In August 1991, Dr. Thomas F. Morgan noticed subtle signs of hearing loss and some high-pitched noise (tinnitus) in his right ear, along with a slight sense of imbalance.

An experienced neurologist at Rhode Island Hospital, he knew he needed an MRI. It confirmed his initial self-diagnosis: he had an acoustic neuroma. So far, everything was relatively easy. Making a decision regarding the most appropriate treatment turned out to be more complicated.

Surgical removal of the tumor was the preferred standard treatment. But Dr. Morgan started doing research on his own, talked to a number of colleagues and participated in the Acoustic Neuroma National Institutes of Health Consensus Development Conference in Bethesda, Maryland, USA, in December 1991. Most acoustic neuroma surgeons attending that meeting favored microsurgery.

At a dinner meeting hosted by the Acoustic Neuroma Association, many already treated patients gave Dr. Morgan their perspective: "Doctors, please listen! Cure or control but do not harm."

Dr. Morgan realized that there was an alternative: stereotactic radiosurgery with the Gamma Knife. It was an outpatient procedure and it could be performed without upsetting his busy daily routine. Additionally, he knew open surgery for acoustic neuroma could cause negative side effects, not to mention the risk of general anesthesia. After extensive research, he was convinced radiosurgery was the treatment of choice for acoustic tumors.

Much to his surprise, the Gamma Knife technique would soon be available at his own hospital in Providence, Rhode Island. He underwent Gamma Knife radiosurgery at Rhode Island Hospital in May 1992. Now, eight years later, the tumor has decreased in size and he still has hearing in that ear. His face has normal appearance, without even the slightest facial weakness. He feels great and is very active.

"My perspective now," he says, "is to help others in the decision-making process and to champion Gamma Knife radiosurgery for acoustic neuromas as the standard treatment with microsurgery as an adjunctive or alternative option."
Stereotactic radiosurgery is not surgery. The skull is never opened. Radiosurgery involves the use of precisely directed single fractions of radiation to create lesions within the brain or to treat tumors or vascular malformations with minimal damage to surrounding structures or tissues.

This works by delivering a relatively high dose of radiation in one session to the target with scalpel-like precision. The dose is designed to injure or kill the cells or their supporting blood vessels, while minimizing its effect on surrounding healthy tissue. The radiation distorts the cells’ DNA, causing them to lose the ability to replicate themselves. The safety and clinical effectiveness of this technique has been established since 1968 in over 150,000 treated individuals.

The benefits include: No risks of infection or anesthesia reactions; virtually no pain; reduced costs; and an immediate return to normal activities.

Radiosurgery may or may not be appropriate for your condition. It may be used as the primary treatment or recommended in addition to other treatments you may need. Only a treating neurosurgeon can make the evaluation as to whether you can be treated. Some of the most common indications for treatment today are:

- Arteriovenous/vascular malformations
- Meningiomas
- Acoustic neuromas
- Pituitary and pineal tumors
- Metastatic tumors
- Glial and astrocytoma tumors
- All other malignant & benign tumors
- Trigeminal neuralgia
- Parkinson’s tremors/rigidity
- Functional disorders

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I Treated My Own Mother

Editor’s note: This story was written by Dr. Steven Goetsch, a medical physicist at San Diego Gamma Knife Center. He treated his mother for trigeminal neuralgia using the Gamma Knife.

Sounds like a cheap science fiction title, doesn’t it? Well, it is true. I am a medical physicist and I have worked at the San Diego Gamma Knife Center since it opened in 1994. My mother has suffered from trigeminal neuralgia pain since 1981. As with most patients, her affliction was mis-diagnosed and mis-treated for many years. A dental surgeon in St. Louis did a root canal, and when that was unsuccessful, he said (insightfully) that it could be a “nerve problem.” However, nothing effective was done to alleviate it.

My parents moved to the San Francisco Bay area where her problems continued. She had a tooth pulled and the pain went away for a while. In 1984, Dr. Gerald Silverburg at Stanford University Medical Center correctly diagnosed the problem as trigeminal neuralgia. She was started on Tegretol, which managed the trigeminal neuralgia more or less effectively for five years.

My parents moved again to Thousand Oaks, just north of Los Angeles. The pain returned intensely in 1989. She saw a neurologist for four years who kept her on Tegretol for another 18 months. She went to see my dear friend and former colleague, Dr. Tony De Salles at UCLA Medical Center, and he managed her condition with Tegretol for another 18 months.

Finally, with Mom taking 800 to 900 mg of Tegretol per day, and liver function becoming an issue, I offered her a treatment at the San Diego Gamma Knife Center.

After much hesitation, and worry that “she would be a bother,” she came to our center...

Steve and his mother

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Current Research...

RADIOSURGERY AND ACOUTIC NEUROMAS...

In an effort to determine long-term outcomes of radiosurgery for acoustic neuroma, researchers at the University of Pittsburgh followed 162 patients for 5-10 years after Gamma Knife radiosurgery. Before radiosurgery, 76% had normal facial function and 20% had useful hearing.

The researchers found that 98% of the tumors were controlled by radiosurgery with no growth. After five years, 79% of patients had normal facial function. Hearing ability had not changed in 51% of the patients. One hundred percent of those who had microsurgery previously and 95% of those who had not had surgery believed radiosurgery was successful. The authors concluded that preservation of facial function and long-term control of acoustic neuromas was afforded by Gamma Knife radiosurgery.

Acoustic Neuroma and Radiosurgery

It is a scary moment when your doctor tells you that you have a "brain tumor" called acoustic neuroma (vestibular schwannoma). You think you are the only one with this disease and you will soon die or at least become a physical wreck. You fear the only treatments available are either ineffective or very dangerous.

