

## **Triumphs and Defeats – Living with Behcet’s Disease**

By Cindy Todd - April 12, 2017

First, let me tell you about how I was diagnosed with Behcet’s Disease. In 2008, late spring/early summer, I started getting these weird “episodes”. Now, I was very active all my life. I was an athlete in school, playing basketball, volleyball and was on the track & field team. When I became an adult, I kayaked, cycled and later, backpacked and hiked. I was always taking college classes (mainly for fun, after I earned my Bachelor Degree), while working full-time. So, I’ve always been pretty active. So, these “episodes” I started getting were odd. I would feel extremely exhausted for a few weeks. And when I say exhausted, I don’t mean a little more tired than normal. I mean that I had trouble walking across a parking lot. I felt like I had a wet, thick wool blanket over me and I was trying to run in a swimming pool. I would have to take naps at work. Fortunately, my employer had a little room off the breakroom. The room had a cot in it. I would just walk away from my desk and take a 45-minute nap – sometimes twice a day to be able to get through the day. Then I’d get home, eat and go right to bed. My spouse said I had no personality or affect. But I thought it was just some weird bug or something.

Well, the “episodes” didn’t stop. In fact, they got more frequent and I got sicker. I was using a cane to walk across the parking lot. I then started getting these strange neurological symptoms. I was walking across a parking lot, when I suddenly couldn’t feel my clothes. Now, “feeling your clothes” isn’t something we think about. But when you suddenly can’t, you know. I panicked and looked down as I was suddenly worried that I was naked. Of course, I did have clothes on. A few weeks later, I was walking for exercise, when I suddenly couldn’t feel anything from my ankles down. So, I decided to go see a doctor. I went through the whole referral process, seeing every specialist in the rural area I

live in. I saw a rheumatologist, two neurologists, an endocrinologist, etc. I had brain scans (as everyone was worried about MS), nerve conduction tests, tons of blood tests, etc.

Three years later, my local rheumatologist and my local neurologist were telling me that I needed to go to a tertiary hospital like USC (University of Southern California), Stanford or UCLA (University of California Los Angeles). I stalled, as I was uncomfortable with this idea. You see, in my mind, you only went to a tertiary hospital if you had some rare cancer or some disease that caused you to grow a horn out of your forehead or something like that. But my local neurologist flat out said to me, “You are going to be back here a year from now, we’re going to have the same conversations and you’re going to be much sicker. No doctor in this area is going to be able to help you!”. I was stunned. Of course he was right. But I was stunned to think that a year later I’d be sicker, probably bed-ridden, and no one could help me. So, I decided to go to a tertiary hospital.

My insurance sent me to USC. Since nobody knew what was wrong with me, I was sent to an endocrinologist to start with at USC. The endocrinologist said she had no idea what was wrong with me, but she wanted me to see a neurologist and a rheumatologist. Apparently, the rheumatologist she wanted me to see was known for liking hard to figure out cases. I saw the neurologist first. She said that she was confident that I didn’t have MS, but didn’t know what was wrong. When I saw the rheumatologist, everything changed for me.

I should back-track briefly for you to understand my state of mind. You see, I was getting sicker and sicker and had no idea what was wrong. I tried to “suck it up” and told myself it was in my head. But nothing helped. I have strong will power (always have) and so I was hoping I could just beat this with “mind over matter”. As time progressed, I felt more and more hopeless, more and more sick. I was in the darkest place of my life. I will just say it...I was suicidal. I had plans for my demise. I researched best ways to end your life, deadly

poisonous plants, etc. By the time I had gotten to USC, I had planned on ending my life if I wasn't diagnosed by them. My spouse was terrified. And rightly so. She was dealing with me getting sicker and sicker and also knowing that I was getting close to my end.

Well, we met the rheumatologist at USC. He comes skidding into the room, literally, with his hair stuck up. We talked briefly, and then he suddenly said he'd be back in 10 minutes. My spouse and I were annoyed and discouraged. Well, about 15 minutes later, he comes back. Apparently, he had rescheduled the rest of his appointments. He spent over 2 hours with us! Amazing!

The USC rheumatologist felt that I had Behcet's Disease. The only criteria and common symptom that I hadn't had, was genital sores. However, over the next 2-3 months, I started having those. I would take photos (and still do) of my rashes, sores, etc., so that if they were gone by the time I saw him, he could see *exactly* what I was talking about. I met the criteria for Behcet's Disease in every way. I was a textbook case. My doctor (rheumatologist) said he wanted to do DNA typing but said he didn't expect it to come back positive, since about half of Behcet's patients don't. But the HLA-B51 *did* come back positive. So, this was even more definitive – between the DNA typing and that I met every diagnostic criteria regardless of what version used. This rheumatologist saved my life – literally. He saved me from myself (though he had no knowledge of this – I didn't tell him about my mental state until many years later, long after I had recovered psychologically).

