Public Comment
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Recently a few lawyer advocates have taken upon themselves to file FOI requests for documents regarding this committee's recommendations, as well as the administration and planning of the upcoming P2P and IOM committees. I've read the documents and they are disturbing, to say the least, given the general attitude of frustration and annoyance toward patient advocates as well as the disorganization and bureaucratic confusion surrounding the purpose and power of all of the committees.

I very infrequently advocate to the federal government on my own behalf as a patient due to the debilitation of my illness. And, my story is similar to so many that have been submitted to this committee over many years that it seems like a futile effort. However, given the recent controversy and ill will toward patients revealed by the FOI requests, I would to like to clarify what it is like to be one of those patients at the heart of the controversy.

I envy the lawyer advocates because I was not able to complete even a semester of law school. My onset was sudden, there was one last day of youthful health and then the next morning illness so profoundly weakening it felt like I had crossed decades into old age. As months wore on I could not decide which was worse: the elements of my life - school, work, relationships, passions - brushed off the table like a child sweeping aside a set of blocks to scatter, or the experience of living inside the new prison of my unhealthy body. Seasons changed out of the window while I bunkered in bed waiting for what felt like an interminable flu to pass. Kitten weakness, muscles groaning in pain, bizarre sensory changes. The clatter of silverware on a glass cutting board pierced my ears. I woke every morning with a sore throat. The effort to bathe and eat challenged me. I could not change my own sheets or do a load of wash. The hours of being alone in silence, resting, would be tantamount to cruelty in a prison or war camp.

I didn't realize it but I had crossed another Rubicon. Once I had been a young woman you would meet on a hiking trail, or your roommate's party, I might be in your study group. But, in those long first few years in my bedroom, I became someone else. It wasn't an internal change, but a shift in how people saw me. I was the girl with the weird disease. My doctors didn't know what to do with me, my friends distanced themselves, extended family puzzled over me in a way they never would over someone with a well established equivalent illness like lupus or MS. My strange exile dawned on me slowly when I tried to reach out, both socially and within the medical system. The perception of my illness, both trivialized and misunderstood, burdened me with a stigma so absurdly at odds with my self-perception that after nearly two decades I am still surprised by a nurse's uncomfortable silence or a neighbor's indifferent glance. I am Boo Radley.

And it is this the stigma that came out in the FOI documents.

The severity of the illness ebbs and flows. In my worst years I am dependent on loved ones to a point that is burdensome and humiliating. It is for them that I am writing this. My losses are their losses. My ongoing suffering pervades their days whether it is observed or mentioned, they have seen it and they know. I write this for my Dad who has watched his daughter shrivel overnight, who has driven me countless miles to doctor's appointments, has brought me food in bed when I couldn't walk to the kitchen. My mom, who for years helped me with the most basic of tasks and lent her shoulder for me to cry on, who was my friend when so many of mine disappeared. My domestic partner who has washed my greasy hair, and carried me up and down stairs, who has pushed my wheelchair, who has crafted a life with me around my illness. My sister who must care for our aging parents on her own, and who is coming to my house for Thanksgiving, acting as hostess in my place. All of the financial, emotional, and physical support they have given me is sadly mirrored by the degree of debilitation in the sister, daughter, and partner they have lost.

If anyone is still reading this, realize that the effort of advocacy, as annoying and frustrating as it may be to encounter during the daily grind of government work, is not just on the behalf of the letter writers or the people you think are the weird ones with the Boo Radley disease. But the tragedy endured by their network of families and friends, their physicians who are helpless to offer more than maybe some sleeping pills and disability signatures, they suffer too. The taxpayers. So much could be accomplished with the right people in the right places.

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