Patient case: myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome June 2016–January 2021

Samuli Tani

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Contents

Preface

I became ill with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in June 2016, immediately after the enterovirus infection.

I've gathered data on my performance, well-being, and treatments into a spreadsheet from the beginning of my illness in summer 2016 to the present. The data I have collected is unique. I believe it will help understand the clinical presentation of the disease and work as a practical example of well-functioning care relationships and well-functioning care pathway.

Experimental and symptomatic medication has been of fundamental importance in increasing my performance and quality of life. I've also received valuable support from physiotherapists and a couple therapist.

Hindsight

- My condition should have raised a suspicion of ME/CFS in the early stages. I had just contracted an infection that was known to have caused severe sequelae that same summer. My muscle weakness was pathological. PEM (post-exertional malaise) would have been noticeable weeks before my observations if it had been asked about and measured.

Performance and life situation before illness

I'm a male, 33 years old at the time of disease onset, height 189 cm, weight 88 kg. My symptom severity was moderate (severe on individual days) according to ICC (International Consensus Criteria) for the first 1.5 years and mild since summer 2018. I consider myself still unable to work.

My job as a chef was physical. I usually did weekly five 7.5-hour shifts, during which I rarely took breaks other than a short meal break. During the high season, working days could last from eight in the morning until midnight.

I went to the gym 2–4 times a week in addition to my work and passed some university math exams from time to time, studying maths an hour now an hour then in the evenings after work.

The rest of my time I spent with my wife and two children. I didn't find my life stressful at the time I became ill. It had been two years since the previous stressful period in my life when I was getting used to my new profession and job. I had regular sleeping rhythm and slept well.

For years, I had occasional coughs at work, and I also often woke up at nights to the feeling that my arm has gone numb or "dead". I was diagnosed with asthma shortly after I became ill.

I used alcohol a bit over the recommended maximum intake, ranging from about 4 to 10 servings a week.

I have been diagnosed with a disorder of activity and attention in adulthood, for which I used lisdexamfetamine (Elvanse) as a regular medication before I became ill. There were no problems with the drug. After becoming ill, my tolerance to the drug weakened and I now use it only when needed, especially when driving a car.

The year before I got sick, I had multiple infections. I got all the flus from my daughter from kindergarten and missed a third of my gym workouts because of flu symptoms. However, I was rarely on sick leave from work.

Data gathering

I decided to start recording data on my performance and well-being after I noticed that my doctors didn't have other experiences of similar patients nor understanding of the symptom picture of my illness. I wanted to give them the best possible information on my condition to support my treatment. I was used to using statistics in my previous profession and my gym workouts.

I was severely ill when I started filling the spreadsheet. I could barely take care of myself, but not my children. I wanted the data collection to be efficient so that I could do it even if my condition deteriorated. The data also had to be in numerical form to be visualized and for possible patterns to be identified from it. I tried to make written notes of my condition in the first few weeks of my illness, but I quickly found it useless because of difficulties in interpretation.

I chose two questionnaires appropriate for my situation from an extensive literature review (IOM report): EIPS and D-FIS.

In addition, I listed the essential symptoms of the IOM criteria: cognitive difficulties, orthostatic intolerance, sleep problems, PEM (post-exertional malaise), and so on. I inserted these into the spreadsheet with boolean values of 0 or 1, one on days when the symptom made life difficult, zero otherwise.

After three months, I went through the material with a statistician. Data seemed viable, and I decided to stick with the same template, as I have done to this day. Filling out the spreadsheet takes 5–10 minutes a day.

PVM	EIPS	D-FIS	PEM	Unref. s.	CogImp	OrtInt	Päänsärky	Lihaskipu	Elvanse	Beta	LDN	Unet (h)	Lapset	Harrastus	Liikunta	Laji	Matka (m)	Aika (min)	inopeus (k
25.11.2016	2	17	0	0	1	0	0	1	0	0	0	7	1	0	0	Kävely	1070	70	0,9
26.11.2016	4	15	0	0	1	1	0	0	0	0	0	7,5	0	0	0	Kävely	3500	140	1,5
27.11.2016	4	6	0	0	0	0	0	0	0	0	0	7	1	1	1	Kävely	1700	44	2,3
28.11.2016	4	11	1	0	0	1	0	0	0	0	0	7	1	0	0	Kävely	2600	134	1,2
29.11.2016	2	13	1	0	0	1	0	1	0	0	0	6,5	1	1	0	Kävely	540	23	1,4
30.11.2016	5	4	0	0	0	0	0	0	1	0	0	6,25	1	1	0	Kävely	1000	50	1,2
1.12.2016	5	4	1	0	0	0	0	0	1	0	0	7,25	0	0	1	Kävely	4480	135	2,0
2.12.2016	2	15	1	1	1	1	1	0	0	0	0	4,5	0	0	0	Kävely	1500	75	1,2
3.12.2016	3	10	1	0	0	0	0	0	0	0	0	6,5	0	1	0	Kävely	0	0	
4.12.2016	3	2	0	0	0	1	0	0	0	0	0	6,5	0	0	0	Kävely	0	0	
5.12.2016	4	2	0	0	0	0	0	0	0	0	0	7	1	0	0	Kävely	1650	63	1,6

Table 1: A sample from the collected raw data

Enteroviral infection and the first weeks

Just before the summer holidays in June 2016, I felt ill in the morning. I would have stayed at home in normal circumstances, but after being ill all the time for the last year, my threshold to take sick leave from work was very high. I did a double shift from morning to evening even though I struggled to stay upright from the afternoon onwards. I moved a chair next to the stove and did the rest of my hot kitchen duties seated.

