

A MODERN GUIDE TO HEARING LOSS

**NEW
EDITION
2019**

*For the Deaf and
Hard of Hearing*



What's Inside

- The Impact of Hearing Loss
- Where to Turn for Help
- Emerging Technologies

What's New

Understanding and
Coping with Trauma
and Hearing Loss

EXCLUSIVE

Foreword includes personal stories from survivors
of mass tragedies who suffered hearing loss

Massachusetts Commission for the Deaf and Hard of Hearing

A Modern Guide to Hearing Loss

for the Deaf and Hard of Hearing



Massachusetts Commission for the Deaf and Hard of Hearing

Boston, MA

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FOREWORD

The Massachusetts Commission for the Deaf and Hard of Hearing is excited to have the opportunity to update its guide, originally known as the “Savvy Consumer’s Guide to Hearing Loss.” Our first guide was written nearly 20 years ago, and has been updated several times, the most recent in 2008, yet so much in our society has changed.

The challenges for Deaf and hard of hearing individuals are at once similar and different. This updated guide is intended to assist both populations in addressing issues of health and wellbeing, accessibility, communications, technology and much more.

Medical and technological advances have given the hearing loss population as a whole a new way to consider, understand and treat hearing loss. In addition, our world is now exposed to constant noise that often crosses over the normal threshold for sound exposure and is creating ever more individuals with hearing loss.

Perhaps the greatest change to impact the Deaf and the hard of hearing is technology. For instance, texting at the appropriate space and time has greatly increased human connection for all those along the hearing spectrum. MCDHH remains optimistic about the use of technology to improve the quality of life for Deaf, hard of hearing and late-deafened people. We want to share what is now available and continue to support the Deaf and those with hearing loss to become Savvy Consumers.

Out of necessity, the Commission has also decided to add a chapter focused on trauma and hearing loss. In partnership with the Massachusetts Office for Victim Assistance (MOVA), which obtained funding through the Anti-terrorism Emergency Assistance Program (AEAP) of the U.S. Department of Justice Office for Victims of Crime (OVC), MCDHH established specialized services to a new population of consumers—those whose hearing was impacted by the blasts during the Marathon Bombings in 2013.



Survivors of the Marathon Bombings who were exposed to the blasts, suffered numerous injuries including limb loss, shrapnel injuries, burns, concussive injuries and hearing loss. In fact, the Massachusetts Eye and Ear Hospital in Boston reported that of the 60 individuals who were seen for hearing loss on April 15, 40 individuals had perforated eardrums. Twenty surgeries were performed, and four repeat surgeries were later done to repair damage. This does not take into account the number of individuals who report symptoms of tinnitus (a buzzing or ringing in the ears). To date, MCDHH has served almost 200 individuals with hearing loss from the bombings.

These numbers are similar to other events that involve massive explosions. In the “Van Campen Study” of the Oklahoma City bombing, 83 survivors were evaluated quarterly for a year after the blast, “tracking the onset, persistence, and severity of ear and hearing-related symptoms along with data from audiologic evaluation.” It was found that 76% of the participants with blast exposure had hearing loss at one or more frequencies. “Most cases showed sensorineural hearing loss, and bilateral loss was present in 74% of the group.” In addition, the reported tinnitus, loudness sensitivity, and ear pain was unchanged after one year. (*Van Campen et al., 1999*).

As an agency, MCDHH learned a great deal about traumatic hearing loss, especially as a result of the terrorist attacks. Early on we grasped the enormity of service provision challenges and understood we would have to expand our knowledge base to meet the short term and long-term needs of this new population. It has been a pioneering effort that requires a new level of expertise and a new model of treatment. We needed to identify victim service providers who specialized in hearing loss, trauma-focused aural rehabilitation and most importantly, peer support.

To that end, MCDHH was fortunate to hire a survivor of the Marathon Bombings, Shannon Silvestri, whose story may help both consumers and providers to understand the needs of this population. Shannon came to MCDHH originally as a client, determined to understand what had happened to her hearing and what she could do to manage it. She possesses a rare tenacity (that she describes as “desperation”) to

understand her condition so that she would not feel further victimized by the events of April 13th. She describes what happened that day:

“My kids (ages 17 and 15), were in attendance near the finish line of the Boston Marathon. I was there to support my husband, who was running his third Boston. I received an automated text message that he had finished the race, so I went out the side door of the Lenox hotel on Exeter Street. I was walking between my son and daughter with a friend behind her. We were making our way towards the family meeting place when the first of two bombs exploded just behind me. I felt the ringing in my ears, but my immediate concern was for my family’s safety. My husband and children were all safe but there was no getting around what they had seen and heard. When the shock wore off, I still had the ringing and buzzing sensation, pain in my right ear and ultimately hearing loss. My condition has remained along with some traumatic memories of my children so close to two bombs. I am still unable to fly and do not take elevators to higher floors due to the pain in my ear.”

Shannon is one of many survivors with a similar story of being at the Boston Marathon and being affected by the bombings. What makes her story unique is her compulsion to learn everything about hearing loss and the desire to use it to help others. What started as a learning experience has grown into a crusade. Taking as many classes and seminars as possible while reaching out to marathon survivors has now become her mission.

Shannon was eventually hired by MCDHH to provide peer support. She has developed a comprehensive peer support program that includes hearing loss education, peer support retreats, service opportunities, and connecting survivors worldwide. Along with connecting survivors all over the United States, Shannon has conducted outreach to survivors of other attacks such as the March 22, 2016 bombings in Brussels, Belgium at the Zaventem Airport.



At a recent Tinnitus Webinar developed by MCDHH for survivors, Shannon remarked, “It has been so rewarding to bring Marathon survivors together with Brussels survivors. It allowed us to share our personal experiences and actually see one another and talk with one another. Shannon was surprised to learn how little help there has been through one survivor, R.S. from Brussels. He explains:

“When the bomb exploded, my jacket burned but I could not remove it. I was standing and couldn’t see my wife. Then I saw her on the floor and started shouting, ‘Are you OK?’ And she told me ‘Yes.’ I raised her and we ran to leave the building as I was scared that they will start shooting. When I finally sat down, my leg was totally paralyzed and my other leg was burned. My wife was also wounded. She had wounds on her face, leg and her feet.”

R.S. also reported how unorganized everything was.

“. . . it took us four hours to arrive to the hospital. Ambulances were arriving very slowly and not enough for the quantity of wounded people.”

It has been an uphill battle all the way for him, fighting for months and months, sending documents to “prove” that he and his wife were wounded, and no help ever arrived. They had to pay out of their own savings for all the costs of hospitals, ambulances, doctors, psychologists, etc. In the end R.S. was told he would just have to live with his tinnitus; there was nothing to be done.

For Shannon, hearing survivors’ stories like this one is all the more reason to keep providing peer support and resources for all of those with hearing loss who have been victimized by a trauma.

“The world has changed since 9/11 and the landscape for new technologies is always moving forward and breaking new ground. We live in uncertain times and hearing loss is projected to increase not decrease. The only constant in all of this is that survivors have each other for mutual support, friendship, and helping each other find good resources. That’s exactly what this book is about.” — Shannon Silvestri

Indeed, that is why we have updated this guide. Regardless of your hearing challenges from birth, or those acquired gradually, through sudden onset or a traumatic event, we hope this guide becomes a valuable resource you can access for years to come.

MCDHH would like to, first and foremost, thank **MOVA** for its commitment to providing support through funding for all victims of crime, especially to those in the hearing loss population. Their profound foresight to collaborate with MCDHH in the aftermath of a mass tragedy is unequalled in the public service sector.

We would also like to thank the MCDHH work group who took on the daunting task of updating this guide. To **Jonathan O’Dell, Carol Menton, Alison Fondo, Shannon Silvestri, Ellen Perkins, and Barbara Johnson**, your firm persistence to wade through multiple versions of outdated text and terminology to create meaningful content is deeply appreciated and most inspiring.

We would like to thank the original author, **Karen Rockow**, for sharing her passion and knowledge to help the Deaf and those others with hearing loss by writing the “Savvy Consumer.” You spared our work group the agony of starting from scratch.

To **Patricia Ford**, Deputy Commissioner of Programs and Policies and **Jonathan O’Dell**, Director of Communication Access Technology and Training Services, who labored over several final drafts with great humor and heart to prepare it for publication. To **Herb Silberstein**, at Flagship



Press, you truly are a Solutions Provider able to navigate, mediate, maneuver, and facilitate the many voices and opinions without losing sight of the goal.

To our Commissioner, **Heidi Reed**, who continues to have a broad, all-inclusive vision of the Deaf community and the hard of hearing population.

To **Dr. Inger Riley**, who contributed the new chapter on trauma, your meticulous understanding of the impact of trauma is surpassed only by your compassion for those you have helped.

To **Stu Nunnery**, our Editor, who used his craft to take multiple perspectives and turn it into a cohesive, compassionate treasure for those who are hard of hearing.

Finally, to our citizens with hearing loss, we hope this guide arms you with the knowledge, resources, and sense of human understanding that reminds you that you are not alone and that there is help when and where you need it.

Very Truly Yours,

Stacey Walsh, Project Director
A Modern Guide to Hearing Loss

INTRODUCTION

I ABOUT THIS GUIDE

The Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) is pleased to present this helpful guide for Massachusetts residents to assist you through the challenges associated with acquired/late deafness and hearing loss.

Here you will find up-to-date information about the causes and treatments of hearing loss, about trauma, where to get help, about hearing aids and cochlear implants, assistive technology and the auxiliary services available in state and elsewhere. You'll also find tips and techniques for living with and moving beyond your hearing loss. There are myriad suggestions about how to customize your day to day life at home, at work, in the marketplace and in situations and circumstances that might challenge you.

An appendix is filled with contact information for those dedicated to helping you on your journey plus books, blogs and magazines to fill in the gaps of your knowledge and understanding, to lead you to discover the newest thinking and activities focused on hearing loss.

You will also find inspiring stories from others who have lived with hearing loss and found the spirit, persistence, creativity, and courage to live full and productive lives despite their challenges.

You can, too.

Equally important, MCDHH created this guide to strongly encourage you to take charge and control of your hearing experience. As many others before you have discovered, it is critical that you do. The tools and techniques included here are transforming the way we think about and address hearing loss today. And they will change your life too.

II THE IMPACT OF HEARING LOSS

The ability or inability to communicate is the difference between a life engaged and a life in the shadows. Hearing loss is especially challenging. It can limit the simplest interactions between us, compromise personal safety, and make day to day functioning a maze of compounding difficulties. It can also erode even the desire to communicate when met with impatience or indifference from others.

There are other concerns looming. The National Academy of Sciences reports that untreated hearing loss in older adults can exacerbate isolation and presage dementia.

Deafness and hearing loss have long carried with them a social stigma. As the result, many with hearing loss are still reluctant to acknowledge it, expose it by wearing a hearing aid, or even reach out for help. Inhibiting still others from taking swifter action is that treating and managing hearing loss requires you to be proactive.

In most cases, hearing loss can be detected earlier but most annual physicals do not include a hearing test. It's often a family member, friend or associate who first identifies your challenge. Cost is still prohibitive for many and hearing aids for adults are not always covered by insurance. Less expensive, over-the-counter options are coming into play though they are not right for everyone or every hearing loss.

The NAS Report on Hearing Loss

The National Academy of Sciences, Engineering and Medicine in the U.S. released a report on hearing loss that for the first time made hearing health care not just an interesting issue, but a critical one. The report revealed startling data:

- Worldwide, 1 of 6 individuals has a hearing loss.
- One of every five individuals in the U.S. over the age of 12 has a hearing loss.

- About 2–3 out of every 1,000 children in the United States are born with a detectable hearing loss in one or both ears.
- Almost 15% of school-age children (ages 6–19) have some degree of hearing loss.
- An estimated 50 million people in the U.S. experience tinnitus (ringing in the ears). 90% of those also have hearing loss.
- Hearing loss is the third most prevalent health issue in older adults after arthritis and heart disease.
- One in three over 65 has a debilitating hearing loss.
- Hearing problems — including tinnitus and auditory processing disorders (often associated with blast exposure) — are the most prevalent service-connected disability among American Veterans.
- Hearing loss is the #1 disability for our returning veterans. 60% of veterans returning from Afghanistan and Iraq are living with hearing loss.
- 67–85% of those with hearing loss either do not, will not, or cannot afford to wear a hearing aid.

You are not alone.

Considering that 1 person in 5 in the United States over the age of 12 has a hearing loss, that translates to a total of 1,374,604 residents in the Commonwealth of Massachusetts with a hearing loss. The State's Deaf and hearing loss population embraces every age, ethnic and economic group. Most of us know someone with a hearing loss. It's your boss or customer, the person sitting next to you in church, the professor or student in a college classroom, the checkout clerk at your local supermarket.

III THE GOOD NEWS ABOUT HEARING LOSS

- Greater professional attention (and public awareness) than ever before is now focused on hearing loss.
- The stigma is lessening.
- Recent research on the brain and hearing is very promising and the positive results are already morphing into new treatments and products for ever more people.
- Today's hearing aids and cochlear implants offer the latest advances in sound transmission. They are lightweight, highly reliable, and provide a host of programs that can be accessed with the push of a button. These programs help you manage your hearing experience for speech, background noise, and more comfortable music listening.
- The benefits of getting a hearing aid far outweigh any inconvenience that appointments with your audiologist may create — and these appointments are often included in the price of the hearing aid.
- Loop technology installed in venues allows hearing aid and cochlear implant users to connect to the sound system to enable them to hear meetings, speakers, theatrical performances, music and other presentations.
- On the market are a wide range of apps and assistive listening devices that can improve your hearing experience in more listening environments.
- The Over-the-Counter Hearing Aid Act of 2017 was recently signed into law and over-the-counter (OTC) hearing aids will soon be available.
- Support can be found throughout Massachusetts. State agencies as well as independent groups and associations hold regular meetings, offer speakers and events, and can be found on the social media to offer links to information and resources.

- 
- Massachusetts also has many hearing specialists from otolaryngologists (ENTs) and otologists, audiologists, speech language pathologists, and hearing rehabilitation specialists, to hearing aid and assistive listening device providers.

Use this guide.

This guide will assist you to be an educated and savvy consumer about hearing loss. You can be proactive in many ways:

- Have your hearing tested.
- Read this guide and share it with family, friends and associates.
- Create a support team — an ENT, audiologist, rehabilitation specialist, hearing aid dispenser and others.
- Join a support group and get involved with others who have experienced and now live with hearing loss.
- Reach out for assistance whenever needed.
- Ask questions.
- Become your own advocate.
- Use the web to do your own research.
- Read books, blogs and magazines.
- Get and stay connected.
- Repeat as needed.

Hearing loss is not the end of your life.

It's a new chapter and but one part of your life's journey. Think of it that way. You can focus on the challenges you will face or focus on strengthening your hearing and communication experiences and along with them, your relationships wherever you go.

Let this guide be your companion. Take that first or next step and get back into life.

You can do it!

Note: *Change happens fast in the hearing loss world. If you read this guide two months from now — never mind two years — there will most probably be something new and revolutionary afoot that you might not find mentioned here because it either doesn't exist or hasn't been publicized as of this writing. Stay informed and up to date. You'll be very glad you did.*

RESOURCES

Statistics Sources

Johns Hopkins Medicine

Other Sources

National Information Center on Deafness and Other Communication Disorders

National Institutes of Health

National Council on Aging

Centers for Disease Control and Prevention (CDC)
and the *MarkeTrak VIII Study* by Sergei Kochkin, Ph.D.

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CHAPTER 1

Understanding Hearing Loss

Our sense of hearing is at once amazingly complex and fascinating and we often take it for granted until something happens. And while the focus of hearing loss is usually on the ears, more is being learned about the neuroplasticity of the brain and the role it plays in hearing.

Your hearing can be weakened or lost entirely from several causes depending on your genetics, overall health, stress levels, environmental exposures, work, diet and lifestyle and/or the consequences of a variety of traumas. In many cases, the exact cause(s) of your hearing loss may be idiopathic — of unknown origin — and may never be identified.

Hearing loss can be present at birth, occur suddenly or gradually over time. It can occur and reoccur, fluctuate, stabilize and change yet again.

Hearing loss is classified by an audiogram as “mild,” “moderate,” “severe” and “profound.”

THREE TYPES OF HEARING LOSS

Source: Hearing Loss Association of America/HLAA
<http://www.hearingloss.org>

Sensorineural Hearing Loss (SNHL)

Also known as nerve-related hearing loss, this is an inner ear problem caused by damage to the hair cells in the cochlea or the auditory nerve. SNHL can have many causes.

CAUSE: Acoustic trauma (noise, concussive force)

Similar to age-related hearing loss, this is often a symmetrical (similar) loss in both ears. It can also be asymmetrical (different degree of loss in each ear) if the cause was a gunshot near one ear or another loud sound



from one side. It is often progressive and noise-related hearing loss can accelerate age-related loss.

Treatment

May respond to corticosteroids to reduce cochlea hair cell swelling and inflammation to improve healing of injured inner ear structures.

CAUSE: Head Trauma

May cause an inner ear fluid compartment to rupture or leak, which can be toxic to the inner ear.

Treatment

There has been variable success with emergency surgery when this happens.

CAUSE: Viral

Sudden sensorineural hearing loss of viral origin is an otologic emergency. **See a doctor immediately** if you experience a sudden hearing loss in one or both ears; hearing loss accompanied by vision problems; dizziness or nausea; or pain or discomfort in the ear(s).

Treatment

In some cases, sudden hearing loss can be reversed or mitigated with steroids if treated within a very short window of time after onset.

CAUSE: Autoimmune Inner Ear Disease

This happens when the body's immune system misdirects its defenses against the inner ear structures to cause damage in this part of the body.

Treatment

Bilateral progressive hearing loss over several months is managed medically with long-term corticosteroids and sometimes with drug therapy.

CAUSE: Meniere's Disease

Fluctuating sensorineural hearing loss may be from an unknown cause or associated with Meniere's Disease. Symptoms of Meniere's Disease are hearing loss, tinnitus (ringing in the ears), and vertigo.

Treatment

May be treated medically with a low-sodium diet, diuretics, and corticosteroids. If the vertigo is not medically controlled, then various surgical procedures can be used to try and eliminate the vertigo.

CAUSE: Tumors

These tumors affect the balance nerve adjacent to the hearing nerve.

Treatment

Generally, these are not reversed with surgical removal or irradiation of these benign tumors. But if the hearing loss is mild and the tumors are very small, hearing may be saved in 50 percent of those undergoing hearing preservation surgery for tumor removal.

CAUSE: Disease in the central nervous system

Treatment

May respond to medical management for the specific disease affecting the nervous system. For example, hearing loss secondary to multiple sclerosis may be reversed with treatment for multiple sclerosis.

Irreversible sensorineural hearing loss, the most common form of hearing loss, may be managed with hearing aids. When hearing aids are not enough, this type of hearing loss can be surgically treated with cochlear implants.

Conductive Hearing Loss

This type of hearing loss is due to a blockage, injury or malformation of the ear canal, ear drum, or middle ear and its little bones (the malleus, incus, and stapes) which prevents sound waves from reaching the cochlea.

CAUSE: Malformation of outer ear, ear canal, or middle ear structures

Treatment

In some cases, surgical correction is possible and beneficial. If the condition is amenable to successful surgical correction, then hearing may be improved with amplification wearing a bone conduction hearing aid, a surgically implanted, osseointegrated device (for example, the Baha or Ponto System), or a conventional hearing aid, depending on the status of the hearing nerve.

CAUSE: Fluid in the middle ear from colds, ear infection (otitis media)

An infection of the middle ear in which an accumulation of fluid may interfere with the movement of the eardrum and ossicles, as well as allergies and/or poor Eustachian tube function.

Treatment

Acute infections are usually treated with antibiotic or antifungal medications. Chronic ear infections, chronic middle fluid, and tumors usually require surgery. If there is no response to initial medical therapy, infectious middle ear fluid is usually treated with antibiotics — while chronic non-infectious middle ear fluid is treated with surgery or pressure equalizing tubes.

CAUSE: Trauma

Treatment

Conductive hearing loss from head trauma is frequently amenable to surgical repair of the damaged middle ear structures, performed after the patient's general medical status is stabilized following acute traumatic injuries.

CAUSE: Otosclerosis

This is a genetic form of conductive hearing loss in which there is bony fixation of the stapes (the third little bone of hearing in the middle ear), where sound cannot get to the middle ear. Otosclerosis usually presents with hearing loss in early adulthood.

Treatment

Otosclerosis can successfully be managed with surgery to replace the immobile stapes with a mobile stapes prosthesis or with a hearing aid.

CAUSE: Viruses

Research suggests that the measles virus may contribute to stapes fixation in those with a genetic predisposition to otosclerosis.

OTHER CAUSES: Perforated eardrum, impacted earwax

Mixed Hearing Loss

This refers to a combination of conductive and sensorineural hearing loss. This suggests damage in the outer or middle ear and in the inner ear (cochlea) or auditory nerve.

Treatment for Mixed Hearing Loss

Audiologist Mark Ross, Ph.D., recommends taking care of the conductive component first. There have been times when the addition of the conductive component made the person a better hearing aid candidate, by flattening out the audiogram for example, while the underlying sensorineural component presented a high-frequency loss. However, still the emphasis would be on treating medically what can be treated. He says that, generally, you would expect positive results.

Presbycusis

This is the term used to describe the slow, progressive type of hearing loss that goes along with aging.

OTOTOXIC DRUGS

Source: American Speech Language Association
<http://www.asha.org>

Certain medications can damage the sensory cells located in the inner ear used in hearing and balance resulting in hearing loss, ringing in the ear, or balance disorders. These drugs are considered ototoxic.

- There are more than 200 known ototoxic medications (prescription and over-the-counter) on the market today. These include medicines used to treat serious infections, cancer, and heart disease as well as simple pain and discomfort.
- Hearing and balance problems caused by these drugs can sometimes be reversed when the drug therapy is discontinued. Sometimes, however, the damage is permanent.
- When a decision is made to treat a serious illness or medical condition with an ototoxic drug, your health care team ought to consider the effects of the medications on your hearing and balance systems and discuss with you how these side effects will affect your quality of life.

- Ototoxic medications known to cause permanent damage include certain aminoglycoside antibiotics, such as gentamicin (family history may increase susceptibility), and cancer chemotherapy drugs, such as cisplatin and carboplatin.
- Drugs known to cause temporary damage include salicylate pain relievers (aspirin, used for pain relief and to treat heart conditions), quinine (to treat malaria), and loop diuretics (to treat certain heart and kidney conditions).

Effects of Ototoxic Medications

- The first sign of ototoxicity is usually ringing in the ears (tinnitus). Over time, you may also develop hearing loss. This hearing loss may go unnoticed until your ability to understand speech is affected.
- Balance problems can also occur as a result of ototoxic medications. You may experience a loss of balance and feeling unsteady on your feet. Sometimes these problems are temporary because the human body can learn to adapt to reduced balance control.
- The effects of ototoxic medications can affect your quality of life. Not being able to hear conversations or feeling a little dizzy may cause you to stop participating in your usual activities.

Protecting Yourself from Ototoxicity

Research is being done to develop ways of protecting people from ototoxicity. At this time, there is no approved protective strategy.

Before you begin any treatment with ototoxic medications:

- Have your hearing and balance systems monitored before and during treatment.
- Have a baseline record of your hearing and balance recorded by an audiologist. The baseline record should include an audiologic hearing test that uses high-pitched testing, word recognition, and other tests when possible. This information can help you and your

doctor make any important decisions to stop or change the drug therapy before your hearing is damaged.

- During the course of your treatment, you should have periodic hearing tests as part of the monitoring process. This will enable you to report any hearing changes, ringing in the ears, or balance problems that you may notice.
- For cases in which the drugs cannot be stopped or changed, the patient and the audiologist can take steps to manage the effects of the hearing loss that results.

Where to Find a List of Ototoxic Drugs

Explore this link for more information.

<http://www.asha.org/public/hearing/Ototoxic-Medications>

TINNITUS

Source: The American Tinnitus Association

<https://www.ata.org/understanding-facts>

Tinnitus often accompanies hearing loss and is a common symptom related to an array of underlying health issues. Its source is a place in the brain though it is experienced in the ears.

Millions of Americans experience tinnitus, often to a debilitating degree, making it one of the most common health conditions in the country. The U.S. Centers for Disease Control estimates that nearly 15% of the general public — over 50 million Americans — experience some form of tinnitus. Roughly 20 million people struggle with burdensome chronic tinnitus, while 2 million have extreme and debilitating cases.

Technically, it is the perception of sound when no actual external noise is present. While it is commonly referred to as “ringing in the ears,” tinnitus can manifest many different perceptions of sound:

People who experience tinnitus describe hearing different and sometimes intertwining sounds including buzzing, hissing, whistling, swooshing,

and clicking. In some rare cases, tinnitus patients report hearing music. Tinnitus can be both an acute (temporary) condition or a chronic (ongoing) health malady.

Related Conditions

Tinnitus can be affiliated with a range of conditions, including vestibular disorders, audiological problems, and behavioral health issues. In general, there are two types of tinnitus:

Subjective Tinnitus: Head or ear noises that are perceivable only to the specific patient. Subjective tinnitus is usually traceable to auditory and neurological reactions to hearing loss but can also be caused by an array of other catalysts. More than 99% of all reported tinnitus cases are of the subjective variety.

Objective Tinnitus: Head or ear noises that are audible to other people, as well as the patient. These sounds are usually produced by internal functions in the body's circulatory (blood flow) and somatic (musculo-skeletal movement) systems. Objective tinnitus is very rare, representing less than 1% of total tinnitus cases.

Treatment

There is currently no scientifically validated cure for most types of tinnitus. There are, however, treatment options that can ease the perceived burden of tinnitus, allowing patients to manage and live more comfortable, productive lives.

VERTIGO

Source: WebMD

<https://www.webmd.com/brain/vertigo-symptoms-causes-treatment#1>

Vertigo can also accompany hearing loss. It is a sensation of feeling off balance. If you have these dizzy spells, you might feel like you are spinning or that the world around you is spinning.

Causes of Vertigo

Vertigo is often caused by an inner ear problem. Some of the most common causes include:

BPPV

These initials stand for benign paroxysmal positional vertigo. BPPV occurs when tiny calcium particles (canaliths) clump up in the canals of the inner ear. The inner ear sends signals to the brain about head and body movements relative to gravity. It helps you keep your balance. BPPV can occur for no known reason and may be associated with age.

Meniere's Disease

This is an inner ear disorder thought to be caused by a buildup of fluid and changing pressure in the ear. It can cause episodes of vertigo along with ringing in the ears (tinnitus) and hearing loss.

Vestibular Neuritis or Labyrinthitis

This is an inner ear problem related to infection (typically viral). The infection causes inflammation in the inner ear around nerves that are important for helping the body sense balance.

Less often vertigo may be associated with:

- head or neck injury
- brain problems such as stroke or tumor
- certain medications that cause ear damage
- migraine headaches

Symptoms of Vertigo

Vertigo is often triggered by a change in the position of your head. People with vertigo typically describe it as feeling like they are:

- spinning
- tilting
- swaying
- unbalanced
- pulled to one direction

Other symptoms that may accompany vertigo include:

- feeling nauseated
- vomiting

- abnormal or jerking eye movements (nystagmus)
- headache
- sweating
- ringing in the ears or hearing loss

Tip: *Symptoms can last a few minutes to a few hours or more and may come and go.*

Treatment

Treatment for vertigo depends on what's causing it. In many cases, vertigo goes away without any treatment. This is because your brain is able to adapt, at least in part, to the inner ear changes, relying on other mechanisms to maintain balance.

Vestibular Rehabilitation

This is a type of physical therapy aimed at helping strengthen the vestibular system. The function of the vestibular system is to send signals to the brain about head and body movements relative to gravity. Vestibular rehab may be recommended if you have recurrent bouts of vertigo. It helps train your other senses to compensate for vertigo.

Canalith Repositioning Maneuvers

Guidelines from the American Academy of Neurology recommend a series of specific head and body movements for vertigo. The movements are done to move the calcium deposits out of the canal into an inner ear chamber so they can be absorbed by the body. You will likely have vertigo symptoms during the procedure as the canaliths move.

A doctor or physical therapist can guide you through the movements. The movements are safe and often effective.

Medication

This may be given to relieve symptoms such as nausea or motion sickness associated with vertigo.

If vertigo is caused by an infection or inflammation, antibiotics or steroids may reduce swelling and cure infection.

For Meniere’s Disease, diuretics (water pills) may be prescribed to reduce pressure from fluid buildup.

Surgery

In a few cases, surgery may be needed for vertigo. If vertigo is caused by a more serious underlying problem, such as a tumor or injury to the brain or neck, treatment for those problems may help to alleviate the vertigo.

TERMINOLOGY

The following terms used in this guide are meant to identify/describe the variety of hearing challenges people may face from birth or at any time during their lifetime. These are not the only terms attributed to such individuals and there can be disagreement over specific definitions. Nevertheless, the authors believe that these terms will serve, in a general sense, most purposes of the reader. Every effort has been made to not exclude or misrepresent anyone with a hearing challenge.

Deaf (Capital “D”)

People who have been Deaf since birth and have been raised in environments supporting the use of American Sign Language consider themselves to be a linguistic and cultural minority. They are usually integrated into what is known as the Deaf community, and members of this community use the capitalization of the word “Deaf” to differentiate their positive cultural identification from what they see as the pathological connotation of the word “deaf” to denote a disability or “missing” ability by the medical and “hearing” world.

To reduce confusion, we will use capitalization of the word “Deaf” when we refer to individuals who are members of the Deaf community and use American Sign Language, and “deaf” or hard of hearing (HoH) to refer to all others within the hearing loss population. (Deaf/deaf or Deaf/HoH).

deaf (Small “d”)

Any other use of the word deaf, absent the capitalization, will refer to individuals who have experienced a loss of hearing later in life. People who have become deaf in their lifetime normally view it as a significantly disabling condition for which they seek technological and medical intervention.

Acquired Deafness (Late-Deafened or Adult Onset)

These terms describe those people who have lost some, most, or all of their hearing suddenly or progressively during or after the teen years (post-lingually, i.e., after they had learned to use spoken language). This is sometimes called “adventitiously deaf.” Some with acquired deafness may have enough residual hearing to experience some benefit from hearing aids and/or assistive listening and amplification devices in order to detect certain environmental sounds. Others may continue to communicate through spoken language but have little to no usable hearing for understanding others.

