The Connection

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Inside this issue:

Scleral Contact Lenses for Patients with Acoustic Neuroma and Facial Nerve Palsy with or without Corneal Anesthesia

By: Edsel Ing MD, FRCSC, MPH; Anastasia Faggioni, BScN, Vishakha Thakrar BSc, OD, FAAO



Background

The cornea is the normally transparent, clear window of the eye. Possible sequelae of acoustic neuroma surgery include facial nerve palsy with or without corneal anesthesia, both of which can severely compromise corneal comfort and integrity required for clear vision. The facial nerve innervates closure of the eyelid and facial muscles.

With facial nerve palsy, the lower eyelid may be everted (ectropion), and the eyelids may not close completely (lagophthalmos). Since the cornea requires constant moisture and protection, facial nerve palsy may lead to corneal breakdown (keratopathy), corneal opacification and infection, with loss of vision and or discomfort ulceration. The first branch of the trigeminal nerve innervates the cornea and provides important nutritional factors and protection for the eye.

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Traditional methods for corneal protection after facial nerve palsy or trigeminal anesthesia include frequent lubrication, moisture chambers, tarsorrhaphy (sewing parts of the upper and lower lid together), punctal occlusion, upper lid gold weights and springs. A newer surgical intervention to restore corneal sensation is corneal neurotization, but this procedure requires a donor graft, may require a year to work, and is not always successful.

Over the last decade, an increasingly popular non-surgical method to protect the cornea in patients with facial nerve palsy with or without trigeminal anesthesia is the gas permeable scleral contact lens (SCL). SCLs are much larger than conventional contact lenses, and rest on the less sensitive white of the eye (sclera) rather than the cornea. A saline solution fills the space between the cornea and the SCL, keeping the cornea moist. These lenses have several advantages over tarsorrhaphies, which are cosmetically unappealing and can limit peripheral vision. SCL offer much better aesthetics than tarsorrhaphy, and can optimize vision, especially in patients with corneal scarring.

Some Canadian optometrists who belong to the Scleral Lens Education Society are found at the website: https://sclerallens.org/find-fitter/?country=Canada

Scleral Contact Lenses

All eyes are shaped uniquely, and as such SCL require customized fitting and measurements of the front of the eye. (Russell, 2016). This process is conducted by an optometrist or contact lens fitter with specialty training in SCL fitting. The initial fitting process may take an hour, and training to learn to insert and remove the SCL may take more than an hour (Woo, 2014). Patients are often dispensed lenses within weeks of the initial fitting, but completion of the custom lens may take several months to finalize.

Of note, due to the lengthy customization of SCLs, they are more costly than conventional lenses. Patients should contact their medical/vision insurance company to determine if they have benefits that may cover a portion of the cost of fitting and/or of the SCL themselves. A letter from their ophthalmologist or optometrist may be required to show proof of medical necessity.

Prior to SCL insertion, non-preserved saline is used to fill the entire lens. (see Figure) To ensure the solution does not spill out of the lens, patients must tuck in their chin while looking down usually into a mirror. One hand is used to open the eye fully and the other hand is used to insert the lens. A scleral lens suction cup (see Figure) is most commonly used to place the lens on the eye.

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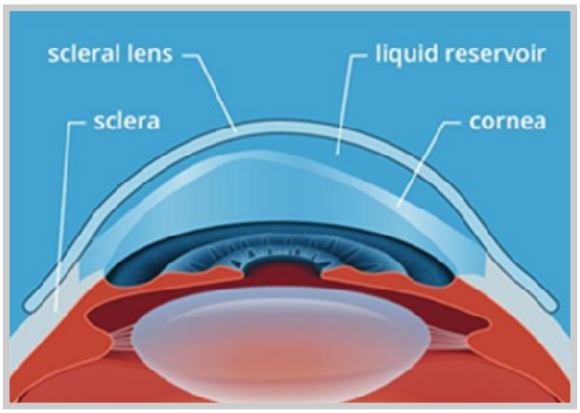

Figure. Scleral contact lens maximally filled with saline positioned on a "DMV" suction cup (blue).

Alternate methods include positioning the fingers into a tripod to balance and insert the lens, but patients often find this method more challenging. For patients who have great difficulty with insertion, a stand may be used so the hands are both free to hold the lids open.