I went straight to the ER for checkup that evening.

Problems
At 22:26 seeks emergency care due to feeling feverish and weak.
Anamnesis
Woke up in the morning feeling unwell but still went to work. At work gasped for breath, tired quickly, and sometimes had to sit to rest.
Has ate and drank normally.
Measures Taur 38, p 110, quick crp 28.
Cons. a dr who listens to his lungs, clean breathing sounds.
Gets fever/pain medication instructions for the night.
Possibly a viral infection, not an ER case.
Plan
Seeks care from regional health center in the morning, if needed

After a few days, I was diagnosed with HFMD (hand, foot, and mouth disease). The infection was severe but rapid. The pain was so severe after the onset of skin symptoms that I could not sleep at all on the first day. The fever subsided in a couple of days. Skin peeled off my palms and soles.

In the first weeks after enteroviral infection, I complained of general exhaustion, not much else. I went to the doctor a few times. I was found to have a streptococcal infection in my throat that was treated with antibiotics. Blood tests including thyroid tests were normal.

My wife was frustrated with my behavior. To her I seemed lazy and slothful. I cut back on what I did and moved less, but I didn't really pay attention to these changes. About a month after the infection, I went out for a run, and after taking a few running steps, I quit and reasoned to myself that "I don't feel like it today". Since June 2016, I have been unable to engage in intense exercise to the point of getting out of breath (en ole pystynyt hengästymään, miten se ilmaistaan englanniksi, hengästyminen on positiivinen tai neutraali asia suomenkielessä, normaali osa liikuntasuoritusta). I was undoubtedly already sick at the time of this jogging attempt, but I explained the symptoms away as my own decision not to run.

I have met patients, including those who live with severe symptoms or have gone through a period with severe symptoms, who have been equally unaware of their symptoms at the onset of the illness and at the most felt that they were suffering from some temporary malaise or exhaustion.

Chronic fatigue syndrome (ME/CFS) was observable

When I returned to work after the summer holidays, my symptoms quickly began to resemble clear-cut chronic fatigue syndrome (ME / CFS). My performance started to fluctuate, deteriorating during and after workdays. Recovery was much slower than usual. I began to suffer from a dizziness-like feeling where I felt the street or floor running beneath me slowly like a treadmill. Based on the information I collected later, my heart rate rose sharply during these episodes, but I did not yet measure it at this stage.

A few months earlier, I had been able to do a hundred squats and twenty push-ups in one go. After a full day of work, I had been able to do an hour of gymnastic strength training without any recovery problems.

After three weeks of work, my co-workers called in a substitute and sent me to the doctor's office in the middle of the day. Because of the muscle weakness, I could no longer grate cheese nor get up from a squatting position without using my hands for support. I was able to walk a few hundred meters without resting in between.

My condition improved significantly at the beginning of my sick leave. After a few days, I felt so good that I thought I could return to work. My diagnosis of asthma was confirmed at the same time, and with my occupational health doctor, we made the assumption that untreated asthma was causing my problems.

I began to treat my asthma according to treatment recommendations with medication and exercise, doing light Nordic walking.

The light walks caused an unexpected response. I was able to do one walk without any problems, but after several days of walking, my performance dropped dramatically. I tested the reproducibility of the phenomenon by resting for a few days between walks, and the end result was the same. My ability to recover had decreased to a fraction of normal.

I gave up Nordic walking and switched to walking, during which I used a heart rate monitor to make sure that my heart rate did not rise above 110 bpm, i.e., it would be at the lower limits of the base fitness zone at most.

I went for two walks on October 20, 2016, for a total of about 1.5 hours. I did not feel unwell in the evening, and there was no noticeable decrease in performance. However, the next morning, my walking speed had crashed and stayed at around 2 km/h for the next nine months.

My occupational health doctor ordered me to take a stress test, which I did on October 14, 2016. I had to interrupt at 100 W due to fatigue. My heart rate was 169 when I stopped. My hands were shaking, and I had a hard time being upright. The cardiologist who performed the test said he had performed 10,000 similar tests during his career without seeing a similar case before.

Towards the end of the exercise test and about 10 minutes after that, I couldn't think clearly. I also had problems standing for the rest of the day. Immediately after the experiment, I lay on the couch in the reception lobby for an hour. Twice during the rest of the day I had to go to bed again because in an upright position, I felt weak and "stars" appeared in my field of vision.

My chronic Fatigue Syndrome (ME / CFS) was observable at an early stage, especially based on clear PEM (post-exertional malaise) symptom.

Cognitive problems intensified at a later stage in November 2016, after more than two months on sick leave.

