

S1Ep2 Speaking Uncomfortably Transcript

Shelly (00:24)

Hello and welcome to the Uncomfortably Speaking podcast. I'm Shelly Rohe, your host. I use she/her pronouns. I'm a disabled white woman in my mid-50s. I have long strawberry blonde hair and blue eyes. I'm wearing a blue shirt and glasses. And it will just be me again in this episode.

Today, I want to talk about internalized ableism and why I named this podcast Uncomfortably Speaking. The two are intertwined for me, and they're really at the heart of this podcast. I also want to talk about some disability basics and my beliefs about disability, because those beliefs shape how I view and talk about everything we're going to get into here.

As I was thinking about doing this, I knew I didn't want to be someone who sat behind a microphone and pretended like I had everything figured out. I don't. I'm still figuring all this out too. So why call the podcast Uncomfortably Speaking?

For me, the name has more than one meaning. Yes, it's about having uncomfortable conversations. It's about questioning things I've thought about myself and about my disabilities. But it's also much more personal than that. Speaking itself is uncomfortable for me. I've worried about how other people will hear me, or even if they can hear me, and will they understand me? I've been aware of my voice in ways that I wish I didn't have to be.

And when something as basic as speaking makes you self-conscious, it can affect more than the words coming out of your mouth. It can affect whether you speak at all. It can affect how much space do you allow yourself to take up. And it can affect whether you join conversations, introduce yourself, speak in front of people, record yourself. Or simply allow yourself to be heard. And then I decided to do a podcast. Yeah.

But that's part of what makes Uncomfortably Speaking so personal for me. I'm doing the very thing that makes me uncomfortable. I'm using the voice that I felt very self-conscious of. I'm using the voice I wished were different. I'm using the voice to talk about why I ever thought I needed it to be different in the first place. And that brings me to my story.

In episode one, I told you a little bit of some of my history, and I'll fill you in on a few more details today, because understanding them will help you understand why my voice has become such a complicated thing for me.

A few years before I had brain surgery on my brainstem, my neurosurgeon asked me what sense I could live without. I thought about that a lot, and I told him I didn't know, I couldn't decide. I knew I wanted to keep my memories. But after I woke up from surgery, every sense I have had been affected except my hearing.

The hardest part for me was not being able to communicate at all.

My eyesight was affected. I was paralyzed on my right side, so writing and typing were out for me. And when I opened my mouth to say something, even the people who knew me best would look back at me with a look of confusion on their face. I knew they couldn't understand the thing I was saying. It has taken me years and loads of speech therapy to get where I'm at today.

I have multiple speech disabilities. I have a vocal cord tremor and a soft palate tremor. I have dysarthria, which can affect speech by making it sound slurred and difficult to understand. I have aphasia, which affects word recall and cognition. I had a speech pathologist once tell me I speak better than I should be allowed to. Yeah, but that's a conversation for another time.

But the trauma from those early days still lingers, and the effects follow me to this day. I felt very self-conscious about my voice. I've been ashamed of it. I've made excuses for it. And I've worried about what people will think when they hear me speak.

And that brings us back to internalized ableism. You may have wondered about my introduction video. To me, this video is actually an expression of the internalized ableism I've started noticing in myself. In the lower left-hand corner is an outline drawing of me sitting in my wheelchair with a quizzical look on my face. I'm looking off to the right where a thought bubble is emerging.

Inside the thought bubble are pictures of my past self doing intricate things like pouring liquid or driving a car, swimming, directing a film, speaking in front of crowds. And these are all activities I've stopped doing. And I know I've done that to myself.

I'm not even sure I want to do everything pictured here again. And that's important. because the point isn't about getting my old life back. The point is to ask myself why I ever thought certain things were out for me in the first place. Are these things I don't want to do anymore? Maybe.

But are there things I don't do because I've decided I can't, or shouldn't, or don't belong there anymore? And that's harder to answer. These are some of the clearest examples of internalized ableism I've recognized in myself. And that's part of why I'm doing this podcast.

I've started wondering how much of the shame I've carried actually belongs to me and how much of it did I learn. Why did I turn those expectations inward and start judging myself? And these aren't easy questions for me, but they're important questions. And they're exactly the kind of questions that this podcast exists to answer. I mean

I must have recorded that teaser video at least 30 times and it's only eight minutes long. Thirty times! I mean if that doesn't tell you how self-conscious I am of my voice, I don't know what will.

