The
Connection

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Radiation Therapy for Acoustic Neuromas: All You Need to Know

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Acoustic neuromas (AN) are benign tumours of the inner ear nerve that can be observed or treated effectively with radiation or surgery. Tumours that are growing over time should receive treatment, of which radiation therapy (RT) is an effective option. Radiation therapy is a non-invasive method of treating acoustic neuromas. Radiotherapy relies on high-energy x-rays that penetrate the head and skull to target the tumour, while avoiding surrounding normal body structures. These x-rays damage the DNA of the tumour cells, causing them to stop growing. There are two main methods to deliver RT for acoustic neuromas, stereotactic radiosurgery (SRS) or fractionated irradiation.

What is stereotactic radiosurgery (SRS)?

SRS is defined by the use of a single, high-dose treatment aimed at a target in the head. SRS typically relies on the use of a rigid, stereotactic frame that is anchored to the outside of the skull using three or four metal pins (Figure 1). The stereotactic frame is a piece of hardware that reduces the patient's head movement to ensure a very high precision of treatment.

SRS can be delivered through a number of technologies, including cobalt-based systems (also known as Gamma Knife, Perfexion, or Icon), CyberKnife, or a linear accelerator (trade names include, but are not limited to, RapidArc, TrueBeam, Versa). SRS is prescribed by a radiation oncologist and a neurosurgeon, who work closely with a physics and therapist team.

Radiation Therapy for Acoustic Neuromas: All You Need to Know

A typical workflow is as follows: A patient undergoing SRS obtains a high-resolution MRI and CT of their tumour. The stereotactic frame is applied by a neurosurgeon on the morning of the treatment with local anesthetic (freezing) at the pin sites. A dedicated team consisting of a medical physicist, neurosurgeon, radiation oncologist, and therapists create a personalized radiation plan. The frame (and the patient) is docked to the radiation machine, and the treatment begins. Treatment length can range from 20 -120 minutes. After treatment, the frame is removed, and the patient is taken home the same day by a companion.

Figure 1: Stereotactic frame for SRS.
Image credit: https://www.uhn.ca/PatientsFamilies/Health_Information/Health_Topics/Documents/A_Patient_Education_Guide_for_Gamma_Knife_Stereotactic_Radiosurgery.pdf

What is fractionated radiotherapy?

The term "fractionated" refers to the fact that this form of radiation is delivered over a course of 25-30 treatments (5-6 weeks). Fractionated radiation is almost always delivered using a linear accelerator. Patients are immobilized using a plastic mask, so a stereotactic frame is not necessary. Each daily treatment takes 5 -15 minutes per day, and patients can attend outpatient appointments at the cancer centre unaccompanied. Patients typically feel well before and after treatments and can continue normal daily activities without restrictions.

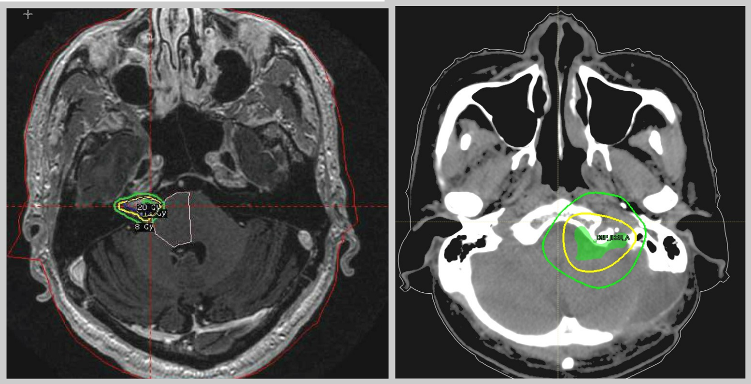

Figure 2. Green lines show moderate radiation dose, whereas yellow lines show high radiation dose. (Left) Stereotactic radiosurgery (gamma knife/Perfexion) plan. (Right) Fractionated radiation plan (linear accelerator). Image credit: D. Tsang

How to choose between radiation treatments?

Factors that affect the choice between radiation treatment type include the tumour size and availability of SRS. In patients with small tumours, SRS offers a more focused, precise radiation plan. This is because the method of immobilization for SRS is more rigid through use of a stereotactic frame. SRS is very precise, which reduces the volume of normal brain tissues that receive a low-to-moderate dose of radiation (Figure 2).

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For larger tumours, SRS is not feasible because a single high dose of radiation can cause more side effects in the setting of a large treatment volume. Thus, larger tumours are usually referred for surgery or fractionated irradiation.

How effective is radiation therapy?
Both SRS and fractionated radiation work very well, with long-term tumour control rates greater than 90%. Both treatments work equally well at controlling acoustic neuromas.

