

SURVIVAL TIPS FOR FAMILY GATHERINGS

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We all have this idea that every time the family gets together, it is going to be like a Normal Rockwell painting. Everyone will be happy and enjoy each other. But quite honestly when we are around our family, sometimes it's very stressful, because we have so much trouble getting people to understand our communication needs. Often times we don't see our family very often and they simply don't know any better. It's frustrating. It is hard enough when it is work related, but when it is your family you think they should know better—and it just makes it that much more frustrating.

So we are going to talk about are some of the problems that come into play so that we can understand why communication is so difficult in these settings. We are going to talk about some of the reasons that we have difficulty talking about what we need to understand speech, and also what lip reading does for us and what it doesn't. We will also talk about some ideas and strategies for recruitment.

Hard of hearing people feel isolated in a crowd. We all know what that feels like. Sometimes I get so lost in a conversation that I don't even know that the subject has changed. I don't know about you, but the thing that drives me crazy is when you ask what is going on and they say: "Nothing." I have a really short fuse for that.

We all have coping techniques that probably aren't very good. There are three techniques that I identified that we make a habit of that are not particularly good. First, is the "Bully method." This is where no matter what the person says we keep saying, "What did you say?" If they say, "Nothing, it wasn't Important." We say: "Yes it was. It was worth saying once. You will say it again." And then they feel like nervous, okay. They repeat it. And you know, the joke is never as funny the second time around. Especially then those with you are feeling so distressed. And then we feel badly because, it really wasn't worth repeating. But we made them do it. When we do this we make our hearing family members afraid to speak to us at all because we are going to make them repeat it over and over and over again.

The second is what I call the "Me method." Somewhere along the line we discover if we are talking we don't have to listen. And then we discover that the party wasn't nearly as stressful if we did all the talking. It makes it easier for us because we don't have to listen. But later, we find out that somebody's cousin is getting married and they didn't tell us. We didn't give them a chance. So maybe it's easier when we do all the talking, but we are still not getting any information. So we are still left out.

And then the third is the method I call “I am gone.” This is where we pretend that we are almost hearing. You know how that goes. When somebody says something and we don't get it at all. And we say “uh-huh.” And somebody says, “Did you hear what I just said?” “Oh, yeah, yeah.” We miss the punch line completely but everyone else in the room is laughing so we say, “That was a good one.” We all do this-- we pretend we heard what was going on. And we didn't.

For us, multiple conversations mean no communication. We cannot understand one person talking to us when someone else is talking nearby. Hearing people can listen to your conversation, eavesdrop on another conversation, and be paying attention to something else. For us, having that TV or music blaring in the background means we can't hear anything. But for hearing people, it's nice background music. It's ambience. For us if someone is talking to us with their back turned, they are not talking. We have trouble with beards and mustaches and those lip reading impediments that men may have. Those don't bother hearing people at all. The lights go down at a restaurant -- I don't know why they do that. Is that so you can't tell if the food's not cooked right? They bring the lights down for the ambience. They call it mood lighting. I call it bad mood lighting because it is going to put me in a bad mood.

Now for people that are hearing, they don't experience this. So they don't understand why it's difficult for us. They don't know a better way. Sometimes they don't even know that there's a problem. The important thing to remember though is that our family members don't want to exclude us. I mean, maybe they do—but that is another topic altogether for another day. But in general, our family members do want us to be a part of family. They just don't know how to include us.

Major holidays are hard. As the event goes on, frustrations mount. We feel isolated because we are missing all the conversations. But we don't hide how irritated we are with that. Our family members see that. So they feel guilty that we are missing everything. We feel irritated that we are missing everything. Basically the whole family event just becomes exhausting. When they feel guilty and we feel upset, it just turns into a downward spiral. I think all of us have experienced it. At first everyone seems to be trying to include us, but then they stop. And it just gets worse by the minute. Eventually no one is happy because we get angry when they won't repeat things.

