

The

Connection



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Summer Edition 2020

Cognitive Symptoms of Vestibular Schwannoma

By: Ravi N. Samy, MD, FACS; Mario Zuccarello, MD, FACS; Scott B. Shapiro, MD; Noga Lipschitz, MD; Allie Mains, FNP, CNRN; University of Cincinnati Medical Center



Acoustic neuroma, also known as vestibular schwannoma (VS), is the most common tumor that occurs in a region between the brainstem and inner ear, called the cerebellopontine angle or CPA. This region contains the nerves of hearing, balance, and facial movement. The

symptoms of VS vary but the most common are hearing loss and tinnitus. Other possible symptoms are imbalance, taste disturbance, headache, facial weakness, and/or facial numbness. Some tumors do not cause any symptoms and are found incidentally. In our experience, a not insignificant number of patients will also describe cognitive difficulties such as slow-thinking, memory lapse, or a non-specific "brain fog". These can be some of the most troubling symptoms affecting patients with VS, but unfortunately, less is known about them because these symptoms can be vague and are also common in the general population.

Fortunately, research into these cognitive symptoms is increasing. While the exact prevalence of detectable cognitive impairment in VS patients is still unknown, recent studies of patients with various cerebellar tumors have shown that most patients were found to have deficits in at least one area of cognitive



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Cognitive Symptoms of Vestibular Schwannoma

functioning,*1,2 and a constellation of deficits (including cognitive and emotional symptoms) as part of a “cerebellar syndrome” has been described. Fortuitously, existing research suggests that most patients see improvement in cognitive function with surgery.*1,3 It should be noted that most of this research is not specific to VS, or even tumors in the CPA, but comes from research on cerebellar tumors in general. Thus, we should be judicious in applying it to patients with VS.

Cognitive symptoms can affect patients with untreated tumors or after treatment with surgery or radiation. Although the exact incidence of development of new symptoms after treatment is unknown, they may be common and transient after treatment. Occasionally, new or pre-treatment symptoms persist; in one study of patients who underwent surgery for VS, 7% of patients self-reported long-term difficulty concentrating in an open-ended questionnaire.*4

At the University of Cincinnati Medical Center, we have begun to utilize biofeedback therapy for patients with cognitive symptoms. We will publish our results in the near future. In summary, cognitive symptoms can be very troubling to patients with vestibular schwannoma but remain poorly understood compared to other symptoms. Most of our existing knowledge comes from research of other types of tumors that affect the cerebellum or CPA, which suggests cognitive symptoms may be more common than realized.

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- This article which appeared in ANA NOTES June 2020 is reprinted with permission of the authors and our US sister organization, ANA.

Jim Rohn, American entrepreneur and author gives wise advise for staying in shape physically and mentally.

“Take care of your body. It’s the only place you have to live.”

What a clever way of stating an important FACT!.

Congratulations to Dr. Gelareh Zadeh Krembil Neuroscience Centre



In July, Dr. Gelareh Zadeh, known to many of you as Chair of ANAC's Scientific Medical Advisory Committee and to some as your neurosurgeon, was named Medical Director of the Krembil Neuroscience Centre at Toronto Western Hospital (TWH). The Institute, established in 2018, aims to help clinicians and researchers at TWH and across the entire University Health Network (UHN) work together in

harmony to seek better treatments and cures for diseases of the brain, spine and nerves.

This appointment is a crowning achievement, recognizing amongst her peers Dr. Zadeh's leadership skills and the significant contributions she is making to neurosurgery and neuro-oncology.

Internationally recognized in both fields, Dr. Zadeh is professor of neurosurgery at the University of Toronto. Among her many professional achievements too numerous to list here, she is an award-winning teacher and a highly published senior scientist who holds the Wilkins Family Chair in Brain Tumor Research at the UHN and co-director of the Krembil Brain Institute which offers integrated, multidisciplinary, comprehensive neuroscience health care that is second to none in Canada and among the best in the world.

