FIRST STEPS INTO LATE-DEAFNESS:

AN INTRODUCTORY MANUAL FOR NEWLY DEAFENED ADULTS

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By

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ABSTRACT

Late-deafened adults are individuals who lose their hearing in adolescence or adulthood. Whether the hearing loss is sudden or progressive, it forces immense psychosocial changes upon the individual, disrupting relationships and work, and impacting every area of the person's life.

This manual serves as a guidebook for the newly deafened adult, giving her understanding, empathy and a road map to help make sense of the adjustment process. The first chapters detail what to expect during visits to the ear specialist and audiologist, and discuss the grieving process and the impact of deafness on identity formation. Information on how to develop new ways of communicating and how to build a support network is shared. An introduction to cochlear implantation, assistive technology, and legal rights for late-deafened adults follows. The manual closes with interviews of three late-deafened adults who share their journey into late-deafness.

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Acknowledgements

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I owe a debt of gratitude to late-deafened adults everywhere. You have courage and passion and the ability to live life to the fullest, and have been the best teachers I could have ever asked for.

I. Introduction

I lost my hearing April 15, 1984 from meningitis. I remember my hearing slipping away as I headed towards oblivion, the doctor leaning over me asking if I could hear him. His voice seemed so faint and far away. Three days later, after doctors had prepared my family for my possible death, I woke up from a coma. I had double vision, no remaining balance, and I was deaf, but I was alive.

Eating well, resting, practicing with a walker, and wearing an eye patch were concrete actions I could take, knowing these steps would help me recover my health, vision and a reasonable form of balance. Deafness, however, left me and those around me at a loss. I'd always taken hearing for granted. I was a musician! My training, my dreams, and my life revolved around music. Now all I had left was a distorted form of inner noise that sounded like a cacophony of Hawaiian steel guitars, train whistles, drums and loud whooshing sounds. Tinnitus by itself does not necessarily mean one has hearing loss. Tinnitus does accompany sudden, sensorineural hearing loss, however, as if the inner ear takes desperate measures to restore sound of any kind, even if it must make something up. Perhaps the inner ear issues a trauma alarm and the brain works overtime attempting to translate the signal and restore some semblance of remembered sound.

Twenty-eight million people in the United States have some form of hearing loss. Of these twenty-eight million people, twenty-six million are hard of hearing and two million are deaf. Out of the two million deaf people, one and a half million are late-deafened (Schein and Delk 12). Late-deafened people lose their hearing after the development of speech and language. In a technical sense, a late-deafened person

depends on visual means to understand spoken language. In this manual, I use a broader definition that includes people with some remaining hearing. For example, I include people headed towards late-deafness via a progressive hearing loss. These people may be able to use assistive technology to maximize what hearing they have left. Also, many newly deafened adults are opting to immediately proceed with cochlear implantation and, likewise, can make use of assistive technology after healing from the surgery and activation of their implants. They are still late-deafened, despite the addition of sound when wearing their implants.

This manual is written for you, a newly late-deafened adult, in whatever specific shape or form that takes for you, to help you on your journey. Family members, friends and professionals dealing with late-deafness will also find the information useful. The manual will take you through the same steps that I traveled many years ago. The first chapter deals with ear specialists and audiologists. The next chapters look at the grieving process and the struggles late-deafened adults have with identity change. Concrete suggestions and tips follow to improve daily communication and to set up a strong network of support. Today, cochlear implant surgeries are viable options to restore partial hearing and the manual will walk you through the steps necessary to become a candidate for the surgery and give you a feel for what to expect regarding implantation. I take a look at assistive technology, from alerting equipment to let you know the baby is crying to innovative ways to continue to use the telephone, to aids to improve any hearing you may have left. Then, three late-deafened adults share their journeys via in-depth interviews.

Our journeys are unique and yet late-deafened adults share many of the same experiences along the way. We grieve the loss, and grow and change as we learn new ways of coping and living. In time, we find the path into late-deafness rich with love, humor and opportunities to grow and experience life in ways we sense we would not have found if our life had taken a different turn. Many late-deafened adults speak of their experiences in terms of death and rebirth, and they would not exchange their experiences for an easier path. Yes, there are many benefits to life after deafness!

2. Medical and Audiological Care

If you lost your hearing as an adult, you have probably been to a doctor and an audiologist. The first step for late-deafened adults or those losing their hearing is invariably a medical one. You will need to see two medical specialists: an audiologist and a medical doctor who specializes in the ear. An otologist focuses entirely on the ear, or you may be referred to an ear, nose and throat specialist (otorhinolaryngologist) or an ear and throat specialist (otolaryngologist).

Audiologists conduct diagnostic hearing tests, and will refer you to an ear specialist if you have not already seen one. Audiologists help people select hearing aids and assistive listening devices and today many specialize in cochlear implant programming. Audiologists work in private practices, medical clinics, hospitals and medical centers, schools, universities, elder care homes and speech and hearing centers or other rehabilitative centers.

An audiologist will have either a master's degree or a doctoral degree. Many states require audiologists to be licensed and registered at the state level and audiologists may also apply for and receive certification from the American Board of Audiology. CCC-A beside an audiologist's name means he or she is certified by the American Speech-Language-Hearing Association with a Certificate of Clinical Competence in Audiology (Mango 95). An Au.D beside the name indicates the audiologist has a doctoral degree (Doctor of Audiology).

2.1 The Ear Specialist

The ear specialist will examine your ear and determine the cause of the hearing loss or deafness, if possible, along with making recommendations for treatment. Many different factors can be implicated in adult-onset hearing loss and new causes continue to surface. Bacterial or viral infections, traumatic injury, even medications can cause deafness. Surgery on or near the auditory nerve creates true silence, with no resulting tinnitus. A progressive hearing loss may be hereditary in origin, or stem from an autoimmune disorder. Sometimes the cause cannot be determined at all or perhaps a combination of factors is involved. The specialist will work to narrow down the particular path your loss is taking. A survey of 348 members of the Association of Late-Deafened Adults (ALDA) revealed that 41.5% were experiencing progressive losses, 40.5% lost their hearing from medical reasons, 12.8% had surgical losses, and 5.2% became deaf because of trauma to the ear (Boone and Scherich 3). Appendix A at the end of this manual goes into more detail on causes of deafness.

Most late-deafness stems from problems in the inner ear or with the auditory nerve. Sometimes the middle ear is involved, or an infection has spread from the middle to the inner ear. Knowing how you hear will help you better understand why you can no longer hear. The ear is divided into three parts: the outer ear, the middle ear, and the inner ear. The outer ear collects and channels incoming sound and sends it towards the eardrum. The middle ear, just on the other side of the eardrum, conducts the sound, and the inner ear receives the sound and transmits it to the auditory nerve whose signals are

translated by the brain as sound. Appendix B gives a detailed explanation of how people hear.

Hearing loss in the inner ear is called sensorineural hearing loss, sensorineural referring to the transmission of electrical impulses from the cochlea to the auditory nerve. With deafness, the hair cells in the cochlea have been damaged and no longer send sounds to the auditory nerve.

Hearing loss originating in the outer or middle ear is called a conductive hearing loss. Otosclerosis, a softening and hardening of the bones located in the middle ear, causes a conductive hearing loss. Middle ear infections also cause conductive hearing loss. Treatment is available to cure these conditions, but if they spread to the inner ear, deafness can occur. Hearing loss that involves more than one area of the ear is called a mixed hearing loss and central hearing loss refers to damage to the central nervous system itself.

The specialist may prescribe medication to help reduce inflammation or in an attempt to halt further loss. When deafness is the result of a serious illness such as meningitis, or happens because of an accident, additional doctors will be called in to halt the infection and deal with other complications.

2.2 The Audiologist

The audiologist will perform hearing tests to see how much hearing, if any, is left. This is necessary to determine precisely what you can or cannot hear. The low roar of a jet airplane taking off, for example, can be heard by most individuals, even deafened

people. For an individual with a progressive hearing loss, hearing tests help track the loss and show whether it has stabilized, improved or worsened.

The hearing test is conducted in a soundproof booth. You will sit in a chair in the middle and will see speakers facing you in each corner of the booth. You will see a window that opens into an adjoining room that houses a pure tone audiometer, which is a machine that produces tones at different frequencies. The audiologist will test your hearing at various frequencies with the audiometer, and then will give you a speech discrimination test. Testing is done with both air conduction and bone conduction. For air conduction, you will wear headphones while the audiologist tests the sensitivity of the ear. For bone conduction, a small bond conduction vibrator is placed on the mastoid bone just behind each ear. The following section gives helpful hints in how to read your results, which are graphed on what is called an audiogram.

Additional tests may be performed. During tympanometry testing, the audiologist places a small probe down the ear to measure how well the eardrum absorbs sound under different air pressures. The probe also makes pure tones, so the audiologist is able to tell if the person can hear the tones as well as if too much fluid is in her middle ear (Haybach 106). Acoustic reflex testing checks how well the small bones in the middle ear react to loud sounds. Under normal circumstances, loud sounds contract the muscles in the inner ear, a reflex, so to speak, meant to protect the ear (Carmen 74). This test can give the audiologist valuable information about the condition of the middle ear, and also the inner ear, the auditory nerve and even the facial nerve. Another possible test that might be

recommended is an MRI, or a magnetic resonance imaging test. MRI's can detect even mild hearing loss (Albright 31).

2.3 The Audiogram

Hearing is graphed on a chart called an audiogram. The vertical lines represent the frequency of the sound which is measured in Hertz (Hz), or the number of cycles per second that the sound waves complete. Middle C on the piano is 256 Hz. Most human speech falls within the range of 300 Hz to 3000 Hz but a low, bass voice can register as low as 125 Hz and certain consonants, such as "th" can be up in the 5000 to 6000 Hz range (Woodcock and Aguayo 4). All of the consonants are higher in frequency than vowels.

The horizontal lines represent the loudness of the sound which is measured in decibels (dB). The decibel is a logarithmic unit. The softest sound, nearest to complete silence, would be 0 dBs. A sound ten times more powerful would be 10 dB and 100 times stronger would be 20 dB. A sound 1000 times more powerful is 30 dB. In daily life, soft conversational speech is held at an intensity of approximately 45 dB, while city traffic moves up to 75 dB. A jet engine at takeoff can be as loud as 140 dB (Rezen and Hausman 22).

The frequency measurement on the audiogram starts with the lowest frequencies on the left and moves to higher frequencies on the right. The softest sounds are on the top and the loudest sounds are on the bottom of the graph. The audiologist tests different loudness levels at different frequencies for each ear and maps the results on the graph.

The letter "x" is used to represent the left ear and "o" is used to represent the right ear for the air conduction test results. The results of the bone conduction test are shown with a ">" for the left ear and "<" for the right ear. A masking noise is sometimes used to isolate one ear from the other. If so, such results show up on your audiogram as "]" for the left ear and "[" for the right ear.

A 90 dB hearing loss in both ears at various frequencies (Hz) indicates profound bilateral deafness. The audiogram in Figure 1 is an example of what a profound hearing loss looks like. The "x's" and "o's" run along the bottom of the chart. An audiogram showing hearing in the 71 – 90 dB range indicates a severe hearing loss. A moderate hearing loss shows up on an audiogram at a 41 – 55 dB range (Rezen and Hausman 23). As you progress towards the top of the graph, the amount of hearing loss diminishes.

Figure 2 shows an audiogram for a person with normal hearing. Note in this audiogram that the "x's" and "o's" for the left and right ears run across the top of the audiogram. Also take note of the shaded area of the audiogram. This area represents the frequencies at which speech occurs. A person with normal hearing can hear frequencies much higher than the normal speech range.

Figure 3 shows an audiogram for a person wearing one cochlear implant. The "C" stands for cochlear implant and the "r" means the implant is in the right ear. You will see that the frequencies heard are lower than for normal hearing but much higher than for profound deafness. The frequencies heard also fall within the shaded area, which are the frequencies at which speech occurs.

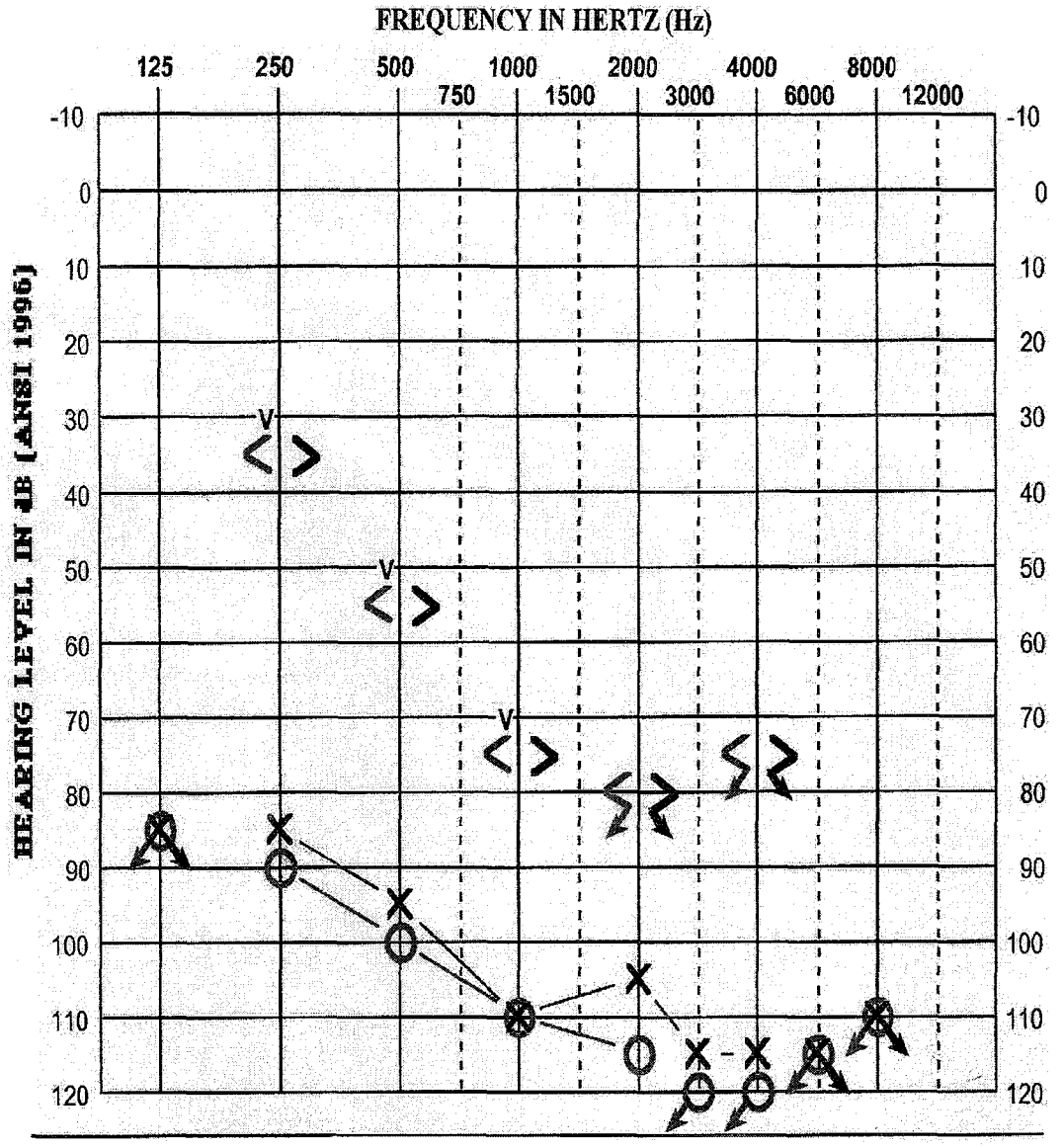

Figure 1. An audiogram showing a profound bilateral hearing loss. Prepared by Tina Worman, M.S. CCC-A

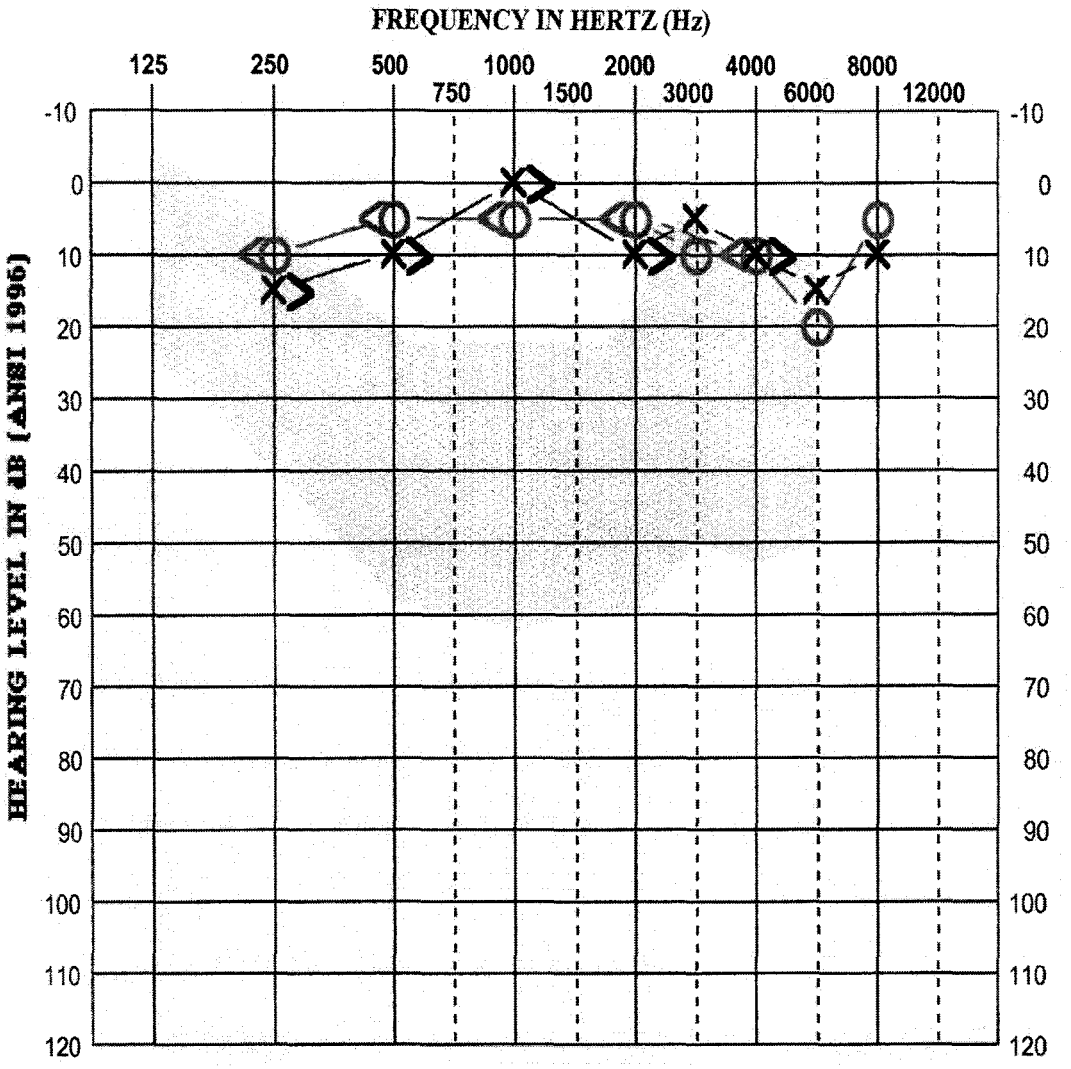

Figure 2. An audiogram showing normal hearing. Prepared by Tina Worman, M.S., CCC-A.

