

Spirituality, Spiritual Sustenance, Connections and Growth

**Presenters: Geoff Brown, Lori Heir, Esther Kelly,
Anne McLaughlin and Ray Trybus**

GEOFF BROWN: Spirituality--how do we see it? We have a great mass of physical data about the world we live in. It is called science. But that doesn't tell us anything about what is good or what is bad. All down the ages, people have been trying to find out more about the world they live in, and they have been asking themselves the question, "What is the meaning and purpose of life?"

This is where we come to spirituality, religion--ethics, if you like. Our workshop this morning is concerned with spiritual sustenance, connections and growth. What do we mean by spirituality? Spirituality concerns the quest for a fulfilled and authentic religious life. This is not confined to any one religion. It covers all religions, so you could say that this morning we are seeking to find out something about the meaning and purpose of life, and how we as deaf, deafened and hard of hearing people understand the idea of good and bad.

Let's start by having the panelists introduce themselves. My name is Geoff Brown, and I come from England. I became deaf at the age of 17 as a result of meningitis, and two and a half years ago I had a cochlear implant which I do get some benefit from. I am a member of the Methodist church in England, and I have been a lay preacher for about twenty years.

ESTHER KELLY: I had a slight hearing loss for a long time and then in 1988 I lost 80 percent of my hearing in the space of about eight months. At that time I also lost my job because of that, because I couldn't hear on the phone. I also lost my contact with my church, because people did not know how to communicate with me, and I did not know how to deal with my own hearing loss. Then in 1996, I got a cochlear implant, which is very successful, and I now hear about 90% of what is said to me. My father was a minister, so church has always been a really valuable part of my life. When I married my husband was very active in a church.

When I first became deaf the church did not address it in any way. I did not sign and I ended up not going to a church service for five years.

ANNE MCLAUGHLIN: I started to lose my hearing when I was ten years old due to sensorineural deafness of the inner ear. I do hear sound but I have no speech discrimination left. I lip-read pretty well, but today I rely on captions. In terms of religion, someone once described people like me as hard core Catholics, and I guess that is what I am, because my faith is the core of my existence.

I do not let my lack of hearing keep me from the church. My husband, who died two years ago, was a permanent deacon, so I have had a lot of involvement with the church over these years.

LORI HEIR: I have had a progressive loss for the last three years, which has leveled off to a severe-to-profound hearing loss. I still wear hearing aids, and I hear a little bit, so I prefer to communicate by lip-reading and I use whatever residual hearing I have. I am Jewish, not very religious, but I feel like I have a strong tie to my traditions and customs. Since I have lost my hearing, I have lost some of the connections that I had in my temple, because I really enjoyed singing. I used to take voice lessons. Music was a huge part of my life, and that's how I identified myself when I went to temple. I was really very proud to participate in all the songs and I thought the music was very beautiful. I think that I have lost that, and I feel a little bit isolated when I go to temple now. I often find myself taking the prayer book and finding passages that I enjoy, and just reading them, and being introspective and contemplative. I have really made no effort to have any access in my temple. I think they do have FM systems but they usually don't work for me. I really don't know what to do about that, and since I'm not really that religious it has not been that important to me. My connection comes from being with my family, and my family, fortunately, is very close. During the Jewish holidays, we all join together.

RAYMOND TRYBUS I am from San Diego, California, and am head of a research portion at the California school of professional psychology. I grew up Catholic with a capital C, and I guess right now I would consider myself catholic with a small c, meaning that I feel partly orthodox, partly Jewish, occasionally Buddhist, and often Protestant, especially when I am in a Catholic church.

I would like to tell you about a small study that I conducted two years ago and finished last year. What I did was very simple; I identified four groups of people with hearing loss. One was a culturally deaf group. Second was a group of late-deafened people. Third was a group of hard-of-hearing people. Fourth was a group of deaf-blind people.

With each of those groups of individuals I did two things: first I asked them to fill out a questionnaire asking about people's opinions, feelings, and practices related to religion and spirituality. Second, I had a structured interview with each group.

And I would like to summarize some of the findings. The first thing we discovered was not very surprising, and that was that churches don't understand hearing loss any better than any other part of society. In general they do little to nothing to help people who have hearing loss to connect or to remain connected with the church.