In her research laboratory the Zadeh lab focuses on establishing the genomics/epigenomic of skull base tumors, including meningiomas and schwannomas. She also studies the molecular mechanisms of glioma angiogenesis and molecular regulators of tumour metabolism, while Dr. Zadeh's clinical practice focuses on Skull Base Neuro-oncology, with a general brain tumour clinic, as well as multi-disciplinary clinics dedicated to skull base, pituitary, brain metastases, gamma knife and neurofibromatosis.



Dr. Gelareh's drive to succeed stems from a desire to help her patients. Along with her fellow researchers, she seeks to "understand more about the biology of the tumour, why the cells came about in the first place, what makes them grow and where we can intervene to stop the tumour cells from growing and from coming back."

As if her professional track record is not enough, what further distinguishes Dr. Zadeh is that she continues to number among only a handful of female neurosurgeons worldwide . . . and did we mention that she gave birth to a second daughter earlier this year!

Congratulations to Dr. Gelareh Zadeh Krembil Neuroscience Centre

How fortunate we are to have Dr. Zadeh as Chair of ANAC's Scientific Medical Advisory Committee. She has been instrumental in orchestrating our biennial *World of Acoustic Neuroma Symposia* and, while it is unfortunate that our 2020 symposium had to be cancelled because of COVID-19, plans are currently underway to hold it in the spring of 2021.

Congratulations, Dr. Zadeh from all the members of ANAC.

ANAC's Newest Board Member



Anna Gurdon joined our board this spring, bringing with her 20 years of Information Technology (IT) experience. After graduating from the University of Toronto with a B. Comm (Management and Economics) in 2000, Anna began working in the field of IT. A systems analyst and senior client advisor, she specializes in enterprise resource planning and business intelligence, guiding clients through all aspects of technology including vendor selection, blueprinting, development, and post-implementation. Anna has also spoken internationally in her area of expertise, i.e., systems analysis.

After being diagnosed with a large acoustic neuroma in 2019 and undergoing translabrynthine surgery towards the end of the year, Anna realized how scary that process can be. She subsequently wanted to help other people, even if it meant simply chatting with them and reassuring them that there is indeed a life after an AN diagnosis. Anna has done that and so much more, having initially agreed, when asked in January, to revitalize our social media. Watch for Anna's regular updates our Facebook page, Acoustic Neuroma Association of Canada, where she posts event reminders as well as interesting and helpful articles. As a board member, Anna, along with fellow board member, Rebecca Raghubeer, is helping Carole Humphries to organize our fall fundraiser, *Walk Online*.

On behalf of all ANAC members, Anna, welcome to our Board of Directors!

Popular performer Willie Nelson shared this personal experience:

"When I started counting my blessings, my whole life turned around."

Notice he didn't say when he made a lot of money but when he counted his blessings everything changed.

My Acoustic Neuroma Experience

By: Bill Wood, Oakville, Ontario



During 2011 and 2012, I experienced four episodes of horizontal double vision while driving. An optometrist could not detect any eye-related problems and suggested that the cause could be medical. My family doctor arranged for testing at a stroke prevention clinic. An x-ray detected no abnormalities, but an MRI showed a growth in my right ear, which I was told would have to be removed. I was referred to a neurosurgeon, who told me that I had an acoustic neuroma about the size of a pea. As these tumours can sometimes stop growing and not require intervention, my options were active surveillance (Scan and Wait) or surgery. Since the tumour was small and I was not experiencing any major problems, it was suggested that I have

another MRI in a year and review the situation then. Apart from the vision problems, I had vague symptoms consisting of light-headedness, minor balance problems and sound distortion in the right ear. The neurosurgeon saw nothing in the MRI that would explain the double vision. A referral to a neuro-ophthalmologist resulted in the diagnosis of a mild sixth cranial nerve palsy, which resulted in a prism prescription being added to my eyeglasses to alleviate the problem. Apparently, there was no connection between the acoustic neuroma and the sixth cranial nerve palsy, which I find difficult to accept, since they both occurred at the same time.