Hard of Hearing (HoH)

These terms describe those people who have lost some, most, or all of their hearing suddenly or progressively during or after the teen years (post-lingually, i.e. after they had learned to use spoken language). This is sometimes called “adventitiously deaf.” Some with acquired deafness may have enough residual hearing to experience some benefit from hearing aids, assistive listening systems and amplification devices in order to detect certain environmental sounds. Others may continue to communicate through spoken language but have little to no usable hearing for understanding others.

~ Jonathan O'Dell's Story ~

Jonathan O'Dell, Assistive Technology and Training Specialist at MCDHH, has led a varied existence, both geographically and in the matter of hearing loss. Born in Jerusalem, Israel, to an Austrian chemist mother and American father who was at the time a part-time archeologist, editor, and basketball teacher, he began life with perfect hearing. He moved to Austria at the age of three, where his parents went their separate ways. His father insisted that he be educated in English, but he spoke German at home with his mother and her parents and considers the latter his “first language” because he spoke it for the majority of his formative years. He did not learn sign language until he was 26 years old.

Mumps at age four left him with decreased hearing; his grandparents noted that he was straining to hear music and sitting far too close to the radio, which was turned to high volume. A few years later, bouts with German measles and meningitis destroyed most of his remaining hearing. After he recovered and found himself unable to hear with no explanation of what had happened, he became angry and withdrawn and started getting into fights when he was taunted.

His grandmother was ill and his working mother couldn't handle her angry child, so he went to live with his father across town. After enduring several months of “charlatan cures,” his father flew him to Indiana University for testing. There, he was diagnosed as having a severe sensorineural hearing loss with accompanying virtual loss of any sense of balance.

At age 10, he began to attend an oral school for the Deaf and hard of hearing in Vienna and faced the first of many difficult years in his educational career. Until then, his formal education had been in English, so he had to learn written German under the guidance of two teachers who heaped on extra work. At the time, he hated them, but

within two years he was at the top of his class, the pride of the school. After completing school, there was literally no place for him to go in Austria. His father, insisting that he was destined for more than vocational school, enrolled him at Dover College, a private boarding school in England favored by international students.

Off he went to the bustling port city of Dover, Kent, England, where as the only student in the school with a hearing loss, he was terribly unhappy. Taunted by classmates, picked on by seniors because of his hearing loss, and humiliated academically, he stuck it out, with the help of an understanding Housemaster and some very good friends. He eventually found some sort of balance, managed to pass his “A” level exams, and obtained a diploma in linguistics.

During his stay there, his mother had remarried and moved to Germany and his father and stepmother had moved to Nairobi, Kenya. He traveled a lot, and was sometimes brought close to tears by seatmates who tried to talk with him during the long flights to Africa, ashamed to admit that he was “different.”

“One day,” he relates, “I just became really, really angry at myself. I decided that I was not going to live like this anymore. I marched to the barber, had my hair cut short so my hearing aids were revealed, and the next time I sat down on a plane, I initiated contact by telling my seat neighbor that I had a hearing loss. As clichéd as it sounds, that decision changed my life.”

After Dover, it was off to America, at his father’s behest, to attend college in Wisconsin. Thrust from a bustling European port town to a rural Midwestern community, his four years there were disastrous. His hearing was worsening, he couldn’t understand family on the telephone, and there were no support services for hard of hearing and Deaf students in those times before the passage of the Americans with Disabilities Act (ADA). After four years of majoring in social life, he left



without having graduated and found employment in a large printing company.

How did he end up in Massachusetts? One of his friends was from Massachusetts, and one of her best friends came to visit her in Wisconsin. It was love at first sight and Jonathan packed his bags to travel across the country with his newfound love. “By the tremendous kindness of this woman’s family and the incredible luck that one of their neighbors’ daughters was an RCD (Rehabilitation Counselor for the Deaf) at MRC (the MA Rehabilitation Commission), I was introduced to MRC and found my first professional job as an Independent Skills Trainer.” Shortly afterward, he was promoted to program coordinator at the Southeast Center for Independent Living, and after another three years, he went to work at MCDHH.

Several years later, the Americans with Disabilities Act passed, and he enrolled in the Division of Continuing Education at Harvard. He spent the next three years taking classes there, using a CART provider (Communication Access Real Time) supplied by the university in each class. He graduated with his Bachelor’s degree in 2000 and a Dean’s List Certificate of Academic Achievement.

In 2010, Jon was implanted with his first cochlear implant; in 2012, the second followed. He has done exceedingly well with them but is quick to remind people that a cochlear implant is not a guaranteed, permanent fix any more than hearing aids or assistive listening devices.

“There is no substitute for simple courtesy — asking what the best communication strategies are for your conversational partner, and then implementing them consistently without the need for constant reminders. It is often human nature that presents the biggest barrier to communication integration.”

CHAPTER 2

Where and When to Turn for Help

If you suspect that you have a hearing loss or have experienced an additional drop in your hearing, speak with your primary care physician (PCP) ASAP. He or she may recommend that you also see a hearing specialist to rule out any conditions that may underlie your hearing loss that can be medically or surgically treated. For example, it might be something as simple to “fix” as an ear wax buildup that is blocking sound from traveling through the ear canal, effectively rendering you temporarily “deaf.”

The average waiting time between a person’s first noticing a loss of hearing and treatment/reaching out for help is 7–10 years.

And that has consequences.

Don’t wait.

To repeat:

Sudden hearing loss is a medical emergency.

See a doctor immediately if you experience a sudden hearing loss in one or both ears; hearing loss accompanied by vision problems, dizziness, nausea, or pain or discomfort in the ear(s). In some cases, sudden hearing loss can be reversed or mitigated if treated within a very short window of time after onset.

HEARING SPECIALISTS

Otolaryngologists and Otologists

Otolaryngology is a medical specialty concerned with the ear, nose, and throat. As the result, these doctors are often called ENTs. An otolaryngologist may also be an otologist with a specialty in inner ear pathology or a neurotologist, a specialist in the parts of the nervous system having to do with the ear.

The overall title of a medical department that specializes in conditions of the ear is usually called the Department of Otolaryngology–Head and Neck Surgery.

After an examination, a preliminary diagnosis of hearing loss, and/or treatment, you will be referred to an audiologist for an evaluation and/or a fitting for a hearing aid.

The Audiologist

Audiologists specialize in the diagnosis, evaluation, and management of hearing loss and have extensive training in hearing loss and rehabilitation. In addition, they have passed a certification exam and hold a credential from the American Speech Language and Hearing Association (ASHA)

Audiologists must earn a professional degree (the Doctor of Audiology, or Au.D.) which typically involves 4 years of academic and clinical training in audiology, following a traditional 4-year bachelor's degree.

What an Audiologist Does

The audiologist will test your hearing and chart the findings on an audiogram. The in-depth assessment of your hearing will include:

- taking your medical and hearing history
- a physical exam of the ear canal with an otoscope
- assessment and documentation of the degree and configuration of the hearing loss
- advice regarding the best treatment options

The Audiogram

Your audiogram will show what frequencies of sound you are able to hear, measured in Hertz; and at what amplification levels you are able to hear these sounds, which is measured in decibels. You will also be tested to determine your speech discrimination level, which tells the audiologist how much of what you can hear you can actually understand. This involves a series of words being read to you and your having to repeat them back to the audiologist.

What happens next?

After you have had a full audiological evaluation, your audiologist may recommend hearing aids or cochlear implants, rehabilitative services, and/or a speech pathologist.

If hearing aids are a possibility, you will then work with your audiologist to determine the best options for your needs or be directed to a hearing aid dispenser or dispensing audiologist if yours is not one.

Hearing Instrument Dispenser or Provider

A Board-Certified Hearing Instrument Specialist has training in fitting and dispensing hearing aids, has taken an exam, and holds a credential from the National Board for Certification in Hearing Instrument Sciences.

Check the American Speech-Language Association (ASHA) website for more information:

<http://www.asha.org/public/hearing/Hearing-Testing>

Tip: *Whoever you work with will help you to select, fit and adjust the appropriate hearing aid or aids to accommodate your hearing loss and lifestyle. The dispenser will also introduce you to the use of the aids, instruct you in their care and handling, and recommend other hearing assistive devices that you can employ to help you hear in various environments and situations.*

Finding an Audiologist

Get referrals — talk to your ENT, friends, family members and other people who wear hearing aids. Contact MCDHH and the local chapter of

the Hearing Loss Association of America (HLAA) or the national office in Washington, D.C. Start with a good referral from someone who has had a positive experience with an audiologist and their hearing aids. You can also contact someone at audiology training programs at local colleges and/or universities as well as local medical centers/hospitals that offer audiology.

You can check the name, credentials and reviews of any audiologist with the American Academy of Audiology:
<http://memberportal.audiology.org/Directories/Find-an-Audiologist>

Questions to Ask Your Audiologist

- Will my hearing improve with a hearing aid? How so?
- What are the limitations to hearing aids that I might experience?
- Will I hear better right away?
- What's the best type of aid for me? Why?
- Will I be able to listen to people, the TV, music better?
- Will I need special programming in my hearing aid?
- What company's product do you recommend? Why?
- Will you (the audiologist) adjust the settings just once?
- Will I have to come in for additional adjustments?
- If yes, do adjustments have a benefit?

Be sure your dispenser knows the tools.

It's important that an audiologist/hearing aid dispenser has some idea of what auxiliary devices are available, not just from the original equipment manufacturer but also from independent manufacturers and vendors. These can expand the usefulness of a hearing aid in a manner benefiting your lifestyle and specific needs.

Bring this guide with you when you go get a hearing aid. Be sure that your audiologist/dispenser goes over with you the telecoil, Bluetooth, telephone accessibility, remote microphones and other features during the fitting process.



Some hearing aid users encountered by MCDHH don't know what a Telecoil is, much less if they have one in their hearing aid. And those who purchased hearing aids several months before speaking with MCDHH said that they were not told about the availability of hearing aids with integrated Bluetooth compatibility, leaving them uninformed about the availability of this option — as it would have factored heavily in their purchasing decisions.

In addition to considering the qualifications of the hearing aid dispenser, it is usually to your benefit to buy your aids from an entity that sells more than one brand of hearing aids. While there has been significant consolidation in the hearing aid industry over the past decades, there are still several major players out there, and you won't really know what you're missing if you don't try more than one manufacturer or one particular model of hearing aid.

Also look for someone who spends time talking to you and asks you questions about what you are hoping to accomplish with your hearing aids. Each of us has a different lifestyle and different expectations, and someone who sees you just as another “customer” is unlikely to spend enough time with you to address all possible usage scenarios.

Rehabilitative Services

Your Audiologist or an auditory trainer may be able to provide rehabilitative services to address and even improve your hearing experience including speech comprehension and coping skills. Also called Auditory Rehabilitation, these are formal or informal programs for training the ear and brain after getting a hearing aid or cochlear plant.

Speech Language Pathologists (SLPs)

These are specialists in preventing, assessing, diagnosing, and treating speech, language, social communication, cognitive-communication, and swallowing disorders in children and adults that may impact hearing and communication.

~ Karin Williams' Story ~

Born hearing, Karin suffered from chronic ear infections as a toddler. “I remember my mother was always putting drops of medicine in my ears. This wasn’t so bad since she always warmed the medicine up in a tablespoon lit by a match before pouring it into my ear. That always felt so nice and warm and soothing.” Her family noticed that she always crawled right next to the speaker of their old console television when it was on, even though repeatedly brought back to a slight distance, but they attached no significance to it.

“As I got older, the tomboy in me flourished and my mom frequently found me outside playing in the elements: the rain without a rain coat, the wind without a windbreaker, the snow without cap or gloves or boots,” she reports. She was plagued by constant colds and, once again, ear infections became a major part of her life. “I was not a happy camper!” she reports.

During this time, her pediatrician recommended perforating her eardrums to drain them, a popular practice in the '60s for treating chronic fluid build-up in a child’s ear. This perforation caused scar build-up on eardrum, leading to a mild conductive hearing loss. A first grade hearing test performed by the school nurse found that Karin had a mild hearing loss in both ears. Her parents consulted a pediatric audiologist, the first of many different audiologists, ENTs (Ear, Nose and Throat doctors) and speech pathologists she would encounter.

Her hearing remained fairly stable until she was 12 years old, when she began to struggle in school. “I wasn’t able to understand my teachers when they talked to the class. They, in turn, were worried by my lack of attention and poor progress in my studies.” Her audiologist diagnosed a mild bilateral sensorineural hearing loss and she received her first hearing aid. “I remember when I first put it on. The sounds I heard were awesome! It was a warm spring day so the birds were singing and the trees were rustling. It was a very positive experience for me.”

Karin still struggled with the daily activities of life. Her teachers made sure she sat in the front of the class and always checked that she was paying attention. “This was great for my education, but terrible for my social situation. I hated this special treatment because my classmates didn’t always understand and I was often ridiculed and called ‘teacher’s pet.’”

Somehow, she managed with a single hearing aid but her hearing became progressively worse. As a senior in high school she received a second hearing aid. “Again, the experience was awesome. I didn’t realize how much information I was missing until I got my second hearing aid.”

In an extremely mature move, she also took matters into her own hands. “Getting a second hearing aid also got me thinking that my hearing was gradually getting worse and that I would eventually become profoundly deaf. I decided to take an adult education level sign language class. I loved it and decided that I would continue to learn sign language in college and learn more about hearing loss.”

By the time she entered college, Karin’s hearing loss had become profound. “I had very little usable residual hearing, so I was basically functioning as a deaf person.” Nevertheless, she persevered through 8 years of college and graduate work, using her hearing aids, and other assistive listening devices such as personal FM systems, and auditory loop with T switch, in addition to notetakers and sign language interpreters to assist with class participation. She graduated with a Master’s degree in Deafness and Human Services and over the next 20 years worked in several different jobs in several different states.

Now back living and working in her native Iowa, Karin was a case manager at MCDHH for more than 18 years. While at MCDHH, Karin received cochlear implants and did so well with them that she went from total deafness to having conversations on the cell phone while driving.

CHAPTER 3

Trauma

written by Inger Riley, PsyD

Many books have been written on the topic of trauma. It's a broad subject and people can be traumatized in a variety of ways. The focus of this chapter will be on trauma as it relates to people within the Deaf and Hard of Hearing (HoH) populations; and then, more specifically, on those whose hearing loss is due to a traumatic event such as a blast injury.

The Oxford English Dictionary defines trauma as “A deeply distressing or disturbing experience” and goes on to include emotional shock that can result in long-term issues. In psychological terms, when someone experiences a traumatic event they usually have reactions to the event and this is a normal response to an abnormal situation. This chapter will cover some of the many reactions people can have to a traumatic event, how they can affect everyday life, and some ways to manage these reactions.

Trauma in the Deaf and Hard of Hearing Population

It would be helpful to know how often individuals who are born Deaf or HoH or become Deaf or HoH at a young age experience trauma and victimization. Unfortunately, most studies that look at rates of victimization lump all individuals with disabilities together and they add Deaf and HoH people to this main group. According to the Vera Institute of Justice, people with disabilities are three times as likely to be victimized as people within the general population. This research includes Deaf and HoH people but does not study them separately.

A research study that looked at Deaf people in particular found that they experience domestic violence and sexual assault at rates double to their hearing peers. (Anderson & Leigh, 2011; Anderson, Leigh, & Samar, 2011) Researchers have begun to try to separate Deaf and HoH people into a sub-category to study how many people have been victimized, but much



more research needs to be conducted to have an accurate picture within the United States and Massachusetts specifically. Generally speaking however, this population is more likely to be victimized and therefore has a higher rate of trauma than the general population.

How Deaf and HoH People are Victimized Other than through Violent Crime:

- Early language deprivation with traumatic consequences
- Poor communication at home resulting in punishment
- Institutional abuse in schools
- Negative social experiences within the Deaf and HoH population
- Negative social experiences with hearing people
- Ongoing frustration and negative consequences from lack of communication access

These examples highlight the experiences of some Deaf and HoH people. These may be singular occurrences or may build upon others which can cause increased harm and increased sensitivity to further traumatic events. It should be noted that for individuals with acquired hearing loss, the transition from being hearing to HoH can itself be a traumatic experience. These examples, added to the increased likelihood of experiencing victimization in childhood, plus being a victim of further violence or criminal activity, provide a substantial context for looking at trauma and its effects within this specific population of people.

Normal Reactions to an Abnormal Experience

Understanding general reactions to traumatic events may be a good place to start when exploring trauma. People who have gone through a traumatic event usually have some responses to that experience and these are called “traumatic reactions.” The following is a chart of *some* of the reactions people can have.

Psychological

Despair
Sadness
Terror
Fear
Isolation
Anger
Frustration
Sorrow
Anxiety
Hopelessness
Rage

Physical

Stomachaches
Earaches
Headaches
Joint pain
Nausea
Muscle stiffness
Lethargy
Insomnia
Hypersomnia
Changes in appetite

Cognitive

Difficulty concentrating
Memory impairment
Loss of time
Loss of language acuity
Poor focus
Changes in attention
Difficulty with decisions

These reactions are separated into categories to provide a sense of how people respond to traumatic events, but it does not mean these are the only ways people react. The above reactions are normal ways to respond to something horrible that a person has just witnessed or lived through in any way. The traumatic event is what is not normal. Understanding that these reactions are a normal way to respond to a terrible event or tragedy can help a person to tolerate these reactions and help manage them better.

Traumatic reactions usually appear soon after an event.

During the event itself, there are several responses that people can experience. For this chapter, however, the focus will be on what happens after the trauma has occurred. Immediately after a traumatic event or experience, the initial response is usually a form of shock and disbelief, with the individual checking in with him/herself to assess “the damage.”

The body responds physiologically to danger.

When a person is in danger their body responds physiologically to that danger. This is the “fight/flight/freeze” response. These are changes that occur in a person’s body in order to fight off, run away from, or try to hide from the danger. It comes from the animal instinct in us to survive. The physiological changes of heart rate, blood flow, digestion, heightened awareness and increased reflexes explain some of the reactions people



have immediately following a traumatic event and also when dealing with its aftermath.

Once people are safe again and ready to rejoin their life, the real work of integrating the traumatic experience begins.

Surviving a traumatic event or experience can affect people in many ways:

Social

- Isolation
- Change in groups
- Difficulty in “normal” social situations
- Feeling or being ostracized
- Talking with others who are not aware of what happened
- Joining groups associated with traumatic experiences

Familial

- Differing willingness to talk about it
- Blame
- Guilt
- The feeling of the home being safe/unsafe
- Changing dynamics in the family
- Uncovering of family history
- Secrets revealed

Occupational

- Going back to work
- Expectations of self
- Expectations of others
- Cognitive changes that may affect job performance
- Physical limitations
- Reactions of others to the traumatic event
- Shifting priorities

Legal

- Understanding victim rights and compensation
- Identifying a Victim Witness Advocate
- Understanding the law as it pertains to survivors
- Court procedures
- Law enforcement limitations
- Negotiating the legal system

Spiritual

- The questioning of beliefs
- The losing of one's faith
- The gaining of one's faith
- The challenge of good vs. evil
- Existential questions about the meaning of traumatic events and experience
- The issues of forgiveness and surrender

These are only some of the possible ways people can be affected. The above information reflects trauma in general and what people may experience when they've been through something that is probably the worst thing they have ever experienced in their life.

When a Crime Is Involved

Now suppose the person's traumatic event was a crime perpetrated onto them by another. Not a natural disaster or accident that by itself can be traumatic, but a trauma that was explicitly the result of someone's or some group's actions. There was a crime committed that resulted in a person or people being traumatized. If they were also the intended target, they were, then, also victimized. Now add that the crime is a terrorist attack and that part of the trauma involved the loss of some or all of their hearing. This group of people is now a new category added to the acquired hearing loss population within the Deaf and HoH population at large. This new group includes the survivors of the Boston Marathon bombing of 2013.

Hearing Loss due to Trauma

Since this new group has become part of the HoH population, it's helpful to talk about this sub-group who are HoH due to trauma itself. There will probably be more survivors over time who become members of this group as bombings and other tragedies involve concussive force, blasts, and other ways in which hearing can be affected. The people within this group are now trying to learn to recover from a traumatic event and also learn to identify as a Hard of Hearing person. With this group of people, the issues related to trauma are added to the issues related to sudden onset acquired hearing loss — and here, one is the cause of the other, not just related.

How Reactions to Trauma Appear and How to Manage Them

The first thing to know is that immediately after the trauma, these reactions are usually very strong and can come and go over time. If after a month or so the reactions are interfering with functioning at home, at work or with the people close, you can do the following:

Seek professional support.

Sometimes, seeing a professional soon after the trauma can provide support and tools to enable you to start managing the intense reactions and help with difficulties such as sleep, eating, and fear for example. This will depend on the survivor and their needs.

Understand triggers.

It's important for survivors to understand that the reactions to trauma will come back when triggered. Among other reactions, these can be in the form of nightmares, reliving the event over and over, or even suddenly feeling the fear they had when the event/experience occurred.

Triggers are things that remind the body or mind about the trauma, including but not limited to: loud noises, smells that bring a person back to the event, certain words, specific times of day, etc. These experiences can elicit traumatic reactions, bringing a survivor right back into the middle of an event, or to thinking about it and revisiting it in their minds.



This can be hard to manage when the individual is in the middle of a work meeting or a child's school play, for example.

Knowing what is happening and why “out of the blue” their heart is racing and they want to hide under the table helps to tolerate the trigger. Having some good techniques for managing triggers will help the reactions recede more quickly and over time it will be easier to manage them. For some people, triggers can appear years after the traumatic event. Nevertheless, having good tools and experience using them with success, helps people manage better long-term.

Tools and Suggestions

For survivors of trauma, here are some quick and simple techniques for managing triggers and traumatic reactions. The idea is to help you to know that you are not in the middle of that traumatic experience currently. Ways to do that involve either talking to yourself, or having your body talk to itself. The flight/fight/freeze reaction is the nervous system getting all worked up. If a person does some relaxation techniques, it cues the body not to go into the trauma response. If you relax your body, it is telling itself it is safe and there is no trauma happening right now, which calms down all the physiological responses to danger and reduces anxiety and tension.

Breathe slowly and deeply.

A key component to any relaxation technique is to breathe slowly and deeply. Some people also tell themselves several times in a row, in a calm and kind inner voice, where they are physically in the moment and that they are safe and in no danger. (“I am on my couch in my living room, and everything is fine right now. . . .”) It sounds a bit strange when you are not in the middle of a reaction, but when you are all worked up, it can be very soothing and comforting. Try it! It can help!

Here's a list of other ways to calm yourself and return to the present when the trauma volume is going up:

Grounding Techniques

- Feel your feet on the ground.
- Feel the chair under your body.
- Look around the room and notice the colors you see and the objects you can name.
- Notice where the sun is and if there are shadows (from a light source if you are inside).

Relaxation Techniques

Use these techniques while slowly breathing in through your nose and out through your mouth. If you are practiced in them, use diaphragmatic breathing techniques.

- *Progressive Relaxation:* Start at the top of your head and slowly move your attention down your body to your feet, stopping to allow all stress and tension, fear and anxiety to leave each area as you move your attention throughout. Make sure you stop at your shoulders and also your lower back as some of the areas to focus on. Many people hold a lot of tension there.
- *Stress and Release Relaxation:* Start at your eyebrows and slowly move down to your feet. Raise your eyebrows as high as you can and hold for a count of 5, and then release. Do this with your eyes closed intensely and then release; smile intensely and release; clench your jaw then release; flex your neck muscles and release; raise your shoulders as high as you can, then release; flex your biceps; your triceps; make a fist as hard as you can, count for five and then release — on and on and down to your feet. Contract muscles, hold and release, or stretch out fingers and toes and release.
- *Walking meditation, breathing meditation, eating, meditation, yoga*

Other Ways to Help Process and Manage Trauma Reactions

- Eating a healthy diet
- Processing, Talking, Sharing, Informing
- Normalizing the reactions as trauma-related (Knowing where they are coming from makes them less powerful and surprising.)
- Creating place-holders for the feelings (Use a visualization of a trunk or other place to put the overwhelming feelings into until you can deal with them at the time of your choosing.)
- Journaling
- Letter writing
- Drawing: Create drawings of what's happening at any moment, then another one that is in the future.
- Creating safe places/times
- Ritualizing experiences (Vigils, ceremonies, remembrances, e.g.)
- Connecting to others socially as well as through survivor groups with others who know or have experienced trauma too; through causes, foundations, and volunteering
- Exercise: aerobics, weight bearing activities, etc.
- Massage
- Distractions: Shopping, Movies, Books, Music, Recreation, Chores, Housework, etc.

These are just some of the ways to help manage traumatic reactions in the moment and in day to day life. Once someone has experienced trauma, the goal is to understand how the trauma has affected them, how to cope with and master those reactions, and eventually, how to incorporate the trauma into the person's life. How that happens, at what pace that happens, and if, in fact, it happens at all, all depends on the survivor, his or her life experiences prior to the trauma, and the supports around them that enable them to do the hard work of living again after they've been traumatized.

The issue of trauma is vast.

The issue of trauma within the Deaf and HoH population is vast and cannot be fully covered in this chapter. However, the hope is to better

understand how trauma can impact someone initially and over time, and offer some ways to manage trauma reactions when they arise.

Reactions are normal.

Reactions to having experienced a traumatic event or events is a normal part of having lived through something horrible, usually terrifying, and sometimes devastating. It takes time to put all of that in perspective and be able to live with what happened. Usually reactions diminish in the first weeks and months after a traumatic event. If they get stronger and more pronounced, then seeking professional help to manage the trauma would be strongly recommended. If depression begins, or suicidal thoughts arise, then seek help as soon as possible. No one should have to tolerate any of that on their own, and there are many ways that professionals can support and help with the healing from trauma. Regardless if you seek professional help or not, be sure to seek out supports from family, friends or groups and organizations. They will help you to know that you are part of a large population that cares and wants to help you through the process of healing from being traumatized.

For more information and resources to help you find assistance after trauma, please contact MCDHH.

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CHAPTER 4

Hearing Aids



Even a mild hearing loss can interfere with your ability to understand speech, use the telephone, and interact comfortably in your world. Your hearing loss might benefit from hearing technology. If so, it's time to explore the many options.

This is a good time in hearing history (hear-story) with an incredible variety of technological tools and toys to optimize your hearing experience. With guidance from your doctor, audiologist, hearing aid dispenser, plus your own trial and error experimentation, you'll find the right instruments to fit your specific hearing loss needs.

Positive Changes Ahead

Hearing research and technology are evolving rapidly, along with the knowledge of how we hear, what happens when things go wrong, and what methods of hearing augmentation, rehabilitation and/or restoration might prove to be most beneficial. It is also an important time to educate yourself about the current medical and technological options from multiple reliable sources and not just from a single individual, website, company or other resource.

The good news is that the growing visibility and an aging public's interest in hearing loss have driven researchers and manufacturers to come up with truly remarkable technology to help you manage your hearing loss.

Tip: *As with other points in this guide, expect this information to change with advances and products right around the corner.*

STYLES OF HEARING AIDS

All hearing aids are custom made and programmed to fit your specific hearing loss needs. The settings can be adjusted by your audiologist and sometimes by yourself through special apps and devices. It's always a good idea to continue to have your aid adjusted until you are comfortable, whenever there is a change in your hearing experience, or you wish to have more connectivity and/or flexibility with your instrument. Often, the cost of adjustments is included in the price of your aid.

Behind the Ear (BTE) Aids

As the name implies, BTE hearing aids house most if not all of the device behind the ear. Sound is sent from the hearing aid into the ear either by a tube connected to a custom earmold or by a thin wire connected to a tiny speaker in the ear canal. The style that includes the speaker in the ear canal is also known as receiver-in-canal (RIC) or receiver-in-the-ear (RITE). The tiny speaker can be in a custom earmold or in standard sizes. Given the range of options, BTE hearing aids can be fit to people with mild to severe to profound hearing losses. BTE hearing aids tend to have more options (such as rechargeable batteries, directional microphones and wireless connectivity).

Tip: *If your aid needs repair, it's easier to get a loaner with a BTE aid. You simply attach your earmold to the replacement aid and you're good to go. Another, often overlooked advantage, is that the size of the hearing aids makes adjusting external controls and replacing the batteries much easier for people with vision problems, arthritis, or fine motor control issues.*

In the Ear (ITE) Aids

The entire hearing aid fits inside the outer ear. Although there are a few powerful models, most are for moderate rather than severe to profound losses. These must be custom made to fit into the ear.

In the Canal (ITC) Aids

These hearing aids fit completely inside the ear canal and are mainly for mild to moderate losses. They must be custom-made to fit into the ear.

Completely in the Canal (CIC) Aids

These tiny aids fit deep in the ear canal and are removed with a stem of wire. They must be custom-made to fit into the ear.

CROS (Contralateral Routing of Signal) Hearing Aids

These are for people who have no hearing in one ear and good hearing in the other. The components look like two behind the ear aids, but the one draped over the poorer functioning ear has no earmold, and instead contains a wireless microphone and transmitter, while the unit draped over the “better” ear contains a corresponding receiver and speaker. This allows sound from someone’s “bad” side to be transmitted wirelessly to their “better” ear.

BiCROS Hearing Aids

Similar to CROS hearing aids, these are for people who have no hearing in one ear and also hearing loss in the other. The microphone is worn in the poorer functioning ear and the receiver is built into an actual hearing aid worn in the better ear.

Bone-Anchored Hearing Aids (BAHA)

This type of aid operates by bypassing the outer and middle ear and transmitting sound directly to the cochlea using what is referred to as an osseointegrated (bone-anchored) implant. A titanium post is implanted behind the ear in a minor surgical procedure. The sound processor then snaps onto this post. Sounds picked up by the processor’s microphone cause the post and the connected bones to vibrate, generating a response in the cochlea. The processor can also be held onto the skull using a surgically implanted magnet. Even without surgery, a BAHA can be used when held onto the skull using a headband.

Tip: *This type of hearing aid is useful for those with chronic conductive hearing loss (such as chronic ear infections, a congenital hearing loss due to malformation or absence of the outer ear or middle ear known as atresia), or for unilateral — single-sided deafness.*

Eyeglass Aids

The temples of these glasses incorporate the hearing aids. These models were quite popular from the 1950s through the '70s. A newer variant, which includes multiple directional microphones in the sides of the frame, has been developed by Varibel, a Dutch company.

