ALDABest

10

1987-1996

Essays and Poems
from the First Ten Years
of the Association of Late-Deafened Adults
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Welcome to ALDA

Dear Friends,

ALDA has grown enormously over the past ten years. The ALDA-Chicago chapter, where ALDA, Inc. was born, is now just one of more than twenty-five groups and chapters spread around the world. The original group of 70 members in 1989 has grown to more than 700 members today. ALDA members continue to cherish their times at ALDAcon, ALDA’s annual conference and the ever popular ALDA News has paved the way for chapter newsletters around the world and other publications such as the Leader Letter, ALDA Biz, and the annual Reader.

ALDA is “home” to late-deafened people who once thought they were alone. ALDA is a place where late-deafened people can empower one another and share in the common belief that becoming deaf need not present an insurmountable barrier to contributing to society and enjoying life.

As President in this tenth year, I am honored to have this opportunity to welcome each and every one of you to ALDA!

Enjoy!!

Mary Clark
ALDA, Inc. President, 1998

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About late-deafness

Although it has been over 20 years since the last major deaf census, the best estimate we have is that 75% of deaf adults became deaf after the age of 19 (Schein & Delk, 1974). Many of the historical causes of both congenital and adventitious deafness have changed in incidence over the years. A new survey would be needed to see how the proportions have been affected. Nevertheless, most people in the deaf community probably don’t think of late-deafened people as the majority. Services provided to “the deaf” are overwhelmingly directed at people who became deaf at birth or in early childhood. Funding and subsidies for “deaf” organizations go overwhelmingly to the same population. When you think of access to services for “deaf” people, you think of sign language interpreting. You think of sign language as being the native language of the deaf population. And yet the simple numerical majority consists of those who became deaf later in childhood, in young adulthood, during the working years, and later in life.

When people think of adults becoming deaf, they think of Granny losing her hearing, being shouted at during the family reunion. In fact, the image is of the hard-of-hearing person rather than the deafened person. While many people do become hard of hearing due to normal aging processes, to overexposure to noise, and other causes, there is a big difference between being hard of hearing and becoming deaf.

It has been wrongly asserted that deafened people are first hard of hearing, implying that deafness is the extreme case of hard of hearing, therefore the coping techniques and needs of both are the same. In fact, the majority of deafened people go quickly from hearing to deaf with little preparation.

Adults become deaf in different ways, many of them the same mechanisms as children. Understanding late-deafness requires a short detour through some of this information. Some people develop an infectious disease like spinal meningitis, or are given medications for a severe illness and end up deaf as a side-effect of that medicine, or develop Menière’s syndrome. A large number are dismissed with the explanation that their deafness was caused by “a virus”. (Doctors don’t seem to realize how meaningful it is to be able to have a reason for something as important as deafness. Because this virus is never given a name, we call it “The Virus”, to mock the doctors.) We call these ‘medical’ causes of deafness. Medical hearing losses may occur overnight, or progressively (often over five or ten years). The person may have more residual hearing than some people who have functioned as hard-of-hearing from childhood, but the shock of the unexpected hearing loss makes them unable to function with lipreading and assistive listening devices that experienced hard-of-hearing people can use.
Other adults develop tumours on the auditory nerves as part of the disease neurofibromatosis type 2. Removal of the NF-2 tumours on both auditory nerves causes absolute deafness. We call these ‘surgical’ causes. These people have no residual hearing at all. They also may have ongoing complications of the neurofibromatosis. Surgical deafness occurs instantly, and the person often knows going into the hospital that he or she will be deaf coming home.

‘Traumatic’ hearing losses are sustained in a variety of adventurous ways: motorcycle collisions, a rumble in the alley behind a bar, fall from a ladder, and so forth. These losses are typically sudden. Like a medical hearing loss, the person may be recovering from other physical problems when the deafness begins.

The final group consists of people with ‘progressive’ hearing loss. If hard-of-hearing Granny lives long enough, she may fall in this category. However, many people with progressive deafness appear to have hereditary reasons for their deafness. Some have deaf relatives, making the genetic connection obvious. Others exhibit common timelines: hard of hearing in high school, no longer able to use the telephone in young 20s, a declining awareness of vowels and environmental sounds by the 30s. The ability to exploit the residual hearing at any age varies, resulting in a range of ages when these people begin to consider themselves ‘deaf’. Some are exposed to a combined deaf and hard-of-hearing school as students, and have the opportunity to become functional deaf people while relatively young. Others are pressured by family and friends “not to give up” and only begin to question the value of this daily struggle in their 70s.

A 1984 NADP survey of over 100 people indicated that 13.4% were deafened from congenital/familial causes, 57.7% from medical and surgical causes, and 3.9% from accidents (Heath, 1987). Among 348 responses from members of the Association of Late-Deafened Adults, 41.5% reported experiencing progressive losses including the apparently hereditary, 40.5% had medical losses, 12.8% had surgical losses, and 5.2% became deaf as a result of traumatic injury (Boone & Scherich, 1995).

Where deafened and Deaf meet

Many deafened people are introduced individually to their local deaf communities. The success of this varies widely. Acquisition of signing skills does not occur as rapidly as most hearing loss, leaving the deafened person with a gap between need and ability. In communities where Deaf people shun or ridicule those who sign poorly or didn’t attend the right deaf residential school, deafened people experience rejection. If those who sign poorly are discouraged from going places where their sign skills can improve, then many late-deafened people will continue to exhibit a conspicuous struggle with sign language. This leads to the claim that late-deafened people do not learn to sign. After rejection by the local deaf community, or perhaps warned off it by doctor, audiologist, or counselor, those people may look for support in hard-of-hearing groups such as SHHH. Others are warned that learning sign language will prevent them from keeping jobs or friends in the hearing world (the logic of which is a little weak).

Those who learn sign language skills more readily can immerse themselves fully with Deaf culture and hope to pass for Deaf. It is not the place of this article to "out" anyone, but many recent and current Deaf leaders were also deafened later than early childhood, remember the auditory world, and benefit from their years spent familiarizing themselves with Hearing customs and values. Only recently have some deafened people begun to admit that they had previously been hearing, and even enjoyed music, although they accepted sign language as their adopted
language and considered themselves deaf. The rejection of those not-Deaf-enough has extended
to late-deafened Gallaudet President I. King Jordan, whose joyous appointment was soon
followed by complaints that a born-deaf President should be selected. However, this
discrimination appears to apply only to living deafened people. Many people held out as
distinguished historical deaf figures were in fact late-deafened, including Edison and Beethoven.
Of the first 23 presidents of the NAD, 12 were deafened at age 10 or later (Gannon, 1981). Three
were deafened at age 15, 16 and 18.

Other than those who felt rejected, many deafened people felt unsatisfied with the type of
support they received when they joined deaf or hard-of-hearing groups. Many felt that deaf
people did not allow them to value both the Deaf culture and the Hearing culture and expected an
all-or-nothing decision. Joining hard-of-hearing groups was no solution. Many deafened adults
found that hard-of-hearing people could not understand why amplification, loops, T-switches,
and other assistive listening devices would not be as helpful for the deafened person as it was for
themselves. Neither deaf or hard-of-hearing group, they felt, really understood the impact of the
change from being hearing (or hard of hearing) to being deaf, and the demands created on the
person, the family, the work situation. At various times, in various places, deafened people have
said “we need a group for people like us.”

In 1983, Jackie Metzger, Joe Weber and John Shiels circulated a 15-page survey that yielded 100
late-deafened responses and a workshop at ADARA (American Deafness and Rehabilitation
Research Association), but regrettably the national association of which they dreamed did not
materialize at that time (Shiels, personal communication).

National Association of Deafened People (U.K.) was founded in 1984. NADP members had been
a segment of the British League for the Hard of Hearing and Deafened (Heath, 1987). It is a sign
of the age of such a group when it must lament the loss of its records: destroyed when the
headquarters was bombed in the war! However, Heath cited a source (“The saga of the ear-
handicapped”, Randle, 1954) referring to recognition of deafened adults back to 1923.

Deafened social worker Michel David started a Deafened Adult Support Group at the Canadian
Hearing Society head office in Toronto in 1986. This group was the seed of the Canadian
Deafened Persons Association, named in 1990, and the group continues to meet. Many members
also belong to the Association of Late-Deafened Adults.

ALDA: The Association for Late-Deafened Adults

A support group for deafened adults that had been meeting at Ravenswood Hospital in Chicago
suspended operations in the spring of 1986, leaving behind a craving for community. ALDA is
considered ‘founded’ on the occasion of the resulting party of support group members and other
late-deafened ‘strangers’ on March 28, 1987. Thirteen deafened people are recorded as having
attended. Even the association’s name has small-scale beginnings: ALDA: The Association of
Late-Deafened Adults was chosen from among 14 suggestions by the 21 ‘eligible’ voters in 1987.
The name has been criticized for various reasons: “late” also means tardy and deceased, it’s
frequently sign-interpreted wrong (no, it isn’t signed NOT-YET DEAF.) People think it refers
only to people in late-adulthood (i.e. old) or is limited to those who are adults already. ALDA
first defined its target membership as those who cannot hold regular conversations on an ordinary
phone and typically felt in limbo among both deaf and hearing groups. Currently, the principle of
self-identification governs. If you consider yourself deafened (or “late-deafened”) you are. There
are people who consider themselves late-deafened who became deaf in the pre-school years. Yet the combination of their early hearing memories plus a hearing-culture education, perhaps, gives them a sense of not being fully "of" one of the other groups.

With the privilege of authorship, I will describe (rather than define) the deafened person as a person who was formerly hearing or hard of hearing then either suddenly or gradually became deaf after early childhood. A deafened person from the ALDA point of view includes those who are currently experiencing progressive hearing loss that is expected to continue to deafness. Although Late-Deafened Adults is a sometimes misunderstood term, the acronym ALDAns is frequently and affectionately used to refer to members of the group, and this has hitherto prevailed against serious campaigns for renaming the association along the lines of the other "deafened persons associations" that have formed elsewhere before and since ALDA formed.

By the way, the generally accepted way to sign "deafened" is to point to the ears then draw the A-hands down wiggling at the wrists (HEAR-DETERIORATE).

Rapid Growth

ALDA was for many years very much a Chicago club. Its culture was founded in parties hosted and attended by a couple dozen people from in and around Chicago. Its main sources of financial and in-kind support were in Illinois. A large proportion of the names on the ALDA mailing list were in Chicago. The early newsletters had the character of play-by-play complete with color commentary: who was first to arrive, who brought what beverage, and who was last to be ushered out the door. As ALDAns became more numerous, this was obviously too much to sustain.

Awareness of ALDA grew through deliberate efforts such as a letter to scientists and engineers with disabilities, and representation at NAD conventions and the Deaf Way. The mailing list at the one-year point was approximately 100 names. It doubled in seven months, and doubled again in seven more. ALDA added over a thousand more names over the next two years, however many were professionals or service businesses who never became paying members. The lack of distinction between 'mailing list' and 'membership roll' as well as an early decision not to distinguish membership privileges between deafened people and anyone else who supported the interests of deafened people became a hindrance to determining how well ALDA had reached deafened people, and in 1992, ALDA began attempting to sort out who was who among the names by then exceeding 2,000.

Organized chapters arose, as did groups not yet petitioning to be recognized as formal chapters, and some lapsed again into inactivity. Groups in Canada also became associated with ALDA and overseas contacts remained steady. Each group has its own flavour, whether oriented towards education, or self-help, or parties, or even political intrigue, just as the different regions they exist in have distinct cultures.

ALDA went through the same transition most young organizations experience, when entrepreneurial serendipity and governance rooted in personal relationships are no longer feasible, and more formalized systems replace them. As ALDA grew to span a continent and reach around the globe, the early majority of members who knew their Board became a minority. At this stage in any organization's life, the desire of veterans to preserve the exhilarating early days and respect traditions conflicts with the desire of newcomers to be included in the process
and try new things. Through the mid-1990s, ALDA has been working to redefine its governance, a task made difficult by the economic environment and lack of paid staff.

**ALDA mission and principles**

Perhaps logically, because it began as a self-help group, ALDA’s predominant mission has been to serve as a support group for deafened people. Rather than functioning as a clearing-house for professional advice (or even peer-to-peer advice), ALDA has aimed to provide a safe environment where deafened people could find support and role models among other deafened people and ultimately make their own decisions on how to cope with deafness. ALDA has weathered its controversies about how these principles are put into operation. Getting “through a day, deafly”, is achievement enough for role-model status, but the prestigious roles within ALDA are particularly important. Relying on deafened people to fill these positions has been an achievement and a symbol to all ALDAns that our embrace of interpreters, court reporters, professionals, and our families does not require us to surrender our independence and self-determination.

The average member sees two consistent things that we think differentiate ALDA from many other groups. First, ALDA discourages advising. A person is certainly free to obtain advice from hearing professionals, deaf professionals, the butcher, the baker, and the candlestick maker, but decisions are the individual’s right and responsibility. A ‘good’ ALDAn will not give advice but will share their experiences with various coping approaches, and how they feel about them. We try to remember that we have deafness in common but many things may differ between us and need to be taken into account when making important decisions. Sometimes individuals feel so strongly about the choices they have made that it’s difficult not to recommend, but few principles are as fundamental in ALDA as this one.

A second fundamental principle is 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. People who have been convinced that their signing skills are awful discover that they can communicate just fine with people who want to communicate.

Because deafened peoples’ needs are so poorly understood, ALDA also is thrust into the position of providing education and advocacy. However, advocacy activities and the development of materials for education have been problematic. ALDA’s membership has vigorously endorsed democratic, even populist, principles. However, with almost no source of funding on the national and international level, ALDA’s economy is essentially plutocratic. External representation has had to be carried out mainly by those who can underwrite their own time and expenses on ALDA’s behalf, or whose jobs or location of residence permit them to attend events, meetings, conferences, or hearings. Overall, ALDA has been blessed with generous, talented, effective volunteers who have made this obstacle invisible to the average late-deafened person. There isn’t one of those burned-out souls who doesn’t dream of a funded staff, toll-free lines, printed matter, and other association infrastructure, to make it possible to reach out and connect with the vast number of isolated deafened people.
**ALDA News**

The young ALDA thrived by publishing a newsletter that focussed on the everyday deafened experiences—including the tedious, the frustrating, the demoralizing—and laughing at them. Bill Graham’s easy-going “southwest Chicagoan” sense of humour took the edge off the uneasiness of being deafened for the readers and his honesty created a sense of quid pro quo that liberated people to share their feelings in writing. Bill shamelessly quoted these deepest revelations in subsequent newsletters, forging a kinship among these increasingly far-flung deafened people who had never yet felt ‘at home’ in any established hard-of-hearing or deaf group. Although Bill had curtailed his writing by 1990, he retained his status in ALDA folklore as a ‘cult figure’ (Lovley, 1992). Dozens of other ALDAns ably took up the task, however, and ALDA continues to cherish the written word, frank personal sharing, and humour.

An informal but increasingly formalized editorial policy was insistent on not recommending any particular approach to dealing with deafness. Considerable rancor arose from time to time over the refusal of articles advocating cochlear implants, hearing dogs, and lipreading. However, ALDA News has continued to emphasize personal experiences and feelings, leaving the decisions about the ‘best’ approach to the readers. Popular continuing features include the ALDAnonymous question, in which anonymous readers respond to a question posed by a fellow member in an earlier issue, such as “how do you handle family functions?” and “do you tell sales clerks that you are deaf?”

Responses to ALDA News pour in. After receiving a sample copy, people who may have for years believed themselves to be the only deafened person in the world are moved to write the most exquisitely personal revelations “to whom it may concern” at the ALDA post office box.

**ALDAcon**

ALDA held the First ALDA Leadership workshop in October 1989. This was the event that later became known as ALDAcon. (The workshop was free to ALDA members, but those who did not attend were asked to send money. Now there’s an innovative idea for getting attendance up!) It was attended by 42 people, from all over USA and Canada.

Of 42 ALDAcon people, 30 returned to ALDAcon II, along with over two hundred newcomers. ALDAcon has since been held in Boston, Toronto, and Rockford Illinois, and at press time plans are underway for ALDAcon 1996 in San Francisco. A feature of every convention to date has been the self-help leadership training conducted by Laurieann Chutis, LCSW. Laurieann’s method is a vital part of ALDA’s belief system that there is no single way to cope with deafness, that each of us will help ourselves, as and when we are ready. Trained ALDA group leaders acquire the skill to lead a group through sharing of feelings and experiences and avoiding advising. Attending the training at ALDAcon enables those participants to go back to their hometown and lead a group if they choose.

ALDAcon workshops range from self-help sessions running throughout the convention, sessions on using the relay service, sign language basic training, cochlear implants, and other deafness related topics, through to lifestyle topics inaccessible to deafies in the typical hometown, from ballroom dancing to Tai Chi. Relationship topics are always popular as many deafened people struggle to redefine relationships with hearing partners, work colleagues, and their family of origin, and families are encouraged to attend the conference. Many workshops in recent years
have featured a panel of deafened people, discussing how they have dealt with a particular challenge, whether it be addiction or parenthood.

In addition to the self-help training, several ALDAcon traditions have already taken root. The buddy program ensures that newcomers can always count on someone to help them break the ice and feel at home. The karaoke soirée provides the opportunity to screech off-key many fondly remembered tunes, some of which have become ALDA anthems (“Jeremiah was a bullfrog/He was a good friend of mine/I never understood a single word he said…”). The Sunday brunch is a perfect excuse to take the stay-Saturday saver airfare and also avoid cluttering the ALDA Banquet evening with awards presentations. Meals are an important part of the ALDAcon program because so much of the candid sharing, bonding, and learning takes place while trying to figure out whether the waiter is offering coffee or tea “and by the way how do you communicate when people have foreign accents?”

Based on years of feedback, ALDAcon is the single most enlightening and important experience for any individual who becomes deaf. ALDAcon veterans go to participate in panels and presentations and renew friendships, but ALDAcon newcomers have reported that the experience has been a life-altering experience.

Access

With very few exceptions, even those deafened people who go on to acquire fluent sign language skills and prefer interpreters over other access media begin the deaf portion of their lives as non-signing people who require access to communication. The solution is found in the printed word.

At the first support group under the ALDA banner, communication was facilitated by a typewriter and four carbons, with pauses to pass around the copies and let everyone catch up. Steve Wilhelm began tinkering with a TRS-80 computer to develop “ALDA Crude”, which consisted of exploiting a sign language interpreter’s well-honed ability to ‘listen fast’ and type as best they can, allowing all participants of the self-help group to read the discussion on the computer display.

ALDA began a partnership with NCRA (National Court Reporters Association) in 1989. It seems good ideas are universal: the use of Palantype (British court reporting) to provide access was reported in 1987 (Heath, 1987). NCRA now offers certification in real-time reporting which is a special skill required by television captioning and real-time reporting at meetings. Many court reporters offer services to self-help meetings on a pro bono basis, while real-time reporting is now considered an access service under the Americans with Disabilities Act.

Summary

ALDA’s rationale is clear: deafened adults are different from Deaf and hard of hearing people because a significant part of their identity entails the transition to deafness. ALDA’s history is still in formation. In less than a decade, it has made a mark on the deaf community landscape. Despite the exhilaration of its early explosion and the enthusiastic “where have you been all my life” reception individuals have given to it, its highlights lie ahead.
References

Boone, S. & Scherich, D. “Characteristics of ALDAns: The ALDA Member Survey.” University of Arkansas Rehabilitation Research and Training Center for Persons who are Deaf or Hard of Hearing ALDA News, 1995


A Brief History of ALDA

Roy Miller

(This is a condensed version of a comprehensive history of ALDA scheduled to be published in the 1998 ALDA Reader)

Legally speaking, ALDA is a not-for-profit organization incorporated under the laws of the State of Illinois on June 2, 1989. ALDA has since been granted a group tax exemption by the IRS as a 501(c)(3) organization, and all qualifying ALDA Chapters are tax exempt under that group exemption. In the ALDA Bylaws, the general objectives of ALDA are indicated to be:

**EDUCATION**... Providing educational information to late-deafened adults, their families and friends, service providers, rehabilitation counselors for persons who are deaf, government agencies, private corporations, and members of the general public concerning the nature of, as well as strategies for coping with, the social, psychological, familial, occupational, economic and communication problems and coping strategies of the late-deafened adult.

**ADVOCACY**... Advocating on behalf of, and representing the needs, desires, and interests of all late-deafened adults in the promotion of public and private programs designed to alleviate the problems of late-deafness, for reintegrating late-deafened adults into all aspects of society.

**ROLE MODELS**... Providing positive role models for late-deafened adults who are striving to cope with the problems of late-deafness and enhancing their personal images, competence, and quality of life.

**SUPPORT**... Providing support for all late-deafened adults and their families and friends regarding how to cope with the problems arising from late-deafness, and providing social enrichment in their lives through activities in which they can meaningfully participate.

Who Are Late-Deafened Adults?

Late-deafened adults are people who were not born deaf, but became deaf after they developed language skills. They cannot understand speech without visual clues, and thus cannot rely on their hearing as a means of receptive communication. Instead, late-deafened adults must primarily depend on some visual mode of receptive communication, such as speechreading, cued speech, sign language, or text reading. Their deafness may have been the result of heredity, accident, illness, drugs, surgery, or "causes unknown." Their hearing loss may have occurred suddenly or very slowly over a period of years. Most importantly, however, regardless of the cause or rapidity of their hearing loss, all late-deafened adults share the cultural experience of having been raised in the hearing community, and having "become" deaf rather than having been "born" deaf.
How Did It All Start?

ALDA traces its roots to a self-help support group for late-deafened adults that was formed and led by Kathie “ALDA Chicago Prez Forever” Skyer Hering, who at the time was the rehabilitation services manager at the Kennedy Job Training Center in Palos Park, Illinois. Kathie has Neurofibromatosis – Type II (NF-2), and she completely lost her hearing in 1978. The first meeting of the support group was held at Ravenswood Mental Health Center in Chicago on October 30th, 1985 and was attended by Kathie, a guy by the name of Bill “Looking for a Friend” Graham, Paulette Pounders, and Bill Pankow. Graham was then the Life Sciences Editor at World Book Encyclopedia in Chicago, and his hearing had deteriorated throughout his high school and college years. Like many other late-deafened adults who struggle with progressive hearing loss for years, Bill had gone through a long period of denial, discontent, depression, bluffing, anger and hurt. He refused to learn sign language for a long time. However, speechreading was inadequate for him, and his job was becoming harder and harder. He joined the self-help group in hopes that he would meet others with whom he could share his feelings and frustrations. The self-help group met only twice before Kathie had to go into the hospital for more surgery in early 1986. After months of inactivity, the group finally disbanded.

Not too long after the self-help group formally ceased to function, Bill Graham organized a purely social gathering for late-deafened adults. Invitations to this historical party were based on a list of 25 local "contacts" that Kathie Hering had accumulated. The party was held at Graham's apartment on March 28, 1987, and was attended by thirteen adventurous late-deafened individuals. Most of the attendees had never met before, but the good feelings generated that evening led to friendships and more social gatherings. After the initial party, Bill sent everyone who had attended a lengthy “thank you” letter. As time passed, Bill continued to send out occasional letters to old and new friends. These periodic letters evolved into ALDA News as Bill's thinking began to focus on the development of an organization for late deafened adults.

Originally, the newsletter was written, edited, and published by Bill “The Town Crier” Graham (he did everything but lick the stamps, a task which he reserved for his faithful canine companion Myron). The newsletter was well received and its circulation grew steadily. By mid-1988, more than 150 people were on the ALDA mailing list, many of them from states other than Illinois. In 1989, ALDA was legally incorporated, and the first ALDA group outside the Chicago area began in Boston. By the summer of 1989 ALDA had established itself as a legal entity, had developed a solid base of support in the Chicago area, had a communications channel in place, and had taken its first step outside the boundaries of Illinois. It was now time to see if ALDA could develop a national base.

The Growth of ALDAcon

The First ALDA Leadership Workshop (retrospectively dubbed ALDAcon I) was held in Chicago on October 20-22, 1989. It was attended by forty-two late-deafened people from different parts of the United States and Canada, and provided the emotional impetus that was needed to sustain a truly national growth in the organization. The Workshop was held at Mercy Hospital, and was definitely a “shoe-string” operation, complete with box lunches, a pizza party at Bill's home, attendees staying in the homes of Chicago ALDAns, and local transportation being provided by volunteers. The workshop was free to ALDA members, but those who did not attend were asked to send money (another creative fundraising idea from Bill Graham).
purpose of the Workshop was to try and stimulate interest in ALDA, and to give people a set of
skills with which they could return to their communities and begin the task of ALDA expansion.

Workshop attendees were also introduced to ALDA’s philosophy of communication, namely that
whatever works is fine in one-to-one situations, but that captioning is the best common
denominator in group situations. Captioning was provided throughout the Workshop by use of
“ALDA Crude.” ALDA Crude was an application developed by Steven “Techno Junkie”
Wilhelm that displayed the contents of a computer screen on a television set and allowed the use
of a regular typist and a standard keyboard. The system is now known as Computer Assisted
Notetaking (CAN).

Workshop participants were also briefly introduced to real-time captioning (what is now known
as Computer Assisted Real-Time Transcription or CART). Most attendees had never before seen
CART, and it seemed like a technological miracle. In reality, however, at that time it too was in
its infancy, and it suffered from teeny sized text, long lag time between operator entry of text and
its appearance on the display, as well as many phonetic glitches on the screen due to limited
dictionaries. All of these shortcomings have since been remedied with improvements in hardware
and software.

Bill “The Eternal Optimist” Graham was definitely stepping out on a limb when he gave the
“First” ALDA Leadership Workshop its title. To suggest that the workshop would be followed
by others demonstrated either a lot of wishful thinking or a lot of vision (or some of both).
Regardless, annual meetings of ALDA have been held ever since, and they have become a
national showcase for ALDA.

The Growth of ALDA News and Related Communication Channels

The origins of ALDA News lie in the “Thank You” letter which Bill “Let’s Do It Again” Graham
distributed to the people who attended the first ALDA party at his apartment in 1987. Soon
thereafter, Bill’s thoughts evolved to organizational development, and he didn’t have either the
time or financial resources necessary to regularly produce and distribute any kind of newsletter
to a growing list of people. With the help of Cleo Simmons, an ALDAn who worked at the
Audiology Department of Mercy for the production and mailing of ALDA News (which was then subtitled
“The sort-of official letter of the Association of Late-Deafened Adults).

In early 1990, Marylyn "Karaoke Anyone" Howe of Boston became publisher of ALDA News, a
position that she held continuously until 1997. Marylyn developed the desktop publishing skills
necessary for the formatting of ALDA News, and she gave the newsletter much of its current style
and looks. At that time Bill “Hand to Nose” Graham became the Editor-In-Chief, and relied more
and more on what was called the “College of Editors” (guest editors). Bill’s labor of love with
ALDA News ended in 1993. David "Relay Junkie" Coco of Texas became the Managing Editor in
1994, a position which he turned over to Candis "It’s Cold Up Here" Shannon of Alaska in 1996.
After Marylyn Howe left the position of publisher in 1997, the ALDA Board agreed that the
publisher should appropriately be ALDA, and it renamed the top position to simply “Editor” – a
position which has been filled by Candis Shannon ever since.

In the early years of ALDA News, it was the only medium for disseminating information to all
ALDA members. Today, there is a separate publication called ALDA BIZ, which carries most of
the ALDA organizational and administrative information. Bill Graham also began a separate publication called the “ALDA Leaders’ Letter” in 1990 to provide a vehicle whereby the leaders of ALDA groups could share information. The Leader Letter was later edited by Nancy Kingsley (NJ) for several years, and is now in the capable hands of Jane Sokol Shulman (MA). In 1991 the ALDA Reader was born as a part of the program book of ALDAcon III as the literary “baby” of Kathryn Woodcock (Ontario). Kathryn was primarily responsible for the production of the ALDA Reader for the next couple of years, but since then has become more of a group activity.

The people who have contributed to ALDA News and the related spin-off publications represent an extremely gifted stable of writers and production people, all of whom have freely given of their time and talent to share the message of ALDA and provide laughter and many insights into late deafness.

**ALDA Leadership**

Between March of 1987 and June of 1989 ALDA was a fledgling organization in search of itself. On June 2, 1989, ALDA’s legal birth was recorded and the founding Board established. During the fall of 1989, a new Board, consisting of seven people, was elected by a mail ballot of the ALDA membership. Reflecting ALDA’s expanding membership base, two members of that year’s Board came from outside of Illinois. In September of 1990 a completely revised set of ALDA Bylaws (drafted by Roy “Legal Eagle” Miller) was adopted.

The ALDA Board has undergone a number of changes and challenges over the years. One of the most significant changes was implemented in 1993, when the ALDA Bylaws were amended so that the Board consisted of a past president, president, president-elect, secretary, treasurer, and three at-large members. In 1996, a Bylaws amendment was approved which changed the three at-large Board positions to a system of four regional directors. Again demonstrating its youthful international flavor, the four regions represent the entire world, not just the United States.

**ALDA Groups and Chapters**

During the early years of ALDA, the Board of Directors struggled with the question of “What does it take to become an ALDA Chapter?” The reality was that there were several loose-knit ALDA groups emerging around the country, some of which were very small, and there were a couple of well-structured, active, large groups (ALDA-Chicago and ALDA-Boston). The ALDA Board felt that there should be a place for both types of local organizations in the ALDA family, and so was born the distinction between an ALDA “group” and an ALDA “Chapter.”

Individuals who come together in joint pursuit of one or more objectives of ALDA begin their effort as an informal ALDA group. An ALDA group can be of almost any size, completely informal in procedure, perhaps meet only occasionally, and have very limited objectives. A Chapter designation implies more formality, structure, and adherence to the policies of ALDA. As one might expect, the first formal ALDA Chapter approved by the ALDA Board was ALDA-Chicago in January 1991 followed less than a week later by ALDA-Boston. These two flagship Chapters continue today and over time have contributed immensely to the pool of resources, talent, people, and energy that drives ALDA.

Since the early years of ALDA, when ALDA-Chicago and ALDA-Boston were effectively the only players in the game, the number of ALDA groups and Chapters has consistently grown. Some groups may start, continue for a time, and then become inactive – hopefully to rise from
their own ashes at some point in the future. Other groups develop their own dynamics, become formal ALDA Chapters, and play an all-important role in the lives of their members throughout the years. Some ALDA groups are city bound, while others are more rural. They have different styles, programs, and objectives, but they all are driven by the general objectives of ALDA.

