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Vestibular Schwannoma (Acoustic Neuroma)

An information guide

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What is Acoustic Neuroma?

You have been diagnosed as having an acoustic neuroma. This is a benign (non-cancerous) tumour that arises from the cells that insulate your vestibulo-cochlear nerve as it travels between your inner ear and your brain stem. Your vestibulo-cochlear nerve carries vestibular fibres (balance) and cochlear fibres (hearing) and is therefore the nerve of hearing and balance.

The tumour is in fact more accurately known as a vestibular schwannoma, as it invariably arises from the vestibular portion of this nerve. Acoustic neuromas often do not grow following diagnosis but if they do grow the increase in size is slow with gradual onset of symptoms.

The average growth rate of a growing acoustic neuroma is around 1-2 mm a year though occasionally a tumour can grow more quickly. Some tumours that have demonstrated growth stop growing after some time and may never grow again.

It is not fully understood what causes acoustic neuromas. In a small minority of patients, they are due to a genetic abnormality called Neurofibromatosis Type 2. This is not common, and your acoustic neuroma will be a sporadic tumour unless your doctor has specifically mentioned that you have this genetic disorder.

There are very few other proven risk factors for developing an acoustic neuroma, and specifically there is no evidence to link them with mobile phone use.

At Salford Royal Hospital we see around 150 new cases per year.

Symptoms

Symptoms almost always start with hearing loss on one side. Approximately 90% of people with an acoustic neuroma experience some degree of hearing loss. This is due to the tumour interfering with the function of the hearing nerve as it grows. Hearing loss is usually gradual and therefore you may not have noticed the hearing loss in its early stages. Hearing loss often occurs even if there is no growth in the tumour - in other words, just because your hearing may have worsened, does not mean that the tumour has enlarged.

Other symptoms include tinnitus and dizziness. Tinnitus is a sensation of ringing in your ears. It affects approximately 70% of patients with acoustic neuroma. Vertigo or dizziness affects around half of patients and can be a debilitating symptom. As the vestibular portion of the nerve is compressed your ability to manage balance may decrease. As this usually occurs slowly, your body adapts and compensates for this change. As a result, some people barely notice any change in their balance although it is common to feel like you are veering to one side when walking.

Facial numbness is an uncommon symptom with small tumours but can occur as the tumour becomes larger. It results from pressure on the trigeminal nerve, which is the nerve supplying facial sensation. You may notice sensation changes particularly to your forehead, around the eye and to the jawline on the affected side.

Your tumour may also stretch your facial nerve which controls the muscles to your face. It runs in close contact with the vestibulo-cochlear nerve and is always stretched or distorted by the tumour. Paradoxically, this nerve seems to almost always retain function, and it is very unusual to have any weakness or

paralysis on the affected side of your face, even with giant tumours.

If your tumour becomes large, it will eventually begin to press against the brain itself (structures such as your brain stem and cerebellum). You may notice your mobility and balance worsening. This compression can lead to life threatening complications if untreated, though this is very uncommon.

Diagnosis

Your doctor may have examined your balance, your inner ears and hearing, and your nerve function if an acoustic neuroma was suspected.

Confirmation of an acoustic neuroma diagnosis is usually through MRI (magnetic resonance imaging). Your surgeon may also send you for a CT scan (computed tomography) though MRI is the best way of detecting these types of tumours.

Once an acoustic neuroma is diagnosed, its relative rarity means that it is important that you are referred on to a specialist team who are used to managing these tumours. That is why you have been referred to Salford Royal.

Salford Royal's Skull Base Team

The Skull Base team at Salford Royal Hospital is made up of:

Consultant Neurosurgeons

Prof. Andrew King

Mr. Scott Rutherford

Prof. Omar Pathmanaban

Consultant ENT (ear, nose and throat) surgeons

Prof. Simon Lloyd

Mr. Simon Freeman

2 clinical nurse specialists

Sr. Andrea Wadeson.

