

Student with Hearing Loss Inspiring Story

Tena McNamara, President-Elect of the Educational Audiology Association, had the opportunity to interview a very unique young woman about her perceptions of her hearing loss and how it has affected her socially and emotionally. Her testimonial is truly inspiring and may offer some support to other students with hearing difficulties.

Lily Watts is a freshman attending Illinois State University. Her story is unique in that she was not identified with a hearing loss until late in her high school career. This has enabled her to develop a distinct viewpoint on the process of accepting her hearing loss and the challenges that she faced daily for listening and learning.

Dialogue

McNamara: I would like to take this opportunity for you to introduce yourself and tell us your name, age and where you're from.

Lily: My name is Lily Watts and I'm 18 years old and I'm from Glasford, Illinois. I am currently going to Illinois State University and I'm freshman.

McNamara: What are you majoring in?

Lily: My major is special education specializing in deaf and hard of hearing

McNamara: So tell me a little bit about yourself; not just about your hearing loss but something about yourself. Things that you like? What are your interests?

Lily: I really like to cheer. I'm currently a cheerleader at Illinois State University. I've been doing it since I was a little girl. I enjoyed (in high school), theater, choir and hanging out with friends and being really social. That's who I am; very social person.

McNamara: Have you carried this on in college?

Lily: Most definitely.

McNamara: So, you are cheering here at Illinois State?

Lily: yes

McNamara: Tell us a little bit about your hearing loss.

Lily: I basically went all my life without knowing that I had a hearing loss. In November 2014, I finally had my last straw of comments that people were saying that I was deaf and I couldn't hear anything. And there were comments made about my speech. For the past four years of high school it was really bothering me so I said to my mom, I think I need to go get my hearing checked. I kind of felt like had a learning disability that I wasn't catching on to things. I was very far behind. I didn't understand why. So, I got my hearing checked and that first day... I will never forget that day... when the audiologist told me I was almost completely deaf in both ears. You qualify for a cochlear implant. I didn't even know what a cochlear implant was. So it was a very big shock to me and my family and my friends. And it was very hard; very, very hard. I have a sensorineural profound hearing loss in both ears.

McNamara: Do you think you had that (hearing loss) for a long time then? Or do you think it progressively got worse?

Lily: It progressively got worse for sure. The doctor thought I lost it around 5 to 7. I've gotten genetic testing done, everything came back unknown. It's not genetic. So, it could've been a virus, anything. I will never know.

McNamara: Do you remember in your early years struggling a little bit in the classroom? Or did it really hit you in those high school years when everything was so demanding?

Lily: It really hit me in high school when everything was a lot more structured. But, looking back on it you remember the little things in that you missed out on. I remember specifically memorizing the kids' voices when they read. And I could name any kid's voice in the class just from focusing so hard. But to me, I thought that was normal. Now looking back on it, I had no idea what they were saying. And I had to follow the text and memorize their voices.

McNamara: You used memorization a lot.

Lily: yes, oh yeah

McNamara: Do you think your hearing loss impacts your ability to communicate at school?

Lily: Communicating with?

McNamara: Like listening in the classroom.

Lily: Oh, listening in the classroom was really, really hard for me in high school. I really had to compensate reading lips. I'm a huge lip reader. I'm really good at it. I'd have to be looking at the teacher when they're talking, or else I'm not catching any information that they were saying. So typically I would compensate by not even paying attention to the teacher in the class and opening up the book or the PowerPoint to the lesson; writing my own notes down and completely avoiding the teacher in general just to get my side of it. That's kind of how I studied and worked on things. I didn't really pay attention to the teachers, I just did my own thing.

McNamara: That's really interesting because we work on developing strategies to help them (children) compensate for the hearing loss. You didn't have anybody working with you and you developed all those (strategies) on your own. I also think that's interesting you said to your mom, I think I need my hearing tested. Did a lot of people think that you were just ignoring them?

Lily: Yeah. I think they thought I was just being rude or ditzy; kind of not really paying attention, doing my own thing. But, really it was because I never heard them.

McNamara: So you had your implant before you left high school. Did you notice a difference in your ability to hear others around you and communicate?

Lily: Yes. It was really hard when I first got implanted. Everything was really loud at lunch and I was really aggravated the first couple weeks it got turned on. I would take it out at lunch, PE, especially music. It was just way too hard for me. And then my speech pathologist got on me really hard and I love her for it. Without her I probably wouldn't have kept wearing it. All the people that have helped me have really, really influenced me on wearing my implant and stressed

how important it was. And when I wore it, my grades went from Cs to As. I got my GPA up; about 2.82 to 3.2. Which for a deaf student, that's not bad. I noticed a huge difference in my grades and socially I was wanting to go out more with my friends and do things on weekends. When I was first diagnosed I was very to myself and it really was hard. I was in a very big denial state. I just locked myself in my room, not wanting to go out. I kind of turned into a paranoid person. So, as soon as I got implanted I noticed a big change.

