

Once Gasping for Breath, Now Breathing Easy

Vocal cord dysfunction, or VCD, is a medical condition marked closing of the vocal folds that impedes the ability to breathe. Its diagnosis and treatment are still poorly understood, and many patients struggle for years to get a proper diagnosis. The symptoms can be difficult to distinguish from those of other breathing disorders, thus preventing patients from receiving effective treatment. This month, with guidance from Claudio Milstein, Ph.D. a Laryngologistt at The Cleveland Clinic's Voice Center, HealthExtra presents a two-part series on VCD. Part I deals with a description of the problem and its most common symptoms. Part II, also presented in this issue, explains the treatment process.

Laurie Danders felt she'd been issued a death sentence in December 2001, when a doctor at the University of Michigan medical school told her there was nothing he could do for her. For the previous 10 months she had been enduring unpredictable throat spasms that left her struggling to breathe. And the problem wasn't getting better. After the appointment, she wondered how long it would be before she stopped breathing forever.

"I never knew when I would stop breathing, what would trigger it or how long the attacks would last," Danders says. "This condition had such control of my life that I actually considered suicide. It was terrible."

Since the first episode in 2001, Danders, a Lansing, Michigan resident, had lived a life of isolation and fear. She suffered symptoms nearly every other day. She was afraid to spend time with her grandchildren because the attacks would scare them. The unpredictability of the attacks also prevented Danders and her husband from partaking of a favorite pastime—hiking in the woods. In short, she became a prisoner of her disease. Her husband lived his life on alert, never knowing when he would get a call from Laurie's coworkers. When that happened, he would drive to her workplace, pick her up, and return home, where she would quickly crawl into bed.

"For the better part of two years, I slept," says Danders. "It was the one thing I could do that would stop an attack."

But Danders decided to give medicine one more try, and she's glad she did. In the summer of 2003, she went back to the University of Michigan. Still unable to diagnose her, an otolaryngologist (ear, nose and throat specialist) there recommended a visit to The Cleveland Clinic Voice Center. Initially, the first doctor she saw in Cleveland told her the same thing all the others had—there was nothing he could do for her. But before she left, he told her that one of his colleagues was doing research about a condition whose symptoms were similar to hers. Would she be willing to see him? Danders agreed.

Danders was soon in the presence of Claudio Milstein, Ph.D., a speech-language pathologist at The Voice Center, which is part of part of the Cleveland Clinic's Head and Neck Institute. After a careful evaluation, Dr. Milstein told Danders that he had diagnosed the condition and that he could provide treatment for it. "I was skeptical," says Danders. "I had bounced around to 11 different specialists over a 3-year period, and none of them helped."

Tough to pin down

Dr. Milstein suspected that Danders was suffering from vocal cord dysfunction (VCD), an involuntary closing of the vocal folds that chokes off breath. Though it has a 30-year history in medical literature, it is still a poorly understood laryngeal disorder, says Dr. Milstein. Like Danders, patients in search of a treatment or cure often see myriad doctors—pulmonary (lung) specialists, neurologists and even psychiatrists. The condition affects people across the age spectrum but is comparatively more common in young, middle-aged women.

Symptoms of VCD can include coughing, shortness of breath, hoarseness, chest or throat tightness, stridor (abnormal, high-pitched breathing sound during inhaling), sensation of choking, dizziness, nausea, lightheadedness, loss of consciousness and fear of suffocation. But cough, says Dr. Milstein, is the most common reported symptom, present in up to 77 percent of patients diagnosed with VCD. Anyone who experiences such symptoms in connection with breathing difficulties, says Dr. Milstein, should consult a specialist.

VCD can easily be mistaken for other respiratory problems, particularly asthma. Dr. Milstein says he learned how to diagnose VCD as part of his training as a speech-language pathologist and that he sees the condition frequently in his practice.

Impairment causes panic

The vocal folds, once commonly—but somewhat inaccurately—referred to as vocal "cords," are bundles of muscle and other connective tissues recovered by mucous membranes. They are housed inside of the larynx, also known as the voicebox. The two folds create a valve that hovers over the trachea, or windpipe, that in addition to producing the voice, help regulate the amount of air breathed.

