

Facing the Challenge of Hearing Loss

A SURVIVOR'S MANUAL



COMPILED BY THE

Hearing Loss Association of America
Oregon State Association

Facing the Challenge of Hearing Loss:

A Survivor's Manual [revised]

COMPILED BY

Hearing Loss Association of America – Oregon State Association (HLAA-OR)
www.hearinglossOR.org/

Our cover shows people of different ages and ethnicity who have a hearing loss to represent the fact that hearing loss can affect people irrespective of any of these factors.

Hearing loss affects everyone differently depending on age, suddenness of onset and a variety of other factors like life situations. Loss of hearing can have an effect on our emotions like depression, sadness, frustration, anger and grief. These emotions come largely from the loss, reduction or other difficulties in understanding verbal communication which is at the heart of living and interacting with others, keeping up to date with what is happening in the world, working and enjoying events where speech, lyrics or sounds are involved.

Hearing loss brings challenges several times a day at meetings in work or school, at social gatherings of any sort, on the phone, in a noisy crowd at games and concerts, or even shopping. At the same time, hearing loss provides many opportunities to cope by changing behavior and using advanced technology.

Losing our ability to hear well has many implications for relationships. Poor hearing affects the hard-of-hearing person, the hearing partner, friends and co-workers because all must adjust their communication style to accommodate for the loss of auditory acuity. The hard-of-hearing person may become frustrated at not being able to hear what is being said while people who hear well and are involved in the communication will feel frustrated because communication styles that work among normally-hearing people do not work when hard-of-hearing people are involved. New communication skills are needed for both sides of the conversation.

Poor hearing certainly does not mean a poor quality of life, but it does create challenges that need to be overcome. The impact of hearing loss depends on the extent and suddenness of the loss, knowledge, patience, determination and understanding. It is our hope that the information in this booklet will make coping with your hearing loss easier and promote better self-understanding, plus understanding and acceptance from family, co-workers and friends.

We deeply appreciate the funding for this booklet provided by the sponsors you will notice throughout this book, and the many individuals who gave financially and of their time, suggestions and encouragement.

If this booklet has been a source of encouragement to you or someone you know, we welcome donations to enable us to continue our outreach and education to hard-of-hearing people and their families and friends.

An order form for additional copies is at the end of this manual, or you can send your request and check to the address below.

All donations will be acknowledged in the HLAA-Oregon newsletter and are tax deductible.

This manual was created and updated by members of HLAA-Lane County, HLAA-Oregon, and many other volunteers and contributors. Many thanks to Leone Miller (HLAA-Lane County) for sharing her idea of a survivor's guide with her chapter and working with us to create it.

Revised Fifth Edition, published January 2015

Survivors Manual/HLAA-OR or Newsletter/HLAA-OR

PO Box 22501

Eugene, OR 97402

info@hearinglossOR.org



THE OREGON HEARING SOCIETY

<http://www.oregonhearingociety.org>

The Oregon Hearing Society proudly supports the Hearing Loss Association of America – Oregon State Association and the “Survivor’s Manual.”

TABLE OF CONTENTS

STATISTICS AND INFORMATION ON HEARING LOSS

Did You Know	1
Do You Have a Hearing Loss?.....	2
Causes and Related Problems of Hearing Loss.....	3
Understanding Your Audiogram.....	7
How We Perceive Sound.....	8
What are the Results of a Hearing Loss?	10
Don't Hide Your Hearing Loss	11

THE EMOTIONAL SIDE OF HEARING LOSS

Frustration and Other Emotions.....	12
Grieving.....	13
Confronting Your Hearing Loss	14

HEARING AIDS, COCHLEAR IMPLANTS, OTHER SYSTEMS, AND YOU

Choosing a Hearing Care Provider	16
A Word About Telecoils and Why They are Important.....	18
Hearing Aid Styles and Features	19
Choosing Your Hearing Aids	21
Costs and Resources for Purchasing Hearing Aids.....	22
Help! My Hearing Aid Has a Problem!.....	24
What Should I Do With My Old Hearing Aids?	26
Cochlear Implants (CIs)	26
Cochlear Implant Surgery: Making Choices.....	30
Two Devices Are Often Better Than One	33
Learning to Use Your New Hearing Devices	34
Caring For Your Hearing Device(s).....	36

HEARING ASSISTIVE TECHNOLOGY

ALDs, Captions, and Other Technical Things that Make a Difference...	38
Telephones, Cell Phones, Smartphones and You	42

GENERAL COPING SKILLS AND HOW TECHNOLOGY CAN HELP YOU


Making Speech Understandable In Difficult Settings.....	45
Making Public Meetings And Meeting Places Accessible.....	49
Accessibility In The Work Place.....	52
Accessibility In Medical Settings	54
Courtroom Accessibility	58
Accessibility In Adult Educational Settings.....	59
Drivers Information	61

ADVOCACY, THE ADA, THE FCC AND YOU.....

YOU ARE NOT ALONE ... HEARING RESOURCES.....

SUGGESTED READING

GLOSSARY.....



Face the challenge with
someone you can trust



Smith Rock, Oregon

Audiologists are healthcare professionals specializing in the evaluation, diagnosis, treatment, management and prevention of hearing loss, tinnitus, and balance disorders in infants, children, and adults. Audiologists earn a doctorate or master's degree in Audiology and are licensed by the state.

Look for the OAA logo when considering an audiologist!

Visit www.OregonAudiology.org to find an
OAA audiologist near you!

OUR MISSION

The Mission of the Hearing Loss Association of America (HLAA), its state associations, and its local chapters is to open the world of communication to people with hearing loss by providing information, education, support and advocacy.

- **Education:** Our primary purpose is to educate ourselves, our families, friends, coworkers, teachers, hearing health care providers, industry, government, and others about hearing loss; to provide adults and children with tools for self-help; to sensitize the general population about the special needs of people who have hearing loss; and promote understanding of the nature, causes, complications, and remedies of hearing loss.

We provide information on many aspects of hearing loss, from technological and medical advances to coping and parenting strategies. In doing so, we want to help you become an informed consumer on what options are available to you to help you make the best decisions on how to deal with hearing loss.

- **Advocacy:** HLAA organizations are a leading voice in improving communication access for people with hearing loss on the national, state and local level. At all levels we advocate for communication access in the workplace, hotels, schools, court systems, medical, and entertainment facilities and we help implement federal and state laws which benefit people with hearing loss.
- **Self Help:** HLAA believes people with hearing loss can help themselves and one another to participate fully and successfully in society. We promote self-confidence, empower individuals with skills to improve their lives, and provide an opportunity for affiliation among people with hearing loss, their friends, families, and professionals. At the local level, chapters provide support through affiliation with others who share your concerns, understand the problems you face and experience the emotions you go through as a person with hearing loss. We have all been there and are survivors of hearing loss.

NOTE: Opinions expressed herein are those of the individual authors and are not necessarily those of HLAA. Mention of products and services does not mean endorsement, nor should exclusion indicate disapproval.

Statistics and Information About Hearing Loss

Did You Know...

- Approximately 48 million adults in the United States report some degree of hearing loss.
- Hearing loss is a major public health issue that is the third most common physical condition after arthritis and heart disease.
- In the United States, three out of every 1,000 children are born hard-of-hearing or deaf. Nine out of ten are born to hearing parents.
- In adults the most common causes of hearing loss are noise and aging.
- Noise-induced hearing loss may happen slowly over time or suddenly. This is usually caused by exposure to loud sounds, noise at work or leisure activities.
- In age-related hearing loss, known as presbycusis, changes in the inner ear that happen as you get older cause a slow but steady hearing loss. The loss may be mild or severe, and it is always permanent.
- Approximately 4,000 new cases of Sudden Hearing Loss (SHL) occur each year in the United States. Hearing loss affects only one ear in nine out of ten cases. Only 10-15 percent of patients with SHL know what caused their loss.
- For 60% of veterans returning from current combat situations the number one disability is hearing loss and tinnitus.
- Those with mild hearing loss are two times as likely to develop dementia, and this risk increases with the severity of the hearing loss.
- In older people, a hearing loss is often confused with, or complicates, such conditions as dementia.
- Depression and isolation are common among those with hearing loss.
- Men are more likely to experience hearing loss than women.
- High levels of cotinine, the chemical that indicates exposure to tobacco smoke and second-hand smoke, has been directly linked to higher risks of some types of hearing loss.
- Only one out of five people who could benefit from a hearing aid actually wears one.

Sources: Hearing Loss Association of America (HLAA), National Institute on Deafness and Other Communication Disorders (NIDCD) and Hearing Health Foundation

Do You Have a Hearing Loss?

You may have a hearing loss if you often ask people to repeat what they've said, give inappropriate responses, find that you can't hear in restaurants and other noisy situations, turn up the volume on your radio and TV, or find it more difficult to understand telephone conversations. Similarly, you may have a hearing loss if you don't hear your alarm clock, frequently mispronounce words, or don't hear or understand people who are not facing you. You may feel embarrassed or avoid meeting new people because you may not know what they are saying, or be frustrated because you believe people are mumbling or not speaking up.

Even a mild hearing loss causes communication problems, making conversation difficult. You may experience headaches, fatigue or irritability and isolate yourself from social situations. Not only will you be frustrated, but those around you may be angry or irritated at trying to make you understand. Your ability to deal with your loss won't get better by itself – **You must take action to compensate for your loss.**

Causes and Related Problems of Hearing Loss

HEREDITARY HEARING LOSS:

Hereditary Hearing Loss may be inherited from one or both parents who may or may not have a loss of hearing themselves. There are about 200 different types of genetic hearing loss.

MEDICAL CONDITIONS RELATED TO HEARING LOSS

Acoustic Neuroma: A non-cancerous, but dangerous, tumor developing on nerve strands that are very close to the inner ear. The size of the tumor can create pressure on other organs and can impact the ability to hear, leading to more profound hearing loss. There are different types of surgeries to remove this kind of tumor, but all usually result in substantial hearing loss or deafness in the impacted ear.

Autoimmune Inner Ear Disease (AIIED) or Autoimmune Sensorineural Hearing Loss (ASHL): A fluctuating hearing loss, usually on both sides, which is the result of an autoimmune disease such as rheumatoid arthritis, lupus, or polyarthritis. The patient's own immune system produces antibodies, which destroy inner ear cells and structures leading to hearing loss. This may also be referred to as ImmuneMediated Sensorineural Hearing Loss (SNHL).

Balance Difficulties: If your inner ear or specific parts of the brain are damaged by disease or injury, the vestibular system that helps control balance and eye movements may be impacted. The most commonly diagnosed vestibular disorders include Meniere's disease, infections of the inner ear, injury caused by head blows, endolymphatic hydrops and perilymph fistula. Other disorders include acoustic neuromas and allergic or autoimmune disorders. There are many different symptoms and many degrees of severity.

Hyperacusis: A painful sensitivity to sound, often a result of excessive noise, head injury, a side effect of some medications or head surgery. Although the person has normal hearing, the tolerance level for some hearing frequencies (low or high) is extremely reduced. See "Recruitment."

Meniere's Disease: A broad term covering a variety of symptoms caused by excessive fluid in the inner ear which impacts balance

and sometimes also the hearing system. The cause of Meniere's is not known, but is thought to involve viruses, allergies, circulation problems, or physical trauma. It can affect hearing in one or both ears.

Nerve Deafness: See "Sensorineural Hearing Loss"

Otitis Media (OM): Infection of the middle ear, which causes pressure on the eardrum due to fluid buildup. This causes temporary hearing loss. At times, the pressure builds up sufficiently to rupture the ear drum.

Otosclerosis: Caused by excessive bone-like tissue growing in the middle ear which prevents sound waves from entering the inner ear thus causing hearing loss. May be corrected with surgery.

Ototoxic Drugs: These types of drugs have the potential to cause damage to the inner ear structure and result in temporary or permanent loss of hearing. The degree of loss and the possibility for recovery depend on the amount and duration of the use of certain medications. Existing Sensorineural Hearing Loss (see below) can be aggravated by the use of ototoxic drugs. Some ototoxic drugs include antibiotics such as streptomycin, erythromycin, and vancomycin when given intravenously; some chemotherapeutic agents such as cisplatin, nitrogen mustard, and vincristine can also damage your hearing.

Presbycusis: This hearing loss is caused by the decline of working hair cells in the inner ear due to aging, exposure to loud noise or a genetic reason.

Recruitment: Involves hyperacusis, a painful sensitivity to sound (see above), even though a hearing loss is present. Besides not hearing certain sounds, sound can be distorted and uncomfortable.

Sensorineural Hearing Loss (Nerve Deafness): This most common form of hearing impairment is due to an abnormality of the inner ear, the auditory nerve, or both caused by a broad variety of reasons.

Tinnitus: With tinnitus one hears sound where there is no external physical sound present. People experience it as head noises or ear-ringing which may vary in pitch and may come and go or remain constant. There are many causes and it is often associated with hearing loss. Several forms of treatment (medical or surgical)

are currently available. All patients with tinnitus should consult an ear, nose and throat physician (otolaryngologist) before seeking any other form of treatment.

The American Tinnitus Association provides information, referrals and support for people who experience tinnitus (ringing in the ears and head noises). For information, contact <http://www.ata.org/>.

NOISE INDUCED HEARING LOSS

Repeated exposure to noise has caused approximately 15% (26 million) of Americans to lose part or all of their hearing (NIDCD estimates). One of the most frequent causes of hearing loss is Sudden Hearing Loss (SHL), usually in one ear, which can be caused by exposure to noise or viruses, although the cause is frequently unknown. This type of hearing loss is usually never recovered.

Such environmentally produced hearing loss has no medical or surgical treatment except for cochlear implants for those who are severely or profoundly impacted. But hearing aids, bone anchored implants, cochlear implants and assistive listening devices can be very helpful. We live in a noisy world.

Note: Exposure to noise at hazardous levels may not result in an immediate loss; the loss (damage) is cumulative across time.

*I believe in the power of the spirit.
The body may falter, but the spirit shines on -
Lighting the way to strength, courage and hope,
Just as the sunrise lights a new day.*

DECIBEL RATINGS/ HAZARDOUS TIME EXPOSURES OF COMMON NOISE EXAMPLES

(Source: Am. Academy of Otolaryngology)

- 0 Lowest sound audible to the human ear
- 30 Quiet library, soft whisper
- 40 Living room, quiet office, bedroom away from traffic
- 50 Light traffic at a distance, refrigerator, gentle breeze
- 60 Air conditioner at 20 feet, conversation, sewing machine
- 70 Busy traffic, noisy restaurant. At this decibel level noise may begin to affect your hearing if you're exposed to it constantly.

