

# Going Public With Cervical Dystonia

From personal mission to national television.

BY NOEL VALERO

A life of disability was not what my wife and I envisioned for our future when I was 47. Our children were grown, and we planned to finish paying for their college education and then enjoy a life of adventure, travel, and relaxation. Those plans were abruptly changed when I began to experience constant searing pain in my neck and back. It adversely affected my personality, degrading my relationships with friends, colleagues, and family. Finally, after a multitude of doctors, I got a devastating diagnosis: cervical dystonia, also known as spasmodic torticollis. I had never even heard of this incurable disease until that day.

The first year after my diagnosis, I wallowed in pity as I discovered that my cervical dystonia was more widespread than initially thought. I was forced to stop working after 32 years of continuous employment and close down my IT consulting business. The treatment for the disease involves medications prescribed in a trial-and-error manner, all with onerous side effects, many offering no benefit. Eventually I met my current neurologist, who finally achieved good results with botulinum toxin therapy and restored some of my function and life.

After months of introspection and the help of old friends, I rediscovered my old “can-do” personality and formed the American Dystonia Society ([dystonia.us](http://dystonia.us)) with the goal of fundraising to bolster research. After a few months, it became obvious that more disease awareness was needed first. So we rearranged our priorities, emphasizing awareness and advocacy as the path to increasing fundraising for research.

I needed to reach a larger audience. But how? To date, no celebrity with cervical dystonia has stepped forward to be a spokesperson. I decided to share my experience in

the Princeton University alumni magazine. Although sharing my story publicly was difficult, the positive response made it worthwhile. Invigorated, I reached out to a local and then a regional newspaper, which posted my story on its Web site. Producers from the TV show *Mystery Diagnosis* read the story and contacted me. Initially I was assigned an advisory role for an episode on cervical dystonia; later, the producers said they wanted to cast me to tell my own story. I balked at first, thinking that my family might not be willing to discuss that painful time in our life together on the air. Eventually we decided that the potential benefits outweighed our concerns.

Taping a show was not easy for someone who could barely cobble together a couple of productive hours a day. Plus, authenticity required that I be at the end of my botulinum toxin treatment cycle to display my painful symptoms. The bulk of the segment was taped over three days, followed by two more days a month

later. Throughout it all, the producers were accommodating, breaking up my scenes so I could rest.

We were anxious to see the final twenty-two minute segment. How would we be portrayed? How would the cervical dystonia community respond? Our fears proved to be groundless: Although it was heavily edited, the show got across many of the points that we wanted to share. (Go to [dystonia.us](http://dystonia.us) to see the video.) The reaction from the public was wonderful. I hope my experience encourages all people with cervical dystonia and other neurologic diseases to speak up.

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*Noel Valero has a degree in mechanical and aerospace engineering from Princeton University. He worked for the U.S. Air Force Space Division and Lockheed-Martin before founding his own IT business and the American Dystonia Society.*

