



## What Is ME/CFS?

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (ME/CFS) is a devastating illness that takes and takes and takes until there is nothing left but flesh and bone. I've lost my friends, my loves, my interests, my passions, my career, my hobbies, everything that brought meaning to my life and all sense of humanity. When an illness takes this much from you, there is hardly anything left and it is a daily struggle to find purpose, meaning and to simply feel human.

ME/CFS is defined by what is called post exertional malaise. This means that ME/CFS patients have a reduced amount of energy compared to healthy people (vastly reduced in severe cases). But most importantly, when an ME/CFS patient pushes themselves

over this reduced limit, they don't recover like healthy people after some rest. The illness gets worse for days, months, or often permanently.

One of the terrible things that ME/CFS patients are faced with is profound prejudice and judgement about their inability to be as active as they would like. This happens because of the lack of understanding in the general public about the illness and how unique post exertional malaise is. ME/CFS patients are constantly told to "suck it up", or that "exercise makes other people feel better you need to exercise you are lazy" etc. Which creates a lot of guilt and shame for patients who already desperately want to do more but physically cannot. Not to mention not feeling understood. And it also pushes people to do more than they should, the results of which can be catastrophic. This is why we need more awareness.

There are many more symptoms as well that vary from patient to patient including inability to think clearly, muscle and nerve pain that in severe cases causes pain throughout the body, unrefreshing or very poor sleep, and digestive problems likely caused by nervous system malfunction that controls the digestive system. When the illness is severe patients physically do not have enough energy for their brains to function to process the world around them and they have to isolate themselves from many aspects of the world to avoid getting worse. These patients often experience sensitivity to interaction with people, or the simple company of other people, sensitivity to colors, sounds, light, noise and any other stimulus that forces the mind to use more energy than a severe ME/CFS patient has (and many more symptoms depending on the patient). Many severe ME/CFS patients live

completely alone in dark rooms with eye masks and ear muffs and all text, colors and sounds around them reduced as much as possible to minimize mental stimulation. Some patients live like this for years or decades, completely isolated from the entire world and everything in it, left with nothing but their thoughts and haunted by the memory of being alive. [Read more about the experience of living with extremely severe ME/CFS in my published manuscript here](#)

ME/CFS affects 4 million Americans, though this number is drastically rising with an estimated 16 million Long Covid patients, which all experts agree is ME/CFS caused by having the Covid viral infection. Although Long Covid has received funding, it has been separated from ME/CFS by NIH and the funds sadly given to researchers unfamiliar with ME/CFS. This has resulted in a real lack of progress since decades of ME/CFS research has been ignored and Long Covid researchers have been reinventing the wheel with basic understanding about ME/CFS that is already known.

Twenty-five percent of ME/CFS patients are estimated to be severely affected, being bedridden with little to no functioning. This population has been shown in studies to have the lowest functioning of any chronic illness, comparable to patients with end-stage AIDS or end-stage renal failure shortly before death, except ME/CFS goes on for never ending decades. There is no known cause or cure.

Some patients slowly improve with time but commonly relapse back to where they were before or worse. However the majority of patients remain sick, and in the worst cases, bed-bound for decades. Very few recover. It is estimated that only 4% of those

with severe ME/CFS have any type of recovery. To die of this illness is atypical; To hover in an in-between state where one experiences a 'living death' for years or decades is quite typical.

For decades ME/CFS patients have faced more prejudice than any other chronic illness and their symptoms have been seen as psychosomatic or nothing but “laziness”. When people hear of this disease they often say things like, “I would love to lay around all day” to the shock of anyone who has experienced the real horrifying symptoms of the disease. It is one thing to choose to “lay around” or a few hours and then resume activity and a normal life. It is quite another to be forced to lay *still* while everything that once brought meaning to your life is taken away from you and you face symptoms throughout your body and mind that cause unparalleled suffering.