The second finding is related to the first one. The majority of people that I talked with said that because of the churches' inability or unwillingness to try to assist them with communication, they basically felt that the church had failed them, and so they left active involvement in their church, developing in its place some form of more individual spirituality to replace their former involvement in the church.

On the other hand, there was a smaller group, a minority group, who said, “There is no way my church is going to get rid of me! I am here to stay.” This group was composed of fighters and did various things to remain connected to their church.

The last few things we found were again not surprising, but a few others were--for example, transportation to a place of worship was identified as a major problem. This of course included the deaf/blind group, but it also reminds us that hearing loss is not always everything in the life of a hearing impaired person. We have to remember, for example, that often hard of hearing people are older, on average, and are thus subject to all of the other things that come with old age such as illnesses and other disabilities. So, the need for spirituality and religious support can be even greater than it would be ordinarily, and is very different than it might be for culturally Deaf people.

For the culturally Deaf the situation varies depending on where you are. Some churches for many years have had sign language interpreted services, so if you happen to live in an area with one of those churches, you might have a good connection. In other places that might not exist at all, or it might be available only with another religious group that you don't feel comfortable joining.

It was, however, late-deafened individuals that were the group who felt the most left out of church life. The comment heard the most was that going to a religious service was one thing, and being able to hear or understand was quite another, including socializing and charitable activities as well as the normal services.

These things point out a very large challenge. Now, I am a psychologist, and psychologists generally will talk about almost anything. But the one thing that they're afraid of is spirituality and religion. That's part I think the way American society, given its concept of separation of church and state, views life. Yet, at the same time, all of the surveys show that something like 90% of people in the U.S. say that they believe in God and/or have some spiritual or religious involvement. So it really is an important part of life for most of us and we need to break the taboo and talk about it.

AUDIENCE MEMBER: I have a question. I work with women in volunteer work who are a great deal older than I am and who are hard of hearing. They have given up on going to church because they can't hear, and they're afraid, I think, to ask for what they need, or maybe they don't know what to ask for. I have been trying to push them to make their needs known and they are very resistant. These are people, I would say, in their 70s or 80s, for whom church has been very important. And I don't know what to do to help.

ESTHER KELLY: Being of that age group is a social situation also. Hearing loss at that age labels you as being old, and it may be that it is for this reason they are reluctant to bring this problem to the front and be assertive. Plus they want to get their hearing back like it was. They don't want to accept that late deafness or being hard of hearing is now part of their lives. After my husband died I changed churches and I went to a singles group. Of course, I had all the usual apprehension--all the same things that older people

feel but don't want to admit to. After a while, the leader said, "Esther, tell these people about yourself." I gave a long talk about how, when my husband died and my hearing failed at the same time—how people were nice but did not know how to interact in the face of either death or hearing loss. And this marvelous group of singles between the age of 40 and 60 decided that this church was not going to let that happen. And they made a video of me giving my story, and they took it to the board of the church and showed this video to the board, and from that experience, the board has put in their budget \$10,000 to pay for real time captioning a service every Sunday. This is wonderful, because seniors are not going to understand sign language, and sometimes, the FM system in a church is not something they can use. And from this is, also, springing a social group.

GEOFF BROWN: I am very envious about that \$10,000. I am still working to get my church to have CART once a month, never mind every Sunday.

ANNE MCLAUGHLIN: To go back to the question about the ladies in their 70s and 80s who hesitate to ask for what they need, I think this goes back to the fact that women in that generation never did ask to have their needs met, and consequently, they're afraid to. They will do anything that is asked of them, but they won't go up and say, "Will you do this for me?" It is just a cultural thing for them.

LORI HEIR: I would like to talk a little bit about my grandmother, who is about 78 years old. Recently I have noticed that she's begun to lose her hearing, and I happen to have an old hearing aid that is not powerful enough for me anymore, and I gave that to her. She has yet to go to an audiologist to have an ear mold made so she can wear the hearing aid. I see her very frequently and I see her struggling to hear me, but she never goes, and I think that a lot of her lack of initiative comes from being a passive-type person but also because she doesn't really understand the technology. This is a world that older people are just not familiar with and it's very overwhelming to them. But, if someone such as my grandmother saw CART or was able to try an FM system first-hand, she would be totally amazed and would want more and more information. So if people like this could see these things they might be more willing to learn about them and want to take advantage of them.

