**My Brain Deterioration Due to Myalgic Encephalomyelitis**

(Please share with professionals, patients, or others who may benefit from a

patient’s firsthand account of this disease.)

My disease is currently so misunderstood, I was hoping my firsthand experiences might provide insight to help researchers looking for a cure. I think the physical symptoms are fairly well documented so I’m only going to focus on the mind. As my disease gradually progresses, I find myself losing mental functions. Some of them I worked very hard to cultivate and their loss is frustrating while others I took for granted. In my youth, I thought anyone could do them with a little practice; however, now that I am losing abilities that I have been able to do my whole life, I realize how special they were, and practice was not the key. These things are higher level functions in the parts of my brain that are being damaged. I lived with this disease for several years before some of these things manifested so they cannot be used to diagnose but they could be used to give someone an idea of what to expect. Due to my computer science degree, I often find analogies between computer hardware and a human brain or between firmware and a person’s philosophy. Thus, I sometimes find myself using terms from one subject to describe the other.

**1. Short-term (10-20 sec) and medium-term (<1 day) memory loss** – This is the most common (and often only) cognitive symptom which is attributed to my disease. For most people, this presents as a simple forgetfulness to do a task such as taking your medication or not remembering that you already did take it. I have noticed a correlation with this type of memory loss: it is directly proportional to the quantity of sleep I get (long term, not day-to-day). When a normal person sleeps, their brain uses this time to sort their memories of the previous day, deciding which memories are important enough to move into long-term memory and which are insignificant and can be deleted. You may be anticipating that I will say sleeping more than normal causes me to delete more than just the trivial files and start removing things which I would rather keep. There may be a little of that going on, but that’s not the important idea here. The excessive sleep isn’t just damaging the memories, it is damaging the memory centers themselves. It prevents me from being able to input new memories. This means I can’t remember things the same day they happened without the need of sleep to remove them. I believe there is some mislabeling going on as well such that things are classified as unimportant when they aren’t. My brain is my most important asset. It is literally who I am. I worked very hard to carefully mold it into what I want it to be. So obviously I go out of my way to manage my disease to prevent as much damage as I can. Unfortunately, it seems impossible to stop the degeneration; I can only control the speed. This means I force myself to live in a low power mode, staying bedridden to minimize my excessive need for sleep. Even like this, there is a gradual deterioration, not noticeable day to day but, if I compare myself to how I was six months ago, it reveals itself. If I ever use too much energy, rather than sleeping for half a day, I’ll sleep for three or more days. Upon waking, I discover a noticeable and permanent jump in my memory problems. I don’t really know how to quantify the changes I see but those three days can be equivalent to three months’ worth of degradation. And it doesn’t just affect my memory; all the following bullet points worsen as well (and I fully expect new issues to come up as my disease progresses). It is worth mentioning that, while these three-day recoveries are usually set off by physical activity, I have been known to instigate them solely by mental exertion, such as spending too much time programming.

**2. Long-term (> month) memory loss** - I used to have a powerful memory. At university, I would sit in class and focus on the lecture, committing everything to memory on the spot. This is done by making my brain believe the topic was interesting. Most of the time it genuinely was, but occasionally I had to artificially induce this state of mind. I found taking notes distracted me and I learned less when I tried. I didn’t need them anyway; I decided cramming before a test wasn’t a true measure of my knowledge, only of how much I’d forget the next day. I got A’s just by listening. And I retained that knowledge. But I can’t do that anymore. Once a week, my friend and I will link our computers and stream a tv show together. We’ll watch two or three episodes per week (the limit of my energy supply). So, if a show’s season was 26 episodes, it would take us several months to complete. After we finished, we’d switch to a different show. The next year, when the new season of the first show came out, we’d return to it. We’ve been doing this far longer than I’ve had my disease. It’s only recently that I find myself unable to recall what happened in the previous season. I remember the show for the three months while we are watching it but, by the time the next season comes out, I’ve lost it.

**3. Mental association** - In computer science terms, I used to be able to consciously set mental event handlers or listeners. These are triggers such that, when one event happened, it would remind me to do the other event. For example, when I would make my grocery list, it was all in my head. I would be able to program my mind, “when I go down the dairy aisle, buy milk.” Thus, when I was making my way through the store and came upon the correct aisle, it would prompt me to buy the corresponding items. This is different from, “when I see milk, buy milk.” I think, in that situation, there is a little bit of on-the-spot calculations going on in the background to see if you really need milk; it is not the memory association I am trying to describe. I could set the trigger to be anything, not just the product itself: “when I see bread, buy milk.” This method freed up my mental to-do list, allowing me to focus on more important tasks. This may seem similar to my medium-term memory loss, but there is a different mechanism behind how it works. The medium-term memory is more like a simple checklist which I could recall at will, but this mental association is not something I would be consciously aware of until the trigger event occurred.

**4. Internal clock** – I used to have a surprisingly accurate internal clock which I could leverage for such things as setting reminders for myself. I would think, “remind me in 3 minutes to go stir the pasta on the stove.” Then I would go back to concentrating on my other task, honestly forgetting about cooking dinner until 3 minutes had passed. This may seem trivial but suddenly finding yourself unable to estimate how much time has passed is disorienting.

