

SD Newsletter
from Mel Dubovick,
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Botox helps woman through vocal cord disorder

By Erica C. Cline | *Lifestyles Editor*

"Trish Wheeler has adductor SD, a vocal cord disorder that impedes her ability to speak. With the injections of Botox in her vocal cords, however, she has regained the use of her voice almost completely.

A metaphorical hand was strangling the words in Trish Wheeler's throat.

Mrs. Wheeler, a registered nurse at the Medical College of Georgia, was told it was depression.

Over the course of more than two years, she also was told it was stress ... attention-deficit disorder ... or maybe it was attention-deficit hyperactivity disorder ... no, wait, it was all in her head.

Unkind strangers even told her it was God's way of preventing her from saying things she shouldn't.

What she actually had is a little-known and frequently misdiagnosed disorder called spasmodic dysphonia, generally called a dystonia, or a prolonged muscle spasm.

The incurable neurological disorder causes the muscles of the vocal cords to either slam shut (adductor SD) or fling open (abductor SD) when the patient speaks. With SD people can sing but not talk, laugh but not talk."

Speech is vital to Mrs. Wheeler's position as a nurse in the oncology department at MCG, but there were times, she said, when she questioned her ability to stay on the job.

"I would wake up from nightmares that I'd have a slate and I'd be walking into a patient's room and I'd have written, 'Hi, my name is Trish and I'm going to be your nurse today. If there's anything you need, could you please write it down on this board for me?'" she said. "It had gotten really bad and I'd gotten to the point where I wondered if there was really any way for me to be a nurse and not be able to communicate."

After years of being treated for everything from anxiety to depression - "Something to wake me up, something to put me down; they treated me for years just trying to figure it out" - Mrs. Wheeler found salvation in Dr. Christine Gourin, the assistant professor of otolaryngology at MCG. It was Dr. Gourin who finally pinpointed the cause of Mrs. Wheeler's voice loss - adductor spasmodic dysphonia.

With a diagnosis in hand, Mrs. Wheeler could finally concentrate on a treatment, one that is better known for its cosmetic applications than its medical use - Botox injections.

Botox, a form of botulinum toxin, is used cosmetically primarily to reduce the signs of aging by temporarily paralyzing the facial muscles that cause wrinkles.

When injected into an area with a dystonia, which Dr. Postma said can be just about anywhere, including arms, legs, neck and areas of the face, the Botox plays a similar role, paralyzing muscles and relieving a patient's symptoms for up to months at a time.

For Mrs. Wheeler, that means long needles to inject Botox into the muscles on either side of her voice box. Dosage is not an exact science, so it's trial and error to get the longest relief period possible.

Mrs. Wheeler, who received her first Botox injection in January, received too high a dosage the second time around, resulting in difficulty swallowing, but she said trial and error is just part of the process.

"The pros really outweigh the cons," she said.

Eventually, she'd like to be able to go six months between injections. Those injections will continue for the foreseeable future because Dr. Postma said there's no cure for spasmodic dysphonia and doctors are unsure what causes the disorder.

"They believe it's a problem in the brain stem," he said. "Even to this day, we don't really know what causes it."

For Mrs. Wheeler, the Botox solution to her dystonia is more than just a way to give her a voice; it's been a way to reconnect with her children, the rest of her family and the job she loves.

"I avoided conversations with my teenagers ... I avoided all phone calls," she said. "It was hard to believe that I had been seeing another doctor for five years (before my diagnosis)."

Regaining her voice is the silver lining in a long line of clouds for Mrs. Wheeler. Her experience has changed not only her life but also that of her oldest daughter, Sheyna Hopkins, who is studying communication and voice disorders at the University of Georgia.

Ms. Hopkins' educational choice is a heartfelt nod to her mother, who never gave up in her fight to raise her voice."

EMPLOYMENT AND SD

You're 30-years-old and on top of the world. Life is just beginning to fall into place. You may be finishing graduate school, starting your first "real" job, or simply planning your future.