Finally, I had a diagnosis and I was relieved. You see, even getting a bad diagnosis was better than not knowing what was wrong with me. I researched Behcet's Disease extensively. I researched treatments and symptom remedies. Meanwhile, my spouse was a mess. She was relieved to see me uplifted and to know what was wrong with me. But she was devastated that I had this rare autoimmune disease. We both had hoped that USC

would find out what was wrong with me and that there would be a simple treatment and I go back to normal. She would cry. It broke my heart, as she's not a cryer.

My elation was short-lived. My dark place where I had been deeply depressed and hopeless, reared up, but had turned into extreme anger a few months after my diagnosis. Between trying various treatments and dealing with the side effects, I was angry about having this life-long disease that could tear me down slowly over the years. I stayed in this dark space for about 2 years. I was angry at the world and had the darkest, ugliest thoughts. How did I work through it? I don't know. I had tried to look at the positive and force my way through the dark times, but that really didn't work (or only worked for about 30 seconds). I continued to work full-time, even though there were many times that I thought I physically couldn't. I continued to workout, saw a therapist for a few weeks, continued to paint (I'm an abstract artist), travelled and even eventually figured out a way to backpack again. I was very ill and just the idea of packing for a backpacking trip or even travelling was so exhausting that I had this lingering negative association about it for years, long after I was feeling better. I eventually figured out that I needed to start the packing a month ahead of the trip, little by little (instead of packing everything in one or two days, as I use to do). I would start prednisone a few days before the trip and continue taking it for the duration. For years, this was the only way I was able to do these activities. But I was determined to lead as normal of a life as possible! However, in spite of these activities and actively trying to "overcome" my dark place, nothing seemed to work. But one day, a little over 2 years after my diagnosis, I just suddenly realized that I wasn't as angry as I had been. It was like the sun and a soft breeze just entered my dark hell. I was finally able to look beyond the negativity and see that it wasn't personal. It didn't seem to be gradual – just one day, I wasn't as angry.

As for my treatment, well, we tried various medication and various combination of medications (Colchicine, IVIG, Plaquenil, etc.). Finally, we came upon a combination that worked better than the others had and I was on these meds for a couple years. I was taking Methotrexate and Azathioprine, together. Anyone who has taken Methotrexate knows that there are some definite side effects that goes along with it. For me, I lost some of my hair (but it was OK, as I have very thick hair), felt unwell for the first couple hours after taking each dose of the medication, etc. But overall, I tolerated it pretty well. That is until I started getting toxicity from it. After a couple years of taking this medication, I started getting these strange symptoms: my eyelashes turned white and then started falling out at an alarming rate, my individual hair strands started getting this banded coloring to it, hyperpigmentation on my face (a lot!), the tips of my fingers started peeling, etc. I did some research (as I live 5 hours from USC, so I just couldn't pop in). Toxicity came up on my research. The next time I went to see my rheumatologist at USC, he confirmed that he too, thought it was toxicity. Normally, we would have been in quite a quandary, as anytime I tried to reduce my Methotrexate, I was so sick that I could barely get out of bed.

Well, at that time a new medication had just come out, Otezla. But it was very expensive and was for Psoriatic Arthritis. Using this drug for any other disease, at the time, was considered using it off-label, and insurances don't usually pay for off-label medications. Well, my doctor wrote a letter to my insurance, but the insurance company proceeded to deny payment of the medication. We appealed it. Again, we were lucky, as the pharmaceutical company who makes Otezla had just published a research paper in the New England Journal of Medicine showing that Otezla was effective for Behcet's Disease. Meanwhile, my rheumatologist was giving me sample packs of Otezla. I got off the Methotrexate and Azathioprine completely. The Otezla was working better than any form of

treatment so far. After about 9 months (2 appeals), my insurance approved the medication and I've been taking it ever since.

So, how am I today and what is the quality of my life? Well, unlike many people with Behcet's Disease, I've never been in remission or even close to it. I continue to suffer from rashes, sores, systemic issues, autonomic nervous system dysfunction symptoms, vasculitis symptoms, memory problems, etc. I've had episcleritis and iritis in my eyes. I've developed a form of mild OCD (minus the "C") which is a component of the disease. But my current treatment plan, has minimized the severity and frequency of these symptoms. I am able to do basically any activity I want, as long as I adjust certain things for my life. I still start packing for my backpacking and travel trips at least 3 weeks ahead of time. But I no longer have to take prednisone before a trip to just be able to go. I enjoy backpacking, camping, painting, etc. I workout for 5 days a week. I continue to work full-time. Sure, I feel crappy or at least less than 100% often, but I don't let that stop me.

