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So Now I'm Deaf: The Psycho-Social Side of Facing Hearing Loss

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>> DONNA: Someone sent me a question and asked, how do you know the audio is working? And hopefully you're hearing me as I am talking. Just to remind everyone that we will be starting in just a few minutes. If you have questions, you can type them in the -- in the area called chat and you can send them to the presenter or all of the attendees. Please go ahead and send those questions to us. We love

it when it is interactive. We would like to know a little bit about you before we start. We're wondering if you're a professional working with adults with a hearing loss and you could just go ahead and vote there yes or no. We also would love to know if you're an adult with a hearing loss. And please vote there as well. We want to know if you have taken a HOPE Online course and if so lastly, we're really interested in knowing if you're using the real-time captioning tonight. That is being provided by our wonderful captioner, Jeanette Christian, and she's usually with us and she's with us tonight. That is helpful to me in knowing our access is being used by our attendees so really great to have all of you with us. And this is the second in our series about adults who use cochlear implants and have a hearing loss and it is a new element of our HOPE program that we started this year. So we're really happy to have you all with us.

Someone just asked the question about getting CEU credits. That will come to you automatically, you'll get a set of questions that will come to you. That will generate your CEUs from ASHA or the American Academy of Audiology. You can also get a feedback or fill out the feedback form that is in the file share area on the left side of your screen. Just download that document to your computer and send it back to us and then we're very happy to send you a certificate of participation.

We also love those from people who don't need the certificate just to know what you thought of the course. It is very helpful to us. We'll be starting in two minutes. Go ahead and vote if you have not done so already.

[pause]

Okay, this is Donna Sorkin from Cochlear America's HOPE program and I think we're about ready to begin our program today. So we'll take those posts down. Thank you everyone for filling those out and there is the captioning link and our session today is so now I'm deaf, the psychosocial aspects of facing hearing loss and our speaker is Kris English from University of Akron.

This program today and all of our HOPE programs are really something that we do from Cochlear because of our commitment to our recipient community. Those individuals that have cochlear implants and their families and the professionals who serve them. We have a new set of online programs this year that are especially designed for parents and adult recipients and this of course is one for adult recipients and the professionals who serve them.

We're really proud to collaborate with the best people in the field to provide these programs for you. And of course Kris English is one of the best in the field on this topic. She is an audiologist and also the President-Elect of the American Academy of audiology. She's an Associate Professor at the University of Akron and she's really a world renowned expert on audiology counseling having done over 100 presentations on this topic around the world.

Kris is doing three HOPE Online seminars for us on the psychosocial hearing loss and the first one that she did was for parents and we archived that, recorded it and archived it so if it is a topic you want to pursue you can hear Kris on that topic from the archived session.

So with that I'm really delighted to turn the floor over to Kris English and I'll be back with you at the end. Type those questions to us if you have them in the chat area and we'll be sure to get back to them at the end. Thanks so much.

>> KRIS: Thank you, Donna. I appreciate the opportunity to be back to talk to your friends here involved with Cochlear. I see from the early poll that we have six persons who have identified themselves as being an adult facing hearing loss and I pretty much am designing this topic or this talk directly to those individuals.

I understand the majority are probably professionals or probably family members as well. But what I would like to do is talk directly in this -- in this medium to persons who are facing their life with a hearing loss and very much would appreciate input in return to get perspectives and objectives and questions to, of course. So don't hesitate to type in those questions and I'll address them as we go along.

And I did want to kind of back off from any claim about being world-renowned or anything. I'm not. I just know a couple of things and mainly from listening to patients. So I wanted to share two things that I am pretty sure about these days and the first one is that all I can share today is some observations that we've gleaned from research, from the patients that I've talked to over the years and certainly as I mentioned from our HOPE attendees. Knowing that, of course, none of us can understand how one another feels but we can certainly try to put ourselves in that position and to reflect and imagine what it might be like just try to absorb other people's stories.

When I've had the opportunity and pleasure of talking to adults with hearing loss that pretty much progresses into deafness which is what many persons face when they're looking at cochlear implants, they tend to use a set of adjectives that have a lot in common and I've often thought of them being organized as a sense of vulnerability which is something that most of us who don't have a significant hearing loss could fairly easily emphasize with not being able to predict what is happening in the environment, a sense of -- of insecurity perhaps that the usual sense of being able to monitor the environment is no longer available and then there is the social isolation which is a very familiar theme that we'll hear because it -- even among those who love us, it gets so hard to communicate. And overall general sense of anxiety because there is an inability to again as we mentioned to predict what was happening or to anticipate and then the social isolation kind of ties into it.

I've tended to think about this over time as a patient journey. That is not an original idea on my part. I've heard it everywhere I go. I just returned from a convention or a seminar rather in Denmark and we had 26 audiologists from I think 14 countries. The Western English parts of the world, we all seemed to talk about journey as a metaphor, for describing the process that patients go through. So I've observed over time that although there is a universalness of that experience there is a uniqueness in each patient in their reports as well.

So over time it is occurred to me that it is something along the lines of a rollercoaster as it were that there is ups and downs, and people have often used the metaphor of a grief cycle. That just doesn't seem to apply when we talk about hearing loss. There is some general sense of it but the grief cycle does imply that eventually someone comes out of a situation and kind of lives their life as it used to be. A little bit scared for the experience but over. And it was applied originally for the loss of the death of a loved one. Once the death was processed and the family member adjusted it usually takes 12 to 18 months but life does go on and people manage to get through it.

