On Being Hearing Impaired Robert S. Griffin www.robertsgriffin.com

A student enrolled in two courses in education I teach at the university was also that semester in a communication disorders course and was assigned in that course to interview someone with a communications disorder. She chose me as her interviewee. I am severely hearing impaired and use a cochlear implant. She gave me a list of questions and asked me to write out my answers to them. This thought is a copy of her questions and my answers.

When and how did you become hearing impaired?

I lost the hearing in my right ear about thirty years ago, and then my left ear in 2002. The cause is somewhat up in the air according to the doctors, but I am quite sure it was from Meniere's disease, an over-secretion of inner ear fluid, which destroys the nerve cells in the cochlea, a spiral-shaped organ in the inner ear.

How severe is your hearing impairment?

Without the implant in my right ear and an aid in my left I am completely unable to hear. I was implanted in 2003 and it has been a godsend. I am able to function in the world so much better now. My head was shaved and a vertical six-inch-or-so incision was made and a titanium coated pellet was placed beneath the skin on the right side of my head and small holes were drilled in my skull to allow wires from it to be inserted into my cochlea. I hook an external word processor with a microphone to my right ear--it looks similar to a behind-the-ear hearing aid. A two-inch coil runs from it to a half-dollar-sized headpiece held to my head by a magnet. The processor transforms sound into electrical impulses and sends them through the skin to the implant by electromagnetic induction and the implant sends them on to the cochlea though the wires and the cochlea thus aided stimulates the auditory nerve.

It took me about three months for the sound to become realistic, and over the years it has become better and better. It has a mechanical quality--I'd describe it as similar to a decent AM radio --but believe me, given my problem I'll take it. Voices are very clear

and realistic. People I knew before my hearing loss have exactly the same voice (that is, if they were on the radio). I get next to nothing from a supposedly powerful hearing aid in my left ear, but I like it because it gives me some sound and kind of fleshes things out, makes them more stereophonic. My hearing is virtually normal in close-up conversations in quiet settings. I have a great deal of difficulty, however, in group situations and where there is incidental or surface noise--restaurants, meetings, social occasions, classrooms, lectures, stage plays, and the like. I can't discern music or amplified sound at all--I couldn't tell you if it's a piano or a violin or one singer from another or even the melody. So no concerts, movie theaters, television, public lectures, or, an especially big problem for hearing impaired people, telephones.

How did your hearing impairment effect your life and your communication with others?

I tend by nature to be an introverted, internal, solitary person, and the hearing loss has accentuated that predilection. Without really thinking about it, I tend to avoid public, group situations where hearing will be a strain and where my ability to hear will be limited if not completely nonexistent. In those contexts I have to focus really hard and stare at people's mouths (which I worry is disconcerting to them), and I miss things and pick up nonverbal cues that what I just said was a non sequitur and I am constantly asking people to repeat what they said, and after a while that gets old and I just want to go home. DVDs, along with reading, and writing--my web site in particular--are central aspects of my life. With a phone jack attached to my word processor and caption help I can discern DVDs quite well. Just about all DVDs are captioned, even those in English, so I watch a lot of DVDs.

I've learned from my hearing loss that every disability is a gift as well as a hit. While I'm different in degree as a consequence of my total hearing loss a decade ago--I don't believe that I'm different in kind--I am not less of a person or professional now; in fact, in my own eyes at least, I'm better in both regards. I appreciate who I am, and that I exist, that I am, much more now. I really get it now that everything--hearing, sight, mobility, the capacity to think and remember, and life itself--can go at any time, now, tomorrow, next month, next year, and someday will go. For all of us, you, me,

everybody, it's all a temporary gift to be cherished and used to its fullest while we are blessed with its possession.

My hearing has empowered and toughened me in good ways: it's taught me that if I can deal with the loss of a sense--and I have, quite well I have decided--I can deal with just about anything, including social and professional disapproval and being alone and cut off from the world; and that has freed me to let go and be who I am, to say and do what I consider true and proper and the hell with the consequences. I'm much more my own person now than before, much truer to myself and autonomous and honestly self-expressive. I'll take people on more now when I think it is called for, fight up close with them. I'm less afraid than I was, or better, less controlled by fear.

There are a lot of reasons for all of that I've just mentioned beyond the hearing issue, but I think the loss of my hearing has turned out to be an asset to me in those areas. While I so wish I didn't have to go through what I do with the hearing impairment, at the same time I really believe I'm a better version of the person I truly am because of it.

The Spanish painter Goya, who lost his hearing late in life, and Beethoven, who lost his in the prime of his life, were different artists after losing their hearing but, and this is the point, not lesser artists. Goya's paintings became softer, gentler, more personal, with his hearing loss, but they were just as good as before. Beethoven's biographer argues that he actually improved as a composer after his hearing loss. It did negatively effect his conducting, however, which was the major source of his income. Contrary to the popular impression, Beethoven was a very social person, and it frustrated him greatly not to be able to hear at the drinking establishments he would frequent in the evenings, and he tried to manage by getting people to write things on pieces of paper (before the implant surgery I used a magic marker board.)

I can relate to the Goya and Beethoven examples. My writing, which along with teaching is my vehicle of public expression, is different now, more personal, more self-revealing, but it's not worse than it was. In fact, it is richer, more nuanced, and truer to who I am. In my teaching, I'm more myself now than before, less a persona, less an act, less hidden behind a facade, more alive in this moment, more authentically the person I really am. I'm teaching my way these days, not simply the conventional, or standard, way. I

think I have greater empathy and compassion for students now, a greater sense that we are all in this life together as human beings.

