

SELF ADVOCACY IS OUR BEST COPING SKILL!



By Alison Freeman, PhD

Getting past our denial about our hearing loss is a continual process that can be both a major revelation and a painful experience. One of the best coping skills is to become our own advocates as we take an active part in helping others learn how to best communicate with us. However, understanding and working through our denial is a necessary prerequisite to being able to advocate for ourselves. This self advocacy creates a sense of empowerment not only for ourselves but also for our loved ones, coworkers and friends as they feel more comfortable in communicating with us.

It may surprise you that people who are blind or visually impaired have a strong political lobby, which undoubtedly requires strong advocacy skills. This may have something to do with the fact that blindness and visual impairment seem simpler for others to understand. When we talk to someone who is wearing glasses, we don't give any thought to what it is that the person needs in order to see. An evaluation of someone's vision is usually easily measured in finite numbers (such as 20/20 or 20/100), whereas hearing loss is very complex with a multitude of factors and variations including frequency, pitch, speech discrimination and volume.

People who wear glasses don't need to explain their vision impairment; it is obvious to others. But people with hearing loss have an invisible disability that is often vague even when described. Even if we show or wear our hearing aids visibly, this ambiguity is a daily stress that we must continually adjust to every person, place or situation throughout the day. It is a rare pleasure to interact with someone who truly understands what it means not to hear.

I have found the best way to cope with this ambiguity is to wear my "educator hat" so people know what I need in order to communicate effectively. Aside from my closest friends, I find that I am always "on" – I must continually explain the difference between volume, speech discrimination, and comprehension. A common example is going to a restaurant: I often need to explain the importance of good lighting (e.g., not in front of windows or in a dark corner) and to identify the location of the quietest area. Planning to eat an earlier time when it is quieter can be a simpler solution. Sometimes when I

explain to new companions that the primary disability of hearing loss is inability to communicate rather than just not being able to hear, people tend to shift their thinking to one where they can be helpful partners in communication.

Personally and as a professional therapist, I talk about the ability to recognize our levels of stress prior to being able to identify what we need. When we educate ourselves, we can take charge and educate others about what those needs are. I believe that the more people know and understand about my hearing loss, the more effective communication will be for everyone involved. In doing so, I often spare them the embarrassment of having to ask me for what I need. When I do this, I not only lower their stress but mine as well.

Struggling to understand conversations, information at professional meetings and music is a constant stress every day. An essential part of dealing with hearing loss is recognizing that stress is inevitable rather than trying to avoid it. Learning more effective stress management and communication skills is much more productive and emotionally satisfying. Communication is a shared effort for everyone – not just for someone with a hearing loss. I have long since moved from a perspective where I see my needs as a burden, to one where I realize that communication is an issue for most people. Now I assume that others want to know how to communicate with me and I feel more confidence that I know I have something important to say and share with them.

Two basic assumptions underlie my communication philosophy: First, I assume that most people know little, if anything about hearing loss. Second, most people will be embarrassed about asking me for what I need in order to communicate. They often think that they should know what I need, and not knowing embarrasses them.

In my work as a psychologist at California State University, Northridge, and in my private practice, I have a standard spiel whenever I meet a hearing client for the first time. It goes something like this: "Hi. Before we start, I would like to tell you that I have a hearing loss and what that means is that I both hear and lipread. So during the course of our conversation, if you are not sure I heard you correctly, please don't be shy in telling me so. Likewise, I may ask you to repeat something if I am not sure that I understood you." When I first started doing this, I felt awkward, as if I were taking up client time with my own problem when they were there to talk about their issues. On the rare occasions when I sensed that the person was uncomfortable, I added, "I understand if you are not comfortable with this and I would be happy to give you a referral to see someone else." I have been pleasantly surprised that in my many years of practice, I have had fewer than a handful of clients who have asked to see another therapist.

For many people with hearing loss, embarrassment and a sense of shame prevents them from telling others about

(Continued on page 16)

(Continued from page 15)

their situation which often results in giving the wrong impression, e.g., being thought rude or foolish. However, if one stops to think about it, not addressing one's own needs is really causing the worst fears to be realized. The question is, "Which would you prefer? Being seen as rude? Or being recognized as hard of hearing or deaf?"

Often, one difficulty in telling others about our hearing loss may lie in distinguishing between the fine line of being assertive and the fear of being aggressive or burdensome. While being assertive may be easier for people who are extroverted, it helps to remember that when we are not assertive, many erroneous assumptions and/or embarrassing mistakes can be made. In his book *Build Your Resilience: How to Survive and Thrive in Any Situation*, psychotherapist Donald Robertson beautifully explains:

"Assertive behavior promotes equality in human relationships, enabling us to act on our own best interests, to stand up for ourselves without undue anxiety, to express feelings honestly and comfortably, and to exercise our personal rights without denying the rights of others."

As part of our self advocacy, it helps to keep in mind that we have choices—what I call the three A's: **avoid**, **alternative** and **accept**. We can empower ourselves to reduce feelings of powerlessness, isolation or self pity. For example, when invited to go out with friends, we may

not be able to control the acoustics of a noisy room but we can definitely take charge of communicating our needs. We can beg off and **avoid** going altogether; we can suggest an **alternative**, perhaps going to a quieter place or getting together at home; or we can just **accept** that we will be uncomfortable for a time because it is important to be there for someone we care about.

The more we recognize our choices, the more in control we feel, over time gradually feeling "more and more okay" about the things that we cannot control. This doesn't mean we have to like those things but they are a fact of life. I choose to save my energy for times when it is very important that I make an effort and I have learned not to "sweat the small stuff" in other situations. While having a hearing loss is certainly annoying and uncomfortable at times, I have learned that the more I advocate for myself in communicating my needs, the more comfortable and less problematic my hearing loss becomes. And the more I recognize my own power and advocate for myself, the better I feel about myself and how I relate to people.

Alison Freeman, PhD, is a staff psychologist specializing in working with deaf and hard of hearing students at California State University, Northridge. She also maintains a part time private practice in Los Angeles and provides teletherapy services for individuals without access to therapists who use sign language. In her spare time, she enjoys her family, her pets and her lifelong love of dancing and music. Contact her at dralisonfreeman@gmail.com



HamiltonCapTel.com

See what you've been missing... at work!

Designed exclusively for business professionals with hearing loss, Hamilton® CapTel® for Business, Interconnected by Tenacity™ allows you to listen and read captions of everything said on your Cisco® phone screen.

For more information, visit: HamiltonCapTel.com/biz



Cisco® 8851