That is not the same thing when you're talking about a disability that does not go away. Things do not return to normal. So if you notice in this particular graph it has some familiar words that we recognize with regard to the grief cycle, including denial, anger, bargaining, depression and acceptance but in the middle is the most important component I would suggest and that would be the time frame. The temporal element of on-going, on-going, adjustment. And what people have reported to me is a sense of there's times when I'm disorganized and times that I'm not. I have good days and bad days. That is what reminded me of this graph where I saw it in the moments of the ups and the downs. Again not my original idea and there is a website to help you find it if you want to look at it further.

So along this journey, these some are topics that we'll be taking a look at this evening. First of all, asking for help. One of the hardest things that we face in our culture I would have to say and then what does it mean when we live with a hearing loss and what does -- how does it affect our concept of who we are? How do we redefine ourselves and, if so how? Throughout there is going to be a set of stressor that will be somewhat familiar to most of us and then also how do we cope with those stressors and then finally a concept of readiness. A psychological stage where we are actually ready, whatever the latest challenge has been, we have figured out a way to manage and then move forward on it. So those are our four themes this evening.

So the first one, this is actually a help-seeking process that I gleaned from another textbook on counseling and it really doesn't matter regardless of what the condition you're asking for help is but there is an extra part in it at Stage No. 4. We'll take a look at that in a minute. Here are the steps then. I don't have a problem that Stage No. 1 and some people call it denial and that would indicate that one of two things: I'm either not aware that there is something going on. Some people call it a pre-contemplative stage or I am aware that something is going on but that doesn't mean I necessarily want to talk to you about it. This would describe an adult who was starting to notice changes in their hearing and makes note of it but doesn't necessarily want to mention it to anyone.

And I've thought about that a lot and I've talked to my students a lot about what does it take for a patient to trust you? They don't know you. You're talking about some pretty personal situations and what -- how a person reacts to it. Initially I don't think I would ever expect a patient to trust me and, so, therefore I would expect to see a certain level of denial.

Denial as I mentioned doesn't necessarily mean there is no problem. Most times people do recognize that there is a problem.

I once talked to a patient who reported, saying he was now ready to move on his hearing problem and get some help and I asked him when did he first actually notice it? And he said it was about 10 years before. And his first inclination that there was a difference, a change, was the day that he closed the medicine cabinet in the bathroom and did not hear the familiar click on the magnet. He had been listening to that click for years. But that day he noticed he didn't actually hear it. He can feel the tug of the magnet. When he leaned closer of course he could hear that click. That is when he recognized something was different. It didn't impair the quality of his life, of course. But he would have said that he would have denied he had a hearing problem because it was not yet a problem many it was just a change.

So the next stage is this. Someone would be willing to articulate I do have a problem but I don't need help. And that would mean that exactly what that patient was saying, I've noticed some changes but it is not affecting the quality of my life and maybe on occasion I need someone to repeat. But it is not really bothering me.

The next stage kind of moves a person along a little bit further. I have a problem and need help. But I don't want to accept help. And this stage would actually describe my grandmother a long time ago. She was about 92 at the time. And she was getting obviously experiencing certain difficulties and my Mother happened to call and asked for an audiologist in the City that they were living in. And I asked why. And she said that my grandmother needed new hearing aids and she was going to take care of it. And I said well, how does Grandma feel about that? She said oh, no, it is going to be a big sure -- surprise. We're going to take her to lunch, my sister and my Mother, we will tell her that we have made this appointment. And you know and I know this is not going to work, right? But they went ahead and made the appointment. My grandmother went along with it for a while and then in the second appointment she just stood up with her purse and said, let's go. I'm not going to do this. I do have a problem affectively and do need help. She was not denying that the hearing had change to a pointed where there was problems but she did not want to accept help. Meaning that she had many other health problems. She remembered before that it was difficult to adjust to hearing aid use. She just wasn't ready for it. Wasn't up for it at the time.

So moving a patient along through this process, we can talk about ferns who would say I have a problem. I need help. I even want help. But I'm not ready to accept help. And that is always interesting to find out what is on your mind at this point. Oftentimes I've heard from patients that there is a lingering doubt that in fact there is real help, for instance, with hearing losses or cochlear implants or they have heard some very negative press releases as it were, PR, from neighbors who have been not satisfied with hearing aids and they're just hesitant to get that far.

One patient told me once, if I actually take this step, it really makes it real. It makes it a permanent situation and there is no getting out of it. No more wishful thinking as he put it.

Well, finally, we have the fifth stage. I have a problem. I'll acknowledge it. I do need help. I'm happy to -- I do want help and I'm actually ready to accept it. Now, when I was in grad school I was led to believe that would describe every patient who walked through the door. So you can imagine my surprise and consternation when I found out it hardly ever described a patient that walked through the door. They were either at stages 1, 2, 3 or 4. I didn't know there were stages and didn't know how to describe them. I just kept trying to fix things when people were not ready to accept the fixing so we're just trying to get the hang of that right now.

Let's go back to the notion of asking for help. This is a quote from George Shames. He wrote a lovely book on counseling and reminds us that asking for help automatically implies accepting change, and accepting change is not easy; even when it is a good change. It is a hard thing to do to move from the status quote to something that is unfamiliar, something that is a little bit perhaps a little nerve-racking and there is also in this context a need to depend upon, rely upon others. And in our culture, and I'm speaking for the United States because I'm not sure about other listeners and where they're at right now, but the United States is quite known for its self-sufficiency, its citizens are very fiercely independent and to ask for help is basically, you know, a very miserable situation and they would rather avoid it if they could.

