



ALDAcon 2007—Rochester, New York

**COPING WITH HEARING LOSS, STEP BY STEP
PRESENTER: DR. SANJAY GULATI.**

SANJAY GULATI: Good morning. Thank you for showing up bright and early on a Saturday morning. They changed the title of the talk to the title I suggested, Coping Step by Step. When I looked at the brochure, I actually liked their title better. That is really more what I want to talk about. I also really wish for the room to be a circle where people could face each other and talk with each other a little bit more because my goal today is definitely not to present. What I find is after I present, people always have a lot to say and questions, and today is a workshop. So what I really wanted to do is start a discussion. It is a little bit hard to see each other, and discuss -- maybe we could, as we go along here, decide if it might actually be best to move in order to better see each other.

Yesterday at his lunchtime speech, I. King Jordan said: "First you are losing your hearing. You don't become deaf. Becoming deaf is a big, different thing." What I want to talk about today is the nitty-gritty of that big, different thing. And I think that I share the experience with many of you of trying to figure that out. It is not a simple, linear process. It is a complicated process that happens at many levels and in many parts of our life. In my talk last year, I divided it into the personal level of getting used to the new you, yourself, the family and into the friends level; how to deal with the people who are close to you who are having to deal with the new you. There is also the societal level of dealing with strangers and advocacy, dealing with society's issues and prejudices concerning people who are different.

My basic view is that we make a journey from feeling weird and strange, and shocked and upset, and frustrated and angry, to where it is -- if we are lucky -- feeling happy. At least as happy, maybe, as we felt before and in some cases happier.

How we make that journey is a mysterious and wonderful process. As a psychiatrist, I try to help people deal with it. And as a deaf person myself, I try to deal with it myself. I really just want to open things up for people to comment on their feelings, on the ideas, on what has helped you, on what obstacles you face. Maybe I can start the ball rolling with a couple of stories about myself.

Last night, I am sorry I missed the dinner because as a good, cultural Indian, I felt myself obligated to visit my aunt and uncle who live in Rochester and whom I haven't seen for a couple of years. The last time I saw them with hearing aids in, I was doing okay. This time I knew it was going to be harder. In most of my life, I feel very comfortable and fine just being a deaf person. But confronted with my family, things felt a little bit different.

I found myself so awkward and uncomfortable. Indians in general don't have a great view of disability, or

being different, or standing out. There is a general cultural belief that if a child is afflicted in some way, this is punishment for the parents. In addition, the Indians who immigrated to this country were from the professional classes that were allowed in by Congress's laws in the seventies and eighties. This group of Indians who are here now are a very striving, ambitious, set. My relatives are engineers and doctors, and their standards for how everything ought to look can be very high.

So I felt all this anxiety, and I still, now, feel a little rattled after spending the evening and part of the morning trying to communicate with these people who were really looking at me with shock and pity and confusion, not knowing how to deal with me, not knowing how to communicate. Being deaf in their presence, I found myself losing my usual feeling of confidence and ease that I usually have. I am sure that example rings a bell for some people.

A second example is from when I rode my bike to an ALDA-Boston meeting. On my way, I decided to stop at a bicycle store. There was a crowd of people in front of the bicycle store, so I had to kind of push my way through the crowd to get to the front door. When I got to the door and pulled on it, it didn't open. It turns out that this was Sunday morning at five to ten. The store was going to open at 10:00. Probably while I was elbowing my way through the crowd, people were saying to me, "Hey, buddy, the store is not going to open for five more minutes," but I didn't hear a one of them. So then I had to turn around and face the crowd and work my way back out through them with my head held high. So I did.

I am curious what others of you would do in that situation. I did that one better than I did last night with my aunt and uncle. So just to start with those two examples and see where people want to take it, please feel free to comment.

AUDIENCE MEMBER: I would like to start with something different. It is a big question I have had for a long time now about my own identity. I have been asking and looking outside myself for the answer. And right now, I am thinking the answer is not who I am, but who I am with.

SANJAY GULATI: Could you give an example? Who you are with in one setting or another setting?

AUDIENCE MEMBER: I think: am I deaf? Am I hard of hearing? You see, I work in the hearing world. I'm a supervisor. I work with Hispanics. I work with Vietnamese. I work with others. I must communicate a lot. I have a lot of responsibility. I identify myself as deaf, but my sign is atrocious.

