ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION

INFORMATION | SUPPORT | AWARENESS | ADVOCACY

Recovering from an Accoustic Neuroma

By Paul Bacon

When I was young I used to run along curbs for fun. As I aged I found I would fall off. To me this was just part of aging. Then by accident it was found that I had an Acoustic Neuroma (AN), a benign tumor that grows on the hearing nerve and involves the facial nerve.

I started to notice the balance issue +/-15 years ago. I had always had outstanding balance in the past, so this was frustrating. Over time I could tell that the hearing in my left ear was decreasing as well. After spending 20 years (not consecutive) as a career and volunteer fire fighter, I thought the noise over time had caused my hearing problem.

I saw a hearing doctor in Tampa who recommended a hearing aid for my left ear, but he did not do anything to further diagnose my problem. In time my lack of balance affected projects around the house. I was a perfectionist painter (no spills, etc.), but in time that was getting worse. More paint in the wrong places.

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(TOP LEFT) PAUL BACON & PAUL BACON TEACHING; (ABOVE) PAUL BACON AND HIS WIFE.

On the Level is a quarterly publication of the Vestibular Disorders Association (VEDA), published in Portland, Oregon, USA and distributed to national and international members. Information in this newsletter is not intended as a substitute for professional health care. VEDA does not recommend any particular course of treatment, clinic, or health care practitioner. The opinions expressed in articles in On the Level are those of the authors and not necessarily those of VEDA's staff, medical and scientific advisors, or Board of Directors. The publisher reserves the right to accept, reject, or edit any materials received for publication. No part of this publication may be reproduced without written permission.

How Counseling Can Help You Cope with a Vestibular Disorder

By Tod Fiste, LPC

Dealing with a chronic illness or medical condition goes far beyond the physiological and medical challenges it poses. Chronic illness can strain your view of yourself, your relationships, your place in society, and your plans for the future.

Psychotherapy (also known as 'counseling' or just 'therapy') is a valuable resource when you are struggling with these challenges. Unfortunately, many people don't really know what therapy is or how it can help them, and there are some common misconceptions that make therapy sound intimidating or even threatening.

My goal here is to help you become more informed about some of the different ways therapy can be helpful. These categories are my own; while I believe they are useful, they do not map exactly to terms you may read or hear in therapist's self-descriptions. In fact, for the purpose of this article I will try to stay away from specific labels; in a future article I will try to link these to specific terminology that you might see.

Consider this a broad way of thinking about the different types of goals or outcomes you might seek from therapy. ***They are not mutually exclusive***, and any given therapist may be more or less expert at helping in one or more of these ways.

RESOURCING

This is the process of identifying resources that would be of help to you (AKA "assessment"), finding or helping you find specific places to go for those resources, and possibly assisting or coaching you as you access

those resources. “Resources” could be counselors, agencies, programs, clinics, hospitals, support groups, doctors, or any number of other sources of assistance.

This is a role traditionally played by social workers. Indeed, social workers at government or private agencies may be able to provide this kind of assistance to you. In private practice, a Licensed Clinical Social Worker (LCSW) might be a good choice. Be aware, however, that not all LCSWs necessarily focus on this kind of work; by the same token, many private practice therapists who are not LCSWs are quite skilled at providing this kind of assistance. Some medical doctors may also be able to provide help of this kind.

A counselor providing this kind of assistance may have specific expertise, such as helping people with chronic illness. Even if they do not have such expertise, a skilled provider should have the knowledge and contacts necessary to research your needs and corresponding resources more quickly, completely, and effectively than you could yourself.

> “IF YOU SUFFER FROM A VESTIBULAR DISORDER...THE LAST THING YOU WANT TO HEAR IS THAT IT’S “ALL IN YOUR HEAD.”

PSYCHO-EDUCATION

This is the process of helping you understand aspects of individual psychology, emotions, relationships, neurobiology, and any of a number of other areas that could be of help in making sense of your experience and making the changes you want.

Psycho-education is usually not enough by itself to create significant change. If it were, reading a good self-help book would be as effective as therapy. For some people, however, intellectual understanding of what is happening for them is a very important part of the process of change, healing, and growth. It could normalize your experience, help you to stop judging yourself as being morally deficient, and give you insight into how to deal with it more effectively. It can promote a sense of safety and control, and therefore provide or increase motivation.