Disadvantage

- The obvious drawback here is that you may still want to hear when you take off your glasses, which is impossible when using this type of aid.

HEARING AID FEATURES

Analog vs. Digital Hearing Aids

Before there were commercially viable digital devices starting in the 1990s, hearing aids were analog. These aids did not have the ability to be precisely adjusted to meet not only the individual's hearing needs, but also to accommodate the variances in different acoustic environments.

Digital hearing aids overwhelmingly dominate the market today. They allow for precise matching of the amplified signal to those frequency bands most affected by the user's hearing loss. They match the amount of amplification needed to the amount of sound in the environment which makes listening much more comfortable. They also improve the signal to noise ratio using:

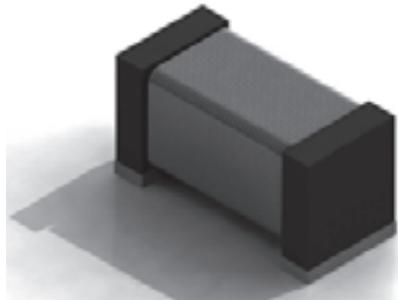
- integrated noise reduction (allows you to block out some of the sounds that you don't want to hear and focus on those that you do)
- directional microphone circuitry (allows you to "aim" your hearing somewhat, with the same purpose).

Digital hearing aids also have situation-specific programs that can be activated automatically or by the user, and advanced algorithms to minimize feedback — the whistling sometimes heard when a hearing aid amplifies its own sound.

Hearing aids have changed dramatically.

Hearing aid features that are commonplace today would have seemed like science fiction only ten or twenty years ago. If you read this guide two months from now — never mind two years — there will most probably be something new and revolutionary afoot that you won't find mentioned here because it either doesn't exist or hasn't been publicized yet.

THE TELECOIL



Telecoil (aka T-Switch or T-Coil) is a small spool or coil of wire that lets the hearing aid pick up electromagnetic energy from a sound source such as a hearing aid-compatible telephone receiver or assistive listening device and converts it back to amplified sound. Since 1989, every corded telephone sold in this country has been required to be hearing aid (telecoil) compatible, a compatibility which has since extended to many models of wireless phones as well.

Telecoils may vary greatly in effectiveness between manufacturers and models. You should have a way to manually activate the telecoil when needed, whether by a program selector switch on the aid, an external control, or via a smartphone app if that is your preference and if it is available for the hearing aid you are considering.

Automatic Telecoil Activation

Here's another option, one that can be somewhat challenging at times as it may turn on when you don't want it to and not turn on when you do want it to.

Positioning is important.

When using the Telecoil, the external telecoil (the one in the telephone handset, for example) should be in close proximity to the internal telecoil of the hearing aid. If not, you may not get a signal, or a very weak one. For best results, they should be in physical contact or as close as possible to one another.

Background Noise

The telecoil setting helps eliminate some or all of the background noise at your location. Some hearing aids and cochlear implants offer adjustable T switch to microphone pickup ratios, allowing you to decide how much you want to hear from the telecoil and how much you want to hear from the hearing aid's or cochlear implant's microphone.

Bluetooth

If you are a smartphone owner, enjoy listening to the television but are afraid of annoying your partner by turning the volume up, or enjoy listening to music, consider Bluetooth. Bluetooth is a wireless connectivity protocol that allows two devices to link together in a process called "pairing," a kind of virtual handshake to establish a private connection between your hearing aid and a smartphone, or a TV "streamer" connected to your TV or audio components.

It is becoming almost ubiquitous and allows for small remote microphones, smartphones, or Bluetooth "streamers" that can be connected to telephones and television sets to send sound information directly from the sound source to the listener's hearing aids or cochlear implants if the latter are equipped with Bluetooth functionality. If they are not, a Bluetooth receiver/neck loop can be used to the same effect.

The beauty of Bluetooth is that it:

- is an open and universal standard already built into many communication and entertainment devices
- does not require a wired connection
- allows you to hear in total privacy since the sound is being streamed directly into your hearing aids or cochlear implants
- can also be streamed into small portable receivers that are linked to your hearing devices (if they predate integrated Bluetooth functionality), and
- can be employed via a small, clip-on “remote” microphones that streams sound directly to your hearing devices, which can enhance speech comprehension in noisy backgrounds.

Feature Overload

Some people with or without hearing loss are not comfortable with technology beyond a basic level of features. Buying an advanced hearing aid that requires a familiarity with other forms of unrelated technology such as a smartphone is often counterproductive and unnecessarily expensive. In some cases, having no technology is almost better than having technology that does not work for you, so keep that in mind before buying the latest hearing aid or gadget for yourself or someone who still remembers and misses their rotary telephone.

PURCHASING HEARING AIDS

Currently, the standard recommendation is to purchase your hearing aid from an audiologist or hearing aid dispenser you choose to work with. Hearing aid companies do not sell direct to consumers but through their channels to the audiologist and other dispensers.

While the times and regulations are changing, you can't go to a hearing aid “store” to get a cheaper aid like you might do when you're trying to decide which TV to buy. You can go online and find a hearing aid for less, but what kind of hearing aid do you choose, and does the cost provide

any servicing? Who will do the testing, and the fitting and adjustments? You will want all that knowledge and service behind your purchase. You cannot get that online.

You can also buy hearing aids at retail at a big box store like Costco. Buying hearing aids at big box retailers can also result in lower prices since they have enormous purchasing power. Sub lines of hearing aids and less expensive options are often sold from reputable hearing aid manufacturers with many years or decades of experience in business. However, it would be wise to investigate the qualifications of the dispensing staff at the retailers you're considering — are they certified medical professionals who can answer questions you might have about hearing loss or the fitting process?

Tip: *You may experience a difference in the quality of services and products available at a big box store vs. working with an HCP — Hearing Care Professional like an audiologist or board-certified dispenser.*

Tip: *The most important advantage of working with an audiologist/hearing aid dispenser is that you will work with someone who knows you, understands your hearing health history, and is intimately familiar with the hearing aid being considered. Normally, your adjustments won't cost anything.*

How much does a hearing aid cost?

Hearing aids are expensive. First, find out if your insurance company will pay for all or part of your hearing aid(s). Find out if there are any health company or community grants (veterans, etc.) or other programs available to you to help defray the cost such as flexible spending accounts (FSA) or health savings accounts (HSA). Cost depends on your needs but aids will run from \$75–\$3,000 or more, per hearing aid — with a great variation up and down. Usually, all of the service (selection of the device before purchase, adjustments and troubleshooting after purchase) is bundled into the price of the hearing aid. Sometimes hearing aids can be purchased separate from the service, which requires the audiologist or dispenser to charge a fee for their service.

Tip: *The best companies make great hearing aids. But the reality is that the costs without insurance can be prohibitive. Most companies also have a “B” line of products — less expensive but with little fall off in quality. Ask your audiologist about the “B” line of products available, but be sure you aren’t sacrificing important features in the process. The process is somewhat similar to buying a lower trim model of a car you might be considering if you don’t need/want all the fancy features — just be very certain that you’re not giving up an option that you’re later going to wish you had included.*

Insurance Coverage

In Massachusetts, hearing aids for children are covered by health insurance. There is, at time of writing, no such mandatory coverage for adults with existing health insurance policies that exclude pre-existing conditions. Even when available, coverages may vary widely, as will deductibles.

Over-the-Counter Hearing Aids and Personal Sound Amplifier Products (PSAPs)

The issue of costs especially has brought us to the era of the over-the-counter hearing aid. Over-the-counter personal sound amplifier products (PSAPs) are already available and sold in a variety of places (such as online, at pharmacies, etc.). By law they may not be called hearing aids for good reason — they are not considered to be such under the Food and Drug Administration (FDA) regulations. They vary in their features. Some are simple amplification devices made to look like hearing aids, and others have the same features as hearing aids and Bluetooth in-ear headphones. Regardless of their features, they are not permitted to be marketed or sold as products to help hearing loss.

In 2017, Congress passed, and the president signed into law, the Over-the-Counter Hearing Aid Act of 2017. This brings new and emerging technology (at least in the realm of mild to moderate hearing losses, which these aids are designed to accommodate) and the potential modification of costs onto the landscape. As a result, it is more important than ever to have a full audiological evaluation and become an informed and knowledgeable consumer of hearing aids and assistive technology before you buy any product at any price point.

Tip: *If you've already had hearing aids before, or have them now and are simply trying to buy a replacement hearing aid, you may be able to do this online as well as through your audiologist or hearing aid dispenser. Since your hearing aids will likely require individualized adjustment, make sure that your audiologist or hearing healthcare provider will adjust hearing aids that they did not sell to you. You may be charged a fee for that service.*

In the days of analog hearing aids, this was a much more straightforward process since many aids could be adjusted by their owners by virtue of changing physical controls on the hearing aid itself to match those of their previous aids. Today, sophisticated computerized equipment may be needed for fine-tuning some devices, which makes professional assistance mandatory. Still others can be adjusted via smartphone apps or remote controls.

Tip: *If you have a very mild hearing loss, PSAPs may work for you. Just be aware that they are not hearing aids. That said, your audiologist can do a hearing test and may be able to verify fit as well as advise on adjustments. You may also need a smartphone or other device to get the best functionality out of them by adjusting listening parameters via dedicated apps.*

Tip: *Legitimate hearing aids sold over-the-counter are not yet available at time of writing, although legislation has passed allowing for this to happen. While the OTC sale of hearing aids may potentially reduce the cost of hearing aids and thereby increase availability, the danger is in the fact that hearing loss is not always a symptom in and of itself, as has been mentioned extensively throughout earlier chapters. It can be a sign that something systemic and more serious is going on in someone's body. If the symptom is treated without the underlying cause being discovered, there could be significant health repercussions. Also, improperly fitted hearing aids can injure the ear or make hearing loss worse.*

On the Flip Side of This Argument

Hearing aids are prohibitively expensive, so much so that many people simply cannot afford them and end up not buying them meanwhile

suffering from the repercussions of untreated hearing loss and the isolation it creates. While dispensers may point out that the cost of a hearing aid often includes adjustment visits and sometimes free batteries, filters and other equipment, not everyone requires frequent adjustments, and batteries and other supplies can be purchased fairly inexpensively by consumers themselves through direct retail.

Tip: Caveat Emptor. (Buyer beware.)

One side of this technological boom is that for every breakthrough and innovation, there are claims made which are simply not accurate and which can be downright misleading. Many of these misleading claims play on the understandable desire of someone with an acquired hearing loss to be able to hear and function just as easily as they previously did in their familial, social and workplace environment. Unfortunately, this may not always be possible, regardless of how much money one spends.

Tip: Search the web and look for more tips on how to save money on hearing aids.

Return Period

By law, you have a 30-day trial period within which you can return an as-new hearing aid for a full refund, minus the service fees up to 20% of the purchase price.

Tip: MCDHH encourages consumers to demand written extensions of these 30-day policies in cases where a hearing aid has to be readjusted after two or three weeks from the initial fitting date. Note that this leaves a consumer with only a single week to decide whether the second adjustment was adequate to make the hearing aid work for them. Make sure any such agreement is written into the sales contract and that you keep a copy of all the paperwork and sales slips and adjustment dates.

Be an educated consumer.

Buying a hearing aid is a major purchase — like buying a car — and you will have to live with your purchase for many years. Get it right from the beginning with the right hearing aid dispenser and never stop asking questions or requesting adjustments when needed. You'll be glad you did.

Do your homework.

Go to the websites of hearing aid companies and find out what they offer.

Google any questions you have that are not answered in your initial search. Each company now has multiple hearing aids with multiple feature sets, accessories, and apps that can further enhance your hearing experience.

HEARING AID COMPANIES

Here is a short list of some popular hearing aid manufacturers. It is not intended to be a complete list; rather, it is intended as a starting point for further research.

Oticon

<http://www.oticon.com>

Phonak

<https://www.phonak.com/us/en.html>

Resound

<http://www.resound.com/en-US>

Signia

<https://www.signiausa.com>

Starkey

<http://www.starkey.com>

Widex

<https://www.widex.com/en-us>

***Tip:** Each of these companies produce other brands or sub-brands that may be less expensive than their top of the line product.*

Here's a website that reviews hearing aids top to bottom:

<https://www.hearingtracker.com/blog/hearing-aid-brands-in-2017>

CARING FOR YOUR HEARING AID

Perspiration is likely going to be a factor with your hearing aid. In fact, moisture is the biggest enemy of any electronic device, including hearing aids. Get help and training in how to effectively dry and clean your hearing aid and/or ear mold/receiver. Ear wax and other detritus accumulates and can make any hearing device less effective or, at worse, unusable. Impact damage and high heat can also render a hearing aid inoperable, so it is a good idea to not drop hearing aids or keep them in the glove box of a car

in scorching sunlight. Conversely, bring them inside rather than leaving them outside overnight in sub-zero temperatures.

Hearing Aid Dryer Options

Many hearing aid users have no knowledge of commercially available, renewable hearing aid drying kits that contain silica gel desiccants for overnight moisture removal. These inexpensive solutions can greatly extend the serviceable life of a hearing aid. There are also specialized electric dryers with both drying and ultraviolet light capability to kill bacteria as well as eliminate moisture.

Tip: *Never use a hair dryer set to high or a microwave to dry hearing aids out, even if they've been exposed to water. If no high-tech solutions are available, place them, with batteries removed and battery compartments opened, in a sealed Ziploc bag containing uncooked rice overnight. The rice will act as a natural desiccant until you can bring the aid to your dispenser for further follow-up.*

WEARING A HEARING AID

Wearing a hearing aid is not like putting on a pair of glasses, even those worn for the first time. There are many more adjustments to be made, not just technically, but physically, psychologically, and emotionally as well before you enjoy the quality of life and comfort that a hearing aid can provide. That said, there are some helpful rules of the road that any experienced hearing aid user knows well.

Physical and Lifestyle Considerations for Hearing Aid Users

What is your overall physical condition?

Will you be able to independently insert a potentially tiny hearing aid into your ear by yourself, or change a filter or battery? What about a year or two from now? Do you have a very sedate or active lifestyle? For many individuals in supported living residences in Massachusetts, hearing aids are uselessly kept in drawers because their owners cannot put them on independently any longer, and staff may not be trained to help them to



do so, or are afraid to do so. This is often the same scenario for many elders with diminishing physical capabilities who are still living in their own homes.

Smaller hearing aids take tiny batteries, which may be difficult to change even with self-dispensing battery packs, doubly so when arthritis, vision loss, and diminishing physical dexterity come into play.

Rechargeable Hearing Aids

If that is an issue, you might want to consider rechargeable hearing aids, but those also have to be placed on a charger correctly in order to recharge. There really is no easy way of getting around a frank assessment of your ability to actually use the hearing aid you are considering purchasing. A larger hearing aid, while more obvious, might actually be easier in everyday use simply because everything about it, from the controls to the batteries will be larger, and consequently, easier to see and adjust. This becomes less of an issue with hearing aids that feature remote controls.

Every hearing loss is different.

Some of us are teachers, social workers or musicians; others, computer technicians, engineers, mechanics or architects. Hearing loss will affect everyone differently depending on their general health, socioeconomic status, jobs and vocations, personality, their psychological and emotional makeup, and the level of support — or lack thereof — they receive from people in their immediate environment.

Even a slight hearing loss can have a great negative impact depending on the importance that hearing acuity has in the individual's life. There are some areas where hearing as well as is humanly possible is not just convenient but necessary, and for people in those situations, even a slight hearing loss may have a much greater negative impact than a more severe hearing loss might have on someone for whom perfect hearing may not be as critical to everyday functioning.

Have realistic expectations.

It's easy to have unrealistic expectations of hearing aids — “Life will go back to normal;” “I'll be able to hear everyone again,” “I can get back to watching TV or listening to my favorite music again,” etc. There are expectations formed from marketing campaigns that make it sound as if hearing aids work as effortlessly and perfectly as eyeglasses do. Neither is true. Imagine your disappointment when you put on your new hearing aid expecting an instant reversal of your hearing loss, only to find that while there may be significant improvement in some areas, your communicative abilities in other environments may actually appear to have become worse at first.

Best Case Scenario

While sweeping generalizations cannot easily be made, it is fair to say that for most people with hearing loss, talking face-to-face with a familiar person who is enunciating clearly, in a well-lit environment free of any other sound source, is much easier than trying to pick out one voice among many in a loud, dark restaurant or at a party full of strangers.

Hearing aids reconnect you to your world.

People don't buy hearing aids to help them sit alone, at home, in a quiet environment, talking to only one or two people at a time. They buy them because they want to be social and interact with other people in most everyday environments, and those environments are often unpredictable. There can be overlapping speakers, ambient noise, poor acoustics, less than ideal lighting, and many other factors that can make picking up one particular voice out of many a real challenge.

There are no guarantees.

It is important to realize that current hearing aids will not function to everyone's satisfaction, all the time, in every situation. Once that is accepted, you can start to enjoy the settings, programs, and functionalities offered by hearing aids.

Adjustments can be made to help optimize their effectiveness across different listening settings and circumstances over time, once you've adjusted to the basics.



Take it slow.

The best result for you will come from gradually adjusting to and getting comfortable with your hearing aid. Don't put on a brand-new hearing aid and immediately seek out a conversation in a challenging environment. In fact, that is a primary reason why many hearing aids end up in the drawer, never to be used again. New hearing aid users can easily become disappointed, disillusioned and frustrated, particularly because hearing aid marketing makes the process look so easy and effortless.

That will change if you take it slow and if you do, you'll discover new things each day that will enhance your hearing experience. If you're still having trouble adjusting after two or three weeks, get back to your audiologist ASAP and work together to make your aid work for you optimally. Take your time to understand what your hearing aids can do, how the different programs work, and get used to hearing things differently than you did before. When you've reached that point, you can start seeking out more complex environments and hearing challenges — and expect that you'll be making more adjustments then too. That's the lay of the land.

CHAPTER 5

Cochlear Implants (CI)

A cochlear implant's external components may well look like an oversized hearing aid, and they are intended to improve a person's hearing. But that's where the similarities end. Unlike a hearing aid, a CI consists of surgically implanted as well as externally attached components, and they function very differently from hearing aids.



A Little History

The first wearable cochlear implant was developed by Dr. William House in 1969 to aid lipreading. It had a single electrode. Nine years later, Graeme Clark implanted a multi-channel device in a fellow Australian. In December 1984, the FDA approved the Australian cochlear implant from Cochlear Corporation for adults. The target audience for the first cochlear implants were people with severe to profound sensorineural losses (and intact auditory nerves) who received little benefit from hearing aids. Now, cochlear implants are approved for adults and children over 12 months of age with severe to profound hearing loss.

Opposition from the Deaf Community

For years, many people in the Deaf community vehemently opposed cochlear implants, particularly for children. They saw them as an assault on Deaf culture and American Sign Language (ASL). Everyone seems to agree that in an ideal situation, children would be able to decide for themselves if they want an implant. The medical perspective is that there

is a short window during which children soak up languages readily, and the decision should optimally be made very early for the best chance of oral language acquisition. In a very positive trend, many children who are implanted as infants are also being exposed to American Sign Language (ASL) these days, and this duality of language acquisition — ASL is a language on its own — can provide a level of choice not present at either of the extreme ends of the ideological spectrum. Of course, adults are free to make choices in a way that children are not, and in fact adoption of cochlear implants among older adults is increasing exponentially.

Three Companies

At this writing, the FDA has approved implants from these companies:

Cochlear Corporation

<http://www.cochlear.com/wps/wcm/connect/us/home>

Advanced Bionics

<https://www.advancedbionics.com/content/advancedbionics/us/en/home.html>

Med-El Corporation

<http://www.medel.com/us>

How a CI Works

- Sound goes to a microphone worn on the head.
- The sound is received by a processor, which is usually worn behind the ear like a Behind the Ear hearing aid, or, in some recent models, can be worn as an integrated all-in-one unit that does not require any wires or earpieces.
- The processor converts the sound to electronic signals which are transmitted inductively — via the headpiece — to the implanted receiver/ stimulator, from which they then travel to the electrode array implanted in the inner ear.
- This electrode array then replicates the functioning of the “normal” cochlea’s architecture by providing stimulation to the auditory nerve, the same way that the cilia or hair cells in an undamaged cochlea would work.

The Implantation Process Procedure

Cochlear implants involve invasive surgery performed under a general anesthetic. Until recently, only recipients with severe hearing loss who could not benefit from a hearing aid could qualify for a CI.

- The incision takes anywhere from 10 days to 3 weeks to heal completely, at which point the implant is connected to the external processor, then turned on and programmed.
- As with hearing aids, the sound that reaches the brain is far different from what one has likely become accustomed to and the brain must “re-learn” how to hear.
- Many implant recipients report that initially, voices sound distorted and unpleasant.
- Results vary considerably from person to person and it has been difficult to predict the functional success of the procedure in advance.
- The initial adjustment period does not take long, and with continued practice, sounds become more natural quite rapidly, usually within the first several weeks or months.

Implants have improved dramatically.

- As minimally invasive surgery techniques have become commonplace, the incision made in the surgical process has become smaller and the healing time has become shorter.
- The requirements for qualifying for an implant have become far less strict.
- Most adult implants are now behind the ear or all-in-one models rather than belt-worn processors with ungainly wires. The number of channels has increased.
- Mapping strategies have improved.
- Some processors are available in waterproof versions or can be outfitted with external sealing mechanisms.
- Insurance companies are far more likely to pay for monaural or binaural (both ears) implants as they are gaining in popularity.

- Telecoils, Bluetooth, and sophisticated noise reduction programs that reduce the distracting impact of ambient sound are commonplace so work very well with hearing aids in cases where one ear isn't yet at the level of requiring an implant. Some hearing aids and implants can share sound information binaurally.
- If there is usable acoustic hearing in the implanted ear (typically in the lower frequencies), sound processors can simultaneously amplify acoustic information where it's useful and electric information everywhere else. (See hybrid cochlear implants below.)

Impressive Results

Many users of current devices report some extremely impressive results, which bear fruit almost immediately. In 1997, Nancy Delaney called her decision to get an implant after almost 40 years of deaf-ness caused by a childhood illness:

“... the most courageous thing I have ever done in my life . . . but it certainly turned out well for me. I became a top performer during my second week of usage. I was using the phone by week #2 with limitations. I have progressed from there so that I can hear well without lip reading, even in moderate noise. I can hear music very well, use the phone with almost everyone.”

Not everyone is such a star. Most people report steady progress over several years. Even those who receive the least benefit are usually able to hear environmental sounds, and find that the implant helps speechreading.

Tip: *It is very important, especially in these days of social media pervasiveness, to not judge one's own progress based on unverified statements of success made by others whom one may not even know outside of their online presence.*

Expectations

Expectations play a huge role in the success of a CI implantation, with reasonable expectations being a positive motivational factor that can encourage postoperative auditory training. Unrealistic expectations — “I will be a better/happier/more successful person” — can negatively impact the post-procedural satisfaction level.

Fine Tuning

Getting the most from the implant involves fine-tuning the processor program (the map) many times over the span of one’s life. With each adjustment, and with continuing practice of repetitive listening techniques and programs, users can gain better comprehension for significant overall enhancement. For many users, it may be possible to upgrade the external processor to the newest model at some point, which would allow increased listening and comprehension benefits.

Get the most benefit from your cochlear implant.

- Work with an auditory rehabilitation specialist.
- Practice listening to audiobooks and take advantage of specially curated websites and programs hosted by implant manufacturers, cochlear implant centers and rehabilitative professionals.
- Be prepared to invest time and effort into learning how to hear again. Many find the experience fun and exhilarating, marveling at each new sound.

With Special Thanks to the Brain

The success of the cochlear implant is a testament to the plasticity of the human brain, which can somehow convert the impulses from a handful of electrodes (up to 22 in some implants) to an approximation of the sound received by thousands of hair cells in an undamaged ear.

Cost

The cost of the device, surgery, and follow-up rehabilitation may exceed \$100,000 which may be covered in whole or in part by your health insurance.

Acid Test

In the past, the acid test of a successful implant was whether the implant user could use the telephone. The focus has now shifted to music. Early implants were designed to maximize speech comprehension, but recent improvements in technology and mapping (programming) the processor now allow many people to listen to music with pleasure. Again, the key to success is continual exposure and practice.

Physical Considerations

- Surgery is performed under general anesthesia with the risks any such procedure involves.
- The surgery may be destructive to the cochlea in the implanted ear, so you may lose some or all residual hearing in that ear. As a result, users of traditional implants will be unable or less likely to benefit from any possible future developments in hair cell regeneration.
- It must be said that this has been a focus of intense research and improvement, and the level of invasiveness experienced by recipients of the first generation of implants was very significantly greater than what is experienced today.
- An April 2007 study confirms that people with cochlear implants are more susceptible to bacterial meningitis and should be vaccinated against the disease.
- Because of the magnet embedded in their heads, in some circumstances, recipients of some implants cannot undergo MRIs, a fairly common and very important medical diagnostic tool, without having the magnet surgically removed from under the skin of the skull.
- At least one CI manufacturer claims to have developed an implant where this is no longer a concern, so speak to your CI surgeon about this if you know or suspect that you will need MRIs frequently.

- There is a slight danger that the surgery might damage the facial nerve. This does not happen often, and is guarded against during surgery by careful monitoring.
- In a very small percentage of people, the body may reject the implant, or implants may fail post-implantation, or any number of other issues common to any implantable devices can occur. These are usually the result of an individual physiological response and not indicative of wider issues. In these cases, the implant can often be replaced.

OTHER OPTIONS

Hybrid Cochlear Implants

A large percentage of people with sensorineural hearing loss (so-called “nerve deafness”) have a severe loss in the higher frequencies — the common “ski slope” audiogram configuration which is often associated with aging and which makes the comprehension of speech sounds particularly difficult.

They may however retain usable and sometimes fully functional “normal” hearing in the low frequencies and are reluctant to sacrifice it via traditional implantation. To address this large population, implant manufacturers have created “hybrid implants,” which capitalize on the fact that the hair cells in the cochlea respond sequentially to different frequencies, running from high frequencies at the beginning of the snail-shaped spiral to low frequencies at the end deep within the inner ear.

By inserting a shorter and gentler electrode array only into the first section of the cochlea, the hair cells at the end of the cochlea that stimulate the auditory nerve when low frequencies enter the ear, remain untouched. This preserves natural low frequency hearing, which is then assisted by a (non-surgical) hearing aid component integrated into the CI processor for a “best of both worlds” approach.

Auditory Brainstem Implants (ABIs)

As mentioned earlier, people whose auditory nerves do not function are not candidates for cochlear implants. The auditory brainstem implant is particularly relevant for people with NF-2 (neurofibromatosis type 2, a hereditary condition in which acoustic tumors grow on the auditory nerve, which must be severed during life-saving surgery). Instead of using a fine electrode inserted into the cochlea, the ABI uses a flat plate implanted directly on the brain-stem to bypass the auditory nerve.

Results from this device are similar to those from the original single channel cochlear implant. They let the user hear environmental sounds and help with lipreading. Some users do even better. The House Ear Institute conducted trials of a second-generation device, the penetrating auditory brain implant (PABI), that uses needle-like electrodes as well as the electrode plate of the ABI. The combination improves the perception of pitch and appears to produce improved understanding of speech.

THE FUTURE OF COCHLEAR IMPLANTS AND YOU

Unexpected Consequences

Few people think about what will happen to their close personal relationships following implantation and the potential reclamation of one's identity as a mostly "hearing" person.

Especially with people who lost their hearing many years ago, and who have in the intervening time adjusted to a high level of facilitation and mutual dependence with their immediate family members, suddenly becoming more independent is just as jarring as having become less so all those years ago.

A family member who has become used to being indispensable may suddenly find themselves literally cast adrift as their newly minted "hearing" partner strikes out on their conversational and communicative own. These changes are not inconsequential and should be dealt with just like any other significant change in any existing relationships if it is obvious that the status quo isn't working any longer.

The Future of Cochlear Implants

- The current generations of implants already incorporate wireless functionality that significantly expands the spectrum of interoperability with external devices such as smartphones, sound systems, televisions, vehicular entertainment and other devices and systems.
- At some point, miniaturization will likely lead to complete subdermal device implantation. Trials on completely implanted processor/receiver combinations have been underway for some time.
- Similarly, is it entirely likely that electrode numbers and placements will be revised upward, and that the method of stimulation might itself change, much like traditional conductive signals are being replaced with fiber optic transmission networks in our IT infrastructure.
- No doubt current advances in truly wireless (non-contact) charging, or self-generated biological process charging, will also find their way to the cochlear implant world.

It is always best to talk about these kinds of things directly with manufacturers and their local support groups and representatives, as these and other innovations are usually considered to be proprietary and generally kept under wraps until announced publicly

What is the best option for you?

The best option is always the one that works for YOU — which means it does what you want it to do, it's easy to figure out how to get the most out of it, you're comfortable with the acquisition, acclimatization and daily use/maintenance process, and it is reliable enough that you're not finding yourself constantly without it while it's being repaired or replaced.

It's important to make your own decisions. Stay informed and up to date to further validate your important choices. Do talk to other people who've been in your shoes, at least to get alternative perspectives, and be mindful that your surgeon and their team are there to support you every step along the way. Don't be afraid to ask questions, challenge answers, and do whatever is necessary to feel comfortable about the overall process.

CHAPTER 6

Options for Speech Communication

Whether you do or do not wear a hearing aid or cochlear implant, everyone with acquired deafness develops unique ways of handling communication challenges. No single method works in every circumstance or is best for everyone. The more tools you employ, the easier the task of communication becomes.

“Let me put my glasses on so I can hear you” may sound like a joke, but it’s not. When our ears fail us, we come to rely more on vision. In fact, using both together strengthens comprehension and communication.

SPEECHREADING

(Also known as lipreading)

You may already know how to speech read or will develop that skill over time. Lip movement, facial expression, and body language all can help you understand the spoken word and are very common. Most people, even hearing people, already speech read to some extent, for example, in noisy places.

Not a Cure-All

Many people who lose their hearing at a young age are phenomenal speech readers, yet speechreading isn’t a cure-all. Many sounds look the same on the lips or are invisible.