But I go to sign language class. I socialize with deaf people. I have a lot of hard of hearing, late-deafened and deaf friends. But there is a part of me that is hearing. There is a part of me that is deaf. There is a part of me that is hard of hearing. There is a part of me that is late-deafened. And I am asking myself, you know, which part am I? I am just beginning to understand it is not one identity. Under them all, I have one, but that cloak, that part of myself with each of my other group of friends, is the question. I need to hear other people talk about that.

SANJAY GULATI: I think that is a fabulous observation, and it is definitely something I have noticed myself, a sense that your identity shifts when you are in different settings. And in your case, probably you are taking into account many social cues and cultural cues, linguistic cues.

How easily can you explain your deafness to different audiences? How well do they understand it already? Like my difficulty last night, I know all my aunts and uncles were thinking, “The poor guy. He has obviously lost more hearing since we saw him last.” I didn't know how to get around that because I knew their beliefs and feelings would be so strong that it would be hard for them to see me as a comfortable person where I am now. They would feel so challenged by that given where they come from.

I was thinking about a similar question recently in regard to being a psychiatrist, where I spend an hour each day with a different person. The range of people that I work with goes from everyone to everyone. I work with mentally retarded people. I work with professionals. I work with children and families, old people, young people. And I do therapies. So I find myself being, in some ways, many different people over the course of the day. At the end of the day once or twice I have asked myself, wait a second. Was I being authentic? Was I being real in every one of these encounters? I'd get a little bit worried about it. I think maybe I am not being real if I am not more the same person with every different person that I meet.

I was at a party in Cambridge, and had the opportunity to talk to an actor about this, John Malkovich. He was there, and I asked him this question. He said, “Sanjay, you are all of them.” He said, “All of us are acting all the time.” Each different thing that we find in ourselves is a true part of ourselves, and he thought it was an oversimplification to see ourselves as being just one thing. He thought that part of the reason he was an actor was to explore all the different things that he is.

So I think it is fair to say that you are many different people in different settings, but that doesn't mean you are scattered or fragmented. What this means is that this is how complicated the human person is, and it shows how rich we are in our ability to try to fit and match ourselves to different situations.

One other last thought about that. It reminds me also of the way very skilled culturally Deaf people are much more variable and flexible in their ability to communicate than most hearing people. With other Deaf people, they will be signing fluently and using a whole range of cultural and dramatic mannerisms and stories and connectedness. When they meet a hearing person, they find all of their parts of themselves that allow them to do as well as possible in working with someone who may be offended by them or may be totally confused or overwhelmed or may have no communication flexibility or skills at all. That Deaf person is expressing a whole range of communicative capacities with a range of cultural and social awareness that is very rich. I think it is much richer than the average hearing person hanging out in their own culture, using their everyday language. As a late-deafened person, you are entering that sort of prismatic field of being many different things. Does that make sense?

AUDIENCE MEMBER: Yes. I am a hearing person who now is deaf. I work in a hearing world. Psychologically, I still have all those feelings I had when I was a hearing person. I try to change myself in different settings. I prefer to just say I have a hearing loss and go on because “hearing loss” covers whatever I am. I really don't think any of us who are late-deafened forget the time when we had hearing. That is part of us, too.

SANJAY GULATI: I think that is really fine. I am really glad that you said that because I do have that little objection when I. King Jordan says, look in the mirror and tell yourself you are deaf. Of course, he is talking about denial, of people needing to own what they are. I think you offer an alternate way of owning what you are, which is to say I am a hearing person who has lost my hearing, and I experience myself as a hearing person with that loss. If you feel whole and happy and comfortable in that position, I think that is great. You

don't have to go any further than that. You don't need to change your identity or your feelings or learn other languages or anything else as long as you are okay.

Some people might continue to suffer at that level. They might be focused on the frustrations or the pain, the discomfort of being in that position, but it sounds like you are not experiencing the discomfort. You are able to just name it and be with it, and so that is terrific, and I am really glad you said that. I think this should be an asterisk on I. King Jordan's statement.

AUDIENCE MEMBER: I think that there is a difference also, depending on the hearing environment you are in. I am a newcomer to this organization. I have been progressively losing my hearing. This is the first time this year that I have actually used the word "deaf" to apply to myself. But, there are situations in a quiet environment with good lighting and one other person when I appear to be completely hearing. And there are other situations, like in an automobile, when I can't hear anything at all. That is very confusing to the people around me who say, well, you heard me perfectly fine this morning and now we are in the car and you can't hear me at all. What's wrong? My audiologist gave me an answer for that. She said, "There are situations in which you are functionally deaf, like at the mall, or in a crowded restaurant, or in a car, and it is okay to call yourself deaf in those situations." She almost gave me permission to call myself deaf. It felt better because I am deaf sometimes, even if I am not deaf all the time, and it is easier to use that word "functionally deaf" with my friends and relatives who get confused because sometimes I seem to hear and sometimes I seem not to hear.