THE HAZARDOUS ZONE:

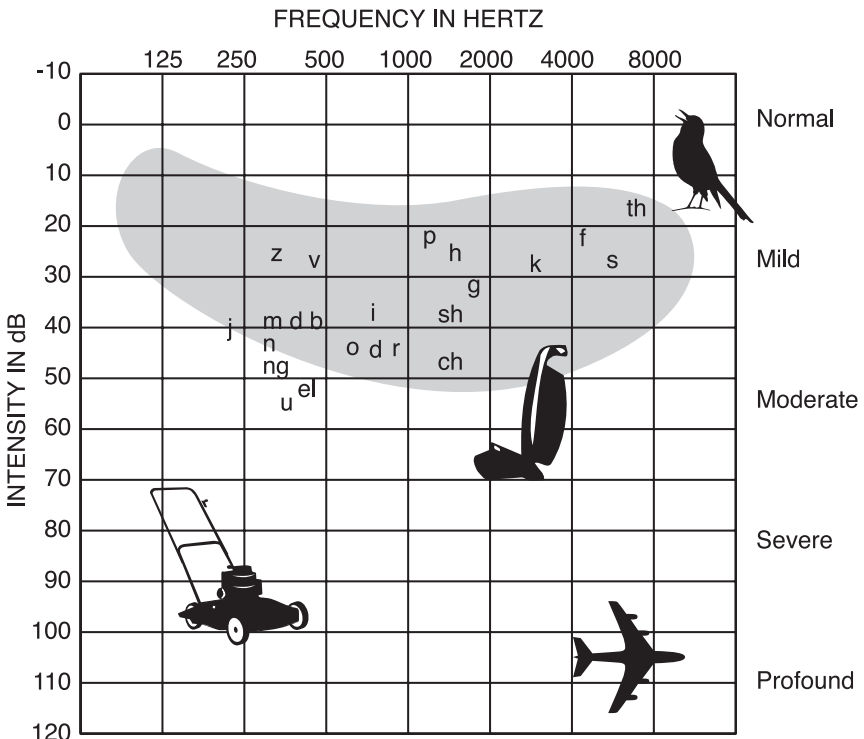
- 80 Subway, heavy city traffic, alarm clock at two feet, factory noise. These noises are dangerous if you are exposed to them for more than eight hours.
- 90 Truck traffic, noisy home appliances, shop tools, lawn mower, leaf blower. As loudness increases, the "safe" time exposure decreases. Damage can occur in LESS than eight hours.
- 100 Chain saw, stereo headphones, pneumatic drill. Even two hours of exposure can be dangerous at 100 dB; and with each 5dB increase, the "safe time" is cut in half.
- 120 Rock band concert in front of speakers, sandblasting, thunderclap. The danger is immediate: at 120 dB exposure can injure your ears.
- 140 Gunshot blast, jet plane. Any length of exposure time is dangerous; noise at 140dB may cause actual pain in the ear.
- 180 Rocket launching pad. Without ear protection, noise at this level causes irreversible damage. Hearing loss is inevitable.

Understanding Your Audiogram

Bewildered by your audiogram? Do you wonder why some people express hearing loss in percentages, while others express them in decibels (dB)?

Sounds can be represented on a graph that shows two different dimensions: pitch or frequency measured in Hertz (Hz) on the horizontal dimension and loudness or intensity measured in decibels (dB) on the vertical dimension. Loudness of “0” is the average of the faintest sound heard by a person with normal hearing (not the absence of sound) so a horizontal line from the “0” would represent so called normal hearing across all frequencies.

Letters in the shaded area of this graph show the pitch and loudness where individual speech sounds are normally heard. If your loss lies



1. Common sounds are shown to illustrate these two dimensions.
2. Audiologists use this chart (Audiogram) to map out the softest level at which you can hear each frequency.

below a portion of the shaded area, the sounds of the letters that are missed will define those sounds you will have difficulty discriminating. The consonant sounds needed to make fine speech discrimination are in the upper right (soft, high frequency) portion of the graph, the area where most hearing loss initially occurs and that is why speech discrimination is often the first thing that is noticed as high frequency hearing loss, the most common form, develops.

Audiologists use this chart to map out the softest level at which you can hear each frequency—the result is your audiogram.

For more details and further information check out the article “The Audiogram” by Mark Ross, PhD, in the May–June 2004 issue of the HLAA magazine (available at www.hearingloss.org/sites/default/files/docs/Ross_Audiogram_MJ04.pdf).

DEGREES OF HEARING LOSS:

Mild (25 to 40 dB): Faint or distant speech may be difficult. Lip reading can be helpful.

Moderate (41 to 55 dB): Conversational speech can be understood at a distance of three to five feet; as much as 50% of discussions may be missed if the voices are faint or not in the line of vision.

Moderately Severe (56 to 70 dB): Speech must be loud in order to be understood; group discussions will be difficult to follow.

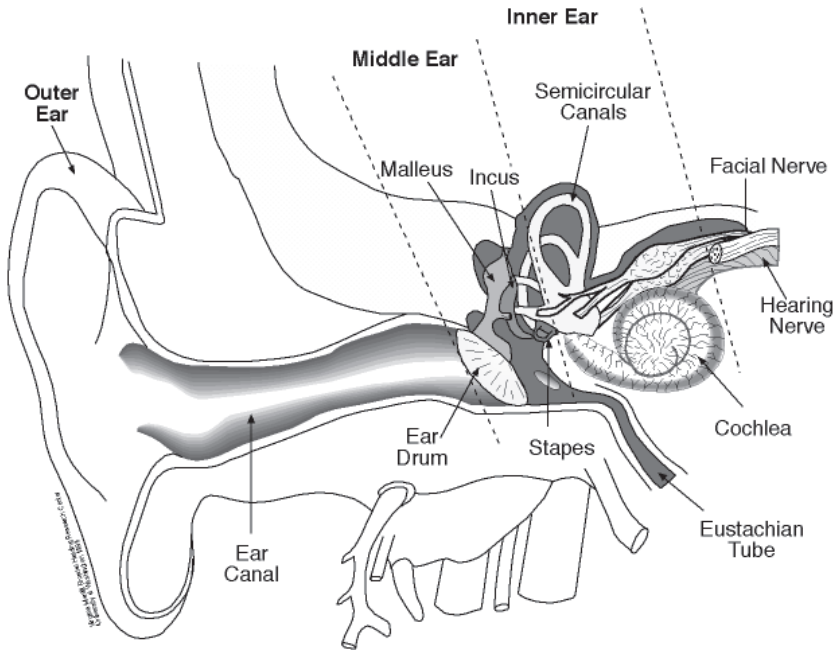
Severe (71 to 90 dB): Voices may be heard from a distance of about one foot from the ear.

Profound (more than 91dB): Loud sounds may be heard, but vibrations will be felt more than tones heard. Vision rather than hearing, is the primary avenue for communication.

How We Perceive Sound

In order for you to hear, sound must pass through:

- the outer ear - the visible portion of the ear and ear canal
- the middle ear – the eardrum and three tiny bones
- the inner ear – the fluid-filled, snail-shaped cochlea containing



thousands of tiny hair cells responsible for hearing and the labyrinthine system responsible for balance.

The outer ear collects the sound and directs it through the ear canal to the eardrum in the middle ear. The sound waves strike the ear drum causing it to vibrate and create a chain reaction in the three tiny bones of the middle ear. The motion of these bones causes movement of the fluid within the snail-shaped cochlea. As the fluid moves, the tiny hair cells lining the cochlea move back and forth. This creates an electrical current which stimulates the hearing nerve to carry the signal to the brain. The brain interprets this signal as sound.

If the hair cells are damaged or diminished, the ability to initiate the electrical impulses to the auditory nerve is affected and the message to the brain is not clear or not carried at all. Hearing aids often may help those who still have some healthy hair cells but for those with a severe to profound hearing and hair cell loss and who are unable to understand speech with conventional hearing aids, a cochlear implant may help. The cochlear implant bypasses damaged parts of the ear and stimulates the hearing nerve, allowing those who are profoundly hard-of-hearing or deaf to perceive sound.

What Are the Results of a Hearing Loss?

Helen Keller struggled with the challenges of being both blind and deaf. When asked about the difficulties of both and which was a more serious problem, she stated that when you're blind you lose touch with things, but when you're deaf you lose touch with people. Her hearing loss caused a separation from people because it was difficult to not only hear what people were saying but to perceive what they were thinking and feeling as well.

Even a mild hearing loss can cause communication problems as we go about our daily lives. A hearing loss makes it more difficult to learn new vocabulary and new language concepts and is a particularly difficult loss for children. The emotional impact can be greater if the hearing loss begins later in life. A hearing loss makes it difficult to participate in meetings, hear on the phone and communicate with those with whom we work or live. It can cause stress and friction among family and friends, especially when the loss is undetected or untreated. It places a hardship on everyone. Many studies have been made regarding the impact of hearing loss. To quote a few:

“The result (of acquired deafness) is limbo, a nowhere land, that few can feel as acutely as a recently deafened person who is not only suddenly ‘different’ but invisibly handicapped and prevented from easily communicating this feeling to others, deaf or hearing.” (Hunter, 1978 as cited in the HLAA Mental Health Committee Brochure)

“The natural environment of the progressively hard-of-hearing is that of the hearing world. It is the threat of becoming cut off from this familiar environment that produces all the reactions common to the emotion of fear. It is, for example, the fear of failure in career and the subsequent effects on the family. The fear of meeting new people. The fear of losing friends. The fear of being thought stupid or being misunderstood, and worst of all, the fear of becoming isolated. These are a few of the contributing facts which can lead to a possible withdrawal from society by the progressively deaf person.” (Cornforth, Woods, 1972, as cited in the HLAA Mental Health Committee Brochure)

Don't Hide Your Hearing Loss: the Truth May be Better Than What They Are Thinking!

When we can't hear or understand what is being said others may make incorrect assumptions about us. Because we don't respond, or respond inappropriately to what is being said people may think that we are unfriendly, incompetent, insensitive or just plain uninterested and can lead to your or others' embarrassment.

Better to let them know that you have difficulty understanding because you are hard-of-hearing and tell them things they can do to make communication better. And, if you are delaying dealing with your hearing loss make a bee-line to your hearing care provider because:

Once A Hearing Loss Is Detected,
Much Can Be Done.

Read On!

The Emotional Side of Hearing Loss

Frustration and Other Emotions

Hearing loss is difficult. We are constantly put in situations in which communication is difficult and we naturally become frustrated. We need to realize that the struggle to hear takes its toll. Each time we are faced with a situation that is difficult for us, we may feel any number of emotions: humiliation, anger, frustration, sadness, or discouragement. Even though we may be assertive and up front about our hearing loss, these emotions remain. We need to recognize how much it impacts our energy to be out there day in and day out, admitting our loss, making our communication needs known and facing obstacles.

When we ask someone to repeat what was said and they roll their eyes or their tone of voice tells us we are bothering them it hits us in our self-esteem. When we want to attend an event and we request an assistive hearing device or computer assisted communication, and the person in charge decides what we have requested is not “appropriate” and that something else will be provided instead without asking our opinion — this is very emotionally difficult.

Many things affect our ability to hear. Many hearing people do not understand that if they refuse to listen to us or tell us what we can or cannot hear, we feel devalued. When we ask people in meetings to take their hands down from their faces so we can lip read, or to have only one person talk at a time—and they remember for only a few minutes or until the next meeting—we need to deal with our feelings of frustration and discouragement.

Some days we are stronger than we are on others. We have the courage and strength to keep trying until the situation is straightened out. Other days we may want to simply crawl into bed and pull those covers up over our head. On our good days, we have the courage to take care of ourselves and acknowledge that being assertive takes energy and sometimes takes away from other parts of our life. We need to surround ourselves with people who understand, people with whom we can share our experiences, people who will help us remember that life is good and we are worth it. We need

people who can help us by listening and encouraging us.

And then there are some people in the world who “just don’t get it”...yet. And they won’t unless we continue to try to teach them. The fact is that hearing loss is not an easily understood condition. But we can learn how best to cope with it and then teach the world.

Grieving

Hearing loss is emotionally painful for many reasons. Our need to communicate is so constant, the situations and environments in which we need to hear are so varied, the support of others is so uneven, and technology, alas, can often break down so there is little respite from our loss. Thus, our hopes and expectations can be frustrated and we experience a myriad of emotions.

How do we deal with those times, and those feelings? Unfortunately, just as the behavioral skills for coping with hearing loss are not automatic, so the skills for dealing with these emotions are not instinctive, and need to be learned. The process of dealing with our lost hearing is one of “going through” stages of grieving. Mourning constitutes a set of behaviors and thoughts by which we can better move through those feelings of grief toward a will to adjust to the challenges of life.

Denial is usually the first stage of grief and is the result of the deep fear that hearing loss evokes in us. The mourning that we must do here is to work toward acknowledging that fear, and know that all human life fears the loss of health and happiness. We are not as alone as we think.

Anger occurs when we burst through the fear and demand of life that somehow, anyhow, we deserve happiness. The great Beethoven, in his response to his growing deafness, showed us how to do the mourning that moves us through anger. He presented his anger to the whole world, but he did it in beautiful ways. We can’t all be geniuses, but we can all find constructive ways to assertively voice our commitment to life.

Bargaining is a stage in which we acknowledge our disability in a halfhearted way, really still hiding, still in fear. We may, for example, buy and wear a hearing aid, but we hide it, and we don’t really help

others communicate with us. Here we need to intelligently analyze our situation, and be sure that we aren't doing ourselves a disservice, moving a step backward for every step forward.

Depression may happen when we finally stop hiding, and allow ourselves to experience the sadness of our loss. Sadness is natural, and is a healthy response. Mourning nurtures, even cherishes this sadness — when you don't fight it. It will gradually lessen on its own, allowing you to begin acting effectively again.

Acceptance and adjustment come when we consciously work to minimize the handicapping effects of the hearing impairment, and go forward doing what we must. After all, everyone is flawed, everyone is mortal, but life goes on.

Confronting Your Hearing Loss

CRITICAL STEPS

1. **Start Now!** Delays are costly! Waiting can make it difficult to regain some of the speech discrimination you have lost as your hearing ability has declined. Waiting poses a threat to your job security, and makes communication and relationships much more difficult.

2. **See Your Primary Care Physician** for an initial exam and a referral to an ENT (ear, nose and throat physician) if your insurance requires it. Your primary care physician can also give you a basic exam to determine if there are any conditions causing your hearing loss which can be readily treated such as wax in the ear canals or fluid in the middle ear. If you were told by anyone that you have “nerve deafness,” and there is nothing that can be done for you, seek another opinion—preferably from a physician who has expertise testing people with hearing loss.

3. **Then See an Ear Specialist** such as an ENT (ear, nose and throat physician or Otolaryngologist) or an Otologist who can check to see if your hearing loss is caused by a condition that can be treated by medical or surgical means.

4. **Consult an Audiologist/Hearing Care Specialist for an Audiogram.** Through a series of hearing tests, they will establish an audiogram for you that shows in visual form, a number of dimensions of your hearing loss. (*see page 7 for an explanation*) Audiologists

are highly educated and trained to determine the type and degree of your hearing loss, and whether you can be helped by a hearing aid (or aids), and what type of aid(s) would be best for you or your child. Check to see if the audiologist's title includes the letters CCC-A (Certified Clinical Competence—Audiology) which indicates certification from the American Academy of Audiology. They also should be licensed in the state.

Once you have an evaluation, you can then work with the audiologist who evaluated you or with a hearing care specialist. Hearing care specialists don't generally have post-graduate degrees in audiology and therefore cannot do diagnostic audiological services. However they do have practical experience in the fitting and selection of hearing aids. They must also be licensed by the state and may be certified by the National Board for Certification in Hearing Instrument Sciences (BC-HIS). Contact the State of Oregon Health Licensing Office (*see the Resources Section at the end of this manual*).

5. Get your Hearing Aids. Your next destination is the office of an audiologist or hearing care provider who will work with you to select, fit and modify the appropriate hearing aids to accommodate the special characteristics of your hearing loss. They'll also introduce you to the use of hearing aids and instruct you in their care and maintenance.

6. Consider a Cochlear Implant

if you can no longer benefit from hearing aids. (See page 26.)

For information on resources and cost of hearing aids, cochlear implants and similar devices, see page 22.

You're braver than you believe, And stronger than you seem, and smarter than you think.

—Christopher Robin
(Pooh's friend)

Hearing Aids, Cochlear Implants, Other Systems, and You

In order to get the best hearing acuity and speech understanding, it is probably obvious that you should work with your hearing care provider (audiologist or hearing care specialist) to select the most appropriate hearing device, such as a hearing aid or cochlear implant, for your particular loss. However, while your ability to hear and understand should improve noticeably, unlike what corrective lenses do for vision, these hearing devices *do not restore normal hearing*. Speech discrimination may still be difficult, especially in noisy situations. It takes time and practice for your brain to learn the new perceptual skills required to get the most from your new hearing devices. So have patience — wear them as often as possible and in different settings. With cochlear implants optimal results from this “brain training” can take several months of use and periodic readjustments (mappings). In fact, for some CI recipients continued improvement can take one or more years.

