



ALDAcon 2007—Rochester, New York

**SPIRITUALITY AND LATE DEAFNESS.
PRESENTER: GEOFF BROWN AND PANEL DISCUSSION**

GEOFF BROWN: I am a lay Preacher in the Methodist church. We are going to be talking about spirituality and late deafness. I think we are all pretty clear about what deafness means. We might be vague about what is the exact meaning of spirituality.

I got this quote initially from a book by Alister McGrath, “Christian Spirituality” (Blackwell 1999). It says that spirituality is an authentic religious experience. It doesn't have to be a religious experience with a faith. It can mean the sort of experience, which is not materialistic. The kind of thing you can get from a beautiful view or a wonderful sunset, that sort of thing. Spirituality has something to say about our inner personality, and about what it is in the world that makes it what it is. It can ask the question: what is our place in the world? And from that we can each develop our specific religions. That is what I want to talk about this afternoon. How our differences and spirituality works together--or fails to work together.

Now, we have a panel of three people here. The idea of this workshop is that you ask questions and the panel will try to answer those questions from their particular point of view. First I am going to ask the panel members to tell you something about themselves. Linda, would you like to start?

LINDA LEWIS: Well, I come from Salt Lake City, Utah, and I am a Mormon, which is the dominant religion there. I go to what they call a ward, which to many of you would be considered a parish or something like that.

The ward I go to does not have very many deaf people there but they do have FM systems that are available to people who have hearing problems. I had a very unique experience. When I became completely deafened, the people in my ward started taking notes for me so that I could understand what was going on. I even had a friend that brought his laptop and typed what speakers were saying. In the ward, for meetings, we have lay people speaking. We just have speakers that prepare talks and give talks. We have regular songs, and we also have the sacrament.

We also have wards in three different towns just for the deaf, and these are signed. So if you cannot understand the regular ward where there is no signing, you go to the particular area.

JUDY VIERA: Thank you. My name is Judy. I became deaf at 17 during my junior year of high school, as a result of meningitis. I grew up in Oakland, California. My family was active in the Presbyterian Church. When I was in high school I started going to the youth group on Sunday nights,

and it was more for the social experience than for the religious experience because that's where most of my friends who went to church went. I was an impressionable hearing teenager, and I wanted that social life.

My parents were very active in the Presbyterian Church and my mom and dad at various times were deacons and elders, and we children attended Sunday school, and vacation bible school during the summer. I also taught Sunday school at one time. My daughter is an ordained Presbyterian Minister, and is working in a church in Sacramento, where I live now.

While she was growing up I made it a point to see that she went to Sunday school. But by that time I wasn't going much myself because it wasn't accessible. And hearing nothing, you waste an hour when you could be doing other things more productively with your time.

My own spiritual path took a different turn from my family, and I'm not sure at what point I went off on a tangent. I do know that I began independently to question and consider what my values and beliefs were, and it became clear to me that I wasn't really a Presbyterian; that I was a Unitarian. I found the Unitarian church in Madison, Wisconsin. And so I stumbled on, and slowly realized my own belief system, and I joined that Unitarian church. When I moved I joined another one, and each one offered interpreting services when I requested it.

LORI MESSING: My name is Lori Messing, I was married this past May and I will talk about how my own spirituality was affected by my wedding. I am now 32, and I began losing hearing at 16. Over time it was a progressive loss. We are not really sure why it happened but I do know I was sick with Lyme Disease and misdiagnosed for about 8 years, and we think that had something to do with the loss.

I was raised in a traditional Jewish home. My parents kept kosher, not strictly Kosher, but we did have separate dishes for meat and for dairy. We tried to use kosher meat. We attended the synagogue and I had a Bat-Mitzvah and went to Hebrew school. It created a very warm atmosphere among both my friends and extended family. We celebrated holidays together, and I don't know if you know about Jewish holidays but there is lots of food and talking, and it is very, very busy.

So when I began to lose my hearing was one of the first things that I lost was the ability to socialize or communicate at a family gathering. I would find myself helping my mother in the kitchen more and more, and, as they say, when deaf you do the dishes because you don't have to communicate with everybody at the table. So I did miss out on a lot.

I went through a whole period where I was questioning, why me?, and wondering why I was going through this hearing loss, and wondering if there was a God. I lost touch with a lot of my spirituality during those years in my early 20s when I was becoming more and more profoundly deaf, and ultimately completely deaf. So it was a very difficult time for me. I couldn't really participate like I used to. I lost those connections.

A big part of going to Temple is singing the prayers and the music is very beautiful. I used to love to sing, one of my most cherished hobbies, was to take voice lessons and sing in different languages. The Hebrew prayers are something I enjoyed and I lost that as well. I didn't know at the time that I could ask for accessibility and I never tried to do so--or thought about it.