Fortunately, this is all wrong. You are not alone: between 2500 and 3000 new acoustic neuroma patients are diagnosed in the United States alone every year. And effective, low-risk treatment is available.

Acoustic neuroma was described for the first time in Holland in 1777. A comprehensive clinical description was presented in 1830. Although the first successful removal of an acoustic neuroma was performed in 1894, the mortality following surgery at the turn of the century was at least 80%. Excision of the tumor was the standard treatment and the only available option for many years. The results improved gradually but were still far from satisfactory in the early 1960s, when microsurgical techniques were gradually introduced into this field in the USA.

In 1951, the Swedish neurosurgeon Lars Leksell presented the idea of letting a large number of converging beams of ionizing radiation crossfire targets in the brain. He coined the term "radiosurgery" to describe this concept, since the way radiation was used differed greatly from conventional radiotherapy. He suggested radiosurgery for the treatment of deep-seated brain tumors.

The first device for routine clinical use based on this idea was the prototype Gamma Knife constructed in 1967-68. Dr. Leksell treated the first acoustic neuroma with the technique in June 1969 at Karolinska Hospital in Stockholm, Sweden. Since then, more than 10,000 acoustic neuroma patients have been treated with this technique worldwide.

The Gamma Knife

This is an 18-ton machine with 201 permanently mounted cobalt-60 sources arranged spherically around the patient's head. These sources emit gamma radiation, which is similar to diagnostic X-ray (not laser as some times assumed) but with higher energy. These beams are precisely shaped through two consecutive sets of tungsten channels (collimators). They all focus on one point. Here, the radiation is very powerful. However, each individual beam on its way through the skull is weak and will not cause any detectable biological effects. The gamma radiation destroys molecules in the tumor cells so they can no longer reproduce and eventually will die.

The Gamma Knife is precise down to half a millimeter or even less (about 1/50 of an inch). Thus, a high dose of radiation can be delivered to targets with little harm to important sensitive structures just millimeters away or even adjacent to the surface.

Stereotactic radiosurgery is performed by a team composed of neurosurgeons, radiation oncologists, medical physicists and a nursing staff. Specialists in neuroimaging join the team when required.

Who can be treated?

In general, all acoustic tumors with an intracranial diameter of up to approximately 3 cm (1 1/4") qualify for Gamma Knife radiosurgery. Over the years, larger tumors occasionally have been treated successfully with this technique. However, there is a greater risk that these larger tumors, even before any treatment, interfere with the circulation of the cerebrospinal fluid (CSF), causing hydrocephalus (an excessive accumulation of CSF). In this case, a shunt may be required to divert the CSF.

Patients with large acoustic neuromas - especially older patients - may still prefer the combination of Gamma Knife radiosurgery and a shunt operation, a considerably less demanding procedure than microsurgical removal.

In fact, there are few reasons why Gamma Knife radiosurgery should not be considered first instead of microsurgery for the vast majority of acoustic neuroma patients, including young and otherwise healthy ones.

What happens to the tumor?

Very few acoustic tumors threaten the patient's general health initially. The rationale for treating the tumor is to avoid the risk that the tumor might cause serious health problems or even death down the road if left alone to grow. By treating the tumor when it is still small, the risk of complications

Continued on page 4
from treatment is generally smaller. Even so, a microsurgical procedure usually poses a greater immediate risk to the patient’s health in terms of morbidity than does the tumor itself.

Gamma Knife radiosurgery is different. The short-term and long-term risks are very low. The goal of the treatment is to kill or inactivate the tumor cells so they no longer duplicate. Since acoustic neuroma is a very benign type of tumor, it need not be completely destroyed. Instead, the aim is to stop further growth. An acoustic tumor that does not grow will not jeopardize the patient’s health in the future.

In a benign tumor such as acoustic neuroma, with a very slow cell turnover, it will take some time for the radiation to affect the cells in a way that can be detected clinically or by imaging. Therefore, radiosurgery has a less immediate effect than microsurgery.

Over a period of 26 years, I have personally treated almost 850 acoustic neuroma patients with Gamma Knife radiosurgery. I would like to share some of my experiences with you. Growth control - shrinkage or no growth - is achieved in at least 95% of the tumors.

Shrinkage actually is found in the vast majority of tumors when they are followed long enough. One year after the Gamma Knife treatment, shrinkage is confirmed in about one-third of the tumors. After four years, two-thirds of the tumors are smaller, and by 10 years, more than 90% have shrunk.

Signs of lack of response to radiosurgery, in general, appear within one to three years of treatment. At least in my experience, failure is extremely unlikely to occur when five years or more have elapsed. This statement may not apply for acoustic neuromas associated with neurofibromatosis 2 (NF2) in which case recurrence may occur later following Gamma Knife treatment as well as microsurgery.

I have found that Gamma Knife treatment can be repeated without increased risks if the acoustic neuroma did not respond as expected (unchanged size/shrinkage) to the first treatment. Microsurgery can also be selected, depending on the patient’s preference.

Acoustic neuromas sometimes increase in size temporarily as a reaction to the Gamma Knife treatment. This is actually a favorable sign indicating a brisk response. Such swelling usually is most obvious between 6 and 18 months after the procedure. It should not be confused with increase due to lack of response in which case the tumor size will not return to the base-
Acoustic Neuroma

Continued from page 4

line but continue to increase. A definite assessment should be made two years after the treatment: was the swelling merely temporary or did the tumor fail to respond to the treatment? In any case, resection should not be considered during this two-year wait.