ME/CFS has been completely ignored by every facet of society worldwide, from the medical community to the scientific community, to every government and most individual people around the world. Most people don't even know it exists which makes private research funding very difficult and allows prejudicial views to spread. In the United States, NIH has systematically ignored ME/CFS as if they do not want to find a cure or beneficial treatments. They have kept funding so low that no one can get much, if any, research done, and they systematically deny grants to even world famous researchers for reasons that do not make sense. (see my blog posts ["Good Science ME/CFS Grants Being Turned Down By NIH"](#) and ["Defying NIH in 2024"](#) for more information about what NIH has done to derail ME/CFS research and make finding a cure all but impossible for decades.) Because

of this complete lack of understanding, wild ideas and theories run rampant. When the medical community is confronted with an ME/CFS patient – they know nothing real about the illness and have no idea what to do. It is a bit like a rorschach test – will they see a sick patient with a serious disease, or someone with a mental illness, or someone who is completely crazy and needs psychiatric intervention? Because of this, patients have been forced into psych wards all around the world for having “mental disorders” and subjected to extreme abuse that often leads to death. One patient was thrown into a swimming pool to force her to “get over it”. Unsurprisingly, she almost drowned and her illness worsened permanently. (See my post [“The True Horror of ME/CFS”](#) to read more about the devastating, harsh reality of ME/CFS)

ME/CFS to this day continues to face extreme prejudice and is still, in 2024, completely ignored. Since governments around the world do not hardly fund ME/CFS research, donations for research come almost entirely from patients, who are unable to work and are burdened with huge medical bills not covered by insurance since the disease is not recognized as “legitimate” by insurance companies. I could not get a wheelchair covered by insurance when I physically could not walk to the kitchen to get food, I cannot get important medications covered, I cannot even get saline covered by insurance and my stomach is paralyzed meaning I cannot drink any water whatsoever, I get all fluids through a tube called a PICC line that goes into a vein in my chest. So without saline I would die of dehydration in 3 days. Yet my family is forced to pay \$14 per bag for saline ourselves and I need 3-4 bags per day. These are just a few examples, my family pays for

innumerable treatments and necessities out of pocket and every patient has stories like this.

ME/CFS is one of the least funded illnesses even among benign illnesses that do not have a serious affect on quality of life. But Serious illnesses like Multiple Sclerosis receive exponentially more research funding. [See the graph below comparing funding to other illnesses]. Multiple Sclerosis is thought to be on average less severe in its impact on patients' quality of life compared to ME/CFS, and affects half the number of people. Yet it receives \$100 million per year from the government for research while ME/CFS received \$11 million last year. With \$100 million per year in funding, ME/CFS would likely have been cured years ago. HIV receives \$28 billion per year and because of this, there are excellent treatments and HIV patients lead relatively normal lives (when they live in places where they have access to these treatments). With so little funding, there is no hope for the millions of people suffering from ME/CFS.

"My H.I.V. patients for the most part are healthy and hearty thanks to three decades of intense and excellent research and billions of dollars invested. Many of my C.F.S. patients, on the other hand, are terribly ill and unable to work or care for their families.

I split my clinical time between the two illnesses [AIDS and CFS], and I can tell you if I had to choose between the two illnesses (in 2009) I would rather have H.I.V. But C.F.S., which impacts a million [to 4 million] people in the United States alone, has had a small fraction of the research dollars directed towards it." —Dr. Nancy Klimas, AIDS and CFS researcher and clinician, University of Miami

“[CFS patients] feel effectively the same every day as an AIDS patient feels two months before death; the only difference is that the symptoms can go on for never-ending decades.” —Prof. Mark Loveless, Head of the AIDS and ME/CFS Clinic at Oregon Health Sciences University

Despite the lack funding, many brilliant researchers have taken on the challenge of finding a cure for ME/CFS over the last decade and research has progressed (though much more slowly than if they had proper research – Ronald W Davis, PhD, has found what is probably a diagnostic test called the Nano Needle, but NIH won't fund it for dubious unknown reasons). ME/CFS researchers have shown without question that ME/CFS is a real, severe, multi-systemic disease. They have found unique abnormalities in the immune system (e.g., inactive NK cells, malfunctioning T cells, alterations in the innate immune system, a plethora of autoantibodies), in mitochondria (e.g., low energy (ATP) production, fragmentation), in the circulation system (e.g., low blood flow and blood volume, heart valve preload failure, lack of deformability of red blood cells, microclotting) , in the brain (e.g., inflammation, elevated temperature, high lactate, abnormal MRI and PET scans), in physical response to exertion (e.g., inability to perform similar to patients with other severe diseases a day or two after exercise, worsening symptoms after physical, cognitive or emotional exertion), in the G.I. system (e.g., altered, less diverse microbiome, low motility, presence of enterovirus, eating problems, pain), in sleep (e.g., non-refreshing sleep, disruptions of diurnal rhythm, other sleep disturbances), and autopsy findings that report dorsal root ganglionitis – a type of inflammation of the spinal cord.