Today, ALDA is "home" for many late-deafened adults throughout the United States, Canada, and several other countries around the world. ALDA gives late-deafened adults a special place where they can be themselves and share their experiences with their "family" of other individuals who have experienced adult hearing loss. Looking back at what began as a small gathering of thirteen people in Chicago just eleven years ago, one can only be impressed by the fact that ALDA has since spanned the North American continent.

**ALDA Mission and Pledge**

ALDA’s mission statement, which succinctly captures the essence of the organization, is “to support the empowerment of deafened people.” Together, ALDAns pledge to:

- provide a support network and a sense of belonging for late-deafened people
- share our unique experiences, challenges, and coping strategies
- help one another find psychological relief and practical solutions to our problems
- provide an atmosphere where late-deafened adults are not judged as flawed, inadequate or imperfect
- work with other organizations and service providers for our common good

The first ten years of the organization’s life have clearly shown that ALDA was an idea whose time had come. The experience of having become deaf when one was once a hearing person is vastly different than either growing up deaf or still being able to function in the hearing world with the use of an assistive listening device of some type. ALDAns are “caught in the middle” between the Deaf and hearing worlds, and throughout its brief history ALDA has provided a welcome “home” for late-deafened adults, where they are no longer isolated and where they can learn to accept themselves as they accept each other.

In the pages of this volume are narratives written by ALDAns which share some of the humor, feelings, experiences, frustrations, joys, heartaches, and desires of late-deafened adults. Just as this brief history is meant to provide a selective profile of the organizational life of ALDA, the narratives that follow provide a selective profile of the lives of its members. Hopefully those narratives will demonstrate the spirit that is ALDA, and will provide evidence that in its relatively short lifetime ALDA is successfully accomplishing its mission. One can only hope that the path that ALDA takes in the next decade is as brightly lit as that which it has walked for the past ten years.
A Word from the Editor

David Coco

The essays and poems in this collection were selected from publications of the national Association of Late-Deafened Adults (ALDA) during the first ten years of the organization's life, 1987-1996. The two publications that served as the sources for this collection are ALDA News, which is the national ALDA newsletter, and the ALDA Reader, which is an (almost) annual collection of articles published in conjunction with the annual national convention, ALDAcon. ALDA News evolved from a personal letter from Bill Graham, one of the co-founders of ALDA, written in early 1987 to a small group of late-deafened friends into a professionally produced newsletter with contributors from all over the world. The ALDA Reader has its roots in a section of the 1991 ALDAcon program book which contained a collection of writings from late-deafened adults. The next year the ALDA Reader was a stand-alone publication distributed at the ALDAcon and has been a regular feature of every ALDAcon since then, with the exception of 1995.

There were two main objectives in developing this collection. First, it was intended to be a tenth year birthday present to all ALDAns: a celebration of our shared experiences and friendships we have developed over the years. The second objective was to provide an introduction to ALDA for those who are interested in finding out more about this fascinating organization. The focus of this collection is on the personal experiences of late-deafened adults: how it feels to lose your hearing, how your life changes, how you struggle to reestablish some means of communication and connections with the hearing world, and what sort of people emerge from this experience.

The reader will notice that the distribution of articles collected is rather uneven, with some years containing only a few and others overflowing. This is mainly due to the variation in the content of the newsletter throughout the years. In the early years, when much of the effort was focused on the logistics of developing the organization, the newsletter often contained a large amount of business related articles, whereas in later years the business articles were relegated to separate mailouts and, finally, published in a separate publication, ALDA Biz.

The articles selected for this collection were intended to give the reader a sampling of ALDA writing over the first ten years. We tried to include examples of regular features, like ALDAnonymous, as well as essays which address major events in ALDA's history, such as the cochlear implant controversy. The articles contained in this collection span a broad spectrum of viewpoints reflecting the broad diversity of ALDA itself. In ALDA you will find avid proponents of lipreading, sign language, cochlear implants, and a host of other approaches to deafness. But ALDA, as an organization, has taken a very unique attitude toward deafness in refusing to promote any one approach as the cure-all for deafness. Individual members are encouraged to try them all out and select the approach that works best for them. This collection presents some, but certainly not all, of the approaches ALDAns use to face the challenges of deafness.

The task of developing this book was a thoroughly enjoyable one for me due to the eagerness and generosity of the ALDA volunteers who made this book possible. I would like to thank the assistant editors who took on the huge task of locating and selecting the articles. Each assistant editor was assigned a year and was charged with locating all of the ALDA publications for that year and then selecting the best of the lot. The associate editors then helped me pare down this list to a more manageable size representing a balance of authors and topics. Mark Dessert was
my right hand man in all phases of this venture; in addition to assisting with the editing chores, he contributed his formidable technical skills to the layout and production of this book. Marylyn Howe, who served as publisher of *ALDA News* for many years, contributed her editorial skills and invaluable guidance to the project, and Dr. Doug Watson, from the Research and Rehabilitation Training Center at the University of Arkansas, managed the publishing aspects. Thanks also to our eagle-eyed staff of copy-editors who ensured the accuracy of these scanned articles: Nancy Kingsley, Carol Postulka, Anne McIntosh, and Bill Zitrin. I would also like to thank the contributors of the introductory section: Dr. Kathryn Woodcook, who graciously allowed us to reprint her overview article of ALDA from the *Deaf American*, and Dr. Roy Miller, who contributed a condensed version of his ‘History of ALDA’ article (the comprehensive version is scheduled to appear in the 1998 *ALDA Reader*). And finally, a round of applause for the authors of these articles - thank you for opening your hearts and sharing your lives with us.

*ALDABest to you!*
Dear Friends,

Hey, what a swell party! That get-together at my place on Saturday, March 28, rated four stars, even with me as the host. Seemed like everybody had a good time, especially Dawn and Karl Maerz, who had to be encouraged out the door by my dog Myron at 1:15 in the morning. Was the night sky lightening in the east, or was it my imagination? Good thing Dawn's name isn't Noon. Four stars in the Mess-Left-Behind Dept. too, folks. Who left the piece of panzerotti in my study? I didn't find it until Wednesday. Credit my nose.

It was wonderful to meet so many of you deafened adults. Best party for strangers I ever had. Maybe for my next party I'll just pick names at random from the Chicago phone book. (Is my inner city bias showing? Mea culpa, mea culpa.) I felt very comfortable with you all, and hope you felt the same. It was such a dynamite occasion I thought it might be a good idea to keep our newly made contacts alive. We need each other, ya know? And many of us would like to get a support group (or two or three) started, so....

I thought, maybe one good way to build upon what we've begun would be to write a letter about what has happened, is happening, and may or will happen in the future. Maybe this casual letter could develop into a regular thing, or maybe a more formal newsletter, or maybe (gasp) a national magazine with a larger circulation than Time, Penthouse, and TV Guide combined. On the other hand, maybe this will be the first and last letter of its kind. Who knows what will happen? Such mystery adds to the excitement. (Wake up, Prudy!) Whatever our niche in history, it will depend largely on you–on your needs, on your reactions and responses, on whether you think our upstart social network is worthwhile enough to participate in some way. I'm writing this letter because, having met you, my own feelings are unusually positive. But then again, maybe it was just Chuck's wine that created the feeling of euphoria. (I had to drink it ... I couldn't find my beer!)
For the record, 22 people attended the party. There were three married couples that I know of (heh, heh), 12 deafened adults, 8 men, 13 women, 1 dog, 1 cat, and, briefly, 1 delivery man from Ranallils. Paulette Pounders was the first guest to arrive. She made the labyrinthine journey from the south side of Chicago by CTA buses and cab. Paulette deserves a lion's share of the credit for getting us all together. Ever since Kathie's support group stopped meeting last spring, Paulette has been a driving force to resume it. Her persistence in not letting a good idea die led to the party idea.

See ya,

Bill Graham
Definition of a Late-Deafened Adult

Bill Graham
(Excerpts from ALDA News, vol. 1, no. 2, May 1987)

It's not surprising that when some really nice people band together with a worthwhile purpose, everybody wants to get in on the fun. But it has also become evident that not everyone has a clear understanding of who or what we are. What exactly is a "late-deafened person," anyway? We are not like all other deaf people. For example, our communication needs and our social problems are often quite different from those of people who were born deaf or became deaf during childhood. And what does the word "deaf" mean? There are various levels of hearing impairment and they all involve different methods of coping. How severe is the hearing impairment of a deaf person?

Kathie Hering and I both thought it might be constructive to develop a definition of late-deafness. Such a definition might help people determine more easily whether we're the kind of group they'd feel comfortable with. So, with apologies to lexicographers everywhere, I wrote down a few sentences and then Kathie added some things and it all came out like this:

A late-deafened person is a person who has become deaf as an adult and whose deafness has caused fundamental changes in the way the person lives. Deafness means that the person cannot comprehend speech without visual clues or use the telephone without the aid of special devices, such as TDDs. The person's loss of hearing may have occurred suddenly or it may have happened gradually over a period of years. The late-deafened person typically feels in a social "limbo"--not entirely comfortable with hearing people or with people who became deaf before adulthood.

There. We think that's pretty decent. But what do you think? Is the definition too rigid? Not rigid enough? Have we left out something essential? Let us know how you feel, then we will revise the definition as necessary and present it to you once again. It may take several attempts, but I'm sure we'll ultimately arrive at something most of us can live with. (So don't get suicidal!)

Cheers,

Bill Graham
Cleo’s Party

Bill Graham

(Excerpts from ALDA News, vol. 1, no. 3, June 1987)

Dear Friends,

On Saturday evening, May 16, Cleo Simmons gave a seminar on how to throw a classic party. The site was Cleo's house in beautiful down home Burbank. That's Burbank, Illinois, but it might have been the one in California if ya didn't know any better. Cleo's house had lush, Palm Springs style landscaping on all sides, a Santa Monica-sized swimming pool in the back yard, and dazzling Malibu blondes moving about constantly. Food and service at the party measured up to anything offered at the Hollywood Bowl, there were drinks enough to fill the Pacific Ocean, and the guests glittered as much as those in Tinseltown on Oscar night. The sun also was unusually bright that day, adding to the La-La Land feeling. If I had known what awaited me at Cleo's, I would have come by skateboard or hang glider, with a case of wine coolers.

What a swell party! I don't know about you, but I left at least part of my heart in downhome Burbank. Blame Cleo's family, a friendly, endearing crew if ever there was one. Cleo's husband Gene greeted the first wave of partygoers outside the front door. Gene's disarming heartiness melted any anxiety of coming to the house for the first time. Meanwhile, Cleo--looking quite marvelous, thank you--patrolled the living room, fueling brushfires of conversation as they broke out while keeping an eye out for the arriving guests.

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SLOWLY THE COURSE OF EMPIRE TAKES ITS WAY. From reading these letters, sometimes it might seem like all our group does is party, party, party. Well, it's true that we party famously and it's certainly nothing to be ashamed of. The parties serve an important social need of local late-deafened adults by keeping us in touch with each other. But of course, our group has other, more earnest goals as well, such as the reestablishment of regular support group meetings to serve our emotional needs. We also would like our group to eventually function as an information center for services and opportunities available to late-deafened people. While it's relatively easy to get a party together, it takes a little more time to attain these other goals.

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Your obedient servant,

Bill Graham
Dear Friends,

This Christmas is a very special one for ALDAns because for the first time we have each other. It's amazing how much has happened in less than a year. New social opportunities for late-deafened people have sprung up, and with them new friendships. We've had four terrific parties and a fifth one coming this weekend. Our ranks have swelled from 14 original contacts to almost twice that, and more late-deafened people are being identified each month. Friends, relatives, and professionals who work with the deaf have learned more about us and have started to support our cause. New activities and services are in the works for 1988, including a workshop for late-deafened adults and self-help support groups. So this holiday season, ALDAns have every reason to be jolly. We've got a good thing going: we've got each other.

Hark, a party! ALDAns sing,
Glory, what will this one bring?
Eats and drinks and lots of smiles,
ALDA people getting wild.
Join us all ye ALDAns wide,
Join the party, don't be shy,
With MM, the host, proclaim
ALDA's latest nights of fame.
Hark, a party! ALDAns sing,
Glory, what will this one bringgggg????

See ya there, folks, and season greetings to all!

Bill Graham
Dear Friends,

Self-Help Group Report: ALDA's North Side self-help support group for late-deafened adults completed its first term of sessions on February 8. As many as nine people have participated in the group, which meets Monday evenings at Ravenswood Hospital. I feel our first try at self-help meetings has been a big success and a fascinating experience. Of course, I'm the group facilitator, so you should expect me to say stuff like that.

The self-help group is an ongoing activity that will continue throughout the year. But sessions are divided into six-week terms to provide some beginnings and ends. New members are welcome to join the group during the first two weeks of any six-week term. The group then is frozen for the last four weeks of sessions. This enables members to grow comfortable with one another, which helps create an atmosphere of trust.

At each self-help session, members have an opportunity to tell how they feel about and cope with a given situation or topic. The topic is decided by group consensus at the start of the session. Each person speaks without interruption while the others listen. Afterwards, everyone has a chance to comment on how the experiences of other members relate to their own—how similar or how different they are. The group does not engage in "problem-solving"—members do not give or receive advice on how to resolve personal troubles. Members speak only about themselves and listen to what others have to say. Sometimes hearing how other people feel and cope can provide useful insights. Everything said during the self-help session is strictly confidential. So if you ever hear somebody talking about what somebody else said at a self-help group meeting, give that person a good whack on the side of the head. Thanks.

One of the primary goals of the self-help group is to have everyone understand what everyone else is saying at all times. Members are encouraged to speak slowly and sign if they can. To aid comprehension Linda and I take turns typing what is being said and then distribute carbon copies for review. The group is working on an ambitious plan to improve the communication process even more. First, we intend to obtain the services of a hearing person to type for the group in order to free Linda and me from this sometimes exhausting responsibility. Then we'd like to rig up a computerized system for displaying the typed words. This system would consist of a computer, a keyboard, and a television. As words are typed they would appear immediately—and enlarged—on the TV screen. The words of the speaker would thus appear in "real time"—that is, as the person is speaking them. If a group member misses something that is said, he or she can glance up at the TV screen and retrieve it. A friend of mine, Matt Pollack, has offered to develop such a system for us from used computer parts. His guesstimate of the cost for this contraption is $100 or less. If the system proves successful, I think it will be useful at other ALDA functions as well.

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Happy Birthday, Dear ALDA! Many of us have developed such fine friendships through ALDA that it seems like the group has been around forever. But actually, ALDA is still a precocious rookie—it isn't even a year old yet. Our first get-together took place on March 28, 1987, a day now widely recognized as ALDA's date of birth. Well, this month is February and that means next month is March and we haven't had a party since December, sooooo ... Yes, Yes, Yes, fellow ALDAns! Iron out your party hats and streamers and be ready for:

ALDA's First Birthday Party:

......

As always,

Bill Graham
Dear Friends,

. . . . .

This letter celebrates one year of ALDA. The warmth and goodwill of that first party has led to wonderful things: more parties, self-help support groups, strong friendships, a psychological homeland for many of us. For me, the year has been a remarkable personal journey as well, an awakening of sorts in which I've learned a great deal and found new strength and meaning in my life. I have come to appreciate the wisdom of Kathie Hering, who was the first to recognize the need for solidarity among local late-deafened adults. It is a need that goes well beyond the Chicago area, as parts of this newsletter will bear out. In one short year, ALDA has become a significant new voice in the deaf and hearing-impaired community. Not only late-deafened people, but also interpreters, audiologists, doctors, teachers, and other professionals who work with deaf people have shown tremendous support for our activities and goals. It's gratifying, of course, to reflect on the steady growth of ALDA. And it's fun and exciting to daydream about the future, which is full of promise, opportunity, and companionship for anyone willing to stop forward. But on ALDA's first birthday, I prefer to think back to that magical night of March 28, 1987, when it all began. That night, each one of us took a big gamble. It was a gamble to attend a party where so many people were strangers. It was a gamble to leave the usual comforts of a Saturday evening and risk communication on unfamiliar ground. It was a gamble that paid off.

. . . . .

As always,

Bill Graham
Chapter 3

1989

Frontiers of Communication

Bill "Hand-to-Nose" Graham


One sunny day a few weeks ago, as my girlfriend and I lay side-by-side on her parents' lawn working on our skin-cancers-to-be, I playfully reached over and grabbed her nose. I squeezed the nose lightly between my thumb and forefinger and maintained this gentle pressure until Karina spoke. I don't remember her exact words—they were probably something insignificant like, "I can't breathe, Guillermo"—but the important thing was this: I understood everything she said.

Without letting go of her nose, I responded to her remark. Karina then said something else and, once again, I understood her perfectly. We continued in this manner for several minutes with growing amazement. With my hand on her nose, I could lipread Karina much better than I normally do. I experimented with other parts of her body—the top of her throat, the back of her neck, near her Adam's apple, but none of these locations aided my discrimination as much as having my hand on her nose.

This finding staggered me. I have never been a good lipreader, and my ability and motivation to lipread have dipped even more in the seven years since I learned the comforts of sign language, I do, of course, recognize the practical value of this communication mode, and so I was elated to find this convenient way to improve my skills. For me, Karina's lovely nose functioned like one of those vibro-tactile devices that pick up speech vibrations and thus help certain deaf people lipread better. But those gizmos are electronic and cost a pretty penny, Karina's nose is 100% natural, free, and available whenever she is near me.

I felt I had stumbled upon a new frontier of communication. I excitedly considered what the hand-to-nose method could mean to late-deafened adults. Anytime a person came within arm distance, an ALDAn could just reach out, grasp the person's nose, and have an easy conversation. Conversations involving two or more people would be equally simple. Everyone could stand in a huddle like football players, grab the closest nose, and start talking. And think of the fundraising potential for ALDA—hands and noses around America!

My discovery of hand-to-nose communication with Karina immediately moved me to test the technique on other noses. First, I cornered my dog Myron. A lifetime foe of animal experimentation, he squirmed fitfully as I clutched his big, wet nose and ordered him to speak.
To my surprise, I could not distinguish his "bow" from his "wow" or even his "wow" from his "arf." The hand-to-nose method had failed. Further tests on unsuspecting friends and family members over the next few days produced similar failures.

Time and again, I returned to Karina's nose, where the magic remained. No matter what she said, I understood her without much difficulty. Eventually, I figured out the answer to the riddle: Karina's voice is more nasal than most people's. Thus, the vibrations of her voice surge through my hand when I hold her nose. With the majority of people, however, the hand-to-nose system is useless.

Although my discovery proved fraudulent, I was hardly distraught. Because in the past year, ALDA truly has crossed into a new frontier of communications. Our use of inexpensive real-time captioning systems at small group meetings represents a tremendous breakthrough for late-deafened adults. It has brought many late-deafened people into group conversations for the first time since they became deaf. Captioning is the "best common denominator" for communicating with late-deafened people because it is something that all of us can understand. More than any other factor, captioning has made it possible for ALDA to function normally as a group.
Making Sense of it All . . .

Bill Graham


This was my first Christmas without my mother who died in mid-October at the age of 80. I suppose it's not unusual to feel that your mother was the most loving person in the world. Anybody who knew my mom wouldn't question the sincerity of my own claim. Ma Graham touched and gladdened a great number of lives - young, old and in between - and many people beyond her immediate family miss her dearly.

I was the last of four sons and she never failed to introduce me as the baby of the family, even when I was well into my 30's. Probably because I came last, my mother smothered me with worry and concern. Although she worked the graveyard shift as a bookkeeper at a hospital she never seemed to sleep when I was home during the day. She wanted to make sure she was there if I needed her. She also tried to provide all the things that a normal boy would want to be happy. In her thorough Polish view of the world, this usually meant food. Every time I turned around, my mother was coming at me with a box of Dunkin' Donuts or a sack of White Castles.

Not surprisingly, my mother's inordinate thoughtfulness backfired. As a teenager I felt a prisoner of her unrelenting attention. I felt I couldn't breathe without her reacting in some overly solicitous way. She seemed to monitor my every move, and I pleaded with her time and time again to leave me alone. But my outbursts only inspired my mother to try harder. She'd substitute pork chops for hamburgers or Suzy Q's for donuts. She felt she could single-handedly make my life a happy place.

During the early 1970's, when I was still living at home, I began to go deaf. I think this development bewildered my mother. She probably felt helpless here was something no amount of food could rectify. Outwardly, both she and my father responded to my hearing loss by denying it existed. We never talked about my hearing impairment or the mounting troubles it caused me. Inwardly, my mother prayed for my hearing to return. Every day she prayed. Earlier this year, she told me that she was still praying that I would someday hear again.

I'm not sure how different my life would have been if my parents had taken a more assertive attitude about my hearing loss, but the facts are these: for many years, I, too, denied that I had a problem. I clung desperately to the "hearing me," refusing to admit I was missing more and more of what people said. I bluffed my way through thousands of conversations, never knowing for sure what was going on. These were dark, difficult years for me, full of tensions, bitterness and self-pity. Eventually, I was too deaf to fool people anymore, and I grudgingly began to admit that I couldn't hear "perfectly well." Several years later, in the early 1980's, I learned sign language. I didn't realize then what an important breakthrough this was for me. Through sign language I brought my deafness out of the closet and began a journey of self discovery that led to ALDA.

My mother never learned sign language, or even fingerspelling. She claimed she was too old to learn. But she had learned how to use a computer for her job at the hospital when she was in her late 60's. My mother was a smart lady - she could easily have learned at least a few basic signs, but she had a wall about my deafness that she allowed to let stand. Very simply, she did not want me to be deaf. To her my deafness was a terrible thing that stood between me and a happy life.
She had seen deafness torment me and it must have hurt her to watch. Even after I had learned to cope better with my deafness, her attitude about it stayed the same.

The last time I saw my mother alive was at a disability awards luncheon in downtown Chicago. I had won an August Christmann Award, which honors Chicagoans who further the dignity and independence of people with disabilities. Because I had struggled poorly with my own disability for so long, the award meant a great deal to me. At first, my mother did not want to come to the awards luncheon, and I did not press her about it much because I sensed she had mixed feelings. But one of my brothers strongly urged her to reconsider, and at the last minute she decided to attend.

She sat with me at a table near the speakers' platform at the front of the auditorium. In my acceptance speech, I described my painfully slow evolution as a deaf person, from days of fear and denial to those of candor and acceptance. I ended the speech with a tribute to ALDA because I felt that this group had enabled me to stop regarding myself as a flawed hearing person and to begin appreciating myself for what I am. Afterwards, my mother said my speech made her cry. She said she felt very proud of me and that she was happy that she had come. I accompanied her to the door of the building and watched her walk off in the rain to shop at Marshall Fields. A few days later I found her dead of a heart attack in her bathtub.

In the strange way that people have of making sense out of unexpected events, I found a connection between my mother's death and our last hours together at the luncheon. I reasoned that by hearing me speak publicly about my deafness and by seeing me honored with an award, my mother finally understood that deafness was no longer my enemy. I had learned to live with it peacefully, without denial or shame. I was happy with my life and happy as a deaf person. I concluded that my mother, having realized that her youngest son had found peace with himself, was now herself at peace and could go.

During the weeks that followed my mother's death, I received tremendous support from ALDAns. There were cards, flowers, TDD calls, and visits from many, many people I did not even know three years ago. It brought home to me again what an important role ALDA plays in my life. By finding other late-deafened adults through ALDA I find myself. I find that I am not alone with my feelings or my problems, and that's a nice thing to know. I also find that sharing with other ALDAns helps me keep my deafness out of the closet, where it always spooks me the most. Out in the open, deafness is not half so scary. In a relatively short amount of time, ALDA has helped make my life a warmer and far less frightening place. I want to thank all of you for that. I'm sure my mom wants to thank you too.

Happy New Year, ALDAns, We have a good thing here.
Deaf Man's Bluff

Bill Graham

(ALDA News, vol. 4, no. 1, February 1990)

During the 1970s I gradually became deaf. I did not make the transition to deafness gracefully. In fact, I spent five or six years of my young adulthood in all-out denial of my hearing loss. There was no way on earth you could get me to admit that I couldn't hear as well as the next person. I didn't want to be different from my friends and everybody else. I wanted to fit in.

As my hearing began to slip away and I started to miss sounds, words, and phrases, I developed a habit of bluffing. I bluffed that I could hear everything that I was supposed to hear. I learned to read lips fairly well, and I became a master of anticipation. I'd watch the facial expression and body language of whoever was talking, consider the situation, and then extrapolate like crazy, trying to figure out what was probably said.

Often, a simple yes or no would be enough to keep the verbal interaction moving along in a fairly normal way. I would nod my head up and down or shake it back and forth whichever seemed appropriate - and hope for the best. In college, the teacher would ask me something and instead of saying: "I'm sorry, I didn't hear you," I'd shrug my shoulders and say "I dunno". These sort of responses didn't help my grades, and I eventually stopped going to classes altogether. I just did term papers and tests and got by that way.

I bluffed with my friends, too. With some of them, I communicated with shrugs and one word responses for several years, rarely knowing for sure what they were saying. That seems preposterous to me now, but 15 years ago this was my way of life. One year I attended a Halloween party as Harpo Marx. Everyone said I was perfect.

Another type of bluffing that I engaged in regularly was "covering my tracks." If a response I made was completely inappropriate, I would try to validate it with my subsequent remarks. This often required a lot of creativity and wild rationalizations. And it often put me in embarrassing situations. I remember an important baseball game when I struck out swinging and, unknown to me, the ball got by the catcher on strike three. My whole team was yelling at me to run to first base (I was later told), but I didn't hear them. I probably could have made it to second by the time the catcher retrieved the ball. Instead, he ran over and tagged me out as I trudged back to the
dugout. My teammates were furious and wanted to know why I didn't run out the dropped third strike. I made up a story about pulling a muscle in my calf, and I faked a limp the rest of the game. I felt uncomfortable on the team the rest of the summer.

Clearly, bluffing had its risks. But I was willing to gamble because there seemed no other way, no conceivable alternative. I grew up as a hearing person and the hearing world was my only reality. How could I catch any dreams if I let go of that reality? It didn't seem remotely possible, so I held on to the "hearing" me as long as I could, bluffing my brains out as needed. If I successfully fooled someone, it made me feel good or at least relieved.

As my hearing got worse and worse, however, bluffing became a losing battle. I just couldn't pull it off anymore. Each attempt brought distressing casualties—confusion, embarrassment, guilt, weird glances, and tension on both sides. Eventually I surrendered and began to admit that I couldn't hear perfectly well. This was still quite a ways from the truth because by then I was deaf—but it represented a dramatic breakthrough.

To my surprise, I found that many people accepted me as a hearing-impaired person, and with these people, my life was far less stressful. I even learned to occasionally joke about my hearing problem, and many of my friends started thinking I was a bright, funny guy, which I was. At that point, common sense should have told me to bury my bluffing forever. But it was a tough habit to kick. And I still resorted to bluff whenever I could get away with it, especially with strangers.

After several more years, I learned sign language. I found I liked this method of communicating because it was easier on my eyes and nerves than speechreading. Later, I realized that by using sign language in public, I brought my deafness out of the closet and made bluffing pointless. Also, through sign language I got to know deaf people and started on a path that eventually led me to co-found ALDA in 1987.

Today my deafness is pretty much out in the open. I sign with friends, periodically use interpreters, and feel reasonably comfortable telling people I am deaf. But I still can't pass up an occasional bluff. Sometimes, when I miss what a person is saying for the fourth or fifth time, I just say "the hell with this..." and give them a well-practiced head nod or shoulder shrug. Or, sometimes when a stranger asks me God-knows-what and I'm not in the mood, I'll mumble "I dunno" and hurry away. But I never feel good about bluffing anymore, even when I can get away with it. I feel better admitting that I'm deaf, though this by no means ensures a happy outcome.

Often, I still won't understand what a person says to me and the conversation becomes an ordeal. But at least it's an honest ordeal. I can live with that.
From The Publisher
Marylyn Howe

As a side-tracked audiologist who ended up in the publishing world, I receive many trade journals and periodicals marketed for this profession. Many of these journals depend on advertisers to keep them afloat financially. And, of course, those advertisers are deaf service providers or vendors of audiologic products.

One of the most disturbing ads that, to me, wins the award for "Untruth in advertising" comes from a corporation that makes and markets cochlear implants. The ad shows happy, smiling implantees engaged in conversations. It shows a young child with her rag doll, happy as a lark, a grandmother apparently overjoyed that she can "hear" her grandchild and - the most offensive of all - a young woman smiling broadly as she listens on the telephone. (C'mon!) And the hearing aid industry is often as guilty. There is more than one corporation that tells us this little device will perform miracles in our ear.

My complaint is not with consumers who sometimes derive benefits from these devices. Rather, my disdain is for the companies that falsely promote these products as "the answer to your misery." The implication, or underlying theme, of the ads is "Gee, why be deaf and miserable when you can be hearing and happy again?" In one really objectionable ad there is a quote from an implantee that says: "I can now have a normal conversation with my wife . . ." (God! I doubt there are even normally hearing men who can make that statement.) And yet another irritable quote calls out, "After 25 years of silence and struggling to survive in the hearing world, I was suddenly hearing sounds I had forgotten existed."

Struggling . . . That is the word that screamed out at me. Many adults with acquired hearing loss struggle so hard to hear again that they search desperately - and most often, unsuccessfully - for a solution to deafness. There is no doubt in my mind that it is the struggle of wanting to hear again that makes many late-deafened people frustrated and unhappy. And it is the struggle that leaves them vulnerable to these erroneous ads that promote audiologic products as bluebirds of happiness.

Acceptance of deafness is tough on those of us who know what it's like to hear. We miss falling asleep to the tunes and lyrics on the bedside radio. We miss telephoning our friends the "old-fashioned" way. We miss the conversational banter that goes back and forth at social gatherings. But we do have a choice of viewing deafness as a perpetual torment and struggle, or viewing it as just another of life's challenges - in which case we accept it and go on with the show. In either case, whether we are aided or unaided, implanted or not, we still have the right to expect responsible advertising that doesn't prey on our circumstances. In a not-so-recent but relevant book, Harold Orlans briefly relates the following story about Thomas Edison, who became progressively deafened from age 12. "It drove him to reading and to concentrate without distraction.... He attributes his invention of the phonograph and the carbon transmitter, which made Alexander Graham Bell's telephone successful, to his deafness. And deafness helped his courtship."
Thus, wrote the inventor in his diary:

"[Deafness] excused me for getting a little nearer to her than I would (otherwise) have dared. And after things were going nicely, I found hearing unnecessary—it may be said that I shut off from that particular kind of social intercourse which is small talk, I am glad of it ... I have no doubt that my nerves are stronger and better today than they would have been, if I heard all the foolish conversation and other meaningless sounds that normal people hear . . . People with good hearing have become so accustomed to the uproar of civilization that the uproar has become necessary to their lives. If all the noise suddenly would stop on Broadway, Broadwayites would fade away. Broadway as it is is a peaceful thoroughfare to me."

