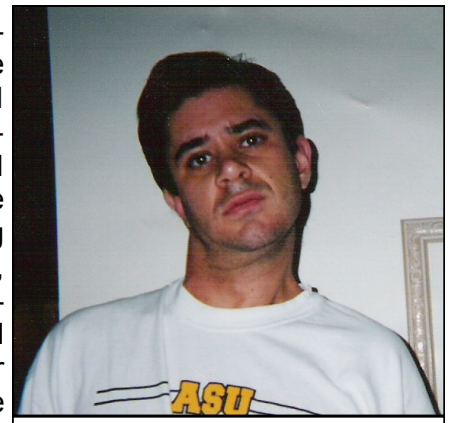


I was diagnosed with Spasmodic Torticollis (ST) in the Fall of 2001, while pursuing a masters degree in counseling psychology. In the very beginning, before getting diagnosed, I noticed that my head would slightly lean to the right when I was sitting and, for lack of a better term, flop to the right when I walked. Thinking it was a musculoskeletal problem, I sought out chiropractic care, where I received daily neck adjustments and extension traction. This just made me worse, as I started having pain and more noticeable spasms. Despite getting worse, I continued treatments thinking this was the nature of whatever I had, but mainly because I did not know what else to do. After about a month of chiropractic, and a few useless visits to a physical therapist, the pain worsened and I was becoming more twisted. I was then referred to another chiropractor who took a very volatile approach which made the pain and spasms increase exponentially within a few days. Utterly frustrated, I stopped all care and began researching the internet like crazy, where I discovered Spasmodic Torticollis.



February 2002

After reading everything I could on the subject, I was convinced that this was what I had and then learned, all too late, that the treatments I was receiving were ill advised for ST. Ironically, within a few days of my learning about ST, an acquaintance of my parents heard about my situation and said that it definitely was ST, as he had suffered with it for the past 40 years. With this information, I sought out a neurologist who made the official diagnosis. Not unlike many ST's, I had to diagnose myself, as the medical community sadly knows so little about ST and seemingly routinely makes incorrect diagnoses, thereby resulting in dangerous treatments, only making us worse.

By the time I finally got an accurate diagnosis, I was in such extreme pain and disfigurement that I was pretty much unable to do anything on my own. My head and neck were stuck in the position illustrated in the photo and the disfigurement significantly worsened with any type of movement because of the intense spasms. As a result of my pain and disability, I had to drop out of graduate school, quit my job and move in with my parents because I had become disabled to the point that I could not function without their help. In addition, since I did not have health insurance and was unable to work, I went into substantial debt and needed their financial support. This was a very difficult pill for me to swallow, having previously been a successful athlete in several sports for years, a full time student, and an active entrepreneur. The transition from an active, independent person to a disabled person almost completely dependent on others was devastating.

As my ST worsened, I began having suicidal thoughts because of the extreme pain and ensuing depression. Actually, I wouldn't say that I was suicidal by definition, but there were many times when I was so miserable that I would tell people that I wanted to drive my car into a brick wall, more as a way of trying to explain the severity of my pain than anything else.

For about 6-8 months, I literally spent my day as follows: wake up, eat breakfast, lie on the floor, eat lunch, lie on the floor, eat dinner, lie on the floor, and then go to bed. In fact, I actually ate laying on the floor also. I spent nearly 16 hours a day on my floor in a fetal position in tears half of the time. I became almost totally dependent on the help of others, as I was unable to shop, cook, clean, do laundry, etc. Everything I could do, or had to do, was with one hand because the other hand was constantly supporting my head and neck to try and alleviate some of the unbearable pain. Over time, I also developed scoliosis due to my body maintaining a twisted posture for so long.

In the Spring of 2002, I attended the ST Recovery Clinic in Santa Fe, NM (www.stclinic.com). With the incredible information I learned at the clinic (a very specific exercise/stretching/massage program, plus daily habit patterning techniques) along with medications (Klonopin and Baclofen), I did begin showing improvements about 4-6 months after attending the clinic. Unfortunately, being the impatient person I am, I was not improving at the rate I had hoped and was frustrated that I could not move on with my life. As a result of my anger and frustration, I essentially gave up on the program and chose to wallow in misery.

