# DIAGNOSIS: ACOUSTIC NEUROMA

# WHAT NEXT?

There are several options in the care of patients with acoustic neuroma. Your physician should recommend one or more options based on your age, general health, the tumor's size, location and symptoms including hearing aids, hearing loss and dizziness. Then you and your physician should discuss and decide upon the appropriate management strategy for you.

The purpose of this booklet is to inform and prepare patients for the process of pre-treatment and post-treatment, triumphs and challenges. For a description of various treatment options, see ANA's publication, *Acoustic Neuroma Basic Overview*.

Acoustic tumors are benign tumors arising from the Schwann cells (the insulating cells) of the balance nerve of the inner ear. A more appropriate term is "vestibular schwannoma" because these tumors arise on the vestibular nerve. While such a diagnosis can only be obtained by a tissue sample, a radiological diagnosis by MRI is very accurate.

The goal of any therapy is to minimize side effects and maximize quality of life. Generally speaking the larger the tumor, the more difficult it is to minimize side effects of treatment, although advances in treatment strategies and the presence of centers of excellence have greatly reduced the adverse effects. Generally early treatment may be advisable.

Acoustic neuromas (vestibular schwannomas) usually grow slowly. The average growth rate is about 2mm per year. Typically, they affect hearing and create a sensation of tinnitus (a noise produced in the inner ear, such as ringing, buzzing, roaring, clicking, etc.). With advances in MRI imaging, smaller tumors are being identified. This provides greater options for patients.

#### OBSERVATION

# NON-OPERATIVE TREATMENT – WATCH & WAIT / WATCH & SCAN

If the person chooses the observation / watch and wait approach for a small tumor, periodic imaging is advisable. Following initial diagnosis, a reasonable plan would be to get a new MRI scan in six months. If there is no growth, wait one year, and repeat the scan yearly for five years. Be sure to inform your physician of any changes that may occur such as worsening of hearing, imbalance, or facial numbness. These changes could indicate that the tumor is growing more rapidly. By waiting, there is a slight risk you could lose part or all of your hearing in the involved ear.

If significant growth does occur during the observation period, treatment is indicated and you and your physician may decide to choose between one of two therapies: radiation treatment (for control) or microsurgical removal.

#### RADIATION TREATMENT FOR ACOUSTIC NEUROMA

The goal of <u>radiation treatment</u> for acoustic neuroma is to stop or control tumor growth. It does not remove the tumor. Radiation is used to treat small and medium-sized acoustic neuromas (<2.5 - 3 cm). Using controlled high-energy rays, radiation works by damaging the DNA inside cells and

making them unable to divide and reproduce and by reducing blood supply or nutrients to the tumor. The benefits of radiation are not immediate but occur over time. Gradually, the tumor may stop growing and in some cases may shrink in size.

Stereotactic radiation therapy, referred to as "radiosurgery" (typically performed in a single session) or "radiotherapy" (typically delivered over an extended period of time in multiple doses of radiation) is a technique based on the principle that radiation delivered precisely to the tumor will arrest its growth while minimizing injury to surrounding nerves and brain tissue. This noninvasive procedure can be performed in general on an outpatient basis.

There are several different ways to deliver the radiation required for effective treatment of an acoustic neuroma. Gamma Knife, LINAC, Novalis, XKnife, CyberKnife are all names of specific machines that deliver radiation. In each case, the beam that radiates the tumor consists of highly charged photons; the differences lie in the way they produce the photons as well as the technology they use to focus the beam(s) to the area of interest. Proton Beam is a different form of radiation therapy. Although proton beam centers are few around the US, there are certain instances when proton radiation has benefits over photon radiation. You should discuss this with your physician.

