

Interviewee: Kristen Pagliuca
Interviewer: Lauren Spadaro
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Abstract: Kristen Pagliuca was born May 27, 1975, in Massachusetts. She attended Emerson College and Suffolk University where she earned a master's degree in Health Administration. Currently she is employed as a bank manager. In this interview she discusses growing with loss of hearing in a hearing family, going to school in mainstream classrooms, and the process of cochlear implants. Kristen reflects upon the experience she went through deciding to have surgery for cochlear implants and the book she wrote describing the operation and after effects for others going through the decision-making process.

Interviewer: What is your name?

Kristen Pagliuca: Kristen Pagliuca.

I: Where were you born?

KP: Massachusetts.

I: When?

KP: May 27, 1975

I: Did you grow up in Massachusetts?

KP: Yes I did.

I: Where?

KP: In Everett.

I: Tell me about your family growing up? Do you have brothers or sisters?

KP: I have one brother that is about one and half year older.

I: And you parents? Where are they living?

KP: My mother is a director for a housing authority, and my father is an inspector for General Electric.

I: Are they both hearing?

KP: Yes, my brother as well.

I: And your main mode of communication growing up?

KP: English.

I: Who in your family did you feel closest to?

KP: Good question. I think that my family is pretty unique so I think that pretty much I took things from attributes from different members of my family. I was really close to my brother growing up.

I: Is he younger, older?

KP: He is a year and a half older.

I: Are you married now?

KP: I'm engaged.

I: When are you getting married?

KP: September 1.

I: That's exciting. Congratulations!

KP: But don't tell my boyfriend.

I: Is there anyone else in your family with a hearing loss?

KP: No.

I: No history?

KP: No.

I: What's the [inaudible]of your hearing loss?

KP: Profound.

I: So do you have any residual hearing?

KP: Very little and one ear. Just low frequency sounds. The other ear has an implant, so there is no residual hearing left.

I: At what age did you first begin losing your hearing?

KP: That was something that they could not determine. I was diagnosed in kindergarten in a routine hearing screening, they found that there was a mild to moderate loss. It continued to progress. It could have well been at birth but could not be determined.

I: How did you cope with your hearing loss?

KP: I didn't really see it as anything to be quite frank. I just wasn't raised any differently from my brother so I really didn't feel that I had to cope with anything.

I: Where did you attend school?

KP: I went to parochial school and mainstream.

I: Did they have any special access, interpreters, [inaudible] class?

KP: No, not at all.

I: Tell me about your experiences.....and fond memory that you have and growing up at school?

KP: Just a regular fond memory? I think it's pretty typical...I don't there was anything in particular that really stands out.

I: Did you go to college?

KP: Yes.

I: Where did you go?

KP: I went to Emerson College for my undergrad and Suffolk for my masters.

I: What was your major?

KP: Undergrad was communication disorders, and master in Health Administration.

I: What do you do for work?

KP: I'm a manager at a bank.

I: How did you come to do this work?

KP: I actually started in banking when I was an undergrad in college, and I just stayed in the financial services for a while and went into health care after for my masters and then decided to go back into banking.

I: If you could think of one person who would be your role model who would it be?

KP: Probably, let me think, I would probably say my mother.

I: Why?

KP: Because she has a really good way of looking at life. She doesn't have a defeatist attitude, she makes the best of everything.

I: OK, now I'm going to talk about your implant.

KP: Sure.

I: So when did you get your implant?

KP: Surgery was February 18 two years ago.

I: For my classmates who don't really know much about cochlear implants, can you briefly explain what an implant is and how it differs from a hearing aid?

KP: Sure, absolutely. Well basically all a hearing aid does is amplify sound so whatever residual hearing you have left it's only going to amplify the sound, it's not going to do anything to the damaged portion of the ear. That is why often times the sound comes through distorted, because it's not going to amplify what you can't hear. The way the implant works is it actually bypasses the damaged part of the ear, the ear cell, and sends signal directly to the nerve. Which is basically, so the damaged part of the cochlear, I have some residual hearing, when they put the implant in they damage all your residual hearing because they are getting right to the nerve, and sending impulses. The difference between an implant and a hearing aid is more so, it's basically a digitized sound with the implant. Sound comes through a speech processor you wear on the outside of your ear, just like a hearing aid, and travels up a coil to a magnet that is on the side of your head, sends a signal via FM radio waves through the skin, to where they actually insert the actual implant that's probably about this big on the side of your head. So the signal comes in, it's digitized on the external portion, goes up the wire to the magnet sends through the skin via FM radio wave and the inside part the implant takes the radio signal and converts it into electrical energy and sends it right down. An implant about this big with a metal rod [inaudible] clearance. The 60 electrodes, I have to stimulate the 60 electrodes based on the incoming signal so the implant receives a high frequency sound then will stimulate, depending on the signal.....it drives it so quickly that you don't perceive any differences in sound.