Sr Helen Entwistle

They also have specialist fellows working with them who are undergoing subspecialty training in this type of surgery.

There is also a wider multidisciplinary team who may be involved in your treatment including oncologists, radiologists and radiographers.

Together they work with other disciplines and ward staff to ensure that the highest quality of care is delivered to you during your stay with us.

Salford is one of the largest Neuroscience centers in Great Britain. It receives referrals nationally and internationally due to its expertise in managing acoustic neuromas and other similar conditions.

Management of Acoustic Neuroma

You are now at the stage where management options will be discussed with you. Your surgeon will have discussed the findings on your MRI with the rest of the skull base team. Treatment for your acoustic neuroma will depend upon many factors including:

- Your age: As these are generally slow growing tumours, older patients may be managed in a more conservative way

- Your overall health: If your health is poor, it may not be advisable to perform surgery and another option may be considered

- The size and configuration of your tumour: Larger tumours tend to be managed with surgery, although this will depend on the other factors too. There are certain other characteristics of the tumour which may influence this decision (for example if the tumour contains cysts)

- The growth rate of your tumour: If your tumour does not appear to be growing or it is growing at a slow rate then you may be observed with periodic scans and clinical follow ups. If your tumour appears to be growing faster, your surgeon is likely to advise an active form of management

- Your symptoms: Sometimes the amount of hearing you still have, or the presence of troublesome dizziness is a factor in deciding treatment

You will, of course, have a say in what type of treatment, if any, you have and the doctor you see in the clinic will help you decide which option would be the most appropriate for you. It is important that you discuss in detail any questions that you may have at this stage.

The options available are:

Watch, Wait and Rescan

If your tumour is small, we will almost always suggest no active treatment until clear tumour growth is demonstrated. Therefore, nothing more than a further scan at a 6 to 12 month interval will be arranged.

If your tumour remains static or if the growth rate is very slow and your tumour still small, your surgeon may simply suggest continued monitoring with MRI and clinical follow ups. This may also be the case for older patients and those with health issues.

It may seem like nothing is being done for you, however, as acoustic neuromas are benign and often do not pose any immediate risk to you, the risks of surgery may outweigh the benefits at this point.

The close monitoring would enable the team to reassess your options at any given time. It is important that you inform the specialist nurse of any new or worsening symptoms in between hospital visits.

Surgery

Surgery is a safe and widely offered option which aims to deal with this condition by completely removing the tumour. In some cases, it is not possible to remove the entire tumour, typically due to adherence to the facial nerve. If this is the case, it is safer to leave a tiny portion of tumour to preserve nerve/brain function, rather than risk permanent injury as acoustic neuromas are benign, slow-growing tumours and a small remnant is unlikely to cause you any problems in the future.

In cases where we leave a tiny remnant, the risk of needing further treatment is only about 2%. By achieving total or near-

total removal of the tumour, surgery offers a 97% chance of successfully dealing with your tumour. In either instance you will be monitored after your surgery to assess the unlikely occurrence of a re-growth.

Prior to surgery, you are likely to be sent for a balance function test to see whether you have any remaining balance function left. The tests will determine whether you are a candidate for a form of pre-operative therapy called "intratympanic gentamicin therapy". Gentamicin, an antibiotic, is toxic to the vestibular (balance) nerve and therefore, if you have remaining balance function, we suggest a series of injections through the ear drum, prior to surgery, to essentially damage the balance nerve and stop the nerve from functioning. The gradual loss of the balance function is generally more tolerable than the acute loss of the function that occurs at the time of surgery and so has a beneficial impact on the patient's recovery, not just from a balance perspective but also in speeding up general recovery and allowing earlier discharge home for most people. More is explained in the intratympanic gentamicin therapy leaflet that you will be given if surgery is recommended to you.

There are 3 main approaches for surgery. The choice depends upon the tumour size and location, your hearing level and your general health. Each approach has its own benefits and risks, and your surgeon will discuss the best option for you.

