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Striking the Right Balance: The People Behind the Tumours

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In this edition of "Striking the Right Balance," Rex Banks, Director of Hearing Healthcare at the Canadian Hearing Society talks about his involvement as a support group facilitator and President of the Acoustic Neuroma Association of Canada. For more information visit: www.anac.ca

If you are a health care professional and would like to be more involved in all things vestibular, please sign-up for the Vestibular Special Interest Group. Sign-up by emailing Erica Zaia at** CAAvestibular@gmail.com **to let us know you want to be included. Also, check out our Facebook page for a free list of online vestibular resources at the CAA National Vestibular Special Interest Group page.

One clinic day in year's past, I was conducting a hearing aid check on a patient with a CROS hearing aid. During the appointment, we talked about the origin of his hearing difficulties, an acoustic neuroma, and that the Acoustic Neuroma Association of Canada (ANAC) used to have chapter meetings hosted by the Canadian Hearing Society's (CHS) Toronto location back in the 1980s. For whatever reasons, the Toronto meetings eventually stopped. He went on to describe the importance of ANAC and how the meetings helped him and so many others who suddenly found themselves thrust into the discovery that they had a brain tumour, and unexpectedly, it was on their "hearing nerve." There was already some bubbling interest to get the meetings going again from ANAC – all that was needed was a meeting space and possibly a hearing care professional to help kick things off. Before I knew it, we were on our way with our first support group meeting scheduled to occur in just a few short weeks. That was 14 years ago.

Before I tell you about what I have learned over the past 14 years, I want to take a few moments to introduce you to ANAC. It was founded in 1983 by acoustic neuroma patients Virginia Garossino, Velma Campbell, and Linda Gray. Based out of Edmonton, the three women underwent acoustic neuroma surgery within a year of each other. They encountered individual sets of difficulties and recovery courses. Through their challenging journeys, they discovered there was little information and support for Canadians dealing with this benign cranial tumour. Finding strength within each other, the three established ANAC, a charitable non-profit organization designed to support the complex needs of acoustic neuroma patients. Since then, through its network of chapters and support groups, the association has touched thousands of acoustic neuroma patients across the country.

At its very core, ANAC is a patient-headed peer support group that also includes a Peer Database Registry. It is through ANAC's goal of information sharing and public education, early diagnosis may result in successful treatment for all patients. Many individuals who face and undergo removal of acoustic neuromas have questions, concerns and physical and emotional adjustments…and that's why ANAC exists.

Before my first ANAC support group meeting, I thought I had a pretty good grasp on acoustic neuroma issues including my role in diagnostic audiologic testing, medical referral criteria, tinnitus, balance difficulties, amplification options and communication strategies for people with unilateral hearing loss. Done, I was ready! No…that was barely just the beginning. I was about to get a big dose of reality. The meetings were not about what I had learned in textbooks or journal articles; they were about people, their lives and their individual journeys.

Shock, confusion, fear, depression, grief – these are the emotions newly diagnosed individuals often display at the support group meetings. And who could blame them? Having a tumour is scary with many unknown factors to consider and a lot of medical information to understand. They want answers and support. There is none of the usual denial or excuses related to hearing loss such as "other people are mumbling." No, these individuals are on a different level. They understand their reality and bravely face it. Actually, hearing loss often isn't even their biggest immediate concern. Over time, I would learn that hearing loss only becomes important at a much later stage in the acoustic neuroma patient's journey. From my observations, the first things they need to tackle, understand, reconcile and cope with are "What is this?" "Why is this happening to me?" And most importantly, "What am I going to do about it?"

What is This?

That's easy enough to explain. An acoustic neuroma, also called a vestibular schwannoma, is a rare, non-cancerous tumour which does not spread to other parts of the body. In most cases, they grow slowly over a period of years, but sometimes the rate of growth is more rapid. Symptoms can be mild or severe, and multiple symptoms might develop rather rapidly. The first signs or symptoms usually are related to disturbances in hearing on one side. When large tumours cause severe pressure on the brainstem and cerebellum of the brain, vital functions that sustain life can be threatened. The most common method of diagnosing an acoustic tumour is by a detailed MRI of the head.