SKILL BUILDING

Most of us learned some very important life skills, like dealing with our emotions or communicating effectively in relationship, by a very haphazard process of observing those around us. For many of us this has resulted in some significant holes in our psychological, emotional, and relational skill sets. Sometimes we learned poor skills that we need to un-learn so we can discover healthier ways to do things.

Therapy can be a kind of life extension course for these skills. This is actually a primary goal of some kinds of therapy, such as couples counseling or relational therapy groups. A good therapist can teach you these important life skills and coach you in practicing them and becoming proficient at employing them.

SYMPTOM RELIEF

The goal here is generally to alleviate painful or disruptive symptoms that a client identifies as causing distress or problems in his or her life. Symptoms can be simple or complex, and symptom treatment can be correspondingly easy or difficult, and quick or longer term. A symptom like “panic attacks whenever you get into a car since being in a bad accident” is relatively easy to identify and treat; a symptom like “a lifelong pattern of apparently random outbursts of rage” is likely to be considerably less straightforward.

Simply identifying a client’s symptoms accurately can in itself be a significant task. For example, if you have experienced low-level anxiety for most of your life you may not even notice it as anything out of the ordinary, but it may be related to an apparently sudden bout of depression or panic attacks.

There are many approaches to providing symptom relief. None of them are perfect, and most come with both pros and cons. We would all like to think that every symptom has a clear and consistent treatment to resolve it, but this is probably even less true for

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COUNSELING CONTINUED FROM PAGE 3:

psychological symptoms than for medical ones. People have different personalities, unconscious patterns, beliefs, etc., and therefore what works very well for one person may be a poor fit for another.

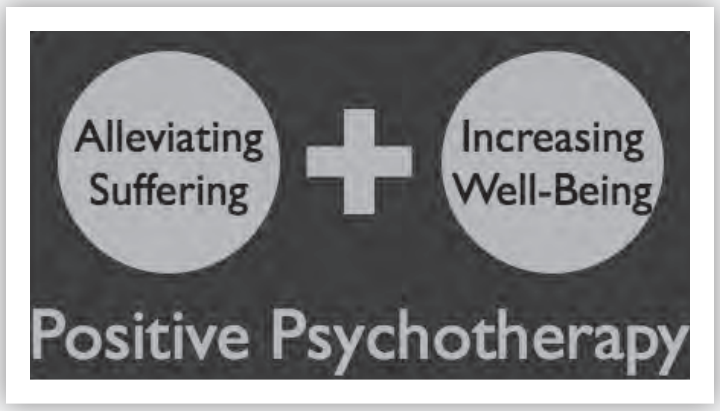
For example, a common choice regarding symptom relief in certain situations is medication or talk therapy. Medication is widely perceived to be faster-acting than talk therapy, with disadvantages such as side effects, the need to remember to take the medication consistently, and a tendency for meds' efficacy to change over time for many people. Talk therapy eliminates drug side effects, but some people may find it uncomfortable in other ways, and symptom relief can take longer and be more dependent on the client's ability to follow the therapist's suggestions. (I use this as an example; in actual practice, a combination of medication and talk therapy can be most effective, as is often true with depression.)

Focusing on symptoms can be both a strength and weakness in therapy. One strength is that identifying a clear, specific problem to resolve helps the therapy stay focused and makes it easier to assess how successful the therapy is and when the therapy is done. A weakness is that it requires a definitive specificity that many clients are not able to provide, especially at the beginning of therapy. Also, some life situations that bring people to therapy are not easy to reduce to symptoms and diagnoses, and attempting to do so can create other problems.

SUPPORT

This is primarily emotional support: the proverbial shoulder to cry on, a place where it is safe to express whatever you need to. It is a role that for some people is provided by friends, family, clergy, or their community.

Unfortunately, many people in today's society have limited support networks or do not want to "burden" those close to them. Some people cannot safely share some of their experience with those who might be expected to be supportive. Sometimes it is difficult to find people who will just listen, rather than try to fix or change you.



This is a legitimate use for therapy. Everyone goes through rough patches in their life at times: the loss of a loved one, a professional setback, a difficult transition from one phase of life to the next, etc. Sometimes temporary emotional support is all that is needed, or part of what is needed.

A good therapist has a large capacity for being compassionate and empathetic. You can unburden yourself to a counselor without having to worry about offending a loved one, being judged, or having someone else find out what you said.

