



2020

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Recommended Citation

McQuivey, Janessa (2020) "Treading the Waters of Chronic Illness," *Family Perspectives*: Vol. 1 : Iss. 1 , Article 9.

Available at: <https://scholarsarchive.byu.edu/familyperspectives/vol1/iss1/9>

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Treading the Waters of Chronic Illness

by Janessa McQuivey

In my only serious relationship, my boyfriend broke up with me, saying, “Your health is hard. It will always be hard. I’m just not sure I love you enough for it to be worth it.”

By that time, I had experienced four years of debilitating chronic pain and chronic fatigue, much of it undiagnosed. My symptoms didn’t follow a clear enough pattern to lead most doctors beyond scratching their heads. I no longer had the energy or will to scratch my head, having mostly resigned myself to living a limited life.

As hard as it was to hear these heartbreaking words two years ago, I felt his answer was incredibly fair. “In sickness and in health” is a much easier promise when you’ve had the perspective of health to explore it from. For me, sickness seemed the only likely trajectory, and that put a lot of pressure on my dating life.

When it first began years earlier, the sickness came on slowly, gradually enough to trick me into believing my symptoms weren’t unique—everyone was tired and in pain at times—maybe I was just handling it more poorly than most. I felt as though I was standing on the sand as the tide inched in around me, getting higher and deeper until I couldn’t ignore it. Fatigue and pain evolved into a much larger and more complex beast. My symptoms of stomach pains and irritable bowel syndrome began to include headaches, joint and muscle aches, nerve pains, and nausea. Tiredness put me on my back for more hours a day until eventually I was in bed 22 hours most days.

These symptoms clustered in an unpredictable pattern around food. Each meal was a roll of the dice because I couldn’t know what symptoms I’d get or how long I had until the onset. The easiest solution

to ensure I’d be well enough to keep a doctor’s appointment would be to not eat the entire day prior. This trade-off had its price, as I knew I’d be hit twice as hard once I started eating again. My life was a circle of frustration and uncertainty.

Unfortunately, my experience is not unique but is the reality for millions each year.

Chronic illness is a burden borne by 133 million Americans.¹ It is also borne by their families, who serve as caretakers, primary emotional support, daily-activity management, and financial providers. It’s no wonder that family members often suffer psychological effects in their care of their chronically ill member and that 92% of chronic illness family members report extreme emotional effects.²

For all the years I found myself swimming in my illness ocean, my family was all-in. They held back nothing in their tireless pursuit of a diagnosis. In good measure, they had to be tireless because I was always tired. I went through a barrage of tests and evaluations, diagnoses which didn’t end up leading anywhere, and extreme treatments for conditions I’m not totally sure I had. Three different times I lived off amino-acid powder mixed with water which I had to choke down to try to get some calories each day. I flew to the Mayo Clinic in Minnesota, and my mother pushed me in a wheelchair between my appointments. I tried eating one meal a day for four months, which meant I was constantly shivering. I drank eight cloves of garlic pureed with olive oil and orange juice every morning and lived off little more than halibut and eggs for a month.

My medical expenses soared, compounded by the fact that I wasn’t able to work steadily to contribute to

any living costs. Chronic illness is an expensive problem in the United States, with more than 75% of all health care costs resulting from chronic conditions.³ In addition to treatment costs, chronic disease also means time lost in economic productivity. The total cost of chronic illness impacted the economy to the amount of \$3.1 trillion in 2016 alone—a cost equal to nearly 20% of the U.S. economy.⁴ My earlier breakup had echoed the refrain I had already felt myself—I was a burden and a drain on resources.

As my family took on that financial load, I appreciated their help while I simultaneously felt incredibly guilty for needing it. I ached for independence and questioned whether I ever would be. At some point, I stopped believing that there was a great solution waiting behind the next blood test or colonoscopy. Optimism is hard to come by when you have to fight like you’re constantly drowning.

In this decline, I started wondering what it was I had to look forward to in life. Like me, Americans report that their [greatest source of meaning](#) in life come from their families.⁵ Additionally, the four things most correlated with [higher life satisfaction](#) are good health, a romantic partner, friends, and a career.⁶ When my good health went, it dragged down with it my dating opportunities, an ability to spend time with friends, and the career dreams I could no longer pursue. My family worked hard to compensate for the joy lost in all four.

Over the years and through each of the potential diagnoses and treatments, my family cheered alongside me every time we thought we had found “the answer.” They mourned with me each time these diagnoses didn’t fulfill our hopes. They supported me each time I tried to make progress in school, get

a part-time job, or do anything much beyond lie in bed. They welcomed me back home when I inevitably started to regress. When I didn't have the mental strength to keep searching, they continued. My father read hours of medical research and suggested unique approaches. My mom listened to podcasts and reached out to friends and friends of friends, looking into every avenue.

I'm more fortunate than most. The [majority of chronic illness](#) exists outside of nuclear families in two-married-parent households. Non-traditional family structure may make children more likely to have incidences of chronic illness, or children's health may alter the structure of the families,⁷ including increasing strain on parent relationships that can push couples apart.⁸ What this means then is that those families are often required to wade into illness without financial resources or traditional mental and emotional support. This in turn decreases the child's chances for future health recovery and stability.