Only about 30% of all speech can be identified from lip movement alone. The other 70% comes from other sources:

- Residual hearing — You can make use of whatever hearing you may have left. You’ll be amazed at how much you can derive from the smallest auditory clue.

- Context — We all expect to hear certain words in certain situations. If you are talking about Tiger Woods, the pro golfer, you might expect to hear the words birdie, par, fairway, putt, among others. If you are in a restaurant, you might expect the waitress to tell you about the soup and vegetable of the day, what salad dressings are available, or ask if you want your hamburger well done or medium rare. Knowing the topic and context allows you to guess at what is being said far more accurately. What can be difficult is when a speaker changes the subject unexpectedly, which removes the contextual clues.
- Body language and facial expression — Few people talk with a completely wooden expression. A raised eyebrow, a pout, a shake of the head all give you clues that you can use to help understand conversation.
- Our intuitive knowledge of the language (called “collocation”) — Some words keep company with other words. Having grown up in the hearing world, we are attuned to the grammar and rhythm of the language, common phrases, the way words are assembled into complete sentences in English.
- We know, for example, that fairytales often begin “Once upon a time,” that people set out to do things, make a dash for their vehicles in a sudden downpour, that events move toward a conclusion, and “all’s well that ends well.” If we get even a few hints from speechreading, our brains can usually fill in the gaps.

“Despite the fact that I am continually confronted by mumblers, I can usually communicate with anyone, using my speechreading skills and communication strategies — providing the other person has a pair of lips, a set of teeth, and does not speak in Swahili.”

— Barbara Liss Chertok, teacher of speechreading in Maryland

Relying Solely on Visual Cues

Speechreading, especially if you are totally Deaf and relying completely on visual cues, is very difficult and calls for real concentration. Mustaches and beards, accents, sloppy speech habits, chewing gum and smoking are all major challenges to speechreading, as are group situations with multiple speakers, and lectures delivered from a distance as speechreading becomes more difficult as the person's face and lips become smaller. A speaker on an elevated platform may also be problematic, even more so if there is a podium and a microphone to contend with.

It takes energy.

Sometimes you may not have enough energy to speech read with much success. It's hard work, so it's important to try to make it easier.

- Remind the speaker — repeatedly if necessary — to face you when speaking.
- If possible, position yourself so that you are near the speaker and on the same level.
- To avoid shadows or light glare, light should be behind you or from the side, and should fall on the speaker's face.
- If you're using signed English support to augment speechreading, you'll want to stand back a bit so that you have a wider visual field for all visual-gestural-behavioral clues.
- Ask the speaker to change the position of his/her hands, and/or remove any pipe, gum, microphone, or whatever else may be obscuring their lips until you can see them clearly.

Learning to Speech Read

You can try to teach yourself from books and videos, but it's far easier to take a class. You really need to be able to practice with a teacher, particularly if you don't have much (or any) residual hearing to provide additional clues.

The Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) can refer you to speechreading classes. You can also practice with friends or family.



As with everything else, some people catch on faster than others. And some people are easier to speech read than others. If you don't like to guess at what someone is saying unless the odds are very much in your favor, you may have difficulty becoming comfortable with speechreading. Speechreading requires a lot of informed guesswork and some leaps of imagination. Remember that in everyday conversation, you don't have to understand every word to be a successful speech reader. It bears remembering that even people with "perfect" hearing don't necessarily understand everything that is being said.

Speechreading has its pros and cons.

Pro: All of us have some existing speechreading skill and even a few speechreading lessons may help significantly. Being straightforward about what we need in order to successfully communicate is pretty easy — for example, a poor lighting situation can often be remedied by using a flashlight app on a smartphone screen to illuminate the speaker's face, or a listening device can help amplify auditory clues.

Con: Speechreading demands concentration and can be tiring, since many sounds look the same on the lips. It can be difficult in groups or if the speaker is far away, has facial hair, an accent, wears tinted glasses or sunglasses, or doesn't move his or her lips much when speaking. It doesn't work at all in the absence of sufficient lighting, which can be a distressing hallmark of many social situations and events — although planning ahead can help.

AMERICAN SIGN LANGUAGE (ASL)

Wherever there are Deaf/deaf people, there has been and will always be sign language because it is a visual language that allows communication to take place without requiring spoken sounds or the ability to hear.

A Little History

American Sign Language has its roots in the early 1800s. In 1815, a young seminarian named Thomas Hopkins Gallaudet went to Europe to study teaching methods, funded by a group of Connecticut businessmen, with the intention of founding a school for the Deaf in Hartford, Connecticut. In France, he studied French sign language with Abbé Sicard before returning to this country with Laurent Clerc, a Deaf Frenchman. Clerc became the first teacher of the Deaf in America.

French Connections

ASL has many borrowings from French sign language as a result, but it has its own idiomatic usage. The school Gallaudet and Clerc founded in Hartford became the first residential school for the Deaf in the country, and continues to this day as the American School for the Deaf. Gallaudet's son, Edward Miner Gallaudet, went on to found what is now Gallaudet University in Washington, D.C., the only university for Deaf students in the world.

American Sign Language is the primary language of the Deaf community in the U.S.

Deaf users of ASL are thought to number about half a million people and the number of hearing people who become ASL fluent is growing. Some Deaf people use ASL exclusively, but most are bilingual and use English and ASL.

ASL is a complete language.

ASL is not simply a miming of English. It is a complete language with its own grammatical structure and orientation. Facial, hand and body positions and expressions all occupy a place in the grammatical structure of ASL. ASL does not have a one-to-one relationship with English. Although it is distantly related to French Sign Language, it continues to evolve as do all languages.

ASL has a vocabulary.

In addition, ASL automatically gives you a vocabulary for Signed English and you can easily make the switch to manually coded English. Fluency in ASL or signed English also gives you access to ASL interpreters or Signed English transliterators, which can be a great convenience, since they are so widely used and readily available.

There is no written form.

Like many other spoken languages, including Native American languages and indigenous languages in Africa and Australia, ASL has no written form for everyday use. Also, ASL is not universal. Almost every country has developed an indigenous form of sign language, so that even Deaf citizens of neighboring countries can have considerable difficulties communicating with one another at first. Similar to Esperanto (created as a universal language for everyone), there is also an “artificial” universal sign language that is used at World Federation for the Deaf events but not widely understood or practiced elsewhere.

Courses are available.

Many colleges, organizations, Independent living centers, and adult education programs in Massachusetts offer courses in ASL. There are a number of books, videotapes and YouTube videos available to supplement interactive classwork. Many hearing people take ASL classes because they have family members or friends who are Deaf or severely hard of hearing. Many other hearing people study ASL out of a fascination for the language.

The Best Way to Learn ASL

The best way is to learn from a Deaf person who is a fluent signer. As with learning any foreign language, you'll have to practice. If possible, try to attend some Deaf community functions. It's a very interesting and eye-opening experience to feel at first, like you are in the minority, unable to communicate easily. Many Deaf individuals are bilingual or even trilingual and will readily help the beginner with sign language.

Pro: ASL is a full language with an inherent beauty. It is fully visually accessible and enables use of ASL interpreters and Signed English transliterators. Even a beginning knowledge of ASL will get you started to facilitate participation in the Deaf community, many of whose Deaf members happily welcome people who are interested in learning their language. Many community events are interpreted and therefore visually accessible.

Furthermore, Videophone Relay Services are now available to those who can communicate using ASL. This will allow for fast, accurate communication on the phone to hearing friends, family and businesses. Knowing ASL allows for easier access to academic information. You may be able to use ASL interpreters in your classes and seminars and meetings.

Con: Like any foreign language, it may take a long time to acquire fluency and it requires regular practice. The use of facial expression and body language is sometimes difficult for English speakers. ASL is of very limited benefit to the average hard of hearing person who may want to communicate with hearing family members, friends and associates — unless they also learn ASL.

FINGERSPELLING

Every late-deafened person should learn fingerspelling. It's a lot handier than using pen and paper when you are with other people who know it. Fingerspelling is taught in all sign language classes. American fingerspelling is a system of shapes made with a single hand (the fingerspelling of Great Britain, Australia, and some former British Empire countries uses two hands) that correspond to the letters of the alphabet.

Signers use fingerspelling for names and to spell out special words (scientific terms, names of corporations, such as IBM, for example). It's especially useful for unfamiliar names and addresses. Friends and family of late-deafened people often learn fingerspelling and find it extremely useful for indicating changes of subject in conversations or for supplementing speechreading for difficult words. Although learning the finger-spelled letters may be easy for some, reading and using finger-spelled words takes practice.

Experienced signers can fingerspell with breathtaking speed.

Pro: Easier than carrying around a pad and paper. Extremely helpful for spelling out names and difficult words. Practiced users fingerspell very quickly.

Con: Needs lots of practice to learn to use with speed. Receptive skills often lag behind. With smartphones, ubiquitous apps that convert speech to text may be more efficient solutions for general usage.

Fingerspelling Alphabet



SIGNED ENGLISH AND ITS VARIATIONS

Various systems of manual English have been created to provide Deaf and severely hard of hearing users with visual support for speechreading English. Many late-deafened adults whose first language is English find signed English easier to learn and use than ASL. They are attracted by the fact that they can simultaneously speak and sign the primary English words in sentences. Visual signs help the speech reader fill in the information for the missing 70% of speech sounds which cannot be seen on the lips.

There are several signed English systems that attempt to parallel spoken English with signs for speechreading support. All signed English systems, all forms of manually coded English, use spoken English and signs simultaneously. All use ASL signs to some extent; some systems also use non-ASL, “invented” signs for many words. And some systems use invented signs for English markers, such as plurals, suffixes, past tense, pronouns, and so on. The two main terms you will hear are:

- **SEE** (Signing Exact English): SEE borrows many word-signs from ASL, uses some invented signs for words and also for grammatical markers (prefixes, suffixes, past tense, plural, etc.). Such a complex system is often very cumbersome to produce manually within the natural flow of speech and to process visually.
- **Forms of Signed English** use spoken English and English structures with ASL signs to parallel spoken (or mouthed) English. It tends to use fingerspelling considerably to “fill in” articles, sometimes pronouns, and other words. Some forms of Signed English also may use invented signs. Signed English is visually complex and hence somewhat cumbersome to produce, especially while simultaneously speaking. It is much harder to process visually than ASL.

Pro: Easier for some late-deafened and hearing people to learn than ASL since it uses English word order and grammar and relies less on facial expression. Possible to speak and sign simultaneously, thus making speechreading easier by supplying the “missing 70%” of speech sounds.

Con: It is not a language. It cannot completely parallel English. It is hard to maintain the flow and normal pace of the spoken language while simultaneously signing English. Because it uses the grammatical structure of English as its base, it is not structured (as ASL is) to accommodate visual reception and memory.

PIDGIN SIGN ENGLISH

You may hear the term is Pidgin Sign English (PSE). PSE is a mix of signed English and ASL, in much the same way that Creole mixes French and English, borrowing from both languages to facilitate communication between two speakers, neither of whom is fluent in the other's language.

PSE generally employs some structures and idioms of ASL and uses some mouthed/spoken words of English. It is often used when a Deaf person who is fluent in ASL and a hearing person who signs but is not fluent in ASL attempt to communicate. Each makes some accommodations to the other. Depending on the users, PSE can lean more towards "the ASL side" or more towards "the signed English side."

CUED SPEECH

Prof. R. Orin Cornett of Gallaudet University developed Cued Speech in 1966 to make the sounds of spoken language visible. For some people, cueing can be an aid to speechreading, helping clarify the sounds that look the same on the lips (such as B and M), sounds that aren't really visible on the lips (such as K and G), and vowel sounds. To use a wonderfully clumsy audiological term, cueing "disambiguates" sounds.

Cued speech is relatively easy to learn. Eight handshapes used in four different positions near the face signify different sounds. To cue, one must learn to think in terms of sounds. For example, there is no handshape for C; in English, it is either an S or K sound. This can be a difficult adjustment to make. Since Cued Speech is based on sound, you can cue

any word you know how to pronounce. For some users, it's been very helpful in learning foreign languages.

Pro: Easier to learn than ASL or Signed English. Presents a complete visual picture of the speech sounds of English, including information not provided by speechreading.

Con: Few people use it. Requires that you think of words phonemically (based on the sounds the letters make) rather than on how the words are written or spelled.

Which should you choose?

There is no “one size fits all” answer. However, many people agree with the communication philosophy of the Association of Late-Deafened Adults: “whatever works.”

For example:

- Many people who have become Deaf or acquired a severe hearing loss have spoken English as their primary language.
- Speechreading is very important, and any technique that supplements speechreading is valuable.
- Some people recommend that anyone who is late-deafened or hard of hearing should meet with a speech pathologist for some instruction and practice in speechreading and fingerspelling.
- Even if you don't become an expert, you'll still find these skills increase your ability to understand the spoken word.
- Whenever you can pick up more clues to conversation, it makes the task of understanding easier.
- From a practical point of view, you will probably want to learn whatever language is used by the people with whom you communicate most frequently.
- Even if that language is not ASL, you might still want to learn it (or signed English) to add a new dimension to your communication versatility.

- Many late-deafened people who have learned ASL enjoy participating in the social, political, and community activities of the Deaf community while maintaining important relationships with their family, friends, and co-workers in the hearing world.
- Many of them have found interesting Deaf friends and have been able to choose jobs in which they work with other Deaf and late-deafened people.

Will this assist your communication needs?

When analyzing your communication needs, ask yourself a few questions. First and foremost: will learning another skill help you?

- Look at your work situation. Do you work in a large office or are you a consultant working from home or in an office of your own? Do you spend time in a classroom situation, as a student or teacher? Do you travel? Attend meetings or lectures? Use the telephone for business? Would the ability to use interpreters be useful?
- Would your family and friends be willing to learn a new language or skill in order to communicate better with you?
- What about your community? Are there any other people who use sign language or want to learn it?
- Do you have the time, resources, opportunity, and motivation to invest in learning new skills and/or languages?
- What kind of person are you? Outgoing or shy? Do you enjoy learning new skills and meeting new people, or do you feel happiest staying at home or in familiar surroundings?
- How good is your vision? Is speechreading a realistic possibility?
- What are your entertainment likes and dislikes? Do you enjoy dining out? Partying? Attending plays and movies? Outdoor activities? Intimate or large groups?

Start there and enjoy the journey.

~ Carl Richardson's Story ~

Carl is a deafblind individual with Ushers Syndrome II — a hereditary degenerative disease that affects both the eyes and the ears. He was not always comfortable identifying himself as an individual with a dual sensory loss. He was born with a hearing loss but was not diagnosed with one until the age of four.

After that diagnosis, his parents enrolled him in the aphasic program at Boston School for the Deaf in Randolph, MA, an oral school where he was taught spoken English. Unfortunately, sign language was forbidden at this school. Because Carl did not grow up in a family who used sign language and he did not sign at school, as a child he did not feel at home in the Deaf School and Deaf community. After six years of intensive speech therapy, he was mainstreamed into the public schools. He did not always feel at home in the public schools either. His classmates thought of him as the kid from the deaf school who talked funny.

Carl's parents worked very hard with him to improve his speech. He was in speech therapy off and on until the age of 19. It was around that time that he noticed he was having trouble hearing; he thought his hearing was getting worse even though he wore hearing aids. He had his hearing tested several times and according to the audiologist, his hearing was not getting worse.

Carl had always had trouble seeing at night and with his peripheral vision, but he thought everyone did — after all he had 20/20 vision. Finally, at the age of 18, Carl's father took him to an ophthalmologist at Mass Eye and Ear where he was received his diagnosis of Usher Syndrome II. It all made sense. Carl's hearing was not getting worse but due to the progressive nature of the vision loss, he was slowly losing the ability to read lips.

Despite the diagnosis of Ushers, Carl went to Emerson College to study his first love, which was film. He loved college, because people did not know his history and accepted him for who he was. He did not tell many people he was slowly going blind and for the most part he was able to pass as a sighted person with a hearing loss. He was still embarrassed.

After graduation Carl moved to Hollywood, CA to work in film and television. He worked on a handful of productions and then one day while he was setting up for a shot in a movie, Carl knocked down a set of the lights and destroyed the set. He was fired; he gave up driving and did not know what to do, so he moved back to Massachusetts. He got a job in a nursing home as he had been an orderly in high school.

At the age of 28, Carl became legally blind. He still remembers when that happened. In many ways being declared legally blind felt like a burden being lifted. Carl did not have to fake it anymore. At that point, he decided to move into Boston, learn how to get around independently, and get another job in film and television. Carl bought a place in town so he could use public transportation. He learned how to use a cane and then got a guide dog. He obtained a job working in the Media Access Group at WGBH, where they make film and TV accessible for the Deaf, hard of hearing, blind and visually impaired. This was Carl's dream job. He could be around his first love, film, but also could advocate for the disabled. This was also when he learned the value of lending his support to that population.

Although Carl worked at WGBH for several years, downsizing meant that he eventually lost his job. He took this time and opportunity to access rehabilitation services. He enhanced his computer and communication skills. He learned how to use a screen reader on a computer, and he learned how to use his hearing differently. He started using assistive listening devices more frequently. Eventually,



Carl found another job, working for the Commonwealth of Massachusetts.

Carl is married to his loving wife, Megan Sullivan, an Associate Dean at Boston University, and they live with their two dogs — Kinley, Carl’s “retired” guide dog, and Merrick, his current one. In work and life, Carl uses many tools and technologies to succeed as a deaf-blind person. He uses a combination of magnifiers, screen readers, assistive listening devices, Bluetooth hearing aids that work with his iPhone, and microphones. He is currently learning braille in order to enhance his communication skills even more. He travels daily to work with Merrick.

Carl feels that it all turned around when he stopped caring what people thought of him and just did what he needed to succeed. He truly believes that all people, regardless of their backgrounds or abilities, have challenges and that he is no different from everyone else. He thinks the only thing that sets people apart is how they deal with the challenges that they have.

Carl works for the Commonwealth of Massachusetts as the Americans with Disabilities Act Coordinator for the Massachusetts State House, where his role is to make the State House’s many programs, services and activities accessible to people of all abilities. Carl loves his job as he learns from people of all abilities about the strengths, coping mechanisms, and compassion they have in order to deal with their challenges.

PERSONAL COMMUNICATION STRATEGIES THAT WORK

As soon as you recover from the initial shock of becoming Deaf/deaf, make your first priority to address the interpersonal communication problem. Because learning new ways to communicate is time-consuming, it's a good idea to start by making the most of what you already know and have in your toolbox. You've probably always taken speaking and listening for granted. Now it's time to take a closer look at communication strategies and do some problem solving. You'll find that there are a number of factors that you can control.

Let people help you.

One of the most difficult adjustments to make is to learn to ask people to work with you to optimize communication. Most people have no idea how to communicate with a Deaf/deaf person. You'll have to teach them. And when you're finished, you'll have to repeat what you said, and repeat it again. Changing speaking habits is very difficult. Asking people to change is also difficult. Have patience, ask politely, smile, use a little humor. Both of you benefit when your communication needs are met.

- ***Be honest.***
Tell people that you're Deaf/deaf. If you're having trouble with the d-word, re-phrase it. Some feel that using the term with certain people will upset them and are not quite sure how to react to stunned silence, embarrassment, or "I'm sorry." It doesn't matter what you call it as long as you get your point across.
- ***Resist the urge to bluff.***
It's far more difficult to tell people you're Deaf/deaf after listening to them speak for 15 minutes and not understanding a word. A little later in this chapter, you'll learn strategies to use when you don't understand the speaker.
- ***Get out of the noise.***
If background noise is a problem, try to find a quiet corner with good lighting. If possible, turn off the television, radio, or any other device that is creating an unwelcome distraction.

- ***Carry a pad and pen or a smartphone with apps that support text and speech to enhance functionality.***
Just in case you get stuck, it is a good idea to have options.
- ***Ask people to face you when they speak.***
Let them know that you won't hear them or even know that they're speaking if they talk to your back or call to you from another room. This can be the most difficult challenge of all, since it is very hard to get people to change the way they've always done things. It is important to remain persistent and not give in to the "it doesn't matter" philosophy. It DOES matter!
- ***Don't hesitate to ask speakers to remove gum or other objects from their mouths — and not to talk with their mouths full in the first place.***
- ***Be polite but assertive about your communication needs.***
Every now and then, you'll meet someone who is rude or uncooperative. In those situations, try and find someone else with whom to speak. But if it happens frequently, with different people, there is a possibility that it may have something to do with the way you're presenting yourself. Ask yourself: Am I being confrontational instead of reasonable? Impatient? Angry? Demanding? There's a big difference between being assertive and being aggressive. Or maybe you're not being assertive enough? Communication is a joint enterprise. Treat your communication partner with consideration, but never to the point where you sacrifice your own communicative needs because someone else feels that you're imposing.

Establish successful habits in difficult situations.

One of the simplest but most difficult things you can do is to get out of the "What?" habit. Sometimes, it takes the brain a fraction of a second to figure out just what the speaker has said. Most of us are guilty of asking "What?" the instant the words are spoken, only to figure out the meaning, in many cases, as the speaker begins to explain.

- Give the brain a split second before asking for an explanation of something you didn't hear.

- Don't say "What?" or "Huh?". Instead, clarify your needs by saying "I didn't get that," "Please repeat that," and other, similarly useful, directions.
- Don't interrupt the speaker in mid-sentence. The second part of the sentence may give you the clue you need to understand the beginning.
- "What?" and its variations are a bit too open-ended to be useful. The speaker is left wondering exactly which part of the conversation you didn't understand and tends to repeat the entire sentence (or more), which may not be necessary.
- Try to be more specific when you request information. Sometimes, repeating back part of the sentence helps. If anything, such attention to what the speaker is saying is considered flattering by many individuals, so don't worry about being politely inquisitive.

When the speaker says, "Janie graduated from Abbey Meadow Pre-School last Wednesday," don't say, "What?" Instead, try:

- "Who graduated?"
- "When did Janie graduate?"
- "What school was that?"

When you receive important information, be sure to confirm it.

- Tell the secretary, "Let me confirm this. I have an appointment with Dr. Jekyll next Tuesday, July 15th, at 10 a.m. And I shouldn't eat or drink anything after midnight. Correct?"
- Ask the speaker to re-phrase what they are saying and write down the key words or numbers.
- If you have residual hearing, you can ask for the correct spelling of a word or name you don't understand, for example, "Was that B like in Balcony or P like in Petunia?"
- Be patient, with the speaker and with yourself.

- When you're totally exhausted and having difficulty giving the speaker the concentration that is necessary, excuse yourself and take a short break.
- At social gatherings, you can control the situation a little bit by asking your conversational partner if he or she wouldn't mind finding a quieter place to speak, because you REALLY want to hear what they have to say but just can't in the current environment.
- If you become overwhelmed by the environment and you're with friends, just explain that you're taking a break, that they should continue whatever they're doing, and that you may ask for a summary or clarification later on.

For Hearing People:

How to Communicate with a Deaf/deaf Person

- Ask the Deaf/deaf person what you can do to make communication easier. Make sure you have the person's attention before you speak.
- Face the Deaf/deaf person. It's important for him or her to be able to see your face.
- Be aware of background noise and try to find a place to talk that minimizes it.
- Pick a spot to speak where the light, artificial or natural, is not behind your face since it makes speechreading more difficult.
- Remove any objects from your mouth that might interfere with speechreading: gum, food, etc.
- Speak clearly and enunciate, especially if you have the proverbial stiff upper lip.

On the Flip Side

- Don't overemphasize lip movements. It will make speechreading more difficult, not easier.
- Don't shout. If the person has no hearing, it won't help. If the person has some residual hearing and wears hearing aids, it will



only distort what you say, not to mention the embarrassment created for the both of you when everyone turns to stare.

- If the person doesn't understand what you have said, don't just repeat it. Re-phrase it. Say it in a different way.
- Try to give the person some indication when you change the subject.
- Make sure that only one person talks at a time.
- Recognize that speechreading and listening involve intense concentration for late-deafened people and can be very tiring.

For your part, it's important not to forget just how difficult it is to change deeply ingrained speech patterns. It bears repetition: Be patient with people and hold tightly to your sense of humor.

CHAPTER 7

Hearing Assistive Technology (HAT)

Hearing aids are widely known and used by many millions of people globally. Nevertheless, many late-deafened and hard of hearing people aren't aware of other devices that can complement their hearing aids and/or cochlear implants to enhance their overall hearing experience in a variety of environments and situations. In this long chapter, you'll find information on gizmos, gadgets, and technologies that you'll definitely want to explore more fully.

“While there is no question about the necessity of a hearing aid for most hearing-impaired people, often, a hearing aid is not enough.” —Dr. Mark Ross

The purpose of assistive listening devices collectively known as “Hearing Assistive Technology” (HAT) is, simply, to increase the intelligibility and clarity of speech in challenging environments where hearing aids and cochlear implants alone may not provide optimal comprehension.

This is usually attempted by supplanting the ear-level microphone of a hearing aid or cochlear Implant with a remotely situated microphone close to the speaker's mouth, or a direct connection to a sound system. By doing this, background noise is often significantly reduced, while the speech or sound one is trying to focus on is preferentially amplified. Audiologists speak of this as increasing the signal-to-noise ratio (SNR).

How They Work

- by routing sound from one or more external microphones, or from an external sound source to the listener's ear, hearing aid or CI wirelessly through inductive, radio frequency, infrared or Bluetooth functionality

- through hardwired amplification devices — where the speaker/sound source and the listener are connected through a device featuring a microphone and headphone jack

Headphones and Earbuds

People with mild to moderate hearing losses who do not use hearing aids can use headphones or earbuds directly to hear the amplified signal from the sound source, whether directly connected or transmitted through a receiver.

Tip: *People with severe to profound hearing losses will not benefit from these HAT devices unless they already use hearing aids or cochlear implants, since they will require much greater amplification than what is normally found in devices not specifically designed for use by people with significant levels of hearing loss. For example, while a smartphone can amplify music for someone with normal hearing, the level of built-in amplification in a smartphone is not nearly sufficient for someone with a severe or profound hearing loss who does not have a hearing aid or cochlear implant.*

AUDIO INDUCTION LOOP SYSTEMS



These systems have been the gold standard for large venue accessibility and are often used in scenarios where handing out equipment components to hard of hearing users is impractical.

How It Works

- An amplifier converts the sound from the microphone input into electrical signals and feeds them through the wire, which is looped (hence the name) around the area in which the hard of hearing users are situated. The electromagnetic field created by this wire loop carries the sound information.
- This electromagnetic field is picked up by, and creates a corresponding signal in a telecoil, which is found in most hearing aids and cochlear implants. (See Chapters 4 & 5.)
- The hearing aid or cochlear implant processor turns this information into sound which is then heard through the hearing aid or the CI.
- The loop can be placed in any size room or area, and can also take the form of a personal neck loop or behind-the-ear silhouette adapter.
- Listeners inside this “looped” area who do not have hearing aids can pick up the signal using an external loop induction receiver with headphones, which must be provided by the facility.

Sound Considerations

Loops are usually encountered in larger venues as a fixed installation to provide the greatest benefit to the largest number of users wearing hearing aids or cochlear implants with telecoils.

A loop can also be placed in homes and even cars. Any space with an adequate sound system and connectivity options will do as long as it is free from interference.

Sound quality can vary widely depending on several factors.

- In a simple installation, a user sitting in the middle of the looped area will generally get the weakest signal because they are sitting the furthest away from the wire “looping” the area.
- This is compounded by the fact that not all telecoils are oriented uniformly inside various hearing aids or cochlear implants, which

also affects the ability to receive a sufficiently strong signal since electromagnetic field orientation plays a role.

- Nearby electromagnetic fields generated by other electronic devices such as copying machines, projectors, HVAC units or proximity to electrical conduits within a structure can also generate undesired interference.
- Spillover of the signal into adjacent rooms can also be an issue, much as it is with single channel FM systems.
- The different looping techniques available to minimize these undesirable effects often affect pricing significantly since they require more labor-intensive installation.

Advantages

- Loops are an ideal solution in very large public venues.
- Loops require little or no maintenance once installed.
- Loops are available in personal sizes, as well. Some loops can be used on countertops, others are worn around the neck (hence the name: neck loops) and can be plugged into any sound source that a hearing person might plug headphones into.
- *Note:* For small venues looking to be cost conscious, or who offer highly mobile, occasional, or simultaneously occurring separate programs in the same vicinity, tunable FM systems are generally a better value proposition.

The Silhouette

A silhouette is a very thin, hook-shaped device containing a small wire loop that is worn between the listener's ear and their hearing aid or cochlear implant.



How It Works

- The silhouette generates a weak magnetic signal that is picked up by the hearing aid's or cochlear implant's telecoil. Because of its proximity to the hearing aid, the weak signal may in fact provide better sound quality than a neck loop placed further away from the hearing aid or CI.
- This electronic signal is converted by the hearing aid or cochlear implant processor into sound information which is delivered to the listener's ear or cochlea.

FM SYSTEMS

FM stands for Frequency Modulation — a fancy way of saying that radio frequencies are used to transmit the sound information from a transmitter to a receiver.

For portable use, both transmitter and receiver can be had in battery-operated variants. Each is approximately the size of a deck of cards. In this portable setup, the speaker will use a lavalier microphone connected to a belt-or-neck-worn transmitter, or a handheld mic/transmitter combination, to transmit to the receiver, which is used by the hard of hearing person with the appropriate listening attachment.



Features

- Can be scalable, from a small one-to-one setup with one microphone/transmitter and one receiver, to a large area system utilizing a more powerful, extended-range, large area transmitter with multiple receivers tuned to the same channel. A base station transmitter typically requires an AC power source and is better suited for stationary applications.
- Anyone with an FM receiver that is tuned to the appropriate channel/frequency can listen to the sound source from a portable or base station transmitter through headphones, a neck loop, or silhouette adapters as long as they have hearing aids/cochlear implants with built-in telecoil capability, or via a physical patch cord where available.
- The receiver can be placed in a pocket, clipped to a belt, or hung around the neck with a lanyard.
- Some hearing aids and cochlear implants have built-in FM receivers or snap-on FM receiver modules.

