

# When a 17-Year-Old Girl Is Diagnosed with Myalgic Encephalomyelitis: A Case Study from the Swedish Health Care System—A Parent Perspective

Eva Bojner Horwitz<sup>1,2,3</sup>, Jonas Axelsson<sup>4</sup>, Olli Polo<sup>5</sup>, Leif Widebert<sup>6</sup>, Töres Theorell<sup>1,7</sup>, Anabelle Paulino<sup>8</sup>, David Ullman<sup>9</sup>, Jonas Bergquist<sup>10,11</sup>

<sup>1</sup>Department of Music, Pedagogy and Society, Royal College of Music, Stockholm, Sweden

<sup>2</sup>Department of Clinical Neuroscience, Karolinska Institutet, Solna, Sweden

<sup>3</sup>Center for Social Sustainability, CSS, Karolinska Institutet, Solna, Sweden

<sup>4</sup>Amelie Clinic and Karolinska Institutet, Solna, Sweden

<sup>5</sup>ME-Center, Bragée Clinics, Stockholm, Sweden

<sup>6</sup>Hälsosjälén, Mölndal, Göteborg, Sweden

<sup>7</sup>Stress Research Institute, Stockholm University, Stockholm, Sweden

<sup>8</sup>Karolinska Institutet, Solna, Sweden

<sup>9</sup>Sophiahemmet, Barnsjukhuset Martina, Sweden

<sup>10</sup>Analytical Chemistry and Neurochemistry, Department of Chemistry—BMC, Uppsala University, Uppsala, Sweden

<sup>11</sup>The ME/CFS Collaborative Research Centre at Uppsala University, Uppsala, Sweden

Email: [eva.bojner-horwitz@kmh.se](mailto:eva.bojner-horwitz@kmh.se)

**How to cite this paper:** Horwitz, E.B., Axelsson, J., Polo, O., Widebert, L., Theorell, T., Paulino, A., Ullman, D. and Bergquist, J. (2022) When a 17-Year-Old Girl Is Diagnosed with Myalgic Encephalomyelitis: A Case Study from the Swedish Health Care System—A Parent Perspective. *Case Reports in Clinical Medicine*, 11, 280-296.

<https://doi.org/10.4236/crcm.2022.118041>

**Received:** June 29, 2022

**Accepted:** August 1, 2022

**Published:** August 4, 2022

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## Abstract

This case study presents different strategies that were explored by the patient's mother (who is a researcher in music and medicine) when her 17-year-old daughter was diagnosed with ME (Myalgic Encephalomyelitis), also known as Chronic Fatigue Syndrome (CFS). ME is not widely recognized in the Global as well as the Swedish population at large, and within healthcare, there are no standardized recommended treatments, partly due to the lack of published evidence-based studies. This case study aims to provide insights into how the Swedish healthcare system works, how different clinics and hospitals within it operate and interconnect; and how these contribute to health outcomes after 15 months of treatment.

## Keywords

Case Study, Myalgic Encephalomyelitis, Parent Perspective, Swedish Health Care

## 1. Introduction

The patient C, currently 18 years old, had been struggling for 2.5 years with infections, throat pain, exhaustion, and PEM (post exertion malaise). She had been taken under the care of lung and respiratory specialists who tried penicillin for her throat pain, but neither antibiotics, nor pain killers, nor nutrient supplements had helped to resolve her symptoms. During this time, no further investigations had been prescribed for a possible diagnosis of ME. After three years of struggling with symptoms, anxiety and associated infections, a private clinic in Stockholm, the Bragée Clinic, diagnosed C with ME according to the Canadian criteria [1]. Upon further investigation, the same clinic also diagnosed a Postural Orthostatic Tachykardia Syndrome (POTS) [2], a Chiari malformation [3] in the left cerebellum tonsil and general hypermobility.

