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EMOTIONAL ISSUES OF DEALING WITH A HEARING LOSS, AND HOW TO SELF-ADVOCATE

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ERIKA LOHMILLER: My name is Dr. Erika Lohmiller. I'm from the wonderful city of Chicago, Illinois, and I work for the Illinois Masonic's deaf and hard of hearing program. I work with deaf and hard of hearing adults, children, families, couples, in a mental health facility.

I've been doing that for about 8 1/2 years now, and before that, I worked at the addiction Recovery Center for the Deaf in Chicago, so my experience is pretty much working with deaf and hard of hearing people that have addiction problems, they have mental illnesses, everything across the board, and a lot of the people that I work with have lost their hearing later on in life and we work on a lot of grief and acceptance issues.

So a little bit about me, how I fell into this field. I was born hard of hearing, and then I lost a lot more of my hearing when I was a teenager, and I started learning sign language when I was a junior in high school. And during that time, there was not a whole lot of support for a teenager that was going through a hearing loss, and it somehow helped me to want to do something to help other people who were going through similar situations, which is why I became a counselor.

I really like what I do. I really, truly love my job! And today, I want to talk a little bit about some of the unique issues that people who are late-deafened face in their daily lives.

We all know pretty much what they are. There are many problems with accessibility to different programs when people need help for mental health or medical issues or just like going to court or anything like that. There are many problems in getting equal access.

Also, the oral communication issue, that's a unique thing that people who are late-deafened go through because we don't belong in the deaf culture or the hearing culture. It's really unique for people who are late-deafened, because a lot of us talk very, very well, so if we tell people that we're deaf, they don't believe us. They think that we're lying, because we speak or lipread so well.

Some of the emotional issues are that we don't belong in one or the other group. We're in the middle. And so there's a whole culture of that. You know, we could call it hard of hearing, late-deafened, whatever, but many people that are in this room that have these experiences that don't relate to being in the deaf culture. Meaning that we didn't go to the state schools for the deaf. Many of us did not grow up learning sign language. We don't always understand what some of the deaf culture issues are, or the jokes. And then we're no longer in the hearing world. We have a rough time going to movies or enjoying some of the things that we did before. So, we're unique people. We're special. We're right in the middle here. We're not Deaf, we're not hearing; we're happily right in the middle.

Some of the other things that people who are late-deafened and hard of hearing have to go through is worrying about emergencies. When there's something like a tornado or a hurricane or like 9/11, some of the problems that happen, as we know, is that on our TV, captioning systems, live reports that happen, usually are not captioned. We don't often know exactly what's going on in our world, the same way that other people who can hear can.

I remember when 9/11 hit, I was in my car driving, and the radio was talking about some of the things that were going on with the issues in New York and the planes and the updates, and I couldn't hear what the radio was saying. I mean, I could hear the music, I could hear some of the words, but I was very frustrated because I didn't know what was going on. I really wanted to know and I could only hear half of it. So, as far as like emergency planning, we often have a little bit of a difficult time. It is a unique issue that we have to worry about.

Some of the other issues that deaf and hard of hearing people face in their daily lives are employment. Going into a job. A job interview. Either hiring an interpreter, if we can sign, or not. Educating our employers how to work with us. When to get an interpreter or when to write things down such as simple accommodation needs (amplified phones or whatever). Employment is always an issue that we all face.

When people become late-deafened, later in their lives, family is often another whole emotional issue that we have to work on and deal with. It's hard to go to family events, like Thanksgiving for example. When everybody is sitting around the table, talking, and us, as the deaf people, cannot understand what's being said. We miss a lot of things with family.

A lot of times, too, it's often hard when there's just a spontaneous conversation and a lot of people who are deaf and hard of hearing or late-deafened deal with a lot of isolation

issues regarding their families.

Another issue that we deal with is affording all the technology. Yes, technology is wonderful. We have flashing lights, we have amplified phones, we have relay systems, we have wonderful Sidekick pagers and all those things that can make life easier. However, they're not cheap. It's not the same as going to a T-Mobile store and getting a \$50 phone that's on special. People who are deaf and hard of hearing often have to shell out a lot more money for their equipment needs. That's another issue that we face.

