



For 22 years, Katherine Bouton had a secret that grew harder to keep every day. As editor at *The New York Times*, she couldn't hear what her colleagues were saying. Writing a book forced an emotional honesty that allowed the author to accept her hearing loss.

By Katherine Bouton

# Shouting Won't Help, But Writing About It Did

“Emotionally, socially and professionally, treating hearing loss can be the difference between a life well lived and a life in shambles. ”

I once sat at dinner next to an elegant British editor who politely asked me how I had gotten into journalism.

“Did you read history at university?” he asked.

I hesitated. “I’m not sure. When was that published?”

So goes the dinner party conversation of those with hearing loss.

This happened during my forties, when I had fairly serious hearing loss in my left ear and good hearing in the other. Buying into the stigma—hearing loss is for elderly people—I refused to wear a hearing aid. I blithely went ahead answering questions that hadn’t been asked.

“Name and address?”

I hear “Means of redress?” so I ask, “You want my insurance card number?”

“Birth date.”

“Bouton. B-O-U-T-O-N.”

“Birth date.”

“Perfect.”

“The date of your birth!”

It’s not just me. “What will you have to drink?” a waiter in a restaurant once asked the musician Richard Reed, who also has hearing loss. “Blue cheese dressing,” he replied.

Like many people with hearing loss, I thought I could fake it. I worked for 22 years at *The New York Times*, a competitive and youthful environment. At first I heard about 90 percent of what was said. By the time I left, I was hearing about 10 percent, and that was with a hearing aid and a cochlear implant. Almost to the end, I convinced myself I was doing just fine.

How did I do it? How do others do it? Email. Lipreading. Bravado. I skipped meetings at work if I could, and when I couldn’t I’d sometimes ask participants to follow up with an email.

## At Work, Then and Now

Really frustrating were company-wide meetings. Every year Bill Keller, the executive editor, would hold a meeting for the editorial staff, bringing us up on plans and answering questions about editorial policy. He called these meetings “Throw Things at Bill.” (Really? Kind of embarrassing.) I’d get the gist of Bill’s remarks, which were amplified. But I never heard a remark or question from the audience. I might intuit the tone—hostile, exasperated, informational—by reading body language. Since I couldn’t hear the questions, I never asked one myself.

Despite the fact that several hundred employees would come to Bill’s meetings and another annual meeting for employees held by the publisher, Arthur Sulzberger, there were no accommodations for people with hearing loss. *The New York Times* has a good record in hiring (and keeping) people with disabilities. How come no one thought to offer hearing assistance? More important, how come none of us asked for it?

Today, now open about my hearing loss, I’d simply have asked human resources to provide CART (captioning) for all company-wide events. I’d also ask for a sign language interpreter, since

*continued on page 14*

## Shouting Won't Help

*continued from page 13*

*The New York Times* has several employees who are deaf and would appreciate it. And I'd sit close to the front so I could lipread as well.

Smaller group discussions were also difficult. I'd lose the train of thought; I'd think we were talking about one thing when we were talking about something completely different. I'd get bits and pieces, and if the subject was familiar enough I might patch them together. But I learned to dodge any subject that was controversial or any person who was intimidating. Not surprisingly, this eventually cost me my job.

All I needed to do was put my FM transmitter on the conference table and wear the receiver around my neck. But I didn't.

### Hitting the Bottom

Just as a substance abuser has to hit rock bottom before he or she can start the recovery process, I had to hit rock bottom before I realized how much damage I was doing to myself by not acknowledging my hearing loss.

It was a long, slow and painful process. I didn't know anyone with hearing loss. I had never heard of the Hearing Loss Association of America (HLAA) or of the Association of Late-Deafened Adults (ALDA). I couldn't find any books that spoke to my experience. There were many books on deafness, but very few on hearing loss in general and those who lost their hearing later in life or had partial hearing loss. And though there were several personal accounts of getting a cochlear implant, they were success stories. Mine was more mixed. The closest I came to a role model was David Lodge's central character in his hilariously funny and astute novel *Deaf Sentence*.