So, when I talk about speaking uncomfortably, I'm also talking about the discomfort that happens when I start questioning something I believed about myself. The discomfort of realizing, wait a minute, maybe that thing I thought was wrong with me wasn't actually wrong with me. Maybe I was taught to see it that way.

Maybe the problem wasn't with my voice. Maybe the problem wasn't my body. Maybe the problem was the expectations I placed on them. I mean, where did I learn what a voice was supposed to sound like? Maybe the problem wasn't that I needed to change anything. Maybe the problem wasn't that I couldn't do something the typical way or the way I had always done it. Maybe there are simply different ways of doing things.

And I've started realizing that I've spent a lot of my life trying to fit into expectations that weren't really designed with me in mind. And that's uncomfortable to admit. But that's exactly what I mean by 'speaking uncomfortably'.

I'm willing to say the things I'm still working through. I'm willing to question myself. I'm willing to say, "I used to believe this, but I'm not sure anymore." So, what exactly is internalized ableism? Trying to clearly define it can be tricky because it's conceptual.

So let's start with ableism. Ableism is more than somebody saying something offensive about a disability. It's a set of beliefs, attitudes, practices, and systems that treat certain ways of functioning and people, specifically non-disabled people, as more valuable, desirable, capable, or superior to others, specifically disabled people. And those messages are everywhere. They're in our buildings, our schools, our workplaces, our healthcare systems. They're in our relationships, our media. And sometimes they're buried in everyday expectations so deeply that we don't even recognize them as ableism.

And here's the tricky part. When you hear those messages repeated over and over and over again, they can get into your head and stick. That's internalized ableism. It's when I take the messages society has taught me about disability and start applying them to myself.

And realizing that has been uncomfortable for me. Because I can believe in disability justice. I can challenge ableism. I can advocate for accessibility. I can believe disability is part of the fabric of human life. And I can still discover ableist beliefs in the way I think about myself. And that's been a huge realization for me.

I can give other disabled people grace and understanding while holding myself to a completely different standard. And internalized ableism doesn't announce itself. That would actually be very helpful. Instead, it can sound perfectly reasonable. "I should be able to do this myself." "I should be able to do this." "I don't want to inconvenience anyone." "I don't want to be difficult." "I should be able to push through this." "I don't need help." "I just need to try harder." "I don't want people to see me struggle."

And for me, internalized ableism can sound like this. "I don't want people to hear me like this." "I wish my voice was different." "What are people going to think when they hear me speak?" And those thoughts feel very personal. I'm beginning to ask myself though, whether they are actually mine or whether they're messages that I've absorbed about how people are supposed to sound, move, communicate, or exist in the world.

And that leads to another uncomfortable question. What am I trying to prove and who am I trying to prove it to? Just because I can push myself doesn't always mean I should. Just because I can struggle through something without asking for help doesn't mean that doing it the hardest way possible makes me any more worthy. My voice doesn't have to meet somebody else's standards before what I have to say matters. There's no gold medal for making my life unnecessarily difficult.

And this is something I really want to explore throughout this podcast. There's a difference between growing and believing I need to get better before I can accept myself. For a long time those ideas were tangled together for me. If I could just get better at this, if I could just be more independent, if I could just change this thing about myself, then I would be okay.

But what if I'm already okay? What if I can want to learn and grow without treating who I am as a problem that needs to be solved? Acceptance doesn't mean I stop growing and it doesn't mean I don't have goals. It means I don't have to completely reject who I am today in order to become who I want to be tomorrow. And that's really what Uncomfortably Speaking is all about for me.

I'm not sitting here as someone who has conquered internalized ableism. Far from it. I'm sitting here as someone who has started noticing it. And once you start noticing it, you see it everywhere, including inside yourself and places you don't want to find it.

That's uncomfortable.

But there's something particularly meaningful to me to do this through a podcast. Because I'm not hiding the thing I'm so self-conscious about. You're hearing it. You're hearing my voice, not the voice I think I'm supposed to have. Not some imaginary version of my voice that I've decided would be more acceptable. Mine. I'm using it to ask questions. I'm using it to challenge ableism. I'm using it to tell stories. I'm using it to have conversations that matter to me.