But George says this, changing the way that we were, is of necessity a profound, awesome and often difficult and painful experience. It is tampering with our basic self-identity and now this is a concept I wanted to get back to in a moment. But letting go of who we are and the way we were can be fraught with both fears and pain, pain over the past and fears about the future. That is one perspective why it is so hard to ask for help. Another part of it I can imagine when I talk with adults who are considering the next step of care for their hearing problems is that they are really bringing back that word again of vulnerable, working with audiologists specifically that they may not necessarily know well. Working with professionals -- a profession rather that they're not particularly familiar with because as of yet audiologist yawling is not a household word. They don't necessarily know who they're engaging with and feel a certain amount of if not distrust at least maybe a little sense of discomfort.

Well, let's get to this idea of letting go of who we are. We really are talking about our self concept, how we define ourselves and that is the process that starts from birth but we'll get to that in a minute. In this particular concept we're talking about redefining our self-concept. It is more than the simple fact of saying, I'm now a person with hearing problems. That has a lot of underpinnings to it that we would want to understand better.

Just pausing a moment to read the questions and a person is wondering if this course is right for them with no audiology training many this is not really about audiology. So if that helps you at all, I would welcome you to stay. We really are talking about living with hearing loss.

So we're talking about self-concept. And interestingly, this idea was first written about more than 100 years ago if you see the date there by William James. And he was thinking about this as a burgeoning psychologist even though the field of psychologist had not really established itself yet. It was still a work in progress and didn't really have a specific name to it.

But he was thinking about the idea of self-concept along these lines, that there is probably two components to it. The first one is the obvious one. The objective data and he thought about describing it as the "me." That would be your gender and age. The first things people see when they look at you or get to know you. Your physical aspects, whether you wear glasses and you're short and tall and so on, your rules and relationships, occupations and hobbies. So, for instance, if we were to bump into each other at a professional meeting or a mutual friend introduced us, you would quickly find out from me that I'm a female of course and that I'm no longer 22 and I'm not tall and I do wear glasses. My roles and relationships come forth very quickly about being an audiologist and a teacher as well as a parent and a spouse and a neighbor and so on and then occupation and hobbies if we have more time to expand our conversation over coffee.

The other part of it though that he wanted to explore further was the eye. And the eye has to do with a looking at those objective characteristics and getting to know a person well enough to know how they would describe what they mean to that person. The subjective interpretation of what it means to be a female who is no longer 22 and is not tall and so on.

How do I feel about it? It is the impact of those characteristics, the importance and value to them. That is when you really do know a person, isn't it?

Well, let's think about that with regard to hearing loss. Let's see, we've got -- if you look at the bullets we could talk about the physical characteristics, the social characteristics and the cognitive characteristics that could be described in terms of objective data for hearing loss. The physical ones mean indicating I have a hearing loss. I can show you my audiogram. I'm a potential user of a prosthetic device or two. Maybe assistive devices and other just logistical issues.

The social characteristics or implications mean something has changed because I don't hear like I used to hear. Perhaps a personality change in terms of being a little more quickly discouraged. Maybe not as optimistic. Some people rebound quickly and some people don't. That is just how that goes. Our roles might change as well. You might be familiar, particularly -- well, anyone on this presentation might be familiar with partners who live or share their lives together and the person with the hearing loss starts to depend on the partner as -- like the so-called my hearing aid. That partner is paying attention to the cues and then making sure that the person with the hearing loss is picking up on them. That probably wasn't the relationship early on when both people experienced fairly normal hearing and so there is now a change on who is kind of like the go-to person as compared to a little more equity there.

Cognitive characteristics could change as well. Not necessarily that we no longer can't think but how we think might be different and how I problem solve. Am I a pro-active -- well, a pro-active problem solver who sees myself actively engaged in a rehab process or do I step back and think this is how life goes when you get older or when you have a disease that the one I had and I was told that hearing loss would be a likely consequence and be a passive recipient of that experience.

That is the "me" and what about the "I" and these are possibilities as we get to know a person with who is facing their hearing loss that the possibilities of how interpret the data subjectively could be some of these possibilities.

Awareness of one's impact on one's life events. I can be passive or act actively make changes. One's uniqueness to the life. My hearing loss has unique ramifications and like no others. I apologize that. Should say unlike any other, I think. I think there is a double negative problem there. There shouldn't be a -- yes, anyway, I'm sure you understand what I'm trying to say there.

And then maybe awareness of personal continuity. I have a lifespan that I can look back on and I see where my starting point is. But as I've acquired a hearing loss my continuity continues but it its course has started to change.

So switching gears a little bit to facing our situation, knowing that many people will know and understand the "me" and few people will know and understand the "I." But what we are learning in audiology is that both parts of the -- of those aspects of self-concept need to be understood. Certainly by the patient. And also a few significant others. It is not likely -- and I won't do a poll here. But when I've asked in other venues how many people know the "me" of you, people could, you know, count on several hands how many people know them well. Maybe 50 or -- know them in terms of physical characters, a dozen up to 100 depending on what you do in your life. But then how many people actually know the "I" and unless you have a really big extended family, that number tends to be pretty small. Because it will typically include family and not every family member and then a handful of friends and maybe a circle of healthcare providers as well. So there is a big, big difference and the main thing that is some people, or at least can be counted within your circle of friends and family to say that they know the "I" of us.