When I was doing my masters in speech processing, I had to print everything out, because I couldn't hear. And one of the things that became evident to me is that speech is like a musical chord. It is like playing a chord of different octaves of the piano. If you play a melody on the piano, in the low octave then the upper octave, it sound like the same melody, only different pitch. So the first note in the vocal chord is the pitch. And that determines whether it's a high or low voice. My hearing is such that I can hear most men speakers. I can hear some women speakers if I can see them. I don't understand children at all. So lip reading is important with a hearing loss. If I can't see you, then a lot of sound sounds the same. So what happens is when we are trying to listen to somebody talking to us is very much like a game of wheel of fortune. In my mind, it's like the letters are up on the board and we have to fill in the gaps, and we have this box of possible letters that might make sense. Using context we try to fill in the blanks.

The problem is that when there is noise in the background, we have more gaps to fill. We have more work to do. And it's hard. There are gaps to fill and letters to fix and if there are two

conversations going on in the room we are getting conflicting information. We might be able to figure one thing out, then all of a sudden the next phrase is there and we have to try to figure that one out. And then the next phrase comes in and you try to figure that out. For me as I struggle to listen, and pay attention, I may get it at first, but then, all of a sudden I am lost again. I follow the conversation for a little while and then eventually I just fall down. And I am just a mess, lost in the woods. One minute I am understand, looking at the person while their lips are going and the next I just can't get it. I can go on for a while, and then I'm done. I am exhausted. And I have never been able to explain to an employer who has perfect hearing why I can sit through a 30-minute meeting but not a two-hour meeting.

People tell me all the time, "Oh, you are hard of hearing. That means you lip read, right?" And I always say: "Only if I want to get myself in trouble." Because lip reading, while it's critical, also gets me into trouble. The idea that when people lose their hearing they automatically learn how to lip-read, like an exchange program-- that only works in Hollywood. The fact is lip reading is a very difficult skill that few people are able to master. In a family setting people will say we don't have to turn the TV down so that you can hear us--you can just lip read.

The fact is, lip reading only is successful if the speaker never moves, you know what they are going to say, and you know what all the words are. It's actually very difficult. And then the one I love is: "Oh, you have an advantage in all of this noise because you can lip read." Lip reading is critical. Lip reading is part of the way I listen. But lip reading is not a replacement for hearing. Lip reading is not an accommodation. I can't use lip reading instead of an interpreter or instead of CART. The fact is, that when you are lip reading you are guessing at 75 percent of what is said. So lip reading is hard. Ambiguous. It's a supplement, not a replacement. It can lead to misunderstandings. I always tell people it's not what I don't hear is the problem. It's what I thought I heard that gets me into trouble.

Lip reading works better in quiet surroundings. It is an essential tool for us to understand. But it's an art. It's definitely not a science.

I also want to talk about recruitment and I am not talking about recruitment for the army. It's recruitment for hearing loss. What I am talking about is a more general phenomenon that most people with hearing loss experience. And the best way for me to describe it is through an example. Let's say a hearing person in the room watching television. And they have the volume set on five. I walk in, and I want to watch the program too. And it's not captioned. So I say: "I am having trouble hearing this. Can you turn it up?" They turn it up to 6. I don't hear any difference. I ask for it to be turned up further. So they turn it up to 7. I still can't understand it. "Can you turn it up more?" So they turn it up to 8. All of a sudden it's great. Now I can understand it. So I am listening and I am enjoying the program. They are in a little bit of pain. The wind is blowing their hair back with the volume that I am happy with. When the program is over I go into the other room to read. They are happy, and quickly turn the sound back down to 5. They are happy I am gone. They can now listen to it like a normal person. Next thing they know I come in the room, and say: "You know, I can't even hear myself think. That TV is so loud. Can you turn it down?" They turn it down to four as they scratch their head a little bit. I come back in. "I am trying to read. Please turn it down." So they turn it down to three. What this means is, for people with a hearing loss,

you need the volume much louder to be expected to understand it. But you need it much softer to be able to block it out. So in the example I just gave you, everything between 3 and 8 is useless.

