Patient Information
Leaflet

Newly diagnosed
Vestibular Schwannoma
Patients
Vestibular Schwannoma

Introduction

This information is designed to help you answer the common questions that are asked by patients after the initial consultation. It is hoped that it will help you understand your diagnosis.

Aintree Hospital and The Walton Centre has a specialist skull base team who deal with rare inner ear tumours known as vestibular schwannomas. Our team aim to help you understand about acoustic neuroma, its treatment options and its effect on you.

What is Vestibular Schwannoma?

You have been diagnosed as having a Vestibular Schwannoma (VS) also commonly known as Acoustic Neuroma. This is a benign tumour which grows from the lining of the hearing and balance nerve (sometimes called the vestibular-cochlear nerve, acoustic nerve or VIII nerve). It is a benign tumour, and therefore not a cancer, which grows very slowly usually over many years.

The vestibular-cochlear nerve (the nerve of hearing and balance) travels through a narrow channel in the bone of the skull to the inner ear (the internal auditory canal). The tumours originate inside the bony channel and grow into the space where the brain is situated. Once a tumour reaches a certain size, it can press on the brain. It does not grow or spread into the brain tissue itself.

What causes Vestibular Schwannoma?

It is not fully understood what causes vestibular schwannomas. These tumours are caused by damage to the genetic material inside the lining of the nerve. The cause of this damage is unknown. It is not caused by anything you have done and it is not passed on to your children.

In a small minority of patients they are due to a genetic abnormality called neurofibromatosis type 2 (NF2), where people may have multiple benign lesions. If we feel that you need any further investigation for this condition, we will discuss this with you at your outpatients’ appointment.

How common are Vestibular Schwannoma?

Vestibular schwannomas are very rare. There is one new vestibular schwannoma diagnosed each year for every 100,000 people in the population. They can occur at any age but are most common in people in their 50’s and 60’s. They affect men and women equally.
How fast do Vestibular Schwannomas grow?

The average growth rate of a vestibular schwannoma is 1-2mm per year though occasionally the tumour can grow more quickly (4-5mm per year), and frequently it stops growing all together. The timing of follow up scan allows for this very slow potential growth which means if surgery is required it is generally safe to plan surgery ahead of time.

What symptoms do vestibular schwannoma cause?

**Hearing loss**

Hearing loss on one side is usually the most common symptoms that people with vestibular schwannoma experience. This is due to the tumour interfering with the function of the nerve as it grows. Hearing loss may be sudden or gradual and therefore you may not have noticed the hearing loss in its early stages. Approximately 90% of people with a vestibular schwannoma experience some degree of hearing loss.

**Tinnitus**

Tinnitus, a ringing, buzzing or wooshing noise in the ear, is also another common symptom. This can be quite troublesome but there are a number of effective therapies, which can help manage this. Other symptoms include feeling of fullness in the ear or aching of the bone behind the ear.

**Imbalance or dizziness**

Some people also experience imbalance or dizziness. As the vestibular portion of the nerve is compressed your ability to manage balance may decrease. It is common to feel like you are veering to one side when walking.

The severity of the hearing loss, tinnitus or balance disturbance does not reflect the size of the tumour.

There are other possible symptoms due to the pressure on the facial nerve (VII nerve) and the trigeminal nerve (V nerve) that sits next to the vestibular-cochlear nerve (VIII nerve).

The trigeminal nerve (V nerve) controls sensation on the side of the face and chewing muscles. Symptoms may be in the form of altered sensation on the side of the face, numbness and occasionally pain or simply altered feeling.

The facial nerve (VII nerve) controls the facial muscles on the same side of the face. Pressure to the nerve can cause weakness of the facial muscles, it is very rare to experience this as a result of the VS, but has been reported by some people with vestibular schwannomas.
Some people have no symptoms at all, and the vestibular schwannoma is discovered incidentally while they are being investigated for something entirely unrelated.

**Are vestibular schwannomas dangerous?**

Vestibular schwannomas are not cancerous and do not spread to other areas of the body. If they grow into the space where the brain is situated, they can compress the brain. This may cause symptoms such as headaches or your mobility and balance worsening.

If a vestibular schwannoma is allowed to grow very large, this compression can lead to life-threatening complications. However we monitor and treat these tumours to prevent this from happening.