So along the way as we go along the patient journey, thinking about how things are handled and coping with things, what I wanted to indicate here that is we know of or we'll talk today about three kinds of stress but of course there is certainly more than that. But this is what we'll focus on today.

The stress of daily effort. Just the effort that it takes to live each day with a hearing loss. The stress of adjusting to a changing self-concept and the stress of society reactions.

Our first one, hold on just a minute. I'm taking a look at a question. I appreciate Michelle's comment. She writes, I was born deaf with a profound hearing loss. I am that person and, therefore, my self-concept has always been one of being deaf and needing help. Thank you, I appreciate hearing that. Just another look at another question. Hold on.

First of all the stress of daily life, daily effort. Audiologists tend to think first of all of understanding speech but of course anyone in our audience that lives with a daily hearing loss knows that there is far more to it than that. It has to do with all the sounds that give you cues about what is happening in your environment, picking them up or not picking them up and then getting caught by surprise by them.

There's also the effects of what could be called chronic stress. We all have fluctuating stress in our day that could depend on traffic or something went wrong at work or other things that are fairly, you know, routine. But the chronic stress is described as the state of on-going wear and tear. And there is a likelihood that people do feel a little far more fatigued by the experience because there is no respite down the road. There is not a day where at least for the -- I can anticipate next week things will lighten up. The traffic will be less. The boss is going to go on vacation and the other things that make life a little bit easier.

The chronic stress I don't think has yet to be really truly appreciated with living with a hearing loss.

But the stress of adjusting, here is another one, another stressor, adjusting to a change in self-concept that we referred to before. This is for a patient who actually acquires a hearing loss over time unlike the comment by Michelle who indicated that this was from birth on. This is a definition of who she was. If in fact someone is acquiring hearing loss over time they might have expectations of what life is going to be like and finding it is taking a different course, a different direction. That could also be another stressor added to a person's life. And then finally stress regarding society reactions.

We do still see some people that don't know quite what to do with regard when they interact with persons with hearing loss. They get uncomfortable. And they will back off because it -- they're just not familiar with it. You could call it the fear of the unknown. There are some old stereotypes out there. Although they're diminishing on a regular bases. Every study that I read indicates that the stereotypes are becoming less and less problematic. I think it is partly because more and more people are bumping into more and more people with hearing loss. It is just a part of life. Rather than something that was closeted away as it used to be 50 years ago and so on.

Overall, however, most people are kind of designed or programmed to have a sense of what is normative in their environment. And we tend to throughout our life want to conform to some -- that notion of normative behavior, normative appearance. We don't necessarily want to deviate too far from that. And in fact this is a good sign of mental health to suggest that we have a sense of what we know what typically is expected and we're pretty much referring to sticking with that.

But in the meantime, society does have its reactions, doesn't it? My husband, I've mentioned to a few people, happens to have MS. And he came to the point where he realized he needed a cane and he -- when he brought it up I thought we were going to speak to the physician about getting, obtaining a cane and he said, oh, no. He actually had already been thinking about this. He was sure that the physician would recommend it, what he called an old man cane. Which tells me he had been looking at who uses cane when is we walked around and he would only notice them to be old men. My husband yet has not defined himself as an old man. So he ordered a cane on the Internet. We find out later it was really highly inappropriate and designed all wrong for him. But for the moment he decided he was going to use this cane. And when he received it in the mail, he showed me how he decided to use it, you know. You push off. You don't dig in. And I suggested that we take for it a spin. We could go to the mall where it was climate controlled and flat. And his first reaction was well not in public. And I was so surprised that there was already that worry about how society would react.

Well, eventually like really within three minutes he decided he was being a little stubborn about that and so he was willing to go ahead and use the cane. But what I noticed was this: When we would go out and he was using the cane, society in general knows what to do. They have enough imagination to figure out what it would be like for them to be a person who needs a cane and, so, they respond accordingly. People open doors for him. They back off to give him room so that he doesn't bump into things. And interestingly he never notices that because he's concentrating on not falling over. But I notice that routinely, that there is an extra level of courtesy and acknowledgment of needs compared to when he is not using a cane.

But at the same time I'm also very cognizant of when a cochlear implant is present on a person or a hearing aid, society does not yet know what to do. And that's -- I would say that is in the hands of audiologists to work out and certainly persons with hearing loss as well. But in terms of public awareness campaign and all, this is something we need to address, don't we?

Okay, so we've been talking about some stressors but we also want to spend a little bit of time on some coping strategies that seem to be effective within the population that we're talking about and the coping strategies are these. Vigilance, respite and reframing. If it is not something you thought about, reframing, we'll talk about it and get to it last.

First coping strategy is vigilance and defined here as maintaining high levels of physical and mental energy. To detect, process and respond rapidly, to unpredictable or hard-to-perceive auditory input. Now, I realize it is kind of silly that I read this as you're reading it but that just kind of keeps us on track. The whole concept is the psychological effort that one puts forth in order to get through a particularly challenging time. You could think about it as putting forth 110% effort.

I used to work in the school settings and could see children who were in school with a hearing loss really putting forth that 110% effort in the morning and could not hang in there and complete that effort through the afternoon. We'll talk about that in a minute.