I began to notice symptoms associated with an acoustic neuroma in 2013. Walking the dog was difficult when she pulled on her leash, and I was afraid of losing my balance. Head movements resulted in increasing dizziness, and hearing in the ear with the acoustic neuroma ear was becoming worse, as confirmed by an audiogram.

The second MRI showed that the tumour had grown considerably. Because I was having symptoms, the neurosurgeon suggested it was time to consider treatment options. Unfortunately, I had poor hearing in one ear from a childhood accident, and the acoustic neuroma was on the side of what was my good ear. He said that if he operated, I would lose hearing in that ear, and suggested Gamma Knife would be effective with the benefit of possibly preserving hearing for a longer time and a consultation was scheduled at the Gamma Knife Centre at Toronto Western Hospital.

When treatment possibilities for the acoustic neuroma had to be considered, I decided to learn more about acoustic neuromas. I found the ANAC website, became an ANAC member in 2013, and attended a Toronto Chapter meeting hosted by Kathryn Harrod and Lynda Nash, which was very informative and reassuring. Carole Humphries has also been in touch over the years and has sent me information and provided recommendations.

My Acoustic Neuroma Experience

Following my assessment, I underwent Gamma Knife at Toronto Western Hospital on September 04, 2013 at 5:45 AM. I only experienced minor pain for a few days where the pins were used to attach the frame. However, during the next few months balance and dizziness during motion seemed to worsen. I contacted a nurse at Toronto Western and received a referral for vestibular therapy. The exercises were helpful, and I continue to do most of them at home. Hearing gradually declined in the acoustic neuroma ear to the point where a standard hearing aid would only amplify a distorted sound. A bicros hearing aid configuration, where a microphone is used on the bad side to transmit to a hearing aid on the better side, has been helpful.

My understanding is that Gamma Knife is effective in stopping acoustic neuroma growth in the majority of cases. Follow-up MRIs in 2015 and 2016 showed that the tumour was getting smaller. However, an MRI in 2018 indicated regrowth, accompanied by the start of new symptoms. I experienced occasional facial twitching and a change in taste sensation. Balance problems and dizziness were becoming somewhat worse. Another Gamma Knife treatment was scheduled, which took place on November 07, 2018. A follow-up MRI on May 08, 2019 seemed to indicate that the tumor was getting smaller, which was confirmed in an MRI on May 26, 2020. The facial twitching has disappeared, but I have recently developed watering in the right eye while eating.

Another MRI will be scheduled for May 2021. My understanding is that if the tumour starts to grow again, I would probably be a candidate for a third Gamma Knife treatment if needed, but it is unlikely, and third treatments are not common.

I am generally in good health except for imbalance, dizziness when moving, poor hearing and change in taste when eating, which I attribute to the acoustic neuroma. Walking has become more difficult, partly because of arthritis, stiffness, and loss of muscle mass, which is not unexpected at age 79. Using a cane has been helpful. I am trying different exercises to maintain mobility and have recently taken up Nordic pole walking. It was unfortunate that the acoustic neuroma affected what was my good ear and I now have to rely on hearing through what was my bad ear. Even with a bicros aid configuration, understanding speech can be difficult. Driving used to be enjoyable, but I now avoid long trips and heavy traffic and therefore have not had a problem.

My wife and I recently moved from Brampton to a condo in Oakville to be close to our son and family. There are many seniors in our building and several in our age group have more severe health problems and are less mobile than we are. We are fortunate that we can still do most of what we want to do, for which I am thankful.

Other Note: I have been participating in a Mayo Clinic study "Prospective quality of life in patients with acoustic neuromas" with Dr. Mathew Carlson and Dr. Michael Link since 2017.

Managing Dizziness During A Pandemic: Rehabilitate While You Isolate!

