

What ME/CFS Patients Often Go Through

by Whitney Dafoe, severe ME/CFS patient and advocate

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- Loss of some or all family
- Loss of all friends
- Loss of job
- Loss of hobbies
- Loss of loved ones/relationships
- Loss of dreams for the future
- Loss of things that used to define who you are
- Loss of connection to the world
- Loss of sense of dignity
- Loss of ability to do anything physical (this includes sports, outdoor activities, chores, using your legs as transportation, and as the illness gets worse, even things like moving in bed, etc)
- Loss of ability to think and remember the way you used to, your mind lost from you in what is often called a "fog"
- Loss of your personality
- Loss of your sense of self and sense of humanity
- Prejudice from everyone in your life, accusations from everyone in your life of the illness being "in your head" even after decades of illness.
 - Inability to find doctors who know anything about ME/CFS and inability to pay for them if you can find them because ME/CFS is not covered by insurance.

- When children get ME/CFS they lose their education, their childhood, their teenage years, and the entire process of growing up into an adult.
- A complete lack of support from society. There is no safety net for ME/CFS patients because most patients aren't diagnosed and even when they are, it is not considered a valid diagnosis. So if patients aren't lucky enough to have friends/family to take care of them they are left on their own. And even patients who do have people in their life who are willing to make the incredible sacrifice to take care of them, very few of these people are prepared or trained or the right kind of person for that job, which is incredibly difficult. A devastating number of Severe ME/CFS patients die or commit suicide when there literally is no hope. And a great number lose hope before this point.
- Lack of funding for research that would give patients something to hope for. All of the above plus no research puts a huge burden of literal hopelessness on patients. Their condition is likely to never get better, their only hope is a cure or treatments. But there is no funding for scientists to do research to find treatments or a cure and for decades there have been very few scientists even willing to research ME/CFS. The Open Medicine Foundation funded research spearheaded by Ronald W. Davis out of Stanford University is the first real serious research effort, but it is fairly new. For the last 50 years there has been nothing but small efforts at research, even if a few have been well meaning and well-conceived. NIH allocated only 16 million dollars for ME/CFS research in 2020. Multiple Sclerosis is thought to be less severe in its impact on patients' quality of life and affects half the number of people. Yet MS received 118 million dollars from NIH in 2020. HIV received over 3 billion.
- Some patients are thrown in psych wards. Likely many more in the past. The number is thankfully declining, but it still happens. There is one woman who was forced into a psych ward and the clinicians at one point threw her into a swimming pool to try to force her to "take initiative" (or something). She almost drowned. She got much worse there but did finally get out after a relentless battle from the ME/CFS community and family/friends. I'm sure there are many diagnosed and even more undiagnosed ME/CFS patients around the world getting worse and worse as a direct result of being locked in psych wards. And many ME/CFS patients likely die from abuse like this. An ME/CFS patient named Sophia Mirza died at age 32 after being forcefully removed from her home and placed in a psych ward. When she finally got released, she was so sick she died soon after. She would still be alive today if they had left her at home under the care of her mother.