My heart rate rose from 80 bpm to 120 bpm while standing, and I had considerable difficulty staying upright, especially when I was standing still, e.g. while queuing or cooking.

In practical chores, my performance had deteriorated to less than a half, which is required by some of the diagnostic criteria.

In November 2016 I met the following diagnostic criteria:

- International Concensus Criteria 2011 (atypical)
- Institute of Medicine 2015
- Revised Canadian ME / CFS 2010
- Canadian Consensus Criteria 2003 (with mild but novel muscle pain)
- Fukuda 1994 (with mild but novel muscle pain)

Symptom description from November 2016

In November 2016, I gave my occupational health doctor a summary of my findings:

Certainly

- My ability to recover has deteriorated to a fraction of normal.
- My tolerance for exercise has deteriorated to a fraction of normal.
- Exercise makes symptoms worse, especially if my heart rate rises well above the resting heart rate.
- The peak of a collapse caused by exercise comes with a long delay (12–48 h).

Quite certainly

- The deterioration started immediately during or immeadiately after enteric and streptococcal infections.
- Dizziness is the result of exercise in which the heart rate is elevated for a long time or for a shorter time near the maximum heart rate.
- After exercise or prolonged exertion (cooking at work), I do not tolerate standing still.
- Elvanse (lisdexamphetamine) raises my hear rate peaks when I get up to stand (Polar heart rate monitor).
- My tolerance to cold and heat has decreased.
- I sweat less than before.
- Prolonged continuous cognitive exertion (especially counting, doing two things at the same time) causes exhaustion.

Perhaps

- Exercise and prolonged exertion (cooking at work) impair my cognitive performance.
- Finger numbness and challenges with fine motor activities were the result of jaw pulls and other fitness drills.
- My pain threshold has decreased.

The effects of illness in everyday life

I have made my life as simple as possible and followed a similar rhythm throughout my illness. My condition improved rapidly during 2018 with several metrics I have monitored. I presume that the natural course of the illness has been

the most significant factor in these changes. The improvement in cognitive performance is due to naltrexone, an experimental medication. My monthly total walking distances have remained steady over the long term, although my power output (walking speed) has increased significantly. The performance of the home chores and the time spent standing up have increased a lot, but I have no numerical data on them.

I connect the increase in my walking speed with taking a month of intense rest in July 2017 and the use of assisting device when going out. Unfortunately, I can't go back in time machine to see what would have happened if I had acted differently.

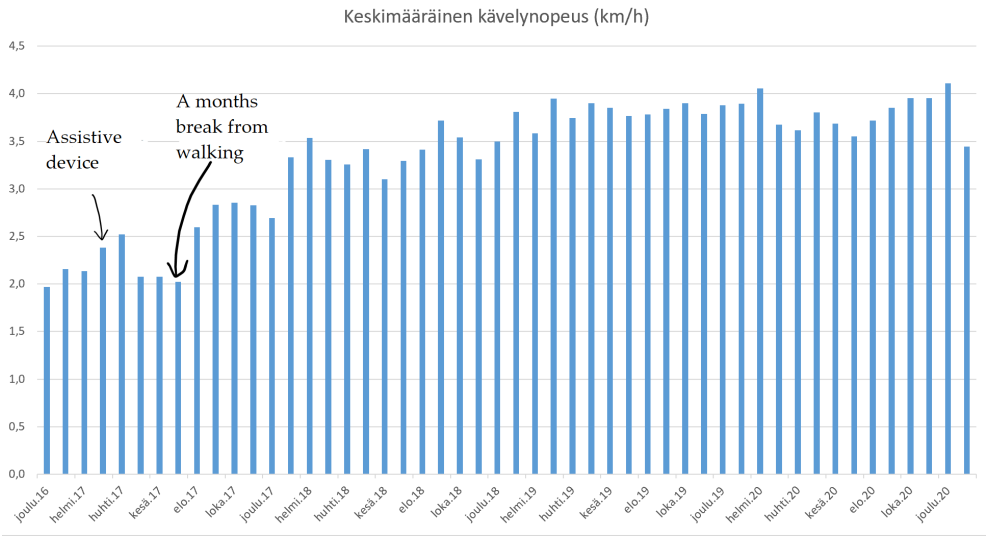

Figure 1: Y-axis: average walking speed (km/h). X-axis: month.

PEM symptom and ability to exercise

From the onset of the illness to the spring of 2018, my symptoms varied greatly depending on how much I strained myself. In the early stages of the illness, light walks caused such a strong delayed muscle weakness that my wife sometimes had to help me get out of bed. During the first year, I couldn't get up from the couch other than by rolling on the floor on my knees and taking support to get up. Recovery from PEM symptom took 2 to 3 days or longer. I used a wheelchair when shopping in bigger stores.

Since 2018, my PEM symptom has alleviated and their duration shortened. My walking speed may drop under exertion during the day but usually returns to baseline the next day without provoking severe weakness or other symptoms with a delay. However, I still find it awkward to walk regularly over 2 km a day.