## 2. What Do We Know about ME/CFS?

It is estimated that 0.1% - 6% of the populations in the Western hemisphere suffer from ME [4]. Women outnumber men by a ratio of 3:1. The age of onset varies between 20 and 40 (investinme.org). First established in 1994, the diagnostic criteria of ME have become more stringent over time [1] [5] [6] [7]. It can be challenging to diagnose ME as there are currently no laboratory tests available for an unequivocal diagnosis [8]. However, the Canadian criteria for diagnosing ME are widely used as they provide a clear framework [6]. An expert consensus on the diagnosis, service provision, and care of people with ME/CFS in Europe was also recently published (European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome [9]).

Research on ME has identified abnormalities in the central as well as peripheral nervous system, the immune system, and in the metabolism in patients with ME/CFS [10]. Several research groups are investigating the link between different viral infections and the development of ME [11] [12], including the role that the Epstein-Barr Virus may have, something that has been discussed for a decade [13]. Recently hypotheses have been offered to explain a possible relationship between hypermobility and cranio-cervical obstructions frequently observed in ME patients [14], as well as potential mechanistic overlaps between critical-ill patients and ME [15] [16] [17] [18]. Whilst it clearly affects the brain, IQ is not reduced in ME patients—patients seem to be able to leverage a larger portion of the brain to perform the same mental performance as patients who do not have ME [19]. Also, the absence of depressions is common in ME [9].

In US researchers have been investigating the increase of pro-inflammatory microglia activity in the CNS of ME patients [20]. In Norway [12], an increase in autoinflammatory antibodies to beta-adrenergic and muscarinic receptors in the central nervous system has been demonstrated. This was first shown by [21]. This has also been validated in two Swedish cohorts [22]. In the UK, impaired transport of calcium between cells has been detected. In this research the transport of calcium and magnesium ions are linked to the body's temperature regu-

lation and experience of pain According to Finnish studies there may be a link between ME and the sympathetic nervous system as well as between connective tissue and blood circulation [23].

Work by Fluge *et al.* [12], offered ME/CFS patients some hope. Results from their first study initially showed positive results that ME could be an autoimmune disease and therefore be treated accordingly. But in the second study, a double-blind placebo-controlled Rituximab study, indicated negative results, although a subgroup of patients did respond positively to the treatment [12]. Another hypothesis is that ME is related to a “gut-brain axis model” [11] [24]. If this is the case dietary interventions could be of importance for ME patients. American researchers [24] have found an increase in lipopolysaccharide content (LPS) in the gut in a majority of patients with ME. One theory behind this is that LPS leaks from the intestinal system to the bloodstream. Another American study has discovered that the citric acid cycle in the mitochondria is disturbed in ME patients. This disrupts glucose metabolism; glucose is converted to fatty acids which are then stored. These theories hypothesize that the mitochondria have entered a form of “protective” mode that prevents them from producing energy, which in turn may suggest an opportunity for treatment in somehow “restarting” the mitochondria. Different studies in England, Switzerland and Germany are focusing on the function of the microbiome [25]. Patients with ME seem to have lowered diversity in their bacterial flora and at the same time elevated levels of bacteriophagic viruses that attack bacteria [25]. This strand of research suggests that if there is a disturbed balance between certain types of micro-organisms, the immune system may start to fight beneficial body bacteria and cells.

In this patient’s own area, Sweden, there is ongoing ME research as already mentioned above. Already in 2011, evidence for neuroinflammatory involvement in ME/CFS patients was presented [26]. Furthermore, one study measured plasma concentration of several immune parameters in plasma [11]. Another Swedish line of ME research is Cranio-cervical obstruction [14]. Dr Jonas Bergquist and collaborators are working with the hypothesis that ME may be triggered by several different viruses such as EBV or influenza, and that partly the symptoms in ME patients could overlap with other post-viral fatigue disorders and critical ill patients. An elevated level of antibodies to HSP60 (a mitochondrial protein that could be involved in energy uptake) has been observed in ME patients [11]. Other research on energy metabolism in ME patients suggests the immune system changes behavior and attacks the body’s energy uptake and signaling systems, observations made by Swedish researchers already in 2013 [27]. This hypothesis has recently been followed up by a home-visit study conducted by the team from the ME/CFS Collaborative Research Centre at Uppsala University (unpublished data).