Why Is This Happening to Me?

The first thing to let someone know is that are not alone. Acoustic neuromas can affect almost anyone, usually adults between ages 30 to 60 years of age. They constitute 6–10% of all brain tumours and are found in roughly 1 in every 100,000 people. Their cause is not well understood but most are attributed to a breakdown in the celluar machinery that fails to suppress growth of schwann cells, which eventually grow into a neuroma. High-dose, therapeutic radiation exposure to the head has also been associated with increased incidences of acoustic neuromas. The vast majority of acoustic neuromas are nonhereditary in nature. About 5% are associated with a genetic disorder called neurofibromatosis type 2. Like many things in life though, there is no answer to "why?"

What Am I Going to Do About It?

That's a more difficult question to answer. Who are the best people to help with that question? Other people with acoustic neuromas who have already faced their tumour. And that's the beauty of what a support group can offer – experience, support and knowledge.

People diagnosed with acoustic neuromas basically have three choices: observation ("wait and see"), surgical removal or radiation therapy. The choice of treatment may be based on tumour size, hearing in the ear at time of diagnosis, patient age, health, and preference. The Toronto support group is mainly facilitated by volunteers whom themselves have experienced acoustic neuromas.

Some volunteers had radiation therapy, some had surgery and some are on “wait and see.” They’ve been through the ups and downs of various treatments and rehabilitation options. They are not there to tell others what to do about their tumour, but simply to share their own stories to provide information, comfort and support.

Surgery and radiation, those are big words to take in for a newly diagnosed individual. As an audiologist, what did I even really know about these options? Were people going to ask me, as the professional, my opinion on all these things? Those were some of my initial fears when helping to start the support group. What I quickly found out was that the patients knew a lot and were well versed. I listened and learned from them.

Let’s start with surgery. There are three different surgical approaches to removal of an acoustic neuroma, all with different pros and cons. They are translabyrinthine, retrosigmoid and middle fossa. Here are the basics for each.

The translabyrinthine approach is the usual option when hearing has already been severely affected or in the case of large tumours where hearing preservation is not possible. It is the oldest approach with the longest history. It facilitates identification of the facial nerve for preservation and allows for excellent exposure of the internal auditory canal so that any size tumour can be removed by using this approach. The biggest drawback is that it definitely results in permanent and complete hearing loss on the tumour side.

The retrosigmoid approach is used for smaller acoustic neuromas when hearing preservation is possible. It’s for tumours that are growing out of the internal auditory canal and approaching the brainstem. The pros to this surgery include possible preservation of hearing and the facial nerve and any size tumour can be removed via this approach. The downsides are that hearing preservation decreases if the tumour is large and headaches are a more prevalent post-op side effect.

Finally, there’s the middle fossa approach. It’s an option for smaller tumours that have not grown beyond the internal auditory canal. Similar to the retrosigmoid approach, it is used to help preserve hearing. It is the best procedure for preserving hearing but is often used only with small tumours, usually ones confined to the internal auditory canal.

What about radiation? The goal in radiation is to damage the DNA within the tumour cells so that they can no longer divide and eventually, die. Radiation can either be delivered as single-fraction radiosurgery (SRS) or by dividing the radiation dose over multiple sessions which is called fractionated stereotactic radiotherapy (FRS).

Technologies for delivering radiation have improved over the past few decades and today, an increasing number of patients choose radiosurgery as the primary treatment for their acoustic neuroma. Gamma Knife, Linear Accelerator and Proton Beam are examples of the different commercially-available machines that are used to treat acoustic neuromas. These technologies differ in their source of radiation and how the radiation is precisely delivered. They are all similar in terms of effectively treating acoustic neuromas and in avoiding side effects. A number of factors determine whether radiation therapy is appropriate including the size of the tumour, its growth rate, the patient’s age, overall health and symptoms such as degree of hearing loss, balance problems, and vertigo. In most cases, acoustic neuromas that are greater than 2.5 – 3 cm in size are not considered ideal candidates for radiation therapy as these larger tumours often compress the surrounding brainstem and the potential for side effects from the radiation is increased.