Identity. Identity is a great one. Are we deaf? Are we hard of hearing? Are we late-deafened? Are we hearing? Many times, when people ask us how much hearing loss do we have, it's hard to say, okay, you have a 30% loss, 50% loss. But as we know, we don't measure hearing loss in quite that way. It's measured by decibels, so a lot of times people are asking, well, you can talk to me so that means you can hear. They don't understand that it's about frequency. For example, I can hear men's voices better than women's voices. I can hear music but I don't understand the words. We all know that trying to explain our hearing loss and our identity is an important issue. Who are we? Many times, how much we hear defines who we are for our identity.

Feelings of isolation. We can all relate to that. If any of you have become deafened gradually and not suddenly, you know that it's a big grieving process. It takes a lot of time to adjust to what's going on with you and why and going to the doctor, and trying to communicate with people -- there's a lot of isolation and a lot of grief issues that people go through.

And with people who are deaf and hard of hearing, many times the grieving process is not just like a death. It's not like you just get over it and move on. It comes up at any given time. There are times when a lot of people don't think about their hearing loss and they're just fine, and then all of a sudden, they'll go to a family event or something else and then that grieving of not being able to hear certain things comes up. So, the grieving process for dealing with isolation in the deaf and hard of hearing and late-deafened communities is a lot different than just like working with a death. Yes, losing your hearing is like a death, but it's never over. We don't often have the luxury of hearing perfectly again, so the grief comes up and it ebbs and it flows, and it comes up at certain moments in our life.

Service accessibility. Again, that's often an issue that is a problem. Many times. And people who are deaf and hard of hearing, when they want to do something like buy a house, it's often an exhausting process to have to teach people how to communicate with us and writing things down and how much we can hear. So services are often an issue that we have to deal with in facing and educating people in what we need. And sometimes if we're recently deafened, we don't know what we need. It's hard for us to know what do we need. It's a new experience. We don't know about the services that are out there.

You know, the Department of Rehabilitation Services, or vocational rehabilitation, many people who become deaf suddenly don't just know that information. It's not common information. Services and accessing services is often an issue for people in our community.

And I broke this down a little bit more to describe some of the issues and what each one means. There are problems that we have with entertainment information and social resources, problems with oral communication.

Emergency planning. Many people are left out of the process of what goes on in our nation or natural disasters that happen, so emergency planning is often an issue.

Employment, again. Getting some of the information to get a job, getting an interview, educating employers about different communication issues, those are often issues that we face.

Many times emotional issues include our family. When I do counseling with people in my practice, family is often a big process that needs to be discussed. There's a lot of anger when our family members don't learn how to sign. If we learn sign language, there's a lot of grief when many family dynamics are happening around us and we don't know what they are. Family and integrating back into the family dynamic system is often a big problem for people who are deaf and hard of hearing or have lost their hearing suddenly. Many times, too, people with sudden hearing loss, the families have to go through their own process of trying to deal with that. They don't know what to do. They don't know how to deal with that. They don't have the right healing words when a member of our family is going through something traumatic such as a hearing loss. It's a new experience for our families, too. And they often need counseling, guidance, and figuring out how to deal with us.

Technology affordability. Again, we know what that's like. I mean hearing aids. In fact, two days ago, I had a family counseling session. The daughter of the family is hard of hearing, and a big problem for the family happened to be that the daughter left her hearing aid out and the dog ate it. Well, many times insurance does not cover hearing aids, and this poor single mother has to shell out \$2,500 for this hearing aid. Those are not normal problems in a hearing family. These are unique things.

Many times with little children, too, they throw their hearing aids out in the yard because they don't want to wear them. They get flushed down the toilet. They are dropped in the bathtub. They're very expensive mistakes. And then a hearing aid battery and all the other equipment stuff that we often have to buy. What was that?

Deaf and hard of hearing kids go through that: they don't want to wear their cochlear. It's an issue that I have to deal with constantly when I do child counseling. Why you're going to wear your hearing aid and why it's beneficial and yes, you're different, and yes, you don't look like the other kids. That's another completely psychological issue that goes into that with child psychology. And in fact, I recognized a face in here. Are you a

child psychologist or a psychiatrist? You're a psychiatrist. Do you work with children?

AUDIENCE MEMBER: Yes. All the time.

ERIKA LOHMILLER: Do you often have those problems where the kids are dumping their hearing aids or they don't want to work with it and adjustment problems?