From this short overview, one can conclude that the pathogenesis of ME is very complex, much is known but the full picture is not yet fully understood.

Unfortunately, there still exist recommendation that ME patients should exercise more in order to boost energy levels. While activity may temporarily improve fatigue, it may also contribute to a post-exertional malaise (PEM) that is common among ME patients [11]. PEM means that patients' symptoms following physical activity or mental exertion could increase 12 - 48 hours post exercise and last for days or weeks [28]. Experimental treatments are occurring among medical specialists. In a clinic in Mölndal, "Hälsosjälén (*Health Soul*)" an osteopath has been working with a technique known as the "Perrin Technique"; a craniosacral technique aiming at increased space between the occipital lobe and the first cervical vertebra. There are ME patients where the foramen magnum is constricted due to pressure from a "Chiari malformation" or due to neck trauma [14]. This technique is well-tested in US on many patients with ME [28]. In the Swedish health care, there is still little consensus on how to treat ME patients. The Bragée Clinique in Stockholm (a clinic specialized in diagnosis and treatment of ME) recommends treatment with low dose Naltrexone [29], pacing [28], sodium chloride—intravenous injections or oral treatments [28] and B-12 injections. Physiotherapy and occupational therapy are also recommended for the patients to cope with their energy levels (Pacing). These interventions seek to decrease pain and increase patients' energy levels to some extent.

Parents of children suffering from symptoms of ME are largely coping on their own. Although there are healthcare professionals such as MDs who have specialized in ME work with patients, they simply do not have the time or knowledge to improve outcomes reliably for their patients. We desperately need to seek more knowledge of how the patients diagnosed with ME experience the health care system, in order to improve this. The present case report offers first-person account of how parents cope with the situation when their child is diagnosed with ME, POTS and hypermobility.

### 3. The Different Health Care Specialists and Their Advice and Treatments

In the following part, thirteen different specialists' recommendations to C and narratives from the parents will be presented chronologically, from April 2021 to June 2022.

#### ***The general practitioner at the hospital:***

April 2021.

The general practitioner wrote a referral to the ME Clinique, presenting the following symptoms/questions:

*"For 1.5 years, C has had the following symptoms*

- *recurrent throat infections with severe pain from tonsils, pharynx and ears*
- *blisters in the mouth*
- *feelings of exhaustion after light physical exertion*
- *flu-like symptoms and feelings of dependence come in flares*
- *intermittent pain in neck, jaw and knees*

- *headache*
- *muscle tension of shoulders/neck*
- *hypersensitivity to sound*
- *cold hands*
- *feeling of fever without fever*
- *slight dizziness when getting up from sitting and from lying down*
- *a sensation of superficial sleep*
- *fatigue and tiredness after cognitive and concentration-demanding tasks in school*

*Symptoms in the last 3 - 6 months*

- *brain fog*
- *tachycardia when ascending*
- *superficial breathing - costs of energy to breathe deeply*
- *concentration difficulties*
- *difficult to find words*
- *extreme feeling of exhaustion after physical exertion*

#### ***The ME specialist***

May 2021. Diagnosed ME, POTS and general hypermobility

June 2021. Recommended Low Dose Nalprexone (LDN), extra NaCl solution, and to drink as much as 2 liters water per day.

November 2021: Commenced B-12 injections and peroral Folic acid. Recommended for IVIG (*intravenous gamma-globulin injection*) treatment, but after three different referrals had failed it became obvious that no physician in Sweden was willing to take responsibility for this treatment.

August 2021: Antibodies test in Germany by CellTrend

April 2022: C started with adrenalin injections recommended from the ME specialist to obtain a better perceived sleep pattern. C has received in total five adrenalin injections and they seem to have resulted in improved sleep.