And, as though he had extraordinary foresight about ALDA, Edison continues: "We are building a world in which the person who is deaf will have a definite advantage. If we keep on as we are going, we will have a general environment which will be impossible to the acutely hearing person."

Thomas Edison obviously didn't struggle with his deafness. Indeed, he had a remarkably strong sense of identity and self-sufficiency. Orlans, commenting on Edison, observes that "To accept one's condition and find fulfillment in it is the beginning and perhaps the end of wisdom."

I wonder what Thomas Edison would say about ads that promise to make us hearing and happy again.

ALDA Crosshairs
Marylyn Howe, Minesweeper
(ALDA News, vol. 4 no. 3, July-August 1990)

My column on cochlear implant and hearing aid advertisement in the last issue got caught in the crossfires, if you let me crawl out of the trenches, I'll show you some excerpts from the mail. Ready? . . . Aim? ... Rebut!

Marylyn, I feel your comments were ill-conceived. Though there is much that I agree with you about on this subject, I feel you were somewhat emotional. When I first read the article, my immediate reaction was to write a strong rebuttal. But as time went by, I realized that all of us ALDAns have strong opinions, one way or another, about implants and everything associated with implants. . . Even though I have an implant I do not feel implants are for everyone. To get an implant is a very personal decision that I would hesitate to even advise another person on, let alone recommend. I can only state my own experiences, which have been good.

—Larry Paulsen, Managing Editor, ALDA News

While I am very supportive of the ALDA organization and promote it whenever the occasion arises, I was shocked at your recent editorial in the May/June edition of ALDA News. As a fellow-publisher, I feel it is our responsibility to present facts, not make judgments on the people who share them with us. Your "disdain for the companies that falsely promote products" is shared by many. However, you have assumed that the advertisers promoting the cochlear implant are "falsely" presenting their products. This is simply not true. . . . The Voice will continue to promote organizations and companies who are trying to advance understanding of hearing loss. This includes manufacturers of products, as well as organizations such as yours.

—Paula Bartone, Publisher/Editor, The Voice

I thoroughly approved of your editorial comments in the most recent issue of ALDA News. Chances are we both have more in common than being deaf audiologists and disliking the kind of advertising that pervades our culture... You are perfectly right and eminently justified in denouncing that kind of deception. In the case of cochlear implants, there is a problem of a specially vulnerable population of those whose hearing impairment is extreme and who are extraordinarily susceptible to false hope and inflated expectations. However, the device is also dependent on the professionals who install it, who do the case selection, the testing, the counseling and follow-up. Thus, the advertising is geared to more than just the gadget. . . I refer to those cochlear implant bulletins that ballyhoo the latest implant device and make several extravagant claims, the most blatant of which says "improved speech discrimination ability," "a richer fuller sound resulting in better music and telephone qualities," and "more efficient listening in noisy environments,. . ." I refer also to a statement made elsewhere in the same issue of ALDA News that says "We do know that by the end of an assessment, a good implant candidate will hear more with the implant than with hearing aid(s)." That statement is at best grossly unethical, irrespective of the fact that it is patently false.

—Otto Menzel, Ph.D., CCC-A (audiologist)
I feel you have not lived up to your obligation to be sure that all information published in your newsletter is accurate and unbiased. I would think you would be more encouraging to those of us who choose this "alternative to deafness" which is what the implant actually is... You seem to be pointing at a refusal to accept deafness as the sole reason for most adults taking the opportunity that has presented itself to hear again. It is the willingness of people like us that will allow the scientists and researchers to develop a truly beneficial device that will help many more hear. I feel you owe the cochlear implant recipients of the world an apology.

—Craig Carpenter, President and CEO, Cochlear Implant Club International (CICI)

For me, choosing an implant was easy because I fought deafness all the way and luckily there was something called an implant available. But it is a very personal decision.... In regard to your editorial in ALDA News, I agree with you that those ads for cochlear implants should have statements that not all persons can benefit from the device. The ads should have disclaimers similar to the ones in the CICI newsletter. If it's okay with you, I would like to see your article reprinted in the SHHH journal. As a chapter president, I also sent a question to the SHHH board asking: "Should they show ads that are questionable?"

—Reg Krystyniak, member of ALDA, SHHH, and CICI

Well, allow me to straighten you out. I am deaf. Okay? ... But I have news for you--the implant does help me. I still have all my friends. I didn't suffer ... I had no struggle. My friends have made few, if any, adjustments. ... And get this, Marylyn, I can hear music [though] not the way I like. ... What is untrue is your belief that deaf people are sold a bill of goods about the implants and we should just accept our being deaf. You are wrong. We who wear implants are better off.

—Richard S. Brown, judge, Court of Appeals

Okay, all comrades in arms. Ceasefire! This is your battle-worn publisher speaking. Unfortunately, there's no room left in this column to include excerpts from all who responded. But get it straight. ALDA promotes tolerance and acceptance--whether it's speechreading or signing, cochlear implants, hearing-aids, or solar-powered tactile aids. It's our choice. And we also tolerate and accept opposing viewpoints.

Like mine. I have a problem with vendors of audiologic products who take a Madison Avenue approach to hawk their wares. Sorry, I just don't put cochlear implants in the same category as cigarettes and breakfast cereal.

To those of you who took umbrage at my reference to "struggling with deafness," I certainly agree that you have the right to do battle. But, hey, perspective is everything. Despite deafness, things could always be worse. You could be managing the Yankees. Imagine that! Prospects are better for Lithuania than they are for A.L. New Yorkers. So let's all chill out. Take a couple of deep breaths, and stop firing. But whether you lay down your muskets or take a few more swipes at me, stick with ALDA. It's a great organization. It just ain't opinion-free.
Chapter 5

1991

ALDAnonymous

Bill Graham, Curator


In an honest, pull-no-punches mood? Feel like sharing? You've come to the right place. Each issue of this newsletter, ALDAnonymous poses a question and invites late-deafened adults to respond anonymously. Their replies appear in a subsequent newsletter. The question for this issue was:

What do you think of the argument that sign language keeps deaf people out of the mainstream and that speechreading is a preferable and more useful communication mode?

I'll argue with anyone that sign language keeps people out of the real world. Sign language is disgusting and should have no place in the hearing world. As a late-deaf adult I try my hardest to stay in the hearing world and "read lips."

I suppose if two deaf people want attention in public, then use sign language. I've known too many kind-hearted souls who take a sign language class in order to "go out and help the deaf." Signing has become a novelty. I am familiar with a community of born deaf people who only communicate by sign because reading lips was too difficult. This deaf community was certainly "hidden" and out of the mainstream.

I disagree that sign language in itself is the reason that has kept people who are deaf out of the mainstream. It's the lack of education and awareness of the general population to understand the needs of the deaf. Speechreading is a very commendable skill. However, many of us are unable to speechread skillfully enough to get all the information necessary.
Sign language is not a barrier to the "hearing world" but a bridge. We need to change perspectives of this highly visual language. Speechreading is visual, reading notes is visual, why then is there stigma on movements of hands, face, and body? It's acceptable in sports. It's acceptable in the theater. Its movements represent words. Speechreading, for myself, is taxing, boring, hard to do with half the population, completely useless in semi-dark situations and not preferred.

Speechreading can be a valuable communication tool for deaf and hard-of-hearing people. Speechreading has allowed me to remain in the mainstream of society, where I feel people with disabilities belong.

I would like to see more ALDAns really try it before they knock it... by seriously studying speechreading, along with coping and communication strategies, with a qualified teacher. Let's face it, the whole world is not going to learn sign. So, as long as we live in a hearing/speaking society, sign language will not get you very far in the "real world."

We don't seem to have any classes in speechreading in this area, but we do have classes in sign language - American Sign Language (ASL) and Signed English (signs in English word order). I have attended classes in both methods. I find them very interesting. My ASL book is always open and most every day I practice a word or two while I am working at other tasks.

By going to sign classes, I meet teachers who teach signs to deaf children in our local schools. This gives me something different to do. I make friends as well as learn signs.

I also find that sign language helps me learn speechreading on my own because as I watch the teachers hands I also see their lips. In making the connection between the sign of the hands and the movement of the lips I see the word on the mouth. It's a big help and I love it. What a joy! Why not do everything we can to help ourselves? Besides, many hearing people are learning the signs.

I've been deaf for 10 years and I utilize both speechreading and sign language every day. Both are very useful to me depending on the situation. At work I use an interpreter for lectures, as speechreading would be impossible. (I have yet to try that situation with a cochlear implant... stay tuned).

With my co-workers, friends, and roommates: if you know it, sign; if you don't, move those lips. For me, I would prefer the whole world to sign, it's much easier and faster than lip reading. Alas, since all do not sign and all is not speechreadable, I think the best approach is to know both and that way you can get the most out of whatever planet you are on.

The method of communication is not what keeps deaf people out of the mainstream!! It is their attitude toward their communication barrier.

I support the right of any person to choose their mode of communication. I happen to be a person who is dependent on sign language. My speechreading skills are poor to nonexistent, depending on the person talking to me. I spent three years after losing my hearing trying to develop my speechreading skills. Those years were "living hell" because I had no effective method of receptive communication.
Fortunately, I was exposed to sign language and learned it fairly well. I use sign language expressively almost 100 per cent of the time, whether I am talking with hearing, deaf, or deafened people. I do not allow myself to become embarrassed or feel uncomfortable about using sign language.

Deafness is an invisible disability. Speechreading too is invisible for the most part and allows the deafness to remain invisible. To those who are able to master the skill of speechreading, I applaud them. But for me, I choose sign language, and if other people cannot accept that, that is their problem, not mine!!!!

This argument is preposterous, utterly absurd propaganda bullshit, used by hearing nonintellectual hypocritical educators lacking competence. It's also used by greedy hearing aid manufacturers to enable them to sell their useless product.

I am very fortunate that I have friends, hearing and deaf, who have an open mind. I am thankful for the wonderful people who bridge the two worlds and are not honored enough, the sign interpreters.

Speechreading is only good for one-on-one communication. It's effective about 50 per cent of the time; 70 per cent is astronomical. It's extremely exhausting. Eye strain, headaches... a frustrating mode of communication. Speechreading is only preferred by hearing people who lack knowledge or who are just too lazy to take the effort to bridge the communication gap. So they leave it all up to the deaf.

Sign language, when once learned, becomes 100 per cent effective. I very strongly believe that sign is the correct way for all hearing-barriered people to communicate.

I think that signing is great and makes communication more easy between people who know sign. But I also feel lipreading is a valuable skill because a person might enjoy communicating in sign, but you can't expect everyone to know sign. I speechread pretty well, but I feel I still don't keep up with the mainstream. So either way of communication, I feel that problems come up.

Before I became deaf, my feeling about sign language was that it was wrong, that it only helped to isolate deaf people and that deaf education should be all oral. Since learning about deafness I have changed my mind. The first thing a child needs is to have ideas and information, and to be able to communicate with other people.

Having said all that, I do not think that sign language is a very good idea for a late-deafened adult. It is a foreign language, with a very different grammar from English. It would be like asking an English-speaking American adult to become fluent in Chinese or Hindi, and then to use that Chinese or Hindi for all of his social communication.

Sign language has enabled me to attend plays, lectures, guided tours, and political meetings I would otherwise not have attended simply because it is not possible to speechread in those "mainstream" events. Even church has become accessible to me as I know how to read signs and can follow the mass and understand the priest's commentary. Certainly I could read the mass books and follow the service - would I enjoy it as much?
I've always felt the what of communication is more important than the how. I prefer to talk in depth to people and not guess at what they are saying to me. Yes, speechreading is useful for answering the questions salesclerks and waitresses ask, but not useful in other situations, such as in a hospital or doctor's office where the person really needs to "know" the answers. No, I can't expect people to know and use signs just as I cannot expect them to repeat themselves six times while I guess at what they are saying.

What it boils down to for adventitiously deafened people is personal choice and each individual's situation, including the amount of residual hearing the person has. I believe we as adults can choose the communication method(s) pertinent to ourselves and our lifestyle. Total communication ... is anything that works anything that helps us concentrate on ideas and meanings not on methods.
Ask Dr. Deaf

Many ALDAns have burning concerns related to the emotional adjustments involved in becoming deaf. Dr. Deaf has been asked to join the illustrious ALDA News staff to help answer some of these questions, such as: Where can I seek psychological counseling? What does it mean when I dream that I can hear? How do I know when someone is knocking on the bathroom door?

A person may pass through a number of stages as he or she loses hearing. The most notable stages are: the losing and/or accidental destruction of assistive-listening devices, the inability to perform simple motor skills (most typically, the fingerspelled alphabet), the hiding-in-the-closet phase, and the biting-off-all-family-members' heads phase. In psychiatry, these are known by such terms as anxiety, denial, withdrawal, and anger.

Let's face it - becoming deaf is not for sissies. It's one hard, long struggle that no one does with grace and that no one gets out of unscarred. The good news is that through the process of facing our worst fears, experiencing loss, and gaining self-understanding, we can emerge triumphant.

So beginning in this very edition of ALDA News, Dr. Deaf will entertain questions regarding mental health issues. For example: Should I tell my family they are driving me crazy? When is it time to stop crying? How do I know they are really not talking about me? Does saying the word "deaf" bring ten years bad luck?

Please hold questions about speechreading, cochlear implants, and the Deaf Community for the Editor-in-Chief. Dr. Deaf is loathe to engage in controversy.

Dear Dr. Deaf: I became deaf several years ago. When I go out with my hearing husband either with family or with friends - all the conversations are directed at him, even if it's about me. How can I tactfully redirect the conversation to involve me?

—Deafened and Feeling Dumb

Dear DFD: Dr. Deaf appreciates this dilemma and hears similar complaints not only from late-deafened adults, but also from born deaf people and people who are otherwise disabled. Unfortunately we live in a world where most people equate all disabilities with low mental functioning or childlike status. This type of thinking often results in the late-deafened person being completely ignored or discounted, a situation that plays havoc with the person's self-esteem.

Dr. Deaf suggests that you and your husband develop a system for dealing with such well-intentioned but uninformed people. First, your husband must agree to never answer a question for you or speak on your behalf. Instead he can redirect the speaker to address you - even if this causes a moment of awkwardness and confusion. Then you can lipread the speaker or your husband can interpret, whatever you two have agreed upon in advance. This way you've joined the conversation, your husband is not burdened with taking responsibility for your thoughts, and your family member or friend will probably learn a valuable lesson about people who are deaf.
Should the person continue to ignore you and to speak only to your husband, Dr. Deaf suggests you unload the insensitive slug and head for a friendlier crowd. Unless, of course, it's a family member, in which case you have the option of telling the person exactly how you feel and storming out. Don't fret about the consequences. You'll have the opportunity to practice Dr. Deaf's recommended system with this person again at Thanksgiving ... Christmas ... and birthdays. Don't Worry, Be Happy!

*We invite readers to send their questions to Dr. Deaf, c/o ALDA News.*
My hearing loss was caused by neurofibromatosis (Type II) which is manifested by bilateral acoustic neuromas (benign tumors on both auditory nerves.) The auditory nerve is just one of the 12 pairs of cranial nerves attached to the base of the brain. These nerves each have a specific function, such as hearing and balance, swallowing, breathing, and facial movement. Acoustic neuromas vary in size, location, and rate and direction of growth. Generally, they grow from within the auditory nerve and swell outward. They often twist around neighboring nerves and damage other neural structures. Treatment of acoustic neuromas invariably means their surgical removal by a neuro-surgeon or neuro-otologist.

Because the acoustic nerve lies adjacent to the facial nerve in the brain stem, the tumor's growth and its subsequent removal often result in damage to both structures. Thus, surgical excision of a tumor on each acoustic nerve often leads to partial or complete facial paralysis. However, current advancements in medical technology now make it possible for the surgical team to sometimes preserve some hearing and/or facial nerve function.

The auditory nerve carries sound information from the cochlea to the brain where it is interpreted in a meaningful way. Thus, surgical removal of this cranial nerve results in complete deafness. In other words, the organ of hearing (cochlea) is perfectly intact, but the acoustic message cannot get beyond the cochlea to be interpreted by the brain. This type of hearing loss is referred to as "retrocochlear" because the damage occurs beyond the cochlea.

As a result of this total loss of sound, I am noisy. I slam doors and cabinet drawers - not out of anger - but to be sure they are closed. Occasionally in the "right" rooms, I can feel strong vibrations. Yet, I can stand next to the roaring engines of an airplane or train and not know if the engines are on or off. No hearing aids, cochlear implants, or assistive auditory devices can help me hear sounds. It is with this reality that I and others with NF-2 live. It is with this complete absence of sound that we cope daily. And it is this reality that makes it so aggravating when well-meaning "others" suggest that we purchase a hearing aid or at least "test for" a cochlear implant, a device that was developed for people with defective cochleas but intact auditory nerves. With NF-2, these conditions are reversed, making hearing aids and implants worthless.

Like all late-deafened adults, I must rely on my vision to communicate. Speechreading was easier when I still had some residual hearing. At one time, I tried a vibrotactile device, which helped somewhat when I was speaking with one person, and when there was no background noise. But to communicate in everyday situations without auditory or tactile cues, I must rely entirely on visual communication which for me includes sign language and text reading.

Interactions with other ALDAans can sometimes present a challenge for me, especially if the encounter is with an experienced speechreader. Although I have lost most facial movements, I am not a hostile grouch or as exceptionally serious-minded as I appear to be. I simply don't have the facial movements required to appear friendly and amused by the jokes people tell me. I am difficult to speechread and some of my interactions with ALDA friends are slowed down a bit.
To compensate for this lack of facial movement, I try to choose my words carefully, sign in a lively fashion, show enthusiasm, and use friendly gestures.

Because NF-2 tumors can occur without any identifiable pattern elsewhere in the central nervous system, a person with NF-2 can become extremely discouraged after multiple brain surgeries. There is always a life threatening fear prior to brain surgery, whether it's the first or fifth operation. Our emotional energy can be depleted by the battle with fear.

For the most part, I've learned to deal with NF-2, my deafness, and the fear of multiple brain surgeries by cultivating:

- **a sense of humor** - I've learned to laugh at absurd situations, such as entering an operating room and being asked the million dollar question, "Can you read lips?" Never mind that everyone has put on their little blue mask.

- **knowledge** - I try to learn as much about the surgery as I can handle. I ask questions and expect answers. I want to know what to expect. Knowledge leads to assertiveness and the patient (including a deaf one) has a right to know what is happening and a right to communication!

- **faith and a firm belief that everything will be all right** - I have developed a philosophy that it's just another part of living, another of life's many challenges.

NF-2 is just one of many causes of adult onset deafness. Yet each etiology brings with it a unique set of challenges. Awareness of these challenges enables us to become more open and supportive toward each other.

*Kathie Hering resides in Glenwood, Illinois. She is president of ALDA-Chicago.*
Selections from Hail the Mail
(ALDA News, vol. 5, no. 4, July-August 1991)

I can't begin to tell you how happy I was to find the organization that I have been trying to find for the last four years! It was four years ago that I finally lost the last little bit of hearing that I had been clinging to for what seemed like an eternity. I am looking forward to a long and happy relationship with ALDA. I feel somewhat like an orphan who has finally found a home. Thank you ALDA for being there.

–Rod W., Noblesville, Indiana

It is hard to explain how much I appreciate reading the newsletter. ALDA is succeeding so well in avoiding the sugar coating and happy face solutions seen in other groups. Reality sometimes pinches at first, but it is always better in the long run.

–Pat V., Grove City, Ohio
Dear Dr. Deaf: People pressure me about "not giving in" to my disability. Is it really so wrong to stop doing things I used to do before, like going to night clubs or to all-hearing parties? Such things don't seem to be worth the effort anymore. I say I am just "accepting myself as I am now." I am discovering new interests that aren't impossible and frustrating. Yet people say this is "giving in" to my deafness. Isn't that a pretty judgmental rap? Everybody changes, but somehow I am supposed to stay the same, fight the most fundamental change that could happen to me!? Do you think that maybe these people are really thinking about what is best for them, not what is best for me?

—Give Me a Break in Canada

Dear Break: Dr. Deaf thanks you for providing such a thought-provoking and insightful question. Dr. Deaf thanks you more for being so considerate as to answer it yourself. This concept of "not giving in" to your disability is new, even to Dr. Deaf, who espouses to have heard everything. "Not giving in" is a term normally reserved for that third helping of chocolate mousse or that unnecessary pair of Italian loafers.

Is socializing with deaf people, learning sign language, and so on just a big, bad temptation one must avoid? No, of course not. Yet those who love ALDAns remain perpetually perplexed when, after a six-hour picnic with hordes of hearies, their beloved deafened relative peeps out "I'm bored." (But what do you mean? We've always gone to Aunt Martha's on Labor Day.)

Let's face it - change is hard. It's hard on you and it can be devastating for those who care about you. When someone we love changes (and becoming deaf often means the inevitable necessity of changing just about everything, including communication styles and activities, not to mention identity), we fear we will lose them.

In your case, your people fear that you will find others like yourself with whom you feel comfort and camaraderie. You will no longer be interested in concerts in the park. They fear you will slip away into the quiet abyss of the deaf world never to return. So while their insistence that you "not give in" seems like a judgmental stance, it is actually fear that you may change too much for their liking.

Courage says: "Grow and do what you need." Dr. Deaf implores you to talk to your people and let them know that you need to become who you will. As Erving Goffman says in a book called Stigma (which Dr. Deaf highly recommends), "Normals really mean no harm; when they do, it is because they don't know better. They should therefore be tactfully helped to act nicely."

Dr. Deaf gladly encourages you to "give in" to your deafness and enjoy it. Explore your new interests, meet new people, go to ALDAcon III (Dr. Deaf was not paid for that endorsement), and get the Italian shoes. Those who love you will eventually understand and admire you for your adventure. They might even join!

Don't worry, be happy.
Let's Face It: We Is Deaf

Bill Graham

(ALDA News, vol. 5, no. 6, November-December 1991)

Publisher's note: As we devote this issue to coverage of ALDAcon III, and as the mail pile gets higher and higher with wonderful letters and words of praise from attendees, I wasn't quite sure how to lead off this issue. My real dilemma was to figure out how to bring the newsletter alive for those of you who were unable to attend the conference and still make it interesting for those of you who did. In the end, I decided to blast off with a speech delivered by Bill Graham at the start of the conference. (Don't fall asleep. It's really a good one or I wouldn't put it here on page one.) - MH

My name is Bill G. and I am a late-deafened adult. . . . Whew! There, I've said it: I'm deaf. The hardest part is over. Let's party! No, really - I've always had a hard time saying that word: deaf, deaf, deaf. Eight years ago I wouldn't have touched that word with a forty-foot pole. It was just too embarrassing to admit that I couldn't hear. And I'm not a guy who embarrasses easily.

For example, I'm a Cubs fan . . . I admit it . . . I've been a Cubs fan all my life. I don't apologize for it and I'm very capable of facing the fact that the Cubs stink! They're overpaid babies! But I'm a fan. Take me for what I am I have no sense of shame.

There are plenty of things about my life that would embarrass most people, but not me. I didn't keep a checkbook until last year, after I got married. I was 37 years old. Until then, I never knew exactly how much money I had at any given time. I bounced checks with the phases of the moon - still didn't wise up. My wife couldn't believe it. She thought I was from Mars. Now she's convinced I'm from Pluto. But not keeping a checkbook didn't embarrass me at all. In fact, I was kind of proud of it. Made me seem like a free spirit with unlimited cash reserves.

There are all kinds of things that maybe I should be embarrassed about but I never have been. But deafness . . . that's another story. When I gradually lost my hearing after high school, I was terribly embarrassed and ashamed. That's not very logical because it wasn't my fault that it happened. I had nothing to do with it - it just happened. But maybe you understand the feeling.

I was embarrassed - embarrassed that I was so different from everyone else in my life. They all seemed so perfect because they could hear perfectly and I couldn't. I was embarrassed about every communication difficulty that occurred. And I was ashamed - ashamed because I denied my hearing problem for many years and then for many more years denied the extent of the problem. I was a con-artist - I bluffed with everybody, including myself. I ran away from the problem. I just could not face it. It paralyzed me with fear. I didn't want to be different. I wanted to fit in and live the life I had been living. Listen to the radio, talk with friends in the dark, laugh at jokes at the right time . . . you know?

The theme of this year's conference is "Facing Deafness." Oooooooohhhh! Give me a break. Facing deafness? I paid a lot of money to come to this conference. I want to have a good time! What kind of idiots picked a theme like that? Why not "Las Vegas Nights" or "November-fest"? Facing deafness? Who the hell wants to do that . . . and on a weekend?
Well, I do. I really do. I want to face my deafness... as well as I can. Every day of the year I want to, even on bowling nights. But I don't. I don't even come close. I'm better at bowling than I am at being deaf. More years of practice maybe, I don't know. A lot of the time, deafness baffles me. I'm a lousy deaf person. Look at how I sign! Maybe some of you think I sign well, but I'm a hack. And this is my most effective way to communicate. It's scary.

But I really do want to face my deafness - today, every day. That doesn't mean I want to be serious and a sourpuss all the time and that I don't want to have a good time. I love to have a good time. I want to party - LOVE to party. I had a great time last night and I'm going to have a terrific time again tonight, and I'm going to be really wild tomorrow night. I LOVE TO PARTY! And ALDAcon is the best place to do it!

But life, alas, is not a 24 hour, never ending party. Eventually, the party hats are put away, the bar closes, people say goodbye... but my deafness remains. It's reality. I've spent enough of my life pretending to be somebody I'm not. Deafness is ME. And I really do want to face it. Don't we all?

But what does it mean to face our deafness? Do the guidelines for being deaf descend upon us like the Ten Commandments did to Moses? Do all our insecurities suddenly go away, our anxiety, our confusion? Does facing deafness necessarily mean total acceptance of it? Do we ever really accept our deafness? Or are there simply moments of insight that build upon each other until we are comfortable as deaf people?

What does it mean to face our deafness? Well, I don't know about you but I believe that we begin to truly face deafness when we can think about it without being overcome by paralyzing fear. When we aren't afraid to think about our deafness. And eventually, when we aren't afraid to talk about it.

We must express our thoughts and feelings about deafness. We must admit the fear and embarrassment we experience attempting simple dialogue with cashiers. We must admit that there are days when we feel that there is absolutely no place in the world for us to fit in. When all the people we meet are nothing more than incomprehensible mouths looking perfectly comfortable in their easy verbal exchanges. I still have many days like that. And they aren't pleasant. But that's how it is.

On the other hand, we must also admit that facing deafness moves us just a bit closer into the circle of humanity. A little closer to understanding what happens to people when challenged with what appears to be insurmountable obstacles. We understand despair and we understand the unfailing strength of the human spirit. We must talk about every aspect of deafness - the tragic, the mundane, and the inspirational.

I did not think or talk about my deafness for many years. I didn't even THINK about THINKING about my deafness. And ironically, as a result, my deafness dominated me. I was a prisoner of my deafness. I spent all my time and energy trying to avoid the reality of it. It was my demon - the unmentioned tragedy in my family. The elephant in the living room that everyone saw but no one acknowledged. I guess we thought that maybe if we didn't say the "d" word it would go away.
Well, it didn't go away. And eventually it just hurt too much not to face it. My self-respect was in
the gutter. I was a fraud. I had to face it. But it seemed that nobody would face it with me. My
parents told me: "Don't make a mountain out of a molehill." If I was with friends and could not
understand them, they'd say: "Oh forget it - it's not important." Or maybe they would summarize
a 15-minute conversation in 10 words or less. Strangers would tell me: "You lipread very well!" I
lipread well? I mean - c'mmmomnn!

All these people were well-meaning, they were all trying to be positive and nice - but they were
all in denial. They didn't know what to say to me. I was the only deaf person in their lives.

So what was I supposed to do with the things I was feeling - the backwash of deafness: the
isolation, the frustration, the confusion, the anger, the embarrassment, the shame? These were all
very real to me. And they needed to be talked through and understood or they would always
haunt me because I didn't believe in myself enough to believe that I could be so different and still
be mentally and emotionally well.

Finally, I was fortunate enough to meet you other late-deafened adults. For the first time I entered
a world where it was okay to be a man in his thirties who couldn't negotiate a drive-through bank
teller. I found a place where I could think about and say exactly how my day went without being
told either to join the Deaf Community or that I should be grateful I could speak so well.

No, I told you that I felt different, that I felt shame and loneliness. I told you that when I walked
down the street and saw someone coming toward me that I'd cross the street just to avoid the
possibility of communication. And you told me you felt and did the same things. And that's how
we face our deafness. We do it together. And through this process, we free ourselves of some of
the demons of deafness.

You help me more than you realize. Because on many days, I'm just tacking into the wind. I can
be a real dope about coping with my deafness. I still go up to strangers -seems like every day -
and try to pawn myself off as a hearing person. Invariably, this gets me into all kinds of trouble.
And I end up asking myself: Is what I just did what I really wanted to do?

We should all ask this question. Next time you find yourself pretending - again - to understand
your bearded brother-in-law ask yourself: "Is this what I really want to do?" Next time you get
the wrong order at a restaurant but eat it anyway because you don't want to deal with the waiter,
ask yourself: "Is this what I really want to do?" Next time you see an old friend from your
hearing days in a store or on the street and you sneak away, ask yourself: "Is this what I really
want to do?" Think about it. Talk about it. Maybe eventually we can change what we do. This is
facing deafness.

Now we'll spend the next couple of days meeting each other, and going to some terrific
workshops and special events. Say what you feel, do what you like, party your brains out. But
know that by being here and facing deafness, you help me face mine. I'm glad you came. Thanks.

*Bill Graham has spent most of his time since the conference budgeting his $1.00 salary as
executive director of ALDA.*
Wise Words for the Newcomer
Kathryn Woodcock
(ALDA Reader, October 1991)

How Do I Know If I am a Newcomer?

The first category of newcomers are the ones who are new to deafness. If you're one of these, be prepared for people to tell you how lucky you are. Sound odd? Yeah, okay, at first, deafness is no picnic. You may still be missing music and the ease of conversation with all your family and old friends. You'll quickly find out that there are many ALDAns who are happy deafies, but the reason people are calling you lucky is for finding ALDA so soon after becoming deaf. Be thankful that you won't have to endure decades of isolation, wondering where you fit in. You're here!

