

In the Summer of 2001, while pursuing a masters degree in counseling, I developed a neurological movement disorder called Cervical Dystonia (CD), also known as Spasmodic Torticollis. CD is a condition caused by miscommunication of chemicals in the brain which causes intermittent or sustained spasms/contractions in the muscles around the neck which control the position of the head, causing the head to lean to one side, or be pulled forward or backward. CD is usually accompanied by pain, from moderate to severe. Performing everyday tasks such as sitting, standing, walking, driving, shaving, brushing your teeth, combing your hair, eating, talking on the phone, etc. become very difficult. Currently there is no known cause or cure for this disorder in most cases. While the symptoms may subside over time, or for a small portion of the dystonia population, a complete remission, dystonia is a condition one will have the rest of their life to varying degrees until a cure is found. The best doctors can do at this time is treat symptoms. I want to note that dystonia can affect any part of the body. In my particular case, the neck and back are most affected.



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 neck adjustments and extension traction. After several months, the pain worsened and my neck muscles were pulling my head to the right more forcefully. I then saw a couple a few other chiropractors, MD's, an internist, a massage therapist, and physical therapist, none of whom helped. Utterly frustrated, I stopped all care and began researching the internet where I discovered Cervical Dystonia. After reading everything I could about it, I was convinced that this was what I had and then learned, all too late, that some of the treatments I was receiving were ill advised for CD. I then sought out a movement disorder neurologist who made the official diagnosis. Not unlike many with dystonia, I had to originally diagnose myself. Unfortunately, much of the medical community knows little about this disorder and often makes incorrect diagnoses, resulting in treatments that can make symptoms worse.

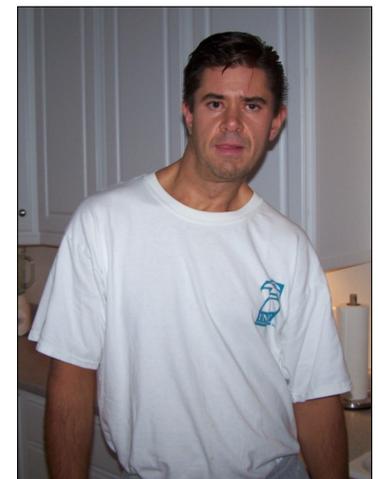
By the time I finally got an accurate diagnosis, I was in such extreme pain and disfigurement that I was pretty much unable to do anything on my own. My head and neck were stuck in the position illustrated in the photos and the disfigurement significantly worsened with any type of movement because of 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. This was a very difficult pill for me to swallow, having previously been a competitive 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. I was only 30 years old at the time.

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 and try to fall asleep. 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 February 2002, I attended the ST Recovery Clinic in Santa Fe, NM (www.stclinic.com). Applying the information I learned at the clinic (a very specific exercise, stretching, and massage program) along with taking medications, I began showing some improvement about 4-6 months later. Unfortunately, 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 gave up on the program and chose to wallow in misery.

At the urging of friends and family, in January 2003 I went to Duke University for Botox injections. While Botox is most well known for cosmetic uses, it has long been used to successfully treat many health conditions. While most people with dystonia benefit from Botox, or one of the other neurotoxins, it did very little to reduce my pain or spasms. I tried several times again in the ensuing years with no success. Additional treatments included chiropractic (just for my back this time), acupuncture, and physical therapy, none of which improved my condition. My frustration and misery skyrocketed. I was not only miserable, but I was miserable to be around. 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.

Because of my disability and depression, I was very sedentary and no longer cared for my body the way I knew how. I began drinking a lot and eating large quantities of high fat foods throughout the day and night. I went from an athletic 180-190 pounds in 2001 to a morbidly obese 330 pounds in 2006. I actually don't really know my top weight because I stopped looking at the scale after I hit 310, and I was still rapidly climbing. 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. 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 caught a stomach virus and was sick for almost 2 weeks. During that time, my neck was a little straighter and I lost about 15 pounds. Getting sick really scared me because I rarely get sick. 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 have more serious health problems.

Considering I had already lost about 15 pounds and my neck somehow improved a little while I was sick, I began exercising again and changed my diet. I changed what I ate and when I ate, I cut back on the amount of food I ate, and I walked everyday. That's it. No special diet, diet pills, drinks, or any unique exercise program. I just ate properly and walked everyday. I started out by walking about 1/4 mile a day and slowly increased it to about 2 miles twice a day. 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 CD over 5 years prior! I currently weigh between 185-190 pounds. If you are interested in learning more about my eating lifestyle, please contact me for an article I wrote discussing it in more detail.



To date, 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 well over 100 pounds, and I no longer take blood pressure medicine as my hypertension is under control through proper diet and exercise.

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, "Getting a better attitude is what motivated me lose the weight." 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 taken the steps to lose the weight. People too often look at this concept backwards. Our attitude must change before we can change anything about ourselves. We can't expect that we will have a better attitude after we have lost a lot of weight or made some other significant change. Mental change must occur first. Then we can reap the rewards for our efforts and enjoy our new, healthier mental and physical state. I used to view myself as a victim. I basically gave up and let my disorder control me, whereas now, I don't consider myself to be a victim of anything, except what I create in my mind.



Life is certainly much better, but I still have problems with my neck and back that prevent me from doing certain activities. However, it is night and day compared to the horror I once lived. I used to be someone who essentially lived on a floor in writhing pain feeling completely worthless and depressed, in debt and unemployed, morbidly obese, and totally dependent on the help of others. I didn't want to wake up in the morning because I didn't want to face the constant physical and mental pain. I am now at a healthy weight and in much better control of my dystonia to where I can live a more normal life with passion and excitement. While I need to take medications and dedicate myself to a healthy lifestyle to help control my symptoms, I don't mind doing any of it. The results that come from my hard work and dedication have made me the strong person I am today.

In 2012, I became certified as a professional life coach through the International Coach Academy. Utilizing this education and the tools I learned from my experience living with dystonia, I now dedicate myself to helping others who are experiencing their own health challenges. Empowering others improve their quality of life is a great passion of mine.

In 2015, I published my book, [Diagnosis Dystonia: Navigating the Journey](#), which has been recognized by the Michael J Fox Foundation and featured in Pain-Free Living Magazine. This combination autobiography, self help, education book provides treatment options, coping strategies, skills for daily living, and tools for dealing with the physical and mental challenges of life with a chronic health condition. It is available at www.tomseamancoaching.com.



I have been faced with major challenges throughout my adult life. What helps me jump over hurdles is my belief that everything has a solution. There is nothing that can't be altered to improve our quality of life. Obstacles provide us with opportunities to grow and become better people, and every day I am grateful for the chance to help myself and others achieve their personal best.

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