SANJAY GULATI: That is wonderful.

AUDIENCE MEMBER: A few days ago, there was a session on cultural differences, and we talked a lot about this. I'm reminded that when my children were very little, they would bring home from school sayings that I didn't like. They repeated prejudicial things. I told them that sayings those things is somebody else's tribal custom. That is not our tribal custom. I said, "We are a different tribe. We don't behave that way towards people." I made my children distinguish between how some people behave and how I wanted our family behave towards the rest of the world. Now I find I have changed tribes myself. I became deaf about seven years ago. From this workshop a few days ago on cultural communication, I learned about this cultural shift, and I actually moved over into a different culture. The way I like to talk about the change from hearing to deaf culture is that I became part of the visual culture. I have been hearing, hard of hearing, late-deafened, deaf. And now I am hearing-deaf, because I have a CI, implant, and call that hearing-deaf, but I am deaf. I am a deaf person.

I have no problem with my painter friends because they are all visual and a lot of more linear people don't understand visual people, but I think that is a big cultural acceptance and change that we can talk about more. Not the functional differences between getting communication (pointing to ear) physically through our ears, but the consciousness of how we process the information. We process it more and more visually as we lose more hearing, as I become deafer. I just think that is an important item that came up at this other workshop on cultural differences. There is visual culture that is part of all of us at various levels of hearing loss.

SANJAY GULATI: I grew up with classical music, playing the piano and listening to it. And I had this great hope as I lost my hearing that I would transfer my interest from music, which I could obviously no longer hear, to the arts. So I tried. I went to art museums and read art books. It didn't work. My brain is stuck on classical music. So a couple of years ago, I got the score to one of my favorite symphonies. And I

asked at Tanglewood, could I sit in the front? I went to the concert and sat in the front with the score and lip-read the instruments. This was music that I knew by heart. I knew every single note of it. I'd heard it for years and years and years. All I was getting through my ears was noise. But somehow between looking at the music and looking at the instruments, I heard that symphony. So it was wonderful.

So I am happy that you have been able to make a visual shift. I have not been as successful with that. I often wish that in my signing I could use classifiers and visual descriptions better than I do. I am so envious of deaf people who are more linguistically skilled people who are really able to do that well.

I think that there is a place where all of us fit ourselves in according to what works for us. I guess one way or another my brain is going to keep figuring out how to try to enjoy music and sound. I don't know if anyone else shares this experience, but another weird way in which I seem to be stuck in "hearingness" is that each time I meet someone or even when someone is just talking, I hallucinate a voice for them.

I had a very funny experience a few days ago meeting someone who was a little bit ambiguous. I wasn't sure if it was a man or woman. And so originally I hallucinated a man's voice. Then a few minutes after talking to her, and realizing it was a woman, my brain shifted and created a woman's voice for her.

Sometimes when I drive, I create road noises that I don't hear. Sometimes I think, wait a second, maybe it isn't that loud, and I turn down the voice in my head. Maybe I am strange that way but do other people have similar experiences? It seems to be part of a way in which my brain is holding on to many, many years of hearing experience.

AUDIENCE MEMBER: You remember running water and you remember to turn it off, even though you haven't been looking at it or actually hearing it, but I imagine hearing it. And I go turn it off.

SANJAY GULATI: No, it doesn't work that well for me. I leave the water on all the time! (Laughter.)

AUDIENCE MEMBER: You mentioned getting the score at Tanglewood. I get the music from the choir director at my church and follow that when the choir sings. It helps a lot.

AUDIENCE MEMBER: As far as hearing voices that are not there, I did that for a long time when I was dating my husband. I couldn't really hear his voice, and I always imagined what it would be. And then I got turned on with my CI and, of course, heard the little Mickey Mouse voice. He was excited about my hearing his voice for the first time and says, "How do I sound?" Because he was the first person who spoke to me when I got my CI turned on, I said, "You sound like Mickey Mouse." He was so insulted! (Laughter.)

But also a strange experience happened for me that I always think about was the first time that I got up at ALDAcon. I spoke to introduce someone at one of the gatherings, at a luncheon or something like that, and it was the first time since I had become completely deaf that I stood up in front of a microphone. That was the weirdest experience for me, because as a hearing person when you stand up in front of a microphone, you expect your voice to be amplified. For me nothing came out. I could not hear anything of my own voice. It was such a strange sensation that I actually laughed in front of everybody in the room and I said, "I can't hear

myself.” (Laughter.)