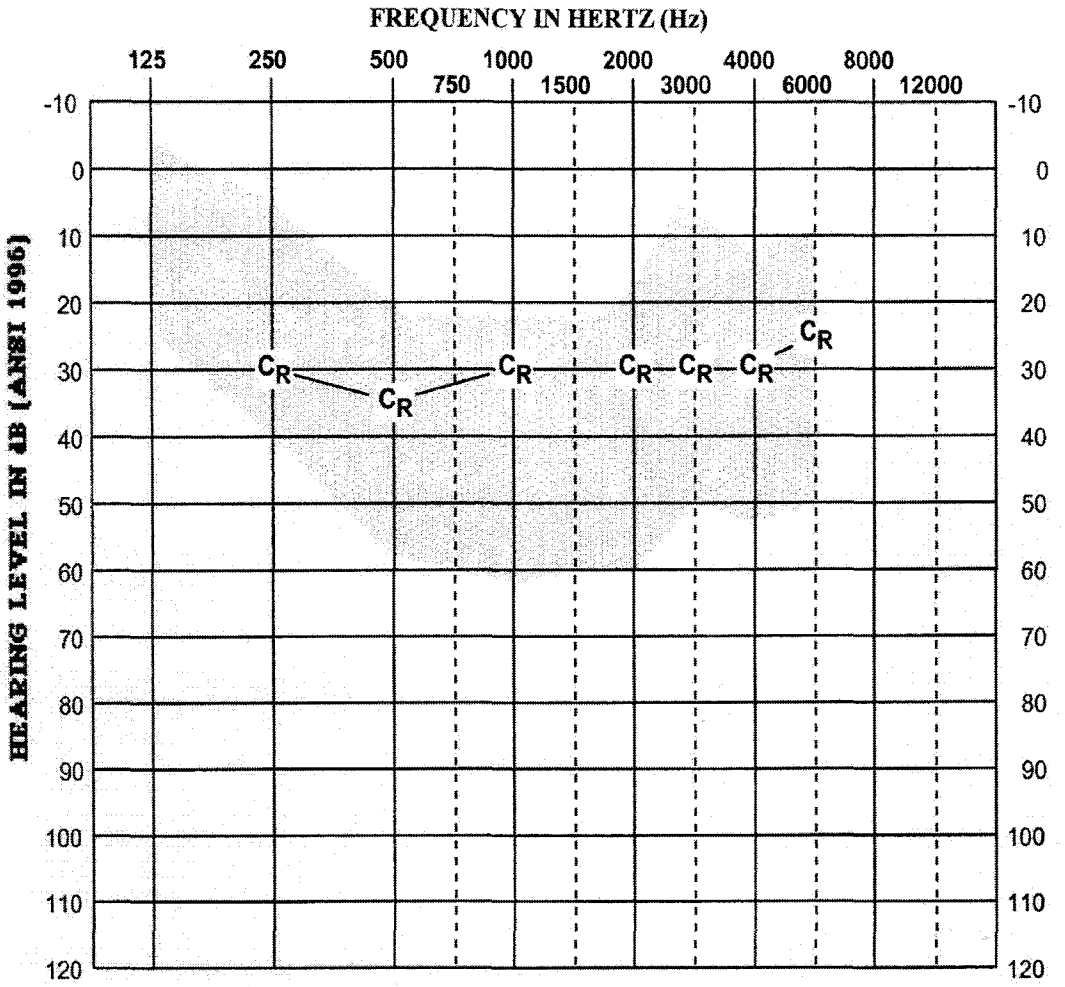

Figure 3. An audiogram showing the hearing of a person with a cochlear implant in the right ear. Prepared by Tina Worman, M.S., CCC-A.

The audiologist also measures speech discrimination or how clearly one hears words. The first speech discrimination test given is a list of spondees, or two-syllable words that have equal stress on each syllable. Examples of spondees are baseball,

football, toothbrush, and hotdog. These words are given at softer and softer levels until the Speech Reception Threshold, or how soft a person can understand speech, is determined. The second test given is the Speech Recognition Score and this test measures how well a person can understand speech. The test is a list of one syllable words that include different vowel and consonant combinations. Sometimes a person will speak in terms of a percentage of hearing loss rather than a decibel loss. He is probably referring to his Speech Recognition Score. A discrimination score of 90% means a person can understand nine out of ten words when taking the test. A score below 45% means the individual is having a difficult time getting any information at all (Rezen and Hausman 24).

If you are deaf, taking the Speech Reception Threshold and Speech Recognition Score tests might seem pointless, but the tests will confirm your deafness for medical and diagnostic purposes, and will open the doors for rehabilitation counseling or other forms of help. It can be difficult to sit through a test and not hear anything. This was the case for me when I had my first hearing test after losing my hearing. During the testing, I kept hoping that I would be able to hear something, anything, but that was not the case. My audiologist was a warm and compassionate woman who warned me the process might be difficult and continued to check in on me during the testing. I knew, going into the sound booth that I had lost my hearing, but taking the tests confirmed the reality on paper, and opened the way for me to grieve the loss.

3. Loss and Change

If you have lost your hearing, you have lost a part of yourself. Late-deafened adults invariably describe the loss in traumatic terms. Jean Mulrooney's words eloquently summarize the journey of a late-deafened adult: "It was not a single trip. It involved learning and relearning, unbelievable isolation, barely controlled rage, the depths of depression, personal devaluation, acute sustained anxiety, and continual feelings of conflict in interpersonal relations" (qtd. in Benderly 95).

When we lose our hearing as adults, we are still a hearing person inside. Yet now, easy communication with friends is no more. How do we communicate with our children? What do we do when our job involves continual, daily contact with customers? How do we go about the daily tasks of life? Everything changes. Deborah Rutman writes: "Acquired deafness must be considered, first and foremost, a social and psychological loss which affects all communication and interpersonal interactions, and which deprives the individual of the type of social relationships, occupational goals and overall quality of life to which he or she was accustomed and which gave life meaning" (305). Frank Zieziula and Katharine Meadows agree: "Late-deafened people are telling us that what happens to them when they become deaf is more than a physical condition of lack of hearing and more than a problem of communication. The ramification of a hearing loss on the psychosocial world of the people affected is profound" (61).

Our reality has changed. We may not feel safe, wondering how we will know if an intruder breaks into the house? We can no longer hear music. If we have lost our hearing all at once, conversation is reduced to reading what someone has written. We

can still speak, but we can't hear ourselves speak. Not hearing the sounds of our own body may make us feel detached even from ourselves (Luey and Per-Lee 8). A sense of unreality permeates our perceptions. We may feel in limbo, in a nowhere land, and we do not know where to go.

Frank Zieziula and Katharine Meadows have developed a model of the grief process specifically adapted to late-deafened adults. Like Elizabeth Kubler-Ross in her book On Death and Dying, Zieziula and Meadows feel that the grieving process involved in hearing loss is healthy and normal and similar to that of losing a loved one. For late-deafened adults, they find the process quite lengthy and complex, however. Kubler's five stages of grief (denial, anger, bargaining, depression and acceptance) remain valid to the process, but there is more of an overlapping of feelings, a simultaneous expression so to speak, of several of Kubler's stages occurring on top of each other.

The feelings experienced by newly-deafened adults do not progress in an orderly state. Deafened adults report feeling a confusing mix of emotions, and mood swings continue for years and get in the way of daily life. In addition, secondary losses can increase the intensity of the grieving process. Loss of the daily ease of life, music, friends, perhaps a spouse – such losses create a deep hurting as intense as the original loss.

Zieziula and Meadows break the adjustment process down into three categories: working through the pain of the loss, adapting and adjusting, and coming to a personal understanding of the loss. They stress these "stages" do not proceed in a progressive

order. One category will take priority at certain times, but there is a cycling and recycling of the stages.

The first step, that of working through the pain of the loss, while a natural process, imitates the feeling of being on an "emotional roller-coaster" (Zieziula and Meadows 61). Late-deafened adults have difficulty coping with the intensity of the emotions. People feel overwhelmed, out of control, and as though they are "going crazy". Family members and friends frequently prove unable to tolerate the expression of such strong feelings, so the deafened adult attempts unsuccessfully to deal with the emotions by trying to hide them from others. Feeling misunderstood, not accepted, and not heard simply prolongs a most difficult process. Late-deafened adults need to take care of themselves during this time and not hesitate to seek help if they sense themselves slipping into the downward spiral of depression.

Depression is not grief. Holly Elliott, a late-deafened adult, shares words of wisdom on this stage of the grieving process:

> There is a great difference between grief and depression. Deafness is a frightening loss and grief is a natural response to loss, an active process that must be experienced to be resolved. Depression is a giving-up process, a long-term withdrawal. The feeling of being "left out" – and not doing anything about it – is a feeling of depression. I have a hunch that depression interferes with communication more than deafness. The combination of deafness and depression makes communication very difficult (Glass and Elliott 23).

The second stage, adjusting and adapting to the environment, is likewise an ongoing process. Learning how to communicate now that one can no longer hear is perplexing, distressing and extremely time-consuming. The necessity of a career change is not uncommon. Dreams may appear to be shattered beyond repair and they will either need to be resuscitated and redesigned to encompass a new reality, or they will need to be replaced. This is a time of growth and learning which feeds new energy into the process as late-deafened adults learn how to cope and make positive changes in their lives.

The last task involves coming to a personal understanding of the loss. This understanding may involve some kind of action, such as helping other people who have lost their hearing or taking concrete steps towards the realization of a goal. Researchers acknowledge that accepting the reality of hearing loss remains a most difficult task and it may never be completely realized. Each new challenge in life brings back the original loss to be worked through. The steps become clearer and easier to traverse with time, however, and the process softens as compassion and understanding grow. The day comes when the grief is in the past, and the future is bright and shiny, indeed.

4. Identity: Who Am I?

Identity issues intertwine with the grieving process, and they are complex enough to deserve a separate look. I was speaking with an interpreter friend recently about the characteristics of late-deafened adults as a group compared with those of culturally deaf people. When she responded, she signed "Late-deafened people are so accepting. They accept this identity. They accept that identity. Oh, there's another identity. Let me try that one! They don't know *what* identity to accept!" We both laughed. My friend had a point. When we lose our hearing as adults, we lose our mooring, our reference points. Our identities, the "jackets" we put on to face the world (father, worker, or excellent bowler), no longer work, and it becomes easy to slide into dependency, accepting the perspectives other people have of us. It is easier to relinquish responsibility.

Relinquishing responsibility does not solve problems, however. And one of the problems late-deafened adults have in identity formation is that our society perceives deafness as a limitation. The late-deafened adult is now different from the rest of the world, which is primarily hearing, and he knows it, but the late-deafened person also knows he's as capable as the next person. He just can't hear. People treat him differently now, or so it seems. Is it all because of his hearing loss? They must know something he doesn't. After all, they can hear. The late-deafened person accepts how the other person perceives him, not knowing what else to do at this point.

Accepting how others define us opens the door to being marginalized. Woodcock and Aguayo propose that late-deafened people acquire a stigma when they pass from hearing to deaf: "People who have or acquire a stigma are aware that others don't fully

accept them. Indeed, they may themselves share the dislike for the attribute" (36-37). Marginalized people do not feel accepted by the larger world. This would explain why hard of hearing people go so long before they are willing to accept the help that hearing aids and practice in assertive communication techniques will bring. Admitting that one can't hear well opens one up to being considered "less than."

An inner conflict thus arises in the late-deafened adult's mind that he mirrors in his outside world. The late-deafened person is hearing inside, but now has been placed in a situation where values held by the group he identifies with no longer match his own experience. He has become "the other" and not only does he find his experiences in the world backing up this new feeling of separateness, he finds his own mind is battling between feeling whole and feeling "less than." The more "normal" he can act, the more likely he can get by in the larger world, but this means minimizing his feelings of isolation and anger and minimizing his own needs for connection and communication. He approaches a clerk in a store and asks them to write, and they speak instead, because he can talk so clearly. How could he be deaf? The late-deafened person then bluffs, pretending to understand when he doesn't. He wants the encounter to go smoothly, but the bluffing makes things worse. It only takes a few difficult encounters before the late-deafened person begins to isolate himself and let the world go by. He knows he needs to build a new set of identities and learn new coping skills, but the task seems insurmountable. He marginalizes himself as he does not yet know what else to do and marginalization is what the world models for him. I believe this marginalization is one reason so many people, myself included, struggle to "overcome" our disabilities, despite

high personal cost. To overcome a disability and be recognized for that erases the stigma of the disability.

Identity issues also arise because there are many different kinds of deaf people in the world, and the late-deafened person, no longer with a steady reference point of his own, no longer knows where he stands in relation to these new people with which he comes in contact. Some people have grown up deaf, but live within the hearing world. These deaf individuals are called oral deaf people. They have the same language as late-deafened adults and tend to be excellent speech readers. Henry Kisor's What's That Pig Outdoors? and Lew Golan's Reading Between the Lips: A Totally Deaf Man Makes It in the Mainstream are both fascinating accounts of growing up deaf within the hearing world.

Other deaf people grow up in a world of their own with their own visual language. The majority of late-deafened adults have had little contact with the culture of these Deaf Americans. Deaf culture has its own behaviors and traditions and its own language, American Sign Language. Deaf people prefer to be referred to as Deaf, with a capital "D." Carol Padden and Tom Humphries' Deaf in America: Voices from a Culture gives a good understanding of the many differences between Deaf and hearing culture.

Identity is important in Deaf culture. Let's assume the late-deafened person has learned sign language and is meeting another Deaf person. Introductions immediately establish each person's identity in relation to cultural deafness: "Are you Deaf? Are your parents Deaf? Where did you go to school?" (If a Deaf person does not have Deaf parents, they learn cultural behaviors at Deaf residential schools.) By this time, the Deaf

person has put together that the late-deafened person is not Deaf, but the individual still has to be "placed" in some way that makes sense to a culturally deaf person. Voice is not valued in the Deaf world, and late-deafened people speak, so they tend to be called hard of hearing by Deaf people because they can speak. "You're not Deaf. You can talk. You are hard of hearing." Once again, the late-deafened adult finds himself accepting the "rules" of the Deaf world and minimizing his own needs because he is not yet strong enough in the core identity he is developing. None of this is bad in itself, as it opens the door to learn new ways of doing things and the late-deafened person has much to learn about a visual approach to life. For example, Deaf people, when they toast at a table, do not clink the glasses together. Sound is not important to their culture. Instead, they make sure to touch each person's hands holding each glass before downing the drink. The late-deafened can appreciate and learn from these differences, but it can be frustrating at times.

Holly Elliott has spoken of this frustration resulting from different perceptions of the late-deafened person by both hearing and Deaf people. Hearing people, finding out she was deaf, made blanket assumptions because she could use sign language. Hearing people have a tendency to group deaf people, not taking into account the actual diversity involved. Deaf people, on the other hand, would assume she was hearing because her sign language skills could not compare with those of someone who has grown up deaf:

> Late deafness invariably brings on an identity crisis. My ongoing identity crisis is the fact that hearing people think I am hearing because my speech is good and Deaf people think I am hearing because I am not fluent in

> American Sign Language (ASL). I prefer to talk and sign at the same time. I am reminded of a conversation I had with a Deaf man some years ago. "I am better off than you are," he said. "You lost something; I didn't." I replied, "Maybe I am better off. I had something; you didn't." Another man introduced me as "Holly Elliott. She's deaf, but she lives like a hearing person," or "She signs with a hearing accent." So we have three major categories in the field of hearing-impairment: the culturally Deaf (uppercase D) whose first language is ASL; the culturally hearing deaf or deafened whose first language is spoken English; and the hard of hearing (2).

This sense of being somewhere between Deaf and hearing, is a major source of identity confusion. Late-deafened adults handle this "between worlds" phenomenon in different ways. Most associate primarily with the hearing world. Especially now, with the advances in cochlear implantation, many late-deafened adults can restore enough hearing to minimize most communication problems with hearing people. A few gravitate to the Deaf community and find a home there, and others work in a field that involves contact with the Deaf community as well as the hearing world. Some prefer more than usual isolation, and some have a foot in each world. Others are creating a new world more comfortable for late-deafened adults.

Holly Elliott said, "Deafness is not the handicap; the real disability is the inability to communicate. So let's communicate knowing that's the way it is. Now where do we go from here?" (4). For myself, when I would let go of the daily struggle of coping,

when I would let go of the belief that life was difficult and that I had to figure out everything right away, life became interesting instead. I realized I was doing just fine and that, step by step, I was learning new ways of being. If I started thinking of myself as marginalized or forgotten by society and family and friends, then I started coming up with "proof" all around me of insurmountable barriers. I began to realize what I felt and thought about me was so much more important than what others might be thinking. Life began to open up again as I realized just how much influence I had on the process.

5. How Do I Communicate?

As a late-deafened person, you no longer take communication for granted. Just ordering food at the local deli can become a laborious process and joining a group conversation feels impossible. At the beginning, talking to other people can feel overwhelmingly difficult. Fortunately, matters improve and it is important to know that full communication is possible. This chapter gives an overview of different ways to reach an understanding, whether using speechreading, sign language, cued speech or by getting the words transcribed into text so they can be read. Tips to improve conversations follow the overview.

How you communicate as a late-deafened adult changes over time as you learn new skills and new ways of understanding what people are saying. How you communicate will depend on the kind of hearing loss (sudden or progressive) you have and your own personal preferences (sign language, writing, speechreading, etc.) People with a progressive hearing loss may have had time to develop reasonable speechreading skills. People who lose their hearing suddenly will have a more difficult time reading lips. Whether you have some hearing left or no hearing will influence your preferences. Large group situations require interpretation of some kind, be it sign language or text-based transcription. You will need to expend energy to make situations work for you and think and plan ahead. Even though communication is a shared responsibility, most people will look to you for guidance in how best to talk with you.

In my own situation, when I lost my hearing, I was not able to speechread nor did I know sign language. Friends and family filled up several notebooks "talking" to me. I

still have those notebooks today and so appreciate having them. They served as my connection to the larger world. Writing is time-consuming, and with our 24/7 society it can be difficult to get people to slow down long enough to write. When they do, however, the writing helps them to center and refocus. "I really enjoyed visiting you those first months after you lost your hearing," a friend told me years later. "I liked writing to you. It just made me feel better somehow to take the time and slow down for a bit."

5.1 Speechreading

Speechreading requires training and practice. For many late-deafened adults, speechreading is a continual struggle and not something that comes easily. People are naturally auditory, kinesthetic, or visual in how they communicate. A visual person might move ahead rapidly with speechreading, while the auditory person is still searching for non-existent sound. A kinesthetic person does her best learning on the go. Rather than pore over a lipreading book, she may be better off getting right out there and practicing with real people. Skill with speechreading is not based on IQ, either, but practice will certainly help the late-deafened adult improve her skills at learning to understand what another person says without accompanying sound. Speechreading is more difficult if no residual hearing remains. Even the smallest amount of hearing can make the task smoother.

Some audiologists offer speechreading classes, as do speech pathologists. If your area has a speech and hearing or other rehabilitative center, check with them to see what

they might offer. Books, tapes and disks are available for purchase and can be studied at home. Refer to Appendix D for a source that lists various speechreading materials.

During all efforts to speechread, you should keep a pad and pencil ready for the speaker to write down what you are not getting. Soon, a deafened person can "graduate" from having all correspondence written to half writing and half speaking. The other person speaks and writes down each new topic along with words and phrases that are not understood. You will become adept at reading nonverbal cues. Two hints to pass on to your hearing friends: Speechreading while someone is laughing is very difficult, and one=s body cues need to match what one is saying. A good example of mismatched cues is telling a joke with a deadpan face.

Speech and hearing professionals estimate that only about 25 - 35 percent of spoken English is visible on the lips. Some sounds look much the same as others. Look at yourself in a mirror and compare "baste" with "paste," "moat" with "boat," or "trip" with "drip." Mary Clark, a late-deafened mother of three, takes a humorous outlook on speechreading: "A good lipreader understands 35 per cent of what's being said, provided you are not standing in front of a sunny window, you have no sunglasses on, you've brushed your teeth, and you are not talking between my knees!" (6).

Speechreading in a group situation is difficult unless people slow down and let you know when they change from one speaker to the next. Some people ask one person to write down the main topics or a brief summary of what is going on. Depending on the importance of the information, you may need more transcription. If you have some hearing, group situations can work well by using assistive listening equipment in addition

to speechreading (see page 57). Having each person who is speaking hold an object and pass it to the next person who speaks reminds the hearing people to maintain a slower pace and to speak clearly.

In my own case, I found speechreading quite difficult and not my preferred method of communication, but I was helped when I met another late-deafened woman who could speechread with amazing accuracy. Seeing that such a feat was possible encouraged me to keep trying. The woman worked as a medical records specialist, and speechreading names of patients was part of her daily work. She had been deafened for some time, but shared that she had also devoted quite a bit of time to learning the art of speechreading. She had a much more visual approach than I, an auditory person, did, and was quite familiar with the shapes of the words and how they looked on people's lips.

Another proficient late-deafened speechreader, Jack Ashley, continued to serve as a member of the British Parliament after losing his hearing at age 45. David Wright, author of the eloquent Deafness, has vouched for his phenomenal lipreading ability: "As for Jack Ashley, his prowess as a lip-reader is astonishing: little short of unbelievable when it is remembered that he taught himself the art in middle age" (xi). Jack Ashley, on the other hand, admits that at the beginning progress was "depressingly slow" (62). He succeeded, however, and remained an active Parliament member for many years.

I include these models as encouragement only, and not in an attempt to declare that all late-deafened adults can and should learn to speechread. Many find speechreading does not work for them, and they prefer to use other communication alternatives. Those late-deafened adults who attempt to speechread but have little success are not alone.

Most of us consider ourselves average to poor speechreaders. The speaker=s skill in communicating and speaking clearly makes a big difference in our ability to understand. Fast speakers will need to slow down, and very likely will need to be reminded several times to speak slower and to enunciate with clarity. Over-enunciation goes too far in the opposite direction and is also difficult to speechread.