Then I found ALDA and started to adjust a little more. I came out of my shell and I also started to date for the first time. And this was after college, after I had pretty much started to feel better from my illness. For the first time I was out in the world experiencing things on my own. I found that the men that I had been seeing weren't interested in religion, which was something I still felt part of, but because I didn't know how to take part in it, I had, at that time, closed my mind to it because it was still so difficult to think about.

But then when I met my husband, my now husband, he also had a desire to become more religious. He was raised in a reform household, a reform Jewish household that is not as strict. He didn't know many of the rules of the religion or practices, and together we sort of started to discover things together. We joined a group that is actually very, very orthodox, the Lubavitch Group, an orthodox section of Judaism. They were very warm and welcoming. It was not a large synagogue, but they hold services in the basement of a store where they used to sell some Jewish items and it was welcoming, casual, religious and celebratory. It has a lot of movement and dancing, and a friend there was very good with learning a little bit of sign language and also my husband, too, knew sign language. So, I was feeling a little more included once again.

When I had my cochlear implant I got a little bit of the music back and was able to hear some of the tunes and knew when I could sing them.

It is very important for my husband and I to develop a Jewish life style. At home we are working on setting it up as a Kosher home. At our wedding, it was also a big challenge to try to incorporate Judaism into the ceremony. So we actually had CART services there, and there were big CART screens at the reception, and we also had an interpreter there. It was a very, very beautiful ceremony. I made sure that we had a program book for the wedding, which had an outline of the ceremony. It was just a really neat experience to have all that coming together.

So I would really love to see more temples and synagogues start to embrace people with hearing loss-- but it is hard to find because the groups that do have accessibility tend to be culturally deaf groups, and there is nothing really that's in place for late-deafened adults. I know that there are some services with assistive listening devices, but by way of CART, I think I had something very novel at our wedding. Nobody had ever seen that before for anything Jewish, at least in my experience.

Audience Member: I am wondering about your faith is in terms of your disability and your relationship to the spiritual God. Is there a relationship?

LINDA LEWIS: I like that question. You know, when it comes right down to it, it is nice to have accessibility so you know what's going on. But faith itself is something you have to develop by yourself. There is a lot of knowledge that you encounter and you need to ask yourself, okay, what am I going to do with it? There are a couple of things you can do. Number one, read the scriptures. Number two, ponder. The nice thing about pondering is that it is like navigating. You take the information you have and start thinking about it.

Somebody told me once that you have to learn to develop spiritual feelings. My father told me about a woman that he knew years ago that came to church all the time. She was deaf. She had to walk a long

distance to get there. One day he asked her, "Why do you come to church? You can't hear a thing, and don't understand what's going on." She said: "Look, look, I come because I want to feel the spirit. I might not understand what's going on but if I can feel that spirit I could take it home with me and it would sustain me for the week and I come back and fill my basket and go back again."

So sometimes you have to know what you believe, ponder on it and look for what sustains you and makes you what you are.

JUDY VIERA: You ask specifically about the relationship between our disability and spirituality. I don't feel that I am disabled in that sense. I think it is the same as if I could hear.

I think that spirituality is a very individual thing, that if every one of us took the time to consider how we define it, we might come to different conclusions and 48 choices. I personally value diversity in every sense. I respect whatever conclusions everyone may come to about their own definition of spirituality as well as to how they express their own spirituality.

I can say that spirituality brings back to my life an opportunity to share with others. Spirituality is hard to separate from the search, the building, the church or whatever it is of that particular denomination. Religion is something else, and I think that most religions have spirituality at some level and though it may be interpreted differently but is something that they have in common. My choice of denomination was a very deliberate one, and a very conscious decision, and was not one that I inherited from my parents. It was something that I really thought about and chose for myself.

LORI MESSING: The first thing that comes to mind for me when you mention disability with spirituality is actually the loss of faith I felt when I first lost my hearing. I did question for quite some time why this was happening to me. I would walk around and say, "why me" all of the time. That was from more a sense of self-pity or fear more than anything else.

But eventually as I traveled on the journey with my hearing loss I came into my own, and reached a point of acceptance of myself. I was able to realize that there was a reason why I had become deaf. I realized that I have actually come to look at this subject in an entirely different perspective, not as a punishment from God but as a gift from God that I am able to use in a very creative way.

Like Judy, I don't feel my hearing loss is a disability but is rather a very special ability I have been given to find creative ways to be successful in life. I really believe that God has given me a gift and a very special window into a world that I would never have experienced otherwise.

