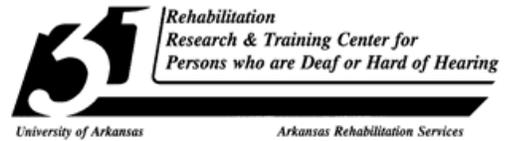




## Selected Proceedings of ALDAcon 2005



### All Over But the Grief

Presenter: MARILYN CALL

**Marilyn:** “A doctor said that you can compare grief to a physical illness. Both require intervention, and to recover both require a range of options. If you have a serious physical illness, and you have something like losing your hearing, or losing a spouse, something that really makes you go into a grieving cycle, you can end up at the end of that with a partial complete recovery, or you can be fully recovered, or you can just go down hill and be more damaged, and go into a progressive decline.”

Some people when they lose a spouse, they never come out of it. I know a woman who went into a depression when her husband died twenty years ago. She never come out of it. I think the same thing can happen when people lose something bodily, whether it's losing a leg, or losing your hearing, or losing your sight. Sometimes the emotional damage can be worse than the physical damage. Like, does losing hearing hurt? Is it painful? Not usually.

Is it painful physically? You know, that's kind of a trick question, I guess, because for some people it is painful physically. I have a friend, who has Meniere's disease, and he's lost all of his hearing in one ear and he's been sick every day of his life, basically, from the tinnitus and the balance problems, and he has **recruitment** where he hears soft sounds really loudly. So it can hurt, but most of us who become deaf, especially who do it gradually, it doesn't really hurt physically. In fact we don't really know it's happening, if it happens slowly enough.

But does it hurt emotionally? Yes. It can really hurt emotionally. So what I want to talk about today is to understand how much the loss issue, or the loss of your hearing, the loss of the ability to communicate impacts how we adapt to our hearing loss and also to understand the tasks of mourning.

I want to introduce kind of a different way of looking at grieving. When we grieve we need to have patience with ourselves, have patience with each other, because besides just going through the physical problem of losing our hearing, we are going through a

deep emotional process that we have to recover from again and again as it cycles, again, and again. And then I also want to look about how can we, knowing that some of that hurt will always be there and bubble up to the surface at times. We need to think about how can we take and reinvest the emotional energy that comes out of being really sad or really angry, and reinvest it towards something positive. Because we all have great gifts to give to others, and give to society.”

I am going to ask for eight volunteers. There are eight people in this room. So each of you come on up. And take some Play Dough. Yeah, choose your color. I want you to take out the Play Dough, and put it in a ball and hold it. There you go. Put it in a ball, then hold it up to me like this. Okay, this represents your, the grieving that comes with having a hearing loss.

Now, I want you to hide it from me. Can you hide it from me? Basically the point of this is, you can think you're hiding it, but you're not really hiding it. You can't really hide it in one hand. It squishes out. And think about that when you just, you want to pretend to the world that nothing is wrong, everything's wonderful. There's no problem with being hard of hearing. It's a piece of cake. It's a piece of cake to be late deafened.

Think about it, you may think you're fooling everyone if you never talk to anyone about the pain, or the grief that you're having, or never allow yourself to have a bad day. But it's going to come out somehow. Mine usually comes out when I want to scream at the clerk at the store for mumbling. Why can't you say your words so I can hear you? Or deciding I don't like my friend because she knows I can't hear her and she will not talk loud. Usually mine comes out in anger, but I don't do anger. You know, so I just keep it all inside, and then it comes out as stress or sickness. Think about that, okay, how when you try and hide the fact that all isn't perfect when you have a hearing loss, it comes out anyway somehow.”

Okay, now, keep your Play Dough, and while I'm talking you can play with it, and think about things, but the last ten to fifteen minutes of this workshop, I want you to make something. Well actually the last ten or fifteen minutes I'm going to have you come up, talk into the mike or sign, whatever you want, and I want you to make something that represents the grief, the emotional struggles that you've had, and how you turn that into something positive. How does your journey through hearing loss become a positive impact in your life? So just make something that's representative of that.

I really love the kind of the metaphor of the 'iceberg'. When you think about hearing loss, I mean you know 20 percent of the population in the United States has some form of hearing loss. A lot of it, I mean most people aren't anywhere nearly as severe as those of us in this room, but they have hearing loss. And so society knows about hearing loss and hearing aids. And if you look at the tip of the iceberg, most people think, okay, you're losing your hearing, and go to an audiologist, get hearing aids. So the tip of the iceberg is what the world thinks of as hearing loss.”

I can say I'm hard of hearing, and people don't really know what that means. It could mean that I have a mild hearing loss and I can hear you just fine even in a big room. You might say the same thing to someone, and you might really have a profound hearing loss, and only under special conditions could you hear another person. Or you depend on lip reading. So think about the tip of the iceberg as what most people know about hearing loss. If they're lucky they'll know, well, if we provide an assistive listening devices, the person who's hard of hearing can probably participate a little bit better.