*By: Joon Nah BScPT, Certified Vestibular Physiotherapist
Cornerstone Dizziness Clinic, Founder*



These are challenging times for most of us. Covid-19 results in altered routines, social isolation, changes to anxiety and depression, and fewer opportunities to meet with the health care providers that we rely on. These factors are especially magnified when you suffer from vestibular impairment. As a certified vestibular physiotherapist in Toronto, I am keenly aware of the struggles that patients have been grappling with these past few months. I've provided some tips to help you manage your dizziness and even reduce your dysfunction while you isolate at home.

If you're reading this, you're likely already aware of the effects that an acoustic neuroma has on your vestibular system. The pressure that this benign growth can assert on your vestibular nerve (part of your 8th cranial nerve) can produce a wide range of symptoms, and potentially leave you with a mild to severe disability.

These vestibular symptoms can include: dizziness, poor balance, motion sensitivity, difficulty focusing while your head is moving. Patients are often unable to live their lives as they've done before, affecting their ability to participate in physical activities, work at their jobs, and interact with their family and friends.

VESTIBULAR EXERCISES at HOME

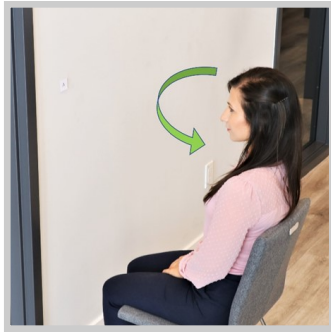
Many patients with vestibular symptoms related to a schwannoma have already been assessed and received treatment from a vestibular physiotherapist. This means you'll have a home exercise prescription that is specifically created for your unique presentation and modified to fit your recovery pattern.

However, many of you haven't seen a professional or perhaps the coronavirus has made your rehabilitation appointments difficult to keep. To help you manage, I've provided some exercises you can try at home that may help. These don't require fancy equipment and are generally safe for most vestibular conditions. Please note that vestibular rehabilitation is not a one size fits all solution, and best outcomes require a detailed assessment and skilled follow up visits with an experienced health professional.

Managing Dizziness During A Pandemic: Rehabilitate While You Isolate!

1. Gaze Stabilization (Vestibular-Ocular Reflex)

This exercise addresses a core and basic vestibular function. Ensuring your eyes stay focused where you want them when your head moves or is repositioned.



- Print or cut out a letter A (about 1cm in height) and tape it to the wall so it is at head level when you are seated.
- Sit in a chair about arm's length away from the letter A.
- Keep your eyes glued to the letter A, while turning your head left and right. About $\frac{1}{2}$ turn in both directions.
- Repeat for 2 min

2. Standing Balance

Balance, and our sense of where our head and body is in space, is another core vestibular function. This exercise acts as a foundation for our vestibular system, allowing us to feel grounded when performing most other motions and activities.

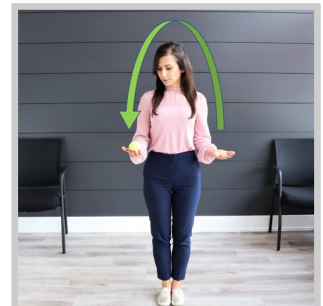
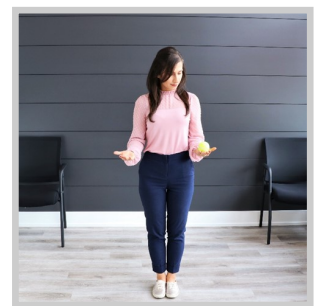


- Stand with feet together in front of a picture on your wall, with a chair behind you (for safety)
- Focus on something specific in the picture for 10 seconds
- Close your eyes for 10 seconds while maintaining your balance
- Repeat for 2 minutes

3. Ball Throwing and Tracking

Our vestibular system allows us to track moving objects even while our head is in motion. When this function is impaired, you may experience difficulty with activities such as shopping or watching traffic as you're trying to cross the street.

- You'll need a tennis ball or something similar
- Stand up straight and throw the ball from one hand to the other.
- Keep your eyes on the ball at ALL TIMES and let your head move with the ball as well
- As you get more comfortable, try to throw the ball higher
- Repeat for 2 minutes



Managing Dizziness During A Pandemic: Rehabilitate While You Isolate!