AUDIENCE MEMBER: Everything that you said is true! But I just don't try to force the kids to use the hearing aids or the cochlear implants. I try to work with them. You know, go through the shame issues and try to help them through that. I also help them to realize that I'm not going to force them to do it. But I understand exactly what you mean.

ERIKA LOHMILLER: I can give a nice example about a kid. He will come for help with a hearing loss or hearing aid or some similar issue. Many of the kids will play with a small Moose that I have. And this Moose has really taught me a lot about how awkward that kids feel about themselves, that we have one picture of a Moose who is trying to live with his family, but it's awful, you know, the story that he's telling about the Moose, about how it's destroying his family. And at the end, he's dying, he's bleeding, he's sad. It's really awful.

But the Moose never did anything bad. Never behaved badly. In his mind, what he saw was, he thought of himself as a bad person. That he had hurt his family very seriously.

Often, too, with children, it's very hard to teach deaf and hard of hearing children feelings. Many times they understand anger, they understand happy, they understand sad. But they don't understand some of the vague feelings like frustration or stress or fear. The big feelings, they understand. The subtle feelings, they have a hard time understanding.

Those are issues that we deal with children. And with adults there's many feelings that happen when we deal with a hearing loss. It's a rough process. It's a long journey.

Another thing that you had said about technology, I think it's a very important point that just because the technology is there, we have cochlear implants, we've got all of these gadgets that are out there. It doesn't mean that they're all right for us.

I think that technology is an individual thing, and that we need to work with what works for us. Why get a flashing doorbell if your dog does the job for you? Some people don't want to have a cochlear implant. Yes, they can benefit from it. That's fine. The technology is there. But it's okay if you don't want to utilize that.

And especially as we get older -- I mean, technology is a scary thing. You know, I have the Sidekick phone that does everything and almost even makes coffee for me. I mean, it's really overwhelming. So, technology is something that a person who is deaf or hard of hearing kind of has to adjust to and learn. It can enhance our life, but also it's an

individual process.

Identity again is another big psychological issue. That whole being in the middle thing. Not being deaf, not being hearing, and identifying yourself as either late-deafened or hard of hearing, that's often an issue that many people need to find, what their roles are. And it's an emerging process.

There is a wonderful book that a guy wrote, and I have the author's information on the handout that's up there. It's a book called "Odyssey of Hearing Loss," and it talks about people's personal journey in accepting their hearing loss, and the other one is Michael Harvey. He wrote a few books. "Odyssey of Hearing Loss," "Psychosocial Aspect of Hearing Impairment." Very good books. Especially the "Odyssey of Hearing Loss" because it talks about people's personal journey and learning the acceptance and grieving process that they face losing their hearing.

Isolation. It's a therapy issue that comes up a lot. It's not easy to just tell a person who is late-deafened, "Well, go out and meet some friends. Get out there. Meet people."

I know that there's another workshop here in this convention about being single and hard of hearing or being single and deaf, and I think that's an important workshop, because a lot of times meeting people is harder. It's not just easy to go up to somebody and say, "Hey, how are you" and have a conversation over dinner.

We have to think about issues like lighting. We have to think about if we can understand the person. I know that lipreading is very hard for somebody with a big moustache. Or my favorite, when they're eating while they're talking. Lipreading is a thing that we do have to think about, so a lot of times people who are deaf and hard of hearing are very isolated. There's a lot of people who just don't want to take the time to communicate with us, or to write things down, or to clarify things, or they say, "Oh, never mind" and roll their eyes. That's something that is unique that we deal with.

Feelings of grief, anger and anxiety. Once again, this is a lifelong feeling that people who are late-deafened or hard of hearing face. It's not something that you deal with in counseling, go through the session, the issue is over, and then they're happily adjusted for the rest of their life. It doesn't quite work like that.

Yes, the feelings of grief and anxiety subside as we learn how to cope with our hearing losses, and we prepare ourselves for certain situations. But there are some times that you just feel normal grief. When you can't hear something. There are times when I know I wonder, okay, what would it be like, if I could hear everything? I know I would probably speak like four or five different languages. Because I'm really fascinated with other cultures and different languages. It's not the same. I've taken Spanish classes. It's harder for me to learn. I have to learn how to read lips in Spanish. That's almost impossible.