*“After several months of C’s symptoms, and several diagnostic assessments including a Tilt test and MRI scan, the ME doctor diagnosed C with the condition. The diagnosis came as a shock both for C and us. We had begun to understand that the symptoms C had been feeling could be related to neck pressure. The ME doctor said the pressure of the left cerebellum on the 1<sup>st</sup> vertebra may not be relevant for the ME diagnosis, but that a neurologist would need to verify this”.*

#### ***The Neurologist***

June 2021.

A Chiari with 7 mm pressure towards the foramen magnum was found on the left cerebellum tonsil. Two neurologists at Karolinska Hospital analyzed the MR finding and provided their consensus that the Chiari finding had no clinical relevance for the ME-symptoms.

*“The neurologists were telling us that they could take part of C’s first vertebra away and fixate the cerebellum, but we did not want to run the risk of that operation. We as parents recognized the importance of trusting the neurologists’*

*consensus. At the same time, we were also skeptical at what the neurologists were telling her, and as parents, we did not want to go through an operation on her brain”.*

### ***The occupational therapist***

June 2021.

Information about PEM and base line

Pacing instructions

*“We found the tools and techniques from the occupational therapist—like a lamp that served to visualize energy depletion as it occurred—very practical and helpful, and they have been meaningful in C’s treatment. We have learnt how to read her body signals, and if one learns to stop right before she gets overwhelmed, her life is more bearable. Even seemingly simple activities can deplete her energy, so she needs to prioritize energy to perform basic functions. We have come to understand this energy exchange is like a “bank account”—you cannot use more energy/money in your account than what you have (and you cannot take loans on energy)”*

### ***The osteopath***

August 2021.

Mechanical work with osteopathy and the Perrin technique

Catherine visited an osteopath—specifically a doctor with 30 years of experience in psychosomatic medicine as well as ME—in Gothenburg once a week for 8 weeks in autumn of 2021. The osteopath described the etiology as “*cranial dysfunction with slight load on the lymphatic system (specifically in the left side of the body), slight head trauma from Catherine having fallen on ice, and static braces*”. The osteopath also mentioned Catherine’s previous bird flu infection as maybe contributing towards ME.

The findings from the osteopath were suboccipital inhibition of movement, inhibition in thoracic spine, findings of inhibited movement in the jaw (in terms of muscle movement), and overall hypomobility.

At these baseline findings in September 2021, Catherine rated her pain about 6/10; her vitality 4/10; and self-rated health overall was 3/10. Two months later in November 2021, her vitality was rated the same, her self-rated health 4/10, and she was in greater pain in the throat area. Catherine described herself as not feeling free, and somewhat locked.

The recommended treatments following this appointment included relaxation movements and micro tractions in the upper part of the spinal cord; C0 - C1. In response to the treatments, increased movement in C1 was achieved, and there was more color to Catherine’s face. The doctor also recommended taking Catherine’s dental braces off, as they were static and counterproductive in relation to the asymmetric part of cerebellum. The braces completely locked up the interrelated movement of the cranial bones and by that caused a decreased flow in the cerebrospinal fluid. Catherine has since then felt at ease without them.

*After the MR, in March 2022, there is a finding that the Chiari malformation is not as obvious as before. Probably, we can trace this finding to the osteopath’s*

efforts with micro tractions in the C0 - C1 during autumn 2021. There is still a question if the MR signals part of an EDS, Ehlers Danlos Syndrome (which is a common finding in ME patients). After the experts analyses of C's MR dated April 2022, there were no signs of the Chiari and no detectable vascular changes related to EDS.

*C's narrative regarding this section of treatment:*

*"I would really like to be in school and continue with my courses. The osteopath treatment has made me believe more that I can come back to school. The osteopath has given me more self-respect, and I believe that I, within a couple of months, can start to enjoy life again. He has given me more patience. I believe that I need more of this during a short period of time ahead."*

### ***The ACT-therapist***

August 2021-May 2022.

