

Episode #42: Advice for Someone Going Deaf (*Neurofibromatosis Type 2*)

Special Guest: Peter Burton



Peter: Once we had that hearing aid, they said, you know, you can feel free to transfer to RIT. You have enough to get by now. And then I transferred over there and then my hearing went away and I used closed captions. And by that time, I had a little bit of sign language, so I used a sign language interpreter for some and just improved my skill as I needed it.

Tonya: Right, right. It's, I mean, you were, you were thrown into the fire. Literally having to learn that as fast as that. I'm gonna start this official interview though, because if I don't, then I'll forget that I have to actually do our, introductions.

Peter: Oh, we don't, we don't need introductions. You know me. I know you.

Tonya: I know, but, but our listeners don't know who you are, so. So, I'm gonna start out right. So, so for those that are listening, Peter and I have been talking for a while, but I want to stop for a moment and actually introduce who our guest is today. Um, Peter is a friend that I met a couple of months ago now.

Um, we just happened to run into each other when I was at work one day, and, um, I enjoyed talking with him so much that I wanted to see if he would come onto the Water Prairie Chronicles and tell you more about his own life. So, um, Peter Burton is our guest today. And Peter if you would like to introduce yourself to us.

Peter: All right hey everybody. So, I'm not awesome at the first icebreaker introductions, but here goes, um, I am pushing the 30-year mark. I am 29 years old. Grew up in Swansboro, North Carolina. I went to Rochester Institute of Technology in New York for college. Graduated from there, moved back to North Carolina after marrying my wife.

Then fiancé Cassie. She is in lab science here. I'm a new product, introduction, and design engineer here for Avantor Fluid Handling. We have four cats. And oh, by the way, why I fit into this little podcast is I have many challenges to my life. You might notice, hey, my face is shut off over here, closed eye, whatnot.

I'm actually deaf completely and don't see out of my right eye, so I'm half-blind too. I've had numerous brain surgeries, spine surgeries. I have a disease called neurofibromatosis type 2. And I'm sure we'll expand on that later. But for short it's NF2. And that's a little bit about me.

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Tonya: So, so let's, let's jump into this. What is NF2? You gave us the name of it, but what actually is it?

Peter: So NF2, how I explain it to people that I don't feel like elaborating on is it's cancer without the word cancer.

Now let's dig into what it actually is now. Fibromatosis. It generates tumors all throughout your body. Anywhere there's nerves you can get one tumor. Primarily how it's diagnosed is you have tumors on the acoustic nerve, which in turn has you be from surgery deaf. That's kind of a cause and effect of those, NF2 is actually because of a protein malfunction.

Part of the gene changes that protein. Everybody has a protein that suppresses tumor growth while NF2 actually pretty much shuts that gene off that protein off, and so that lets tumors run wild. Most of them are benign tumors, but as you see my life right now, majority of tumors will have some kind of impact.

You could have simple ones that just get removed, but that's really sensitive until I get it removed. There's ones in the brain, there's ones in my spine, there's ones in my legs, wherever. There's nerves and they're all gonna impact in different ways with different treatments.

Tonya: So, so I, I have multiple sclerosis and, and that that also affects the nerves, but it eats away the nerve.

So in your case, it's not harming the nerve, it's growing on the nerve. Is that correct?

Peter: Yes. They're called nerve sheath Tumors usually in the tumor. If you have a nerve, the tumor will be inside of that nerve.

Tonya: Okay.

Peter: And grow. Cause that nerve to expand and stretch.

Tonya: So is it also cutting off the signal from that nerve?

Peter: Any signal with the nerve will be different, such as right now I have hypersensitive on my left leg. One of the tumors somewhere is causing that, but if I'm in bare feet, I change from carpet to tile and I don't make mental note of it, that shock of change will send a spasm up my leg. So the signals, majority of them will just cause the signal to be changed how it normally would be.

Tonya: I know the body's nervous system is, is incredible the way it works and um, and it can retrain itself sometimes too, depending on which nerves are affected. I know I haven't

experienced it, but I know with MS you can feel like your foot is on fire and nothing is happening, but it's just the signal that's coming with the nerves.

