

Farewell – A Last Post from Anne Örtegren

Nobody can say that I didn't put up enough of a fight.

For 16 years I have battled increasingly severe ME/CFS. My condition has steadily deteriorated and new additional medical problems have regularly appeared, making it ever more difficult to endure and make it through the day (and night).

Throughout this time, I have invested almost every bit of my tiny energy in the fight for treatment for us ME/CFS patients. Severely ill, I have advocated from my bedroom for research and establishment of biomedical ME/CFS clinics to get us proper health care. All the while, I have worked hard to find something which would improve my own health. I have researched all possible treatment options, got in contact with international experts and methodically tried out every medication, supplement and regimen suggested.

Sadly, for all the work done, we still don't have adequately sized specialized biomedical care for ME/CFS patients here in Stockholm, Sweden – or hardly anywhere on the planet. We still don't have in-patient hospital units adapted to the needs of the severely ill ME/CFS patients. Funding levels for biomedical ME/CFS research remain ridiculously low in all countries and the erroneous psychosocial model which has caused me and others so much harm is still making headway.

And sadly, for me personally things have gone from bad to worse to unbearable. I am now mostly bedbound and constantly tortured by ME/CFS symptoms. I also suffer greatly from a number of additional medical problems, the most severe being a systematic hyper-reactivity in the form of burning skin combined with an immunological/allergic reaction. This is triggered by so many things that it has become impossible to create an adapted environment. Some of you have followed my struggle to find clothes and bed linen I can tolerate. Lately, I am simply running out. I no longer have clothes I can wear without my skin "burning up" and my body going into an allergic state.

This means I no longer see a way out from this solitary ME/CFS prison and its constant torture. I can no longer even do damage control, and my body is at the end of its rope. Therefore, I have gone through a long and thorough process involving several medical assessments to be able to choose a peaceful way out: I have received a preliminary green light for accompanied suicide through a clinic in Switzerland.

When you read this I am at rest, free from suffering at last. I have written this post to explain why I had to take this drastic step. Many ME/CFS patients have found it necessary to make the same decision, and I want to speak up for us, as I think my reasons may be similar to those of many others with the same sad destiny.

These reasons can be summed up in three headers: unbearable suffering; no realistic way out of the suffering; and the lack of a safety net, meaning potential colossal increase in suffering when the next setback or medical incident occurs.

Important note

Before I write more about these reasons, I want to stress something important. As for most other ME/CFS patients who have chosen suicide, depression is not the cause of my choice. Though I have been suffering massively for many years, I am not depressed. I still have all my will and my motivation. I still laugh and see the funny side of things, I still enjoy doing whatever small activities I can manage. I am still hugely interested in the world around me – my loved ones and all that goes on in their lives, the society, the world (what is happening in human rights issues? how can we solve the climate change crisis?) During these 16 years, I have never felt any lack of motivation. On the contrary, I have consistently fought for solutions with the goal to get myself better and help all ME/CFS patients get better. There are so many things I want to do, I have a lot to live for. If I could only regain some functioning, quieten down the torture a bit and be able to tolerate clothes and a normal environment, I have such a long list of things I would love to do with my life!

Three main reasons

So depression is not the reason for my decision to terminate my life. The reasons are the following:

1. Unbearable suffering

Many of us severely ill ME/CFS patients are hovering at the border of unbearable suffering. We are constantly plagued by intense symptoms, we endure high-impact every-minute physical suffering 24 hours a day, year after year. I see it as a prison sentence with torture. I am homebound and mostly bedbound – there is the prison. I constantly suffer from excruciating symptoms: The worst flu you ever had. Sore throat, bronchi hurting with every breath. Complete exhaustion, almost zero energy, a body that weighs a tonne and sometimes won't even move. Muscle weakness, dizziness, great difficulties standing up. Sensory overload causing severe suffering from the brain and nervous system. Massive pain in muscles, painful inflammations in muscle attachments. Intensely burning skin. A feeling of having been run over by a bus, twice, with every cell screaming. This has got to be called torture.

It would be easier to handle if there were breaks, breathing spaces. But with severe ME/CFS there is no minute during the day when one is comfortable. My body is a war zone with constant firing attacks. There is no rest, no respite. Every move of every day is a mountain-climb. Every night is a challenge, since there is no easy sleep to rescue me from the torture. I always just have to try to get through the night. And then get through the next day.