I mentioned my grandmother before. She actually made it to 100 years old and I would notice that her hearing challenges became such that during dinnertime she tried very hard to follow the conversation with the family and I could see her fatigue right in front of me. It was so challenging that I knew the family dinner was very important and she was being vigilant, participating, doing her best to follow the conversation. But I could also see the energy there, the toll that it took. And I again when you talk about that notion of empathy I was trying to imagine what is that like to put so much effort into something that is so simple and easy and effortless for other individuals without the hearing loss.

So ultimately what the outcome is a heightened state of attention becoming quite exhausting. And this bring us to the next coping strategy described as respite. Mentioning my grandmother before invariably after those very challenging communication situations, specifically the family dinnertimes, she basically would call it a break. Call for a break and walk off to another room and take a short nap.

People would tease her and say she was trying to get out of washing dishes, for instance, but looking back I know that this was her -- what she needed to do was to pull away to withdraw from all of the noise and all of the challenges and it actually is a very wise mental health decision to make rather than trying to push yourself so far that you exhaust yourself beyond any logical efforts. So thinking about this is temporary withdrawal from vigilance in order to conserve and regain energy. Either by withdrawing from others or just actively removing amplification just for some down time.

I'm basically in passing this along to my students who have drill it into my head, patients must have amplification in order to activate the 8th nerve and rewire the brain and so on but it is a little naive to think that patients don't need down time. Of course they do the report and report it to us all the time. So making sure that they know that the option to remove one's amplification in order to rest even if it is a 15 minute break in the middle of a work day, that is perfectly appropriate.

I have a colleague that is an audiologist and very hard of hearing and he said that after a very long work day, once he gets into his car and turns on the engine to make sure it is running, he whips off his hearing aids and keeps them off for the drive home and for the next hour until family shows up again because he really can't -- he just really needs rest. That recharging of one's batteries.

And I bring this up because families tend not to know this. That respite is actually a very legitimate coping strategy.

I'm sure most attendees in our workshop here or presentation have heard other family members say about the person with the hearing loss, he only hears what he wants to hear. And I'm becoming as I get older a little impatient with this comment because it is simply meaning to me that professionals haven't communicated well with family to talk about respite.

He's either withdrawing in order to get some rest or he just simply couldn't understand what was being said because of -- it was garbled and he's just selectively listening not in a way to be obnoxious or rude but just to cope.

So I have actually been thinking a lot about how to develop worksheets or excuse me not worksheets but handouts for family to say emphasize this because with -- if it doesn't get affectively addressed we're going to get this vicious cycle, first of all, I'm going to blame the family member for not putting forth their best effort and then I resent the fact I don't see that happening and that is all adding to the stress that we're actually trying to alleviate to some degree so we have this kind of a handout going around in different environments and it does seem to help. If this is a prescription for families, not for the patient but this is a family issue, because your loved one has a hearing loss you will notice that he or she has to concentrate while listening and this concentration is really hard work. I tend to underline that or get a highlighter and make a big deal about that part of it. Because you don't see physical effort or exertion put forth that doesn't mean it is easy. The cognitive effort of course is a very, very high demand.

Listening breaks help and if your family member is not listening he or she is probably tired and then I might expand. It may not be tired. It might be noise. Not enough visual cues but don't assume that they're not trying because of course they are.

Okay, coping strategy No. 3 is called reframing and probably has been around for a long, long time but came into broad use by a psychologist named Albert Ellis. He just died recently about a year ago. But there is his website if you would like to take a look at his institute. And he was well-known for thinking about developing what can be called cognitive therapy and can be sum riled as to how you think affects how you feel and act. And I'm sure you've all heard this. The power of positive thinking will result in making lots of friends and having a satisfying job and all of that.

Let's take a look how reframing looks here. If in fact we find ourselves struggling and looking for a way to cope maybe we are thinking in black and white that. Life has to be one way and it is not and therefore I'm going to withdraw or people are not cooperating with me or not supporting me and therefore I'm going to be angry about it and resentful. Reframing suggests that we simply think about different ways to say things. That is one way to think about it. But here are some others. Can you say it differently to help you think about it differently?

This is the first line basically comes from my work with teenagers more than perhaps the persons on this presentation. But I will often hear them say I hate hearing aids and so I won't use them. What I ask them to think about, is there another way to think about that? For instance, can you hate hearing aids and still use them? In other words, live with both of those conditions? That kind of flabbergasts teenagers because they had thought they had the answer and then they realize there is more than one answer here.

Reframing also involves the notion of replacing words where we kind of describe our expectations about life and it should be a certain way or people ought to act like this or they must be this way. To change those to preferred or desirable or convenient. I should be like everyone else. That is very prescriptive and also discouraging because the reality is that we're not like everyone else. But if to change it to say it would certainly be convenient if I was like everything else or I -- everyone else or I would prefer it. It gives you cognitive wiggle room to consider the alternative, kind of the grays between the black and the white.

If this sounds familiar it is because you see it everywhere. I just happened to see a book before we put these PowerPoints together at a half price book club called, "It Is Not About Food." I thought, if it is not about food, then what is it about? It is actually about changing your mind. Change how you think about food and change how you become obsessed about your weight and so on. This is absolutely what reframing talks about and cognitive therapy talks about. It is also very Dr. Phil. If you watch TV and see him on his show, he is known to challenge a person to say think about it differently. Keep trying. If you go to self-help bookshelves that is basically all those books that are based on this theory or this philosophy.

