

A patient-centred approach from the patient's point of view

BY SHARI EBERTS

Seeking help for hearing loss is often a big step for patients. **Shari Eberts**, a hearing health advocate living with hearing loss, explains why, and gives us her five top tips to improve patient-centred care in such cases.

Sensorineural hearing loss is frustrating. It is hard to diagnose and the cause is often difficult to determine. There are few, if any, biological treatment options. There is no cure and most of the time what you hear from doctors, even some of the best doctors, is, "I'm sorry, there is nothing I can do." With an eye toward patient-centred care, I think we should be able to expect more.

I have an adult onset genetic hearing loss that started in my mid-20s. When I first noticed it, I was not surprised, since my father and grandmother had trouble hearing, but I was also not happy. In fact, I was in denial and did my very best to ignore it and blame others for my inability to hear. This one mumbles, or that one always talks with food in his mouth, for example.

My family told me that we had "nerve hearing loss" and there was nothing that could be done about it, so when I finally decided to get a hearing test, I skipped the doctor and went right to an audiologist. This was in 1994. Five years later, I broke down and got my first pair of hearing aids. I still had not visited a doctor to evaluate my hearing loss.

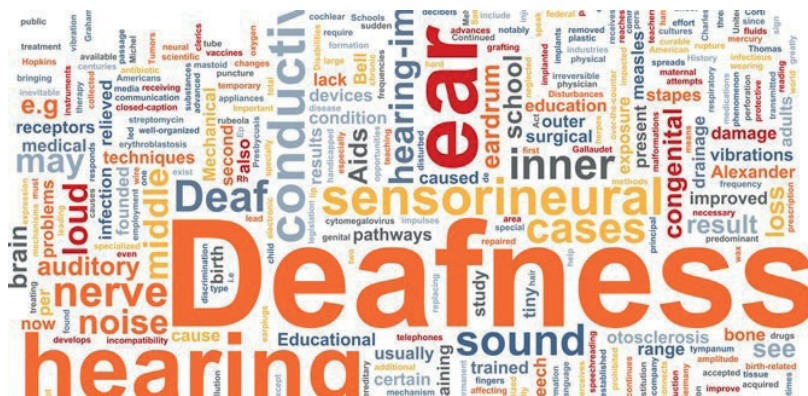
Fast forward eleven years to 2010. I was now a parent of two young children and a board member of Hearing Health Foundation (called Deafness

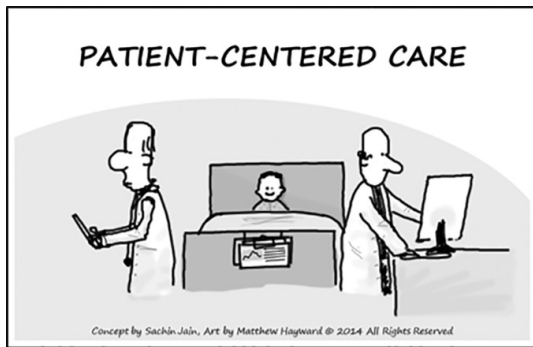
Research Foundation at the time; <http://hearinghealthfoundation.org/>). I decided it was time to learn more about my hearing loss, especially since it was genetic. Had I passed it on to my own children? Perhaps after all this time, there was something that could be done for this type of hearing loss.

Unfortunately, things had not changed very much. The outstanding and highly recommended ENT surgeon that I visited confirmed that I had a sensorineural hearing loss (at least it was a fancier word!) and that there was nothing she could do. I was advised to continue seeing my audiologist to treat my condition with hearing aids. End of story, but not a satisfying one.

Recently, I decided to try again. I had shared my audiogram with a prominent scientist involved in hearing research, and he suggested a possible diagnosis. I made an appointment with a doctor to confirm or deny the scientist's hunch. Once again, I hope things have changed, that progress has been made, and there might be something that can be done to help me with my hearing loss, which

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has now progressed to a 50 dB loss in the mid-range frequencies.

I share my story with you, not to complain, and not to belittle the great work that is being done by the doctors in this field, but to provide the patient's perspective. From the patient's point of view, it is often a very big step coming to see the doctor in the first place. Stigma and denial are so common with hearing loss that making the first appointment can take a while. In fact, according to Hearing Loss Association of America (HLAA; <http://www.hearingloss.org/>), on average, it takes people seven years from the time they think they might have a hearing loss to the time they seek treatment.

Once we have mustered up the courage to get there, we are hoping for information, not more uncertainty. While the science may still be inconclusive and there is nothing that can be done medically, there are many other things that can be done to help someone with hearing loss and to keep him or her motivated and engaged in seeking treatment. Here are my suggestions.

What can you do to be more patient-centred from the hard-of-hearing patient's point of view?

1. Improve the entry experience. I realise a doctor's office is very busy, with appointments often not available for several weeks, but the receptionist needs to treat new patients with respect and empathy. Hearing loss so often goes untreated and a rude receptionist can be off-putting to someone who may have been building up the courage to call for this appointment for some

time – sometimes years! Speaking slowly and clearly is also very much appreciated by people with hearing issues.

2. Provide additional resources for information and support. While there may not be much medical information available, providing brochures or links to leading advocacy organisations for those with hearing loss would be very helpful. Is there an HLAA chapter or the equivalent in your area? Find out and point patients in that direction.
3. Put it in writing. It is very difficult for someone with hearing loss to process information rapidly, particularly if unfamiliar or scientific words are used. Providing a written report of his or her visit (this can be a simple checklist you fill out real time) can help the patient take more away from the appointment. This will also help the patient better communicate the doctor's recommendations to an audiologist or family member.
4. Stay current on scientific research. While there may not be a cure today, providing links or information on scientific research that is underway can provide hope and support to someone suffering from hearing loss. Who knows – one of your patients may be a big potential funder of research.
5. Explain the risks of untreated hearing loss. While there may not be a biological solution for your patient, encourage them to seek treatment with technology. Explaining the risks of untreated hearing loss, including its possible link to dementia, can be highly motivating to someone to continue with or to start treatment.



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Shari Eberts is a hearing health advocate. She blogs at LivingWithHearingLoss.com and serves on the board of trustees of both the Hearing Health Foundation and Hearing Loss Association of America. In 2015 she was named a HearStrong Champion for her work to change the stigma surrounding hearing loss. Shari has an adult-onset genetic hearing loss and hopes that by sharing her story it will help others to live more peacefully with their own hearing loss.

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