For more statistics, visit:
Article by Lo et al. 2018: https://doi.org/10.1016/j.ijrobp.2017.09.024
Article by Persson et al. 2017: https://dx.doi.org/10.1007/s00701-017-3164-6

What are some side effects of radiation therapy?
These can include: fatigue, headache, rash, hair loss (partial), hearing loss and ringing in the ears (tinnitus). Very rarely, patients can get seizures, facial weakness or numbness, brain swelling/ normal pressure hydrocephalus, or other brain tumours after radiation treatment. The risk of hearing loss, facial weakness or facial numbness does not differ between SRS or fractionated radiation.

How does radiation differ from surgery?
Surgery is sometimes preferred for patients with large tumours, tumours that are pushing on surrounding organs (brain or brainstem), patients with symptoms, those whose hearing may already be lost, or younger patients. Radiation is sometimes preferred for patients with intact hearing, smaller tumours, or for whom surgery is not possible or safe (due to other medical conditions).

The recovery from surgery takes longer (in the range of many weeks), whereas the recovery from radiation is shorter (in the range of a short number of days). There is no one factor that predisposes one to choose a specific treatment over another. Patients should speak with their doctors to discuss what is best for them.

What is the follow-up plan after radiation?
Because acoustic neuromas are very slow-growing tumours, they do not always shrink after radiation. In fact, some acoustic neuromas swell slightly after treatment, and then stop growing or shrink over time. The goal of the treatment is to stop the tumour from growing. Most tumours remain stable after time, without any growth or shrinkage. A minority will shrink slightly with time, over the course of many years.

Radiation Therapy for Acoustic Neuromas: All You Need to Know

After radiation treatment, your doctor will usually arrange for a follow-up MRI and clinic visit 6 months after treatment, then annually. After 5 years, your follow-up will stretch out to every 2 years. After 10 years, you may be discharged from follow-up, or receive MRIs every 2-3 years. Your doctor may order audiograms to check your hearing and offer hearing aids if needed.

If you have any questions about whether radiation is a suitable treatment for your acoustic neuroma, contact your doctor and ask her or him about this option.

Dr. Derek Tsang, MSc, MD, FRCSC is a fellowship-trained and board-certified radiation oncologist. He is an Assistant Professor of Radiation Oncology at the University Toronto. Dr. Tsang works at Princess Margaret Cancer Centre and Toronto Western Hospital at University Health Network in Toronto and at the Hospital for Sick Children. He holds a Master's degree in clinical epidemiology from the Harvard T.H. Chan School of Public Health. Dr. Tsang treats primary central nervous system and paediatric tumours.

Nasim Sarhan, MD. Having graduated in Jordon in 2010, Dr. Sarhan undertook specialty training in radiation oncology at King Hussein Cancer Center where he was a consultant for three years. He currently is doing his fellowship at PMH in CNS, Stereotactic Radiosurgery and paediatric tumours.

Mary Ann Radmacher, author, artist, and trainer offers a new way of looking at courage:

"Courage doesn't always roar. Sometimes courage is the quiet voice at the end of the day saying, 'I will try again tomorrow.'"

At the end of the day listen for that small voice that encourages you to try again tomorrow. No one reaches one's best potential or highest goal in one sitting. It's an ongoing process that requires a commitment to incremental improvement over time.

How Can Vestibular Rehabilitation Help You?

Acoustic Neuroma is the third most common tumour in the brain. Initial symptoms are typically a slowly progressing (or in rare occasions, more sudden) one-sided hearing loss and possibly tinnitus, with a sense of dizziness and/or imbalance coming on later, but this isn't always the order depending on what nerve fibers are being compressed by the tumour. Blurry vision during quick head movements may also be noticed as this relates to the inner ear, as well as sensitivity to busy or complex visual environments. Sometimes people only have hearing symptoms, and don't experience dizziness, unsteadiness, blurry vision or visual sensitivity (collectively referred to as vestibular symptoms) until AFTER they have treatment to remove or irradiate the tumour.

One reason some people have limited vestibular symptoms is that an Acoustic Neuroma is typically a slow-growing tumour, and our brains have a remarkable ability to compensate for reduced vestibular information about head position and movement coming in from one inner ear. The slowly declining vestibular information gives the brain lots of time to figure out compensatory strategies to keep symptoms at a minimum. If, however, a person undergoes surgery to remove the tumour the vestibular information coming in has a sudden change, this is harder for the brain to compensate for in the short term, and symptoms appear. If a person undergoes stereotactic radiation ('gamma knife') to kill the tumour cells, new vestibular symptoms can come on even months after the treatment as the cells die. This is potentially due to fluctuating or abnormal nerve activity, inflammation or radiation-induced changes to the nerves.