Deciding to write my own book was the first step in my recovery. If I was going to write about hearing loss, I was going to have to own up to it publicly. I spent about a year writing a proposal. Looking back on the many drafts I tried, I see a progression that mirrored my own progression in coming to terms with the loss.

“People who lose their hearing are afraid to be open about it because they fear the reaction—the prejudice, fear of seeming old or stupid. But what really makes you seem old or stupid, I know now, is not acknowledging the disability.”

Despite my resolve, the early drafts reflected my depression and anger. Gael Hannan, an actor, writer, and public speaker who grew up with a hearing loss, calls it “ear rage.” I was angry at *The New York Times* for not somehow intuiting my problems and making things easier for me. I was angry at my friends for continuing to carry on normal conversations in my presence, (I never really told them how hard it was for me to hear.)

I was angry at my teenage children for dismissing me as out of it, when in fact I couldn't hear them. But did I tell them that? No. I was angry at my husband, despite his patience. Most of all I was angry at myself, and that self-loathing came through all too clearly.

### Shouting Won't Help

The finished book, *Shouting Won't Help: Why I—and 50 Million Other Americans Can't Hear You*—is still not entirely an optimistic account of the experience of midlife hearing loss. I thought it was important to be honest. The many people with hearing loss I interviewed for the book reinforced my impression that losing your hearing can unmoor you. But they also showed me that it was possible to move on. To make hearing loss part of your life, ever present, but not the dominant factor.

I now realize that even when I finished the book I was only halfway there. I had wrestled with the epilogue, forcing myself to find some positive things to say. I was still caught in the insidious tangle of hearing loss. It defined my every waking moment—and my sleeping ones as well, invading my dreams. When I was alone, it kept me in a constant state of vigilance. Awake, I positioned

my desk where I could see out the window to the street and the driveway. At night I made sure the dog was in my room.

“Once you enter the world of the near deaf,” I wrote in the epilogue, “you don't leave.”

But you do. And I did.

### Shared Experiences

After the book was published many people wrote to me about their own hearing loss, their own stories eerily similar to mine. I used to feel that my reaction to my hearing loss was symptomatic of some deeper psychological problem. Why else would I deny it for so long, fall into a deep depression over it, lie to friends and family and work colleagues about the severity of the loss? Why else would I pretend, day after day, to be someone I'm not?

But those who wrote to me, who commented on my blog, who found me through Facebook, were writing to thank me for describing their own experience. They too thought their reaction to hearing loss was overwrought, abnormal. Between my experience and that of others I wrote about in the book, they came to realize they had plenty of company. In addition, I gave them the tools for talking about their loss. Hearing loss is hard to understand for those who don't have it, and people with serious hearing loss are often misunderstood or not believed.

The most important thing I learned about dealing with hearing loss is, don't do it alone! The temptation, as hearing worsens, is to avoid situations where you'll have to hear. People stop going out, they stop seeing friends, they leave (or are fired from) their jobs, they withdraw, they often become depressed. Depression and isolation often go hand in hand, and isolation can often contribute to cognitive dysfunction.

Emotional well-being and quality of life are directly affected by having a strong social network. So is a longer healthier life, as Howard S. Friedman and Leslie R. Martin found in their decades-long study on longevity. In an interview with them at the time their book on the study was published, I asked

them what the single strongest social predictor of long life was. Their unhesitating answer: a strong social network. Widows outlive widowers, they added, noting that they had also found that women tend to have stronger social networks than men.

So even if you don't want to tell the world about your hearing loss, tell your close friends. I was surprised to see how quickly my friendships became more intimate as I started seeing them one on one, because it was easier to talk that way. I also expanded my circle of friends as I began to meet others with hearing loss.