# QUESTIONS FOR THE RADIATION MEDICAL PROFESSIONALS

If you have opted for radiation treatment of your tumor, you may want to ask some of the following questions of your radiation therapist, nurse, neurosurgeon, neurotologist, radiation physicist, radiation oncologist or neuroradiologist:

- □ Howlong have you been performing radiation treatment of acoustic neuromas? Have any problems emerged in any of your patients?
- Have you been certified to do radiation for patients with acoustic neuroma?
- Will this be a one-dose procedure radiosurgery, or will it consist of several smaller doses radiotherapy?
- What type of radiation treatment (e.g., Gamma Knife, LINAC, CyberKnife, Novalis FSR,proton beam, etc.) do you most commonly perform? What are the advantages of this type ofradiation over the others that are available?
- Why do you recommend this particular form of radiation treatment over others?
- Do you expect hearing, balance or ringing in the ear could be altered by radiation treatment?
- Do you anticipate that the tumor will swell after treatment? For how long?
- What are the long-term side effects of this treatment? Say 10 years or more? How will I know if something is changing?
- Are physicists involved in the planning of your radiation treatment?

- What symptoms are commonly experienced by your patients after treatment? How do you define "side effects"?
- What are the more serious complications such as malignancy, hydrocephalus and others that can happen with treatment and the relative frequency?
- How many of your patients have experienced continued growth of their tumors following treatment? How many of yourpatients have you followed long-term to draw your conclusion? If this happens to me, what would be my best follow-up procedure, can I have microsurgery?
- After radiation treatment, may I go about my business as before treatment, or are there any special precautions I should take?
- When and how often should I schedule follow-up MRIs after treatment? Will I get these MRIs for the rest of my life?
- Why would you choose radiation for me?

# A TYPICAL RADIATION TREATMENT

Although the details of radiation treatment techniques differ somewhat from system to system, the basic idea is quite similar everywhere. Below is a detailed description of a typical single-dose radiosurgical treatment at a large medical center using the LINAC (linear accelerator) device.

Almost all radiosurgical procedures in adults are performed on an outpatient basis. You will report to the Radiotherapy Suite the day before treatment for a detailed medical history interview and physical, as well as an in-depth review of the treatment options. If radiation treatment is deemed appropriate, you will be sent to the Radiology Department for a special MRI scan. You will arrive for treatment early the next morning. A stereotactic head ring will be applied with four small pins under local anesthesia. No hair shaving or skin preparation is required. Alternatively, some centers use a stereotactic face mask instead of a head ring with pins. A stereotactic mask is made of thermoplastic mesh and custom-fit to the contours of your face. The front and back pieces of mesh are secured to a U-shaped frame that attaches to the treatment table to hold the head still.

Once the head ring / face mask is securely placed, a CT scan is performed. Images are made of the inside of the entire head at one-millimeter intervals. You will then be transported to an outpatient waiting area where you and your family may relax until the treatment planning process is complete.

The CT scan and the MRI scan are transferred to the treatment planning computer where they are quickly processed so that each image has a front to back, side to side and vertical stereotactic coordinate (representing the exact location of any point in the patient's head as it appears on the computer screen) relative to the head ring. The head ring allows the exact mapping of any point on the CT scan to its corresponding location within the head. This enables the radiation oncologist to design complex treatment plans in "virtual reality" on the planning computer, which can then be delivered accurately to the real target within the head. Using image fusion software, the non-stereotactic MRI is matched up with the stereotactic CT, so that either image can be used for

planning. Dose planning then begins and continues until the neurosurgeon or neurotologist and radiation oncologist are satisfied that an optimal plan has been developed. A variety of options are available for choosing the best dose. The fundamental goal is to deliver a radiation field that precisely conforms to the tumor shape, while delivering a minimal dose of radiation to the surrounding brain.

Once dose planning is complete, a special radiosurgical device is attached to the LINAC. You will be attached to this device using the previously applied head ring or face mask, and the treatment will be delivered. The head ring / face mask is then removed. After a short observation period, you will be discharged. Radiosurgical procedures do not usually require a hospital stay, and most patients are able to return to work within a day or two following treatment. Typical follow-up for acoustic neuroma patients consists of MRI scans on an annual basis.