The whole room broke out in laughter. That was my honest reaction to not hearing my voice through a microphone for the first time after becoming completely deaf. To talk in front of an entire room of people was a neat experience because everybody in the room -- it happened to be at ALDAcon -- had experienced that at one time or another. It was a really nice icebreaker.

SANJAY GULATI: I definitely experience that when my hearing varies. I hear nothing externally, but I hear my own voice a bit, but when I hear less of my own voice, I start to get so uncomfortable speaking. There have been a few times I have just signed and let my interpreter speak for me because my voice sounded so weird and unreliable. In a particular setting I want to make sure I am understood properly and my external voice is right, and I am not too loud or soft or monotonous. Sometimes I stop voicing for a few days in that situation. I don't find it that easy to voice when I can't hear anything of my own voice.

AUDIENCE MEMBER: I would like to go back to your earlier comment about authenticity because that is something that I am now obsessing about. I think for myself, I have had this hearing loss evolution. I lost my hearing when I was six years old. I had the process of learning as a child and then losing more hearing as an adult. Even though it was not a whole lot of hearing, it was significant to me. I find that even now, the process continues. For example, I realize that a lot of the way that I react to things comes from the people I am with, but also comes from the way and how much control of a situation I have.

Often when I am traveling or with another person, if it is a person who hears better than I do, then they will, for example, hear someone making a comment to me and answer it for me. My husband, Fred, is very good dealing with the situation. He will just pass the comment or information on to me. That way I have a chance to react the way I want to. If I am with someone who has an attitude about deafness that is kind of negative or patronizing, they will say, “Oh, she is deaf.” And the other person will say, “Oh, okay” and just walk off. In those cases, I have no opportunity to handle the situation or take any control of it. That is difficult.

As I try to find my way, how I want to handle that, I ask myself, do I want to tell this person, “Next time, could you let me do it?” Or, “Could you maybe say this instead of that?” It is complicated because you are up against their emotions, their beliefs and their cultural views. All of those things flow together. So with authenticity, a lot of times when I respond to a situation, it is also because, even though I want to say something, I know that the person is not going to understand it, so I say something else. It doesn't feel right in my gut exactly. I don't want to be this person in this situation I feel I have to be, but I don't want to be. It is a continuing process.

SANJAY GULATI: I think you just helped me figure out why last night and this morning was hard for me with my aunts and uncles. In an Indian context, a younger person is really not supposed to have very much control over the social flow. It is really bucking the culture for me to say, “Wait, let me change everything.” I am just thinking how much better I do with my wife's family where I can say, “I am going to go to that party but don't expect me to be out in the social environment. I am going to grab one person at a time and go in the back room or outside or on the steps and focus my eyes on that person's lips and have a good conversation with that person.” Because her culture is not Indian, it is okay for me to have that much control, you know, in parallel situations, so I think you are right. Control is a big part of it.

In terms of authenticity, I like the idea that we are moving forward with people's comments that you can be all of those things and you can also be uncomfortable sometimes. Maybe it is a strange parallel, but I think it's like when I want to go kayaking in winter and the water is rough and I have looked at the weather forecast. I have some difficult decisions to make. Do I go around the island or do I stay safe and stay in the harbor?

There is anxiety that we create sometimes when we make choices and commit ourselves to different paths. I think that would be parallel to the social situation of thinking I really wish I could do this, but I don't think it is going to work. The waves are too big to go that way or the current might be too strong. Likewise, it is going to be too hard to convince this person what it means that I am deaf, and that is okay and we can still have this conversation. It is going to be better that I can pretend a little bit that I am hearing them until they are okay enough for me to be able to say something.

Some people say the only way to be authentic is to announce at beginning of every conversation, "I am deaf." I don't agree with that. I think we are more complicated creatures than that, and we are reading more signals from each other. We are allowed to make a judgment, but making that judgment will sometimes be an anxiety-provoking process. I don't think that the fact that you feel anxiety makes you less authentic. I think that is authentic anxiety. Does that make sense? It is an anxiety that you have because you are weighing different factors in a real situation. You are empathic to where other people are and so, of course, you should be nervous just like me on the water. Okay, the tide will be pushing me back in but it will be okay for me to try those waves today. It is that very complicated multi-factorial judgment that you are making.