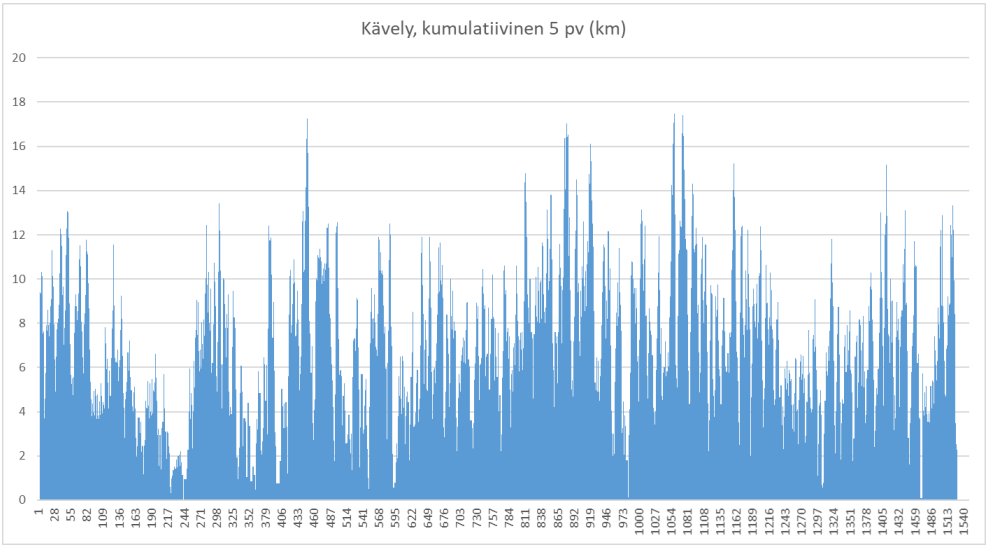

Figure 2: Y-axis: total walking distance in the last five days (km). X-axis: date's ordinal number.

Pacing and monitoring of activity

When my physical abilities collapsed, I was quite worried about what was happening to my body as a result of not being able to exercise. I felt that I was moving extremely little and believed it would cause damage to my body. So I made myself a rule to move as much as I can but reduce strain if my condition worsens.

My performance remained consistent this way, with my average walking speed staying close to 2 km/h. Orthostatic intolerance and feverish colds eased somewhat over the months, so I stuck to my rule. However, in spring 2017, my performance deteriorated further. I couldn't get up from the dining chair without support anymore and had short periods when I had difficulty walking from room to room in my home.

I decided to try stronger actions. I had got myself an assistive device, a two-wheeled personal transporter (Segway), but in addition, I decided to stop walking for a month and see what happens. The decision was made easier by the fact that my physiotherapist had told me that I was moving enough to avoid rapid muscle wasting.

I used my assistive device and walked only if I had to. In July 2017, I walked only 9 kilometers in total. My walking speed bounced from 2.0 km/h to 2.6 km/h (30 % improvement) and continued its slow climb, being already 3.5 km/h (75 % improvement) after six months. During these six months, I walked an average of 38 km a month, which was almost the same as what I had walked on average for the six months before my experiment.

Two day cardio-pulmonary exercise testing

I had a CPET (cardiopulmonary exercise testing) done on two consecutive days in February 2018. In some ME/CFS patients, functional impairment and PEM

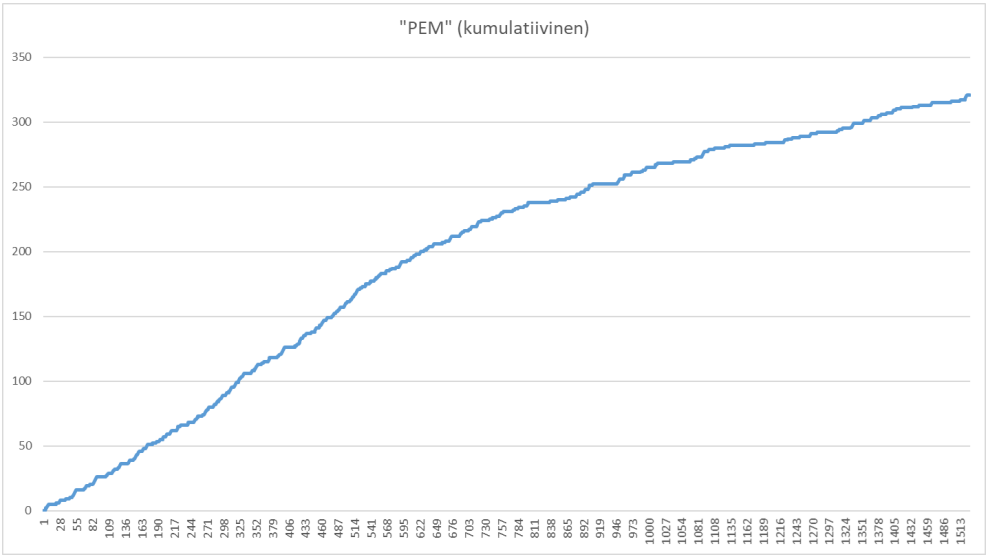

Figure 3: Y-axis: accumulation of ”YES”-answers to the question ”PEM” Yes (1)/No (0) Has my condition suddenly deteriorated? X-axis: date’s ordinal number.

symptoms can be objectively observed with this testing protocol.