Cranial nerve function

At experienced Gamma Knife centers, the incidence of temporary facial and trigeminal nerve dysfunction among acoustic neuroma patients is as low as less than 2-3%. Preservation of useful hearing currently is achieved in 55-75% in different series with the better results usually in smaller tumors. Hearing tends to remain stable when the first one to two years have elapsed after treatment.

The tinnitus (spontaneous noise) so frequently associated with the hearing loss in acoustic neuroma patients is usually not affected, for better or worse, by Gamma Knife treatment initially. Over time, some patients say they have experienced some improvement. It is hard to say whether this is a real reduction of the intensity of the noise or an adaptation to a steady noise level.

Even though most acoustic neuromas arise from the balance nerve (and not from the adjacent hearing nerve), hearing loss in the affected ear is a much more frequent presenting symptom than balance disturbance. When asked about it, however, most acoustic tumor patients admit to some feeling of unsteadiness or episodes of dizziness. Sometimes these symptoms may increase temporarily after the Gamma Knife treatment, indicating a transient reaction in the balance nerve to the radiosurgery.

Radiosurgery or microsurgery?

Traditionally, tumor treatment is defined as successful when the tumor has been completely removed. This apparently does not apply for Gamma Knife radiosurgery for which other standards have to be accepted when the results are evaluated.

Stereotactic radiosurgery has a number of evident advantages over microsurgery including no mortality, no risk of intracranial bleeding or infection, no post-surgical complications, short or no inpatient time, and almost no recovery period. In addition, Gamma Knife treatment almost eliminates the risk of permanent facial weakness and the need for further surgery to restore proper facial functioning including eyelid closing, excessive tearing or dry eye.

The features are in themselves usually so attractive to the patient that they may decide on radiosurgery based on the very low risk of side effects. Of course, such a decision should focus primarily on the best way of eliminating the impact of the tumor and secondly on the risk of disturbances in adjacent structures, such as surrounding cranial nerves, induced by the treatment.

Patients should get information about the different treatment options to be able to participate actively in selecting the best alternative. Some of the results following Gamma Knife radiosurgery and microsurgery in a recent study have been summarized in Table 1, published in the Journal of Neurosurgery in May 2000.

It has been reported that acoustic tumors that were first treated with radiosurgery without response were difficult to remove with microsurgery because surrounding nerves and other structures were more adherent to the tumor’s surface. The radiosurgical treatment would stimulate the formation of scar tissue outside the tumor. The surgeons reporting these problems base them on the experience from a small number of tumors resected. The experiences reported are far from consistent. Because of lack of experience we do not conclusively know to what extent and how often this is a real problem. We should not be able to expand our experience very much since a second Gamma Knife treatment is almost always possible to perform in those few patients in whom the response to the first treatment was inadequate.

Another objection against radiosurgery sometimes mentioned is that the treatment would induce the formation of new tumors or change the character of the treated tumor to become more aggressive. These are known risks with radiation in general. Based on known clinical data and theoretical considerations that risk is equal to or less than 1 per 1000 persons treated. This is an extremely low risk level, which in my mind is not a reason to withhold Gamma Knife radiosurgery from young individuals who prefer radiosurgery to microsurgery.

Dr. Georg Norén, M.D., Ph.D., serves as Director of the New England Gamma Knife Center at Rhode Island Hospital in Providence, Rhode Island. A native of Sweden, Dr. Norén received his medical degree in 1971 from Karolinska Institute, the birthplace of the Gamma Knife, and completed most of his neurological training there. He has been an associate professor in the Department of Neurosciences at Tufts University School of Medicine in Boston, Massachusetts. He may be reached at +401-444-4257 or by e-mail at gnoren@lifespan.org.

Acoustic Neuroma
Fast Facts

- Also known as vestibular schwannoma
- Found in about 1 in 100,000 people
- Usually benign and slow-growing
- Located on the 8th cranial nerve
- The 8th cranial nerve transmits sound to the brain
- Occur most frequently in adults age 30-60
- Twice as likely to occur in females
- Treatment with Gamma Knife began in 1969
- Symptoms include hearing loss, balance difficulties and facial numbness
Editor’s note: Gamma Knife radiosurgery was not available in the United States until 1987.

In 1983, Janette started having hearing loss in her left ear. “I was a medical assistant, and it got more difficult to hear patients,” she recalls.

Jan went for a hearing test, but had a head cold at the time, and had to return for a second test. During both hearing tests, “There was a squawky sound which masked the good sound,” she says.

“The only thing I can compare it to is Alvin and the Chipmunks.”

After the second hearing test Jan was sent for an evoked response test, and then an air contrast CT scan. During the CT scan air was pushed through Jan’s spinal column. “ Afterwards, I had quite a headache,” she says. The CT scan revealed a 1 cm acoustic neuroma on the left side of her brain.

“It only took about three to six months to go from good hearing in my left ear to no hearing,” Jan recalls. “And I didn’t have any headache symptoms.”

In November of 1983, Jan had her first surgery for her acoustic neuroma. Dr. Roderick Smith performed the surgery at Kaiser Permanente in Sacramento, California.

“I worked for Kaiser Permanente as a medical assistant, and I worked with Dr. Smith before I found out about the acoustic neuroma,” she says. Jan trained to be a medical assistant while in her mid-forties.

After the first surgery, Jan’s acoustic neuroma grew to 2.5 cm.

In October of 1984, Dr. Smith performed a second surgery in an attempt to remove the remainder of the tumor. Again, the tumor was incompletely removed.

Jan suffered some facial damage from the second surgery. “I didn’t realize I was going to wake up with my face in my lap,” she says. “But Dr. Smith is an excellent doctor. He’s performed many acoustic neuroma surgeries with no facial damage.”