If too much of the saline spills out, a bubble will form between the lens and the eye. In this case, the lens will have to be removed and re-inserted. To remove the lens, a removal plunger should be used. Patients should be proficient at putting the lenses on and taking them off prior to taking the lenses home. There are many assistive tools to facilitate insertion and removal of SCLs, including application and removal plungers, plastic rings, and stands. These can often last up to three months and can be purchased at contact lens fitter's office. Whether an assistive device or fingers are used for application, SCL wearers should insert the lens and then release their eyelids before letting go of the lens.

When scleral contact lenses are properly cleansed and adequately maintained, they may last up to two to four years. The gas-permeable material allows for oxygen to readily pass through the lens to maintain the health of the eye. The lens protects the surface of the eye from environmental factors, hydrates the surface of the eye, while correcting irregular astigmatism caused by corneal scarring

To ensure proper long-term use of the SCL, follow-up appointments are booked every one to two weeks until completion of the fitting. Ultimately, the goal is to have a properly fitted lens that does not compromise the cornea or conjunctiva and provides optimal vision and comfort for the patient. Orange coloured eye drops (fluorescein) are often used to examine the presence and quality of the tear film between the lens and the eye.

The amount of time a patient can wear the SCL varies from patient to patient. Typically, patients with facial nerve palsy are encouraged to wear the SCL during all waking hours to protect the

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cornea and ocular surface. All contact lenses including SCL should not be worn at night to decrease the risk of corneal infection. In patients with facial nerve weakness, taping the lids closed, nighttime lubricating ointment and moisture chambers are advisable alternatives. If patients have an upper lid gold weight, the head of the bed should be raised to help the lids close at night.

Corneal infections are a potential risk with SCL, but the risk is minimized with good lens and hand hygiene. In a large study of over 84,000 patients who were fitted for SCLs, there were only 70 cases of reported infected corneas. Wearing contacts overnight (even gas permeable lenses) can lead to the eye being starved of oxygen. Other complications include corneal swelling, new vessel growth in the eye, conjunctival redness, fogging, and dryness of the lens during the day.

In summary, SCL are non-surgical options in acoustic neuroma patients who have corneal exposure and/or loss of corneal sensation. SCL can help protect and heal the ocular surface, recover vision, and reduce pain for patients with facial nerve palsy. However, SCL need to be worn appropriately and checked regularly to avoid corneal infection or other ocular surface compromise.

References

DeLoss, K. S., Kaz Soong, H. & Hood, C. T. (2019). Complications of contact lenses. Trobe, J. & Givens, J. ed. UpToDate. Waltham, MA: UpToDate Inc. https://www.uptodate.com (Accessed June29, 2019).

Fadel, D. & Toabe, M. (2018). Scleral Lens Issues and Complications Related to Handling, Care Compliance. *Journal of Contact Lens Research and Science, 2*(2), 1-13. doi 10.22374/jclrs.v2i2.24

Griffin, G., Fey, A. & Azizzadeh, B. (2017). Facial Nerve Palsy. In A. Fey and P. J. Dolman (Eds.), *Diseases and Disorders of the Orbit and Ocular Adnexa*. Retrieved from Elsevier ClinicalKey.

Lasby, A. (2016). The Scleral Lens Industry: Where are we Headed? *Canadian Journal of Optometry, 78*(1), 32-35. Retrieved from https://opto.ca/sites/default/files/resources/ documents/cjo_contact_lens_supp.pdf

Michaud, L. & Liao, J. (2016). Scleral Lens Troubleshooting Q&A. *Canadian Journal of Optometry, 78*(1), 25-31. Retrieved from https://opto.ca/sites/default/files/resources/ documents/cjo_contact_lens_supp.pdf

Charlie Chaplin, British comic actor and filmmaker, had this to say about the woes of life:

"Nothing is permanent in this wicked world, not even our troubles."

Remember, "This too shall pass." How encouraging it is to know that even in the worst of times, troubles will pass. We always have a new day tomorrow to dust ourselves off and start over again.

