

Stuttering with Pam Mertz

Speaker 1:

Welcome to The Sunflower Conversations where we explore the Hidden Disability Sunflower and its role in supporting people with hidden disabilities.

Chantal Boyle:

Welcome to The Sunflower Conversations with Chantal and Paul. Today we are joined by Pam who works with the National Stuttering Association and is a positive advocate in supporting people who stutter by using her own lived experiences. Hello Pam, how are you doing?

Pam Mertz:

I'm very good and I'm delighted to be here with you. Thank you for inviting me.

Chantal Boyle:

It's our pleasure. I guess this is where we need to start. Can you explain what a stutter is and why it occurs?

Pam Mertz:

Well, thankfully we're at the time in our society that stuttering is no longer considered a psychological or emotional problem. It's actually neurological. And simply put, there is a glitch in the brain of people who stutter that creates a disorder, essentially, that interferes with the normal flow of speech. It manifests in repetitions, like that, prolongations and it can also include blocking. And that's essentially where people try to say something and it won't come out. They may look like, "Uh, uh," and for people that are looking or watching that, that can be very uncomfortable. Essentially that's what stuttering is and it occurs based on neurological reasons, not psychological. And it's also genetic. It often runs in families, for many people. And in some people, like in my case, I'm the only one.

Chantal Boyle:

Is there a likelihood, then, that if you were to have children... I don't know if you do have children, but if you were to have children, that then they might then have it, do you think it's maybe you might be starting that genetic course?

Pam Mertz:

It's very likely, but it's also just as unlikely. There's been a lot of work on the genetics and a family in Pakistan was studied because there are nine people in the family that stutter and that's highly unusual and sometimes stuttering skips a generation, so again, piggybacking on your question, it is possible if I were to have children that it would pass down.

Paul White:

Hi Pam, it's lovely to speak to you today. My father had a stutter. He suffered with Parkinson's for quite a few years of his life and one of the most prominent features of his Parkinson's was his stutter. And one of the things dad used to say was it really was exhausting for him to have to work so hard to be understood. Is that something that you feel when you stutter?

Pam Mertz:

Absolutely. There are times when I stutter in high stakes situations, for example, where I tense up, my shoulders tighten, my vocal chords actually feel tight because sometimes when the word won't come out I'm trying to force it out. And also not just the physical exhaustion, but it can be even more exhausting mentally by what goes on in a person's head. When you don't want to stutter, you stutter more. You could be, in your head, furiously working to choose words that you feel you won't stutter on or to just randomly talk about something around the issue. If you can't say December, somebody might say, "Yeah, it's in the month, after November." And people will be like, "Why didn't she just say December?" People will do that, which absolutely can be exhausting.

Paul White:

How many people in the US stutter, then?

Pam Mertz:

It's statistically quoted as a three million, because it's 1% of the population who stutters. I suspect though that it's more because many people are covert and they don't disclose or announce that they stutter, so they're not included in that pool. I suspect that it's actually two to three percent of the population, so I think there's four or five million people, so there's a lot of people that are not receiving any support or services.

Chantal Boyle:

Well, that brings us on quite nicely then about support. This year the theme for international stuttering day is being seen, being heard. Can you tell us about that, please?

Pam Mertz:

Sure, because I was the actual one that came up with that theme. I'm very actively involved in the International Stuttering Awareness Day online conference, which is held for the entire month of October. And we chose this theme for two reasons. People who stutter often do not feel seen because there are so few people who do stutter. And so there's few chances for somebody to encounter somebody who stutters. Like I mentioned, a lot of people are covert so they go out of their way to not be seen.

But more importantly, being seen and being heard in the media. Little girls and little boys that stutter, they don't see somebody that sounds like them in the media. And there's been a real push for characters in movies and on TV. They're more for comedic purposes, which

perpetuates the myth that there's something wrong with us. And people who stutter in the movies are often portrayed, well, mostly portrayed by people who do not stutter. We would really like to see people who really stutter star in roles where stuttering is not the focus. It's just, you're playing a role, talking about anything, and they happen to stutter. Being seen and being heard in that way would help people realize, "Oh, somebody's out there openly stuttering, maybe I can do that too."