The greatest resource for me in meeting others with hearing loss, in sharing experiences, has been the Hearing Loss Association of America, publisher of *Hearing Loss Magazine*. If you're reading this, you probably already know that, but it's an important thing to share with those who are reluctant to acknowledge their loss.

### Treating Hearing Loss

The second most important thing I learned is how important it is to treat hearing loss. Emotionally, socially and professionally, treating hearing loss can be the difference between a life well lived and a life in shambles.

In a 2000 article, Sergei Kochkin and Carole M. Rogin reported on a study of 2,069 people with hearing loss, commissioned by the National Council on Aging. The study found that users of hearing instruments were likely to report improvements in their physical, emotional, mental and social well-being. Physically, for instance, those who used hearing aids were less likely to report pain from other conditions. Interestingly, family members were even more likely to notice these changes than those with the hearing loss.

As recent studies at Johns Hopkins Medical Center and elsewhere have shown, hearing loss also has a statistical correlation with early onset and more severe dementia. The role of hearing aids in this correlation remains to be determined, but certainly the isolation and confusion, and the cognitive load, that come with untreated hearing loss are a factor.

### My Experience with a Cochlear Implant

The third most important thing I learned is, alas, illustrated by my own experience. It's well known that the longer a cochlear implant recipient has been without hearing in the ear to be implanted, the harder it is to be successful with the implant. All those years I ignored the hearing loss in my left ear took their toll.

Despite aural rehabilitation and wearing my cochlear implant virtually all the time except when I'm sleeping, I don't do well with it. On a hearing test in May 2013, three and a half years after my implant, I heard only 12 percent of individual words. In the hearing aid ear, I heard only 36 percent. But with both I managed a respectable 60 percent. That doesn't mean I hear only 60 percent of what's said to me, though. Outside of the hearing test booth I do pretty well. I read lips and I am fluent in filling in the gaps that I miss.

My implanted ear had actually gotten worse since the previous test eight months earlier; so had my hearing aid ear, though since my hearing loss is progressive that was to be expected. But this is interesting: even though my hearing aid ear had dropped from 44 percent to 36 percent, my bimodal hearing—both ears—had actually improved, from 52 percent to 60 percent. It's often said that we hear with our brain. This is probably a good illustration of that.

I asked Brad May, a researcher at Hopkins, if my theory that I had harmed myself by not treating the hearing loss made sense. His carefully phrased answer was, essentially, yes.

"But not because of permanent changes in the underlying plasticity of the brain's auditory pathways," he said, dismissing my explanation that the brain speech pathways had withered. "Think reorganization not atrophy."

Although a researcher would not use such a crude term, I think in this case "use it or lose it" probably applies. Dr. May did add this thought: "Is immediate intervention more successful in the adult auditory system (presumably in the case of sudden hearing loss)? Again, the answer is probably yes."

Hearing loss often develops slowly. It's easy to ignore. Sometimes people don't even realize they have it until someone suggests a hearing test. Even then they might say it doesn't bother them. No need for hearing aids. Those same people when they do finally get hearing aids realize that they are hearing sounds they've forgotten existed.

If I brush my teeth without my hearing aids I often forget to turn off the water. I don't hear it. It doesn't seem unusual that I don't hear it. It just seems like something that doesn't make much noise. But then when I put in my hearing aid I hear a loud rushing sound from the bathroom. The running water sounds like Niagara Falls.

Think of leaves rustling—you can easily forget it's not only a visual but an aural experience. Or traffic noise. This might be one you'd just as soon not hear, but it's surprising how normal it can seem to see but not hear traffic.

A cat purring. It's a tactile sensation—you feel the vibration. And then you remember that purring is a sound as well. The coffee pot gurgling. With just my hearing aid, I figure the coffee pot is a pretty quiet machine. When I put on my cochlear implant, which picks up lower frequency sounds better, I can hear it well enough to know when the coffee is done. I can also hear the beep at the end of the dishwasher cycle.