Choosing a Hearing Care Provider

Make sure you have confidence and trust in the hearing care provider you choose. They should spend time to help you find the right hearing device, schedule several visits to work with you for adjustments and to teach you how to use and maintain your hearing devices. They should also be available to provide warranty and other services for the life of the aid. In addition:

- Find out what program they have in place to teach you to use the aid or implant, and to communicate most effectively.
- Make sure the hearing care provider allows at least a 30-day trial period. This is the law in Oregon. This gives you time to “test drive” the aid, just as you would when buying a new car. And if you need to extend this trial period, be sure to get the extension agreement in writing. Some hearing care providers allow a trial period of 60 or more days to get the correct fit. Negotiate for the longest period you can!

- Check beforehand which fees are non-refundable should you need to return the aids. Typically, costs for testing, custom-fit parts, and/or ear molds, are non-refundable.
- Does the hearing care provider offer repair services for your model? Is a loaner available should your aid need repair?
- Select a hearing care provider who offers different brands and models of hearing aids: behind-the-ear, in-the-ear, and in-the-canal styles. There are many manufacturers and there is no “best” hearing aid just one that might be better for you.
- Consider the aid’s potential usefulness rather than its cosmetic appeal. Many people want the smallest aid available, but a small aid may not have the power or the features that you need to get the best results. **Don’t short-change yourself.** Be open to trying several styles of aids to see what difference they make.
- Make sure the hearing care provider takes time to ask about your listening needs in detail. Do you need to hear in noisy rooms? Do you use the phone a lot? Listen to young children? The selection of hearing aids depends on your degree of hearing loss, your listening needs, your dexterity, and your financial situation.
- Ask about various options available in hearing aids, such as a telecoil. For a small, additional cost, the telecoil enhances telephone use and allows you to use assistive listening devices in theaters, meetings, in noisy situations and with TV and stereo. (*See the next section for more information on telecoils*).
- Don’t be pressured into purchasing specific aids or aids you are unsure about. Seek a second opinion if you want more information or want to compare prices.

Good hearing care providers have a lot of creative solutions available: venting the ear mold, making it from different materials, changing the diameter of the ear tube or ear hook, and making adjustments to the way the hearing aid amplifies sound. They will spend the time to teach you how to maximize your use of the aids — including the proper use of the telecoil. Fitting a hearing aid is both art and science, so be prepared to work with your hearing care

provider to get the proper fit.

- If you need to file a complaint, please contact: State of Oregon, Health Licensing Office (HLO; formerly the Oregon Health Licensing Agency) at 503-378-8677 or e-mail hlo.info@state.or.us
- A Consumer Checklist for Purchasing a Hearing Aid can be obtained through your local HLAA chapter or online at www.hearingloss.org/ under “Support/Order Materials.”

A Word about Telecoils and Why They Are Important

A telecoil (t-coil, T-switch) is a very small coil of wire within the hearing aid that functions as an antenna when it is activated and picks up sound that is being broadcast as a magnetic signal. This will allow you to take advantage of a variety of devices that will help you build on the strengths of your hearing aid or CI and go a long way to solving some problems that hearing aids or CIs alone don't solve. The main problems they help with are hearing on the telephone, using a range of assistive listening devices (ALDs), and hearing the desired voice(s) in a large or noisy room.

When you activate your telecoils by moving a switch or pressing a button on your hearing device or on a remote control, the sound transmitted from your phone or your assistive listening device is amplified and background noise is significantly reduced or eliminated. In addition, with a telecoil in your hearing aid or CI you can take advantage of the assistive listening systems installed in many public facilities without first having to remove your hearing aid to use headphones or ear buds which may not work for any but the mildest hearing losses. Telecoils can be viewed as the foundation for getting results beyond those of your hearing device.

Except in a room that has a hearing or audio loop (where a loop of cable surrounds a designated area, usually a meeting room or auditorium, and which generates a magnetic field picked up by a hearing device fitted with a telecoil) you will need to use a neck loop to pick up and transfer the signal to your hearing device's telecoil. Many facilities do not provide neck loops or if they do the neck loops may not be strong enough for your hearing loss. Therefore it is a good idea to have a personal neck loop, preferably a powered

one, to bring along to use with the ALD's they do provide. A neck loop is not required when the area is equipped with an audio loop and you have a telecoil in your hearing device.

Some adjustment may be needed to get the greatest benefit from the telecoil. Experiment and ask your hearing care provider for advice on how to use the telecoil in your hearing aid or CI most effectively. For example, since telecoils are positioned differently in different hearing devices you may need to determine the best angle to hold the handset of the telephone with respect to your hearing aid, and you may need to increase the volume on your hearing aid when using it, and then **practice!**

Be sure you talk to your hearing care provider about the need to have a telecoil in your new CI or hearing aid or having your current aids retrofitted. It is also important to let them know the primary uses you will make of it which will determine the best position for the telecoils. A telecoil may add a small amount to the cost of your hearing aid, but the benefits far outweigh the cost. They are available in behind-the ear and in-the-ear hearing aids but, due to space limitations, often are not available for the smaller hearing aids.

If you hear buzzing or hum-ming when your hearing aid is on t-coil it could be caused by electrical interference from fluorescent lights, power lines, or your computer monitor. Try moving your head or sitting or standing in a different place to see if you can reduce the noise.

Hearing Aid Styles

There are different sizes and shapes of hearing aids to consider, and you need to understand the advantages and disadvantages of different styles. Different styles differ in function

as well as in appearance; in fact, smaller less noticeable hearing aids usually offer fewer programming options, features, user control, and less power. Therefore, it is very important to select the style of hearing aid that best suits you and your lifestyle.

Styles range from completely in the canal (CIC) which are the smallest and least visible of all types because they fit deep into the ear canal, to in the ear (ITE) which are in the outer ear, to the behind the ear (BTE) style which is worn behind the ear and connected to a soft ear mold that fits into the outer ear. The ear mold can either be open or at the other extreme completely closed to provide for more power without feedback. Within this range there are other styles and there are variations of these styles that offer even more user options.

The contrasts in function between CIC and BTE aids tell something about the functional capabilities within the range as well. Because of their size and location in the ear canal CIC aids are the least visible, are less affected by wind noise and make telephone use less awkward. At the same time, because of their small size and location, CIC aids have few if any programming options, less power and user controls, cannot accommodate a telecoil (*see the earlier information on telecoils*) and are generally considered appropriate for milder hearing loss.

A BTE aid has the greatest amount of flexibility for fitting, and for more functions like directional microphones, programming options like noise reduction and often has external controls to change listening programs and volume without removing the aid. BTE aids and their variations are generally used with losses from moderate to profound. Most of the BTE aids will be equipped with t-coils and those are often stronger and therefore are compatible with assistive listening devices, making them an attractive choice for many listening situations. The ear mold can be easily changed and changing batteries and inserting and removing the aid may be easier.

Hearing Aid Features

Hearing aids can have a number of important features and programming will fine-tune these features to deal with very specific problems and lifestyle needs:

Programming: Modern hearing aids are basically tiny comput-

ers that use a computer chip to provide features and programming capability used to modify the sound information to fit your specific hearing loss. Through programming, the hearing aid is capable of selecting certain sounds to be more or less prominent depending on the user's needs and preferences, suppress feedback, automatically control volume, and use directional microphones to make the desired sound, like the speaker's voice, more prominent.

Because sound quality and noise change over time and in different settings, many programmable hearing aids also have different programs that can be used for example, in noisy environments (like air conditioning, extraneous voices, and traffic noises). While these adjustments can occur automatically, manual controls are still helpful, for example with volume.

A hearing aid has **channels** and **bands**. Channels refer to the number of divisions of the frequency spectrum that are processed more or less independently by the hearing aid. Bands are used to adjust the hearing aid's amplification characteristics and for fine-tuning the hearing aid to address the wearer's loss and preferences. Especially for individuals with complex hearing loss, the **more** channels and bands, the better the sound quality in different situations.

Directional microphones provide hearing aids with a method of amplifying sounds to the front of the wearer compared to sounds surrounding the user. This is especially useful for improving audibility of speech in background noise such as in restaurants or large groups.

Feedback reduction technology helps prevent the annoying whistling that can sometimes happen when the sound from the hearing aid leaks back into the instrument's microphones.

Smartphone Applications are becoming readily available and can be used to provide a number of adjustments and functions to some manufacturers' hearing devices.

Choosing Your Hearing Aids

Because styles and features continue to change, and because these aspects affect your satisfaction with your hearing aids, it is important to spend a good deal of time with your audiologist or hearing care

provider to make this first decision. And of course it is important that your audiologist or hearing care provider have the different styles and feature options available for you to try.

A smaller aid is not necessarily better. You may need more power than the smaller aid can provide, and you'll definitely want to consider a telecoil to help you use the telephone and assistive listening devices (ALDs). Your audiologist or hearing care provider will help you decide what's right for you based on your audiogram, but the hearing of those with identical audiograms can be noticeably different and their best hearing aid and programming can differ greatly.

Be ready to try more than one model of hearing aid to find the best one for you. Negotiate the longest trial period (at least 30 days) return fee and warranty period and get a written contract—after a house and car, a hearing aid or two might be your greatest expense in a year! Ask your audiologist or hearing care provider if classes are offered to help you adjust to your hearing aid and cope with your other hearing needs.

Costs and Resources for Purchasing Hearing Aids

Hearing aid costs vary because of design and power, but none are inexpensive. Your hearing care provider will work with you to find the one that works best for you. The greater your loss and the more diverse the situations in which you need to hear, the more expensive your hearing aids are likely to be. Even though your hearing aids may be expensive, our advice is to get the best hearing aids for your loss that you can afford.

What about the cost? Medicare doesn't cover hearing aids and few insurance plans cover them entirely, although some plans will pay for the audiologist exam. Medicaid may cover one hearing aid every three years.

But there's good news! Today, there are a number of organizations that offer hearing aid assistance programs to help those in need. Most programs have income requirements that you'll need to meet to be eligible, and they all require a hearing evaluation by an audiologist, which in most cases you'll have to pay for yourself.

Here's where to look for help:

AARP

Hearing care program provided by HearUSA offering 20 percent savings on hearing aids and hearing healthcare products. Contact them at:

Website: <http://aarp.hearusa.com> or Phone: 800-203-7048

AUDIENT ALLIANCE

An affiliate of Sight Life (formerly the Northwest Lions Foundation for Sight & Hearing) and EPIC Hearing Healthcare. Candidates qualify for the program based on their annual household income.

Phone: 866-956-5400 X2 E-mail: hear@epichearing.com

Website: www.AudientAlliance.org/

BETTER HEARING INSTITUTE

Financial Assistance Guide; download helpful and informational resource guides.

Phone: 1-800-EAR-WELL

Website: www.betterhearing.org/publications/

SERTOMA

A civic service organization with a national mission for hearing health. They have compiled a list of organizations that have programs to assist disadvantaged individuals obtain hearing devices.

Phone: 816-333-8300 Website: www.Sertoma.org/

TRAVELERS PROTECTIVE ASSOCIATION OF AMERICA (TPA)

The TPA provides financial aid to people who suffer deafness or hearing impairment and who need assistance in obtaining mechanical devices, medical or special treatment or specialized education as well as speech classes, note takers, and interpreters. To contact or download an application:

Phone: 314-371-0533 Website: www.tpahq.org/

VETERANS' ADMINISTRATION (VA)

The VA offers hearing tests and hearing aids free of charge for most veterans. To find the nearest VA facility, check:

Website: www.oregon.gov/odva/benefits/

VOCATIONAL REHABILITATION

If you are employed or seeking employment, the State of Oregon's Vocational Rehabilitation may be able to help you obtain hearing aids and other assistive technology to help you keep your current job or become employable. To find your nearest office, check:

Phone: 877-277-0513

E-mail: vr.info@state.OR.US

Website: www.Oregon.gov/DHS/vr/

OTHER RESOURCES

Depending on where you live, other programs may be available to you. Check with your area aging agency (in Oregon: Aging and Disability Resource Connection of Oregon: ADRC - www.adrcforegon.org/ Phone 855-673-2372) or your state assistive technology agency (in Oregon: Oregon Technology Access Program: OTAP - www.otap-oregon.org).

Individual chapters of service groups such as Easter Seals, Optimists, Rotary, and Quota International may also be able to offer assistance.

Help! My Hearing Aid Has a Problem!

MY HEARING AID WHISTLES

- How well does your ear mold fit? If it is too loose the sound will leak out and feed back to the microphone. Ears can gain or lose weight and the mold may no longer fit snugly and need to be remade.
- Is there moisture or a break in the tubing?
- Is there wax buildup in the ear canal?
- Is there a crack in the hearing aid casing?
- Could there be fluid behind the eardrum?
- Has your hearing changed so that you are increasing volume to compensate?

MY AID SOUNDS “TINNY”:

- Too many high frequencies are being amplified.
- Ask your audiologist or hearing care provider about compression and reprogramming your hearing device.

I’M TALKING IN A BARREL:

- There may be too many low frequencies amplified.
- There might be too little venting in the ear mold.
- The ear mold may fit too deeply or be obstructed.

THERE IS TOO MUCH BACKGROUND NOISE:

- Background noise makes hearing difficult for most people. It is one of the most difficult problems for people who are hard-of-hearing yet hearing aids often seem to make noisy situations worse.
- Try turning the volume down so the hearing aid is not amplifying the background so much or you can use the directional microphone and noise program option on your hearing aid if you have them. You can also try moving closer to the speaker.
- Use an assistive listening device such as an FM system or a personal listening assistant to transmit the desired sound to your ears via an ear bud or directly into your hearing aid via the telecoil. Often a directional microphone works best in noise and the car.
- Programmable hearing aids often offer features such as multiple microphones, or a separate program that allows better understanding of speech in noise.

SOUNDS SEEM DISTORTED:

- You may have turned your hearing aid up too high and the sound is saturated. Get your saturation level checked.
- You may need a second aid to help you hear well.

- Your hearing aid may have gotten wet, or for other reasons, needs repair.
- You may need to put in a fresh battery.
- You may have also forgotten to turn off your telecoil.

What Should I Do With My Old Hearing Aids?

Most people replace their aids every 5 to 10 years, but it is handy to keep your old pair as spares to use when your primary hearing aids stop functioning and need service or repair.

If you have extra hearing aids that you don't want, contact your local Lions Club or Hear Now. Lions Clubs in Oregon work with local clinics to refurbish hearing devices. Hear Now/Starkey Foundation collects hearing aids for recycling purposes. Any make or model, regardless of age, can be donated to the hearing aid recycling program. All donations are tax deductible and a letter of acknowledgment will be sent to all identified donors.

If you wish to donate a salvaged hearing aid or other assistance device, please securely package donation and mail to: Starkey Hearing Foundation, ATTN: Hearing Aid Recycling, 6700 Washington Avenue South Eden Prairie, MN 55344; Phone 1-866-354-3254; e-mail: recycling@starkeyfoundation.org.

Cochlear implants (CIs)

If you have a severe to profound hearing loss or are deaf and receive minimal benefit from your hearing aids you are likely a candidate for a cochlear implant (CI) or other implanted device.

A CI is an electronic device that changes sound into electrical impulses and uses these electrical impulses to stimulate the auditory nerve. The damaged hair cells in the inner ear are thereby bypassed and the stimuli pass directly to the brain. The brain then learns to interpret and identify this stimulation as familiar sounds. A CI consists of several parts. Externally there is a microphone that picks up sound and sends it to a sound processor. The microphone/sound processor is worn on the head, body or behind the ear like a BTE hearing aid. Internally there is a receiver that is implanted under the

skin behind the ear. The internal receiver uses the electrical signals from the processor and sends them down a thin wire (electrode array) that is implanted into the inner part of the ear, the cochlea. The number of electrodes in the array depends upon the manufacturer.