Advantages

- Highly portable and can be very effective in bridging the gap between speaker/sound source and listener
- Allows for multiple microphones and multiple transmitters to be used simultaneously when used with a base station transmitter or different frequencies
- Less risk of signal spillover to adjacent rooms than a loop system when used on different frequencies
- When directly connected to a sound source, provides superior clarity than is possible over a public address or sound system where reverberation and echoes will distort sound
- Allows for the use of spoken language interpreters in the same room, e.g. amplifying an English speaker on channel 1 to English listeners on channel 1, while allowing a second language interpreter on a microphone set to channel 2 broadcasting to participants listening on channel 2

Tip: *These systems are not welcomed in secure environments where highly sensitive or proprietary information is being discussed because there is always a small risk of interception.*

Tip: *These systems may not be suitable for large venues where it would be impractical to hand out hundreds of receivers and listening attachments, or in situations where staffing concerns preclude individual assistance.*

Integrated FM Receiver Functionality

Some hearing aids and cochlear implants may feature integrated FM receiver functionality or can be retrofitted with FM receiver adapters, making listening attachments unnecessary.

With this feature available, sound can be sent directly from the microphone or large area transmitter to the hearing aid or cochlear implant.

HARDWIRED DEVICES



These devices contain an amplifier, battery and volume — sometimes also tone control, and either a built-in microphone or a jack for an external one. They are the size of a pack of cards.

These are best used as personal amplifiers in one-on-one situations, such as a social worker or visiting nurse making a home visit to an elder with a mild to moderate hearing loss who is sitting at the table with them.

In this scenario, the social worker/VN would speak into the microphone, and the elder with hearing loss would listen through headphones at their preferred amplification level.

Advantages

- Inexpensive
- Easy to use
- Extremely portable
- Not intimidating to the average user
- Can make a tremendous difference in one-to-one settings where more expensive and complicated wireless functionality is not necessary
- Can also work with hearing aids or cochlear implants either through inductive or hardwired coupling

Disadvantages

- The disadvantage of these systems is that the speaker or sound source and the listener are connected by microphone and/or headphone/neck loop/patch cord wires, limiting the functionality to close quarters. While extension headphone or microphone cords can extend functionality, these quickly become impractical in crowded or busy settings.

INFRARED (IR) SYSTEMS



These look very similar to FM devices, but transmit sound using infrared light pulses rather than by radio frequency. The sound from a public-address system or microphone is transmitted by an infrared light emitter to an infrared receiver worn by the user.

Features

- Can be portable or permanently installed
- Favored for use in enclosed theaters and auditoriums
- Function best indoors where the receiver is in “view” of the transmitter for maximum clarity
- Some newer systems have reduced absolute dependence on direct line-of-sight functionality
- Can be used with headphones, neck loops, silhouettes, and other listening attachments with accessory jacks
- Best suited to confidential settings as they cannot easily be “intercepted” outside of a closed room in which they are used
- Personal variants can be used for sound/TV amplification without affecting overall volume in the area

SOUND FIELD SYSTEMS (SFS)

Not explicitly considered to be Assistive Listening Devices (ALDs), they can still be useful in providing auditory assistance.

Features

- Function by providing evenly spaced wall or ceiling-mounted speakers to project the speaker’s voice or desired sound output throughout the entire listening area at equal sound levels
- Eliminates drop-off of in sound that occurs the farther one sits from a speaker at the front of the room
- Addresses almost all communicative challenges a hard of hearing participant is likely to encounter, whether they wear hearing aids or not

ALERTING DEVICES AND SIGNALING SYSTEMS (ADSS)



Hearing loss creates challenges above and beyond communication issues. It is also important — and oftentimes critical — to be aware of what goes on around us while we're engaged in, or distracted by, other activities, asleep, and unaware of audible alerts because we don't have or aren't wearing hearing aids or CIs.

There are a multitude of devices that will shake your pillow or bed, flash a strobe or connected lamp when your doorbell rings or your baby cries. Still others will alert you to the sound of a fire alarm or carbon monoxide detector by triggering a signal that can activate a bedside unit as well as remote units in other parts of your home so you are aware of the danger wherever you may be at the time.

While the marketplace provides a vast array of existing technology, it is rapidly changing and evolving. Here are several different aspects of these technologies to help you think about and ask for in your own life and circumstances.

Accessibility and Building Codes

- Compliance with state and local building codes has little to do with accessibility. To use an example, if a state or local building code requires an audible fire alarm to be placed in the hallway outside someone's bedroom, that is completely useless for a hard of hearing person who takes their hearing aid off at night to go to sleep.

- Simply replacing this audible unit with a visual alarm at the same location will be equally pointless if the individual closes their bedroom door when they go to sleep, as many of us tend to do.
- In a scenario such as this, a visual fire alarm should be provided in the bedroom, preferably with some form of tactile alerting component (a pillow or bed shaker, e.g.) for heavy sleepers.
- Usually, that is not covered by building or safety codes and is also not spelled out in sufficient clarity as being a reasonable accommodation in most housing regulations.

Connections to Building Systems

Often, little or no thought has been given to whether a fire alerting device is connected to the overall building system, or whether it is a stand-alone system that does not respond to other units and does not trigger other units.

Imagine for a moment that a Deaf/HoH person rents an apartment in a high-rise building and they happen to live on the 10th floor. It will do them absolutely no good if their management company provides them with a plug-in or battery-operated fire alarm in addition to the audible common area and hallway alarms, even if it is visual as well as audible, unless they happen to experience a fire in their own unit.

In that case, and that case only, their in-unit visual alarm will certainly give them sufficient time to escape

If, as is much more likely, the fire starts elsewhere in the building — say on the third floor — then the hard of hearing tenant will be completely unaware that every other alarm in the building is going off, as theirs will not because it isn't connected to the building system.

It is critically important to install an alarm system that will alert the Deaf/deaf person if a fire breaks out anywhere within the building. It is also critically important to install an alarm system that will alert the Deaf or HoH person — not just in common areas — but also anywhere within his/her unit, whether they are asleep or awake. An accommodation that does



not provide the same functionality to a person with a disability as it does to a non-disabled person in the same context, is not an accommodation.

In Your Home

For people living in their own private homes, these are largely negligible issues. Although the best way to accomplish perfect accessibility is to design it into any new construction from the ground up, it is quite possible to retrofit most existing housing to make almost any dwelling completely accessible for someone who is Deaf or HoH.

Stand-alone Single-function System

A stand-alone single-function system that only functions in the rooms/locations where it is installed and doesn't "talk" to other remote inputs or outputs, is a recipe for frustration. With these, you are left with separate receiving units and an ugly mess of alerting devices and power cables in each room of your house.

Disadvantages of Single-function Systems

So, you've bought a bed-shaker alarm clock to wake up your hard of hearing grandmother so she doesn't miss her doctor's appointment. What if she's also missing Visiting Nurse visits to her home, or Meals on Wheels, because she cannot hear the doorbell? What if you're worried about leaving your kids with her, because the last time they were, one of them snuck into the back yard and almost fell into the swimming pool because she couldn't hear the back-door opening? It is for reasons such as this that an integrated alerting system is almost always a better idea.

The Integrated Alerting System

In almost every instance, an integrated alerting system — one that alerts you to every conceivable sound trigger in your environment — is a better functional and economic choice than several different stand-alone devices, even though it is slightly more expensive initially. Nevertheless, it will allow for expanded alerting capability over time and as needs change.

Features

- Some systems integrate all alerts visually and via tactile notification through watches or body worn pagers.
- Some are Bluetooth compatible to pair with smartphone apps for environmental alert notification.
- One system will alert you to everything that is going on in your house, wherever you've installed remote notification units. You won't have a tangle of wires and have to make notes about what this or that flashing light means, and you're less likely to have interference issues as well.

Tip: *While such device consolidation potentially coupled with smart wearable technology might be the wave of the future, it is important to provide alerting technology that is in sync with the user's technological competency level. This bears repeating: the single most important aspect of alerting devices and systems is their user-friendliness. There are outstanding integrated systems on the market that MCDHH staff would not recommend to some individuals because they are too complex to use, even if someone else handles the setup.*

If the system is too confounding to be used and adjusted on a daily basis, it will not be a good fit for someone, no matter how technically advanced it might be or how many different alerts it can handle.

HEARING EAR DOGS



Not all assistive devices are inanimate.

If you're an experienced dog trainer, you may be able to train your own dog to respond to a number of signals, but it takes a great deal of work,

time, and effort. And typically, each dog has his or her own skills and singular ways of responding to signals no matter how taught — which may make it difficult to decipher what exactly he or she is alerting you to.

The Law

Hearing ear dogs, much like seeing-eye dogs, are by law permitted to accompany their owners into places of public accommodation. But while this usually goes smoothly, having an “invisible disability,” paired with the fact that many people try to bring their pets or therapy animals everywhere with them, can and does result in the occasional unpleasant encounter. If this has happened to you, you can contact the Massachusetts Commission Against Discrimination, the Disability Law Center, and/or the Attorney General’s Office for assistance.

“Every morning, Creature, a shaggy little dog of uncertain ancestry, jumps into bed to wake up Barbara at the ringing of the alarm. As they drive to work, Creature, now formally dressed with her orange leash and service animal vest, alerts Barbara to the sirens of any approaching emergency vehicles. Creature has become a fixture at the large high-tech company where Barbara works as a technical writer.

After greeting the security guard, she makes herself comfortable on her bed under Barbara’s desk. The dog responds to ringing telephones and also alerts Barbara when someone comes into her cubicle or calls her name. At home, Barbara feels more secure knowing that Creature will let her know if someone rings her doorbell or knocks on the door. Creature has also been trained to lead Barbara to the sound if the phone rings, the kettle whistles, or the smoke alarm sounds so she doesn’t have to wonder what sound Creature is alerting her too.”

There are many programs that train assistance dogs, such as the National Education for Assistance Dog Services, also known as Dogs for Deaf and Disabled Americans, in Princeton, Massachusetts.

<http://www.neads.org>

TELEPHONES

For many hard of hearing and late-deafened people, telephones are the ultimate nemesis. In every hearing person's life, telephones play or played a very large role. For those with hearing loss, phones often become veritable instruments of torture, particularly for those of us who still depend on our ability to understand what the other party is saying.

It is extremely frustrating when you don't always hear the telephone ring; and can't always hear or understand what others are saying. When you raise a receiver to your ear, your hearing aid may buzz from interference or you may experience a loud whistling if the sound from the aid is reflected by the phone back into the hearing aid microphone (feedback). Luckily, you can address this situation from a number of angles.

Hearing Aid (Telecoil) Compatibility of Telephones

As of 1988, all corded phones sold in this country have been "hearing aid compatible" (HAC), able to work with a hearing aid telecoil.

Using a strong telecoil eliminates background noise where you are and effectively lets you amplify the speaker's voice without amplifying the background noise all around you. In 2003, the Federal Communications Commission expanded HAC to also include wireless phone compatibility, so that manufacturers would make a certain percentage of their cellular phones compatible with hearing aids.

How to Tell

To assure yourself that your hearing aid or cochlear implant is compatible with the HAC of a specific cell phone, research the phone you are considering and look for the T and M ratings that should be prominently listed on the manufacturer's literature as well as their website. In simple terms, the T rating quantifies compatibility with your hearing aid/CI internal telecoil, and the M rating quantifies compatibility with the microphone of your hearing aid/CI. The higher the number, the better the overall compatibility.

Tip: *There is such enormous variability among hearing aids, phones and user preferences that is absolutely critical that you do as much comparison testing as is feasible before settling on a particular model. No one can conclusively tell you that any particular phone is best for you — it's an investigative process that we all have to undertake on our own. The best we can hope for is to filter for options and features that we know we must have, and to whittle down the potential selection to manageable proportions.*

Bluetooth Connectivity

Many very recent hearing aids and CIs support some degree of Bluetooth interoperability with similarly equipped cellular phones. Some hearing aids and CIs allow you to stream sound from the phone to both ears directly, if you're a bilateral hearing aid user or from one hearing aid to a CI or vice versa, or to both of your CIs if you have two.

Apple has worked with hearing aid manufacturers to develop “made for iPhone” hearing aids. This feature enables expanded interoperability between Apple mobile devices and compatible hearing aids, and allows for the use of compatible iPhones as remote microphones of sorts — a feature that could come in handy in smaller settings, within reason and expectations of course.



About Speech Comprehension

It must be said that neither HAC nor any other technological feature on your landline or cellular phone (or in your hearing aid/CI) can do anything to promote speech comprehension beyond providing the best possible sound quality on your end.

Nothing can truly compensate for background noise on the other end of the phone, or heavy accents/indistinct speech patterns, a speech disability, a poor connection, or any other of the myriad issues that make some calls difficult even for people with perfect hearing, never mind for those who struggle to understand others even in the best of circumstances.

Amplified Phones

These phones can help some people with mild to moderate hearing losses hear better on the phone. The Massachusetts Equipment Distribution Program (MAEDP) (<http://www.mass.gov/eopss/agencies/massedp/>) provides income-dependent free or sliding-fee scale amplified phones to Massachusetts residents upon verification of hearing loss. Amplified phones can also be purchased directly from specialized equipment vendors if eligibility for MAEDP should be an issue. Please note that MAEDP also provides phones for individuals with disabilities other than hearing loss.

Tip: *As of this writing, MAEDP is restricted to distributing landline telephone equipment and cannot yet provide cellular phones.*

Features

- Most models provide significant volume boost along with tone control, ring amplification, visual ring confirmation and other specialized features.
- Speakerphone functionality is available on some phones in this program, and historically there have been some models with amplified answering machine capability as well, although availability will depend on current equipment lineup at any given time.

Captioned Telephones

For individuals with severe to profound hearing losses, amplified phones will usually not be of as much assistance as a captioned phone.

- Captioned telephones allow you to continue to use your voice as you normally would when speaking to the other party.

- When the other party responds, the hard of hearing individual is able to read what their conversational partner is saying on a large, adjustable touchscreen set to an individual's visual preferences.
- The captioning service is provided free of charge thanks to the Federal Communication Commission (FCC), which reimburses for-profit entities who provide both the phones and the service directly to the consumer.
- The above-mentioned MAEDP also provides captioned phones for hard of hearing or late-deafened individuals upon eligibility verification.



Telephone Headsets and Adapters for Business

There are a variety of ways to make business phones accessible. The HAC compliance requirement applies to business phones as well, so if you have a telecoil, and find that feature to be helpful, you should not have problems using it with most recent model business phones. Having said that, many users report greater incompatibility on business phones than they do on personal cellular phones.

Tip: *If you want to use an external accessory, there are a variety of phone adapters available that will allow you to connect a neck loop, silhouette or a patch cord to the phone.*

Tip: *Business phones used in large organizations have slower refresh cycles than personal phones and are upgraded far less frequently.*

Tip: *Many business phones in use today may have been designed to take advantage of the DECT (Digital Enhanced Cordless Telecommunication) standard, which is incompatible with Bluetooth devices.*

Tip: While your colleague may be happily using a DECT-compatible headset, you may not have an equally simple solution since neither hearing aids or CIs support DECT.

Tip: There is at least one DECT phone that is made specifically for people with hearing loss, but that is not the same thing as enjoying fully wireless sound directly piped from your office phone into your hearing aid or CI.

Tip: In order for full wireless integration, in most cases, you will need to either have a business phone that provides Bluetooth integration natively, or a Bluetooth hub adapter, which may then also require a handset lifter depending on your phone model.



In Noisy Environments

If you work in an environment with a great deal of background noise, consider wired or wireless over-the-ear headphones with integrated microphones. They may look very unflattering, but they have the benefit of fully enclosing the ear to block out sounds, while being able to fit over many ITE, ITC, and CIC hearing aids, as well as cochlear implant earpieces (but possibly not the all-in-one CI designs).

Of course, the other consideration is to reduce onsite background noise by having an enclosed office that offers sound privacy for hard of hearing individuals who have to use the phone frequently. While this is definitely a rather more involved solution, it is well within what can be considered a “reasonable accommodation” under the Americans with Disabilities Act if it is the only workable solution to a communication access problem. Unfortunately, many modern offices employ an open floor plan, and this

may be less than ideal for someone who needs to amplify phone calls via speakerphone, or who may speak loudly because they cannot hear themselves if they are connected via telecoil or other listening methods.

Ask your employer.

You can also consider asking your employer if they would be willing to provide you with a smartphone for work if you find that you simply aren't able to benefit from the business phones provided. Smartphones are designed from the outset to maximize wireless connectivity via Bluetooth, are mostly HAC compliant, and as some claim, also offer better sound than the voice over internet protocol (VOIP) systems that are in common use today in many business environments. They are additionally enhanced by the availability of features such as headphone accessory jacks and visual voicemail.

TTY (Text Telephone)

TTY is an acronym for TeleTYpewriter, which were actually the telegraph-inspired precursors to modern TTYS.



A TTY is a small, table-top unit with a standard QWERTY keyboard, a one-line screen for visual display of text, and an acoustic coupler, into which one placed the telephone handset.

Advanced models, while retaining the telephone coupler capability, were able to connect directly to analog phone lines and could be used to directly make, answer, and even record incoming phone calls, based on model variant.

Some models also had built-in printers for recording the conversation or printing out answering machine messages when one was away.

For TTY Calls between Two People who are Deaf or Hard of Hearing

All that is needed are two TTYs, one on each end. The conversation would simply be typed back and forth, with special “codes” inserted to share non-verbal information such as Go Ahead (GA) or Stop Keying (SK) so the other party knew what to do next, and when to do it. Typing QQ meant question, typing XXXX meant a mistake had been made, PLS meant please, TMW meant tomorrow, and generally speaking, older Deaf/deaf folks used text abbreviations years before today’s text-dependent teenagers were even born.

For Calls between a TTY User and Hearing Persons

The Massachusetts Telecommunications Relay Service (MA Relay, also under the Massachusetts 911 Program) provides help in the form of a relay service, also federally funded, that places hearing operators between the (typing) TTY user and a (speaking) hearing person on the other end of the phone. The operator would read to the hearing person what the deaf person was typing, and type to the deaf person what the hearing caller was saying.

All this was done — and still is done — in the first person. In fact, MAEDP still provides TTYs today, even though the numbers have declined drastically due to the advent of new and improved telecommunications options.

Tip: *Probably the single most useful offshoot of telecommunications relay services for a hard of hearing person was a service called “voice carry over” or VCO, which is very similar to captioned phones. It allowed a hard of hearing person to speak their part of the conversation directly to the other party in the call, and the TRS operator would only type the hearing caller’s spoken response back to the hard of hearing caller, who could use a TTY or a phone with a small LCD display to read the text. This eliminated the need for a hard of hearing caller, who was usually perfectly capable of speaking for themselves, to have to type their part of the conversation to the other person.*

Features

Hearing carry over (HCO) allows people with speech disabilities to use a TTY to type their part of a conversation to the TRS operator for voicing to the other party. When the other party responds, their voice is heard directly by the person with the speech disability.

Other Varieties of TRS

Speech to Speech

Voice Relay

Spanish TRS

TRS services are not restricted to Massachusetts. Any TTY user anywhere in the continental U.S. can call 711 and be connected to their state's TRS service.

Tip: *TTYs are sometimes also called TDDs, or Telecommunications Devices for the Deaf. Either way, it is one and the same thing. It's worth noting that TTY use has declined precipitously based primarily on Deaf user preferences for newer and more natural communication methods (See Videophones below.) as well as incompatibility with newer IP-based telephone networks.*

Videophones

Videophone technology is now omnipresent. Anyone who has ever used Skype, FaceTime, Hangouts or any other of the many available video programs or applications on a laptop, tablet or smartphone can readily understand the concept behind Videophones as used by Deaf people who communicate in American Sign Language (ASL).

In fact, the use of Videophones and associated Video Relay Services (VRS) by Deaf individuals is the reason why TTYs are now close to being extinct within that demographic. ASL is a visual language and therefore can only be expressed in a visual format, which was not possible prior to the advent of commercially available — and affordable — high speed internet and associated computing and webcam functionality.



Tip: Any Deaf/deaf individual in Massachusetts who uses ASL and has access to high speed internet can obtain a Videophone at no cost from one of the currently operating Video Relay Service (VRS) providers. These are for-profit entities that make their money by inserting ASL interpreters (usually working out of large call centers) between the Deaf/deaf person signing in ASL and the hearing party responding via voice, at no cost to either caller. Similar to the MA Relay, VRS services are reimbursed, and regulated by, the Federal Communications Commission (FCC) via the Telecommunications Relay Fund.

Tip: Most VRS providers offer standalone applications which allow mobile VP calls — point-to-point calls between two Deaf/deaf callers using ASL — and VRS calls to be made and received on laptops, tablets and mobile phones.

Tip: Similar to traditional TRS services, VRS has expanded to offer VCO services, so a Deaf/deaf person wishing to speak for themselves can do so while receiving the hearing person's spoken response via ASL through the VRS interpreter.

Tip: Spanish VRS is also available.

Smartphones

It is impossible to overemphasize the use case scenario for smartphones. Most models today can easily be connected wirelessly via Bluetooth or Wi-Fi, or physically via neck loop, silhouette, Direct Audio Input, or patch cord to any hearing aid or cochlear implant. They have adjustable volume controls and can be used with headphones, ear buds and ear phones when desired.

Features

- Can play music, video, movies, and stream live TV and radio
- Many have subtitles and captioning capability, although it may not be enabled by default; some applications require in-app caption activation
- Can function as standalone voice amplifier using free applications
- Can record pictures and video
- Allows composing and reading email and text
- Provides sound meter functionality via downloadable applications
- Can do text to speech and speech to text
- Provides emergency location information
- Helps locate nearby accessible resources and venues
- Can function as GPS units while applications may provide live traffic updates
- Can provide localized weather and disaster alerting capability in visual and auditory format
- Can be used for plain old phone calls, with amplification and HAC, as well as video calls via Skype, Facetime, Hangouts and other communication applications
- Can be used to make video calls and video relay service calls, and applications exist that allow phone calls to be captioned for hard of hearing users preferring to use VCO
- In some locations, you can even dial 911 via text, although this functionality is not yet available in Massachusetts at time of writing (<https://www.mass.gov/orgs/state-911-department>)

Simply put, while they are not inexpensive, they are among the best possible purchases that someone with hearing loss can possibly make, even if they didn't also increasingly do double duty as hearing testers (via applications and websites) and remote controls for your own hearing aids.

Two Operating Platforms for Now

There are two major competitors in the Smartphone landscape today: Apple, which is predominant in the USA, and Android, which is by far the most dominant global smartphone operating system.

Tip: *Apple does not license its operating system for mobile devices, IOS, to other manufacturers; as a result, it has a small phone portfolio but much less product and software version fragmentation.*

Tip: *Android, on the other hand, Google's mobile operating system, is licensed to other manufacturers such as Asus, Samsung, LG, HTC, Huawei and many more, resulting in a vast range of phones from these manufacturers, often at much more competitive price points.*

Tip: *This relative dominance of the two mobile operating systems leads to the consumer having to make sometimes difficult choices on which side to come down on.*

Tip: *If your car uses Apple's IOS as the basis for Bluetooth, voice navigation and audio systems interoperability, you should consider getting an Apple phone. If it uses Android, you should get an Android phone.*

Tip: *Keep in mind that Bluetooth is not dependent on either phone operating system, just on the availability of the feature on the specific model of phone that you are considering.*

Tip: *The same goes for hearing aids — most hearing aid applications are available for both operating systems in their respective app stores.*

Tip: *Always test before you buy a smartphone to avoid unpleasant surprises. People become so obsessed with feature sets they forget simple yet vital things such as whether the carrier they are considering provides good service in their home area.*

Telephones Revisited

For those who haven't completely abandoned the voice telephone or sometimes need to understand voice messages on an answering machine, here are a few additional tips:

Multiple voice to text applications are available.

- You can install applications on your phone that will convert a voice message to text and you can use these applications instead of captioned telephones. The difference is that these app programs are software programs that are using voice recognition technology to caption your call rather than relying on a third person operator who is listening in on your call — a great advantage.
- You can use these applications and/or services from the cell phone companies themselves. Some cell phone companies provide speech to text software programming for their specific products (phones) that can convert voice mail messages to typed text messages. To find the technology that will provide the best fit for your needs, do some online research.

Answering Machines

Many people have found that getting a captioned phone allows them to receive captioned answering machine messages on their phone. You may apply for a free or low-cost captioned phone through the Massachusetts Equipment Distribution Program, mentioned above.

Transcribed Voice Message

Another option would be to have your answering machine messages transcribed by voice recognition software as discussed above. You can research online using the keywords “visual voicemail,” “voice to text,” “voice recognition technology” as well as going onto your phone's app store and searching for voice transcription applications on your phone.

In addition, if you become comfortable with ASL, you may use your videophone's sign mail system to retrieve voicemail messages that are interpreted by the videophone's interpreters.

APPS (Applications)

“Apps” is an abbreviation for “applications.” They are essentially programs created by software development companies that provide certain functionalities in addition to the base operating system of the smartphone. The following are just some of the applications that can turn your phone or computer into a very handy tool and resource with a wide range of functions. New applications appear and others are updated almost daily so stay ahead with the latest information from your phone and internet services.

uHear: Hearing Test App

Features

- Lets you test your hearing anywhere and at any time with the push of a button
- Tests you for the quietest sounds you can hear and how well you hear speech in noise
- Built-in questionnaire helps you and the app assess the quality of your hearing
- A results graph will rank your hearing loss from mild to profound and warn you if you are at risk of further damage
- Gives you easy-to-read, informed results. Keep in mind that the results are indicative only and you should still consult a professional if you suspect you have hearing loss.

Cost: Free

Too Loud?: Hearing Loss App

While we all know that loud environments can hurt our hearing, sometimes we don't know when those places are actually too loud.

Features

- Provides sound information directly from the sound source to the listener's hearing aids or cochlear implants if the latter are equipped with Bluetooth functionality. If they are not, a Bluetooth receiver/neck loop can be used to the same effect

Cost: Free

Hearing Loss Simulator

Here's an app that can explain hearing loss for you. If you find yourself constantly asking the people around you to speak up, this app will let them know exactly how you feel. With this handy app, your close friends and family come one step closer to understanding hearing loss.

Features

- You can make pre-recorded common sounds and illustrate how they sound to a person with hearing loss.
- You also have the option to record your own voice as a sample.
- Choose between various degrees of hearing loss to show the difference between mild and severe cases.

Cost: \$1.99

soundAMP®: Hearing Loss App

Features

- Lets you use your mobile device like a hearing aid by amplifying sound and speech
- Records lectures, presentations or conversations
- Plays them back with clear, loud sound
- Bookmarks sections of a recording for easy reference
- Exports files straight to your computer

Tip: *For the best results, you will need to use wired headphones and microphones. There is, however, one drawback to soundAMP: the hearing aid app cannot amplify music or phone calls.*

Cost: \$4.99

Purple Communications Video Relay Service: Hearing Loss App

Purple Communications VRS helps individuals who are Deaf or hard-of-hearing make voice phone calls with American Sign Language.

Using a video phone, you would simply sign to a qualified interpreter, who would then speak to whomever you called. The interpreter will then use sign language to communicate the response to you.

Advantage

VRS is a step up from text, as you can have a faster conversation, interrupt one another, and use facial expressions.

Cost: *Free for Deaf or hard-of-hearing individuals*

Ntouch APP VRS/VP APP by Sorenson Communications

Sorenson has an app called the Ntouch, which turns your smartphone, tablet or computer into a fully featured videophone to make point to point video calls with other videophone users; it also allows you to access Sorenson's Video Relay Service (VRS) to call people without videophones through an ASL interpreter. You must register with Sorenson as someone who uses ASL to become a qualified user of this application.

iHEARu: Hearing Loss App

Quiet places and spaces

A newly launched app, iHEARu addresses and seeks to alleviate such concern by helping people in the United States and across the globe find ear-friendly places to hear and be heard.

Features

- Allows people to report sound levels and share them with others
- Through crowdsourcing, people can choose to avoid the noisiest times at restaurants and other places.
- Those who simply want a quiet eatery, bar or café can turn to the app's GPS for guidance.
- Users note which places are ear-friendly—if, for example, the business offers customers the option of sitting in a quieter area or is open to turning down the volume on music.
- For those who like it loud you can use iHEARu to see whether a venue's noise levels warrant the use of hearing protection.

- Serves as an accessibility tool. People can use it to let others know if hearing assistive technology is available onsite in a particular public or commercial spaces. The app then guides users to those sites.
- Can also provide useful guidance to clinicians. Audiologists, for example, can tell their patients about quiet places as well as where they can find hearing-looped venues. They can also tell their patients to look for the iHEARu signs in the windows of participating restaurants and establishments.

Cost: *Free*

Apps for Kids

Follow this link to a spreadsheet with great information about kid-friendly apps.

<https://elearningindustry.com/10-top-educational-apps-for-kids>

CHAPTER 8

Auxiliary Services

Hearing aids, cochlear implants, speechreading, and assistive listening devices and systems work well in a one-to-one or small group situation. Hearing and understanding can become more difficult and stressful in larger scale situations where it is important to get every word accurately such as a legal or medical meeting or appointment.

If attending a lecture, class, or presentation, other devices are available and employed to help you stay comfortably engaged. This means that you may be able to negotiate a variety of situations: from a speaker's position and placement relative to yours, a foreign accent or unclear speech, to someone who faces away from you or who goes off-mic at the worst possible moment.

INTERPRETERS/CART SERVICES

For many years, Deaf, late-deafened and severely hard of hearing people have been using American Sign Language Interpreters, Oral Transliterators and CART — Communication Access Realtime Translation — to interpret or transcribe the spoken word into a more accessible form of visual communication.

ASL Interpreters, Oral Transliterators, and CART providers are highly skilled and accredited professionals who are usually requested by, and paid directly by agencies, services or businesses who have a legal obligation to provide communication access whenever it is requested.

CART Service

Communication Access Realtime Translation (CART) Service is often the accommodation of choice of hard of hearing or late-deafened individuals who read English fluently, do not use or are not fluent in sign language,

and who are comfortable speaking for themselves, CART is strictly for language reception and there is no reverse expressive component as there is with ASL interpreters who voice “for” a Deaf person.