As a nation, we need to invest in ME/CFS. Ignoring it as we have been doing costs America an estimated 25 billion dollars per year in lost productivity and medical care which is only going to continue to grow exponentially as people around the world are infected and reinfected with Covid and eventually wind up with Long Covid or in other words ME/CFS. ME/CFS destroys millions of American lives, tears families apart and shatters dreams as people are isolated in bedrooms, nursing homes or left homeless with very little medical or societal understanding or support. All genders, races, ages, and socio-economic backgrounds are affected. Anyone could wind up sick and just drop off the map. And we will likely lose everything that person would have become or contributed to the world.

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If you are able, please consider making a donation to the Open Medicine Foundation (OMF) and if possible make it a monthly donation, which helps sustain research and solidify their future.

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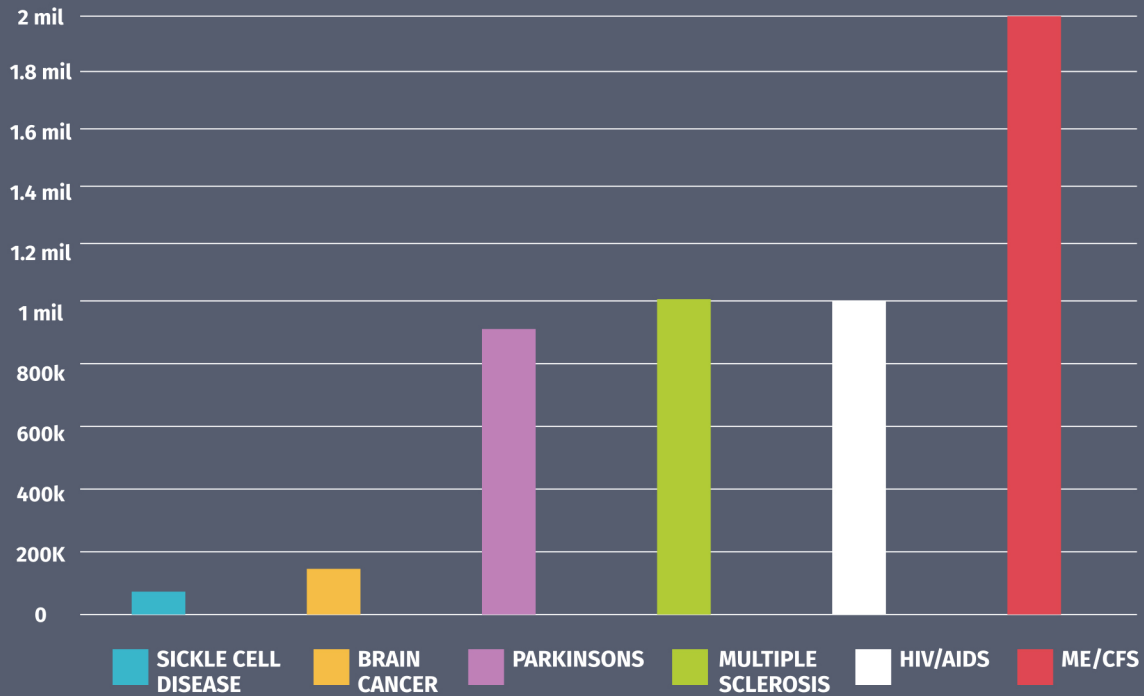
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# THE IMPACT OF ME/CFS vs. FUNDING



## AFFECTED PEOPLE IN US - 2020 (<https://cdc.gov>)



## FUNDING - 2020 (<https://report.nih.gov/funding/categorical-spending#>)