AUDIENCE MEMBER: I myself can hear, but it seems to me that a lot of this problem is about education. It seems to me like we are trying to cope with it mostly on a one-to-one basis. I do not see that many articles in places like the daily newspapers or the religious newspapers, and I think the education has to be done more on a mass production basis.

GEOFF BROWN: One of the questions in the questionnaire that Ray Trybus gave to his volunteers asked them if they felt that God was punishing them by making them deaf.

AUDIENCE MEMBER: I used to feel that way. When I first became deaf I would ask myself "why?" and "what for?" Now I feel like God has really given me a gift through my deafness, for when my son was born hard of hearing I realized that it was through my own deafness that I had gained the knowledge, sensitivity, and strength to be of help to

him. But I see every day, as a professional, that people are angry at God for their hearing loss, and many of us have a long way to go to find our spirituality again.

ANNE MCLAUGHLIN: I feel the same way. I see deafness as a gift. There is so much strength we have to develop because we are deafened, and this gives us the strength to deal with anything that comes to us in life. I know it gave me the strength to deal with my husband's last illness.

ESTHER KELLY: I don't know why--maybe it's because I have such strong faith--but I've never felt angry. I felt down, but I never felt angry with God about that. I just thought, "Why?" But now, looking back, before I lost my hearing, I think that God was preparing me for my career now where I work with hearing loss every day. Everyone has a different reaction, whether it be anger or just giving up--which is kind of what I thought I did--not get angry, but just kind of give up a little bit.

LORI HEIR: When I first started to lose my hearing, especially when it became a very profound loss, my favorite question was, "Why me?" And I questioned God a lot. I said: "Why are you doing this to me?"--especially because I was sick for a long, long time without a diagnosis. I eventually found out I had Lyme disease, which is why I lost my hearing. I went untreated for 8 years without antibiotics, and I developed a lot of different problems because of that. I wondered, "How much more are you going to give me to handle? How much more can I take? Why was I chosen to suffer like this?" Then about three years ago I was talking with a friend. I was going through this same spiel, and he said to me, "Well, why not?" I sat there and I could not think of one reason why I couldn't do those things and I had a real epiphany. My whole line of reasoning and thought just changed. I thought, "Maybe God did this to me because it was a gift." And right now, standing in front of you, I feel like it is a gift because it has given me a window into a world I would not have known otherwise. I have developed a sense of compassion for people who have disabilities and I have been able to meet so many new friends-- inspirational people who have lived through far more than I have.

So I do feel like it is a gift. I did question it. I had to go through a long period of acceptance. There are so many different ways to see life, and I think that God gave me this because he wanted me to use my creative ability and my strength to find different ways to communicate. Sometimes I do get down and it's hard, but I have gotten past that, and I am proud of myself for doing that.

GEOFF BROWN: I think it was Esther who said that when she first became deaf, she asked, "Why me?" I suppose if you are a praying person, you tend to turn to God and ask that question. But then you look around you and see all the other people in the world who have different sorts of disabilities, and the question takes on a different aspect. It becomes, "Why should I be relieved of mine, when nobody else is?" I think most religions are looking for a world in the distant future where there will be no more evil and suffering. We have not yet reached that age. Meanwhile, God has asked some of us to carry on our share of suffering. So in a sense it is really a privilege that he is asking us to do some share of his work in keeping things going, until the time in the distant future

when all will be sweetness and light--not, I think, in our lifetime, but never mind, we are working towards it.