Complications after radiation may include headaches, balance disturbance, hearing loss, or facial weakness. Because radiation can take up to 18 to 24 months to have its full effect, these symptoms may develop over the course of several months after radiation treatment. You should report any problems you are having to your physician so that any appropriate treatment may be given. For additional information regarding radiation treatment, please refer to the ANA patient information booklet, *Acoustic Neuroma Basic Overview*.

# MICROSURGICAL REMOVAL OF ACOUSTIC NEUROMA

Surgical removal is the most common treatment for acoustic neuromas. Priorities in surgery are: first, the maintenance of facial nerve function; second, the preservation of socially useful hearing in the affected ear; and third, complete tumor removal. Total tumor removal carries a higher risk of hearing and facial nerve problems. During tumor removal, a probe is used to stimulate and monitor the facial and in some cases auditory nerves. Because acoustic tumors grow slowly, new research supports partial or near-total removal, whereby small remnants of tumor capsule are left attached to critical nerves. Partial removal techniques have higher rates of facial functional preservation; however, the long-term results of these techniques are still being investigated. Most studies show that near total removal, leaving less than 5mm, results in excellent long term outcomes (reoccurrence <3%) and facial nerve function. If the tumor remnant grows, radiation may be used.

For additional information regarding microsurgical treatment, please refer to the ANA patient information booklet, *Acoustic Neuroma Basic Overview*.

# QUESTIONS FOR THE ACOUSTIC NEUROMA SURGEONS

If you have decided to have your acoustic neuroma surgically removed, you may wish to ask some of the following questions of your surgeon:

- □ How many acoustic tumors have you removed this month/this year and/or what specific training in acoustic tumor surgery have you had?
- What is your total experience in operative cases of acoustic neuroma tumors over what period of time?

- What microsurgical approach do you recommend for my tumor size, location, age, health and level of hearing? What approach do you routinely perform?
- Do you feel that the facial nerve results or the hearing results are more important in the long-term outcome? How do you achieve their preservation and what are your success rates?
- Do you electrically monitor the facial nerve during surgery?
- Do you use the newer technique to preserve the facial nerve? In your experience, when leaving in small pieces of residual tumor on the brainstem or facial nerve, does tumor growth usually stop?
- For a tumor the size of mine, what have been your results with respect to facial nerve function, both temporary and permanent?
- What is the likelihood that my remaining hearing will be preserved after this surgery?
- Do you anticipate total tumor removal with a single operation? If not, what are my follow-up options? Surgery? Radiation?
- Will this surgery be done by a team of physicians with more than one specialty?
- What has been your rate of surgical complication with respect to stroke, infection, bleeding, cerebral spinal fluid (CSF) leak and headache?
- When and how often should I schedule follow-up MRIs after treatment? Will I get these MRIs for up to 10 years?
- Does your hospital have a neurological intensive care unit?
- About how many days will I be in the hospital?
- What follow-up care will I need?
- How much discomfort should I expect from headaches and from the incision after this surgery?
- What do you do to minimize post-surgery headaches? NOTE: If you have a history of headaches, discuss this with your physician.
- Did you feel comfortable with the surgeon, the information shared, access to a nonbiased sample of his/her previous patients?
- All other things being equal, when can the surgery be scheduled?

NOTE: It is your right to get more than one opinion. Since acoustic neuromas are benign and slow growing (usually developing over several years), surgery should not be considered an emergency in most cases. Be cautious of anyone who tries to convince you to rush into surgery before you have taken the time to make an informed decision.

# **OUTPATIENT ADMISSION**

In the past few years, there have been considerable changes in admission procedures for patients prior to surgery. In many areas of the country, patients are not automatically admitted the night before surgery.

With the advent of insurance changes, prior authorization, and new hospital procedures, it is now possible, in some instances, to avoid the overnight hospital stay before surgery. If your medical health is good, you may be asked to schedule a pre-surgery testing time with the hospital where your surgery will be performed. This appointment will be used to do all lab work, chest x-rays and EKGs, and will be scheduled close to the date of surgery. You may also visit with an anesthesiologist before surgery. Your primary care physician may be able to perform some of your tests.