I: What size and where is it?

KP: The left.

I: Were you considering having the right one done?

KP: I'm somewhat on the fence. Maybe in a few years, insurance isn't a fan of cochlear implants.....I don't have to worry about it.

I: So has your communication changed at all? You seem much more vocal, you sign all.....

KP: Yeah, so maybe a little sharper, I can hear word endings clearer, because my loss was progressive so at 5 or 10 or what not my hearing aids worked very well with moderate loss. With a progression you use lip reading, visual queues and whatnot.

I: Why did you choose to get an implant?

KP: So that I could hear, it's as simple as that, so I could use the phone.

I: What were your feelings leading into the surgery? Were you nervous about it? Excited?

KP: I think I was relieved for one. You get to a point where if you are an implant candidate, you really just don't have any hearing. They are really concerned when they decide to use an implant candidate. Because any residual hearing, they wipe it out. I knew I would do pretty well, just because I knew I was going to work hard and make sure I would do well. I was a little bit excited. I knew I would have better [hearing] than what I had.

I: What were your experiences with the surgery?

KP: I really didn't think about the surgery until the day before. Wait a second they are going to drill a hole in my head. OK this isn't the right time to think about it. I think I was very [inaudible] and anxious, honestly I was more nervous about the IV. I'm afraid of [inaudible in my arm. The day of the surgery I was actually much to my surprise, relaxed I was joking around. Once you make the decision and you are there, you can't really conceptualize what it means that they are going to drill a hole in your head. Don't even think about it. You can't conceptualize it. The day after the surgery I did pretty well. I felt a little dizzy a little off balance the first couple of days, pretty much you feel wiped out, you just got out of surgery and you are under anesthesia, more so than the actual implant.

I: How long is the recovery time? Did you go home the same day?

KP: Yeah, surgery is only, for me it was two and half hours. By the time you get in there and then they prep you and they couldn't wake me up. I was out cold. I was more concerned that they couldn't have coffee in the morning of the surgery. It's a long day because of the procedure, mine was in Worcester and I live down the Cape, so an hour and half drive. The recovery, you take it slow, I was drinking coffee the next day which is not smart. I took a week off of work just to kind a get back.

I: So after the surgery, can you tell me a little about the mapping process and the train that's

involved?

KP: Sure. Well right after the surgery, I think about three and half to four weeks, before it was activated, and the day the implant was turned on it just basically sounded like high pitched. I basically lost my high frequency hearing first so that's what my brain keyed into. So the first day I put an audio book in on my drive home, and I didn't understand a thing from it. It was just a matter of constantly exposing myself to sound. The first, I caught on pretty quickly I was able to understand pretty good amount, use the phone within the first few days, with familiar people, and I hadn't used the phone in years. I was able to understand withoutI did go through some oral rehab, probably twice a month for an hour. Somebody I knew in the field. So it really wasn't consistent. I think most of rehab was yourself. Listen to audio books listen to music, picking up the telephone and just kind of constantly communicate. I still use lip reading in the beginning but it helped bring in thinks quicker.

I: How is the sound different from what you remembered hearing?

KP: It's better, it's sharper.

I: Does it sound different than normal hearing?

KP: No.

I: So is the implant everything that you expected to be?

KP: Probably more, absolutely. I didn't expect it to be that clear, especially on the cell phone. Cell phones are weak, especially in the car.....

I: Is there anything you don't like about the implant?

KP Battery life maybe....and it actually doesn't bother me, but of course if I had battery that would last weeks. The battery that I have lasts about a day and then you recharge it. So it's really not that much of an inconvenience, but it would be nice to have a longer battery life. I don't really, I was wearing a hearing aid all the time, this isn't much different.

I: Is there anything that you wish you would have known before the surgery?

KP: Maybe that I was going to try...I wasn't worried about the surgery per se. The surgery, you are uncomfortable, you are out of duty for like a week. Kind of comes and goes, wondering how it was -- how effective it was going to be. [Inaudible] researched it for a long time before I got it.

I: I have an internship with Dr. Lee at UMass, and we do a lot of implants on small children, ages twelve months and up, and I was wondering what you feel is an appropriate age for someone to get a cochlear implant.

