

## ME/CFS patient Evelien pleads for more funding for research

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*Evelien (36) has been suffering from ME/CFS for more than twenty years. She became ill as a teenager and never got well. Evelien thinks it is important that more money goes to research on ME/CFS. That is why she went, on a gurney, to the European Parliament to tell her story.*



Everybody suffers from tiredness, headaches, or other flu-like symptoms once in a while. But for ME/CFS patients, this is a daily reality. After taking a shower or eating breakfast, they can be extremely tired and are forced to go back to bed with muscle- and headaches that won't go away. And those are the milder cases.

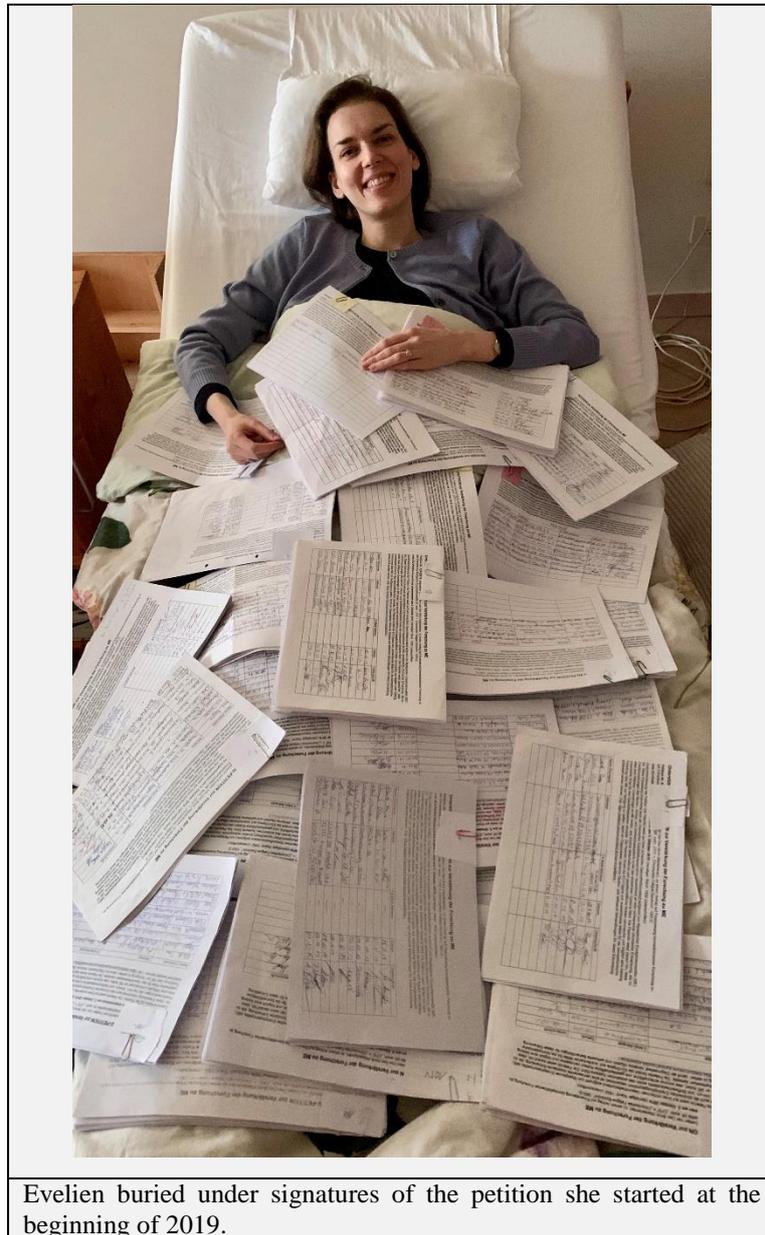
Some patients can't bare light and can hardly stand. There are even those who lie in a dark room 24/7 because every stimulus is one too many. ME/CFS, also known as chronic fatigue syndrome, is a serious disease.

The exact cause remains unclear. What is known, is that there is always a trigger that starts the disease. This could be a viral infection, a car accident, severe stress, or maybe even COVID-19.

Evelien has had ME/CFS for more than twenty years and is confined to bed. Recently, she told her story - from a gurney - in the European Parliament in Brussels, to request funding for scientific research so that a diagnostic test and effective treatments can be developed. We communicate by email, because she is too weak to receive visitors or even make a phone call.

The trip to Brussels was an enormous effort for Evelien. Yet she felt she had to seize the opportunity. "I knew it would be physically difficult and afterwards I also had a major setback from which I had to recover for a long time. But I was able to make myself heard in Brussels on behalf of all ME/CFS patients and hopefully my story will soon make a difference.