Peter: And that's a lot of how NF2 is. It'll send those. Some people have almost the equivalent of phantom pain, but they don't have an amputation. Like you said, just out of the blue, your foot's tingling or whatever.

Tonya: For NF2, how, How rare is it? You had told me, but if we can share this for our listeners.

Peter: So, if you want, statistically it's about one in 30,000 people. NF2 is actually a lot more rare than NF1. NF1 is a lot of outer tumors, some of the listeners might actually know someone with NF1 um or a form of NF1 or a form of neurofibromatosis in general. NF2 is so rare because it's genetic inside and there's no way to track it.

Tonya: Is it an autoimmune or is it genetic malformation, or what? I'm not sure how to ask that question.

Peter: It's just genetic mutation. It normally, it's hereditary. Okay. Why? As I said about that protein. anyone could have NF2, because we all have that protein that suppresses tumor group. NF2 happens when there's a mutation and causes that protein to not act the same way.

Tonya: When did you first know that you had NF2?

Peter: So that was a blessing in disguise. When I was, right after my 15th birthday, I was playing soccer and I was in a soccer tournament and had a foul on a kid, whatnot. The kid retaliated to the next play and knocked me out with his elbow and. Got knocked out, didn't play the rest of the weekend.

I tried but wasn't stable on my feet or anything. Went to the doctor. Doctor, said, you know, you have a really bad concussion, but I think something's not right with how you are reacting to tests. I'd feel better if he went and got a CAT scan. . So went and got a CAT scan, the CAT scan only showed blobs in my brain.

So with what happened and how I was reacting, they said, You have a brain bleed. Go to the ER right now to have an MRI. I had an MRI. It showed the acoustic neuroma tumors in my brain. From there, it trickled down tons and that's how NF2 came to light. So, although I got knocked out, it was definitely worth it.

Tonya: So if that had not happened, how long do you think it would've been before you had any symptoms?

Peter: So that's unknown, honestly. So, a little bit more onto that. They were originally going to operate on my brain right away because those tumors were large in compressing the brain stem. . Oh, and one of the surgeons that was gonna do surgery said, I think he needs a full back MRI.

There's abnormal widening at the brain stem where it connects to the spinal cord. Had that MRI and it showed a 32nd of an inch spinal cord fluid was flowing still. There was a tumor in my spinal cord inside of the cord. They told me go to Boston right away, have surgery on that. When I saw the doctor, he said, you don't have any symptoms.

Your legs aren't weak or anything. I said, No. I was playing soccer. Yeah, and I got knocked out. He said, You shouldn't have been walking. He said, At any time I could have fallen wrong on my head and it would've pinched enough to stop the flow of spinal cord fluid. So I mean, that timing probably couldn't have gotten much better.

Tonya: Yeah.

Peter: Than it did.

Tonya: That's a pretty serious risk that you didn't even know you were taking.

Peter: That I am thankful for, but at the same time, I was 100% doing 100% what I wanted to do in my life at that time. Going to the beach, going in water, playing soccer, whatever. There were no limitations on life.

Tonya: How has NF2 impacted your life since then?

Peter: I was anticipating this question, and that's why I said the limitations part because some of the listeners might say, yeah, he lives a limited life now. He can't go to the beach, can't go underwater, can't do this, can't do that, can't hear, whatever. All of those limitations in my life I have. I'm an engineer.

I've had to think outside of the box. On many of those limitations, how can I get past that limitation, and that you ask how it's affected my life. Do I have bad days? Sure. Everybody has bad days. Mm-hmm. , why in all honesty, I found the woman of my dreams. Married her. I graduated college. I have a job in the field that my degree is in.

If anything, it's just made me work harder. That's what NF2 has done to my life.

Tonya: I like that attitude. Um, it is, I mean, your life is your life. So it sounds, and, and I've seen this in you already, between our emails and our conversations, you're making the most of your life and it's because this is your life.

And I like that positivity that you're spreading to others too. I think it's important that some of our parents and even older children who are listening to this hear that.

Peter: I just feel like gotta make the most of the cards that were dealt, and I mean even before NF2. That's how I looked at life and that has gotten me to where I am now and it's thankful that I have the support system that I do that reemphasizes that on the bad days that I mentioned.