McNamara: How about in your stamina? When you weren't wearing any device and then you look at when you got your cochlear implant, do you feel that with your cochlear implant that you are less fatigued?

Lily: Oh yes. Especially after I was first diagnosed. When I look back, I didn't realize that I had to take a nap every day when I came home from school. I would wake up go to school, come home from cheer practice. Nap. Eat dinner. Nap. Wake up. Maybe spend a little bit of time with the family. Go to bed. So it was constant. I needed my sleep. I didn't realize I was so drained from having to pay attention so hard at school. Ever since I've been implanted, I don't take a nap every day. Sometimes I have to slide a 15 to 30 minute power nap, but not three hour naps or anything like that. So I am definitely not nearly fatigued as I was.

McNamara: That's a great point because it's going to take someone with a hearing loss three times more energy to listen and pay attention. Even though your cochlear implant has made a difference in your ability to communicate, do you still have situations you feel are a little taxing?

Lily: That's a hard question because everything's been so great. It can still be hard at times because obviously I'm not implanted in my right ear yet. It is just my left ear. I am going to get my other side done eventually. When people are talking to me from my right side, I can't always hear them right away. I think the hardest part for me is that some people think because I am implanted now, I can't hear perfectly. I am still human. I'm doing a great job with it (cochlear implant) but sometimes I can't hear everything. So, that can be a little frustrating

McNamara: You are doing a great job hitting on some main points here. We see this on the other end as a professional; when a kid gets a hearing aid or cochlear implant. It takes education with teachers to understand that they may not be up to hear everything. Wasn't there a little period when you tried a hearing aid hearing aid before your cochlear implant? So what was that like?

Lily: The hearing a trial was a mandatory part of the cochlear implant process so I had to get them. My type of hearing loss does not work with hearing aids and it was constant buzzing. It was absolutely awful. I refused to wear them. And the audiologist told my mom she's not going to wear these. And I didn't. I think because she said that I was more apt to not wear them. Obviously the implant is what I needed. I just wish they would get rid of that part of the cochlear implant process for some people. For some people it might benefit them and they may realize this is the type of device that helps. But to put somebody through that buzzing. It was not the best and I got over it.

McNamara: Because your experience with your hearing aid wasn't very positive did you have a fear that the cochlear implant was going to be something like that?

Lily: Yes. That is when my fear kicked in; when I was starting to second-guess everything. This is really not much difference because I'm getting a hybrid cochlear implant where I have the hearing aid device that goes in my ear. I'm thinking it's going to be just like the hearing aid. This is not going to go well. This is going to be annoying. I'm not going to be able to adjust. My doctor let me know this is going to work. This is for you. He was right. He was definitely right. By there was definitely a big fear of there being complications and not being what I hoped for. Because you really can't go back after you have the surgery.

McNamara: Yes this was a permanent, lifetime thing. I'm really glad that it worked for you. So you talked about your feelings a little bit when you first found out had a hearing loss. What was the biggest thing that bothered you about it?

Lily: Well, the first thing that ran through my head was I'm not wearing something on my head that other people can visibly see; that would make me stand out or look different. I like to get ready for the day. I like to wear makeup and do my hair and go to school. And people know that. And go to school when I wear my hair in a bun one day, someone can see this big device on my head. People are going to ask questions. I got paranoid about everything, and that was another reason why I didn't wear my hearing aids during my trial. That was a big, big issue with me; being judged. I was a teenager. I was a 16, 17-year-old girl in a small school and so somebody's going to say something. I just thought it would be better if I just didn't wear them at that point.

McNamara: So being different was hard

Lily: definitely

McNamara: What happened that made you really accept this hearing loss?