Okay, back to our patient journey. I wanted to get us to the point of acceptance to say a few comments on that. Just a moment, please.

Okay I'm ready for you here. Acceptance would suggest that one is ready to move forward, to make a decision and to live with the consequences of the decision and so on. What I found to be helpful to find out if in fact a person really was ready is to use this really simple idea people used it all the time of a 1 to 10 scale. On a scale of 1 to 10, 1 meaning no way, absolutely not, 10 meaning absolutely ready, are you ready to take the next step? It might be really settling in on cochlear implantation. And the interesting thing to me is I used to try to predict based on the conversation that we'd had what a patient would actually say when we were ready to discuss readiness to move forward thinking about that patient journey in the back of my mind. And I was quite surprised to realize I was rarely correct. I would always be either underestimating or overestimating one of the patient's responses.

One time in the same morning I had two different patients with the exact same audiogram but more importantly they had completed some self-assessments and indicating that they didn't seem to have any difficulties. So I was screening them for OSHA hearing test which is just a requirement by the Federal Government. I was not interested in pushing an agenda. I just wanted to know if they had thought about getting some hearing help. They were reporting not really any problems but their audiogram would suggest that maybe they were struggling. I just couldn't know until I asked. So the first patient I asked, I asked her on a scale of 1 to 10 would you be ready and describe yourself as ready to consider amplification and she just jumped up from the chair and she said, actually if there is an 11 or a 12, that would describe me. I have been putting this off for a really long time. I probably lost my last job because I wasn't getting phone messages correct and so on. And now I really want to do something about this.

So we got her moving forward because she was very clear on how ready she was.

Well, then I asked within half an hour another employee who had very similar test results and I asked him the same question, would you be -- you seem to be a candidate for amplification. Would you be -- are you ready to discuss it? And he looked me straight in the eye and he said, on a scale of 1 to 10, I'm a 3.12. Now, that struck me as very funny. I've never heard anyone be quite so precise about it. And that was my answer. And he said what I'm telling you is I'm an information gathering mode so I asked him what kind of information can I provide? He told me what he needed. I gave that to him. And about six months later he swung by my office. With real -- no preamble he stuck his head in and he said so I'm a 6, maybe a 7. Which tells me that he was moving forward in terms of readiness to take this next step. That is terribly important for me to know this because to assume that someone is ready without confirming it could just be a recipe for a disaster, couldn't it? You could find yourself moving along and then the patient starts to drag their feet and no one really checked with them to find out, are you ready? I happen to be but that is not the point.

With regard to readiness, this brings us to another psychologist who is well-known from a different point of view with regard to his therapy approach which would be described as patient centered. Another website to find out more information about him is there. But what he was suggesting is that when or if and fact a person is not ready, however when conditions and the environment are supportive, humans are designed to choose growth. So they will find a way to become ready if they don't feel pressured, if the stressors are being managed with the coping strategy that we described. Often, too, it is important to point out if it is hard to choose growth maybe the environment or the support system is a problem. Because both of those conditions have to be there. An example -- a nice example would be, for instance, this -- a different population but a -- say a 5th grader would be very willing and interested and able to use an FM system in class so he is choosing growth. We could say. But let's say his teacher just is not cooperating. She just seems to forget wearing the microphone all the time. Or would say, you know, for this activity you don't really need me to wear it. Now we have a problem. And I would say in this situation the environment or the support system is not conducive and so she needs to be modified or rather the classroom needs to be modified to find a new classroom teacher.

Another thing to think about if a person is not ready for change and moving forward in that patient journey, Ellis would suggest can we change our own thinking? That is what could be modified as well?

Finally I mentioned there are two things that I know for sure and here is the other one. We are not designed to go it alone. Social support is found to be extremely valuable and I'm hoping that the persons with hearing loss in our presentation today have social support system. I would love to hear more about it if you do. Taylor wrote a very interesting book called "The Tending Instinct." Just as an FYI I want to pass on why I happened to read her book.

She was a -- she is a Professor at the University of California in Los Angeles, UCLA. She had some graduate students taking a look at some seminal research on stress reaction. They were looking at studies that would measure what would happen when organisms, in this particular institance mice, but also humans, when they were experiencing a sleet or fear or other anxiety situation, a hormone would kick in and the responses that the researchers recorded at that time were described kind of coined in the phrase, to either fight or flight. There was a strong intense reaction to either react strongly to defend one's self or to runaway.

Well, Taylor's grad students were taking a look as I said at the seminal research and they started to ask and realized, did you know Dr. Taylor that all the subjects in these studies were men? The studies were quite long ago. Before there were research protocols to make sure that the subjects were balanced in terms of gender and representation of the ethnicities of the region and so on. So they suspected that if these really were, in fact, hormonal responses wouldn't there be differences given the fact that men and women have different hormones. They replicated the studies and came up with a really interesting outcome. They found out for the most part when women, females, experienced threat or fear or anxiety, they don't have the fight or flight response. In fact they have a different response system that they coined to say to either tend or befriend. In other words, they will seek out and protect those who are vulnerable such as the elderly or disabled and so on, make sure that they're being taken care of. Small children. And then be friending had to do with the social systems and the networks to make sure we're all talking to each other. Everyone knew what was going on.