Down below underneath, is a little bit of the iceberg which I describe as the level of knowledge and emotional understanding that people have who are like members of SHHH or members of ALDA or have gone to a few classes and learned things such as how to manipulate the environment and choose to communicate with people one on one and getting the best seat in the restaurant. They learn communication strategies. And all of that is so helpful. That alone can change your life if you have a hearing loss, especially if you can teach those around you those same concepts.

But if we go all the way down to the bottom of the iceberg, this is what's not talked about very often. You know, has your doctor or your audiologist, your ENT, ever told you how to live with being socked in the gut two or three times a day when people ignore you, or say things like "Oh, tell her that this happened". You know, that type of thing. That little subtle discrimination that each of us have to go through and feel every day, and yet somehow buoy ourselves up despite it ongoing repetition.

I think I've seen that discussed here at ALDA more than anywhere. I've been to several SHHH conventions and I've never heard it discussed. But here at ALDA it's kind of like you're my family, you understand, you know, you've been through it too. What do you do when you've had a day like that and everyone at work has ignored you because they're too busy or they forgot to tell you about the staff party? And it is here, at the bottom of the iceberg that it hurts the most from the subtle discrimination, because it is here that we don't get any help and acceptance, except for through a support group like ALDA, I don't know if everyone has one locally or not, having a family member or a friend that you can just be honest with and just say, you know, look, I know most of the time, 98 percent of the time I pretend like everything's okay. But today it's not. You know, I'm just sick of not being able to understand anyone, and let a friend listen to you having a pity party for an hour. That's okay. That's part of grieving. One of the ways we get through emotional trials is to talk to someone else about it. Instead of, like, our luncheon speaker (See Presidents lunch transcript of Dr Gabriela Frank) said just stay in denial and pretending to the world that it's okay, that it doesn't hurt.

Most of the time we can do that, but once in a while we have to go deep. Whether that is if you have a counselor or a therapist or a clergy person, or a friend. It's important that you talk about what you're feeling."

One thing to keep in mind that while other people may not have had, have lost their hearing, everyone has lost something. There's no life experience that's more common

than loss. Whether it's losing a friend, losing a parent to death, losing a child, losing a leg, losing our sight. There's just so many ways we can lose things, and the reaction is usually the same. When we have a loss, even if it's just a little thing like losing your wallet, or losing, I mean when you think about it, losing your wallet in this day and age, it's horrible because people steal your identities. Twenty years ago losing your wallet was no big deal, you know? Everything could be replaced.

I heard a speaker say one time that if a problem can be fixed with money, it's not really a problem. But the problem is, even though every person in society is grieving over something, we don't talk about it. We just really don't talk about it. I remember when my dad died, and I got three days off work for bereavement leave. Isn't that a joke? In our society, bereavement, do it in three days. I wasn't even feeling the reality of the situation in three days. I know when my sister-in-law died, I tried to go to work in the middle of two days and in the middle of a staff meeting I just exploded and finally could cry for the first time. But you know, I'd had my leave that was due to me. That's kind of how we are in the western society. In other societies it's not like that at all. They have all sorts of rituals, and you can dress differently for a whole year so people know that you're grieving.”

Now, can you imagine us, every time we lost another 5db to 10db of hearing, and we are grieving? I mean I've just gone through that recently where I can't pretend to be hearing in very many situations any more. Not even with a group of three people. I'm going to have to get brave and get an interpreter. But for many years, because my hearing's been going down gradually, in certain situations I was able to function very much like a hearing person.”

But can you imagine putting on a cloak and ashes and painting my head, painting black things like some cultures do, so people would know, hey, I'm grieving this week, or this month. We can't even do that. And if you try to explain to another hearing person that you've just lost your ability to hear your child, they really cannot understand. They really can't.

It is because of my hearing loss that I really started to want to study grief. Let's see, 29 years ago I had my first child, and we didn't know for a few months, but we knew within six months that something was really wrong, when she didn't progress, she wasn't sitting up, she was barely holding her head up a little when she was six months old. And we started going to the neurologists and getting bounced from this doctor to that doctor to that doctor. And basically, over a three-year process we found out she was deaf, and then we found out she was autistic. Now, as an adult, she has also been diagnosed as having bipolar disorder and OCD. But it was when she was a child and we were gradually learning all of these things that were wrong with her, and then as soon as we got the autism diagnosis for her, I had had my second baby girl, and we found out she was deaf. And we kind of assumed that deafness was all that other stuff, too, that was going on with the autism.

But anyway, somebody sent me a poem that just really made a difference when I was going through the depths of grieving over the fact that my children, my life as a mother, was never going to be what I thought it would be. I wanted a large, you know, I'm a Utah Mormon, I wanted a large, normal family. And that just wasn't going to be for me."