Features

- CART Service provides a visual text on a screen with nearly instantaneous translation of the spoken word.
- The CART provider types the speaker’s words on a stenotype machine, which is connected to a laptop computer equipped with software that translates the steno input back into English.
- The hard of hearing or late-deafened individual can read the resulting English text translation on a large room screen, on the screen of a notebook computer, or streamed to their own browser-capable laptop, tablet or smartphone.
- Because they “type” in a phonetic shorthand, CART Reporters can type at speeds of 225 words per minute, which roughly approximates the average speaking pace. However, speed is only part of the picture — it is just as important that a CART provider be as accurate as possible.
- CART Service is an excellent choice for group meetings; even hearing people appreciate the convenience of not having to strain to catch poorly articulated or amplified words. For conferences, CART can be projected onto a screen or displayed on monitors. It can also be streamed to end-user devices such as laptops, tablets

and smartphones depending on the comfort level of the CART provider and the needs of the audience.

- Streaming to a portable device allows the flexibility to move the display so watch the speaker while also reading the text output, rather than being forced to look at a screen when the speaker is at the other end of the room.

With You in Mind

Many CART providers (but not all) are former court reporters with very good “real time typing skill.” They also have special trainings and certifications, and adhere to a strict code of ethics and confidentiality. They are skilled in the communication needs and access issues of hard of hearing and late-deafened people, thus CART is much more of a human service orientation than a courtroom or legal environment.

How to Arrange for CART Service

To obtain CART service, the agency or individual who is paying for the service should call MCDHH’s Interpreter/CART Referral Service at the numbers below or fill out an online request form on the MCDHH website.

MCDHH provides free referral services for ASL interpreters, Certified Deaf Interpreters (for Deaf people using visual gestural communication rather than ASL), and CART providers.

MCDHH Interpreter/CART Referral Service

617-740-1600 (V)

617-740-1700 (TTY)

617-740-1880 (Fax)

Toll Free: 800-530-7570 (TTY)

Toll Free: 800-882-1155 (V)

8:45 a.m. – 5:00 p.m., M–F

Video Phone Information

Boston office: 617-326-7546 Toll Free

Springfield office: 413-301-0915 Toll Free

Westborough office: 508-762-1124 Toll Free

<http://www.mass.gov/mcdhh>

8:45 a.m. – 5:00 p.m., M–F

For legal emergencies only: 800-249-9949 (V/TTY) 24 hours a day,
7 days a week

Tip: *Demand for this service has been rising steeply, so try to make requests well in advance of the actual date on which you will need it.*

Tip: *If you want a transcript from the session, you MUST state this in your request to MCDHH and also inform people at the event that you have requested a transcript so they are aware they are being recorded. CART should never be used as a pure transcription service, however.*

Tip: *Plan to provide the CART provider(s) with a list of names of people who will be speaking, as well as uncommon technical terms, acronyms and other words that you will be using so the providers can enter these into their software dictionary.*

Tip: *During long meetings, remember to schedule a break as CART reporting is very intensive work. Sometimes at very long events, two CART Reporters work together, taking turns.*

Remote CART

There are never enough CART providers to go around. The job pays quite well and can be extremely rewarding, but it also pays far less than court reporting and does not provide the benefits of being an employee of any one agency or system. As a result, those freelance professionals who provide CART under contract to MCDHH will understandably seek ongoing employment such as working for schools and universities, which provide regular and predictable schedules and incomes. This increases the scarcity of providers and leads to lack of onsite coverage for shorter, irregular, or inconveniently located meetings.

As a result, remote CART has become quite popular. If you wish to use remote CART, you'll need:

- a computer or tablet with an Internet connection in the locale where the event and the consumer are located. This can be hardwired, Wi-Fi, or even cellular, as long as the quality of the connection is sufficient. This should be tested beforehand if not known.
- a good conference telephone with extension microphones for small groups, so that the remote CART provider can hear the proceedings of the meeting which is required to be able to caption it.
- If it is a large group, using several wireless microphones feeding into a telephone connection is highly recommended. A single microphone in a large room is never sufficient if there are multiple speakers, especially when some of them are far away from the microphone.
- The remote CART provider types everything that is being said — meaning everything they hear, which is why good audio is so important — into the steno machine at their location. Their laptop will convert the phonetic input to written English, which is then sent to a webpage which is viewable at the remote location on any browser-capable device as long as there is a viable internet connection.
- Because the remote CART provider is not in the room to take a seating chart, participants must identify themselves before talking, and strict turn taking must be observed. If the provider cannot hear a comment, they cannot write it, and the consumer will not know what is being said — or who is saying it, because they will be looking at the screen and not around the room.
- Depending on what streaming service is used, it may be possible to superimpose captions over the presentation itself or over an enlarged video image of the presenter. This eliminates the need for a second screen and may also make for less distraction as the individual CART user doesn't have to divide their attention between two different views.

Interpreters/Transliterators

For late-deafened adults who are able to use ASL or signed English, or who are competent speech readers, using an interpreter or an oral transliterator may be an excellent way to handle communications at important meetings and conferences.

There are several different types of Interpreters:

- ASL Interpreters interpret spoken English into American Sign Language and interpret ASL into spoken English. One must be fluent in ASL to use an ASL Interpreter.
- Signed English Transliterators translate spoken English of the hearing person into mouthed (no voice used) English supported by signed English for the Deaf/deaf individual. They also translate the signed English and spoken English of the Deaf/deaf person into standard spoken English. One must learn signed English or ASL to use this type of interpreter effectively, although good speech readers sometimes find it useful to watch a Signed English Transliterator in a meeting.
- Oral Transliterators soundlessly and very clearly mouth the words of the speakers. Extensive training enables them to present a very visually clear model of what is being spoken for the person with the hearing loss to receive, paraphrasing when necessary for words that are not visible on the lips.
- Oral Transliterators may also voice the message and intent of the speech and mouth movements of the person who is Deaf/deaf or hard of hearing, so that the hearing person can understand. The Deaf/deaf individual must have good speechreading ability to take advantage of oral transliteration.
- Certified Deaf Interpreters are used by Deaf/deaf people who are not familiar with American Sign Language, as many Deaf/deaf people from other parts of the world are only familiar with their own regional sign language and may have developed their own form of visual gestural communication instead.

Tip: *When you call MCDHH for a referral (See above.) you should specify location and time of the event, the topic, preferred mode of communication, who will attend the event, and names of preferred interpreters, if you wish. Some interpreters have expertise in specialized areas, for example, medical, court, or legal settings. Try to make arrangements at least three weeks in advance, since the demand for interpreters is greater than the supply.*

For Hearing People: How to Use an Interpreter

- Speak at your natural pace. The interpreter must hear a complete thought before signing it.
- Look at the Deaf/deaf person and speak directly to them. Don't say, "Tell them."
- Stand or sit opposite the Deaf/deaf person and next to the interpreter, if possible.
- For meetings in large rooms, try to reserve seats in the front for people who will be using the interpreter so they can see more clearly.
- Remember that the Deaf/deaf person must be able to see the interpreter's hands and upper body. Make sure the interpreter is visible whenever slides or movies are shown, as people often dim room lights to enhance projection — which renders the interpreters difficult to see.

Video Remote Interpreting (VRI)

These interpreters are also in short supply. In addition, the recent popularity of video relay services has drawn many interpreters from the pool for permanent full-time employment with agencies providing this service. As with CART, help has — conditionally — arrived with the advent of remote interpreting (also known as video remote interpreting). MCDHH strongly encourages the use of VRI only with the express consent of the Deaf individual whom the service is designed to assist. If a Deaf person indicates that VRI does not work for them, they should not be coerced into using it and all efforts should be made to immediately procure an onsite ASL interpreter.

How It Works

- Using a laptop or videophone with integrated camera, microphone and speaker at each end, the remote interpreter signs what is being said just as an interpreter in the room would, but in front of a webcam.
- The picture appears on a laptop or videophone screen at the deaf person's location.
- When the Deaf/deaf person signs, the interpreter watches and voices what is being signed through a microphone for the hearing users.

Tip: *For this service to work, good lighting, good audio, and a stable high-speed internet connection are an absolute must. In some situations, VRI is simply not the best option to use, just as remote CART is limited in the situations where it can approximate onsite service provision.*

Note-takers and Computer-Assisted Notetaking (CAN and C-Print)

When CART is unavailable, you may be able to turn to note-takers, although this does not satisfy the Americans with Disabilities Act requirement for reasonable accommodation if the requester specifically asks for a verbatim transliteration of what is being said.



Tip: *These can be professionals or volunteer classmates or co-workers. They can take notes by hand, or they can type them on a computer, to be read from the screen. This is known as CAN, Computer-Assisted Notetaking.*

Tip: *Because note-takers don't use shorthand, it isn't possible for them to provide verbatim transcription. Instead, they summarize the proceedings, much as you would if you could hear and were taking notes yourself.*

Tip: *C-Print, a hybrid of CAN and shorthand abbreviations, and often used at colleges and universities, does not provide verbatim accuracy as does CART, but may provide more information than CAN's summary of key points.*

Tip: *Keep in mind that there are many situations where putting yourself at the mercy of a note-taker is essentially relying on someone else's grasp of what is important in any given situation.*

Tip: *If an absolutely faithful rendition is needed, or you are providing communication access as part of your ADA obligations, CART is still the way to go.*

Captioning

Captioning is a solution with a far broader audience and has made many television programs, movies, and visual content on the internet (YouTube, e.g.) accessible to millions of Deaf and hard of hearing people. Although the end result is much the same, subtitling and captioning differ in the way they are displayed on the screen. Both display the audio part of the movie or broadcast as text at the top or bottom of the screen.

Subtitles

This is similar to foreign language translation in that it displays the dialogue but not peripheral sound or musical elements, onscreen with no special decoding required. Usually, there is a default caption setting that does not allow for extensive customization of the displayed text.

Open and Closed Captioning (CC)

Open captions are always visible and cannot be turned off, whereas closed captions and subtitles can be turned on and off by the viewer. In contrast to subtitles, closed captions also include non-narrative sound

information (“door slamming”) since they are created specifically for individuals with hearing loss rather than language access, which subtitles address. Closed captions can only be seen when they are activated on the viewing device and when the material being viewed has been captioned by the producer of the material. Digital captions allow the font style, character size, background color and opacity of both text and background to be changed.

How It Works

Captioning videos and broadcasts is very similar to CART.

- For live television broadcasts, captioning is done in real time.
- The captioner may be in the studio or may receive the audio over the telephone or Internet at a remote location.
- For pre-produced programs, captioning does not need to be provided in real time — the captioner can backtrack to review a passage, and accuracy can be far higher.

Tips:

- *In 1972, the WGBH Caption Center in Boston captioned the first nationally broadcast television program, supported by funding from the Department of Health, Education and Welfare (HEW). The program? Julia Child’s “The French Chef.” Since that time, captioned telecasts have increased dramatically.*
- *In the past, it was necessary to have a small “decoder” connected to your television to display closed captions. However, since July 1993, every television set manufactured or sold in this country with a screen 13 inches or larger has been required by law to have built-in circuitry to display closed captions.*
- *Since the conversion to digital television, the capability to individually adjust captions to one’s particular preferences has been available to any HDTV user.*
- *Most portable internet-connected devices by the major manufacturers — such as iPhones and Samsung Galaxy phones — also have integrated accessibility features, including closed captioning.*

- *Handheld Captioning Systems are display devices with wireless connectivity that allows them to receive captions being streamed and displayed while being moved from location to location within a defined area such as a museum, theater, or sporting venue.*
- *Many movie services such as iTunes, Google Play, Netflix, Hulu and more also offer in-app subtitle functionality, sometimes even in different languages.*
- *Online content, classes and webinars are often stumbling blocks for Deaf, hard of hearing and late-deafened students because of missing or poorly implemented captioning of content. It is important to advocate for yourself when this happens, as much content is required to be accessible under the Twenty-First Century Communications and Video Accessibility Act (CVAA)*

More information here: <https://www.fcc.gov/consumers/guides/21st-century-communications-and-video-accessibility-act-cvaa>

GOING TO THE MOVIES

Movie-goers with good hearing have said that open captions on the screen can be distracting and do not want to see them. To address that, several different systems have been tried to deliver closed captioning to people with hearing loss without annoying hearing viewers in the process.

Currently, there are three systems in place, with different iterations.

Rear Window Captioning

One such system was developed by Larry Goldberg and Dan Glisson of WGBH and filmmaker and inventor Rufus Butler Seder.

How It Works

- With RWC, a large LCD display is mounted on a back wall of a theater and displays captions backwards.
- Viewers receive a reflective plastic unit as they enter the theater, mounted on a substantial stand or a gooseneck that attaches to

the cup holder on their seats. They sometimes have to sit in a particular part of the theater.

- The user then adjusts the reflector so that it displays a mirror image of the backwards captions on the rear wall, right way around, under the large screen they are viewing ahead of them.

Disadvantages

The main complaints about Rear Window Captioning are that:

- the user must shift between the screen and the reflector to follow the performance
- the units are quite obvious and become scratched easily
- the gooseneck portion can come loose necessitating frequent readjustments
- RWC does not always work or work well and may not be available for a particular showing
- user experience can vary widely.



Caption Glasses

Currently in use at Regal Cinemas, these glasses present a dramatic improvement, although they are not without faults.

How They Work

- The glasses fit over existing glasses. They can be hard on people who have small ears and hearing aids, cochlear implants or glasses already taking up space there.

- The glasses are connected to a receiver unit which can also be utilized as an assistive listening and descriptive video system.
- Two tiny projectors are concealed in the temples and project the dialogue of the movie onto the bottom part of the glasses for a floating in air captioning experience. Adjusting them precisely can take some time.



Seatback LED Panels

These are utilized to provide slide-out captioning capability that is attached to the seat in front of the viewer. Depending on whether this is a fixed or portable installation, the LED can be provided ahead of time at the service desk similar to the above two systems, or the viewer has to sit in a reserved seating area to have access to this device.

CAPTIONING AND UNIVERSAL DESIGN

Captioning is a prime example of how intelligent design features intended for one audience can, in fact, find favor with other segments of the population. Captions have been found convenient and useful by people who aren't deaf or hard of hearing, including:

- children learning to read
- people learning English as a second language
- television viewers who don't want to bother others in the room
- patrons in noisy bars
- restaurants and health club patrons who wish to follow the action on widescreen televisions and monitors.

CHAPTER 9

Living with and Moving beyond Hearing Loss

This is where you can take your hearing experience up several notches. Technology and medical and professional help have gotten you to this point. Your future success and happiness now depend on your willingness to take charge and control of what comes next.

Now, all that came before will have much greater meaning as you learn to adjust and adapt your day-to-day to your new realities and to transform your life into whatever you wish it to be. The only additional limits now are the ones that are self-imposed.

STRATEGIES FOR DAILY LIVING

As you've read, hearing loss has no one size identity, treatment, solution or protocol to make life easier though there are countless remedies and adjustments you can and will have to make to find your own level, employ helpful resources, and explore ways of managing life.

That said, remember that you are not alone. This guide offers countless people, places, and things to assist you all along the way. In addition to seeking help from other individuals, groups, services, and agencies, it's most important to take the initiative to help yourself as well. You can do it!

There are many ways to apply proactive self-care with hearing loss and you'll find that you will be the teacher, student, and advocate all in one for the many things you will need to learn and experience for yourself. To begin with, as everyone with hearing loss before you has learned, there are certain rules of the road to guide you.

Stay connected.

Don't become isolated and fall to loneliness, depression or dementia. Keep family, friends, coworkers and others close and share with them your challenges and ask for their love, support and understanding in return.

Become assertive.

To borrow a quote about growing old, hearing loss is “not for sissies” — whatever your age. Be assertive in ways that tell others that your hearing loss does not make you any less of a person. If you need some training, you can find assertiveness training sessions where you can get the opportunity to role-play and test out different approaches. The more you practice assertiveness, the more you refine your technique and the easier it becomes. And the more in charge of your hearing loss you will feel.

Join a local/national support group(s).

Support groups are very valuable especially if you feel alone and uncomfortable being assertive. They will provide friendship, compassion, understanding along with many unique resources to get you where you're going. They will also direct you to much of what you will need to fill in the gaps of this guide and your own knowledge and wisdom about hearing loss.

The personal experiences of others will be your greatest support, so connect and stay connected.

Often members of such groups as Association of Late-Deafened Adults (ALDA), and the Hearing Loss Association of America (HLAA) and other support groups frequently come to think of their groups as “extended families.” They're brought together by hearing loss, but stay together because they find other interesting people and many things to enjoy within the groups.

Many of these support groups hold annual national and regional conferences, another way to take a vacation, enjoy relaxed interactions with



others, and make and meet friends in a communication-accessible, stress-free atmosphere.

These conventions also attract specialized manufacturers who showcase the latest and greatest in “accessible Deaf/HoH products” and sometimes conduct workshops and focus groups.

Ask for assistance and accommodations when and where you need them.

Learn to do so matter-of-factly. Being demanding on the one hand or apologetic on the other doesn’t really work all that well, simply because they encourage counterproductive responses in people.

Inform others how they can work with you to improve communication.

Remember that when you improve communication for yourself, you’re most likely also improving it for friends, family, colleagues at work, and people in your community. Contact event organizers well before an event to discuss communications access as it may be something they haven’t considered.

Remember that your hearing loss is invisible.

Don’t expect people to change the way they interact with you unless they know that you have a hearing loss. As mind-reading is not yet possible, don’t assume people will even realize you have a hearing loss until you tell them that you do. Your hearing loss is most likely only glaringly obvious to one person — yourself. If you assume every person’s response to you is based on a hearing loss only you can “see,” that is going to create many awkward interactions with others.

Remember that few hearing people know much about being hard of hearing or Deaf.

Hearing people have many misconceptions about the best way to help. You can teach people about hearing loss and what they can do to make communication easier. Once people know more about hearing loss and

effective communication and learn how many people are affected by it, they will often work with you to improve access however they can.

Approach your “hearing” contemporaries with an open and friendly attitude.

They will appreciate your forthrightness and be more willing to engage with you as a result.

Become your own best advocate.

In your family, at school, at your job, even in your off-time, when you participate in activities you enjoy you are your own best advocate.

Jane Sokol Shulman tells of meeting with her professors each semester to tell them about her hearing loss (she was severely hard of hearing at the time) and explain what they could do to help her follow lectures and class discussions. “By going through the process of speaking to my professors, by using the words ‘hard of hearing,’ I got used to the words, I got used to the ideas. At first, of course, I cringed every time I had ‘the talk,’ but after a while it got to the point where I could do it calmly.”

Ginny Mazur, a member of the Greater Boston chapter of HLAA, lamented the fact that she couldn’t attend accessible films at her local cinema. She discovered that the management, which had brought some of the first open-captioned films to the area many years ago, was open to her proposal to create an accessible movie night. Working with the Boston Guild for the Hard of Hearing at Northeastern University, the theater installed an audio loop system in a small screening room and showed closed-captioned films once a month for a dedicated film club.

Make your home and work environment communication friendly.

Have you been wanting to redecorate? Here’s your chance. Start by analyzing where you normally sit during the day: at meals, when just relaxing or entertaining.

There are a number of things you can do to improve the environment for communication.

Carpet and Wall Covering

Sound bounces off bare floors and walls, so if you have residual hearing, you may want to make changes in wall and floor covering.

- Rearrange furniture: It's important for you to be able to see the speaker's face without straining. Place your favorite seat so that the light isn't in your face and so that it's opposite where guests or family members usually sit. If you're speechreading, you'll want to sit fairly close to the speaker. If the speaker is signing, you'll want to sit a bit farther away to widen your field of vision.
- Position yourself so that you don't have to crane your neck. If the speaker is sitting, sit. If the speaker is standing, stand.
- Make adjustments as you go along at home, at work, and when visiting. People will understand if you close blinds in back of them so that you aren't looking into the sun, or move lamps, remove vases from tables, move a chair. Just explain what you're doing and why.
- Install visual alerting and signaling devices so you can feel secure in your home environment.
- Investigate and make use of the most effective telecommunication options for yourself.
- When all else fails, you can always resort to a low-tech combination of paper pad and pen, or text on your smartphone if you're a little more advanced technologically. Or you can use speech-to-text if you really want to impress your conversational partners. It means they will have to speak clearly and there can't be too much noise in the background.

Most importantly, relax.

Don't attempt the impossible. When you have a hearing loss, spoken communication can become an exhausting and stressful process.

- Try to plan your days to include time for rest and relaxation. Schedule important appointments when you know you'll be fresh.

- Don't be hard on yourself when you're in impossible communication situations. Part of any successful coping strategy is realizing when things are hopeless, and accepting rather than fighting them.

As Kim Grebert, a deaf expert on hearing loss and stress who gives frequent workshops, has said, “We (people with hearing loss) work so hard to make communication exist, no wonder we’re stressed.”

Manage your stress.

Always easier said than done. The stresses associated with hearing loss can affect you physically, emotionally and psychologically. The initial “fight or flight” reaction may help in the short term as your body responds by pumping out chemicals that raise your heart rate and blood pressure, tighten your muscles, and make your brain work faster. You can always be on “high alert” for visual cues. All this, as well as the stresses of modern life can contribute to a sense of fatigue, powerlessness, and physical ills.

Grebert advises, “Breathe deeply from the belly, exercise, meditate, slow down, sleep, eat healthy foods, take care of yourself.”

Be clear about your priorities and distribute your energy accordingly.

“A few years ago, when my dog graduated from obedience class, I decided it was a good excuse to celebrate, and invited a few friends to drop by afterwards for cake and coffee. My dog loves company and is very lively and sociable, often to the point of becoming a nuisance. But that night, having performed during class and been very excited over company for half an hour, she decided that she’d had enough and crawled under an end table in a corner and went to sleep. Every now and then, when I’ve overextended myself and following conversation becomes too much of a burden, I have to stop and ask myself, “Why aren’t you as smart about this as your dog?”

— Karen Rockow, author of the original *Savvy Guide to Hearing Loss*

Be conscious of the “hearing fatigue” factor.

There are times when you just will not be able to muster the energy and concentration necessary to follow spoken communication, or when the environment is so inhospitable to communication that any attempt is almost certain to fail. Don't keep banging your head against the wall when that happens. Make your apologies and fade into the background, or move to a quiet corner for a while.

Cultivate and employ your sense of humor.

You're going to encounter some strange, uncomfortable and even laughable situations and predicaments in your life that directly relate to your hearing loss. It's best to keep your sense of humor available to deal with those when they arise. Patience, laughter, and not taking yourself too seriously are all wonderful tools to keep you grounded.

Remember that the other person may be uncomfortable as well.

Any communication-challenged interaction can be an embarrassment for you and others because of their own inability to know how to respond.

Impatience is a given.

You're also going to meet people who are impatient with you, if not downright rude and dismissive— and you'll have to handle those too. But remember that's their problem. If someone growls at you “Are you deaf?” look them straight in the eye and say “Yes, do you have a problem with that?” It's always a showstopper.

Vote with your feet and pocketbook.

Always remember that you're part of a very sizable 20% of the population and there is no reason to allow yourself to be treated like a second-class citizen. Patronize and reward those who make your life easier and more pleasant; avoid those who don't. It's a simple yet effective strategy. Almost everyone has a manager or boss — take it upon yourself to praise good service, or to tell the manager why you won't be back if you were treated poorly. Chances are, the offending staff won't be there much longer if they turn customers off.

Become an advocate for issues that you believe in.

If you're looking for Battles to Wage or Good Works to do, you've come to the right place. The Deaf, late-deafened and hard of hearing population has made great strides in the past few years, but there are miles to go on many issues. Don't be complacent or over-confident. What has been accomplished can also be taken away, whether by politics, poorly crafted legislation or poorly applied technical advances.

Because hearing loss is invisible and isn't life-threatening, it's easy for legislators, corporations, employers, and providers of services to overlook issues related to it. Get active when you can be. There are many causes to campaign for and everyone has their favorite. For example:

Accessibility

- Become familiar with the Americans with Disabilities Act (ADA) and support communication access in your communities and workplaces.
- Lobby for CART and interpreter services, scripts, and assistive listening devices in public places.
- Be aware that laws have been passed to require newborns to be screened for hearing loss. Another requires hearing aid dispensers to be certified and responsible to a board of examiners. A third requires insurance companies to pay for the cost of hearing aids in children. Most recently, the Over-the-Counter Hearing Aid Bill was passed and signed into law with bipartisan political support and backing from HLAA.

These laws were passed because people like you advocated for them.

There will continue to be many possibilities for action in the political arena. Visit MCDHH on Facebook and on the internet (www.mass.gov/mcdhh) for information about current and pending legislative bills.

Affect change by speaking up.

Life is full of small annoyances that sometimes only need to be brought to the attention of organizations and manufacturers.

A member of Self Help for Hard of Hearing People (now the Hearing Loss Association of America, or HLAA) in Montana received a Black & Decker bread maker as a gift. It arrived with recipes, instructions, and a videotape that showed how to use the machine. But the videotape was not captioned and, therefore, useless to the woman.

She wrote to the company and requested a captioned video, or, alternately, a transcript of the tape. Black & Decker arranged for a transcript from the production company in Canada and she had it within two weeks. She then wrote to MCDHH to identify herself after picking up an earlier version of this guide at the SHHH convention in Boston.

Learn about Deaf culture.

Contact a Deaf and Hard of Hearing Independent Living Service (DHILS) Program (an Independent Living Program, providing services for Deaf, late-deafened, and hard of hearing people). You may meet other people who share your interests and will help you become fluent in sign language. You can also find frequent informal social gatherings in the state where attendees practice their ASL skills. Even if you're not interested in learning sign language, knowing the fingerspelling alphabet is very useful as it allows you, your family, and friends to get past those "impossible" words by the simple expedient of fingerspelling them.

Familiarize yourself with assistive technology.

It can help you to communicate and function better. The MCDHH Communication Access, Training and Technology Services (CATTs) is an excellent resource, and they can provide free trainings in your local community if you can arrange for them to be invited. They also provide free worksite and home evaluations which can be used as the basis for requesting support from other organizations, or from your own agency/program.

Use search engines.

Google to your heart's content, ask questions online, and join forums about hearing loss and related issues to get answers. You'll find them all over the web. There are so many people with hearing loss in the world that someone else is likely to have posted some helpful or related information on Facebook, Twitter and/or on their own website. Manufacturers, vendors and experts abound. Take advantage of their information but be sure to cross refer and verify anything you read. Fake news isn't just restricted to political events, it unfortunately often finds its way into product marketing and the promotion of services that may be of dubious value.

Find new activities and interests.

You'll be surprised at the number of activities that don't require perfect hearing. Try walking or hiking, cycling, jogging, swimming, riding, boating, golfing, skating, water and snow skiing. Realize that hearing loss can actually be a blessing in many situations, such as sitting on a crowded beach with thousands of strangers, and being able to close your eyes and imagine you're the only person on a deserted beach in a tropical paradise.

And there are any number of other activities to try: writing, reading, painting, antiquing, pottery, knitting, weaving, cooking/baking, sewing, gardening, going to museums, keeping up written or computer correspondence, surfing the Net, yoga, and meditation. The list is endless.

Just be aware that for some particularly challenging physical activities, if you do use hearing aids or cochlear implants to hear environmental sounds for safety's sake, or to supplement your speechreading skills, it is probably a good idea to either take them off or use "disposable" spares. For example, an old hearing aid that you've hung onto that still works is a good option in situations where you **MUST** hear but the risk to the hearing aid from water, sweat, or impact is great.

Engage in individual therapy.

Today, the stigma attached to seeking professional guidance — if you're having a hard time coping — is lessening. Many informative and self-help

books, blogs and articles are available on a vast variety of topics related to coping with hearing loss.

There are also professional therapists who specialize in addressing hearing loss related issues — and some of them even use American Sign Language.

Finally, if you seem to be constantly in conflict with people, or feel like you're being isolated, it may be time to analyze what's happening. For one thing, it's very easy to cross the line from assertive to aggressive. For another, it's easy to let your anger over your hearing loss taint unrelated relationships, episodes or activities.

A woman who had begun to lose her hearing as a teenager, became late-deafened as an adult, and was now working as a librarian at a school for the Deaf. She was active in the Deaf community, well respected by her co-workers, and was fluent in ASL. But she still seemed enraged at her parents, who had insisted when she first began to lose her hearing that she remain in a mainstream classroom. She had never been able to resolve that issue with them and seemed to need to create conflicts with others so that she could vent her righteous indignation. When she traveled with her hearing dog, she left his identifying leash behind, then walked boldly into the ladies' room with him, apparently looking for a confrontation (and often finding one). Because he was a service dog, he was legally entitled to this privilege, but no one could tell that he was a service dog. She became furious whenever a hearing person spoke to her while her back was turned, but refused to tell people that she was deaf and how best to communicate with her. A number of us listened in dismay to her stories of run-ins with various strangers. We tried to tell her that she couldn't expect people to be mind-readers, that they would be happy to meet her halfway, but that she had to take the

initiative and teach them. “I spend all day teaching,” she replied. “I don’t want to have anything to do with it when I’m on my own free time.”

When you meet people like this very bright and talented woman who simply didn’t want to understand that certain responsibilities come with the territory and that she was behaving in an unreasonable and manipulative manner, individual therapy might be a good option.

Losing one’s hearing at any stage in life can be difficult and lead to repressed anger, resentment and, of course, grief. This often comes out at the wrong time and at someone who doesn’t deserve to be the focal point of all these emotions.

Be responsible for your own happiness.

How many times have you heard this? Like it or not, you’re responsible for your own happiness. And how you behave influences the way hearing people will regard not just you as an individual but, very likely, everyone else they meet with hearing loss as well. Unfortunately, the tendency to generalize is widespread, and if someone has a terrible experience with you they are apt to approach the next person with hearing loss with a very defensive mindset in anticipation of a challenging encounter.

Live well.

Living well with hearing loss isn’t much different from living well with anything else. A great deal depends on attitude. Is the cup half empty or half full? Do you think that most people are eager to oblige or are they totally self-absorbed and uncaring? Is deafness a challenge or a burden? Are you responsible for your own happiness, or are you more comfortable blaming others for your not being happy?

~ Helen Fleming's Story ~

Helen's hearing loss was first diagnosed when she was a sophomore in college. "I had absolutely no idea the impact that this hearing loss was going to have on my life. I think that if I had been able to see down the road, to see some of the traumatic experiences that I have had, there is no way in God's world that I would have had the courage or the nerve to go on and do the things that I did."

Her first hearing aid came by way of a cookie box top that she mailed into a contest. She actually won a go-kart, but the company let her take the money instead, and she bought a hearing aid.