At the recommendation of friends and family, in January 2003 I went to Duke University for Botox injections. Unfortunately it did very little to nothing to reduce my pain or spasms. I tried again 6 months later with zero success. I then began seeing a physiatrist and in the next three years tried Botox with him three times, with only mild success on the first attempt. Additional treatment protocols included chiropractic (just for my back this time), acupuncture, physical therapy, and counseling, all of which were unsuccessful. This just added to my frustration and misery. I was not only miserable, but I was miserable to be around. I had a negative attitude towards everything and everyone, and as a result, I fell into a pit of depression, became almost completely homebound, began having severe panic attacks, drank alcohol to help reduce the pain and spasms, and had an awful diet.



*December 2005
(gained 30-40 lbs. more in 2006)*

Because of my disability and depression, I was very sedentary and no longer cared for my body the way I knew how and began eating large quantities of high fat foods throughout the day and night. One of the reasons for eating so much was because my ST posture caused me to feel dizzy all the time, but I thought it was due to low blood sugar, so I ate. I went from an athletic 180-190 pounds in 2001 to a morbidly obese 310 pounds in December 2006. About the time my weight was around 240 pounds, I was put on blood pressure medication for hypertension.

While I never did anything to change my bad habits, every single day I told myself that the next day would be the day I would make the change and get back in shape, but this went on for almost 4 years and I just became more depressed, disfigured, and overweight. Thinking back, I guess I didn't feel bad enough or care enough to make the change. I began thinking that I needed something serious to happen to me in order for me to make the necessary change, which is exactly what happened.

In December 2006, I got sick with a stomach virus for almost 2 weeks and during that time my neck was almost perfectly straight and I lost about 15 pounds. Getting sick really scared me because I rarely ever get sick; so when I do, I always think the worst. In addition, considering my sedentary lifestyle and poor diet, I thought that my getting sick was a sign that I might have developed a more serious problem, such as diabetes or some kind of organ dysfunction. While this was not the type of motivation to change I would have chosen, this was exactly what I needed to jump start my brain into action. It was a wide open window of opportunity and I jumped through it. I knew that if I didn't, I would eventually begin to have more serious health problems.

Considering I had already lost about 15 pounds and my neck somehow significantly improved while I was sick and for a few months thereafter, I began exercising again and changed my diet following the recommendations at www.deflame.com, one of the most comprehensive websites devoted to reducing inflammation with diet and nutritional supplements. This was a crucial step for me, as the muscles and joints in people with ST are typically very inflamed, which does not allow for healing to take place. Eating an anti-inflammatory diet and taking proper nutritional supplements plays a crucial role in my ongoing recovery.

To date, I am back on the ST Recovery Clinic's stretching/exercise/massage program, my neck is significantly better on a more consistent basis, I have much less pain, I am working again, I'm socially active, I've lost over 120 pounds, and no longer take blood pressure medicine as my hypertension is under control through proper diet and exercise. All of this in just 7 months!

How did I lose all the weight? Quite frankly, it wasn't really that difficult. I simply changed what I ate (following the food guidelines and taking the nutritional supplements offered at deflame.com), I cut back on the amount of food I ate, and walked everyday. That's it. No special diet, diet pills, or drinks, or any unique exercise program. I just ate properly and walked everyday. The weight literally dripped off me. When I initially began losing weight in December 2006, I set a goal of being 250 pounds by Summer 2007. I hit this goal in March and by June I weighed 200 pounds! This is only 10-20 pounds more than what I weighed before I was diagnosed with ST over 6 years ago! Currently, I weigh between 180-185 pounds.

I started walking $\frac{1}{4}$ mile a day and within 3 months I was up to 3 miles twice a day. My diet consists of an abundance of fresh fruits and vegetables, and modest portions of lean protein. I do not eat bread, pasta, grains, or sweets of any kind and the only thing I drink is water. If I am hungry between meals, I have a piece of fruit, which always gets me through to my next meal. Luckily, I have absolutely no cravings for any particular kind of food or drink. The only craving I have is 'food' when I'm hungry.