Maybe this isn't about waiting till I'm no longer uncomfortable. Maybe it's allowing myself to be heard while I'm uncomfortable. I'm going to get things wrong. I'm going to change my mind. I'm going to learn from guests. And there may be episodes I listen back to and think, what was I thinking? And that's okay. This isn't a podcast about perfection. It's about discovery. It's about asking honest questions. And it's about challenging the ableism around me while still being willing to examine the ableism I've absorbed myself.

And that's what speaking uncomfortably means to me. Internalized ableism isn't something I expect to identify today and magically eliminate by tomorrow. This is a process. I'm learning, I'm questioning, and hopefully I'm unlearning.

I've spent years making excuses for my voice without really allowing myself to realize that the shame was internalized ableism. And I'm still working through that. I'm still learning what it means to hear myself without immediately judging myself. I'm still learning what it means to simply let my voice be my voice. And that's the journey I want to explore on Uncomfortably Speaking.

But before we go much further on that journey, I want to explain how I view disability. Because understanding that will help you understand where I'm coming from throughout this podcast. I believe disability is part of the fabric of human life. It's natural, it's everywhere. And it doesn't mean, "doesn't work" or "broken".

Sometimes we treat the word disability like it's a four-letter word. Something we're not supposed to say. Something impolite or unfortunate. Something that needs to be whispered. She has, you know, a disability. No. I don't know. Say the word. Disability. It's not a bad word and it's not an insult.

Calling me disabled doesn't diminish my humanity. I use identity-first language. I say, "I'm disabled", rather than person-first language, where you might hear someone say, "I'm a person with a disability." I was already a person before you added the word disabled. You don't need to verbally remind yourself that I'm a person. For me, disability is a very important part of my lived experience.

But that doesn't mean every disabled person uses the same language. We don't. And we don't have a monthly meeting where we take a vote on terminology. That sounds exhausting! People have different preferences. Language changes. Communities

develop their own language. So, instead of being so afraid of saying the wrong thing that you don't say anything at all. Listen. Pay attention to how people describe themselves. And when you're talking to a particular person, respect that language. And if you don't know, ask.

Some people avoid saying the word disability because they think they're being respectful. They'll say things like, "differently abled," "special needs," or "handi-capable."

And I can understand the intention, but I think we need to ask why the word disabled makes us so uncomfortable that we feel the need to replace it. If we need to soften the word disability by coming up with other descriptive words, we can unintentionally reinforce the very stereotype that we're trying to avoid. That disability itself is bad.

And I think fear is underneath a lot of our discomfort with the word disability. Disability reminds people of something our culture tries desperately to avoid. Bodies change. We age, we get sick, we get injured. Things happen that we cannot control.

Some of us are born disabled. Some of us become disabled as we develop. Some of us can acquire a disability through illness or injury. It can be temporary or permanent. And for many people, disability comes with aging. Disability isn't an exception to the human experience. It's part of it.

Disability isn't some tiny group of people living somewhere outside of the ordinary human experience. Disability is ordinary human experience. Anyone can become disabled at any time. And I don't say that to scare you. Actually I think understanding it can do quite the opposite. Because maybe disability wouldn't seem so frightening if people stopped treating it as a catastrophe. Maybe instead of spending so much time and energy fearing disability, we could spend that energy creating a world where becoming disabled doesn't mean losing access to opportunity, community, dignity, or belonging. Because if disability is part of human life, accessibility isn't for, "those people." We're creating a society that recognizes human beings for what they actually are; unique, changing, interdependent, and worthy of belonging.

And maybe that's where all of this comes together. The way society talks about disability affects the way we think about disability. And the way we think about disability affects the way we treat disabled people. And when you're a disabled person, those same messages can eventually affect the way you think about yourself. And that's internalized ableism. And for me, recognizing it means questioning some of the things I believed about myself for a very long time. About independence, about disability, about my body, about my voice, about myself. I don't always expect to be comfortable, but that's kind of the point.

Sometimes understanding ourselves starts with being willing to speak uncomfortably.

In the next episode, I will begin having conversations with guests. And my first guest will be my older sister Raquel. So, tune in to hear us talk about the relationship between sisters and acquired disability.

Please visit Uncomfortablyspeaking.com for show notes and transcript from today's episode.

This is Uncomfortably Speaking.

Thank you for joining me and I'll see you in the next episode.