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Speaking out: Telling their stories helps people who stutter lessen isolation

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Alex Young, a 22-year-old carpenter who lives in Easthampton, stopped at a pizza place one night a few months ago to pick up two pies, a plain and a pepperoni, that he'd ordered for himself and a friend.

As he walked up to the counter, Young, in the back of his mind, knew that this simple, mundane encounter might not go well.

The waitress asked for his name. Young tried to answer - Alex - but nothing came out. Then he started stuttering on the first syllable of his name. Aaal-Aaaal-Aaaal...

He could see a second person behind the counter watching him, giving him that puzzled look he'd seen before, then starting to laugh.

Young got his name out and got the pizzas. But by then, he was a roiling mix of frustration and anger. With a single impulsive sweep of his hand, he sent the salt and pepper shakers on the counter flying.

"I just kind of snapped," he says now. "But I know I shouldn't have done that."

In the spotlight

Everyone who stutters has stories like that.

Laura Titrud, 23, describes ordering American cheese on a sub at a sandwich shop.

"I got stuck on that," she recalls of trying to say American. Suddenly nervous, she scanned the menu, looking for whatever might be easier to say. Swiss? Provolone? In her haste and embarrassment, she says she doesn't remember what she got.

"It's the feeling of lack of control and that's scary," said Titrud, a student at the University of Massachusetts who lives in Amherst.

The stories of people like Young and Titrud have come out of the shadows of late, thanks to the

"The King's Speech," the 2010 Oscar winning film that cast a light on England's George VI, who became king in 1936. Bertie, as his family called him, stuttered nearly all his life.

In an interview on "60 Minutes," actor Colin Firth, who played the king, said he believed George VI would almost rather have faced a firing squad than a live microphone. But as a member of the royal family, and later as king, he had no choice but to speak publicly and to do that he desperately needed help. He found it in the person of Lionel Logue, a speech therapist who worked with him for years and became a trusted friend.

Seven decades later, treatments and strategies for stuttering have changed from those depicted in the film. But for most adults who stutter, there is no complete cure, just as there wasn't for George VI. And in some ways, the experiences of Alex Young and Laura Titrud aren't so different from those of the king.

Scenes in "The King's Speech" show the king stuttering badly while those around him avert their eyes, not knowing what to do or say. As he watched, Young knew what those awkward moments were like.

"They were pretty real," he said.

Old myths

The precise cause of stuttering isn't known, according to the National Stuttering Association, a non-profit organization that provides education and support services. Contrary to old myths, stuttering isn't caused by certain personality traits or by lack of intelligence or by family dynamics, the NSA says. Stutterers by nature are no more shy or anxious than their peers, though researchers say stress and anxiety can make the condition worse.

Recent research suggests there may be a genetic component in some cases, according to the federal government's National Institutes of Health. In others, stuttering can be linked to brain injury, such as stroke.

Stuttering can show up in young children, beginning as early as 2, according to the NIH; some outgrow it, while others don't.

Today, early intervention can help pre-schoolers become stutter-free, according to Carla Bernier, a Northampton speech-language pathologist in private practice. But, she says, a child who is still stuttering at age 8 or 9 is likely to face lifelong challenges.

Support in facing those challenges is the reason behind a group that began meeting in Bernier's office several months ago. Sponsored by the NSA, the group is currently the only one of its kind in Hampshire County, she said. Though she provides the space and attends the sessions, Bernier doesn't dictate the group's topics - that's up to those who attend.

On a recent night, the conversation among the five people there was compelling and wide-ranging. One woman spoke of wondering sometimes if she might have become "a rocket scientist or an actress" if she didn't stutter. Another spoke of noticing that her stutter became less severe after her divorce. A young man spoke of the perils of trying to place an order at the drive-up without stuttering.

They shared information, advice - and compassion. "It's totally exhausting, spending your whole day struggling with your speech," said one woman. And there were even moments of wry humor.

It would be easier to talk to people about his stuttering, one man said, if the word itself wasn't so hard to say.

"It's great getting to hear stories and interact with others who stutter," Laura Titrud said later. "I knew it was a communication disorder, but I'd never met anyone who stuttered. It makes me feel like I'm less alone."

For Alex Young, the jury's still out. Being with others who stutter is "all fine and good," he said, but he's not sure it will help him.

Varied experiences

Beyond their takes on the role of group support, Young and Titrud's stories show how variable stuttering is. The disorder not only varies from person to person but those with it say the frequency and severity of their stuttering varies a great deal.

Young says he has stuttered since he began talking and that he stutters daily. As a kid growing up in New Jersey, he said, there were some things he would avoid doing - like calling up someone he didn't know. But by and large, he says his speech wasn't a huge problem.

"I just kind of rolled with it," he said as he sat and talked on a downtown Northampton bench one recent morning before heading off to work. "I always had friends. It didn't matter to them and it didn't wear on my emotions." True, he wasn't exactly a "sterling student," but says he doubts that had anything to do with his speech.

