

Employment Considerations for Acoustic Neuroma Patients



ACOUSTICNEUROMA
ASSOCIATION

Forward

The Acoustic Neuroma Association is the premier resource for AN patients, and we're committed to improving the lives of acoustic neuroma patients and their families through communication and support.

We've created this employment reference guide as a starting point for you. The information you'll find comes from patients, volunteers, and caregivers - a reflection of the supportive nature of both the Acoustic Neuroma Association and the AN community.

Each AN journey is unique, and employment situations can certainly be distinctive. We encourage you to use this resource to consider a variety of situations, questions, and options. Please remember that this brochure is not meant to be comprehensive, nor should it be considered legal advice.

For 40+ years, the ANA has been a patient-first organization. We're available to provide a variety of resources, as well as answer any questions you may have. You can connect back to us at anausa.org, or give us a call at 770-205-8211.

A handwritten signature in black ink, appearing to read "Jim Shea". The signature is fluid and cursive, with the first name "Jim" being more prominent than the last name "Shea".

Jim Shea
Chief Executive Officer

At Diagnosis

- I've just been diagnosed with an Acoustic Neuroma (AN) sometimes called a vestibular schwannoma. How will this affect my job? Who do I need to inform and how much should I disclose?
 - Determining what to share and with whom should be considered carefully, and will vary depending on what you and your medical provider determine to be the best course of action to manage and/or treat your AN. It will also depend on your job function and responsibilities at your place of employment.
 - Thoughtfully consider how and when to have these conversations. For example, if you and your provider decide the "[Watch and Wait](#)" approach is best for you, you may find there is no need to discuss your diagnosis with anyone at work, especially if you are symptom free.
 - Consider reviewing your healthcare/benefits plan annually.
 - Check deductibles, out-of-pocket expenses, available providers (in/out of network), Flexible Spending Account (FSA), Health Savings Account (HSA) if applicable, etc.
 - If you are able to travel for your treatment, will your insurance cover your treatment out of state?
 - Does your company offer an EAP (Employee Assistance Program) or similar service for initial support or recommendations for legal, mental health, etc. resources?
 - Your Human Resources (HR) department can help you understand what time off allowances are available to you. You may receive the following:
 - Paid Time Off (PTO)
 - Sick Days
 - Vacation
 - Short-term Disability (STD)
 - Long-term Disability (LTD)
 - Leave of Absence (LoA)
- My AN treatment has been scheduled. What should I consider next?
 - How much time will I need to take off for my AN?
 - Each treatment option will impact your ability to work and when differently. Speak with your medical provider about your specific role and responsibilities to get additional insight that will guide your time off decisions.
 - Ask your provider if there is a patient navigator on staff with whom you can consult. If so, their help can be invaluable in assisting you with returning to your normal work routine.
 - You'll want to evaluate any potential financial impacts of your time off, e.g. out-of-pocket medical and prescription (Rx) expenses and potential reduction in or loss of income.
 - It's important to discuss with your provider if your treatment choice will impact your professional capabilities and how. Depending on what you do, there may be minor accommodations necessary to return to work. Depending on treatment, some patients have experienced lower stamina for a period of time post-treatment, potentially affecting their ability to work long hours. Consider discussing this with your employer to review any specific plans for your return to work.

- My AN treatment is next week. What should be on my to-do list for work?
 - Confirm your projects and work responsibilities are in order.
 - Confirm any out-of-office notifications and chain of custody/responsibilities are set and communicated.
 - Confirm your time off (PTO, short-term disability, etc. as needed) has been properly scheduled and approved.
 - Consider providing updated personal contact information (during recovery/post-op and/or if traveling if you don't expect to be focused on screens). Some patients have found it helpful to identify a point of contact ahead of a particular treatment or procedure and/or during the initial recovery phase. This proxy could help relay important information back and forth with specific people so that the patient can remain focused on recovery.
 - Document all of your usernames/passwords so that you remember them upon your return to work.
 - Work with your HR and IT teams (where applicable) to let them know that you'll be away from your computer/systems access for a certain amount of time and to understand if there are any system/organizational changes that will be happening during that time (new tool rollout, new time reporting systems, etc.) to ensure that you will have access to training and support upon return.
 - Potentially consider if they are able to preemptively update your systems and tools while you are available to get ahead of any known security updates or forced password expirations, etc. so that you are less at risk of being locked out upon return.
 - Confirm with your company that any important meetings or educational/informational sessions will be recorded and collected for you so that you can review once you are back or potentially as part of your return process.

During Treatment

- It's important to focus on your health and healing as much as possible and follow the recommendations and treatment plan as established with your medical provider.
- If you have decided to take FMLA-approved leave ([Family and Medical Leave Act](#)), your employer should not contact you regarding any work related issues while you are out.
- Many patients agree, in the first few weeks after treatment, reducing or eliminating as much screen time as possible can help considerably to prevent headaches, nausea, dizziness, etc.