There must be structural funding and awareness for this disease. We need a solution. There are so many heartbreaking stories of patients who lose their jobs and their income, children who can't go to school and have no future prospects at all. That really has to change", says Evelien.



Evelien buried under signatures of the petition she started at the beginning of 2019.

## **Powerless**

According to conservative estimates of the Dutch Health Council, there are 30,000 to 40,000 ME/CFS patients in the Netherlands. Evelien was 14 when she contracted bacterial pneumonia. “I only partially recovered and was only able to go to school for half a day. A few months later I got the flu and since then I have never been healthy again.

So my disease clearly had an infectious onset. I mainly had headaches, sensitivity to light and sound, vomiting and diarrhea. I was often very exhausted and this worsened with everyday efforts, such as showering, getting dressed, or having a conversation.

In addition, I suffered from hair loss, muscle weakness and fasciculations. From a daughter who never had health complaints, who did well at school and loved sports, my parents suddenly had a deadly sick child. A child that was constantly lying in a reclining chair with the feeling of a heavy flu. This had a huge impact on our family.

My parents had to take care of me, and of course they did everything they could. We saw a lot of doctors. Everything was examined. They thought of a virus, a muscle disease, even a metabolic disease. My parents often felt powerless. They wanted to see me healthy again, but for a long time there was no doctor who could help me. My mother once said that my illness felt to her like sand slipping through her fingers. She had no grip on it and felt enormously powerless.

Even doctors didn't know how to help me. This caused frustration for some, but others didn't take my complaints seriously anymore. I had to face a lot of disbelief. When I got ME, less was known about the disease than now. More than once I was told that it was all in my head. There were even doctors who held me responsible for my illness. They said loud and clear: 'If you try harder and follow a rehabilitation program, you'll get better.' That rehabilitation program consisted and still consists of exercise and cognitive behavioral therapy."

### **Counterproductive**

"Unfortunately, these therapies are still seen by many doctors as the solution for ME patients. But for many it is counterproductive. During the therapy, I was told that the infection that made me sick was gone. So, according to those therapists, there was nothing physically wrong with me. The symptoms persisted, because I showed unhelpful behavior or had wrong thoughts. A rehabilitation program teaches you to think: 'I'm not tired, I'm not sick.' You learn not to listen to your own body anymore.

And parallel to this, activity and exercise were increased, something my ill body could not handle at all. So in my case this treatment did not lead to an improvement, but rather the deterioration of my health. In retrospect, this makes sense. ME/CFS is not in my head, it is not psychological. It has a biomedical cause. There is something physically wrong with me. My ability to produce energy and recover from an effort is disrupted."

#### **Money needed for scientific ME/CFS research**

Currently there is no targeted treatment for ME/CFS patients. They are still (too) often told by their (family) doctor or social security to follow behavioral therapy in combination with increasing activity. However, a report by the Dutch Health Council states that ME/CFS patients report in surveys that they become sicker as a result of this therapy. According to the Dutch Health Council, this evidence should be taken seriously. Doctors should discuss with their patients which treatments can help alleviate the symptoms. Cardiologists Linda van Campen and Frans Visser of the Cardiozorg foundation measure the blood supply to the brain by examining the carotid artery. In ME/CFS patients the blood supply to the brain differs considerably. Van Campen: "Because too little blood flows to the brain, all kinds of other body parts that are controlled from this central organ fall out. Think of the thyroid gland, the intestines or the immune system. Unfortunately, we still don't know where exactly in the brain ME/CFS is located, this requires more research."

### **Downward spiral**

"During rehabilitation therapy I did my very best, but instead of getting better, my health went into a downward spiral. I noticed very clearly that I was getting worse and worse. After 2008 I got a number of additional infections which made me so sick that I couldn't talk and had to communicate by hand

gestures. I was completely bedridden and received tube feeding through my nose, into my stomach. I couldn't sit or walk and my parents had to lift me out of bed for toilet visits.

Nonetheless, I have never been depressed. I always kept the hope that I would improve. I didn't give up. Of course, there were times when it was terribly difficult. But I grew stronger mentally. Now I hold on to the determination to get better. Because, quite frankly, I never thought I would be sick for so long. I had so many dreams, so many plans.”

### **Care home**

Evelien's health improved somewhat after several experimental medical treatments. What helped her, at least partially, is symptomatic treatment, especially pain relief. In spite of those small improvements, Evelien is still seriously ill and confined to bed. In her care apartment, she can walk small, necessary distances with a walker. She also has a powered wheelchair, but she can rarely go outside. It costs too much energy.