By 1986 Jan’s facial nerves had recovered from the second surgery. “I still couldn’t smile quite right,” Jan says. “Now, I still can’t lift my eyebrow, but my smile has improved.”

“Coming out of the second surgery, Dr. Smith said, ‘We didn’t get it all out again, but we can go in and debulk it from time to time.’ I said, ‘No way,’” Jan reports.

“Dr. Smith said, ‘Well, let me look into it,’ and before I was discharged, he told me about Dr. Robert Rand at UCLA, who had a Gamma Knife study,” Jan recalls.

In September of 1985, Jan visited Dr. Rand and found that his study involved animals only. “He showed me slides of rabbit brains before and after [Gamma Knife],” Jan recalls. “Dr. Rand said that he was sending everyone to the Karolinska Institute in Sweden as Gamma Knife was not available in the US at that time. He wrote me a referral, and told me to go get an MRI in San Francisco,” Jan says. “At that time there was no MRI in Sacramento.”

“I was the first person Kaiser Permanente paid for to have the Gamma Knife,” Jan says. “Kaiser paid for the radiosurgery, but I paid for the trip to Sweden.”

In April of 1986, Jan traveled alone to Sweden for her treatment. “I was not afraid after traveling all over the world,” she says. Her husband Duane was in the Air Force and because of this they traveled extensively. “We were an Air Force family,” Jan says.

“Besides, my husband is not any good in hospitals. I figured I was better off without him,” she quips.

Jan made her own travel arrangements and stayed in a hotel that was a five minute walk from the Karolinska Institute in Stockholm.

“I had a thorough neurological workup on Friday the 17th, and went sightseeing on the weekend,” Jan says. “I had my treatment on Monday and left on Tuesday.”

“The city was very clean, and I felt safe on the subway,” she recalls. “I did some bus and walking tours, and went to see the construction of the great ship Vasa which had been found in the Stockholm harbor. It snowed on Sunday!”

Dr. Georg Norén performed Jan’s treatment. He is currently working in Providence, Rhode Island as Director of the Gamma Knife center. The treatment was a “good experience,” Jan says. Her tumor was shaped like a pear and treatment took about 40 to 45 minutes.

“After Gamma Knife I had some balance problems for about nine months,” Jan recalls. “Because of this I also had some related nausea. The symptoms were unpredictable. Something as little as driving down a shady street with flickering sunlight could set me off.”

“I went back to work the Monday after the Gamma Knife treatment,” Jan states. “I was working part-time, but I also worked part-time before the treatment.”

In October of 1986 my company went on strike, and I wasn’t working, and the nausea stopped. Maybe I’d been working too hard,” Jan says.

She now has a digital hearing aid. “I started having age-related hearing loss in my right ear, perhaps even before I went to Sweden,” she says.

Jan had no further problems until February of 1996, when she found out she had breast cancer. “It was a small stage one tumor on the left side,” Jan says. “Dr. Ernie Bodi at Kaiser recommended that I not have radiation treatments. He said, ‘Let’s not add to your cumulative radiation load.’ So I had a modified radical mastectomy and one year of Tamoxifen treatment. I had a lot of side effects from the Tamoxifen.”

“Since then I haven’t had any problems with the breast cancer,” Jan says. “Hopefully there will be no recurrence.”

There is some history of cancer in Jan’s family. “My dad died of prostate cancer which had metastasized to the liver,” Jan says. “He also had a benign meningioma and had a craniotomy to remove it. And my maternal grandmother died of what they called ‘stomach cancer.’”

Jan continues to travel to many acoustic neuroma meetings throughout the country. “What I really enjoy is counseling and sharing my experience with people thinking about Gamma Knife. Probably the hard part is sometimes I don’t know how it turns out - what decisions these people make,” she says.

These days Jan is enjoying retirement. “I love to read,” she says, “and I like to sew. I enjoy cooking and traveling with my husband. And I really enjoy not having any set schedule.”

“But I probably enjoy most having the grandchildren come to visit,” she says.

Jan, 64, and Duane, 67, have two children: Kathy, 41, and Duane Jr., 43. They also have four grandchildren aged 10 to 17.
"Around 1998, I had trouble hearing in my left ear," Alfred recalls. Al, 65, works in construction. "When you work in construction, there are a lot of devices and loud noises, and you lose your hearing. I went for a hearing test at Sears, and they told me I had only about 20% of my hearing left in that ear. They told me to go to an ear doctor."

"I went to my wife's ear doctor, and he sent me for an MRI," Al says. "It turned out I had a tumor wrapped around my ear canal."

"The doc called me and said, 'I hate to tell you this over the phone. It's a million to one that you got the same tumor your wife did,'" recalls Al.

That's right, Al and his wife Julie both had the same type of tumor. "About ten years ago, Julie had a large acoustic neuroma," states Al. For a year, Julie had headaches and her ear disturbed her. "She went to the ear doctor for a year. Then she switched docs, and the new one sent her for an MRI. She had an acoustic neuroma. It's a million to one that you got the same tumor your wife did," recalls Al.

Julie and Al have two daughters. One of their daughters and her husband are building a house next door.

"We have four dogs and a bunch of ducks out in the pond," Al says. "My daughter has two horses here that she takes care of. We have 10-15 cats in the barn. And we have some hayfields, for the horses."

"I was retired three years ago, but got bored last summer and went back to work," Al says. "Now, he is about to retire again. He says he'll fill his time with housework, cooking and gardening. Al also likes to cut wood for the woodstove. "The heat feels nice and the price is right," he says. Julie is busy as the head of volunteers at St. Mary's Hospital."

