

Making the Change from 'Working to Live' to 'Living to Work'

bionewsfeeds.com/2019/04/18/making-the-change-from-working-to-live-to-living-to-work/

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April 18, 2019



For the first time in more than 20 years, I'm not working a full-time, 40-hour-a-week job. This was a difficult decision to make, especially because I'm only 45 years old and have a good 20 or so years ahead of me before I can tap into my retirement funds. However, after my liver transplant in 2017 and restarting my Crohn's treatment shortly after in 2018, I decided life was too short to deal with the commute and stress of teaching advertising at a state university 40 miles from my home in Austin, Texas. This January, after juggling work with my chronic illness my entire professional life, I chose to focus on my physical and mental health instead of my career.

When I think back to how poorly I felt when my Crohn's peaked, I'm astounded that I was able to continue working a full-time job, hardly ever taking a sick day unless I was contagious to others. I kicked into survival mode, and dealing with my illness became an issue of mind — and money — over matter. I attribute my tenacity to my financial need, ingrained Asian work ethic, and high pain tolerance.

Health insurance has always been my main motivation for working through my illness. Before the passage of the Affordable Care Act (ACA) in 2010, the only way I could get and retain health insurance was through continuous, employer-sponsored coverage because of my preexisting conditions. Because Crohn's was my second chronic disease diagnosis, my need for healthcare became even more desperate. I also needed a steady salary to pay the deductibles and copays for my growing list of medications, tests, and doctors. Even after the ACA passed, I had excellent health benefits that were too good to give up, so I continued to work as my health declined.

My work ethic and Type A personality pushed me through the most difficult days. As an American-born Filipina, I was the stereotypical Asian student and employee. I was a quiet, hardworking perfectionist who was never satisfied with my accomplishments because I knew I could have done better if I had tried harder. Not working, or even the thought of being unable to work, was akin to giving up and being a failure. Every day was a competition with myself. Admitting I didn't have the strength or energy to finish a project or to do my job was never an option.

The mental and psychological hold I had over myself was a lot stronger than any physical pain felt with Crohn's. Somehow, I battled through the frequent abdominal cramps and distension, the fevers, the lymph nodes that were so painfully swollen that I could barely turn my neck or move my arms, and the hives and rashes that sometimes accompanied bad flares. If any of these symptoms happened during work, I fought to ignore them until I got home and could curl up in my bed doubled over in misery.

For the most part, fatigue was the most constant aggravation, especially when I had sleepless nights of running back and forth to the bathroom, or tossing and turning to find a comfortable position to sleep in during bouts of bloating and gas. Somehow, I powered through the workday knowing that I would be able to go home and take a nap.

It was only a few years ago, while doing my biannual Equal Opportunity Employment training for work, that I learned that the entire time I was literally working myself to death, I was protected under the Americans with Disabilities Act of 1990 and the Americans with Disabilities Act Amendments Act of 2008. Those acts allow employees with gastrointestinal disorders to request workplace accommodations. Had I been aware that I had legal protections, I may have approached work differently by being more forthcoming about my disease and my symptoms rather than worrying that I would lose my job or risk promotions because of my illness.

Now that I know better, and with the popularity of telecommuting on the rise, I'm better prepared to advocate for my rights as an employee if I ever decide or have to return to the corporate world at a full-time capacity. Until then, I'm enjoying being covered on my husband's health insurance and following my bliss working as a freelance graphic designer and writer. I may have taken a huge pay cut, but health and life are worth it.

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