Maybe you've been deafened for some time, but ALDAcon is your first exposure to ALDA. You won't need to be told how lucky you are to find this group: you'll know it the minute you get into the groove. Go nuts!

A very special category of ALDA newcomers are those who have been ALDAns but have never made it to ALDAcon before. This is your chance to meet all the people to match the names showing up in each issue of ALDA News, maybe people you've been writing to for months or years.

Welcome to all of you! For a bit of reconnaissance, here are some reminiscences from my own newcomer days. In addition to what you can read here, do avail yourself of the special newcomers' program activities, including the newcomers' orientation and reception.

About the Vets

Vets are the ones with the big smiles, hugging all and sundry. About three-quarters of past ALDAcon participants have come back to a subsequent ALDAcon. What can we say? It's habit forming. (We don't have a Surgeon General's warning, but we do have that testimonial from Dr. I. King Jordan.) You're a newcomer now, but odds are that you'll be introducing others within 24 hours. Want the fast track? The leadership/self-help workshop. Oooh -- came close there to giving advice, the big ALDA no-no. Beware of people giving advice. ALDAns will tell you, openly, what they have experienced, tried, liked, and disliked in their deaf life, but nobody can tell you what will work for you, so a 'good' ALDA won't try.

What's This Self-Help Thing Anyway? (and who the hell is Laurieann?)

"Laurieann" is part of the ALDA lexicon. Proper name: Laurieann Chutis, commonly paraphrased "self-help guru". Look up her biographical particulars in the program section.

Unlike certain other "self-help" organizations, ALDA is based on the principle that we each help ourselves, as and when we are ready. ALDA does not consist of a structure wherein dominant veteran deafened people "help" by advising the similarly "afflicted" newcomers. We are all at different stages of readiness for different aspects of coping with deafness. Some newly deafened people may be strides ahead in some aspects of coping than a longtime deafened person. For
example, with my progressive loss, I had a wealth of experience with practical living skills, before I crossed the borderline from hard of hearing to deaf, but because I wasn't born deaf and could still hear some useless noise, I was reluctant to declare myself deaf; the confident and unhesitating use of the adjective 'deaf' by people with overnight hearing losses showed me that it was legitimate to use that title myself.

ALDA will talk to you about their experiences, but don't expect veterans to have all the answers. ALDA is a haven where even the long-time deafened person can admit to having difficulties with some aspect of coping, or can share lingering feelings from hardships buried long ago. As a new ALDA, I found it heartening to learn what confounds even veterans; more heartening than receiving some facile list of tasks to accomplish on the road to happy deaf-dom. More than the suggestion that I should just snap out of it, get over it, get on with it, get with the program, don't let it get me down, don't give in to it, why don't I measure up, why don't I cope as well as everybody else, what's wrong with me, . . .

We get those kinds of feelings everywhere we go, even from well-meaning people in our families, well-meaning professionals, but not here at ALDA. Here, we have the sense of comfort and community and struggling together, the sense of belonging -- in contrast to the isolation that is historically so characteristic of the individual deafened adult. Gosh, I'm getting touchy-feely. Well, that's the ALDA self-help thing.

Just Talk

You can talk to anybody. It doesn't matter that you don't sign, or that you don't lipread, or whatever. Like Bo says, just do it. Make up a way to communicate. Remember, every late-deafened person here at ALDAcon is experiencing the very same thing, or loves somebody who is.

You can ask anything. "Say, is that a cochlear implant I see behind your ear?" "Why would you sign when you can lipread and speak perfectly well?" Perfectly normal ALDA conversation. Whether you should turn the conversation to "How do you whisper sweet nothings in the dark?" should hinge on polite standards; ALDA don't automatically turn to a life of depravity -- but then we are still normal, too, so "play it by ear"! You don't have to be strong. Leave the stiff upper lip at home. Talk about what gets you steamed about the hearing world, strangers, your family, your boss, television, doctors. Talk about what kills your spirit, saps your energy, breaks your heart. My recollection was that "these were people who had lived my life in other cities". That common history seemed to obviate the need for a period of long acquaintance before having pretty personal conversations. Sample conversation: "What's your name? Where are you from? How did you become deaf? What work do you do? I haven't been able to get a decent job since I lost my hearing."

Bob Elkins wrote in ALDA News of his first ALDAcon (II, in 1990), how tears filled his eyes as he took his turn in a self-help group of people he hadn't met two hours before. In any other setting, you'd die first! But Bob spoke for half the people in the group with his wordless comment. At the same time, you don't have to share what you aren't ready to share.
What's All that Flapping I See?

Whether or not you have had any exposure to sign language, oral interpreting, or print interpreting (captioning) back home, you'll be overwhelmed with the quantity and quality of access at ALDAcon. You may also be overwhelmed at the amount of sign language you'll see in conversations around you. Many people presume that late-deafened people are better off sticking to lipreading and the hearing world (usually called the "Real World" -- see the Devil's Dictionary). ALDA's official position is that the decision is yours to make. Many ALDAns have chosen to add sign language to their communication arsenal. Many of them actually prefer sign to oral language. But the ability to sign does not diminish their other communication skills, and they are still happy to talk to you if you can't sign. If you have zero sign language experience but are curious, you can give it a whirl at the beginners' sign workshop (see Thursday's program).

Welcome Newcomer.

Welcome Home to ALDA.
At ALDAcon II, my first contact with ALDA up-close-and-personal, I met many people and swapped stories and feelings about becoming deaf. It was heartwarming, the many shared feelings under all of the stories. But there wasn't an infinite number of stories. In fact, I kept hearing diverse ALDAns tell just a few life stories over and over. It was particularly eerie that some of them were telling mine, with just a few geographical revisions!

I've done some superficial looking to see if there were any accepted classifications and descriptions of hearing loss etiologies, but most of the medical books about hearing loss are full of bloody pictures of internal parts (presumably ears) and words telling doctors how to fix it. Audiology books seemed to focus on testing and aural rehabilitation (staying in the hearing world come hell or high water), on the trickery involved in getting a reluctant patient to use a hearing aid, and on generally milder hearing losses than we have. These didn't provide what I needed for descriptive purposes, so I decided to make up categories based on the stories ALDAns have told me. I am no anthropologist, but I ended with four broad stories: medical, surgical, traumatic, and progressive hearing losses.

**Medical**

Medical hearing losses are those resulting from chronic and acute illnesses such as Meniere's syndrome, reactions to ototoxic medications, and The Virus. Now, we don't know what this virus is, but a friend of mine (a Virus guy himself) likes to say, "Whenever doctors don't know what something is, it's a virus". Sometimes medical losses are overnight losses, but some people with medical losses became deaf more gradually, say, over five or ten years. But that is not as slow as the typical progressive-loss case, and the onset can usually be linked to some illness. Many of these people tell the tale of being so very sick that deafness was the least of the problems at the time. Especially in the view of the doctors. They tell of having the deafness given short shrift by the caregivers whose training better equipped them to deal with the illness and not with the deaf patient. Their first deaf experience might have been something like a nurse towering over them saying, "What are you complaining about not understanding me for? You're lucky to be alive." (Of course, with no hearing and no lipreading experience, the chances of understanding any more than the hostile facial expression are slim.)

Medical losses may not be profound, and the medically deafened person may have had conflicts with professionals and others who believe that they should be able to function as well as a born-hard-of-hearing person with the same audiogram. But lack of lipreading and coping experience may make the residual hearing functionally useless. The perceived marked contrast with one's former hearing makes it easy, though not pleasant, to realize the need to acquire deaf tools: caption decoder, TDD, etc.

Besides hearing loss, some conditions like Meniere's have additional symptoms, such as dizziness, which further interfere with normal activities of living: walking, working, driving.
Surgical

Surgical losses are those requiring removal of tumors on the auditory nerves: neurofibromatosis type-2 (NF-2) and bilateral acoustic neuromas. Usually, these people know going into the hospital that they will be deaf when they come out. Forewarned does not necessarily mean forearmed, though, either in the case of the patient or the hospital. Although you'd think that they would get some mental health preparation and ample technical support with the luxury of advance warning, it seems that the general approach is not much better than for those struck by The Virus. On the same basis that born-deaf patients may have sign language interpreters in the hospital, don't you think that a clinic that does this sort of surgery should have a print interpreter (real-time captioning) standing by postoperatively to assist the patient to communicate?

Severing the auditory nerve creates an absolute silent world, which may not be as annoying as dealing with people who persist in providing information on this miraculous Bionic Ear (cochlear implant) that they just read about in the paper. Bionic ears have nothing to offer a severed auditory nerve.

In addition to deafness, NF-2 requires coping with numerous operations.

Traumatic

Traumatic losses are incurred in a wide variety of exciting and adventurous ways, from motorcycle riding to settling an argument in the alley behind a bar. Again, the "you're-lucky-to-be-alive" argument is used to deflect criticisms that the medical environment should have more assistance to offer. Rather than assist the patient to function without hearing, acceptance of deafness may be discouraged because deafness is temporary in some trauma cases. False hopes, nurtured by the medical experts, don't evaporate painlessly. Wouldn't you think that it would be easier to get used to having your hearing back? The long-term therapy and treatment for any other concurrent injuries can be more difficult with new deafness.

Like many accidents, deafness from traumatic causes can be overlaid with a lot of "if only's": "if only I hadn't been there", "if only I had taken a cab", etc. The anniversary of the event can revive the sense of loss.

Progressive

Progressive losses sometimes result from aging -- though simple presbycusis is usually a milder loss -- and from overexposure to excessive noise. Although noise cases seem mostly to be mild or moderate, even a small proportion of these equates to plenty of cases of occupational noise resulting in deafness. As well, I know two deafened adults whose milder medical hearing loss was pushed over the brink into deafness by occupational noise exposure. There is a form of hereditary hearing loss that is progressive. Then there is the idiopathic progressive loss. The medical term "idiopathic" does not mean that the doctor is an apathetic idiot, though you may be forgiven for thinking so as you're pushed out the door to make room for a case he can understand and/or actually do something about. Idiopathic refers to "no known cause". Maybe the idiopathic cases are genetic, but all of the cases in previous generations had died of other causes before becoming deaf. Or your mother brought home the wrong baby from the hospital (I wonder about mine).
Generalizing a bit about the rate of its progression, it seems that by the teen years the loss is mild or moderate, becoming severe to profound through the twenties and thirties, though some environmental noise perception can linger awhile. In contrast to the other ways of becoming deaf, the person with a progressive loss may not strongly identify with "hearing" people (inexplicably always feeling outside the hearing world), and may develop satisfactory deaf functional skills (i.e. elaborate ways of faking comprehension), but has no discernible prompt to change their self-image from hearing to deaf.

I didn't make up this classification to factionalize ALDAns. Indeed, I think we can all feel linked even though we may have taken different roads to get here. But in my own deafened support group, everyone else was an overnighter, coping with new ways of functioning, mourning absent music. They were sure they were deaf, and didn't know how to cope; I knew how to function but wasn't sure I was deaf. In common, we had feelings and frustrations about situations in the hearing world and our homes, but it wasn't until I met people with similar progressive losses at ALDAcon that I really felt "normal": not only our present feelings but also our memories were identical. If you haven't found exactly the help you're looking for from ALDA, maybe you haven't met someone who traveled the same road to get here.

On a lighter note, maybe etiologies would be like horoscope signs if ALDA ran a singles bar. "Medical -- right? I knew it!" "I'm a surgical guy myself, on the cusp of NF-2." "Bilateral progressive seeks same." "Traumatic -fractured skull with off-road vehicle ascending." Whatever works for you!
ALDAcon I: "WELCOME TO ALDA..." A Workshop Diary
Elizabeth Ruegg
(ALDA Reader, October 1991)

It took a lot of courage to go.

For all that ALDA has meant to me in the past year, for all the friendships I've made, for all the help I've offered and all the support through rocky times I've accepted in return, I still had to struggle with myself before making the trip. My smokescreen considerations (what if Cash, my hearing dog, wasn't welcome? What if I couldn't getaway from work?) eventually gave way to more unsettling fears. What if I couldn't understand anyone? What if no one could understand me? What if -- and this was the worst -- what if I surrounded myself with all these others, late-deaf Just Like Me, and still felt the same essential isolation from them as I do from most hearing people?

But Marylyn Howe was going, and Andrea Cahill. Roy Miller and Donna Noland, fellow members of the ALDA College of Editors, would be there. Eventually, curiosity won out over fear, and on Friday October 20, during a horrific New York thunderstorm, I found myself workshop-bound. For me, ALDA networking started early: another local ALDAn, Sid Howie, was booked on the same flight, and, since I had trouble with his accent and he had trouble with my sign we used a takeoff delay to practice the pad-and-pencil method of ALDA-style communication.

After a safe landing at O'Hare, we were met by Linda Harrington, who made me laugh out loud for the sheer pleasure of it by introducing herself in voice and sign. I can lipread, but names are hard, and it was a good feeling to get a dose of clear, unambiguous fingerspelling. Truth is, I reveled in clear understanding during the whole workshop. Reliable communication -- be it through lipreading, sign, writing, typing, smoke signals, whatever -- was a red-alert priority in ALDANation all weekend long.

Linda drove us to Bill & Karen's house on W. Cuyler, where the kickoff party was already underway. Plied with beer and Chicago-style pizza, I made my way through the house, attaching faces to the names I'd read and written about many times in various issues of ALDA News. There was a lot of laughing and signing (and laughing AT signing), lipreaders lipreading, pencils flying on notepads. When Sid's Scots accent proved hard for most people to understand, Techno-wizard Roy Miller saved the day by plunking his laptop computer on the kitchen table for quicker-than-handwritten communication. Bill's Myron and my Cash and Andrea Cahill's Amber chased each other around the basement until they managed to escape and beg for handouts at the party upstairs.

Overwhelmed, at one point I backed myself into a corner and stayed quiet for a couple of minutes, just looking. Diana Thorpe, ALDA interpreter and sometime ALDA News editor, watched me watching. I tried to explain, phrased it clumsily, tried again. "Never seen anything quite like this," I said. "All these people, who can't hear, and they're all talking or signing or typing, and nobody looks left out ... This is something pretty amazing, y'know?"
Diana grinned understanding and drew me in for a quick hug. "This is ALDA," she said. "Welcome to ALDA."

The rest of the weekend is pretty much a blur, now. I can remember laughing a lot and crying, some. I can remember sitting in a self-help group and feeling tight bonding with people I had not known just the day before. I can remember lunches around the big tables at Mercy -- once trying to get Marylyn's attention, waving my arms extravagantly over my head, finally in desperation flinging a plastic spoon at her (gives me compassion for what my family has to go through to get MY attention!). I can remember flagging down Karen and Diana and Steve: "what's the sign for ... ?"


Welcome to ALDA, indeed.
**Selections from The Devil's Dictionary**  
*Karina Graham*  
*(ALDA Reader, October 1991)*

**ALDA Crude**: Relatively inexpensive computer system by which the spoken English language can be typed and projected onto a video display monitor. Second cousin to realtime captioning (see Real-time captioning). Involves typing at the speed of light, abbreviating where possible, and interrupting every other sentence with a pleading request to slow down.

**ALDAn**: An individual who lost his or her hearing after adolescence. ALDAns sometimes slip into the hard-of-hearing or Culturally Deaf worlds. Real ALDAns know that they're really deaf and not part of Deaf Culture (see Deaf Culture). That's why they really love ALDA.

**ALDA social**: Good excuse to get together and eat, dance, drink, or play pool and other games. Main difference between ALDA social and any other social: nobody looks at you funny when you don't understand the punch line.

**Assertive ALDAn**: One who says "huh?" (see Huh?) rather than nodding head compliantly.

**Court reporters**: New breed of interpreters. They magically transform spoken English into written text quickly by means of massive amounts of expensive equipment. Highly regarded by all members of the ALDA community.

"Huh?": Most utilized word in ALDA vocabulary. Can be interspersed anywhere in a sentence. Often means: "Rephrase the question, please." May also mean: "I don't sign." or "I don't read lips." or "Even if I could understand you, I wouldn't know what you're talking about."

**Lipreading**: The professed main mode of communication by most ALDAns. Consists of staring at another's mouth (often containing food, gum, and dribble) and making semi-wild guesses at the context of the conversation.

**Real-time captioning**: Mysterious technique of producing simultaneous printed English. The sometimes amusing, always cherished, printed material rolling along the bottom of the television during a captioned live broadcast. The stuff ALDA dreams are made of.

**Self-help group**: A ritualized get-together of folks sharing the same life experience. A source of stimulation, fun, belonging, sharing, safety, and comfort. A place where you can go and be accepted exactly as you are -- with your hearing aid, cochlear implant, loop system, sign language, what-have-you.
Another Deaf Way

Bill Graham

(Presentation at The Deaf Way, Washington, DC, 1989; published in ALDA Reader, October 1991)

When I was in college, I gradually began to lose my hearing. I had a sensorineural hearing disorder that I apparently inherited. By the time I was 25 years old -- about eleven years ago -- I couldn't hear on the telephone anymore. As my deafness progressed, I went through denial, frustration, anger, confusion -- the usual things a person feels after suffering a serious loss. I became isolated from most of my old friends and had trouble feeling at peace in any kind of social situation.

By the early 1980's, I had become so frustrated with trying to read people's lips that I decided to learn sign language. I took the entire ASL curriculum at the Chicago Hearing Society, and then I headed for the nearest deaf club to meet some people who were like me -- deaf people. I figured I'd make new friends and feel good about myself again. But it didn't work out that way. My first visit to the deaf club provided a stern dose of reality. I was, quite clearly, an outsider. And after several visits to the club, I wasn't sure I wanted to become an insider. I felt more confused and lost than ever.

But I didn't give up. I became involved with a group that worked to make theater accessible to deaf people. I soon had some deaf friends, and I eventually learned to sign fairly well. But every deaf person I knew communicated far more easily than I. Even worse, I didn't feel I had much in common with any of them except for deafness. I still felt isolated socially. I had both hearing and deaf friends, but I didn't seem to fit in with either.

Then, a little more than two years ago, some big excitement came into my life. Twelve Chicago people who, like myself, had become deaf as adults, came to my house for a party. Only three or four of us had met before. I got names for the party from a list of late-deafened adults developed by Kathie Hering, a social services worker who is herself late-deafened.

The party was a smash success. Although most of us were total strangers who had never so much as spoken to another late-deafened person, we found it easy to be in one another's company. There was a special feeling in the room -- a feeling of belonging, of unspoken understanding, of patience with our similar communication difficulties. A week after the party I wrote a letter to all the people on the mailing list, expressing my view that something extraordinary had occurred. The enthusiastic response to that letter led me to begin a regular newsletter, through which we consolidated a group that eventually became known as the Association of Late-Deafened Adults (ALDA)

The ALDA newsletter quickly became a hot item and its circulation grew. Within several months, I was in touch with late-deafened people in several parts of the country. The letters I received had recurring themes: late-deafened adults felt socially isolated; their lives had changed markedly because of their deafness; they were excited to hear that a group for late-deafened adults had started; and they wished that they knew some late-deafened people in their area. Most of the late-deafened people who wrote lived entirely in the hearing world. Many of them knew about Self-Help for Hard of Hearing People (SHHH), and some were members of that organization. But by and large, they felt that the focus of SHHH -- on assistive listening devices
and techniques -- missed their needs as deaf people. Only a few letters came from late-deafened adults who socialize chiefly with people who grew up deaf. Many people sent money so they could continue to receive the newsletter. Everyone sent their best wishes and encouragement.

This great outpouring of interest and support made it clear that ALDA had touched a nerve among late-deafened people. As I gradually learned more about the hearing-impaired community in the United States, it was easy to understand why. Interaction among late-deafened adults and support services for them were virtually nonexistent. Only a handful of institutions and organizations seemed to recognize that late-deafened people comprise a unique population group with special needs. These widely scattered outposts of awareness included the National Technical Institute for the Deaf (NTID) in Rochester, N.Y., which conducts special education and rehabilitation programs for the late-deafened; Deaf Counseling, Advocacy and Rehabilitation Agency (DCARA) in San Leandro, California, where Edna Shipley-Conner works as a rehabilitation counselor specializing in late-deafened adults; and Gallaudet University in Washington, D.C., which has a late-deafened president and programs that late-deafened people can find helpful. But the focus at Gallaudet, of course, is on people who grew up deaf. Clearly, very little was being done for late-deafened Americans.

Amazed and intrigued by this situation, I continued writing newsletters and worked to further ALDA's development in any way I could. Meanwhile, many other late-deafened people became actively involved in ALDA and the group grew tremendously. Today, a little more than two years after we started ALDA with names of 25 late-deafened people in the Chicago area, our group has a mailing list of more than 400 names nationwide.

A variety of activities and support services for late-deafened adults has developed through ALDA. In the Chicago area, ALDA sponsors three weekly self-help groups for late-deafened adults. These groups give members the opportunity to share feelings and experiences related to their deafness. Also in Chicago, ALDA holds monthly social events that give late-deafened people a chance to mingle. These socials have included captioned movies, dinners, bowling outings, and numerous parties.

Most members of ALDA, however, live outside the Chicago area. The ALDA newsletter serves as their meeting place, with several regular columns that encourage the exchange of ideas, experiences, and information. Through the newsletter and other forms of networking, ALDA has become an information and resource center for late-deafened adults. Members of ALDA have given presentations on late-deafness at seminars and conventions and serve as consultants to deaf service providers on matters related to late-deafness. This year, the first chapter of ALDA outside the Chicago area was established in Boston. The response to it has been terrific. We expect other chapters to start soon in such places as Carbondale, Ill., Rochester, N.Y., Washington, D.C., and the Bay Area of California.

All of these activities have created a growing, vigorous network of late-deafened adults nationwide. It is the first time this kind of interaction has occurred among late-deafened people in the United States. And for the first time, many late-deafened adults are realizing that they are not alone. Through ALDA, they are finding many other people who share their problems, feelings, experiences, and attitudes. In ALDA, late-deafened adults are finding a place where they fit in.

By interacting through ALDA, late-deafened people also are finding new approaches to recurring problems. For example, communicating with a group of late-deafened adults poses a particularly challenging problem because the receptive skills of late-deafened people vary widely. Some late-
deafened people prefer lipreading to sign language, others prefer sign, and others do so poorly at both that they may have no preference. When ALDA began self-help groups for late-deafened people, it became essential to find a communication method that was easily understandable to everyone. We dealt with this problem by devising a simple real-time captioning system consisting of a $100 computer, a television set, and a typist. The computer is hooked up to the television, and as the typist types the conversation on the computer keyboard, the words appear on the television screen. Members of the self-help group use the captions as necessary to retrieve words that they ordinarily would have missed. We also use this captioning system at ALDA business meetings and many other group activities.

As ALDA continues to grow, late-deafened adults will achieve greater and greater solidarity. Through interaction with one another, late-deafened people will consolidate their ideas and develop certain ways of dealing with their special problems. In this way, late-deafened adults will forge their identity and culture.

The Deaf Way celebrates deaf culture as it has developed chiefly through people who grew up deaf. It celebrates a rich and remarkable way of life that developed over many years of such deaf people interacting with one another. But The Deaf Way is not the only way of life for people who are deaf. For the vast majority of late-deafened people, The Deaf Way will always be somebody else's way. Through ALDA, late-deafened adults are finding their own way.
The SONIC Challenge

David Coco

(ALDA News, vol. 6, no. 1, January-February 1992)

There is a peculiar institution in Texas, and in other civilized parts of the South, which presents a unique challenge to ALDAns. This institution is called SONIC, a drive-in hamburger joint where you order from a bleeping box and lovely young ladies in matching red outfits bring out your order with a smile. I thought it would be helpful to share some of my SONIC coping strategies with y'all non-Texan ALDAns, so that y'all will be better prepared to enjoy the fruits of civilization when you visit Texas.

First, I need to explain the layout of a typical SONIC. There are several rows of drive-in parking spots, and each parking spot has its own order station. The order station is quite simple, a SONIC menu and a speaker/microphone combo for placing your order. In the middle of the parking lot there is a rather small building where they prepare these wonderful SONIC burgers, with a large sign on the front door which says, "EMPLOYEES ONLY." This layout makes it very clear that the SONIC management expects you to stay in your car and place your order from the order station.

This is a great idea, in general, but it presents some challenges for ALDAns. Now the typical ALDAn's first inclination might be to try to flag down one of these young ladies and ask her to take your order in person. This method, however, is discouraged and, in fact, may even be hazardous to your health. These gals are trained to ignore people waving at them from their car windows. Once, however, I did manage to stop one of these gals by grabbing her arm; but I quickly decided that I did not really want a SONIC burger after all when I noticed two very LARGE cowboys climb out of their pickup truck and rush over to her aid.

In order to enjoy the joys of SONIC cuisine I have developed a set of almost foolproof coping strategies for ordering at SONIC. These strategies only require a sensitive index finger and a bit of self-confidence. What you do is push the button at the order station to get the inside SONIC man's attention and then place your index finger very lightly on the speaker. When the finger hears "May I help you?" you proceed to order very slowly and distinctly. Now you have to listen carefully because the SONIC man sometimes comes on and instead says, "I will be with you in a
minute." If you misfingerread this phrase you will find yourself wasting your breath ordering to a dead microphone and will remain hungry for quite some time.

After you place the order the SONIC man will repeat the order and then ask you, "Will that be all, sir?" Now listen closely with your finger to the part where he repeats your order because this is the most crucial step. If you flub this step it can mean paying for ten SONIC burgers when you only wanted one.

It is a challenge to speechread with your index finger, but I assure you it can be done. A well-trained finger can easily distinguish between a hamburger, which is "buhbuhubhuh," and a double cheeseburger, which is "buhbuh buhbuhbuh." If you have any doubts about your fingerreading ability, however, just repeat your whole order twice and cross your fingers. When you are fairly confident that he has your order straight you say, "Yes, that's all," and he tells you how much you owe. I generally skip this part and look for a twenty-dollar bill since it is difficult to fingerread "two dollars and fifty seven cents," especially with a Texas accent. Then all you have to do is sit back and wait. I assure you that nine times out of ten the SONIC gal will bring you exactly what you ordered ... or at least, what they thought you ordered.

There are some dangers in using these coping strategies. I won't tell you all of them because that will only make your future SONIC visit less interesting, but I should warn you about one particular situation. Don't try this strategy right before closing time.

One evening I pulled up to my local SONIC at 11:00 and proceeded to order in my usual self-confident manner. I thought it was kind of odd that the SONIC man asked me to repeat my order five times but I thought, "Hey, maybe his hearing aid is on the bleep," and patiently repeated my order each time. You gotta be nice to these hard of hearing folks, you know.

I waited and waited for that SONIC burger. Finally, all the other cars left, the parking lot lights went off and the manager came out of the building and approached my car. He looked at me kind of weird and said, "I just told you five times, we are closed! Whaddya want?" I just smiled back at him, and in my most sincere voice, replied, "I'm sorry sir, I must have misunderstood you. My finger is kind of tired tonight."

It should be apparent to the reader that I have not yet fully accepted all the ramifications of my deafness. I still expend enormous amounts of creativity and energy trying to fit into the hearing world. These SONIC coping strategies represent just one example of how I still cling to the idea that real life is what hearing people do. Through ALDA, however, I have come to realize that these coping strategies are merely stepping stones in a lifelong struggle to accept my deafness. Someday, real soon, I will take this one step further along this path of self-acceptance and give up this SONIC nonsense. Watch out, McDonald's, here I come!
Bluer Than Velvet Were My Ears
Jerry Barnhart
(ALDA News, vol. 6, no. 1, January-February 1992)

It happened again when I was in the bookstore this past weekend. Just when I think I have accepted my deafness it happens. Yes, it's very frustrating trying to talk with a hearing person and having them repeat, repeat, until I understand, and yes, I would like to hear the voices again, of people I hold dear. But the thing that still gets me teary-eyed is this: not hearing music.

When I was in the bookstore I found they had enlarged their stock of merchandise to include cassette tapes, many of which were well-known oldies from my past. I saw a tape of Bobby Vinton and I remembered in junior high putting on his LPs when I went to bed and letting the song Blue Velvet serenade me to sleep. And Neil Diamond - I remember singing the words to Blue Jeans each time I would put on my own. How about Tommy James and the Shondelles? My first steady girlfriend surprised me one night with their single Crimson and Clover. And Emmylou Harris - I loved to hear her sing Queen of the Silver Dollar. So many of the songs I found were tied to special memories that caused me to get choked up. They did that even when I could hear them.

Periodically they televise Dick Clark's old "American Bandstand" with the original performers. I am able to lipread some of them, causing me to drift back and think of the eras in my life in which the songs occurred. Then I yearn for a chance to really hear those songs just one more time, but eventually I find the television screen becoming blurred and a lump emerging from my throat so I change the channel.

People often say that losing your hearing later in life is much harder than growing up deaf because we know what we are missing. In many cases, I disagree because I can still use my voice and because I lipread knowing what the words are supposed to sound like, and because I am glad I did have the opportunity at one time to hear so many glorious sounds.

But when it comes to music, I think it is much harder to be late-deafened than born deaf for a number of reasons. I mean how can you tell a born-deaf person about the emotions that music elicits? How can you tell them about being upset for some reason and then hearing a lively tune and finding your foot tapping blithely along with the beat? How can you tell them about listening to a sad folksong and having a tear run down your cheek? How can you tell them about the sense of pride and patriotism that wells up inside of you as you listen to the tune and lyrics of America the Beautiful? How can you tell them about a song you have heard with a very special person and declared it to be "our song"?

So when I am asked what I miss most about not hearing, there is no hesitation on my part. It's music. If I could have my hearing back for 24 hours, you would find me in my Levi's visiting the old record shop listening to Blue Jeans and every other golden oldie I could get my hands on.
Confessions of a Relay Junkie

David Coco

(ALDA News, vol. 6, no. 4, August-September 1992)

I admit it... I'm hooked, I've become an uncontrollable relay junkie, making up for 20 years of no phone calls. Some days at work, I'm on the relay system all day, taking a break only for lunch. At home, as soon as I walk in the door, I run past my wife, knock down the kids, and dial up the relay. Sometimes I break for dinner; other times, I type on the TTY with one hand while eating with the other.