The late-deafened person can talk, so your half of the communication will still work easily. If you have any residual hearing, monitoring the loudness of your voice will not be a problem. If you have no residual hearing, it is still possible to monitor by watching the people you are with for nonverbal cues. If your voice is too loud, people tend to lean back, or shift in their seat. If it is too soft, people lean forward and concentrate harder. With time and practice, it gets easier to monitor one's own voice. Some situations remain difficult. The hardest situation is in a public area such as a restaurant, where the noise level fluctuates. Having the other participants in the conversation help out by providing feedback at such a time is best.

5.2 Cued Speech and Cued Speech Interpreters

Cued speech is a visual communication system that uses handshapes near the mouth to aid in speechreading. In the United States, eight handshapes represent consonant sounds, and they are signed in four different locations around the face. The different locations are used to represent the possible consonant and vowel combinations. Cued speech can make visible the large portion of the English language that is invisible on the lips. The system takes much less time to learn than sign language. Cued speech

interpreters can interpret larger meetings or gatherings. Cued speech is not as widespread as sign language, however, and it can be difficult to find a teacher or interpreter (Black et al 41). The Cued Speech Association can assist with information and locating other cuers, as they are known, (www.cuedspeech.org) and materials are available on the website for self-instruction.

5.3 Sign Language

You may be wondering about the effort required to learn a new language when family and friends are unfamiliar with the language. Just as with speechreading and cued speech, learning sign language depends on personal preference. Some deafened people learn basic sign language and then teach it to loved ones or coworkers. Some will take classes together. Using basic signs and the manual representation of the alphabet can make speechreading easier for a late-deafened adult.

Most colleges offer courses in American Sign Language. American Sign Language is not a visual form of English. American Sign Language is the visual language of the culturally deaf community and has its own distinct grammatical structure which must be mastered in the same way as the grammar of any other language. It is composed of precise handshapes, movements and specific nonmanual expressions. Just as hearing people speak different languages in different countries, so, too, do Deaf people sign in different languages. ASL has been strongly influenced by French Sign Language.

American Sign Language is a beautiful language, and some late-deafened adults become fluent and move easily between the Deaf world and the hearing world. Most

late-deafened adults do not become fluent in ASL, however. Many sign in English word order, or they will use sign-supported speech, which is speech with signs added. Signed English is taught in some areas, and another class that is growing in popularity is a class designed for hard of hearing and late-deafened people that teaches basic vocabulary for common words. A good example of this kind of class is that offered by the Deaf Counseling Advocacy and Referral Agency (DCARA) in San Leandro, California (www.dcara.org). All of the classes teach fingerspelling, an aspect of sign language that can be helpful on its own. American Sign Language has a manual alphabet that corresponds with the letters of the English alphabet. It consists of twenty-six different handshapes, one for each letter of the alphabet. Using this manual alphabet to create words visually is called fingerspelling. If family members and close friends learn fingerspelling, it can be used as an adjunct to speechreading and is much faster than writing.

5.4 Sign Language Interpreting and Oral Interpreting

Late-deafened adults who learn sign language can use interpreters at meetings, conventions, church worship, etc. Interpreters are professionals, having gone through years of training in American Sign Language. Many are nationally certified through either the Registry of Interpreters for the Deaf or the National Association of the Deaf. The two certifying agencies have reached an agreement, and future interpreters will apply through the RID for National Interpreting Certification (NIC). Sign Language interpreters learn how to interpret from English to American Sign Language and also how to

transliterate, which means changing the spoken English into signs in English word order. When transliterating, the interpreter mouths the English words and signs them as well. Transliteration is what most late-deafened adults prefer, as they will speechread the interpreter and use the signs to pick up what they cannot speechread.

Oral interpreters are most often requested by oral deaf people, but some late-deafened and hard of hearing people also prefer this mode of communication. Oral interpreters mouth the words being spoken, enunciating clearly and generally a few words behind the speaker, and the late-deafened person or hard of hearing person reads their lips. A skilled oral interpreter will sometimes rephrase or substitute a more visible word to make speechreading easier. They use natural body language and facial expressions to aid in understanding.

5.5 Computer-Assisted Notetaking and Speech Recognition Software

Computer-assisted notetaking (CAN), in its simplest form, is a person typing, on a computer keyboard, what is said during a meeting or verbal exchange. The typist will not get every word spoken, but this method works very well for late-deafened adults. They sit beside the computer and read what is being said. They don't need to learn a new skill, such as speechreading or sign language, and, instead, just need people willing to type for them.

Professional CAN operators use special software to improve their accuracy and speed. C-Print was developed by the National Technical Institute of the Deaf primarily for classroom notetaking but is also being used for business, community, and church

meetings. Typewell is a similar transcription system using different software. These programs are faster than simply typing what is said. The typist uses an abbreviation system and the software translates the abbreviations into full text (Speech-to-Text Services 1).

A new development in CAN uses automatic voice recognition software. Since voice recognition software works best with someone trained to use the software, this process uses a trained speech-to-text speaker who voices what the lecturer is saying. The trained speaker speaks directly into the computer which turns the spoken words into text.

Speech recognition software is also a viable option for one-on-one communication with family members or close friends. You will need a computer running a speech recognition software program such as Dragon's Naturally Speaking. The person speaking needs to practice with the computer program to "train" it to recognize her voice. She will need to speak into a microphone hooked up to the computer and punctuation must be voiced for it to show on the screen. A typical conversation becomes quite computer dependent, with both people looking at the screen, and the error rate can be high, but speech recognition software holds much communication potential for late-deafened adults as it is refined and improved.

If trained CAN notetakers are not available locally, it is possible to use remote typists by transmitting the audio portion of the meeting to the typist and having a computer onsite to receive the text as it is typed. Computer-assisted notetaking is quite popular with late-deafened adults taking classes at a university or attending lectures or other public presentations. In a convention or other large group setting, a digital projector

can be hooked up to the computer and the words typed shown on a screen for all to read. This system is used when more than one person is in need of text translation, and those with normal hearing have expressed gratitude at having the words available on screen, saying that they felt their comprehension improved at being able to both hear the meeting and read any portions they missed or didn't understand.

Computer-assisted notetaking does not permit easy participation for the late-deafened adult in a group discussion, however, because a significant time lag occurs between the spoken portion and the typed result. This is why real-time text transcription has become such a favorite for late-deafened adults.

5.6 Computer-Assisted Real-Time Transcription (CART)

Computer-assisted real-time transcription allows every word spoken to be transcribed instantly into text. CART captionists use a stenotype machine just as court stenographers do to provide a complete transcription of the meeting, discussion, lecture, church worship, etc. The stenotype machine is hooked up to a laptop computer, and, as with CAN, a digital projector can allow the information being transcribed to be shown on a screen for a large group. CART captionists go through the training to become court stenographers and then take additional training for CART transcription. As with CAN notetaking, CART can be offered from a remote location.

CART is the communication tool of choice for late-deafened adults and is much preferred over other forms of translation. Speechreading and sign language involve guesswork and considerable attention to the process itself. CART, with its almost

simultaneous transcription of the spoken word into text, comes closest to mimicking the easy flow of communication and understanding we used to have. In my own experience, CART has allowed me to participate fully in classes and even serve on a jury. For one poetry class, I needed to replace the sign language interpreters I was using with a CART transcriptionist as I was unable to follow the class discussions without a full text translation of the class lectures. With CART, I was able to participate just as any other student in class, even joining in on class discussions. During my time as a juror, the CART transcriptionist sat right next to me, and I was able to read the court proceedings on the laptop screen. During jury deliberation, the transcriptionist again sat right next to me, and I participated in the discussion with all of the jurors with no difficulty. I stayed tuned in to the emotions of the speakers and could read everything they said as they spoke. The transcriptionist also added any relevant auditory cues.

5.7 Communication Tips

Dr. Sam Trychin is a hard of hearing psychologist who has devoted his life to using psychosocial concepts to help people with hearing loss improve their communication skills. I had the good fortune to be able to attend one of his training sessions and have found his techniques valuable in improving how well I understand in different situations.

During the training session with Dr. Trychin, we had a good group discussion on the communication needs of late-deafened people versus hard of hearing people. Late-deafened adults will need to use more auxiliary aids (computer-assisted notetaking,

writing, interpreters, etc.) in communication situations. The following tips apply, however, even when additional transcription is being used. The most difficult issue for late-deafened adults is taking the steps to ensure full communication is possible. Perhaps it is because we remember the effortless talks we used to have and feel we are putting people out by asking for what we need. Yet if we don't, no one involved will have a satisfactory experience. We can't expect others to know how to talk with us, and if we do not tell them what we need, we will all suffer the consequences. Picking the communication situations that are most important and expending effort on those and letting other situations go is one way to conserve energy.

Below you will find Dr. Trychin's communication guidelines for people who are hard of hearing or late-deafened and also his guidelines for the people talking to hard of hearing and late-deafened people. In order for you, the late-deafened adult, to give active feedback, it helps to understand the process from both sides, as a late-deafened person and as the person speaking to a late-deafened person.

Communication Guidelines for Hard of Hearing and Late-Deafened People

1. Pick the best spot to communicate by avoiding areas that are poorly lit or very noisy (if any hearing remains) or with many visual distractions.
2. Anticipate difficult situations and plan how to minimize problems
3. Tell others how to talk to you best. This may involve the use of an interpreter, written communication, or other visual display technology.
4. Pay attention to the speaker.

5. Look for visual contextual clues to what is being said.
6. Ask for written clues to key words, if needed.
7. Provide feedback that you understand or fail to understand.
8. Do not bluff.
9. Arrange for frequent breaks if discussion or meetings are long.
10. Provide feedback to speakers about how well they are communicating.
11. Try not to interrupt too often.
12. Set realistic goals about what you can expect to understand.

Communication Guidelines When Talking to Hard of Hearing or Late-Deafened People

1. Get the person's attention before you speak.
2. Do not put obstacles in front of your face.
3. Do not have objects in your mouth such as gum, a cigarette, or food.
4. Speak clearly and at a moderate pace.
5. Use facial expressions and gestures.
6. Give clues when changing the subject.
7. Rephrase when you are not understood.
8. Don't shout.
9. Avoid noisy background situations or situations with much visual distraction.
10. Be patient, positive, and relaxed.
11. Talk to a person with hearing loss, not about him or her.

12. When in doubt, ask the person who has a hearing loss or is late-deafened for suggestions to improve communication.

Pay attention to your body as you attempt to communicate with someone difficult to understand. Muscles tense, particularly in the neck or shoulder region. Tension headaches and eye strain are not uncommon. Communication can be stressful and learning relaxation techniques essential. One sunny afternoon, while attending a workshop in Daytona Beach, Florida, I took a break for lunch with several others attending the workshop. We enjoyed a walk out to the end of a fishing pier, where we came upon a young boy who proudly showed us several fish he had caught. Having grown up in a fishing town far from Florida, I wanted to know the names of the fish as he showed us each one. I understood the name for bluefish, but had difficulty with the name of the next fish. "White fish?" "Whiting?" It took me several tries and the assistance of one of the people in my group to get the name "white grunt." If you think about grunt for a moment, you will see why. Grunt is spoken from the back of the throat and cannot be seen on the lips.

After our encounter with the young fisherman, we headed back towards the workshop facilities, stopping for a bit to enjoy the scenery. The lady who had helped me understand the name of the fish struck up a conversation. She was from Italy, and English was her third language. Speaking from her personal experience, she shared that her ability to understand improved when she remained relaxed. She had noticed my tension, my leaning forward to understand, my intense stare at the young man. She recommended I

"let go," lean back, use "soft eyes" and simply appreciate the communication in front of me, and that those actions alone would give me significant improvement in comprehension. That advice has been so valuable to me. I confess I do not always follow it successfully, but when I do relax, lean back and enjoy, I understand much better.

6. Support and Rehabilitation

A newly late-deafened person needs support. So many changes will be happening in her life, and any family members will have their own share of adjusting to do. Deafness does not occur in a vacuum, and will affect everyone surrounding the late-deafened person as well as bring new people into her life. This chapter takes a brief look at the different shapes support can take. Support organizations, on-line internet support, hearing ear dogs, self-help, counseling and services offered by the Vocational Rehabilitation and speech and hearing centers are discussed.

One organization tailor-made is the Association of Late-Deafened Adults, a national organization dedicated to serving the needs of late-deafened adults. ALDA has local chapters available throughout the country and hosts a conference every fall in different locations of the United States. Attending the conference is a good opportunity to meet other late-deafened adults and share with others who have had similar experiences. Being able to enjoy the full communication access the conferences provide is worth the registration fee. CART, sign language interpreters, written information, and assistive listening systems are all available to ensure clear understanding. Membership includes a quarterly newsletter with stories and sharing by other late-deafened adults. Many members know sign language, or a more rudimentary form affectionately called "ALDA sign," and many other members depend on speechreading or writing for communication.

The Hearing Loss Organization of American also has a yearly conference that is full of helpful information on the latest in technology, support, and coping skills and an even larger network of local chapters and groups. The conference is accessible with

CART and assistive listening devices, and sign language interpreters upon request. The Hearing Loss Organization of America used to be called Self Help for Hard of Hearing People, and its focus has expanded to include late-deafened adults, in particular those who use cochlear implants. The organization absorbed the former Cochlear Implant Association International in the early 2000s.

The internet is a growing source of support and information for late-deafened adults. On-line support is available through chat rooms and e-groups and weekly e-newsletters. The Say What Club is a nonprofit internet organization for late-deafened and hard of hearing adults and other interested people. Members provide support and encouragement to each other through e-mail. SWC has several general e-mail lists that function as meeting places for the online community. Hearing loss issues are discussed as well as other topics. SWC also has specialized lists devoted to topics such as cochlear implants and deaf/hearing couples, which is a group discussing relationships where one person is hearing and the other is deaf, late-deafened or hard of hearing. The Say What Club now puts on a yearly conference in different locations throughout the country during the summer, also fully accessible for late-deafened adults.

Beyond Hearing is another excellent e-mail list on Yahoo that provides a communication forum for hard of hearing and late-deafened people. This list maintains a focus on issues pertaining to hearing loss, covering topics from cochlear implants to communication issues to hearing aids. Technology is a major focus of this list. Subscribers post responses to the various issues being discussed.

For real-time discussions with other late-deafened adults, go to ALDA=s LDA-Chat. You will be able to meet and share with others without having to leave your house. The Say What Club also hosts weekly chats on various topics. For those who prefer a less direct approach, a weekly summary of the latest news and research of interest to hard of hearing and late-deafened people is available. Sign up at The Hearing Loss Web for their e-mail newsletter (www.hearinglossweb.com). The newsletter is distributed every Saturday evening and helps keep subscribers up-to-date on items of interest.

Cochlear implant users and people interested in or considering the technology have several choices available. CI-York is a cochlear implant forum that hosts discussion on all brands of implants, and each cochlear implant company offers an e-mail forum for their particular brand (Cochlear Corporation, Advanced Bionics and Med-el). Refer to Appendix C for details on how to sign up for these internet resources.

Late-deafened adults who love dogs should consider getting a hearing dog. Hearing dogs are extensively trained to respond to sound. The dog will nudge, paw or push at their person and then lead them to the source of the sound, be it an alarm clock, telephone, doorbell, smoke alarm, or even someone calling their person's name. Hearing dogs wear a bright orange vest while working and are allowed, by law, to accompany their person wherever they go, including into places of work, restaurants and stores. Dogs for the Deaf, Inc. and Canine Companions are two of the organizations devoted to training hearing dogs and you can find their contact information in Appendix C.

Another form of support can be found by connecting with other late-deafened adults in self-help groups. Kathryn Woodcock and Miguel Aguayo offer extensive

information on setting up a self-help program in their book Deafened People: Adjustment and Support. The group decides how often to meet and topics are selected at each meeting pertaining to hearing loss. Then each person in the group shares their experiences and feelings about the topic being discussed. CART is used to ease understanding, or CAN if a CART operator is not available or affordable. No advice is given, but sharing and listening to others with similar experiences is cathartic, indeed.

Support on a deeper level can be provided through individual counseling. A good counselor can provide significant help with grief and adjustment issues and a growing number of counselors today are trained in issues pertaining to deaf and hard of hearing people. Others may not have specific training with deafness but can help nonetheless. Much depends on the success of the connection you develop with the counselor, so it is important to trust your instincts and make a change if things don't feel right.

Rehabilitation services are yet another form of support late-deafened adults should consider. Vocational rehabilitation is the federal and state system of agencies designed to help disabled people find and keep employment. Each state and U.S. territory has a vocational rehabilitation office in every major city. The Rehabilitation Services Administration with the U.S. Department of Education oversees the vocational rehabilitation program. People with deafness or hearing loss can qualify for vocational rehabilitation services. An individual makes an appointment to see a VR Counselor for an intake interview. If accepted, the VR Counselor then works with the person to design an action plan to help the person obtain or maintain employment. Vocational Rehabilitation can help with assistive equipment to make work and home accessible to a deafened

individual. VR can help with employment services, counseling services and by providing education about adult onset deafness.

The National Institute on Disability and Rehabilitation Research (NIDRR) funds Rehabilitation Research and Training Centers (RRTC) at different locations throughout the United States. These research centers do not have any formal relationships with the vocational rehabilitation offices, but their research does assist the rehabilitation process and it is accessible to both agencies and individuals. Each center has a different focus, and the RRTC located at the University of Arkansas dedicates its time to research designed to enhance rehabilitation for deaf and hard of hearing people. Appendix C lists the contact information for this RRTC.

Another form of rehabilitation assistance can be found in specialized centers that have support and information for late-deafened adults. These are usually non-profit agencies and the names of the centers may vary. They include independent living centers, speech and hearing centers, deaf community service centers, etc. A few visits or telephone calls can help you find out who, in your community, provides services for late-deafened adults.

7. Cochlear Implants

A cochlear implant is a medical device with both internal and external parts – in essence, with internal and external computers – that, when surgically implanted, helps you hear. The external portion consists of a speech processor, headpiece and batteries. The speech processor is a small micro-computer worn behind the ear or as a walkman-type unit on the body. The headpiece portion has a coil/transmitter that attaches via a magnet to the implant (which also has a magnet) in the skin behind the ear. Sounds in the environment are picked up by the microphone of the speech processor. The speech processor then codes the information and sends out an electrical stimulus to the coil which transmits the signals via radio waves across the skin to the implanted receiver/stimulator on the other side. The implant then sends the signals to the electrode array in the cochlea. The auditory nerve picks up the electrical pulses from the activated electrodes and sends the signals to the brain, which interprets the signals as sound. Figure 3 gives an illustration of the internal and external parts of an implant.

The operation costs close to $50,000, but most insurance plans do cover the operation, as does Medicare. Today, the surgery is considered routine and the technology continues to improve in its ability to translate sound. While there are no guarantees and not every surgery results in useable sound for the implantee, the majority of the operations do improve one's ability to communicate (Yeagle 24).

Not every late-deafened adult automatically qualifies for an implant and not every late-deafened adult wants one even if they do qualify. Many do not feel a need to undergo the risks of surgery in an attempt to restore a sense of sound. Others are leading

full and rich lives and are simply not interested. Others point out that when the external processor is removed, the individual remains as deaf as he or she was before implantation. The choice must be made on an individual basis.

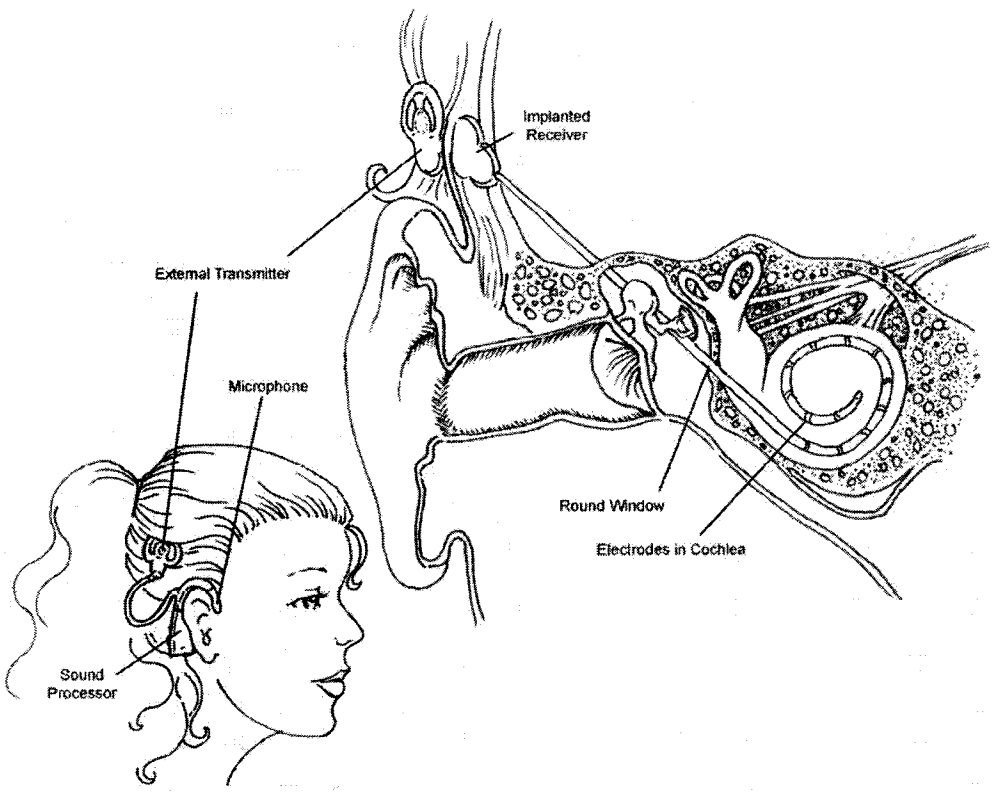

Figure 4. Internal and external parts of a cochlear implant. Drawing by Ellen Million.