LIFE WORK

Sometimes the task at hand is in the form of major healing or growth that is more like a caterpillar turning into a butterfly than a broken bone healing. The written Chinese character that means "crisis" also means "opportunity" because in every crisis is an opportunity for something new to emerge.

As with many significant life events, chronic illness can present a risk of becoming hopeless and self-hating as well as possessing a great potential for transformative psychological healing and growth. This is the domain of life work, where people transform deeply held unconscious beliefs and patterns, expand their awareness of possibility in their lives, and find ways to create more satisfaction and fulfillment in their relationships with themselves and others.

This is the work you want to do when you are asking big questions, such as: "Who am I?" "What is my purpose in life?" "Why am I never satisfied?" "What do I want from an intimate relationship?" There can be a spiritual aspect of such work, although this is

not essential.

The most powerful life work will often move fluidly between bigger spiritual or philosophical explorations and specific personal challenges and wounds. Some therapists do this better than others; if this is your goal, it is worth the effort to find someone adept at this kind of work.

THERAPY AND CHRONIC ILLNESS

Having a chronic illness would pose a challenge to even the most psychologically healthy individuals. We all use conscious and unconscious coping strategies, and none of those strategies is perfect. Chronic illness sometimes produces a "perfect storm" that exposes and magnifies every weakness in those strategies. On the other hand, for some people their medical condition presents a less earthshaking but still challenging set of logistical and practical obstacles to deal with. There are a number of ways therapy can be helpful throughout a wide range of degrees of distress.

If you suffer from a vestibular disorder or other kind of chronic illness, the last thing you want to hear is that it is "all in your head." However, it is true that stress, anxiety, depression, and a number of other mental health challenges can sometimes exacerbate and even precipitate some medical conditions. Also, medical conditions, especially chronic ones, can certainly cause or create "mental health" problems. So there are very good reasons to think that counseling could be helpful and appropriate for people dealing with chronic illness – reasons that have nothing to do with hypochondria or craziness.

Some people are understandably put off by the language of the mental health field that is currently common, particularly the label "mental illness." Please be aware that you do not need to be "mentally ill" to benefit from therapy and that plenty of therapists will work with you without pathologizing you. It is true that some therapists work from the "medical model" – where the steps are assessment of the symptoms, diagnosing the illness, and treating it – but this is not a prerequisite for good therapy.

A MEMORIAL TO VEDA MEMBER, SANDI FILLMORE

VEDA would like to extend our deepest condolences to the family of Sandra Ann Fillmore, who passed suddenly on May 24th, 2013. Sandi suffered a year-long struggle with severe, chronic, debilitating vertigo. Sandi's family requested that memorial donations be sent to VEDA in Sandi's honor. We are humbled and grateful to report that so far $1,350 has been received from Sandi's friends and family, funds that will be used to provide support to others suffering from inner ear balance disorders. What a beautiful memorial for a beautiful woman.

BALANCE AWARENESS WEEK *to* DEFEAT *DIZZINESS*

HE
A

WE INVITE YOU TO JOIN VEDA TO DEFEAT DIZZINESS DURING BALANCE AWARENESS WE
THIS GRASSROOTS CAMPAIGN IS VEDA'S ONLY EVENT EACH YEAR.