Before the Texas relay began two years ago, my wife interpreted all my phone calls. Every phone call I made had to be important to me and my wife. She never consented to calling my friends just to see if they were watching the ball game. Or calling Sears to see if they had a circular saw on sale for $2 less than the local hardware store. My calls were rationed, and I paid for them dearly. My wife's attitude was, "You wanna make a phone call? Sure, I'll help you. But first wash the dishes and clean the bathroom, and then we'll make the phone call."

Actually, my wife was the most cooperative, unselfish phone interpreter one could ever hope for, so I really can't complain. But still there are some drawbacks to this sort of arrangement. Don't even bother trying to use your wife to interpret a call to your old girlfriend just to chat about the good old days. It just doesn't work.

I used to avoid making phone calls at work, like the plague, but now I have two phone lines, one for the computer with a modem, and one for a TTY. Both are in constant use. Many times, I make two relay calls simultaneously, swiveling back and forth between the two keyboards, without missing a word - twice the productivity of those poor hearing folks.

I must admit, though, that I have a love/hate relationship with the relay service. I love the newfound freedom that the relay service gives me, but I hate the limitations imposed by the current technology. I will not be satisfied until I can make a call with the same ease as my kids do. They just pick up the phone, push the speed dial, and plop down on the couch and chat for an hour while watching cartoons.

The new modes for accessing the relay, such as voice pass-through (also called voice carryover, or VCO) and computer hookups, are moves in the right direction, but they don't go far enough. I want the relay agents replaced by a supercomputer that does 100% accurate voice-to-text translation at the speed of light, and I want the TTY display replaced by a direct wire to my brain. Then I'll be satisfied... maybe. Bill "Technodunce" Graham called to tell me about a new advanced relay mode making the rounds that was originally suggested by Tim Walls of Evanston, Illinois. Basically this mode requires two phone lines—one for a computer with a modem (or TTY) and the other for a voice phone with conference call capability. You can use this mode (which I call the VCO Conference Call mode) to converse directly with a hearing person on the voice phone without interruption. The relay operator listens in via the conference call setup and types the hearing person's words, which are then displayed on your computer screen.
Thanks, Tim! I tried out this new mode recently and it was fantastic! I talked to my wife at a normal rate, without interruptions, for a full fifteen minutes, while the relay operator repeatedly typed to my computer, "Shut up and let me say something (wife)".

This remarkably simple and effective relay mode got me thinking about possible new applications for a relay service. These applications require a slight adjustment in our perception of a relay service. If the relay service can provide a voice-to-text translation for a person who is thousands of miles away, why can't it do the same for someone sitting right beside you? Say, for instance, someone with a nasty-looking mustache and an unintelligible Boston dialect? Imagine the following scenarios:

Scenario #1: Joe, whom I have never been able to lipread very well, walks into my office. I ask him to have a seat while I set up my Personal Communication System by dialing the relay service on one of my phone lines and asking the agent to call the other phone line in my office, which is hooked up to my computer. When the call is connected, I turn on the speaker phone, which picks up Joe's voice and sends it over the phone line to the relay agent, who transcribes it into text and sends it back to my computer. My display system projects the text onto a screen hanging on the wall behind Joe's head (just like at ALDAcon). Because I already know Joe speaks fast, I have instructed the operator to use abbreviations wherever possible and skip the easy words, I fill those in from lipreading or the context of the conversation.

What I have here is instant access to a free voice-to-text interpreter--every ALDAn's fantasy!! The relay agent's typing speed is the main limiting factor in this setup now, but just imagine what it would look like if the agent were a court reporter. NOW I'm getting excited!

However, as we all know, communication challenges are not limited to the workplace; they arise in social situations too. But don't despair. With a few minor modifications, the relay service can be used as a personal communication system in a social setting.

Scenario #2: I am in a dark and noisy bar. A blonde bombshell pulls up the barstool beside me and begins to whisper into my ear. I wink and ask her to wait one second. Then I open my Portable Personal Communicator System, which consists of two portable phones and a lightweight TTY. I dial up the relay on one phone and ask the agent to call the other phone, which is connected to the TTY. When the call is connected, I hook up a remote microphone (which I have cleverly hidden behind my hearing aid) to the voice phone, and set up the second phone on the bar.

I turn back to this lovely lady who is still sitting patiently beside me, but now with a somewhat puzzled look on her face, and whisper in her ear, "What did you say, sweetheart?" When she whispers again in my ear, I glance over her shoulder and read the TTY display which says, "Is that your hearing aid screeching like crazy? Turn that thing off, will ya?"

Ah well, dream on, ALDAns.
I was reading Bill Graham's (in)famous speech made at ALDAcon III about facing deafness. Bill made a strong point about the need to admit our deafness in otherwise precarious situations. That's a great idea, Bill, and I tell myself after each embarrassing episode that "next time..." but too often I continue with the same denying behavior you see, I am a HEARAHOLIC. It's a disease - almost as bad as being a Cubs fan! It's a disease that I and many other hearing-impaired people feel helpless in overcoming.

What is a hearaholic? It's the need to pretend I am a hearing person. I know I'm not, my friends know I'm not, but that cute waitress who just asked if I wanted dessert when I thought she was asking if I wanted the tab doesn't know (she soon will, because I said "yes" to every side order on the menu and I can't hold much more!). The problem with being a hearaholic is that so often I get away with it. So many times I can "bluff" my way through and come out with no one the wiser. It's like gambling, every time you win you think you can win again. Sure you're going to lose once in a while, but you never know if "the next time" you will win. That's where the addiction comes in.

Wherever I go, I constantly figure the "odds" of getting caught. I have better odds going to McDonalds than going to a real sitdown restaurant. Some days when I'm feeling especially lucky, I go to McDonalds' drive-in window - Hey, I've done it! ... YESSSS! At stores, I have better odds of using my credit card than writing a check. When I write a check they ask for (mumble) kinds of identification, my (mumble) number, and if I (mumble, mumble mumble). With the credit card, they (usually) just point and say "Sign here." Of course, it's easiest just to use big bills - I use twenties from the ATMs all the time.

Conversationally, I have better odds of talking to a salesman than to a psychologist. A salesman talks constantly about himself (or whatever he is selling), and all I have to do is nod and say "Really?" A psychologist asks too many questions. I found that out one evening at a party when one was talking about (mumble, mumble), and when he asked what I thought, I said I do it all the time. I found out that he was talking about child molesters - it took some explaining to get out of that one!

Yes, I'm a severely addicted hearaholic who sometimes wakes up in the morning ashamed of my behavior. I make excuses to my friends and family and even deny that I have a problem - I've even been caught with the radio on! But how long can I keep going to movies and laughing at punchlines that don't make sense, or buy $99.00 shoes when I thought they were $29.99, or keep nodding "yes" when the auto parts man is asking me what year my car is?

I have to remind myself that I can overcome this disease. I must be strong. I must admit my disability! I must accept myself for what I am! No more pretense! Never again! Uh, excuse me, my dessert just came... "Thank- you miss ... What? Oh, yes, thank you." (I hope she asked if that was all - I'm becoming quite ill.) Now, as I was saying ...

Jerry Barnhart and his hearaholic sidekick Jonathan Livingston ALDAgull live in Ocean Grove, New Jersey.
Technology is Not the Whole Answer

Bill "Technodunce" Graham

(ALDA News, vol. 6 no. 5, October-December 1992)

Publisher's Note: Don't freak out with this title, folks. Hear this guy out. Technology is certainly an important part of our deafened lives, but Bill G. told us at ALDAcon '92 why it shouldn't be the biggest part. We reprint his speech here for your reading pleasure.

I'm not what you'd call a controversial guy. I pretty much try to avoid controversy. Whenever I can, I try to say things that make people feel good. If you tell me that your brother is a faith healer who can cure late deafness, I won't laugh in your face and say, "Well, what happened to you?" I'm more likely to say, "Oh, how nice. What does your sister do?"

No, I'm not normally a controversial guy. My closet is full of blue and brown clothes, most of them polyester blend. Safe clothes. This tie is flamboyant for me ... Red and gold and green with drawings of animals on it ... My God! When I got it from my wife Karina last Christmas I thought I had the wrong gift. This is really walking on the wild side. But I usually try not to dress, act, or speak in a way that will draw attention to me. Deafness made me more different than I ever wanted to be. Perhaps I make up for it by being bland ... most of the time.

The title of my presentation is: Technology is not the Whole Answer. Well, that doesn't seem bland! That seems controversial! No, that's beyond controversial – that's nuts!! You've got to be nuts to address the ALDA convention with a theme like that. Absolutely nuts! ALDA would not exist without technology. Look around! You've got realtime captioning everywhere here. You have people with cochlear implants and hearing aids and tactile devices and state-of-the-art wheelchairs and laptop computers and TTY's and captioning decoders and signaling systems and on and on. How can I say technology is not the answer? "It is too the answer," sez you. "Get your head out of the ground, man!"

Now, now. Hold the lynch mob. I'm not here to knock technology. I'm not about to suggest that we should abolish electronic mail, or outlaw cochlear implants, or God forbid - boycott captioned television. I'm talking about adding something important to all those gizmos we genuflect to. So see me out.

First, let me win some points here by saying that technology is indeed amazing. That okay? Bland enough? "Technology is amazing!" Everybody knows that, everybody says it. My mother said the very same thing 25 years ago when we got an electric can opener. It's undeniably true. Technology is remarkable.

Recently, by using only a TTY, the Illinois Relay Center, and a fax machine, I carded out the better portion of a complicated real estate transaction, the purchase of my house. Now I'm not saying this was a pleasant experience - the day before the closing took at least 5 years off my life - but the fact is that I was able to experience this terrible stress all by myself. Technology made this possible. Because of technological wonders like computers and modems and fax machines, I am a productive capitalist competing with hearing people on an everleveling playing field. And while at times this can bring great stress, it also makes me feel powerful and in control of my life. I can do important, complex things that involve communicating. I feel independent, self-reliant. I
feel my wife might stay married to me because I can manage family business. And this, without question, is very good.

I'm fully aware that we ALDAns in general are in love with technology. Some of us know more about our e-mail systems than we do about our children's schoolwork. Many of us wouldn't dream of walking out the door without our hearing aids or implants or pocket TTY's. And what we don't already know about technology we are desperate to find out. We have all kinds of questions. "What does Voice Carry Over mean? Does it mean that when I talk on the phone at work everyone else can hear me?" "Should I get a cochlear implant? And if I do, will I really be able to hear crickets?" "If I buy a modem for my computer, does that mean I will be elected to the ALDA Board of Directors?" Yes, I'm sure a good many of us came here this week to have our pet questions about technology answered. And you know what? They probably will be.

But you want to know something else? I'm uneasy about all this stuff. Technology makes me uneasy. For one thing, it's all so addictive it absolutely cannot be healthy. You have no idea how much TTY, fax, and e-mail correspondence I sift through every day. Reading it all and responding to it takes up an increasingly enormous amount of my free time. I find myself interacting less and less with human beings in person. And in many ways my electronic relationships are easier. I'm good at it. People tell me I have a wonderful TTY personality. I type fast. I spell right. I can be funny. I'm a star!

Nevertheless, this whole scene makes me nervous. I'm afraid that one morning I'll wake up and realize that Hal the Computer is my closest ally; that I'd rather e-mail my best friends than go out for a beer with them; that I'm more comfortable talking to a TTY than talking to my wife in person. That's scary and sad.

About a month ago I received a big thick book in the ALDA mailbox. We get a lot of mail at ALDA but this piece was particularly noteworthy because of its size - about 200 pages long. The title was "Living with a Hearing Problem: Coping Strategies for the Hearing Impaired." Well, wow, when I saw the title I thought: "This should be interesting!" But the whole book - every single page - was about technological devices for the hearing impaired. I looked through it awhile and it seemed very comprehensive with a lot of information. But the title offended me: "Coping Strategies for the Hearing Impaired" and the whole thing looked like Popular Mechanics. I mean, the title of this book seems to imply that technology is the whole answer to coping with hearing loss - as if putting on a hearing aid or installing a cochlear implant or reading captions is all anyone has to do to meet the challenge of hearing loss.

Well, I've had a hearing aid for 25 years now - it helps me hear my own voice a little bit better, and for that I'm grateful. But for many of the years that I've worn an aid, I was the worst coper imaginable. I was a champion bluffer in almost every conversation I had, and I would hide the aid under my hair so people wouldn't suspect I wasn't 100 per cent hearing. You call that coping?

So when technology is held out as the big ticket answer to coping with deafness - as it often is by doctors, advertisers, the government, and others - I feel something very important is getting lost, and it makes me nervous. It's almost like human things don't matter any more: how you yourself feel about becoming deaf and how you work through those feelings; and how important other people are who honor and validate those feelings and don't hold out snap solutions to whatever ails you.
But, of course, human things - people do matter. Now my own story in dealing with deafness is not the same as everyone else's, but I don't think it is so unusual, either. When I think about what was most important in pulling me out of my despondency about deafness, I don't think about technology at all. I think about people. For example, I think about the people who taught me sign language - and though I'm still not a very good signer, it helps me interact comfortably with many people, especially my wife. And I think of the people of ALDA who let me know that it was okay to be deaf the way I was - a poor lipreader and a so-so signer.

Getting to know you ALDA people made me feel at ease about my deafness. You made me realize that I was not alone with what I thought were my unique inhibitions about being deaf, and that was reassuring. You accepted me for what I was - and I believed in your acceptance - and I really needed that to get on with my life. I've watched this magic of ALDA people reaching ALDA people for five years now, and it always amazes me. I have witnessed many gratifying stories of people finding themselves as deafened people and learning to like themselves again.

And if you asked most of those people what fueled the fire for their ability to grow, I'm sure they'd say technology helped. But if you asked them what really made a difference in helping them come to grips with deafness, I bet they'd say it was you and me. It was us telling them that it wasn't any fun to go to parties and not have a single decent conversation. That it was demeaning to learn important information second hand, and much later. It was us telling them that they didn't have to be afraid to ask for help in communicating. It was us telling them that they could do any job they wanted to. That if things were frustrating today, tomorrow they would probably be easier. And maybe most importantly, sometimes it was just us having a good laugh or a good cry with them.

It's hard to find this kind of interaction "out there." Most people that we deal with every day, don't have the patience or understanding to accommodate our communication needs. Communicating with us is not very glamorous and can be time-consuming, especially when we first lose our hearing. People get confused by our deafness and frustrated or even terrified and are apt to hurry away to be with people who can hear. And even those who don't, maybe we don't fully appreciate them because we feel we are being a burden. It's hard to find a basic rapport except in other ALDAns.

And through the years, while technology has made it possible for ALDA to do things on a grander and grander scale, it's the simple understanding and sharing of one person with another person that is the heart and soul of ALDA. And technology is not needed for that. After I lost my hearing, what I really needed to make me feel human again was some satisfying people contact.

That's the magic of ALDA. There is absolutely nothing technologically comparable with someone's smile or warm embrace.

Don't underestimate the impact you can have on the lives of other late-deafened adults. Maybe some of you feel you have absolutely nothing to offer other people. Maybe your self-esteem is low right now, and you think you could not possibly have any effect on another person, let alone a positive effect. Well, let me assure you that you are very wrong about that. Each one of you, simply by reaching out with a simple "Hello," or an attempt at conversation or a letter, can help change another late-deafened person's feelings about himself or herself and his or her outlook on life. You can make every difference in the world to another - maybe many - ALDAns, and you don't need an ounce of technology to do it. Technology means very little in this situation - YOU mean everything.
Don't get the idea that I think this is all very easy. Good answers don't necessarily come easy. I still get freaked out interacting with other people, including other ALDAns. I'm a minor league signer. I have struck out so many times lipreading that I don't even want to play anymore. Communication can be so goddamn hard I just want to shut the door, pull down the shades, and watch Northern Exposure. But that isn't the answer for me. I have a need to interact with people or my world seems kind of empty. And to have a real relationship with people, at some point I have to come out from behind the fax machine and computer and TTY and do some real interaction, face to face, difficult though this may often be. And I think in a way that's why many of us are here this week. We've talked through our faxes, TTY's, and modems, and we're ready to connect a little more. We're ready to try some eyeball-to-eyeball conversation and see where it takes us.

So while you're here at ALDAcon, go ahead and get excited about the realtime captioning and the many workshops and exhibits on technology that we have for you. They are fabulous and can be of great assistance to you today and in the future. But also reach out to other people while you're here, and let yourself be open to the reach of others. Because when you get home on Sunday or Monday, you'll remember the people of ALDA the most. You'll remember meeting other people who, just like you, can't understand what their relatives are saying half the time. And who, just like you, understand what it's like to have to look at the world differently at midstream in life, reevaluate yourself and your relationships with people, and move forward.
My recent deafness has made me understand more fully the restrictions of communication in everyday settings. When I was hearing, I remember having lunch or going out after work with a group of people and conversing about a multitude of topics. Interactions went something like this: sometimes two or three people would talk among themselves or, at other times, perhaps all would listen to just one person. As people conversed, they often listened in on the conversations of others, and would feel free to jump in and out through the course of the gatherings. Each member was able to stay abreast of what was going on and was free to contribute to the overall dynamics as he or she chose. As a deaf person, that became quite impossible for me. I was on the outside looking in.

At group get-togethers, I was lucky to understand even the person sitting across from me. When someone at the end of the table said something and everybody laughed, I would just nod, perhaps smile, or pretend to be concentrating on my meal or my drink (I was good at counting ice cubes in my Tom Collins). But inside I was frustrated and angry that I could not be apart of that hearing world.

Infrequently, someone would say "We're talking about...." But by then the joke, or whatever, had passed, and the conversation was on to other things. Sometimes, when I did not understand, instead of repeating, people would say "Oh, it's not important." (When I hear these words I want to kill – it implies I'm not important enough to get the point across).

Let me make an analogy that illustrates a deaf person involved in communication with hearing groups. Imagine a large family gathered around the dining room table enjoying a wonderful feast of ham, turkey, mashed potatoes, gravy, biscuits, vegetables, and many other fine foods. The food is passed around and each person partakes, taking whatever he or she wants, and often asking for second helpings of favorite foods. Let us also imagine the family dog sitting on the floor watching everyone enjoy their meal and hopeful to get any bit of food that he can. Maybe he prefers ham, but he must take the turkey that is slipped to him, being ever so thankful that one or two people care enough to give him anything.

After becoming deaf, I found that I had become the "dog." I was no longer able to participate in the "meals" of conversation that were taking place at the table around me, I had to depend on the "table scraps" of information from one or two others who took the time to care. Perhaps I was not interested in what was being said, preferring to know instead what another person had just said. But I had to accept what was being "fed" me. I no longer had control of what I wanted to hear. I was being fed bits and pieces of information that other people chose to give me. The information was being "filtered." Others determined what was important for me to know or not. Censorship.

But many people just "don't get it." Even parents, relatives, and professionals who supposedly understand the needs and feelings of the deaf just don't understand what it is like to be on the outside looking in. Parents will fight tooth and nail to get an "appropriate education" for their deaf child, but will do relatively nothing to ensure that their child understands all communication at home. Many parents will say, "Oh, we communicate well. He understands me just fine."
Hah. Yes, I'm sure the child knows when mom or dad is telling him to shut the door or pick up some things, but what about an ongoing conversation that discusses abstract feelings or ideas? How many times are the child and parent able sit down and talk about the whys and hows of various day-to-day happenings? These people cannot understand why their child is not on grade-level reading when the child's exposure is limited basically to the hours he or she is in school. Hearing children are listening every waking hour. Their contacts vary more widely as they get older. This is in contrast to the limited conversational contacts that deaf and hard of hearing people have.

I now have interpreters to help me in many professional meetings, and associate with other people who can communicate with me. However, there is always the anxiety of having to interact with people of the hearing world, never knowing if the interaction will turn out negatively. I suppose it is wishful thinking to hope that the world will learn sign language, but as I read the book *Everyone Here Spoke Sign Language*, about most people (hearing and deaf) using sign language a few generations ago on Martha's Vineyard, I was envious of those deaf people who were not relegated to only table scraps of conversations while associating daily with their hearing families and neighbors.

*Jerry feeds table scraps to the seagulls from his home in Ocean Grove, New Jersey.*
While My Guitar Gently Weeps

Michael Aguayo
(ALDA Reader, October 1992)

Perhaps it is fitting that I was holding my trumpet when the chills first came. I shook so uncontrollably I dropped the trumpet. The Deaf Reaper had come right into the Music classroom, undeterred by the trappings of the Hearing World, to select a musician to drag back with him. Dismissed "ill" by the teacher, I stumbled towards home, meningitis sapping my vision, hearing, and mobility. My year-long hospitalization and convalescence began.

I had taught myself to play the piano, with the assistance of my older brother, who had done the same. In Band, I was First Trumpet. While I was a very good all-round musician, my real love was the guitar. I got my first guitar for my seventh birthday. Name it, I played it: 6-string, 12-string, lead, rhythm, bass. My love was so fanatical that I cut grass, shoveled snow, saved birthday money, and worked in the local corner store so that at 14, I could be the youngest on the block to own a Gibson 'Les Paul' Custom, gold pickups and keys on a sandalwood body. I was the envy of my bandmates. Until that day three months later.

In time, my vision returned, and after six months of silence, enough hearing came back that I could hear unaided in my right ear. I lived for that. I had been told it was a simple ear infection, nothing of a chance of remaining deaf. I had held that guitar, caressed it, tested my hearing with it. It was the charm that would bring my hearing back and now I could play it again.

It was a short-lived "gig", I was playing some very out-of-tune songs. But you couldn't tell me that at the time. Cuts healed, bruises faded, why can't my hearing come back! Deep inside, though, I knew my singing voice wasn't the same. I wasn't used to people being so... polite when I sang. And I could tell that the 'Paul' sounded a bit distorted. But in deep denial, and to Mom's dismay, I played on for another year.

With band after band giving me an unappreciative look when I auditioned, I finally accepted that I wouldn't play again. I laid the guitar to rest. Over the years it became just a memento. Every once in a while, I played a few chords just to see my fingers losing it. My identity: dysfunctional musician.

Seven years later, an old bandmate came by to visit. I had seen Roman from time to time. He knew a little fingerspelling. His conversations seemed always to be punctuated with, "Hey Mike, will ya sell me the guitar?" I always said no. That was the running theme of our relationship. On this occasion, we talked of a lot of things. (Or perhaps it just seemed like a lot because with my weak lipreading it took a long time.) He didn't mention music. He was getting married, and had that on his mind. Just as he was leaving, half-heartedly and almost out of habit, he asked, "Sell me the guitar?"--and this time I said yes.
Nothing Is the Whole Answer

Neil Biddle


Okay, so technology is not the whole answer, and it's a good thing, too. The day they electrify (or worse, computerize) the paddle I will be up a creek without one. But you know what? Signing is not the whole answer either. Wait! Don't touch that dial. I did not say it wasn't an answer; I said it wasn't the whole answer; nothing is.

Here's the part where, if you want to keep reading, I need to show my sign language credentials. Here they are. I like sign language, I think it's beautiful and helpful and hope to get better and better at it. My sign teacher is my friend. She came to the beach with us last summer to teach my humongous family. She comes to our neighborhood Christmas Party and helps us sign carols, a seasonal hit. When I meet someone who signs (slowly) to me, I am grateful. But the philosophy I'm warning against is that which says "if anyone wants to know me they can learn my language." That attitude can isolate us more than our faxes and our laptops. Worse, it hardens and embitters us. I'm sorry to say, it is an attitude I encounter all too frequently among both the Deaf and the deafened, and I find it chilling.

I'm even uncomfortable with the "if only" mentality, with the yearning for an ideal world where everyone uses sign language. That attitude invites us to believe that all our communication problems would be solved in a red-hot minute if only they would change, a change that matches the one we went through when we lost our hearing. Surely the people who love us have made enormous adjustments, which sometimes includes learning sign language ... but not always. I can communicate pretty well with a few good friends, some of whom don't know as much as the manual alphabet. The reason they haven't learned it is because we haven't found it necessary. When I consider the relationships that have not survived my deafness very well, I can see, in retrospect, that I never communicated well with these people when I could hear. I doubt their use of sign language would help much either.

I think that deaf people who expect or even wish for the whole world to know sign language are a little like ugly Americans who visit France and pout because the language of choice there is French, not English. Sure, it's nice when someone speaks your language. But is it a moral obligation for them to? And do you really want to limit your contacts to those who do, even if
you could? I think it's better to carry an interpreter in your pocket everywhere you go if that helps you get out into the world.

Recently, I had the experience of a lifetime. I was able to participate in the presidential inaugural festivities. Not that I could "understand" most of what was being said around me. I couldn't, but it wasn't for a lack of interpreters. They were at every function. But I had the feeling that these interpreters were more symbols of "inclusiveness" than anything. I sure would have enjoyed captions on the big screens that were everywhere in sight. For one thing, the interpreters had to sign as fast as Bill Clinton talked. This was fine for any lightning-fast ASLers who happened to be in the crowd. I didn't see any of those. In fact, most of the time I had the impression that I was the only deaf person there giving these folks a job. They loved me. (I pretended I understood them.)

The debate over the appropriate ways for deaf people to communicate - whether we should get out in the mainstream or stick together both exasperates and fascinates me. Living here in D.C. under the shadow of Gallaudet University adds to the fascination and complicates the issues. But for the life of me, I don't understand why the bitterness and anger get so out of hand. I respect and admire deaf and deafened people who are getting along nicely in the world without sign language. I am also in awe of happy, well-adjusted people who find their fulfillment in association with a culture defined by their Deafness. This is the main reason I feel sign language is not the only answer: any time we latch onto anything as the whole answer it tends to make zealots of us, and anytime we're sure we're right, we're probably wrong.

If we have to be deaf we are lucky to be deaf in 1993. Technological advancement, a new respect for sign language, and yes the emergence of ALDA, are working in our favor. But you know what? ALDA is not the whole answer either. Nor is a faithful spouse. Nor is a faithful dog. The list is endless. The point is to make these things work for you, and help you get on with your life. If your computer, ASL, your ALDA support group, or your faithful spouse is causing you to withdraw from life, or is fertilizing the chip on your shoulder, it's time to give your obsession a rest, and to discover why it's not the whole answer.
My New Tribe

Randall Canote

(ALDA News, vol. 7, no. 4, October-December 1993)

During those turbulent years near the end of the Vietnam war, I loaded my backpack and left home to live on a commune in the backwoods of southern middle Tennessee. When I arrived, there were almost 700 people on The Farm, as the commune was called, most of them kids. At its peak, six years later, close to 1,500 people lived there, sharing in the day-to-day struggle of trying to grow enough food to feed this ever-expanding family.

My progressive hearing loss became noticeable by the age of seven, and by the age of 19, when I got to The Farm, I had been wearing hearing aids for six years. Growing up as the only one around who couldn't hear the words to the latest song, it was often difficult to make close friends. In group situations, it seemed I could always hear the joke but never the punchline. So partly in an effort to rebel against the military/industrial complex, and partly to feel like I belonged somewhere, I grew my hair long, smoked a lot of dope, and dropped out of traditional society.

The three years I spent on The Farm were very interesting. Good times were had and many lessons were learned. In a group that size, struggling as we were to survive, each individual's actions were felt by everyone else, so it was important to be very careful to do the right thing.

For example, if we had 1,000 mouths to feed and we bought 1,000 apples, obviously there was one apiece. But if someone decided to take more than his or her share -- just one extra apple -- that meant someone else wouldn't get his. The word would get out that someone cheated and that would put a little dent in everyone's consciousness. We would all be a little less trusting and a little more suspicious of others. So the lesson learned was one of cooperation, fairness, and selflessness -- be fair, don't take more than your share, and when your selfish desires arise, consider what's best for the whole group rather than yourself. These are still valuable and relevant lessons that can be applied every day.

Although I lived in very close quarters with many other people, I had a hard time developing close friendships. I blamed it then, as I do now, on my inability to join in the conversation, to participate in those little jokes and "meaningless" communications that happen in light conversation so essential to get to know other people. Because I was unable to overhear conversation, I was often left unaware of many things that were common knowledge to others. I don't know how many times someone said to me, "You mean you didn't hear about so-and-so?" No, I didn't hear about it. With ears like mine, I didn't hear much of anything.

Even though the friendships I had were not all that close, they were better than nothing. So I stayed on. The community itself provided a sense of belonging, although I was frequently alone in the crowd.

Although I left after three years for reasons I won't go into here, I still have contact with some of those I met on The Farm, and I still have a lot of good memories from those days. When a reunion was organized, I jumped at the chance to attend. It was billed as a "celebration of our tribe" (you know how old hippies think), and it was to be held at a campground in northern California the weekend before ALDAcon '93. I arrived early with lots of enthusiasm, hoping to
see people I hadn't seen in years. 250 people showed up, many in tie-dyes, and some who still had long hair.

It was a very colorful and visually entertaining event. We slept in 20 big teepees arranged in a circle, with colored ribbons flying from the top of the poles. I enjoyed swimming and diving in the lake, and the kids enjoyed the waterslide, but one thing was missing. Communication. No one but me knew how to sign. We all sat around the campfire one night. It was dark, so lipreading was impossible. As I watched everyone laughing and talking and playing on drums, I realized I didn't belong there. This wasn't my tribe anymore.

Without communication, there is nothing beyond "Hi, how you been?" I had very little communication. I spent the day throwing the frisbee and pretending to enjoy myself instead of doing what I really wanted to do: get to know people.

What a contrast to what I found in Chicago a week later at ALDAcon '93. People I had known for years and people I had never met all wanted to communicate. Through lipreading, signing, note writing, or telepathy, communication was happening. While I went to bed early at The Farm reunion, in Chicago I still couldn't sleep at 3:00 a.m. I was that excited. I feel I made closer friendships in three days in Chicago than I did in three years on The Farm. We got beyond "Hi, how are you?" and even beyond "So, how did you become deaf?" With communication we were able to explore each other's thoughts and feelings and really get to know each other. My only regret is that I didn't get to meet everyone. Ah, well ... next year ...

ALDA has become my new tribe. ALDAns are the ones I feel I have the most in common with, and ALDAns are the ones I want to have a reunion with. With cooperation, fairness, and selflessness, ALDAns were able to throw the best party since the Boston Tea Party. In short, ALDA is the best thing to happen to me in years.

In between ALDAcons, old hippie Randy Canote from Campbell, California, enjoys tribal communications with the warriors and squaws in ALDA-East Bay.
What Deafness Looks Like

Karen Avena
(ALDA Reader, October 1993)

I became profoundly deaf in 1981. At that time in my life, I had many friends, a live-in boyfriend, and support from the college community regarding my deafness. Many of my teachers and friends at this small college in Vermont learned sign language to communicate with me. I felt accepted and part of the community. In most respects, it seemed as if I was well-adjusted to my deafness.