What advice do I have for others with Behcet's Disease, autoimmune diseases or Vasculitis (or any health issues for that matter)? Well, I am not a psychologist, medical doctor or guru. I can only tell you that these factors are beneficial to me:

1. First of all, don't define yourself by your disease. Now, I know that sounds cliché. But when I was in my dark place, all I could think about was my disease and how I was being ripped off. When I emerged from that dark place, I made a list of identifying aspects of myself. For example, I am a wife, a painter, a backpacker, a nature-lover, an employee, a traveler, etc. It took a while, but I started seeing myself separate from the disease. This brings me to #2.
2. You have to let yourself process the anger, depression, etc. For me, I found that trying to force myself out of it just made it worse and likely prolonged it. You know the saying, "What you resist, persists". Now, I am NOT saying to wallow in it. I'm

saying don't force yourself to be happy. Just be. Just be comfortable with "It is what it is". Looking back, I think painting, backpacking etc. did help even though it didn't seem like it at the time. In other words, going through the motions of doing the things that you normally would have enjoyed. Maybe, living a healthy life, helps you emerge from that dark place. Do I know this? No way! But having healthy hobbies can't hurt. Right?

3. Get enough sleep when possible and eat healthy foods (I know that's easier said than done). There are times that I struggle with sleep. And I had read years ago that people with autoimmune diseases should get enough sleep and eat well. Well, to be honest, that made me angry to read. I was like "Really?! Eating an apple and taking a nap is really going to cure me!?" No, it's not going to cure you and it might not make you feel any better when you're feeling crappy. But for me, it seems to stave off the flare-ups. If I get stressed out, go a couple weeks with little sleep, etc. it'll often trigger a flare-up. So, gradually, I had started giving a little credence to the sleep and eating well thing. At the same time, though eating healthy is essential for everybody's health, be creative. I enjoy the taste of foods. And to be frank, healthy eating isn't always yummy. So, for a while, I tried to make myself eat better but was hating it. I tried off and on for years, but then realized that if I wanted to consistently eat healthier, I had to be creative. So, I started eating healthy homemade quesadillas that had potato, chicken, maybe some cauliflower, a slice of low-fat cheese and a few olives. They're so yummy and it is a healthy meal. I also started buying lesser-healthy snacks in the 100 calorie individual bags. It allowed me to have a small, individual size treat of the unhealthy stuff (only eat one bag! ha, ha). I crave chocolate so I'd eat one mini candy bar. It's enough to feel like you've had a treat but is less than 50 calories, usually.

4. Do the hobbies you love to do, even when you don't feel like it! As previously mentioned, I think, or at least for me, doing healthy enjoyable habits starts to allow a crack in the door, allowing a small amount of joy to seep in. As previously mentioned, I use to force myself to do the fun things that I normally would have enjoyed. What happened is that the first 5 times, I was forcing myself, but the next 7 times I thoroughly enjoyed it and actually felt excitement.
5. Avoid stress! Ha, ha – yes, I know. It sounds like a hollow, unrealistic suggestion, but actually it's not. Obviously, we can't avoid most of the day-to-day stressors. However, I started noticing patterns in my life. I started realizing that interacting with certain people stressed me out and often set the stage for me to have a flare-up. Or that certain topics of conversation stressed me out. Or the way or order that I did certain things in my life, added stress. So, I started telling certain people that I couldn't talk about specific topics, as it was detrimental to my health. I started reducing how often I talked to certain people. I rearranged how I did certain tasks or responsibilities. I found that *communication* and *honesty* was crucial for me. Now, did I creatively word certain issues so not hurt people's feelings? Of course! But I ensured that I got the results that I was looking for. Try to communicate with your life partners. Talk about how certain processes or issues add to your poor health and ask for their assistance. My spouse is my biggest advocate! In other words, start looking at your life creatively. Start being cognizant of patterns in your life and then try to find ways to improve your quality of life. Just because you can't eliminate specific stresses in your life doesn't mean you can't find a creative way to *reduce* the stress. Searching for patterns in your life will help identify the specifics to your stress. Then you can work towards reducing it.



Again, I'm no guru, medical doctor or psychologist. I'm just an average person with an autoimmune disease. I've found ways that have helped me, and I sincerely hope you do too!

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