September 16 – 22, 2013

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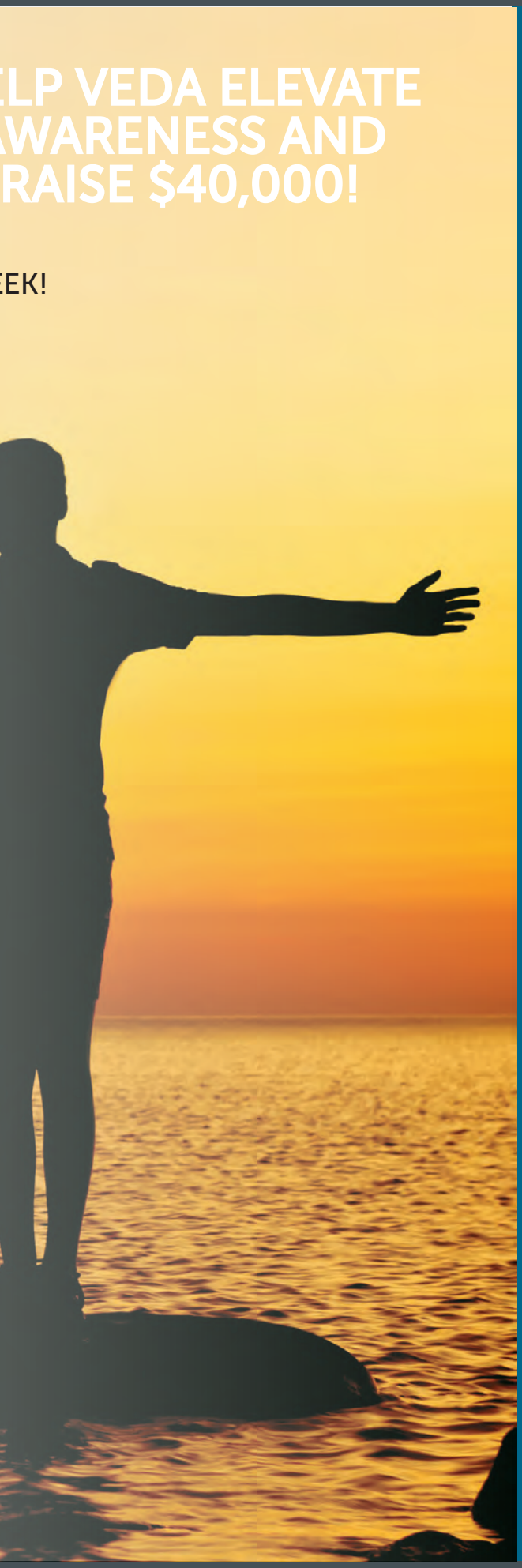
- Create a Personal Campaign Page to raise awareness and funds for VEDA. Pages can be created for an individual or an organization. For step-by-step instructions, please visit vestibular.org/baw.
- Request a 2013 Balance Awareness Week poster to hang at your doctor's office or a local business. You may also download and print a poster from our website: vestibular.org/baw.
- Host an event during Balance Awareness Week. Invite friends for a gathering and share Facts, Figures and Trivia about balance disorders. If you are hosting an event, please let VEDA know so we can promote it for you!
- "Like" VEDA on Facebook and receive up-to-date happenings about Balance Awareness Week: https://www.facebook.com/vestibulardisorders.

YOUR GIFT CAN MAKE A POSITIVE DIFFERENCE IN THE LIFE OF SOMEONE LIVING WITH A VESTIBULAR DISORDER. MAKE YOUR SECURE ONLINE DONATION AT HTTPS://VESTIBULAR.ORG/DONATEBAW2013.



ELP VEDA ELEVATE AWARENESS AND RAISE $40,000!

EEK!

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Otometrics is a proud sponsor of Balance Awareness Week. VEDA is excited to partner with Otometrics to help raise awareness for this year's campaign.

Otometrics would like to challenge all of VEDA's healthcare professionals to take action during Balance Awareness Week. Simply host an event, do an email blast, hang a poster or create a Personal Campaign Page and submit your information to VEDA.

All healthcare professionals who submit their Balance Awareness Week activity to VEDA will be entered into a drawing to win a complimentary registration for their high-demand Seminar Series "Revolutionize Vestibular Assessment: Assessing all six semicircular canals: Why? How? When?" During the seminar, participants will learn about video head impulse testing (vHIT) technology found only in ICS Impulse.

Entries must be submitted to VEDA by August 31st. VEDA will also promote your event on Facebook and the VEDA web site. The winners will be announced during Balance Awareness Week. To learn more about the seminar, visit **www.otometrics.com/impulse**. To submit your event to VEDA, send details to tony.staser@vestibular.org.

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OUT HOW YOU CAN GET INVOLVED.

ACCOUSTIC NEUROMA CONTINUED FROM PAGE 1:

I found out about my AN in a rather startling manner - I passed out from hunger before my colonoscopy and broke my nose. I went to an ENT who fixed my sinus, and when I told him I had a hearing problem on one side he decided to do an MRI to rule out an AN. His call two days later was a shock. He gave me the phone numbers of John's Hopkins and Dr. Prasad. Dr. Prasad is about two miles from my house, so I called his office and they took me in that day. His office has the best staff I have ever experienced. I never felt uncomfortable there.

The AN was removed during seven hours of surgery, which happened to be on my birthday. I was not prepared for the balance issues I would face since I did not understand the extent of post surgery recovery.

> "I KNOW I WILL NEVER RECOVER 100% BUT I WILL STRIVE TO MAKE IT THERE."