Cochlear implant candidacy is determined by information gathered by an audiologist who has specialized in CIs. Because implantation is a surgical procedure, FDA has established criteria for implant eligibility which can be further shaped by the surgical service that will conduct the implantation. First the audiologist will administer several tests to obtain information about the auditory performance of the candidate, both with and without hearing aids. If the person meets the audiological criteria, he or she is sent to the surgeon to see if he/she meets medical criteria. The person will then undergo medical tests including an MRI and/or CAT scan to establish medical eligibility. During that time, the candidate will receive counseling about the risks and benefits of an implant.

Single cochlear implants are covered by some health insurance plans, Medicare, Oregon Medical Assistance Program, and the Veterans' Administration. In Oregon if an insurance company covers one CI they must cover a second assuming qualification under FDA criteria. Your surgical service will usually assist you in obtaining preauthorization from your insurance company.

Once the surgery is performed and healing is completed (usually about 3-4 weeks), you will meet with your audiologist, receive the external speech processor and related accessories, have the CI activated and receive your initial mapping,



Western Oregon
UNIVERSITY

REGIONAL RESOURCE CENTER
ON DEAFNESS

The Regional Resource Center on Deafness offers degree programs to prepare professionals to meet the unique communication, rehabilitation, and education needs of individuals who are hard of hearing, deaf, late-deafened, and deaf blind.

Please visit our Web site:
www.wou.edu/rrcd
or contact us at **503-838-8444**
or e-mail: **RRCD@wou.edu**

*Applications are generally due
mid-March each year.*

resulting in one or more initial programs. It takes a period of time for people to learn how to interpret some of the sounds from their implant. You will need to return to the audiologist several times the first year and occasionally in future years to update the settings in the processor, as your auditory system becomes accustomed to the implant and your brain “learns” more of the meaning of different sounds. Be patient!

Remember that each person’s results with a CI are unique depending on a variety of factors. Most recipients find the implant helps them hear environmental sounds, improves speech reading, helps them understand voices without looking at the speaker, and helps them monitor their own voice. Some CI users are able to enjoy music again and many are able to have full use of the telephone.

Many cochlear implant users find using assistive listening devices (ALDs) along with their cochlear implant very helpful in a variety of situations. Cochlear implants with telecoils work the same way as a hearing aid with a telecoil does and provides the same benefits for understanding on the telephone and in noisy environments and using a personal FM system or a personal listening assistant. Most CIs have an option to link with these ALDs using a special cable and some use Bluetooth to connect. A neck loop provides another option. If the room is outfitted with an auditory loop system, just your telecoil is needed.

Most clinics now do bilateral cochlear implants. The second implant can provide better hearing in noisy environments, enhance sound quality, and improve ability to localize sounds. Some also note that the quality of music is better and gives a stereo effect. The bilateral implant is used primarily when a hearing aid is no longer effective for the non-implanted ear.

The Food and Drug Administration’s (FDA) criteria for cochlear implants have changed over the years and will continue to change as implant and implantation improvements are made. At press time current criteria for cochlear implantation are as follows:

- People age 2 years and older with severe-to-profound deafness (i.e., pure tone average thresholds of 70 dB HL or greater), and
- Children 12 to 23 months of age with profound deafness (i.e.,

pure tone average thresholds of 90 dB HL or greater.)

- Whenever possible, outcomes from word and sentence recognition testing are also used to determine candidacy. Current guidelines permit implantation in adults with open-set sentence recognition scores of approximately 50% to 60% words correct.

As cochlear implant devices continue to improve, the criteria regarding the degree of hearing loss and the performance with a hearing aid that warrants consideration of a cochlear implant also will continue to evolve.

Medicare criteria are a bit more restrictive than the FDA. If you are Medicare eligible, the clinic can help you understand the differences in criteria. Each CI manufacturer has guidelines for implantation of their unit.

If you do not qualify as an implant candidate, you may want to check back with the clinic each year to see whether the criteria or your hearing has changed enough to qualify.

Contact the CI manufacturers below. They will also function as a resource for information on local clinics and doctors who evaluate and perform that surgery.

Advanced Bionics

28515 Westinghouse Place, Valencia, CA 91355

Customer Service: 877-829-0026

Email: info.us@advanced.bionics.com

Cochlear Americas

13059 East Peakview Ave, Centennial, CO 80111

Customer Service: 800-483-3123

Email: customer@cochlear.com

Med-El

2511 Old Cornwallis Rd. Suite 100, Durham, NC 27713

Customer Service: 888-633-3524

Email: customerservice.us@medel.com

Cochlear Implant Surgery: Making Choices

Once you have qualified for a CI, the next decisions will be choosing a Cochlear (CI) Implant brand, choosing a surgeon, and selecting the hospital where your surgery will take place. These decisions can happen in any order and for different reasons, for example there might be only one hospital within a reasonable distance from you and that could well dictate the selection of a surgeon or surgeons available to you. Or it may be the case that a hospital or surgeon does not accept an insurance, for example, Medicare. Similarly, the CI brand that you end up choosing may not be commonly implanted in your area and you may want to go farther afield to find a surgeon who has the most experience with that brand. Because the sequence of these decisions is dependent upon personal and local factors, they are not presented in any particular order.

CHOOSING A COCHLEAR IMPLANT BRAND

There are a number of information sources that can be used to help with the CI brand decision:

- **People** who have an implant.
- **HCAA chapters** are a great place to learn about others' experiences.
- **The three current CI manufacturers** available in the U.S. also have a panel of consumers who will consult with you and can be reached at:

Advanced Bionics www.advancedbionics.com
telephone 877-829-0026

Cochlear Americas www.cochlear.com
telephone 800-483-3123

Med-El www.medel.com
telephone 888-633-3524

The manufacturers' websites listed above are sources of information for their brand of CI.

- **Comparative Information.** While manufacturers' websites provide

basic information about their brand they don't always provide the information you need to compare brands. There are some websites that do provide comparisons that will be easily found using a search engine, among them <http://cochlearimplantonline.com/>.

- **Your CI Audiologist.** The CI-trained audiologist that you used to qualify for implantation should have demonstration models of the three manufacturers' devices to try for fit and be able to point out the different features of each brand.
- **Internet Listserves.** Internet lists are another way of getting opinions about particular brands. Keep in mind that there is great brand loyalty and nobody has the same experience with more than one brand: few have had 2 different brands implanted and most of these find that the experience differs very little. Where there is a difference in outcome there are other variables beyond brand: different nerve quality, different times of implantation, and so on.

CHOOSING A SURGEON

Your insurance may dictate which surgeon you need to use to get coverage. Although Medicare covers much of the cost of implantation, not all surgeons or hospitals accept Medicare. But if you have a choice of surgeons, you can find out which has had the most, or significant, experience implanting the device you have chosen. Some surgeons may have a preference for a particular brand because of their training or the outcomes they have observed. This information may be enough for you to make the final decision regarding both the device and surgeon you use.

OTHER THINGS TO KEEP IN MIND

- You may have to go out of your area to be implanted in a particular CI center only to find out afterwards that there are no audiologists in the area where you live that have the equipment or experience to program the device which you chose. As a result, you will be forced to travel farther than expected for mapping and programming but try not to let the inconvenience of travel keep you from getting your CI programmed as often as you need it.
- The CI manufacturers and the hospital you choose can help you determine the extent to which Medicare and/or private insurance

will cover the CI device and implantation surgery.

- Most people struggle when making the decision for a particular brand of CI but once the decision is made, most are happy because the results are life-changing.
- Cochlear implants are speech processors and since understanding speech is so important to communication and participation in all aspects of social life, it is, and should be, on the top of the list of things accomplished by your CI. Anything beyond that is an added benefit to be cherished and enjoyed.
- What you hear with a CI may not sound normal, at least at the beginning. Instead what you may hear is an electronic or synthetic sound as part of speech sounds. Over time, this electronic sound becomes more and more normal as you use your CI for everyday listening.
- Everyone's experience with a CI is different. Many people may experience understandable sound when their CI is activated or it may take weeks. Keep in mind that your brain needs time to learn what you are hearing so keep your expectations and your hopes in balance: it does get better! Very few people report no improvement at all. Patience, patience, patience.
- Your job is to make the decision of which type of CI you want for yourself or your child. Once this is done, don't look back or let others try to tell you that your decision is wrong. You have made the decision that is best for you.

(NOTE: Some of the above information has been adapted from "Making the Choice," a post by listowner Alice Adams on CI Hear)

BAHA AND HYBRID SYSTEMS

There are two other types of hearing device system technologies on the market: Bone anchored hearing aids (BAHA) and hybrid systems.

BAHAs are used when the cochlea is healthy. They work by using bone conduction to bypass the damaged outer and middle ear, sending sound directly to your healthy inner ear.

The Hybrid system developed by one manufacturer combines ear

acoustic amplification via a hearing aid to improve the low-frequency hearing while also using a cochlear implant to provide the high-frequency hearing that is missing.

Together, these two technologies give a more complete hearing experience than either together. Both these technologies require specific remaining hearing capabilities.

Two Aids or CIs, Or a CI and an Aid, Are Often Better Than One

For many people, it is beneficial to wear two hearing devices. Consider:

- The clarity and accuracy of the message will be optimized by the brain.
- Optimum hearing and processing of information occurs when we use both ears and the brain between them! Using two hearing devices provides greater efficiency and clarity than just one aid because the brain needs less volume for understanding. This makes loud sounds less annoying, listening is less stressful and your ears are better protected from excessive amplification.
- Safety increases because you are better able to determine from which direction a sound is coming with two hearing devices.
- You'll avoid being unintentionally rude due to the fact that single-sided listeners tend to ignore someone speaking into their "deaf" ear while the good one is listening to other things.
- Auditory synergy is an advantage because the right side of your brain functions differently than the left. When the two can operate together, it helps auditory intelligence.
- Hearing in noise ranges from difficult to impossible with only one good ear. Together the blended voices can often be converted to a collection of one distinguishable voice.
- A person with a hearing loss in both ears who wears a hearing device in only one ear loses much of the ability to recognize speech

in the other ear. This is called auditory deprivation. For many people, it is beneficial to wear two hearing devices. Binaural amplification is crucial to the development of speech and language skills in children who have a loss in both ears. Two ears really are better than one. Wearing two hearing devices doesn't make sounds twice as loud, but with two the brain has more information to help you hear and understand.

Learning To Use Your New Hearing Devices

Adjusting to a new hearing device takes time, determination and patience. Some people react differently. Your age, the severity of your hearing loss and your acceptance of the need for a hearing device may strongly influence your reaction to hearing with amplified sound.

Adjusting also requires practice and an application of common sense. Do not expect perfection. People often think they can put on the devices, walk out of the office, and hear perfectly again. The reality is that once you've gotten your device, your work has just begun. Here are some tips for adjusting:

- Take advantage of hearing rehabilitation programs offered by the major hearing device manufacturers. Programs can be accessed or ordered from websites. These programs help you with speech discrimination, music appreciation, and hearing on the telephone.
- Use the hearing device first in your own home environment. Your hearing device amplifies noise as well as music or speech. You may be disturbed temporarily by background noise. Concentrate on listening for all the normal household sounds and try to identify each sound you hear. Once you can identify background noises, such as the hum of the refrigerator, the roar of an electric fan, the clink of the dishes or the slam of doors, these noises will tend to be less annoying and distracting to you.
- Get used to manipulating your devices by inserting and removing them, changing the battery, adjusting the controls, etc. in the relaxing environment of your own home.
- Accustom yourself to the use of the hearing device by listening to

just one or two other persons in a quiet setting—friend, spouse, or neighbor. Talk about familiar topics. Use common expressions, names, or a series of numbers for practical purposes. Then try watching television and reading aloud to yourself. Involve your family. Let's face it: we don't really wear hearing devices simply because we want to hear better. We wear them because we want to improve communication with our friends and family. It's all about relationships. Relationships are probably one of the main reasons you got your hearing device in the first place.

- The importance of listening carefully and concentrating on what is being said cannot be overemphasized. But don't worry if you miss an occasional word. People with normal hearing miss individual words or parts of sentences and unconsciously "fill-in" with the thought expressed. You'll need to become even more visually attuned—intently observing facial expressions and body language (speech reading) in order to pick up clues about what is being said. By keeping your eyes on the face of the speaker, you'll find speech reading to be a great help as a supplement to the hearing device.
- Increase your adaptation to volume. At first, hearing device wearers tend to be displeased with the volume of sound in different situations. Experiment with different volume settings or programs to get an optimal volume. And remember: sounds that seem too loud at first become more comfortable with time so don't set the volume control at a level too low for efficient listening.
- Gradually increase the number of situations in which you use your hearing devices. After you have adjusted fairly well in your own home to background noise and to conversation with several

*To find a Real-Time Captioner or
CART Provider visit our website.*

WWW.ORCRA.ORG

O	C
R	A

**OREGON
COURT
REPORTERS
ASSOCIATION**

people at once, you'll be ready to extend the use of your hearing devices to the supermarket, house of worship, office or other public places. Turn the volume low to reduce the impact of unfamiliar background noise. Experiment with adjusting volume and, if your aid is programmable, try changing programs in different situations.

- Use the aid's telecoil (t-coil or -switch) with the telephone and see if it helps you hear on the phone. You'll need to experiment with the position of the telephone handset on your ear, since the location of the T-coil switch varies from model to model. Some older telephones may not be hearing-aid compatible. Getting used to the placement of the telephone and getting used to listening in this manner requires practice. Ask a friend or family member to practice with you.
- Keep a written record of your experiences so you can tell your hearing care provider how you've done when you return for a follow-up visit. This is important. The more accurate and specific you can be in telling what works or doesn't work for you, the better help you will receive.
- Sometimes with hearing aids, the ear mold or hearing aid case can be irritating. If yours is, go back to your hearing care provider and ask to have the ear mold or tube adjusted. If you experience an allergic reaction to the mold or casing, ask for them to be re-made using hypo-allergenic material.
- Have patience. Your brain needs time to learn to interpret the new sounds it hears. You need time to become comfortable with the aids.

Caring For Your Hearing Device

Your hearing device is an electronic appliance like a radio, cell phone or digital watch. It needs a battery to work and requires regular maintenance and cleaning. Treat this costly investment carefully and with respect.

The two most common causes of hearing aid problems are earwax and moisture. Earwax can obstruct tubing from the microphone or the vent. Use the tools you received with your aid to clean it daily and get tools if they weren't supplied.

For most hearing devices, moisture is the cause of significant damage to the mechanical and electronic components and for hearing aids, obstruct sound from passing through the tubing. Whenever possible, do not expose your hearing device to moisture, including perspiration, the shower, heavy rain, hot tubs or swimming. When you are not wearing your hearing devices, store them in an airtight container that contains a drying agent (desiccant). Remove the battery to avoid possible corrosion of the battery contacts.

To clean the battery contacts use a cotton swab with a little rubbing alcohol. Battery doors break now and then and new ones are easily installed by your hearing care provider. Hair spray clogs microphone openings and discolors the shell casings. Turn the instrument off when it is not being used. If it is not used for a few days, remove the batteries and store them separately.

Disposable batteries need to be replaced fairly frequently because they function constantly and must power the hearing device's circuitry and microphone. You can use a battery checker, available from most hearing care providers to see if you need to change the battery. Many hearing devices now give warning "beeps" that only you can hear to let you know that the battery is low and needs changing. Always open the battery cover at night to allow moisture to evaporate and prevent battery power drain. Keep batteries handy so you can replace one that goes dead.

Hearing Assistive Technology (HAT)

ALDs, Captions, and Other Technologies That Make A Difference

Current models of hearing devices (hearing aids and CIs) use programming and specialized circuitry to reduce environmental noise relative to the desired sound (for example, speech). Even then, hearing devices by themselves are not successful in all environments. Hearing assistive technology (HAT) increases the effectiveness of hearing devices or substitutes a visual signal for the sound signal.

Assistive listening devices (ALDs) or systems can improve on the advanced technology of your hearing device by making the desired sound more understandable in suboptimal listening environments. ALDs do so by effectively reducing the distance between the listener and the sound source, reducing competing noise, and diminishing the effects of poor room acoustics. Some examples of ALDs are given below.