For me, the performance of the second day was interrupted earlier than the first day, but it was not possible to objectively demonstrate from the respiratory gas analysis that I had reached maximum performance. I am morbidly incapable of panting, and I invariably lose strength from my muscles before I can raise the intensity of the performance high enough to breathe hard.

(Machine translation, Microsoft Translator, Finnish-English)
Opinion of a specialist in exercise medicine on the first stress test:

Length 190 cm, weight 89 kg. In the rest ECG, the sinus rhythm 92/min, the conduction skins and QRS complexes within normal limits. Blood pressure at rest 110/78 mmHg. In rest spirometry FVC 6.88/109%, FEV1 4.79/95%, FEV1% 69.98/87%, PEF 9.93/87% and MEF50 3.77/63%. FEVV1% marginally reduced.

Pedals first in spiroergometry with 2 min 0 W, then load staircase 20W/2 min ad 120W/1 min and 18 s at final heart level 168/min. Interruption due to leg fatigue, subjective exertion 18/20 on the Borg scale. Blood pressure rises to a maximum of 156/84 mmHg (80W), then drops to 122/70 (100W) and rises again under maximum stress ad 136/80. Maximum ventilation 88 l/min, breathing reserves remain 52%. Oxygen pulse rises ad 9.0. Oxygen saturation remains normal during exertion.

Under maximum stress, tremors in the upper limbs, no other symptoms. In the stress ECG, no takyarythmions, including abnormal st-level changes, are registered for 2 individual ventricular boosters.

Maximum oxygen uptake 16.3l/kg/min corresponding to fitness class 1/7. Lactats rise to 2.60/mmol/l.

RATING: Performance weak. In the second half of the strain, blood pressure fluctuosized slightly, otherwise the circulatory function was not special. Maximum ventilation remains low.

Opinion of a specialist in exercise medicine on the second stress test:

Make spiroergometer No 10. II, first done the day before. Pedals first in spiroergometry by 2 min 0 W, then load staircase 20W/2min ad 120W/28 s at final heart stop 166/min. Interruption due to leg fatigue, subjective strain of 17/20 on the Borg scale. Blood pressure rises to a maximum of 148/84 mmHg (100W), then decreases slightly to 138/70 mmHg. Maximum ventilation 41 l/min, breathing reserves remain 77%. Oxygen pulse rises ad 8.6. Oxygen saturation remains normal during exertion.

There are no symptoms of maximum stress. There are no takyarythions or additional batting in the stress ECG, including abnormal ST-level changes.

Maximum oxygen uptake 16.3/l/kh/min corresponding to fitness class 1/7. Lactats rise to 2.30/mmol/l.

RATING: Performance weak. Moderate blood pressure reaction, otherwise the circulatory function is not specific. Maximum ventilation remains very low.

Compared to spiroergometry on 27 February 2018, the strain is 6.3% shorter. The maximum oxygen uptake remains unchanged, as does the maximum heart rate. Lactats rise to the same level.

Fatigue and sleep problems

I felt suffering from fatigue in its usual sense only at the beginning of my illness before starting asthma medication.

Instead, in the first months of my illness, I had trouble falling asleep and waking up. My fatigue was completely different from what I had ever experienced. I call it a "drop-in alertness" in my own mind. In the first months, there was more of it, often around the same time in the early evening. Listening to and keeping track of other people's speech became more difficult first, then supporting myself and keeping my eyes open turned into a fight, and eventually, I fell asleep on the couch I was sitting on.

As the symptoms of the disease abated, sleep-related problems changed their nature. After a few months, the difficulty of falling asleep and the exceptional morning spryness (I'm normally most active in evenings and at night time) switched to a difficulty waking up. I feel dead tired in the morning, no matter how much I have slept, and I can start getting out of bed 30-45 minutes after waking up. Fortunately, the condition is made easier by waiting and only requires me to set an early alarm.

Sleep has been unrefreshing throughout my illness in the sense that sleep does not affect things like muscle weakness or cognitive problems, they live their own lives and are partially relieved by rest, but rest periods or lightening the load must be longer than a night's sleep to have effect.

Cognitive problems

I've had and still have difficult problems at times with concentrating, working memory, and recalling. At a practical level, these have manifested in the following ways:

- While having mortgage negotiations with my bank in early 2017, I had to ask my father to listen to the conversation through a speaker. I couldn't follow the conversation with the bank clerk, and my dad whispered my answers to my ear.
- Sorting my children's laundry into a couple of piles from the drying rack was impossible without using post-it tags on top of the piles. After folding a piece of cloth, I immediately forgot which type and which size of clothing was in which pile.
- I could not have a group conversation for longer than 10 minutes at a time because the plot of the conversation was so hard to follow and I couldn't recall what had been said a moment ago. One-on-one conversations were much easier to handle.
- Before I fell ill, I had read Fyodor Dostoevsky's The Brothers Karamazov. I had paused in a chapter that begins like this: "The Karamazovs' house was far from being in the center of the town, but it was not quite outside it. It was a pleasant-looking old house of two stories, painted gray, with a red iron roof." For the first 1.5 years after falling ill, I was unable to continue the book from that point forward because it was insurmountably laborious to imagine the house's location or its color and shape. I was somewhat able to read familiar non-fiction. Mathematical reasoning was hard or impossible.