She went on to receive a master's degree in education from Salem State College. "I still thought there was nothing in the world wrong with me," she recalls. "I kept thinking: There is nothing in this world that I can't do if I make up my mind about it. I think that the first time I began to acknowledge that I was having trouble was when I was labeled — that's why I don't like labels. I think labels hurt people. When they said, 'she's hearing-impaired.' Impaired? Like there was something faulty. You know, the package isn't right, send it back."

Helen taught school for 40 years. During the final 20 years, she taught remedial reading. "And that was a real blessing for me. I only had one to five students at a time. That way, I was able to cover up." She was terrified that the parents of her students would find out about her hearing loss. She was even afraid to ask for a personal day because "they would think, oh, she's not capable of doing the job."

Finally, she applied for a personal day so she could go to the annual luncheon of the Boston Guild for the Hard of Hearing to hear Rocky Stone, founder of Self Help for Hard of Hearing People (Now the

“Hearing Loss Association of America”). “He gave me so much to think about that day, I could not believe that a man who was deaf or that had to struggle in the hearing world could be so upbeat. And when I confronted him about that, he said, ‘Aren’t you upbeat?’ I said “if I had the money, I’d buy a deserted island in the middle of the Pacific Ocean and I’d set up a tent and stay there.” He asked why. I said “so that I wouldn’t have to listen to people. I didn’t mind talking to them. It’s the listening that bothers me.” He then said, “No, no, no. That was not a luxury any of us could have in this world. Like it or not, we had to listen.”

When Helen’s husband died, it was like losing her hearing all over again because he had been so supportive. “I was an angry, angry person,” Helen recalls. “And I didn’t know what the heck I was angry about. I thought I was angry at my family because they wouldn’t cooperate with what I needed. How could they know what I needed when I didn’t know that myself? And that’s how my involvement with Self Help for Hard of Hearing taught me how to cope. It taught me how to modify aggressiveness to assertiveness. It taught me how to manage stress. I’m still working on the stress part.”

Helen received her first cochlear implant in 1999. “I found I still needed to read lips, however the fact that I could hear birds chirping, the ringing of the telephone and doorbell, sirens from ambulances, fire trucks and police cars was music to my ears. I could finally drive with both eyes on the road instead of one on the road and one on the rear-view mirror.” She feels fortunate that she was implanted at the Massachusetts Eye and Ear Infirmary (MEEI) because they spent so much time with her on aural rehabilitation.

Five-and-a-half years later, in late December of 2004, her implant “went kaput.” Thinking it was the external element, she underwent three days of testing only to discover that for some unknown reason, the implant had simply failed. When she asked for a temporary replacement, she was told that no hearing aid on the market could

help her. “There was nothing left to do but grin and bear it.” During the family get-together at Christmas, one of her grandsons told her it was just like old times. “I spent four months with no hearing at all and it was one of the worst experiences in my life. I had become totally spoiled. Having had hearing for five and a half years, I was desolate.” She was re-implanted in the same ear in March 2005. A month later, she was hooked up. This time, she did not need to spend as much time in aural rehabilitation.

“I am still alive and well and hearing as well as I did with the first implant. Was it worth it? Definitely. If this one ever goes on the fritz, I’ll have it done again, only this time in my right ear,” she reports.

“So, from the individual who thought there was nothing left for her to do, who was afraid to be in a crowd, afraid to get up in front of a microphone because she was going to make a mistake, this individual now feels that she still has plenty of miles left on her engine, but she has miles to go before she sleeps. And I hope I will be able to keep going as an advocate for the rights of hard of hearing people.”

Helen Fleming was a key figure on the Massachusetts Hard of Hearing scene for many years. Her efforts on behalf of people with hearing loss have been recognized by the Boston Guild for the Hard of Hearing, Self Help for Hard of Hearing People (SHHH, now the Hearing Loss Association of America, HLAA), the Independent Living Center (ILC) of the North Shore and Cape Ann, and by Channel 6 (the Independent Spirit Award). She served on the Board of Directors of the Boston Guild for the Hard of Hearing and the ILC of the North Shore, and on the first Statewide Advisory Council (SAC) for MCDHH. Along the way, she founded the North of Boston Self Help for Hard of Hearing People (SHHH) Group and spent six years as state SHHH coordinator. Helen passed away in August of 2015.

OUT AND ABOUT WITH HEARING LOSS

Each of us, hearing or otherwise, develops a personal “style” for handling complex communication situations, and it’s helpful to observe and learn how others cope. Here are some scenarios common to those with hearing loss.

Explaining Deafness to Hearing People

One of your first tasks will be to develop a short spiel to explain your deafness to hearing people with whom you come into contact. You’ll want to give people some guidelines for talking to you, for example, “I’m hard of hearing and I speech read.” “I need you to speak more slowly, face me, and please don’t yell.” Some people will also need an explanation of the nature of your hearing loss. If you have some residual hearing and wear hearing aids, it becomes more difficult to make people understand that just because you can speak perfectly, it does not mean you can hear perfectly as well.

One deaf individual handled it this way:

After several years of explaining to people that her aids do not correct her hearing the same way glasses correct vision, she told them that she can hear them speaking but understands them about as well as if they were speaking Tibetan. She also tried telling people that she just doesn’t hear the consonants in most of their words. Since few people have thought about consonants since the third grade, it definitely makes them pause and think.

Shopping

“Where are the canned peaches?” can become a major research project when you’re Deaf/deaf. If you can’t seem to locate the canned fruit department using the overhead signs on aisles, the best method of getting an answer may be to ask an employee to show you the number of the aisle by holding up the appropriate number of fingers. Some supermarket employees will welcome the respite from stacking boxes of corn flakes and lead you to the peaches, or you can carry a pad and pen.

At the Register

- Position yourself so that you can see the total.
- Pay with larger bills or use a debit or credit card so you don't have to worry too much about hearing the precise amount.
- Ask to look at the digital display listing the amount owed.

In supermarkets and other large stores, it's important not to forget that the sales people are there to help you, though they sometimes lose sight of the fact. Remind them. Some chains have experimented with shopping carts that can actually lead you to what you're looking for or display a map of the store and your current location relative to the item you are looking for, on an LCD on the handle, or apps that use GPS locating on your smart-phone to show you where a product is relative to where you are.

Doctor's Offices and Hospitals

Strangely enough, the medical profession as a whole can often miss the mark when it comes to dealing effectively with people who are Deaf/HoH. Why does the nurse always call your name to summon you? Unless you want to spend the entire time you're in the waiting room in a state of high alert, you'll have to explain that you're Deaf/deaf and tell the receptionist that you won't hear anyone call your name. It's then their problem, but you can help things along by sitting where you can easily see and be seen by the nurse. No, it doesn't work every time, but it's a starting point.

Jonathan O'Dell recently had an appointment in a large doctor's office. He told the receptionist that he would need someone to walk over to him in the waiting room to call him. Imagine his frustration when the assistant opened the door, stopped, and called out something unintelligible repeatedly. It wasn't until all the other patients in the room began to look at each other that he realized that this must be for him. When he inquired, a little upset, why his instructions had not been followed, the assistant showed him what the receptionist had written on a sticky paper: "Get him." How the receptionist expected an assistant to "get" someone she had never met before remains a puzzle.



Some hospitals and clinics now use a pager system similar to the pagers that buzz at restaurants so when it is the Deaf/HoH person's turn, the pager lights up and vibrates.

When You Need Additional Assistance

If you need an interpreter or CART service to communicate with some medical professionals about your medical appointment, be prepared for a potential battle. Unless you're dealing with a large hospital, some doctors are reluctant to foot the bill for interpreter or CART services, although they have an unequivocal responsibility to do so under the Americans with Disabilities Act. It is always best to make a request for communication assistance in writing, in advance of the appointment, and to keep a record of this communication so that if or when things go wrong, you have proof that may carry the day in a court of law. If you use remote CART for an appointment, make it clear to the medical provider that it is their responsibility to have everything set up and ready to go. It is not your responsibility to bring your own technology in order to read the remote CART output.

If You Know Sign Language

- Ask the doctor to provide VRI (Remote ASL interpreter) services during the appointment, if you are comfortable with that and if onsite ASL interpreters are not available for some reason.

If Your Doctor Continues to Refuse to Provide CART Services and/or an Interpreter

- Call MCDHH and ask for someone from Communication Access, Training and Technology Services or a Case Manager to help you with this issue. MCDHH staff advocate for communication access all the time
- Don't be afraid to tell the receptionist that you want to reschedule your appointment to a time when ASL, or CART services can be provided.

Please know that doctors, even doctors from small practices, are MANDATED to provide communication access. You have a right to understand everything the doctor has to share with you regarding your health. If you prefer not to use CART or ASL services you may also choose to ask the doctor to type his replies on a notebook computer.

If You Are Hard of Hearing

Doctors' offices, hospitals and clinics are also responsible to provide you with assistive listening systems (ALDs) upon request. Be sure to ask for this when you make the initial appointment so that the devices can be obtained and provided to the appropriate location and office ahead of time so it is ready for you. If you need special attachments, such as a neck loop, be vocal about this so it is provided — and if possible, bring your own with you if you have one.

Some hard of hearing patients have recounted that they are comfortable with physicians using speech to text apps rather than CART. If you do not object to that, then by all means feel free to use that; just be aware that one of the chief problems with hearing loss is that you won't necessarily know that you've missed or misunderstood something unless a third party makes you aware of the fact.

Making an Appointment by Phone

- Always repeat the date and time to double-check, to make sure that you heard it properly or the relay/captel or videophone operator typed/signed it correctly.
- If you are planning elective surgery and know you will be in the hospital, make plans for an interpreter or for CART well in advance of the procedure and afterward, as having communication access while you are unconscious is quite useless.
- Call your doctor and/or hospital and let them know that they need to make arrangements for CART and/or ASL interpreters at least two weeks in advance to improve the odds of getting access.
- Alert the hospital to any difficulty you may have communicating. Have your family place a poster over your bed telling people to

face you on the side of the bed away from the window, and to be sure that the lights are on when it is dark. If you speech read, all of this will give you time to put your hearing aids or CIs on.

- If you wear hearing aids or a cochlear implant, speak to the hospital beforehand and ask if you can wear them during surgery or if they'll be kept close at hand so you can put them on in the recovery room. This also minimizes the risk of loss or theft, which sadly does happen to some unfortunate people.

Dining Out

When was the last time you were able to hear the name of the soup du jour? Dining out is often a major challenge. If you have some useful residual hearing and/or use a hearing aid/CI, here are some tips to keep in mind.

- Start by asking for a table away from the kitchen, bar, and any other particularly loud area. Often wait people stack everyone in the same area for their convenience — explain to them that you must have a quiet and relaxed environment.
- Explain to the waitperson that you may have difficulty speechreading and hearing and want him or her to write down information delivered orally, such as choices of soup, vegetables, salad dressings, and pies.
- Specials can be very challenging because they are often not written down anywhere other than in the waitperson's own notepad. Most waitpersons will be happy to assist you further, if for no other reason than to expect a larger tip.

At the Table

A challenge that many face, whether they have good hearing or not, is conversing with others in your group once you've sat down at your table. This can be addressed in several ways:

- Seat yourself so that you can face as many people as possible without any awkward positioning or sightlines.

- Be realistic and know that often you will not be able to follow the larger conversation. Pick and choose where and when you can participate.
- If candles, flowers or other centerpieces block your view, relocate them.
- If you can use an assistive listening device, it may help, particularly if you can pass a Bluetooth microphone around the table to the speaker.
- You may also have a directional microphone setting for your hearing aids or CIs, or a program that quiets background noise. Learn how to use these to optimum effect.

Otherwise, and unless you learn sign language and are with a group of people who can sign, your conversation will probably be limited to your near neighbors.

At Fast Food Drive-thru Windows

A number of restaurants now have display screens at the ordering station that show the items you have ordered and the total cost of the meal, but many do not, or their systems don't work. You can always go inside to order.

Deaf and HoH people may ignore the menu/loudspeaker system and simply drive up to the order window to deliver their order by speaking directly to staff or handing a piece of paper with their desired choices to the window attendant.

Jonathan O'Dell recounts how, several years ago, he was involved in a situation where someone's Deaf parents had driven up to the drive-through window directly to place their order, and the ignorant hearing manager of the fast food franchise would have none of it and ordered the deaf seniors to move their car immediately. They refused, and the manager called the police. It was only after horrified national executives of the franchise had received a complaint from the Deaf

seniors' daughter that Jonathan was asked to go and educate the franchise staff at this location about the communication needs of Deaf and late-deafened individuals.

This sort of moral stand is important. Had the Deaf seniors simply decided to move, there would have been no lessons learned and no progress made. Because they knew their rights and refused to be treated as second-class citizens, they made change happen, unpleasant and frightening as it was with the police involved.

At Parties

- Arrive early so that you can chat privately with your host and hostess before the other guests arrive.
- During the party, try to find a quiet spot where you can position the speaker to best advantage.
- If possible, you may be able to find less crowded or otherwise more suitable area for communication.
- If you find an interesting person you'd love to talk to but the noise and lighting level make this impossible, then by all means, say as much and ask the person if they would be interested in continuing the conversation somewhere quieter.

Driving and Traveling

Traveling presents an interesting set of challenges although, just in case you were wondering, Deaf/HoH drivers as a group have an impressive safety record due to their enhanced visual awareness of what is happening around them.

In the Car

- Conversing with a passenger while behind the wheel isn't really recommended, unless you can use an ALD that allows you to keep your eyes on the road.
- As a driver, try to avoid the temptation of turning toward the passenger so you can speech read without taking your eyes off the road for extended periods of time.

- If someone wants to talk to you during a trip, ask them if they wouldn't mind driving, so you can sit in the passenger seat and focus on what they are saying. If they are hearing, they won't need to take their eyes off the road to hear you — unless, of course, they are Deaf/deaf and use ASL, in which case they (or you) can use an additional convex mirror clipped onto the rearview mirror to see each other without taking your eyes off the road.

Other gadgets — the turn signal (audible/visual blinkers), wide angle rear-view mirrors, and overhead lights are practical, too. There are even portable audio loop installations specifically for cars. Of course, other ALDs can also be used, as can Bluetooth microphones. Most cars today have the ability to integrate with smartphones via Bluetooth, and making a call using the car's sound system is a pleasant experience for many people because they can control the sound environment.

When leasing or buying a car, look for a car that is as quiet on the road as you can possibly afford. Often, roof racks, sunroofs and other add-ons make a car louder, and even a cheap set of tires can increase road noise to objectionable levels.

Bigger cars are usually quieter than tiny economy cars.

Air Travel

There is a well-known story about the stewardess who gave a deaf passenger a card with Braille instructions. Other Deaf/deaf people have reported airline employees greeting them with a wheelchair. It usually isn't that bad.

- Most airlines now have monitors that list whether a plane is on time, delayed, cancelled, at gate, or boarding.
- It is still a good idea to arrive early and notify the ticket taker that you're deaf and that someone should personally deliver any announcements that come over the loudspeaker.
- Aboard the plane, remind the stewardess again.
- If you are Deaf or HoH, federal law prohibits you from sitting in an exit row, so be aware of that and notify the flight attendant if you find yourself in one. The reason for this is practical — in the event

of a crash and evacuation, the circumstances will probably not be conducive to communication, so it makes sense for a person who is able to hear, see, and move independently to sit next to an emergency exit.

- There are many airlines that use mobile ticketing apps or automated boarding kiosks that may make it easier for you to check in than speaking to someone.

Hotels and Motels

Under the Americans with Disabilities Act (ADA):

- Places of public accommodation are required to provide communication access to Deaf and hard of hearing people when given advance notice.
- This means that you should be able to request closed captioned televisions, visual smoke and fire alarms, TTYs, telephone amplifiers, alarm clocks, and door knock signalers when you make the reservation, and find them ready when you arrive.
- Call ahead to make sure that the items you need are there and properly installed. Sadly, it still happens often that hotel staff will show up with a suitcase full of equipment and leave it for you to install yourself, which really isn't appropriate. If you don't want to advocate — it can be tiring business, and you're comfortable setting it up yourself, that may be the easiest way to go. But it's not what should be happening.
- If you have the ability to do so, make requests in writing, so there is a paper trail available should you need hard evidence that you requested something and it wasn't provided.

It's important for hotel management to know that this is not a trifling matter. Too often, people think that “accessible” is synonymous with wheelchair ramps. If there are conference rooms and meeting spaces, tell management about ALDs, CART, interpreters, etc. Ask that captions be left on in all TVs in public areas.

Before You Leave Home

- Pack extra batteries for your hearing aids or cochlear implant and everything else that takes batteries.
- Bring the appropriate charger for rechargeable batteries, paying attention to the plug configuration and the voltage that you will need at your destination.
- Don't make assumptions about the availability of batteries or electronics where you are going. Bring irreplaceable items onboard in your personal luggage, never in the aircraft hold as checked items.
- You'll want to bring any external microphones you normally carry, and perhaps invest in a vibrating watch/fitness tracker/Bluetooth bed shaker ideal for waking you without your needing to give some stranger a room key or lug along a big AC alarm with a bed shaker and power converter.

For domestic travel, the ADA applies.

- Call or write in advance to the hotels where you'll be staying and ask for a room with the accommodations you need, as mentioned above.
- Check with the sites you plan to visit to determine if they have ALDs, CART, interpreters, a script, an ADA Kit or whatever else you need.
- Check for cell phone/pager compatibility before you leave — most countries other than the U.S. operate on GSM, not GPRS. Dual SIM phones allow you to purchase data SIM cards abroad and use your own devices, rather than having to buy a second phone.
- WiFi offers pre-paid portable hotspots that can be ordered before you travel. These come preloaded with SIM cards that should work in the countries you identified at time of ordering, and allow you to connect your existing electronics via Wi-Fi. Many overseas carriers sell portable hotspots that can be loaded with prepaid and reloadable data SIM cards. These are good options as they allow you to take your existing devices with you and connect to the hotspot (and through it, the cellular network) via Wi-Fi. You

may also be able to purchase a generic unlocked hotspot online ahead of your trip as long as it is zoned for use in the area where you will be traveling to. You will still need to buy a data SIM card to activate it.

- Be certain to turn off cellular data roaming or you will face extremely high bills on your return.

When Traveling Overseas

- Take electrical outlet adapter plugs with you, since few countries have the same plug configurations.
- If your gadgets are rated at 110V only, you'll also need a converter that converts the more commonly used 220 — 240 Volts in Europe and elsewhere to the 110 Volts at which your device operates. Most smart- phone and CI chargers are compliant with both standards, but you'll still need the correct adapter plugs.

Different advice applies if you are traveling domestically or overseas, and how you plan to travel: staying close to “civilization” or forging a trail through the wilderness. You'll need lots more preparation for the latter.

Assume that your checked luggage will be lost.

- Identify it inside and out and keep everything you need desperately in your carry-on bag.
- You may want to pack everything in “dry bags” and sealed containers such as those used for kayaking, then place these bags in your luggage.
- You may also want to take a roll-up solar charging panel that can recharge almost anything, and a portable power bank with at least one 2.0 AMP USB power port if you are traveling to a location really off the beaten path.

And if you're going to be engaging in risky activities that absolutely demand some hearing ability:

- Pack old hearing aids or processors so that you won't destroy your expensive new equipment when you capsize or get caught in a monsoon.
- Use a hip pack/pouch for vital items: passport, medications, tickets, wallet, etc.
- Stick this hip pack into your carry-on bag when you're screened, then take it out and keep it on you wherever you go.
- Take literature about your implant to calm the baggage screeners in case they think you may be an "ear bomber."

Abroad

- Be aware that there is no ADA in effect. Demanding rights you don't have is not going to win you any popularity contests.
- "Be polite when asking for assistance or you won't receive any," is the right approach.
- Make sure that the hotel will alert you in case of fire.
- Give a spare key to your room to a hearing group member if you're traveling as part of a group and are comfortable with the idea of this individual having access to your room.
- Use a gadget that mounts on the door using Velcro that will trigger a vibrator under your pillow or bed when someone enters your room while you are sleeping.
- Motion detectors can be strategically placed to alert you to any presence in a specific area.

"The way you conduct yourself with a group will impact other travelers with hearing loss down the road." — Jonathan O'Dell

- If you're traveling in the U.S., you may have to educate hotels about how to use their ADA equipment kits and you may have to insist quite firmly that tour groups not discriminate against you. Often guided tours haven't even considered the needs of Deaf/HoH travelers.
- Remind any travel entity you are dealing with, from airlines to hotels, from car rental agencies to group operators, that there are

many millions of potential customers with hearing loss out there and that, like anyone else, we tend to vote with our wallets.

- Support those who provide accommodations even if they cost a bit more or don't have the specific itinerary you may dream of. It's worth it in the end knowing you haven't implicitly supported discriminatory practices.

Churches and Meetings

Places of worship do not fall under ADA regulations, unless they are used for public meetings. But most churches and synagogues are very responsive to their congregation's needs. The point, after all, is for as many people as possible to sit in one area where the technology can have an impact.

- Teach the church clergy/officials about available assistive listening systems.
- Offer to help try them out.
- See if you can persuade people to donate money to buy the systems.
- Ask for volunteers to distribute receivers at services, or check batteries periodically, or make sure that the microphones are set up appropriately.

MCDHH tries to maintain a list of churches and synagogues that have interpreters or CART services. If you're concerned about the accessibility of meetings, phone ahead and speak to the organizers. Many have no idea that there are such things as CART service, interpreters, or ALDs. In that type of situation, you can be an advocate as well.

For Small Meetings around a Conference Table

- Ask for CART, or if it is a short meeting, you may not need CART. Sit next to whoever is taking notes for the minutes and read over his or her shoulder.
- Ask for an interpreter/transliterater of your choice (oral, ASL, Signed English) if that's how you want to participate.
- Ask for a written agenda.

- Ask to reconfigure seating arrangements.
- Encourage use of a U-shaped or circular table.
- Suggest that the chairperson use a whiteboard to write important points.
- Use an ALD if it can help you.
- Make sure that a communication protocol is firmly established and do not be afraid to raise your hand and interrupt when people are starting to break communication rules.
- Ask associates to speak one at a time and to face you.
- Ask the chairperson to repeat questions from the floor if it is not feasible for the microphone to be passed back or for the person to be asked to come to the front.

In School

- Many of the tactics listed above will also work in a classroom setting.
- For those who benefit from an assistive listening device, the teacher can wear a microphone and carry a pocket-size transmitter in a pocket or around the neck which can send sound to an FM receiver or to a sound field system, or both.
- CART, interpreters, and FM Systems are all possibilities. Some students have been successful asking their teachers for copies of the teaching curriculum.
- Today, CART service is commonly used by late-deafened and severely hard of hearing students in schools and colleges. If the classroom and the course are amenable to the use of microphones and internet, CART may be provided remotely directly to the student's laptop if desired.

RESOURCES

Knowing Your Rights under the ADA

The Americans with Disabilities Act was signed into law on July 26, 1990.

- It protects people with disabilities, including those who are Deaf or hard of hearing, from discrimination in employment, access to state and local government services, places of public accommodation, telecommunications and transportation.
- Employers and business owners are required to make “reasonable accommodations” unless that creates an “undue financial burden or fundamentally alters the nature of the program or service provided.”

The ADA also amended the Communications Act of 1934 to require that each state provide 24 hours per day Telecommunications Relay Service for consumers with hearing loss and speech impairments. Today, this also includes Video Relay Services and Captioned Telephone Services.

The Rehabilitation Act of 1973

The ADA is not the only law protecting the rights of disabled individuals. Section 504 of the Rehabilitation Act of 1973 states that “No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.”

Massachusetts Office on Disability

If you live in Massachusetts and you were discriminated against in MA, you may contact the Massachusetts Office on Disability. They will help you file a complaint with the Massachusetts Commission Against Discrimination. You can also contact the Disability Law Center to see if they will take your case and help you file a complaint in court. You will find links to these offices in the Appendix.

If you feel you need help with contacting these legal agencies, please do not hesitate to contact MCDHH and ask for Communication Access, Training and Technology Services, or for a Case Manager.

The MCDHH website also has information about the ADA and how it pertains to hearing loss (www.mass.gov/mcdhh).

Emerging News

Supplement 1

DEMENTIA AND THE POTENTIAL IMPACT OF HEARING LOSS

Prepared by Jonathan O'Dell

For most of this guide, hearing loss has been presented as being somewhat of a self-contained condition — that is, the assumption has been made that it is the readers' hearing loss that is the primary issue affecting their quality of life. However, that is not always the case. Hearing loss can be both a symptom and a cause of serious underlying medical conditions.

Much of the news about hearing loss in the past several years has come from the Johns Hopkins Medical School. For example, the Johns Hopkins/National Institute on Aging reports that “findings add to a growing list of health consequences associated with hearing loss, including increased risk of dementia, falls, hospitalizations, and diminished physical and mental health overall.”

At first glance, this information can be very troubling. However, not everyone who has hearing loss will necessarily go on to develop memory, cognition and balance issues or experience above-average hospitalizations. There is evidence that doing something is definitely better than doing nothing, so we should at least examine the published research and see what we can do differently to minimize undesirable outcomes as much as it is possible to do so.

For example, the finding that hearing loss can impact a person's balance and increase their fall risk is not news to this writer, a contributor to this Guide. My own balance has been dramatically affected by my profound hearing loss, as was my — also profoundly deaf — grandfather's. I vividly



recall my grandfather forcefully launching himself from a very low chair, losing his balance immediately then crashing through a full-length interior glass door, sustaining cuts and lacerations as a result but luckily, avoiding any long-term injuries.

It is my belief that often we live in environments that are no longer conducive to our physical and mental capabilities, and yet we often don't do anything to change them.

In the example above, had my grandfather had a motorized chair lifting mechanism in place, it would have prevented his dangerous fall by making it unnecessary for him to launch himself out of the chair with such momentum to cause his loss of balance in the first place. Even putting a higher chair in place would likely have prevented what could have been a catastrophic fall. And placing the chair next to a wall rather than next to a full-length glass door would have provided a bracing surface.

Many strategies exist for improving balance — some of them can strengthen an individual's ability to prevent falls by improving their physical condition and coordination. Others are more common-sense remedies such as eliminating uneven travel paths and trip hazards such as area rugs, extension cords, and sudden unmarked changes of elevation inside the home. Using a walker or cane outside, having railings or grab bars in strategic locations, and not walking outside after dark without a broad-beam flashlight are additional strategies that are inexpensive and easily achievable.

A theory put forth by Dr. Frank Lin, the lead researcher in the study connecting falls to an increase in hearing loss, is the potential impact of “cognitive load” — the idea that our brains possess a finite amount of computational power. Simply, if our hearing loss is taking up an inordinately high percentage of that total by refocusing resources usually devoted to other things like understanding speech, we can experience cognitive overload when engaged in other resource-intensive tasks. Most of us take the ability to stand upright and to move without falling for granted and do not realize that it is, as Dr. Lin states, an activity taking up significant mental resources.

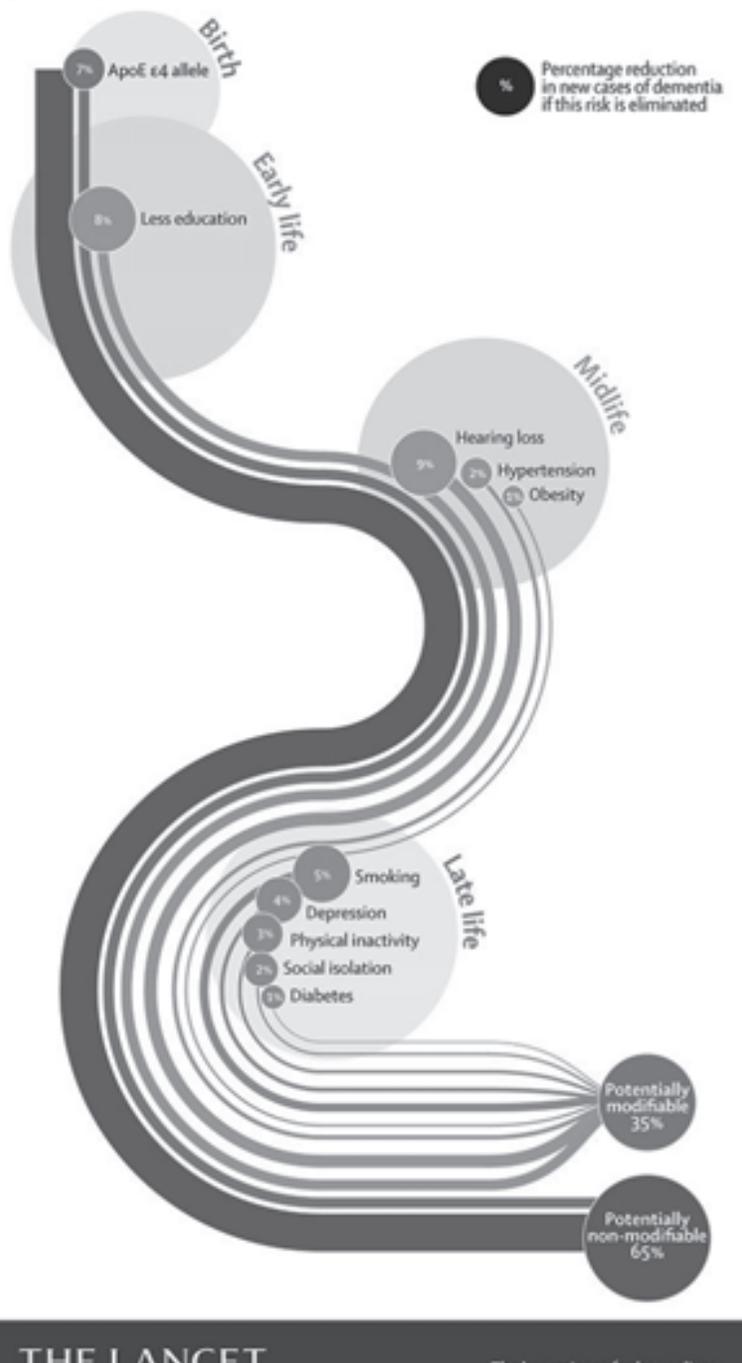


A similar methodology has been proposed as being one, of possibly several risk factors underlying the well-publicized link between hearing loss and dementia. In short, what Dr. Lin and his colleagues found is that “. . . study participants with hearing loss at the beginning of the study were significantly more likely to develop dementia by the end. Compared with volunteers with normal hearing, those with mild, moderate, and severe hearing loss had twofold, threefold, and fivefold, respectively, the risk of developing dementia over time. The more hearing loss they had, the higher their likelihood of developing the memory-robbing disease. Even after the researchers took into account other factors that are associated with risk of dementia, including diabetes, high blood pressure, age, sex and race, hearing loss and dementia were still strongly connected.”