- ***Auditorium Type Listening Systems.*** Many auditoriums and theaters, places of worship, and other public places are equipped with special sound systems for people with hearing loss. Essentially, they consist of a transmitting system which uses FM, infrared or electromagnetic energy (auditory loop systems). These systems, loops in particular, must be used with a telecoil or a specialized hearing device. FM and infrared systems can be used with or without a hearing device but require using headphones or earbuds.
- ***Personal Devices or Systems.*** Many types of assistive devices are available to an individual to enhance understanding in noisy environments. Personal FM systems are great for understanding a speaker who wears a microphone and FM transmitter while the listener has the receiver fitted with headphones, earbuds or a neck loop. Other devices transmit the speaker's voice to the hearing device using Bluetooth technology. Many brands of hearing aids offer "streamers" which are worn around the neck and communicate with the hearing aid via Bluetooth or electromagnetic energy and allow you to control sound volume and quality from the TV, telephone or companions.

- **TV listening systems.** These are another personal listening device that give the user control of the volume, and perhaps tone, of sound from TV, radio, or stereo. When using a listening system, the hard-of-hearing person does not need to turn up the volume, which makes others with little or no hearing loss uncomfortable. There are also hearing loops that can be placed in a room or under a cushion on your seat and connected wirelessly or wired to your TV or stereo.

Signaling or Alerting Devices. Besides ALDs there are other categories of hearing assistive technology that substitute a visual signal for sound so that a ringing telephone, smoke or CO2 alarm, burglar alarm, alarm clock, baby alarm or a door knock can use a flashing strobe light to get your attention. These devices accomplish more than making every day sounds noticeable. They can reduce the feeling of vulnerability hard-of-hearing or deaf individuals can experience when cut off from signals of danger.

Captions. Captions translate voice and other sounds to text that is displayed on the television or other video screens. Televisions, 13 inches or larger, built for sale in the US since 1993, have a built-in decoder chip that can display the text of dialogue and sounds in the form of captions for TV programs and DVDs (if the program has been encoded). As a result of recent lawsuits, major movie theaters are now required to offer captions as they convert to digital projection. Captions are displayed on individual viewing devices such as special glasses or an individual display anchored in a cup holder and fixed to a gooseneck that can be positioned in the viewer's line of sight.

Thanks to the Twenty-First Century Communications and Video Accessibility Act (CVAA) protections people with disabilities are enabled to access broadband, digital and mobile innovations -- the emerging 21st century technologies for which the act is named. Much of the act requires that information or programming available on the internet is accessible to people who are hard-of-hearing—that is, it must be captioned.

Captions can also be made available for live presentations or performances. Realtime captioning (CART) is a service provided by court reporters who have training and experience in realtime captioning. The captioner, while listening to the speaker or performer, uses a

stenographic machine which is connected to a computer which, in turn, translates the stenotype shorthand into English. The translation is then displayed as captions on a computer monitor, TV screen or large wall screen. In that way, hard-of-hearing people can read the captions and enjoy live performances.

Realtime captioning can be used in any situation where verbal communication is needed. Some examples where realtime captioning is used are group meetings, athletic events, legislative hearings, lectures, workshops, classroom settings, court proceedings, advisory councils and board meetings.

Telephone calls can be captioned as well. These special telephones operate just like a regular phone in that you can hear the caller's voice and also talk into the receiver, but the caller's side of the conversation is translated to text that is visible on a small screen. Captioned telephones usually require a telephone landline service and an internet connection, and are also available for a phone, tablet, and computer.

(In Oregon amplified phones are available free on loan from the State of Oregon's Telecommunication Devices Access Program (TDAP) to qualified individuals; see the Resource Directory for providers and vendors).

OTHER ACCOMMODATIONS.

E-mail is a wonderful communication tool, especially for those of us who are hard-of-hearing. It requires a computer with an internet connection but one does not have to be very computer literate to use it. When using the phone is difficult, e-mail is a great way to keep in touch.

Amplified Telephones and Telephone Amplifiers. There are small amplifying devices available that are attached to a corded phone and have adjustable volume and, in some cases, tone control. In addition, special amplified phones are available through some of the vendors listed below. (In Oregon amplified phones are available free on loan from the State of Oregon's Telecommunication Devices Access Program, TDAP, to qualified individuals.)

OTHER INFORMATION.

If you are considering assistive listening technology, check with your hearing care provider and other vendors who specialize in this type of technology for help in determining which device is best for you. You can also contact HLAA for more information:
www.hearingloss.org/content/hearing-assistive-technology/

An excellent presentation of assistive listening technology can be found at:
www.wou.edu/education/sped/wrocc/demyst_files/frame.htm

Catalogs or webpages for vendors are a great way to find out about different options that might help you. A sampling of hearing assistive device sources is listed below. Additional vendors can be found at www.wou.edu/wrocc/

GENERAL TECHNOLOGIES

3806 Security Park Drive, Rancho Cordova, CA 95742
Phone: 800-328-6684; email: devices4less@hotmail.com;
website: www.devices4less.com/

LS&S (LOW VISION AIDS)

145 River Rock Drive, Buffalo, NY 14207
Phone: 800-468-4789; email: LSSinfo@LSSproducts.com;
website: www.LSSproducts.com/

HARRIS COMMUNICATIONS

15155 Technology Drive, Eden Prairie, MN 55344
Phone: 800-825-6758; email: info@harriscomm.com;
website: www.harriscomm.com/

CLEAROUNDS

1743 Quincy Ave., Unit #155, Naperville, IL 60540
Phone: 800.965.9043; email: info@clearounds.com,
website: <http://www.clearounds.com/>

WILLIAMS SOUND

10300 Valley View Road, Eden Prairie, MN 55344
Phone: 800.328.6190; website: www.williamssound.com/

Telephones, Cell Phones, Smartphones And You

CHOOSING A TELEPHONE:

For many people with a hearing loss it is often hard to hear well on the telephone. But there are at least three ways that using the telephone can be made easier by using your telecoil, amplification and voice-to-text.

First, take the time to check out different telephones because not every phone will work for everyone: some have better sound quality than others. Beyond that, use your telecoil! First, you have to activate your telecoil, either by switching from “M” (microphone) to “T” (telecoil) on your hearing device using either external controls (a remote) or automatically depending on how your device is equipped. Because all standard telephone receivers come with a built-in amplifying coil, with the telecoil activated, the caller’s voice is clearer and unaffected by background noise and feedback. (See page 18 for more information about the telecoil.)

You may need to turn the volume up on your hearing device when you switch to telecoil mode. Furthermore, because telecoils are positioned differently in different hearing aids or CIs, and are not usually located where the microphone is located, try holding the telephone speaker in different positions close to your hearing device until the sound comes in clearly.

Amplification can make understanding on the telephone easier. There are small amplifying devices that are attached to a corded phone and have adjustable volume and, in some cases, tone control. In addition, special amplified phones are available, and in Oregon amplified phones are available free on loan from the State of Oregon’s Telecommunication Devices Access Program (TDAP) to qualified individuals. (See the TDAP’s address and phone number in the Resources Section.)

If you can no longer use the telephone due to the severity of your hearing loss, different methods of translating the caller’s voice to text are available. Text telephones (TTYs) and Telephone Relay Services are good options. A TTY looks much like a typewriter keypad with a text screen. It allows a hard-of-hearing or deaf person to make

a telephone call by reading the conversation on a lighted display screen and/or a paper print-out from the TTY. The relay service uses a special operator and allows a person who uses a TTY to call someone who uses a standard telephone and vice versa. You can also request a TTY as a free loaner phone from the State of Oregon's Telecommunication Devices Access Program (TDAP) if you qualify.

Because of their effectiveness, ease of use and increasing accuracy, captioned phones are gaining in popularity. These phones function like regular phones, but besides hearing the caller's voice (and you can use your telecoil and amplify the speaker's voice) the caller's words are displayed on a screen for you to read. At least two captioned phones are available to make and receive captioned calls. If you qualify, one phone is loaned free from the State of Oregon's Telecommunication Devices Access Program (TDAP), or you can purchase one from a vendor. These captioned phones usually require that you have a telephone land line and an internet connection.

Other options available to you are VCO (voice-carry-over) telephones that function somewhat similarly to the captioned phone. There are also a variety of internet relay services where you can log onto your computer to connect to the relay service which displays word-for-word captioning on your computer screen and, using your cell phone, allows you to speak and hear the caller. This service is provided by several carriers. In order to use an internet relay service you need to have cellular phone service and, of course, a computer.

Other communication options using your computer or cell phone are texting and instant messaging functions.

CHOOSING A CELL OR SMARTPHONE:

For hard-of-hearing users, the ability to understand conversations on a cell phone is probably the most important consideration. Although still not easy, choosing a cell phone that works for you is made easier by the M- and/or T-rating that is required for some phones.

The M-rating refers to the microphone mode of your hearing aid and designates phones with radio frequency levels that are less likely to interfere with a digital hearing aid. An M4 rating is considered best.

T-ratings designate the capability of the phone to link with a hearing

aid that is set to telecoil and to avoid electronic noise and feedback. Phones with a T4 rating are considered best when using a cell phone with hearing devices on the telecoil setting. One more reason to get a t-coil!

Theoretically, choosing a cell phone with a M4/T4 rating should guarantee that you will hear better with that phone than with one that has lower ratings or without ratings at all. But like many technical specifications, the M- and T-ratings only tell part of the story. Each person, even those with identical audiograms and trying to use the same phone, will probably hear the caller's voice differently. With that in mind, when choosing a cell phone it is best to try a number of them rather than to, say, order one online without trying them out. You might even try phones without M and T ratings, before you decide to buy. And don't forget, there are a number of assistive devices, like powered neck loops, even neck loops with Bluetooth wireless, to help you hear optimally on your cell phone.

Smartphones are increasingly offering applications to provide captioned calls so if captions are likely to make a difference to you. See what applications are available when you are ready to buy and consider that feature along with the M- and T-ratings.

It takes some effort to select the phone that will work best for you, but that effort is well worth it.

Sometimes our light goes out; but then is blown into flame by an encounter with another human being. Each of us owes the deepest thanks to those who have rekindled this inner light and to remember that we can be the light for another.

—Albert Schweitzer

General Coping Skills and How Technology Can Help You

Those of us with hearing loss sometimes forget how difficult it is for others to understand our hearing loss or remember how best to communicate with us. But it's self-defeating to think others don't care. Even our family and our best friends will forget from time to time – sometimes just because they're so excited and interested in the conversation that they don't think about how it's coming across to us. We think they're mumbling; they think we're not paying attention. We think they're talking too fast; they think we're really slow on the uptake. We notice they are walking away before finishing their statement; they think we can still hear them talking.

We must try to remember that the hearing world really does not know that, unlike glasses, hearing aids and cochlear implants do not correct, they merely AID, they do NOT restore normal auditory function. We must keep in mind that others may not comprehend the importance of, for example, maintaining visual contact with the speaker because we depend so much on lip- or speech-reading.

As another example, even those with whom we live, may not understand that our ability to hear can depend on the time of day, how we are feeling, or our surroundings. People may mistake our lack of instant response for indifference or even consider us a bit dull, not knowing that it takes time for our brain to sort and process the somewhat muddled sound we receive.

All this means that we must educate our friends, family and coworkers – and enlist their help –sometimes repeatedly, but in a manner that does not alienate them. That calls for considerable finesse, a good sense of humor, and patience, patience, patience!!

Making Speech Understandable in Difficult Settings

Many of us can have trouble understanding speech even under ideal conditions, and we frequently find that even the best technology and programming of our hearing devices does not totally help when we are trying to separate speech from the environmental noise surrounding us. Whether from an air conditioner, our car, other voices,

traffic or a restaurant kitchen, these noises mask speech sounds and hearing aid or CI technology is often not enough to deal with the problem. As a result, when we go to a public lecture, a concert or a play, have dinner with a group of friends, serve on a jury, attend a house of worship, go to class, have a restaurant meal or attend an athletic event we are often unable to understand speech.

BEHAVIORAL COPING METHODS

When you started having trouble understanding speech you might have developed some behavioral coping methods without thinking about it. Examples include:

- choosing a quieter restaurant;
- sitting where you have a good view of others' faces;
- using a round table for meetings;
- asking people to speak one at a time;
- checking with others to be sure you understood correctly;
- asking people to speak clearly and slowly or
- sitting with your back to a window so that the light doesn't interfere with your ability to read lips or speech read.

In some cases you can modify the environment to make it better for understanding speech. For example, area rugs, window curtains or carpeting, padded chairs and table cloths as well as tapestries as wall hangings help to keep sound from reverberating (echoing) and interfering with our ability to understand.

Providing written material is also helpful, even when technological solutions are provided. Scripts of plays, the bulletin for a house of worship or a lecture outline are examples of handouts that can aid people who are hard-of-hearing or deaf.

Here are some specific examples of behavioral coping strategies that are often helpful:

- Try to be no more than 3-6 feet away from the speaker. That is

about as far as most hearing aids can pick up sound. Keep your head turned toward the speaker because most aids pick up sound best from the front. Tap or cup your ear as a cue for the speaker to speak up.

- Let people know that you have a hearing loss and ask them to help by speaking a little more slowly, by moving hands away from their faces, and by not smoking or chewing gum. Ask them to get your attention before speaking to you. If they are speaking too softly, ask them to speak more loudly but not shout. Ask them to be patient, and maybe to state the topic of conversation, if there's been a change from Aunt Hattie's big toe to the football scores.
- Using vision to speech- or lip-read is very important to help with understanding speech. It is estimated that people with normal hearing receive 25% of their information visually, and it is even more important to us, the hard of hearing. Therefore, face the person with whom you're conversing so you can see his/her lips and facial expression and observe gestures. Also, ask the person to move so the light from the window shines on their face – not on the back of their head.
- Move away from, or turn off, background noises such as a fan, TV, radio, washing machine, dishwasher, or air conditioner. These make it more difficult to hear because you can't separate those sounds from the speech patterns you want to hear.
- You won't always understand everything that is said but don't bluff. Repeat what you think you heard to confirm that you got the message correctly. Ask questions that are specific if you miss something: don't just say, "What?" but ask, "Who were you talking about?" or "When did you say we would meet?" The speaker may become frustrated if constant repetition is needed, so try to keep your requests for repetition or verification in the context of a conversational exchange.
- Use a pencil and paper if needed to confirm a date or verify a name. This may seem embarrassing, but it's better than missing necessary information.
- Don't forget that there is a slight delay while your brain processes

sound and tries to make sense of it. We'll often ask, "What?" just a second before we actually understand what has just been said. Wait a bit before responding so the brain can process the information received.

- Also remember that listening requires a great deal of energy. Try to accomplish the most important things that require listening earlier in the day. Arrange for breaks in a long conversation.
- Thank speakers for helping you. If you always complain that they don't remember your needs (and they won't) they will avoid talking to you.
- Use humor. Lighten up. If the other person had the hearing loss and you did not, would you always remember to help? Be patient with others and with yourself. If you take things personally, everyone loses.
- **Wear your hearing aid!!** It does no good in your jewelry box or sock drawer.
- Use Assistive Listening Devices (ALDs). (See the chapter on Hearing Assistive Technology for examples.) Keep batteries handy so you can replace one that goes dead.
- Use e-mail, a fax, an answering machine, and/or Caller ID. All of these are great helps and can be used in lieu of or in conjunction with a telephone. But when you do use the telephone, especially when you use it for business purposes, be sure to state that you're hard-of-hearing and how the other person can help you hear. Often, though certainly not always, those on the other end of the line will try to help by speaking more distinctly or turning up the volume on their handsets.
- And be sure to explain to family and friends that this is not just YOUR hearing loss, it is OUR communication problem and they have to deal with it too. Everyone needs to work together to make it easier for the hard-of-hearing person to understand and for communication to be clear.