Each involves an incision on the affected side of the head though in slightly different places. There is the possibility of preserving your hearing function with some approaches (but only with small tumours and useful pre-operative hearing), although this will be discussed in detail with you by your surgeon if appropriate.

The most significant risk from surgery is damage to the facial nerve. The risk of this is directly related to the size of the tumour,

but overall, the vast majority of patients have normal or near-normal facial movement some months after surgery. A larger number of people will have a temporary weakness which recovers as the nerve gets over the manipulation involved to remove the tumour. If you do have a facial weakness, it affects your ability to close your eye, make facial expressions, and eat or drink with that side of your face. Your surgeon will give you a more accurate idea of the risk of surgery to your facial nerve with your specific tumour.

Occasionally surgical removal of acoustic neuromas may be complicated by damage to other cranial nerves, such as the trigeminal nerve (facial sensation), nerves that control eye movements or the nerves for swallowing. These are rare occurrences, and any resulting problems will be dealt with by the appropriate therapists.

Surgery can also have other rare complications, and this includes a tiny risk to your life (<1%), a tiny risk of a stroke (<1%), bleeding inside the head or infection. A particular complication of the surgical approach through the inner ear is that cerebro-spinal fluid (the clear fluid that surrounds the brain) can work its way out of the wound or through the middle ear to the back of the nose. This needs to be treated promptly to remove the risk of infection getting into the brain. This might involve a drain being placed in your lower back to divert this fluid, or occasionally a repair operation.

With all types of surgery, you can expect to stay in hospital for approximately 3-7 days although a small minority of patients require a slightly longer stay. We advise that you have somebody at home when you are discharged as you will be tired and possibly dizzy for a few weeks after surgery.

Some patients experience a dry mouth, altered taste or dry eye even if facial function is normal.

Fatigue can linger for many months after surgery but often abates over time.

Radiosurgery

Radiosurgery is a technique that uses a single highly targeted dose of radiotherapy to arrest the activity of the tumour and prevent further growth. There are several different machines capable of delivering "radiosurgery", and the differences in these relate to the targeting mechanisms and the radiation source, rather than the principle by which the radiotherapy is delivered. In other words, the "GammaKnife", the "CyberKnife" and "Linac" just refer to different machines rather than different treatment modalities. Most of our patients wishing to have radiosurgery will be treated in The Christie radiotherapy satellite centre at Salford Royal NHS Foundation Trust. This satellite centre is equipped with two modern high precision linear accelerators ("linacs") which are specially designed for radiosurgery.

Whilst the tumour control rate of radiosurgery is not as high as with surgery, approximately 95% of tumours are successfully controlled using radiosurgery. The advantage of radiosurgery is that there may be a smaller chance of facial weakness than with surgery, and if you have useful hearing to begin with, it may be more likely to preserve this than with an operation. It is also a day case procedure without most of the other risks associated with surgery. It does, however, have other risks that should be considered. This includes the development of a new benign or even malignant tumour or conversion of the acoustic neuroma itself to a malignant tumour over the decades that follow treatment. Thankfully, the risk of this, based on worldwide reports, appears to be extremely low, around 1 in 10,000 patients

undergoing this treatment. There is also a slight increase in the risk of stroke in the long run, but this is small. Smaller risks include a buildup of fluid around the brain that may require drainage and an increase in significant imbalance. Hearing can also be acutely affected in a small number of cases. We will discuss this in full if this treatment is considered.

Radiosurgery is usually only advised for tumours less than 2cm due to the risk of early swelling of the tumour, and the increased potential of damage to surrounding structures such as nerves or the brainstem with the higher radiation dose required for larger tumours. It does not involve a surgical incision. The treatment is delivered by focusing X-rays on your tumour. You will have a mask custom made to fit you, to hold your head still during each stage of your planning and treatment. To plan your treatment, you will have a CT scan wearing this mask. You will also have another MRI scan, but you will not need to wear the mask for this. The mask, the CT and the MRI scan will all be done in a single visit to The Christie at Salford. These scans allow the team of experts preparing your treatment to locate the position of the tumour and to prepare a plan to very precisely target the radiation dose, so that the tumour is irradiated with minimal dose to surrounding structures.