Working with acceptance

*How do you accept something so frustrating to live with? Sure, there are therapies that can help you handle and cope with your thoughts and emotions—the key here is that you have your thoughts, but you aren't your thoughts.*

*About every second week, the meeting with an acceptance commitment therapist (ACT) has helped C to cope with her ME diagnosis and symptoms. Through this, she was encouraged to share her thoughts and feelings with a person outside the family. These meetings have been conducted digitally 1-on-1, and they have met for about 10 times.*

*These sessions have been very meaningful in the sense that C has understood that she is not alone in her suffering. It has been a relief for C to hear that other patients have been able to work with tools to handle a situation wherein one needs to put one's whole life on hold. With mindfulness and meditation techniques, she is able to accept that she has hard times during the day, C has been able to use these techniques between ACT meetings. In the most recent session, C told the therapist that she doesn't need the therapist anymore as she now feels able to take care of her own situation.*

*This has been a positive thing to observe from the sidelines as a parent. C has become much wiser this year, and she now seems to have a very mature perspective compared to when she started school. This has been a silver lining of everything that has happened. In a way, it is an existential "win", as C has gained deeper wisdom about life because of all the things that have happened.*

### ***The Immunologist***

August 2021, December 2021, April 2022.

Working with antiviral treatments.

Long-standing clinical experience links viral infections such as infectious mononucleosis to the development of long-term illness. This experience is increasingly supported by scientific evidence linking infection with Epstein-Barr virus (EBV; the causal virus behind infectious mononucleosis) with immune dysfunction [30] [31] [32], neurological diseases [33] [34], as well as ME/CFS

[32].

As an immunologist at the Karolinska University Hospital, Dr. Axelsson works mainly with bone-marrow transplantations and cell therapies. However, the relatively recent adoption of autologous hematopoietic stem cell transplantation as a treatment for multiple sclerosis (MS) has awakened an interest in ME as another putatively virus-linked disease that involves the immune system. With limited options to see such patients in his role at the hospital, Dr. Axelsson in 2017 co-founded the Amelie Clinic together with the family of a patient. The clinic is a non-profit organization, organizationally and physically separate from the Karolinska, dedicated to the treatment of, research on and education about para-viral diseases, including ME, long-Covid [35], and chronic Lyme disease [36].

Based on a thorough assessment of immune parameters a diagnosis of Epstein-Barr linked immune exhaustion was made. Tests included serologic reactivity to common viral proteins, nucleotide analyses, immune cell populations by FACS, and T-cell proliferation assays [37]. Treatment was initiated with valganciclovir (450 mg, bid), an antiviral treatment, and metformin (500 mg, bid), a diabetes medication with immunomodulatory actions [38]. Due to eosinophilia and an excessive mast-cell degranulation response, sodium cromoglycate in an enteric formulation was also prescribed to be taken as needed.

#### ***The Cardiologist***

October 2021. Recommendation to take Inderal.

*“The primary care physician had understood that C’s POTS warranted a visit to a cardiologist, who suggested a beta blocker (Inderal 40 mg). This was in view to improving C’s ability to move around the house, from bathroom to room and so on. In our eyes, this was a short-term solution, and we were wondering how long someone could take this medication without long-term damage. We also wondered why the ME doctor and cardiologist had not been able to work together from the beginning—at this point, C had already spent 5 months with hyperactivity in the heart. Although we were happy that the treatment had beneficial effects (reduced tendency to tachycardia), we now wondered what it must be like for families who may not be able to bring a cardiologist in to the considerations for treatment. There has been no follow-up physically with the cardiologist since then, and we do not know why. We wish to contact him”.*

#### ***Funmed-Diet***

November 2021.

*“The doctor presented us with 25 pages of analysis. It was a chaotic presentation of two and a half hours. C herself expressed feeling overwhelmed by the information and did not want to go through with the proposed treatment of starting antibiotics for the gut, given that the treatment had not been verified by the scientific community. We felt devastated after this meeting, and we could not believe that medical doctors would try to make money from this treatment plan. After a second meeting with the FunMed doctor, we still find it unbelievable that some caregivers say that they have experience of treating ME patients but ob-*



viously do not”.