Since 2011, when the above study was published, additional research has followed apace. A July 2017 paper in the British medical journal *The Lancet* entitled “Dementia Prevention, Intervention and Care “is particularly informative. In the introduction to this report, the authors state that “We have brought together all this evidence and have calculated that more than a third of dementia cases might theoretically be preventable. An increase in childhood education and exercise, maintaining social engagements, reducing or stopping smoking, and management of hearing loss, depression, diabetes, hypertension, and obesity could all contribute to prevention or delay of dementia.”

Risk factors for dementia

The Lancet Commission presents a new life-course model showing potentially modifiable, and non-modifiable, risk factors for dementia.



Graphic provided courtesy of the Lancet



The authors go to great lengths to explain the interrelationship between many complex factors as they correspond to the cause and effect mechanisms present in the development of dementia. For example, it has long been known that the incidence of hearing loss rises with age, and that age itself is a risk factor for the development of dementia. This is not necessarily through the mechanism of decreased hearing alone, however, but also because hearing loss generally leads to social isolation and withdrawal — both of which, by themselves, are independent risk factors for dementia. Thus, this is somewhat like the chicken and the egg conundrum: in some cases of cognitive impairment, hearing loss may well be the cause, while in others, age is the culprit and hearing loss is “merely” a side effect of the aging process. While this does not change the overall conclusion that there is a link between hearing loss and dementia, it does highlight the fact that we’re not absolutely clear about what the exact mechanism is.

The authors state that “The mechanism underlying cognitive decline associated with peripheral hearing loss is not yet clear, nor is it established whether correction, such as hearing aids, can prevent or delay the onset of dementia. However, tellingly, it has been shown that hearing intervention strategies can reduce social isolation, withdrawal and associated depression, all of which are implicated in the long list of potential risk factors for dementia.”

The Lancet paper also highlights likely distinctions between different types of hearing loss and their impact on dementia. For example, “Central hearing loss is distinct from peripheral hearing loss. It is a difficulty in understanding speech in noise that is not explained by cochlear (peripheral) hearing impairment and does not improve with peripheral amplification (such as hearing aids). It is unlikely to be a modifiable risk factor and could be a prodromal (early sign) symptom of Alzheimer’s disease causing impaired speech perception, especially in the presence of competing sounds. This theory is consistent with the fact that central auditory areas are affected by Alzheimer’s disease pathology. “Again, this should not be misinterpreted as saying that anyone who struggles to understand one out of dozens of voices is on the way to developing Alzheimer’s.”



Please Note: The authors of this Guide are not medical professionals and strongly encourage readers to get their information from the sources listed — and have it explained by their hearing healthcare provider in more detail. However, there is one indisputable conclusion that should be evident to anyone who has hearing loss or lives with someone who has hearing loss, which is beautifully summed up by the motto of the national advocacy group Association of Late-Deafened Adults (ALDA): “Whatever works!”.

Under the heading “Dementia Intervention: what, when, how long and for whom” *the Lancet* authors provide a similarly positive interpretation: “. . . numerous examples exist in which public health interventions have reduced disease incidence before the disease process has been understood.” They go on to say that “The interventions most likely to be beneficial (increasing education in early life, increasing physical activity and social engagement, reducing smoking, treating hypertension, diabetes, and hearing impairment) are safe and confer other health benefits.”

In other words, most anything that is done to help someone with hearing loss to be able to communicate more effectively with others, and participate more fully in daily life activities, is guaranteed to have a net positive effect on that person’s life. We may not know for some time yet whether such intervention confers a directly measurable degree of protection against the development of dementia, but we do know that it improves our lives significantly otherwise. And more importantly, being limited in our knowledge, would we want to risk not taking action when we already know from empirical evidence that there is a connection between hearing loss and dementia?

I remember an incident that illustrates the point made above. Some years ago, I was asked by a colleague whether I could visit his mother who was described as having dementia, and who was residing in a specialized care facility. Meeting the mother, I had brought with me an assistive listening device to see if it would make a difference in the mother’s ability to understand family and caregivers — and what happened next was magical: the mother’s face lit up at the ability to suddenly understand what was being

said to her, not just by family, but by caretakers at the home as well. The son was overcome by the realization that the hearing loss was far more prominent than anyone had expected. Yes, his mother still had dementia, but she also had hearing loss, and once that had been addressed, she was able to regain some of her communicative abilities and interact more successfully with family and caretakers.

Again: whatever works, for as long as it works, is always better than doing nothing.

Keep up to date on the emerging news on hearing loss from professional agencies and organizations and through books, magazines, newspapers, and other media mentioned in the Appendix of this Guide starting on page 158.

Source Links

https://www.hopkinsmedicine.org/news/media/releases/hearing_loss_linked_to_accelerated_brain_tissue_loss

https://www.hopkinsmedicine.org/news/media/releases/hearing_loss_linked_to_three_fold_risk_of_falling

https://www.hopkinsmedicine.org/news/media/releases/hearing_loss_and_dementia_linked_in_study

[http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(17\)31363-6.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(17)31363-6.pdf)

APPENDIX

Key Agencies, Associations, and Organizations Serving the Deaf, Late-Deafened, and Hard of Hearing Populations

MASSACHUSETTS AND NATIONAL SERVICE AGENCIES

Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)

600 Washington Street, Boston, MA 02111

617-740-1600 Voice / 617-740-1700 TTY / 617-740-1810 Fax

800-882-1155 Toll Free Voice / 800-530-7570 TTY Toll Free

Video phone information:

Boston office: 617-326-7546 Toll Free

Springfield office: 413-301-0915 Toll Free

Westborough office: 508-762-1124 Toll Free

<http://www.mass.gov/mcdhh>

MCDHH serves as the principal state agency providing leadership, education and advocacy services directed to empowering Deaf, late-deafened, and hard of hearing individuals and their families in receiving equitable opportunities including:

- general information and referral
- direct information and education for consumers about topics related to communication access
- case management services for children and adults
- information on assistive technology, help in finding out what might work for you at home and at work
- interpreter and CART Referral Services

<http://www.mass.gov/eohhs/gov/departments/mcdhh>

The Case Management Services

Case Management Services offers an array of services to Deaf and Hard of Hearing infants, children, and adults and their families on a voluntary basis. The services include but are not limited to cross agency case coordination, advocacy, consultation, adult case management and family and children's services. MCDHH administers state contracts with 9 independent living programs for the Deaf and hard of hearing with offices located throughout the Commonwealth, and accepts Massachusetts Equipment Distribution Program (MassEDP) applications for certification and processing. You can receive assistance in answering these questions:

- What are my rights to communication access in the workplace?
- What assistive technology is available to help me feel safe at home?
- How can I learn to speech read better?
- What can I expect from an audiological exam?
- How can I know how to identify a qualified hearing aid dispenser?
- I am curious about American Sign Language and signed English. Where can I visit a class or meet people, including late-deafened people, who are studying either of these?
- Where can I go to get financial aid?
- My life is just falling apart. Who can help me?
- What special services and programs are available to help me?

Department of Communication Access, Training, and Technology (CATTs)

This Department responds to telephone, e-mail and postal inquiries; offers information in print and electronic media, through educational exhibits and through internet self-service on mass.gov/mcdhh; provides free trainings and presentations to public, private and government agencies on Deaf culture and ADA compliance, communication access compliance, assistive listening and environmental alerting technology; consultation and guidance on providing accessible events and services, and workplace evaluations.

Services

- Environmental evaluations to determine the applicability of assistive technology in a given environment, and to the removal or mitigation of barriers to accessible communication. These evaluations and assessments are informal and non-binding. We do not provide Acoustic, Audiological or Audiometric testing or evaluation.
- Product guidance in the types of technology or service that might prove to be useful in improving communication access and/or environmental alert awareness in any given situation.
- Objective Information regarding choices in assistive technology, including the selection of products, the applicability of a particular product for a specific situation or individual, and resources for financial assistance, if applicable.
- Troubleshooting of assistive listening systems and communication access technologies, particularly for state agencies and other public-sector services. We do not repair technology, but in cases where the problem is related to the user's unfamiliarity with a particular technology or service, we may be able to provide resolution and training.
- Communication Access and Reasonable Accommodation training and consultation. The best technology is of little help without knowledge in how to create open and communication accessible locations, services and policies.
- Event planning guidance. This is targeted at, but not limited to, state and public agencies that may need guidance on how to best plan for communication accessible public events.

MCDHH Interpreter/CART Referral Services

Provides statewide interpreter and CART referral services to ensure full communication access for Deaf and hard of hearing individuals at all levels — state, public and private — in accordance with federal and state laws, including provision of after-hours legal emergency interpreter services. The department also conducts screenings for prospective American Sign Language (ASL) and Certified Deaf Interpreters (CDI)

wishing to attain certification, as well as setting standards for Communication Access Realtime Translation (CART) Providers on contract with the Commonwealth.

MCDHH Victim Service Program

The Victim Service Program offers a private, trauma informed, wrap-around model of service delivery to victims of crime who are Deaf, Hard of Hearing, Late-Deafened, or Deaf/Blind. Individuals who have experienced a violent crime such as sexual assault, domestic violence, elder abuse, child abuse, or other crimes are connected to a Victim Service Navigator, who is fluent in ASL to help with resources, referrals and communication access. This service is confidential, free of charge and able to serve individuals who speak English and/or other languages. If you need assistance, please call the Main Office and ask to be connected to our Program. MCDHH is able to offer these services through a Federal Victim of Crime Act Grant (VOCA) for a two year, one-million-dollar program in partnership with the MA Office for Victim Assistance. The new grant leverages experience gained through completing a 3-year grant with MOVA to serve over 200 survivors of the Boston Marathon Bombing.

Independent Living Programs for Deaf and Hard of Hearing (DHILS)

The MCDHH contracts with agencies to provide DHILS programs (Deaf and Hard of Hearing Independent Living Services) at sites throughout the state. The programs provide a peer based consumer oriented environment enabling Deaf and hard of hearing persons to increase their independence and achieve their life goals. These programs employ persons who are themselves Deaf, late-deafened, or hard of hearing. Consumers work with Independent Living Specialists to set and achieve their own personal goals for independent functioning in family, school, employment, and community situations.

DHIL services include:

- peer mentoring and support for deaf and hard of hearing persons
- self-advocacy and independent living skills training
- topical workshops for consumer education
- information and referral

Berkshires**Viability Inc.**

2 South Street, Suite 290
Pittsfield, MA 01201
www.viability.org
DHILS@viability.org
413-536-4880 Voice
413-650-5365 VP
413-536-4880 Ext. 111 TTY

Boston Metro**DEAF, Inc. Boston Office**

215 Brighton Ave.
Allston, MA 02134
<http://www.deafinonline.org>
dhils@deafinonline.org
617-254-4041 TTY/Voice
617-505-4823 VP/Voice
617-254-7091 Fax

Cape Cod and the Islands**DEAF, Inc. Cape Cod & Islands**

106 Bassett Lane
Hyannis, MA 02601
<http://www.deafinonline.org>
dhils@deafinonline.org
774-470-4492 TTY/VOICE
508-815-4070 VP/VOICE
774-552-2896 Fax

Central Massachusetts**Center for Living & Working (CLW)**

Deaf and Hard of Hearing IL Services
484 Main Street, Suite 345
Worcester, MA 01608
<http://www.centerlw.org>
508-755-1003 TTY
508-798-0350 Voice
508-762-1164 VP

Northeast Massachusetts**DEAF, Inc. Lawrence**

Riverwalk, Building 5
360 Merrimack St., 2nd Floor
Lawrence, MA 01843
<http://www.deafinonline.org>
dhils@deafinonline.org
617-254-4041 TTY/Voice
617-505-4823 VP/Voice
617-254-7091 Fax

North Shore**DEAF, Inc. Salem**

35 Congress Street, Suite 204
Salem, MA 01970
<http://www.deafinonline.org>
dhils@deafinonline.org
978-740-0394 TTY
978-740-0329 Voice
978-910-0165 VP

Southeast Massachusetts

DEAF, Inc. Taunton

71 Main Street, Suite 1300B

Taunton, MA

<http://www.deafinonline.org>

508-802-5833 TTY/Voice

508-802-5835 Fax

508-692-9390 VP

DEAF, Inc. New Bedford

105 Williams Street, Room 25

New Bedford, MA 02740

<http://www.deafinonline.org>

dhils@deafinonline.org

508-990-1382 TTY/Voice

508-858-5178 VP/Voice

Western Massachusetts

Viability Inc.

302 High Street, 4th floor

Holyoke, MA 01040

www.viability.org

DHILS@viability.org

413-536-4880 Voice

413-650-5365 VP

413-536-4880 Ext. 111 TTY

Financing through Independent Living and DHILS Services

Title VII, Part B

This is federal money made available to all of the Deaf and Hard of Hearing Independent Living Services (DHILS) programs and Independent Living Centers (ILCs) in Massachusetts for purchase of equipment and services to help people to maintain or achieve independence. The program can provide funding for assistive technology but there is generally a long waiting list.

Tip: *Title VII-part B is not available to anyone who is eligible for services under the Massachusetts Rehabilitation Commission, and must be the last choice for funding. To find out which IL or DHILS serves your community, contact MCDHH.*

The Massachusetts Assistive Technology Loan Program

Operated by Easter Seals Massachusetts, this program is an alternative financing project that gives people with disabilities and elders access to low interest cash loans to purchase assistive devices and services. The program has many options that can help — even for people who don't think they would qualify for a loan. It also offers a Long-Term Device Loan Program where assistive technology up to \$ 500 can be provided directly to the individual at no cost. Please visit www.massatloan.org for more information and application guidelines.

Massachusetts Commission Against Discrimination

The MCAD offers numerous services, initiatives, and opportunities for the people of Massachusetts to help advance the mission of the agency: Eradicating discrimination in the Commonwealth.

<http://www.mass.gov/mcad>

Massachusetts Equipment Distribution Program (MAEDP)

The Massachusetts Equipment Distribution Program (MassEDP) is a service that provides residents with a permanent disability access to the telephone network in their homes. By offering specialized telephones for free or at a reduced cost, depending on income, this program fosters independence, empowerment, and freedom of choice.

<https://www.mass.gov/massachusetts-equipment-distribution-program-massedp>

MassMatch

MassMATCH is the Commonwealth of Massachusetts' initiative to Maximize Assistive Technology (AT) in Consumers' Hands. It is one of 56 state-level AT Act programs in the United States. Its mission is to promote the use of AT and AT services to enhance the independence of people with disabilities, enabling equal participation in all of life's activities.

<http://www.massmatch.org/index.php>

Massachusetts Office for Victims Assistance (MOVA)

The Massachusetts Office for Victim Assistance (MOVA) was established in 1984 with the enactment of the Commonwealth's first Victim Bill of Rights. Its purpose is to advocate for and assist victims of crime. MOVA's activities are governed by the Victim and Witness Assistance Board, chaired by the Attorney General.

<http://www.mass.gov/mova>

Massachusetts One Stop Career Centers

Massachusetts One Stop Career Centers serve as a vital link, connecting workers and employers to bring about economic opportunity.

<http://www.mass.gov/lwd/employment-services/career-services/career-center-services>

Massachusetts Rehabilitation Commission (MRC)

MRC's Vocational Rehabilitation Program assists individuals with disabilities to obtain and maintain employment.

<http://www.mass.gov/eohhs/consumer/disability-services/vocational-rehab>

MassHealth

In Massachusetts, Medicaid and the Children's Health Insurance Program (CHIP) are combined into one program called MassHealth. MassHealth members may be able to get doctor visits, prescription drugs, hospital stays, and many other important services.

<http://www.mass.gov/eohhs/gov/departments/masshealth>

Boston Guild for the Hard of Hearing at Northeastern University

Language and Hearing Center, Bouve College of Health Sciences

The Boston Guild for the Hard of Hearing at Northeastern is committed to serving the needs of people with hearing loss and finding innovative ways to disseminate information to professionals and others in order to increase awareness about the total impact of hearing loss and the importance of hearing conservation.

Services include: Hearing Instrument Outreach Program, Assistive Listening Device Program, Aural Rehabilitation and Speech Reading Classes and the Community Outreach Program.

<http://www.northeastern.edu/bouve/csd/guild>

Hearing Rehabilitation Foundation (HRF)

The Hearing Rehabilitation Foundation (HRF) in Woburn, MA offers auditory training and listening support to people from all over New England and works internationally to develop innovations in communication training for people with hearing loss.

<http://hearf.org>

Disability Law Center

Provides information, referral, technical assistance and representation regarding legal rights and services for people with disabilities.

www.dlc-ma.org

National Education for Assistance Dog Services (NEADS)

Also known as Dogs for Deaf and Disabled Americans, NEADS was established in 1976 to train and provide independence to people who are deaf or physically disabled through the use of canine assistance.

<http://www.neads.org>

FOR MILITARY PERSONNEL AND VETERANS

You can seek coverage through the Veteran's Administration which provides extensive coverage for hearing aids and also covers cochlear implant and assistive device costs on an individual determination basis.

Hearing Center of Excellence (Department of Defense)

The mission of the Hearing Center of Excellence is to optimize operational effectiveness, heighten medical readiness, and enhance quality of life through collaborative leadership and advocacy for hearing and balance health initiatives.

<https://hearing.health.mil>

To find a local provider:

<https://hearing.health.mil/Help-and-Support/Find-a-Provider>

Local VA Audiology Services

https://www.boston.va.gov/services/Speech_and_Audiology.asp

MASSACHUSETTS AND NATIONAL CONSUMER ADVOCACY, SOCIAL, AND SUPPORT GROUPS

Acoustic Neuroma Association (ANA)

ANA is a patient member organization, providing information and support to persons diagnosed with or treated for acoustic neuromas and other benign tumors of the cranial nerves.”

<https://www.anausa.org>

Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell)

The AG Bell Association is a resource, support network and advocate for listening, learning, talking and living independently with hearing loss. Through publications, advocacy, training, scholarships and financial aid,

AG Bell promotes the use of spoken language as well as hearing technology for children with hearing loss. It is headquartered in Washington, D.C., with chapters located throughout the United States and a network of international affiliates.

<http://www.agbell.org/>

The Alzheimer's Association

Formed in 1980, the Alzheimer's Association advances research to end Alzheimer's and dementia while enhancing care for those living with the disease.

<https://www.alz.org>

Dementia Friendly Massachusetts

Dementia Friendly Massachusetts is a grassroots movement to make communities safe, inclusive and respectful for persons with Alzheimer's disease, or a related dementia.

<https://www.mass.gov/dementia-friendly-massachusetts>

Massachusetts State Association for the Deaf (MSAD)

Mission:

- 1) To advocate and protect the rights of the Deaf, Hard of Hearing and Deaf-Blind people in the Commonwealth of Massachusetts which will allow full participation in the civic, educational, social, cultural, and economic aspects of daily life.
- 2) To further enhance the quality of life for Deaf, Hard of Hearing and DeafBlind individuals living in Massachusetts and provide referrals to appropriate agencies and organizations for services or support as necessary.

<http://www.massdeaf.org>

National Association of the Deaf (NAD)

The National Association of the Deaf (NAD) is the nation's premier civil rights organization of, by and for Deaf and hard of hearing individuals in the United States of America.

<https://www.nad.org>

Association of Late-Deafened Adults (ALDA)

This group supports the empowerment of people who become deaf. ALDA provides resources and information and promotes advocacy and awareness of the needs of deafened adults. Kathryn Woodcock, the first deaf president of the Canadian Hearing Society and a former ALDA board member, has written about ALDA's official communication policy:

“Whatever works. If that entails standing on your head and blinking in Morse code, then we try to work with that. Pencil and paper, keyboards, cochlear implants, fluent sign language, lousy fingerspelling, lipreading, and a great deal of laughing are all observable at ALDA gatherings.”

<https://www.alda.org/>

ALDA Boston Chapter

<https://aldaboston.org>

Hearing Loss Association of America (HLAA) (National HQ)

The Hearing Loss Association of America (HLAA) is the nation's leading organization representing people with hearing loss.

<http://www.hearingloss.org/>

HLAA Boston

<https://www.hearatboston.org>

HLAA North of Boston

<https://www.hearatboston.org/north-of-boston>

HLAA Central MA

<https://www.facebook.com/HLACentralMA/>

HLAA Plymouth

Contact: sspekman@gmail.com

The NF2 Crew

The NF2 Crew is “an informational and support group for people with NF2 [*ed. note: Neurofibromatosis Type II, recurring tumors affecting the auditory nerve*] and their family members,” conducted through email messaging.

<http://nf2crew.org>

SayWhatClub (SWC)

The SWC on-line communities provide access to people who know the feelings, frustrations, and yes, even the humor you are likely to encounter. This is a great place to share and support each other without having to strain to hear a conversation. A friend who understands is only as far away as your computer.

<http://www.saywhatclub.com>

CAREERS AND HIGHER EDUCATION

Association on Higher Education and Disability (AHEAD)

The premiere professional association committed to full participation of persons with disabilities in postsecondary education

<https://www.ahead.org>

National Center for College Students with Disabilities (NCCSD)

NCCSD is the only federally funded national center in the U.S. for college students with any type of disability, chronic health condition, or mental or emotional illness.

<http://www.nccsdonline.org>

Job Accommodation Network (JAN)

The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues.

<http://askjan.org>

National Deaf Center on Postsecondary Outcomes (NDC)

NDC is a technical assistance and dissemination center funded by the Office of Special Education Programs (OSEP). It continues the Pepnet2 mission supporting postsecondary outcomes for individuals who are Deaf, Deaf/blind, Deaf disabled, hard of hearing, or late-deafened. NDC activities draw on evidence-based strategies to educate and engage with stakeholders across the nation.

<http://www.hearingloss.org/content/access-college>

Massachusetts One Stop Career Centers

Massachusetts One Stop Career Centers serve as a vital link, connecting workers and employers to bring about economic opportunity.

<http://www.mass.gov/lwd/employment-services/career-services/career-center-services>

Webinar: Career Success after Hearing Loss

David C. Baldrige BGS, MBA, Ph.D. Career Success after Hearing Loss: Webinar. Hearing Loss Association of America, 2017.

<http://hearingloss.org/content/career-success-after-hearing-loss>

NATIONAL MEDICAL AND HEALTH ASSOCIATIONS

American Academy of Audiology (AAA)

<https://www.audiology.org>

American Doctors of Audiology (ADA)

<http://www.audiologist.org>

American Speech-Language-Hearing Association (ASHA)

<http://www.asha.org>

American Tinnitus Association (ATA)

<https://www.ata.org>

Hyperacusis Research

<http://hyperacusisresearch.org>

FEDERAL OFFICES

Federal Communication Commission (FCC)

Regulates audio and visual communications, etc.

<https://www.fcc.gov>

Food & Drug Administration (FDA)

Regulates food, medicines, drugs, et al.

<https://www.fda.gov>

Occupational Safety and Health Administration (OSHA)

Regulates workplace safety, including noise levels.

<https://www.osha.gov>

Office for Victims of Crime (OVC)

OVC administers the Crime Victims Fund (the Fund), which is financed by fines and penalties paid by convicted federal offenders, not from tax dollars. Federal revenues deposited into the Fund also come from gifts, donations, and bequests by private parties. OVC channels funding for victim compensation and assistance throughout the United States, raises awareness about victims' issues, promotes compliance with victims' rights laws, and provides training and technical assistance and publications and products to victim assistance professionals.

<https://www.ovc.gov>

Social Security Disability

To qualify for Social Security disability benefits, you must first have worked in jobs covered by Social Security. Then you must have a medical condition that meets Social Security's definition of disability. In general, SSDI pays monthly cash benefits to people who are unable to work for a year or more because of a disability

<https://www.ssa.gov/disabilityaudiossi>

BOOKS, BLOGS, AND MAGAZINES

Information and inspiration about almost anything you want to know about hearing loss can be found in this starter list.

Popular Books

A Quiet World: Living with Hearing Loss, David Wright (Yale Univ. Press, 2000).

Baby Boomers and Hearing Loss: A Guide to Prevention and Care, John M. Burkey (Rutgers Univ. Press, 2006).

El Deafo, Cece Bell (Amulet Books, 2014).

I Danced: A Cochlear Implant Odyssey, Dora Tingelstad Weber (Beaver's Pond Press, 2004).

Listen with the Heart: Relationships and Hearing Loss, Michael A. Harvey (Dawnsign Press, 2001).

Living Better with Hearing Loss: a guide to health, happiness, love, sex, work, friends and hearing aids, Katherine Bouton (Workman Publishing, 2015).

Living with Hearing Loss, Marcia B. Dugan (Gallaudet Univ. Press, 2003).

Missing Words, Kay Thomsett and Eve Nickerson (Gallaudet University Press).

New Beginnings, Acquiring and Living with a Cochlear Implant, Michael Stinson and Gerry Buckley, editors (RIT Press, 2013).

Not Fade Away, Rebecca Alexander with Sascha Alper (Gotham Books, 2014).

Odyssey of Hearing Loss: Tales of Triumph, Michael A. Harvey (Dawnsign Press, 2004).

On the Fence: The Hidden World of the Hard of Hearing, Mark Drolsbaugh, editor (Handwave Publications, 2007).

Rebuilt: My Journey Back to the Hearing World, Michael Chorost (HC edition: Souvenir Press; Pb edition: Mariner Books, 2006).

Shouting Won't Help: Why I and 50 Million other Americans Can't Hear, Katherine Bouton (Sarah Crichton Books/Farrar, Straus and Giroux, 2013).

Song Without Words: Discovering My Deafness Halfway Through Life, Gerald Shae (Da Capo Press, 2013).

Steel Will: My Journey Through Hell to Become the Man I Was Meant to Be, Shilo Harris (Baker Books, 2015).

The Complete Idiot's Guide to Hearing Loss, House Clinic, William M. Luxford M.D., M. Jennifer Derebery M.D., Karen I. Berliner Ph.D. (Alpha Books, 2010).

The Hearing-Loss Guide: Useful Information and Advice for Patients and Families, Burkey, John M. Daniels, Robert L. (Yale University Press Health & Wellness, 2015).

The Unheard: A Memoir of Deafness and Africa, Josh Swiller (Henry Holt, 2007).

The Way I Hear It: A Life with Hearing Loss, Gael Hannan (Friesen Press, 2015).

Threading the Snail: My Journey Through Deafness, Stephanie D. Halvorson (Tate Publishing & Enterprises, 2006).

Wired for Sound: A Journey into Hearing, Beverly Biderman (Trifolium Books, 1998).

Popular Blogs

“Cochlear Implant HELP”

(A smart consumer's guide to all things related to cochlear implants)

<https://cochlearimplanthelp.com>

Gael Hannan: Hearing Loss Advocate, Writer, Speaker, Humorist

<https://www.gaelhannan.com/blog>

“Hearing Aids, Hearing Loss, Hearing Help,” Katherine Bouton
<https://katherinebouton.com>

“HearingLikeMe”
(Blogs published by Phonak written by individuals about living with hearing loss, raising children, family and community support, learning, music, interviews, for all ages.)
<https://www.hearinglikeme.com>

Hearing Tracker
<https://www.hearingtracker.com/blog>

Shari Eberts: “Living with Hearing Loss”
<https://livingwithhearingloss.com>

Popular Magazines

Hearing Health Foundation
<http://hearinghealthfoundation.org>

Hearing Life (The Hearing Loss Association of America HLAA)
<http://www.hearingloss.org/content/hearing-loss-magazine>

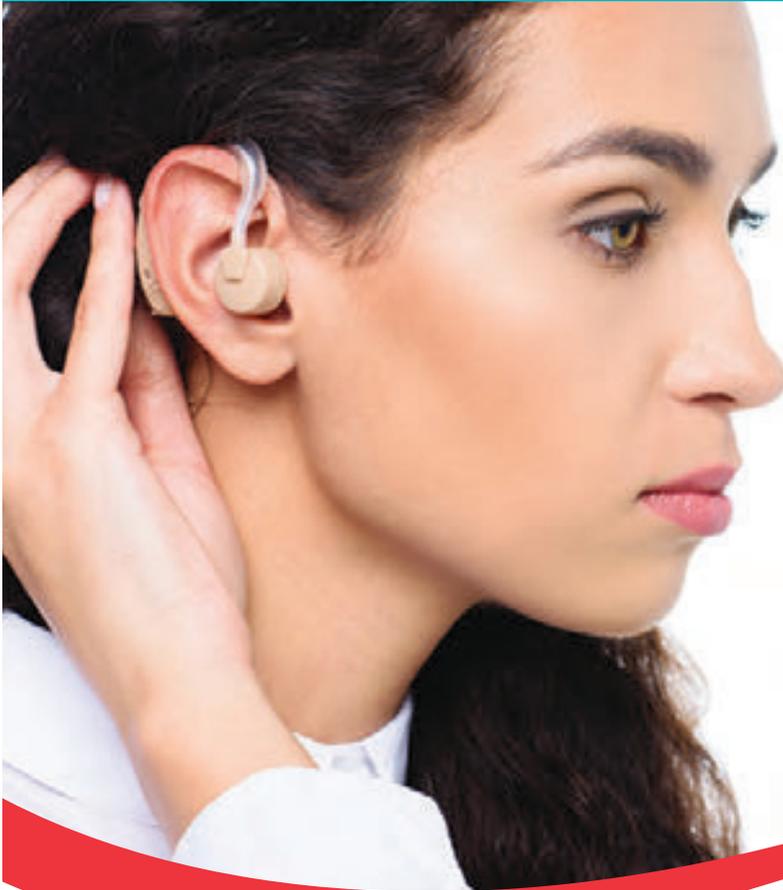
The Hearing Journal
<http://journals.lww.com/thehearingjournal/pages/default.aspx>

The Hearing Review
<http://www.hearingreview.com>

The Journal at Hearing Health & Technology Matters
<http://hearinghealthmatters.org/journalresearchposters>

The authors would like to thank others in the consumer and healthcare fields who contributed their time, energy and suggestions to make this guide additionally comprehensive and accessible.

www.mass.gov/mcdhh



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