What she wanted to get at was regardless of our gender, male or female, we need social supports. She cited study after study showing that when patients reported having a secure support system, families who cared for them and worked with them, and tended classes and whatever it took, they were far more likely to advance in terms of their own rehab.

Just a moment while I take a look at our questions.
>> DONNA: What I think I would like to do, Kris, is go through the remaining three slides while you're taking a look at the questions and preparing for those responses.

And I did just want to tell those of you that are new, particularly to HOPE Online, that we do have these online courses live several times a month. The next one is really for parents and for professionals who work with parents. It is on November 11th and the topic is

Learning with Literacy. And then coming up on Thursday, December 4th at 8:00 p.m., we have another adult session. It is actually Part II of Adult Cochlear Implant Rehabilitation. And this particular segment is on working with a rehabilitation professionals. If you missed Part I, it has been recorded and you can take that one first if you wish. You don't have to. The first part was really on the hows and whose, the hows and whats of rehabilitation. We really went through what it was for adults and tools and then an adult can pursue and this is going to focus more on working with the rehab professional. As I mentioned earlier, we have over 60 courses that we have previously given that are up online. You can take them at any time. We hope that you will.

And we also have some upcoming live workshops, and one of them is on adult rehabilitation. It is called, Lively Listening. And the second is called Conversational Competency and it is an inter-mmediate level course on pediatric habilitation. Those are both going on in four sites. I have given you the dates there. So if you're anywhere close, I encourage you to come. The adult one is always in the evening the first day and the second day is the pediatric rehabilitation course.

And we want to just leave you with some other resources for adults. We have a new guide that you can download from the HOPE area of the website. It's called Cochlear Implant Rehabilitation. It is not just for kids. So if you're interested in that topic please take a look at it.

Getting started for adults is a CD from Cochlear that is coming soon. So keep an eye on the website and that is one that you can request. It is free.

Music and implants is a bit on helping adults enjoy music. That also is in the Cochlear HOPE area of the website. That is www.cochlear.com/HOPE. I also recommend articles by Mark Ross that appear in the Hearling Loss magazine, and those are published on the website that I have given you there. And one more resource for professionals that are looking for adults, the adults overall rehabilitation. The CI for professionals is available from Cochlear, and it is a really nice resource for adult rehabilitation.

Two of the resources that I would like to mention as support mechanisms and Kris spent a lot of time talking about that. Hearing Loss Association of America of course has a series of Chapters -- a set of Chapters all around the country and a wonderful annual convention so that is a great source of support for adults.

And Cochlear is actually launching a new community area on its website for adults with cochlear implants. Kind of a social networking site. It should be launched very, very soon. I'm told before the end of the year. So keep an eye out for that. And the idea of that is really to provide mechanisms for adults to find each other and support each other.

With that I'm going to turn the in regard back to Kris. She has some great questions there to respond to.

>> KRIS: The first one is more of a comment. I'll read the comment first. I find this to be true for me even though I have been quite successful with my bilateral cochlear implants. And I think that is in response to the idea of vigilance. That vigilance is -- it takes its toll and even being successful with cochlear implants doesn't mean that the need for vigilance does not -- goes away. There is also with regard to vigilance an extra level or layer of complexity to it. It has to do whether we're extroverts or introverts and we're basically born that way. I don't think we can change one way or the other. By introvert I don't mean painfully shy and social anxiety kinds of things. I mean the impact that social interactions have upon us, I can speak as a very committed introvert that interacting with people on a daily basis, let's say intensively all day long, is absolutely exhausting to me. And I need respite. I need quiet time. I need a quiet house. I need my quiet ride home in the car and so on as compared to extroverts who love social engagement and social activity and want more of it because that makes them happy and stimulates them and it has to do with how the brain is functioning.

There is a great book on it called the "Introvert Advantage, How to Succeed in an Introvert World." I have often thought, let's think about the challenge of being an introvert and then also having to deal with the vigilance required to function with cochlear implants. That is a lot of cognitive energy so, yes, I could imagine a lot of people could feel very exhausted at the end of the day with that.

One individual writes how can we help individuals advocate for themselves? I imagine we're talking about adults with or who are facing their hearing loss. Advocacy or self-advocacy is a favorite topic of mine and it is something that has to be a & proposed like any other learning process. First of all, a learner only learns what they want to learn. That readiness part again. When people are ready to learn and feel motivated to learn because again it is about change. Then they're more likely to be receptive to learning self-advocacy skills and then how to learn then I would suggest that would have to be specific to one situation at a time and look at the skills that it takes to manage success in that particular situation just from analytical point of view. How would you describe it? How would you define the challenges and then although it seems rather unusual, what seems to work best is to rehearse it before you're thrown into real-life. How do you actually say what you want to say? How do you actually get the attention of an approach of a person that you don't know and speak up for your needs? How do you negotiate when they seem to be uninterested or perhaps refuse? How do you do it in an assertive way without being aggressive or threatening to sue? There is a whole set of skills in that way. And then some immediate feedback in the rehearsal process on how did it feel when you spoke your mind when you said what you wanted to say? Could you think of a ways to it that it wouldn't make you feel quite so uncomfortable? How would you respond if this -- if it -- if the person responded to you differently and so on? And then a person might be ready to ease one's self into a real-life situation and then practice that self-advocacy skill.

I appreciate the question. I know it is not an easy one to answer. I don't know if that helped or not but I appreciate having it posed.