For those with vestibular symptoms, Vestibular Rehabilitation can be a very important and useful part of management and recovery and is highly supported by research. Vestibular Rehabilitation should start with a thorough assessment by a medical professional with advanced training in this unique field. The assessment findings enable the vestibular therapist to develop a customized program of techniques that help the client's brain re-establish accuracy around its perception of the position of the head and body relative to gravity, and its interpretation of head movement. Once the brain is more accurately integrating this information it can do a better job at telling the muscles what to do to maintain balance and telling the eyes what to do to stay clearly focused during head motion. Depending on an individual's areas of deficit a Vestibular Rehabilitation program may include techniques such as:

- trying to maintain a position that challenges balance with eyes closed,
- moving the head while trying to maintain clear focus on a target,
- walking while moving the eyes and head,
- watching objects in motion with busy backgrounds to reduce visual sensitivity,
- repeatedly performing a motion that brings on dizziness so that the brain can habituate to it, or
- adding a cognitive challenge or reactive movement while performing a balance task.

How Can Vestibular Rehabilitation Help You?

A Vestibular Rehabilitation therapist can also help clients tackle the numerous secondary complications that can result from a vestibular disorder, such as nausea, decreased concentration, fatigue, anxiety, depression and the tendency to adopt a reclusive, sedentary lifestyle (with the decreased fitness, strength and enjoyment of life that go along with that).

When it comes to Vestibular Rehabilitation, Acoustic Neuroma is rather unique because there are two very different scenarios: one where the tumour is still present and growing, and another where the tumour is stable because it is no longer growing or has been removed/arrested with surgery.

Vestibular Rehabilitation works best when there is a *stable* or unchanging deficit that the brain is trying to compensate for so if the tumour is continuing to change size, the vestibular information coming in along the nerve may fluctuate, forcing the brain to have to 'catch a moving target'. Vestibular Rehabilitation can still be effective in this scenario however it needs to be worked on as an ongoing regime. If the tumour has been removed or halted with radiation, then a person is left with a *stable* deficit, so in this situation, once Vestibular Rehabilitation has helped the brain compensate, symptoms are eliminated or minimized, and a person can normally discontinue the training.

Occasionally, a person may experience a re-occurrence of symptoms long after a successful recovery, referred to as a decompensation. Common culprits for triggering a decompensation include a highly stressful physical or emotional event, a new problem with the vestibular system, a new medical condition or illness, intense fatigue, medication changes, a period of inactivity, or a new activity that heavily challenges the vestibular system in a way that it is not accustomed to. It is important to be re-assessed by the doctor or vestibular therapist to make sure there isn't a new issue with the vestibular system that is behind the 'flare-up', but if not, your vestibular therapist can help you briefly reinstate rehabilitation techniques appropriate for the current symptoms, so the brain can compensate again.

At Lifemark, our vestibular therapists are trained to do a comprehensive assessment aided by infrared goggles to analyze eye movements for additional information about the vestibular system. They all have education and treatment experience relevant to assisting those with reduced vestibular input from many causes, including Acoustic Neuroma. We have locations all across Canada, coast to coast. For more information or to find a Lifemark Dizziness & Balance Program vestibular therapist near you, click **HERE**.

Additional information about Acoustic Neuroma and Vestibular Rehabilitation can be found at the Vestibular Disorders Association website: www.vestibular.org.

Acoustic Neuroma: https://vestibular.org/acoustic-neuroma
Vestibular Rehabilitation: https://vestibular.org/understanding-vestibular-disorder/treatment/treatment-detail-page

Coping with Hearing Loss

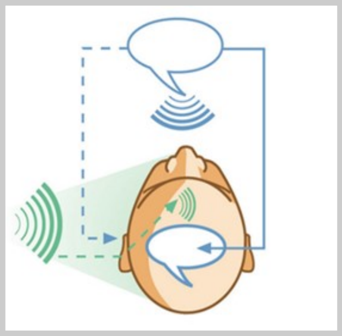
By: Rex Banks, Au.D., Reg. CASLPO

Single-Sided Deafness (SSD), or unilateral sensorineural hearing loss, refers to significant or total hearing loss in one ear. The hearing loss is usually permanent and may be the result of a variety of conditions including:

Acoustic Neuroma

- Sudden deafness – can occur at any time, often for unknown reasons
- Physical damage to the ear
- Pressure on the hearing nerve
- Inner ear problems including infections (viral or bacterial)
- Diseases such as measles, mumps, meningitis
- Disorders of the circulatory system
- Severe Meniere's disease
- Trauma – e.g. head injury

Head Shadow Effect



An issue which affects communication for people with SSD is the “head shadow effect." Sounds that originate from the side of the deaf ear fall in the shadow of the head. Vowel sounds which have longer wave lengths may still travel from the deaf side to the hearing side, but consonants which have a shorter wavelength and carry the most meaning for speech and conversation, don’t do as well in terms of making their way from the deaf ear around the head to the hearing ear.

This can cause a great deal of frustration for the individual with SSD especially when trying to communicate in the presence of background noise.