I can now share that world with others, and I can help others who are going through a similar journey, and volunteer work is actually a form of spirituality for me. When I volunteer for ALDA it makes me feel that sense of religion, that sense of peace, that sense of contributing to the world in a better way, which is really doing God's work if you think about it. So it is a journey, and a very important part of my life.

LINDA LEWIS: Something about spirituality. It is interesting. When you have the right kind of spirituality in your life it gives you nine different things that might be best for you. Our faith says it will

give you love, joy, peace, long suffering, guidance, Godliness, faith. You want to have peace and joy in your life.

I think through this we develop ourselves, and see things that give us confidence in spite of everything.

GEOFF BROWN: What Linda was saying is very true. You find your deafness cuts you out from the world you used to know and you find you have to look within and find yourself and the resources that can influence and help to develop your spirituality.

There used to be a program on the television back in Britain called "Any Questions?" I'm wondering: what are the questions you might have in your own minds?

There are two things I ask people to think about. One is, do you think in any way that your deafness is a punishment for something in the past?

The other is, what is your experience of trying to follow some service of worship and what are you doing about it? Does anybody want to ask any questions?

Audience Member: I introduced captioning into our synagogue because there were so many Jewish people that quit going to services because they couldn't hear. And at ALDA I learned about captioning and I persuaded the Rabbi to go ahead and have some captioning, and now we are trying to get captioning for all levels of Judaism the services at the High Holidays.

GEOFF BROWN: If you can afford CART, it is great.

LORI MESSING: I have a question for that response. In your synagogue, how do they handle the mixture of languages? How do they handle the Hebrew and is it all in English, the captioning?

AUDIENCE: The woman who does the captioning studied it and does not translate all of the Hebrew. Mostly the captions are of the English parts for responsive reading and, of course, they caption the sermons.

LORI MESSING: That was a problem that we had at my wedding. We did try to interpret with sign language for the portions that were in Hebrew. I was very fortunate because I found an interpreter who was fluent in both Hebrew, English and also sign language. But the CART was a little bit different. We didn't have the CART for the ceremony and just did it for the reception where we had some speeches and various other things going on. But that's a challenge that I think we face that's unique to the Jewish religion because we have a situation where there are actually three languages going on at once, Hebrew, English and the sign.

Audience Member: I went to an Orthodox wedding and they prepared a book so non Jewish people could understand the ceremony.

LORI MESSING: That's what I did at my wedding. We had a program book made up.

Audience Member: I went to Lori's wedding. And it was the most accessible service I have gone to since I lost my hearing. I was not able to see the interpreter from where I was sitting but those books gave an explanation of what was happening--things that even I didn't know though I too am Jewish.

But I'm surprised that I'm finding this workshop very emotional, and Geoff asked the question, do you feel God was punishing us. I have told the story that as I was losing my hearing; my mother asked me why was God punishing her.

I grew up a conservative Jew, and Judaism was very important to my life, and for my children. I became involved in my Temple and was active in Hebrew school. One day, at the school where I worked, the principal called me and I couldn't hear him but I knew it was him because you know how you can hear that little bit? -- and you know who is calling but can't understand one word? I told him I know it is you but can't understand you. Please call me back through relay, and he never called. I went to the Rabbi and said to the Rabbi, "I'm losing my hearing and do not feel in touch." He told me to be grateful that I was not Christopher Reeve—who was totally paralyzed. That's not a response.

After that I lost my connection to my Temple completely. I have since moved and I don't want to go, which is terrible. My spirituality is there but I don't want to feel like I'm a burden to ask for an interpreter because it is costly. I can't ask for CART because it is costly.

JUDY VIERA: I'd like to respond to that. You talk about not wanting to ask for something that's costly. You never know until you ask. Often you will be surprised.

I also want to come back to your mother's reaction. It triggered something that I remembered. Shortly after I recovered from meningitis I would go to church with my parents. I understood nothing and I didn't enjoy being there at all. There were other things I wanted to do with that one hour. And my mom would always say, "You have to keep a stiff upper lip." And that was all she knew.

And I kept a stiff upper lip for years until I went to my first ALDAcon, and I went to a particular workshop taught by Dr. Frank Zieziula. We used to work together here at N.T.I.D. At that workshop I sat in the back of the room and cried and I just released all the emotions that I should have been able to release after I became deaf.

Why did it take years before I had that opportunity? I have to say that it was partly because my upbringing was to keep that stiff upper lip--and letting go is a very important part of what you need to work through with your hearing loss.