4. Walking with Head Turns

Your gait (walking pattern) is often affected by vestibular impairments, particularly in busy places such as in crowds or at the supermarket. Your vestibular system is responsible for much of the head, eye, trunk and limb coordination that is involved with the simple task of walking.

- Start at the end of a long hallway or a part of your house where you can safely walk back and forth
- With your head turned to the left, walk a few lengths of your hallway
- Repeat with your head to the right
- Finally try it with your head rotating right and left
- Repeat for 2 minutes



GENERAL ADVICE

Exercises and Activities

Dizziness is produced when your vestibular system experiences an error in the perception of movement. Generally speaking, the more “errors” you experience, the faster your recovery. This means that you must experience controlled instances of dizziness to get better, faster. The vestibular home exercises I’ve outlined above should produce some mild dizziness (errors) which your brain will correct through compensation. This also means that trying to keep moving and participating in activities that make you a “little” dizzy will help! The worst thing you could do is avoid any motion that makes you dizzy or imbalanced.

Anxiety and Depression

The vestibular system and depression and anxiety have neurological links within our central nervous system. This means that symptoms related to these areas often appear together. This also means that the recovery of one of these systems depends on the positive functioning of the other system. Ensure that you are doing all you can to manage anxiety and depression, or better yet, ask your doctor for more resources to assist you.

Click for article on managing stress, anxiety and a chronic impairment.

<https://cornerstonephysio.com/resources/chronic-pain-stress-anxiety-covid-19/>

Healthy Eating and Drinking

It’s no secret that what we put into our bodies has an effect on how we heal. The pandemic has made healthy eating and drinking habits particularly difficult to sustain and can directly result in

Managing Dizziness During A Pandemic: Rehabilitate While You Isolate!

an exacerbation of symptoms. My top tips include:

- Staying hydrated. Drink more water, less caffeine and alcohol.
- Decrease dietary salt. Read nutritional labels and fewer shakes with that shaker.
- Don't let your blood sugar levels spike. Avoid have a high sugar food after a long fast (e.g. breakfast time!)

Virtual Vestibular Rehabilitation

Battling dizziness and imbalance on your own can be confusing, uncertain, and stressful. And getting help can be difficult when travelling to a clinic, or if leaving the safety of your home is questionable. At my Cornerstone Dizziness Clinic, many vestibular patients have benefitted from virtual or telehealth rehabilitation to connect with a physiotherapist from the comfort of their homes. Learn more about whether this option may be right for you:

<https://cornerstonephysio.com/resources/can-virtual-physiotherapy-work-for-me>

Joon Nah is a certified vestibular physiotherapist with credentials from the Emory School of Medicine and the University of Pittsburgh's Dept. of Physical Therapy. As someone who has suffered from a chronic vestibular dysfunction himself, he founded the [Cornerstone Dizziness Clinic](#) in 2008.

Research Abstract

Journal of Clinical Neuroscience. 2016 Oct;32:1-8. doi: 10.1016/j.jocn.2016.05.003. Epub 2016 Jul 20.

Growth Rate of Vestibular Schwannoma

[Iddo Paldor](#), [Annie S Chen](#), [Andrew H Kaye](#)

Vestibular schwannoma (VS) is the most common tumor in the extra-axial posterior fossa compartment in adults. Growth rate is paramount to decision making regarding treatment and follow up of these tumors.