**How are vestibular schwannomas diagnosed?**

Your doctor may have examined your balance, your hearing and your nerve function if a vestibular schwannoma was suspected.

Confirmation of a vestibular schwannoma is usually through a MRI scan (magnetic resonance imaging). Your surgeon may also send you for a CT scan (computer tomography) to gather more information.

Once a vestibular schwannoma is diagnosed, its relative rarity means 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 Aintree Hospital.

**Aintree and Walton’s Skull Base Team**

The Skull Base Team consists of specialist both from Aintree Hospital and The Walton Centre and is made up of:

**ENT (ear, nose and throat) surgeons**
Miss N Munir
Mr A Youssef
(Mr T Lesser)

**Neurosurgeons**
Miss C Gilkes
Miss A Visca

**Oncologists** (Radiation Specialists)
Dr D Husband
Dr A Shenoy
Dr A Haridas

**Neurosurgical Clinical nurse specialist**
Emma Wilby
ENT nurse specialists & Advanced Nurse Practitioners
Caroline Smith
Rebecca Donald
Nicky Carmichael
Charlotte Halpin

Lead Audiologist
Tony Kay

Balance Physiotherapy Team
Nova Mullin
Cathy Morrow

There are specialists’ senior trainees working with the team that you may encounter who are undergoing subspecialty training in this kind of surgery.

There is also a wider multidisciplinary team who are involved in your treatment including radiologists, radiographers and therapists. Together they work with other disciplines and ward staff to ensure that the highest quality of care is delivered to you.

How can vestibular schwannomas be treated?

You are now at a stage where treatment options will be discussed with you. There are three main ways of treating vestibular schwannomas. Your surgeon will have discussed the findings on your MRI scan with a team of specialists at our multidisciplinary team meeting.

Treatment for your vestibular schwannoma will depend upon many factors including your age, overall health, symptoms, and size and growth rate of your tumour as well as your symptoms and your personal preference.

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. This means that we do not perform any intervention and simply monitor the situation by repeating your MRI scan of the head to see whether the tumour is growing or not. Therefore you will undergo a period of observation known as ‘watch, wait and rescan’. This has no potential side effects unlike the other treatment options but you do require periodic scans to make sure that the tumour is not growing.

How often will I have a scan?

Patients undergoing observation of their vestibular schwannoma are usually scanned:
• Six months or a year after the original scan depending on size. If the growth is stable:
• Scan yearly for three years
• Then scan every two years for the following six years
• Then scan every three years for the following six years
• Five yearly scans lifelong

If your tumour shows slight growth, you may continue to have scans every year in case any intervention is needed.

An MRI scan is the best type of scan to use for monitoring these tumours. However, occasionally a CT scan will be used instead if an MRI scan is not possible, for instance if you have any magnetic metal work inside your body. These scans are generally performed at Aintree Hospital so that your specialist can look at the scans carefully themselves. The MRI scan takes around 45 minutes and you may have an injection in your hand. The scan is painless but it can be quite loud inside the scanner.

Once the scan is done, the specialist will arrange an outpatient appointment in our Wednesday morning skull base clinic to discuss the findings with you.

It may seem like nothing is being done for you, however vestibular schwannomas are benign and often do not pose any immediate risk to you, the risks of surgery or radiotherapy 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 or concerns in between hospital visits.

**What happens if my vestibular schwannoma grows?**

If the scan shows there is growth, we will discuss with you and what your treatment options are. These options include, continuing to watch and wait and further scans in some cases or intervention by way of radiotherapy or surgery in order to treat the tumour. These forms of treatment will be fully discussed with you so that you can be informed about which type of treatment would be best for you taking all factors for you as an individual into account.

**Surgery**

Surgery on vestibular schwannomas is an option, which aims to deal with this condition by removing all, or as much of the tumour as is safely possible. The operation is performed under a general anaesthetic and is a major operation. It is not always possible to remove the entire tumour, because vestibular schwannomas are often stuck onto the facial nerve or important parts of the brain tissue. If this is the case, it is safer to leave a tiny amount of tumour rather than risk permanent damage. After all, this is a benign, slow-growing tumour, that you will have had for many years and a small remnant is unlikely to cause you any problems in the future.
There are two main approaches for surgery. The choice depends upon the tumour size, location and your hearing. The risks are similar and your surgeon will discuss the best option for you.