Suddenly, you're robbed of the ability to produce a clear, audible voice. If you have a job, it could be in jeopardy. If you're looking for a job, you begin to wonder how in the world you'll manage to get one without a good voice.

SD can be devastating and is not easy to cope with. Don't let anyone minimize the situation or tell you otherwise. But, let's face it, we're young, we have many years ahead, and we should try to figure out how to be happy and make the best of it!

KEEPING YOUR CURRENT JOB

A diagnosis of SD doesn't necessarily mean you have to give up your current job. Depending on the severity of your symptoms, your response to treatment, the amount of talking involved in your job, and your employers' willingness to accommodate, you may be able to continue in the same job and/or field you're in.

Tips to help stay at your current job:

- If you're lucky, your voice responds well to treatment, and/or you don't think your employer will notice or care, it is up to you whether you disclose this information. Don't feel obligated to do so, especially if it does not interfere with your ability to perform.
- If you feel your job is in jeopardy simply because of your voice and you would prefer to keep it, consider setting up a meeting with your supervisor. Before the meeting, think about the

organization and plan a discussion about how you can continue to contribute to it. Don't be afraid to ask for help and admit that there may be some things with which you'll need assistance (phone calls, amplification during presentations), and keep the discussion positively focused. If you're a valuable employee, and depending on your ability to continue to perform the essential duties of your current position, many employers may be willing to accommodate your situation.

- Look for opportunities to move to other positions in your organization that don't require as much vocal use.
- When speaking with your supervisor or perspective boss, always paint your disability in the most positive light possible. Try to downplay the severity of it, if that is possible. Some thoughts to consider: This disability can be accommodated through phone amplification devices and increased use of e-mail. Therefore, accommodation costs are minimal and having you on board would count towards their people diversity targets. Focus on how you can "make it work" together.

It may not always be possible to keep your current job, and some employers will be more receptive than others, but you have little to lose through honest communication. Keep in mind that it's not always discrimination if you're let go because of your voice. For example, an individual with SD may not be able to function as a 911 operator or a tour guide in a museum where, without a clear voice, the individual cannot perform the essential functions of the job safely and/or effectively.

JOBS WITH LOWER VOCAL DEMANDS

If you would like to work a field with lower vocal demands, consider some of the following fields. (You can also consider going back to school.):

Computer Programming

Medical billing, Coding and/or Transcription

Legal Billing

Word-processing

Court Reporter/Stenographer

Data entry and/or Data analysis

Proofreading, editing, copyediting

Paralegal (*in an environment focused on legal research/writing*)

Professional cleaning

Teaching in a deaf school/teaching computer skills to deaf adults (*of course, you'd need to learn sign language*)

Working in a Library

Fed Ex, UPS or messenger jobs

U.S. Postal Service

Writing

Bookkeeping

Accounting

Web design

Graphic Design

Archivist

Art Restoration

Artist

Repairman/technician (*auto body, mechanical, electrical, phone, cable*)

Cable Installer

Truck driver, bus driver, chauffer

Stock Photography Researcher

Lab Tech

Chef/Cook/Food Service

Working in a Greenhouse/Floral Arranging/Basket Making

Seamstress/Tailor

Researching/Research Assistant

Pet Groomer

Grantwriting/Program Development

Real-time and/or Offline Captioner

Go to medical school and come up with a cure for Spasmodic Dysphonia

VOCATIONAL REHABILITATION

Another option is to contact your State's vocational rehabilitation facility. They are there to help individuals with disabilities find a job that fits their abilities and accommodates their disabilities. In some cases, they will also pay for education and training for you to get into a new field, and counsel you on workplace accommodation and assistance. They may even pay for initial medical treatment to make you more employable and provide information regarding low-cost housing for individuals with disabilities.

Their job is to place people with disabilities into well-paying jobs (often with health insurance) suited to one's education and experience. If you need help, don't be shy about using them! It usually takes a letter from your doctor (ENT or neurologist) to certify your disability. From there, you're assigned a vocational counselor who will work with you. Most of the employment placement assistance services they provide are free, while some of the offers for job training/paid education will be based on income.