For an outsider, my cognitive problems manifest as slowing down, being silent, and indifference or forgetfulness.

My personal experience of cognitive problems is that everything, including normal daily chores and conversation, starts to feel like I'm trying to solve a little too difficult sudoku or other puzzles. After a short time, struggling against my illness becomes impossible as I get exhausted. Trying the same task again requires a break of many hours.

In my case, cognitive problems were not noticeable in neuropsychological tests, before which I was well-rested.

(Machine translation, Google Translate, Finnish-English)
Excerpts from a neuropsychologist's statement from May 2017:

"According to TV, cognitive difficulties appear in the conversation, can talk for 1–1.5 h between the two of them, are not able to follow the conversation in the group. Reads light text, web, magazines, but is not able to analyze deeper read text, etc. Studied mathematics at university, but today is reportedly unable to keep mathematical expressions in mind so as to be able to analyze and structure them. When it comes to memory, you feel like you don't remember the events of the previous day or it takes a lot of effort to remember things. "

"Tva describes his cognitive situation in such a way that more demanding thinking is awkward and therefore tries to pinch more at that time, which then results in exhaustion."

"There is no systemic neurological memory impairment. Tva's cognitive factors have no effect on work ability. Fatigue-related problems experienced by TV, such as muscle fatigue, the need for rest, strain and fatigue due to physical and cognitive exertion, are central to work ability. "

"Now still strong muscle fatigue, exhaustion from sensitively greater stress, also describes cognitive problems. Now you can't get up from the squat in the status and one-legged jumping is only a couple of times uncertain, you say that you have been active in the gym and done repeated squats without any problems. "

Orthostatic intolerance

Standing, especially when stationary, was very stressful for me in the first months of my illness. After standing for a while, my heart rate rose from resting heart rate (~80 bpm) to 110–150 bpm. Doing household chores while standing was exerting, and I could take it for only 15 minutes at a time.

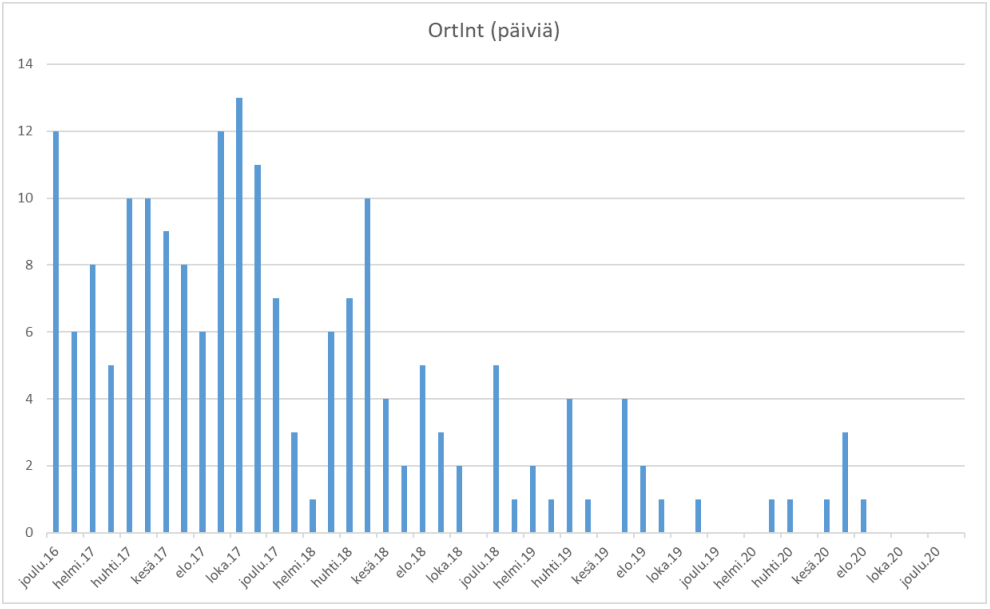

Figure 4: Y-axis: the number of days I've answered "YES" to the question OrtInt Yes (1) / No (0) "Have I had to quit a daily chore because I felt a compelling need to lie down or sit while standing?". X-axis: month.

Other symptoms

Alcohol intolerance. I no longer get any pleasure from drinking alcohol, and I get a hangover quickly after consuming even a single alcohol unit.

Reduction in sweating. I've been sweating all my life profusely until I got sick. My armpits and back were often wet even after a light walk, and I always sweated if it was hot. After falling ill, my sweating (that can be sensed) stopped entirely for months and has only partially recovered.

Falling asleep in a new position. I was a side sleeper until I fell sick, but afterwards, I've been able to fall asleep only while lying on my stomach.

Feeling cold. For the first months of the illness, I felt cold constantly and tolerated heat poorly. Taking a sauna raised my heart rate quickly to over 140 bpm and caused dizziness and weakness.