But there are times when my hearing loss doesn't bother me for days, weeks, months,

and then there will be like something that will be like, hmm, you know, I wish I could hear that. Or I really would like to hear the words to a song. Not always, though, because sometimes when I watch music videos, the music sounds wonderful and then I see the lyrics, and I'm so disappointed. So many swear words and all about body parts. It's really a downer. So sometimes, I think it's better if we don't know what all of those lyrics are about. And I certainly don't miss it when I can't hear things like the honking outside or somebody belching on the bus or whatever. No big loss!

But once in a while there are times when we think about what would it be like if you could hear? What conversation can we spy on and eavesdrop on? Those feelings of grief sometimes come up when we wonder "what if," or "why me," "why did this happen to me." Those are very common factors that happen. And again, they don't just go away immediately. They come up, they subside, they come up again.

People who were born deaf, I often think that their identity and their isolation issues are easier to deal with, because they've been exposed to the deaf world much earlier. They've learned sign language. They've been surrounded by community resources, some of them. It depends. Often a person who was deaf and got the proper services earlier and then know where the things are -- like vocational rehab services or different technology or how to hire an interpreter, when they've learned that younger, I think that their identity is solidified a lot earlier in life than if somebody has a sudden and traumatic hearing loss later in life. It's a lot different. It's a whole new learning experience.

Services. Again, the whole Americans with Disabilities Act compliance thing. Huge issue. Learning how to advocate for ourselves and to get what we need, and not just accept the writing back and forth. Especially in agencies or government institutions like hospitals. Still even today, with all of our technology, a lot of times with people who are late-deafened walking into a hospital, they ask for certain services and they think, "Oh, well, you can talk to, therefore, you must hear." Or, "Let's use another family member as an interpreter." Or, "Let's just find, you know, whatever's available, you know, that can sign."

It's really important that when we advocate for ourselves, we know what we want, and how to get it. So, we can get the services that we need. We need to have those interpreter phone numbers handy, or the CART interpreters handy or whatever it is that can help us. If we don't have it handy, many institutions just don't know. They're not faced with deaf and hard of hearing people very often. And I know a horror story of a woman who said that she needed an interpreter for her gynecological appointment and the hospital thought that it was adequate to get a cafeteria worker who was male and hard of hearing to come up and sign. They thought that that was following ADA compliance rules. It isn't! But then when I talked to this young woman and I asked her if I could help her with possibly suing the hospital or getting a lawsuit against it, she didn't want to do it. She didn't want to go through the hassle.

It's often exhausting having to educate people, and by the time that they advocate and advocate and advocate for themselves all the time, some people are just exhausted

with the process.

So it will help us for our quality of life if we are very sure of what we need, exactly what we need, because a sign language interpreter is not adequate for some of us. Some of us need a CART person or something else. And we have to know what we need. You have a comment?

AUDIENCE MEMBER: I ran into a similar situation where I was asking for accommodations and services at parent meetings for my children's school, and most of the time, they refused. Or came up with excuses that they don't have the time, like note-taking is a luxury. I wish I had known and had legal information with me, and had the legal services contact the school to advocate for me or with me. Because it was exhausting by myself.

So, I also recommend having, like you said, having a phone number for CART services and interpreting services, and have the legal. It's easy to forget about legal. When I'm feeling exhausted as it is.

ERIKA LOHMILLER: But if we can have some of the things prepared with us, such as phone numbers for interpreting agencies or the legal resources like you said or the CART number, then sometimes if we have that ready, it can make the process a little bit more smoother, and hopefully we get what we need a lot quicker.

And, you know, creativity and flexibility is very, very important in figuring some of this stuff out. I'm working with a mother who is deaf who has a child in the Catholic school system. Well, because the Catholic schools don't get many government funds, they are not obligated to provide interpreters. So, instead of just giving up, I had her call the Chicago hearing society and I found out that they have a grant that can provide interpreters for people who are deaf to provide interpreter services for those situations where somebody else will not cover the cost of an interpreter. Such as like weddings or funerals or other events. It's really important to advocate for ourselves and have a resource ready, to really know our own community. Not just for us but for other people, too.

And because a lot of hard of hearing people don't have lettering on their forehead saying that they're deaf or hard of hearing, our disabilities are invisible. So it's not that obvious.