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Russell, B. (2016). Visual Rehabilitation with Contact Lenses for Irregular Corneal Astigmatism. *Canadian Journal of Optometry, 78*(1), 4-17. Retrieved from https://opto.ca/sites/default/ files/resources/ documents/ cjo_contact_lens_supp.pdf

Scleral Lens Education Society. (2018). *Patient FAQs*. Retrieved from https://sclerallens.org/for-patients/patient-faqs/

Weyns, M., Koppen, C. & Tassignon, M. J. (2013). Scleral Contact Lenses as an Alternative to Tarsorrhaphy for the Long-Term Management of Combined Exposure and Neurotrophic Keratopathy. *Cornea, 32*(3), 359-361. doi:10.1097/ICO.0b013e31825fed01

Zaki, V. (2015). *A non-surgical approach to the management of exposure keratitis due to facial palsy by using mini-scleral lenses*. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/ articles/PMC5312998/

Woo, S. L. (2014). *10 Dos and Don'ts of Scleral Lenses*. Retrieved from https://www.reviewofcontactlenses.com/article/10-dos-and-donts-of-scleral-lenses

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Anastasia Faggioni, BScN, *is a Medical Student at Northern Ontario School of Medicine and participates as a Local Exchange Officer on the school's Global Health Committee.*

Vishakha Thakrar BSc, OD, FAAO, *is an Optometrist and Contact Lens Fellow, Vaughan Family Vision Care. Dr. Thakrar has worked in optometry clinics in both Canada and the United States. She held the role of Director of Contact Lens Service at the Cole Eye Institute, Cleveland Clinic Foundation. She also participated in research activities in collaboration with the Department of Ophthalmology. In recent years, Dr. Thakrar has served as a contributing editor for the journals Contact Lens Spectrum and Eye Care Review and has written many articles on various optometric topics. She also speaks in the United States and Canada on contact lenses and eye diseases. Dr. Thakrar has received contact lens awards from Johnson and Johnson Vision Care, CIBA Vision, the GP Lens Institute and the College of Optometrists in Vision Development.*

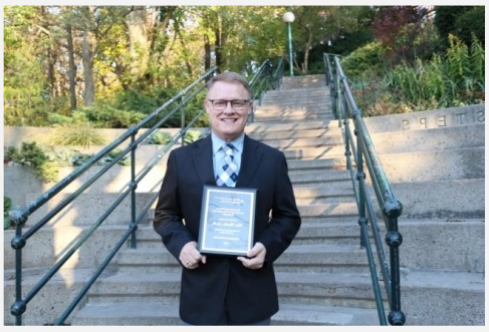
Brandon Burchard, one of the most-followed personal development trainers, in the world has this to say about the importance of giving thanks.

"Walking the grounds of Gratitude, I came upon the Palace of Happiness."

He equates gratitude with happiness, suggesting that when we focus on the things we have to be grateful for, we will find happiness. And when we are happy we are in a position to create, inspire, and influence others by our attitude and actions.

Look at What We Found in the News!

Rex Banks AuD, CASLPO, ASHA; First Recipient of Audiologist of the Year



Hats off to Dr. Rex Banks, Director of Hearing Healthcare and Quality and chief audiologist at Canadian Hearing Society (CHS) on being named **Audiologist of the Year by the Ontario Association of Speech-Language Pathologists and Audiologists**. Rex is past president of ANAC and a founding member along with Lynda Nash and Joanne Bennett of the Toronto Support Group which started in 2003.

This prestigious award recognizes his outstanding contributions to the field of audiology through his leadership, research and passion for helping people with hearing loss. ANAC has been the recipient of Rex's unwavering dedication, leadership and recognition of the need for a vehicle and place for those impacted by acoustic neuroma to come together, to learn and to share experiences. At the meetings which have been held for some sixteen years this coming May at CHS he listens, provides insight and shares his knowledge.

"Receiving Audiologist of the Year Award inspires me to continue to advocate for both my profession and for people with hearing loss," said Rex.

This award coincides with his 30th anniversary as an audiologist. Meeting a deaf man when he was just 12-years old was just the inspiration for him to pursue a career in audiology. Rex also holds the Certificate of Clinical Competency in Audiology (CCC-A) designation.