If you are scheduled to enter the hospital through outpatient admission, you will not come to the hospital to be admitted until the morning of surgery. You will be instructed to have nothing to eat or drink after midnight the night before surgery. You will be required to arrive very early in the morning, usually two hours before the scheduled surgery time.

Whether or not you enter the hospital the night before or the morning of the surgery is a decision that should be made at your doctor's discretion. He or she will base this decision on your past medical and surgical history.

Be sure to discuss your routine home medications with your doctor, especially if you are diabetic, asthmatic, hypertensive, or have any other significant medical illnesses. Take a list of all routine medications with you to the hospital. Don't forget to include pain medication and over-the-counter drugs, such as antacids, vitamins and aspirin.

# HOSPITAL ADMISSION AND PREOPERATTVE CARE

If you are scheduled to arrive the day before surgery, you will check in at the admissions office. Make a list of medications and past surgeries ahead of time, and remember to bring your insurance card with you. All personal and insurance information will be obtained at this time. When you arrive at your assigned floor, a nurse will take your medical and surgical history. For your first night in the hospital, take as few personal possessions as possible. Since you will go to the intensive care unit after surgery, your family will have to remove your belongings from your hospital room when you are taken to surgery. Your family can bring your personal items to the hospital after you have returned to your regular hospital admission room.

Several professionals from the hospital will visit you, each from a different department. You will have some laboratory work done, which may include a complete blood count, urinalysis, blood-clotting studies and blood typing. It is very rare for an acoustic neuroma patient to need a blood transfusion during surgery, but blood should be available if it is needed. Some institutions have self-donor and directive blood programs through which you or your family may give blood in advance for your use if it is needed. Ask your surgeon or nurse whether this type of arrangement is available.

Do not take aspirin products before surgery because they may thin the blood and reduce the normal clotting ability, thereby causing excessive blood loss during surgery.

The radiology department will take a chest x-ray. Most patients will have already had a CT (computerized tomography) scan or MRI (magnetic resonance imaging) before admission to the hospital. It is essential to have your X-rays available to the doctor on the day of the surgery. Do not forget to bring them with you.

An electrocardiogram will also be done preoperatively. If you have any significant medical problems, an internist may become involved in your preoperative care, and additional tests may be ordered.

There is a slight risk of reaction to anesthetics. Your anesthesiologist will discuss this with you before surgery.

You will have a pre-surgical discussion with the surgeon and/or nurse, which may include comments about just how much hair will be shaved from your scalp in the area where the incision is to be made. Almost all incisions used in this kind of surgery can easily be concealed especially in patients with long hair and there is an increasing number of surgeries performed with no hair shaving at all. Most men and women want only as much hair removed as necessary. Some women later decide to have the entire head shaved so that they can wear a wig.

Before your surgery, your tumor ear may be temporarily "painted" with a dye to ensure that the correct ear is identified for surgery. In the operating room, the CT scan or MRI, the auditory brainstem response, and the "painted ear" all must agree on which side the tumor is located. The nurses will check preoperatively for the "painted" ear. When you are prepared for surgery, the operating room staff will be able to see your "painted" ear.

Medications given before surgery vary if you enter the hospital the night before. A sleeping pill will be prescribed if needed the night before surgery. This medication may not automatically be brought to you, but if you feel you need it, ask for it. A prescription is also usually provided if needed for pain.

# THE MORNING OF SURGERY

The morning of surgery can be an anxious time for you and your family. If you have not stayed in the hospital the night prior to surgery, you will probably be required to arrive at the hospital at least two hours prior to the scheduled start time of the surgery for lab work to be completed. Most patients receive an injection before going to surgery. The medication in this injection will calm you, but will not put you to sleep. You will feel relaxed, but you will be fully aware of your surroundings, and you will be able to talk with your family and the nursing staff. Some people are more sensitive to medication than others, so the degree of relaxation varies.