AUDIENCE MEMBER: I just want to respond to all of this because it is something that I deal with every day at work. I am a teacher in a completely hearing school. I have an aide in my classroom, but she doesn't sign. We get by with a greeting, and she assists me when a student says something to me that I can't understand. That happens a lot. My CI is successful but not perfect, and oftentimes a child's voice is difficult to understand, but in other situations things happen right. We daily have a team meeting of all the teachers in the different subject areas. My aide takes notes for me, which she shares with me later. But, there are many instances where something will be directed at me, a question of some sort, and I will totally miss even my name being called. Then somebody will just jump in and take over for me. I always feel that twinge of anxiety that hits me right in the stomach. I don't know really what to do about it except just laugh it off and move on with it. I just accept it about myself and let it roll off my shoulders. I really don't allow myself to get upset in that way anymore. Something that has helped me is that in certain situations, I do feel confident enough to say something authentic and take that control. I find that in little steps I am improving.

Within my family, the story that I always remember took place at a holiday in my house. We had this big dinner with my whole family sitting around and somebody told a joke. Everybody is laughing and I am sitting there. This is before my cochlear implant. I was completely deaf. Everybody is having a great time and my mother jumps in and says, "Oh, poor Lori." I said, "What?" I got very angry. I told my mother off at that moment because I was just so surprised that she would say, "poor Lori."

I was not feeling sorry for myself. That was not my reaction. My authentic reaction was to be a person who does not let that sort of thing bother her. I just let it roll off my shoulders. I will find out later or I will ask the person next to me. I will do something that is helpful to me, but she took over and said, "poor Lori." Then, of course, the whole room full of laughter stopped completely and everybody stared at me thinking how sad I am, and I wasn't sad at all. I really felt I needed to take control in that situation.

There are times like that where you feel comfortable and you can take that control, and my advice would be to take advantage of those times as much as possible because those are the ones that build strength for the other times where you may not feel as comfortable in a work situation or something like that.

SANJAY GULATI: My image when you said your mom said, “poor Lori,” was of your mom waving a red flag in front of a bull. (Laughter.)

If we think about the levels of personal acceptance and then family, friends, and then society, one thing you are getting at is this societal level. I think that you are outnumbered in situations like where you are at your school, and it is very hard to advocate or to figure out what is going to work for you. We deal with paternalism, really, everywhere. It is, I think, part of the thing that people do when they meet someone disabled. I think what happens is that when a so-called normal person meets what I call a different person, the normal person needs to go through an internal process of imagination and a little bit of emotional work. If I meet someone who is missing a leg, for example, I need to be comfortable with the thought, well, how would I deal in my life if I were missing a leg?

We have a natural empathic thing where we put ourselves into the shoes of every person we meet. If I haven't done a little bit of internal imagining and work to the point where I am okay with losing my leg, that I know I could be a happy person and fine if I lost my leg, and I know how I would deal with a bicycle and what I would do about running and how I would get from place to place, if I spent just a few minutes thinking through that in my life, then I can meet someone without a leg and act like a normal person.

If I haven't done that, then my reaction to meeting someone who is missing a leg is going to be a reaction of fear and confusion. This person is actually going to represent a potential threat to my well-being. I think that that is how many people respond to people with disabilities or differences if they haven't thought through it.

Related to that, is a sense among the so-called normal people that because they might have that leg and the other person doesn't, that that somehow makes the person with both legs better. Sometimes they feel guilty that they have the leg and the other person doesn't, and maybe that feeling feeds into the kind of paternalism that they need to take over for the other person. Disabled people of different types report this in every situation and setting: a sense of being looked at as less than, or sometimes younger. Many people in wheelchairs will say they get talked to as if they are a child rather than an adult. People will try to do things for a blind person that a blind person doesn't want done for them without asking. Robin says she gets patted on the head, something you would never do to someone who was not a wheelchair.

I think that on the one hand that reaction is terrible and it stigmatizes and devalues us, and it makes us feel bad and it challenges us to stand up for ourselves. On the other hand, I try to have a little bit of empathy for the misguided attitude.

Do you remember when I spoke last year I talked about my friend, Valerie? She was a signing therapist who had a terrible accident when she got out of bed in the morning. Even though she was a skilled athlete and dancer, her feet got tangled in the sheets, and she fell down in a really awkward way, broke her neck and become quadriplegic. Her family wanted to do everything for her and wanted everything done for her, and she describes how she was incredibly irritated by that, but on the other hand, because it was her family, she finally

for the first time understood their kind of paternalism had its origin in love and caring. So when a person is treating you that way, when they are taking over, it is maybe not the most effective thing they could do for you but Valerie would say that they are coming from a good place, mostly. They are caring for you. They are trying to reach out and do something they think that you need done. They are making all sorts of mistakes based on not knowing where you really are.