Rex has been an active advocate in audiology, working as a volunteer with other organizations including:

- Canadian Academy of Audiology (President and board member)
- Ontario Association of Speech-Language Pathologists and Audiologists (President)
- Toronto Central Local Health Integrated Network
- Ontario Special Olympics Healthy Hearing / Healthy Athletes Program (1st Ontario Director)
- Statistics Canada (research advisor) and Health Quality Ontario (clinical advisor)

Professional golfer Ben Hogan compared golf to life with these unforgettable words:

"As you walk down the fairway of life you must smell the roses, for you only get to play one round."

What a beautiful piece of advice for all of us. Enjoy this one round you are blessed with and don't forget to smell the roses along the fairway of life.

Striking the Right Balance—Vestibular Migraine

By: Jamie M. Bogle, AuD, PhD, University of Colorado, Boulder

Migraine is one of the most common disorders in the world, impacting 16% of the world's population over the course of a lifetime[1] and an estimated 2.7 million Canadians are impacted by migraine. Migraine has long been associated with dizziness symptoms – up to 69% of patients diagnosed with migraine also report at least occasional vertigo or dizziness. While complex and poorly understood, the relationship between migraine and dizziness may be due to anatomical and pathophysiological factors, such as neural pathway and neurotransmitter overlap and vascular and inflammatory processes.

Updated Diagnostic Criteria

Dizziness and headache have long been associated; however, the definition of this disorder has been unclear and variously defined. Researchers have used several descriptions over the years to describe this relationship between dizziness and headache: migraine-associated vertigo, migrainous vertigo, vertiginous migraine, migraine-associated dizziness to name a few. In 2012, the Bárány Society6 and the International Headache Society provided consensus documents for proposed criteria for vestibular migraine (Figure 1) in order to better evaluate and manage these patients.

Vestibular Migraine Criteria

A. At least 5 episodes with vestibular symptoms* of moderate or severe intensity**, lasting between 5 minutes or 72 hours
B. Current or previous history of migraine with or without aura
C. One or more migraine features with at least 50% of vestibular episodes:
   i. Headache with at least 2 of the following characteristics: intensity, aggravation by routine physical activity
   ii. Photophobia, phonophobia
   iii. Visual aura
D. Not better accounted for by another or ICHD diagnosis (international classification of headaches)

Probable Vestibular Migraine

A. At least 5 episodes with vestibular symptoms* of moderate or severe intensity**, lasting between 5 minutes or 72 hours
B. Criteria B or C (migraine history OR migraine features during the episode
C. Not better accounted for by another or ICHD diagnosis (international classification of headaches

*Spontaneous vertigo, internal/external perception of motion; positional vertigo, head motion- induced vertigo; head motion- induced dizziness and nausea
** Moderate: interfere but do prohibit activities of daily life;
Severe discontinue of activities of daily life;

Figure 1. Current diagnostic criteria for +vestibular migraine and probable vestibular migraine

Striking the Right Balance—Vestibular Migraine

Once these diagnosis criteria were put in place, earnest research could begin to evaluate the clinical presentation and management outcomes of this disorder when using a common diagnostic criterion. While we have understood dizziness to be a common concern in patients with migraine, recent epidemiological data suggest that those patients meeting the diagnostic criteria for vestibular migraine may be higher than previous expectations. Formeister and colleagues[8] utilized a population-based survey of adults in the United States, finding that 23% of those who reported a one-year prevalence of dizziness or imbalance met the diagnostic criteria of vestibular migraine, translating into a prevalence of 2.7%. This means that vestibular migraine may be the most common cause of dizziness, surpassing benign paroxysmal positional vertigo (BPPV) and Ménière's disease. The authors found that vestibular migraine was more likely in those less than 40 years of age, in females, in those with a prior head injury, and in those with self-reported anxiety and/or depression. Unfortunately, this study found that, while a significant number met the diagnostic criteria for vestibular migraine, only 10% were given this diagnosis. This lack of identification is significant. These patients are likely to be limited in their ability to carry out activities of daily life, including attending school or work. Awareness of vestibular migraine is an important step in developing appropriate management strategies for a large cohort of dizzy patients.