Having my world swirl around me, even when still, had me very concerned. When I was walking I often had to stop, look down, hold the wall, sit down, or close my eyes and try to not fall or get sick.

When I started balance therapy, Stacey (at the Balance Center of Maryland) explained to me where we would be going and how I would get there. However, I have to admit that I did not understand the logic of the exercises. I was very impatient and wanted to be "normal" as soon as possible. I wanted to know how long it would take to fully recover. Unfortunately, as those of you who have suffered through and recovered from an AN know, this was to be a long process.

One of my more challenging experiences was at an airport. I was walking through the Minneapolis Airport when I rounded a corner and my mind went into warp drive. There was this checkerboard patterned floor that made my eyes twitch; I actually had to stop and close my eyes. Then I went back and practiced walking over the floor. I fly through this airport at least four times a month, so I needed to be able to deal with this. It is still the hardest thing for me to conquer.

My wife, as my caregiver, knows my drive and determination. She had no doubt that I would do well and progress. Most of the time my attitude has been very positive, but I also learned my situation would get worse before it was better.

Preparing yourself for the unexpected can help. I typically know where I will have an issue and prepare my mind for the moment. I know I will have problems when I am very tired or turning my head and stepping down at the same time.

I travel for work and on the second flight six weeks after my surgery I was watching the flight attendant in the front of the plane. Slowly, like a Hitchcock film, it looked through my eyes like the plane was very slowly rolling to the right. It "rolled" almost 90 degrees before it snapped back. I asked the person next to me if the plane had made a turn and he said no. The oddest situation is that I am stable walking up the aisle on a plane during turbulence!

I also found it helpful to attend support group meetings, where I could hear from others who were going through the same challenges. It is one thing to understand your condition from a clinical perspective, but to hear the experience of other patients gave me a great deal of comfort.

I know I may never recover 100% but I will strive to make it there. The most important lesson I can pass along is to be very positive, diligently do the exercises your therapist prescribes, and do not feel you are different. Everyone has an issue. Some just hide it better.

Visit Paul's personal campaign page to help him defeat dizziness: https://vestibular.org/paulbacon.

Happiness is not a matter of intensity but of balance, order, rhythm and harmony.
–Thomas Merton

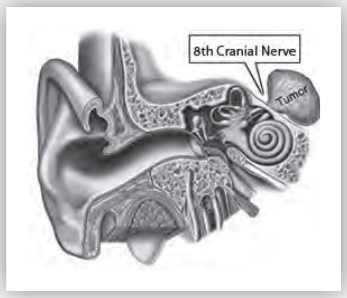
Accoustic Neuroma! Oh My!

By Bonni Kinne

Last month I began to experience some mild imbalance, as well as fullness and ringing in my right ear, so my family physician referred me to an otolaryngologist (an ear, nose, and throat specialist or ENT). I assumed that this specialist would send me to a physical therapist trained in vestibular rehabilitation. After all, a friend of mine experienced similar symptoms about a year ago, and she greatly benefited from this type of intervention. Although the ENT thought that I might have labyrinthitis (an inner ear infection that can cause these types of symptoms) since my tinnitus was only in my right ear, he ordered a couple of diagnostic tests, just to be sure. After the tests I followed up with the ENT and our conversation went something like this:

ME: "Hi Doc! When can I begin my vestibular rehab?"
DOC: "I'm afraid vestibular rehabilitation won't be appropriate in your particular case."
ME: "Why not? I thought I had labyrinthitis."
DOC: "Actually, you have an acoustic neuroma."
ME: "An acoustic neuroma! What in the world is that?"
DOC: "Let me explain."

WHAT IS AN ACOUSTIC NEUROMA?



An acoustic neuroma (see fig. 1), also known as a vestibular schwannoma, is a benign (non-cancerous), slow-growing tumor that originates from the outer covering of the vestibular component of cranial nerve VIII (the vestibulocochlear nerve). This nerve is responsible for transmitting the sense of balance and hearing from the inner ear to the brain.