For breakfast I have a protein shake which consists of a banana, frozen cherries, soaked almonds, and egg protein powder all blended with water. Lunch consists of fresh melon, red grapes and cottage cheese or yogurt, and for dinner I have a variety of meats (mainly chicken, fish, steak, pork tenderloin, & lean ground beef) with steamed or sautéed vegetables (broccoli, carrots, asparagus, zucchini, cabbage, etc.) and/or a large salad. That is basically all I eat. While this may sound boring, if the food is fresh and prepared properly, each meal is delicious. I found that if I view food merely as a means to satisfy hunger, I have no desire or purpose to eat otherwise. I just make sure that when I eat, I eat the right kinds of food...those that are as anti-inflammatory as possible. When I feel full, I simply stop eating.

People often say to me that I must have a much better attitude now that I've lost all the weight. My response is typically, "No, getting a better attitude is what helped me lose the weight." Please don't get me wrong; my attitude now is certainly much better and I absolutely feel better, but had my attitude not changed I never would have lost the weight. People too often look at this concept backwards. Your attitude must change before you can change anything about yourself. You can't expect that you'll have a better attitude AFTER you have lost a lot of weight or made some other significant change. Mental change must occur first! Then you can reap the rewards for your efforts and enjoy your new, healthier mental and physical state.

I once read that life is 10% what happens to you and 90% how you react to it. For over 5 years suffering with ST, I lived my life thinking that 90% of life was happening to me and I only devoted 10% of my time reacting to it, or rather, doing anything productive about it. Since I have worked to reverse these numbers, I have improved significantly in all facets of my life. Another thing that helped me was what I heard Dr. Wayne Dyer, an inspirational speaker and noted author, say: "If you change the way you look at things, the things you look at change." I truly took this to heart and began looking at everything differently, and yes, things began to change. Most importantly, I began to change. I used to view myself as a victim and I basically gave up and let my disease control me, whereas now, I don't consider myself to be a victim of anything, except what I create in my mind.

Please don't get me wrong, I still have problems with my neck that prevent me from doing certain activities and I probably will the rest of my life to varying degrees, and I still suffer with the psychological ramifications of living with severe, chronic pain for over 5 years. In addition, I still need to take Klonopin and Baclofen to help with spasms. The point is that I have come from being someone who lived on a floor in writhing pain feeling completely worthless and depressed, unemployed, totally dependent on the help of others, gaining over 120 pounds, and basically didn't want to wake up in the morning because I didn't want to face the constant physical and mental pain, to someone of normal, healthy weight who now has more energy than I know what to do with and can't find enough hours in the day to do everything I would like. Most importantly, my ST is under control to the point that I can live a more normal life again. Not that I do this as often as I should, but I try my best to remember that even on my worst days, I can always find something positive in which to focus, and that there is always someone out there suffering far worse than I am or ever did. I have found this to be a very key component to not becoming your disease and maintaining your sanity.



August 2007

Another important component to living with ST and working towards a recovery is support. I could have not gotten through my ST battle, and continue to battle, had it not been for Abbie at the ST Recovery Clinic, the information dispensed by Howard, et al. at ST/Dystonia, and other STr's. On a more personal note, I never would have been able to do it without the unbelievable love and support of my parents. They have stuck by my side from day one of my diagnosis and continue to be by my side to this day. Plain and simple, they literally saved my life. In all honesty, it scares me to think where I would be today if weren't for their constant support. Despite my many ups and downs, they never once gave up on me and I can't think of anything in the world that I could ever do to repay them for all they have done.

Whenever you find yourself feeling depressed or worthless because of the physical and psychological ramifications of living with ST, do your best to muscle up the strength needed to continue fighting and take both solace and inspiration in the words of Charles Lindbergh: "Success is not measured by what a man accomplishes, but by the opposition he has encountered and the courage with which he has maintained the struggle against overwhelming odds." I believe that ST is a great opposition and struggle, so in order to not become our disease and let it run our lives, we must have the courage to continue fighting. In addition, we should fully embrace even the most minor accomplishments every day and use it as a stepping stone to a brighter tomorrow. When life kicks you, let it kick you forward!

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