Late-deafened individuals unable to benefit from cochlear implant surgery include those with neurofibromatosis 2 (NF2). NF2 is a genetic disorder in which benign tumors can grow on the auditory nerve. Some of these individuals have chosen to try a different kind of implant, an auditory brainstem implant (ABI). This implant bypasses the cochlea

and damaged auditory nerves, sending signals from an external microphone and processor to a small electrode placed on the brainstem. The ABI is not yet able to provide the same benefits as cochlear implantation, but research continues to help improve the technology.

It takes time for a person to learn how to use the Asounds@ made by the implant. With exposure and practice, the brain adjusts and the sounds begin to have meaning to the person. An implant does not cure deafness, but it gives major help in communication and in hearing environmental sounds. Implant users enjoy music and can learn to use the telephone again. Varying factors play into how well someone will hear with an implant: the condition of the auditory nerve and the cochlea, how long someone has been deaf, the degree of motivation, etc.

The operation to insert the electrode array takes one to three hours and usually involves an overnight stay at the hospital. One month to six weeks is allowed for healing and then it is time to visit the audiologist's office for "hook-up day." Each electrode will be programmed via computer to adjust the levels of loudness and softness. After the programming, all of the electrodes are activated and the individual hears her first sounds. Bev Biderman grew up with a progressive hearing loss and chose to undergo cochlear implantation. She writes about her first experience hearing with a cochlear implant in Wired for Sound:

> David [the audiologist] gives me a little pep talk about how at the beginning, some people find that voices are mechanical-sounding, like cartoon-character voices, and how others find that voices sound good

> almost immediately. He then turns on all the electrodes and asks, 'How does that sound?' I am startled and do not realize that he is no longer simply presenting single tones to me for testing. When he had tested each electrode, they had sounded like either whistles or horns. Now, with them all turned on, I hear a cacophony of horns and whistles going off together. David's voice, when I realize it is a voice I am hearing, does not sound like Donald Duck or Mickey Mouse as David had warned it might. It sounds like Harpo Marx working his horns and whistles. (6)

The sound improves after hookup, as the brain learns how to translate the new signals it is receiving. With time, the sound feels quite normal. People's voices sound as they did before. Ocean waves still crash, leaves crunch underfoot. Differences exist as well. The implant cannot yet duplicate the richness and fullness of sound heard with a fully-functioning cochlea. Implantees have difficult hearing well in noisy situations, for example, and do not have the same frequency range as someone with normal hearing does. Michael Chorost received an implant after losing his remaining hearing as an adult. He was born with a severe hearing loss in both ears because his mother had rubella (German measles) during her pregnancy. In Rebuilt: How Becoming Part Computer Made Me More Human, Chorost shares his impressions with his new hearing one month after his implant was activated:

> I had hoped to hear the world whole and full – a door opening to reveal a blinding light – but now I was grudgingly realizing that my world would still be fragmentary and partial. Very well: forget about reality. Hearing

> with a cochlear implant, I realized in the third or fourth week post-activation, was going to be like a stone skipping across the surface of a lake. I would have to learn to glide over the soundstream, not always fully in contact with it but getting the general meaning. I would have to learn to backfill the incomplete information in my mind. I would have to give up the expectation that it would truly feel like hearing, and learn to use the implant as a tool that would enable me to do something which resembled hearing. It would not *be* hearing. It would just be the equivalent to hearing. How bizarre. (79)

Learning to hear again becomes a process of change and adaptation, in the same way that learning to be deaf was a process of change and adaptation. Three cochlear implant manufacturers are currently operating in the United States: Cochlear Corporation, Med-el and Advanced Bionics. Cochlear Corporation is an Australian company, Med-el is based in Austria, and Advanced Bionics is a U.S. corporation. All three companies are reputable and provide quality implants. Various implant centers offering all three implants are located in medical facilities in the larger cities throughout the United States. A late-deafened adult interested in researching implants and learning about the surgery should visit one of these centers to get information about the pros and cons of implantation and about the various implant devices.

The implant center also determines eligibility. Candidate criteria vary from implant center to implant center, and some insurance companies and Medicare also have criteria of their own that must be met in order to receive reimbursement. In general,

adults must have a bilateral sensorineural hearing loss of 70 dB or greater. They must be able to understand less than 50% of words in sentences, whether wearing hearing aids or not.

At the implant center, the late-deafened adult will meet the surgeon who will perform the implantation, and the audiologist who will do the programming. Both the surgeon and the audiologist will discuss the implantation process. They will cover what appropriate expectations might be and share information on the various implant manufacturers. The implant staff will also discuss "readiness." Is the interested person emotionally ready for an implant? Is this person committed to follow up and dealing with a technological device on a daily basis?

The individual will need to get his hearing tested, both with hearing aids (if he wears them), and without. Speech discrimination scores will be part of the testing. The Auditory Brainstem Response measures the neural response to sound to make sure the auditory nerve is working properly. The Otoacoustic Emissions Test lets the otologist check hair cell function (Yeagle 25). The CT or CAT scan is an important diagnostic tool that lets the doctor find out the condition of the cochlea and if it is able to handle insertion of the electrode array.

After the testing, the surgeon and audiologist meet again with the individual and go over the results of the tests. If the tests are favorable, then it is time to choose which implant to use and schedule the surgery. The audiologist will have demonstration devices that show how the implants look and their size (much smaller than one thinks). Appendix

C lists contact information for the devices and online forums that can help with this phase of research.

. You need to be motivated and willing to spend the time necessary to learn to hear again with an implant. You will need to make regular visits to your implant center for mapping, the process used to program the interior electrodes. Having an implant requires a lifelong commitment to maintaining the equipment and working with one=s hearing to maximize its potential.

Today, more and more late-deafened adults are getting bilateral implants, an implant in each cochlea. In my case, I was fortunate enough to be able to get a second implant, and my insurance company covered most of the expense. I have been enjoying better ability to understand conversation in noisy areas and to locate where a sound is coming from.

Cochlear implants do not restore full sound. With the implant, I am able to function in the hearing world more as a hard of hearing individual can. As implant technology improves, however, I can look forward to new software and hardware improvements which will result in better hearing. A major hardware improvement is already on the horizon. Researchers at the University of Michigan have announced success with a new, ribbon-like implant that would allow for easier insertion and increase the range of frequencies that the current electrodes provide for. They expect the technology to be available to the public in about five years (Bailey).

8. Assistive Technology

Assistive technology makes life easier. You may not be able to hear a telephone ring, but you can see it ring when a light starts flashing. Technology exists to make most every task a late-deafened person needs to do easier. Alerting devices help us know if someone is calling or ringing a doorbell, or if the smoke alarm goes off. The relay service allows us to make telephone calls. If we have any residual hearing or wear a cochlear implant, assistive listening devices can bring the speaker's voice directly to our ears. Most assistive aids are reasonably priced and funding sources can be located to help pay for more expensive items. The Lions Clubs International and Quota International are two organizations that help fund this type of equipment. Appendix C lists contact information for stores that sell assistive equipment.

8.1 Alerting Equipment

Alerting devices give fair warning for the daily intrusions of life. Alarm clocks are available that turn on or flash a light, shake a bed vibrator located under the pillow, make a loud noise, or do all three at the same time. Transmitters can be hooked up to the telephone, the smoke alarm, and the doorbell and send signals to receivers located strategically around the house. When the telephone rings, lights plugged into the receivers will flash accordingly. Baby cry lights will pick up baby's cries during the night or nap time. Motion sensor alarms will alert you to any intruders or teenagers arriving home after curfew. Several systems are sold as all-in-one units that have an integrated doorbell, alarm clock, telephone, smoke alarm and baby cry signaler. Each

room can be set up to flash lights in response to incoming information or you can wear a receiver on your belt and "hear" a telephone outdoors in the yard, if you wish. Video cameras can help you keep an eye on baby's room or on activity occurring outside or in different rooms.

Alerting systems are easy to set up. They work as well as the sound signals they replace. Just as noisy environments make it difficult to hear a telephone ring, bright sunshine through the kitchen window makes it possible to miss a flashing light. Strategic location minimizes these problems, however, and the equipment is sturdy and long-lasting.

8.2 Telecommunications

Alexander Graham Bell invented the telephone in 1876. He was trying to invent a device to help in the education of deaf people (his wife was deaf), but his "electrical speech machine" which became the telephone, ended up being a device that would be used against the Deaf community, barring Deaf people from employment because they could not use the telephone. Today, the telecommunications industry has transformed into a place full of options, and many choices are available for late-deafened people.

8.2.1. Hearing Aid Compatible Telephones

If a person has no residual hearing, using the regular telephone will not be possible. Late-deafened adults with cochlear implants can use a hearing-aid compatible telephone or amplified telephone. Hearing aid compatible telephones have a built-in

telecoil, which sets off a magnetic field that can be picked up by the telecoil or t-switch in the hearing aid or speech processor of the cochlear implant. The magnetic field cuts out acoustic sound waves and background noise, making it much easier to hear the voice at the other end of the telephone. People with bilateral cochlear implants can use both ears by wearing a neckloop that is plugged into a headphone jack on the telephone. Both implants are set on t-coil. The t-coils pick up the magnetic field from the neckloop, and the volume can be controlled by the telephone or the implant. If the telephone does not have a headphone jack but is a modular phone, a device such as the Williams Sound Telelink can be used to connect the telephone to an amplifier (such as a Williams Sound Pocketalker) and a neckloop is then plugged into the amplifier.

8.2.2 Text Telephones or TTYS

Text telephones or TTYs can be used to communicate with another person who has a TTY, or can be used in conjunction with the state relay system. You do not need any hearing to use a TTY. Text telephones are typewriter telephones that allow one to "type" on the telephone. You can hook them up to a regular telephone and use the telephone to dial calls, or dial directly from the keyboard with the more sophisticated models. Smaller, portable devices can be plugged into compatible cell phones by using a special patch cord.

8.2.3 Telecommunications Relay Services

The Americans with Disabilities Act of 1990 requires that each state provide free interstate and intrastate relay to people who are deaf, hard of hearing, late-deafened, or speech impaired. Trained specialists, called Communication Assistants (CAs), relay messages electronically to text telephones, or verbally to hearing parties. This 24-hour service allows late-deafened people to make personal or business calls with full confidentiality, and no limit on the length of the telephone call.

Assume you call a relay system with the TTY. A relay operator, or communication assistant, will answer. Tell the operator what number you wish to call, and the CA will call the number and type to you what the hearing person is saying and voice to the hearing person what you type. Relay services also have Voice Carryover (VCO), so you can talk directly to the person that has been called, and the relay operator listens in and types the other person=s conversation to you and it shows up on your TTY screen. During VCO, it is also possible to hear the other person on the line, so if you have residual hearing or a cochlear implant, you can hear the other party and yet still get support in understanding what the other person says. You can even call another late-deafened person using VCO to VCO. In this situation, the relay operator will type responses to each party in the telephone conversation, serving as each person's "ears."

8.2.4 CapTel Telephones

CapTel is a new telephone by Ultratec that uses a combination of voice recognition software and captioning to translate what the other person is saying in real time. Rather than the relay operator listening in to the conversation and then typing the message, resulting in delays in the conversation, the CapTel allows almost simultaneous translation of the phone call. The relay operator is still involved in the call, and calls will still need to be routed through the relay service. An even better option is to get a 2-line Captel system set up. This system requires two separate telephone lines. With this setup, the late-deafened person can call someone directly, without first dialing the relay service. The relay service is automatically dialed on the second phone line as he places the call on the first line. As the conversation ensues, the relay operator delivers the captions to the CapTel phone from the second line. The late-deafened caller uses his voice and speaks into the telephone receiver of the CapTel and can read and listen to what the other person is saying on the CapTel screen. This system also allows other people to call the late-deafened person directly rather than calling the relay system to place the call. When the late-deafened person answers, the captioning service automatically connects and provides captioning of what the other person is saying via the second line. The Captel is getting rave reviews from late-deafened adults and is allowing them to participate in direct and much speedier telephone calls at work and elsewhere. Not every state has this service yet, but the number is growing.

8.2.5 Video Relay Services

A video relay service provides a new and fast-growing option for communication. An inexpensive video camera and a high-speed internet connection are needed, and a relay service that provides relay interpreters. These services work best for someone who knows basic sign language as the resolution of video cameras is still not clear enough to allow speechreading. Calls can also be made to another person that has a video telephone setup. For a relay call, call the video relay service. The interpreter answers and you can see her either with a computer monitor or a television screen. The interpreter signs what the other person is saying. You can talk directly to the person being called and watch the relay interpreter sign what the other person is saying. You can even hear the other person, if that is applicable to your situation. The person being called does not need to have any special equipment other than a telephone.

8.2.6 Wireless Communication

E-mail and instant messaging programs are quite popular and completely accessible to late-deafened people. Instant messaging programs are similar to a TTY conversation except that computers are used instead of TTYs. They even allow for small group discussions similar to conference calls. MSN Netmeeting, which is a free download at www.msn.com has an option for video conferencing. With a high-speed internet connection, a late-deafened person can chat via MSN Messenger, an instant messaging program and watch the person via video through MSN Netmeeting.

Alpha-numeric pagers are handy, and the newer two-way pagers allow users to reply to text messages via email. Cellular telephones can send and receive text messages, and Smartphones surf the web as well as send and receive text messages. PDAs (personal digital assistants), or handhelds, can be connected to the internet and utilize email and instant messaging. It is even possible to use a PDA or a Smartphone to receive remote CART captioning.

8.3 Television

All televisions built for sale in the United States after 1993 that are larger than 13" have a built-in decoder chip that can display the text of spoken dialogue. Only programs that have been captioned, either previously or in real-time, will show the text on the screen. A growing percentage of television programs are closed captioned today, and many news broadcasts are being captioned live by CART transcriptionists, or captioners. All emergency information broadcast over the television is required to be captioned.

8.4 Assistive Listening Devices

If a late-deafened person has some residual hearing and uses a hearing aid, or wears a cochlear implant, then assistive listening devices should be considered. This section covers the general kinds of devices.

8.4.1 FM Systems

FM Systems are wireless, with radio waves used to transmit information from a transmitter to a receiver. Distance can be a problem when trying to speechread or hear someone. If the speaker wears a transmitter with a microphone, then the sound can be sent directly to the listener via a receiver. The system can allow up to 500 feet between the speaker and the listener with no loss of integrity in the transmission of the speaker=s voice. Large-area FM systems work on the same principle, but the transmitter is hooked up to the sound system or works as a stand-alone system with a microphone (Black 46).

To use the FM system, the transmitter and microphone are handed to the Aspeaker.@ The speaker attaches the microphone to her collar and the listener uses the receiver to listen. Just as with the telephone, there are numerous ways to connect to the receiver, depending on whether the listener is using hearing aids or a cochlear implant (patch cords, neckloop, ear buds, etc.).

8.4.2 Infrared Systems

Infrared systems use light waves rather than radio signals to transmit sound. Otherwise, they work much like the FM system, with a transmitter and receivers. The infrared system produces a strong, clear signal with excellent sound quality, but it can be susceptible to interference from natural or incandescent light and is best in theaters or concert halls that do not have windows.

8.4.3 Induction Loop Systems

An induction loop system is another method of bringing the sound of the speaker directly to the late-deafened person. An induction loop system consists of a coil of wire surrounding a room or area. The wire is connected to an amplifier that controls the volume of the sound transmitted through the wire. Microphones can be used anywhere in the area. The electro-magnetic energy radiating from the loop is picked up and amplified in the telecoil or t-switch in the hearing aids or implants. A receiver with earbuds can also be used if one does not have a telecoil. Loop systems can be permanently installed or be portable. Computer terminals and fluorescent lighting can cause interference at times and it takes a bit of trial and error to find the areas within the loop that have the best sound.

8.4.4 Portable amplifiers

These devices come with a small amplifier device and microphone. Just point the amplifier/microphone in the direction of the sound. Amplifiers can be used with headphones, earbuds, a neckloop or a patch cord. Pocketalker and Turbo Ear are two of the more common brand names.

9. Legal Rights for Late-Deafened People

Assistive technology and communication assistance can make life much easier for late-deafened adults and we are fortunate in this country to have laws that protect our rights to have full communications access to state and federal government agencies, public businesses and public transportation. Two laws have had a major impact on improving accessibility for late-deafened adults: Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA) of 1990. With their mandates for accessibility, these laws have significantly improved lives. It is important to know one's rights, however, as many places are far from meeting the guidelines of these laws.

9.1 Section 504 of the Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973 requires all government offices and programs to be accessible. It also requires that hospitals, schools, and other institutions receiving more than $2,500 in government funds be in compliance with Section 504 and therefore be accessible. This means that if a deafened person needs to go to the hospital, the hospital is responsible for providing a qualified interpreter to facilitate his or her communication. This includes CART or CAN or other means of providing access. The same applies to other community services such as Social Security, food stamps, social services, public assistance, crisis centers, health clinics, universities, and most state buildings.

9.2 Americans with Disabilities Act of 1990.

The Americans with Disabilities Act (ADA) of 1990 gives disabled individuals access to services they would not have otherwise. Unlike Section 504, which deals primarily with government agencies and programs receiving government monies, the ADA covers public services. The Act has four parts: Title I deals with employment, Title II with access to state and local government and public transportation, Title III with public accommodations, and Title IV with telecommunications.

The ADA states that employers cannot discriminate against a person with a disability in hiring or in promoting that individual to a better job. Employers with fifteen or more employees must also provide Areasonable accommodation@ to enable people with disabilities to perform their jobs without structural or communication hindrances.

The second section requires all state and local government agencies to make their services accessible to individuals with disabilities. This section expands the coverage of Section 504, since not all agencies receive federal financial assistance. ADA does not apply to federal facilities, but they are covered under Section 504. AMTRAK and all transportation agencies must be made accessible. Visual communication systems and signage are to be added to new transit buses as the old ones are replaced, so riding public transportation becomes easier with each passing year.

Title III covers public accommodations such as restaurants, hotels, retail stores, theaters, museums, libraries and doctors' and lawyers' offices. Meetings must be made accessible to late-deafened adults by providing communication access such as CART or sign language interpreters or assistive listening devices. It is the late-deafened adult's

responsibility to request the service, but the agency will need to pay for the service. Public facilities that have more than four pay phones are required to provide a TTY pay phone. Hotel rooms need to provide visual smoke alarms, visual wake-up alarms, text telephones and amplified telephones upon request. Fire alarms that flash a light, TTYs and amplified telephones need to be added to all new construction and renovations of facilities.

The telecommunications section requires that all telephone companies that serve the general public must offer a telephone relay service to translate calls for people who are deaf, hard of hearing, or speech-impaired (Black 34).

9.3 Television Decoder Circuitry Act of 1990

The Television Decoder Circuitry Act of 1990 passed immediately after the ADA. The Act requires television manufacturers to include a decoder chip in all televisions 13 inches or larger built after July 1, 1993, which allows anyone to access the closed captions without hooking up a separate decoder machine.

9.4 Telecommunications Act of 1996

The intent of the Telecommunications Act of 1996 was to deregulate the industry and promote competition but it also provided benefits for deaf and hard of hearing people by requiring that new television programming be closed captioned. Unfortunately, the act does not cover captioning for the internet.

9.5 Hearing Aid Compatibility Act (HAC Act) of 1988

This act requires that all wireline and cordless telephones manufactured or imported for use in the United States be compatible with hearing aids. Telephone receivers must be equipped with telecoils that are compatible with telecoils in hearing aids and cochlear implants. All pay phones must be hearing aid compatible and each cell phone manufacturer is required to make at least two brands of cell phones equipped with telecoil capability.