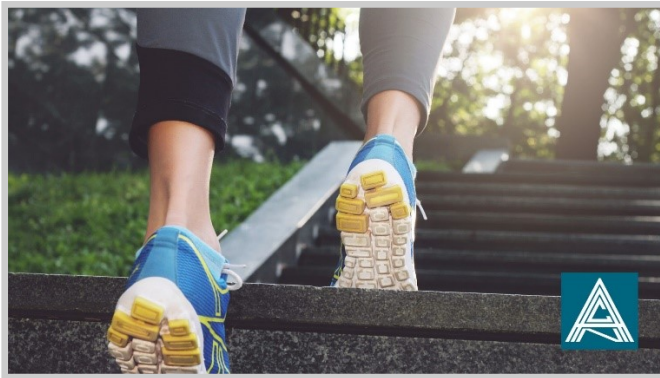
We conducted a comprehensive review of the literature to answer four questions: What percentage of newly diagnosed VS will grow on follow-up? What factors correlate to tumor growth? What is the "normal" growth rate for sporadic VS? What factors characterize VS with rapid growth?

Thirty-seven reports, with more than 4000 patients, fit our review criteria. One-third of newly diagnosed VS will grow on follow-up of 1- 3years. However, after 5 years, up to one-half will grow. Patient age and sex do not influence growth of VS. Hearing loss and vertigo at presentation do not predict tumor growth. It is unclear whether balance disturbance or tinnitus predict tumor growth. Tumor size and location do not predict tumor growth. Growth in the first year of observation is a strong predictor of tumor growth. The average growth rate of a VS is 0.99-1.11mm/year.

However, the expected growth rate for VS that have been shown to grow at first follow-up is 3mm/year. Factors that may predict tumor growth of above 4mm/year are cystic and hemorrhagic features in the tumor, and hormonal treatment. VS grow at an average 1mm/year. VS that have been shown to grow at first follow-up should be considered for treatment, unless contraindicated. Long term follow-up is recommended for VS.

Join ANAC's First Annual Virtual Walk!

Saturday September 5, 2020 – Sunday September 13, 2020



We are excited about taking a Walk Online – or virtually – so we can continue to offer the vital programs and services that are needed for people living with an acoustic neuroma in communities across Canada.

We know it's a bit harder to ask for support right now. But we also know that living with an acoustic neuroma is even harder and we need you. Let's

raise awareness for people who have an acoustic neuroma.

We are challenging ANAC – members, their family and friends to join the AN community and raise funds for ANAC. Every dollar helps ensure ANAC will be here to provide support for those diagnosed with an acoustic neuroma tomorrow and help them make the best decision about their treatment. ANAC can't take its continued existence for granted.

Tired of Working from Home or Staying In-doors? Take your first 2020 ANAC Walk Step!

Pick a Day and Time. Be Creative! Have Fun and Stay Safe!!

Choose to Be an ANAC Fundraiser and Ask Family and Friends to Support You!

Walking with others in your social circle can be an enjoyable activity. It can also increase your level of fitness.

- Walk instead of driving to the grocery or drug store
- Walk to the park or to library to pick up a book
- Use walking as a way to discover a new part of the city or town
- Explore natural historic sites in the community
- Hike along a trail
- Hop on your treadmill and exercise for ANAC
- Encourage your friends or neighbours to join you

Walking also gives us an opportunity to gather an awareness that so often becomes stuck when the mind is left to its own devices especially during this unprecedented times. We may be physically distant, but we will still come together in a new way through our **ANAC Virtual Walk Online**. Our AN community is strong and our spirits resilient. We can do this!

[Click here to See Ideas How to Prepare and Participate in Our First Virtual Walk](#)

[Join ANAC's Walk](#)



Upcoming Chapter Meetings Planned

KITCHENER—WATERLOO CHAPTER

Date: Wednesday, September 30, 2020—7pm—9pm
Location: Virtual Meeting—Details to follow.
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: Fall 2020 TBD—1pm
Location: TBD—White Spot, 2299 Cliffe Ave., Courtenay, BC
For more info: Evalyn Hrybko
 (250) 282-3269 / wehrybko@saywardvalley.net

TORONTO CHAPTER

Dates: September 29, 2020—Tuesday 6:30pm—8:30pm
Location: TBD—Details to follow.
For more info: Kathryn Harrod
 (905) 891-1624 / kath.harrod@live.ca
 Linda Steele
 (416) 993-0065 / lindasteele2@gmail.com

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