"Understanding life and getting along is the hardest thing in life," Al says. "I thought it [Gamma Knife] was really easy. I'm not through yet, but I wouldn't be afraid to do it again."

"Another Perspective, Volume 5, Number 3

Husband and Wife Diagnosed with Acoustic Neuroma

I Treated my Mother

Continued from page 2

ter on October 21, 1999. We had three patients to treat that day and no other physicist, so I participated in her treatment. She tolerated the procedure quite well (90 Gy at the 100% point, one "shot" with the 4 mm helmet) and felt bad that the nurses had to get up so early and work so hard. She did extremely well post-op and went out to dinner the next night. Slowly, her pain decreased and she dropped down on her medication. Now, she no longer takes Tegretol and has not had any attacks in quite a while. My mother and father now have the confidence to plan a two week cruise to Alaska, something they never would have done while she was in such pain.

Not every patient we treat gets such prompt and effective relief, but I can now tell our nervous patients, "I treated my own mother with this machine." I can truthfully say I did not treat her any differently than I have treated our other 950 patients.

Dr. Steven Goetsch may be reached by mail at: San Diego Medical Physics, 665 San Rodolfo, Suite 124-113, Solana Beach, CA 92075 USA; by phone at +858-452-5020; by FAX at +858-452-5677 or by e-mail at sgoetsch@earthlink.net.

For More Information, Contact:

American Tinnitus Association
PO. Box 5
Portland, OR 97207-0005
Web: http://www.ata.org

Oregon Health Sciences
University Tinnitus Clinic
NRCO4
3181 S.W. Sam Jackson Park Road
Portland, OR 97201-3098
Phone: +503-494-2954
E-mail: ohrc@ohsu.edu
Web: http://www.ohsu.edu/ohrc/tinnitusclinic

Acoustic Neuroma Association
PO. Box 12402
Atlanta, GA 30355
Phone: +404-237-8023
Fax: +404-237-2704
E-mail: ANAusa@aol.com
Web: http://www.anausa.org

E-mail: sgoset@san.rr.com.

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Acoustic Neuroma Association
PO. Box 12402
Atlanta, GA 30355
Phone: +404-237-8023
Fax: +404-237-2704
E-mail: ANAusa@aol.com
Web: http://www.anausa.org

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Acoustic Neuroma Association
PO. Box 12402
Atlanta, GA 30355
Phone: +404-237-8023
Fax: +404-237-2704
E-mail: ANAusa@aol.com
Web: http://www.anausa.org

E-mail: sgoset@san.rr.com.

For More Information, Contact:

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Web: http://www.ohsu.edu/ohrc/tinnitusclinic

Acoustic Neuroma Association
PO. Box 12402
Atlanta, GA 30355
Phone: +404-237-8023
Fax: +404-237-2704
E-mail: ANAusa@aol.com
Web: http://www.anausa.org

E-mail: sgoset@san.rr.com.
Everyone has been on a plane and experienced the uncomfortable feeling in the ears as air pressure changes. Acoustic neuroma sufferers say this feeling can be very painful for them.

The ear is composed of air spaces. When the air pressure around us changes, the air spaces in our ears can feel blocked or clogged. As the plane descends, the Eustachian tube in the middle ear tends to collapse as the outside pressure builds. The middle ear becomes filled with fluid and blood.

What you can do:

- Get a mild decongestant from your doctor and begin taking it at least one day prior to your plane trip. This will help keep the air passages clear and open.
- Practice lowering your jaw and wiggling it from side to side. This will usually open the passages.
- Try yawning or swallowing during the plane's ascent and descent and periodically during the flight. Chewing gum may also help.
- When ears fail to open, try the Valsalva maneuver: close your mouth, pinch your nose and blow gently with your nose, to push air up through the Eustachian tubes and open them. You will probably hear your ear "click." This can be repeated as needed.
- Do not wait until the pain builds up in your ears. Learn to adjust yourself and equalize the pressure between your ears and the cabin several times as the plane takes off or prepares to land.

Patient Update - Jo

Editor’s note: We first brought Jo’s story to you in 1997. She had both surgery and Gamma Knife for an acoustic neuroma in her left ear.

"It’s been five years since I had Gamma Knife," Jo reports. She had an MRI in July, and her next MRI will be in three years. "The doctors are satisfied with what they see, that the acoustic neuroma is not going to give me problems."

"I still have symptoms of dry eye and facial numbness from my previous surgery. There really have been no changes," Jo says. She keeps her eye moist and uses a humidifier at night and in the winter. Jo has found the product "Puralube" to work well with her severe dry eye at night. She gets the lubricant at Wal-Mart.

"I went to an oculoplastic surgeon, because I was interested in having a gold weight put in my eyelid," Jo recalls. "The surgeon felt my problem was not serious enough to have the operation at this time." Jo states that she can close her eyelid sufficiently at times, but she must concentrate mentally to do so.

Jo and her husband Bill are retired, and live in a golf course community near Gettysburg. Jo does water aerobics, and she and Bill enjoy golfing. They look forward to the frequent visits by their children and grandchildren.

"We go to Florida for one month in the winter," Jo says. "We like to get away in February for a break."

"I enjoy talking to anyone who is interested in Gamma Knife," Jo says. "I will answer anyone, as soon as possible, if there’s anything I can do to help."

