

**ALDACon2017
Use It or Lose It
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SHEILADAWN FITCH:

Good morning. I am so excited to see all of the Newcomers this year. It was just three short years ago that I was a newcomer here myself. I want to congratulate you on making the decision to be here, because you have taken the first step to changing things in your life. And it is going to be a good step positive step.

Every one of us here at ALDA have a hearing loss story to tell. Some of us feel that it ruined our lives; others are grateful that we don't have to listen to certain things or certain people. Whichever category you fall under, stop and think about the times in your life before your hearing loss. Your life was not perfect, things did not always go so well. There were probably times that we wished we could just stop and start our lives over again, like the song says, "Stop the world, let me off. I am tired of going around and around." I know that was the way I felt numerous times in my life.

My hearing loss gave me that opportunity to start over and I embrace that opportunity every day. When I was a young child, my mom had an extended stay in the hospital. I was quite a bit younger than my siblings who were already in school. My dad had his business to run, so he hired a nanny from Mexico. We were living near the border. Back then it was safe and common practice to get help from Mexico. My nanny could speak no English. She was an excellent cook, housekeeper and was my constant companion for months. Then the big day came. My mom was released from the hospital and came home. I was so excited. There was a big problem because I could not speak English and my mom could not speak Spanish. We had to "wing it" for a few months until I became bilingual.

When I started school, I could speak, read, and write Spanish. As the years went on, I spoke it less and less. Then I picked it back up around the middle of my freshman year. When I moved away from home to go to a private school and after that to college, I was in an area, and around people where there was not a need for Spanish. I spoke it less and less as the days, weeks, months, and years went by. I love the Spanish language but I have lost it. It is such a pretty language.

At nine years old, I went to a youth camp where there was a class for sign language being offered so I signed up for it. I love sign language and could just sit and watch you who are signing all day long. At that time, I did not know anybody who was deaf. I did not live in a community where anybody even knew sign language which meant I did not have a way to practice it. And as time went on, I lost sign language also. So that is two languages that I have lost.

Speaking of loss, I am going to fast forward to 2003. I suffered the biggest loss of my life ever. My husband and I were separated. My oldest daughter left for college and I

found myself at home with two little girls; but I had a plan. Have you all ever seen that sign that says “We plan, God laughs”? God must have been rolling on the floor when He heard my plan. On a Friday afternoon, I got a call from my estranged husband who wanted me to pick him up from work. I drove an hour and a half to his work with our two little girls in order to give him a ride. We picked him up and we were not even a half mile down the road, when I saw a pick-up truck coming towards us. It was pulling an 18-foot utility trailer filled with pipe. The trailer started swaying and it came off of its hitch. That trailer came loose. I moved over as far as I could to get off the road, hugging a fence line in a ditch. We watched the trailer pass us. I thought we had cleared that one. As the trailer left the pavement it dug into the ground and flipped over three times; it got us. It hit my car three times.

There is no short version of the events that followed. But I am going to try to summarize the highlights for you. I walked away from that crash with no visible injuries. Within a three-and-a-half-week period, I became increasingly and gravely ill. I went into a coma, had a heart attack, woke up, and then had a stroke. Somehow during all this long stay in the hospital, I picked up meningitis.

One night about nine and a half days after waking up from the coma, I was told I had meningitis. I went to bed and everything with my hearing was normal. The next morning, I woke up completely deaf; I had no hearing at all. And there had been no warning that I was losing my hearing.

Now remember that I told you all that I lost my sign language and I lost my Spanish, because I was not using them. Well, I was using my ears; I have never been accused of being a good listener, but I was using my ears. After testing, I was told, that I was never going to hear again. Strangely enough, I was okay with that. (I have always been an excellent lip reader) because I was not going to have to listen to the ugliness of this world anymore. I realized at some point I had to let go of what I thought should happen and live with what is happening.

What was happening was the start of a new life, a new norm which was my deaf journey and I was embracing that with a sense of protection. I was having so much fun with this new norm with the questions people would ask me, like, can you hear yourself when you talk? And, if you are deaf, how are you talking to me?

I also learned a trick. If you walk into a store and you are going to return something, sometimes it takes an act of Congress to get it done. If you take the items you want to exchange and you walk up, you lay them on the counter and you say, “hi, I am deaf and I just want to exchange this stuff”. They will stop you right there and give you just about half the store, because they do not want to deal with you because you are deaf.

One of my favorite experiences was when I walked into a spa. I thought to myself, “I have never been in here before, they don't know me, I am going to be up front about being deaf.” I walked up there and I said, “Hi, I am deaf and I need....” but before I could say “a pedicure”, the lady said, “Hi, how can I help you, Beth?” She did not

understand what I said; she thought I had said “Beth” not “deaf”. The people in my small town heard about that, and they changed my name to Beth for a long time.

Then, little by little, things were not so fun anymore. I started dreading social situations; people started avoiding me; even people I thought were my friends. I could see the “deer in the headlight” look when they saw me coming. I would come almost face to face with these people who were supposed to be my friends whom I had known forever. I could see that they were thinking, “Oh, my gosh, I am going to have to talk to her. I don't know if she is going to understand me. I don't know if I am going to understand her.” And it was a look of panic. I still had my voice, so I could talk to them and I could pretty much figure out what they were saying. I did not understand why they were scared of me.

By 2010, I had purposely chosen to stay deaf for seven and a half years, but things just were not working out for me anymore. Then, a young girl moved to our town; she went to school with my daughters. She had a cochlear implant. I began watching her very closely. She was living a pretty normal life. She was attending public school, and interacting with others just fine. I decided that I wanted what she had so I found her doctor.