Lily: I was talking to my hearing specialist one day and I was really interested in her job. She goes to schools and she helps people cope with hearing loss and helps them learn how to advocate for themselves. I was thinking, how'd she get this job? I really like what she does. It is truly inspiring. So I asked her about it and she told me where she went to school. She told me what she majored in. So I thought, I want to do that; to help people like myself. I looked into it. I applied at ISU and I got accepted. I was really excited. The big kicker for me was I got to work at an early education school for children with hearing loss, ages three through five. To see them so full of life; they were truly inspiring to me. This is what made me think, this is what I want to do with my life. They can accept who they are at such a young age and be so happy. I can be happy for them. I have to be an advocate for myself and them and show them what a role model is. It just really all came together. That this is who I am and I wasn't going to let it stop me. I just started feeling more determined and happy. This is going to be me for the rest of my life and nothing's going to change that. So why not be positive and embrace who I am. I started wearing my hair in a bun to school. I started letting people see what it (cochlear implant) looked like. Surprisingly, I got the opposite effect of what I thought was going to happen. People were very supportive; my teachers, my friends, my family was so supportive of the look of it, which to me was big. They wanted to know, what kind of hearing loss do you have? They were really interested. All my friends would ask me questions. It became more of an inspiring type of thing.

McNamara: That's great. You realized that the hearing loss is a part of you, but it's not all of you. What kind of advice would you give to young people who have hearing loss?

Lily: Definitely stay true to yourself. Know your worth. Don't let your disability define you as a person. Just because you can't hear, doesn't mean you can't do other things. Don't let it hold you back. As long as you try hard, you can do just as well as anyone else.

McNamara: That's great advice. What are some things you do to advocate for yourself? I know in some of these lectures, you can have 150 students in the class.

Lily: You have to introduce yourself to the teachers at the beginning of the year. Let them know you have a hearing loss. I have to sit up in front of the classroom, which doesn't bother me. It helps me stay focused. If I was in the middle or back, I probably would not be paying attention; just like any other typical college student. It really keeps me motivated to have these accommodations. I'm very grateful for them; to have a notetaker, to have preferential seating, to have closed captioning on videos that I want. It helps me and it makes me do better in school.

McNamara: So you went to the Office of Disability and made sure everything was set.

Lily: Oh yes

McNamara: Even though you went to that office, and they provide you with assistance, you're finding that you still have to be the one to advocate for yourself.

Lily: Definitely, you have to.

McNamara: What's been the biggest transition from high school to college?

Lily: In general?

McNamara: Yes. Has the hearing loss even been that much of an issue?

Lily: I'm becoming so use to my cochlear implant and it's been the biggest blessing of my life, that it really doesn't affect me anymore. If I wear it, I do well. So going from high school to college has been a great experience. The end of high school was good because I was starting to become familiar with noises and different sounds. But definitely, college has been nothing but positive experiences for me. Living in a dorm room isn't all it's cracked up to be, but I have met so many people. Especially through my hearing loss. It's just been a great experience.

McNamara: So the hearing loss really has not been an issue in this transition as much as just you getting accommodated to the college life.

Lily: Not an issue at all. If anything, it has helped me.

Have you met any other individuals that have hearing loss since you have been here?

Lily: Yes, I got to meet a professor here that is deaf and has a cochlear implant as well. She's awesome. I love hearing other people's stories. That really interests me. I've introduced myself to one student in a classroom who I saw had an FM system. So I'm like, he has a hearing loss.

I'm going to introduce myself so maybe in some way he can relate to me. If he has any questions he can ask me.

McNamara: You gave some good advice for younger students. What advice would you give to a professional working with you, whether it be the audiologist, itinerant hearing impaired teacher or the SLP?

Lily: Just remain positive. Keep them motivated. Let them know that you care. Everybody that has worked with me, I can genuinely tell cares a lot about me. And those people have truly shaped me into who I am today. Everybody who has helped me along the way has made me a better person. Without the hearing loss or with it, they have made me more positive, outgoing and social. As long as someone stays positive with you and lets you know that you matter, that's the advice that I have.

McNamara: Going beyond, I'm the professional, I'm going to help you with this. But going a little more and saying, Hey, I'm here if you need me. You can do this.

Lily: Right, being a little more personable is always good.

McNamara: I have to tell you, you are an amazing. You are going to influence many young individuals the rest of their lives. You're going to be my age one day and you're going to be very proud of what you've done and the people you have helped. You've picked a great profession. This has been an amazing interview. We cannot thank you enough for doing this.

Lily: Thank you. Thank you for having me.

At the conclusion of the interview, Lily stressed the importance of thanking her family most of all. The guidance and support she received from her parents and relatives has been imperative through her emotional journey with her hearing loss.

This interview reflects the importance of a good support systems for any student with hearing loss. It also reveals the significant effect that a positive attitude and self-acceptance can have on the social-emotional well-being of students. EAA would like to thank Lily for her time and sharing her thoughts and feelings. She is truly an inspiration to us all.

For a full unedited version of the interview, please visit EAA's website at www.edaud.org.