KP: As soon as possible. Absolutely, unless there is a medical.....I don't know where there may be medically a problem for a child to be implanted, from what I understand.....I don't see why....

I: So if someone is considering a cochlear implant what kind of characteristic do you think are important for them to have in order to be successful with the implant?

KP: Realistic expectations. If you have the implant turned on and you expect to understand everything or anything then you are at risk in being very disappointed. You have to understand that I didn't understand anything the first day. The only success that you want in the first day, even the first week, is that it works. You build on; I think you have to be excited about every word you hear. And that's what I did, because these were words that I didn't hear before. So if I heard somebody say something behind me, and I got one word then I just got one more than I had before. So you have to let yourself be excited about everything. Some people say it is hard work, I guess it could be considered hard work; I didn't find it to be hard work. I found it more exciting, like let's see what more I can hear, so you have to have a positive attitude. I was very lucky I had family and friends that were very supportive. They will get excited, a positive attitude, so support system is always great and realistic expectations.....and Dr. Lee as your surgeon.

I: Yeah he is a great guy. You also mentioned that you were writing a book about your experience, can you tell me a little about that?

KP: Sure, so my book is out there, hopefully someone will publish it. It's called "Everything Makes a Noise." It's broken down into three sections, and the reason that I chose that -- it seems such a simplistic title -- but if you get noted that everything makes a noise, every single thing, like a noisy refrigerator, and the same guy that made the refrigerator obviously made the air conditioner because they are so loud for some odd reason, but and you really kind of like, "Oh my God, everything makes noise." So it's broken down into three sections, one is just my background, so people get to know the author, and why I decided on an implant. The second is the process, because mine was so expensive, just a matter of the questions I would ask so try to find out, so just forget about I want to get an implant, but who you are going, which manufacturer because they are all saying they are the best, and their results are pretty similar. I would ask different people that had the implant, the same ten questions because you have to stay objective and you are not going to be able to make a decision, people don't do that. In my book I have the questions I ask and how I came to that process and also I have a piece from all three manufacturers that contributed, although my book is meant to be impartial decision-making guide and the third is how I came to my decision. Third part is pre-surgery, because nobody talks about how did they feel a couple of weeks before your surgery, to surgery day and activation day. Seems like a lot of people start with activation and so for this time that you are going through what about if you don't have any parent at all that.....so I talk about that. I have a piece written by the rehab [name] is the person who I did rehab with so he wrote a small piece of my rehab. It's a decision-making guide for the consumer. It's not right for everybody, and I think it's important, this is the process I took and the third is from that point all the way to the first year and then I have my school..... brag a little bit.

I: Why did you choose Advanced Bionics? Did something really stand out by them?

KP: A few things. The fact that they analyze sound at a faster rate and I know arguments can be made either way as to how that is more effective. In my mind it just made more sense, they are going to send impulses at a faster rate than to me it made sense. I like the fact that they can stimulate all the electros at the same time, which generally you are not going to have that kind of [inaudible] where you are going to stimulate 16 electros at the same time but whatever that signal is they are going to do it at the same time. Whether or not it makes sense technically, it made more sense to me. I liked that. I like the fact that they had T mike, and accessory item. It fits right near the ear easy and if you wanted to use the phone you just pick it up and use it you don't need to switch to a telephone switch, it's just pick up the telephone. And the other reason was, I spoke a few different people, and when I would interview people per se about the different devices, the Advance Bionics, people who had Advanced Bionics, consistently talked about music. I don't think I asked them about music directly, or too directly, and all others never brought up music. So if they can handle music very well, and that's very important, because I knew I would get speech. It's almost --music was key and actually the last part was I spoke to somebody who had normal hearing all the way and lost their hearing at 25, well educated, when I met with her, and she, she told me that everything sounded exactly as she remembers, even with music. Technically is it exactly, well obviously, we know it's not the same, but her brain is interpreting it as exactly the same. I wasn't hearing all my life, she was. She's saying it sounds exactly the same, so that's got to be part of it.

I: What kind of accessories do you have? Everything plugs right into it, right? Like your Ipod or anything?

KP: Yup, absolutely. There is an ear hook that you can remove. You can plug in this other ear hook that has a little place, input, where you can put a wire, that will plug right into an IPod. I can use regular headphones with music, but when I'm at the gym who would want to block out all the gym noise, or like if you were on an airplane do you really want to hear.....so I use it when I travel, and I always use it for the IPod, but other than that, I have the T mike and the direct connect.

I: Is there anything else you want to share, or any other comments that you could give us?

KP: No, I can't think of any.

I: OK then thank you so much.

KP: Thanks for asking.