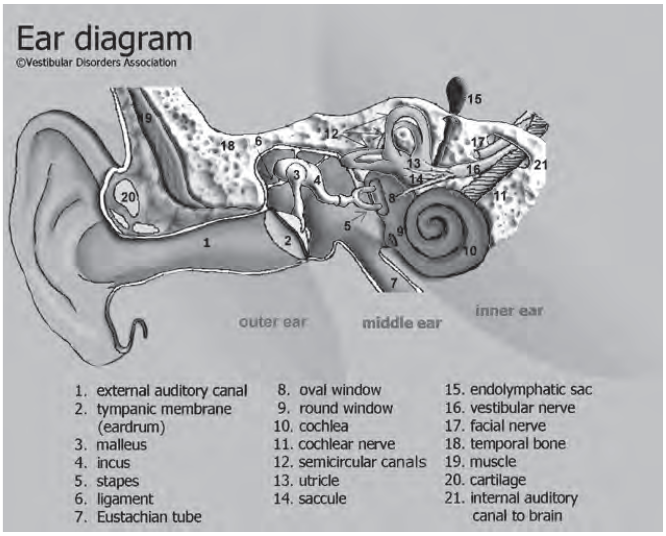
An acoustic neuroma, usually located in the region of the internal auditory canal (see fig. 2), is an uncommon occurrence. This type of tumor is only diagnosed in approximately 10 out of every 1,000,000 adults (children are rarely affected), and just 5-10% of all brain tumors are classified as acoustic neuromas.

WHAT CAUSES AN ACOUSTIC NEUROMA?

In approximately 95% of all cases, an acoustic neuroma occurs on a random basis. However, it has been proposed that individuals who received head and/or neck radiation therapy as a child may be more susceptible to developing an acoustic neuroma as an adult. In approximately 5% of all cases, an acoustic neuroma accompanies von Recklinghausen Disease (neurofibromatosis type II). Neurofibromatosis type II is an autosomal dominant disorder in which the children of an affected parent have a 50:50 chance of inheriting the disease, even if the other parent is unaffected. This disorder is thought to result from a defective gene on chromosome #22, and those individuals who have the disease often develop an acoustic neuroma in both inner ears.

WHAT SYMPTOMS ARE ASSOCIATED WITH AN ACOUSTIC NEUROMA?

Because an acoustic neuroma is a slow-growing tumor, it may not cause any noticeable symptoms for several years. The initial symptom associated with acoustic neuromas is frequently a gradual hearing loss that only affects one ear. This hearing loss, often accompanied by tinnitus (ringing in the affected ear), is usually a high-frequency sensorineural type of deficit. A high-frequency hearing loss means that high-pitched sounds are difficult to detect. A sensorineural hearing loss means that there has been damage to the cochlea (the hearing component of the inner ear) and/or to



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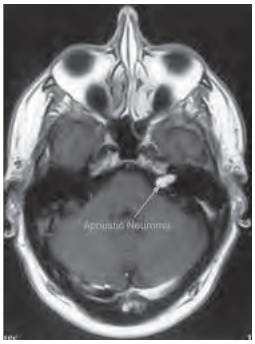
OH MY! CONTINUED FROM PAGE 9:

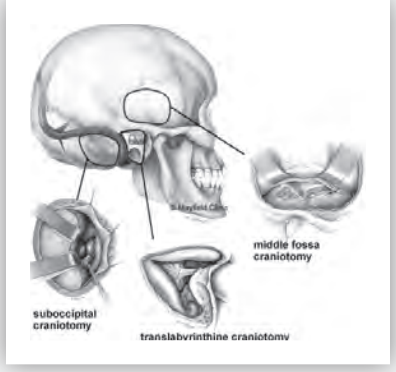
cranial nerve VIII. Although imbalance may also be associated with an acoustic neuroma, true spinning vertigo is uncommon. The imbalance caused by an acoustic neuroma is usually worse when an individual performs rapid head/body position changes, walks in a dark environment, and/or walks over a compliant surface. If the acoustic neuroma is large enough, it may compress cranial nerve V (the trigeminal nerve), cranial nerve VII (the facial nerve), the brainstem, and/or the cerebellum. Cranial nerve V is responsible for facial sensation and the muscles of mastication (chewing). Cranial nerve VII is responsible for the muscles of facial expression. Although facial numbness and tingling occur in approximately 50% of all individuals who have a large acoustic neuroma, weakness of the mastication and/or facial expression muscles is rare.

HOW IS AN ACOUSTIC NEUROMA DIAGNOSED?