Another issue for people with SSD is directionality. Directionality (or sound localization) is an important aspect of managing communication and environmental cues. When you’re unable to hear out of one ear, crossing the street, cycling and jogging can all become difficult and even dangerous. Unexpected communication challenges arise in situations such as:

- Communicating in the car (deaf side facing driver)
- Interacting in circular group meetings (can be difficult even if participants are speaking one at a time and even worse if distance is a factor for large circular discussions)
- Whispered communication into the deaf ear in quiet environments such as church, lectures, movies or training

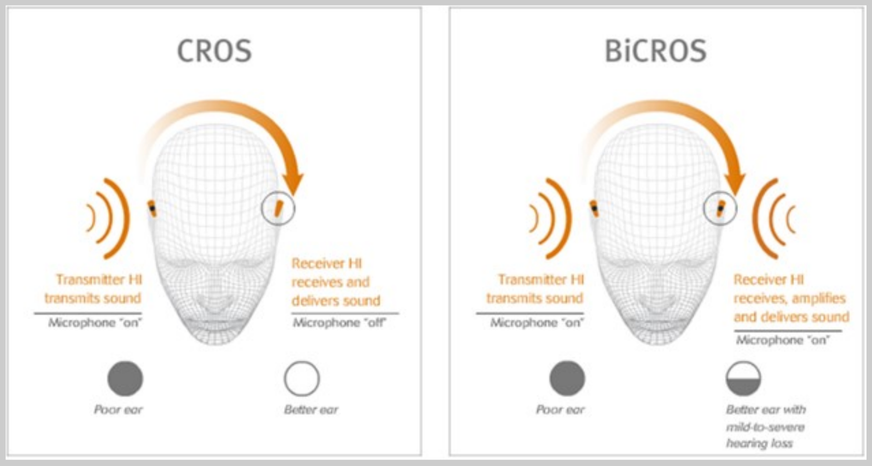
Coping with Hearing Loss

All of the above situations can greatly affect day-to-day life. As a result, some people with SSD find themselves exhibiting irritability and jumpiness, have frequent headaches (due to stress), feel socially isolated and experience chronic interpersonal communication difficulties. Undetected SSD in children may even be misdiagnosed as ADHD.

CROS and BiCROS Hearing Aids

In cases of SSD, the deaf ear receives no clinical benefit from amplification. This means that no matter how loud we make things through a hearing aid, speech is not clear or usable in that ear. The other ear often has typical or regular hearing ability, but not always.

As with any hearing loss, we cannot restore the hearing once it has been lost. For SSD, there are treatments available which can restore the *sensation* of hearing to the deaf side. One treatment option available for SSD is a CROS or BiCROS hearing aid system.



CROS hearing aids systems are worn by individuals with one deaf ear and one ear that is unaffected by hearing loss. With a CROS hearing aid system, a transmitter (which looks like a behind the ear hearing aid) is worn on the deaf ear. The transmitter's microphone picks up sound from the deaf ear and sends it to a receiver (hearing aid) that is worn in the ear that has hearing.

BiCROS hearing aid systems are worn by individuals with hearing loss in both ears, but one ear is deaf and unaidable. In this case, a transmitter is worn on the deaf ear. The transmitter's microphone picks up sound from the deaf ear and sends it to a receiver/hearing aid that is worn in the better ear. But as the better ear still has hearing loss, amplification is provided to that ear along with the information coming from the deaf ear.

Coping with Hearing Loss

Communication Styles

Having a hearing loss doesn't mean you need to take a backseat in life. One important step is to understand the type of communicator you are and with the right adjustments, you'll be on the road to a lifetime of good communication. On the most basic level, there are three kinds of communicators: Passive, Aggressive and Assertive.

Passive communicators often start out in denial about their hearing loss before comfortably sliding right into the background – not wanting to call attention to their problem or ask for help. "Passives" will avoid situations and conversations where they may need or want to participate.

"Aggressives" have no problem letting you know that they have a hearing loss or that you may need to modify some aspects of your communication. Aggressive communicators tend to dominate conversations – the more they talk, the less they must try to listen.

Aggressives often place blame on others during communication rather than accepting their own role and responsibility to ensure that they understand. They may even go as far as ignoring their communication partners when they don't understand.

Unlike passives, "assertives" ask for communication help when necessary, but don't demand it like aggressives. Assertive communicators stand up for themselves to ensure that their needs are met. They do this through a blend of mastering effective communication strategies and advocating for themselves.

The Basics of Being an Assertive Communicator

- Let others know that you have a hearing loss upfront.
- Don't be afraid or embarrassed to ask for what you need.
- Keep background noise low.
- If you are unsure you understood, summarize what you think was said so the speaker can confirm or explain again.
- Face the person you're speaking with.
- Try to keep a sense of humour.
- Don't be too hard on yourself and give yourself a break in a quiet area to regroup.
- If you're too tired or distracted for a conversation, ask to postpone.

Coping with Hearing Loss

Things to Consider about the Environment

- Do your best to have a conversation in a place with good lighting, so you can see the speaker's face, gestures and body language.
- If you're going to a restaurant with friends or family, try to arrange a time that is not during peak dining hours. Try to sit somewhere away from noisy spots such as the server's station or kitchen.
- When you're with a group of people, try to position yourself in the middle of the room or group so you have visual access to most people's faces.
- If you're joining a conversation with a group, ask for the conversation topic so you have contextual cues.