**The Functional Medicine expert:**

November 2021.

Supplements to strengthen the liver, kidneys, stomach

Diet

*This expert (not a doctor) suggested going to a store where you could buy supplements to strengthen one’s organs. Per this expert’s suggestion, C started an anti-inflammatory diet—including not eating meat and limiting dairy—until December of 2021. At this point, C felt that continuously having to monitor what to eat and not to eat was too frustrating, so we decided to simply give her what she wanted to eat; in other words, she ate the same things as the rest of the family. She has continued taking the supplements, but not as consistently as before”.*

**The Massage therapist:**

November 2021. Working with lymph drainage.

*C visited a massage therapist to help “open up” a lymph node on the left side of her body, after we had read about lymph drainage. We visited a few times, and after each visit, C would need a lot of rest. While we did not accompany C to these massage therapy sessions, we know from the after-effects that these visits were too draining for C. We would not recommend this specific plan of treatment to others if one were low on energy, since the treatment involves releasing muscle tension, and muscle tension is actually needed to aid healing”. One recommendation from the massage therapist that really has helped is supportive stockings.*

**ME researcher**

Spring 2022.

*I have been in correspondence with Dr. Jonas Bergquist, who hypothesizes that ME can be at least partly triggered by Epstein-Barr virus and influenza in resemblance with other post-viral fatigue syndromes. His research is being conducted at the ME/CFS Collaborative Research Centre at Uppsala University. This lab has partial funding for finding biomarkers in cerebrospinal fluid and blood from ME patients. He has shared his findings on neuroinflammatory markers, on autoantibodies in blood and disturbances in energy metabolism.*

*He has suggested intravenous gamma-globulin injection (IVIG) treatment, which influences the immune system activation (the mechanism echoes that of a vaccine). Although this treatment is expensive in Sweden, there are doctors in clinics in Sweden, Denmark and USA who administer this treatment.*

*He has additionally discussed plasmaphoresis or immune absorption as potential treatment options with one of his German colleagues (Dr Carmen Scheibenbogen), who have seen improvements in a subgroup of patients with ME; however, it was based on risk-benefit evaluation determined that C would need to be experiencing more severe symptoms before electing to undertake this sort of treatment with their potential side-effects.*

### *A perspective from Norway*

*We have been in correspondence with a professor in Pediatrics from Norway (whose son has ME).*

*The first piece of advice this professor recommends is that due to C's POTS, we should try IVIG [39]. One-third of his colleagues in the UK have had good results when it comes to IVIG treatment, although the professor notes it can take up to 12 months after treatment to see results. The second recommendation of this professor has been to try plasmaphoresis. His third piece of advice is for C to take an IV saline infusion—1 - 2 times a week in conjunction with B-12 injections + folic acid.*

## 4. Results

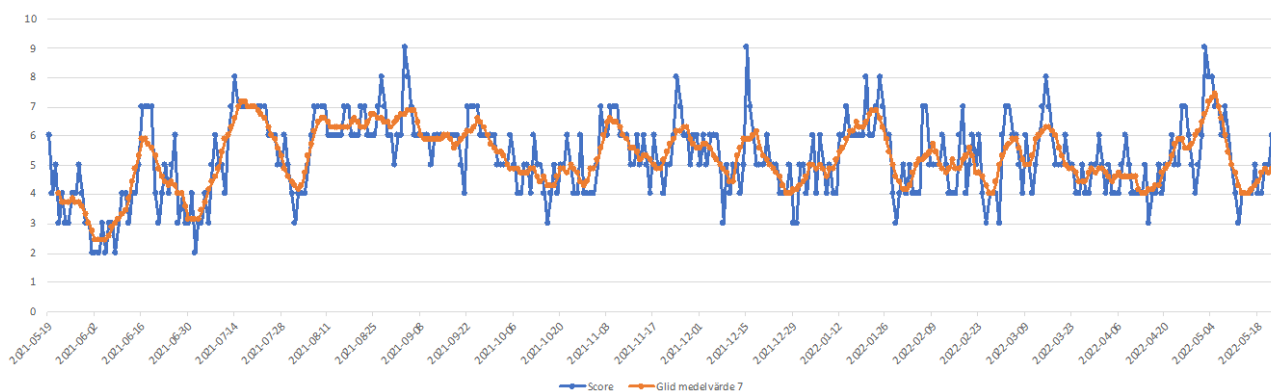
Pacing seems to be the method that has given the best results of all the recommendations C has received. In other words, coping and reading pre-signals of available energy levels have been key. Additionally, B-12 injection treatments have been proven to help ease symptoms, along with ACT treatment and supportive sockings to decrease C's POTS and hypermobility has also been something that has helped C lately.

