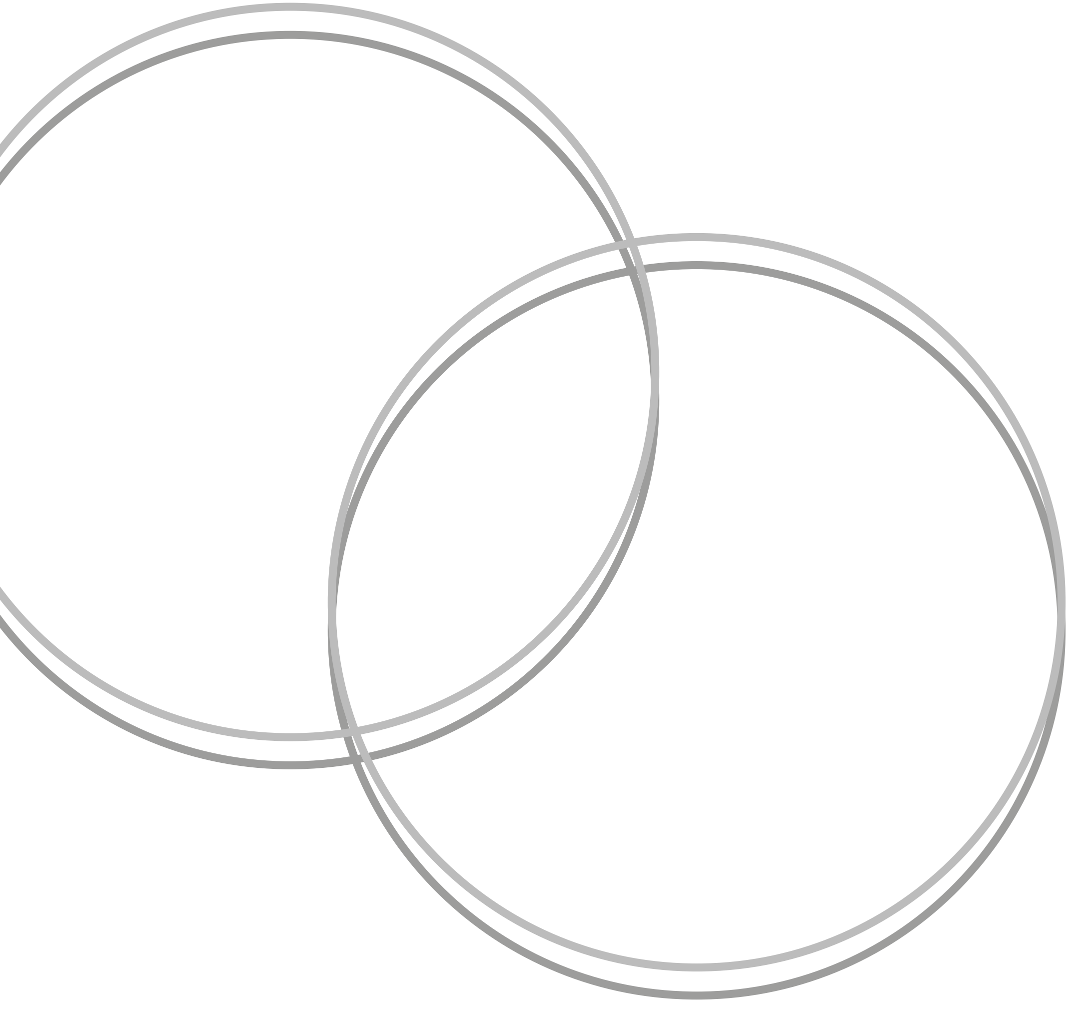
Oxford University Hospitals
NHS Foundation Trust

Surgery for Vestibular Schwannoma

Information for Patients



You have been diagnosed with a vestibular schwannoma and together with your Doctor are considering surgery as the most appropriate treatment. This leaflet aims to provide further information on that surgery to help you and your family.