As an audiologist how can I know if they're using coping strategy or if they are drawing depression? That is an excellent question. I think the difference has to do with time. Respite is a short-term choice. Depression is something that you don't rebound from you. You are starting to sink further into the -- the abis, as it were, and I think that would be my answer. Especially if I have a long-term relationship with the patient and I know how they have been handling life so far and then I see a change and it doesn't seem to be a rebound coming up in the near future and it is not situational. In other words, to the best of my knowledge there is no death in the family or loss in the job or situation that could account for it. That would tell me it is probably -- it is probably not just respite. In fact, if you were to see as an audiologist seeing a patient in an appointment, they probably are in vigilance mode. They're probably trying extra hard to work with you, focus on what is being said, understand the thread of conversation and so on. So it -- it would be unlikely to see respite responses in an appointment or in a rehab session. That is a super question.

I think I have addressed them all. I apologize if I have not seen it. Someone wrote, would you suggest any resources? This has to do with self-advocacy and this sounds shameless, but I authored a book called "Self-advocacy Skills for Students Who are Deaf and Hard of Hearing," and it is designed for high school students but really adults have used it, too. Unfortunately, it is out of print so I am not real sure how to provide it like on-hand. I don't have anything on-hand immediately, but you might be able to find it on eBay. I'm not sure. Certainly libraries as well. But I apologize, I don't have more. I actually ended up writing that book because I could not find anything myself. The title -- there we go.

The other question, I also have some difficulties finding a place and resources to provide a -- I'm having a hard time reading the question. I'm also having difficulties finding places and resources to provide a place or a club or social situation to meet others. And this is one of the most common remarks I have ever heard. And I'm -- I struggle with that myself. I don't have a good answer for this. Maybe I might ask Donna if she has any suggestions. Of course it depends on where you live. Some people enjoy me get other people at social engagements with their church but not everybody goes to church. That is why I feel like I'm not able to answer this particular question.

>> DONNA: I really think that the HLLA on network and the chapters, particularly in communities is a really wonderful place to find support for people. Sometimes clinics, if you have a cochlear implant or a hearing aid sometimes your clinic can match you up with like people that you can talk to.

Thinking back at my own journey and I -- I've had a cochlear implant for 16 years. But prior to that I -- I think the difficult time that I remember was before I got an implant and I was using hearing aids and I had so much difficulty communicating and so many issues with identity and all of the changes that Kris covered in her talk today. I sought help from my audiologist and she was actually very good at matching me up with other people who had gone through what I had gone through and I invited them to my home. I used to actually have people or a group of us got together every month or so and it was very helpful to me in terms of getting through that phase until I got a cochlear implant and from my perspective once -- once I had a big change in my -- my access to sound, a lot of those other issues really were very much mitigated. I don't know whether that is true for others as well but for me once that -- once I was able to take care of that, that really made a big change in talking to other people. I think it helped me a lot in being able to move forward.

>> KRIS: Thank you for reminding me about The Hearing Loss Association of America. Their chapters are just wonderful organizations. And sometimes I have been told they're kind of the lifeblood of some people's lives. They get through work. All the rest of it they know once a month they're going to be with people who understand the room is equipped with all kind of technology. There is captions and they can kind of just relax as it were and be able to take in the information because other people are working with them.

Along those lines there is another comment to say, no matter how much I advocate for what would help me to understand in my job, my co-workers seem to forget what would be helpful. I also have to be vigilant for them as well. That is a very common refrain that we hear that the others in one's life just tends to -- they may keep up the effort for a while and then they let it go. And I don't have any advice except to pass on some wisdom from somebody I met once and if you ever sought the incredible hulk in the 70s or 80s that Lauff Rigno would be the man that played the Hulk. A wonderful man and a bodybuilder and has always been profoundly hearing-impaired. And he told me how he -- he had lots of stories to describe about his background. But relevant to this situation, he was a famous person at a certain point in his career and met a woman in a restaurant who eventually they fell in love and they got married. So he's always been deaf. She's always known him to be deaf. But she keeps forgetting and she will talk to him from another room and do the usual mistakes and then he says, I'm still deaf. What are you thinking? They made a decision just to laugh at it and not get upset about it because they wanted this to be a relaxed situation, not tense all the time.

Now, that was a partnership agreement between owns. That is not the same as what's being described here with co-workers who are not as necessarily committed to one's well-being as a owns or partner might. But I guess the only thing I can think of is if you reframe it and think is there another way to think about it instead of being frustrated, there is a -- you can think of a dozen different reasons why they forget. And then think about how -- ways to routinely remind them and maybe not enable them. In fact, if you did not hear them and they forgot what to do in order to make sure you could hear them, then don't necessarily be that vigilant for them. I guess it is kind of like that -- what do you call that enabling dysfunction or something like that? I'm not sure how to describe it. But I hope that helps a little bit, too.

One more comment. The very fact that hearing aids, wearing hearing aids is cognitively labor intensive and deserves respite is also proof that wearing hearing aids helps keep the brain active and working. Absolutely, doesn't it? That is a very good point. I appreciate that. Donna, I think we have got all our questions posed and answered.

>> DONNA: I think we had some really great questions and a wonderful presentation, Kris. We thank you very much for being with us tonight.

>> KRIS: Thank you.

>> DONNA: Thanks to all of you who joined us. Have a great evening. See you soon at HOPE Online. This is Donna Sorkin from Cochlear America's HOPE program.