Tonya: Well, I, I meet people and I find everyone either seems to approach life with their glass half full or half empty. And um, and my guess is that yours is always half full.

Peter: So mines half full, but I know my glass is half empty too, and I know that's a weird answer, but it's about recognizing what's in front of you, recognizing what you still have, what you're still able to do, and making those two one, and that's how you're gonna get through.

Tonya: Thinking about your deafness, you talked a little bit earlier before we started the official interview about when you had started college. Can you just kind of summarize that again for me as far as if you had any warning ahead of time and how the change was from your hearing to your hearing loss?

Peter: I would say it started before I even graduated high school. I was 16 or 17. I had my first brain surgery. That in turn made me deaf in one ear, so I was half deaf. At that time I started learning some sign language at a community college, but I could still hear, so I wasn't all about sign language. I could still hear. I was fine. Then around the time of college, before I started college, I had proton radiation.

And at that time, I went in with half of my hearing and after proton radiation. They don't know if the proton radiation hit the other nerve or what happened, but my hearing slowly decreased and decreased to the point of. When I started college, I had the sense of I don't have any hearing left. After about two months in college and only being comfortable with finger spelling, sign language, all of my lessons, everything was in sign language, so I'm flopping like a fish, trying to grasp onto something.

An audiologist at college. Catherine Clark said, why, why don't we try an amplifier? And this amplifier was very high tech and lucky enough, Voc Rehab helped to pay for it. And that gave me a little bit of hearing. That I didn't even know I had for maybe six months, and then my hearing eventually went completely.

They couldn't turn the amplifier up anymore, or anything. But in that six months, I was able to transfer over to academic side of college hearing classes. I was able to pick up enough sign language to get by and constantly being immersed in it back in my dorm. Let me learn it in no time. But because of that little bit of hearing that I had, just a little bit in college, it was kind of six months of prep for the real college when I had more in depth classes and then I was actually understanding things.

Tonya: When you first were losing your hearing, what was your first reaction to that? Was it, did you just kind of take it in stride or was that a, a hard report to get?

Peter: Honestly, when I first became half deaf, I have good friends. I had friends that would joke with me and talk on this side, and I could feel the breath of vibration and they'd do it in a joking manner and not in a bullying manner. But they'd come up to me in the hallway and I don't hear them coming up and they'd just talk in my ear. Oh, oh, okay. I know someone's there, whatever. But that let me in a way, just kind of merge that with my life already.

So half deaf wasn't bad, and as I lost my hearing more and more I felt like everyone around me, friends, family, everyone wanted me to appreciate what may be their last time being heard. So they'd just call me out of the blue. Hey, I just wanted to talk to you while you could still hear me, whatever. And so that was a pick-me-up about my hearing getting less. Cause the first thing they say on the phone, Can you hear me?

And I'd say, Yeah, what's up? Or whatever. And just that little blip was nice to be able. Okay. Yeah. Still going fine. And once my hearing went away, I mean, For that stretch of two months, I was a little miserable with complete hearing loss cause it was just a shock. I was starting college. I said, wow, this is my life now.

How I met my wife. We were in a little meeting in at the start of college. And I didn't know her and I said, Hey, do you understand this? I finger spelled all that. And she said, yes, and turned back. And it really opened my eyes to, this is another limitation in life. I gotta get above this. And after those two months figured out the amplifier, I still remember what my wife's voice sounded like with the amplifier.

I still remember how things sounded. By being given that little bit of hearing after two months of no hearing made me mentally sound that, Hey, I know what's coming. Let's appreciate what I have right now until that happens. Yeah, so I guess I got lucky being able to see like people that maybe die in surgery, but then they're resuscitated.

And sometimes they have afterlife things. They're lucky to have that experience to know, hey, what's on the other side?

Tonya: Interesting. Yeah. I never thought about it that way, that the time that you got the hearing back with the amplification would've given you a buffer of knowing ha, having experienced it for a short time, and then getting it back for at least a, with the amplification, um, was almost like a grace period there to give you some extra time.

Peter: I dunno if it was luck or, hey, my last heave ho of hearing or what, But it was definitely a big benefit.

Tonya: We've referred to you learning ASL cause you were finger spelling and um, and you learned ASL, um, and you started learning at the community college first. Right?