We are fortunate to have laws in America that protect our rights and foster access to the same services and facilities that hearing people enjoy. The reality, however, is that many services are still not accessible, TTY pay phones can't be found or don't work properly, doctors refuse to pay for interpreting services, and the assistive listening system at the concert hall doesn't work. The Americans with Disabilities Act was originally designed to protect anyone against discrimination based on disability. In that respect, it was conceived in the same spirit as the Civil Rights Act of 1964, which was designed to protect people against discrimination based on race, religion or gender. Unfortunately, the courts don't relate to the ADA in that spirit. The ADA contains an economic loophole in the wording "undue hardship." Rights of access don't have to be allowed if they cost too much. Granting equal access to disabled people costs more money than opening doors to people from minority groups, so businesses protest that they can't afford to provide equal opportunity, yet providing equal opportunity is what the ADA is all about. It was not designed to single out a group of disabled people and give them special treatment. Now

people have to have medical proof of a "true" disability to be considered under the law, and the courts attempt to determine what a "true" disability is. In addition, the ADA was passed with no federal enforcement mechanism. A lawsuit needs to be filed in order to force a doctor to pay for a sign language interpreter.

Thankfully, other less drastic methods can be successful. If you run into discrimination as a late-deafened adult, speak up. Oftentimes just meeting with the agency or company or individual involved and explaining the law being violated will make the difference. Contact a local independent living agency and network with them to find out if there is nonprofit legal support in your community. Write letters to the editor of the local newspaper and write to your representatives in Congress, if need be. Many states have commissions or councils for deaf and hard of hearing people that can help with enforcement.

Telecommunications complaints are handled differently. The Federal Communications Commission is an independent government agency in charge of forming regulations for interstate and international communications by radio, television, wire, satellite and cable, including wireless telecommunications and emergency broadcasting. For any problems arising with compliance of the laws pertaining to these areas, you can file a complaint directly with the FCC if you cannot resolve the matter locally. Refer to their website at www.fcc.gov for information on how to file a complaint.

Disability rights are rights, not benefits. We don't need to be "cured" or "fixed" or treated as special, and by that, I am not precluding our seeking improvements such as cochlear implantation. What I am saying is we do need to be accepted and allowed to

participate fully in our daily affairs as we are, and in today's world, that may mean accommodations need to be provided.

10. Interviews with Late-Deafened Adults: Jacqui Metzger

One of the benefits of seeking support from other late-deafened adults is that they understand what you are going through. Late-deafened adults share many of the same experiences. Below you will find the transcripts of interviews with three late-deafened adults. I am grateful for their willingness to share how they became deaf and what part deafness has played in their lives over the years.

Jacqui Metzger

Jacqui Metzger MSW, LICSW is currently a psychotherapist and psychoanalyst in private practice in the Seattle, Washington area. She is sought out as a speaker on managing hearing loss. Jacqui grew up hard of hearing with a progressive hearing lost and received a cochlear implant in 1997.

Jacqui Metzger first entered my life when I arranged a meeting with her to discuss coping skills for late-deafened adults. The information she shared with me made such a difference in my life. In the interview that follows, she shares some of those tips along with her personal story.

March 1998

Candis: I am at the home of Jacqui Metzger in Seattle, Washington and we are going to be talking about Jacqui=s life and how she has dealt with her hearing loss.

Jacqui: I was born in 1950, and I am the first generation of my family born in America. Both of my parents were born in Europe. My mother is from Germany and England and my father is Swiss, but grew up in Spain. They both grew up in Europe and came to this country as young adults. My father was about 24 and my mother 18 or 19 when they first arrived in America.

My hearing loss is hereditary. My father is hard of hearing and his grandmother and grandfather were first cousins and their grandmother was deaf. In other words, they had a grandmother in common, and she was deaf. That gene was passed on, and my father=s sister has a significant hearing loss as do I.

My parents first noticed I had hearing loss when I was in kindergarten. I was missing the higher frequencies. Every year I had my hearing tested and slowly, my hearing was getting worse. When I turned thirteen, my hearing began to fluctuate. Sometimes it was okay and sometimes it got really bad. For about one week out of the month I wore a hearing aid. but by the time I was sixteen, I was wearing two hearing aids.

Candis: Did you do anything else other than wear hearing aids?

Jacqui: I did take lip-reading classes. I remember learning that Ap@ Ab@ and Am@ look the same and I remember lipreading as being very tiring for me. I also remember not having a clue what to do, that is, how to handle my hearing loss or what to say to people about it. What should I do if I did not understand something? I did not even realize the reason I did not understand someone was because I could not hear them.

Candis: Hearing loss was not a topic for discussion in your home?

Jacqui: It was never really talked about. My parents were good about getting hearing aids and I remember my mother driving me to the Ahearing aid guy.@ My father went with me to lip-reading lessons for a while. As far as talking about hearing loss itself, however, and the impact on me and how it made me feel – nothing was said.

When I was thirteen or fourteen, I kept wondering how I was going to manage my life. I knew that my hearing was getting worse. I would think to myself, AWhat will happen when I start to date?" "How do I meet people?" "How am I going to manage?" I had no answers so I would stop thinking about it and just kind of go on forward. This family characteristic of "making the best of things" encouraged me to really keep trying, but, on the other hand, it was difficult, confusing and hurtful to not really know what to do. I think it is really important to have expectations for your children but to also help them with their limitations as well.

I remember playing clarinet in high school. I was first chair during my senior year of high school. It was stressful for me since my hearing was getting much worse, so I stopped playing music after high school. I was still using the telephone some, but with great difficulty. By the time I entered college that next year after high school, the only person I could talk to on the phone was my mother and even that was a struggle.

Candis: Where did you attend college? And where did you grow up?

Jacqui: I grew up in New York and then I attended college in Colorado. I had a good friend in college. I remember her telling me, ALook, Jacqui, you have got to tell people you don=t hear. When we travel together, it makes me look really domineering and it makes you look really stupid, so you need to tell people you don=t hear!@ That was my

first real introduction to coping with hearing loss! [Laughs.] Those were my early twenties, and I probably had about a 75 – 80 dB hearing loss.

Candis: You were attending college with a major, major hearing loss. How did you understand what was going on?

Jacqui: I probably missed a lot! I graduated from college in 1972, one year before the 1973 Rehabilitation Act passed. That law required reasonable accommodations for people with disabilities for federally funded programs and services and most universities receive some kind of federal funding. When I was attending college, FM systems or other assistive listening equipment had not yet been invented. I had no exposure to sign language at that time so sign language interpreters would not have helped. I just sort of muddled along the best I could. There was one class I had to quit because the teacher had this horrendous mustache and I could not see his mouth at all. I gave up and said AI have to drop your class.@ That was too bad. In other classes I would get the notes from other students and just ask for help. I majored in political science and much of the coursework involved writing papers.

After college, I got married and my husband and I worked in ski areas together. I taught skiing for the next seven or eight years and we lived in Colorado, Wyoming and then New Mexico. I then taught one year in New Zealand. And what was really interesting about going to New Zealand is that many people from Australia were there. I could not understand people from Australia.

They spoke English, but between the idioms and the different words and the accent, it was impossible for me to understand. People from New Zealand sounded

similar to people from England. But the Australians were at the other end of the spectrum. I remember sitting with one man for an entire hour, understanding nothing. Nothing. Australians say things such as APut your sticks in the boot.@ What that means is APut your ski poles in the trunk of the car!@ [Laughs.] I was really deciphering a foreign language.

Candis: For sure!

Jacqui: After that, I went through many changes. I left ski life, I divorced, and I moved back to New York. I enrolled in the M.A. program at New York University in Deafness Rehabilitation.

The M.A. program was my first introduction culturally deaf people, and all of the Deaf stuff. That was in 1978 to 1979 and quite an eye opener for me. I remember going to the orientation. I walked in and there were all of these people using sign language and I could not believe what I was seeing. I immediately felt comfortable and at home. Some of the interpreters I could understand pretty well because they would be signing in a more English format and mouthing the words and I could lipread them. That was wonderful. I was really using them as oral interpreters. It was amazing! I started classes. I got all AA=s.@ It was so easy after everything I had been through! [Laughs.] The interpreters who signed American Sign Language, ASL, I could not understand, but the ones transliterating, or signing in English word order, were quite fabulous.

I started learning about Deafness. I took off my hearing aids and tried to become very, very Deaf to try and learn sign language faster, and also to try and feel part of that Deaf group. All the talk was about cultural deafness, or people who grew up Deaf and

whose first language was American Sign Language. My hearing loss fit the audiological definition of deaf, but I was not culturally deaf.

During that M.A. program, I attended an ADARA conference [American Deafness and Rehabilitation Association]. I met John Shiels who also presently makes a home here in Seattle, and Joe Webber. All three of us were late-deafened and we found a connection through our common experiences. For the next year we communicated by TTY. John was in Seattle, Joe was in Minnesota, and I was in New York. By TTY and by letter we put together a workshop called ALate-Deafness.@ It was about our stories, as we thought people might be interested in hearing about people who had become deaf as opposed to people who grew up Deaf.

Candis: The focus was on culturally deaf people in your NYU Deafness Rehabilitation program, correct?

Jacqui: Yes, it was on early deafened people. Culturally deaf, the ASL Deaf. It was confusing for me because in some ways I fit, such as in use of equipment, and use of interpreters. Liking sign language helped me a lot. I could relate to the challenges and difficulties Deaf people had. I fit the definition of hearing loss: Acan=t hear or understand speech even when amplified through the ear.@ But my experiences growing up were so different than those of culturally deaf people.

It was wonderful to meet with Joe and John and for the three of us to talk about this. When it came time, we presented the workshop at ADARA. That was 1982. Our workshop was at 8:00 a.m. in the morning and had tough competition. Several interesting workshops were being offered at that same time slot, but our room was full.

We had about sixty people show up, a lot compared with the size of a typical workshop at the conference. We shared our stories and there were so many questions. We found out that many of the therapists and the counselors attending the conference were actually late-deafened, but no one had had a concept or definition of this. People wanted to continue, so we met again that evening to continue the discussion.

That was a very exciting time. We felt like we had tapped into something. Many deaf people were not born deaf and were not born into the Deaf community, but joined it later. Their collective experience was having some hearing or a lot of hearing and then losing their hearing, either gradually or suddenly. This was before the Association of Late-Deafened Adults came into existence.

I finished my Masters in Deafness Rehabilitation and went to work at the New York Society for the Deaf. I was pretty fluent with signing by then. I went to Gallaudet University one summer and took an intensive ASL Class. [Gallaudet University is a liberal arts university for Deaf people located in Washington, D.C. All courses are presented in voice and sign language.] I took my hearing aids out for a few days during the class. My mom showed up in Washington, D.C. to surprise me for my birthday, so I put my hearing aids back on and she said, Ayour voice sounds like you have potatoes in your mouth.@ So even with four days of not talking a lot my voice had changed. Interesting.

Despite the signing, my first language is English. I think English, I read English, and I talk English. When I am not signing, I am talking with people. So when I am signing with other hearing people, I use pidgin sign English [a mix of ASL signs and a

more English word order]. If I am signing with a culturally Deaf person who wants ASL, I use ASL.

Candis: So, you went back to New York after you finished the intensive ASL class?

Jacqui: Yes, I was busy working, busy seeing people, and just busy B New York busy! [Laughs.] And then I decided my education was not enough. I wanted to do counseling and my Masters in Deafness Rehabilitation was not enough to do counseling. I applied for and was accepted into the School of Social Work at New York University. I began the program, but then came a time of personal questioning. Did I want to stay in New York City? I decided in the middle of the program that I did not want to stay in New York. I had been working with deaf-blind people and Seattle, Washington has a large deaf-blind community, so I made a trip out here to Seattle and decided this was the place I wanted to be.

In March of 1984, I made the big move and I=ve been here since. I was able to transfer to the University of Washington social work program, and I graduated in 1985 and began counseling, mostly hearing but some hard of hearing and Deaf people. It was during that time that I met Dr. Sam Trychin. Dr. Trychin gave "Coping with Hearing Loss" training workshops and this was what I was looking for in helping me cope with my own hearing loss. I traveled back to Washington, D.C. to study with him and that was the beginning of my developing my own ideas on how to cope with hearing loss. Since that time I have done a lot of workshops here on coping with hearing loss, and group and individual work as well. Working with hard of hearing people in terms of helping them develop skills and coping strategies for better managing their hearing loss has been

exciting work. I find that most people just don=t know what to do. It goes full circle for me. It goes full circle back to my childhood, really not knowing what to do and not being able to find anyone to help me. There is much that one can do. Many techniques and skills can help improve communication matters.

Candis: Can you give me a few tips right now?

Jacqui: First, let people know you are hard of hearing or late-deafened. You need to tell them what to do. And you need to provide reinforcement if they are doing it right. Don=t bluff, because people know and it does not help you in the long run.

Candis: Yes, I admit. I bluff at times. It is always a risk. Perhaps I will be finishing a conversation with someone and I think they have said something more along the lines of Afiller@ so I will let it pass and then I can tell from their face that it was something more important than just Afiller@ and the damage has been done.

Jacqui: Yes. Bluffing does not work in the long run. And when you think you understand and then find out later that you didn=t, that=s the hardest. It is frustrating for all involved. It is frustrating for other people because they say AYou should have told me you did not understand!@ I get frustrated too: AI thought I DID understand.@

Another important coping skill is to remember that we have many options. We are not just stuck with a difficult situation. For example, suppose you are at a restaurant and having a difficult time understanding. Three possible actions are to ask to turn the lights up, get additional candles if appropriate, or ask to turn the music down. Restaurant personnel are usually very accommodating about such requests.

Where you sit makes a big difference. A chair by the wall is much better than one in the middle of the room, or near the kitchen. If it is a hopeless situation, and some restaurants are extremely noisy, take your business elsewhere.

Regarding assistive listening devices, it's important to really use them. Professional people think that when they recommend an assistive listening device that the problem is solved. It=s not. It is just the beginning. First, you must learn how to use the equipment. You have to know how to troubleshoot. What looks easy is not. Under the stress of attempting to communicate, people can=t think clearly. Battery. Wires. Are the right buttons on or off? Are the hearing aid buttons on or off? So many things can go wrong. Then you have to train people you are communicating with how to use the equipment itself. "Please use the microphone. Please talk one at a time.@ It takes a lot of energy to do that and a lot of confidence and assertiveness.

Candis: In a computer class I took, I was using an FM system and we went into the next room to do some hands on work on actual computers. I left all of my batteries in the first room and, of course, as soon as I got into the new room, the battery died. I went back to the first room and the door was locked!

Jacqui: There is a saying, "You can be sure that your battery will go dead if you don=t have a replacement with you.@

Candis: It=s true!

Jacqui: It=s really true. After the equipment is working, it is a good idea to set up communication guidelines. Ask that one person talk at a time and that he or she use the microphone. No bluffing. In a nice way, let people know what you need them to do.

Candis: And then you need to reinforce the information.

Jacqui: Exactly! You need to reinforce the actions because people are, as Sam Trychin says, AHB=s.@ We are all a bunch of HBs, or Human Beings, and we forget. So you ask a person to speak louder or slower, and he or she will forget. Even a group of hard of hearing or late-deafened people will forget. If they forget, and they live with hearing loss every day, how do you expect a person with normal hearing to remember? People need to be taught and trained, and reinforced. When they are doing it right, you say ATerrific! Thank you for your help.@ When they forget, you remind them, and tell them later how much you appreciate their efforts. This goes for people you live with as well.

I remember the first time I used an assistive listening device. It was in a restaurant. I was having lunch with a friend. The experience was like someone turned on a light. Suddenly I realized there was a world out there that was going to open up to me. When I took Sam Trychin=s workshop, I insisted on a sign language interpreter. But when I got there and started using the FM system I learned I could use it very, very well. It was really wonderful. So I really didn=t need the interpreter as much as I thought.

Candis: That was a new experience for you! Do you use the FM system with your counseling?

Jacqui: Yes. I use it now all the time. The FM system is wonderful because it allows me not to be attached literally to the person I am working with. We have distance. They have a microphone and a transmitter and I have my receiver. And I use it with my cochlear implant now.

Candis: You are working full-time at an agency in Everett, Washington, correct?

Jacqui: Yes. I=m working with hearing, hard of hearing, deaf people, and culturally Deaf people. It is a non-profit community mental health center. I really like where I am working now.

Candis: Please tell me about your experience getting a cochlear implant.

Jacqui: Well, in about June of 1996, my right ear got noticeably worse. I had terrible tinnitus and I realized my hearing was not as stable as I thought, or wished or fantasized that it would be. I thought AOkay, it is time to do something. But what?@ Because for the longest time I said that I would never get an implant. It sounded too invasive and too big a deal. I thought I did fine with my hearing aids and the FM system. But it was getting harder to talk to me. I met with different doctors and decided to be implanted with Cochlear Corporation=s Nucleus 24 at the University of Washington.

I had the implant surgery in February of 1997, and was hooked up one month later. I went on a huge emotional rollercoaster ride prior to the surgery. How much hearing would I be able to get back? What about all the work I had been doing to adjust, to accept my hearing loss? What would it mean to get this cochlear implant? I wondered if trying to get my hearing back would be a betrayal of my deafness, a betrayal of my friends in the Deaf community.

Some people just want to get their hearing back. I didn't want to lose more hearing. I had become used to walking that fine line of neither being Deaf nor hearing. At the same time, the pending operation confronted me all over again with my hearing loss. How hard it is. How really tough it is.

Candis: You have a hearing loss that has gradually deteriorated over the years. Each time further deterioration occurs, you have to go through the grieving process again. Does it ever get easier?

Jacqui: No, but it=s hard to say. It has been such a gradual process. This most recent hearing loss, prior to cochlear implantation, really hit me. AWhat am I going to do?@ It reminded me of my experience as a teenager, slowly losing my hearing. I was resolving issues from way back when I was a teenager and losing my hearing. After my cochlear implant surgery, I lost additional hearing in my other, my good ear. That was difficult, because the sound from the implant is not as good as the sound through the hearing aid was. I can understand words better through the implant, but the quality of sound is not the same. So, a real loss.

When I meet people I haven=t seen for a while, they almost always say, ABoy, it=s so much easier to talk with you!@ I find that surprising. You know, this business of losing hearing is a pretty scary business. You read about what the experience is like for people to lose their hearing. It is a loss of identity. It is a loss of the easy flow of communication. It is a loss of the use of the telephone. It can mean so many losses.

Candis: How do you feel about the word Adisabled?@ Do you ever use the word yourself?

Jacqui: I usually just say I have a hearing loss. I talk with people about the difference between handicap and disability. I define disability as what the limitation is. Hearing loss, vision loss, illness, a physical or mental problem, an arm that doesn=t work, arthritis – these are the disabilities. The handicap is the impact or the potential impact of that

disability on a person=s life. And so what all of us in the helping professions try to do is to minimize the potentially handicapping impact of a disability on a person=s life.

Candis: I think you have done that very well.

Jacqui: Thanks. I feel strongly that people have disabilities. Disabilities happen, you know. I saw a wonderful bumper sticker in Seattle and it said ARain happens.@ [Laughs.] So disabilities happen. It is what we do about them that really matters. Are we going to let those disabilities handicap us or are we going to try to minimize the negative impact?

I think managing hearing loss is a life-long endeavor. You get comfortable in one place and then something happens or you meet a new person and you have to start all over again, explaining the communication thing, so it is an ongoing process.

Candis: Thank you so much, Jacqui, for sharing your story

11. Interviews with Late-Deafened Adults: John Shiels

John Shiels

John Shiels is presently a Vocational Rehabilitation Counselor for the Washington Division of Vocational Rehabilitation. His addendum below the interview catches us up on the latest happenings in his life, which have been positive for him.

I first met John when I visited the Seattle Hearing, Speech and Deafness Center to set up an internship with the agency at their assistive technology store. His success in his job and easy acceptance of his deafness inspired me and gave me hope at a time when I was still struggling with my own deafness.

March 1998

Candis: I am here in Seattle, Washington, at the Hearing, Speech and Deafness Center. I am meeting with John Shiels. John, tell me a bit of your story, how you lost your hearing and what happened after that.

John: When I was a senior in high school in January of 1968, I became very sick with the flu or something. I was in bed for two days and very dizzy. My hearing went down and I thought I just had a cold and needed to clean out my ears. I went into the hospital and found out I had lost the hearing in my left ear. The doctors were able to restore some of the hearing in my right side, but not my other ear. For the rest of the school year, I was basically deaf in one ear. I work with people in vocational rehabilitation who are getting services because they are deaf in one ear. For some people it can be very

bothersome, especially if they have tinnitus, or have to work where there is considerable background noise. It can be hard to locate sounds. I don't remember it being much of a problem except when someone talked softly on my bad side. I did lose the ability to enjoy a true stereo experience with music, with everything coming in one ear.