Anyway I want to read you this poem, and I usually bring copies of this. This is called 'Welcome to Holland' written by Emily Perl Kingsley © 1987.

"When you're going to have a baby, it's like you're planning a vacation to Italy. You're all excited, you get a whole bunch of guidebooks, and you learn a few phrases of Italian so you can get around. When it comes time, you pack your bags and you head to the airport for Italy. Only when you land, the steward says, "Welcome to Holland". And you go "Holland?!?" You look around at each other in disbelief and you say, "What are you talking about, Holland?? I didn't sign up to go to Holland. I signed up to go to Italy!"

"But they explain that there's been a change of plans, and you've landed in Holland. That's where you must stay. But you complain, but no, I don't know anything about Holland. I don't want to stay. But you do stay. You go out and you buy some new guidebooks, you learn some new phrases, and you meet people that you never knew existed. The important thing is that you are not in a filthy, plague-infested slum full of pestilence and famine. You are simply in a different place than you had planned. It's slower paced than Italy, and less flashy than Italy, but after you've been there a little while and you have a chance to catch your breath, you begin to discover that Holland has wind mills, Holland has tulips. Holland even has Rembrandts, but everyone else you know is busy coming and going from Italy. And they're all bragging about what a great time they have there, and for the rest of your life you will say, "Yes, that's where I was going. That's what I'd planned." and the pain of that will never, ever go away. You have to accept that pain, because the loss of that dream, the loss of that plan, is a very, very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you will never be free to enjoy the very special and the very lovely things about Holland."

I just think that could be so easily converted to discovering you have a hearing loss. I might mention that, this was written by the mother of a child who has Down syndrome. Down syndrome kids are usually, once you get through the first two years, quite pleasant and happy. A mother who was given this poem and her child had autism, she rewrote it and said, "Welcome to Beirut". I thought that yeah, that was it. I mean raising an autistic child is very, very difficult. But losing your hearing is very, very difficult. But to me, that could be more like just ending up in a place you didn't plan to be. Learning a new language. I mean there is so many comparisons in this poem.

I heard someone mention in another workshop that they would look at deaf people, you know, since I loved the way I. King Jordan said 'I had to learn how to become deaf, and how that is usually much harder than being born deaf'. And I heard someone in a different workshop say, you know, I'd meet deaf people and they were just doing fine. They didn't seem to have any of the problems that I'm having. And I have these two

deaf children so that's not necessarily true. I mean there can be a lot of the hurt and rejection when you're deaf and growing up too. But the one thing that's really different is that they don't have to learn how to become deaf, and that they don't know anything different. So in many ways they have the hurt, they have to be used to people staring at them and being marginalized and overcome that. But on the other hand, they don't have to; they don't miss what they never had. I mean my daughter asks why does everyone like music so much? She can't understand why people would like music so much, because it's very boring when you can't hear it, or can't hear it very well. Whereas I know, people that become deaf, that is probably one of the hardest things to lose, is access to music. But how we look at deafness, or look at hard of hearing, will really influence how we adapt to it."

Signing when you first see it can look crazy. I remember when I saw the first person I ever saw that used sign language at Lagoon, and it was just a really weird experience when I had deaf children, and I thought about using sign language, that that memory just came back to me like, 'No, I can't have deaf children. Deaf children are weird. They're going to have to be, you know, doing that and everyone's going to stare at them and they're going to have to go live at the school for the deaf and be isolated.' Luckily it's not that way any more, and it wasn't that way when my children were born."

But how you adapt may be very much colored by how you looked at deafness or hard of hearing issues. If as you were growing up you kind of looked at hard of hearing people as kind of stupid, they talk weird, and you had some of that going through your mind, then you're looking through this window of that's your perception of how deaf or hard of hearing people are, and then it happens to you, happens to me, you really have to do some work to overcome that and realize that not everyone has that same window that you do.

Not everyone does this I have actually have met people who want to have deaf children. They want to. They think they're so cool, and so this is your window, and you need to challenge those perceptions. And realize that not everyone in the world is going to think the same way you thought.

There are other things that make grieving hard, and I'm just going to skip through these. But I mean like if you're a musician, and you lose all your hearing, that type of lifestyle and job, I mean I just, Wow, I can't say her name but our speaker on Thursday.

**Audience:** "Gabriella Frank?"

Wow, I just feel like the conference was worth it just hearing the speakers that we had. I feel like I learned so much from her to bravely carry on in the field of music when she has so little hearing. If you were most people, that would just devastate you. Just like in that movie Mr. Holland's Opus, it was so devastating for the dad to have a deaf child when his whole world was music.