In the operating room, an IV (intravenous line), a blood pressure monitor, a catheter and other devices may be put in place, usually after you are asleep. This procedure may be done in your hospital room to save time in surgery and to provide more privacy for you.

If family members wish to see you before you go to the operating room, they should be at the hospital two hours prior to the scheduled start time for surgery. In most hospitals, the family will be allowed to accompany you to the operating room area. One family member may then go with you to the holding area, which is directly outside the operating room. Here, several last minute checks will be done by nurses before you go into surgery.

You will be taken on a stretcher (a rolling cart) to a preoperative waiting area or directly to the operating room. Upon entering the operating room, you will be awake and aware of much activity. Usually, there will be the anesthesiologist, your surgeons, the primary nurse and the audiologist who are present to monitor the 7th and 8th cranial nerves and often, two or three other nurses. Do not be alarmed by all this activity. Be assured that everyone is working together to take care of you in the best possible way.

After you are moved onto the operating room bed, a strap will be buckled around you. It is simply a seat belt for the bed. The anesthesiologist will start your IV, putting you into a deep sleep. After you are asleep, a portion of your head will be shaved if this has not already been done before you entered the operating room. The shaved area will then be thoroughly scrubbed with antiseptic solution to reduce the risk of infection.

The length of the surgery is determined by the size of the tumor and the ease with which it can be removed from all of the vital adjacent structures. During surgery everything will be monitored continuously; your breathing, heart rate, blood pressure, urine output, facial nerve and acoustic nerve functioning if needed, and other functions as well. One person is in charge of monitoring at all times. Even the slightest change in your body function can be detected and the surgeon will be informed if any problem arises.

A nasal gastric tube may be inserted through your nose down into your stomach. This procedure is done so that if you experience any nausea and vomiting postoperatively, you can be taken care of without any complications. The tube will probably be removed as soon as you are fully awake. You will begin waking up in the recovery room. You will be in the intensive care unit before you become fully alert.

# NOTES FOR FAMILY MEMBERS

Even though you probably last saw the patient several hours ago, the surgery may not have started until an hour later than that due to the many necessary preparations—and may take many hours. The family has the toughest job during major surgery. A waiting room can be a very lonely place during this time.

Don't forget that you need to take care of yourself, too. Make yourself as comfortable as possible while you wait. Bring a picnic lunch, a cooler with your favorite beverages and your own personal necessities if you will be there for any extended period of time. Don't forget something to read, maybe a pillow and since hospitals sometimes can be cool in the summer time, a sweater may be a good idea. The better you take care of yourself, the better you can take care of your family member having treatment.

As surgery progresses, reports are usually sent out to family members every few hours. When the surgeon has removed the tumor and starts to close the incision, the family is customarily notified.

### **INTENSIVE CARE UNIT**

When you wake up in the intensive care unit, you will have an IV in your arm, a catheter in your bladder, a blood pressure monitor on your arm, maybe an arterial line in the wrist, a nasal gastric tube if needed and a large head dressing. You will also be attached to various monitors.

You will be in a room close to the nurses' station so that you can be watched carefully and all functions can be monitored. Do not be alarmed. This equipment is routine in the intensive care unit and is there to help you recover as quickly as possible. The main reason for intensive care is for careful monitoring. Patients often complain that they cannot get any rest because they are so closely monitored, but this care is what your surgeon intends. You will probably be there for twenty-four to forty-eight hours.

### DAY AFTER SURGERY

Patients who have had small to medium-sized tumors removed will probably be asked to sit up on the side of the bed the first morning following surgery. It is normal to have some level of nausea following surgery. Depending on your degree of alertness, you may go to a regular hospital room or you may remain in intensive care for another night. If you stay in the intensive care unit, you will continue to be monitored very closely. Occasionally acoustic neuroma patients have CT scans or MRIs the day after surgery.