If somebody who is blind comes into the hotel with a dog and with a cane, obviously people are going to jump up and help accommodate those people. With us, it's a little bit different. Our disabilities are not glaringly obvious. Just because we have a hearing aid doesn't mean that people automatically know what to do with us.

And so the people who don't sign, getting a sign language interpreter is not meeting our needs. We have to be very specific and we have to be ready to tell people exactly what we need.

So basically in this life, we have two choices. If we have a hearing loss, we can be either a victim or we can be a survivor. I chose to be a survivor, which is why I'm standing up here. I know all of you people choose to be survivors because you come to these conferences to learn and to network and to socialize. This is really a beautiful thing. This helps us with the healing process, and it helps us to network with people like ourselves.

A person who is victimized by their hearing loss, have thoughts of pity and depression. A lot. Not just sometimes. A lot. There's a lot of self-defeating behaviors, such as addictions or cutting or other things that people do when they deal with a hearing loss. The lack of motivation in life. Blame and denial. It's very easy to choose to sit on the couch and collect Social Security and blame our hearing loss on the lack of happiness in our lives. We can do that. We easily can do that. Anybody has those choices. Or, we could try to become survivors. And have a positive outlook on our life and our attitude. Do actions towards our healing and acceptance. And view the little obstacles that we have as challenges. I also think that a sense of humor is really important. To just make life a little bit lighter. Everything is not so serious!

And many people tend to be pretty good and accommodating and very nice. There's not that often when we are criticized or blamed or we get the eyes rolling. Once people know that we're hard of hearing or they're deaf, many people are pretty good about trying to help. And if we see the goodness instead of all the negative things, it's going to be better for all of us in the long run.

I talked for a long time about all of the challenges that we already know with like affordability of technology, employment, people understanding us, all of the feelings of grief and isolation, how can we overcome that. Well, a few things that we can do are take good care of ourselves. To really know who we are and what we need to take care of ourselves emotionally, whether it means to get therapy to help us through this, whether it means to take some time out and so we can practice yoga or breathing or taking vacation. All of that self-care is important.

When we go to conventions or like a class and we have a headache from lipreading for hours and hours and hours, our self-care means that we take a break. We can come back refreshed. Our self-care means to educate others so we can take better care of ourselves.

Community involvement. Going to places such as ALDA or participating in some of the social events in the deaf and hard of hearing community, those are important for our own well-being. And our nice sense of self. It makes it get out of our own self and our grief and our anger and it helps us and it's rewarding because it's rewarding to help other people.

Using what we do have. Unfortunately, some of us are isolated in rural communities or we don't have a whole lot of services, you know, for interpreters or for captioned movies

or other things like that. But they are out there. And if we do a little bit of our own research, we can find out what is available in the community. Find out what grant money is out there. That might help us for affording hearing aids or for getting interpreters or whatever it is.

And also, passing out our own positive experiences. That can help us to feel better about ourselves and to help our younger people who are going through these things, to feel that being deaf, being hard of hearing, is not the worst thing that can happen in the world.

AUDIENCE MEMBER: How do you find grant money?

ERIKA LOHMILLER: It depends on what you need the grant money for.

AUDIENCE MEMBER: Captioning. CART.

ERIKA LOHMILLER: For CART? I don't know. I do know that our Chicago hearing society in Chicago, they have certain money, I think, for that. Our state rehab services, our vocational rehab services, or centers for independent living, whatever you guys call them in your state, I'm sure that they do have some resources for people with disabilities, and you can ask what might be available. It does involve doing research.

Taking care of our mind and our body. Self-care again. It's important to take care of our physical health, because if we're tired, if we're exhausted, if we're sick, then it's not so easy for us to communicate because you know that reading lips takes a lot of work. It takes a lot of stress out on our body, and if we're in good physical health, then we're in good mental health and we can communicate a little bit easier.

Taking care of your emotional well-being. Having good boundaries and good relationships with others. That can help us.

Therapy and self-development. Even if you don't have specialists in your area that work with deaf and hard of hearing people, if you can find a good therapist that is willing to take the time to write, or to communicate with you, then that can help.

I know that now, in our state of Illinois, we're doing therapy through the VP relay. You know, the TV and you can sign through the TV and we can reach out to other people, and these people who can sign, they are going to their centers for independent living and they're getting therapy with me and I've never seen them in person, face-to-face, but they're at least getting something. It's better than absolutely nothing. So people that are in rural communities, they can benefit from some of those services now.

