

## Coping with a CADASIL Life

By Sarah Moris

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As we all know, coping with life's circumstances while dealing with the circumstances and symptoms that CADASIL brings us everyday can be a daunting and overwhelming challenge at times. We know this because we can assume that if you're reading this letter you may have CADASIL, or know of someone who does. Or perhaps you know of someone who has the genetic mutation for a disorder, but remains symptom-free, as is my case. I am almost thirty years old and was made aware of CADASIL in our family just last year. I knew right away that I wanted to be tested for the mutation, but yet took some time to be sure that it was the right decision. And while I did question whether or not it was the right thing to do at times, I never did change my mind. I wanted to know. While the test results were positive and it wasn't the news that I wanted to hear, I immediately felt relief in knowing. However, I do know that predictive genetic testing is not for everyone. We all have different coping mechanisms in dealing with life's circumstances. But whether you know you have CADASIL or not, or whether you know you might have CADASIL or might not, the bottom-line is that we all have to cope with this. We all have lives to live. Our friends and families deserve to have the best of us. Before getting tested, I made the conscious decision that these test results were not going to control my life. If that was going to be the case, then I should've never have been tested.

I believe that I am coping with CADASIL in my life today pretty well. I know I am dealing with it much better than I was last year, and I hope that I'll be doing better next year than I am now. But there were certain steps I took to get myself to where I am today. First of all was seeking the medical help that I so desperately needed in the beginning. The fear and anxiety were overwhelming, and finding a good Psychiatrist (a doctor who prescribes medications) and a Psychologist (a Therapist) was essential to getting me well again. It was the combination of medications and therapy that allowed me to start to feel like myself again. The amazing part was that I never realized how bad I felt until I started to feel good again. And I hid it well. I know that even my closest friends and family had no idea how hard it was for me to get out of bed some mornings. Or I could tell even my own small children were happy to get their playful mother back again, instead of this tired, irritable, anxiety-ridden woman pretending to be their same mother.

The next pivotal step for myself was "finding my faith." I had so many questions, but I never asked "Why me?" or "Why my family?" I do believe that I was given CADASIL in my life for a very specific reason. And even though I don't understand the reasoning, or what I'm supposed to do about it, I know that I will understand someday. I also believe that the timing in which I discovered CADASIL in my life was meant to be. My father was tested seven years earlier, before there was a DNA testing method available. He had a brain biopsy performed, and the results were falsely negative. It wasn't until last year that his primary care doctor heard of a DNA test available and thought we should test again, even though there was any family history of early-onset stroke or dementia. For myself, I personally know that I would've never have had children had I known about CADASIL ahead of time. It amazes me that I have these beautiful children in my life,

and it baffles me to think of my life without them. Therefore, I know these children were meant to be. Even though they're already amazing little people, I know they're going to grow up to be something great someday.

A friend of mine was giving an analogy of life and happiness to that of flying an airplane. Every airplane needs two things to fly: "thrust" and little "drag" or "resistance". The tiniest little screw that can create drag against an aircraft can significantly reduce its efficiency. We all deserve happiness (i.e.-"thrust") in life. What is it in your life that is your thrust? Whatever that is: embrace it! What is it in your life that is your drag? Whatever it is: diminish it! You can't soar in life until you diminish your drag. At that moment my friend was telling me this, I realized my fear was my drag. I couldn't soar or obtain happiness until I diminished my fear. My fear of what 'might be some day' was robbing my family and me of my daily dose of happiness. This friend gave me two assignments to absolve my fear. First was to think of whatever it was that I feared, in other words-the worst possible outcome that I could think of, and tell yourself that if that happens to me: IT'S OKAY. Whatever it is, everything will be okay because it was all meant to happen. There will be a lesson as a result of it. The second assignment was to stop with the negative thinking. For every negative thought I worried about disability, dementia, or any of the symptoms of CADASIL could bring, I had to think a positive thought. For me, any thought I had of my father's disabilities and wondering if I would suffer from the same limitations, I pictured myself as a perfectly healthy 90-year-old grandmother enjoying her grandchildren. Before my friend had given me this assignment, I was ashamed to admit that I hadn't even done this once since I got my test results! I had taken the information from the geneticists and Internet and thought this is the way it will be for me. But I realize now, that nobody can predict the future. And I also know now that even if that is my fait, it was meant to be.

In a strange way, CADASIL has enhanced my life. My priorities are crystal clear to me now. But I won't pretend for one minute that I still have my good days and bad days. But it is because I have surrounded myself with people who are supportive, positive, optimistic and encouraging to rely on when I need it most that I can get thru those bad days just fine. I don't want people's pity. Do I want compassion and understanding, absolutely! But pity won't get me anywhere in life. Negativity, fear and worry won't get me anywhere, either. I'm at a good place with my life now. I feel that I've reached the "land of acceptance", but it's been a journey. And there is no doubt in my mind that the journey will continue. Life is what you make of it, and I look forward to the journey that I have in my future.

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