Since last June she lives independently in a care apartment. Five times a day a nurse comes to help her with food and personal care. She also gets help with housekeeping. “Living independently was a giant step for me. But I can manage. The fact that I live on my own is very important to me. My parents are a bit older now and it is nice that they can hand over the care for me after all these years. They still do a lot for me and I am grateful for that. Without them the move would have never been possible.”



Evelien sincerely hopes that time and money will now provide solutions. "It is not certain whether I will benefit myself."

### **Social contacts**

“One of the most difficult aspect of ME/CFS is that it is almost impossible to maintain social contacts. I'm often too sick to receive visitors and if I try, it always causes a setback. Through the internet I try to keep my world as big as possible. I also have a strong desire to make myself useful. That is why I have started to dedicate myself to ME/CFS advocacy. People who are already ill deserve a better life. And people who get sick now, should have a better future, so they don't have to go through the same things I did. I think it's terrible that children who fall ill today are getting the same bad treatment that I got 22 years ago and have the same prospect.”

Evelien refers to young patients and their parents, who still face disbelief and investigations from child protection agencies if they refuse to participate in cognitive behavioral treatment that does not make them better but rather sicker. And she also refers to ME/CFS patients who lose their social security benefits for the same reasons and therefore get into financial trouble. These are extra worries that you don't need when you're so sick.

### **ME in numbers**

For years hardly any money has been spent on (research into) ME/CFS in the Netherlands. There are almost no figures available. There is, however, an American overview with data on the expenditure per patient for various diseases. It should be kept in mind that the U.S. still spends the largest amount on ME/CFS research. Per disease, per year, in millions, that is:

Cancer: \$ 7120  
HIV/AIDS: \$ 3076  
Diabetes: \$ 1179  
Parkinson's: \$ 239  
MS: \$ 118  
ME: \$16

The number of MS patients is about the same as the number of ME patients in the U.S. (about 1 million patients for both diseases).



In October 2019, Evelien gave a speech in the European Parliament in Brussels. She was transported by people of the Red Cross.

## **A positive development**

ME/CVS determines your life. This has to change, says Evelien, and with that in mind she told her story in the European Parliament. She also started a petition and collected over 15,000 signatures. The European Parliament has now adopted a resolution recommending more funding for scientific research into ME/CFS. A positive development. Although it remains to be seen whether these words will be translated into concrete action, says Evelien.

“We still have a long way to go, although things are already changing. In the Netherlands, the Dutch Health Council published an important report two years ago stating that doctors hardly learn anything about the disease and do not receive any further training. As a result, practitioners have little knowledge about ME/CFS, and prejudice persists. The report also clearly states that ME/CFS is not a psychological illness, but a serious physical disease. This was an important step forward, although there are still doctors who think differently. This is incomprehensible.”

## **In love**

Evelien sincerely hopes that time and money will now provide solutions. “It is not certain whether I will benefit myself. I do hope that there will be effective treatments as soon as possible, which will help as many patients as possible. Until that time I will have to live with my limitations.

Since April this year I have a boyfriend, Michiel. We got to know each other through the petition I started. Michiel also has ME/CFS, so there was immediate mutual understanding. We started talking online and that's how we fell in love. I assumed that as long as I was sick, I wouldn't find anyone to share my life with. So this love came totally unexpected. We are happy together. We don't live together yet, but he's with me as often as possible and things are going great despite our limitations. Michiel gives my life a whole new dimension.”

### **Does COVID-19 trigger ME?**

According to cardiologists Linda van Campen and Frans Visser, COVID-19 is going to lead to many new cases of ME/CFS. The American virologist Fauci also mentioned a link between the diseases a number of times. “We don't know much about ME/CFS, but what we do know is that there is always a trigger that starts this disease. Former COVID-19 patients have recently made the news because they are suffering from the after-effects of the coronavirus infection. In most cases these are serious fatigue symptoms similar to those of ME/CFS.”

Van Campen en Visser would like to start a study on former COVID-19 patients with mild or more severe symptoms and patients who have fully recovered. “If we can show that COVID-19 can act as a trigger of ME/CFS, then that would put ME/CFS in a different light. The next step is for ME/CFS patients to be taken seriously.”

For more information on ME/CFS: Steungroep ME en Arbeidsongeschiktheid (<https://www.steungroep.nl/>) en de ME/CVS Vereniging ([www.me-cvsvereniging.nl](http://www.me-cvsvereniging.nl))