During a VCD attack, those two folds can close suddenly, creating shortness of breath and sometimes cutting off one's air supply. The shortness of breath often mimics an asthma attack; sometimes it occurs in conjunction with the pulmonary disease. Nevertheless, the causes of the two conditions are very different. Asthma is caused by an inflammation of the airways and is treated with inhalers that release anti-inflammatory drugs (corticosteroids) into the lungs. Airway inflammation does not cause vocal cord dysfunction. Vocal cord dysfunction, however, can coincide with an underlying pulmonary disorder like asthma.

Vocal cord dysfunction attacks range from mild to severe, with the most serious attacks leading to a loss of consciousness and hospitalization, where the patients are often given high doses of corticosteroids and sometimes emergency measures to ensure breathing (e.g., intubation, tracheotomy). For most people, says Dr. Milstein, the worst symptom is panic.

"Breathing is so fundamental to life that the inability to do it naturally creates a sense of overwhelming helplessness," says Dr. Milstein. "It's quite scary for people when they can't breathe and don't know what's going on."

Next: One Step Closer to a Cure

Once Gasping for Breath, Now Breathing Easy (part 2)

Laurie Danders was ready to give up hope that she would ever find a doctor who could diagnose, and more important, treat her throat problem. For years she had been enduring unpredictable throat spasms that left her struggling to breathe. The problem affected her work life, her relationship with her husband and prevented her from spending time with grandchildren. Breathing is the essence of life, yet most of us do not have to give it much thought. Danders breathing problems, however, made her fear for her life. But an evaluation by Claudio Milstein, Ph.D., speech pathologist at The Cleveland Clinic Voice Center, changed all that. Part 2 of this two-part series on vocal cord dysfunction (VCD)—a closure of the larynx muscles that impedes normal breathing—recounts how Dr. Milstein helped Danders learn to control the VCD symptoms, and, in turn, get her old life back.

One step closer to a cure

The first step in treating vocal cord dysfunction is understanding what triggers the attacks. The list of potential VCD triggers fall into three major categories: irritants, physical activities/sports and psychologic.

Irritants can include chemicals, pesticides, fumes (from carpet glue, paint, solvents), strong odors or perfumes, and cigarette smoke. The back flow of stomach acid into the throat—a condition known as laryngopharyngeal reflux (LPR)—can also irritate the vocal folds and cause a VCD episode. It is quite common to find evidence of LPR in patients that suffer from VCD, says Dr. Milstein. Physiologic triggers may include coughing, laughing, exposure to cold air, and intense physical exercise (a common trigger among high-school aged girls). Psychologic triggers include stress, anxiety and depression. Some individuals can be affected by multiple triggers, says Dr. Milstein.

At the Clinic's Voice Center, effective diagnosis and treatment involves taking a detailed patient history and performing a careful physical evaluation. It also includes nasopharyngeal laryngoscopy, a procedure that involves guiding a slender, flexible fiberoptic scope up through the nose and down into the throat so that the movement of the vocal folds can be viewed and videotaped. If possible, Dr. Milstein will purposely induce a VCD attack to record the behavior of the vocal folds during such an episode. This process serves two important purposes. First, it allows Dr. Milstein to confirm the diagnosis; second, the recording is used as a teaching tool. (An ear, nose and throat specialist, or otolaryngologist, can also perform nasopharyngeal laryngoscopy, says Dr. Milstein, but expertise in this disorder is necessary for diagnosing VCD.)

'100 percent sure'

Various tactics are used to safely induce an attack. For instance, if exercise is the trigger, the patient might be asked to run up and down a set of stairs. Patients may be exposed to strong odors to elicit symptoms. If coughing is the trigger, patients may be asked to cough loudly until VCD symptoms arise. In some cases, the laryngoscopy procedure itself will induce the attack.

"I have to see how the vocal folds are moving during an attack or else I can't be 100 percent sure of the diagnosis," says Dr. Milstein. In patients with VCD, the behavior of the vocal folds during an attack is unique, he says. "You don't see it in any other respiratory or airway disorder. Being

able to visualize the larynx during an attack allows me to determine whether the problem is at the level of the vocal folds, or not."