And I had always been told that when you are looking into being a cochlear implant candidate, that you should go through some counseling and you need to get approved. I had never undergone surgery in my life and knew this was a major surgery. I consulted with this girl's doctor and told him that it had been seven and a half years since I lost my hearing and that I did not want or need any counseling. I said that I had read up on this myself, and I had watched somebody who had an implant. I said “This is what I want. If you do not do this for me, like tomorrow, it will be never, or seven and a half more years before I get the courage to do it.” He laughed. And he said to me, “Tomorrow is Friday. I don't do surgery on Friday. How does Monday sound?” I said “Let's do it!”

I had the surgery. Seven days later I was activated. I was told that I wouldn't understand anything. While I was sitting there getting programmed, as they call it, the audiologist and my husband were talking about me. And it came through! It just went from all the little noises of first getting activated and it smoothed right out and their voices came through. The audiologist could not believe it. She said this does not happen. At my six-month checkup, my listening and understanding were already where most recipients only get to after two years. I was very blessed.

I just had to learn how to listen and to pay attention, (and I am still working on that). For those seven and a half years, I learned not to listen and not to pay attention, because I knew nobody was talking to me. They were all too scared to talk to me. I was so happy because I realized something. Yes, I got the cochlear implant, but I had the choice to listen or not. And I loved that control.

That was the time I turned my disability into a Fitch ability. Our minds are powerful, when we fill them with positive thoughts and our lives start to change. Three years ago,

I had no clue ALDA or any other organization existed. I knew that living in the real world was exhausting, having to listen and understand. Marty, who I met online, invited me to the "Say What" convention. I lived near San Antonio, and I thought why not? I did not have anything to lose. When I walked into that room, and I was with all those people who had a loss like mine, I was relaxed. Everybody in that room "got it". I had a blast with these people. I found my "common place".

While I was there at "Say What", Cynthia, invited me to ALDAcon in Scottsdale. I thought, why not? When I got there and walked into that lobby, though, and everybody in there was signing, I thought, "Oh, no, what have I done? I don't belong here. I am not going to be able to talk to them." And obviously, nobody had their speech because everybody was signing. I thought nobody was going to talk to me.

I was ready to pack it up and go back home. I got the materials that ALDA hands out when you register and went back to my room. When I read about ALDA and how they have this saying, "whatever works", I decided to go to the welcome reception. And sure enough, I saw so many different forms of communication that night, some that I had never seen, some that I did not even know existed. But everybody in there talked to me, and they made sure I understood. And again, I found my "common place". No one said "never mind", or "what?" or "I can't understand you."

"Y'all" have been welcoming to me and putting up with me for the past three years. I did not want to leave ALDAcon, I thought: this is too good; I did not want to go home. I was already planning for the next convention. At the con, spending time with others like myself, the positive thoughts and feelings were starting to return to my life. I wanted to start giving back. I wanted to do anything I could do. But what could I do? I lost my Spanish, I lost my sign language, I lost my hearing, but I still had my speech.

I began volunteering and sharing the tricks and tips that worked for me with others. In return, those people started sharing their tips and tricks with me. In reality, I was actually the one getting the help.

All of us have lost our hearing; but what do we still have? Do you have your voice? Your hands? Your sight? We cannot have the attitude that we are the ones who need help or don't have anything to offer. I ask you: what do you have? What do others say you have? A talent? A passion? A willingness to help others?

I think we all agree that our biggest frustration with our hearing loss, is that we have to deal with the world that is not very aware, educated, or knowledgeable about our hearing loss. Every time I talk to somebody and they share their story with me, that is their frustration. The world does not "get it." They do not know. It is up to us to educate the world out there.

I met a man last year at ALDA, very kind, compassionate, and loveable man. I saw him signing, and only signing. When he came over to introduce himself to me, I told him that I do not sign. I said I can read your lips. He started talking to me and he had a

beautiful voice. For someone that lost their hearing so many years ago, he had an amazing voice that is even in tone; he did not speak too loud, and he did not mumble. When I asked him, why he did not speak he said, "If I speak, people will think I can hear." That broke my heart but right then I knew that we can all choose to communicate and live our lives any way that we want to.

I believe it is up to us to communicate information about hearing loss in this unknowing world. It is much more effective to learn about hearing loss from people that have gone through it than from people who only learn about it from a book.

We can take each day here at ALDAcon to spend time with others in like situations. We give and receive a lot from each other when we come together at these conventions. Here, you can create a new comfort zone for yourself. You can be honest about what you can do, what you cannot do, and also what you would like to try to do. You can be with people and practice listening, understanding, and learning. If there is an option for a hearing device, you can try one. You do not have anything to lose. Your success is not a matter of winning a race, your success is a matter of handling the worse and still finishing the race. We "have" a hearing loss, it does not "have" us. We are the boss of our hearing loss. We have been assigned this huge mountain to show others that it can be moved. We need to be confident enough to encourage confidence in others. One of the best feelings is to inspire someone; to know that you helped somebody. The pleasure of success feels best, however, after the pain of failure. We have all experienced a life changing loss, but not a loss of life. So, find your passion, your "common place."

There is a saying: "Use it up, wear it out, make it do, or do without."

I encourage you, no, I dare you, all of you, to search yourselves. Please use what you have so that you do not lose it. Help others and while doing so you will actually help yourself. Thank you.

Sheiladawn Fitch was born and raised in South Texas. Mother of 4 girls and a stepson, she is also a former fashion model, designer, and singer. Recently she became a licensed private investigator.

In 2003, following an infection caused by an airbag which led to other health related problems, she woke up one morning completely deaf. After remaining deaf over 7 years, she received a Cochlear Implant in 2010. She then became a Cochlear Awareness Ambassador and Volunteer. Sheiladawn, whose passion is helping other with hearing loss, is a member of The Say What Club and ALDA.