That's a great thing. Our world is getting smaller. And hopefully, the quality of the VP services, the Sorenson services, or whatever they are, can be better, so we can clearly see the faces of people and so, therefore, maybe we'll be able to read lips with somebody instead of using like a TTY or whatever. It might be the wave of the future. I

also have some recommended reading, like from Michael Harvey, who wrote those two books about hearing loss.

There's also, I'm sure in every state, like deaf e-resources. You know, there's e-mail lists. I know that in Illinois, we have deaf Illinois news where we get all of the events and the social things and the interpreted church services or other things that are happening right on your e-mail, and I know that for us, it's free to subscribe to them. And so often when I go on to work, I have like 30 or 40 e-mails from Deaf Illinois News talking about, you know, events for kids or, you know, the deaf fishing association or the deaf campers or the deaf bowlers or, you know, the other social events that are going on. And even if we don't sign fluently, there are people who are hard of hearing that go there. Many people are very willing to accommodate us as we are to accommodate them.

Isolating ourselves is not a good thing. If we isolate ourselves, then we're not going to get the self-confidence that we need to practice communicating with other people. As humans, we need other humans. Yes, it's easy to isolate ourselves. It's very easy to blame our hearing loss for isolating ourselves. But it's not going to help our emotional well-being, so it is important to try to get out there and to foster relationships with others.

Passing on our experiences. If you're single and you want to meet somebody, if you have another friend, you can ask, "Well, how did you meet your husband? How did you meet your -- you know, your wife?" You know, "how did you guys communicate?" "What do you do in this social situation? What do you do when you go to a school meeting and an interpreter is not available?"

You know, learning from each other in a positive way is a free and easy way that we can benefit our own selves. It's also important to pass on our experiences, because when we do good things for people, they're going to do good things for us too. It's all about karma.

I wanted to point out that our program, which is for deaf and hard of hearing people, has a website which has video clips in sign language and captioned on diabetes, breast health, HIV/AIDS, and STDs. We are developing a smoking cessation one also, and we're getting other grants through other big agencies such as the American cancer society to do our smoking cessation one, but we have some wonderful video that we can use for the deaf and hard of hearing community or to learn for ourselves about some things. A woman in here had told me that she does like a breast cancer support group, and that you're using videos to help with the education process. This website has a few resources for education that is free.

Any questions? Comments? Concerns?

AUDIENCE MEMBER: It's not really a question. I have a comment. I was a hearing person all my life. I lost my hearing when I was 60 years old. So, yes, I do feel in the middle, as you say, because I don't relate to the culturally Deaf, and I'm still, in a lot of ways, feeling like a hearing person. All of my friends are hearing people. But you find

out when you become deaf, really fast, who your real true friends are. Because some people, it's goodbye. You never see them again. But like you said, a lot of people are good, and they try very hard.

A couple of my friends learned sign language for me. Others speak very distinctly, and they learned the alphabet, the sign language alphabet. But I have a very large family, and as you said, at Thanksgiving, things like that are hard, because I have 30 people coming to the house Thanksgiving, and you just can't keep track of everything.

It's like concentrating so hard. It's stressful. Also, many people have more than one thing wrong than just deafness. I have NF2, so there are other things that I deal with, and I know a lot of people are in wheelchairs and can't walk or other things, so there's a lot of more stress that you deal with than just the deaf, but I've found this meeting very helpful, and thank you so much for your comments and help.

ERIKA LOHMILLER: Thank you. And I think it's great that there are good people that are our friends, and they do learn some sign language, and they do accommodate us. There are people that don't. But like everything else, in every tragedy in our lives, whether it's the death of somebody or if we're stricken with cancer or whatever, those are times that we find out who our real friends are. Who sticks with us and who doesn't. And it's not just becoming deaf; it's also a lot of other major life events in our life.

The people who are willing to learn sign language, a lot of them are very excited to learn. They want to learn! It's not a burden to them. And we can teach them. Children especially. They pick it up so quickly. My kids were starting to sign at 6 months, and it's just wonderful watching them learn that. So, yes, sign language is rough for some people, but it's not impossible, and there are a lot of people who are hearing that are willing to learn.