It would also be easier if there were distractions. Like many patients with severe ME/CFS I am unable to listen to music, radio, podcasts or audio books, or to watch TV. I can only read for short bouts of time, and use the computer for even shorter moments. I am too ill to manage more than rare visits or phone calls from my family and friends, and sadly unable to live with someone. This solitary confinement aspect of ME/CFS is devastating and it is understandable that ME/CFS has been described as the “living death disease”.

For me personally, the situation has turned into an emergency not least due to my horrific symptom of burning skin linked to immunological/allergic reactions. This appeared six years into my ME/CFS, when I was struck by what seemed like a complete collapse of the bodily systems controlling immune system, allergic pathways, temperature control, skin and peripheral nerves. I had long had trouble with urticaria, hyperreactive skin and allergies, but at this point a violent reaction occurred and my skin completely lost tolerance. I started having massively burning skin, severe urticaria and constant cold sweats and shivers (these reactions reminded me of the first stages of the anaphylactic shock I once had, then due to heat allergy).

Since then, for ten long years, my skin has been burning. It is an intense pain. I have been unable to tolerate almost all kinds of clothes and bed linen as well as heat, sun, chemicals and other everyday things. These all trigger the burning skin and the freezing/shivering reaction into a state of extreme pain and suffering. Imagine being badly sunburnt and then being forced to live under a constant scalding sun – no relief in sight.

At first I managed to find a certain textile fabric which I could tolerate, but then this went out of production, and in spite of years of negotiations with the textile industry it has, strangely, proven impossible to recreate that specific weave. This has meant that as my clothes have been wearing out, I have been approaching the point where I will no longer have clothes and bed linen that are tolerable to my skin. It has also become increasingly difficult to adapt the rest of my living environment so as to not trigger the reaction and worsen the symptoms. Now that I am running out of clothes and sheets, ahead of me has lain a situation with constant burning skin and an allergic state of shivering/cold sweats and massive suffering. This would have been absolutely unbearable.

For 16 years I have had to manage an ever-increasing load of suffering and problems. They now add up to a situation which is simply no longer sustainable.

2. No realistic way out of the suffering

A very important factor is the lack of realistic hope for relief in the future. It is possible for a person to bear a lot of suffering, as long as it is time-limited. But the combination of massive suffering and a lack of rational hope for remission or recovery is devastating.

Think about the temporary agony of a violent case of gastric flu. Picture how you are feeling those horrible days when you are lying on the bathroom floor between attacks of diarrhoea and vomiting. This is something we all have to live through at times, but we know it will be over in a few days. If someone told you at that point: “you will have to live with this for the rest of your life”, I am sure you would agree that it wouldn't feel feasible. It is

unimaginable to cope with a whole life with the body in that insufferable state every day, year after year. The level of unbearableness in severe ME/CFS is the same.

If we knew there were relief on the horizon, it would be possible to endure severe ME/CFS and all the additional medical problems, even for a long time, I think. The point is that there has to be a limit, the suffering must not feel endless.

One vital aspect here is of course that patients need to feel that the ME/CFS field is being taken forward. Sadly, we haven't been granted this feeling – see my previous blogs relating to this [here](#) and [here](#).

Another imperative issue is the drug intolerance that I and many others with ME/CFS suffer from. I have tried every possible treatment, but most of them have just given me side-effects, many of which have been irreversible. My stomach has become increasingly dysfunctional, so for the past few years any new drugs have caused immediate diarrhoea. One supplement triggered massive inflammation in my entire urinary tract, which has since persisted. The list of such occurrences of major deterioration caused by different drugs/treatments is long, and with time my reactions have become increasingly violent. I now have to conclude that my sensitivity to medication is so severe that realistically it is very hard for me to tolerate drugs or supplements.

This has two crucial meanings for many of us severely ill ME/CFS patients: There is no way of relieving our symptoms. And even if treatments appear in the future, with our sensitivity of medication any drug will carry a great risk of irreversible side-effects producing even more suffering. This means that even in the case of a real effort finally being made to bring biomedical research into ME/CFS up to levels on par with that of other diseases, and possible treatments being made accessible, for some of us it is unlikely that we would be able to benefit. Considering our extreme sensitivity to medication, one could say it's hard to have realistic hope of recovery or relief for us.

