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Obsessive-compulsive disorder: Nearly a lifetime without treatment

'I missed so much,' 72-year-old patient says

By Deborah L. Shelton

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By age 7, Anthony Barone was already descending into a confusing world of obsessive thoughts and compulsive behaviors that would dominate his life.

As a boy, he recalled, he felt driven to do things over and over. He would obsessively run his hands across his school desk. He would constantly move his pencils and pens in and out of his desk. He would complete his schoolwork and then erase it, repeating the ritual endlessly.

He could not stop tapping, touching and counting things.

Even the promise of sleep did not offer relief. Unable to resist the urge, Barone said, he would repeatedly crawl out of bed to stroke a crucifix hanging on a dining room wall or handle other objects in the darkened room.

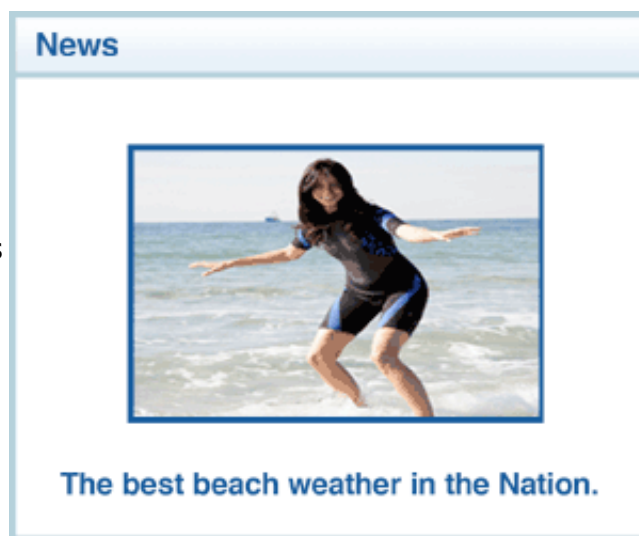
In part because of doctors who failed to diagnose his condition, it wasn't until Barone was 50 that he realized that he suffered from obsessive-compulsive disorder, or OCD. It was 13 more years before he received effective treatment that allowed him to lead a more normal life.

Barone's experience may be extreme, but it is not entirely uncommon. People with OCD frequently struggle for years with the disorder because they do not get an accurate diagnosis or appropriate treatment.

Now 72, Barone said he is content with his life, savoring experiences he once avoided and cherishing old friendships while cultivating new ones.

But he also feels a profound sense of loss for the life that could have been. He dropped out of high school and never married. The product of a large Italian-American family, he thinks about the children and grandchildren he never had.

"OCD affected every part of my life -- emotionally, sexually, professionally, mentally," said Barone, who wears silver-rimmed glasses that match the remaining wisps of his silver hair.



"I missed so much."

Now that he is doing well, Barone has made it his mission to educate teachers, doctors and mental health professionals about the disorder.

"I don't want young people to go through what I went through," he said, his booming voice quieting.

During Barone's youth in the late 1930s and 1940s, OCD was rarely talked about and little understood. Now it is getting regular airtime on TV shows such as "Monk" and, more recently, on A&E's documentary-style program "Obsessed," which focuses on the lives of people being treated for OCD.

Yet experts in the disorder say that despite greater awareness of OCD, too few therapists have received specialized training to treat it. Research conducted in conjunction with the Obsessive Compulsive Foundation found a 14- to 17-year gap between the onset of symptoms and effective treatment.

"I call that a crime," said Daniel M. Potter, Barone's therapist. "That's years of needless suffering. What's even worse is that much of the delay is a consequence of clinicians not making the diagnosis and/or using the wrong treatment for it."

Scientists believe obsessive-compulsive disorder is caused by abnormalities in the structure or functioning of the brain. An estimated 4 million people in the U.S. have the disorder, said clinical psychologist Jeff Szymanski, executive director of the Obsessive Compulsive Foundation, and up to 3 million more have some symptoms but don't fit the psychiatric diagnosis.

Shana Doronn, a Barrington-based therapist who is featured on "Obsessed," describes obsessions as unwanted thoughts, images, impulses, urges and fears. "Compulsions are what the person does to reduce the anxiety caused by these thoughts," she said.

Barone said that when he turned 12 his worried mother carted him to the family doctor. The doctor diagnosed his unusual behavior as a normal sign of puberty -- even though Barone had failed 4th grade and was about to repeat 6th grade for the second time because of it.

Decades later, Barone recognized his symptoms while watching a TV program about OCD and sought help. When his condition was finally diagnosed, he was treated by a psychoanalyst untrained in his disorder.

By the time Barone met Potter, Barone's illness had ballooned to encompass nearly every aspect of his life. He washed excessively. He avoided using the phone during certain hours, traveling down certain streets, entering certain buildings. He also obsessively checked door locks and stove burners.

"Imagine 60 years of this stuff," Potter said. "This guy had his life robbed from him. And at this point, that's what he's dealing with."

According to the Yale-Brown Obsessive Compulsive Scale, a standard psychological instrument that measures OCD, Barone used to fall somewhere between the severe and extreme range, leaning toward extreme.

But with the help of medication and talk therapy, Barone was able to stop behaviors he had been exhibiting for decades, Potter said. Like many people with a diagnosis of severe OCD,

Barone was prescribed antidepressants, which he continues to take.

Now he falls in the low to moderate range for the disorder, "a huge, huge change," said Potter, executive director of the Midwest Obsessive-Compulsive Disorders Center, which operates three area offices.

Bert DeLegge, Barone's friend since age 9, said he had no idea of the agony Barone was going through. Like many people with OCD, Barone hid his symptoms.

"I was really shocked because it was a long time before I found out," said DeLegge, who has known about his friend's OCD for only a few years. "It never dawned on me that he was so sick. I never saw that side."

Barone works as an information clerk at the Illinois College of Optometry, where on a recent day he wore a whimsical black tie with large white letters that mimic an eye chart, a gift from some of the college's students.

Dr. Daisy Chan, a Chicago optometrist, sought him out during a break from her continuing medical education class.

"He's my grandpa; he's everybody's favorite," Chan told a visitor as she embraced a jovial Barone. When she pulled out a photo of her chubby-cheeked baby son, Barone beamed like a proud grandfather.

The college's students and former students have become like an extended family to Barone. Their photos are carefully arranged on his desk along with those of his relatives. He has been invited to students' weddings, birthday parties, graduation banquets.

Barone, who is known for his charm and warmth, credits personal relationships throughout his life with saving him from isolation, loneliness and despair.

"I'm so thankful for the last 10 years of my life," said Barone, who volunteers with the Chicago affiliate of the Obsessive Compulsive Foundation. "I have good friends. A good job for me. For me, I've been accepted -- even more than accepted, respected."

Potter marvels at the turnaround in Barone's life.

"This is him living life in the best way he can in the time that he has, and there is a richness in that," Potter said. "He's certainly somebody who makes sure at this point in his life to enjoy the richness when it's available."

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