A Series on Families Living With Tinnitus

We often have little influence on a loved one’s chronic condition. However, we can learn about the issues, remain supportive and take care of our own well-being. For some, working to enhance treatments, find cures and raise awareness are ways to cope and create hope. This is certainly true in the tinnitus community.

This is the fourth story in our series on families made up of members with and without tinnitus. The series explores their experiences, the feelings that penetrate their lives and the frustrations they face. It also illuminates some of the solutions that diminish their stress and allow families to settle into a “new normal.”

How One Couple Challenged Tinnitus

Katie Fuller, ATA Executive & Development Associate

Barbara Kennedy is a retired middle school teacher, a Master Gardener and a member and the secretary of ATA’s Board of Directors. She is also a tinnitus sufferer.

When her tinnitus struck, Barbara was in the midst of her teaching career, working with 7th and 8th grade students. She and her husband, Dean, enjoyed taking motorcycle day tours. And though Barbara experienced episodes of tinnitus after a few of their rides, it seemed to always go away. But on Aug. 3, 2000, it was here to stay.

Turning Panic into Positive Action

On this day, Barbara says she “went into panic mode, with a bit of hysteria.” Knowing nothing about tinnitus, she found her way to ATA’s 1-800 number and to a tinnitus support group in her area. Upon learning that she wasn’t alone with her disquieting experience, she immediately felt better. But before attending her first group meeting, Barbara saw an ear, nose and throat doctor (ENT) who said the dreaded words that too many people with tinnitus hear: “Go home and learn to live with it.” Barbara left the appointment with zero information and no suggestions on how to cope with her tinnitus, which lead her to literally “fall apart.”

To this day, Barbara says she owes her survival to her school principal. Totally distressed by her tinnitus, Barbara tried to quit teaching – but he wouldn’t let her leave. “He worked with me to provide the work environment that I needed by excusing me from cafeteria duty, loud assemblies, games and pep rallies. I presented two school assemblies called, ‘Turn it Down,’ to raise awareness of the dangers of noise abuse.”

A Husband’s Perspective

Dean wanted to understand what his wife was going through, so he read and listened to every piece of information Barbara gathered. On days when Barbara struggles most, Dean says he drops everything and stays with her until she calms down. “It is amazing how in one instance she can be happy and relaxed; then all of a sudden she will get this look of sheer fear on her face while she holds her ears.”
Advice From a Sufferer and Supporter

Barbara encourages people first diagnosed with tinnitus to try to be calm because tinnitus often increases under stress. She suggests finding as many positive distractions as you can, such as “sound therapy, a good walk or time with family and friends.” She also recommends talking with your doctor about taking medications to help with the hard times. “Attend a group meeting to learn more ways to manage your tinnitus or to just share with others. It is a give-and-take experience,” says Barbara. “Some [people] are there to help and others come because they need help.” She admits to attending for both reasons.

Dean finds that people who do not have tinnitus have a hard time understanding what someone with the condition is going through. He admires his wife’s strength and wants people to support their loved ones and never underestimate their level of suffering. “Comfort and understanding are the best care that you can give.”

Today: Managing Her Tinnitus & Helping Others

When Barbara’s tinnitus flares up, she takes a prescribed sleeping and/or anti-anxiety medication. She uses sound therapy CDs, a sound-generating pillow and a fan for background noise for easier sleep. She practices relaxation and yoga, exercises, keeps busy as a Master Gardner and takes her puppy on long walks. Her custom-molded musician’s earplugs help her enjoy a normal social life and go places where noise might be loud.

Barbara has not accepted having tinnitus for the rest of her life, and says, “I pray for a cure.” However, she does understand what to do when tinnitus strikes. As a facilitator for the Southern New Jersey Tinnitus Support Group, she shares this information with others. “I thrive on learning more about tinnitus each day – it helps me to help others as well as myself.”

Those first days with tinnitus are memorable for Barbara as well as how much better she felt after sharing her struggle with others. She strongly supports ATA’s mission to find a cure and enjoys working with her co-directors on ATA’s board to find ways to raise financial resources that will support the talented researchers that ATA funds.

What Barbara and Dean Miss

Their passion for motorcycle rides led them to beautiful, quiet places. Understandably, that has ended; Barbara doesn’t want to risk the chance of her tinnitus worsening. “I miss the fun we used to have and regret the plans for post-retirement trips that might never happen,” she laments.