Titrud says she didn't start stuttering until late in high school and then only infrequently. Even now, it tends to be "very situational," she says.

"It kind of crept up on me," Titrud recalled, and became more noticeable during the transition from home to the University of Connecticut, where she went to college.

"It just sort of made me clam up more," she wrote in response to an emailed question. "Instead of initiating conversation, I'd wait for someone to approach me first."

Young sometimes grimaces or hits himself when he stutters, habits that therapists call secondary characteristics. It's as if, he says, he's trying to force the words out. Titrud doesn't do that, but she's had other complications to deal with. She tends to speak as she inhales - not as she exhales, as is normal - a breathing pattern that sometimes gives her speech a rushed, out-of-breath quality.

Never mind

Titrud says she was what they call "a covert stutterer" - someone who tried very hard to hide her problem.

"You do everything you can so it doesn't get noticed," she said. She'd raise her hand in class, and then, if she suddenly felt she wasn't going to be able to speak correctly, she'd pull her hand back down, or come up with an excuse.

"I'd say never mind, or I forgot," she recalled. The problem is, you wind up holding yourself back, she said, even when you have something to say.

Titrud, though, did find another way to speak out.

"In high school, I sang along to Gavin DeGraw's CD until I wore it out," she said, "and that's how I learned to sing." At 18, she began singing publicly, doing covers and writing some of her own songs. These days, she's a regular at the open mic nights at the Yellow Sofa in Northampton.

"There's this great sense of community," Titrud says of the gatherings there.

One recent night there, she sat on a stool at the keyboard, showing no hesitation as she sang in a strong, full voice and chatted easily with the audience between songs.

She probably breathes more deeply when she performs, she said afterward, even though she's not aware of making that change. Nor is there any trace of a stutter when she sings - music, researchers say, involves a different part of the brain than speaking.

Titrud is a graduate student in the department of communication disorders at UMass, a field she got interested in back in college. She was drawn by the diversity of the field, she said, and not, at the outset, because of her own speech.

But at UMass, as she delved into her studies and into her clinical training, she says she became more aware of her on-and-off stutter and her rushed rate of speech.

Last spring, Titrud contacted Carla Bernier, whose name was recommended to her by people in her department at UMass.

"I was interested to see what it would be like to receive therapy after I'd been giving therapy myself for a semester," she says. "And it was something I wanted to do for my own self-improvement."

'In a shell'

As a toddler, Alex Young remembers seeing a counselor who showed him flash cards with pictures to help him practice saying words. Later he remembers sitting with speech therapists - "lots of them," he said with smile - who had him read sentences out loud over and over again.

"Most of it was a waste of time," he says now. He's quick to add, though, that he doesn't blame the speech therapists or the therapies they used, because back then he wasn't really motivated to improve.

After high school, Young opted to pursue carpentry, an interest he'd discovered during high school. Three years ago, he moved to this area to attend the New England School for Architectural Woodworking in Easthampton. After a stint there, he worked for a time at the Northampton Lumber Co. His stutter notwithstanding, he talked to customers "all the time," he said, and enjoyed it. Then he left, signing on with an area carpenter to get more hands-on experience.

Last winter, Young said his spirits started sinking.

A relationship with a girlfriend had ended, he said, and it hadn't been easy to build a circle of friends here to replace the ones in New Jersey who'd accepted him, no matter what. Winter's gloom didn't help, he added, nor did having time on his hands during the seasonal slowdown.

"I was lonely," he said, "and kind of depressed."

Young's struggle to get through what he calls "a bad period" led him to confront something he hadn't faced before: Just rolling with it, to borrow the term he used to describe his high school days, wasn't working anymore. And maybe his speech was part of the problem.

"I started thinking about it a lot," he said.

On a trip home to New Jersey, Young talked to his parents, who had always been supportive of him, about what was going on. His father, he says, did some research, came across the name of Carla Bernier, and passed it on to his son.

Alex felt pushed and pulled. He knew the stuttering had become more and more "a major part of my life," he said, and he knew he wanted to try to bring it under control. He'd heard about people who stutter "who kind of wind up in a shell" and he didn't want that for himself.

But making that call meant using the phone - and he'd never liked that.

Days went by, then weeks.

"It was like pulling teeth," he said.

Coming Tuesday: In part two Alex Young and Laura Titrud give speech therapy a try.

For more information: The National Stuttering Association, www.nsastutter.org [1]; The Stuttering Home Page at Minnesota State University, www.mnsu.edu/comdis/kuster/stutter.html [2]; The Stuttering Foundation of America, www.stutteringhelp.org [3].

A support group for people dealing with stuttering meets regularly on the second Wednesday of the month, at 15 Brewster Court, Northampton. For information, contact Carla Bernier or Alex Young by email at carla@comtherapy.com [4] or a.young52@hotmail.com; or call 586-1945.

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Links:

[1] <http://www.nsastutter.org>

[2] <http://www.mnsu.edu/comdis/kuster/stutter.html>

[3] <http://www.stutteringhelp.org>

[4] <mailto:carla@comtherapy.com>