If you happen to go through losing your hearing when you've also got another health crisis, or if you're going through, you know, a divorce, or because of your hearing loss you go through a divorce, there are so many things that can just make the trauma so much harder. Sometimes I wish that God would let us just do one challenge at a time. But it often doesn't work that way. You know, in fact, I always have had these little rules that I thought, okay, because I have two children with disabilities, then I had a bad accident and almost lost my leg so I couldn't walk for the last 15 years, now I can because I've had a knee replacement, but I thought, that is enough. Nothing else bad is going to happen, and we should be rich too. You get these little rules about life being fair. You think that if you have this much, there's going to be that much to compensate. And life just isn't that way. It's not that way.

I've met a lot of people at this conference who, besides having their hearing loss have multiple health challenges, and they just somehow have gotten through that grieving process, which has probably challenged them on every side, and seem to feel okay about themselves and happy and energetic and are doing things to change the world.

Some people, maybe your friends, you want them to come and join ALDA and to be more up front about their hearing loss, but they can't. We all come from different places. We all have those different perceptions, and we all may have other things going on in our lives.

We may have gone through something horrible before and come out on top, so we know we can do this too. Maybe another person went through something horrible before, came out on the bottom and they're not wanting to try again.

We also need to think about, when you just say, I just feel a lot of grief because of my hearing loss, it's not really our hearing loss, is it? That's kind of the umbrella. But what are the things that really underlie that loss?

**Audience:** I've been underemployed and unemployed for many years as a result of that. So that's my self-esteem and my income.

**Marilyn:** Okay, that's a huge one. You lost your job and that was tied into your identity, and your money, how you're going to support yourself. And that happens to so many people with a hearing loss. It's really a shame. And hopefully society is going to be less that way. I mean you hear about, well there's deaf doctors, there's deaf this, there's deaf that. Well, unfortunately the majority of us don't have that situation.

What are some other intangible losses that we face because of our hearing loss?

**Audience:** Losing part of your health.

**Marilyn:** Losing part of your health. Okay, did that go with your hearing loss or you lost another part?

**Audience:** No, that's without the hearing loss.

**Marilyn:** You lost a different part of your well being and your health.

**Audience:** A couple of years ago, I got back pain and I had it for a year and all of the sudden it went away.

**Marilyn:** Oh, wow. That would be very difficult. And I think so many of us, we tie our self-esteem and our well being to how well our body looks and how well it functions. You know, I still buy athletic-type things, thinking I can do them. I went and got some roller skates. And I couldn't stand up on my roller skates for one minute. But in my youth, and before this accident, I was like a P.E. Major type of person, and I know those people that work with me in this room would never believe that because I trip over everything. But you know that's my identity and I forget that that was maybe 30 years ago since that was it. But really, our bodies are very much... they're tuned, our identity is very wrapped into how we look and how our bodies function."

Anything else? What else do you lose?

**Audience:** When I was younger and I could hear better, if I had a problem I could go to support groups. Now the support group itself is more traumatic than my hearing loss because I can't... it is just such a struggle to learn from other people's experiences.

**Marilyn:** Okay, that is like the major thing, where every communication is a struggle. All of the supports that you used to be able to depend on, you no longer can, even if it's a best friend who can't project their voice. Or even if it's like support groups, family, yeah, it's just... it's those kind of things, it's the ability to communicate easily with a great number of people. It's what we can't do any more because we can't hear."

Okay, one thing we really need to remember is grief is our reaction to what happened, and it's actually a great process that we can go through that makes the pain manageable. And when you talk about that usually the first reaction is denial, and the strongest reaction is denial. We should be so grateful for denial. We need to be very, very grateful for denial. I mean can you imagine having to accept all in one day that you've lost your hearing and it's not coming back? I mean can you imagine that? It's like too much. When someone you love has died, your body would shut down, you might die too if you had to somehow process that, that it really happened, all at once. We can't, as human beings we're not made to do that. That's why, really, it's a God-given gift that we have denial, that we're able to deny things until we can start understanding, oh, yeah, this has really happened, and gradually learn to deal with it and change our life.

The grief reactions, they influence so many things. Sometimes we think they just influence how we feel and they make us cry. But really, so many things, physical

sensations, health problems, affect us when you're grieving. Just being so tired you can't even get out of bed and face the world another day. So many times when someone dies, especially if it's a spouse, the spouse dies within a year, just from grief. They literally die of a broken heart. Perhaps if they let themselves grieve in a more healthy way, they wouldn't die. You know, it's hard to say for everyone it's different.

But also our thoughts and our behaviors are really influenced by the grief process that we're going through. When you're feeling down and feeling like you just can't do it one more day, you can't go out to dinner with your friends one more time, your hearing friends, or go to another family function, you may just be in a really hard part of the grief cycle at that time. And you have to sometimes let yourself say, fine. You know, I can't do that. I'm just too tired, too worn out, too sad today and I'm not going to do it, and do something different. Stay in bed all day. Read a book. Whatever it is that will help you, that builds you up. Do some of your favorite things instead of doing what everyone else expects you to do to go and pretend like it doesn't hurt to be left out of the conversation. Once in a while we have to be selfish and do what meets our needs.

