Information for patients, family and carers: Small Acoustic Neuromas (Small Vestibular Schwannomas)

Acoustic Neuroma/Vestibular Schwannoma, what is it?

Your symptoms and imaging findings are consistent with a small acoustic neuroma, also known more correctly as a vestibular schwannoma. This is a benign tumour, usually slow growing, that has not come from somewhere else in the body, and that will also not spread anywhere else. It will most likely have been present for a number of years. Such tumours arise from ‘Schwann cells’ in the vestibular nerve, the nerve to balance, as it runs from your brain into the bone of your skull. The hearing is affected because the tumour stretches the adjacent cochlear nerve, the nerve to hearing.

For most patients with an acoustic neuroma (vestibular schwannoma), the cause is unknown. Very rarely, these tumours occur as part of a hereditary condition known as Neurofibromatosis Type 2. This is usually obvious at the time of initial diagnosis with either the patient’s brain scan showing more tumours than just a single acoustic acoustic neuroma (vestibular schwannoma) or other family members having similar problems.

How can my tumour be treated?

With your tumour being small, you have three choices concerning how your tumour is managed. These three choices are (1) interval imaging, (2) stereotactic radiosurgery, or (3) an operation.

What is meant by ‘interval imaging’?

With interval imaging, you undergo a scan each year to see if your tumour had increased in size. Only if there is an increase in size demonstrated do you then undergo either stereotactic radiosurgery or an operation. About half of small acoustic neuroma (vestibular schwannoma) tumours do not increase in size when followed over many years with interval imaging, i.e., they appear ‘burnt out’.

The usual type of scan is an MRI (magnetic resonance imaging), which provides the best detail about your tumour and also avoids exposure to X-rays. A CT (computerised tomography) scan is only performed if you have a pacemaker preventing you from having an MRI or in the work-up for an operation. A CT scan uses X-rays and provides the best detail concerning bone structures.
You should always keep your scan appointments even when your tumour has not caused you problems for many years. Note please contact your consultant neurosurgeon’s secretary if you have difficulties with making a scan appointment or your scan appointment is earlier than you anticipated or you do not receive an appointment for a scan when your scan date is due.

It may also be such that you do not need to come to a clinic appointment if your scan is unchanged as compared to previous and that the result of your scan can be communicated to in writing and arrangements can then be made for the subsequent scan. You should enquire with your consultant neurosurgeon or his secretary about the specific arrangements for communication of results and scan follow-up if you feel an appointment would not otherwise be required, in particular if you live at a distance.

**What is meant by ‘stereotactic radiosurgery’?**

Stereotactic radiosurgery involves the fixation of a stereotactic metal frame to your skull usually under local anaesthetic, repeating an MRI scan, and then treating the tumour using highly focused beams of gamma radiation.

Radiosurgery aims to stop the growth of a small acoustic neuroma (vestibular schwannoma), about a 90% chance, and occasionally does result in some tumour shrinkage. Radiosurgery does not get rid of the tumour and does not generally result in improvement in symptoms caused by your tumour.

Radiosurgery can be given with less risk than surgery but the effects of radiosurgery take many months. The first scan after a radiosurgery treatment is performed at one year following the treatment.

There is less than a 5% chance of problems, usually temporary, with 1-2% being permanent, including facial muscle weakness (a facial palsy).

Hearing is often lost in about one third of patients in the months that follow treatment. A further one third of patients lose their hearing as per the natural course of hearing loss associated with small neuromas, but a third of patients do have their hearing successfully preserved over the long term.

Stereotactic Radiosurgery does involve radiation exposure. There is a possible very small risk of long term issues with radiation exposure but in reality this is likely only to be a consideration in a young person.

Stereotactic radiosurgery is generally a single treatment planned and delivered all in one day with a one to two night hospital stay. This is carried out at the National Centre for Stereotactic Radiosurgery in Sheffield (see [www.gammaknife.org.uk](http://www.gammaknife.org.uk) or patient information leaflet on Radiosurgery).
What does an operation involve?

The aim of open surgery is complete tumour removal. Occasionally the surgery is performed to also get rid of severe vertigo (room spinning/balance difficulty).

The operation itself is in the order of six hours. A ‘trans-labyrinthine approach’ is most often used, i.e., drilling out the ear bone to arrive directly down upon the tumour so as to avoid retracting the adjacent brain. The procedure is done jointly by Mr Carroll, Consultant Neurosurgeon, and Mr Yardley, Consultant ENT surgeon.

You will spend a day or two in the neuroscience high dependency unit after your surgery (see patient information leaflet on Neuro-Intensive Care Unit). You would be in hospital about one week after the surgery. We would expect you to be independent and self-caring on discharge and be off work subsequently for approximately six weeks.

Any remaining hearing on the side of the tumour is always lost. You may feel vertiginous (‘room spinning’) initially after the surgery but this resolves over about a week.

The risks of surgery include: clot in the leg/clot in the lung (‘DVT/PE’) 1:100; infection 1:100; stroke/blood clot (with the possibility of permanent paralysis and also having a very small risk to life) 1:100; brain fluid leakage down nose/hydrocephalus (‘water on the brain’)/meningitis 1:100; and facial nerve palsy 1:100. There are a whole range of measures that the surgical team take to stop problems happening and a whole range of measures that are taken to reduce the impact when problems do happen. You will spend a day or two in the neuroscience intensive care/high dependency unit after your surgery (see patient information leaflet on Neuro-Intensive Care Unit).

