

Help Sheet for Family and Friends, living with an 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, while others are likely to come across perhaps one patient in their career as a GP.

A diagnosis of Acoustic Neuroma brain tumour can be traumatic for the individual and their family and friends. There are more often than not a number of side effects that will develop and they often stay beyond treatment. The individual, family members and friends will have to develop coping mechanism to live with these day to day life changing situations. Changes can include single sided deafness, tinnitus, balance issues, facial weakness/palsy, fatigue, vertigo, headache, anxiety. All 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.

Mostly AN's are diagnosed in the 50+ age group, although the acoustic neuroma can and has been diagnosed in people in their twenties. So it can affect any age group.

The only way an Acoustic Neuroma can be diagnosed is via an MRI scan. The tumour grows on the acoustic nerve behind the inner ear; it can take a long time to get a diagnosis. 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.

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.

You may find the person diagnosed may tire more easily than previous and they may find that their balance will suddenly fail them; their hearing will be affected on the side of the AN and it may well 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. 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. There may need to be many changes.

The treatment options can be a real dilemma for those diagnosed and they may wish to discuss their options.

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

It can be a hard time for all when an acoustic neuroma has been diagnosed and it is important that you take care of yourself and look after your wellbeing in order to be able to give support to your family member/friend.

Although not medically trained we are happy to answer any questions for you, please contact us at admin@bana-uk.com or telephone on 01246 550011 we are available Monday to Friday 10am -3pm