It influences our behaviors, like I said, getting angry at something that's really just the tip of the iceberg type of thing. Like deciding I hate that person because they don't project their voice. Well, that's really... and basically feeling sorry because I feel like that, my friend doesn't really care for me. If she really cared about me, she would change the way she spoke. She would talk so that I could understand her. And in reality, nobody can change the way they normally talk, just like that, because you happen to be deaf. You know, the way they talk works for most people all the time. So you have to keep reminding them and reminding them. And it's a chore.”

“I told you I was not going to spend time on the Kubler-Ross stages, because most of us know them. But I keep saying stages of grief. I'm trying to train myself to think of the tasks of mourning instead of stages of grief. Like in Kubler-Ross, it talks about, and we all knew these. These stages, and usually they're presented as little circles, and when you think that way, you think, well I'm going to go from here to here to here to here to here, finished. And I just have to wait, you know. Until I get through the denial and wait until I get through the bargaining, wait until I get finished with the anger, the guilt. Maybe in a year I'll be finished and then it will be over.

Well that's really not how grief works, but it's good to be aware of these things that you will go through. But it's not like: stage one, stage two, and stage three. Everybody's different. Another psychologist, Bolby, said ‘Well no, you don't go through stages, you really go through phases.’ And he said, ‘First you'll feel numbness, then you'll feel a yearning for the life you used to have, then your whole life will feel disorganized and you'll feel despair, and then all of the sudden, not all of the sudden but eventually you will reorganize your life, reorganize your behavior, and things will be fine again.’ Those are all things we recognize, right?

**Audience:** I just had a quick comment. One time someone was presenting this list, and someone misheard one of the words, 'bargaining', they thought they were saying 'tobogganing'. And I just loved it. Because I thought, you go through a couple of stages and then you go 'tobogganing'. And it changed the whole thing for me. That's kind of what ALDA is too. You have to remember to have fun somewhere along the line. Now when I look at that and I always think 'tobogganing', and that's my reality because of a misunderstanding. And it just added so much to that.

**Marilyn:** Thank you. That is really cute. And maybe 'tobogganing' would help. Maybe after shock and denial we should all go 'tobogganing'. That is really funny.

**Audience:** Also hobbies, change environment, it depends on the situation. Like me, when I lost my grandson I had to change environment.

**Marilyn:** To get over that.

**Audience:** It's hard.

**Marilyn:** Yeah. So that's a really good suggestion. Did all of you see what she said? Just to change, sometimes you have to change your friends, change your environment, or you can just get stuck. You know, to get un-stuck, you have to have something new to look forward to.

One thing I'd like to suggest that I found is when you talk about the stages, if you talk about acceptance, I think of percentages. I think you're still maybe 5 percent in denial, and you might be 10 percent in anger, and you might be 80 percent in acceptance, but I think you are in all those stages at the same time. And like you said it's not going from one stage to another, they're all there, but in a different percentage.

**Audience:** You know. I really do like that. I think that would help, too, if it were presented that way. Because isn't it amazing how, well especially at ALDA, you can feel so good about yourself, and think I have finally gotten to acceptance. And you might go home and your first day at work or wherever, something horrendous happens, and you just, you 'Go-Boom!'

**Audience:** My statement would be to somewhat to follow up somewhat on hers, and I think it's very important to just find whatever few positive things you can do, and do them.

**Marilyn:** That's a healthy outlook.

**Marilyn:** I want to introduce you to this other way of looking at grief, and many ways of looking at it as tasks to accomplish. I want to do that real fast and then I want to use the last ten, fifteen minutes for each of you to come up and show your, what you've created

out of your Play Dough. So if you haven't created anything, you need to do it. Okay, and you're going to have to come up and explain.

**Audience:** What if you can't do it? I was never very good at Play Dough.

**Marilyn:** We don't have to know what it is you've made, okay? Just can you think of some sort of symbol? I think you two came in a little bit late, but I wanted the Play Dough to represent the emotional issues, the grieving you've gone through because of your hearing loss. But I wanted you to make something that could symbolize how you've come out of it, how you've gone through the grief and found positive things to reinvest into life. And you can tell us what it is. It can look like a rock, but you can say, 'This is a mansion,' okay? It doesn't have to be good. I mean it doesn't have to look like what you want it to represent. And if you don't want to participate you don't have to.