**Figure 1** presents C's VAS scores made from 19<sup>th</sup> of May 2021-24<sup>th</sup> of May 2022, where 10 is “the worst possible overall health” and 0, “the best possible overall health”. The different cyclic stages may be related to energy consumption especially different cognitive activities, such as reading, hormone cycles, warm temperatures, school visits and traveling. The last peak seen in the trend analyses were evaluated when C. had high fever.

## 5. Discussion

With the unfolding of this case, and all the elements at play, what can we say about firstly the role of the parent, living with a child who has been diagnosed with ME, and secondly the Swedish health care system?

### *The parental role*



**Figure 1.** Scores measures on a scale from 0 - 10, where 0 is related to the best possible overall health and 10, is related to the worst possible overall health. C. has evaluated the scores every morning from 19<sup>th</sup> of May 2021-24<sup>th</sup> of May 2022.

As a parent, one is playing a key role in the “dramatic play” of what unfolds. As C says, “How could an ME patient survive without support from a caring and loving family?” Without a well-organized treatment process with continual respectful and compassionate communication, it is likely, from our perspective, that this case would have ended up with a patient in deep depression. The role of the parents is not only to be a parent, but also to be a therapist, supportive friend, pharmacist, researcher, social worker, and nurse, all at the same time [40]. We might consider these roles as part of the healthcare system, but they end up being the responsibility of the family. Considering this, we need to ask: Who is taking care of the parents? Who is supporting the caring family in performing these roles? Currently, it is very rare that there is organized mentorship or methodology to take care of the caregivers. There is also a question of equality here [41]; which patients have access to parents who can support them in this way, and which patients do not?

Looking at what we have learnt through our investigations of C’s condition, one can think of C’s ME as a branch that has fallen into a flowing river. Similarly, with regard to the way the branch forces the water to flow in alternative ways, C’s Chiari malformation is maybe occluding the cerebrospinal fluid. As a result, her body is having to cope in a different way, which has resulted in a disease targeting the immune, hormonal, cardiovascular, and cognitive systems. C’s body has been coping with something that is poorly understood. At the age of eighteen, many physical, emotional, cognitive, and hormonal systems are developing, and her body is still very much under construction. Every day, one can be working with a varying baseline of energy and emotions. This adds a layer of complexity to considering the options for treatment—how can one as a parent know if they are doing the right thing, especially in relation to the rapidly changing systems of the adolescent body?

A key question throughout this case study has been whether to perform an operation that, although risky, could potentially increase the quality of life for patients such as C. As parents, we have spent a great deal of time deliberating whether an operation would be worth it. While time can help in weighing the options, it is traumatic as a parent to see one’s child spend time suffering in order to gain this wisdom. There is a steep emotional cost of waiting, and we ourselves have experienced dark and difficult thoughts from the weight of responsibility, trying to work out what the “right thing” is to do.