Speaking to Someone with Hearing Loss

- Keep background noise to a minimum
- Face the person you are speaking to
- Use bright lighting
- Do not move your head while talking
- Speak one phrase at a time
- Place yourself between three and six feet away
- Keep facial hair trimmed away from the lips
- Be aware that sounds such as "th" in "this," "ss" in "hiss" and "sh" in "wish" are difficult to hear

Flying with an Acoustic Neuroma

Everyone has been on a plane and experienced the uncomfortable feeling in the ears as air pressure changes. Acoustic neuroma sufferers say this feeling can be very painful for them.

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What you can do:

- Get a mild decongestant from your doctor and begin taking it at least one day prior to your plane trip. This will help keep the air passages clear and open.
- Practice lowering your jaw and wiggling it from side to side. This will usually open the passages.
- Try yawning or swallowing during the plane's ascent and descent and periodically during the flight. Chewing gum may also help.
- When ears fail to open, try the Valsalva maneuver: close your mouth, pinch your nose and blow gently with your nose, to push air up through the Eustachian tubes and open them. You will probably hear your ear "click." This can be repeated as needed.
- Do not wait until the pain builds up in your ears. Learn to adjust yourself and equalize the pressure between your ears and the cabin several times as the plane takes off or prepares to land.

Improve Your Communication

Patient-doctor communications work better with a little preparation. Before your next appointment, try the following:

- Be patient and be prepared to wait. You want the doctor to talk with you as well as others.
- Prepare a list of what you need to discuss. One for each of you is better.
- Be brief and get to the point. You may need to practice.
- Be clear and assertive. Ask for what you want, don’t expect the doctor to read your mind.
- Be appreciative and say "Thank You."
Cathy, 46, is blessed with a close family. She and her husband Joseph (Jody), along with their daughters (Anna, 21, and Amanda, 24), work in the family landscaping and lawn maintenance business. Cathy and their daughters work in the office. It was the support from family and friends that "really helped" Cathy through surgeries for acoustic neuroma.

"I had a head cold," Cathy recalls. "After a few days of not feeling well, I went to see the doctor, who gave me some medication."

"Then I thought I had an ear infection, so I went to see an otolaryngologist, New Jersey," Cathy says. "He put me on medication, and when I came back for a follow-up, I wasn't any better so he sent me for a CT scan."

"When I came back to see the doctor about the results, he told me I had an acoustic neuroma. I was floored," Cathy states.

"I had no idea - no symptoms, and no headaches," she recalls. "But I took the news about the tumor very well. I wanted to have the tumor gone as soon as possible."

"I didn't know anyone with an acoustic neuroma," she says. "I had no resources, like a support group. I didn't know how to research it."

Cathy’s doctor referred her to an ear, nose and throat doctor, who referred her to a surgeon in August of 1990.

A very large 6 cm acoustic neuroma was removed from the left side of Cathy’s brain on September 5, 1990.

"I trusted the surgeon, he came highly recommended," Cathy says.

Because of its location, they were unable to remove the entire tumor. The residual tumor was 2 cm. "He told me that further surgery to remove the residual tumor was impossible, because the tumor was too close to the brainstem," Cathy recalls. "At this time, I had never heard of stereotactic radiosurgery."

"My facial nerves were cut during the surgery, because the tumor was wrapped around the nerve," Cathy says. "After the surgery my eye was dry and I couldn’t close it, and I had trouble eating and talking. I also had problems with balance. The left side of my face was more or less paralyzed, so I went to physical therapy."

Further surgery was recommended and on December 6, 1990, Cathy had surgery to connect the nerves of her tongue to her facial nerves.

At least six months passed before Cathy noticed facial improvement after the nerve surgery. "Now, I have some feeling in my face," she says. "And I still have a little facial disfiguration, but most people can’t tell."

"My eye is still sensitive," she reports. "The surgeon had recommended that I get a gold weight put in my eyelid, but I decided to wait. It turned out that I didn’t need it, and I can make my eye close without it."

"I have no hearing in my left ear, but my right ear is fine," Cathy says.

"I had been going for various follow-ups and at my one year follow-up he suggested that I have Gamma Knife radiosurgery on the residual tumor, which was still 2 cm," Cathy recalls. "He recommended Dr. Dade Lunsford at the University of Pittsburgh. Jody and I went home to call and set up a meeting with Dr. Lunsford."

In December of 1991, we drove to Pittsburgh to meet with Dr. Lunsford. "He said I was a good candidate [for Gamma Knife radiosurgery]," Cathy recalls.

"I was lucky to have made the decision to go to the doctors that I went to," she says.

Cathy was in attendance when Cardinal John J. O’Connor blessed the Gamma Knife unit at New York University Neurosurgery and Radiation Oncology Center in New York City in 1997. "Rebecca Emerick called from Pittsburgh to meet with Dr. Lunsford. She was released the next day."

"I thought the procedure was wonderful. I had a good experience with Gamma Knife," Cathy says. "I just wished I could have had Gamma Knife initially."

"Six months later an MRI showed no major changes," Cathy recalls. "But then from July of 1993 until 1995, each MRI showed a little shrinkage in the tumor."

"In 1996, Dr. Lunsford said that he was pleased with the tumor response, and that the tumor showed no significant change from the previous MRI [1995] but was smaller than at the time of the Gamma Knife procedure," Cathy states.

Cathy became a member of IRSA as soon as it was founded in early 1996 after hearing about the association from Dr. Lunsford’s office. "It’s nice to have a support group," she says. "I pore through the newsletter when it comes. It makes you feel like there are other people going through what you’re going through."

"My last MRI was in February of 1999," Cathy says. "I received a letter from Dr. Lunsford that said that the tumor was in a dormant state."

"I was lucky to have made the decisions to go to the doctors that I went to," she says.