In my personal relationships, I'm even more withdrawn than before, but I think I'm more sensitive and kinder and more understanding and accepting of other people now than I was before my hearing became so terribly bad. I don't think my relationship with my seven-year-old daughter, who lives in another state with her mother, is less rich and complete than if I were able to hear her better. Even though she and I only see each other every couple, three months, we are very close--closeness, I've learned, isn't dependent on hearing someone well, or geographical distance, for that matter--or anyway, not significantly.

My daughter's understanding and kindness and even protectiveness around my hearing disability touches my heart and deepens and strengthens our relationship. I think of last New Year's Eve with her and her mother and some friends at a very noisy restaurant. I couldn't hear a thing and just sat there silently. After an hour or so, my daughter came over to me and leaned in very close and said, "Are you lonely?" The truth is, on that occasion I was feeling lonely, or at least cut off, but at that moment my strongest reality was the love and respect I felt for this dear little soul.

I get down at times when I think about never hearing music again, and from the constant screaming fire engine sirens and Niagara Falls roaring noises I live with every waking moment-deafness does not necessarily mean silence. My ears always feel plugged and hurt a bit, the feeling you get when you are in an airplane, and that is uncomfortable, and yes, it is all the time, all the time, all the time.

Actually, as I think about it, I do have times when my ears doesn't feel plugged and don't hurt and there's silence, and when I can hear perfectly, including music, with glorious clarity--in my dreams. But then I wake up, and, Oh, that was a dream; it's me, I'm here, it's now, I'm back in this reality, back in my life, back where it will always be this way. Then I get right on with my day and do the best I can with it. I want to live.

What part of your life did you struggle with most being hearing impaired?

Anything public--organizational activities, a professional conference or something of that sort, meetings, concerts, social gatherings, teaching, anything like that. Logistics are difficult for me: I can't phone a taxi to go to the airport, I can't discern the announcements at the gate about when to board the plane. If I take the trip to Europe I'd like to take, will the electrical outlets work for my processor's battery charger? This week I needed a handyman to fix my kitchen ceiling, and I can't use a phone, so how do I find one and contact him? I'm very alone in my life and there is no one to assist me with things like that. I find myself looking forward to what I am doing this weekend: getting away from all of the challenges of communicating with the world and reading my books and cooking my meals and eating them and perhaps writing, as I'm doing right now, to you. Nobody's ever asked me about my hearing loss before. It feels good to me, it gets something outside of me that has been inside, it's clarifying for me, to be sitting here on my leather couch at home with a cup of coffee and writing this down.

What led to your decision to get a cochlear implant?

I wanted to be in the world, not cut off from it, to communicate with people and especially I wanted to work. I'm grateful to be able to be able to do my work as a university professor. I'm honored to go to the office every day and to be in the classroom with students, including the two courses with you. I think to myself, "I'm here! I can do this!!"

I am so thankful for the cochlear implant technology and the excellence of my surgeon. Cochlear implants replicate an ear--that is stunning, mindboggling, to me. Someone thought this up! I think of how fortunate I am that this technological advance happened not long before my total hearing loss. Beethoven and Goya weren't so lucky. Cochlear implant surgery typically takes two and a half hours. I was under a general anesthetic, but I'm told by my audiologist who was there that my surgeon, who himself was suffering from cancer at the time, devoted four hours to it. Many patients have difficulties following the surgery, including having to have it redone, but I've had no problems with the implant at all, and my understanding is that neither has anyone else who has been implanted by this fine and dedicated surgeon.

It's allowed me to be in the two classes you and I are in together. And I can hear my daughter. The sound from the processor is slightly aversive and I spend a good bit of my time without my hearing equipment on, and she has a signal to let me know when she wants to talk to me. She flicks her ear where the processor sits and mouths "hook up," and waits patiently for me to do so. That's her world, that's her dad, and she's deals with her reality with good cheer and with love, and I think she's absolutely great.

Would you recommend cochlear implants to others? Why or why not?

Whether to go with a cochlear implant is a personal decision to be individual in consultation with made by an his or otolaryngologist (ear specialist), but certainly from my experience I would recommend looking into it as a possibility. I am especially moved when I see young children with implants. I'm so sorry that they are hearing impaired; at least I experienced sound until I was well into adulthood. At the same time, I am very gratified to know that they have the implant. With it, they will be able to learn to speak and to discern spoken language and won't be limited to signing, which in my view cuts them off from the center stage of life. Many hearing impaired people value a separate hearing impaired, or deaf, culture, which includes its special, private ways of communicating, and I respect that; I just don't share their commitment. I think the action in life, as it were, is in the mainstream and not on the periphery of social, cultural, business, and political affairs--at least it is for me. To the extent I am capable of it, that is where I want to conduct my life. And if my daughter were hearing impaired, that is where I would want her to be.

My basic orientation toward hearing impairment--and really, any handicaps, and we all have them to one extent or another--is that people who are hearing impaired are best off learning to deal with the world on its terms, rather than retreating from it or demanding that it accommodate them. My message to my corner of the world is, I need to you to adjust to me some--I pull students close to me in classes, for example--but basically make me come to you, don't come to me. Don't do things for me; instead, encourage

me to do things for myself, and support me in that where you can. (I practice lip reading news on television without the jack and captions.) Don't lower your standards and expectations with regard to me; keep them right at the very top, and challenge me to match up with them. Despite the obstacles I face, I want to get as close as I can to realizing my full possibilities while I have the gift of life, and that's the best way for you to help me to do that.