PERSONAL TECHNICAL SOLUTIONS

Personal Technical Solutions to help with understanding speech are becoming more and more available and too numerous to list here in detail. Whether the method used to transmit the speaker's voice to you is a hand-held personal listening device with an integrated microphone or an FM or Bluetooth device, the principles are the same:

- effectively reduce the distance between you and the speaker, and
- eliminate or reduce background and interfering noises.

For gatherings at a table, like meetings or meals, special microphones can be placed in the center of the table which allow you to use a personal FM system and make it easier to understand everyone. Similarly, there are Bluetooth devices where the detachable microphone and transmitter are placed on the table and the receiver with an integrated neck loop is worn by the listener. This set-up feeds the sound to your hearing device as if it were equipped with a telecoil.

There are also devices to make speech and music from a stereo system or television easier to understand. You can purchase such devices from specialized vendors or catalogs, which include small area loop systems that can be installed in your home, on a chair or the area surrounding your chair.

There are telephones that translate the caller's speech to text (captions) on a small video screen built into the phone as well as providing voice amplification (see p..... for more information on telephones)

NOTE: For more helpful information see also the section in this chapter on Helpful Technology in Public Meetings and the chapter on Hearing Assistance Technology.

Making Public Meeting & Meeting Places Accessible

Imagine attending a public meeting and not being able to hear what the presenter or other participants are saying. Public gatherings and meetings can be very frustrating for people who wear hearing aids or cochlear implants. When people cannot hear in large meetings or presentations, they often decide to stay home and not attend or

participate, and then they feel left out. This should not be the case because affordable practices and technology exist to make public spaces user-friendly for the hard of hearing.

GENERAL TIPS:

Many of the coping skills, suggestions, and technological tools described earlier are also very helpful in public meeting places. In addition, for large public meetings, the following are very helpful:

- Padded seating, carpeting and drapes all help with acoustics.
- Seating arrangements are crucial to facilitate speech reading, bonding and audience participation. The hard-of-hearing person should sit close to the presenter or leader in order to hear better and see the faces of those speaking. Too much distance from the speaker makes it hard to hear or lip read.
- In meetings, a quiet room with small groups where you can be seated around a table or in a half moon style is helpful. For a little larger group try for a “V shape” with the presenter at the tip.
- An outline of the lesson or presentation or words to songs can be loaded on a computer prior to delivery and then projected on a large screen. A white board and/or handouts are helpful.
- A well-lighted room without shadows and minimal facial hair around the mouth is helpful for speech reading.
- When eating out, ask for a quiet room, booth or table along a wall to have distracting sounds coming mostly from the your front and away from the dishes and the door to reduce that source of noise and explain why to the hostess or host before asking for a table. Be sure you are not next to a large party of people. Eat in off peak times and avoid places with live entertainment.
- If the public speaker did a good job addressing your hearing needs, thank the person after the presentation. It will inspire speakers to be more aware of the needs of hard-of-hearing people at their next presentation.
- Maintain a sense of humor.

HINTS FOR PUBLIC SPEAKERS:

- Face the audience when speaking, not the screen or chalkboard.
- Learn to consistently condense and repeat audience questions and comments.
- Speak up and consistently hold the microphone close, but do not cover the mouth.
- Adjust the height of the microphone stem to maximize effective usage and to accommodate variations in speaker height.

HELPFUL TECHNOLOGY IN PUBLIC MEETINGS:

Installed Assistive Listening Systems are available at an increasing number of performance centers, lecture halls, information booths, houses of worship and even buses. With installed systems, personal listening devices (with the possible exception of a neck loop) are not needed.

These systems can either be audio loops, FM or infrared systems. When the system is FM or infrared the venue will provide a receiver and earbuds, headphones or sometimes a neck loop (if you have a telecoil). Earbuds require taking off your hearing device and therefore do not take advantage of hearing aid technology and, therefore, will not work well or at all for people who wear hearing aids or cochlear implants. A very effective alternative is a neck loop for those with a telecoil in their hearing aid or CI. If your hearing device does not have a telecoil, you can use a receiver with an earbud or headphones. For some people, wearing headphones carry the stigma associated with “standing out” and they may find that embarrassing, but sometimes using your telecoil(s) with headphones work wonderfully!

If a listening system is not advertised or posted, you need to be proactive and ask if one is available and if so, suggest that a notice of availability be posted. If one is not installed, ask for one. You are not the only one to need it!

Captions. Many public meetings, theater performances, and sports events can be much more enjoyable and comprehensible for hard-of-hearing people when captions are provided. They are a necessity

for those who do not understand speech well even with hearing devices and amplifications. Captions translate speech to text, either automatically, at production of a movie or DVD, or at live events by a CART operator (real time captioning). In some environments like athletic stadiums where few hard-of-hearing individuals can understand announcements, everyone benefits. All of this is very helpful because you can read the words while you listen.

As they move to digital projection, movie theaters are providing closed (optional) captions using a small screen (rear window display) or special glasses to translate voice to text. Captions can be accessed with all televisions when the video has captions built in. Subtitles are a form of open (visible to all) captions in movies, especially foreign and educational films.

A few days before an event **ask** if captions have been scheduled; if not, request them. The ADA requires that reasonable accommodations be provided.

Internet video content must be accessible (captioned) to people who are hard-of-hearing. However, there is no requirement that the captions be accurate and, especially when automatic captioning is used, the inaccuracy of the captions is often frustrating and, at times, amusing.

Special Settings, Special Coping Skills! **– In The Workplace**

All the feelings and difficulties hard-of-hearing people face are accentuated in the workplace. This is not surprising since our jobs, or our accomplishments at work, provide us with both an income and a sense of competence and self-worth. If there is an element of competition in the workplace, performance (or threats to our performance), can become an even more crucial measure to us of our value.

Because of the importance of performance in the workplace, denial can be a powerful temptation. A hard-of-hearing person might avoid wearing hearing aids in order to hide a “flaw” which we fear could be interpreted as weakness or incompetence. We might be afraid that hearing aids make us look older than we’d like, and age discrimination can and does occur in the workplace. Yet, the mistakes and misunderstandings that occur when we don’t acknowledge our

hearing loss really do threaten our ability to perform effectively and therefore to hold a job.

Even with hearing aids or CIs it is important for you, and those you work with, to know that your “corrected” hearing is aided, and not “normal.” You may not be able to understand banter and rapid-fire discussion because you can’t follow the conversation from one person to another or process their speech fast enough. Without seeing each speaker’s face as they speak, you lose your ability to speech-read. Even noise from a heater, air-conditioning duct or copier may mask the speech you need to hear. Unless you let your co-workers know your needs, they may think you are aloof, unmotivated or even slow or easily confused.

As in all situations where you can make a difference, it is important that you take the initiative by letting your co-workers know about your needs and how they can support your efforts to participate, and what you need as reasonable accommodations.

For more information about available technology, check out the earlier section in this chapter.

Here are some of the coping strategies that will help with meetings and communication in the work place:

- Establish common business etiquette, for example: Take turns speaking.
- Repeat directions, agreements, appointments, instructions and so on to be sure you are understood.
- Some peoples’ voices may be more difficult for you to hear, (for example higher pitched voices), so let it be known to avoid future misunderstandings.
- Request that people speak more slowly or more loudly if needed.
- See if you can hold meetings in rooms with good acoustics and lighting. Be sure and sit where it is best for you to hear and understand.
- Use captions for phone meetings (use your PC to display captions).

Look in other sections of this booklet to find more coping skills that may apply to your work situation. Regardless of the severity of your hearing loss, your positive and pro-active attitude will go a long way toward having others see you as the effective and dynamic person you are.

Know your rights. A person being hired cannot be questioned directly about their hearing, but can only be asked if they can perform the job with “reasonable accommodations.” Although that term is not clearly defined, when you have the job you can negotiate for such things as:

- an amplified (try it first because not all of them will work for you) or captioned phone,
- an FM or loop system for meeting rooms,
- a work area that is as free as possible from background noise.

For information about your rights in the work place and guidance in filing a complaint, see the section on ADVOCACY, THE ADA, THE FCC, & YOU.

In Medical Settings

In hospitals or outpatient surgery, whether you are a patient, visitor or employee in a medical setting, you can request a captioned or amplified phone, captioned TV programming, TTY, visual alerts (for the phone ring, door knock and smoke alarm), CART/real-time captioning or sign language interpreters without additional cost to you. You can also ask that reasonable changes in policies, practices and procedures be made that will help you communicate as all are covered under the Americans with Disabilities Act (ADA).

Because it involves your health, it is very important for you to explain your hearing loss to doctors and other staff. Don't assume that if you tell one person, everybody will know. **Don't wait to be asked if you are hard-of-hearing; tell them!**

Here are a few tips to improve communication in medical settings:

IN THE HOSPITAL:

Use your pre-admission visit to discuss what your hearing loss needs will be during hospitalization and to discuss any special notes or stickers to be used to alert staff to your hearing loss. A Communications Access Symbol sticker is an immediate, easily recognizable indication of your hearing loss.

(See: www.hearinglosslane.org/how-to-make-your-own-hospital-kit/ for these stickers and also a selection of helpful information and samples on how to make your own hospital kit)



- Advise hospital staff of your preferred methods of communication: speech reading, written, amplification, captions, sign language, or a combination of these.
- Inform all medical personnel and stress that it should be prominently displayed in your chart, that you have a cochlear implant if there is the possibility of an MRI which involves strong magnetic energy. While some CI brands are FDA-approved for low power MRIs, others cannot have an MRI without removing the implant. An individual with a BAHA (a bone anchored implant with a titanium post) can have an MRI as long as the sound processor is removed for the procedure.
- It is important that you find out from the manufacturer of your implant whether or not an MRI is advised and, if so, at what level. You should carry a card with that information with your other medical cards to inform all medical personnel.
- Make sure your doctor, anesthesiologist and surgeon are aware of your hearing loss; inquire about any procedure or medication that might negatively affect your hearing. Ask them to give you instructions before they put on their masks as you will not be able to understand anyone wearing a surgical mask. Ask to view captioned videos if the procedure(s) are explained to you with the use of a video. It is important that you understand how the procedure will work because you will be asked to sign an Informed Consent form which indicates you were told of the process, given instructions and all the risks involved.

- Learn the policies concerning retaining your hearing aids during surgery or procedures. You may be able to keep them if you explain their importance. You may be asked to sign a waiver absolving the hospital in case of loss. If the aids or cochlear implant are to be removed, determine where they will be kept, and when you will regain use of them. Make it clear if you prefer to have your hearing devices on at all times. If necessary, place your hearing devices in a zippered plastic bag that is attached to your medical chart. The chart stays with you from surgery and recovery until you can wear them again.
- Advise nurses and other hospital staff at the nurses' station that you will not understand public address announcements or comments over the intercom. Ask them to place a sticker on their intercom or an alert on the computer to remind them. Since you'll be dealing with many different nurses and aides, you'll need to keep reminding them of your hearing loss and telling them how to best communicate with you. A sign on your IV pole or a sticker on your medical chart will be a good visual reminder.
- Be sure you clearly understand any medication instructions given you, including dosage, purpose and special procedures, if any. Repeat instructions to make sure you have them straight. Don't hesitate to ask for written instructions.

Listening is hard work and will be an even greater drain on your energy when you are in the hospital or not feeling well. Inform visitors that you and your ears are tired and need a rest.

Be cooperative and pleasant but assertive and persistent concerning your needs while in the hospital. If you run into problems in having your needs met, ask to speak with the patient liaison, patient advocate or patient care coordinator for help in solving your problems.

IN OTHER MEDICAL SITUATIONS:

- Tell the receptionist when you check in for your appointment that you are hard-of-hearing and probably won't hear your name being called. Ask them to catch your eye or walk over to tell you.
- Ask your dentist, family physician, eye doctor or other medical person to place the Communication Access Symbol sticker on

your file where it will be readily visible. It goes on the outside of the file by your name. Another could be placed on the inside of the file in a place likely to be seen.

- Plan to use a personal listening device if one is not provided and if it will help you understand better. Ask that a nurse be present to help with communications.
- In meetings insist on microphones with ALDs, FM or loop system or real-time captioning if you need them to understand.
- In diagnostic or treatment radiology, if you're lying on a dark flat surface, tell the technician you are hard-of-hearing and will not be able to speech-read instructions in the dark. Have them flash a light on and off when you should exhale and inhale. For some diagnostic radiology procedures of the head or brain it is usually OK to keep your hearing aids on. However, please note that MRI's are **generally NOT OK** for cochlear implant users and the internal parts will likely need to be removed prior to the MRI. (*See the information provided in the earlier "In the Hospital" section.*)
- Before eye surgery, talk with the surgeon about what you will and will not be able to do after surgery. This is especially important if you are also rely-ing on your vision to assist with hearing speech.
- For examinations when you cannot see the doctor's face, arrange for a nurse to stand next to you to repeat instructions if necessary or ask the doctor to move alongside you to explain the findings. Use a personal FM system. See-through face masks are now also available; ask your doctor/dentist to use them. Make arrangements before the exam so that you are both able

to communicate. If a drape is in the way, ask that it be moved to enable you to see the doctor's face so you can speech read during the exam.

Most importantly, don't just nod and pretend to understand the doctor's orders when you don't. It's far better to repeat a question two or three times than to land in the emergency room because you misunderstood an instruction. Repeat the doctor's instructions to be certain you understood them. As a final precaution, you can ask the doctor to write down important instructions.

Being a patient can be scary and stressful without hearing loss. Hearing loss can make the experience much more difficult. Making our needs known is critical to making life easier in or out of a medical setting!

Courtroom Access

Going to court is stressful for anyone, but it is often far more traumatic for a person who has a hearing loss. If you need some special aids or services when appearing in court in any role (for example as a litigant, witness, or for jury duty) you should make a written request to the court administrator as early as possible. You can ask for an assistive listening system, real-time captioning, or an interpreter to be available on the day, time and place that you need these services.

Appropriate accommodations are your lawful right and will make a big difference in your ability to function in this situation. The Americans with Disabilities Act (ADA) prohibits discrimination based on mental or physical disability in gaining access to public services.

Your ability to function and obtain justice should not be left to chance. To deal with your communication needs in court you should:

- Educate yourself about the accommodations that are available upon request. These include Real-time Captioning which means you'll be able to read on a screen everything that is being said. Assistive Listening Devices can also be very helpful if all court participants use a microphone. Infrared style Assistive Listening Devices can work well in courtrooms, and in the rooms where

the jury is deliberating because the signal cannot pass through the walls so all proceedings are confidential as required by law. FM and Induction Loop systems do not provide this level of privacy and should not be used in a court room setting.

- Make a written request to the court administrator for appropriate accommodations as early as possible and check back to confirm that the accommodations you have requested will be in place.
- Keep dated records of all correspondence and phone calls.
- Stand firmly by your request.
- Plan to arrive a bit early and be sure the devices or services you requested are there for your use, and reject poorly provided accommodations (or a total lack of accommodations).
- Ask for a continuance (a later day in court) if services or devices are unavailable.

To obtain the best possible outcomes, plan ahead, be assertive about your needs and exercise your rights. If necessary you can file a complaint with the US Department of Justice: www.justice.gov/crt/complaint/.

(See also the next chapter on “Advocacy” for more information)

Accommodations in Adult Educational Settings

When we consider continuing our education, we often choose the institution based on cost, location, or a specific course of study. If you are planning on attending a college or university and have a hearing loss, be sure to talk with someone in the campus equivalent of the Office for Disability Services—even if you initially think you might not need their services! If you have difficulty identifying the office, contact the campus Human Resources department and they should be able to direct you to the appropriate person.

The college environment is often a surprising challenge for those with hearing loss: large rooms with many students create challenging listening environments; group discussions may be difficult to follow if participants are seated behind you; and instructors may

lecture for lengthy periods causing fatigue and eyestrain. It is important to seek accommodations for your hearing loss because you will be held responsible for and tested on information presented in class. Some accommodations require some time to set up, so it is wise to check in with Disability Services early to find out what the process is to qualify for services, what documentation is required, how long it takes, and how familiar they are with service providers.

