

Stephen's Story:

Stephen is a musician and a music teacher with Meniere's and this is his story.

"Though I had hearing problems for 20 years, it wasn't until a moment standing in front of my high school choir when I realized that there might be a problem.

My hearing difficulties started just a few years into my teaching career when I finally went for an audiogram after realizing that I didn't seem able to hear clearly. The audiogram revealed a slight loss, which I assumed was due to many years with bands and choirs in small, inappropriately protected rooms. The audiologist said this was possible, though the fact that it was a unilateral loss necessitated "investigation," especially as I had also been living with tinnitus for so long that I thought it was normal. I had custom hearing protection made, designed for musicians, and never did undergo investigation as I soon launched into an international teaching career, very happily moving all over the world to share, teach and learn theatre and music.

While standing in front of a high school choir in Abu Dhabi, I began admonishing my sopranos who were not giving enough power to balance what I was hearing from the rest of the choir. The sopranos stood on my right side. Finally, one of them was brave enough to speak up and tell me they were giving me everything they had. Realizing they were on my poor side, I decided to experiment - what happened if I simply turned around? Suddenly, I could hear the sopranos clearly and the rest of the choir dulled. The problem was my ear.

The following year I faced my first health challenge - the sudden growth of a lesion in the brain called a Cavernoma - that grew on my left temporal lobe causing seizures and threatening speech and musical rhythm. As it was bleeding and growing quickly, it had to be removed through an awake craniotomy - yes, I was one of those people who played piano and sang while the doctor poked around in my brain! Some of the tinnitus seemed to be gone after the surgery, so I assumed that there was a connection to the hearing loss and assumed that, though the hearing might not come back, it would not get worse - and I moved on with my life.

However, a few years after the surgery, the tinnitus was back, the vertigo appeared, and the hearing loss worsened. Now I had reached my second challenge - a diagnosis of Ménière's disease.

As a musician and a teacher of music, the loss of hearing has been a challenge. Recently, I was teaching some students in a musical theatre rehearsal while playing the piano. I had to stop the rehearsal because I simply couldn't hear if they were in tune. It wasn't that I couldn't hear them - I could - but my ears just didn't seem to be able to understand the pitches and their relationship to each other. Once the students left, I played the piano on my own and the pitches seemed to move - a very strange experience. I would play simple octaves which should sound very stable, and - they didn't. Everything sounded out of tune. Thinking it might be the piano, I went to an electric piano only to have the same experience. I later read of something somewhat common amongst Ménière's sufferers, especially musicians, called Diplacusis - perhaps this is the beginning?

My hearing started taking its more dramatic dip downward about 2 years ago after the Cavernoma surgery. Though my ENT says they are not directly related, he also said that sometimes one disease can hurry another along. I am grateful that there is now more attention paid to my Ménière's disease, to try and recover what I can and slow the progression of the hearing loss and vertigo. At the moment, I live in China (and I speak little Chinese,) so being able to communicate my needs sometimes comes with an additional language barrier; but I am grateful to have now found the right team and the right hospitals to help.

Thankfully - even with now severe hearing loss on the right side, my moments of musical distortion don't seem permanent - at least not yet. As we all know, this is a frustrating disease, rendering one completely unable to predict the future and having to remain only reactive instead of proactive. However, I'm grateful to have the support I need, and to be able to continue to do what I love to do - at least for now."

Thank you Stephen for sharing your story with us.

If you have a story to share, please email me: dizzyanne.wfps@gmail.com