While you are in the intensive care unit, your family may visit for very brief periods, and the number of visitors is usually limited. When your family first sees you, they will notice some changes. Even when surgery goes quite well, patients often appear pale and are attached to many monitors. Everyone needs to remember that all of the equipment, tubes, dressings and other devices have a specific purpose in the overall care of the patient. Slowly but surely these devices will be removed.

# IN YOUR HOSPITAL ROOM

Your work begins when you return to a regular hospital room!

At this point, you should be free of most devices except your IV and possibly the catheter. Catheters are usually discontinued when patients can sit up alone and begin to move about the room. The IV will be removed after your nausea subsides and you start drinking fluids. While in intensive care you will be given ice chips. You will then progress slowly from a liquid diet to a regular diet.

Headaches may occur for a short time due to the incision and/or spinal fluid after surgery. Pain medication will be provided to relieve your discomfort. Remember, pain medication may cause constipation.

You may have experienced some physical changes, which are more than temporary because of the tumor's involvement with surrounding tissue and the necessary manipulation or cutting of this tissue in tumor removal. Your surgeon places a high priority on the preservation of the facial nerve. Priorities in surgery are: first, the maintenance of facial nerve function; second, the preservation of socially useful hearing in the affected ear; and third, complete tumor removal. The facial nerve (the 7th cranial nerve), controls muscles in the forehead, eyelid, cheek and mouth. With these muscles, you close your eyelid, smile, and purse or pucker your lips.

Due to the tumor's close proximity to the facial nerve, some patients experience facial paralysis following surgery. This paralysis may be temporary, but there are cases, usually in larger tumors, when the facial nerve has to be severed in order to remove the tumor. If this happens, the nerve will probably be sewn back together, and return of facial nerve function will take longer than when the nerve is not cut. If you have facial weakness, ask your surgeon how involved the facial nerve was with the tumor.

In the event of loss of facial nerve function, precautions with your eye should be taken. If you have a facial weakness, it may mean you will not be able to blink or close your eye. Therefore, it is very important that the eye be artificially protected from drying out. Should the eye become too dry, corneal abrasion and vision problems may result. You may want to inquire about the need for a nerve graft, or the possibility of surgery to reanimate the face. More information on facial issues is available in ANA's publication, *Facial Nerve and Acoustic Neuroma, Possible Damage and Rehabilitation*.

Eye drops, such as artificial tears, are prescribed if your eye is not producing natural tears. At night, an ointment will be applied in the affected eye and a plastic eye bubble placed over the eye. This precaution creates a moisture chamber to protect the eye while you sleep, which should also be used as needed during the day.

If your eye gets red or starts to hurt, it is not being moisturized adequately. If you do NOT have sensation in the eye, it is even more important that your eye be closely supervised. If you have eye care while hospitalized, you will need to continue self-care for a period afterward. It is important that you follow any specific instructions about eye care from your surgeon or nurse. They may, for example, ask you to avoid rubbing your eyes, so that the eye will not become further irritated. More information on eye care is available in ANA's publication, *Eye Care After Acoustic Neuroma Surgery*.

Eating and drinking may present problems. Most patients find that, for a while, it is advantageous to use a straw for beverages. Since the facial muscles are used to chew, you will need to eat slowly. You will not be able to move food around in your mouth as easily as before. If swallowing becomes a problem, a speech pathologist, nurse, or occupational therapist may do a swallowing test or give you exercises to help move food down your throat.

After eating, brush your teeth well on both sides. Food tends to collect on the paralyzed side, and if you do not brush or at least rinse your mouth well, you may develop new cavities.

Get up and sit in a chair as soon as your surgeon permits. Have your family member bring warm, non-slip socks for you to use once you are out of the bed—hospital floors can be cold. This movement will seem difficult at first, but the more you do it, the easier it becomes. At first, get up two to three times a day. Gradually increase the amount of time you stay out of bed each day.

As you get stronger, you will want to go to the bathroom and start participating in your own care. The first time you try walking, have someone with you just in case you experience any balance problems. Do a little more each day until you can walk the hospital halls unassisted. Most patients are allowed to go home when they can walk the halls unaided and take care of their personal needs.