But I also know that in terms of getting sign interpreters for church that I'm at my church, the only one who benefits from that, and I know there are a lot of people there who are hard of hearing who would benefit from CART. I love interpreting so much and I know I'm being selfish, and that I really should be asking for CART, instead of, or in addition to, interpreting. And so I think that you will find that there are a lot of people in your Church or Temple who will benefit from CART, and are probably more afraid than you to ask for it. And doing that is part of coming to terms with who we are, and we need to think about that.

Audience member: I consider myself to be a very spiritual person. I'm very fortunate to live in Rochester because we have many, many interpreting services in Churches. We also have a deaf Priest and I go to that church because I like the music. Even if I can't hear much of the music, the rhythm, seeing people singing, watching interpreters singing-- I love that. So I choose to go to a Church that has that.

I also want to say, talking about myself, my mother always felt very guilty that she had two deaf children. She always felt God punished her by giving her two deaf children. One was bad enough. But then she had a second deaf child, me, it was worse. She would share stories about the time she almost wanted to kill the two of us to end our lives because she couldn't handle it. A lot of that was her upbringing. I don't blame her. It was the upbringing, the mentality that she was brainwashed with. I was able to get away from that warped attitude. It was a challenge but I chose a different view.

Now I see my deafness as—well, so what? It does not limit my spiritual growth. I am a better person because of it, and it took my mother a long time to see that. Before she died she was finally able to say, “I love you,” in sign, for the first time. So deafness helped my spirituality. It helped me in many, many ways.

LINDA LEWIS: I grew up in a situation where the attitude was that before we came here we actually made a choice of what kind of a life we would come to. Because of that particular information that I grew up with, my family never thought it was something where God was punishing us but rather God was giving a gift that we were able to work with.

It may be a frustrating gift in ways, in that one is always running into problems. But the gift you are given is to grow with it and make the best of it. People question me about it and I say: “Look, I have something to look forward to. Next time I will be able to hear again, be able to enjoy life. But right now I make the best of it. “

What I can do is help other people to be able to walk that valley, so they can enjoy life, too. That's what I like about having my family feel that way. They never felt bad, never felt frustrated they couldn't fix me, but looked at all the opportunities because of it. The thinking is: “Consider now where would you be if you weren't deaf? What kind of spiritual road would you have gone if you hadn't had that particular opportunity to learn from those little things you have to overcome? “

Audience Member: I have to add one more thing. After my husband became deaf he became angry. He wanted nothing to do with anything and would not go to church. Once in a while we would have an argument. Why do you believe God did that? And I must have not understood. I couldn't understand. But he had a reason to be angry because his illness had impacted him and it impacted our two children. But near the end he was finally able to understand and change his belief system. So deafness does for some people cause a tremendous inner struggle. It was hard for him.

Audience Member: I grew up and I didn't know how to sign. My family always went to Church. I lost my hearing. A few years went by and it was a struggle. But then I was led to learn how to sign. I became a bible study teacher. I saw it as a gift that I learned to sign due to my hearing loss. I feel that God is not punishing us, but that when things happen to us they provide an opportunity for us to go on. I feel that it helped me to be the person that he wants me to be--able to help other deaf people. I don't

look at it as a punishment but a new opportunity. I know I would not be here if I had not lost my hearing.

Audience Member: When I was becoming deaf I learned that silence was sacred. I wanted the panel to talk about that.

LORI MESSING: I was just actually talking to my husband about this last night. He is a psychiatry resident and had to present a case and was complaining to me because he only had patients that fit the classic textbook case of either a drug addiction or bipolar disorders. He wanted a case that was more interesting. I wanted to talk to him about a new angle for cut and dry cases, to try to open his mind a bit. Somehow our conversation evolved, and he made a comment that if you were sick you would do anything to cure that illness, do anything to reverse it and make it better, or not have it at all. And he said to me, of course, you wish that you weren't deaf. Of course, you wish you had normal hearing. I said to him, no, I don't. And he said, of course, you do. I said, no, I don't. And he couldn't understand why I was saying that I liked that I was deaf.

One of the reasons that I feel his way, as I tried to explain to him, is because of that silence, which has become sacred to me. And there are times when I enjoy that silence--retreating inside myself, and just having that sense of peace and introspection. But also, because, as some other people in this workshop have mentioned, it is a special gift and a window into a world that I otherwise wouldn't have been able to experience. And being deaf is also an opportunity to help others who are going through the same challenges, be the person that I feel God really wanted me to be.

So it was interesting that you brought that up. I don't know if he believes me, but I really feel that I wouldn't trade losing my hearing for anything. It has made such an impact on my life, changed my life in so many ways. Just as I could have never imagined being deaf when I was maybe ten years old with normal hearing, I now can't imagine what it would be like not to have lost my hearing because it has changed my life in so many wonderful ways and opened my life to so many wonderful people.