AUDIENCE MEMBER: You mentioned NF. Can you talk about dealing with the complexity of grieving not only with the sudden deafness but also with health issues related to NF?

ERIKA LOHMILLER: We go through the grieving stages and we talk about the certain stages with people, and a lot of times just talking about it and having a person give that unconditional, positive support is often very helpful for people that are dealing with any kind of grief.

Now, people who are deaf and hard of hearing, they have a rougher time when there's something like a medical problem, because there's a lot more of a process that they have to go through to get the education that they need. A person who is hearing that has cancer, they can find out through television programs or books or word of mouth from others, from doctors, from lectures, radio stations, whatever about their condition. People who are hard of hearing and deaf have a little bit of a harder time. So, because of that lack of information, the grieving process is often a little bit different. Is that answering your question?

AUDIENCE MEMBER: No. I'm thinking more of dealing with the grieving of the deterioration from the illness. The grief of the deterioration of the illness, Not the information about it, no.

ERIKA LOHMILLER: When somebody goes through a decline in any kind of illness, sometimes in order to help deal with that sadness a little bit better, getting information and education does help. Also, maybe going to support groups, you know, can help a lot. Getting books about that can help. Often, when somebody is grieving, they just need somebody to talk to, to help them through with some of their feelings of shock and denial and deep sadness.

Sometimes if somebody is very deeply emotionally sad, they may need medications to help them deal with depression or with grief. And that's for anybody. Whether they're deaf or hard of hearing. Anybody who has a tragedy or a chronic illness especially one that may be fatal, you know, they need all the help that they can get.

It's an individual process. I really think it depends on a person's coping skills that they have internally, whether they're an optimist or a pessimist, whether they see that glass as half empty or half full. It depends on an individual's support group. Some people have wonderful families that will rally around them, while other people don't. That's a very individual thing.

You had a comment?

AUDIENCE MEMBER: Yeah. One of your slides says, "How can we overcome the challenge of hearing loss." And I personally feel that we never overcome it, and I think what you really mean is how can we lessen the challenge of hearing loss. Because I've been dealing with this for many, many years, and I don't think I'll ever overcome it, but I sure try to fight it.

ERIKA LOHMILLER: I agree. Maybe a better title for this would be, "Coping" instead of, "Overcoming." Because you're absolutely right. You never fully do overcome. You never fully go through the grieving process. You never fully accept the fact that you're deaf or hard of hearing.

I think that as we go through our journey, those feelings of grieve can lessen, but they do come up, and you never do fully overcome them. And you really can't predict when they're going to come up. Everything can be fine one year for the holidays among some family members and the next year it might be a total disaster if we have an ear infection or people are not as understanding or the lighting is bad.

I agree with you completely that we never fully do overcome, but we can choose to be those survivors rather than just being victimized by it all the time. Choosing to cope and deal with what we have on a positive basis. But you're right, it does come up. It's never going to heal and resolve quickly all the time. Yes.

AUDIENCE MEMBER: I lost my hearing when I was three years old, so my whole life up until three years ago, I've been around hearing people. I totally agree with this gentleman that you never overcome. This follows you throughout your whole life.

ERIKA LOHMILLER: And because hearing loss is such a constant issue, we don't know what our hearing is like all the time. There are some times when communication is great because the lighting is great. And we're energized and we slept well. And then there's some times when we're sick or we're tired and we don't lipread as easily or people are not as accommodating. When there's a full moon and everybody has a bad attitude. It's harder to deal with a hearing loss than when we interact with people who are more friendly.

Yes. You have a question?

AUDIENCE MEMBER: I wanted to say about the Chicago hearing society, I called about the grant and I did get a call from my grandson's friend and a man came to my house to and I had an interpreter for that. I cannot get it to go to the doctor because the doctor has to pay. But you can call and ask, but you never know.

ERIKA LOHMILLER: If we ask, we just might get it. If we don't ask, and we just assume that nobody's going to help us, then you know what? Nobody will. Because people can't read our minds. It is important to do our homework and to ask and not to give up if we get a "no" right away, to keep asking, asking others what they did. Yes.

AUDIENCE MEMBER: Is it true it happens to other types of disabilities that it kind of follows them along, just like the hearing loss? As far as the grieving process? Does it always pop up?