**5. Multitasking** – I once heard a theory that humans are incapable of true multitasking and that what we do instead is the same as how an operating system uses paging. In essence, we can only focus on one task at a time but our attention switches between tasks in fractions of a second, so we don’t notice it. It gives the illusion of multitasking but we’re really only processing one at a time before changing and updating the next one. At the time, I disagreed with this. If I was only doing one thing, I could feel my mind getting bored. To prevent this, I would regularly play a video game, watch tv, listen to music, follow a chat log and talk on the phone simultaneously. I’ve heard of people who can’t stand silence and put on white noise but that’s not what this was. I could follow the thread of each of these things and draw enjoyment from them separately yet concurrently. When I was in high school, I would bring a book and read during class. My teachers thought I wasn’t paying attention and so would call on me to answer questions, but I always gave the correct answer, then went back to reading. I could follow their lecture and the novel’s storyline at the same time. So, when I heard this paging theory, I countered with my own: that I was parallel processing on a quad core. But now, my disease has destroyed my multithreading capabilities, as if I can no longer access my extra cores and am restricted to a single one. At this level, perhaps I have been reduced to paging after all. I find myself needing to turn one thing off before I can focus on the next.

**6. Concentration** – One aspect of this is that I get distracted more often than I used to. More importantly however, I lose my train of thought more easily, even with no distraction. I can be in the middle of typing a paragraph and forget where it was leading, in spite of the fact that I knew how I wanted to end it when I started. I’m usually a very deliberate planner and it’s unnerving to lose that skill.

**7. Proofreading** – I have a little bit of a perfectionist streak in me about certain topics, so I always try to reread my writing before I let others see it. This previously simple task has grown into a major chore. Since I now have trouble organizing my thoughts, I am constantly wondering if my words would make sense to someone else. Additionally, I find myself rereading the same sentence or paragraph over and over but unable to internalize the concepts therein. I sort of zone out in this state, stuck in a loop. This is a new experience for me. Until now, I’ve always had a strictly disciplined mind, so this loss of control is deeply troubling.

**8. RAM capacity** – I still enjoy programming and will sometimes try to write code just for fun. Previously, when designing an algorithm, I could keep a clear mental image of the entire project in my active memory. Now however, the amount of the data I can hold is shrinking so I find myself needing to go back and refresh certain parts again. This makes coding very tedious; if I can’t see all the parts simultaneously and how they function together, it drastically hinders the process.

**9. Comprehension speed** – I find my conceptual understanding takes longer than it used to. We’re talking fractions of a second here, so it is almost negligible. It is most noticeable with pattern matching. If I’m browsing thru a long list searching for a particular entry, I pause slightly longer to compare each item than I used to.

**10. Memory playback** – Did you ever get nostalgic and rewatch an old conversation like a movie in your head? I used to enjoy falling asleep while reliving past experiences. Recently however, the ‘video’ has become choppy and skips. This is not a memory loss issue; I have not forgotten anything. I am simply unable to replay it at a smooth, natural pace. This previously leisurely reminiscing now takes effort to maintain.

**11. Sleep** – I actually have three sub issues related to sleep:

**a. Lucid dreaming** – I used to be able to control my dreams. I’ve had countless grand adventures exploring alien worlds, casting spells in epic wizard battles, outsmarting Bond-style super villains, questing for my true love, watching my children grow up, traveling thru time to study ancient cultures or forward to marvel at future tech etc. This sounds fun (and it is! I highly recommend it), but after doing it every night for several years, you start to run out of things to accomplish. After several more years, even the reruns start to lose their appeal. There are only so many times you can fly through the sky before you get jaded to it; given enough time, everything becomes boring in the end (with one exception: I have very strong empathy with others so I can still share their sense of wonder while teaching children). Eventually, I exhausted everything I could imagine in my dream playground and decided to shut it off.

**b. Dream frequency** – Upon flipping my mental switch, I stopped dreaming. Going from being such a prolific dreamer, having several per night for a decade to suddenly having none was a profound change, but in a good way. It’s a very surreal feeling to get bored by your own dreams so I considered this a welcome respite. For reasons unknown, on very rare occasions, a dream might still slip in. Perhaps two or three times per year I would have a dream. This was my average for about two decades. But recently, as my disease advances, it strips my discipline and I have started dreaming uncontrollably. The abrupt juxtaposition of how I used to be to how I am now makes the change stand out vividly. My mind was absolutely peaceful. It’s not like now where, even if I can’t remember the dream, it leaves a lingering feeling that I had one.

**c. “Epiphanies”** – I know this is not the correct word, but I don’t think there is a word for this final concept. Sometimes, during my waking life, I would come across a problem which was so difficult that I could not solve it right away. There can be many reasons for this. It might be very complex, deeply philosophical, or requires an exceptionally creative solution. Right before bed, I would load a summary of this puzzle into my subconscious. I would then go to sleep and allow my subconscious to crunch the variables for me overnight. Every morning after doing this, I would wake up inside a eureka moment with the answer. I believe in the Middle Ages, people would sometimes accidentally do this and attribute it to divine inspiration while, in more modern times, they give it the name epiphany. To me, the word epiphany makes it sound like it was unexpected and not in their control. But the process I used was very deliberate. This is a powerful tool that I sadly miss.

I do not know enough about neurology, but I would be very interested to see if the parts of the brain which control each of my numbered points have any commonalities, besides the obvious one. My points are all symptoms with the same cause: excessive sleep. And the sleep itself is a symptom of the exhaustion. Treating the symptoms would be nice of course, but for a real cure, we must look for the source. How does the disease cause the exhaustion? Having lived with it for several years now, I offer my perspective. I believe anyone looking inside the brain is wasting their time. It’s not a mental disorder, it's a physical one.

Even assuming it is physical, I still think the brain is the wrong place to look. I know it’s tempting because the exhaustion effects the entire body and so you want to blame it on something systemic but, from my point of view, that’s a dead end. I believe the correct location is intracellular; someone should try to find out how my cells differ from a normal person’s. Additionally, with my background in CS, I propose this is an ideal opportunity to apply big data and machine learning. I wish you luck in your endeavors. I am willing to consult should you have any questions.

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