AUDIENCE MEMBER: I think I became angrier with people, society, friends and my church. I got very upset when people would tell me that the reason this happened was to make me a stronger person. And I wanted to say, "Hmm, thank you. I'm strong enough. Let someone else have the opportunity for a while." I try very hard, work very hard every day to look at all the good things that I can do. I am not angry with God. I don't believe in that type of a God, but I am angry with society. And yes, we do need to keep trying to educate the hearing world. I happen to be very fortunate that I finally found a church, and I have been acting as a board member until just recently when I had a lot of things happen in my life and I had to drop out. But they had an interpreter for me for every board meeting. They have an interpreter for every service. There are some other deaf people coming to the church, but every time I am involved with a committee, they have an interpreter for me. I belonged to a church before I became deaf for some 50 years--a wealthy church. And when I became deaf and they asked me what they could do for me I told them, but they said, "Sorry." And I became angrier with that than at God.

RAY TRYBUS: One of the things that I have learned is that the Europeans are ahead of us in this regard. A couple years ago, I became involved in a group called the International Association for Pastoral Care of Hard of Hearing People. It's mostly a European association, but I'm trying to get a U.S. affiliate going. They have been making significant advances. Almost all churches, at least in northern Europe, have either FM or infrared systems or induction loops, which helps people, of course, who are hard of hearing. Very few churches, if any, have CART service, so they're not ahead of us in that regard. But in terms of assistive devices they are.

One last thought from me. Some years ago, I had a serious bout of depression. I was going to a church more or less regularly at that time, but what came out of my depression eventually was the realization that part of the spiritual message of all religions is that we need each other-- that no person is an island. One of the things that resulted from my experience is that I began to say, "What do I do with this now, how do I get past this?" When you begin asking questions like this, sometimes the universe seems to respond in ways that it didn't before.

During this time a friend at work started talking about going to church. He asked me if I went to church and invited me to come to with him the following Sunday. And I was immediately accepted there, and that is where my wife and I have gone ever since. And this has made all the difference in the world--giving us a sense of personal connection. Of course, this is just where hearing loss hits us the hardest--in that loss of a sense of connection--whether it's with your spouse or family or anybody else.

So I think that our unique challenge is to continue or recreate or start from scratch those connections with other people, and that, I think, is the root of spirituality, whether we are church people or not.

AUDIENCE MEMBER: I have a little sign up on my refrigerator, and I think this is very important. It says, "It's not what happens to you, it's what you do with what happens."

Now, to be assertive is important, but I think there is a tremendous need to put some responsibility on the churches and there is some improvement there. I have been visiting churches where they have full-time ministers to work with disabled folks. There are not many, but those that are there are doing fantastic work. The National Council of Churches of Christ is doing some fantastic work. The National Organization on Disability has a religion and disability division that is promoting accessibility to congregations and different churches here in the United States. There are other groups out there, and they are growing. But, still, I feel that there needs to be some responsibility put on the church at large for not having the compassion and the knowledge about how to work with disabled people.

ANNE MCLAUGHLIN: In reference to what you are saying about expecting the churches to understand--for many years, I expected the church to understand completely about my deafness. After all, they were God's helpers on earth. I finally woke up to the realization that they do not receive degrees in audiology when they receive their Holy Orders, and that put it in a different light. At one point my church combined Deaf ministry with a ministry for the mentally challenged, and that was a very, very painful thing for the culturally Deaf people. So for the past 25 years or so, they have separated them. There are at least five Deaf parishes in the United States. But it is up to us to teach people what late deafness means and to help them understand. It is not enough simply to ask a priest for a captioned Mass once a month. When I did that, he said no. He said, "Maybe we can have a signing interpreter to move around." So it was necessary for me to educate him that very few of us who are late deafened know how to sign. We do need to educate and realize we cannot dump too much responsibility on the churches themselves. They are doing the best they can, and they are made up of human beings with limited resources.

AUDIENCE MEMBER: I would like to talk a bit about deaf history. If we all had lived 50 years ago we would all be stone deaf with no hope. There were no assistive devices then. A few hundred years ago, if you were deaf, they weren't sure you had a soul. In Orthodox Judaism before 1947, deaf persons were not allowed to marry because they were not considered really people. In Arab countries, because we cannot hear and thus cannot hear the word of God in the language of Arabic, which is the language of the Koran, we might not even last that long. I have talked to someone who does a lot with hearing impaired people in Afghanistan. He said to me, "They get killed. They say they are children of Satan." We need to remember how extremely lucky we are to live in a culture that allows us participation. Even the Catholic Church once held that people with hearing loss were sinners. The concept we now have that we are just people with a problem is something that is relatively new in the spiritual realm. It didn't exist a hundred years ago. We are living in the most magnificent time for being hearing impaired.