I think that the type of mistakes people make when they think about disabilities is related to the difference between an acute and a chronic condition. For example, if you meet someone who is quadriplegic, your initial response might be, how would I feel tomorrow and the day after if I became quadriplegic tonight? It is much harder for the so-called normal person to think how would I feel a year from now or seven years from now if I became quadriplegic tonight? The chances are that seven years from now you would actually feel pretty good even if tomorrow you might feel horrible. The normal person needs to be taking all of that into account when she meets the person who is different. That is a lot. We are not taught when we grow up how to think about people who have differences.

One other excusing factor for the so-called normal people is the history of what we have done with disability in this culture. It is only with the mainstreaming and inclusion movements that we have allowed people with disabilities into the regular schools. Prior to that they went to hospital schools or special institutions. They were out of sight and out of mind to the rest of the population. In my daughter's school, there is a girl who has seizures, and another girl who has cerebral palsy and kind of walks on her tiptoes and often falls down. Those two kids, being in her school have been such an education for all the other children and for the teachers who are in the school.

Everyone has had to go through this thinking process, what would it be like if it were me? How would I deal with that? What is it like for this person? How do I work with this person as a person, as opposed to seeing only their difference or disability and being so shocked by it that I can hardly move? It has been fascinating to me to watch the elementary school kids learn how to do this, but in many cases it has taken them years to know how to do it.

I say all that in partial excuse of the paternalistic, helping people who come at us and do things for us and pity us and make us feel bad in that way. I don't think they are out to make us feel bad, even if that is what ends up happening.

AUDIENCE MEMBER: Earlier a lady touched on asking someone is it okay to call myself deaf? Is it okay to be deaf? That brings up a topic about who I am. I know I still find myself looking for external validation as to who I am, and am I okay as who I am. Here at ALDA it is wonderful because, yes, it is okay you can't hear. I get home and I am going to be with all hearing people. It is not going to be okay that I can't hear. Any pointers on how to turn for the validation back to myself and make it internal instead of meeting it externally only?

SANJAY GULATI: I am very curious about what other people think about this. I think that the focus on your experience and the need to honor yourself that comes with a hearing loss or any different sort of disability is maybe the biggest and best gift that you get from that experience. So many people live their entire lives basically responding to the reactions of others, going with the flow, being who they are supposed to be, not challenging, not changing, not listening, maybe, to everything that is going on inside. But when we have something like a hearing loss, we are forced to.

I come from a conformity culture of Indian and medical school, and nothing could be more rigid than the medical system to one's needs to stand up. I can't do that rotation. Can I do this one instead? Or, I can't do that class or join that. I was in medical school before the ADA, and most of the time the answer was no, what are you talking about? For one person? No way. What are you doing in medical school? To have to deal with that was hard for me, but it focused me on who I was inside and allowed me to be whatever I felt with less concern about other people's reactions.

AUDIENCE MEMBER: Yeah, thank you. Every day I go through a process of self-validation. Every morning I go to work with an immense list, people to call back to apologize for some action I have done, a call I did not return, a piece of paper I didn't send to the right place. I ask myself every day in every action certain questions. The purpose, the goal for me is at the end of the day, when I am done, I want to feel clean. I want to feel that I have done the right thing. It may not be the comfortable thing, but I have done the right thing. I ask myself, have I been in denial about something? Is there some unacceptable truth or emotion that I am not willing to face? Is there something that I did not admit into my consciousness? I ask myself, is there any resistance on my part? Do I have knowledge but failed to act on it? Have I done this out of fear? What kind of fear?

Most of the time I succeed. Sometimes I don't. One important thing I have to remember is not to always go through everything because I am always going to think something bad. I am always going to think something paranoid. I am always going to think it is their fault. There is always going to be some excuse for my action. There is going to be some something I can hide behind. I have to try and move myself beyond that. That is my daily journey.

SANJAY GULATI: Okay. I really like that. That is an authentic experience of yourself.