Peter: When I was at the community college, I still had half that hearing, so, I didn't feel like I needed it. And once I was at college, I mean, every day I had a deaf roommate and signing with him in the morning and the evening, whatever, picking up little bits that I could from him, and then I got that amplifier and that helped me to grasp on to sign language.

With the sounds, with anyone talking, following sign language, it was a real, a quick learning experience Once I needed it, compared to community college, I didn't need it. So, I didn't. I learned it, but I didn't use it.

Tonya: I would, I would equate that with any language that you're learning, if you study French in school, you may learn to speak French, but it doesn't, You're not thinking in French, you're not immersed in it.

If you go to France and you live with the French speaking family and nothing else, you're immersed in it. So then, You have to learn it. If you want to communicate and be part of the world around you, you, you learn it. So having learned the reality that you need to learn, this probably made that easier for you.

Peter: Yes, for sure.

Tonya: Hello,

Peter: This is Cassie, my wife,

Tonya: nice to meet you.

Peter: Who was way back when That I mentioned about the start of college. That she said, Yep, I understand kid. Don't talk to me anymore. .

Tonya: Well, she changed your mind at some point.

Peter: After enough persistence, .

Cassie: I did have some experience with ASL, so I did some of it.

Peter: Yeah,

Tonya: Okay. So, uh, let's, let's get back to where we are now. So we've talked about some of the tools earlier too. Um, are there any other tools that we haven't mentioned that you found helpful?

Peter: I feel that the Live Transcribe app is the golden tool. I mean, it helps so much with everyday life. I mean, of course, The alarm in the morning, the bed shaker, and flashing lights in an apartment.

I don't use tons of different things other than that alarm or transcribe and the captions that are letting me talk with you now, .

Tonya: So for the captions, what is, Are you using just the, the build in captions or are you using a separate program?

Peter: So it is just on Google Chrome. I go on settings, advanced settings, accessibility, and you can turn on live transcribe with Google Chrome and the doorbell too. A doorbell mounted outside and when someone presses it, it'll flash the light to let us know. Hey, there's someone at the door.

Tonya: Right. Do you have, um, the flashing lights on your fire alarm?

Peter: So, interestingly enough, I don't and, Last year there was a fire in our apartment building and I didn't know, and I was work from home.

The fire was on the floor above me and I smelled a little bit, but I thought somebody was smoking in the vents. And I said, whatever, and I was working, and then all the power in my apartment got shut off and I went outside so mad because I was using a 3D printer. I was using different screens for the computer, everything and everything shut off.

So I went outside all mad. And there's fire hoses going up the stairs and everything. I said, Oh, okay. , lock my door. Okay. Went downstairs.

Tonya: So, you need to get the flashing lights on your alarm.

Peter: Yeah. for sure.

Tonya: You mentioned the, the alarm that you use, is that the Sonic Bomb or do you have a different brand?

Peter: Yeah, it's the Sonic Bomb.

There's a lot of different ones. Sonic Bomb, Sonic Boom, Sonic Shaker, uh, whatever. And I feel like this one, it's actually called the Sonic Bomb, and I feel like the vibrations are, Better for me. I don't know if that's just me getting more adult-like and noticing them more. . But it also has some LED lights that flash.

And it makes noise, and my wife gets mad at me if I don't get up. So

Tonya: For someone who may be losing their hearing, they still have their hearing, but they're in that in between stage now. Do you have any advice for someone at that stage?

Peter: Listen to your music and not on a high volume. But more of listen to the music as far as can you feel the bass? Because something that I miss, that I pick up a little bit.

Now I can pick up songs that I heard that I know the bass part. New music. I'm never gonna follow those cause I don't know what the song sounds like. And music was a big part of my life when I could hear, as I'm sure anybody that can hear is. I'd also say that any lessons that you have in sign language, don't write them off like I did with community college.

I mean even listeners that are completely hearing if you can take sign language take it because you never know when you're gonna be in a situation that you can use it. And having that ability to learn sign language. From an instructor that's voicing to you as well will help your cognitive skill of sign language to learn sign language.

Tonya: So for, um, work, I wanna talk about that a little bit. The, um, whenever you apply for a job, do you disclose that you have a disability up front or do you wait till later.