AUDIENCE MEMBER: I'm a mother of a Presbyterian minister. I am a Unitarian, and one thing I appreciate about my denomination is its strong sense of social justice.

It strikes me as a contradiction that we should have to fight for access to the church, of all places! But what several people have said is true--the individual churches often do not know what to do. They depend on us to tell them. And I have found that when you go through the process of telling them, you have this almost sublime moment when things work out. And for me this is a spiritual experience in itself.

I think that it would be helpful if an organization such as ALDA would develop a booklet that our members could give to our individual churches that would help explain what we need. Almost all the focus is given to amplification rather than the needs of late-deafened people who need visual accessibility.

GEOFF BROWN: That is a good point. The United Methodist Church in the USA does have a United Methodist Congress of the Deaf. They have a conference in Los Altos, California, next July [2001]. There is a heavy bias toward the culturally Deaf who use signing, although the hard of hearing and late-deafened are beginning to make an impact. They have done me the honor of asking me to be one of the speakers for the congress next year so I will take the opportunity to bang the drum for late-deafened people. Late-deafened people need to band together and make an effort on their own behalf, because, as someone else pointed out, there is a great lack of awareness--not only in the church, but also in the public at large.

AUDIENCE MEMBER: My personal feeling is that there is a big need--a big missing link out there--in the failure of seminaries to provide training for the young pastors and the educational ministers and the other people who are working in the field. There is a lot of work to do. We need to work with the churches to help them understand so that seminarians can be trained. A group I work with made a menu of about 50 things that can be done to support people with disabilities. And the churches were amazed at how cheap they were. One pastor told me, "I always thought it would be so expensive." There are many things you can be doing that are not that expensive.

ESTHER KELLY: I really appreciate the comments about putting together a booklet to educate people—but here is a little different slant on that: you have the Deaf community, the Deaf culture, the Deaf people who have their own churches. We have late-deafened people who use various means of communication. Some of us don't sign. Some sign. So it becomes very mind-boggling for people who are not educated in what we need. We have to be careful in how we approach that.

ANNE MCLAUGHLIN: Last January or so a question came across the ALDA e-mail list about something connected with spirituality and late deafness. The response was just unbelievable. E-mails were coming in ten at a time, with people asking questions, or making comments, or sharing how they felt. Finally, it got to be so much that one member said, "Hey, will you people get off the line?" So we formed a separate group for spiritual issues. It is HearInSpirit. I invite anyone interested in joining this group to do so [send an email to HearInSpirit-subscribe@yahoogroups.com or contact Nancy Kingsley at Kingsnan@aol.com]. We would love to have you.

RAY TRYBUS: I want to read one comment that is in my paper. "Church people, as a whole, do not understand our problems, our grieving, whatever. But then, on the other hand, they will never know, unless we tell them." So if we isolate ourselves from them, they never learn, and it never improves. So I feel that we have to, in effect, force ourselves back into the church, to make them aware of this. I feel very strongly, churches need people with disabilities, hearing and otherwise. They are not whole without us."

Geoff Brown was deafened by meningitis at 17. He has been a Methodist lay preacher in England for 20 years and serves as chairman of ALDA's International Committee, chairman of the International Federation of Hard of Hearing People's Late Deafened Commission, and board member of two British deaf organizations.

Dr. Raymond Trybus is a clinical psychologist who serves as Director of the Rehabilitation Research and Training Center for Persons Who are Hard of Hearing or Late Deafened in San Diego, California. He has worked since 1969 with people who are late-deafened, Deaf or hard of hearing.

Anne McLaughlin lost her hearing when she was 10. After raising two sons, she obtained a BA in English. She was a charter member of ALDA Silicon Valley and has served as its president, secretary and program chair.

Esther Kelly has had a hearing loss for over 20 years and received a successful cochlear implant 5 years ago. She works at the Deaf Action Center in Dallas as Assistant to the Executive Director and Coordinator of Hard of Hearing Programs. She had previously worked for many years as an Administrative Assistant in Church Ministries.