There's a book that I bought as a counselor by a man named William Wooden, and he kind of takes the... looking at grief, as there's certain tasks that you have to be able to come to. So instead of like being in denial, which we all are, and it's a great gift, you eventually, to get through grief you have to accept the reality of the loss. We eventually have to accept the fact that we're probably not going to get our hearing back, we might get an implant and it might work wonderfully for us or it might not work. And we have to come up with different things we can do to be okay about having a hearing loss and learn how to communicate differently.

Then we need to take the time to work through the pain. So many of us are afraid to actually kind of go down to the bottom of that iceberg, and to cry, have a day where you're just crying and crying and crying, or you just need to talk to someone. We're afraid of that so we'll just stay so busy, or just so focused on something that we never let ourselves get there. And after you've been to the bottom, and you've actually had some days where you've just had some really good cries, or pity parties, you usually come out feeling a lot better. So you've got to somehow be able to feel the pain and to work through the pain.

And then this one, you know, he's really wrote this book for counselors who work for people who are dying or their loved one was dying. But I thought this is so perfect for our group. You need to learn to adjust to an environment that's different. There's many ways we all do that. I love ALDA's philosophy, 'that anything to do to communicate that you can do that works for you, works'. You know, we'll do anything to communicate.

And then withdraw that emotional energy from grieving, and from that loss, because when you're angry or sad, or just having to make a lot of changes in your life, there's a lot of energy that comes from that. But instead of just using it to, on negative things, we need to learn how to use that energy for positive things that can make us a better person, that make the world a better place. And in reality, isn't that what this group is all about? I mean I see ALDA doing so many things to support each other, but also to

make changes for the world, that benefit the world. And I'm not saying all of us have to go out and change the world.

**Audience:** I particularly like that balance between withdraw the emotional energy, and reinvest it. The wording of that is just so great. I'm going to use it.

**Marilyn:** I really like these words too. When you're having a really bad day, just this one sentence has helped me so much, when I just feel like I don't want to go on any more, that's probably on page, it's the bottom of page 6. If I could tell myself, you know, I really feel like crap today. I don't want to do anything. And I mean what I just... it's so dumb, I tell myself all the time, with my autistic daughter, she still lives at home and she's almost 29. And she goes through these periods where she's very depressed, which I feel bad, but it's actually easier because she sleeps a lot, and then she goes manic, and it's just awful.

I mean you should see what my house looks like right now. She cuts up things out of catalogs and gets every book off every shelf and doesn't sleep. She's been going through that this week. And I just, I just sometimes in my brain I just feel like, I can't do this any more. I can't do this any more. Well, in reality, I have to do this any more. You know I'm not going to kill her, or I don't think she's going kill me soon. That's not very good self-talk. Something better to say would be, 'I won't always feel as I feel today.' I won't. Sometimes we're afraid that when we're depressed that we're going to feel like that forever, and we're not. We might wake up the very next morning and feel good and want to go do something new. And so that helps me to let myself actually feel how I feel today, because I realize I probably won't feel that way tomorrow. If I take care of myself, if I do things that reinvest and fill up my cup, I won't.

I have to say something about this real fast. I found in some of my research, I just love using the metaphor of Ivy, symbolizing grief. I was reading about Ivy, and Ivy representing us, it's ever lengthening, it's intertwining, it's always green. But when you cut off a branch of Ivy, the plant, it feels pain, and it remembers that that part was cut off, and it will never, ever grow anything out of that shoot again. But it will grow off in a different direction very beautifully. I don't know if other plants are like that, but that's what Ivy does, and that's what we need to do.

Okay, this is some of the books that I've read that are really, really good. But I have one more. It's called *Broken Open: How Difficult Times Can Help Us Grow* by Elizabeth Lesser. She is a a of a life coach, but she writes, basically, she's collected stories from all of the people she has worked with throughout the years. And she writes the most beautiful stories of people who have gone through a very difficult situation and come out of it better. I would highly recommend that book.

**Audience:** Marilyn, Michael, is this the psychologist in Boston, Michael Harvey?

**Marilyn:** Yes.

**Audience:** I've read his other books that deal with a lot of issues related to grief and emotional impact of hearing loss. What's the... the one 'Listen with the Heart', is that mostly on grief?

**Marilyn:** "Yeah, that is also on stories and relationships of people with hearing loss. He has done a lot of work and extensive study. Beautiful stories of people he's worked with.

Okay, who wants to volunteer? We have about ten minutes. Who will come up and show us their Play Dough, and explain what it means to them?