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What we don’t know

Tinnitus, described as a ringing or buzzing sound in the ear, is a symptom that can be related to almost every known hearing problem. It is unpleasant and often painful.

Presently, tinnitus can be controlled but not cured. It predominantly affects those 40 to 70 years old, with a higher incidence in males (71%). Tinnitus occurs more frequently in the left ear (46% of cases) than the right ear (29%) with the rest occurring in the middle of the head.

Tinnitus usually is described as hissing, ringing, buzzing or roaring. For some, usually older people, tinnitus can take the form of a song or phrase that is endlessly repeated. Tinnitus is often said to be high pitched. In addition, most people suffering from high-pitched tinnitus often have a high-frequency hearing loss.

We know that normal conversation occurs at around 60 decibels. In a sample of over 1,000 tinnitus sufferers, 77% had a loudness match of seven decibels or less. This has made researchers question how such low values could be so intrusive and destructive to someone’s life.

An estimated 50 million people in the USA suffer from tinnitus. If that statistic holds true worldwide, then slightly over one billion people suffer from tinnitus. Of these, 25% or 250 million people worldwide suffer tinnitus so severely that it affects their quality of life by constantly interfering with concentration, recreational activities, and personal relationships. Sometimes, the inner noise is so bad that sufferers commit suicide.

We know very little about why and how the auditory system, under certain circumstances, can produce a sensation that is similar to that of a sound while no external sound is present. In some cases, tinnitus can be caused by obstructions in the ear canal or swelling in the middle or inner ear. However, we do not know how tinnitus is generated, whether it’s generated in the ear, the auditory nervous system or the brain.

We do know that tinnitus in some patients is matched to a pure tone and in others to a noise. Some people who have tinnitus are hypersensitive to sound. Tinnitus will sometimes change when atmospheric pressure changes. Tinnitus does not interfere with a person’s hearing, but it may affect his or her ability to concentrate on what is actually being said.

Some people experience tinnitus constantly; for others, it varies unpredictably. For some, tinnitus decreases or increases during sleep. Tinnitus sufferers perceive where they hear it differently: in their ears, in various locations in the head or outside their body. Scientists and researchers are not sure whether the perceived sound, location and intensity are all indicators of the underlying mechanisms of the disease or not. As far back as 1821, Dr. Itard of Paris recognized the seriousness that tinnitus could impose and stated that as many as 95% of the cases had no underlying cause.

Noise is especially known to have a harmful effect upon hearing and tinnitus. Noise can stress our circulatory, respiratory and digestive systems as well. Continued exposure to noise may cause headaches, fatigue and elevated blood pressure. As a general rule, if the noise around you forces you to raise your voice to make yourself heard by someone standing three feet away, your hearing is at risk.

What we do know

We can trace some causes of tinnitus to damage from excessive noise, acoustic neuromas, diabetes, common drugs like aspirin - some 200 prescription and nonprescription drugs list tinnitus as a side effect - ear wax buildup, sinus infections, allergies, jaw misalignments, cardiovascular disease, undiagnosed thyroid, head and neck trauma, surgical injury and Ménière’s disease. Some people have experienced relief when a blood vessel compressing the hearing nerve was “cushioned” or decompressed as with treating trigeminal neuralgia. For others, tinnitus has resulted from this.

More than 80% of acoustic neuroma patients also have tinnitus. It is believed that the tumor may have compressed and damaged neurons and blood vessels or the tumor caused some chemical to be released that resulted in the tinnitus.

Many people with tinnitus also have hearing loss. Normal hearing may somewhat “mask” the sound of the tinnitus, as many people say their tinnitus is worse as their hearing loss increases. Indeed, when the hearing nerve is severed, patients most often still have tinnitus and may perceive it as having worsened. Researchers have found that when a person dwells on the sound of tinnitus, he or she is more bothered by it and it affects the quality of life. People can be trained to pay attention to other sounds instead of their tinnitus. This may take one or two years.

Treating tinnitus

In most instances, we can’t cure tinnitus, but there are effective treatments, such as masking and drug therapy, that can help. Sufferers should visit a medical doctor to rule out tinnitus caused by medical problems (high blood pressure, thyroid problems, etc.) or medications. Seeing an ear, nose and throat specialist (ENT) or otolaryngologist (an ear specialist) should be the next step. After ruling out pathological and medical reasons, hearing should be checked by an audiologist.

Masking

Masking is simply the addition of an outside sound that serves as a substitute for the tinnitus. Masking is often misunderstood by those who doubt the effectiveness of replacing
one sound with another. However, when
masking is properly arranged, the substitut-
ed sound is aesthetically more acceptable
than the tinnitus. For instance, turning on a
fan at bedtime allows the mind to focus on
the fan’s “white noise” and not on the tinni-
thus, so one has a better night’s sleep.

If you have tinnitus, the faucet test can
help you understand more about your con-
dition. Open a water faucet to full force.
The sound of running water contains many
different tones or frequencies. If it covers
your tinnitus, masking may relieve your
condition. If water sounds do not cover
your tinnitus, your hearing may be reduced
in the tinnitus pitch region. If so, your
hearing loss must be treated before mask-
ing can work.

Wearyr masks, similar to hearing
aids, relieve tinnitus in up to 65% of suffer-
ers. In-the-ear and behind-the-ear units are
available. There are three basic types that
can offer a hearing aid and masker in one
unit, depending on the need. There’s also a
table model unit.

Masking is the preferred treatment for
tinnitus, but it’s not appropriate in all cases.
The only way to determine if masking works
for a person is to try it.