I think that people might worry, if they are going to challenge social norms that they might go too far, and there certainly is a risk. I think within the disability community, there is a known risk of over involvement in your issue or your thing. We all have to strike that balance. I think that that is one of the fears that people have who are very socially attuned. They ask, why should I be thinking so much about myself all the time? I really want to be focusing on these other people around me. It is a balancing act. There is that wonderful Jewish expression: "If you are only for yourself, what are you? But if you are not for yourself, who will be?" You somehow need to be for yourself, and at the same time for others. The experience of something like a hearing loss gives us a chance to get that balance right, and we are always adjusting it.

Among my colleagues at Cambridge Hospital, Children's Hospital, we send these e-mails back and forth. We put in the headline something like Department of Neurotic Fears, and then underneath that we will write, when I said that thing, was I really being too pushy, or when you had that expression on your face, what were you feeling? And so we go back and forth with each other trying to adjust and make sure we haven't overstepped or haven't honored ourselves, and I guess maybe that would be the best phrase to capture what I am hearing from people. We need to honor our own internal experiences.

I think if they are exploratory, like what you are describing, or anxious, that is okay. I don't think we need to assume that acceptance means we feel good all the time. It is part of normal life to have anxiety and fears. To throw something like a hearing loss into the question, and then hide our fears a little bit, doesn't mean we aren't well adjusted to have some fears about our hearing loss. What is important is that we are honoring ourselves in our interactions with the world.

AUDIENCE MEMBER: I have a problem. I grew up at the church. I always have somebody with me. Or I'm with my family and they overprotective. When I sit in the group and one of my kids is with me, I am invisible. People talk to her. I say, "I'm here. Talk to me." They continue talking to the other person. I get so upset about that. I have been trying to tell them, I can hear some of the talk. But somehow they are afraid of me or they just try to ignore me. The same thing happens whenever I go on missions to other countries. They are kind of afraid to take me, but I am very good with the children. I have made mistakes because I didn't hear what they said. I did something the way it's not supposed to be, and they said, "Okay, you are not going to help with that child today." It is hard to communicate with the people. They know that I am deaf. If they talk to me one-to-one, I am okay.

How do I handle this instead of being angry? I just want to punch that person in the nose. It is very difficult. I am also very protected by my husband. I wish he would let me do what I want to do. He won't. He says, "Oh, no, she is deaf. Just talk to me and I will let her know." And I don't want to go anyplace with him anymore. I have a sister here who is the one that communicates with me. So how do I handle this, Doctor, to keep me from being so angry?

SANJAY GULATI: I think that the situation of being outnumbered in a social setting where there are strong expectations for behavior, like church or the school or family, is the single hardest situation to have. I wonder if it is possible to take people aside and say, this is new for you. This is different. But let me tell you how this could work, and how it would work much better for me. Let me tell you what it feels like to be me when I am in that situation and you talk to my husband rather than me. I don't know how other people go about this, but I personally feel, after you have made a good faith effort in certain settings to get a change, and if you are still feeling authentically furious, that maybe you don't want to participate in that thing anymore.

AUDIENCE MEMBER: I am very curious about other people's opinions, but I feel okay about opting out of things where I feel like I can't make a change.

I love classical music. I was 12 years old and belonged to a street gang, but none of my running mates knew I liked classical music. And I would play classical. I would see people having a conversation with sign language, and I would feel deep pity for them. And I remember when I was first told by an audiologist I had a progressive hearing loss, was probably going to become deaf, I thought that was the worst thing that could happen to me. I imagined myself sitting in my room at home alone with no friends for the rest of my life and never having conversations with anyone, losing music, and not having value in my life.

I kept that thought with me all through that process of losing my hearing until I finally became comfortable with myself being deaf. And now when I am in a situation, and I am trying to communicate with someone, and another person is standing behind me or with me and one of my hearing friends says, "Oh, he is deaf, he can't hear you," they take control. I might be in an airport. I am trying to find out where my gate is and they are telling my ticket agent, "Don't bother, I will take him to the gate," that really bothers me. I am a very independent person. I don't need help. I know when to ask for help, but I don't need to be helped.

Sometimes the way I deal with that is I look at the relationship I have with this person. Which is more important to me, my comfort level or their comfort level? If it is my comfort and my respect that is more

important than my relationship with that person, I will get in their face and say, “You stop that! I am not incapable. I just can't hear.” And I will turn to the other person and say, “You talk to me. You don't talk to them.” I don't worry about insulting people anymore unless the relationship is so important to me that their feelings are more important than mine.

SANJAY GULATI: That is a nice way to look at it.

AUDIENCE: How did you communicate with your relatives? I am curious.