**Audience:** "I'm going to go back a page. That number 4 really hit me hard."

**Marilyn:** "The withdraw and reinvest?"

**Audience:** Withdraw emotional energy from grieving the loss and reinvest it into life. I made an 'I Love You' sign.

**Marilyn:** Look at that, it's wonderful.

**Audience:** The reason for that is, I was born and raised hard of hearing. In both ears, I was very independent, I was never involved with deaf or hard of hearing people, and I thought I was fine. I had three children, and I live on the farm. Then one day, January 2000, I came home from shopping for groceries, and all of the sudden my world spun. And I don't know what happened, but I must have passed out. But from that day on, everything changed. I put my hearing aids on, and my balance was off. I went to my doctor, couldn't figure out what was wrong with me. Then I noticed my hearing was going down. I thought, okay, wait a minute. 70 percent hearing loss, I'll have that for the rest of my life. But I didn't. So I lost my hearing in my right ear, six months, 18 months in my left ear. I totally freaked out. I thought, why is this happening to me? I was so wrapped up in my own world. I didn't have anything to do with anybody. But who helped me? My husband. He's a wonderful man, and I miss him a lot. I always talk about him.

He looked at me and he goes, 'Honey, look. You can lip read. That's a positive.' He tried to get me back on track. I was going down hill. He was trying to get me back on track. 'You know, listen, you can read. You can read'. My dad had this motto, 'Keep the brain busy. Learn'. That's why I went back to school, got my bachelors degree. That's when I became involved with deaf, hard of hearing people, late deafened, deaf-blind. That's when I learned sign language. I reinvested, from my hearing loss from negative to positive. And it changed my whole life, all because of love from my husband.

**Marilyn:** That's a great example. Who wants to be next?

**Audience:** I'm not nearly as creative as Robin. I have been wearing hearing aids for 49 years, and have had basically a progressive loss that began as moderate-severe and now it's profound. I think more of what I've been dealing with was the disappointment about some of the things that I was no longer able to do well in my public relations and communications field. But I've always been an educator, and I've always shared knowledge with people. So there came a point, maybe 20 years ago that I started looking for other ways to work with people and share what I had learned. Especially since in the mid '80's I discovered SHHH and ALDA, which really filled in that level of the iceberg with the information about coping and strategies and so forth."

And I, too, went back to school, starting in 1996, working on the psychological and social impact of hearing loss on, and that people with hearing loss and their families. And then I decided, I went back and got, as a very late student, I was older than my professors, I got a masters of science in counseling. And I created this Play Dough, which I don't think I've seen in 70 years, which represents a 'vessel' that holds the knowledge that I have. And you know, I feel that I'm sharing it with others in the presentations that I give, and in the work that I do with groups, and you know, doing seminars and so forth. So that's my Play Dough.

**Marilyn:** Thank you. Well, and both of you deserve a big congratulation for going back to school with a hearing loss. I, too, did that and it is very, very difficult when you can't hear. And when you're just learning to read an interpreter.

**Audience:** Okay, actually this can represent a couple of things. It can be a 'muscle' for strength, and it can be a 'mountain' that I'm still climbing. And I have NF, too. And so in the back of my mind I always knew that some day I would, you know, lose my hearing. I lost hearing in this ear, maybe about 36 years ago. But it wasn't a problem. The only thing was I couldn't hear stereophonically. And when my kids would say, 'I'm here, Mom,' I didn't know which direction to look. This ear I lost five years ago. So I've essentially lived all my life as a hearing person, and all of my friends are hearing people. And we don't have a chapter of ALDA in Miami. So I've been coming to the meetings for the last four years."

But I had belonged to a book group for maybe 12 years. I really liked it. We read books that we would never read by ourselves, because they were good for discussion. And I missed it dreadfully. So I've been working with someone, learning sign. But I'm very slow. I think when you get older your head is full of junk, and you don't learn as fast as when you're a child. But anyway, I have someone I have been working with and I talked to someone in my book club and I said I think can I come back with that person as an interpreter. And they said that sounds nice. And then they all took a vote. 'No'. They didn't want me to come back with that person as an interpreter, because I had given her name to someone else who was losing their hearing, and she was working with that person on lip reading."

And she said, what if I say something bad about my husband, and that person will hear? And she comes to our house. I said she's professional. She works with these things all the time. Well, they said to me, I can only come back if I brought a strange interpreter. Someone I didn't know, someone who knew my level of signing, which is pretty bad. And I went home and I cried for three days. Because I thought these people were my friends. And I found out some of them were not really my friends. But three of the people called me up and said we want to start a mini-book club with you. And it made me feel so nice, you know, that they cared. But did make me stronger in that I realized, you know, not everybody is who you think they are, you know, from their outward appearance. And I found out there's some people that stand by you."

**Marilyn:** That is wonderful. And I found that same thing when I had this monster daughter with autism. A lot of my friends didn't stick around any more. But the ones worth knowing did. And that made it worth it.

Now, I see a couple of people on the front row, are you ready to share?