At that time, I was studying art, mainly ceramics, painting, drawing, and photography. I chose to do my senior year thesis and art exhibit in photography, a medium that was relatively new to me but in which I found much excitement. I enjoyed expressing myself through the two-dimensional images I captured on film.

When I began taking photographs, I noticed a theme in my pictures. Over and over again, images of houses and yards emerged in the darkroom. I took pictures of boarded-up beach houses, abandoned trailers, and houses with closed doors. None of the images depicted people. All had a lonely, isolated feeling to them, as if someone had packed up and left home, leaving a few scattered items to remember them by, such as a clothesline, a beach chair, or a religious statue.

One day, in a critique session, one of my photography classmates mentioned that my photographs were all quiet, that in some way they looked as if I was showing what being deaf felt like. Suddenly, the closed doors in my photographs made sense ... these images were a window to my subconscious where my true feelings about my deafness were hidden. In reality, I was still struggling to accept my deafness. Though I appeared to fit in well in the college community, part of me still felt isolated. The frustrations I experienced in the hearing world when outside my close-knit campus were reflected in the images of closed doors, as if this part of the world was closed to me forever.

It still fascinates me when I look back over these pictures, to think how strong these subconscious messages are no matter how hard we struggle to suppress and push them aside. In the end, they emerge in one way or the other. For me, these true feelings found a vehicle through my artistic expression. Though I still put on the pretense and say I am adjusted for the most part to my deafness, looking over these images makes me question myself and wonder, will I ever be fully adjusted? Will my next series of photographs depict different feelings?? It has been several years since I last went out with my camera to capture images. I wonder what will deafness look like for me now?
Deaf in the Job Hunting Jungle

Jane Sokol Shulman
(ALDA Reader, October 1993)

Last January, the unthinkable happened, I was laid off from my job. Although I knew the company was in financial trouble and I anticipated an eventual downsizing, I never expected so large a layoff. I certainly did not expect to be included in one. After all, I had been with the company practically since the day it began. I ran a department, my boss was a vice-president! Nonetheless, there I was, reeling from the shock of abrupt termination and contemplating with a dread bordering on terror the prospect of launching my first job hunt as a deaf person.

Actually I hadn't been happy with my job for at least a year and from time to time I had thought about making a change. But whenever I started to consider the logistics of looking for a new job, I froze. I worked in a young, technology-based industry. The type of middle-management job I wanted was usually filled not through advertisements or employment agencies but by word-of-mouth. In other words, to find a new job, I had to work the telephone.

How were people going to react to my inability to use the phone in the usual manner? Would I face prejudice and discrimination from potential employers? Would big-deal executives even talk to me through a relay system? Would the difficulties undermine my self-confidence? And how would I handle interviews?

Recognizing that I had little choice in the matter now, I plowed ahead. As is standard in job-hunting, I compiled a list of target companies and people to speak to. I almost always sent a letter and resume to each person and told him or her to expect a call from me in about a week. So that telephone conversations would be as natural as possible, I used voice carryover (VCO) exclusively. I began each call with a three-sentence explanation of why I was using the relay system and how it worked, and encouraged the person to ask questions at any time. When leaving messages requesting a return phone call, I initially left our house voice number but soon shifted to instructing the person to use the relay system to reach my TTY line.

Within a very short time, I was spending over ten hours a week on the phone. The phone work in many respects was easier and more comfortable than during my last job hunt six or seven years ago when I struggled to make calls the conventional way. When I eventually met with some of the people I spoke to, I asked about their reaction to the relay system. To my absolute amazement, virtually all of the people I spoke to—and these are presidents and vice presidents of companies—felt that the way I used the telephone was unimportant—it was a non-issue!

Face-to-face interviews presented a somewhat different challenge, but I used the same approach of stating my needs and requesting help as necessary. I communicate through speechreading with occasional assists from writing. Because group meetings are very difficult for me, when arranging interviews I specifically asked to meet with only one person at a time. For situations where I would be sequentially interviewed by several people, I asked for a written schedule with names. Most of the people I met with were already attentive to my needs (good lighting, visual contact, a pad at the ready, and so forth). A few required instruction or direction. When I needed some special help, I explained things in as matter-of-fact a way as possible, ("Words you can readily distinguish all sound the same to me, so I would appreciate your writing down those names.") People were glad to comply. If I perceived hesitation or reluctance from the person I
was speaking to, I gently reminded him or her that all my professional achievements were accomplished with this hearing limitation—in other words, it didn't hold me back in the past, so it wouldn't hold me back in the future. To complete the picture, I described some of the accommodations I would require on the job and their likely cost. Again, when I asked for feedback and reactions, people told me that since I didn't make a big deal out of my deafness, they saw no reason to do so either. They also told me that they appreciated the opportunity to talk about it and ask questions.

My job search is not yet over. I have my ups and downs, but I think these emotional swings are no different from those of any other job seeker. However, these past months have been a vivid and heartening lesson in how wrong I was about the impact of my deafness on my job search. You don't have to feel stuck in an unsatisfying job just because you are deaf.

The basic steps I follow:

1. Tell potential employers what my needs are and how they can help me. Encourage them to ask questions.

2. Because I rely on my cover letter, resume and supporting material to introduce myself, I make them the best possible.

3. I make sure potential employers realize that, while I do certain things differently than they do (e.g. use the telephone), I am still able to do them! I remind them when necessary that my accomplishments and my hearing loss are both part of my history. In fact, I emphasize that it takes extra special drive and talents to achieve despite a hearing loss.

Finding a job is still a grueling process, but deafness is not proving to be an insurmountable barrier to me.
Karaoke Therapy: Just Do It
Scott Christern
(ALDA News, vol. 8, no. 1, Spring 1994)

ALDAcon '93 was my first, but surely not my last, ALDAcon. I was able to communicate so easily with so many people. I didn't have to fake anything either, because everyone was so . . . aware. I didn't need to repeat over and over, "Please look at me so I can read your lips," or "Please speak more clearly," or "Please slow down." In a large gathering of hearing people, I find myself either a) going to the bathroom often to escape, b) at the bar imbibing alcohol to relax, or c) stuffing myself with anything edible that is not about to enter someone else's mouth. Ever since I can remember, food has made me feel better, especially high-sugar, high-fat junk food--the healthy stuff. None of that was necessary at ALDAcon '93. I had nothing to escape from. I could even make a fool of myself and it wouldn't matter, because everyone else had gone through the same thing.

Not that making a fool of myself is anything new. I have at times been afflicted with what I call DBS, known in its longer form as "Dumb Blond Syndrome." The phrase was coined to describe one of my female friends in college who, despite being near the top of our class academically, often managed to exhibit an incredible lack of common sense. In my case, DBS comes from being a lazy thinker, because my brain waves sometimes take a temporary leave of absence. When I became deaf, this wonderful personal quirk of mine got worse. After all, everything was so quiet, it was easy to sort of "zone out," especially when deep thought and concentration were not needed.

This has produced some funny situations. My personal favorite happened about a year and a half ago in the middle of the winter. I live in a two family house, and was washing dishes about 10.30 p.m. (yes, by hand--I am not a yuppie, and proud of it!) The phone rang, and my trusty light started blinking to alert me. When I hung up the phone about half an hour later, the only thing on my mind was sleep. The next morning, I woke to find there was no hot water for my shower. Since I had just installed a new water heater, I threw on my robe, slipped into my trusty (and cold) boots, and went out to investigate. On my way outside to the basement storm door, I sped through the kitchen. Something caught my eye, thanks to my peripheral vision, which, unlike my other senses, is nothing short of extraordinary since I became deaf. I stopped short in my tracks. There was the gushing faucet, which had been releasing God knows how many gallons of piping
hot water since about 10:15 the previous night. I could visualize the board of directors of my water utility smiling all the way to the bank.

I told this story at a subsequent ALDA party to a couple I had never met before. The guy turned to his wife and proclaimed, "See, I'm not the only one who leaves the water running." As it turns out, he had done the same thing, except the sink drain had been closed. He flooded his kitchen, part of the family room, and did a neat job of creating an indoor waterfall in his basement. Two thousand dollars later, and in therapy to save their marriage, jeopardized by his late-deafness, they had been advised to go to ALDAcon. I seriously question whether meeting me helped the matter at hand.

Last January, at the hands of a brilliant surgeon for whom I have the utmost respect, I received a cochlear implant in my left ear. My profound hearing loss was already too great for even the most powerful hearing aids unless I wanted to put the hearing world around me through "feedback hell" every time I turned them on. I was excited, and I had nothing to lose.

It has been over a year now, and I say with some trepidation that the implant has helped, but the results have been somewhat disappointing. To put that in perspective, I did not have realistic expectations. My CD player was ready to rock with all my favorites of the mid-to-late-'80s, which I haven't listened to for years. I was gonna have an "I Can Hear Again" party that would last a week, during which time the music would never stop. As you might guess, losing the ability to hear music has far and away been the worst aspect of my hearing loss. If you were at ALDAcon and don't remember me, I was the fool who was constantly wailing off key during the karaoke party. Of course, if you are deaf too, you had no idea just how off-key I was. I can't express what a therapeutic experience it was.

I have been back for reprogramming of the implant on numerous occasions since my surgery, each time with high hopes. Always I have been confronted with the grim reality that although I now have some sense of hearing, I am nowhere near the point of not needing lipreading skills to understand speech.

When the input level on the implant is increased to the point where experts predict great benefits, the left side of my face starts to twitch violently to the rhythm of the speaker or the music I listen to. There is no real pain, just a strange feeling as my face goes through a sort of involuntary aerobics. The twitching may be due to radiation treatments I received as a child. No one knows.

I have control over the amount of input my implant receives, so I can sort of control the facial aerobics, like playing with a light dimmer switch. Since I am a little kid at heart, this has become another toy in my arsenal. I do still have a great deal of hope that my party will happen. In the meantime, I will let my twitching and "DBS" keep me and others entertained.

It is funny how I now concentrate on getting the most out of life's moments. If I were hearing, there is no way I would ever have got up in front of a roomful of people to sing, even if I wasn't off key. I may now be on the Westin's "undesirable guest" list, but it was worth every sour note. I only hope I can teach myself "to get up in front of people and sing off key" in all my life's activities.
Believe it or not, in a way we are all very lucky. Someone has given us the opportunity to be "better." I have seen a glimpse of "better" through my own experiences, and I want more. There are horrible commercials on T.V. where we learn about constipation and yeast infections. But I'm an advertising nut. In my eyes, the most powerful and meaningful ad campaign ever to have been created was brought to us by a famous American athletic shoe maker. "JUST DO IT" the company tells us ... how right they are! And may those words never mean the same thing to you again.

Think of it--the sky's the limit. Here's a personal challenge to all readers: think of something you want to do, no matter what the reason and no matter how crazy (within ethical boundaries of course; I am not inviting you to become a serial murderer.) If it makes you nervous, good: DO IT. If it really scares you, even better: DO IT. The truth is that our lives now can be infinitely better due to the challenges we go through every day.
Are Late-Deafened Parents Really Weird?

*Edited by a really weird late-deafened parent, Melanie Sexton*  
(ALDA News, vol. 8, no. 1, Spring 1994)

*Ed. note: The following highlights are from the Aladdin workshop on late-deafened parents. Participants in this workshop shared some of the agonies, joys, and hilarities that go with being a late-deafened parent. - DC*

My kids have trouble understanding why I want to know what's going on if it doesn't involve me. My daughter will come in and say something to my husband and I'll be sitting there and I won't understand what's going on, and I'll say, "What are you talking about?" and she'll say, "I'm not talking to you."

I'm going on 26 years of marriage and I have never dealt with this problem. This is difficult. From day one, there's been a huge communication breakdown. To this day I never discussed with my kids how they feel about their mother being deaf because they have always known me to be actually hearing because I bluffed all my life. I denied my deafness, and I verbally abused my kids really bad, really bad. It's hard for me to say that. I've never admitted it, but I did. I took all this anger out on them.

I have two girls -- two girls who are very artistically inclined, one is an award-winning violinist the other one is a ballerina. I went to all the recitals and concerts. Once, my oldest daughter was a solo violinist and I was very, very proud of her, but I couldn't hear a damn thing going on. I had to show enthusiasm and I had to clap and stand up and cheer. Inside I was absolutely dying, because I wanted so much to hear what she was playing and be so proud of her. I certainly was proud of her, but I couldn't appreciate her music or her talent.

When my daughter was about three or four we were driving to preschool. She asked me something and I had no idea what so I tried to bluff. That didn't work and she got frustrated and started to cry a little bit. I said, "We will talk about it when we get home." She started crying harder and harder. By the time we got to preschool she was hysterical because I couldn't understand what she was saying. I asked somebody from the preschool to help interpret for me. I realized we had a big problem. It was very hard for me to explain about the hearing loss, and hard for me to understand what she was going through. Hard for her to explain what she needed. I remember we came back home and she was in bed and I thought we needed to talk about this. So before she went to sleep I said, "You know, mommy's ears are broken, they don't work like other mommy's ears." She cried and cried. I'll never forget it. She was so upset.

There's a little bit of role reversal that goes on when I ask my 10-year-old to make a plane reservation for me or when I need to ask my 12-year-old to make a reservation at a restaurant or to call a doctor for me. Then I don't feel like I'm in control anymore.

The way I compensate is to go up before bedtime and talk individually with my kids one-on-one and get a feel for what's going on in their lives and let them know I'm interested in them and care about them.
I was driving my daughter and her girl scout troop to a party when she was seven or eight years old. The little girls in the back were talking when one of them tapped me on the shoulder and asked me a question. I couldn't figure out what she was asking me. I was looking in the rear view mirror and couldn't see her face and just couldn't get it. Rather than say I have a hearing problem or I'm deaf or something like that, I gave her an answer to a question I thought she might be asking. I was bluffing, and it was clear from the little girl's reaction that I gave a completely off-the-wall response. So my daughter said to her friend, "Don't pay any attention to my mom, she's just really weird." I think it's a lot easier when you're seven or eight years old to say to your friends, "My mom is really weird" rather than "My mom is really deaf."
Phone Perverts Beware

Calamity Jane

Several years ago, before there was an ALDA -- before I had an identity as a late-deafened person -- I would sometimes answer the phone. If I was expecting a call from a family member or just felt like persecuting myself, I would actually try to answer the phone. One particular day, my dad was going to call to tell where to meet him for lunch. So I answered the phone, but it sure wasn't my dad. It turned out to be one of those harassing obscene calls that late-deafo gals don't have to worry about anymore. (Excuse me sir, would you breathe a little louder? I can't hear you.)

After the caller uttered some horrendously vulgar words that I didn't understand, I replied very politely "I'm sorry. I didn't hear you. Would you mind repeating that, please?" hoping I could get it on the second pass. But the sicko hung up. While I was trying to figure it all out, my husband came flying down the stairs saying "Jeez, honey, do you know what he just happened?" He explained that he picked up the upstairs phone the same time I did and heard this moron making his monstrous remarks. I felt sick and stupid at the same time, but my sympathetic husband said, "Hey, babe, don't worry about it. You probably just cured the bastard."
"Om Nami Shivaya." The chant rose around me, deafening in its volume, while I remained oblivious to the words, even with my cochlear implant turned on high. Word discrimination, as always, failed me, and when the guru began to speak I understood not a word and was aware only of my desperate need to leave this place.

I had come to the Ashram filled with curiosity and enthusiasm, fueled by a lifetime interest in eastern religions. I left with a new awareness of myself as a deaf person.

Deafness has for me been a process of many stages. Physically, I arrived at the profound level some ten years ago after years of gradual hearing loss due to a childhood illness. Emotionally, I hung onto my hearing identity long after prudence would dictate it was better not to do so. This was partly the result of living a rural life where no other ALDA folks were available to me. Consequently, I never learned to sign with any fluidity and relied on speechreading almost exclusively. It was only at the Ashram, where I ran into a brick wall, that I was forced to take that last step and acknowledge that I was no longer able to function in my old world.

Arriving at the Ashram for a weekend visit was spellbinding. Books piled up at home were to be supplemented by actual experience. I was told that the Ashram was normally perceived as a bit of a sleepy place, but today, being a high Hindu holiday, it was jammed with people from all over the world. Men and women in colorful native garb swirled around me as I wandered around in wide-eyed fascination, confident that here among such well-intentioned people, my hearing would not be the problem it was in everyday life.

I was wrong, of course. After hours of staying hyperalert to understand even a minimum of what was going on, I was exhausted. Not understanding instructions about lining up, I wandered out of place and was herded back with obvious annoyance and steely-eyed looks. Struggling to hear one-on-one directions that included a Hindu word, I apologized for being a "problem" and was treated to the instant analysis that it was I that was creating the problem. At that point I was in tears. All my feelings of loneliness and desperation while trying so hard to belong to the hearing world overwhelmed me.

The temple ceremony was the last straw. With tinnitus echoing the noise of my chants, my psyche battered by the hearing world's lack of understanding, and my back killing me from sitting on the hard floor, I gave up in a way I had never done before. At last, after a journey lasting 20 years, I fully accepted my deafness and the restrictions it imposed on me. In that moment I knew that no matter how much I wanted to, I could no longer function in the hearing world as I had in the past. I realized once and for all that my desire to be part of the normal, flowing human crowd was impossible, and that I would have to restructure my life around my limitations.

Twenty years. I'm a slow learner, I guess.
The repercussions of that weekend are still with me. Just how does a person living in a community with no other deaf people among neighbors, friends, or family restructure her life? For one thing, I realized that if I am going to survive, I must have the support of others like myself, who can truly understand the problems of adult-onset deafness. No hearing person, no matter how well-meaning, can do this. Miraculously, I found ALDA at just this time through a newspaper article. It took me a while to track it down, but here I am!

While I am a new member, I intend to participate in this lovely network of support to as large an extent as time and circumstances allow. Then too, I am learning to say "I can't do it" when faced with situations that I know will overwhelm or be futile for me. In the past I would try anyway, hoping, almost always with futility, that I would be able to fit in somehow. I seldom did.

No more do I volunteer to help sell refreshments at our yearly Haunted Forest. It results only in frustration for myself and others when I cannot keep up with the verbal flow of orders. No more do I go to events where I know the noise level will overwhelm me and prevent even a minimal level of understanding on my part. I try to avoid what I call the "Window Dressing Syndrome," situations where I simply sit in bored incomprehension because it makes the hearing folks feel better to include me. Life, I have concluded, is too short to spend long stretches in silent frustration, with an inane smile glued to my lips. I do acknowledge that as a deaf mother of hearing children there are some situations which cannot be avoided, but all in all, I am learning to use the word "no" appropriately and enjoy the times when I can say "yes" that much more.

It is an interesting journey, this adjustment to the world of silence. I long to hear music, birdcalls, and ungarbled speech that is not a crossword puzzle from hell. I am not by nature a patient person, and my soul continues to chafe under the limitations imposed by deafness. I know the names of the ropes that bind me: isolation and loneliness. I also know that the struggle to retain my personhood and worth in a hearing world is not something that I will ever "overcome." It is something I will deal with week to week, day to day, and sometimes, minute to minute. But in order to do this, I first must accept, with clarity, my differences. Only then can I begin the task of discovering my uniqueness.
Letter to My Family

Carolyn Piper

(ALDA News, vol. 8, no. 2, Summer 1994)

Dear Pipers,

Well, it's reunion time again! Seven days filled with catch up chatter, gotta see movies and squealing sunburned children. It has been several years since I attended, but I remember it well. Now, metaphorical ear to the ground, I have heard there is dissension and some anger among the troops at my failure to attend.

I gave it a try, you know. I once sat for four hours (yes, I timed it), insane grin plastered on, waiting to see how long it would take for someone to initiate conversation with me rather than vice versa. I sat through hours of uncaptioned TV and movies, and my head rang, both literally, from tinnitus, and figuratively, from being turned on and trying to understand a crowd of chattering people for hours on end.

At the end, all of you were always profuse in your praise "But you do so well!" and shouts of "So glad you could come!" rang out, and not one of you had a glimmer of the effort it had cost me - and how long it would take to rid myself of the tension, anger and loneliness which had accumulated during the week.

I know now that hearing people really cannot be expected to understand the problems facing a deafened person. The anger I once felt is, for the most part, gone, but I have come to a point in my life where I need to accept myself for what I am. I feel the need for a vacation to be a time of rest and renewal instead of loneliness and fatigue.

I love you all - one on one, but en masse I can no longer keep up, nor do I want to. So I hope that you will try to understand why this year I shall once again choose to stay home. For this one brief period of time during the year I can be alone to cherish silence rather than fight it. To appreciate once more that deafness can bring blessings as well as hardships. I shall visit with friends one on one, and potter about the garden feeling joy at what I, with nature's help, have wrought. I shall sleep outside, watch the stars, and dance on the grass in quiet glee. I might even pull up that stump that's been in the middle of the yard for fifteen years!

May you have as wonderful a time on your vacation, as I shall on mine. My love to you all.

Carolyn (Piper)
Life In ALDAland
(ALDA News, vol. 8, no. 2, Summer 1994)

Vermont Style
Carolyn Piper

Living in a small rural Vermont town allows me to indulge in two of my great pleasures: walking and meditation. One day, while combining the two on a narrow country road, I was unusually deep in contemplation. With my hat pulled down against the cold and my eyes half closed to concentrate on my walking, I was oblivious to my surroundings, all the more so as I do not wear the processor for my cochlear implant on such outings. Looking up after a period of time, all the peace I had been accumulating vanished, for two feet in front of me was our town's very largest snowplow. High above me I spied the operator, no doubt engaged in an exercise of patience himself, as he slowly, in perfect time with my pace forward, backed the giant machine up foot by arduous foot along the narrow, twisting road.

The Bawwwston-Awwwston Connection
Calamity Jane

Years ago before airlines used boarding passes, I relied on my somewhat shaky perception of vowels to understand what was said through the PA system. Once while waiting at an airport in Florida for a flight home to Boston, I heard them announce "Boston." I hurriedly showed my ticket to the flight attendant and jumped on the plane. After a snack, I asked for a pillow, wanting to catch some shuteye for the three-hour flight home. It seemed I had just dozed off when the attendant awakened me to unboard "Are we already there?" (I must have miscalculated my sleeptime.) She shook her head up and down, so I got off the plane. But imagine my horror when I found myself in a terminal I had never before seen! Grabbing a stranger, I anxiously said, "Excuse me, sir, where am I?" He pointed at a large blue sign that said, "Welcome to Austin!"

Silence
Carolyn Piper
(ALDA News, vol. 8, no. 2, Summer 1994)

Did you know that
silence has texture?
Hard and sharp,
unyielding harshness
when in a room of talk.
And then, alone,
among the trees,
the softness comes, and
silence feeds my soul.
ALDA Mom's (mis)Adventures

Mary Clark

(ALDA News, vol. 8, no. 3, Fall 1994)

Publisher's Note: In the summer edition of ALDA News we promised you a special focus issue on ALDA in the family. We asked you to write letters to your family and submit them for publication. How does deafness affect your relationship with your family? Inside this edition, you'll find both heart-warming and heart-breaking "letters to my family." We start off with an enchanting tale from ALDA's most popular Morn, Mary Clark.

I read the flier a second time. "Talent Show given by the fourth grade music class." That sinking feeling I get when I realize I've left the garbage disposal on begins to surface. My nine year old is jumping up and down, explaining how important it is that I attend this event of the year. I can think of many things I could be doing from 1:45 to 2:30 that particular afternoon. I need to clean the bathroom floor on that day (and at about that time, too), wash my hair, and maybe even replace the garbage disposal. Ahhh ... maybe there's an ALDA social or even an ALDA self help group that day. (I think I need self help right now!!)

Lindsay is writing a postcard to her grandmother in Maine. "How do you spell 'runt'?" she asks. I start going through the list of "real" words that look like runt. "Once?" I ask. "No, runt," she says again. "Oh Went," I say. "No, runt." Her face begins to get that frustrated, runty look. I've got it! "What! Is what you want to spell?" She says again ... "runt". I want to say, "Spell it for me," or "What's it sound like," or "Show me what you are talking about," or "Do we have one in the refrigerator?" I finally say. "I've got it ... R-U-N-T" and put a mental note to call my mother to explain it's just another one of those ALDA mom's vocabulary words.

I'm sitting in the music room at school. My nine-year-old, Lauren, whose real aspiration at this point in life is to be a singer, is dressed in black leggings, a white button-down shirt, and a vest with fake rhinestones on it. She stands with her friend, Alicia. Alicia is dressed in the same outfit and they are holding fake microphones. The music starts (I think). They dance and lip sync to "Dreamlover." The kids in the class look over at the ALDA mom to see her reaction. The ALDA mom smiles and uses appropriate body language to indicate how much she is enjoying herself. She wonders if she should ask if she can hold the record player on her lap to feel the beat and be a "true" ALDA mom, or sway a little bit and hope the song ends soon. She wonders what the words are and then starts to worry about that more than necessary. The ALDA mom remembers "Dreamweaver" from the seventies and convinces herself the words must be the same. Maybe Mariah Carey sings it. She looks like a nice girl on TV. It's not a rap song, after all. And besides, Alicia's mom is not even an ALDA mom (she thinks it's strange just knowing one) and yet has still allowed her daughter to take advantage of this golden opportunity.

Lauren asks the ALDA mom how she liked the show. "It was great," I say, "You were terrific!" (I have no idea what you sang but your hair was cute and you danced like you knew what you were doing.)

Lindsay is writing another postcard about her trip to Florida. "How do you spell Journey into Imagination?" I lipread her perfectly. I am thrilled! It will compensate for "runt." It will show that ALDA moms actually do have a decent vocabulary and can spell too!!
Ten years from now, the ALDA mom will find out the real words to the song Lauren sang. Perhaps Lauren will tell me before then and we will both laugh about it. Or maybe the ALDA mom will need to wear a paper bag over her head every time she goes out in public. I can see it now. "There's the ALDA lady whose kid sang that song back in '94!" Perhaps too, the ALDA mom will discover the real word behind "runt."

Sometimes the ALDA mom just needs to do the best she can and let it go at that. ALDA moms can't be perfect all the time but they can have happy children that sing inappropriate songs and use inappropriate vocabulary... It still beats drugs and gangs! And hope is just around the corner as the ALDA mom's ultimate fantasy comes true... that soon Lindsay will only speak in multi-syllabic words and Lauren will learn to lip synch old Frank Sinatra tunes!!
Audiogram
*Sal Parlato, Jr.*

As asked
but unsure
how much din
a new deafness from me hid
I saw my ear-self filtered
onto a decibel-graded grid.
Its off-kiltered raw and linear score code-answered me (not less, not more) math
\(\text{trig} \text{geometric} \text{ly}.

On My Impending Deafness
*Edna Shipley-Conner*
(*ALDA Reader*, October 1994)

When I consider hearing
Is the last sense lost before death,
And know that I've been dying
Since soon after my first breath,

Impatient, my soul seeks sound,
Not for God's need
But to store experiences not found
Written, thunder being lightning's deed.

How best the yoke of silence
Can my spirit bear?
What work to do while waiting?
What talents left to share?

Meanwhile, I'll use my hands like lightning
And transform the silence borne,
Into signs with new meaning, brightening
the darkness of fear into a new form

Milton, like you, I will not wait and stand,
But create a new world with mind and hand.
Grandma's Ears are Broke

Cleo Simmons

(ALDA Reader, October 1994)

I have three grandchildren: David 14, Nick 10, and Alex 2. When I first became deaf David was three years old and talking. When his brother Nick was born, I was too ill to spend much time talking with him or helping my daughter-in-law care for the boys. Fortunately, it has been a very different situation with my third grandson, Alex. I have spent a lot of time with him, and together we have learned to communicate.

For me it's important to be able to communicate with and really get to know and enjoy my grandchildren. To accomplish this without my hearing I had to learn new methods from my friends in ALDA. During one of my pool parties, I watched as Mary Clark asked her young daughter to repeat what she had said using signs, explaining that "mommy's ears are broke." I realized then that was precisely what I needed to do. I started speaking and signing to Alex that useful phrase "Grandma's ears are broke." Although he is only two, he has quickly learned how to communicate his needs and desires to me nonverbally.

Recently I gave him some blocks to play with. He came over to where I was sitting and, taking my hand, led me to where he was playing. He sat down, patted the floor, and looked up at me expectantly. He had just finished showing me that he wanted me to join him! Later when the telephone rang, Alex once again took my hand and walked me to the phone, patting the couch for me to sit while on the TTY. His actions surprised me since I have never shown him how to do this.

As I have learned to cope with my deafness, I have also experimented with various communication methods. Some have had a significant effect on my grandchildren (they are good spellers and typists). For example, I use sign language flashcards to teach both my middle grandson (Nick) and myself signs. Nick reads the back of the cards, which describe how to make the sign, while showing me the front of the card with the sign on it. He and I then try to make that particular sign. I tell Nick to say the word as he signs it—that way I practice my lip-reading skills too. It never matters to me if he makes the sign correctly; what matters is how our relationship develops through sharing an experience.

My oldest grandson, David, is quite adept at using fingerspelling when talking to me. Sometimes the adults in the room will try to "help" with the spelling when they see a confused look on my face. This "look for help" is a bad habit of mine. I need to concentrate on what the kids are trying to tell me instead of looking for help. Besides, it just doesn't seem fair for me to lose patience with them, especially when they do try so hard.

Another way the boys and I communicate is via the TTY. David already types as fast as I do. Nick has started to type and recently told me about his report card on the TTY. He received five A's and was so proud of himself. I am as proud of him for taking the initiative to call me himself as I am of his good grades.
I really enjoy spending time with my grandchildren communicating with them using all the methods available to us: signs, fingerspelling, TTY, and speechreading. I am now not only watching them grow up, I am also helping them grow and develop into caring individuals. My family is enormously supportive, and I am pleased. It has taken time and patience from all of us to adjust to my hearing loss, but our family communicates and that is essential for happiness.

One last boast. Alex has learned how to sign "I Love You." His fingers are so little that they sometimes won't stay in place. But he persists, and when he flashes "I Love You" I feel blessed.

Selections from Hail the Mail
(ALDA Reader, October 1994)

"To whom am I forever indebted for sending me a copy of ALDA News? ALDA is like a drink of cool water to a person suffering from thirst in the desert. Since this deafness has been creeping over me I have felt so isolated, always alone, it really hurts to be so "shoved out" of society. When I ask someone to repeat something and they say "Oh, never mind" it is as though they slapped me in the face. I wasn't worth the effort of repeating the word or sentence. I guess it is true that misery loves company because I find the fact of others (late-deafened people) a comfort.