Paul White:

The perception in movies is everything is delivered so smoothly and that's in media in general. The reality is so different from how it's portrayed and I couldn't agree more that if there was some more reality in the public eye and they could see people being normal and stuttering or stammering, however it is framed, I think that would be hugely beneficial to society, really.

Chantal Boyle:

Being your authentic self is really important, isn't it? What are the barriers and the stigma that are associated with stuttering, Pam?

Pam Mertz:

Well, I think the largest, the stigma around stuttering is that there's something wrong with you, there's something wrong with the person that stutters. There's the false assumption that we can't do the same things as other people. It's assumed that we're not up to the task. We're assumed to be incompetent, nervous, unable to regulate our emotions. And stigma is actually discrimination because one should not assume that a person can't do those types of jobs and can't perform in school or university. And the really difficult part of this is that people who stutter sometimes believe what society says and they internalize that and that just makes it all the harder, because it's now both a public and a personal stigma.

And let me just add that people who used to stutter but don't stutter anymore are often held up to us as role models. And sometimes what happens, especially for children and teens, they see so-and-so in the movies or on the news who used to stutter and the message is, "If you work as hard as I did, you can overcome stuttering," and a child might just feel like they failed if they cannot measure up to a role model that said they stuttered, but they don't actually stutter.

Chantal Boyle:

It's a very harmful approach, isn't it?

Pam Mertz:

It is, because a child who stutters has enough to deal with. Being made fun of, being laughed at, maybe being forced to attend speech therapy because their parent wants them, and then to feel like a failure. The child may think, "Well, why bother going to therapy? It's not working for me." That's very difficult for children.

Chantal Boyle:

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Paul White:

There are obviously strategies that people can employ to avoid or to hide their stuttering, Pam, so what do you think about that?

Pam Mertz:

Well, there are many people who are interested in therapy techniques that can help them become more fluent. The traditional stuttering therapy is called fluency shaping, where a therapist will work with a client or a patient to help smooth out the repetitions or the prolongations in order to obtain fluency. But the difficulty with that is that oftentimes, it's successful in the therapy room where there's only two people, and it doesn't necessarily transfer over into real-world situations like school and work. I think it's wonderful for people who stutter that want to attain more fluency, but it didn't work for me, because I felt like teaching me techniques to cover my stuttering was reinforcing the 30 or some odd years that I spent hiding it. I didn't want to be taught techniques to hide it. What I wanted was somebody to just tell me, "It's okay to stutter. It's how you talk. There's nothing wrong with that."

Paul White:

Sure.

Chantal Boyle:

It's what you say, not how you say it.

Pam Mertz:

Exactly, exactly.

Paul White:

Can I ask when your stuttering first started, Pam, and how has your relationship with the condition evolved over time?

Pam Mertz:

Well, firstly, I'd like to just jump in and say I don't consider stuttering a condition that I have. I consider stuttering to be a different type of communication or just the way I talk. But I was told by my mom that I started stuttering around five after speaking at around two and a half, fluently. And then suddenly at five I started stuttering. And I actually don't remember the moments of stuttering. What I remember was the reactions that I got from stuttering, particularly, sadly, from my father. He was very critical. It embarrassed him. He would loudly

reprimand me. "Shut up," or, "Spit it out. We don't talk like that." And that is one of the things that can fuel shame in a child and sometimes it can be lifelong.

In my case, though, my stuttering has evolved because like I said, I hid it for 30 years and I reached the point where I just felt like I can't be fake anymore. It's too much work. I don't want to be fake. Like Chantal said, I was not being authentic, I was not being who I was, and I was hijacking my own personality. I carefully and cautiously stuck a toe out the door of the closet and began to experiment being me. Stuttering nakedly. And what I found out was I didn't get struck by lightning. I didn't sink in quicksand. What I did do was just the weight of caring, stuttering shame, just kind of lifted. And I felt so liberated and I finally felt me and free enough to bring my whole self to whatever I do. And that was greatly important. It's far easier to just stutter than it is to work to not stutter.

Paul White:

Sure. And do you feel that the public is empathetic towards you to in regards to your stutter or do you face real barriers when speaking to people you don't know and have a relationship with?