If you can't find your State's local vocational rehabilitation office, call your local social security office (or visit www.ssa.gov) and ask them to point you in the right direction.

ADDITIONAL SUGGESTIONS AND CONSIDERATIONS

Work for family or start your own business. Ask other SD people what they do in their current job to cope, or in finding a less vocally demanding job. Post questions on the NSDA Bulletin Board (www.dysphonia-bb.org/forums/sd) requesting information or talk with others at your local support group. Some agencies actively recruit and/or are willing to hire individuals with disabilities. Many state and local agencies, including hospitals, etc. may fit this category - you may want to briefly and positively discuss your abilities and accommodation needs in the cover letter with your resume.

Much thanks to Mary Bifaro and the Charlotte NC Support Group for contributing the above two articles from their Newsletter

Comments on an potential alternative to Botox

(These comments are mine from personal experience and it does not reflect upon my position within the NSDA)

Since Botox is no longer effective for me, I went to a neurologist who said he had several alternatives. The first alternative was a new drug called Lyrica. In www.lyrica.com the drug is described as a medicine useful to treat severe pain from diabetic nerve pain, pain after shingles and relief from partial onset seizures.

"LYRICA was designed to treat your specific kind of pain. LYRICA works by reducing the number of "extra" electrical signals that are sent out from damaged nerves in your body." Some of you may

recognize that the term extra electrical signals is familiar to how SD is believed to occur.

Lyrica was a mixed blessing for me. It actually WORKED, reducing my vocal spasms significantly. The mixed part is the side-effects. I had joint pain in my neck, shoulder, hand and foot but that went away in a week. I was tracking well with the pills but realized that I was having sudden weight gain, another side-effect. Before I knew it, I had gained 20 pounds! I could not tolerate this added weight and slowly discontinued taking the Lyrica.

There is no assurance that the Lyrica will help you. But is also no assurance that if it does help, you will get the same side effects I had.

Comments of those who have succeeded in being approved for SSDI (Social Security Disability Insurance)

- Getting a doctor's letter stating your condition prevents you from working is a core requirement
- You need to be an occupation where your voice is important, i.e. salesperson, educator, customer support (phone) for example
- You must answer every question, leaving none blank
- You must have tenacity and expect a near automatic rejection the first time
- You don't necessarily need an attorney to represent you, unless you should reach the point where you've been rejected a few times and still think you've met their qualifications

Question: Is there any linkage between SD and thyroid problems?

Answer: No. The National Institute of Health (NIH) tested the thyroid levels on 50 patients several years ago and did not find any difference between SD and "normal" patients. The NIH considered the 50 a small sample size, so the information was never published.

Essential Tremor

While Essential Tremor is not SD related, a number of people with particularly those between age 60 and 70 or older, suffer from it. The following advice comes from Harvard educated alternative medicine guru, Dr. Andrew Weil.

Essential tremor is a common condition, affecting millions of people worldwide. Characterized by the involuntary shaking of the hands, head, or neck, the symptoms and severity can vary from day to day, even hour to hour. Some people experience tremors when in certain positions, or when writing or eating. Unfortunately, no one knows the exact cause, though it is known that stress, anxiety, and fatigue may worsen the tremors.

If you experience essential tremors, try the following (each may help to reduce the length and frequency of the tremors):

- Eliminate consumption of caffeine, including coffee, colas, and caffeinated tea.
- Limit alcohol. (A small amount of alcohol may temporarily reduce tremors, but should never be used to treat symptoms.)
- Know the side effects of prescription drugs or herbs you are taking. Amphetamines, lithium, or ephedra can all exacerbate shaking.
- Begin a regular practice of relaxation techniques such as meditation or tai chi.

- Consider cranial osteopathy or some form of energy medicine such as Therapeutic Touch or Reiki. You might also experiment with acupuncture, hypnosis, and massage.
- Try herbal relaxants such as valerian. Follow the dosage directions on the products.