I am enclosing a stamped envelope. COULD SOMEONE TELL ME HOW TO GET CLOSED CAPTIONING ON MY TELEVISION? Where does one learn lip reading? Is there a book? I am in a wheelchair and do not get out and around, and this magnifies my problem. I am taking up too much of your time, but I am so excited to find ALDA and hear of others in the same situation."

—Anonymous
Chapter 9

1995

Now Where Do We Go From Here

Holly Elliott

(ALDA News, vol. 9, no. 2, Summer 1995)

Publisher's note: ALDA's 1994 winner of the "I. King Jordan Achievement Award," Holly Elliott wrote the following 1995 revision to a presentation she originally delivered in 1978 to psychiatric residents at Langley Porter Psychiatric Institute, University of California, San Francisco. As a late-deafened counselor in San Francisco, Holly has been a long-time champion of quality mental health services for adults with hearing loss.

About twenty-four hours ago I came to the sudden realization that for the last couple of weeks I have been experiencing one of the basic psychological problems involved in adventitious deafness--avoidance. Although this workshop has been on my mind a great deal during that time--and from time to time I would sit down and write a few "epigrams" to share with you--I have also been extremely "busy" with other things that seemed important (and some were really important).

But what I was really doing was avoiding the pain of self-examination that is necessary in order to do justice to the psychological issues I have experienced as a late-deafened person myself, and experience again and again through my work with deafened patients. As is often true with psychological issues, I had to recognize the fact of avoidance before I could free myself to attack the problem. Last night I was really busy getting my act together.

As I was organizing my thoughts, I found it difficult to separate the personal and professional experience of late deafness. I would like to share with you special ways in which my professional experience has been influenced by my personal experience. My thinking seems to be focusing in three broad areas of what I call "inside deafness," i.e., deafness as an identity crisis; deafness as a cultural phenomenon; and deafness as an inconvenience.

Let me start by saying I have been hearing, hard of hearing, and deaf. I have communicated by speech, speechreading, signs, and various combinations thereof. I can even play it pretty well "by ear" if I know the context. For example, I was standing in a line at the Kentucky Fried Chicken place last Saturday evening. It was a line of very heterogeneous people whose only interest in common was getting home with their chicken. Then the earthquake hit and there was instant
communication as the line coalesced into a group. The fact that I couldn't understand a word they were saying made no difference at all. All I had to do was say, "I know what you mean," or "I feel the same way," and there was instant understanding.

Prelingual deafness is a sensory deficit. Late-deafness is a sensory deprivation. A sensory deprivation can precipitate a crisis situation. The renowned psychologist Erik Erikson defines crisis as "a necessary turning point--a critical moment when development must move one way or another, marshaling resources of growth and recovery to prepare for further differentiation." That's been a credo in my personal as well as professional life. That, and a certain tendency to remove the two words "if only" from my vocabulary and replace them with a more workable phrase: "That's the way it is. Now, where do we go from here?"

I became deaf when I was a junior in college, majoring in music. It happened over a period of several weeks and was not immediately recognizable as deafness because my hearing was normal at 500 Hz, but I had no detectable hearing at 1000 Hz. The basic difficulty was that people were not talking clearly; the problem seemed to be with them, not me. But I noticed the upper half of the piano keyboard was gone, so I knew something was wrong and made an appointment to have my hearing tested. The audiologist told me that I was severely deaf; it would probably become worse; a hearing aid would not help me; and I would just have to learn to live with it. My response was rage and denial. Nobody's going to tell me I'm deaf! I can hear, I just can't understand very well. It was twenty years before I had another audiogram and it was thirty years before I ever saw an audiogram. That is called "denial," and it's all too common with people who lose their hearing as adults.

I set myself on a course that is called "task-oriented response to stress," and set out to prove to myself that I could do anything I wanted to do. I even directed a church choir for 16 years. I could hear the bass and lipread the sopranos. I could pattern the music in my head and I knew if the sopranos were off pitch by the expression on the tenor's faces. I always had very expressive tenors! But I never allowed myself to experience grief and I paid dearly for those repressed feelings. I had the feeling that deafness was my problem and nobody else's and I was dealing with it in passive-aggressive ways. I was forty-eight years old before I finally faced the issue, went back to college, learned sign language, and found a new identity.

Late-deafness invariably brings on an identity crisis. My ongoing identity crisis is the fact that hearing people think I am hearing because my speech is good and Deaf people think I am hearing because I am not fluent in American Sign Language (ASL). I prefer to talk and sign at the same time. I am reminded of a conversation with a Deaf man some years ago. "I am better off than you are," he said. "You lost something; I didn't." I replied, "Maybe I am better off; I had something; you didn't." Another man introduced me as "Holly Elliott. She's deaf, but she lives like a hearing person," or "she signs with a hearing accent." So we have three major categories in the field of hearing-impairment: the culturally Deaf (upper case) whose first language is ASL; the culturally hearing deaf or deafened, whose first language is spoken English; and the hard of hearing.

"Blindness separates people from things," Helen Keller once said. "Deafness separates people from people." Becoming deaf often involves the stressful side effects of isolation, exhaustion in coping, the emotionally deadening effect of the absence of sound--especially the human voice--and the distortion of sound accompanied by roaring tinnitus that has no meaning. With deafness also comes the realization that other people must experience the discomfort of coping with your disability. Becoming deaf involves finding a new identity without denying your past life. Identity confusion often results; you feel in limbo, no longer part of the hearing world, yet not a part of
the deaf world. Becoming deaf involves building a bridge between both worlds and finding a new place in the community of human beings—deaf and hearing. This is not easy.

But even more important in this new and frightening experience is learning the difference between grief and depression. Grief is a natural response to loss, an active process that must be experienced to be resolved. Depression is a long-term withdrawal process, a giving-up process. I have a hunch that depression interferes with communication more than deafness. The feeling of being "left out" is a feeling of depression. If I can overcome my depression, I will find a way to communicate—by writing, by signing, by speechreading, by helping the other person find a way to communicate that is comfortable for both of us.

Too often we are controlled by the "shoulds." I should learn sign language; my family should learn sign language to communicate with me (if we don't we feel guilty asking) or I should join the Deaf community; or I should be oral, not manual. Why? Why not? I want to be me. I am unique. I want to communicate with both deaf and hearing people. I want to learn sign language, but I don't want to limit my associations only to those who know sign language. I want to communicate with other deaf people, but I want to talk and sign at the same time, so no one is left out. Not "I should," but "I want." If I don't understand what the hearing person is saying, I ask him or her to write. I carry a pad and pen with me all the time. I call it my "supplementary communication device." Because I am comfortable using this, other people seem to be comfortable, too.

One way to attack the problem of communication breakdowns is to find creative solutions. I can't use the phone, so I have a TTY. I am comfortable using the relay service, so I can call anywhere. I can't play the piano anymore, so I play the computer keyboard. I also have a laptop computer with two keyboards, and it's a great communication device. I talk and my grandchildren type (they teach computer in elementary school these days). I can't hear the doorbell, so I can get a flashing light—or better yet—a hearing guide dog. I can't direct a singing choir, but I can organize a signing choir.

What can professionals do? Understand my defenses; I am using them to ward off anxiety. Underneath those defenses, I am feeling scared. Give me clear explanations. Information is crucial to me. When I know what's happening, I can deal with it better. Don't tell me what I "should" do. Offer me options that I can investigate on my own. If I can't understand what you are saying, write it down. Tell me where the resources are: speechreading, sign language, counseling. Listen to me. Tell me it's okay to cry. Acceptance means: "That's the way it is. Now where do we go from here?" And understand that it may take me a while to get there.

Now compare my most recent experience when I moved from severely deaf to profoundly deaf. I have an ear-nose-throat doctor and an audiologist who clearly and supportively share all the information with me. I have a psychiatrist who doesn't know sign language and is hell to lipread, so he writes. I have an associated vision problem and an ophthalmologist who periodically turns off his equipment, turns on an overhead light that shines directly on his face, and explains to me what is happening. I have a family who is willing to write (or type) when I don't understand. I can experience grief—I still miss music and casual conversation—and I am learning to express anger in more productive ways. Professionals have helped me with this, and I am very grateful to them.

And that is the primary message that I want to leave with you today. Deafness is not the handicap; the real disability is the inability to communicate. So let's communicate knowing that's the way it is. Now where do we go from here?
Balancing Act

Carolyn Piper

(ALDA News, vol. 9, no. 2, Summer 1995)

It's been years since I've been able to hear music, having gone deaf some twenty years ago. I miss it terribly. I vividly remember lying under the stars at a Texas campground listening to "Hey Jude" drift lazily through the air. I remember the toe-tapping rhythm of Henry Mancini that I grew to love in college, and the heart-stopping beauty of a well sung "Ave Maria." Though I have come to feel that deafness has brought many blessings as well as problems to my life, the absence of music is a loss that I have never been able to come completely to terms with.

Through the years I have tried hard to learn to enjoy music using hearing aids and, eventually, a cochlear implant. No matter how I fiddle, however, music continues to be ear-numbing noise rather than the soul-lifting beauty that I remember so vividly. In time, and in desperation, I turned to inner concerts; playing memories of melodies through my head, and singing aloud while alone and not subject to remarks from little pitchers that run along the lines of "Good God, Mom's trying to sing again!"

I often ask deaf friends how they deal with this problem, and can only accept incredulously those who tell me they still enjoy what they can hear of music, especially the rhythm of the beat. I even know one woman with a loss in the 110 dB range who is taking piano lessons! Bound to the past, by the memory of the fluidity and beauty of the music I remember, I cannot understand this at all. Perhaps this is due to the magnitude of my own loss which is so total that it does not register even the loudest tones on an audiogram. Perhaps it is due to failure on my part to adapt to changing circumstances. I only know that no matter how hard I try to appreciate music as it sounds to me now, I cannot do so.

Yet, the other day, I heard it once again. As I lay in bed at dawn, half awake and half asleep, a melody of music swelled up within my head, deep down on the lower right hand side. (I know no other way to describe it.) As I lay there slowly emerging into consciousness, I realized I was listening to this melody--not imagining or conjuring, but listening. It was not remotely similar to my ever-present tinnitus. It was pure music as I had never heard it before, not even in my well-mourned past; playing a concert of beauty that I could not even have begun to imagine on my own. As I came fully awake, it gradually faded away, and was gone.

Where did it come from? I have no idea, other than I know it originated in a place over which I have no voluntary control. Some might say it was angels, playing a special concert for me. Others, undoubtedly, would call it auditory memory. As for me, I prefer not to speculate. Rather I prefer to accept the fact that it was an odd and glorious happening. Another layer of experience given to me in this life without sound. Another blessing to balance the loss.
My First Time
Larry Littleton
(ALDA News, vol. 9, no. 3, Fall 1995)

What could be more wonderful than finding a long lost family member? What would it be like to find not just one family member, but, god forbid, a whole convention of them? I found out at ALDAcon '95 in Rockford, Illinois.

Okay, so what if I didn't get the scholarship I applied for, and so what that I didn't have the registration stuff taken care of when I arrived? When one finds long-lost (or is it newly-found?) family, he has to try and make up for the lost time in a very short period. I spent most of my effort making up for lost time and finding people who, like me, had experiences of hearing loss similar to mine—people who were my age, and who grew up with the same songs and music I did!!! Mind you, there were many others who had very different experiences than my own, but that's what makes a family, right?

I presented a workshop entitled "Navigating the Corporate World." It was my first workshop as a self-employed speaker. I was pretty confident about my subject, since I was speaking about my own experiences. For the past 18 years, I had "navigated" my way through one of the largest utility companies in the United States. While employed there, I was trained in public speaking, and had presented more than 400 speeches. Now, the difference was, I no longer had a job with them, so this was "my first time."

I was touched when I invited the audience to share their experiences with the group. Specifically, when Bob—a guy I knew from only one brief encounter—related his thoughts. Bob stood up and thanked me for some committee work I had done for the California Relay Service (CRS). A guy whom I barely knew, but who obviously was aware of my efforts, thanked me!

Now, for some of you, this might not seem like a big deal, but for me, it was! Why? Because for years, I have volunteered my time, my energy, and my ideas to work with the deaf community, and never has anyone thanked me before (other than for politically correct reasons!) That thank you was from the bottom of Bob's heart. The guy made me cry, for god's sake, in my own workshop!

I went to Fred and Cheryl Heppner's, "Late-Deafened/Hearing Couples." How I wish my wife could have been with me for that one. It was great! It was fun, educational, and inspirational. Later, I had the honor of having Fred and Cheryl sit at my table for dinner. Again, I found people who, like me, knew what it takes to make a marriage successful. And we discovered we were all sailors. Getting a group together at a table and talking about sailing is my kind of an enjoyable evening.

Some of you will only remember me as "the guy who got his tie cut off at the magic show." Hopefully, I made some other sort of impression on you.

The karaoke party ... well, that was the "party-of-all-parties" for me! Never before had I seen so many people, all of us with some degree of hearing loss, have so much darn fun singing! I grew up with music. I know it, understand it, and appreciate it as much as any hearing person does. Standing up there with so many other people who love music, and being provided with the lyrics, was just great! You definitely had to be there! There were four weddings in the hotel that night
and one of the brides from the wedding parties upstairs came down to boogie with us. She said, "Your party down here is better than mine. Can I dance with y'all?"

When I sat down, (and I only sat down for a few minutes, as I was up there with Ken Arcia and Steve Larew doing our improv of "The Sex Machine"... whew... you had to be there!) I experienced my most touching moment of the evening. I glanced across the room and saw one person say to the other, "I can't get the music. I can't feel it or hear it." I immediately jumped up, ran to my room, and brought back three balloons. I inflated one, gave it to this lady, and told her to hold it in her hands and "feel" the music. I walked back to my table, and watched her. She was so amazed! I could see the glow in her face beam up. She later came to me and said, "I used to be a music major. When I lost my hearing, I never thought I'd be able to enjoy music again. You have just taught me something I will never forget."

Right then, I cried again. I don't know why... but the feeling of understanding, acceptance, love, and support all came together. It was a very touching moment for me... something so simple - a balloon could bring so much joy back into a person's life! Not two minutes later, Edna Shipley-Conner came back into the room with a handful of balloons to pass out to people who wondered, "What the heck are those crazy California people up to now?" Edna had raided one of the wedding parties upstairs to retrieve all the balloons.

I even learned the words to songs I had never heard before, and the words made me think of my wife, and for god's sake, I cried again! I have never in my life sang so many songs at one place. The whole California Bunch sang "I Left my Heart in San Francisco," "California Girls," and "Sitting on the Dock of the Bay." Boy, did we kick it up! I cannot wait for the next ALDAcon, which, by the way, will be in San Francisco and is guaranteed to be a blast!

I've been to hundreds of my own family gatherings in the past. I've stood in a room full of people, and felt so alone. At ALDAcon, you are never alone, even if it's your "first time." I want to thank you all, every one of you, for your love, support, understanding, and acceptance. I'd also like to thank Greg Kimberlin, my pal and ski partner, for encouraging me to give ALDAcon a try.
Damn Your Deafness

Carolyn Piper

(ALDA News, vol. 9, no. 3, Fall 1995)

Patient child what growth you bring.
Striking out against my lack,
as ready smile and careful speech
become those rolling eyes,
with voice so high it wounds the heart
that hears what ears cannot.

Someday perhaps, you'll understand
the tears I cry within.
Dependent now, on grace without,
or growth within,
when grace is nowhere seen.
The subject of my presentation is cochlear implants--particularly the history of the implant in ALDA, in my life, and what all this means to the free world. This is obviously a very timely topic for me. I was hooked up with the implant just two days ago and have spent the last two days getting programmed. And that's why I am a weekend warrior here. I've been held hostage in an audiologist's office. This is my first day with the implant without clinical supervision. I'm very, very new with this gadget, and if something goes wrong I might need some help. If the side of my head starts smoking or my eyes start to glow, please let me know and I'll see if I can adjust this thing.

I don't think it's a secret that cochlear implants have been a source of tension in ALDA. Maybe some of you are even a bit nervous wondering what I'm going to say up here. ALDA was built on the concept of accepting each other and ourselves as deafened people. By meeting and sharing with other late-deafened adults, many of us find a place where we fit in just as we are and for the first time internalize the simple but elusive reality that it's okay to be deaf -- that we don't need to hear again to have a full, enjoyable life. Perhaps nothing better exemplifies this ideal than ALDAcon. And that's why we keep coming back.

On the other hand, late-deafened adults make up the prime market for cochlear implants. We come from a hearing world, not a deaf world. Not hearing, for us, is a loss. The lure of implants is, understandably, very strong. I don't know many late-deafened people who wouldn't want to hear again if it could happen magically, without head surgery, without electronic gizmos, and if the sound was perfectly natural. If there was a magic wand for hearing, I think we'd all get in line in a minute.

But there isn't. So for many late-deafened people, implants create tension and a great quandary. Should I get an implant, or shouldn't I? Is the implant my salvation? Or is it a return ticket to limbo? Is getting an implant courageous? Or does it mean I'm too wimpy to live with my deafness? Will my ALDA friends still like me if I get an implant? Will I still like them?

I've seen this tension played out many times in ALDA, almost from Day One. The first institutional support that ALDA received was from a cochlear implant center. In 1988, when ALDA was in its first year, Mercy Hospital--through its A. C. Buehler Foundation Cochlear Implant Center--began to copy, sort, staple, label, and mail the ALDA newsletter, *ALDA News*. I was delighted to have Mercy's help--happy to find help of any kind for our fledgling organization--but this relationship with implants ruffled the feathers of some people in ALDA--some of our best-known leaders--who thought it an awkward marriage. And it eventually proved to be so. For a long time, though, I had no problem with the situation, and I often had to defend ALDA's connection with the implant center.

Another example...as most of you know, *ALDA News* has a long-running feature called ALDAnonymous. Each issue a question is asked relating to late-deafness and readers send in responses that are published anonymously, without editing for content. This provides a nice snapshot of how late-deafened people think and feel about a subject. And that's all it's supposed
to be: a realistic snapshot, not an editorial or a fact sheet. Well, in one issue the ALDAnonymous question was the same one being asked in the present issue of ALDA News: "Would you get a cochlear implant? Yes or no?" I think the responses five years ago were pretty evenly divided between "yes" and "no". But this column infuriated a number of implant users who read the newsletter. They angrily insisted that some of the "no" responses contained serious misinformation about the implants. They chastised us for publishing such misinformation in ALDA News and demanded we print corrections and even apologies in the next issue. It was the first -- probably the only -- time that the newsletter received rebuttals to ALDAAnonymous. Ooooh, sensitive, sensitive issue, these implants.

We didn't apologize. Rather, in a subsequent edition, Marylyn Howe wrote an essay critical of advertisements for cochlear implants that seemed to make somewhat inflated claims. Well, that essay hit Mercy Hospital like an atomic bomb. Soon after the hospital received the newsletter for copying, one of the administrators there called me up -- which had never happened before -- and insisted that we allow her to attach a rebuttal or disclaimer to that issue or they wouldn't mail it for us. Naturally, this intervention made Marylyn -- who wrote the essay -- livid. And as the editor of ALDA News, I was angry to have any type of outside censorship threaten the newsletter. I eventually relented and the newsletter went out with a disclaimer about Marylyn's essay. But our relationship with Mercy had been seriously fractured, and within a year ALDA was publishing the newsletter without their assistance.

Faced with such disgust and indignation about implants, it was perhaps only natural that we privately began to poke fun at cochlear implants. For example, many people who use implants give glowing testimonials about how well the devices work. In an unusually large number of these testimonials, the implantee mentions their ability to hear crickets with the implant. I'm not sure why this animal gets singled out all the time--maybe now I'll find out--but the sound of crickets seems to be the number one sound reported by implant users. And every time we read about implants, we'd read about crickets. For some of us ALDAAn, it got to the point that just saying the word "crickets" would make us convulse in laughter. When someone in ALDA got an implant, we'd say things like: "Does she hear the crickets?" or "His implant works so well he hears crickets in the middle of winter."

Here's another example of our implant humor: During ALDAcon in Boston a few years ago, a group of ALDA leaders went out for dinner one night. We walked through Boston Commons and Beacon Hill, and an ambulance or police car went by with its lights blaring and somebody -- maybe it was me -- signed: "It's the implant police, run!" And over dinner, that phrase wouldn't die, and so for some of us the term "implant police" became a part of our laugh track. We'd tease each other with warnings like: "The implant police will get you if you don't watch out" or simply say "They're cominnggg." 

One month ago the implant police got me. A lot of people were surprised. I think even my wife was surprised at first. I had to mention to Karina several times over a period of months that I was interested in getting an implant before she realized I was serious. But when she understood I wasn't joking, she became very supportive of my decision. I guess that's not too surprising. Some of you may remember the essay I wrote in ALDA News about holding Karina's nose to understand her voice better. That can't be too much fun at her end. Maybe she's secretly been telling the implant police about my whereabouts all along.
My implant journey goes back many years, almost to the dawn of cochlear implants. I'm an editor at The World Book Encyclopedia, and I've been in charge of the encyclopedia's medical coverage for more than 13 years. Not a whole lot of medical-related stuff gets by me. And implants sure didn't. In the early 1980's, I received a press release seeking participants for cochlear implant studies being conducted at the University of Utah. I wrote to them, they sent me a questionnaire, I filled it out and sent it in for evaluation. They wrote back telling me that my hearing loss—at that time—was not profound enough to qualify for this study. I hate to be unqualified for anything, so I was somewhat disappointed by this snub, but I got over it pretty quickly—the idea of cochlear implants seemed pretty weird back then.

Over the next several years, relatives and friends sent me articles about the implant that they had clipped from newspapers and magazines. I think once I got the same article from four different people. They were all very well-meaning, I'm sure, but it started to get bothersome. After all, according to the University of Utah, I wasn't a candidate for the implant. And I always wondered if they were sending these clips for me or for themselves. I had learned sign language and could interact pretty well using it, but they hadn't. The implant gave them hope that they would be able to communicate with me without making special accommodations. It seemed a form of denial, and I was tired of denial.

After ALDA began 8 years ago, I started to meet cochlear implant users. These were the true pioneers—the Apollo astronauts—of the industry. They had single-channel implants and first or second generation speech processors. I have to admit I wasn't too impressed with most of the early implant users I met. Their receptive communication skills often were pretty poor. To make it worse, a lot of them would bluff when I tried to talk with them. It's hard to bluff with me. If I'm an expert at anything it's bluffing. Been there, done that—for too many years of my adult life. And bluffing by late-deafened people—especially here in the friendly confines of ALDA—is one of my biggest pet peeves. So these implant people who bluffed tended to get on my nerves and gave me a negative impression about implants. I mean, why should someone pay $35,000 to do something I did for 15 years for free?

On the other hand, some of the implant trailblazers plainly got good results with the devices. They must have impressed me quite a bit because in 1989 I was evaluated for an implant at Mercy Hospital. I think I was in denial then about my fascination with the implant. I told myself that I only wanted to go through the evaluation process to see exactly how profound my deafness had become and because I wanted to have that CT scan. That's what I wanted—the CT scan. I never had any type of medical imaging done on my head and I reasoned that maybe there was a simple, curable cause for my deafness that my doctors hadn't been able to diagnose with standard otological tools.

The CT scan found nothing unusual. But the doctor at Mercy did determine that I was an eligible candidate for the implant. Clinical proof of my profound deafness! I felt like sending a postcard to the University of Utah saying: "So there!" or "Touche!" . . . I didn't get the implant in 1989. Back then, I didn't think the potential gain was worth the trouble.

And here we are six years later.... and I have a loop of metal in my head, a computer on my belt, and wires attached to my scalp like an IV. I sing the body electronic. Why did I stop ducking the implant police? What had changed since I so easily said "No" to implants in 1989? Why did I decide to get a cochlear implant? Over the past few months, a whole lot of people have asked me that: Why?
Well, I had plenty of reasons—some of them very complex and extraordinarily well thought out—and I could take up the rest of this hour enumerating and explaining them. Maybe you want to meet me at the bar later. But what it basically boiled down to was hardly remarkable: I got the implant because implant technology and results had improved dramatically, because I found an experienced implant surgeon who I had confidence in, and because—well, because I wanted to. I just wanted to try it. I was curious—fascinated by the technology of the implant and intrigued by the possibility of hearing some speech—even if only in a one to one situation in a quiet room. I had grown increasingly weary of the demeaning attempts at conversation that I had with most people on a daily basis. If the implant could help a bit there, I wouldn't care if I heard crickets or not. After I began to give it serious thought, the decision to get an implant was actually very easy.

That's not to say that I haven't had ambivalence and anxiety along the way, because I certainly have had plenty of Angst—about the operation, about whether the device would work, but most of all, I was concerned about the ramifications if the device actually did work well. Nowadays, some implant users can pass for hearing people. Late at night, I pondered the prospect of such success and the changes they would bring to my life.

It took me many years to become comfortable with my hearing loss, and I only did this through ALDA—by meeting other people like myself. Finding my identity and some peace of mind as a hearing-impaired person was a long, disheartening struggle. I worried that getting the implant might push me into another existential limbo. I worried too about all the wonderful relationships I had developed as a deafened person. It's easy to rationalize that a change in one's hearing status won't change anything between friends. But I had seen many of my relationships gradually wither when I became deaf—the dynamics of relationships change with a change in hearing. Look at the fragmentation in the deaf and hard of hearing communities. Auditory status can influence relationships profoundly. So I worried about it.

We all know the disadvantages of losing our hearing—they are pretty obvious. People can be rude—even nasty—about deafness; deafness can make the simplest tasks challenging—it's hard to be a completely independent, responsible adult as a deafened person; deafness pushes people away from us, isolates us, and so on.

There's no question deafness has its drawbacks. But if you've been deaf for a while you come to realize that deafness also has certain advantages. For example, maybe people can be rude about deafness, but they also can be extraordinarily nice. You can get preferential treatment in many situations, just by being deaf. Have you ever gotten out of a traffic ticket because the cop couldn't communicate? It happens.

And sure, our occasional dependence on hearing people interferes with being a responsible adult. But do you always want to be responsible? Isn't it neat to be out of the loop sometimes? A big fight with the relatives? Let the hearing spouse deal with it. Need to find a golf course with an open tee time on Saturday morning? Let the hearing friend call around, the relay service is too slow. Deafness can be a welcome mandate for irresponsibility.

Deafness does indeed push people away from us—and that's unfortunate. But is it always bad? I mean, do you really want certain people around? Salesmen, panhandlers, in-laws, politicians, perverts, Hare Krishnas...deafness keeps them all at bay. Being deaf is like having a Doberman with you 24 hours a day.
Another nice thing about deafness -- and it may take years to appreciate this -- is the silence itself. I became so used to not hearing things that the idea of suddenly having sounds jangling at my auditory nerve made me cringe. There can be a calmness and solitude in deafness that a lot of hearing people probably would pay good money for.

In the weeks immediately after my surgery, with the implant hookup imminent, I was in no hurry to get to the Big Day. Most implantees, I think, find the five or six weeks to hookup interminable. They're excited, eager to be connected and possibly leave deafness behind. But I was in no hurry. Leaving deafness -- if that's what would happen -- would not be a 100% positive thing for me... there would be some loss attached. I was terribly irritable in the weeks before hookup -- Karina had never seen me so testy and temperamental. I had unpredictable temper tantrums -- at times I didn't know what was coming over me. There was a sense of impending loss about possibly leaving the deaf world. For those of you recently deafened, I must sound absolutely crazy.

So what's the bottom line here, now that I'm hooked up? Does the implant work? Do I hear crickets? Well, it's too late in the year for the crickets, and too early to tell for the implant. For sure, I'm not an overnight sensation. It takes most people a long while to get good results with the implant and I'll just have to be patient and persistent. But I already have had the enormous thrill of hearing Karina's voice. I've never really heard my wife's voice before. These last two days I've felt so much more connected to her. It's been like falling in love all over again. I don't want to go to work anymore, I just want to stay home and listen to her voice. I guess this will eventually become an everyday thing, but right now it's very exciting. Beyond that, my victories in listening will clearly take some time.

But what happens if I do become a highly successful implant user? Where will that leave me? Will it make me a hearing person? A born again hard of hearing person? Will it mean I'm out of ALDA? I have an implant police record now. Am I out of ALDA? No longer a late-deafened person, now that I can hear my wife's voice, and potentially a lot more, with the implant?

In the early days of this organization, an enormous amount of energy went into trying to define what late deafness means so that we'd have some baselines for ALDA membership. I bet a lot of this still goes on. It's important to define the population you serve. But in ALDA, this can be tricky. The boundaries between hard of hearing and deaf, early deafness and late deafness, can be argued forever and a day.

ALDA has never been defined strictly by functional parameters. There are ALDA members from many areas of an audiogram, and the age of hearing loss among the membership is so broad as to be virtually meaningless. To me, ALDA represents an approach to hearing loss--a philosophy--one that is based on openness and candor about ourselves, and patience, understanding, tolerance, and respect for others in the same boat. The glue that binds this organization best is an attitude--an atmosphere--that accepts and embraces each one of us exactly as we are. Many people come to ALDA wounded by hearing loss. Their lives have changed seemingly beyond their control, and they feel that they'll never be able to accept it. They feel vulnerable and alone. ALDA provides a safe harbor, a place where others reach out to them, tell them it's okay, and accept their changes without question.

This is my public debut with the cochlear implant, and I feel fortunate to be making it among ALDAns. This implant experience so far has been quite strange, and I feel very vulnerable. There's no group I'd rather be with when I'm like this than ALDAns. No group I'd rather share my feelings with, no group I'd dare expose myself to quite so openly at the start of this transitional
phase of my life, if it be that. Not my relatives, not my coworkers, not my old hearing friends. You've always allowed me to be myself--whoever that is--and talk from the heart of my crazy late-deafened soul, and it helps keep me honest with myself. With or without crickets.
"Mommy, You're Deaf"

*Candis Shannon*

*(ALDA News, vol. 10, no. 1, Spring, 1996)*

"Mom, my back's sore. I think I hurt it." Carolyn rubs the tender spot behind her right shoulder blade and I know why my right side feels stiff and awkward. The bond I share with my daughter passes through the artificial boundaries we create for ourselves. The connection brings me great joy, now that I can accept myself as the imperfect role model that I am.

Carolyn was ten months old when I lost my hearing. Meningitis ravaged the insides of my cochlea, leaving only loud tinnitus behind. Most of what Carolyn knows about me is shaped by my deafness.