My experiences of treatment

By coincidence, without top-down instructions, I've been treated in accordance with the new treatment guidelines (released in February 2021). My diagnosis was confirmed about six months after my first visit to an occupational physician. Diagnosis was preceded by comprehensive tests in specialist care, functional capacity testing, and close monitoring. Diagnosis was made on the basis of symptoms and exclusion, according to IOM, ICC, and Fukuda criteria, on ICD code G93.3 (postviral fatigue syndrome).

The key was the collaboration between myself and my doctors. Three public sector specialists (psychiatrist, neurophysiologist, neurologist) gave me an unofficial suspicion of diagnosis. In addition, I sought information on reactive muscle weakness and found out that it is a strong indication for chronic fatigue syndrome (ME/CFS). My occupational health physician was unfamiliar with the disease but made accurate observations and delved into the materials I had been able to collect and send him during my first months of illness.

The medical certificates of my occupational physician were of a very high standard. The Social Insurance Institution of Finland granted me a sickness benefit with the sole diagnosis of G93.3 for 10 months out of a maximum of 12 months.

The symptomatic medication (temazepam), for sleep problems, and the experimental medication (naltrexone 3 mg), for the disease itself, prescribed by my occupational physician were carried out in agreement, and I kept a careful record on my condition during treatments.

After becoming unemployed, my treatment continued at the local health center. I selected my physician by making a search engine query of the names of the physicians at my nearest health center, looking for positive customer feedback. My physician has continued the experimental treatment and, in addition to careful follow-up, has carried out a placebo-controlled n=1-trial with me to ensure that the medication is necessary.

Since my initial examinations, all my health care needs have been met in occupational health care and primary care, and I spend 1–2 appointments per year at a doctor's office.

Experimental medication multiplies my performance and may allow me to return to work (in some desk job) in the future. Without naltrexone medication,

I am completely incapacitated for work, but medicated, I am partially able to work at the moment. If I had worked in a specialist position before I fell ill, I believe I could've already returned to work part-time.

Naltrexone

After it became clear that I had chronic fatigue syndrome (ME/CFS), I quickly decided not to use medication.

I had read patients' experiences, and my impression was that everything possible is perceived as helpful and everything possible is associated with recovery from the illness. I was grateful that others had taken care of experimenting for me and concluded that it was better to spend my time on something else. The condition often fluctuates on its own, and spontaneous recovery is possible.

Yet one drug caught my attention. There were more positive comments from ME/CFS sufferers using naltrexone than from users of other medicines. It was also a cheap drug and, at the dosing used for ME/CFS (1.5-4.5 mg per day), quite harmless in its side effects.

I brought the information I had dug up online about the drug to my occupational physician and asked him to give it a go. We agreed to do a follow-up, and if the medication weren't helping, he'd stop prescribing it.

The first experiment lasted only two weeks due to sleep problems. Next time went better after I ramped the dosage up slowly. After two months (June 2017–July 2017) of using naltrexone, my wife told me that I'd changed completely. I hadn't been able to have a group conversation for longer than 10–30 minutes for six months due to troubles with keeping focus and memory problems, but now I was able to talk for a couple of hours in a restaurant and follow the conversation.

Then, after a three-month period (August 2017–October 2017) without medication, my wife said that she feels like she's living with someone who has dementia. I didn't feel the changes were that dramatic and was skeptical about the drug's efficacy. I continued taking the medicine in on-off-cycles. It seems obvious that the drug has had a strong positive effect on my capabilities in the long run.

Severe cognitive problems have become infrequent and almost disappeared since I started the drug, and when I'm off it, clear spikes in the frequency of the issues appear.

The last on-off period on the chart is placebo-controlled. At my request, my physician prescribed me placebos. It was easy to do because the pharmacy presses the 1.5 mg naltrexone tablets and placebos of the same size.

My wife used duct tape to tape the labels and tossed a coin to decide which packs she labeled as" A" and" B". I tossed a coin to decide between As and Bs. The test period lasted 100 days + 100 days, and neither of us knew whether I was on placebo or not.

The tablets do not have a protective layer. I thought that I might be able to sense a difference, so I swallowed them with plenty of water without looking at them. I caught a glimpse of the tablets two times while opening their bottles and contemplated if there was a difference in color or size to the usual.

At the end of the test period, I compared the A and B series tablets side by side. The diameter of the tablets is the same, but there was a noticeable

