

CAREGIVER INFORMATION SHEET

Someone close to you has been diagnosed with Acoustic Neuroma. We want you to be educated, informed and encouraged by the fact that, as a caregiver, you are not alone. Caregivers devote tremendous time and energy meeting many new challenges in an effort to care for and improve their loved ones' lives, while trying to balance their own needs. Feelings of grief, including shock, anger and depression are often experienced by the patient **and their loved ones**. *Caregivers are special people with overwhelming responsibilities.*

Being a caregiver is one of the most challenging roles a person can experience. Caregivers are people from all walks of life; they are spouses, parents, children, friends and siblings who have a special bond with their loved one. If you're a caregiver, you're not alone. A joint study conducted by the National Alliance for Caregiving and the AARP found that an estimated 43.5 million Americans age 18 or older are providing care to an adult.*

In an effort to better meet your needs as a caregiver, we offer the following suggestions:

- 1. **Take care of your own physical and mental health needs**. You've probably heard this before, "You can't take care of someone else if you don't take care of yourself." Be aware of your stress levels, take breaks, exercise, and talk to a friend. Only you know what works best for you.
- 2. **Ask for help!** We all have our limitations, be aware of your strengths and abilities. When people offer to help, accept the offer caregiving is definitely more than a one person job.
- 3. **Be flexible.** You will encounter situations where you may have to reevaluate your needs and priorities. Things you did in the past may have to be looked at in new ways and new strategies developed to help you accomplish your tasks and manage your new responsibilities.
- 4. **Educate yourself about your loved one's condition**. This will help you better communicate with medical health professionals and other health care providers about treatment and care. Attending physician appointments can be extremely helpful.
- 5. **Seek resources.** Ask yourself, "What people/organizations/information will make my caregiving easier/better?" Be specific and selective about the resources you need.

*2015 National Alliance for Caregiving in collaboration with AARP

Acoustic Neuroma Overview / Symptoms

A person diagnosed with acoustic neuroma may have one or many physical needs that need to be addressed, including hearing loss, tinnitus, balance/equilibrium issues, headaches, fatigue, eye problems and facial nerve weakness/paralysis. Some patients also report cognitive and emotional issues, including depression and/or memory deficits. Some of these physical and emotional needs may or may not improve with treatment. Our patient information booklets on most of these topics are designed to answer many of the questions and concerns you may have.

Acoustic Neuroma Treatment Options

Choosing the best treatment is a decision that must be made by both the patient and the physician after careful review of the patient's age, symptoms, physical health, tumor size and hearing. There are benefits and risks with each treatment. As a caregiver, please understand that evaluating treatment options can be challenging, especially when the decision may influence long-term physical effects.

Finding Helpful Information

Information is vital to caregivers so that they can support acoustic neuroma patients through diagnosis, treatment and recovery. Caregivers struggle on many levels, including managing their own responsibilities while juggling the multiple demands of caring for a loved one. In addition to the materials included in this packet of information, we have developed the following services and programs that will be beneficial in helping you find practical guidance and solutions throughout the treatment journey:

ANA Services and Programs

It is easy to become overwhelmed by the stress associated with the responsibilities of caregiving. We are dedicated to providing caregivers with the knowledge and support they need. Please take advantage of the following programs and services to assist you with the daily issues affecting your role as a caregiver.

ANetwork, Nationwide Peer Support Program

A very valuable resource available to acoustic neuroma patients is the **AN**etwork program. This program is a list of ANA volunteers who are acoustic neuroma patients, as well as several caregivers/family members, who are available via telephone and email. They share their treatment and recovery experiences and provide information, encouragement and support. The **AN**etwork list is included in this packet of information.

Support Groups

ANA support groups provide networking opportunities for newly diagnosed and post-treatment AN patients and family members. The support groups educate and inform and also provide emotional support to help to reduce the feelings of isolation. They help patients and caregivers develop realistic expectations and help adjust to changing life situations. In addition they share helpful tips for dealing with specific problems. A schedule of support group meetings is available at our website, <u>www.ANAUSA.org</u>, as well as contact information for the Support Group Leader/Facilitator in your area.

ANA Website, <u>www.ANAUSA.org</u>

Caregivers Overview/Resource Page

At our website, you will find information and links to many helpful organizations that provide a variety of caregiver resources, including online support groups, community resources, newsletters, conferences, workshops and other tools that will assist you in finding the help that you need.

ANA Discussion Forum

Please visit our Discussion Forum at our website featuring a category just for Caregiver comments, questions and tips.

*If you do not have internet access, please contact us and we will be happy to provide you with a copy of the caregiver information and list of resources that is available on our website.

We believe that **contact** with other patients and caregivers, **preparation** about what to expect, **support** in attending to your needs as well as your loved one's needs and **research** on our website (and others) will give you opportunities and practical information to maximize your functioning as a caregiver. **March 2017**