Communication Repair Strategies

- Get your attention before starting a conversation
- Face you when speaking
- Repeat more slowly
- Rephrase what he or she has said
- Give you the key word or subject of conversation
- Spell a word
- Write something down, especially important dates, times or appointments
- Use gestures
- Simplify or shorten the sentence

Ask for Help When You Need It!

- Use "I" statements (e.g., "I need you to please repeat that last number")
- Explain why you need an adjustment
- Be specific
- Be polite

Canadian Hearing Society (CHS)

If you live near an office, CHS may be able to help you in the following ways:

Audiology - hearing tests, hearing aids, tinnitus help	**Connect Counseling** – mental health challenges
Hearing Care Counseling – In-home hearing counseling help for 55+	**Employment Services** – Job search activities and work place accommodations
CART – Communication Access Real Time (CART)	**Hearing Help Classes** (communication strategies, hearing aid workshops)
ANAC Support Group – Toronto	

Coping with Hearing Loss

Although being diagnosed with an acoustic neuroma can and often is an overwhelming experience for most people, understanding how you can make the most out of your communication options can help you cope better and stay connected to others.

Dr. Rex Banks is the Director of Hearing Healthcare and Quality at the Canadian Hearing Society. Rex completed his Au.D (Doctor of Audiology) degree from A.T. Still University of Health Sciences and a M.A. in Audiology from the University of Tennessee. His audiology experience spans private practice, ENT physician offices, hospitals, the non-profit sector as well as holding adjunct faculty positions at several universities. In addition, he earned the Certificate of Clinical Competency in Audiology (CCC-A) designation and is also certified in Tinnitus Retraining Therapy (TRT). Rex has served as President of the Board of Directors for the Acoustic Neuroma Association of Canada; the Canadian Academy of Audiology; and the Ontario Association of Speech Language Pathologists and Audiologists.

A Tip for Tinnitus

Mindfulness Based Therapy for Tinnitus

A randomized control clinical trial was undertaken to determine whether Mindfulness - Based Cognitive Therapy (MBCT) adapted for tinnitus was more effective for alleviating tinnitus compared to Relaxation Therapy.

Each group attended a 2-hour session each week for 8 weeks and were allocated tasks to be completed at home. Follow-up showed both groups achieved a significant reduction with tinnitus. However, individuals in the MBCT group experienced greater improvement and a reduction in severity which also continued following the formal sessions held.

This study was funded by the British Tinnitus Association.

To view go to: http://youtu.be/zTt-MNkNEPE?a via @YouTube

Wall Street Journal writer, Arnold Glasow had this to say about our ideas…

"An idea not coupled with action will never get any bigger than the brain cell it occupied."

Now there's something to ponder. Mulling, thinking, musing won't get us very far if we don't take action. In fact, it may simply drift away. DO the thing you think you cannot do!

What a Difference a Day Makes! My AN Journey

By: Ruth Toskas

What a difference a day makes! I have heard this little saying many times in my young 49 years of age and I can certainly hum the tune as Dinah Washington croons these words in my head, but I didn't realize the impact these few little words and meaning would have on me, until this year. More to come on this later in my story . . .

I awoke one night in September 2016 with a loud ringing in my ear and that's where it all started. I won't bore you with all the details of my various doctors' appointments, hearing tests and ultimately the confirming MRI, but fast forward to February 2017, a Valentine's Day that I will never forget, where I was diagnosed with a left-sided acoustic neuroma. I couldn't believe the words I heard from the ENT that I have a "rare brain tumour". I have two young daughters and they were my first initial worry and how this news and outcome would affect my family. I was devastated. I tried to carry on every day as normal as possible but at the end of the working day and when my family went to sleep, that's when I would really think about it and I admit, I cried myself to sleep many nights.

My husband, Demetrios, and I spent a lot of time researching what an acoustic neuroma is and by the time I initially saw a neurosurgeon in my home town of Hamilton, Ontario, I was prepared with a list of questions. Unfortunately, my appointment did not go as well as I had hoped, and I was left with more questions. I did however find out that my tumour was on the larger side, being almost 3 cm, and that my brainstem was being compressed.

I continued reading and researching everything I could about my AN. I reached out to close family and friends and those in the know in professional circles. I had decided that I also wanted to explore other options such as advanced radiation techniques. After a couple of meetings, including a much appreciated one by a close connection, my quest eventually led me to Dr. G. Zadeh's name at Toronto Western. I politely insisted for a referral from my family doctor who gracefully indulged my request to see Dr. Zadeh. I had also found the Acoustic Neuroma Association website and sent a quick email. I immediately received a call from Carole Humphries and felt, for the first time, that I was not the only person in the world dealing with this kind of tumour.