In all, we know little about this disease [42]. The existential weight of living with such unknowns in relation to evidence-based research needs to be taken more into account by our health care system and providers [42]. This combination of existential confusion and dread surrounding a rare disease can be difficult for the patient to handle [43], as major life events and day-to-day processes alike can be brought to a sudden halt. As a parent, it can also be difficult to provide the child the confidence and reassurance that things will turn out okay. We are left with the need to trust the process of diagnosis and treatment to avoid a sense of total hopelessness. The importance of this belief cannot be overstated:

from our experience if the members of the support system lack belief, they can add negative energy, anxiety, and despair into the process, which will hinder the healing process. The feelings of parents that are not able to handle the uncertainty of their child being ill could impact the patient in a detrimental way.

If a child with ME does not have a support family system, they would have to exert even more energy taking them far beyond their coping limits.

At this point in our journey, we have reached a set of fundamental questions about the relationship between patient-parents and the health care system. If a patient cannot handle their symptoms, diagnosis or treatment alone, how can a support network be created and maintained? As parents and family members of patients, how can we support the healthcare system in Sweden? And how can that health care system help them?

### ***The Swedish healthcare system***

We conclude by examining what we can learn from this case study about the Swedish health care system as it stands today.

A key problem faced in this case has been a lack of coordination. Why can the medical field not coordinate doctors—specifically doctors with different areas of expertise—in one clinic or a Centre of competences? This lack of coordination can also be seen in relation to researchers. Why do doctors not coordinate with researchers in the field?

The healthcare in Sweden needs to combine clinics and knowledge exchange with researchers and parents. So why does this not happen? Lack of funding and lack of organizational/management expertise are important contributing factors [44]. There is also a crisis in the Swedish primary care since there are fewer primary care physicians per citizen in Sweden than in other comparable countries [45]. This means that the Swedish primary care system is unable to handle illnesses that are not accepted in mainstream medicine.

This issue extends to a lack of coordination between doctor and patient, which often must be mitigated through external platforms of support. This can include real-life support shown, for example, through the school system, or distributed online. For instance, there exists a meaningful Facebook database where people have shared their narratives with ME. In this Facebook page, patients share data and treatment information. The administrator of the research page is very involved with quality control, report validity, and the sharing of results. There exist various support systems in parallel. This means that patients and parents can compare medicine treatments, diets, and rankings of experts [46]. Why can we not bridge the gap between patient experiences and what doctors currently know? Could this idea of developing platforms of support in between meetings be a cost-effective way of handling the anxiety and despair in parents, the school system, and healthcare staff?

Overall, there is a gap in the healthcare system, where 35,000 patients with ME in Sweden are not able to get the help they need. To date, there have been no other case studies published in Sweden partly since there is no one in the healthcare system that can take responsibility for this process. When a parent

starts to lose trust in the healthcare system, one might enter a loop of distrust between not only patient and doctor, but between patient/parent and society. There is a danger in this process, not to mention the high financial and emotional cost to the family, which ultimately ends up taking 100% responsibility.

ME research has started to become a priority in the wake of post-COVID recovery [47]. Post-COVID patients are prioritized because, in the eyes of our society, they are suffering more than long-term ME patients [48]. This is unfortunate and intolerable, in particular since the long-term chronic fatigue that develops in some covid-19 patients may actually be ME. Who is ultimately in charge of our society's priorities related to new post-modern disorders? More broadly, how can we use this shift as an opportunity to begin addressing the gaps in coordination and care in the Swedish healthcare system?

## 6. Conclusion

This case study provides insights from a first-person parent perspective on how Swedish healthcare works in a newly discovered ME in a 17-year-old woman. Specific recommended medications, treatments, and therapies from 13 different specialists are presented but coordination between them does not exist. When you as a parent begins to lose confidence in the care, we end up in a loop of mistrust between not only the patient and the doctor but between the patient/parent and society. More resources are needed to coordinate ME treatments with ME research between different health care providers in Sweden.

## Acknowledgements

Warmly thanks to MD, PhD. Jacob Theorell and MD, PhD Walter Osika for all good advice and support during C's, struggling with her ME. We also direct our thanks to Open Medicine Foundation (OMF).

## Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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