SANJAY GULATI: You know, I am a good lip-reader. I lost my hearing over 20, 25 years so I have had lots and lots of time to practice. I am sure all the lip-readers here know that to the extent you can predict the context, you can do very well. So if you are getting a ticket from a counter and you pretty much know what the person is going to say, or you are buying your groceries, you know if they are going to ask you paper or plastic, you are going to lip-read paper or plastic without any difficulty whatsoever.

The fortunate part is I could pretty much predict that my cousin would be talking about medical school and my aunt would be talking about the Indian food she cooked for us, but my uncle, I could not predict for him. I don't know him well enough. This is not a close branch of the family, and I could not hear one word he said. And after a lot of difficulty, I finally had to say to him, I'm not able to hear you. And he was confused by it.

But then he woke up early this morning to help me get out of the house, and he brought me the paper. Today's newspaper has a lovely article about NTID and a program there. He gave that to me, and so that was his way of saying that he was accepting or thinking or starting to process what it meant who I was and the difficulty that we had the night before. I felt a little bit better than I did last night. And so I gave him a little sign language information. He took it and showed his wife, and so I think it is going to be okay. They are perfectly nice people. It is just a question of challenging the cultural assumptions and getting over the awkwardness.

AUDIENCE MEMBER: I wanted to pick up what Sanjay said about dropping out of something. I became deaf when I was 17 in the middle of my studies. My attitude to deafness, indeed my attitude to anything which proved a barrier, was simply to feel, well, let's see what we can do without this getting in the way. If I hurt my knee playing sports, I would find it difficult to get upstairs, so, okay. That's something we have to deal with.

You find there are things you can do and things you can't do.
That is it. There is no point in worrying about it.

Well, before I got my cochlear implant, I began to realize I was sitting there in church, not really knowing what was going on at all. I couldn't hear the prayers. I couldn't hear the singing. I couldn't hear the sermon. So I just thought, oh, I don't want to go for this and I stopped going.

Well, this was important because I was at the time a lay preacher in the church, and although I carried on preaching my own services, I wasn't going to anybody else's services. I think the ministries in charge were looking rather doubtfully at this. Anyway, when I got my cochlear implant, I realized I was going to be able to follow things again. I can read music so I could follow the hymns if only I could hear where people were. I am gradually finding it possible to pick up parts of the sermon through speech reading and the implant. The point I am making is just like when I hurt my knee, I find there are things I can do and things I can't do. I just accept it

at that. When something new turns up, which might be able to help me, I grab it with both hands, as I did with the cochlear implant. For the rest, I just don't let it worry me.

SANJAY GULATI: That goes back to the point about imagining that you would lose music and be cut off, you know, from everything for the rest of your life. When I read the many accounts of people with quadriplegia and other major disabilities and how they adapt over time, what I really arrive at is a feeling that our brains are so adaptable and life is so rich.

There is a lovely poem by Seamus Heaney, an Irish poet who writes about an elderly lady. She is confined to her chair and to her house and looks out through a window into the field. That little window, that little view of the outside is her entire world. Yet, it is rich enough to keep her busy and occupied and stimulated and happy. That is exactly what the successfully adapted people with various disabilities say. That as long as there is some little tiny space in your life where you have some control and some choice, and where there is some pleasure available to you, you can get used to it.

We haven't talked about grieving and sadness here. I think it is important that we recognize that losing our hearing is similar in its impact on us just as quadriplegia might be. Losing your ability to communicate with others and be social is just about equal to not being able to move around or move your body. So when we honor ourselves, we should honor that sadness, too, and the size of the challenge we are taking on, and we should be a little bit proud of ourselves for even being willing to look at that. It would be much easier maybe to run the other way.

Thank you so much. I think this is helpful. If anyone missed my talk last year and would like it, just give me your e-mail address and I will e-mail it to you. It's about how various people with disabilities adapt, and adapt to the process of hearing loss.

AUDIENCE MEMBER: Sanjay's talk from last year is also on last year's proceedings, the ALDA 2006 proceedings. You can go on line and read it there. It is a wonderful talk.

SANJAY GULATI: That is right. Thank you for reminding me. Thank you so much.

*Sanjay Gulati is a child psychiatrist who developed a profound hearing loss slowly over the course of college, medical school, and residencies. He works full-time in deafness, at three locations: the Deaf & Hard of Hearing Service at Cambridge Hospital, the Deaf & Hard of Hearing Program at Children's Hospital, Boston, and as consultant psychiatrist to the American School for the Deaf. He teaches at Harvard University and is co-editor of the textbook **Mental Health Care for Deaf People**. He is married and has a daughter he's nuts about.*