Episodic Vertigo – Differentiating the Possible Etiologies

There are significant challenges in diagnosing vestibular migraine. Keep in mind that there is no objective test specific for vestibular migraine – it is a diagnosis based on consensus criteria. These criteria are in beta form, meaning that they are still under evaluation and may be adjusted in the future as we learn more about this disorder. Additionally, not all patients with recurrent dizziness and headache history will meet the criteria for vestibular migraine, and therefore may need different management options. Other disorders that include recurrent dizziness, such as BPPV and Ménière's disease may also be considered for these patients. To further complicate the diagnosis process, there is overlap among vestibular migraine and these other disorders presenting with recurrent dizziness. It is important to remember the diagnostic criteria for each of these disorders to determine the diagnosis; however, there is evidence that these pathologies may also co-exist in some patients.

Vestibular Laboratory Findings

Can we isolate the vestibulopathy and identify vestibular migraine? This is challenging as there is no clinical diagnostic test for vestibular migraine. Look at this in terms of what we do in the vestibular laboratory – the vestibular diagnostician evaluates the vestibular system for what is working and perhaps what is not, but a management team is needed to determine the etiology.

Striking the Right Balance—Vestibular Migraine

Audiologists do provide significant input to this team by providing objective measures and functional data for these complex patients. Now that a consistent criterion is used for vestibular migraine diagnosis, we can better look to our diagnostics to determine a "laboratory profile" (Figure 2). The majority of vestibular laboratories start with videonystagmography (VNG). In our laboratory, the VNG has not provided much in the way of a clinical profile, aside from ruling out a peripheral vestibulopathy. Occasionally, patients will demonstrate significantly saccadic smooth pursuit (10%). Caloric asymmetry is rare in our patient cohort, with 7% demonstrating significant asymmetry. Importantly, there was no evidence that these asymmetries were uncompensated. These data are somewhat less significant than previous reports, which found a larger percentage of caloric asymmetry in patients with headache. This is not too surprising as the diagnostic criterion have varied over time, leading to perhaps a wide range of patients included in these samples. Interestingly, recent literature suggests that otolith reflex pathway abnormalities may be a common characteristic in vestibular migraine. Our data found a significant proportion of bilaterally absent ocular VEMP responses (28%) as well as reduced amplitude and significant asymmetry as compared to controls. Importantly, these otolith reflex pathways have shown functional abnormalities as well, as measured by subjective visual vertical and horizontal tasks.[13,14]

Common Clinical Presentation

- **Normal VNG results, except in those with additional/ overlapping pathology**
- **Abnormal otolith reflex pathway function: ocular/ cervical VEMPs, subjective visual vertical**
- **Abnormal function integration: reduced balance, poor gaze stability, increased symptoms with visual tasks such as smooth pursuit, optokinetic nystagmus**

Figure 2. Common vestibular laboratory findings for those meeting diagnostic criteria for vestibular migraine and probable vestibular migraine.

Because migraine impacts multisensory information processing, functional measures should be emphasized when a patient has suspected vestibular migraine. Posturography testing has found increased postural instability in patients with migraine while experiencing headache especially in eyes-closed conditions. Further, as many patients with vestibular migraine experience motion sensitivity, evaluating the influence of abnormal visual reference on postural stability is important. Our clinical data finds abnormalities in 44% of patients diagnosed with vestibular migraine when using the Sensory Organization Test. The abnormality pattern, however, is variable and demonstrate patterns associated with vestibular (12%), somatosensory (10%), and visual preference (6%). Another 6% demonstrate global imbalance while 10% were described as "aphysiologic" or "physiologically inconsistent." This concept of aphysiologic balance function is

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interesting and may not actually be "aphysiologic" as we would describe in a malingering patient. It may relate more to the prevalence of anxiety in this population. Gaze stability is another functional metric that may be helpful in evaluating patient with vestibular migraine. Many patients with vestibular migraine describe increased dizziness with quick head turns. Tests such as the Dynamic Visual Acuity Test or Gaze Stability Test can quantify the changes in visual acuity with head movement and provide a target for rehabilitation services. The literature in this area is limited, but our clinical data has found abnormalities in 68% of patients with vestibular migraine using this test paradigm. Because semicircular canal function is generally appropriate in this group, these findings suggest atypical multisensory integration as contributing to dizziness symptoms.

