

Super Model by Cheryl Dillon

If I were a Supermodel, I probably would welcome the stares. I receive a lot of attention from people trying to understand what they're looking at. "Are you on the phone?" "Are you having a seizure?" "Are you really going to drive?" While the public's trying to understand what they're seeing, I'm trying to live inconspicuously.

I was diagnosed with Cervical Dystonia, a movement disorder that causes involuntary contractions and spasms of the muscles in the head and neck. In this disorder, the normal mechanism of the brain that makes muscles relax is not functioning properly. The involuntary muscle contractions that occur often force the body into repetitive and twisting movements that cause irregular postures and pain. Sometimes, I experience a neurological 'storm' where my entire body shakes uncontrollably, like a Parkinson's patient. These storms can happen anywhere and at any time, lasting 15 to 30 minutes, and are exhausting.

I heard that anguish prepares us to teach others. I don't always want to be 'the teacher'. I don't want to be 'the student'. Heck, given the choice, I would love to 'drop' this 'course' altogether! As I prepare to take my dogs out for their walk, we each get a collar. We, all three of us, would love to run away, yet our circumstances (the collar) hold us in place.

Having this condition has forced me to look at how I do things. In considering employment, there are many positions I wouldn't be well suited for. I know I'll never be a pole racer, pole vaulter, or even a pole dancer; something about being upside down, loss of balance...Driving instructor, Customs Officer, even fry cook, although I did try to be a fry-cook.

I my neck movement usually stops when my head is at rest, fully supported. Great! Can you think of any jobs I can do lying down? Mechanic maybe? Astronaut? Not likely. With this diagnosis, I've had to reflect on my skills and gifts to find a purpose. What is my purpose? Without purpose, a life has no meaning. Conversely, when a life has no meaning, there is no purpose for living. Yes, I had some very dark thoughts, but I knew that there was something out there for me. A reason I developed this disorder. I just had to find it.

I continue to search for an answer. Anyone who knows me knows that I live life gregariously and do not shy away from being in the spotlight. I belong to a public speaking club and regularly provide speeches and education sessions. I chair various church committees. I organized fundraising for our local Dystonia group. I train twice a week with a personal trainer. I'm not ready to give up the fight to move freely and on my terms. My wish is for a cure and for compassion. If you see me, please, Stop Staring! It's not like I have two heads, just one moving really fast. Maybe I am a (super) model after all.