A variety of accommodations, many with which you may not be familiar, are possible. Assistive Listening Systems can be a great help in auditoriums and classrooms. Depending on what your functional needs are, these accommodations might include assistive listening technology, speech-to-text technology, captioning of audio/video media, using a personal FM system with a neck loop or earbuds, a note taker or whatever accommodation the school can provide that meets your needs. *(See the earlier discussion on technology in this chapter)*

Regulations for access to academic programs for adults are established by Section 504 of the Rehabilitation Act and also the Americans with Disabilities Act. For more information, go to www2.ed.gov/about/offices/list/ocr/transition.html

If the institution does not provide accommodations that meet your needs, such as listening systems described above or speech-to-text technology or a note taker, there are regulations that define access to academic programs in Section 504 of the Rehabilitation Act and also the Americans with Disabilities Act. See for example: www.hhs.gov/ocr/civilrights/resources/factsheets/504.pdf

Remember, we all stumble, every one of us.

That's why it's a comfort to go hand in hand.

—Emily Kimbrough

Driver's Information

The information below can be copied and carried in your vehicle (for example, keep it on your visor so it is readily accessible). Check all areas that are applicable.

Also, in order to let people know that they need to communicate differently with you because you are hard-of-hearing, you might consider printing the card below and putting it next to your driver's license for easy retrieval.

- I am not able to hear well, and I may not be able to communicate effectively in all situations.**
- I use speechreading to communicate. Please do not shine a light in my eyes or cover your mouth with your hand.**
- Please face me and speak clearly.**
- Please speak slowly — shouting does not help.**
- Please write notes if necessary.**
- Please have your dispatcher send a sign language interpreter.**

Advocacy, the ADA, The FCC, and You

ADVOCACY AND YOU

The **ADA (Americans with Disabilities Act)** and the **CVAA (Communications and Video Accessibility Act)** give a legal and regulatory basis for obtaining many accommodations for people who are hard-of-hearing and deaf. And, while there is at times voluntary compliance with them, often you as a hard-of-hearing or deaf person must ask for those services or devices. For example, hotels/motels must provide visual smoke alarms, door knock alerting devices and visual telephone alerting devices, but even if you request them when you make a reservation often the person who checks you in may not get the message or know where those devices are. It is up to the hard-of-hearing guest to know the requirements and advocate strongly for compliance and, if warranted, file the necessary complaint.

Self-advocacy is also a part of day-to-day life. Asking someone to speak slowly and to enunciate is a form of self-advocacy as is requesting that a restaurant turn down or turn off music that interferes with your understanding of your companion. For some asking for an accommodation is embarrassing, perhaps because advocacy makes your hearing disability obvious to others. Reluctance is a barrier worth surmounting: getting needed accommodations allows you to enjoy your life more fully and helps insure your safety.

Remember, you are not alone in advocating for your interests. HLAA works at the national level and in Oregon HLAA-OR advocates on behalf of hard-of-hearing individuals as do local HLAA chapters. In Oregon a sister organization, Oregon Communication Access Project (OR-CAP, www.or-cap.org/), works with organizations to make their events accessible to hearing impaired individuals, primarily through captions. The National Association of the Deaf (in Oregon, Oregon Association of the Deaf) is also an active advocacy group.

The Ada (Americans With Disability Act) and You

The ADA is a Federal civil rights law for persons with disabilities. The basic purpose of the ADA is to prohibit discrimination in employment (Title I), ensure equal access to services of state and local governments (Title II), and ensure equal access to places of public

accommodation (Title III). One of the major areas of equal access is “effective communication” for persons who are hard-of-hearing, late deafened, or deaf.

In general, the concept of “effective communication” for persons who are hard-of-hearing, late deafened or deaf, refers to the assurance of equal access to any aurally delivered communication that is part of a service, activity, or event of a covered organization. This is usually accomplished with auxiliary aids and services. In general, the ADA requires that covered organizations provide the auxiliary aids or services, at their own expense, that are necessary to ensure effective communication, unless doing so creates an undue burden.

Usually, the auxiliary aid or service that the client, customer or participant is requesting is likely the one that is required for effective communication under the ADA. There are many kinds of auxiliary aids and services. The most common ones, which ensure effective communication in many interactive settings, are assistive listening devices, real-time captioning and qualified interpreters including sign language, oral, cued speech and tactile communications.

If you have questions about the ADA and how it can impact your situation, see: <http://www.ada.gov/> or contact the Oregon Deaf and Hard of Hearing Services (ODHHS), 500 Summer St. NE E-16, Salem, OR 97301, 503-947-5183 voice; 800-521-9615 (TTY), 503-947-5184 (fax). A very good detailed summary of ADA requirements by the National Association of the Deaf can be found at www.nad.org/issues/civil-rights/ADA.

Responsibility for enforcement of the ADA lies with the US Department of Justice. If the DOJ takes on a particular case there is an initial attempt to negotiate and mediate compliance and, if that fails, they may bring suit in federal court. Courts may order compensatory damages and back pay to remedy discrimination if the Department prevails. Under title III, the Department of Justice may also obtain civil penalties of up to \$55,000 for the first violation and \$110,000 for any subsequent violation.

To report possible violations of the ADA contact U.S. Department of Justice: 950 Pennsylvania Avenue NW, Civil Rights Division, Disability Rights Section – NYA, Washington, D.C. 20530. Phone: (202) 307-0663, Fax: (202) 307-1197.

The FCC (Federal Communications Commission) and You

Another law and government agency that has great influence for hard-of-hearing and deaf people is the FCC. Most recently, the Twenty-First Century Communications and Video Accessibility Act (CVAA) was signed into law. The CVAA updates federal communications law to ensure that telephone and television services would be accessible to all Americans with disabilities. But these laws were not able to keep up with the fast paced technological changes that our society has witnessed over the past decade. The new law contains groundbreaking protections to enable people with disabilities to access broadband, digital and mobile innovations – the emerging 21st century technologies for which the act is named.

The CVAA is divided into two broad titles or sections. Title I addresses communications access to make products and services using Broadband fully accessible to people with disabilities. For example, smartphones will be required to be usable by blind and visually impaired people as well as people with hearing aids. Title II of the accessibility act breaks new ground to make it easier for people with disabilities to view video programming on television and the Internet. For example, programs shown on television with captioning will be required to include the captioning when they are re-shown on the Internet. Both titles include provisions to ensure that people with disabilities have access to emergency information such as the next generation of 911 services and emergency information on the television.

For more information see: www.fcc.gov/guides/21st-century-communications-and-video-accessibility-act-2010. To file a complaint use the online process: www.fcc.gov/accessibility-complaints-categories, call: 202-418-2517 or email: dro@fcc.gov.

Some days we need support, some days we have support to offer.

Join HLA today! Get support – Give support.



You Are Not Alone . . . Hearing Resources:

Hearing Loss Association of America (HLAA)

7910 Woodmont Ave. Suite 1200, Bethesda MD 20814

301-657-2248 Voice, 301-913-9413 FAX

E-mail: info@hearingloss.org;

Web page: www.hearingloss.org

This is the HLAA organization on the national level. States can create state associations or local chapters.

Hearing Loss Association of America – Oregon (HLAA-OR)

PO Box 22501, Eugene, OR 97402

Phone 541-689-7242; Web page: www.hearinglossOR.org

E-mail: info@hearingloss.org

HLAA-OR is Oregon's state association. We publish a statewide quarterly newsletter (HEAR IT IS) that is supported through donations. If you'd like to receive this newsletter, please send your mailing information and contribution (if you can) via e-mail (preferably) or mail your request to our address above. (*See the order form at the end of this booklet.*)

There are also several **Hearing Loss Association of America** chapters in Oregon. Local meetings are open to all, and family and friends are encouraged to attend and become involved. Through chapter meetings and newsletters you'll find:

- Insights into effectively living with hearing loss
- Support/Referrals/Information
- Information about the latest technology
- Opportunities to share concerns and hear from others

We believe in education—for those who hear well and those who cannot—so that all may understand the causes, challenges and possible remedies for hearing loss. At our meetings, you'll find a comfortable place where hearing loss is accepted and not a problem. Please check us out. Meet new friends who, perhaps like yourself, are learning what they can do about their hearing loss. Talk with some of the "old hands" who will be glad to share what they have learned about dealing with the challenges of hearing loss. You'll be glad you did.

You can learn about a Hearing Loss Association of America chapter in your area or how to start a chapter by contacting HLAA-OR or HLAA's State & Chapter Coordinator at the address below.

State & Chapter Coordinator
Hearing Loss Association of America

7910 Woodmont Avenue Suite 1200
Bethesda, MD 20814
301-657-2248 Voice
301-657-2249 TTY
301-913-9413 FAX

Access Technologies, Inc. (ATI). Specialists in ergonomic and assistive technology. For more information, write:

2225 Lancaster Drive NE, Salem, OR 97305
Phone: 800-677-7512 voice/TTY; 503-361-1201 voice/TTY;
503-370-4530 FAX
E-mail: info@accesstechnologiesinc.org
Web page: www.accesstechnologiesinc.org

Acoustic Neuroma Association (ANA). ANA provides information and networking support for pre-and post-treatment acoustic neuroma patients. For information, write:

600 Peachtree Parkway, Suite 108, Cumming, GA 30041-6899
Phone: 877-200-8211 voice, 877- 202-0239 FAX
Email: info@anauas.org , Web page: www.anausa.org

Alexander Graham Bell Association has as its mission to promote early identification of hearing loss, and to encourage individuals who are deaf or hard-of-hearing to learn to speak, speechread, and use their residual hearing to communicate. For information, write:
3417 Volta Place NW, Washington, DC 20007

Phone: 202-337-5220 voice

E-Mail: info@agbell.org; Web page: www.agbell.org

American Association of the Deaf-Blind (AADB). AADB is a national consumer organization of, by, and for deaf-blind Americans and their supporters. "Deaf-Blind" includes all types and degrees of dual vision and hearing loss. For information, write:

P.O. Box 8064, Silver Spring, MD 20907-8064

Phone: 301-495-4403 voice; Video Phone: 301-563-9064 (communication via American Sign Language Interpreter)

E-mail: aadb-info@aadb.org, Web page: www.aadb.org

American Tinnitus Association provides information, referrals and support for people who experience tinnitus (ringing in the ears and head noises). For information, write:

PO Box 5, Portland, OR 97207-0005

Phone: 800-634-8978 or 503-0248-9985, 503-248-0024 FAX

E-mail: tinnitus@ata.org; Web page: www.ata.org

Association of Late-Deafened Adults (ALDA) supports empowerment of people who are deafened. Provides resources and information and promotes advocacy and awareness of the needs of deafened adults. For information, write:

8038 Macintosh Lane, Suite 2, Rockford, IL 61107-5335

Phone: 815-332-1515

E-mail: info@alda.org, Web page: www.alda.org

Blanche Fischer Foundation is a nonprofit charitable institution founded for the purpose of assisting persons who have a disability that challenges them physically and who have financial need. You must be an Oregon resident to apply. You may apply for financial education or special equipment. For information, write:

1509 SW Sunset Blvd., Suite 1-B, Portland, OR 97239

Phone: 503-246-4941, 503-246-4941 FAX

E-mail: BFF@BFF.org; Web page: www.bff.org

Described & Captioned Media Program (DCMP). The DCMP is funded by the US Dept. of Education and administered by the National Assoc. of the Deaf (NAD). Its mission is to promote and provide equal access to communication and learning through described and captioned educational media. For information, write:

1447 E. Main Street, Spartanburg, SC 29307

Phone: 864-585-1778 or 800-237-6213 voice,
864-585-2617 or 800-237-6819 TTY, 800-538-5636 FAX
E-mail: info@DCMP.org, Web page: www.dcmp.org

Dogs for the Deaf. Trains dogs to assist people who are hard-of-hearing or deaf. There is no charge to the applicant for a hearing dog from this organization. For information, write:

10175 Wheeler Road

Central Point, OR 97502

Phone: 541-826-9220 voice/TTY, 800-990-3647

E-mail: info@dogsforthe deaf.org

Website: www.dogsforthe deaf.org

Hearing Health Foundation (formerly The Deafness Research

Foundation). A national source for research in hearing and balance science with a mission to prevent and cure hearing loss and tinnitus through groundbreaking research. They also publish the *Hearing Health Magazine*.

363 Seventh Ave, 10th Floor, NY, NY 10001-3904

Phone: 212-257-6140 or 866-454-3924

Email: info@hhf.org

Web page: www.hearinghealthfoundation.org/

House Clinic, Inc. (Hearing Ear Institute) aims to improve the quality of life of those with ear disease or hearing or balance disorders through research and education. Provides a nationwide referral and information service at:

2100 W. 3rd Street, Los Angeles, CA 90057

Phone: 213-483-9930; 213-989-7473 FAX

E-Mail: info@hei.org; Web page: www.houseearclinic.com/

Independent Living Resources promotes the philosophy of independent living by creating opportunities, encouraging choices, advancing equal access, and furthering the level of independence for all people with disabilities. For information, write:

1839 NE Couch St., Portland, OR 97232

Phone: 503-232-7411 voice, 711 TTY, 503-232-7480 FAX,

E-mail: info@ilr.org; Website: www.ilr.org

National Center for Rehabilitative Auditory Research (NCRAR), located at the Portland VA Medical Center, is a multi-disciplinary, multi-site resource dedicated to research to improve the rehabili-

tation of veterans with hearing disabilities. The Center conducts research, trains new scientists, and disseminates current research findings to the scientific community, to veterans, and to the community at large.

3710 SW U.S. Veterans Hospital Road – NCRAR

VA Medical Center – P5-NCRAR

Portland, OR 97239

Phone: 503-220-8262 x54525, Fax: 503-273-5021

Email: ncrar@va.gov; Website: www.ncrar.research.va.gov/

Office of Vocational Rehabilitation Services (OVRS) (State of Oregon) works with people with disabilities to find employment opportunities, obtain training as needed to become employable and in helping them overcome obstacles in the work place. Phone numbers are listed under “State of Oregon—Vocational Rehabilitation Division” throughout Oregon.

500 Summer St. NE E-87, Salem, OR 97301

Phone: 877-277-0513, 503-945-5880, 503-947-5010 FAX

E-mail: vr.info@state.or.us; Website: www.oregon.gov/dhs/vr

Oregon Court Reporters Association is a professional association of court reporters employed in the fields of judicial reporting, broadcast captioning and communications access realtime translation (CART). Resource information is available at www.orcra.org and at HearinglossOR.org

1219 SW 18th Ave, Portland, OR 97205

E-mail: contact@orcra.org

Oregon Deaf and Hard of Hearing Service (ODHHS) provides information and referral sources on deafness and hearing loss issues: Training on deaf awareness and sensitivity, and how to communicate with those with hearing loss. For information, write:

500 Summer St NE (E-16), Salem, OR 97301

Phone: 503-947-5183 voice; 800-521-9615 voice or TTY, 503-947-5184 FAX

E-Mail: odhhs.info@state.or.us

Web page: www.oregon.gov/dhs/odhhs/

Oregon Department of Education (ODE) Regional Programs. The ODE contracts with local agencies to provide a statewide system of free services for young children with developmental delays and disabilities and their families. This includes early intervention (children

birth to three) and early childhood special education (ECSE) for children three to the age of public school eligibility and includes specially and individually designed instruction in the areas of physical, speech/language, mobility, social or emotional and other situations. For information write:

255 Capitol St. NE, Salem, OR 97310-0203

Phone: 503-947-5600, Fax 503-378-5156

E-Mail: ode.frontdesk@ode.state.or.us

Web Page: www.ode.state.or.us/

Oregon Health Licensing Office (HLO) is a state department that deals with all health licenses and regulates hearing health professionals. If you can't resolve a problem or issue with a practitioner, you may file a complaint. For information write:

700 Summer St. NE, Suite 320, Salem, OR 97301-1287

Phone: 503-378-8667, 503-370-9004 FAX

Email: hlo.info@state.or.us,

Web Page: www.oregon.gov/OHLA/HAS

PUBLIC UTILITY COMMISSION OF OREGON

Programs:

- **Oregon Lifeline:** Provides eligible Oregonians with either a discount on monthly landline or wireless phone bills or free monthly prepaid wireless minutes with participating companies.
- **Telecommunication Devices Access Program (TDAP):** Loans adaptive telephone equipment at no cost and with no income restrictions to eligible Oregonians who have a loss in hearing, speech, vision, mobility, or cognition.