An MRI with gadolinium (a contrast agent) is the gold standard test for detecting an acoustic neuroma. The purpose of using a contrast agent is to improve the visibility of the tumor (see fig. 3). Another test that may be used to detect an acoustic neuroma is the auditory brainstem response (ABR) test. Although an ABR test is less sensitive than an MRI with gadolinium, it's also less expensive. Because hearing loss is often the initial symptom associated with an acoustic neuroma, audiometry (a hearing test) is administered during the diagnostic process. One other test that should be mentioned is the CT scan, with or without a contrast agent. This test usually has trouble detecting a small acoustic neuroma. However, it may be used when an MRI is contraindicated.

HOW IS AN ACOUSTIC NEUROMA TREATED?



Approximately 50% of all acoustic neuromas are treated with a surgical intervention. There are three common surgical approaches (see fig. 4), and each of these approaches is associated with some distinct advantages and disadvantages. For example, although the middle fossa craniotomy is often able to preserve whatever hearing is present, this approach may result in damage to cranial nerve VII. The translabyrinthine craniotomy, on the other hand, is often able to preserve cranial nerve VII function. However, this approach will result in a complete hearing loss. Another type of treatment, radiotherapy, is used in approximately 25% of all cases. This treatment technique is a non-invasive intervention in which very specific beams of radiation are introduced into the acoustic neuroma in order to halt its growth. Although hearing and cranial nerve VII function are often preserved, this type of intervention is not appropriate if the acoustic neuroma is extremely large or if it has already caused significant symptoms. Finally, approximately 25% of all acoustic neuromas are monitored with yearly or biannual diagnostic testing. This "wait and see" method is most appropriate for those individuals who are older, who have no significant symptoms, and/or who are unable to physically tolerate a surgical intervention or radiotherapy.

BONNI KINNE IS AN ASSISTANT PROFESSOR IN THE DEPARTMENT OF PHYSICAL THERAPY AT GRAND VALLEY STATE UNIVERSITY, WHERE SHE HAS BEEN CONDUCTING RESEARCH IN THE AREA OF VESTIBULAR REHABILITATION. BONNI ALSO WORKS PART-TIME IN A CLINIC WHERE SHE SPECIALIZES IN THE TREATMENT OF PATIENTS WITH VESTIBULAR DISORDERS. BONNI RECEIVED HER BACHELOR'S DEGREE IN BIOMEDICAL SCIENCES AND MASTER'S DEGREES IN EXERCISE SCIENCE AND PHYSICAL THERAPY.

"AFTER MY VESTIBULAR NEURITIS WAS UNDIAGNOSED FOR MONTHS BY THREE VERY COMPETENT DOCTORS (G.P., E.R. AND A NEUROLOGIST), I WAS ABLE TO USE THE (VEDA) PROVIDER DIRECTORY TO LOCATE AN ENT SPECIALIZING IN VESTIBULAR DISORDERS, AS WELL AS A PHYSICAL THERAPIST, TO HELP ME ON MY WAY TO RECOVERY. I ALSO FOUND A GREAT SUPPORT GROUP." - ANONYMOUS

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The Vestibular Disorders Association (VEDA) is a 501(c)(3) nonprofit organization with a mission to serve people with vestibular disorders by providing access to information, offering a support network, and elevating awareness of the challenges associated with these disorders.

NOTICE: If you would like to receive your newsletter printed on grey matte paper, please contact us!

Race to De-Feet Dizziness

When Melissa Bosserman was 13 years old her world began to rock. She was diagnosed with perilymph fistulas and endolymphatic hydrops after both ears ruptured during a commercial airline flight. Since then she has struggled to regain her independence, eventually graduating with a Master's degree in Speech and Hearing Sciences.

To celebrate her 30th birthday, Melissa is joining with VEDA to "de-feet dizziness" by participating in the 25th Annual Aluminum Man Triathlon in The Dalles, Oregon, a race that includes a 10K run, 50K bike ride, and 1K swim in the Columbia River.

YOU CAN HELP DEFEAT DIZZINESS BY MAKING A DONATION TO MELISSA'S PERSONAL CAMPAIGN PAGE: HTTPS://VESTIBULAR.ORG/BAW/MELISSA.

THANK YOU TO OUR DONORS!

VEDA would like to thank all our donors, whose generosity makes it possible to provide information, support and advocacy to people suffering from vestibular disorders. In the past we have listed donors from the past quarter in each newsletter. Going forward we will be including a list of all donors in our annual report. Please email us at info@vestibular.org with feedback on this new policy.