But, just when this ordeal seemed insurmountable this past February, I underwent a laparoscopic surgery that gave me the diagnosis of widespread endometriosis. "Endo" is a condition in which cysts made of endometrial tissue grow on abdominal organs and the wall surrounding them. The surgery removed the lesions and provided me a medical team that could formulate a treatment plan. Almost six years exactly since the pain started, I finally found out why.

Looking back, I appreciate more than words the support of my family, the dear family and friends who encouraged us to pursue the diagnosis and helped us to get into the clinic. Intelligent doctors steered us in productive directions and expressed earnest concern and effort. Caring friends reached out in numerous ways. Kind roommates made me meals when I was too weak to cook for myself.

My journey is far from over. Endometriosis is not curable, and it only provides a voice to a portion of my laundry list of symptoms. Yet, it gives me something concrete to focus

on. Treating it the last seven months since my diagnosis has provided me with the blessing of remarkable improvement and has given my family a great deal of relief. And it's made me feel as though dating relationships may be a possibility again.

I recall an experience I had a year ago before my diagnosis. My mother called and lamented to me that a sibling had started experiencing acute pain after meals. With a sudden onset and no clear explanation, he voiced that maybe he had whatever it was that I did. My mother's pleading response was heart-wrenching: "Oh no, I can't go through this again with another one."

It turns out she didn't have to. But the phone call was a reminder to me of how much my health impacted my family's life, as it does for so many families. After all, in my loss, my parents were suffering as well. Families who act as caregivers for their chronically ill family member may suffer psychological effects that can impair their ability to care for the ill and themselves.⁹ Siblings can sometimes be neglected, parents' relationships can suffer, and the ill

family member can feel a loss of identity and depression. Understanding the strain that illness can put on a family is a powerful tool in getting everyone involved in finding balance.

Incredibly helpful for most families facing chronic illness is an awareness of resources. One of the most empowering aspects can be feeling as though you understand the condition, which requires speaking to doctors, connecting with others in similar situations, and reading everything you can find. Hospitals have social workers who can help make families aware of financial options, as well as the availability of support groups and programs. Finding new outlets for expression and learning pain management techniques can be instrumental in returning to a sense of self and accepting difficult changes.

Thinking about my family's position for the last six-and-a-half years makes me feel both pain and incredible gratitude. Staying alongside me in the deep end, they've demonstrated daily that they consider me worth it, health and all. And that's a love that keeps me buoyant.

For families experiencing chronic illness, helpful online resources include the following links:

- <https://www.onlinemswprograms.com/resources/social-issues/resources-family-support-chronic-illness/#Family-Members>
- <https://invisibledisabilities.org/coping-with-invisible-disabilities/disability-benefits/finding-help/>
- https://www.aamft.org/Consumer_Updates/Chronic_Illness.aspx
- <https://www.health.harvard.edu/staying-healthy/10-steps-for-coping-with-a-chronic-condition>

Endnotes

¹ Centers for Disease Control and Prevention. (2009). The power of prevention. Retrieved from <http://www.cdc.gov/chronicdisease/pdf/2009-Power-of-Prevention.pdf>

² Golics, C. J., Basra, M. K., Salek, M. S., & Finlay, A. Y. (2013). The impact of patients' chronic disease on family quality of life: An experience from 26 specialties. *International Journal of General Medicine*, 6, 787-798. doi:10.2147/IJGM.S45156

³ Centers for Disease Control and Prevention. (2009). The power of prevention. Retrieved from <http://www.cdc.gov/chronicdisease/pdf/2009-Power-of-Prevention.pdf>

⁴ Waters, H. & Graf, M. (2018, August). The costs of chronic disease in the U.S. Milken Institute. Retrieved from <http://milkeninstitute.org/sites/default/files/reports-pdf/ChronicDiseases-HighRes-FINAL.pdf>

⁵ Pew Research Center. (2018, November 20). Where Americans find meaning in life. [Report]. Retrieved from <https://www.pewforum.org/2018/11/20/where-americans-find-meaning-in-life/>

⁶ Pew Research Center. (2018, November 20). Americans who find meaning in these four areas have higher life satisfaction [Report]. Retrieved from <https://www.pewresearch.org/fact-tank/2018/11/20/americans-who-find-meaning-in-these-four-areas-have-higher-life-satisfaction/>

⁷ Sutherland, A. (2014). Family structure and children's health. *Institute for Family Studies*. Retrieved from <https://ifstudies.org/blog/family-structure-and-childrens-health/>

⁸ Reichman, N. E., Corman, H., & Noonan, K. (2004). Effects of child health on parents' relationship status. *Demography*, 41(3), 569-584.

⁹ Holmes, A. M., & Deb, P. (2003). The effect of chronic illness on the psychological health of family members. *Journal of Mental Health Policy and Economics*, 6(1), 13-22.