It is rarely possible to save the hearing on the affected side. In patients who have small tumours and very good hearing (such as can use the telephone), an attempt can be made to preserve the remaining hearing on the affected side.

With larger tumours and almost no socially useful hearing, it can be assumed that hearing will be permanently lost on that side after surgery.

**Who performs the surgery?**

An ENT and neurosurgeon will perform your surgery jointly. The operation will take place in the Walton Centre and you will be cared for on a neurosurgical ward. The ward which you will be admitted to have highly experienced staff that are familiar with the complex needs of patients following removal of a vestibular schwannoma.

If surgery is decided as a treatment option a pre-operative appointment will be made for you at The Walton Centre to discuss the process and recovery period in more detail.

**What are the risks of surgery?**

The most significant risk from surgery is damage to the facial nerve. The risk of this is directly related to the size of the vestibular schwannoma. Overall the majority of patients have normal or near-normal facial movements after the surgery. In a small number of patients the surgery may cause a temporary or permanent damage to the facial nerve resulting in weakness/droopiness of the face on the affected side. There is also risk of injury to the trigeminal nerve which may lead to facial numbness/pain/altered sensation.

If you do have a facial weakness, it may affect your ability to close your eye, make facial expressions and eating or drinking may be difficult with that side of your face. This will often recover but it may take several months.

Following any type of surgery there is a risk in the immediate post-operative period of infection (wound infection or meningitis), bleeding, hydrocephalus (fluid on the brain) and external leakage of cerebro-spinal fluid (CSF leak). All neurosurgery under anaesthetic carries a very small risk of death.

Your balance may be worse after surgery but generally this recovers with time. You will experience worsening hearing/dead ear after surgery and if you have tinnitus it may become louder. New onset tinnitus can also occur after the operation. Other risks are very rare and include speech, swallowing and breathing difficulty after surgery that may require a feeding or breathing tube (tracheostomy) to be inserted.
Before undergoing surgery an opportunity will be provided to discuss the risks with the surgeon who is due to perform the operation.

Most people who have surgery will need to stay in hospital for approximately five to seven days.

We recommend that you have somebody at home when you are discharged home as you will be tired and possibly dizzy for the first two weeks after surgery. We advise that you gradually increase your levels of activity in order to recover at a safe pace.

The nurse specialist will initially follow you up via the telephone. This takes place approximately 1-2 weeks after discharge following surgery. You will have an MRI scan around 8 -12 weeks after surgery and the consultant will see you in clinic after the scan to monitor your recovery and arrange follow-up.

Radiotherapy

Radiotherapy is increasingly used as a treatment for vestibular schwannoma. It involves radiation targeted onto tumours. It works by stopping cells from dividing and therefore stopping tumours growing. There are two ways of carrying out radiotherapy: stereotactic radiosurgery and fractionated radiotherapy.

Stereotactic radiosurgery

This is often referred to by people as gamma knife although the gamma knife is only one type of machine which delivers stereotactic radiosurgery. There are several different types of machine which deliver similar treatment, for example the Cyber knife and Novalis. This treatment involves delivery of high dose focused radiation onto the tumour in a single treatment.

To do this you are brought into hospital on the same day as the treatment. The radiotherapy machine delivers a high dose of radiation to the tumour but very little radiation to the surrounding normal brain. The aim is to stop the tumour growing. The tumour is not removed. For most small tumours this is a very effective treatment and in 95% of small tumours it is effective in stopping the tumour from growing any further. There are risks including damage to the facial nerve (causing weakness or paralysis of one side of the face), the trigeminal nerve (causing numbness on one side of the face) and the hearing and balance nerve (causing deafness on the side of the tumour and loss of balance), but these risks are lower with this technique than with open surgery. Therefore for small tumours we would usually advise stereotactic radiosurgery in preference to surgery.

Fractionated radiotherapy

This is also a type of radiation treatment which tries to stop the tumour from growing but it is delivered in more than one session. It is used in treatment of
large acoustic neuromas if surgery can not be performed, or in treatment of small acoustic neuromas if preservation of hearing is very important, for example in people who have no hearing on the opposite side.

If I have radiotherapy do I need follow-up after treatment?