Management Strategies

Vestibular migraine management requires a team approach for optimal outcomes. This team generally includes vestibular diagnosticians and otologists, physical therapists, psychiatrists, psychologists, and neurologists. The management strategy will vary based on the patient, but importantly there are numerous options that may be used for successful treatment. Table 1 provides a summary of the management options available as reported in the literature. Given that I am not a physician, I can only comment on what is reported in the literature regarding medical management. Collaboration with a headache specialist is best to manage these options. Recent literature has found valproic acid, venlafaxine, and flunarizine helpful as prophylactic treatment options to reduce the number, frequency, and severity of vestibular attacks.

Medication Options 20,21	Physical Therapy	Additional Considerations
Betablockers Propanol Metoprolol Anticonvulsants Topiramate Valproic acid Lamotrigine Calcium Antagonist Verapamil Flunarizine Lamotrigine Antidepressants Amitriptyline Venlafaxine Nortriptyline Supplements Magnesium Carbonic Anhydrase Inhibitors Acetazolamide Other Prophylaxis Onabotulinumtoxin A	Balance Gaze stability Oculomotor function Visual Motion Sensitivity	Diet Reduce caffeine Reduce Alcohol Avoid foods associated with symptom increase Sleep hygiene Triger avoidance Anxiety/depression management Cognitive behaviour management Exercise / reconditioning

Table 1. Various Strategies for Management of Vestibular Migraine and Probable Vestibular Migraine. Note the Multidisciplinary Approach Needed for These Patients – Including Neurology / Headache Specialists, Vestibular Rehabilitation Specialists, Vestibular Diagnosticians, Otologists, As well As the Psychological Care Team Is Key To Appropriate Management

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While medications may be indicated in many of these patients, the importance of vestibular rehabilitation should not be overlooked. Alghadir and Anwer provide a current review of available literature on the use of vestibular rehabilitation for those with diagnosed vestibular migraine. Because many of these patients do not effectively incorporate vestibular information, they are at risk for falls. Patients with vestibular migraine are challenging candidates for rehabilitation as they present with various comorbid conditions that also need to be addressed, including anxiety (overall anxiety as well as anxiety about dizziness), significant motion sensitivity, and hypervigilance. Even though this may be challenging for the patient to complete, our team finds that vestibular rehabilitation is a vital component of the management protocol, addressing the functional limitations present in these patients.

Emerging literature that suggests that vestibular rehabilitation may also aid in reducing headache symptoms, anxiety, and self-report dizziness symptoms,further highlighting the importance of this component.

Conclusion

Vestibular migraine is a common, but unfortunately, overlooked etiology for patients with recurrent dizziness symptoms. Because these patients are often evaluated in the vestibular laboratory, we have the opportunity to assist in guiding them to the appropriate management team by ruling out characteristics associated with other etiologies, as well as providing information regarding the functional capabilities of the patient. All this information helps to determine planning for rehabilitation options. Now that vestibular migraine has a standardized criterion, we can work together to better identify the patient characteristics and clinical laboratory findings associated with this patient group, further improving our ability to provide effective management.

Jamie M. Bogle is an Assistant Professor of Audiology at the Mayo Clinic College of Medicine and Science and the division chair of Audiology at Mayo Clinic Arizona. Clinically, Dr. Bogle's research interests include the integration of visual and vestibular information in individuals with neurological impairments, including understanding of the importance of vestibular gravito-inertial information into overall body function. She was awarded the James and Martha Crawford Endowed Clinical Research Fellowship in Otolaryngology at Mayo Clinic Florida and the 2018 Outstanding Early-Career Audiologist Award from the American Academy of Audiology.

Note: Please refer to 2017 study by the University of California outlined in Research Abstracts in this newsletter edition.

This article originally appeared in Canadian Audiology Vol 6 Issue 2 - 2019.

My AN Experience—From Diagnosis to Recovery

By: Chelsea Shanoff, Toronto

In December 2016 I was finishing my first semester in a PhD music program in Toronto, when I started experiencing strange sensations through the left side of my head: tingling, electrical "zaps" on my face, fluttering in my ear, and what felt like dental pain. I was worried about these symptoms, but I figured I had overdone it with playing my instrument, the saxophone, and assumed I was suffering from a musculoskeletal disorder in my jaw or neck.