Pam Mertz:

Right, so that's a great question. Because stuttering is such a small percent of the pop population, many people have never encountered a person who stutters. And because it's a hidden disability, you don't know I stutter until I open my mouth. People that are not well educated or don't know me and that I stutter, people laugh. And if I have trouble getting my name out because P sometimes gives me pause, people will say, "What, did you forget your name?" Which is one of the most annoying comments that people get. That comes from a lack of education.

And one of the challenges, I guess, I feel about that is, do I have to educate people about stuttering every time something happens like that? That gets exhausting. Should I bother if it's the person in Starbucks? Should I bother if I'm not going to likely see that person again? But if I'm entering into a relationship where I likely will see that person again, I feel I need to tell them, "Hey, I stutter and I'm okay with it. I hope you will be too." And then usually what happens is the person becomes mortified and apologizes 10 times. And that was not my intent to embarrass them, it's just, "Hey, I stutter. This is the way I talk."

Paul White:

"Deal with it."

Pam Mertz:

Yeah. Definitely it's a challenge because it's hidden, essentially.

Chantal Boyle:

I think as a society we all need to think before we speak and not jump to conclusions and allow people that the space they need.

Pam Mertz:

Exactly.

Chantal Boyle:

Do or say or be, feel whatever it is they need to, which is hopefully with being seen, being heard, and The Sunflower will push home those messages. That's a barrier if somebody's laughing at you before you've even sort introduced yourself. The barriers that exist in schools and in workplaces, have you got any ideas of how we can remove those barriers?

Pam Mertz:

Well, in schools, children who stutter are identified as needing an Individual Educational Plan. They're put on an IEP and there are goals and adjustments that are built into that. The child is allowed to take a few more minutes when they're doing a book report. Sometimes if the child who stutters has a severe stutter, they may choose to opt out of having to do a public presentation and all the teachers have to provide and accommodate those adjustments.

When you get into university, those disappear and what happens is that the person, the individual, the college student, needs to go to the disability resource office on campus and disclose that they stutter in order to take advantage of adjustments that may be available. The similar types that you would get in lower grade schools, asking for more time, sometimes asking a professor if they can write an essay as opposed to publicly speaking. But so many people who stutter have difficulty using the word "disability" that they won't go and ask for those accommodations. And even in the workplace, people are reluctant. But my thought on that is you need to get over that. You need to own your disability so that you can take advantage of the accommodations that will offer you a level playing field so that you can be successful in school or work.

Chantal Boyle:

I mean, I've heard this before, how there's support. In England, we call it primary school. Really, these reports should continue with you throughout your education. You shouldn't have to reapply as such. It's not going to go anywhere is it? It stays with you. You might need to be enhanced, adapted. But to have to go through those hurdles is difficult for many people for a variety of reasons.

Pam Mertz:

It is, it is. And here in the United States, the IEP stops when you graduate high school. Again, the next steps for university or work are for the individual to publicly disclose and take that risk. And some people would just prefer not to, and then they struggle silently and don't get what they need.

Chantal Boyle:

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What do you think about The Sunflower when we think about invisible? You just used the word "silently". How do you feel The Sunflower is a useful tool? Do you think it's a useful tool?

Pam Mertz:

I think it would definitely be useful to people in situations where they find themselves stuttering severely, and perhaps blocking and using secondary behaviors, like trying to push the word out. I think it would be helpful for that person to have a card to give to another person to make it easier for the person who stutters to let the other person know, "I'm okay, I'm okay. I just stutter." Yes, I think it would be a useful tool for the person to have as an option. Some people may not be comfortable with that, but I think it's a good tool to have in your back pocket if you feel that you need help in explaining what's going on. Yes, I think it's a useful tool to have.

Chantal Boyle:

And so for anybody who's listening that has a stutter and feels alone, what advice would you have for them?

Pam Mertz:

Meet other people who stutter. I mean, very simply, meet other people. Here in the United States, the National Stuttering Association has over 200 support group meetings across the USA in-person and virtually, which we've all been doing forever. But a lot of them are going back to in-person. And just meeting other people that sound like you almost immediately provides that wave of relief that comes with seeing, "I'm not the only one." And particularly women. I'm biased because I'm a woman who stutters. Of the one or two percent of people who stutter, four of five are male. There's only one in five that are female. We're a minority within a minority.