In the past couple of years I, being desperate, have challenged the massive side-effect risk and tried one of the treatments being researched in regards to ME/CFS. But I received it late in the disease process, and it was a gamble. I needed it to have an almost miraculous effect: a quick positive response which eliminated many symptoms – most of all I needed it to stop my skin from burning and reacting, so I could tolerate the clothes and bed linen produced today. I have been quickly running out of clothes and sheets, so I was gambling with high odds for a quick and extensive response. Sadly, I wasn't a responder. I have also tried medication for Mast Cell Activation Disorder and a low-histamine diet, but my burning skin hasn't abated. Since I am now running out of clothes and sheets, all that was before me was constant burning hell.

3. The lack of a safety net, meaning potential colossal increase in suffering when the next setback or medical incident occurs

The third factor is the insight that the risk for further deterioration and increased suffering is high.

Many of us severely ill ME/CFS patients are already in a situation which is unbearable. On top of this, it is very likely that in the future things will get even worse. If we look at some of our symptoms in isolation, examples in my case could be my back and neck pain, we would need to strengthen muscles to prevent them from getting worse. But for all ME/CFS patients, the characteristic symptom of Post-Exertional Malaise (PEM) with flare-ups of our disease when we attempt even small activities, is hugely problematic. Whenever we try to ignore the PEM issue and push through, we immediately crash and become much sicker. We might go from being able to at least get up and eat, to being completely bedbound, until the PEM has subsided. Sometimes, it doesn't subside, and we find ourselves irreversibly deteriorated, at a new, even lower baseline level, with no way of improving.

PEM is not something that you can work around.

For me, new medical complications also continue to arise, and I have no way of amending them. I already need surgery for one existing problem, and it is likely that it will be needed for other issues in the future, but surgery or hospital care is not feasible for several reasons:

One is that my body seems to lack repairing mechanisms. Previous biopsies have not healed properly, so my doctor is doubtful about my ability to recover after surgery.

Another, more general and hugely critical, is that with severe ME/CFS it is impossible to tolerate normal hospital care. For ME/CFS patients the sensory overload problem and the extremely low energy levels mean that a normal hospital environment causes major deterioration. The sensory input that comes with shared rooms, people coming and going, bright lights, noise, etc, escalates our disease. We are already in such fragile states that a push in the wrong direction is catastrophic. For me, with my burning skin issue, there is also the issue of not tolerating the mattresses, pillows, textile fabrics, etc used in a hospital.

Just imagine the effects of a hospital stay for me: It would trigger my already severe ME/CFS into new depths – likely I would become completely bedbound and unable to tolerate any light or noise. The skin hyperreactivity would, within a few hours, trigger my body into an insufferable state of burning skin and agonizing immune-allergic reactions, which would then be impossible to reverse. My family, my doctor and I agree: I must never be admitted to a hospital, since there is no end to how much worse that would make me.

Many ME/CFS patients have experienced irreversible deterioration due to hospitalization. We also know that the understanding of ME/CFS is extremely low or non-existent in most hospitals, and we hear about ME/CFS patients being forced into environments or activities which make them much worse. I am aware of only two places in the world with specially adjusted hospital units for severe ME/CFS, Oslo, Norway, and Gold Coast, Australia. We would need such units in every city around the globe.

It is extreme to be this severely ill, have so many medical complications arise continually and know this: There is no feasible access to hospital care for me. There are no tolerable medications to use when things get worse or other medical problems set in. As a severely ill ME/CFS patient I have no safety net at all. There is simply no end to how bad things can get with severe ME/CFS.

Coping skills – important but not enough

I realize that when people hear about my decision to terminate my life, they will wonder about my coping skills. I have [written about this before](#) and I want to mention the issue here too:

While it was extremely hard at the beginning to accept chronic illness, I have over the years developed a large degree of acceptance and pretty good coping skills. I have learnt to accept tight limits and appreciate small qualities of life. I have learnt to cope with massive amounts of pain and suffering and still find bright spots. With the level of acceptance I have come to now, I would have been content even with relatively small improvements and a very limited life. If, hypothetically, the physical suffering could be taken out of the equation, I would have been able to live contentedly even though my life continued to be restricted to my small apartment and include very little activity. Unlike most people I could find such a tiny life bearable and even happy. But I am not able to cope with these high levels of constant physical suffering.