I met with Dr. Zadeh and knew immediately she was the doctor I was looking for. Dr. Zadeh exuded competence and confidence in a humble way and she understood our concerns and addressed them in a graceful, straight-forward, sincere manner. Dr. Zadeh's wealth of experience and knowledge and her calmness was exactly what I needed. I knew surgery, as scary as it

What a Difference a Day Makes! My AN Journey

seemed, was probably going to be the road I needed to take but, in the meantime, I still had a couple of appointments booked to explore radiation options. Ultimately, after weighing all the options and because of the size and location of the tumour, radiation was not the right choice for me. After meeting with Dr. Zadeh again, it was agreed that surgery was the best option for me. I waited for the date and surgery was scheduled for February 2018.

Almost a year to the day that I was diagnosed, the surgery day was upon me. For almost a year, I had tried to stay as positive as I could but there were days that the worry, stress and anxiety got the better of me. Although he hid it from me, I knew it took a toll on my husband, but he remained supportive and reassuring. I did, however, surprise myself that I was relatively calm the morning of surgery. I know that had to do with the fact that I was very confident in my neurosurgeon, Dr. Zadeh, and her very skilled surgical team, plus I had done everything I could do to prepare myself and be ready for this day. With my husband by my side, I was prepped to go and then rolled into the operating room.

The surgery was very successful. It was a long, almost 10-hour, surgery. When they woke me up in the operating room, I was told to smile and wink and told all looked good. I was taken to the ICU to be monitored. I had many tubes and wires hooked up and then of course the nausea set in. Needless to say, it was an incredibly rough night.

Well, back to the beginning of my story and what did I mean by that little phrase? The next morning, after only a couple hours of sleep, I felt different. Sure, there was the expected recovery, the risk of brain fluid leakage, which did occur, and other risks which did not. What I really mean by that is it was a new day, surgery was now done and all that worry, stress and anxiety I had leading up to the surgery, was now behind me. So yes, what a difference a day makes.

I lost my hearing on my left side completely and the tinnitus is still as annoying as ever. There is also some residual tumour which we will keep an eye on with periodic MRIs and follow ups. These of course are things that I expected and was prepared for, so I feel so very grateful.

I am still adjusting to a world of single-sided deafness and the fatigue that still hits me after I have taken on too much is still a gentle reminder of what I have been through.

My husband has been my biggest advocate and supporter during this journey. I can't thank him enough and am blessed to have him by my side. We are also very proud of our young daughters as they handled this with such grace and positivity. We are all adjusting to the new us. As many have said before me, the love and support from family and great friends is truly a blessing. I have also made some new friends at the AN support group throughout this journey and they too have similar stories to share. They have given me great advice and insight with their journeys which

What a Difference a Day Makes! My AN Journey

was appreciated, as it has helped me understand my journey and recovery. I am honoured to also be there to lend an ear (well at least my one good functioning ear) to newly diagnosed patients and hope sharing my story with them can help in some small way.

If there is one thought I can share with anyone going through this, it is this: Stay positive and surround yourself with support -- you will get through this and you are much stronger than you think you are!

Dancing a Half Marathon:
How a Daughter’s Love Generated Funds for ANAC

By: Judy Haust

Abigail Kaczmarek exudes energy and warmth. In early November, I had the pleasure of meeting this special 24-year-old who single-handedly took the initiative to raise $2,500 for ANAC through her Go Fund Me campaign.

Abbie’s mother, Cathy, a keen rider, fell from her horse a couple a years ago, and it was a subsequent brain scan that serendipitously led to her AN diagnosis. The news of the tumour hit her hard. As with so many impacted by an AN, she ruminated over what to do. She was suffering with vertigo and hearing loss, not to mention anxiety, so she decided to have it surgically removed. The operation itself was successful but, seven days later, Cathy developed facial paralysis. Slipping into a depression, Cathy dealt with this misfortune by refusing to look in the mirror and removing all the photos of her former self. “It was devastating for all of us,” Abbie acknowledged. “Mom’s personality completely changed.”

During this time, Abbie was away at university, but she would come home most weekends to visit. In the meantime, Cathy had started to undergo facial therapy and, slowly but surely, Abbie was seeing subtle improvements. “Eventually, Dad would say, 'She's back' or 'She’s having a good day!'” Abbie smiled, “and that was so exciting and inspiring.” Today, Cathy's facial paralysis is virtually gone and her sunny personality has returned. In September, Cathy Kaczmarek participated on the Patient Panel along with four others at ANAC's 2018 Symposium, where she told her story and responded to questions from the audience.

Cathy is awaiting the arrival of her beloved horse Theodore, she says, “He is very special. Because of his breeding, he is calm and has the patience of an old soul, which makes him a very safe horse for someone with balance issues. This is proof that there is life after acoustic neuroma surgery.”

