



My name is Rachel, I am one of the Millions Missing.

I believe pregnancy was my initial illness trigger 2010. I didn't realise my tiredness was anything other than normal pregnancy, and then having a small baby. After my son was born I had some difficulties with feeling very faint on standing, and episodes of vertigo and nausea. I returned to work and did my nurse prescribing course which tipped me into increasing fatigue and nausea in 2014. I had what I thought was tonsillitis and all of a sudden I was no longer able to walk without extreme fatigue and severe palpitations. Until then in my life I was very active.

I worked in the NHS and was an Emergency Care Practitioner with 20 years experience in healthcare. I tried to keep as active as possible as recommended by the NHS after becoming ill. I kept trying to exercise myself better, but just got worse and worse. A year or so ago I became bedbound. Currently I can only crawl to the bathroom at best. Huge family adjustments have been necessary as I'm unable to care for my son. We all work to keep his life as normal as possible. I spend my days in solitude and silence so I can spend a little time each day with him in my room. I am devastated that I can't be more fully in his life. I was very outdoorsy and hate being unable to get outside. Even if I could get there, I'm so temperature sensitive I couldn't tolerate it. It's like being a prisoner in my own body. Trapped by something I can't see. Symptoms I battle with daily are gastric and cardiac, along with cognitive impairment and severe neurotransmitter and endocrine disturbance. I spend much of my time in meditation so I conserve my energy. I am unable to sit up with severe symptoms and decline. I am often boiling hot and unable to tolerate clothing. Even eating raises my heart rate to a level that causes both fatigue and gastric problems.

I am missing the richness that was my former life. I miss life outside the house with my son, and being a healthy mother to him. I miss human contact, because I can only tolerate small amounts. I am missing the joyful active outdoorsy life I led...climbing, cycling, swimming and being in nature. I miss the drama classes I was taking. I miss my independence. I miss feeling strong and well. I miss my career, as helping people was a part of finding meaning in life.

This is a very serious illness, and we desperately need both more research and better care. My old colleagues have it wrong on this condition and things must change...