What causes the problem in the family living room is that everything between 3 and 8 sounds pretty much the same to us. And this is hard for people who hear to understand, and those of us with hearing loss then think when they fail to do what we need that they are not taking us seriously. And you may have family members saying: "She can hear when she wants to hear." Ever heard that phrase? You can hear if you want to hear. You can hear if you try harder. And that's something we all deal with. And it really makes us mysterious and inconsistent to our family members.

So what are some ideas and strategies to deal with this? The first and most important thing is to talk about it. With my young nieces and nephews, all they know is that when they talk to me I just look at them with panic filled eyes. And so I try to explain to them what my hearing loss is. I show them my hearing aid. I let them try it on. I let them know that I am just not a strange aunt. It has to do with hearing and the squeakier their voices get, the less I understand.

I was coloring with my niece once and she kept saying something and I am looking at her and nothing was making any sense. I said, "I'm sorry, say it again?" You know that sigh that a three-year old can make-- just double the size of their body mass with air and let it out? And she said it again. And it just still sounded like a squeaky toy to me. I said: "I'm sorry, say it again?" Another huge sigh and she stormed out of the room. I just kept coloring. So she trots off, comes back with my sister. And so my sister stands there and says: "Well, tell me what you wanted to say to Aunt Beth. And I will repeat it for you." And she looks up at my sister and squeaks. And my sister, trying to stifle a smile and a laugh, while acting like a serious neutral interpreter repeats to me: "Aunt Beth, you are doing a good job."

So it's important to talk about your hearing loss. To explain your hearing loss. To explain how background noise makes things worse. To explain why you need the stereo turned down. Explain the recruitment, that three to 8 problem that we all have. So that you don't just look mysterious and inconsistent. Make it a subject.

You ever notice people don't want to talk about your hearing loss when you are in the room. It's almost like if they mention it, you might notice you have one. Well, it's not really a mystery to me that I can't hear. And so if you bring it up as an acceptable subject, then it becomes something that you can talk about and make your needs known. You need to let people know that you are having trouble with this environment, that you need to have the lights brighter. The trick is doing it nicely. Because every year at the Christmas table, somebody in my family gets the bonehead idea that we turn off the lights and use just candles. It's a darkroom. I don't understand the reason we need to go through this every year. But every year someone decides we need to turn the lights down so we can see the candles.

And so, for a couple of years I would yell out, you know, as somebody would reach for the switch, "I can't hear when you turn the lights off." And it would make things uncomfortable. Not good. So now I have learned to let them go through this little thing. And then let it go for a little while. And then say: "Wasn't that nice? We really get the spirit of the day and the calming effect. But can we turn the lights back on now because I can't hear what you are saying." And that works.

At our family gatherings we have this thing where you have the big table and then a card table at the end for the kids. And then it's a big process where you graduate from the card table to the big table. Well when you get this long table, and you are trying to pay attention to all of the conversations it's very difficult. There's something that took me a long time to understand about hearing people—first, they don't have to look at each other when they talk. So oftentimes I don't even know a conversation is happening. The second is that they can have two conversations also going on at the same time. With a hearing loss you simply cannot do that. You cover one thing and then you move on to the next item on the agenda. That's how dinner conversations should be. But they are not. Hearing people babble on about whatever comes to mind. And I am never on the same program.

So what I have learned to do is to identify what I call my sphere of capability. I try to make an imaginary circle. I say I can understand this one. I can understand that one. I can hear this one. And I am familiar with this other one. These four people I will communicate with. And the rest of the table doesn't exist. And I don't even try. Instead I really enjoy the people I can understand. And it's not as hard. And sure they are talking over there. But I am enjoying myself where I am too. So let them talk. I just worry about my sphere of capability.

Finding a quiet place in the house in the house to talk can be hard to find at family gatherings. A room may start out quiet until the football game comes on. Suddenly you hear anything and you are about 20 minutes away from a headache, and 30 minutes away from getting ugly—maybe 45-minutes away from a migraine. So the count down begins. How long can you tolerate this? So this is when I say, “You know what, let's go into the kitchen because I want to hear what you are saying.” Sometimes you just have to keep moving—keep finding new quiet places because something is always starting up—whether it is a blender or a football game.