Abbie's adoration for Cathy further lit up her face when she spoke of how she had wanted to do something special for her. She decided to run a half marathon (21.1k)

Dancing a Half Marathon:
How a Daughter's Love Generated Funds for ANAC

and raise funds for the Acoustic Neuroma Association of Canada in honour of her mother. Training started in February when she ran a 10k with her best friend, Heather, then she really "hunkered down" over the summer, running three to four times per week, her first very long run (18k) being in beautiful Stanley Park in Vancouver, where she was attending a friend's wedding. Just one week later, on September 9th, Abbie and Heather ran the MEC Half Marathon through Tommy Thompson Park on Toronto's waterfront.

Abbie felt buoyed by the support of her friends on race day and by all the encouraging comments from donors and supporters on her Go Fund Me page, Face Book (164 shares), Instagram and anac.ca. "I am NOT a runner!" she assured me, "but I had fun competing with myself. It felt like I was dancing!" Along the way, Abbie kept in touch via Snap Chat with her mother in Florida. Cathy was so happy and kept rooting for her daughter, with a big "Woo Hoo" as Abbie crossed the Finish Line. Abbie's impressive finishing time for her first half marathon was 2 hr., 3 min. -- after all, only serious runners care about the seconds!

Abbie, we are all so proud of you and grateful for your creative fundraising idea and your determination to succeed. On behalf of the ANAC community, thank you for your contribution towards improving the lives of those affected by an acoustic neuroma. May your story serve to inspire others, just as you were inspired by your mother's journey. Your self-described label of "Life Enthusiast" suits you well!

Dr. Phil McGraw, popular television show host and psychologist clearly states:

"Goals are dreams with a timeline and accountability."

It's one thing to dream of what you want to accomplish, but without a timeline and accountability your goal will remain in a dream state. But add the two essentials Dr. Phil emphasizes and your dream will become reality.

As Dr. Phil loves to say, "How's that workin' for ya?"

Research Abstract

Neurosurgery, nyy416, https://doi.org/10.1093/neuros/nyy416
Published: 04 September 2018

Repeat Stereotactic Radiosurgery for Progressive or Recurrent Vestibular Schwannomas

Christian Iorio-Morin, MD, PhD, Roman Liscak, MD, Vilibald Vladyka, MD, Hideyuki Kano, MD, PhD, Rachel C Jacobs, BS …

Background: Stereotactic radiosurgery (SRS) is a highly effective management approach for patients with vestibular schwannomas (VS), with 10-yr control rates up 98%. When it fails, however, few data are available to guide management.

Objective: To perform a retrospective analysis of patients who underwent 2 SRS procedures on the same VS to assess the safety and efficacy of this practice.

Methods: This study was opened to centers of the International Gamma Knife Research Foundation (IGKRF). Data collected included patient characteristics, clinical symptoms at the time of SRS, radiosurgery dosimetric data, imaging response, clinical evolution, and survival. Actuarial analyses of tumour responses were performed.

Results: Seventy-six patients from 8 IGKRF centers were identified. Median follow-up from the second SRS was 51.7 mo. Progression after the first SRS occurred at a median of 43 mo. Repeat SRS was performed using a median dose of 12 Gy. Actuarial tumour control rates at 2, 5, and 10 yr following the second SRS were 98.6%, 92.2%, and 92.2%, respectively. Useful hearing was present in 30%, 8%, and 5% of patients at first SRS, second SRS, and last follow-up, respectively. Seventy-five percent of patients reported stable or improved symptoms following the second SRS. Worsening of facial nerve function attributable to SRS occurred in 7% of cases. There were no reports of radionecrosis, radiation-associated edema requiring corticosteroids, radiation-related neoplasia, or death attributable to the repeat SRS procedure.

Conclusion: Patients with progressing VS after radiosurgery can be safely and effectively managed using a second SRS procedure.

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.

2018 ANAC World of Acoustic Neuroma Symposium

September 29, 2018

BMO Education and Conference Centre, Toronto

By: Linda Steele, ANAC Member

ANAC's symposia, held every two years, are designed to capture the latest research, to discuss management of an AN diagnosis including treatment options, and to offer guidance on dealing with hearing loss, tinnitus, balance and facial paralysis, any or all of which may affect the lives of individuals diagnosed with an Acoustic Neuroma.

More than 100 individuals from across the country, including patients and their families, as well as leading healthcare practitioners and specialists such as neurosurgeons, radiologists, neurologists, plastic surgeons, audiologists, physiotherapists, professors and researchers participated in person or by live webcast.

The 2018 symposium discussed important topics starting with a discussion around the Anatomy and Natural History of an Acoustic Neuroma and Neurofibromatosis Type 2. The presentation demonstrated exactly how the brainstem and nerves work to help one balance, hear, smile and swallow, as well as many other essential functions. The growth of an Acoustic Neuroma means that those nerves are impacted, and patients may experience hearing loss, tinnitus, balance issues, vertigo and on occasion numbness.