In short, to sum up my level of acceptance as well as my limit: I can take the prison and the extreme limitations – but I can no longer take the torture. And I cannot live with clothes that constantly trigger my burning skin.

Not alone – and not a rash decision

In spite of being unable to see friends or family for more than rare and brief visits, and in spite of having limited capacity for phone conversations, I still have a circle of loved ones. My friends and family all understand my current situation and they accept and support my choice. While they do not want me to leave, they also do not want me to suffer anymore.

This is not a rash decision. It has been processed for many years, in my head, in conversations with family and friends, in discussion with one of my doctors, and a few years ago in the long procedure of requesting accompanied suicide. The clinic in Switzerland requires an extensive process to ensure that the patient is chronically ill, lives with unendurable pain or suffering, and has no realistic hope of relief. They require a number of medical records as well as consultations with specialized doctors.

For me, and I believe for many other ME/CFS patients, this end is obviously not what we wanted, but it was the best solution to an extremely difficult situation and preferable to even more suffering. It was not hasty choice, but one that matured over a long period of time.

A plea to decision makers – Give ME/CFS patients a future!

As you understand, this blog post has taken me many months to put together. It is a long text to read too, I know. But I felt it was important to write it and have it published to explain why I personally had to take this step, and hopefully illuminate why so many ME/CFS patients consider or commit suicide.

And most importantly: to elucidate that this circumstance can be changed! But that will take devoted, resolute, real action from all of those responsible for the state of ME/CFS care, ME/CFS research and dissemination of information about the disease. Sadly, this responsibility has been mishandled for decades. To allow ME/CFS patients some hope on the horizon, key people in all countries must step up and act.

If you are a decision maker, here is what you urgently need to do: You need to bring funding for biomedical ME/CFS research up so it's on par with comparable diseases (as an example, in the US that would mean [\\$188 million per year](#)). You need to make sure there are dedicated hospital care units for ME/CFS inpatients in every city around the world. You need to establish specialist biomedical care available to all ME/CFS patients; it should be as natural as RA patients having access to a rheumatologist or cancer patients to an oncologist. You need to give ME/CFS patients a future.

Please listen to these words of Jen Brea, which sum up the situation in the US, but are applicable to almost every country:

“The NIH says it won't fund ME research because no one wants to study it. Yet they reject the applications of the world class scientists who are committed to advancing the field. Meanwhile, HHS has an advisory committee whose sole purpose seems to be making recommendations that are rarely adopted. There are no drugs in the pipeline at the FDA yet the FDA won't approve the one drug, Ampligen, that can have Lazarus-like effects in some patients. Meanwhile, the CDC continues to educate doctors using information that we (patients) all know is inaccurate or incomplete.”

Like Jen Brea, I want a number of people from these agencies, and equivalent agencies in Sweden and all other countries, to stand up and take responsibility. To say: “ME! I am going to change things because that is my job.”

And lastly

Lastly, I would like to end this by linking to this public comment from a US agency meeting (CFSAC). It seems to have been taken off the HHS site, but I found it in the Google Read version of the book “Lighting Up a Hidden World: CFS and ME” by Valerie Free. It includes testimony from two very eloquent ME patients and it says it all. I thank these ME patients for expressing so well what we are experiencing.

https://books.google.se/books?id=6QMrDQAAQBAJ&pg=PA321&lpg=PA321&dq=CFSAC+moore+billie&source=bl&ots=glh7zwwXzE&sig=wbeBOe2EMhk3lxhyeUMG2EZf_4&hl=sv&sa=X&ved=0ahUKEwjIqafq76XQAhUC_iwKHYkUCxUQ6AEIKzAC#v=onepage&q=CFSAC%20moore%20billie&f=false

PS. My previous blog posts:

[**From International Traveler to 43 Square Meters: An ME/CFS Story From Sweden**](#)

[**Coping With ME/CFS Will Always Be Hard – But There are Ways of Making It A Little Easier**](#)

[**The Underfinanced ME/CFS Research Field Pt I: The Facts – Plus “What Can We Do?”**](#)

[**The Underfinanced ME/CFS Research Field Pt II: Why it Takes 20 Years to Get 1 Year's Research Done**](#)

My Swedish ME/CFS newsletters, distributed via e-mail to 2700 physicians, researchers, CMOs, politicians and medical journalists:

<https://mecfsnyheter.se/>

Take care of each other.

Love, Anne