

What Does Brain Fog Feel Like?

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Generally, brain fog refers to brain dysfunction or cognitive impairment. Something caused by ME/CFS makes the brain not function well. I believe it has to do with the brain not getting enough of something vital that is in the blood, perhaps oxygen, perhaps some other vital nutrient or substance in the blood. But that is only my personal theory based on a lot of observation of my own body.

This cognitive impairment can change from day to day, week to week or month to month depending on a patient's condition. After over exertion or during a crash, brain fog generally worsens until the patient is able to rest and recover, if they do recover from the crash. The worse a ME/CFS patient becomes, the worse the brain fog can be.

We don't know what causes brain fog yet, but I can describe the experience in detail so it is better understood by the world. Knowing what we experience helps people understand what we are going through, how to best help care for us, and helps doctors guess where to look for causes and problems. It also shows ME/CFS patients that they are not alone in what they are going through.

I would categorize brain fog into MILD, MODERATE and SEVERE, but keep in mind that these levels of brain fog severity do not necessarily correlate to a patient's general ME/CFS severity. In other words, a patient who mostly fits into the "mild ME/CFS" category doesn't necessarily have "mild brain fog". It is also important for us not to get stuck in concrete definitions. ME/CFS exists on a scale that is a million shades from mild to severe, the labels we create are our own; an attempt to help us describe our experience and define the illness. And this is important to do, but we must remember that ME/CFS does not adhere to strict definitions. Each patient is unique and experiences some version of this, but patients do not go from mild straight to moderate, then straight to severe. There are a million states in between these categories. Let's not turn a communication tool that can be helpful into a reduction of the experience of having ME/CFS in the real world.

MILD BRAIN FOG

Mild brain fog doesn't cause the same cognitive symptoms as moderate or severe brain fog, as I will describe below, but patients with mild brain fog still experience cognitive issues which are likely stemming from the same root problem. So mild brain fog is very different from moderate and severe brain fog, but important to include as it is likely all the same problem to varying degrees of severity.

For me, looking back at my life with mild ME/CFS and mild brain fog, I had many cognitive issues. The most stark of which was a pretty severe loss of long and short term memory. It was as if my past was starting to be wiped clean, I simply could not access my memories and was often drawing a blank when people referred to

experiences we had together; I couldn't remember them at all. It was also much more difficult to remember anything new and at times I would look back at my days in school with a kind of awe that this same person was able to study and remember so much information for exams.

I also couldn't think as well as I could before ME/CFS. I think if I took an IQ test my score would actually be markedly lower than before ME/CFS. I was less able to solve complex problems, less able to think deeply about issues, less able to concentrate, and less able to process ideas.

I would say roughly, that mild brain fog reduces cognitive function to about 70-80% of a person's healthy mind.

So the term "brain fog" doesn't really describe the symptoms of mild brain fog very well as there isn't so much a feeling of "fog" as just impairment. But I think it should be included because it is very likely the same cognitive impairment caused by the same root cause, only not as severe.

MODERATE BRAIN FOG

Moderate brain fog feels like, well "brain fog". "Fog" is actually a very apt word and used by patients for a reason. Imagine all of your thoughts and feelings and picture a fog descending onto them, making them hard to see clearly. With moderate brain fog, you have thoughts and feelings/emotions, but they are hard to access in order to really think about them or feel them. It's as if they are out there in front of you, but you just cannot reach them. And yes, this applies to thoughts as well as feelings/emotions. Thoughts and feelings are therefore reduced to abstract versions of what they actually are. They are still there, no doubt, because they will come back in full clarity at some other time in the future even if temporarily. But when you have moderate brain fog, most of the time you can see the outlines of the thought or feeling/emotion but your mind cannot access any of the details and has trouble processing thoughts or feelings/emotions to work through them or change how you see/feel them like your healthy self could. They are unreachable, vague, blurred versions of the full thoughts and feelings/emotions that are there in your mind. You can think and feel the general idea or feeling, but you cannot think or feel any details about it.

And this applies to ALL thoughts and feelings, not just some. So your whole mind feels incredibly dull. Where there should be a world full of ideas and thoughts and feelings and emotions, there are only these blurry shapes and you cannot access any of the intricacies of any of them.