It's important to take a time out. Know what your timetable is. Know how long your fuse is. Take care of yourself. Because sometimes you just need to step out. Sometimes you need to rest your eyes. Take your hearing aid off. Go for a walk. Go for a drive. Just go some place else where you just don't have to listen, and sneak off to some place quiet. What I found though is when I would do this originally, I would just be like— “Oh, god I have had it. I just have to get out of here.” And the family, because they are so sensitive to what's going on, that when you put your coat on and walk out of the house, they go—“That's it. She's not handling it.” So now I learned to get my coat and tell people that I need to rest my lip reading eyes. So it's not that big a deal that sometimes I just need a time out.

The important thing is to not hide your hearing loss. Because everybody knows anyway so you might as well talk about it. Explain why it's difficult. Talk about the lip reading myths. Talk about the recruitment problem. Offer strategies that make it easier for you. Because you have the best ideas. You are the one that's been living with your hearing loss. So you know what the best things are to make things easier for you. And be firm about your communication needs.

Most of all stay positive. Because that way, you can join the circle and enjoy what's going on. And be part of the family again.

One last story before we go. When I was growing up with the hearing loss, we didn't have hearing aids that I could use. So I spent most of my grade school years sitting in the front of the room, staring at the teacher. And when Neil Armstrong landed on the moon, that was a big family event. Now I was nine years old at the time. And the whole family gathered to watch the first man walk on the moon. And my mother, she said to me, I don't want anybody to interrupt this historic event. If you have any questions, you write them down and you ask when it's all over.

And when it's all over, my mother turns to me and she says, "Do you have any questions." And I said, "Yes, I have one. Why is it easier to go to the moon than to make me a hearing aid?"

Now that was the first of many difficult questions I would ask my Mother, but she did pretty good with that one. She said to me, "It's easier to make you a hearing aid. But the scientists that do that sort of thing are more interested in the moon."

And that was the day I decided to become a scientist. Because I said, I am going to make sure they become interested in hearing aids.

Now many years later, when I was going to college, I was talking to go a friend of mine. She and I were in this church play together. Now let me describe the differences in our roles. She was the choreographer, the lead, and the dancer. Now I mean she was important stuff. Her brother took my sister to the junior prom but neither of them could drive at night. So we schlepped them around to the dinner and dance. While we were waiting for this thing to be over, we kept talking about what we wanted to do with our lives. She asked me, what are you studying in college? I said, "I am in engineering." She said, "Wow, that's tough. There aren't that many women engineers and that's going to be a tough program." She gave me a lot of encouragement. She asked why I wanted to do that. And I told her the story that I just told you. So then I asked her, what she was going to do. And I am thinking Broadway, Hollywood, something like that. She said I am going to be an astronaut. I said, "You know I think you need a plan B." And she was furious. "I encouraged you, how could you not encourage me?" And I said, "It has nothing to do with you being a woman. You are short. NASA has height requirements. You need to be able to reach the lower buttons." She said, "Oh, that. I will make them change them." I said, "Okay. I hope you do."

Well, let me tell you. One year ago, that woman landed the shuttle. I watched on TV as she was floating around in the shuttle, doing the interviews. And I sat and I watched. I was watching it on the web. And the tears rolled down my face as I thought about how badly she wanted that and how hard she worked for that. And they were tears of pride and tears of inspiration. At Christmas time my mother gave me a little shuttle with little toy astronauts. I have that on my desk. Every day I look at that shuttle, and every day I think about her being up there. It reminds me to dream big to live our dreams.

So, remember that. And think about the challenges that we face as people with hearing loss as a choice for us. They can be limitations or they can be challenges. And I invite to you face them as challenges.

Thank you.

Beth Wilson is the Executive Director of Self Help for Hard of Hearing People (SHHH). Born with a hearing loss Beth believes that we are often the best source of ideas and strategies to cope with our communication needs. “Dr Beth” is the sign name given to her by the Rhode Island Deaf community as she worked towards and successfully completed her PH.D. in Electrical engineering. While living in Rhode Island Beth was active as the SHHH state coordinator, CDHH chair and a member of RIAD, She was an engineer at Raytheon Company for 18 years.