Peter: So, this was an interesting question. I actually didn't write down the answer to it cause I didn't wanna answer at first. I have two things that I have started doing since I came back to North Carolina and interviewed for the job that I have now.

And that's on the application, on the paper application, there's always a question that says, do you have, or have you had a disability in the list or the disabilities or whatever. I mark yes then I get looked at for a phone interview and, okay, I use captions on my cell phone. I get through the phone interview fine.

Maybe they, maybe they think I have a little bit of a cognitive processing because there's a pause between talking or whatever. Okay, that's fine. I have waited until I get into the interview and then I turn on my transcribe and set my phone down. And proceed with the interview. Don't mention anything "Hey I'm deaf," or whatever.

I let the interviewer make their own. In life, you only give one first impression, and I feel like that gives me the most beneficial impression that I can give. I've had numerous interviews while I was still in college. I had an interview in California. They flew me out there, interviewed fine. I interviewed with like a board of people.

There was many people I had requested an interpreter. I had multiple rounds of interviews and whatever. It was a hassle. And I feel like in turn, in one of my interviews, I had a staged interview that I had asked for an interpreter and whatever, and in that, in one of those stages, they interviewed me about my technical skills.

And something that comes up in engineering is GD and T. And I told them at the start, I said, I have not been in depth in GD and T. I took this three years ago, but I feel comfortable that I'm gonna understand the symbols now. Fine. Okay. But the interpreter interpreting, trying to look at the paper, understand the symbols and whatever.

Doing all that, there was some communication loss and in turn that almost put me directly in the avenue of, well he doesn't know what he is doing, Okay. Because they provided all this, they weren't understanding of this, and now this is happening or whatever, and so I found share enough to get by and let, let things go how it will, maybe in one case.

My phone doesn't work. It's happened before in the interview. I turn on Live Transcribe and it doesn't work, and I say, Hey, I'm deaf. I explain the situation and I normally follow up with . It'll work better if we can go in a quiet room. or it'll work better if I can connect to Wi-Fi or whatever. I show that, hey, I know this experience is gonna happen.

Let me show you again how I am bridging that. It's giving fuel to your advocacy of yourself to be treated the same as everyone else. That's gonna be the biggest benefit for you is that you have, you hold all the knowledge and it's your decision of when and how to communicate that knowledge.

Tonya: You're using some accommodations for work.

Do you just use the transcription or do you have any other accommodation?

Peter: I mainly just use Live Transcribe. I have Microsoft teams that our company actually uses. It has captions in there. Okay. That's what I use. Yeah. Virtual meetings. Um, something that is my field specific.

I have my boss tell me I want this, this, and this. In my field, I have the ability to draw that in 3D, and now 3D does the communication for me. He communicates any problems that he sees, anything. It helps for presentations or whatever, if you can convey things to where talking isn't needed.

Tonya: You mentioned Voc Rehab, and for those that are listening, that's Vocational Rehabilitation In North Carolina, that's what it's called. In your state, it may have a different title, but you should have some agency that's doing the same type of work with you. So Peter with Voc Rehab, did you have a job coach or anything like that?

Peter: I had a job coach at the exact same time that I applied to this job currently. And so it was more or less a resume review and. I said that the next day.

Okay. But I do know that Voc Rehab will help to advocate for you if you don't feel comfortable in interviews in the interview process. They'll have you do mock interviews so that you can get affiliated with the pressures that, Hey, they're gonna ask me all these questions. How do I address those without seeming nervous about them or whatever. Yep.

Tonya: Um, I'm glad you were able to get connected with them because I think they offer a lot of good for the students in North Carolina.

Peter: They have been a blessing, even from when I became deaf. I mean, like I told you about, there are samples of things showing you all the different technology. That opened up a lot of doors just for learning what's out there.

Tonya: The, um, so those that are listening, I'm gonna put the link for Vocational Rehabilitation Services in the show notes, so that if anyone in North Carolina that's listening is not connected with them, and you have a need to work with them, you'll be able to get in touch with them. And if you have a, if you're a parent listening, when your child is 14 is when they can begin working with your child and you can refer them for that, or the school can, or the child can themselves.