Then, in October of that same year, a few months after I graduated from high school, I noticed the hearing going down in my right ear. I was home, asking my siblings, "Did you turn down the TV?" "No!" I called my doctor and he told me to take two aspirin and call him in the morning. When I woke up the next morning, I was deaf. I mean, completely deaf.

I went into the hospital, and the doctors attempted to drain some fluid from my ears. I was given antibiotics, one ending in "mycin" and you know those are famous now for causing hearing loss.

Candis: Streptomycin, neomycin ....

John: Yep. One of those "mycin" drugs, though not one of those that you mentioned. Anyway, I became deaf. A few years later, when I was attending Gallaudet, the audiology professor, upon hearing my story, asked for my medical records to review. He said that my hearing loss was conductive at first, and became a sensorineural loss later. Was it from the medicine? I don't know, but I was definitely deaf. I was eighteen when I lost all of my hearing.

Fortunately, my doctor knew about the Division of Vocational Rehabilitation. I have found out that other late-deafened adults often don't find out about DVR until they have been deaf for two or three years. I was also fortunate in that my DVR counselor

was the first DVR counselor in the country focusing on deaf people. She encouraged me to enroll at Seattle Community College.

Seattle Community College got federal funding to establish support services for deaf students who wanted to go into college. They provided interpreter support and also tutoring and other kinds of services. I didn't know sign language or anything at that time, so I wasn't socializing with the other Deaf kids. I attended for one year, and then my DVR counselor encouraged me to think about going to Gallaudet, the "accessible" university for Deaf people in Washington, D.C. At first I was resistant. It was so far away and I didn't see myself as being Deaf like the other students who couldn't talk. I felt different.

Later, however, I did decide to give it a try and entered Gallaudet in the fall of 1970. I still couldn't sign. Prior to heading over to Gallaudet, I was coming here to the Center for some audiology services and I took a few lip-reading classes here. I still hung out with the same friends I had before I lost my hearing. Looking back, I realize I was in a period of denial about my situation at that time. I didn't want to admit to myself that I was really deaf.

After becoming deaf I got a hearing aid that helped a little bit. I remember the doctors at the hospital telling me that after I got a hearing aid I'd be just fine again. Then I got the hearing aid and put it on and all I could hear was noise distortion. That was not helping anything. The audiologist said, "Just give it time. You need to get used to it." After a few months, I got used to wearing it, but it didn't really help me understand

speech much. I can hear sounds, but I can't talk on the telephone or understand speech without visual cues.

So I went to Gallaudet where I started learning what it is like to be Deaf and how to act like a Deaf person. Because I was late-deafened, the people I socialized more with hard of hearing kids from the mainstream high schools than those who attended state residential schools. Communication was easier for me with other students whose backgrounds were more "oral" than "manual." Talking was still my preferred method of communicating.

I spent two years at Gallaudet, and I did develop sign skills. I decided to leave at the end of my sophomore year. I was majoring in English and planned on becoming an English teacher. Academically, I was not challenged at Gallaudet. Most of the students there were born Deaf and they had some difficulties with English. I had no difficulties and was getting "A's" without even trying. I did enjoy my time there, though, and had fun socially.

I transferred to the University of Washington for my junior and senior years and completed my degree in English. I remember when I registered at U of W, I got a letter back in the mail that if the student was handicapped, he or she should go to such-and-such office on campus and let them know. So I went there and the guy behind the desk laughed at me, saying, "We don't have anything for deaf people. We mean handicaps like people who are blind or in wheelchairs." This was 1972, well before the Americans with Disabilities Act, and a year before Section 504 of the Rehabilitation Act was passed.

I did manage to get some interpreter support, and though the quality of the interpreting was very poor, I did get my degree.

Right after that, I applied for and was accepted into a graduate program in special education at the University of Washington and was planning to start in the fall of 1974. That summer, however, I was working for the Seattle Department of Parks and Recreation which had a small program for children with hearing loss. The program involved camping, playing sports, tennis and different activities. Through that job I met a man working here at the Hearing, Speech and Deafness Center. He was planning to leave his job in the residential program and the opportunity to apply for his job gave me second thoughts about going on to graduate school. I decided to wait on school, and started working at HSDC – then called the Seattle Hearing and Speech Center. In the fall of 1975, I signed up for the graduate program in rehabilitation counseling at Seattle University and got my M.A. degree there. So I am still here with the Center today, but in a much different capacity.

Candis: Did you work at the same time that you were attending school?

John: Yes. I had two small children at that time. As I look back, I would never do that again: full time work, graduate school, and two kids at home. That was crazy.

Candis: You got married somewhere in there!

John: Yes. When I left Gallaudet I was dating someone. We had been going together for more than a year and I asked her to come with me to Seattle and to marry me. She said yes and our marriage lasted about 19 years.

Candis: Was she hearing or deaf?

John: She was Deaf. She attended the Alabama Deaf School. She could talk, but was very culturally deaf, having grown up in a Deaf school. We both returned to Seattle together and began a new life together.

So I married, became a father, was attending graduate school and working full-time doing vocational work. Later I became the Director of Vocational Programs here, and I still am. Over the years we have both grown and downsized and we have added different services. My own specialty area is in vocational assessment – evaluation and testing. I'm pretty well recognized as a national expert in that area. There really is no one in the United States I know of who has done more vocational evaluations on deaf DVR clients than myself. I've been doing it a long time! [Laughs.] I'm excited right now as I am helping an agency in Atlanta, Georgia set up a new evaluation program.

Candis: You've done a lot here. Tell me about the kinds of people you are working with here as clients.

John: I work with deaf, Deaf, deafened, hard of hearing and hearing clients. Hearing clients can be a challenge. Sometimes I can lip read them very well and communication is smooth. Other times, it is a challenge and I get an interpreter to help.

Candis: How has your personal life been going?

John: My wife and I split in 1991 and then I spent about three years single until remarrying in 1994. Really, that last year I was going out with my future wife, but I remember looking back on those two years single, playing the dating game again as a deaf person. A time of high anxiety! [Laughs.] Almost like being in high school again, worried about how I looked and what I would say, attempting to put on my best

impression and so forth. I dated one or two women who were hearing and found it difficult. No matter how sensitive they were, communication was strained, at the best. Eventually, I met my present wife who herself is hearing, but she signs. She was working for the Seattle Mental Health Program in their Deaf program at that time.

We got married in 1994 and had a child in 1996. My first children grew up in a house where both parents were deaf. We both talked and signed to each other, so I don't think our kids learned sign at the same rate as a child would with Deaf parents who don't use their voice. Both children did learn sign language, though my daughter took to it better than my son. In fact, I remember in pre-school or kindergarten, his teacher at the time knew some sign, so she taught all the kids to sign one particular Christmas song. And guess who the only kid in the class who refused to sign was? [Laughs.] Don't get me wrong, though. They're both great kids.

Candis: Looking back now, how do you feel about having lost your hearing at age eighteen?

John: I think it was a good time. I had just finished high school and hadn't yet started college. So I was already in a transitory period. I was young enough to be quite flexible and just included deafness in my career plans.

Candis: You didn't have to struggle with changing careers midstream.

John: Right. Exactly.

Candis: You said that you still do use your voice. How is that going?

John: Once in a while I will mispronounce a word. That can be embarrassing because I am really a fairly literate person. I know what the word means, but learned it after I

became deaf so I never really learned how people say it. But when I mispronounce a word people might get the impression I don't know what the word means just because I did not say it correctly.

Candis: What do you do when lecturing or giving a talk?

John: It depends on who is in the audience and what I am talking about. Sometimes if I try to sign and talk English at the same time, a person who is more culturally deaf is very likely going to miss some things. So, in that case, it is probably better to use an interpreter.

Most of the people my wife and I hang out with are other professional people who work in deafness. They might be hearing, but they probably can sign. They might be Deaf. But they tend to be other people in the same profession. There are a few people that don't fit that description. Once in a while we will go out to dinner and I am the only deaf person and my wife has the burden of trying to sign everything. It's uncomfortable for me. I don't like that and find it stiff and an uncomfortable interaction.

It's worse if you talk! People can't understand how a person can talk but not hear. They are more used to people who can't hear and don't talk. If you can talk, then you must be able to lipread or be able to hear something. If it's important, such as a meeting with a banker, I will ask to have the conversation written down. I want it to be clear. "Could you please write that for me?"

Candis: Do you ever bring an interpreter to a meeting?

John: We've done that. My wife and I are looking for a new house. We decided to pick a real-estate person who either signs or is willing to pay for an interpreter. That way my wife doesn't have to feel the burden of doing all the interpreting. That's not fair.

Sometimes, again, depending on the kind of information I need to get, I will try to lip read and do the best I can. If it is really important, I will use an interpreter. Deaf and hard of hearing people are famous for bluffing and pretending. We all do it, but the key is to know when it is okay to fake and when it's not. If you are in the grocery store, and the person you're talking with is "blah, blah, blah it's a nice day...blah, blah, blah," I don't need to know everything they are saying. It requires so much energy to try to understand, so in a situation like that I might just nod my head in agreement. In another situation, that would be disastrous. So the key is to know when to bluff. [Laughs.]

Candis: Did you learn most of your sign language at Gallaudet? I'm curious if you took classes as you sign really well.

John: Not when compared to people who were born Deaf! Right now I'm signing and talking and yes, I can sign ASL. But you probably know also that when you are in a group of Deaf people, the way you sign marks you and it is clear to the group if you are not a native ASL signer. I felt a lot of attitude in the Deaf community. In the past, it used to bother me a lot. I wanted to feel accepted, but I realized that ASL was not my native language. English is. I can communicate better through English than ASL and now I am at a point in my life where I don't really care a lot what other people think of my signing. If they want to accept me, fine. If not...

Candis: I understand! We've talked about sign language. What about speechreading? You mentioned taking a few lip reading classes some time ago.

John: I'm probably rather average at speechreading. Having become deaf young, and having a good DVR counselor, I was able to create a world and working environment that reasonably accommodates my deafness. For many late-deafened people, it is only the hearing world. I'm not sure how well I'd cope if I left here and went into the business world/hearing world. It is scary to think about that.

Candis: Thank you, John, so much, for sharing your story.

March 2006 Addendum:

John: In July 2001 I underwent surgery for a cochlear implant. At that time I was totally deaf. During the preceding few years the little hearing I had in my right ear dwindled down to nothing, so even wearing a hearing aid just for some environmental awareness was no longer an option. Eventually I went through the cochlear implant evaluation process, was told I was considered a good candidate, and went ahead with the surgery.

I've been using the implant for almost five years now and it has been a life-changing experience. Within a period of a couple of months, my ability to understand speech (with no visual cues) went from 0% to above 90%. Prior to the implant I was totally dependent on interpreters when meeting people who did not sign, even in simple one-to-one meetings. Currently I can join a small meeting of 4-5 hearing people and get along very well; only in really large meetings do I need some assistance like interpreting

or captioning. And to top it off, I am no longer (or so it seemed) the only person on the road without a cell phone!

12. Interviews with Late-Deafened Adults: Bill Graham

Bill Graham

Today, Bill Graham continues his work at Microsoft. He and his wife, Karina, have two adopted children. Eva, 9, is from the Republic of Georgia. Tony, 7, comes from the Russian enclave of Kaliningrad, on the Baltic Sea.

Bill will always be the face of ALDA for me. I first learned about the organization by reading one of his newsletters. I contacted Bill via TTY, and soon was in contact with other late-deafened adults in the area. It was not long before I was on my way to Chicago to attend my first conference of the Association of Late-Deafened Adults.

March 1998.

Candis: It has been so good to see you and Karina again. What, specifically are you doing here in Seattle for Microsoft?

Bill: I'm managing editor for Encarta Reference Suite. Encarta is a CD/DVD reference tool that includes an encyclopedia. My job is to manage the people who write and edit the articles. I've also been involved as the lead of numerous other education-related projects during my time here.

Taking this job meant several things to me on an emotional level. It meant I was leaving World Book in Chicago. It meant I was leaving Hearing Loss Link, the social services agency Karina and I had set up for late-deafened adults. I had not that long before left a leadership position with the Association of Late-Deafened Adults and that had been a heart-wrenching experience. This move meant I was dragging my wife

somewhere she didn't want to go and it meant I was giving up my friends and family. I also was going through the identity changes that go along with getting a cochlear implant, which happened just months before we moved.

Candis: It must have been a difficult process for you.

Bill: Having dealt with becoming deaf helped through the change. All my emotions were telling me "You're crazy! Why are you doing this? But I also had as a model my father, who never did what he said he should have done—he had a great opportunity at one time in his life and he never took it—and he became haunted with regret for the rest of his life. Karina thinks that that was a big part of my decision to make this change. I saw that this was an opportunity and Karina thought I would regret it if I didn't go, that we had to do it. There was something pulling me to make yet another change and I think it helped knowing that I had gotten through becoming deaf. This could not be any worse. It seems to me that I get into a problem in life and I don't think it is as bad as being deaf. Deafness is hard. I mean it. Maybe not on everybody, but I just have not gone gently into the deaf world.

Candis: Tell me about your journey into the deaf world.

Bill: I grew up on the south side of Chicago, the last of a family of four boys. My mother was a bookkeeper and my father was a dentist. I don't know why my hearing started to deteriorate, but I would guess it is a hereditary loss. My oldest brother lost some of his hearing when he was young. I'd already lost some hearing at the higher frequencies around the age of six or seven, when my mother took me to an ear doctor. I don't even know if I ever heard the high frequencies.

I started speech-therapy classes that summer and I hated it. All my friends got to play and I had to go to stupid speech therapy classes. When I was thirteen, I got my first hearing aid, but I don't think anyone ever saw me wear it! [Laughs.] It was one of those hearing aids that fit in a pair of glasses. My vanity didn't let me wear those glasses! I did fine through high school without a hearing aid, though.

I started losing more hearing after beginning college. I was attending the Illinois Institute of Technology, majoring in architecture. I didn't really understand at first what was happening – that I wasn't hearing well. I just knew I wasn't doing very well. I started learning how to bluff! [Laughs.] When the teacher called on me, I would say I didn't know the answer. I did well on the papers I turned in which helped me get by in school.

I didn't enjoy architecture and tried to get into some journalism schools at that time but it was during the Watergate years and everyone was going into journalism, so it was hard to get in. I stayed at Illinois Institute of Technology, but changed my major to English. That's why my English degree has a B.S. in front of it. [Laughs.]

I didn't have much of a social life during my college years. Women's voices are higher, so they were impossible for me to understand. And small talk? Forget it. I didn't know how. If you can't hear, how are you going to learn those kinds of things?

My family was in major denial as well. I was still living at home at that time, and the general consensus there was "I could hear when I wanted to." Yet my hearing was getting worse and worse.

Sports helped. I played varsity baseball at IIT and was most valuable player my senior year there. I also played some semipro baseball. It was getting harder as I lost

more hearing, but most of my teammates knew I couldn't hear well. They would point to where I was to throw the ball, things like that. I'll never forget one game though. I was so embarrassed. I struck out but didn't see that the catcher had missed the ball. I'm headed back to the dugout, head down, bummed, and the whole team is yelling at me to run to first. "Run to first! Run to first!" I didn't hear them and got tagged out. I faked a limp for the rest of the game, saying I had pulled a muscle! I just couldn't admit that I didn't hear my teammates and I lost my confidence in the game after that.

I applied to graduate school after IIT, and joined the creative-writing program at Colorado State University. I was still bluffing, but I did start to use humor during my time in grad school, and humor has served me well ever since.

I never graduated, though. I failed my oral exams. I couldn't understand one of the professors on the orals committee and that was a big reason I failed. Seriously, and I didn't try again. I eventually moved back to Chicago in 1976, and lost most of the rest of my hearing those next few years. I turned into quite a loner, but that's not who I felt I was. I knew I was more outgoing inside. I call those my dark years.

I did get hired on as an editor at World Book. I didn't need to hear for the job and it was good for me. I was isolated in other ways, though. Even though most of the people at World Book knew I couldn't hear, I would panic when attending meetings. What if I had to respond to something I couldn't hear? What if? I would try to sit somewhere inconspicuous and try to hide and just wait in misery for the meetings to be over with.

This went on for awhile until I realized I couldn't go on isolating myself and trying to bluff my way through things any more. I started taking sign language classes. I

felt that somehow I was a failure, having to learn to use my hands to communicate, but it turned out to be an important breakthrough, and was the first step I took for myself as a late-deafened person.

My world gradually opened up again after that. I was promoted to life sciences editor at World Book in 1982, supervising several people. I was starting to meet people who were deaf, and in 1986 started attending a support group of late-deafened adults. In March of 1987 I threw a party at my apartment inviting late-deafened adults from a list provided by Kathie Hering, the leader of the support group and a vocational rehabilitation counselor. The party had a major impact on us as a group and that was the beginning of what became the Association of Late-Deafened Adults. I sent a letter to everyone who attended, and then another one, and pretty soon I was sending a newsletter out beyond Chicago to more and more people.

I realized there were many late-deafened adults out there who could no longer communicate with the hearing world but couldn't communicate with the culturally deaf world either. Many late-deafened adults don't learn sign language and what they do learn is used more to help out with speechreading. I think it's difficult enough to learn a new language as an adult, but the visual language of culturally deaf people is so radically different that it is hard to become really fluent in that language if you didn't grow up with it.

I had touched a chord with many people with ALDA. Many, like me, felt we were in a limbo area between hard of hearing people and the culturally deaf world. Although equally deaf, a late-deafened person may have a hard time with people who

grew up deaf and learned ASL as their first language. You feel like you don't measure up to the real Deaf world because your experiences are so different. Yet there are so many more late-deafened adults than culturally deaf. More than three-quarters of the estimated two million deaf people here in America became deaf after 18 or 19 years of age.

It's hard for late-deafened people to find an identity, because we can't easily coexist with hearing people any more, but we're not that interested in the Deaf community either. So we hang on to our hearing part, but we're just ghosts of what we were.

Candis: When I attended my first ALDA convention, it meant so much to me to meet other people like myself. It was also communication heaven. Steve Wilhelm was still doing ALDA Crude back then.

Bill: That's right. Steve had those television monitors hooked up to computers. ALDA Crude was our version of computer-assisted notetaking, and it worked. ALDA made a key communication breakthrough when we were able to get court reporters to do real-time text translation. That was a major bonus for the growth of ALDA.

Candis: It gave us a common communication medium that worked. Some of us knew sign language, some of us didn't, but we could all read. I remember one of the early socials I attended and it was so comfortable to write back and forth, or type on a laptop if needed. I wasn't nervous, worrying about how I would communicate. ALDA grew rapidly those first few years. And your life opened up with it.

Bill: Yes. I met my future wife Karina at that time. That didn't happen through ALDA, but the romance was going on at the same time. The Americans with Disabilities

Act really helped matters for accessibility. Many good things came together at the same time.

Candis: The newsletter that you wrote and edited for ALDA meant so much to me and other ALDAns. The ALDAnonymous column was great, asking those questions that we all wanted to talk about: "How do you react when someone tells you that you have good speech for a deaf person?" "Are you deaf in your dreams?" One of my favorite articles was when you wrote about moving to a new apartment: "I now live on the second floor of an old frame building that houses a music school on the first floor. Who else but a deafo could live in blissful peace with screeching violins and cellos down below?"

Bill: It was a great apartment!

Candis: The most famous of the articles you wrote remains the one about "Karina's nose."

Bill: That shows you what a great wife I have, that she put up with that kind of communication. [Laughs.] I really could understand her voice when I held on to her nose! Those were the good old days. More and more people became involved with ALDA. We incorporated as a non-profit organization with a Board of Directors and began putting on yearly conventions. We were getting national recognition as an organization and I was getting national recognition as ALDA's leader. I felt uncomfortable with much of that, like I was becoming a symbol or something, and just all the attention made me uneasy.

We had growing pains, like any organization. Gradually we began doing more advocacy work and less self-help and people were disagreeing on issues and nasty emails

were going back and forth. I got in a dispute with another board member, which was a painful situation.

I resigned and started working with Hearing Loss Link as executive director. A couple months earlier, ALDA had gotten a grant to start a service agency in Chicago for late-deafened adults. One of the issues that had come up through ALDA was the poor service late-deafened adults received when we did reach out for help. Social service or rehabilitation agencies would suggest we learn sign language and join the culturally deaf community and that was not working at all.

Hearing Loss Link opened in 1993 and offered classes for late-deafened adults, counseling, and referrals to other agencies. The agency was filling a strong need, but I missed the personal connections of ALDA, the ongoing dialogue with other late-deafened people like myself. I was still working full-time for World Book. In addition, Karina and I were looking into adoption, so life was changing again.

Candis: That's when you started seriously considering a cochlear implant.