Physicians and surgeons explored all current treatment options including "wait and watch" protocol, various surgical approaches and types of radiation. For the most part, Acoustic Neuromas are very slow growing, so the good news is that patients have time to consider their options. Surgical and radiation treatments must take into consideration hearing and facial nerve preservation as ANs are located near or adjacent to the brainstem, an important structure. Each Acoustic Neuroma is different, and treatment must be chosen accordingly.

While treating tumours was one of the main topics at the symposium, quality of life was also addressed in detail, as one deals with various quality of life issues whether in a "watch and watch" scenario or in post treatment. Facial paralysis, considered an important post-treatment indicator affecting quality of life, was covered in three presentations. Physicians explained the various options including eyelid weights, cosmetic procedures and facial reanimation surgery options.

Hearing loss is another critical quality of life issue, and coping strategies for this were presented at the symposium. Many of those impacted with an Acoustic Neuroma experience single-sided deafness which leads to the "head shadow effect" and loss of directionality, ultimately resulting in anxiety, frustration, stress and fatigue. When there is hearing loss in one ear, then the other ear must process the sound information from both sides of the head, thus, the term "shadow": the

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head blocks the sound in the same way that it would block sunlight. Coping strategies that were discussed for single-sided deafness included the use of hearing devices, various types of communicators, attending AN support groups, and utilizing the resources at the Canadian Hearing Society.

“Let people know you have a hearing loss.
If you can’t do that you’re still at the passive stage. Ask for help.”
Dr. Rex Banks; Au.D., CCC-A, Reg. CASLPO; Director, Hearing Healthcare, Canadian Hearing Society

All tumours are not the same. Understanding Tumour Biology, one of the more scientific presentations, provided an exciting look at the new research being completed in Dr. Zadeh’s Lab. Research is being undertaken to find systematic treatments and more precise medicine to treat acoustic neuroma tumours based on their individual biology. Clinical trails are also being examined involving drugs that are proving to be helpful in controlling tumour growth, thereby preserving hearing for several years before other treatment might be required. Physicians and researchers are very optimistic for the future.

The Physicians’ Multidisciplinary Panel, led by the outstanding healthcare practitioners and specialists, discussed and debated individual case scenarios highlighting treatment approaches with the associated pros and cons. The panel was an excellent opportunity for patients to ask questions and network directly with faculty and doctors.

“These are tumours that require a lot of thought and personalized medicine.
No one size fits all solution.”
Dr. Anthony Zeitouni; FRCSC; Director, Department of OTL-HNS: Royal Victoria Hospital, Director (OTL-HNS) Skull Base Program: McGill University Montreal

The Patient Panel, re-introduced this year to the format, provided not only important insight for the specialists, but also the opportunity for audience members to dialogue with the participants, who shared their personal experiences, treatments and stories.

The last part of the symposium was set aside for newly-introduced Break-Out Sessions about balance, vestibular and facial rehabilitation, as well as living with tinnitus. Patients, new and old were able to listen, learn and interact with physiotherapists and audiologists about issues that affect most Acoustic Neuroma patients.

This type of forum provided the perfect platform for patients to interact with faculty as well as other attendees, and to learn, engage and participate, in order to help with their own Acoustic Neuroma journeys.

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ANAC is grateful for the leadership of Dr. Suganth Suppiah and Dr. Gelareh Zadeh, ANAC's Scientific Medical Affairs Committee Chair, and the financial support made possible by the University Health Network Neurosurgery Associates.

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Finally, this symposium would not have been possible without the additional support of:

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Speakers 2018 Symposium Left to Right:
Dr. Joseph Chen, Dr. Edsel Ing, Dr. Karolyn Au, Dr. Heather Baltzer, Dr. Derek Tsang, Dr. Suganth Suppiah, Dr. Gelareh Zadeh, Dr. Anthony Zeitouni, Dr. Farhad Pirouzmand

Patient Panel Left to Right:
Cathy Kaczmarek, Americo Meneguzzi, Kathy Dingwall, Nick Kucharew, David Ellison

2018 Symposium

2018 Ask the Panel Experts

Linda Steele & Chrissie Rejman

Dr. Gelareh Zadeh

Upcoming Chapter Meetings Planned

KITCHENER—WATERLOO CHAPTER

Date: **Spring 2019 TBD**—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: **Spring 2019 TBD**—12 noon—3pm
Location: Atrium at Crown Isle Resort & Golf Community
399 Clubhouse Drive, Courtenay, BC
For more info: Evalyn Hrybko
(250) 282-3269 / wehrybko@saywardvalley.net

TORONTO CHAPTER

Dates: **Tuesday, January 29, 2019**
Tuesday, March 26, 2019
Location: Canadian Hearing Society
271 Spadina Road, Toronto, ON (Parking in the rear)
For more info: Lynda Nash
(416) 282-0036 / lynda_lu123@sympatico.ca
Kathryn Harrod
(905) 891-1624 / kath.harrod@live.ca

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