Oregon Lifeline & TDAP Contact Info:

Phone: 800-848-4442 (voice); 800-648-3458 (TTY);

971-239-5845 (Videophone); 877-567-1977 (Fax)

E-mail: puc.rspf@state.or.us, Website: www.rspf.org/

Oregon Telecommunications Relay Service (OTRS): A service that allows persons with hearing or speech disabilities to place and receive phone calls. It operates twenty-four hours a day, seven days a week and 365 days a year. There are several forms of the relay services available depending on the telephone equipment and the needs of the user including TTY to Voice, Captioned Telephone

Voice Carry Over, Hearing Carry Over, Speech to Speech, Spanish, and Voice to TTY.

For information, dial 800-676-3777
or go to www.oregonrelay.com

Vestibular Disorders Association (VEDA) is an information and support organization for people with dizziness, inner ear balance disorders and related problems. For information, write:

5018 NE 15th Ave, Portland, OR 97211

Phone: 800-837-8428 voice mail, 503-229.8064 FAX

E-mail: info@vestibular.org,

Web page: www.vestibular.org

Western Region Outreach Center and Consortia (WROCC) provides consultation, training, information and resources to insure that the access needs of hard-of-hearing and deaf individuals are met in all post secondary education and training settings. Web page included training materials on using assistive devices, internet resources and more! For information, write:

WROCC - Regional Resource Center on Deafness

Western Oregon University

345 N. Monmouth Ave., Monmouth, OR 97361

Phone: 503-838-8642 voice/TTY, 503-838-8228 FAX

E-mail: WROCC@wou.edu, Web page: www.wou.edu/wrocc

HEARING LOSS RELATED INTERNET AND E-MAIL RESOURCES

(Good Stuff.... and free!) There are some wonderful resources available to you on the Internet. One way of gaining access to a world of great hearing loss related information is to subscribe to one of the free electronic mail lists available to you, or to join a forum, chat groups, or similar online communication options, like Facebook, Yahoo, and Google groups. When you subscribe to an electronic mail list, the listserv software will add your name to the list. Generally you will receive a letter of welcome or some type of confirmation that your name has been added to the list. The confirmation letter will also include important information about the e-mail address to send messages to, recognized commands, and information about how to unsubscribe. It is always a good idea to keep this information accessible for future reference. From that point on, you will receive any message that is generated by that particular list. And you can join in the discussion by sending a response to the listserv

address, or simply read (“lurk”) anonymously. In order to respond to a post you can address your response to the entire list or privately to an individual on the list. In order to participate in or just read in forums, chat/discussion groups and similar websites, you will usually have to sign up to join the group. Instructions on how to do this are provided on the specific website.

Here are some popular online sites:

GENERAL RESOURCES:

Association of Medical Professionals with Hearing Loss (AMPHL)

AMPHL provides health professionals a way of networking with others who have similar hearing losses. Website: www.amphl.org/

Parent to Parent - The goal of this site is to empower parents of hard-of-hearing and/or deaf children by providing the resources necessary for them to make informed decisions about their children’s hearing loss. www.kidsandhearingloss.org

Hearing Loss Web is dedicated to people who have hearing loss, but are not members of the traditional Deaf community. This includes people who consider themselves to be hearing impaired, hard-of-hearing, late deafened, and oral deaf. Hearing Loss Web provides information on events, issues, medical topics, resources, technology, and they have a Discussion Forum. www.hearinglossweb.com

Meniere’s Discussion Group - Menieres.org was founded to provide a “home” of support for those of you who are suffering from Meniere’s Disease. www.menieres.org

COCHLEAR IMPLANT DISCUSSION SITES:

Cochlear Implant Forum - the focus in the following three groups is cochlear implants. The discussion is sent via e-mail and covers topics related to the cochlear implant experience. This is a good place to ask questions if you are considering getting an implant, have an implant, simply want to know about the experiences of others who have them, or other questions you might have related to Cochlear Implants.

Cochlear Americas - a cochlear implant manufacturer has a “Cochlear Community” page for meeting people who have experience with implants (via Facebook, Twitter, and YouTube)

Hearing Journey – by Advanced Bionics - a cochlear implant manufacturer. www.hearingjourney.com

Hear Peers – by MedEL - a cochlear implant manufacturer. www.medel.com

CI Circle for Parents: Connecting Parents of Children with Cochlear Implants – CI Circle arose from the need for parents to gain accurate and non-judgmental information about pediatric cochlear implants. The original group started with just eight members and has now grown to over 2000 members internationally. www.cicircle.com

cihear@yahoogroups.com This group is a place to share this journey and get ideas for making the journey more effective and enjoyable.

problemci-subscribe@yahoogroups.com Some who have had this surgical procedure have been disappointed by its results. This group is the place to discuss those difficulties. If you are investigating an implant and wish to get a well-rounded view of the product, this list may be just the place.

ONLINE DISCUSSION GROUPS:

To find an online group on a topic you are interested in, check out the Yahoo and Google directories and enter the topic in the “search” area. You will find a wide variety of forums, chat rooms, and information-sharing sites. For example:

Groups on Facebook: www.facebook.com (enter the topic you are interested in their “search” area)

Captioning@yahoogroups.com - Discussion of open and closed captioning and subtitling for deaf, hard-of-hearing, and hearing people.

Beyond-Hearing This is a great place to talk about living in mainstream society with hearing loss, often partial or acquired. Topics range from the technical to the supportive; if it’s about hearing loss, then it’s on-topic. beyond-hearing@yahoogroups.com

Better Hearing News Better Hearing News (bhNEWS) is dedicated to the dissemination of interesting and beneficial information for the

“Hearing Loss Gang,” and more. A flexible format, with some comedy, and whatever. It is an upbeat place to enjoy and learn! Comments and discussion are always welcome!

bhNews@yahoogroups.com

Dizzinews - Dizzinews is an email-based discussion group that's devoted to helping people who are suffering with inner ear and balance disorders.

<https://groups.yahoo.com/neo/groups/Dizzinews/info>

Loops_and_Telecoils@yahoogroups.com - Discussion of all things related to induction loop technology and telecoils as they are used by people with hearing loss.

Suggested Reading

Non-Fiction Books

Bouton, Katherine. (2013) *Shouting Won't Help: Why I and 50 Million Other Americans Can't Hear You*. NY, NY: Farrar, Straus and Giroux.

Doek, Ellis. (2014) *Overcoming Deafness. The Story of Hearing and Language*. London: Imperial College Press

Hammond, Monique. (2012) *What Did You Say? An Unexpected Journey Into the World of Hearing Loss*. Minneapolis, MN: Two Harbors Press.

Kisor, Henry. (1990, 2010) *What's That Pig Outdoors?: A Memoir of Deafness*. New York: Penguin Books, 1990; First University of Illinois Press Paperback, 2010).

Myers, David. (2000) *A Quiet World: Living With Hearing Loss*. Michigan: David and Carol Myers Foundation.

Sacks, Oliver. (1989, 2000) *Seeing Voices. A Journey Into the World of the Deaf*. NY, NY: Vintage Books

Schamadan, Charlotte. (2010) *Hearing Aides: What I don't Hear I Make Up*. Autobiography. Backwords Press

Shea, Gerald. (2013) *Song Without Words: Discovering My Deafness Halfway Through Life*. Boston, MA: Da Capo Press.

Educational Papers And Essays

Bauman, Neil. (2013) *When Your Ears Ring! (6th Edition): Coping with Your Tinnitus – Here's How*. Stewartstown, PA: Integrity First Publications

Carmen, Richard. (2009, 3rd Edition) *The Consumer Handbook on Hearing Loss and Hearing Aids: A Bridge to Healing*. Sedona, AZ: Auricle Ink Publishers.

The Consumer Handbook on Tinnitus, Richard S. Tyler (Editor)

(2008). Sedona, AZ: Auricle Ink Publishers

Davis, C.D, Atcherson, S.R., and Johnson, M.L. (2007). ***Demystifying Hearing Assistance Technology: A guide for service providers and consumers.*** Northridge, CA: PEPNet West, National Center on Deafness, California State University, Northridge.

Stone, Rocky. (1993) ***An Invisible Condition: The Human Side of Hearing Loss***, by the late founder of the HLAA (formerly SHHH). (available for download from HLAA: www.hearingloss.org/about-us/history/1993)

Trychin, Sam. (2003, 2009) ***Living with Hearing Loss*** (books & materials (available at www.Trychin.com/bookstore.html)

Fiction

Lodge, David. (2008) ***Deaf Sentence.*** NY, NY: Penguin Group

Vikram, Seth. (1999) ***An Equal Music.*** London: Phoenix House.

(Please check the booklist on our website www.hearinglossOR.org for additional books and other materials.)

Praise does wonders for our sense of hearing.

—Arnold H. Glasow

GLOSSARY

ADA	Americans with Disabilities Act
ALD - Assistive Listening Device	A device that transmits, processes, or amplifies sound (usually a personal device) with or without a hearing device. ALSs are also sometimes called ALDs. They improve the "speech-to-noise" ratio.
ALS - Assistive Listening System	Usually used to mean an audio loop, FM or infra-red system installed in a large area.
AT - Assistive Technology	Devices that assist people who have disabilities.
Audiogram	A record, in graph form, that shows the results of a hearing test. A line for each ear shows the volume of sound that is required for a tone to be heard 50% of the time.
Audiologist	A health care professional who is trained to evaluate hearing loss and related disorders, including balance disorders and tinnitus, and to rehabilitate individuals with hearing loss and related disorders.
Auditory Loop System	A system that transmits sounds as magnetic energy that is then picked up by the telecoil in a hearing aid or CI.
BTE	Behind The Ear (one class of hearing aid)
Captioned Telephone	A telephone where a person can see every word the caller says on a display and also hear the words (if desired)
Captions	Shows in writing what is said on television, video screen, or other visual displays.
CART - Computer Aided RealTime Captioning	A trained court reporter or stenographer uses a special stenotype machine to display a spoken dialogue on a screen. Remote CART can be performed at a different location from the event and transmitted to the site.
CC - Closed Captioned	Captions that can be viewed if activated.

CI - Cochlear Implant	An electronic device that partially restores hearing in those who have severe to total hearing loss due to damage of the inner ear hair cells. A processor behind the ear captures the sound and transmits it to an implanted receiver and electrode array that stimulates the auditory nerve.
CIC	Completely In Canal (one class of hearing aid)
CVAA	Video Accessibility Act
FCC	Federal Communications Commission
FM	Frequency Modulation (one type of listening HAT)
HAT	Hearing Assistive Technology. Includes signaling and assistive devices.
Hearing Aid Dispenser	Someone who is authorized by the state to measure hearing and to fit and sell hearing aids. Credentials for becoming a hearing aid dispenser vary by state, but typically involve working for some time with a certified dispenser and passing a test about hearing aids.
Hearing Care Provider	Generic term that includes audiologists, specialists, and dispensers.
Hearing Aid Specialist / Hearing Care Specialist	Similar to a Hearing Aid Dispenser. Selects and fits hearing aids for customers; administers and interprets hearing tests; assesses hearing instrument efficacy.
HOH	Hard of Hearing
IL – Inductive/Audio Loop	A loop of cable around a designated area, usually a room, which translates sound into a magnetic signal that is picked up by a hearing aid or CI equipped with a telecoil.
ITC	In The Canal (one class of hearing aid)
ITE	In The Ear (one class of hearing aid)
Loop System	See: IL
OC - Open Captioned	Captions displayed without needing activation; always visible.


Personal Listening Systems	Device that helps one HOH person (differs from an ALS that helps more people)
Realtime Captioning	SEE: CART
Relay System	A telephone service that allows persons with hearing or speech disabilities to place and receive telephone calls with the help of an offsite operator.
Signaling Device	A type of HAT, also called "alerting device"; devices and systems that help deaf and HOH people to become aware of environmental noises like from smoke alarms.
TDD / TT / TTY	Telecommunication Device for the Deaf (also called Text Telephone or TeleTypewriter) used for phone communication.
Telecoil	A small coil of wire inside a hearing aid or CI that is designed to pick up a magnetic signal. When using the telecoil setting on a hearing aid, it turns off the microphone so that only electromagnetic signals are picked up and then converted to sound.
VCO - Voice Carry Over	Allows a person who can speak but not hear well to talk on the phone via the Relay System.

Many people believe that support is something that you give to someone you feel sorry for or that it means proping up someone who would fail unless you were there to give him a boost. But that's not the way I see it.

Support is the boost you can give someone who can help himself but who needs a partner to open a window or push aside a roadblock.

—Dave Thomas

ORDER FORM



Hearing Loss Association of America - Oregon (HLAA-OR) www.hearinglossOR.org publishes a statewide newsletter about hearing loss. Read about coping strategies, assistive technology, personal experiences, telephone options, and more.

Donations to help us pay costs are welcome. HLAA-OR is a 501(c)(3) charity and depends on donations & grants. All personnel are volunteers.

Yes! I would like to receive the HLA-OR's statewide newsletter.

Name _____

Phone _____

Organization Name _____

Address _____

City, State, Zip _____

E-Mail _____

Please check if you would like to receive the newsletter via e-mail.

I learned about the newsletter from: _____

Enclosed is my contribution of \$_____ to support HLA-OR's outreach programs in Oregon. Contribution will be acknowledged in the next newsletter issue.

Please check if you would like to remain anonymous.

I cannot contribute but would like to receive the newsletter.

Please send me ____ copies of this book ***Facing the Challenge of Hearing Loss: A Survivor's Manual***, at \$4 per copy or \$35 for 20 copies.

My check is enclosed. Please send me an invoice.

Please send this form and your donation to support our efforts to:

Hearing Loss Association of America - Oregon (HLAA-OR)

P.O. Box 22501

Eugene, OR 97402



Please consider becoming a member of our national association: HLAA. It is easy, inexpensive and rewarding. HLAA membership brings you:

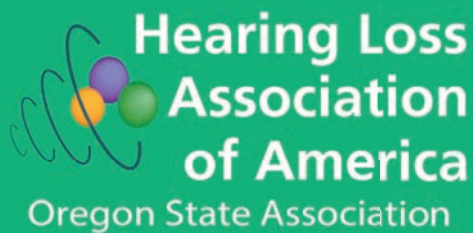
- ***Hearing Loss Magazine*** (HLAA's bi-monthly publication, containing the latest information on technology, legislation and coping with hearing loss.
- access to the HLAA information and resource center
- active advocacy and representation on the national level
- discounts to the HLAA annual convention held in different locations, reaching out to everyone with a hearing loss and their friends, families and co-workers
- automatic membership in the Hearing Loss Association of Oregon

Individual membership costs just \$35.00 per year. For more information about HLAA, go to www.hearingloss.org/ or contact:

**Hearing Loss Association of America (HLAA)
7910 Woodmont Ave, Suite 1200
Bethesda, MD 20814**

Founded in 1979, the Hearing Loss Association of America (HLAA) is a volunteer-led organization of people with hearing loss and people who care about them. HLAA is a membership organization with nearly 200 local chapters and state associations/offices throughout the United States.

HLAA is devoted to the welfare and interests of consumers with any degree of hearing loss who are committed to participating in the hearing world.



PO Box 22501, Eugene, Oregon 97402

Phone: 541-689-7242 voice

E-mail: info@HearingLossOR.org

www.hearinglossor.org