Chantal Boyle:

That's interesting. You have any reason for that? Is there any research?

Pam Mertz:

Well, it's similar to the statistics for autism. It's more boys than it is girls. And I think there's research and I believe it to be that it's assumed that girls grow out of it quicker, but of course not all of us do. It can be very disconcerting for women because we may never have met another woman. And I've heard from men who stutter who say, "I didn't know women stutter." That was very revealing.

Chantal Boyle:

Well, I'm just wondering, actually, on that point, because I think actually it is an equal number of boys to girls who are autistic, but girls mask, so diagnosis comes a lot later in life, quite often, or not at all, because they've developed masking. Because that's more, I guess, in the nature of women. We try to emulate who we are with. I wonder whether... You were talking about covert stuttering. I wonder whether not as many women are being diagnosed with that. Interesting.

Pam Mertz:

Right, because we do tend to conceal more, because women are traditionally in society seen as the nurturer and the one that has to call their kids' teachers and make the doctors' appointments. Women don't want to be seen any as any other than that role, so they'll work hard to conceal or be covert. I like to use the analogy of a swan, a swan gliding gracefully over the lake, looking as peaceful and serene as possible, but underneath furiously paddling to make it look like everything's fine.

Paul White:

Yeah, I think that analogy could be used in a number of different ways, that analogy. And I think from what you said earlier, Pam, because how does that relate to yourself? Because you said that for many years you also tried to mask or hide your stutter and it was only in later years where you decided just to let it all out and be yourself.

Pam Mertz:

Well, part of that was the early childhood messages I got from my father who, in my opinion, clearly was ashamed of me. And I had a similar reaction when I got to kindergarten, which I think in the UK you might call them nursery. The teacher again told me similar things. "Stop that, what are you doing? We don't talk like that." As a five year old, those things deeply became internalized. And my thought process as a five-year-old was, "There must be something wrong with me. This must be bad. I shouldn't do this." And all I knew how to do as a five-year-old was to not talk. And that became so internalized, that's what stayed with me for years. It was a protective armor, coping mechanism. And it wasn't until years later when I was fired from a long-held job after a new manager came in and heard me stuttering and deemed that I was not appropriate as an influence for young people, and my poor communication style was not what they needed for working with teens. I'd been there 20 years.

Chantal Boyle:

Oh my gosh. I mean, do you have in the US constructive dismissal, disability discrimination? I mean, that's surely a case for that.

Pam Mertz:

Yes, I did file a complaint with our Equal Employment Opportunity office. Well, commission. It's called EEOC. I did file a complaint what for wrongful termination and I filed a lawsuit. But what happens with those things, they can drag on for years, and staying in that mode, I had

no way to move forward. I was also told in the process that it was not egregious enough, like racial or sexual discrimination was so, "Why are you bothering? You're not..." So we settled after two years, which to me was a minor victory, because by settling, the employer was acknowledging that they had done something wrong. And then I was able to move on and that experience propelled me for the first time ever to do a Google search and type in "stuttering". And then I was like, "Oh my God, there's so many resources."

Chantal Boyle:

Oh wow, that's the first time you had done that.

Pam Mertz:

First time.

Chantal Boyle:

We say that we should back ourselves and look after ourselves, but I'm guessing there was a fear factor there for you, which is why you'd held off for so long doing that. And now here you are fronting the Be Seen, Be Heard campaign for the National Stuttering Association and really giving a voice to the three or five million people in the US, so well done. It's great to know that you are supporting other people.

Pam Mertz:

Thank you.

Chantal Boyle:

And I just want to thank you for your time. It's been really informative and I'm really excited to get this podcast out and let's raise some awareness and just let people know where to go for support. We'll include your details of the National Stuttering Association in the notes, but what is the name of the website?

Pam Mertz:

westutter.org.

Chantal Boyle:

Fantastic. Well, thank you very much, Pam.

Pam Mertz:

Thank you for having me, and I look forward to hearing the podcast.

Paul White:

Thank you, Pam. It's been an absolute joy to talk to you today and to hear your story.
Thanks so much for joining us today.

Speaker 1:

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