ERIKA LOHMILLER: Absolutely. I mean, I'm not an expert on that, and I thank the Lord that I don't have to deal with going blind or a chronic illness. People who have any kind of disability or like a sudden accident, it would be the same thing. People who are in car accidents and they become quadriplegic, they have to deal with all of that loss and all of that grief, and accessibility and learning a whole new way of life all over again.

AUDIENCE MEMBER: Can you recommend other books besides Elizabeth Kubler Ross? She wrote the book on "Death and Dying" many, many years ago and I'd like to see some more current books that discuss this topic today.

AUDIENCE MEMBER: There's one excellent book written by Richard Cohen titled "Blind Sided."

AUDIENCE MEMBER: Yes, yes, yes. Excellent, excellent book.

ERIKA LOHMILLER: There's a lot of great books. There's a lot of great books that are written on suicide, too, and that's something that I'm researching more and more,

because there's a lot of suicides that seem to have been happening lately, and those also talk a little bit about some of the grieving processes. Not just for, of course. There are some very good books that are specific to grief from different medical issues that come up or other family members.

AUDIENCE MEMBER: I find that the acceptance of grief helps me through my healing, my emotional healing. And with Elizabeth Kubler Ross, the acceptance, the final stage and facing the truth, whether I like it or not, the fact that I can grieve through it is helpful. So I think it is applicable.

ERIKA LOHMILLER: There's a wonderful book, and the author's name is Meg J. Ryan and it's called "The Happiness Makeover," and it's really easy reading and it talks about the psychology of happiness. And it talks about some of the reasons why we are not happy or some of the reasons why we grieve, and about the universal truths in life that we learn, such as that life is not fair and that tragedies do happen, and accepting the good with the bad. It's a good book talking about just grief in general and our own conceptions of happiness.

AUDIENCE MEMBER: You're on my favorite topic, which is books, and one of the books that I've found most helpful is a book by a psychologist in California called Timothy Miller, and the title is "How to Want What You Have." He talks about the stages you have to go through to get to the fact of acceptance and what is on your plate in life, and I find him very, very common sense and very helpful to me and I would recommend that one.

ERIKA LOHMILLER: There's a poem that I really, really enjoy and I'd like to read it to you guys:

"Celebrate You."

You are worth celebrating.

You are worth everything.

You are unique.

In all the whole world, there is only one you.

There is only one person with your talents, your experience, your gift.

No one can take your place!

God created only one you, precious in his sight. You have immense potential to love, to care, to create, to grow, to sacrifice, if you believe in yourself.

It doesn't matter your age or your color, or whether your parents loved you or not. Maybe they wanted to but couldn't. Let that go. It belongs to the past. You belong to the now.

It doesn't matter what you have been, the wrong you have done, the mistakes you have made, or the people you hurt.

You are forgiven. You are accepted. You're okay. You are loved in spite of everything. So love yourself and nourish the seeds within you.

Celebrate you. Begin now. Start anew. Give yourself a new birth.

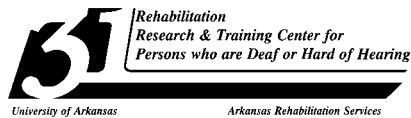
Today!"

So, my challenges for you for the day are to discover what your strengths are. What is inside you that makes you special? And to celebrate yourself today. And I'm challenging you guys to actively network with other people. Go up to people. Shake their hand. Find out where they're from. And who they are. And to challenge yourself to take what you have learned today and apply it to your life.

I don't have all the answers. I know some of these words are easier said than done. We always will have struggle, but hopefully we can apply some of this and improve the quality of our lives.

Biographical

Dr. Erika Lohmiller has a PhD from the International University of Graduate Studies in New York in Addiction Studies and Mental Health Counseling. Her Master's degree is from Northern Illinois University's Deafness Rehabilitation Counseling. Erika became more severely hard of hearing at the age of 16. She learned sign language for the first time at Hinsdale South High School. Erika personally understands the challenges of coping with a hearing loss and learning a new language. Coping with these issues, and not having a lot of emotional support at that time, has helped her develop a passion for helping others who have similar experiences. Erika has been employed as a psychotherapist at the Illinois Masonic's Deaf and Hard of Hearing Program for the last 8 and a half years. She has experience doing individual, group and family psychotherapy with Deaf and Hard of Hearing people and their families. Erika is committed to encouraging emotional strength and healing.



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