Neither the doctor nor the nurses can make you get out of bed. You will have to motivate yourself. Most patients decide preoperatively that they will be out of the hospital in a week to ten days, and they succeed—barring complications. A positive mental attitude plays an important role in a speedy return home.

Depending on your surgical approach, you may have a head dressing for about a week following surgery. There will be staples and/or stitches in your incision line which may be removed before you go home, or you may be asked to return to your doctor's office for their removal. If you go home with the stitches in place, keep that area clean. It is a good idea to keep the incision areas moist with an antibiotic ointment, which can be purchased without a prescription from your pharmacy. Ask your surgeon whether you may take a shower or even get the incision wet after you leave the hospital.

If you have an abdominal incision after a translabyrinthine approach, this incision may contain a small tube, which will be removed a couple of days after surgery along with the dressing. The care following removal of the tube is the same for the abdominal incision as for the head incision. The purpose of the abdominal incision is to obtain a small amount of fat to be used for packing the surgical area when the translabyrinthine approach is used.

CSF (cerebrospinal fluid) leaks happen occasionally. They can occur either through the nose or from the incision. Such leaks appear as clear watery discharge. Any leak should be reported to your doctor as soon as you notice it. You may notice this leak as a salty taste in your mouth or a dripping feeling from your nose or incision. If such a leak occurs after you leave the hospital, call your surgeon right away. If left untreated, an infection which could lead to meningitis may follow.

If a leak occurs from the incision, another dressing may be used to create more pressure on the wound. In a few instances, a spinal tap may be done to ascertain whether or not an increase in CSF pressure is causing the leak.

If the translabyrinthine approach was used, the eustachian tube (a canal between the back of the throat and the middle ear) is filled with tissue to prevent a CSF leak. Patients who have had this approach should not blow their nose after surgery until the surgeon gives approval. If you sneeze, it should be done with the mouth open. This extra precaution will ensure that the packing placed in the eustachian tube will create a good seal, prevent a leak through the nose, and will not be dislodged by the force of the sneeze.

Most patients experience some problems with balance after surgery. Since the balance system may have been destroyed on the side of the tumor, it is important that you stimulate your functional side to take over. The best way to accomplish this is by activity. Start walking as soon as you can after surgery. Walking may be difficult at first, but it is like exercising a sore muscle - the more you use it, the better it gets. You may also wish to contact ANA for a copy of their publication entitled *Improving Balance Associated with Acoustic Neuroma*.

A rare complication which your surgeon or nurse should have discussed with you preoperatively is the possibility of a stroke due to damage to major blood vessels in the brain. Remember, you are having brain surgery, not ear surgery. Fortunately, with microsurgical techniques, a stroke is quite rare. Your surgeon works carefully to preserve all the major blood vessels encountered during removal of the tumor. While you are recuperating in the hospital, report any significant changes in your thought processes or neurological functioning to your doctor or nurse.

Educating yourself about any potential changes which you should report and discussing them fully with your professional team will help you toward a speedy recovery.

### **GOING HOME**

Upon leaving the hospital, you may have prescriptions to be filled and an appointment made for a return checkup. Many patients are seen one to two weeks following surgery to remove any remaining stitches, and monthly thereafter for two to three months. Gradually, the frequency of visits is reduced. Be sure you understand fully all instructions given to you, especially about eye care and facial exercises, if necessary. Ask your doctor or nurse if you have questions.

At home, you may feel well for a few days and later become depressed or tired. Many patients have experienced this change. If it becomes a chronic problem, let your doctor know. There are several medications which can help.

Postoperative headaches can be a problem for patients who have undergone intracranial surgery. There are several different medications and other therapies which can be used for treatment. While most headaches diminish after six months, in some cases treatment must continue for a longer period. More information on headaches is available in ANA's publication, *Headache Associated with Acoustic Neuroma Treatment*.