So there are many different ways to get connected with them. You don't have to go through a, a pre-screening process. You just need to make the referral, and then they, they will take, take it up from there. So Peter, for our listeners who have any questions for you, if they want to ask you anything specific or if they have, um, want more information about anything that we've talked about, do you have an Instagram account that you would want to share?

Peter: I actually don't use Instagram. But, if you would like to include my email, something that may be beneficial to the parents. If you're worried about what do I do as a parent with a deaf child, how do I help them, I'm sure my mom or dad would be willing to connect with you guys to answer any questions. I mean, even in the NF2 group.

My dad has numerous times navigated with new NF2 patients and their families. Hey, how can we help? Uh, something that simple as Boston has the Hope Lodge La Quinta Hotel that works with the hospital. Having that knowledge of our stay there we know things that others may benefit from or whatever the case may be.

Don't ever be afraid to reach out and say, hey, do you know anything about going to California, the San Diego Hospital there? And say, Well I don't, but hey, there's an NF2 person that just did something there, let me talk to them and I'll see, or whatever the case, I'll try to help and my parents will too.

Tonya: Excellent. So those that are listening, what I'm gonna do is I'll put the water Prairie email in the show notes, put Peter's name in the subject if you send a note, and I'll forward that directly to him.

Well, then that means that it's time for our speed round.

Peter: Yeah. I won't be fast on this, but yep,

Tonya: It's okay. I call it a speed round, but Well, for those that are listening, if you haven't listened to a podcast episode before, we give all of our guests the same set of 10 questions, and we call it a speed round.

But it doesn't have to be fast because it's just a list of 10 questions that have absolutely nothing to do with the interview . It's just a way for us to get to know each other a little bit better. So Peter, I'm going to start with three open ended questions. And then I'll have seven either or questions for you.

So first question, what is your favorite color?

Peter: I'll go with Aqua Marine

Tonya: Aqua, You are my first Aqua Marine.

Peter: I always wanna be unique.

Tonya: All right, next question. What was the last book that you read?

Peter: It Ends With Us. Um, Hoover, I think is her last name. It was good. And recently, I'm now reading, It Starts With Us, and it's the sequel to It Ends With Us. It just came out. So yeah, reading the that, so,

Tonya: So It Ends With Us, came out first, and then It Starts With Us came out?

Interesting.

Peter: I know it's weird. I thought so too, but it's so far it's good.

Tonya: Good. All right, and so the last open ended question, what is your favorite holiday?

Peter: I'd go with Thanksgiving, honestly. Okay. And it's not just because of the food, but family and Black Friday, the day after.

Tonya: Now I've had a lot of people say Thanksgiving because of family.

But you're the first one to say because of Black Friday.. See, you're,

Peter: It was growing up. My mom always took me out at 3:00 AM on Black Friday.

Tonya: All right, so the next seven questions will be either two words or two phrases, and you choose one, or you can say both or neither. So, there's no wrong answer. All right, so the first one is cake or ice cream?

Peter: Ice cream,

Tonya: Batman, or Superman?

Peter: Oh my goodness. Batman. And I'm gonna send you another picture so that the listeners might know me.

I have a Batman truck.

Tonya: Oh wow. All right. Ocean or mountains?

Peter: Ocean.

Tonya: Winter or summer?

Peter: Summer.

Tonya: Watch a movie or read a book?

Peter: Uh, five years ago I would've been watching a movie. Now I'd say both, just so I can get mad at the movie for not being as good as the book.

Tonya: Harry Potter or Lord of the Rings?

Peter: Oh, Harry Potter, for sure..

Tonya: And the last one is Twitter or Instagram?

Peter: I'd probably go with Twitter.

Tonya: Peter, thank you for being on the podcast today.

I appreciate you sharing your story with us and, um, giving us some useful information that both parents and children who listen to this will be able to use in life.

Peter: Hey, I appreciate you having me here, Tonya. I mean, when you proposed this to me, I said. Wow, this is, people hear my story and my life and Wow.

Yeah, that's, it has inspiration and has a show of life's challenges and whatnot, but there's never been a reach to that. So, I don't public speak at places. I don't, I don't out and about with everyone, but as I told you, when you ask me, I'm in open book. Whatever you wanna ask, I will 100%. Feel free to share.

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