This leads to a feeling of extreme dullness. Nothing you do can be done with as much depth or make you feel as much as you felt before ME/CFS. Your mind cannot process or feel as deeply, so anything you try to do, you won't feel as much from it, or be able to think about it as well. For example, watching a movie with moderate brain fog, you won't understand it as well, you won't be able to follow the plot as well, you won't feel the same height of emotion from it, you will feel much much less, and be able to follow it and process it much more poorly compared to your healthy self. Many movies will

not be possible to follow or just too exhausting to try to follow when you have moderate brain fog. Or for some patients ALL movies/series may be too draining to try to watch and concentrate on.

I believe all ME/CFS patients say this is the worst symptom, because it is the symptom that makes you feel like you are not actually alive, yet you are. You are fully alive and aware experiencing this state of emptiness/dullness. Alive but not able to feel alive. Alive only to bear witness to a lack of life.

It varies in shape and form from patient to patient, but I would say that in general, with moderate brain fog, all thoughts and feelings are reduced to 5-10% of what they are when you have healthy mental cognition - depending on the severity of the brain fog. So picture the world that exists in your mind, both thoughts and feelings, and take away 95% of the details and nuances of all of those thoughts and feelings. Picture how dull that would feel. Picture how lifeless you would feel, how close to being dead.

This is a state that many ME/CFS patients live in every single day, all day. They are ghosts of their former selves.

SEVERE BRAIN FOG

Severe brain fog takes that 5-10% and reduces it to 0-1%. Yes, 0%. It can be so severe that you literally cannot think or feel ANYTHING. I have experienced it when I was at my most severe, frequently and often for days. It is the worst thing I have ever felt. I often call it a "thoughtless, feelingless void that is worse than anything I could ever have imagined". You are alive and completely conscious, and completely aware of yourself and how you feel, but your mind cannot think or feel anything. Let me say that again, you are alive and the only thing you feel is the lack of any thoughts or feelings/emotions. You cannot see outlines of thoughts or feelings in your mind like with moderate brain fog, there are no outlines left. It is like your mind and soul are dead but you are somehow still alive and fully aware and conscious bearing witness to this state as time slowly ticks by.

When I was at my worst, if I crashed once at any time during the day, I would wind up with "0% severe brain fog" for the rest of the day and would be stuck in that state until sleep reset my system. So crashing became a very serious thing for me. I put all my energy into not crashing so that I could have hours at night with mental clarity to think and feel and retreat into my imagination. If I crashed during the day, even once, I would wind up laying there at night with nothing in my mind or soul; No thoughts or feelings/emotions whatsoever.

There are no words to describe the horror of this feeling. I can imagine reading this and thinking that it might be a relief or a good experience like taking some kind of drug. But it is not the same. Certain drugs or alcohol dull your mind but not nearly to the same extent. They also dull your awareness at the same time and this combination of dulled cognition and dulled awareness can be pleasing to experience. ME/CFS patients are fully aware. Some drugs and alcohol also induce new feelings or ideas compared to your healthy state of mind even if they also dull your awareness. So brain fog is not

remotely comparable to any recreational drug or alcohol. With severe brain fog, you are fully conscious and aware, your senses are not dulled or altered. You experience all of it with a sober mind, every painful excruciating minute of nothingness. Alive but devoid of everything that defines being alive to all healthy people. Without any thoughts or feelings, what is left? Who are we? What are we? Severe brain fog really feels like we are just bodies that are pumping blood (maybe poorly) and staying alive, but that's it. Just bodies staying alive and nothing more.

Important Note:

i want to remind you that these states of mind are not permanent. I know this because the symptoms of brain fog change from day to day or week to week and often worsen temporarily during a crash but then later get better, even if only a little bit better. Furthermore, when patients experience any level of recovery, even a 5% recovery, their level of brain fog improves; Their cognitive functioning improves. And certain drugs make brain fog symptoms better like Ativan, even if only temporarily. This tells us that our minds and souls are still there, they are just not accessible due to problems caused by ME/CFS. But when we get better, when there is a cure or better treatments, our minds will return to us just as they were when we were healthy. And even if you are worried about brain damage, the brain is incredibly adaptive and can rewire itself, grow new connections, and heal. So please do not read this and feel like you will never have the same mind or heart that you once had. It is all still there, just waiting to be set free.