

Rhapsody in C and D

Music has been my refuge from cervical dystonia.

BY BETTE J. FRANKE

My first symptoms of dystonia appeared in about 1982 in Phoenix, AZ, while I was living with my first husband, Al. I was initially diagnosed with temporomandibular joint dysfunction (TMJ). Because of my facial tremor, the specialists I consulted found it difficult to keep the fit of my splint, an orthopedic device that I still must wear, mostly at night.

I felt as if I was walking through a dark tunnel. With a 22-year-old son in college and an 18-year-old daughter in high school, I needed to keep working in real estate. I tried everything to relieve the TMJ pain: aspirin, muscle relaxation, talk therapy—I even spent two weeks in a pain and stress clinic in South Phoenix. Finally it became necessary for me to have both TMJ discs surgically removed.

When both kids were settled in careers and relationships, Al and I decided to move to Illinois. I'll never forget that drive, because I started to feel my chin mysteriously being pulled down to my chest. I couldn't sleep and was also having trouble eating due to the TMJ. I wasn't even able to work part time. Through it all, I tried my best to keep up with normal activities of my church—including playing piano—and continued to take piano lessons. Thank God for my music.

I was resolved to find out what was wrong. A neurologist in Chicago was unable to give me a diagnosis, but the medication he prescribed was the first one that kept my chin from being pulled down to my chest. I felt ecstatic. Unfortunately, this relief only lasted one month, and then I was back to my tunnel. This is how it is when you and your doctor are trying to find the right treatment.

Al and I divorced in 1994, after 37 years of marriage. The money and time we spent trying to find out what was wrong with me played a major part in the divorce, and I think the slow death of my marriage was more painful than anything else.

So I moved back to Phoenix to be near my children and was referred to Drake Duane, M.D., a neurologist

formerly with Mayo Clinic and director of the Arizona Dystonia Institute (arizonaneurology.com). Dr. Duane diagnosed me with spasmodic torticollis, also known as cervical dystonia (CD), and he gave me injections of botulinum toxin for the spasms. I saw some light at the end of that tunnel again.

Cervical dystonia is a neurological movement disorder that causes muscles in the body to contract or spasm involuntarily. It is the third most common movement disorder after Parkinson's disease and tremor, and it affects an estimated 300,000 people in the U.S. alone. It isn't a psychological disorder and doesn't affect intelligence. Dystonia isn't fatal, but it is chronic, causing varying degrees of disability and pain, from mild to severe. The negative effects of CD on quality of life are comparable to those seen in Parkinson's disease, stroke, and multiple sclerosis.

In 1999, I married for the second time, to a wonderful man named Louis Franke. I also began to teach piano at home after obtaining my certification with the Music Teacher's National Association in

June 2005. It was hard work—the certification involved two difficult tests and a piano performance—but I was determined to do it in spite of the physical pain of CD.

I am now one of the chartered teachers for the Sun City Piano Club in Phoenix and have started playing at concerts to raise awareness about cervical dystonia.

At my most recent performance I played some Chopin, excerpts of *Rhapsody in Blue*, a Bach prelude, some Haydn, and a few original compositions—including “Desert Places,” “What Do I Want For My Children?” and “A Prayer for People in Pain,” which reminds me of one of my favorite sayings: “May my life be like a tuned instrument upon which the Master musician creates a melody that brings peace to all who hear.” NN



Bette Franke lives in Phoenix, AZ, where she plays and teaches piano.