She fares well during those early months of my recovery. After the illness, others help with daily chores. I learn to walk again, as I learn to use my eyes and body for the balance my ears used to provide. We install a light that flashes when Carolyn cries, a doorbell light and phone light, too. But then I miss seeing her signal light, and others rush to share their concern for Carolyn's safety. A cold blocks Carolyn's nose and I'm the last to know. "Can you tell if she's coughing?" the others ask. "Her cry sounds really raspy." I see their eyebrows furrow and I bow my head, doubting my competency.

As I grow stronger, personal shadows and newer crises pull the others away. During the day, I hold Carolyn close, keeping her where my eyes can see. I save the tears of grief for four a.m., standing over her crib, and then her bed, my hand on her chest to feel if she still breathes. During the day, I buy books on how to parent. At night, I search them for answers I cannot find.

I don't remember my daughter's first spoken words. I have it written down somewhere. I do remember my daughter's first sign—the one meaning "happy." I hug her warmly after she makes the sign, hope shooting up my spine. The sign "happy" moves on to shoes, food, cat, mother—love. I teach her signs the same way I learn them—slowly and with great spaces in between—spaces filled with grief that block the natural process of change. Years later, I meet others deafened as adults and find they, too, balked at learning sign. Sudden loss of hearing chokes the throttle and clamps down hard—for our protection, I assume.
Carolyn turns four years of age in early morning, and the smell of delphiniums carries across the bathroom window sill. She splats toothpaste on her front tooth and watches me with interest as I roll paste smoothly onto a blue toothbrush.

"I'm deaf," she announces, lifting her chest.

"No, you're hearing. I'm deaf."

She pauses, puzzled.

"See, it's like this. Mommy wears glasses to see better. If I take the glasses off (I take the glasses off), I can't see you very well. If I put them on (I put the glasses on), I can see how pretty you are. You don't need glasses, because you can already see well."

"I want glasses," Carolyn peers at the brown frames, climbs up on the toilet seat, and clumsily attempts to pull the glasses from my face.

"Oh, brush your teeth," I laugh. Carolyn giggles, frees the frames, uses me as a bridge to the sink, stands up to face the mirror, and plops the glasses on her face. "You missed your ears!"

We drop laughter on each other. Deep inside I worry, vague recollections of various readings clogging my mind. Parents imprint themselves on their children. The mother continues to be a womb, the source of energy and possibilities, a harbor for her children. She's a bridge to the mother earth. My stomach churns. How long, this unasked-for path through the labyrinth of grief and growth? Surely I can reach out for a smoother road and find the key to the magic garden. I brush my hair instead.

School days arrive. The first year, I can drive Carolyn to an out of district school. The teacher knows sign language, the deaf education program is housed in the building, and I feel a part of Carolyn's new world. The second year, however, the separation cuts deeper as Carolyn transfers to the school of her friends, her neighbors. We make an early trip to meet her teacher.

"Hello, I am Carolyn's mother. Carolyn is excited to be attending here." The teacher stands a few inches taller than me, hands crossed above the small vertical stripes on her slacks. I look at the woman with care, assessing her face and her lips. She smiles and begins to speak. I stare at the words, as if by holding on tightly, I will understand what she has to say.

I don't understand. My nose itches. I itch my nose. I get distracted. She seems to be done talking. My turn again.

"Oh, yes, I'm sure ... wonderful ... uh ... can you repeat that please? I'm deaf and you need to enunciate clearly for me."

She repeats. I still can't understand. My face flushes as I ask her to write for me. She makes a start for paper, then turns to Carolyn. They have a lovely conversation, or so it seems. I burn under a pasted smile of encouragement, and then leave, vanquished and subdued. I withdraw. The school provides sign language interpreters, but I ask for only minimum coverage: the teacher-parent conferences, the concerts of music and song. I'm comfortable with sign language now, but not comfortable with the world in which I used to communicate so freely. I depend on the weekly parent letters that the teacher sends home. I get by.
Carolyn enjoys going to her school and being with her friends. She rides the cold weather bus, arriving home with the bus strobes flashing in the winter dark. She brings me smiles, but she no longer signs. The world surrounding her is full of noise and wondrous activity. The world surrounding her speaks; it does not sign.

"Hi, Carolyn. How's it going? I missed you today." Carolyn hugs me and then dumps her snowpants and backpack by the door. She's excited about something. I see her lips moving, her eyes dancing. I want to know what she is telling me.

"Carolyn, please sign for me," the sound of my voice rises in frustration. "I want to know what you are saying."

I am not to find out what Carolyn is saying. Instead, more words stream towards me, biting at my skin, slipping under my fingernails.

"Carolyn, I can't understand you!" my voice pushes back at her, matching her intensity.

"That's - because - You're - deaf" Each word slaps at me, the enunciation clear, the meaning clear. The slam of the door as Carolyn tears into her room reverberates through my heart.

I remember my parenting readings. I remember words by Joseph Chilton Pearce. "Sight is the great synthesizer," he claims. More of the brain occupies itself with seeing than with the other senses. I remember the comfort those words gave me, and I stare at the closed door, wishing with my deafness and my dependence on sight that I could synthesize Carolyn's disparate worlds for her. I stare at the closed door and wish that I could hear.

Second grade. Third grade. Fourth grade. Carolyn does okay at her neighborhood school and I continue to ignore the words collecting, unopened, between the vertebrae of my spine, unsure anymore which words come from forces outside me and which words originate within, unsure that grief ever ends.

"Carolyn has a tiny voice." "I can barely hear her in class." "She gets distracted easily." "Such a sweet child, but she needs to be more assertive." The words, whether voiced or written, settle deep inside, and I again doubt my competence as a mother.

It's just a genetic trait. I'm soft-spoken; at least I used to be back when I could hear. I'm just modeling who I am. But the words collecting inside push at me and weigh me down until I end up at the chiropractor's office, returning home with a list of back exercises to perform. I make an appointment with the school counselor.

I lean into the counselor's face, wishing counselors would use brighter lights in their rooms. "I'm thinking of moving Carolyn back to the original school she started in. They have a special program where hearing and deaf children learn together. Everything is done in both spoken language and signed language."

"I think you should." I lean back in surprise. "You have a right to be able to communicate well with your daughter, and to be able to participate fully in her school program." He speaks quickly yet clearly, as if he is trying to go back and re-enunciate each word after he has already spoken it.
"Let me make sure I understand you." I repeat his words. I'm distracted by his speaking style and by a wonderful flow of relief, but I have understood. The transition process to the other school begins.

Carolyn meets the announcement with little resistance and fifth grade turns into a year of smooth adjustments. Whether Carolyn wants to please me, or genuinely enjoys her new/old school I cannot determine, so decide a combination of both issues likely to be the truth. The days form a welcome routine and good communication - that case of listening and sharing - becomes the norm.

"Mommy, everyone signs!" and by everyone, she means the teachers and the students, her new friends. "And I like it when you come and visit."

Visiting the class is fun for me. I especially enjoy pulling up a chair beside Carolyn's classmates. They teach me new signs. I share my ideas for their many projects. During the "Wagons Ho" presentation on prairie life during the wagon trail days of our country, the students cook dinner and perform a skit for all the parents. I eat up much more than food alone.

Yet, as the year moves along, I feel increasingly unsettled. My growing knowledge of issues pertaining to and my own participation in the Deaf community hold the key. Deaf activists spend much time protesting education policies for deaf children.

Deaf education, they claim, is unbalanced, with an unhealthy over-emphasis on speech training. Other subjects do not receive the attention they deserve. Students, mainstreamed in public schools with support from sign language interpreters, feel isolated from their fellow classmates. I know the specifics of the arguments don't fit the reality that Carolyn learns in - the program she is involved in has been blessed as a breakthrough, successful innovation. However, the essence of the arguments stirs my thinking. The essence seems to claim that school policies try to make deaf children something they are not - hearing. I sit in Carolyn's classroom and watch her body attempt to follow the signs of her hands and wonder what I and others are modeling for her. How much of this is she doing just for me? How much of this is she doing to be deaf like me?

The temperatures warm. Water runs over the ice as I chip away, attempting to make the porch passable during the spring thaw. Someone taps my shoulder, and I turn to catch Carolyn's grin. She's returned home from a neighborhood slumber party.

"Oh, I didn't hear you come home." I lean on the shovel. "Did you get any sleep at all?"

The grin widens as she tosses the hair out of her eyes. "Of course you can't hear me. You're deaf!"

We laugh.
"I had a good time. It was sooo much fun. Mommy, I miss my friends from here. I never get to see them anymore." Carolyn looks down, toeing an ice chip as if attempting to launch it.

"Well, I wouldn't exactly say that. Your best friend lives two houses away, and another just one block over."

"But, it's not the same!" I can see Carolyn's voice begin to increase in volume, keeping pace as she signs "not same-as."

"I know." Carolyn stops midstream toewise and same-as wise and looks at me. "You're right. It's time for you to go back to your own school and friends." I tell her. "Next fall."

Silence.

"Just do one thing for me. Don't be ashamed that you know sign language and don't hide that you know sign language."

The ice floe begins moving again.

"My friends will think sign language is weird."

"Teach it to 'em. They'll love it. You can even use it like some kind of secret code or something. Everyone's going to be coming up to you wanting to know signs for different stuff."

Carolyn pauses and then nods. Satisfied. "Yeah. Cool."

That fall, she returns to her own school, her own life. My breath catches as I remain behind, watching her leave, my hands fingering a design on the living room window.

But I do still have a significant part to play. I teach sign language to her class, an inch taller when I enter the room, and she rushes to greet me, face open, inviting. That day I teach the signs for animals. She raises her hand to volunteer a sign, then hesitates and holds back. I wait, filling the space with encouragement. Thumb and forefinger together, the rest of the fingers spread open, she tentatively traces the sign for cat along imaginary cheek whiskers beside her chin. Then she drops her hands and giggles, eyes peeking at another girl copying her sign.

"Carolyn does very well with her peers, but still lacks assertiveness skills in structured classroom situations," the teacher-parent conference notes read. I have done what I can to help. In most daily occurrences, communication barriers have kept me from modeling the behavior Carolyn needed to see. With time I have learned new ways to meet these barriers. Perhaps that will help, perhaps others will provide that instruction or Carolyn will find it within herself.

Seventh grade. I receive a newsletter announcing an upcoming performance by Geri Jewell. I remember Geri from her recurring role on The Facts of Life, a popular Norman Lear television comedy that aired in the early 1980s. Geri has cerebral palsy and is one funny entertainer. I buy tickets, one for myself and one for Carolyn.
Carolyn does not know what to expect. This is her first experience of a live comedy performance. I watch the jokes through a sign language interpreter. Carolyn watches Geri, tapping my shoulder to emphasize anecdotes she especially likes. Our mutual favorite turns out to be the restaurant story. In the story, Geri attends a restaurant with a deaf friend and the friend's hearing guide dog. They explain to the manager how the hearing guide dog acts as "ears" for her master, letting the person know when the doorbell rings, etc. The friends sit down and pick up their menus while the dog finds a place underneath the table. The manager rushes to the server, instructing her about the significance of the hearing guide dog. The server then heads for the table, lifts up the tablecloth, and yells out her request for the order to the dog.

Carolyn spills out her laughter on my arm. I breathe in her excitement and applaud. Afterwards, we are invited to a reception for Geri upstairs. Art and photography from local high school artists perch on the walls; pastries, smoked salmon, and wafers rest near shiny serving tables and silver coffeeware. I search for a group in which to blend. Carolyn takes charge.

My eyes follow her, trying to maximize the incoming delights. After collecting autographs from Geri and the two comedians who opened the performance, Carolyn initiates conversations with others in the room. One hand lifts her plate and the other hand gestures in synchronicity with the movement of her lips as she speaks with a woman dressed in sequins. I see her facing paintings with a man, earnestly discussing the view at hand. A friend approaches me. She, too, has noticed the sudden transformation. We watch a moment longer, then turn away. "Come," my friend takes my arm. "Let's eat some cake."
Courage

Carolyn Piper

(ALDA News, vol. 10, no. 1, Spring, 1996)

I hardly know what to say,
to do,
to think or laugh or cry,
when someone comes up to me
and whispers in my ear:
"You're brave," they say
"I couldn't be deaf, I'd have
no strength to be."

Should I let them know the truth?
Show night's loud underside,
awash with prayers,
remembered tunes,
and music on a beach?

Or should I tell them how instead,
while ambling along,
life took ahold and snatched me up
and shook me back and forth?
Releasing me when all was done
into a different place -
where sound was dim and music screeched
and loneliness was kin.

Or,
perhaps, I simply should just say
that life withheld the choice,
and courage sir, for this one thing,
is just another word.
Stone Deaf

Melanie Sexton


When I was fifteen, I could no longer pretend that something was not wrong with my hearing. The definitive moment came in physics class. I was used to failing tests in physics. I never could relate to what seemed at that time to be pure abstractions, applicable to my life in no way I could make sense of. I was not prepared, however, to fail a simple demonstration of equipment. The teacher Miss Harris, a powerful no-nonsense woman with a firm grasp on the laws of physics and an equally firm grasp on her field hockey stick - told us to put up our hands when we could no longer hear the tone emitted by the sound meter she was demonstrating. I saw hands go up around me before I even knew we had begun.

You can only bluff when you have at least a dim understanding that you are in a situation that calls for bluffing. I was caught out. Brought to the front of the class for an individual test, this time I faked as well as I could. With relief I escaped as an excellent illustration of the limitations of the textbook concept of the "normal" range of ability to hear high frequencies. I had pleased Miss Harris.

But inside I knew it was bad news and therefore something to be concealed. I'd always been dimly aware that I had some kind of nameless problem no one had ever quite formulated, that I was in some way different. Looking back now, I see how many of the strange puzzles I faced in life were really no more than the result of a hearing loss. As a small child, I had amused my parents by stubbornly insisting on calling my favorite fairy tale Snow White and the Seven Dorfs. Various expressions I picked up got new twists on my infant lips, such as "adding for nightam" which is what I understood for "ad infinitum." On one occasion at school at Christmas time, I was deeply perplexed when we were called on to rehearse our greeting to the mayor who was about to visit. I could not decide if we were to shout "Happy Christmas Mr. Mayor" as seemed likely, or "Happy Christmas Mr. Bear," which is what I heard every time we rehearsed. On another occasion when I was five or six, I scrambled a message to the headmistress from my mother who was a lunch attendant at my school. I can still feel Miss Bamard's contempt as she shaped her lips around her assessment of me: "stupid child." At such a young age, my quirks and errors were easily put down to a childish lack of grasp on the language. But only now can I explain to myself why people's responses to what I said were a source of such bewilderment: I heard no difference between what they said and what I repeated back.

My high school, a hard-driving academic school for girls in the South of England, was the scene of even more painful problems. I specifically recall my German teacher making me repeat the pronoun "Ich" in front of the class. Again and again I repeated: "ick, ick, ick." Rebuked and despised in that class for my incorrigible impertinence, I cannot see a German word even now without a trace of the old shame and blind panic rising to my throat.

My intermittent complaints to my father that I could not hear certain sounds were met with a standard response, "You hear perfectly well when you want to hear." This, despite the fact that my sister -almost fourteen years older than me - had a severe hearing problem that had shown up when she was in her teens and had become progressively worse so that she was almost completely deaf.
Why my father's denial in the face of the luminously obvious, his insistence that hearing is an act of will, not audiometry? He was no doubt afraid to face the reality. But it was something more complex than that too. A kind of tunnel vision that has its roots in the folklore of rural England where he grew up. The cryptic lore was applied unselfconsciously and forcibly to many situations and determined how to conduct yourself in public and how to manage your health. (My complaints that I could not see the blackboard had been fended off for several years with the observation that "once you start wearing glasses, you'll always have to wear them." It's true actually. I can't imagine willfully returning to the blur that was the physical world before corrective lenses.)

What my father's philosophy seemed to say reduced to crude terms - was that if you had a pain in your foot, you simply hobble. If your will is not strong enough to keep you going, you capitulate and accept the label of cripple. Deafness carried special dimensions. Deaf was dumb, and dumb was a stone's throw from the village idiot, the shame of his relatives. Pride in deafness was a concept as alien as the notion that people without legs might sprout wings to take them where they want to go. There was no beating around the bush with dignified terminology, either. You were "deaf as a post" or "stone deaf." These terms seem to me now singularly appropriate to describe how deaf people were seen: objects with no external reality anyone could penetrate.

So, hearing was an act of will, and through my teens my will continued to fail. My mother died when I was ten and my formative years between ten and eighteen were defined solely by my experience with my father. Even after my deafness was properly diagnosed - initially by a doctor who held his watch to my ear - the response of family and even doctors was, it seemed, to ignore it as long as possible. My sister's life did not instruct me much about deafness. Anxious to escape, at eighteen she had defied my parents and got married, shut herself in a cottage in the country, and proceeded to become the mother of two children. She lives there still. Deeply attached to her family, she has not watched TV or used the telephone in more than fifteen years. She walks her dogs. She digs her garden. She will not travel. For me, she is a version of myself in some alternate reality.

At eighteen I went to Stirling University in Scotland. It was the beginning of a long journey on which I first recognized, and then shed myself of, some of the crippling notions that undermined my self-image. But it was an early stage in that long journey. Social interaction was, for the most part, another of those bewildering puzzles my childhood had familiarized me with, only this time it was more complex, and much more was at stake. Whenever I could not deal with it, I took off on my bike and explored the country around me or I caught the train into the seedy and complex city of Glasgow. Predictably, all through University I kept the steady deterioration of my hearing under wraps. I sat at the front in lecture halls. I looked dedicated and attentive. I devoured books. I did well. In my spare time I wrote: I wrote about philosophy, about the individual's quest for freedom, and about suffering and love. I would have written about life in a uranium mine before it occurred to me to write about deafness.

It's almost twenty years since that physics class in which I felt a normal life definitively receding from me with the velocity of a heavy object dropped from a high altitude. Today I am not the person I seemed destined to become. I have moved from England to Canada where I live with my child. I have close and deeply satisfying friendships with people I cherish as well as a wide circle of connections. Far from being the shy introvert I thought I was, I find I am outgoing and not instinctively drawn towards solitary pursuits. Although I still sometimes feel the humiliation that the cripple model of deafness automatically brings, I feel confident enough about my deafness to teach classes of hearing students, to speak in public, and to tackle difficult situations head on.
The SOUND of Silence

Ismael Vargas, Josephine D'Aniello, Justin DeMello, Phyllis Twinney, Carolyn Piper

Hello darkness, my old friend, I've come to talk with you again,
Because a vision softly creeping/Left its seeds while I was sleeping,/And the vision
that was planted in my brain/Still remains/Within the sound of silence.

I lost 75% of my hearing at age 19 because of a streptomycin injection. I was watching a three-
dimensional picture when I first noticed the hearing loss. What I noticed, actually, was the sound
of mosquitoes. I swatted my ear thinking "Why are mosquitoes around?" Moments later I froze,
not because of the cold theater, but because mosquitoes are not present in winter. At first I was
very depressed. However, two months later, a friend who had taken the military test with me got
killed in the Korean conflict. I became deaf just two weeks prior to the military duty call.

Ismael Vargas, Arecibo, Puerto Rico

In restless dreams I walked alone/Narrow streets of cobblestone,
'Neath the halo of a street lamp/I turned my collar to the cold and damp
When my eyes were stabbed by the flash of a neon light/That split the night
And touched the sound of silence.

I sure do have tinnitus. It started along with the Meniere's Disease attacks. After the initial shock
of these noises day and night with no let up, I found it amusing at times as the tinnitus sounded
like music. The specialist I was seeing said my subconscious mind was turning the noises into
music.

One Saturday night when I went to bed, I heard a beautiful rendition of "Home On the Range."
Without thinking, I got up to look across the street to a neighbor's house. They often had parties
on Saturdays, so I thought they had hired professional entertainers.

When I looked out, all the lights in the neighbor's house were out. I went back to bed and as soon
as my ears touched my pillow, I heard the same song again and realized what it was.

Josephine R. D'Aniello, E. Norristown, Pennsylvania

And in the naked light I saw/ Ten thousand people, maybe more.
People talking without speaking/People hearing without listening,
People writing songs that voices never share
And no one dared/Disturb the sound of silence.

When I became profoundly deaf, I lost all of my tinnitus (that was a blessing, although a bit of
annoying noise now and then would be a welcome diversion). But for approximately two years
prior to the arrival of my profound deafness (when I was hard of hearing), I experienced all sorts
of strange sound effects that kept changing. The sound I liked best, and the one that did not last
as long as I wanted, consisted of wind chimes. The "chimes" had no pattern, but they were very
pretty. They would come and go throughout the day, some days more often, other days not at all.

Justin De Mello, San Francisco, California
"Fools" said I, "You do not know/Silence like a cancer grows.
Hear my words that I might teach you./Take my arms that I might reach you.
But my words like the silent raindrops fell./And echoed /In the wells of silence

Before and since acoustic neuroma surgery, the hissing in my affected ear has been a constant companion. It increases in direct proportion to the amount of noise around me but also is a strange barometer of the weather to come. To reduce noise, I've found that the Westone style #49 earplug in my hearing ear is a salvation. So too is weather forecasting. My family loves to ask me whether or not to wear raincoats on the morrow? We get a chuckle out of it.

Phyllis Twinney, Bloomfield Hills, Michigan

And the people bowed and prayed/To the neon god they made.
And the sign flashed out its warning/In the words that it was forming
And the signs said "The words of the prophets are written on the subway walls
And tenement halls."/And whisper'd in the sounds of silence.

Many of us connect tinnitus with the vibration of damaged hair cells in the cochlea. Cut and dried. Discussion ended - or so it seems. But life is a wondrous and varied thing, and little about it, when examined closely, turns out to be quite as we thought it was.

My own tinnitus is usually nerve-wracking. I have good days and bad days, but for the most part I live with an incessant monotonous hum; a hum that often takes the form of a remembered tune, unchanging in pitch or melody, which plays and plays and plays, like a DJ run amok.

Thus, when a dear friend, also deaf, told me she heard music rather than the beeps, hums and assorted memory sounds that most of us mean when we talk of tinnitus, I was skeptical despite my utmost respect and trust for her judgment. Sensing my skepticism, she wrote to me in more detail:

"It (the music I hear) used to be almost constant during my growing up years (she was deafened at the age of six) and into early adulthood. My head was literally filled with beautiful melodies . . . sometimes sad when I was sad, and sometimes lighthearted when I was feeling light-hearted. It is not so constant now (written at age 81) but it still comes from time to time, and will throw me into a brief rapture and I will ... pause and turn my full attention to this inner music. I never knew enough musical terms to be able to describe it, and I wish now I could write it down. When absent I (have) found I could coax it back by concentrated attention given to listening for the melody, which would then begin to sound afar off and slowly approach until the whole atmosphere vibrates with its clarity."

This fascinates me, for I have heard music like this once, and it was exactly as my friend described. On waking one morning I heard music slowly begin to approach, almost as if on tiptoes and beginning a journey forward from far, far away. It was clear melodic music, totally different from the usual songs of memory that I am forced to listen to. Instead, it was crystal clear and presented itself with great clarity of tone. Within it I could distinguish individual instrumentation, and the feeling of hearing something of great harmony, beauty and importance was strong. It lasted for perhaps half a minute, and then faded as it had come, and has never reappeared. Tinnitus? Inadvertent firing of neurons in the brain? I don't know - I just know I wish I were lucky enough to have this phenomenon on a regular basis as my friend apparently did. I
suspect if I did, I would not only have a positive slant on tinnitus but would spend the majority of my time sitting around with an awestruck expression on my face, allowing the ordinary chores of life to fall by the wayside.

Carolyn Piper, Huntington, Vermont

There is not a day that goes by that I do not feel, at least momentarily, that I am standing on the edge of an abyss taking that insane leap-of-faith off into oblivion.

Did you ever see "Indiana Jones and the Temple of Doom"? There was one scene that took place within the temple when Jones had to step across this great bridgeless chasm and have "faith" that he would not fall into the abyss to his death. Of course to the eye it looked like pure suicide, but he knew that if he had faith, he would not be destroyed. He closed his eyes, stepped with a little faith, and a lot of fear, that one terrifying step forward. Just as he was about to descend into nothingness, a stone slab appeared beneath him and he did not fall. Then he had to step forward again. This time he had just a tad more faith than the first time, but he still feared. A stone appeared again and he was able to go another step. On and on it went until he was on the other side standing on solid ground.

The image of this scene comes to me over and over again as I press forward into the 21st century as a deaf person. "Have faith," that inner voice tells me, "keep going; you'll be safe; you're doing just fine; onward; don't stop any longer than it takes to recoup lost composure; you're going to make it just fine." Step by precarious step we, the once hearing and now deafened, move into a great unknown with more than a little obstacle in our paths. Sometimes "nothing" can be more of an obstacle than "something:" it is not what we have that stops us - it is what we don't have. But unlike the Temple of Doom, our lives are not fictitious creations projected on a screen but real-life experiences consisting of constant faithful steps forward - even if they are barely perceptible - out across the chasm of daily living.

ALDA has helped me find out that I have a lot more going for me than I had ever previously realized. In my hearing days, I would have never dreamed that I would be able to step into the abyss of the unknown, have that little faith that is required to prevent you from your own self-destruction, and continue to emerge from a weakened, "little", state of thinking just because I lost my ability to hear the world. ALDA helped me get there because I met others like myself who were, and still are, determined to keep on keeping on in spite of those invisible obstacles.

It was here in the middle of the San Francisco Bay just a little over two years ago that ALDA and I met - here on the edge of our continent, floundering as I was in this great booming metropolis, trying to figure out what on earth was going to become of my life now that I was deaf. I just wanted to be happy; it did not seem like too much to ask from life, but under the circumstances the asking of it seemed more than a bit ridiculous. How can happiness be found in loss?

I will tell you a little secret. Be careful who you repeat this to because it's highly contagious and there are no known antidotes: I found out that I have not lost anything in deafness; I've gained. I am far richer in this great Golden State than I have ever been in my entire life. You see, I no longer need sound effects in order to enjoy life. Oh, don't get me wrong: if I could have it all back tomorrow, I would take it with no complaints. But since I do not have that option at this time I opt not to decide that my joy is dependent upon auditory input. Maybe a survival mechanism kicked in somewhere within my brain. Whatever happened, I'm glad that it has. ALDA helped me get there because I met a lot of people who are very strong, centered, and
determined not to be undone by their physical loss. I have met people who know how to laugh and enjoy life, while others who have everything often scowl and grumble (yes, the way I used to do when I had no "real" problems).

So every day is a leap of faith; no, not just every day, every moment in every day! This used to scare me since it's almost as if you are walking blind into quicksand, certain that you are finished for good, resigned to the idea that it is just not going to work out. But it is that faith, that little something inside of you that tells you that it is going to be all right. Maybe that little something is a written phrase on a box of tea bags; maybe it is a kind word from a stranger or hug from a friend; maybe it is simply the feel of the warm sun on your face as leaves scurry here and there seemingly directionless in the autumn winds; maybe it is something that speaks to you from the darkness in the middle of the night when you cannot see anything at all. It does not matter how you hear it - it just matters that you listen - and none of these things require hearing in order to understand or receive their message.

My personal thanks to ALDA and all those whose lives have touched my own. I thank you for being here, for creating a foundation upon which one can stand and find some form of stability in a very unstable world. It doesn't matter how big we are, how much money we have, how "slick" our look is. It matters how kind we are, how much we care about one another, how we reach out a hand to one another in support and friendship, and how we seek out those who are still out there floundering, hurting, feeling lost and beyond hope.

Thank you, ALDA. It has been a rough journey at times but you were there and you helped me work through it - you gave me time, you gave me understanding, but most of all you gave me your friendship, and that means more to me than all other things.
Priorities
Sharon Cooper
(ALDA Reader, October 1996)

At this point in my life, I have only to consider what is important. The things that used to give meaning no longer apply. Now, I just tell people when I like them. It seems so futile at this point to try to convince anyone of anything other than the realities of my own humanity.

As one who lives with a profound hearing loss and who will probably go deaf, what gives the most meaning is not to feel cut off from the rest of the universe. To feel the brush of angels wings and human touch through cyberspace, moving lips, flying hands, a CART that carries words instead of food, and what is called assistive devices, makes all the difference.

Accessibility simply means that I am better able to extend a heart and make a connection to another life who may desire or need the touch of honest passion and warm heart. It means joining the ranks of hundreds of thousands of other such souls.
What Are The Odds?

Holly S. Taylor
(ALDA Reader, October 1996)

Before my most recent significant hearing loss three-and-a-half years ago, I enjoyed going to music concerts with my husband, Stan, and friends.

We've always enjoyed the Rolling Stones. Well, we found out that they would be appearing in Oakland, and we wanted to go. I hesitated because this would be my first concert since my hearing loss had become so profound, and I was worried that I would be frustrated and unable to enjoy the concert. I decided to give it a try; after all, half the performance is visual anyway and I could at least enjoy that part of it. I was concerned that I would not be able to recognize which songs they were doing. As many of you have probably experienced yourselves, I knew that I could "fill in the gaps" in the music if I at least knew what song was being performed. I was counting on Stan to help me with that.

The concert at the Oakland Coliseum coincided with Halloween. Many people came in costume (Or did they? It's hard to tell at a Stones concert!). We took our seats, awaiting the concert. There were more than 50,000 people there. We watched people come and go around us, many in costume. It was very bizarre.

As luck would have it, a woman sat in front of us who was either in costume or possibly a member of a motorcycle gang! She was wearing mostly leather but had on a somewhat skimpy top. She was very tough looking and had a bottle of Jack Daniels in her back pocket. She was boisterous and gave us reason to wonder how this concert would go.

When the concert began, she stood up and began to dance right in front of us. Our first reaction was one of "Oh no, now what?" We thought she would spoil it for us by making it so we couldn't see. But before we could get too upset, we noticed that she wasn't just dancing. No, she was performing something much more special. She was signing along with the music! She signed the entire concert, and in a form that was poetic and touching. What I couldn't hear, I could see! It was unbelievable. I had never seen anything like it.

Neither Stan nor I wanted to spoil the magic. So we said nothing until the concert ended. He asked her then. And, yes, she was an interpreter! She often interprets at musical events. But she wasn't "on duty" that night. She just signed for practice and because she enjoys doing it.

Fifty thousand people! And we had tickets that put us, randomly, in those seats. A gifted sign language interpreter also sat in her randomly assigned seat. Right in front of us. What are the odds?