Over the next half year, my symptoms progressed and fluctuated, and I saw dentists, doctors, manual therapists, and an ENT who finally discovered that my high-range hearing on the left side was lower than on my right. Again, I thought this was just the wear and tear of being a musician. She said she was being overly cautious but that she would like to send me for an MRI to rule out this rare condition. Fast-forward a number of months, and we arrive at my diagnosis of the "really rare condition" – a 2cm Acoustic Neuroma (AN). Looking back, I see some mild dizziness and balance symptoms that had been present for a long time but that were subtle enough to not alert me to any issues.

The specialists advised me that although I would likely need to have surgery down the road, we would first "watch and wait", with MRI scans every six months. The waiting period allowed me to gather as much information as I could and to seek multiple opinions. I explored different hospitals, surgical approaches, and doctors in order to make the most informed decisions. I continued on with my life; most people did not know what I was dealing with, but the facial symptoms continually worsened. I learned that the electrical sensations I was experiencing were caused by my tumour pressing on the trigeminal nerve (one of the other cranial nerves), and it gradually progressed to the point where eating and talking would send incredibly intense shooting pain through my face. It became clear from the scans that my tumour was slowly growing (it was about 2.5 cm at the time of surgery), and the surgeons said it was time to take action.

Almost two years after diagnosis I had translab surgery at Sunnybrook Hospital in Toronto. The team was able to remove almost the whole tumour: a few cells were left behind in order to preserve the facial nerve (hopefully these cells won't show up on an MRI for many years, if ever). The surgeon reported that the facial nerve was extremely thin and if I had waited much longer, they wouldn't have been able to save the nerve, and that the tumour appeared much larger once they actually got inside my head. Needless to say, hearing this made me very glad that I did not wait longer to do the surgery.

My AN Experience—From Diagnosis to Recovery

I feel incredibly lucky that my recovery has been straight-forward and positive: I did not have any surgical complications or permanent facial paralysis, I was walking (gingerly) on my own by the end of the first week, and the dizziness and nausea that I experienced immediately following the surgery improved greatly with time, regular walking, and vestibular exercises. I was socializing at restaurants by the end of the first month, did a (slow) yoga class at six weeks, and got back on my bike after two months. I'll never really know how much of my great outcome can be attributed to luck, the surgical team, or my pre-op health, but I would assume it to be a combination.

My surgeon was honest with me, saying that many people feel frustration after a few months post-op, when they are in most respects "back to normal," but still don't feel like themselves and are adjusting to internal sensations. Many refer to this part of recovery as "chasing the final 10 or 15 percent" and that even with a textbook no-complications surgery, it likely takes about a year for the brain to fully heal from the surgery and adapt to the loss of balance and hearing nerve.

I am writing this at four months post-op, thinking a lot about this in-between stage. Patients often don't get a lot of information from doctors as to what this part of recovery is like, and it can be an isolating and emotional time. The brain is working overtime to adapt, and this often shows up as intense fatigue, brain fog, and the "wonky circus head" phenomenon. Adapting to single-sided deafness post-surgery is often the hardest part to adjust to long-term. I am still getting used to the challenges of filtering sounds and noisy environments, and also coming to terms emotionally with this huge loss, and what it means to me. I have learnt what triggers my fatigue and the circus-head feeling and how to minimize the effects, but also that total avoidance of triggers can make recovery slower.

This stage of recovery can be frustrating because it is invisible to others and can be hard to explain. With such huge leaps and bounds of recovery within the first month, during this middle stage it can feel like progress has stagnated. This is where connecting with others who have gone through the same thing, and understand these challenges, can have a huge positive impact.

Shortly after diagnosis, I connected with another AN-er who lives in the same city as me. We are similarly aged and had the same surgical team with our surgeries two months apart. We have become close friends from this experience, with a level of connection that is only possible when you share a diagnosis and neurosurgeon! Acoustic Neuromas are often referred to as the best type of brain tumour to get, but they pose their own challenges due to the multiple treatment options (yet no "perfect" treatment), hearing loss, and a myriad of possible symptoms.

The emotional toll of living with an AN, and going through the surgery, should not be neglected; recognizing the emotional impact is an important part of the long-term recovery process. For that reason, it is crucial not only to seek out the best neurosurgeons and specialists, but also a varied support system that can help guide you through diagnosis, treatment, and recovery – whatever that may look like for you.