After surgery we will carry out a further scan as an outpatient once you have recovered, usually an MRI around the three month mark as a baseline for any future interval scans.

What about risk to facial muscle weakness with either stereotactic radiosurgery or open surgery?

The risk to the facial nerve, the nerve that controls your facial muscles, is similar for both procedures with a 1:100 chance of long-term facial muscle weakness. Injury to the facial nerve is an issue because your acoustic neuroma (vestibular schwannoma), although arising from the vestibular nerve, is closely associated with the facial nerve.

A device for identifying the facial nerve, known as a facial nerve stimulator (with facial muscle electrodes), is always used during an operation to identify the facial nerve and prevent it from being injured.
Can my hearing be preserved or improved with either stereotactic surgery or open surgery?

Neither treatment can bring back hearing that is already lost.

Most patients diagnosed with an acoustic neuroma (vestibular schwannoma) already have significant hearing loss and therefore preserving functional hearing is not an issue. However, occasionally, patients diagnosed with small tumours do have intact functional hearing on the side of the tumour.

In the situation where there is good hearing on the tumour side and the tumour is treated with stereotactic radiosurgery, hearing is often lost in about one third of patients in the months that follow treatment. A further one third lose their hearing as per the natural course of hearing loss associated with small acoustic the disease, but a third do have their hearing successfully preserved over the long term.

If an operation is performed, the usual surgical approach, i.e., the translabyrinthine approach (which involves drilling out the bone containing the ear structures), always result in complete loss of hearing on the side of the tumour.

You may come across on the internet information concerning a ‘middle fossa’ surgical approach that may be used in some centres abroad as a hearing preserving operation, assuming good hearing to start with. Success at preserving sufficient hearing function to use a hearing aid or functional otherwise to the patient is achieved in about one third undergoing such surgery, albeit with a risk of epilepsy (not present with the trans-labyrinthine approach), increased risk of facial nerve injury (7%), and increased risk of long term tumour recurrence. We do not perform this type of operation. We are also not aware of any centre in the UK routinely offering this operation.

For those patients with intact hearing undergoing interval imaging rather than stereotactic surgery or an operation, most will loose their hearing within seven to ten years of diagnosis, irrespective of whether the tumour grows or not.

What impact can complete hearing loss on the side of my tumour have on my life?

Most people with hearing loss in one ear and normal hearing on the non-tumour side are able to live a normal life. Some people report difficulty in blocking out loud background noise when engaging in conversation. Some people have difficulties with ‘directional hearing’, i.e., knowing exactly where a sound is coming from. If directional hearing is important in a person’s life, e.g., a teacher in a class room or roadside worker, a bone anchored hearing aid (‘BAHA’) may be of benefit.
Can my tinnitus be helped with either stereotactic surgery or open surgery?

Tinnitus (noise or buzzing in the ear) as a result of your tumour will not be helped by either treatment. Tinnitus tends to become less troublesome over time. There are also simple measures that may help the tinnitus have a less impact on your life, e.g., having a radio on in the background if in a quiet environment.

Will I come to any harm if I choose interval imaging?

In general, half of small acoustic neuroma (vestibular schwannoma) tumours do not appear to grow. Most of the remainder will grow at a rate of 1-2mm per year. It is correct to say that the smaller a tumour is, the more successfully it can be treated by either stereotactic radiosurgery or open surgery and with less risk. However, usually, with annual MRI scans, any small growth is likely to be picked up before it has progressed to a size to significantly affect outcome of either treatment or the extent of associated risks.

What should my expectations be over the long term?

We would expect that the vast majority of people with a small acoustic neuroma (vestibular schwannoma) to be able to have a normal life in terms of quality of life including employment and relationships and also to not have their lives foreshortened.

Is there anybody I can talk with to get further advice and information?

You will be assigned a skull base ‘key worker’ who can provide further advice and information. Your assigned key worker is usually either your consultant neurosurgeon and/or skull base specialist nurse. They should provide you with a means of contacting them. They will also provide you with copies of correspondence such as your clinic letters for your own records and additional information material such as further patient leaflets referred to within the text above.

You may wish to discuss your diagnosis with your GP.

The hospital also provides a chaplaincy service for different faiths or indeed if you do not belong to any faith group. Note that if you are an inpatient the chaplains will not automatically visit you, even if you belong to a particular faith group. If you would like to see a chaplain, please ask a nurse, relative or friend to leave a message on 0114 271 4999.

In addition, there are some local, national and international patient information groups/charities who can offer further advice and information including:
**British Acoustic Neuroma Association**  
Website: [www.sheffieldsarcomasupport.org.uk](http://www.sheffieldsarcomasupport.org.uk)  
Tel: 0114 2261436

**Brain Tumour UK**  
Website: [www.braintumouruk.org.uk](http://www.braintumouruk.org.uk)  
Tel: 0845 4500386

**British Tinnitus Association**  
Website: [www.tinnitus.org.uk](http://www.tinnitus.org.uk)  
Tel: 0800 0180527

**Facial Palsy UK**  
Website: [www.facialpalsy.org.uk](http://www.facialpalsy.org.uk)  
Tel: 01273 803040

This information sheet is to be used only in the context of attendance at or admission to the Department of Neurosurgery, Royal Hallamshire Hospital, Sheffield Teaching Hospitals NHS Foundation Trust. No responsibility is held for the advice provided by external support groups listed or the information content provided on their websites. If in doubt, ask your doctor.

Compiled by Mr Thomas Carroll, consultant neurosurgeon, and Mr Mark Yardley, consultant ENT surgeon, 21st September 2012