After Treatment

- Follow the medical recommendations as outlined by your provider.
- Many patients have found working with a physical, occupational, and/or [vestibular therapist](#) to be beneficial. Consider discussing your specific needs with your employer to communicate and coordinate any support you might need and align on any impact to your expected work routine.
- Review your current work setup to ensure it matches your needs.
- Evaluating when to return to work will depend on a range of considerations. Consider sharing the impacts of your AN with your co-workers, business relationships, and managers. Some side-effects have included, but are not limited to, the following:
 - Fatigue
 - Headaches

- Hearing Loss or Single-Sided Deafness (SSD)
- Facial Paralysis/Weakness
- Dry Eyes/Eye Weight and future surgeries
- Mental/Emotional Fatigue
- Stress or Anxiety
- Balance
- Mood
- Sensitivity to light/sound/stimulus
- Difficulty locating origin or direction of sound.
- Keep in mind, what you experience in the first three months after treatment will likely change in the next year.
- Evaluate the long-term impacts of the AN side effects on your career. Consider the following questions:
 - Are you still able to meet the demands?
 - Are you experiencing any dips in performance?
 - Are there any role changes or professional duties that have been changed?
 - Were you part of that discussion?
 - Do you feel supported or discriminated against?
 - If you find yourself without the feeling of support professionally, or the target of discrimination, we encourage you to speak with your HR department, seek professional legal counsel, and/or union representation where applicable.
 - How have your side-effects changed your professional relationships?
 - How can I help my co-workers understand?
 - Consider getting support from your HR department.
- Many patients have found the desire to reflect on their happiness and satisfaction with their current profession to accommodate any changes to their new lifestyle. As with any major event in your life, consider carefully before making any significant decisions too soon after treatment.
- How might I prepare for any lasting impacts as a result or side effect of my AN or treatment?
 - If your hearing, balance, or facial nerve function has been disrupted due to your AN or related treatment, there may be special accommodations needed for you to perform your best at work. Open communication with your supervisor and HR Department is usually the best way to go.
 - Coping with hearing loss, facial paralysis, and/or loss of balance is difficult and potentially overwhelming emotionally, physically, and from a sensory standpoint as well. Loss of orientation/sound origination difficulty is common.
- Many patients have found asking for these potential solutions can help significantly. Consider speaking with your manager about any [accommodations](#) you believe would be helpful to your situation such as the following:
 - Quieter work space
 - Optimized desk set up for single- sided deafness (i.e. Not having a co-worker on deaf side, phone on the optimal side of the desk).
 - Asking for different seating during meetings or perhaps use of closed captioning during video conferences can be helpful to those with hearing loss or SSD.
 - Other auditory supports (headsets/mono-speakers, etc.)

- Temporary or permanent schedule adjustments (to support treatment/therapy needs or impact of fatigue, etc.)
- Reviewing any video conferencing etiquette expectations - Fatigue, hearing-loss, and/or facial paralysis can change how comfortable some are with being on video calls or having in person meetings - especially in the early stages after treatment.
- Reviewing travel needs and expectations - Fatigue, hearing-loss, facial paralysis, balance changes, etc. can impact
- Telecommuting opportunities - Potentially more acceptable and commonplace in many industries given recent global conditions. Remote work can help bridge the gap for you to transition back to your previous worksite or potentially be a longer term or hybrid arrangement to help accommodate your needs.

Gamma Knife/CyberKnife/Radiation Therapy/etc.

- Partner with your medical provider to understand the potential impact of this treatment course and determine what communication plan is needed.
- Some have a one-time treatment while others might have a series.
 - Consider your situation and discuss with your manager/HR representative as needed to plan for any out of office or coverage needs.
 - Evaluate your symptoms pre and post treatment and consider discussing your situation with your HR representative and/or manager.
- Working with a therapist to manage the emotional burden of having an AN has been beneficial to many.
- You may decide not to disclose anything related to the diagnosis, in particular if you are symptom free.

Watch & Wait - Active Surveillance

- The emotional burden of living with an AN in Watch and Wait can be difficult. Some have found the ANA support groups to be beneficial as well as seeking counsel from a therapist.
- Review your healthcare/benefits plan (HSA planning), check deductibles and out of pocket maximums to consider how your needs could change year to year around open enrollment.
- Similarly to other situations, you may decide not to disclose anything related to the diagnosis, in particular if you are symptom free.

Additional Resources and Reference

Glossary of Terms

FMLA - Family and Medical Leave Act - The FMLA entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave.

LTD - Long-term Disability

Reasonable accommodations - any change or adjustment to a job, work environment, or the way things are usually done that would allow an individual with a disability to apply for a job, perform job functions, or enjoy equal access to benefits available to other employees.

STD - Short-term Disability

SSD - Single-sided Deafness or asymmetrical hearing loss.

Useable or serviceable hearing - A degree of hearing most likely not considered profound or severe hearing loss. Discussion with an audiologist is recommended.

Vestibular therapy - a type of physical therapy designed to help reduce effects of dizziness and improve balance.

Watch and Wait (W&W) - active surveillance and monitoring of an acoustic neuroma to observe how things progress over time to determine if a particular treatment or alternative course of action is needed.

Links and Other Resources

[Equal Employment Opportunity Commission \(EEOC\)](#)

[Family and Medical Leave Act](#) - Employee Guide

[Americans with Disabilities Act \(ADA\)](#)

[ADA - Fighting Discrimination](#) - Employment Resource

[Job Accommodations Network \(JAN\)](#)

[Acoustic Neuroma Association - Home](#)