It works in interesting ways, this life of ours.

LINDA LEWIS: One nice thing about silence, especially if you have a cochlear implant, you can turn it off and it gives you a time when nothing around you can bother you.

JUDY VIERA: I agree. If I decide to take it off, and with my hearing, if I just take it off I am completely deaf without it. I have always said that deaf people have fewer ulcers than hearing people because we don't have to put up with all the noise pollutions. I think there is calmness in our center more than there is for hearing people.

LORI MESSING: One thing that I wanted to kind of open up to the room is something that has been bothering me for quite some time. I want to talk about cochlear implants and psychology a little bit. I'm not sure if any of you are aware but in the Jewish religion, if you are very, very Orthodox you cannot use any type of technology on the Sabbath. So sundown Friday night you can't flip a light switch, flush a toilet, you can't tear paper. If you go to the bathroom, you use tissues from a box and not tear paper. You can't do any type of work. Turning on electricity is a type of work, whether you connect an electrical outlet, a circuit. That includes our cochlear implants. That includes our CART services.

And when I went to that very, very Orthodox group that I was telling you about before, I asked the Rabbi, I just had my surgery done and I could hear. He said, "Oh, this is wonderful, I'm so happy for you, thank God." I said, "What do I do on the Sabbath? Can I wear my cochlear implant to your Temple?" He thought about it for a second and he didn't know what to do. He said, well, as long as I put it on before Sabbath started on Friday night at sundown and I wore it until the end of Sunday night when it ended, that would be fine because I wasn't disconnecting the circuit or turning it back on. I said that's fine but my battery doesn't last that long. He said, "Well, you are out of luck."

So it was a very interesting discussion. It is a very controversial thing because in that very Orthodox sect of Judaism they do not embrace this type of movement with the technology that is progressing every day. Those ancient laws of the religion are not transferring over with our disability.

So does anybody have any ideas for that one?

AUDIENCE: Lori, wouldn't you consider that medical and the religion oversee that? The cochlear implant is medical device and wouldn't the religion look the other way?

LORI MESSING: Not when you are that religious. This Rabbi is a very, very good friend of ours. He is young, very, very religious. I'm talking about extreme, a small sect of the religion. We went to him and asked him if he would marry us. But we weren't religious enough, and he couldn't marry us. Even with medical issues, disability, friendship, there is a set of rules that they have that can't be broken.

I think the only time actually they overlook these rules is when there is a birth, an emergency birth, and they have to go to the hospital on the Sabbath and have to drive the car.

GEOFF BROWN: I was thinking of telling you that a couple of years ago in the Methodist region where I live, they were having a meeting for two of us Ministers, and we were working out what we could do to help people with hearing loss. We decided that because we would need assistive listening devices and interpreters and CART, the best way to do it would be to have one big service once a month and provide all of the accessible services.

So we did that. We went to all the trouble and we used pointers on the screen to help everybody follow, publicize it widely to be sure that people with hearing loss knew about it. Three people showed up. The conclusion simply was that people would worship the way they want to worship in their own Church and were not going to go to some special service.

I suppose in all fairness, we should have continued doing this in the hopes of eventually attracting more of a congregation but we didn't have the manpower available.

JUDY VIERA: I just wanted to say one more thing. Something that helps a lot with my Church. I started a sign language class. We have an adult education program and people can volunteer to teach different subjects, anything. And so I decided to teach a sign language class and that enabled me to meet a group of people who were interested in meeting me. And these people I can now chat with, even with just a basic level of sign, and have suppers with and things like that. I think that we can engage other people in the Church to help us by taking notes or asking them if they want to learn sign language.

These are different things that we can do to help make our churches be more accessible and more helpful to us.

GEOFF BROWN: I'd like to finish off with a quotation. Many years ago, there was a former Olympic medallist, a devout Christian named Jonathan Edwards and this is what he had to say: "You don't have to rely on a particular religion to be able to gain value from exercising your spirituality."

Do you think he was talking about the religion of blind faith, which obliges you to suspend all reason, without looking into what you believe? No, I think he was thinking more of an immersion in religion. He was able to make understood an idea which I find it very difficult to express here now, but it is almost as though you are rising up above the world, and seeing it from a distant height and realizing that somewhere in that world you have a place to be; a place where feeling may be different, and which makes you feel suddenly more worthwhile, and enables you to see a purpose in what you are doing.

Geoff Brown comes from England and has been an ALDA member for many years. He is a lay preacher in the Methodist Church and earlier this year he was at a conference in England on what the Church should be doing for deaf people, and for disabled people in general