Vocal cord dysfunction involves abnormal closing or constricting of the vocal folds that prevents adequate passage of air in and out of the trachea, or "windpipe." Showing patients a video of the abnormal vocal-fold activity serves as a valuable biofeedback tool used by Dr. Milstein to teach some of the basics of vocal-fold anatomy and physiology. For instance, he points out that because they are "voluntary" muscles, patients can control the vocal folds when VCD symptoms arise. The final step involves respiratory and laryngeal-control therapy, teaching patients exercises that can help them prevent the vocal folds from completely closing during an attack. Dr. Milstein spent several years modifying breathing and biofeedback techniques to come up with the VCD treatment for his patients.

For Danders, the laryngoscopy Dr. Milstein performed during her first visit was enough to induce the attack that confirmed the diagnosis. After reviewing the videotape together, Dr. Milstein taught Danders a breathing technique that she could use both to manage and prevent a VCD episode. As Danders would happily learn, this tactic prevented the vocal folds from completely closing. In fact, it helped her avoid a full-blown attack.

Hopeful, but cautious

After spending nearly two years debilitated by VCD, Danders left The Cleveland Clinic that day hopeful about a possible cure. Still, she was not convinced that the breathing exercises would work all the time. Dr. Milstein advised her to practice the breathing exercises twice a day, every day. He wanted the techniques to become second nature so that Danders could use it effectively during an attack. After several weeks of successfully using the breathing techniques to control the VCD symptoms, the attacks stopped altogether. Danders had her life back.

"I can play with my grandchildren again without being afraid that I'd scare them if I stopped breathing," she says. "I can travel again, something I couldn't do when I was suffering from attacks every other day. It's been a miracle."

Dr. Milstein cautions that his breathing exercises are only part of the overall management of VCD. They can help patients avoid a severe attack, but the key is identifying the underlying cause of the problem, he says. If laryngopharyngeal reflux is causing it, no amount of breathing exercises will eliminate the problem. Enlisting a team composed of speech-language pathologists, otolaryngologists, pulmonologists (lung and airway specialists), gastroenterologists and other specialists is best for identifying the cause of VCD, says Dr. Milstein. In Danders' case, it was determined that multiple triggers, including reflux, caused her VCD symptoms.

Diagnostic challenge

Dr. Milstein says the biggest hurdle facing individuals with VCD is that the disorder is still not well understood across medical disciplines, although he and his colleagues are trying to educate physicians about it. For instance, he has hosted educational seminars at The Cleveland Clinic for physicians working or training in geriatrics, internal medicine and pulmonary, allergy and critical care medicine. He also tries to get the word out by presenting talks about VCD at national and international medical conferences.

Dr. Milstein advises individuals experiencing any kind of breathing difficulties or VCD symptoms to see a pulmonologist; if patients suspect VCD, they should mention this to the physician. (Symptoms include coughing, wheezing, difficulty breathing, hoarseness, chest or throat tightness, stridor, sensation of choking, dizziness, nausea and lightheadedness.) By being proactive, patients might save themselves time and money and minimize frustration.

Dr. Milstein also encourages the medical community to familiarize itself with the condition. "It's crucial for physicians to be on the alert for the condition so they can refer a patient to a specialist who can diagnose or rule out VCD. And for the specialists, differentiating between VCD and other airway problems is important because the treatments are so different."

Danders agrees that more doctors need to be aware of VCD, its causes and Dr. Milstein's treatment, and she is doing her part to help educate them. After her experience at the Clinic's Voice Center, she sent letters to the 11 doctors who had been unable to diagnose the VCD, letting them know about her experience with Dr. Milstein.

"When I think of all the people out there who might be suffering from this and who may not have the resources I had, I feel compelled to educate as many people as possible about it," says Danders. "I've gotten my life back, and I'd like to see others receive the same gift."

Copyright January 2004, HealthExtra, The Cleveland Clinic Foundation