Radiation is a good plan for patients in their mid-50s and older or for those with health issues that make having surgery a risky option. Radiation is typically done as an outpatient procedure and there is usually no need to take time off from work. There are usually no immediate complications but in the long run, there could be complications as radiation takes time to fully present symptoms.

Not to oversimplify things and as noted, there are medical reasons as to why some patients need surgery and others opt for radiation, but my observation is that people psychologically fall into one of two camps: (A) Those that cannot bear the thought of having a tumour in their head and “want it out” - they go for surgery. (B) Those that are satisfied with just “killing the tumour” and can live with the idea that it’s still in their head and could come back - they go for radiation.

Finally, there are those patients who are on observation or “wait and see.” The tumour is an everpresent part of their life; it’s there with an unknown outcome. These patients have small tumours and there is no immediate need to do anything at all. Psychologically, this is a tough space to be in though as the tumour has to be “put in check” and prioritized with everything else that may be going on in that patient’s life. Observation is possibly “good news” though for older individuals as all medical treatments, surgical radiation, carry some risks. Who knows, maybe their acoustic neuroma won’t grow or require any treatment all. Most surgeons recommend having a second MRI at least 6 months after the first to establish the growth rate. If the tumour is not growing, avoiding treatment altogether is a possibility. There’s even a possibility that safer treatments beyond surgery or radiation, may be found in the future. These patients just “wait and see.”

Beyond hearing loss, tinnitus and balance difficulties, patients undergoing treatment for acoustic neuromas may experience a range of side effects, many beyond the scope of audiology including: cognitive and emotional issues, CSF leaks, meningitis, eye problems, facial paralysis, headaches, hydrocephaly, seizures, strokes and mouth issues. All of these conditions weigh heavily on the minds of acoustic neuroma patients. They understand and seemingly feel they will be able to cope with the hearing loss but some of these other health concerns feel a bit scarier and less familiar. There’s also the recovery period after treatment. Patients want to know what to expect in terms of how much time they will need to take off from work and how long it will take to fully heal. Support group members can relay their own experiences and challenges in coping with each of these issues and provide important information about how they worked through issues with their employers and can provide suggestions for therapists, physicians and other professionals who can help with any related medical side effects.

I mentioned earlier that newly diagnosed acoustic neuroma patients come to their first support group meeting with many fears and unanswered questions. ANAC is their beacon of hope, provider of solace and place to find others who understand. My years helping facilitate a support group for acoustic neuroma patients and in serving as President of the ANAC Board of Directors, have been some of the most rewarding things I have done as an audiologist. In your career, you have most likely already helped diagnose someone with an acoustic neuroma. After their diagnosis, they will embark upon a journey that will take them far outside of the realm of the sound booth. Let them know that they do not have to do this by themselves. As their audiologist, you play a vital role on multiple stops during that journey and one of the best things you can do is tell them about ANAC.

For more information about ANAC, please visit www.anac.ca

Now you know a little more about ANAC and why it’s such an important organization for both patients and audiologists.

The Acoustic Neuroma Association of Canada:

- Produces and distributes a newsletter which contains professionally authored articles, self-help and other information and news about ANAC and its activities.
- Acts as an information exchange for patients.
- Makes available information booklets to newly diagnosed patients.

- Responds to individual members' non-medical needs.
- Provides opportunities for patients to communicate with others in their geographic area.
- Promotes public education about symptoms which may indicate the presence of these tumours.
- Encourages research into the diagnosis and treatment of cranial nerve tumours.
- Provides information upon request on physiotherapy and neuromuscular rehabilitation and the alleviation of post-surgical problems.