You will normally attend The Christie at Salford on a second day to have your treatment. The radiosurgery treatment is painless and should last approximately 30 minutes. You will be lying on your back on a table that moves into the radiation unit, similar to having a scan, during your treatment. You will be able to speak to the radiographer at any time and are observed on a camera. You can go home as soon as treatment is done. You may have some mild pressure headaches immediately after the treatment though this should quickly subside. Many patients resume normal activities the following day. You can go back to work as soon as you feel well enough and there are no specific restrictions on

daily activities. You may notice a degree of facial weakness in the months following treatment, as discussed in the section on surgery, though this is less likely (fewer than 1 in 10 patients) than with surgery. If it does occur, it is usually temporary. You may also notice some facial numbness, which is a little more common than after surgery, but again fewer than 1 in 10 patients should be affected, and it is also usually temporary. Preservation of hearing is not guaranteed with this method though the chances are usually better than with surgery. We can discuss this in more detail with you for your particular tumour. You may feel tired after treatment, but this should only last a few days.

Aftercare

Aftercare of patients with acoustic neuroma depends largely on the treatment given. If you are undergoing observation, then you are likely to be observed for the rest of your life at intervals determined by your team. You will be given a contact number for the Skull Base specialist nurse in case of any questions or worries you may have.

If you have surgery, you will be cared for on a neurosurgical ward. Each ward has highly experienced staff who are familiar with the complex needs of patients following removal of an acoustic neuroma.

You may also need to have input from other disciplines such as Speech and language therapists, dieticians, physiotherapists, audiology and ophthalmology. You are likely to be tired for some weeks after surgery and we advise that you gradually increase your levels of activity in order to recover at a safe pace.

You will initially be followed up by the Specialist Nurse via telephone. This takes place approximately 2 weeks after discharge for surgery. The consultant will see you in clinic around

6-8 weeks after discharge and then you will be seen again after one year. Assuming all your tumour has been removed (which is the case for most people) you will be offered a scan 2 years after surgery. A further scan is carried out 5 years after surgery and you are then likely to be discharged from the care of the Skull Base team if there is no sign of recurrent tumour. Some patients may require ongoing observation and scanning, particularly if a small fragment of tumour was left behind at surgery. Your surgeon will discuss this with you.

Following radiosurgery, you will be periodically scanned for the rest of your life. You are not likely to need any further treatment for your acoustic neuroma and should be able to return to a normal daily routine. Most patients are seen by the Specialist Nurse 6 months after radiosurgery, and you may be recalled for periodic clinic visits thereafter.

Who to Contact?

Many questions can arise after diagnosis of an acoustic neuroma. There is always someone here who can help you.

We advise that if you have any questions, no matter how small, or if you have any changes in your symptoms, contact the skull base specialist nurse:

Andrea Wadeson - Skull Base specialist nurse

Tel: 0161 206 2303

Email: andrea.wadeson@nca.nhs.uk

or

Helen Entwistle - Skull Base Specialist Nurse

Tel: 0161 206 5090

Email: helen.entwistle@nca.nhs.uk

Secretary to Prof King

Tel: 0161 206 0631

Secretary to Mr. Rutherford

Tel: 0161 2060119

Secretary to Prof. Pathmanaban

Tel: 0161 206 8340

Secretary to Prof. Lloyd and Mr. Freeman

Tel: 0161 206 5754

Or if the issue is more urgent, attend your local A&E Department.

Other useful numbers and websites are:

British Acoustic Neuroma Association

http://www.bana-uk.com

BASIC

Brain and Spinal Injuries Charity

http:/www.basiccharity.org.uk

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Copies of this leaflet are available in other formats (e.g. large print or easy read) upon request. Alternative formats may also be available via:

www.northerncarealliance.nhs.uk

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