It is interesting that Dr. Itard back in
1821 suggested that his tinnitus patients
stay close to a fire and listen to it. He sug-
gested making the fire with dry wood if the
tinnitus was low-pitched and with green or
moist wood if the tinnitus was high-
pitched. This is similar to the maskers that
hearing specialists utilize today. Dr. Itard
encouraged one patient with severe tinnitus
to live in a water mill so that its constant
sound would mask her tinnitus.

Drug therapy

Another relief procedure involves
drugs such as Xanax, which in a double-
blind, placebo-controlled study brought reli-
ief to 76% of the patients. For the average
tinnitus sufferer at a 7.5 decibel level,
Xanax brought the perceived tinnitus sound
down to 2.3 decibels after treatment.

Xanax is habit-forming and is pre-
scribed on a very minimal schedule.
Xanax is started slowly at bedtime with a
0.5 mg dose for two weeks. After two
weeks, a 0.25 mg dose is added in the
mornings and at noon for another two
weeks. Finally, 0.5 mg is taken morning,
noon and bedtime for four weeks.
Whatever dosage causes the patient to ex-
perience relief is utilized as the mainte-
nance dose. In the study, most patients
found relief taking 0.5 mg morning, noon
and bedtime. When stopping Xanax, it
should be gradually decreased as it was in-
creased.

Patients have also noted improvement
of their tinnitus while on antidepressant
drugs. It is not known whether these drugs
causeds a reduction in the perceived tinnitus
sound or they simply helped the person
deal better with the tinnitus and its effects
on his or her life. Tegretol, an anti-convul-
sive, has also been used to treat severe
cases of tinnitus.

There is some literature supporting
calcium deficiencies as a cause of tinnitus.
The brain’s neurotransmitters need calcium
to function properly. Theoretically, a lack
of calcium could have a potential effect on
tinnitus.

Protecting from future damage

Everyone, especially tinnitus sufferers,
should learn how to protect their hearing
and avoid things that make tinnitus worse.

Wear ear protectors or ear plugs when
around loud equipment, power tools, lawn
mowers or vacuum cleaners. Any noise
above 105 decibels can damage your hear-
ing immediately. Also, remember to pro-
tect yourself and wear ear plugs the next
time you have an MRI.

Avoid excessive use of alcohol and
recreational drugs such as marijuana as
these may make tinnitus worse. Caffeine
- found in coffee, tea, cola and chocolate-
also is known to increase tinnitus. Nicotine
causes vascular effects that are associated
with an increase in tinnitus. Aspirin, quin-
ine, some antibiotics, oral contraceptives
and hundreds of other drugs can cause tinni-
itus or make it worse. Always ask your
doctor if the medicine you are taking is
harmful to your tinnitus. If so, ask if there
is a similar medication that is safer for you.
For a listing of drugs that affect tinnitus,
contact the American Tinnitus Association.

Treating tinnitus in the future

Studies of the brains of tinnitus patients
using MRI have been performed. By de-
tecting subtle increases in blood flow, one
“see” where tinnitus may be experi-
enced by the brain. When a tinnitus patient
reported hearing a ringing in the ears, the
MRI noted an increase in blood flow in the
part of the brain responsible for perceiving
sounds. Experts believe it is only a matter
of time before technology such as the
Gamma Knife will be able to treat tinnitus.
However, there are research limitations,
such as being able to measure the patient
without tinnitus and then with tinnitus in-
duced. (High dosages of aspirin are usually
given to induce tinnitus.) The patient
may be measured with an MRI, but the heat
seeking picture ability of the PET scanner
may offer more potential.

Questions arise when we think of treat-

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Happy and Content

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IRSA to ask if I would come to the Cardinal’s blessing of the Gamma Knife," Cathy recalls. "I was so excited. I spoke at the ceremony."

Cathy and Jody like to travel, and just returned from California. "We did some coastal highway drives while we were there," she says. "And we like cruises. Next we’re going to the western Caribbean."

In addition to their other activities, the couple belongs to the Italian American Association. "We do things like fund-raising, giving away scholarships, promoting Italian heritage, and giving away Thanksgiving baskets," Cathy says.

The Vaccarellas have three dogs. "Bella is a Rottweiler. She’s a big puppy. We keep her at the office," Cathy says. "The girls each have a Lhasa Apso from the same litter. Amanda has Jake, and Anna has Tango."

"We often go into New York City to sightsee or to go to Little Italy," she says. "My daughter and I just went to see Faith Hill and Tim McGraw at Madison Square Garden."

"Both of our daughters are getting married next year, so we’re planning for both weddings right now," Cathy says. "We’re a close family, and we enjoy each other. We’ve been to Hawaii, Jamaica and Cancun with our girls."

"We’re content and happy," Cathy says. "Everything is going well. We’ve raised good daughters and everything is good. You’ve got to be thankful for that."

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Signs of Hearing Loss

Fast Facts

- 1 in 15 people have some degree of hearing loss
- Inability to hear ‘soft’ sounds, like birds singing or footsteps
- People sound as if they’re mumbling
- Thinking people are saying one word, when it is another
- Asking people to repeat themselves
- Missing portions of conversations when there is background noise
- Trouble understanding dialogue at the movies or theater
- Tinnitus or ringing in the ears

Tinnitus Fast Facts

- Appears in more than 80% of acoustic neuroma patients
- Common in 1 out of 5 people
- Is a symptom of Ménière’s disease, an inner ear disorder which involves vertigo
- 75% of those with tinnitus say they are not bothered by it
- Anyone can develop temporary tinnitus from loud noises or medications

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ing tinnitus with instruments such as Gamma Knife. Will the brain decide to compensate and take over for the treated area, producing the tinnitus again? We just don’t know. ☹️

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