you can't sit, you lie down. But now I am already lying down and I don't have the strength for that either – what to do then? Stop breathing? Another common thought is: One *can't* possibly feel like this! But I *do!*" (*Britt-Marie Thurén*)

"I belong to the veterans among ME/CFS patients, since I fell ill already at the age of three and have been ill for 58 years now. In spite of that, I have had tremendous luck, since it seems that my case is relatively light. (---) I became abnormally tired too quickly and too easily, I had constant infections, had often headaches, dizziness, nausea, a bad sense of balance, I often stumbled, my body shook and trembled, I got irritated for nothing, sweated easily and a lot. (---) My parents took me to one doctor after another. The same cocksure message everywhere: "The boy is completely healthy." Finally a general practitioner suggested an examination with a psychiatrist and a psychologist. Same result: "The boy is completely normal." (*Anton*)

"If I could have a wish granted, it would be to be taken seriously and get help. That doctors and my friends and colleagues at work would believe that something is really wrong with me. That people would realize that this disease is a serious handicap, instead of saying that they too are "a little tired." That (---) ME was a disease for which you could be treated and that there was research to show what might help. I feel envious of people who suffer from recognized diseases. The respect,

the understanding, the resources, the treatments, the scientific results – I, too, want all of that.”

(Anja Klarin)

” I have been on full time sick leave since 2008 and my health has deteriorated over the years. Unfortunately that is the effect of having been forced to go through the whole medical process with attempts at rehabilitation and the demands from Social Security. Don’t get me wrong – in many ways I am grateful for all the resources that have been spent on me. But they have made me worse instead of better. (---) Today I depend wholly on those close to me. They cook my food and freeze it in suitable helpings. They take care of the cleaning and help me with all the ”administrative” chores that come with sick leave. (---) My life today consists of eighty or ninety percent of rest. Most of the time totally void of stimuli.” *(Saga Börrefors)*

“Early on in my illness I made the mistake of listening to medical personnel who advised me to ”push my body”, in spite of what it was telling me. The theory was that if I just got started and exercised, my immune system would improve and I would get my health back in time, even if there was strong resistance in the beginning. All I wanted was to get better, so I did as they said. Pushed myself to take walks. Went back to work, even though I really wasn’t strong enough. (---) *How I regret it! How I wish I had met a doctor who knew about ME/CFS in those early stages, someone who could have given me correct advice and prompt treatment. Had I done so I might perhaps have been a free, or at least freer, human being.*” *(Anne Örtegren)*

My illness has developed in a ”crash pattern.” After a sudden onset, there have been periods when I have been extremely ill for a while, and after a few months my general level has risen again. I have likened the process to a bouncing ball that is dropped from a high altitude. It hits the ground during a crash period and bounces back up. Little by little the ”peaks” get ever lower. In the end there is hardly any difference between peak and crash, the ball stops bouncing and just rolls along the bottom. (---) For each crash, I have been forced to give up more things I can no longer do. First, to work and live abroad. Then to go out, take care of myself. Then everything I used to enjoy, like seeing friends, watch movies, read books, sit by the computer, talk on the phone, knit and now recently to talk. To be able to talk now, I have to push the words out from my stomach and this makes me much worse. The last thing I have in the way of distraction is to listen to audiobooks, but now I have to ration even that.” *(Malin Näfstadius)*

”The family doctor wrote referral upon referral and sent me to all sorts of specialists: x-ray of my

lungs, x-ray computed tomography, a neurologist, a cardiologist, internal medicine. New sets of antibiotics "just in case." But my health neither worsened nor improved. I had no strength for anything. My throat was sore almost every day. I worried more and more. What is wrong with me? (---) The anxiety was worse than the fatigue. Oh, if only one of all these doctors had at least heard about ME/CFS!" (*Britt-Marie Thurén*)

"I have tried all sorts of treatments, vitamins, minerals, and folk cures that people recommend, including eliminating milk and gluten from my diet – nothing makes the least bit of difference. Public health has not offered any help or support. Each time my mother describes my situation to someone, all they say is that I should be hospitalized, preferably in a mental hospital. If they make me perform some little activity, they praise me, as if it were my *will* that failed!" (*Malin Näfstadius*)

"I have completely stopped having goals – when you don't know if you'll be able to shop for food or not on a given day, five-year plans don't make much sense. Dreams, on the other hand, is something I try to cultivate as often as I can. But rather than framing them in gold, I try to keep them in my pocket and take them out more often, with less pomp and circumstance. One dream is to be able to go to the shopping center and buy myself a bag of cinnamon cookies. Another one is to get a driver's license. One dream is to wear nail polish for a festive occasion." (*Anja Klarin*)

"In the end I gave up on public health and Social Security. Starting from the stress hypothesis, I turned, on my own, to a private stress specialist (---). It was then that I was diagnosed with ME/CFS. (---) It was later confirmed by a private ME/CFS specialist that I also found on my own. (---) There, I was given invaluable basic information about the disease, recommendations about B12, sick leave and wise words of advice about my now having to change my life style and take it easy if I was to have any chance at all to slow down the long-lasting deterioration process that I was in. If I had been given that advice when I first fell ill, I am sure I would have been much better today, perhaps able to work." (*Ann-Kristin*)

"In the summer of 2008 I felt that, in spite of everything, I just can't give up my life yet, so just for fun I applied to university. Before I started there, I discovered a new controversial medicine that gave me back fifty percent of my life. Several ME/CFS doctors abroad recommended a drug for epilepsy which I take in a small dose, and it works so that I don't have to be over stimulated by all sorts of everyday situations, like light, noise or any kind of movement. All these factors were reduced, so that my brain could rest. Anyway, here I am now, after studying for more than six

months. (---) My message is that the right treatment and recognition of the disease can make you feel much better and even give you part of your life back.” (*Fredrik*)

“Just imagine, early in the deterioration process somebody suggested that I ought to use a wheel chair, and I thought, ”No, a wheel chair, that doesn’t seem like me. I’m not that ill.” Now, I have been bed bound for four years, and to be able to sit in a wheel chair would be a dream. (---) I can’t understand how one is supposed to be able to struggle for one’s life because of a physical disease and at the same time fight for one’s right to medical care. (---) I wonder how many years and how many lives will be lost before society really realizes the need for research and care.” (*Andrea*)

CONTENTS

Facts

Introduction: The invisible disease – *Britt-Marie Thurén*

Between chairs – *Rose-Marie Bergmark*

Report from a house arrest of 40 square meters – *Anne Örtegren*

Quite a few percent of life – *Ingela Wiman*

Norwegian diary – *Tone Myhrer*

7 000 days – *Urban Götling*

A long and uneven road – *Xena*

The puppet life with ME/CFS as your boss – *Anna*

That thing that could never happen to me – *Malin Näfstadius*

Sorrow and hope – *Britt-Marie Thurén*

The gift of being able to work – *Monika*

In God’s eyes we are all valuable – *Tanja*

One evening in January: a telegram style story – *Fredrik*

To live in an extreme – *Eva, 41 years*

«Completely healthy» for half a century – *Anton*

A far from lazy gal – *Saga Börrefors*

I miss my desk – *Anja Klarin*

A nightmare awake: four bedbound years – *Andrea*

A career woman’s collision with ME/CFS – *Ann-Kristin*

The research picture of ME/CFS – *Birgitta Evengård*

Experiences from the Gottfries clinic – *Olof Zachrisson*

Ongoing research – *Anna Fenander and Anne Örtegren*

Summary of a survey study