

FACES OF ME/CFS

(CHRONIC FATIGUE SYNDROME)

TOM C

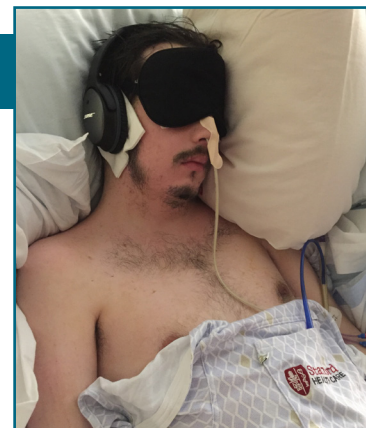
Tom was a healthy 19 year-old maintaining a 4.0 GPA at Stanford University's computer science program when, during his sophomore year, he came down with a series of viral infections. At first, Tom experienced lingering fatigue that was not improved with rest. But within eighteen months, Tom was unable to get out of bed. Now, Tom cannot tolerate any light or sound. He can no longer speak and has been unable to read for two years. His eyes and ears are covered 24/7.

Tom just returned home after being hospitalized for 95 days. He is sustained by a feeding tube and cannot



even sit up. His mother has needed to suspend her medical practice in order to provide 24/7 care for Tom and the family is now struggling to find full time nursing care.

Despite his mother's expertise, Tom needed to see 20 doctors in 8 months before he was diagnosed with ME/CFS. Even now, his health insurance program has no ME/CFS specialist. Despite consulting with ME/CFS specialists at Stanford—and having seen 40 specialists at this point—Tom, now 23, remains at death's door without any treatments to alleviate his symptoms. ■



KELLY S



I am 24 years old, unable to work, and live at home with my parents. I started showing symptoms of ME/CFS around age 5 and I have never

experienced a normal life. I struggled to finish high-school. Now, my symptoms are so severe I cannot complete college classes on-line.

Fatigue and pain have always been my worst symptoms and every medication has failed to alleviate them. Over the years, I have

worsened and I remain mainly bedridden. I am always resting, but getting no rest; it feels like trying to charge broken batteries. Sometimes it feels as if my body is shutting down on me. I think about going to the emergency room, but I rarely do anymore—it just doesn't help. I think this is worse than actually dying, because I feel like I am dying repeatedly—I just live through it again and again.

It took me 14 years and many doctors to be diagnosed. I was 19 by then. I'd like to say the diagnosis made a real difference, but it didn't.

I obtained the psychological relief of knowing what I have and that I am truly sick, but even with a diagnosis the doctors have never been able to help my symptoms. Due to these issues, I have thought about suicide. I live a very isolated, lonely life, as most sufferers do. But, I could never do that to my family/loved ones. They've given their whole lives to me and I will continue to do the same for them. I pray that somehow/someday there will be proper funding for research and a treatment. That is all I can do. ■

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EJ C-S

In 2014, EJ, a 34 year-old communications specialist, became extremely ill with a persistent flu like illness. Five months later, while attempting to get out of bed, EJ was crippled by excruciating pain, preventing her from walking. She has never recovered.

Once gainfully employed and an international missionary, now EJ can hardly get down the stairs. She is housebound and bed-bound 90 percent of the time. She finds it difficult to do the most basic of tasks, such as showering and eating. She



experiences unrelenting pain and muscle spasms and cannot regulate her body temperature. EJ also experiences a hyper-sensitivity to visual, auditory, and kinetic stimuli. She is completely dependent on her husband and mother for physical and financial support.

EJ consulted 12 medical professionals and neurologists. None has been able to explain her symptoms and she has never received a formal diagnosis. There are no ME/CFS specialists within 1500 miles of her home. Based upon her extensive research, EJ assumes she is among the estimated 91% of patients who have not been diagnosed. EJ is trying to qualify for disability insurance, even more challenging without an official disease diagnosis. ■



MELANIE D

As a school psychologist and mother of two young children, my life was full and happy. After painful surgical complications when I was 37, ME/CFS took hold. The tiniest effort made me feel like I was fighting through quicksand. Within a year, I was unable to work, perform basic household tasks, or play

with my kids. For a while, I was completely confined to bed. My incredible husband cared for me and our family, along with maintaining his full-time job so that we could retain health insurance through his employer.

Brain fog and dizziness make it very difficult to do anything. Despite my graduate-level education, I struggled to read middle school books for the first

10 years. Now, I have some periods of respite and can occasionally leave the house. But, I pay for these trips by being confined to bed for days after.

I desperately consulted dozens of specialists, none of whom were able to help me. They questioned why I was talking to them because ME/CFS did not fall within their specialty. Indeed, I had to wait 3 years and drive over 3,000 miles, including a two hour plane trip, to get diagnosed. I only found a sympathetic and knowledgeable doctor because his daughter had ME/CFS.

After 16 years with this disease, I have yet to benefit from any treatment for ME/CFS. And beyond my own suffering, I am devastated by the impact my illness has had on my husband and kids. ■

To read more stories, visit the Humans of ME/CFS project at www.homecfs.solvecfs.org

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