Bill: It was a struggle for me to make that decision, but more and more I was getting pulled back into the hearing world and the technology had improved to make it worthwhile. Our philosophy at ALDA was "whatever works," which meant whatever form of communication worked was okay, whether it be speechreading, sign language, cued speech, real-time text translation, hearing aids or cochlear implants. Still, many of us were suspicious of cochlear implants and they seemed to undermine our message that it was okay to be deaf. If it was okay to be deaf, then why get an implant?

Despite all my work on a new identity, part of me wanted to hear again. I had gone through the testing process back in 1989, so I knew I was a viable candidate. And the technology had improved tremendously. It was a time for me of intense questioning.

I had the surgery at Northwestern Memorial Hospital in September of 1995 and was hooked up October 5th. I wasn't one of those people who got hooked up and could hear and understand immediately. I heard a lot of noise, but I worked with audio books and listened to music. I was still speechreading, but it was no longer as hard. And hearing Karina's voice made her so much more real to me. I felt so much more connected to her. It was like falling in love all over again.

Another emotional moment was listening to music. I was listening to Peter, Paul, and Mary via my cochlear implant. I really enjoyed them back when I could hear. I couldn't make out all the words on the tapes just by listening, but I could still recognize the music. I just started crying and couldn't stop, because that had been such a big part of my life. In this case I remembered the words in the songs from before so it was easy for me to pick up what was happening on the tape by linking it with my memories.

Environmental sounds worked the same way. The first time I heard a doorbell, I didn't know what it was. Karina had to tell me, "That's a doorbell." So the next time I heard it I knew what it was and after several times it sounded like a doorbell to me because my brain put it all together with my memory and with what I was actually hearing. I think memory plays a big part in improving one's auditory skills with the implant. The other side of it is just improvement in how your nerves interpret sounds. Sound recognition, etc. I reached a plateau for a while and then I received a new

microphone for the implant and that helped a little bit more. I look forward to future technological improvements as they come along that will help me improve my understanding even more.

Candis: You've gone through an incredible amount of change.

Bill: I don't accept change very easily. I didn't accept deafness very easily. It took a long time before ALDA came along and I got to a point where I think I was doing the best I could with my deafness. I never called it "accepting my deafness." Adjusting or something, I don't know. In some ways I am no better about my deafness today than I ever was. I don't like to go up to a stranger; I feel like I am going to fail. But at least now I don't think about it all night and all week. Now my failings as a deaf person bother me at the time, and then I move on to other things. Diapers to change! [Laughs.] Deafness isn't shaping my life as much as it used to, though it is still with me. All I have to do is turn off the implant. [Laughs.]

Deafness can be like a shield that keeps you from dealing with your real problems. I've stopped blaming deafness for things. Now it's just me. We've gone full circle, haven't we?

13. Conclusion

Deafness does, indeed, bring us full circle in our lives as we reconnect and move beyond perceived walls and barriers. The stories of Jacqui, John, and Bill have shown us that deafness encourages self-growth. What fascinating journeys! Their experiences provided a reference point for me to follow. As late-deafened adults, we have found that we share common themes and experiences.

With the ongoing improvement in cochlear implant technology, more late-deafened adults are opting for the surgery shortly after losing their hearing. Being late-deafened in today's world is easier than even just a few years ago, as people become more aware of who we are, and what is required for full communication. Laws such as the Americans with Disabilities Act continue to foster increased accessibility.

Yet, as Bill Graham said, "When I remove my implant, I am still deaf." Even with the implant on, we must still cope with communication. Late-deafness isn't going away. Many people cannot benefit from the surgery, or choose not to go that route. Many realities exist within late-deafness and there is the ongoing need to increase understanding and acceptance of deafness of our situation.

Hearing is so much more than actual sound. There is indeed an inner hearing, and when we tap into that, we know we are whole and real. We begin to open to new ways of listening to ourselves and others. I can see music as I watch the wind blow through the trees, or as I watch the leaves float to the ground. I can sense a friend's angst well before she voices her concern. I can feel a slight stirring of the air when someone walks into a room behind me.

We have work to do as well. We need to continue to educate people about hearing loss to increase awareness of communication and accessibility issues. We can share our compassion and strength and keep on changing and creating a world that works for all of us. Enjoy your journey!

Works Cited

Ackerman, Diane. A Natural History of the Senses. New York: Random House, 1990.

Aguayo, Miguel. ARehabilitation for Deafened Adults: A Puzzle with Missing Pieces.@ MS thesis. Wilfred Laurier U, 1998.

Albright, Janet. "The Application of Audiology and Technology." Rehabilitation of Individuals Who Are Hard of Hearing and Late-Deafened. Little Rock: U of Ark, [1993].

American Hearing Research Foundation. <http://www.american-hearing.org/name/autoimmune.html>. 6 Feb 2006.

Ashley, Jack. "A Personal Account." Adjustment to Adult Hearing Loss. Ed Harold Orlans. San Diego: College-Hill, 1985

"Auditory Neuropathy." National Institute on Deafness and Other Communication Disorders. 1 Jan 2006 <http://www.nidcd.nih.gov/health/hearing/neuropathy.asp>

Bailey, Laura. "New Cochlear Implant Could Improve Hearing." The University of Michigan Record Online. 2 Feb. 2005. 19 March 2006 <http://www.umich.edu/~urecord/0506/Feb13_06/22.shtml>

Bauman, Neil G. Ototoxic Drugs Exposed: Prescription Drugs and Chemicals That Can (and Do) Damage Our Ears. New York: GuidePost Publications, 2004.

Benderly, Beryl Lieff. Dancing Without Music: Deafness in America. Washington, D.C.: Gallaudet University Press, 1983

Biderman, Beverly. Wired for Sound. Toronto: Trifolium Books, 1998.

Black, Kathy, Candis Shannon, Kirk VanGilder, Robert Walker. Signs of Solidarity: Ministries with People Who are Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind. Ed. Nancy Kingsley. 2nd ed. New York: National Committee on Ministries with Deaf, Late-Deafened, Hard of Hearing, and Deaf-Blind People, 2003.

Boone, Stephen and Dayl Scherich. "Characteristics of ALDAns: The ALDA Member Survey," ALDA News Fall 1995: 1-3.

Carmen. Richard., ed. The Consumer Handbook on Hearing Loss & Hearing Aids: A Bridge to Healing. Sedona, Az.: Auricle Ink, 1998.

Chorost, Michael. Rebuilt: How Becoming Part Computer Made Me More Human. Boston: Houghton Mifflin, 2005.

Clark, Mary. "Hi Ho! Hi Ho! It's off to the Doctor We Go!" ALDA News. Summer 1995: 6-7.

Combs, Alec. Hearing Loss Help. San Luis Obispo, California: Impact, 1986.

Cued Speech Association. <http://www.cuedspeech.org>. 27 March 2006.

Deaf Counseling, Advocacy, and Referral Agency. http://www.dcara.org/. 27 March 2006.

Elliott, Holly. ANow Where Do We Go From Here?" ALDA News. Summer 1995: 1 – 4.

Federal Communications Commission. <http://www.fcc.gov>. 29 March 2006.

Glass, Laurel. "Maybe the Walls Have Ears: I'm Not Sure I Do." Blueprint for Aging Conference. 1 June 1995.

Glass, Laurel and Holly Elliot. Adult Onset Hearing Loss Project. San Francisco: Langley Porter Psychiatric Institute, 1995.

Golan, Lew. Reading Between the Lips: A Totally Deaf Man Makes It in the Mainstream. Chicago: Bonus Books, 1995.

Hain, Timothy C. "Ototoxic Medications." 11 Nov. 2005. Northwestern University Medical School, Chicago, IL. 19 March 2006 <www. dizziness-and-balance.com/disorders/bilat/ototoxins.html>.

Haybach, P.J. Meniere's Disease. Portland: Vestibular Disorders Assoc., 1998.

Hearing Loss Web. ADo Air Bags Cause Hearing Loss?@ Ed. Sivertson, Larry. June 2005. 18 Feb 2006. <http://www.hearinglossweb.com/Medical/Causes /causes.htm>.

Hoversland, Roger. "Gross and Microscopic Anatomy of the Ear." Histology and Embryology. Fort Wayne, U of Indiana, 18 Dec 1996. <http://histo.ipfw.indiana.edu/histo-embryo/histear.html>.

Kisor, Henry. What's That Pig Outdoors? A Memoir of Deafness, York: Penguin, 1990.

Kubler-Ross, Elizabeth. On Death and Dying. New York: MacMillan Publishing Company, 1969.

Luey, Helen S. and Myra S. Per-Lee. What should I do now? Problems and Adaptations of the Deafened Adult. Washington, D.C.: Gallaudet College, 1983.

Mango, Karin. Hearing Loss. New York: Franklin Watts, 1991.

Martin, Frederick N. Introduction to Audiology. Englewood Cliffs, New Jersey: Prentice-Hall, 1975.

Moore, Guy. Physics and Psychophysics of Music. Lecture 3 and 4. Montreal: McGill U, Sept 2005. <http://www.physics.mcgill.ca/~guymoore/ph224/>.

National Cued Speech Association. <http://www.cuedspeech.org>. 20 Feb. 2006.

Padden, Carol and Tom Humphries. Deaf in America: Voices from a Culture. Cambridge, Mass.: Harvard University Press, 1988.

Rezen, Susan V. and Carl Hausman. Coping with Hearing Loss: A Guide for Adults and their Families. Fort Lee, New Jersey: Barricade Books, 1993.

Rutman, Deborah. "The Impact and Experience of Adventitious Deafness." American Annals of the Deaf (Dec 1989): 305 – 310.

Schein, Jerome D. and Marcus T. Delk, Jr. The Deaf Population of the United States. Silver Springs, Maryland: National Assoc. of the Deaf, 1974.

Skurzynski, Gloria. Bionic Parts for People. New York: Four Winds, 1978.

"Speech-To-Text Services." 21 March 2006. Midwest Center for Postsecondary Outreach. Saint Paul College, Minnesota. 21 March 2006 <http://www.mcpo.org/sts_stss.asp>.

"Statistics about Hearing Disorders, Ear Infections, and Deafness." National Institute on Deafness and Other Communication Disorders. 14 Feb 2006 <http://www.nidcd.nih.gov/health/statistics/hearing.asp>.

Suss, Elaine. When the Hearing Gets Hard. New York: Plenum, 1993.

Thompson, Janice. ASudden Deafness.@ Hearing Health Fall 2002:12 B 13.

Tonsgard, James H. Understanding Neurofibromatosis: An Introduction for Patients and Parents. Chicago: U Of Chicago, 1999.

Trychin, Sam. "Living and Working As An Adult Who is Hard of Hearing Or Late-Deafened." Rehabilitation of Individuals Who Are Hard of Hearing and Late-Deafened. Little Rock: U of Ark, [1993].

Vernon, McCay and Andrews, Jean. The Psychology of Deafness: Understanding Deaf and Hard-of-Hearing People. New York: Longman, 1990.

Woodcock, Kathryn. "All Roads Lead to ALDA." ALDAcon III Reader. Ed. Kathryn Woodcock. Fairfax, Virginia: Assoc. of Late-Deafened Adults, 1991. 23-24.

Woodcock, Kathryn, and Miguel Aguayo. Deafened People: Adjustment and Support. Toronto: U of Toronto Press, 2000.

Wright, David. Deafness. London: Faber & Faber, 1969.

Wright, J.W and Silk, K.L. AAcoustic and vestibular defects in lightning survivors.@ Laryngoscope, 84 (1974): 1378 B 1387.

Yeagle, Jennifer. AThe Road to Getting a Cochlear Implant.@ Hearing Loss Magazine. Nov/Dec 2005. (pgs 24-28)

Zieziula, Frank and Katharine Meadows. The Experience of Loss and Grief Among Late-Deafened People: A Report of Research and Theory. Boston, Massachusetts: Presentation at the Association of Late-Deafened Adults Conference, 1992.

Appendix A

Causes of Hearing Loss and Deafness

Hearing loss and deafness stem from multiple causes and it is not easy to separate out the causes of hearing loss from the causes of deafness, since there is much overlap, so I have chosen to include both in this appendix. Perhaps you, the reader, have a progressive hearing loss, or an autoimmune problem. If so, reading the section on ototoxic medicine and noise-induced hearing loss may be helpful as you work to avoid any situations that might increase your hearing loss. For those of you who are deafened, the list serves as an educational tool in learning about deafness and where you fit in the larger picture. Please note the list is not exhaustive, though I have tried to include the majority of the culprits involved in hearing loss and deafness.

Injuries

Kathryn Woodcock, herself late-deafened, has colorful words for physical injuries that affect hearing: ATraumatic losses are incurred in a wide variety of exciting and adventurous ways, from motorcycle riding to settling an argument in an alley behind a bar" (24). Automobile accidents, sports injuries, war injuries, work injuries, underwater diving, being struck by lightning (Wright and Silk 1378), all these adventures and more can result in hearing loss or deafness.

Another, albeit less traumatic danger comes from the deployment of air bags in automobiles. Both temporary and permanent hearing loss can result from car accidents in which the driver's ear or passenger=s ear is near the area from which the bag releases. The loss occurs from the concussive effects of the air bag against the head. The Hearing Loss Web site has a good article on air bags in their June 2005 e-newsletter. Go to the web site www.hearinglossweb.com, click on Anew to hearing loss@ and then scroll down the article and click on Acauses of hearing loss@ to locate the most recent information. Larry and Char Sivertson, who are hard of hearing and late-deafened, respectively, run the site and keep it updated with recent news pertaining to hearing loss.

Surgical

Surgical causes of deafness involve complete or partial removal of the auditory nerve. Brain tumors and bilateral acoustic tumors on both auditory nerves such as those found in neurofibromatosis 2 belong in this category. Neurofibromatosis 2 (NF2) is a genetic disorder that affects the nerves next to the brain or spinal cord. Benign tumors grow on the hearing and balance nerves. Surgery becomes necessary to remove the tumors, and the surgery itself causes deafness; however, left untreated, the tumors would do the same thing. Facial paralysis, both with unchecked growth and during surgery to remove the tumors, is an additional concern because of the close location of the facial and auditory nerves to each other (Tonsgard 10).

Often the word "silent" is used in print when referring to deafness, yet most people do have some residual hearing and/or tinnitus in varying degrees of intensity.

Surgical deafness, or any severing of the auditory nerve, results in complete silence (Aguayo 7). There is no tinnitus and no residual hearing in these cases.

Illnesses

A long list of illnesses can cause hearing loss and deafness. Meningitis, both bacterial and viral, is a major cause of adult-onset deafness and for children who become deaf after birth. Vaccines are now available that can protect against meningcoccal and pneumococcal meningitis. If caught in time, the bacterial form of the illness can be treated with antibiotics, but no protection is yet available for the viral form.

Rubella, or German measles, is usually harmless in either an adult or a child. If a woman is pregnant, however, and becomes infected, the unborn child can be born deaf, or with a hearing loss. Rubella occurs in cycles and a serious American epidemic from 1963 to 1965 left behind many deaf children and children with a progressive hearing loss.

Mastoiditis is an infection of the mastoid bone, located directly behind the ear which, if left untreated, results in deafness. Other illnesses such as chronic otitis media, cancer, and even multiple sclerosis (Vernon and Andrews 63) have been implicated in hearing loss. Sexually transmitted diseases cause hearing problems: herpes, the cytomegalovirus, syphilis, and chlamydia (Vernon and Andrews 62-63). Viruses such as mumps, rubeola, chicken pox, influenza, the adenovirus, Epstein-Barr are other culprits (Woodcock and Aguayo 16). Scarlet fever, or any prolonged high fever, can cause hearing loss and deafness. Typhoid and smallpox left behind many deaf and hard of hearing people among those fortunate enough to have survived the illness.

Ototoxic Drugs

Ototoxic drugs are medicines that can cause damage to the ear. Patients end up dealing with up with permanent hearing loss, balance or tinnitus problems. Sometimes the medicine is needed to save one=s life, but other times it is a prescription taken for an unrelated medical condition.

Many chemotherapy drugs can cause hearing loss and deafness, so it is important to study possible side effects before taking them. The drugs react differently with different people, Researchers continue to investigate the reasons for the wide variety of reactions found and theorize one's genetic makeup may plan a role. New drugs to help minimize hearing loss during a chemotherapeutic regime are being developed.

Antibiotics of the aminoglycoside variety are dangerous. Elaine Suss lists several aminoglycosides on her list of most dangerous medications to take. She recommends against taking gentamicin, streptomycin, neomycin, kanamycin, or any antibiotics ending in icin or ycin (213). Other chemicals such as mercury, formaldehyde, benzene vapors, lead, strychnine and any products containing quinine are dangerous to the ear. Aspirin (salicylates) in large quantities can cause hearing loss, though this is usually temporary. Dr. Neil Bauman recently published the second edition of his Ototoxic Drugs Exposed, in which he details hundreds of potentially hearing hazardous drugs.

Other drugs known to be ototoxic include certain anesthetics and cardiac medications, Lasix, also known by its generic name furosemide, is a loop diuretic used

with congestive heart failure. It has caused hearing loss in some people. Dr. Timothy Hain, M.D. at www.tchain.com/otoneurology/disorders/bilat/ototoxins.html goes into this in more detail.

Progressive Hearing Loss

Noise

Exposure to too-loud sounds or prolonged loud noise can cause hearing, both temporary and permanent. War injuries or similar injuries from weapons fired or bombs exploding at extreme close range can cause deafness. Noise-induced hearing loss is growing at an epidemic rate in our fast-paced and loud society. Listening to music on portable devices is growing in popularity but many people do not take care in keeping the volume at a safe level.

Autoimmune problems

Autoimmune inner ear disease (AIED) is a cause of progressive hearing loss. With autoimmune problems, the body turns on itself, in this case creating antibodies or immune cells that attack the inner ear. Hearing loss is also linked to lupus. Some Meniere=s cases are autoimmune in origin. The cause of Meniere's disease is unknown, but it is thought to be associated with abnormal enlargement of the innermost fluid-filled spaces of the inner ear (Haybach 8). Extreme vertigo (perceiving movement that is not really happening), dizziness and tinnitus that "attack" and then subside are symptoms of Meniere's, and hearing loss or deafness is a frequent result. Another autoimmune

disease, Cogan=s Syndrome, involves inflammation of the eye accompanied by bilateral hearing problems and dizziness. The American Hearing Research Foundation has a good web site on autoimmune disorders of the ear which covers in detail the wide variety of problems found: www.american-hearing.org/name/autoimmune.html.

Genetic and unknown losses

Approximately one-half of childhood deafness is caused by genetic mutations (Vernon and Andrews 22). Many cases of progressive hearing loss can be attributed to genetic causes, but for many, the cause remains unknown. A common pattern with progressive hearing loss is for the loss to begin in childhood and grow more significant over time. The individual becomes deafened during the middle years of adulthood (Aguayo 7).

Presbycusis

Presbycusis is a progressive hearing loss attributed to the aging process. It affects 30% of adults who are 65 or older. According to the National Institute on Deafness and Communication Disorders, about half the population over 75 has significant hearing loss. Among seniors, hearing loss weighs in just behind arthritis and hypertension in numbers of people affected (Glass 1).

Sudden Hearing Loss/Deafness

Vascular problems, fat embolism, leukemia, even TMJ (temporamandibular joint disorder) can cause sudden deafness, though oftentimes the hearing loss can be partially or completely restored (Thompson 13). Many cases of sudden deafness occur in one ear.

Auditory Neuropathy

With auditory neuropathy, the problem is with the transmission of signals from the inner ear to the brain. The loss can be complete or partial and it fluctuates. A person might be able to hear sounds but have difficulty understanding speech. Sound and understanding may come and go. The problem may have multiple causes and involve faulty connections between the inner hair cells and the auditory nerve. Auditory neuropathy affects people of all ages. The National Institute on Deafness and Other Communication Disorders (www.nidcd.nih.gov) has good information on this topic.

Psychological

Though it doesn't happen often, it is possible for someone to "fake" their deafness and there is a psychological disorder in which the person shuts out sound and really cannot hear, but physically has nothing wrong with him or her (Woodcock and Aguayo 19). Both of these situations are extremely rare.

Appendix B

How We Hear

Diane Ackerman writes about the anatomical aspects of the ear in *A Natural History of the Senses* as looking Asomething like a maniacal miniature golf course, with curlicues, branches, roundabouts, relays, levers, hydraulics, and feedback loops@ (177). Her description is quite apt. The path sound follows until our brain decodes it and we "hear" is, indeed, a major journey that looks to be full of rough terrain and major challenges and yet it happens so fast that those of us who hear accept the sounds as we hear them, with little thought to how we are hearing or how what we hear is shaping our reality.

When I lost my hearing and was thrust into a new reality, that of not hearing, I realized how little I knew about hearing itself. How *do* we hear? I wanted to know what I had lost and how I had lost it. Later, when I met with a specialist to discuss cochlear implantation, the mechanics of hearing took on a new significance as I pored over information about the surgical part of the implantation process and studied how the implant works.