**Audience:** I kept changing my Play Dough shape many times, I just couldn't find something that really sunk in. First I started out with an 'ear', kind of like honoring my hearing loss, and acknowledging the loss with the hearing, but also accepting that the hearing is still there with whatever's left of it, and moving on, to mashing it up and writing the word 'trust', emerging from a pile of stuff, a pile of junk, and that that 'pile of junk' is the grief that I've had, and that the trust comes out of it, that the process will come back again that I had gone through this. But I mashed up the dough and then, created a 'spiral', which is symbolic. That process of trust and the process of healing and grieving and mourning and reinvesting and withdrawing and reinvesting.

So the trust isn't, I have to remember that is there, that when I'm in that really low place, that there is hope. That's what the spiral still symbolizes. It's really powerful. It has a lot of meanings, birth, death, life, and rebirth, things we're all going through. And I have gone through losses with my hearing, also a grieving process losing a friend, one of my best friends I've known for 10 years, I had a falling out with her, and just kind of experiencing as I go through these steps has been helpful. And I have some hearing issues related with her on that too. It's not just a hearing loss, it's the loss of the friendship, loss of changes, and reinvesting that from, I was in a woman's group of all hearing people, and now I'm in a group of all hard of hearing women, which I feel I really needed to get back to. There's hope out there.

**Marilyn:** Thank you, that 'spiral' is beautiful. We probably... I need to look at the time. Who else wants to share?

**Audience:** I have a short one. I'm just going to tell you, that my dough is supposed to be a 'book'. The best I could do for a book. And it was part of the grief for the way I've looked at it in terms of the changes after my hearing loss, is reinvesting that into knowledge and learning new things. Knowing that things are different all of the sudden,

and to make things better would be for me to learn new things. I lost my hearing when I was 15 years old, so I was right in the middle of high school, and the decision to go off into college and that stuff that a lot of people have gone back into going to school I thought was the best thing for me. To give you the confidence that you're getting something, you're moving forward with each part that you learn. You're better off after you learn something new than if you just sat still, turned the TV off and sat in the couch and didn't read a thing and just ate food, you don't get anywhere with that. So by going forward and learning new things is what I made this for, and that's how I've been getting through everything.

**Marilyn:** Is there anyone in this room who doesn't love to read? Does it come naturally with losing your hearing? How many love to read? It is great to have that.

**Rebecca:** Hi, my name is Rebecca, and my artistic development got arrested in preschool with making snakes. So that's about what I can make with sculpture. So what I made was a 'braid'. This 'braid' has the three parts to represent my three identities. One of them is a hearing person, because that's how I started out with a very mild loss as a kid. I don't know that, but I know I had enough hearing to acquire speech pretty easily. I got my first hearing aid when I was 21.

I grew up with hearing culture. I wasn't mainstreamed. I had no accommodations in school. I have no idea how much I missed but probably a lot. Then my second identity was hard of hearing. When I got my hearing aids I became dependent on this machine that really kept me connected with people. So that I could put my head down to take notes in college without missing what the professor said. That was cool.

So my hard of hearing identity, I had some 21 to, let's say, 45. And at that point I lost so much of my hearing, it just progressed and I couldn't use the telephone any more. Three years ago a hearing test kind of went way down low, and I thought 'Oh, deaf.' Okay. That's where I'm going. And that was really scary to me. But in the last three years, especially after learning sign language, now I'm okay about it because now I know where I will live when I lose the rest of my hearing. I'm not afraid of deafness any more. And that's huge to me."

So what I like about this is that this thing breaks real easily, and this one takes maybe a little more effort. So I feel stronger with these three identities."

The other thing is I can hop from one to the other. I get tired of hearing people. They just don't get it. So I get tired of them and I need to hop to another identity. With hard of hearing people, my signing and my identification with deaf communication interferes with that identification sometimes, and I just feel like I've gone beyond that in terms of what my needs are.

In the Deaf community, most of my socializing now is with deaf people and I love it, because they just, they have more fun than I do. And so I like that part. But I also get

tired in the Deaf community. I miss my English. I miss my love of reading. I miss not being able to share that with some of my deaf friends, so I can't stay there too long either. So now, I'm very comfortable not fitting really well into any of these three worlds. But I can land in one for a while and jump to another. And that really feels safe to me. That feels like I've got three places to belong instead of one place, the hearing world, that I don't belong.

**Marilyn:** “Thank you. That was beautiful. I want to share with you one of my favorite quotes. ‘There's nothing predictable about life. Everything changes. Life is always changing. Growth is optional. We can go down in the dumps and stay there, or we can choose wisely and go down in the dumps for a little while and come back up and reinvest that energy’.”

Marilyn Call is director of the Utah State Division to the Deaf and Hard of Hearing. She has an adult onset progressive hearing loss. Two of her children were born profoundly hard of hearing. She received her Masters Degree from the University of Utah in Social Work and is a licensed clinical social worker. Her goal to become a therapist in private practice has been put on hold while she serves as Division Director. She has presented workshops on hearing loss at several national conferences. Her prior work experience includes 15 years in disability advocacy fields.