Because the radiotherapy will not remove the tumour, we would recommend a follow-up schedule that includes MRI scans in order to check that the vestibular schwannomas do not show evidence of further growth. An outpatient appointment will be made following your scheduled MRI scans to discuss the findings with you. You are not likely to need any further treatment for your vestibular schwannoma if it stops growing and should be able to return to a normal daily routine.

What happens after my treatment?

Aftercare of patients with a vestibular schwannoma depends largely on the treatment given. You will be given the number for the specialist nurse in case of any questions or worries you may have.

Other follow-up while under observation, or after surgery or radiotherapy

Depending on your symptoms you may also need the input from other disciplines such as nurse specialist, speech and language therapists, dieticians, vestibular (balance) physiotherapists, audiology and ophthalmology.

We are able to offer other services that you may require after diagnosis or treatment for a vestibular schwannoma.

Nurse specialist led clinic

If your condition remains stable and your consultant feels it is appropriate then you may be followed up by our nurse specialist team. However if your condition changes you will be referred back to your consultant.

Hearing Tests

We may offer you hearing tests called PTA (pure tone audiogram) and Speech Audiometry on your arrival at the skull base clinic prior to seeing you in your outpatient appointment. This enables us to see how the tumour is affecting your hearing, and how you are able to communicate with other people.

Hearing Aids
If we feel you would benefit from a hearing aid, we will refer you to your local audiologists to be assessed and discuss the options available to you. You may also wish to discuss this with your GP and they can also refer you to your local audiologist.

If your hearing has been affected by the vestibular schwannoma and you are also hard of hearing on the side with no tumour, then it may be worth considering a lip reading class to gain additional skills and confidence with communication. Information on support groups are listed at the end of this document.

**Tinnitus and Balance Problems**

Tinnitus, a ringing, buzzing or wooshing noise can be quite troublesome and often becomes worse after any form of intervention. There are a number of effective therapies, which can help with management of tinnitus.

For those patients with balance disturbance or dizziness we can arrange a vestibular assessment by a specialist physiotherapist and teach you exercises to retrain the balance system and provide strategies for dealing with difficult environments.

**Who to contact?**

Many questions can arise after diagnosis of a vestibular schwannoma. We advise that if you have any questions, no matter how small, or if you have any changes in your symptoms to contact the clinical nurse specialist.

**Contact details:**

Consultant seen in clinic: ______________________________

Clinical Nurse Specialist: ______________________________

Telephone: 0151 525 5648

Bleep via the switchboard 0151 529 3611 bleep 5342 / 5391

E-mail: tumournurse@thewaltoncentre.nhs.uk

Alternatively, please call:

Carol Taylor, secretary to ENT surgeons on:

Telephone: 0151 529 3404

Fax: 0151 529 5263

E-mail: carol.taylor@aintree.nhs.uk
Other useful support groups and websites are:

**British Acoustic Neuroma Association**

The British Acoustic Neuroma Association (BANA) was formed in 1992. BANA is organized and administered by people affected by acoustic neuroma. It is a registered charity and exists for mutual support, information exchange and listening.

The British Acoustic Neuroma association
Oak House B, Ransom Wood Business Park
Southwell Road west
Mansfield
Nottinghamshire
NG21 0HJ

Tel: 01623 632143
Fax: 01623635313

Website: [http://www.bana-uk.com](http://www.bana-uk.com)

**The Neuro Foundation**

The Neuro Foundation is a UK charity that aims to improve the lives of people with neurofibromatosis (either type 1 or type 2).

For more information, you can visit The Neuro Foundation website, call its helpline on 020 8439 1234, or email info@nfauk.org

**British Tinnitus Association**

The British Tinnitus Association
Ground Floor, Unit 5
Acorn Business Park, Woodseats Close
Sheffield, S8 0TB

Tel: 0800 018 527
Website: [info@tinnitus.org.uk](mailto:info@tinnitus.org.uk)

**Action on Hearing Loss**

Information Line:
Telephone 0808 808 0123
Text phone 0808 808 9000

Email: [informationline@hearingloss.org.uk](mailto:informationline@hearingloss.org.uk)
The Brain Charity

The Brain Charity provides support that complements medical provision, to people with a neurological condition, their families and professionals who care for them throughout their journey.

Norton Street
Liverpool
England
L3 8LR

Tel: 0151 298 2999

Website: www.thebraincharity.org.uk