Acoustic Neuroma Research Abstract

PubMed.*gov*
U.S. National Library of Medicine, National Institutes of Health

Sahyouni R, et al. Otol Neurotol. 2017

Vertigo in Vestibular Schwannoma Patients Due to Other Pathologies

Sahyouni R[1], Moshtaghi O, Haidar YM, Mahboubi H, Moshtaghi A, Lin HW, Djalilian HR.

Division of Neurotology and Skull Base Surgery, Department of Otolaryngology-Head and Neck Surgery †Department of Biomedical Engineering, University of California, Irvine, Irvine, California.

Citation Otol Neurotol. 2017 Dec;38(10):e457-e459. doi: 10.1097/MAO.0000000000001567.

Objective: To report findings from a cohort of vestibular schwannoma (VS) patients presenting with vertigo from a secondary comorbid vestibular disorder; and to discuss management strategies for this subset of patients presenting with both episodic vertigo and VS.

Patients: All VS patients who presented with vertigo as the primary symptom from 2012 to 2015 and endorsing no other major complaints were examined.

Intervention: Treatment with migraine lifestyle and prophylactic therapy, or Epley maneuver.

Main Outcome Measure: Resolution of vertigo following medical treatment alone.

Results: Of the nine patients studied, seven (78%) suffered from vestibular migraine, and two (22%) experienced benign positional vertigo. All patients experienced complete resolution of symptoms after treatment. As a result of symptomatic improvement, seven patients (78%) avoided surgery in favor of observation, while two patients (22%) underwent radiosurgery due to continued tumor growth and other non vertigo symptoms.

Conclusion: VS patients can sometimes present with a history of recurrent episodic vertigo. The etiology of the vertigo could be due to the tumor itself or may be due to an underlying comorbidity such as vestibular migraine or benign positional vertigo. VS patients presenting with vertigo should undergo a standard vertigo history and examination to identify other potential causes of vertigo. Most VS patients in our cohort avoided intervention and had resolution of their vertigo.

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Leaving a Legacy

"The Small Charity that Comes from the Heart is Better than the Great Charity that Comes from the Head." – Ivan Panin

A bequest is a lasting statement of your generosity and an opportunity to say that you care about individuals, an institution or a charity. By choosing to remember the Acoustic Neuroma Association of Canada (ANAC) through a gift in your will – known as a bequest – you will help ensure that ANAC continues to be here to help Canadians diagnosed with an acoustic neuroma make informed decisions about their treatment and health.

Your planned giving helps ANAC to plan for and provide the needed resources, and to create the most effective educational programs.

A bequest is as simple as inserting a few sentences into your will or living trust. Changes in a will can be made at any time. We encourage you to review your options with your financial planner, tax advisor and/or lawyer. You and your heirs may benefit from considerable tax credits on your estate, and you will also feel good knowing that your decision is helping others in the AN community.

For more information, contact Carole Humphries, Executive Director of ANAC, today at director@anac.ca. If you have already included ANAC in your estate plans, please notify us so that you may be part of our special Legacy group.

Giving is not just about making a donation, it's about making a difference.

Kathy Colvin

Upcoming Chapter Meetings Planned

KITCHENER—WATERLOO CHAPTER

Date: **TBD Spring 2020**—10am—12pm followed by a potluck lunch
Location: Home of Tom & Helen Horlings
#30—50 Bryan Court, Kitchener, ON N2A 4N4
For more info: Linda Darkes
(519) 696-3445 / pdarkesc659@rogers.com
Helen Horlings
(519) 954-5581 / healto@rogers.com

BRITISH COLUMBIA: COURTENAY/NANAIMO CHAPTER

Date: **TBD Spring 2020**—1pm
Location: White Spot, 2299 Cliffe Ave., Courtenay, BC
For more info: Evalyn Hrybko
(250) 282-3269 / wehrybko@saywardvalley.net

TORONTO CHAPTER

Dates: **Tuesday, January 28, 2020**—6:30pm—8:30pm
Tuesday, March 31, 2020—6:30pm—8:30pm
Tuesday, May 26, 2020—6:30pm—8:30pm
Location: Canadian Hearing Society
271 Spadina Road, Toronto, ON (Parking in the rear)
For more info: Kathryn Harrod
(905) 891-1624 / kath.harrod@live.ca
Linda Steele
(416) 993-0065 / lindasteele2@gmail.com

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Twitter: @CanadaAN