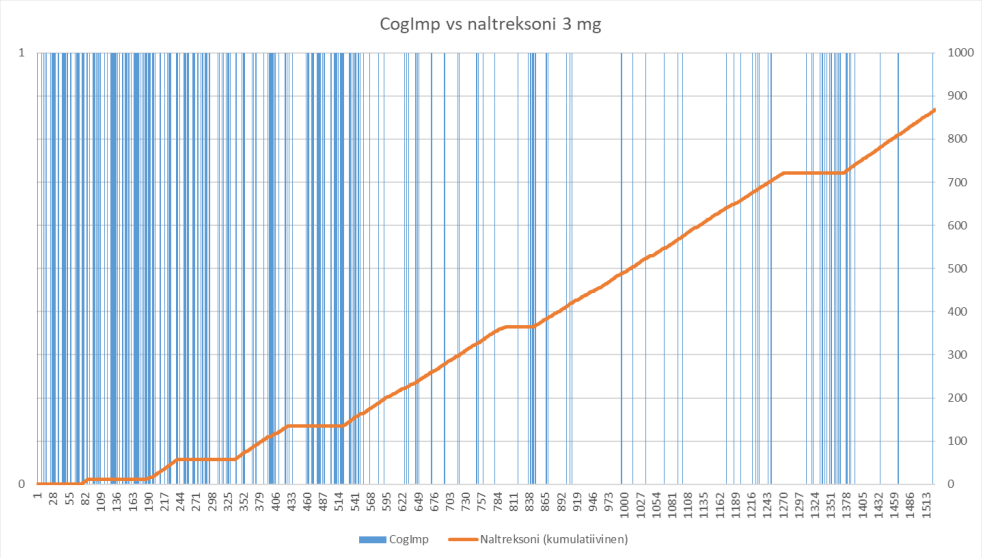

Figure 5: Y-axis: the blue line is ”YES”-answer to a question CogImp Yes (1)/No (0) ”Have I had noticeable cognitive difficulties, the kind of that I’ve had to quit reading a paper or stopping a conversation or quitting a similar everyday task?” Y-axis right side: The cumulative number of naltrexone doses (orange line) Y-akselin oikeassa laidassa kertyneet naltreksoni-annokset (oranssi viiva). X-axis: date’s ordinal number.

difference in thickness side by side.

The effect of the drug begins with a noticeable delay. I don’t notice any immediate effects when quitting or starting. In my records, the entries related to difficulties start to get higher and grow in frequency after stopping the medication, with a 4–6 weeks delay. After starting the drug, the first positive signs appear in the records after 2–4 weeks.

The placebo-controlled period was my longest period without naltrexone during my entire follow-up. The perceived harm slowly increased and was at the end of the test period at the same level as at the beginning of my illness.

I don’t feel that naltrexone has an effect on physical performance. My physical performance improved after starting naltrexone medication, but at the same time, I radically reduced walking using an assistive device, and on the other hand, when I’m off the drug, there are no effects on the average walking speed.

While on naltrexone medication, I can do stuff that resembles office work 2–4 hours per day. If I take a break from the drug for a few months, the time reduces to an hour per day.

Two things, naltrexone and activity management (pacing), have been the essential parts of my rehabilitation based on my record keeping. I also use a few other treatments and methods.

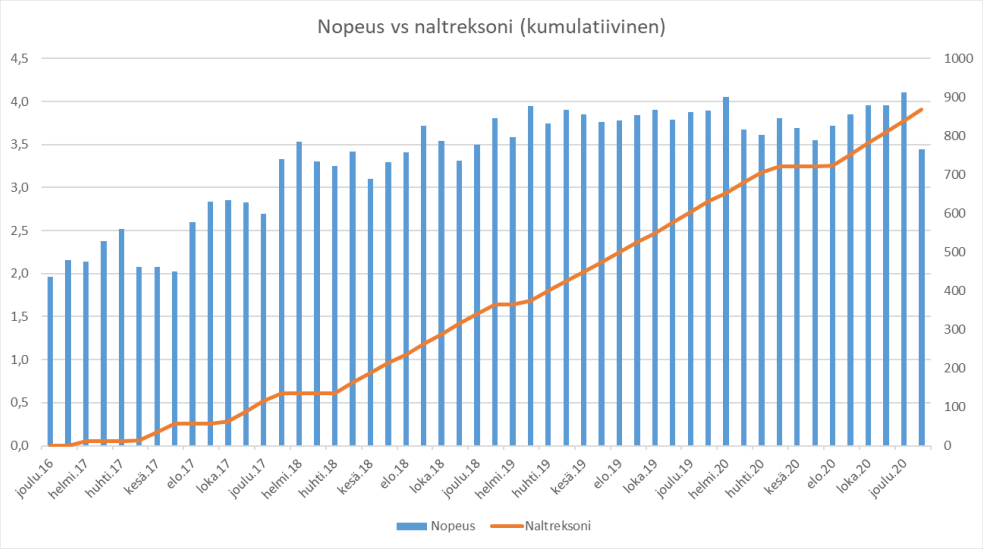

Figure 6: Y-axis left side: average walking speed (km/h); right side: the cumulative number of naltrexone doses (orange line). X-axis: month.

Other treatments and methods

Lisdexamphetamine (Elvanse). Original treatment indication was for ADD. After falling ill with ME/CFS, using it for multiple days in a row causes a decrease in performance. It has been helpful for ME/CFS-symptoms also because it predictably reduces cognitive difficulties for a few hours on a single day. The drug is beneficial if something needs to be done at a specific time. I've had to use a beta-blocker with lisdexamfetamine since falling ill.

Tematzepam (Tenox). Has a significant psychological effect because I know that I can certainly fall asleep with the drug, so I stress less about sleeping. I use it every 1-2 weeks. I think that difficulties with sleeping are related to overload and PEM-symptom.

Meditation. I learned the skill in the late 2000s before I got sick. Helpful in calming down and falling asleep. I always use meditation as a first recourse before relying on medication.