

Family and Friends

Acoustic neuroma help sheet



What is acoustic neuroma?

An Acoustic Neuroma is a rare brain tumour that approximately only 2 in 100,000 people are diagnosed with. In fact, many GP's will never see an Acoustic Neuroma or only come across one patient in their career. The tumour grows on the acoustic nerve behind the inner ear; it can take a long time to get a diagnosis and the only way an Acoustic Neuroma can be diagnosed is via an MRI scan. Acoustic neuromas are usually diagnosed in those aged 50+ but can be diagnosed in those in their twenties.

People usually begin to notice that their hearing is deteriorating and/or their balance is causing an issue (people have been accused of being drunk)! Or tinnitus is invading their everyday life. Sometimes symptoms may have been around for months or even years.

How does acoustic neuroma effect the patient?

The diagnosis of a brain tumour can be unexpected and frightening for all involved; with family and friends wondering how best to support the person diagnosed. There are more often than not a number of side effects that will develop and they often stay beyond treatment. These can include;

- Fatigue
- Single sided deafness
- Vertigo
- Tinnitus
- Headache
- Balance issues
- Anxiety
- Facial weakness/palsy

Those diagnosed will, most likely lose their hearing completely in the ear affected by the Neuroma. Many of those diagnosed can feel isolated as they know of no one who has had or heard of Acoustic Neuroma.

It is important to be patient and ask what they need from you. They may need to move to a different seat around a table or sit in a different place from usual place while watching TV. They may not always hear what you are saying and there may need to be many changes.

Acoustic neuroma treatment

The treatment options can be a real dilemma for those diagnosed and they may wish to discuss their options. The individual, family members and friends will have to develop coping mechanism to live with these day to day life changing situations. It is important to remember that many of the effects of an acoustic neuroma are invisible and even after treatment many of the symptoms are likely to remain.

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Acoustic neuroma impact on carers



Diagnosis



You may have been on the diagnostic journey with the patient for some time. This process **can be stressful and upsetting**. Or, it may have been a sudden diagnosis which **can be a shock**. A diagnosis **can provoke further worry or having answers may give some relief**. Through the diagnosis journey you may have **attended appointments** and **provided emotional support** to the patient.

Watch and Wait

If the patient is on 'watch and wait' you may be providing **ongoing emotional support, attending MRI scans or appointments** with healthcare providers. You may find the person diagnosed **tires more easily**, their **balance may be effected** or their **hearing may gradually deteriorate** further. **Tinnitus** can be one of the most intrusive and never ending experiences for someone with an AN and the individual **may lose confidence** in doing some activities they had previously enjoyed.

Approaching treatment

As your loved one approaches the treatment stage you may start to prepare the home for their return. If the patient is undergoing surgery, this may include **stocking up on groceries, preparing a room** for them or spending time **researching support services**.

Recovery

Carers of patients recovering from acoustic neuroma treatment may:

- Take care of the home and bills, prepare meals
- Assist the patient up and down stairs or in and out of bed
- Help the with showering/bathing
- Help them with personal care and getting dressed
- Assist them with walks out or vestibular therapy
- Drive the patient to post-treatment appointments
- Communicate with healthcare providers



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Acoustic neuroma hints and tips

A study carried out with acoustic neuroma carers shared their hints, tips and coping mechanisms.

Practical

Hint: Carers may be parents, partners, children, friends, siblings.

Tip: "Talk to the patient about what personal care they are comfortable having and whether you are comfortable doing it"

Hint: It is easier to do this before treatment.

Tip: "Have a trusted GP in place"

Hint: Ensure you are aware of what you are facing physically and emotionally.

Tip: "Ask questions"



It is possible your family member/friend may not return to the same physical and emotional health as before their diagnosis.

Although not medically trained BANA is here to offer support and information.

Please contact us at:

Email: admin@bana-uk.com

Telephone: 01246 550011

We are available Monday to Friday 10am -3pm

Emotional

Hint: Looking after yourself will help you be a better carer.

Tip: "Look after your own mental health and wellbeing".

Hint: It is ok to ask for help if you need a break.

Tip: "Keep doing things you enjoy"

Hint: Carers may need support too.

Tip: "Talk to friends, family or charities"

Coping mechanisms

- Caregiver and patient supporting each other
- Connecting with other carers/patients
- Positive reframing
- Distractions; hobbies, dog walking, family
- Focusing on life returning to normal
- Not dwelling on the negative aspects
- Acceptance of a "new normal"
- Conscious decision; AN does not rule life
- Researching the condition
- Focusing on goals and practicalities
- Maintaining your own good health
- Maintaining a routine throughout recovery
- Taking it one step at a time



BANA
British Acoustic Neuroma Association