Gradually work into your previous routine, but try not to overtire yourself. It is a good idea to have someone stay with you for a few days to help with meals and other household chores. As you feel stronger, gradually take on more activities.

A walking program is an excellent way to regain your strength and does wonders to help the balance system retrain itself. Start by walking about half a block with someone else. When you can walk that distance easily, gradually increase the length of your walk to at least one-mile daily.

Many people ask when they may resume driving their car. Resumption of this activity is hard to predict. Usually a patient will know when driving feels safe. One recommendation is that when they are able to turn their head quickly without becoming disoriented, it is safe for them to drive. This usually occurs two to four weeks after surgery.

For patients who have lost hearing in the affected ear, there are special hearing devices that create the sensation of hearing in your non-hearing ear. If you are interested, talk to your surgeon or audiologist about a trial period with one of these devices. More information on hearing devices is available in ANA's publication *Hearing Loss Rehabilitation for Acoustic Neuroma Patients*.

Much of the recovery phase is up to you. Most patients do return to whatever work and personal activities they did before surgery. This effort takes determination, time and patience. Contact your health care professional during all phases of your treatment and recovery as needed. You also may get in touch with the patient-founded Acoustic Neuroma Association for literature, support and information regarding an active ANA support group or other patients in your area.

#### THE MORE INFORMED THE PATIENT, THE EASIER THE RECOVERY PERIOD

Patients who begin treatment with a positive mental attitude and who maintain that attitude throughout the recovery period seem to have an easier and more complete recovery. If possible, talk with a former patient about his or her experiences. Often it is helpful to hear how others have coped with having had an acoustic neuroma. Contact the ANA national office for the "Willing to Talk" list which consists of ANA members who are AN patients. They have agreed to share their contact information and acoustic neuroma experience with acoustic neuroma patients.

There are active local acoustic neuroma support groups in many states across the United States. For more information about the group nearest you, contact the national office of the Acoustic Neuroma Association.

#### WHAT IS THE ACOUSTIC NEUROMA ASSOCIATION (ANA)?

Acoustic Neuroma Association was founded in Carlisle, Pennsylvania, in 1981 by a recovered patient, Virginia Fickel Ehr. She found no patient information or patient support available when she had surgery for the removal of an acoustic neuroma in 1977. She resolved that future acoustic neuroma patients should have easy-to-read medical material about their condition, and support and comfort from each other. With the help of her physician, she contacted eight other patients and formed the organization.

The association is incorporated and is a 501(c)(3) non-profit organization. The patient-focused, member organization now serves close to 5,000 members, is governed by an all-patient Board of Directors and is operated by a small staff in metropolitan Atlanta, GA.

ANA membership benefits include receipt of a quarterly newsletter, patient information booklets, access to a network of local support groups, access to a list of acoustic neuroma patients willing to talk about their experience throughout the country, our website Member Section and an invitation to a biennial symposium on acoustic neuroma. Our exclusive website Member Section includes published medical journal articles on acoustic neuroma and all of our patient information booklets and newsletters and many symposium presentations. ANA also maintains an interactive website at www.ANAUSA.org with an ANA Discussion Forum.

ANA is patient-founded, patient-focused and patient-funded. ANA recommends treatment from a medical team with substantial acoustic neuroma experience. Although the association cannot recommend specific doctors, medical centers or medical procedures, guidelines for selecting a qualified medical professional can be found at the ANA website, www.ANAUSA.org. Now available on our website is a listing of medical resources. The physicians and organizations listed have self-reported data to meet criteria established by ANA for having substantial experience in treating acoustic neuromas. The listings should NOT in any way be construed as an endorsement or recommendation by ANA. It is every individual's responsibility to verify the qualifications, education and experience of any healthcare professional.

#### ANA PUBLICATIONS

You may want to order other ANA publications. Address your request to the following:

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#### Cumming, GA 30041

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**NOTE:** ANA Members can view patient information booklets and newsletters online on our website at <u>www.ANAUSA</u>.org in our Member Section.

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