The following explanation and accompanying illustrations will serve as a beginning guide to understanding the complex and fascinating process by which we hear.

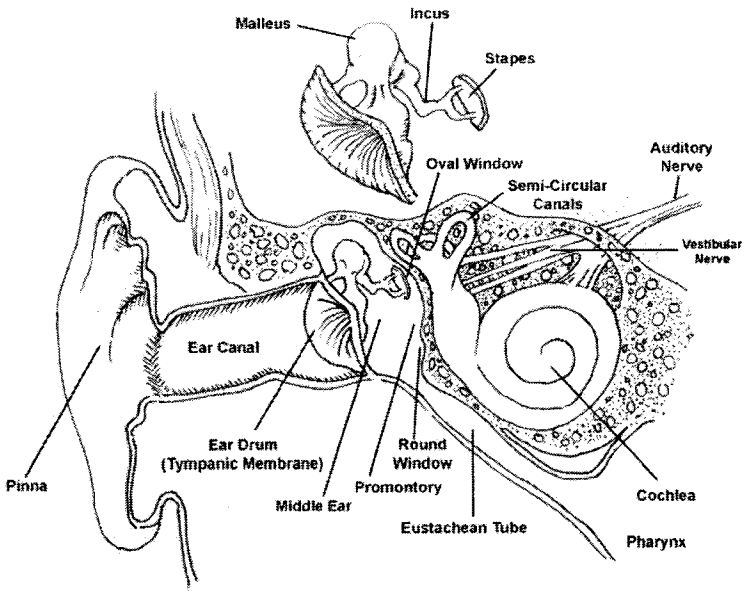

Figure 5. Anatomy of the Ear. Drawing by Ellen Million.

The Outer Ear

The act of hearing begins with the ears on each side of our head. The outer ear, also called the pinna, collects sound waves and acts as a funnel, channeling the waves towards the eardrum. The outer ear increases our hearing sensitivity and helps us locate the source of the sound.

The ear canal is about 1 ½ inches in length. At the end of the canal lies the eardrum, or tympanic membrane. When the sound waves pass through the ear canal and reach the eardrum, the eardrum vibrates. The eardrum is very thin. You can actually see through it, and it is quite elastic. The eardrum transfers the sound waves to the bones of the middle ear.

The Middle Ear

The middle ear is filled with air and also holds the three smallest bones in the human body: the malleus (hammer), the incus (anvil) and the stapes (stirrup). These bones are collectively called ossicles, which means "little bones." The responsibility of the ossicles is to concentrate the force of the sound waves in preparation for the inner ear, which is fluid-filled, rather than air-filled.

The ossicles are connected to each other, leading from the eardrum to the oval window. When the eardrum vibrates, it pushes against the malleus, which is attached to the middle ear side of the eardrum. The malleus pushes against the incus which pushes against the stapes. The stapes responds by tapping on the oval window, an entrance to the inner ear. Here the medium for the sound waves changes from air to fluid. More pressure is needed to move fluid than to move air and the oval window assists with its small size. Because it is approximately fifteen times smaller than the eardrum, the pressure is twenty-two times greater by the time the sound reaches the oval window.

The Inner Ear

Just on the other side of the oval window is a fluid-filled labryrinth that leads directly into the cochlea and upwards to three semicircular canals. The semicircular canals use hair cells to help maintain balance (Haybach 33-34).

The cochlea's job is to serve as a rather complex microphone. No larger than a pea (Chorost 69), the cochlea looks like a snail and, if unwound, it would be less than an inch and a half long. If you think of the cochlea as if cut open (Figure 6), you will fine

three fluid-filled channels separated by two membranes. The channel closest to the roof is called the Scala Vestibuli. Reissner=s membrane separates it from the middle channel, called the Scala Media. The basilar membrane separates the Scala Media from the lower channel, the Scala Tympani. The gel-like Organ of Corti, the hearing organ and home of the cochlea hair cells, sits on top of the basilar membrane (Moore 4).

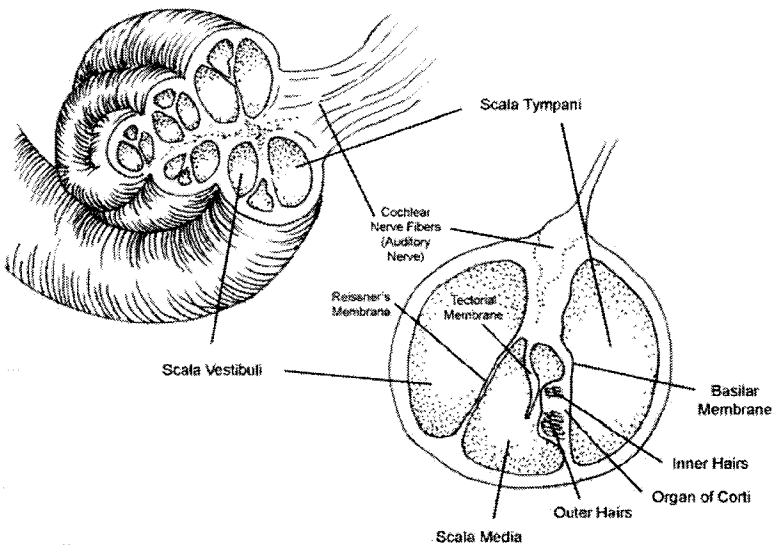

Figure 6. Cross-section of the cochlea. Drawing by Ellen Million.

Sound vibration from the middle ear creates a wavelike motion that moves from the oval window to the upper chamber of the cochlea, the Scala Vestibuli. The sound is in a closed system. If you picture the cochlea straightened out, at the end of the Scala Vestibuli there is a small hole near the tip, or apex, called the helicotrema that leads to

the lower Scala Tympani, and if you follow the Scala Tympani back to the larger base, or opening of the cochlea, you will find the round window (Moore 4). The round window leads back into the middle ear (Figure 7).

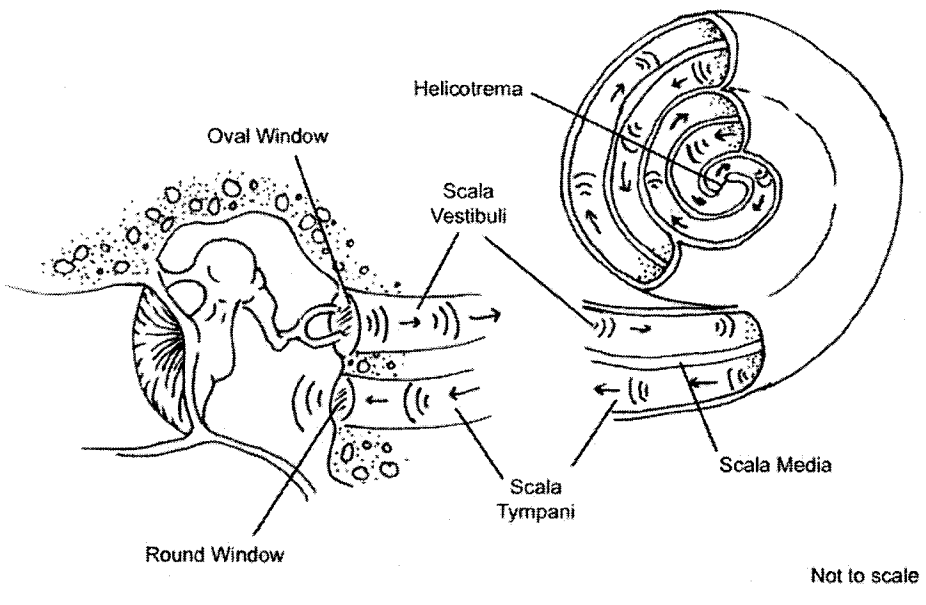

Figure 7. Soundwaves traveling through the ear. Drawing by Ellen Million.

Now, returning to the sound waves, they travel through the outer ear, are further concentrated by the ossicles in the middle ear and are then sent through the oval window. The fluid moves into the Scala Vestibuli of the cochlea and returns to the round window via the Scala Tympani. The round window dents outward when the vibration reaches that window. While the fluid is moving through the cochlear chambers, both Reissner=s membrane and the basilar membrane yield, and this movement and resulting engagement of the hair cells results in an accurate translation of the particular sound (Martin 273).

The faster the oval window moves in and out, the less distance the fluid will travel and the Adenting@ of the membrane walls occurs closer to the larger end of the cochlea. The slower the oval window moves in and out, the farther the fluid travels and the denting or yielding of the membranes occurs nearer the apex, or smaller, end of the cochlea. The pitch of the sound heard is related to where the denting occurs, with higher frequencies associated with the larger end of the cochlea and lower frequencies associated with the apex.

The Organ of Corti resides on the basilar membrane and is home to thousands of hair cells whose jobs are to change the sound waves into electrical impulses to send to the brain. Approximately 20,000 hair cells are lined up in four rows in the Organ of Corti. They extend along the length of the basilar membrane. About 16,000 of the hair cells are called outer hair cells and they form three rows. The fourth row consists of approximately 3,500 inner hair cells (Martin 272). The inner cells are the cells that communicate information to the brain via the auditory nerve. The three rows of outer hair cells receive messages from the brain, which is used to refine the sound (Chorost 68). Each hair cell has fibers called stereocilia on its tip. Inner hair cells have about 50 to 60 stereocilia on each cell and outer hair cells each are topped off with 100 stereocilia (Hoversland 1). The stereocilia are like miniscule hair fibers. When the stereocilia go to work, however, they dance with abandon, shooting off electrical impulses.

One reason for the wild dancing is because the stereocilia are caught up in yet another membrane, the tectorial membrane (Skurzynski 54). This gossamer membrane clings to the wall of the Scala Media (the middle chamber of the cochlea) while the

basilar membrane is clinging to the floor. The Organ of Corti sits on top of the basilar membrane, and the rows of hair cells in the Organ of Corti stretch between the tectorial and basilar membranes, touching and anchored on each end. The hair cells are nerve sensors, and at their base in the basilar membrane, they are connected with the neurons, or nerve cells. When sound vibrations make it through the oval window, the pressure creates waves in the cochlea and that pushes against, or "dents", the Reissner=s membrane which then pushes against the tectorial and basilar membranes. Doing so disturbs the Organ of Corti, and the hair cells dance (Moore 4). They twist in different directions (Martin 274), releasing electrical charges that connect with the nerve endings in the basilar membrane and then head to the brain to be translated and heard as sound.

The process of hearing is a complicated one, yet it happens without conscious thought or effort. That cochlear implant researchers have been able to duplicate the sense of hearing by inserting an electrode array into the Scala Tympani is amazing indeed. The electrode array of the cochlear implant is inserted through the round window into the scala tympani of the cochlea. The array does not go all the way to the apex, which explains why it is easier to hear higher frequencies with the implant than the very low frequencies.

Appendix C

Resources

ASSISTIVE TECHNOLOGY:

Harris Communications
15155 Technology Drive
Eden Prairie, MN 55344
800.825.6758 Voice
800.825.6758 TTY
www.harriscomm.com

Weitbrecht Communications, Inc.
926 Colorado Ave.
Santa Monica, CA 90401-2717
800.233.9130 Voice/TTY
www.weitbrecht.com

COCHLEAR IMPLANT MANUFACTURERS (US OFFICES):

Advanced Bionics
12740 San Fernando Road
Sylmar, CA 91342
800.678.2575 Voice
800.678.3575 TTY
818.362.5069 Fax
www.bionicear.com

Cochlear Corporation
61 Inverness Drive East, Suite 200
Englewood, CO 80112
800.523.5798 Voice/TTY
303.792.9025 Fax
www.cochlearamericas.com

MED-EL Corporation
2222 East Highway 54
Beta Building, Suite 180
Durham, North Carolina 27713
1.888.633.3524 Voice
1.919.484.9929 Fax
www.medel.com/ENG/US

HEARING EAR DOGS:

Canine Companions for Independence
P.O. Box 446
Santa Rosa, CA 95402
800.572.2275
www.caninecompanions.org

Dogs for the Deaf, Inc.
10175 Wheeler Rd.
Central Point, Oregon 97502
541.826.9220 Voice/TTY
541.826.6696 Fax
www.dogsforthedeaf.org

SUPPORT ORGANIZATIONS:

Alexander Graham Bell Association
3417 Volta Place NW
Washington, D.C. 20007
202.337.5220 Voice/TTY
www.agbell.org

Association of Late-Deafened Adults (ALDA)
8038 Macintosh Lane
Rockford, IL 61107
815.332.1515 Voice/TTY
www.alda.org

Hearing Loss Association of America
7910 Woodmont Ave. Suite 1200
Bethesda, MD 20814
301.657.2248 Voice
301.657.2259 TTY
301.913.9413 Fax
www.hearingloss.org

National Association of the Deaf
814 Thayer Ave.
Silver Spring, MD 20910-4500
301.587.1788 Voice
301.587.1789 TTY
301.587.1791 Fax
www.nad.org

RESEARCH AND GOVERNMENT SOURCES:

ADA Information Line (Americans with Disabilities Act)
800.514.0301 Voice
800.514.0383 TTY
www.usdoj.gov/crt/ada/adahom1.htm

American Hearing Research Foundation
8 South Michigan Ave., Suite #814
Chicago, IL 60603
312.726.9670 Voice
312.726.9695 Fax
www.american-hearing.org

Federal Communications Commission
445 12th St. SW
Washington, D.C. 20554
888.225.5322 Voice
888.835.5322 TTY
866.418.0232 Fax
fccinfo@fcc.gov
www.fcc.gov

National Institutes of Health
National Institute on Deafness and Other Communication Disorders
NIDCD Information Clearinghouse
31 Center Dr. MSC 2320
Bethesda, MD, U.S.A. 20892-2320
800.241.1044 Voice
800.241.1044 TTY
301.402.0018 Fax
www.nidcd.nih.gov

University of Arkansas
Rehabilitation Research and Training Center
For Persons who are Deaf or Hard of Hearing
26 Corporate Hill Drive
Little Rock, Arkansas 72205
501.686.9691 Voice/TTY
501.686.9698 Fax
www.uark.edu/depts/rehabres

INTERNET RESOURCES:

ALDA LDA-Chat can be reached through their website: www.alda.com

Beyond-Hearing

An email list for people with hearing loss. Their web page has information for subscribing:

http://www.geocities.com/Heartland/Prairie/4727/bhnew.htm

Cochlear Implant Forum

This forum is for users of all implants.

To subscribe, send an email to:
listserve@yorku.ca
Leave the subject line blank. In the body of the message type:
Subscribe ci first name last name

Cochlear Implant Forums focused on particular implants

Each cochlear manufacturer's website has information on an e-group forum for their implant users:

Advanced Bionics: www.bionicear.com
Look for "Join the B.E.A" Bionic Ear Association
Cochlear Corporation: www.cochlearamericas.com/Community
Click on Nucleus Forum
Med-el Corporation: www.med-el.com/ENG/US
Click on Hearing Companions

Hearing Loss Web

This web site is for all those with hearing loss who are not part of the Deaf community. They have a weekly e-newsletter and provide many resources on the web page.

www.hearinglossweb.com

SayWhatClub

This is a large group of late-deafened and hard of hearing people. E-groups are available on different topics. Their web site has information on subscribing.

www.saywhatclub.com

Appendix D

Recommended Reading

Ashley, Lord Jack. Journey into Silence. London: Bodley Head, 1973.

The autobiography of Jack Ashley, who lost his hearing while serving as a member of the British Parliament.

Bauman, Neil G. Ototoxic Drugs Exposed: Prescription Drugs and Chemicals That Can (and Do) Damage Our Ears. New York: GuidePost Publications, 2004.

A comprehensive book on ototoxic drugs.

Blatchford, Claire. Full Face: A Correspondence About Becoming Deaf in Mid-Life. Butte Publications, 1997.

A series of letters between Blatchford and a fictional man who has lost his hearing. Blatchford is late-deafened and in these letters she shares information and coping skills she has learned to the newly deafened man.

Biderman, Beverly. Wired for Sound: A Journey into Hearing. Toronto, Canada: Trifolium Books, 1998.

Biderman has written a comprehensive, personal and well-researched account of her experience with cochlear implantation.

Cohen, Leah Hager. Train Go Sorry: Inside a Deaf World. Boston: Houghton Mifflin, 1994.

Cohen's father was the superintendent of the Lexington School for the Deaf in New York City and this is her story as a hearing person deeply involved in the Deaf world.

Chorost, Michael. Rebuilt: How Becoming Part Computer Made Me More Human. Boston: Houghton Mifflin, 2005.

Chorost's book is a scientific memoir about his experience getting a cochlear implant. He views implantation from a cyborg/bionic perspective and includes descriptions of the science behind implantation.

Glennie, Evelyn. Good Vibrations. Long Preston: Magna Print, 1991.

An autobiography by the Scottish deaf percussionist.

Golan, Lew. Reading Between the Lips: A Totally Deaf Man Makes It in the Mainstream. Chicago: Bonus Books, 1995.

Golan can be blunt and opinionated, but his story of growing up as an oral deal person is fascinating.

Harvey, Michael. Listen with the Heart: Relationships and Hearing Loss. San Diego: Dawn Sign Press, 2001.

True stories of how parents, children, and spouses are transformed by helping each other heal and grow through situations involving hearing loss and deafness.

Harvey, Michael. Odyssey of Hearing Loss; Tales of Triumph. San Diego; Dawn Sign Press, 1998.

Ten stories of people dealing with hearing loss written from the perspective of psychological adjustment.

Heppner, Cheryl M. Seeds of Disquiet: One Deaf Woman's Experience. Washington, D.C.: Gallaudet U P, 1992.

An autobiography by the executive director of the Northern Virginia Resource Center. Heppner lost her hearing from meningitis when young and attended mainstream schools growing up. She is active with the Association of Late-Deafened Adults.

Kisor, Henry. What's That Pig Outdoors? A Memoir of Deafness. New York: Penguin, 1990.

The book review editor of the Chicago Sun-Times, Kisor's book is about his experiences growing up oral in a hearing world.

Lovley, Shawn. Now What? Life After Deaf. Washington D.C.: iUniverse, 2000.

Lovley lost his hearing from an operation for a brain tumor. The book gives general information on living life as a late-deafened adult.

Orlans, Harold, ed. Adjustment to Adult Hearing Loss. San Diego: College-Hill Press, 1985.

An excellent collection of articles on the psychological and sociological aspects of late-deafness.

Padden, Carol, and Tom Humphries. Deaf in America: Voices from a Culture. Cambridge: Harvard U P, 1988.

A good introduction to Deaf culture and American Sign Language.

Romoff, Arlene. Hear Again: Back to Life with a Cochlear Implant. New York: League for the Hard of Hearing Publications, 1999.

Arlene Romoff began losing her hearing during her college years. Thirty years later she was profoundly deaf and had surgery for a cochlear implant. This book shares email correspondences that she kept on her experiences with relearning how to hear.

Sacks, Oliver. Seeing Voices: A Journey into the World of the Deaf. Berkeley: U of California P, 1989.

You have to read this book for the profuse and interesting footnotes. Sacks takes an enthusiastic outsider's look at cultural deafness.

Shuster, Bena. Life after Deafness: A Resource Book for Late-Deafened Adults. Ottawa: Canadian Hard of Hearing Assoc., 1995.

Shuster became deaf overnight as the result of a viral infection. Shuster includes both Canadian and American resources.

Suss, Elaine. When the Hearing Gets Hard: Winning the Battle Against Hearing Impairment. New York: Insight Books, 1993.

Suss is a hard of hearing journalist. She writes on coping with hearing loss and has a good section on ototoxic drugs.

Thomsett, Kay, and Eve Nickerson. Missing Words: The Family Handbook on Adult Hearing Loss. Washington, D.C.: Gallaudet U P, 1993.

Written by a mother deafened in adulthood, and her hearing daughter, this book takes a good look at the dynamics of hearing loss.

Tucker, Bonnie Poitras. The Feel of Silence. Philadelphia: Temple U P, 1995.

A memoir of a deaf woman who succeeded in a hearing world as a lawyer.

Woodcock, Kathryn and Miguel Aguayo. Deafened People: Adjustment and Support. Toronto: U of Toronto P, 2000.

Describes acquired deafness and its impact and presents a model for the adjustment process.

Walker, Lou Ann. A Loss for Words: The Story of Deafness in a Family. New York: Harper, 1986.

A sensitive account of what it is like to grow up hearing with Deaf parents.

Wright, David. Deafness. New York: Stein and Day, 1975.

A beautifully written autobiography by a British poet who was deafened by scarlet fever at the age of seven.

Speechreading and Sign Language Resources:

Gallaudet University's Laurent Clerc National Deaf Education Center has a website with good information on speechreading and sign language resources. Go to www.clerccenter.gallaudet.edu/InfoToGo and scroll down to the section on Communication and Sign Language