But if I didn't have a hearing aid and an implant, and had only mild to moderate hearing loss, I might not notice that I wasn't hearing these things. I have sometimes heard people say, "I don't have hearing loss! I just don't always hear everything." When friends and family begin to comment, it's time to check it out.

People who lose their hearing are afraid to be open about it because they fear the reaction—the prejudice, fear of seeming old or stupid. But what really makes you seem old or stupid, I know now, is not acknowledging the disability. The more of us who accept and acknowledge our hearing loss with dignity, who continue to participate in professional and social activities, who refuse to let our hearing loss define us—

*continued on page 16*

## Shouting Won't Help

continued from page 15

the more we will defeat the stereotype and stigma of hearing loss.

People with hearing loss come in all ages, sizes, shapes and colors, and we account for one in five of all Americans. There's nothing shameful about hearing loss, the majority of us aren't old. So let's speak up and make wearing a hearing aid as routine as wearing eyeglasses. ■■■

*Katherine Bouton is a former editor at The New York Times where she worked for The New York Times Magazine and The New York Times Book Review, as well as the daily Science and Culture desks. Her nonfiction appeared in The New Yorker and many other magazines and reviews. She is currently a regular reviewer and contributor to Tuesday's Science Times section. She's an HLAA member and lives in New York City with her husband, Daniel Manaker. They have two grown children. She can be reached through her website at [www.katherinebouton.com](http://www.katherinebouton.com).*

## Shouting Won't Help: Why I—and 50 Million Other Americans—Can't Hear You

By Katherine Bouton

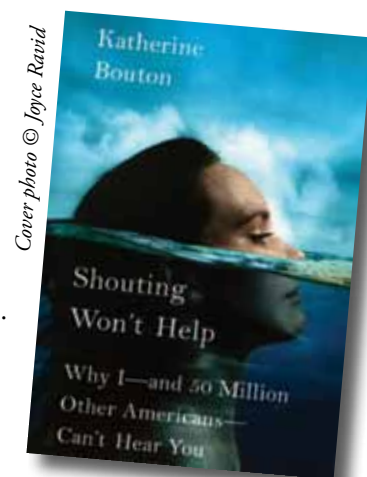
Sarah Crichton Books/Farrar, Straus and Giroux, 2013

Order on Amazon.com or Barnes&Noble.com. Find your local independent bookstore at [www.IndieBound.org](http://www.IndieBound.org). Available in hardcover and as an e-book.

Janet McKenna, HLAA member, writes in her review of Bouton's book (May/June 2013 *Hearing Loss Magazine*):

Although late deafness experiences are strikingly similar, we are all unique in our reactions to hearing loss and how well we do with technology. The author is disappointed that she doesn't do as well as she had hoped, but individual outcomes with cochlear implants and hearing aids vary tremendously and many have great success. She admits pestering her doctors and audiologists for a cause ("idiopathic"). Ignoring it for the first 20 years, "existing in a relatively stable state of denial," she writes, "when it could no longer be ignored, I spiraled into depression."

The extensive research is very current, almost all from 2010 and later. Ms. Bouton's entertaining writing style makes technicalities accessible to non-scientists. ■■■



# Start Something

*You're Invited to Join  
our Mobile Community!*

# BIG

## You're mobile...so are we!

Be the first to know what is happening. We'll keep you posted. Text EAR TO 50555.\*

If you haven't joined our mobile community yet, you're missing out on opportunities to give, connect and receive alerts about events, news and opportunities to give back. We promise we won't annoy you with a bunch of texts. Join now!

\*SMS subscription service. Up to 4 msg/mo.

Message and data rates may apply. Text STOP to 50555 to STOP.

Full terms: [mGive.com/E](http://mGive.com/E) Privacy Policy: [mGive.org/P](http://mGive.org/P)

**Join by December 1, 2013, for our Winter Drawing for a \$100 gift card!**