If you have any questions or concerns that have not been covered please do contact us.

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About us

The Oxford skull base service is a busy, multidisciplinary specialist service looking after a large number of patients with vestibular schwannomas. Clinics, multidisciplinary team meetings and surgeries are based at the West Wing, John Radcliffe Hospital, Oxford. Radiosurgery is typically undertaken at the Churchill Hospital in Oxford. We work as a multi-disciplinary team of surgeons, specialist nurses, neuroradiologists, oncologists and pathologists. We all work closely together to ensure patients are comprehensively managed and supported. Listed below are some of our core team members:

Neurosurgeons

- Mr Sanjeeva Jeyaretna
- Ms Jane Halliday

Ear Nose and Throat (ENT) Surgeon

- Mr Samuel MacKeith

Oncologists

- Dr Claire Hobbs
- Dr Meera Nandhabalan

Specialist nurses

We have a team of specialist nurses.

Audiology

- Ms Eleanor Mace

Specialised Physiotherapy

- Ms Kate Browne

Neuroradiology

We have a team of specialised Neuroradiologists with whom we work closely.

Pathology

We have a team of specialised pathologists with whom we work closely.

What are vestibular schwannomas?

Vestibular schwannomas are benign (non-cancerous) tumours that arise from the cells that insulate the vestibular nerve as it travels between your inner ear and your brain. They are also known as acoustic neuromas. The vestibular nerve is the nerve of balance, and it travels together with the hearing nerve, the cochlear nerve. Together they are called the vestibulo-cochlear nerve.

There are a range of treatment options available. Treatment will vary according to a wide variety of factors such as the size and configuration of the tumour, its growth rate, symptoms, overall health age and patient choice.

As you will know the available options are:

- Active surveillance with scans
- Stereotactic Radiosurgery (SRS)
- Surgery

Surgery for vestibular schwannomas

Surgery is indicated for a wide range of reasons. Typically surgery is considered in patients with larger tumours, and young patients with growing tumours. It is a widely offered treatment option, which aims to remove as much tumour as safely possible to reduce pressure on the brain. Surgery cannot restore function in nerves that have already been damaged or destroyed by the tumour. Often the tumour is very adherent to the facial nerve and/or brainstem surface. In those situations it is safer to leave some tumour to preserve the function of those important structures than risk long term damage to them.

Small amounts of tumour not removed (remnant) are unlikely to cause any problems in the future. The risk of needing further treatment from a small remnant of tumour is approximately 5% in the long term. If a larger remnant has to be left to preserve important structures, treatment with stereotactic radiosurgery at a later date may be required. After surgery you will have follow up scans for up to 10 years.

There are three main surgical approaches and the one selected depends on tumour size, shape, position and hearing levels. It is uncommon to be able to preserve hearing with surgery and is usually only achievable in small tumours where there is good hearing before surgery. Attempting to preserve hearing may lead to a larger tumour remnant being left and even if hearing is preserved immediately after surgery, it may still deteriorate in the future.

The approaches will be discussed in detail with you by your surgeon before your operation. Each approach involves a general anaesthetic, an operation usually by both a Neurosurgeon and an ENT surgeon, and an incision on the affected side of the head, in slightly different places depending on the chosen surgical approach.

Surgery is a routinely used option for managing vestibular schwannomas but does carry risks.

The risks specifically related to the surgical removal of vestibular schwannomas

Facial weakness:

This is one of the most significant risks from surgery. The facial nerve (the nerve that supplies muscles of facial expression) and the vestibulocochlear nerve (hearing and balance nerve) run very closely together. Due to their position, the facial nerve is always attached to the surface of the tumour and is therefore at risk of damage during tumour removal. This risk is higher in larger tumours. During surgery the nerve is specifically monitored to try and reduce the risk of injury.

If you do have facial weakness it can affect your ability to close your eye, necessitating eye drops and sometimes patches to protect the eye in the short term. It can also affect your ability to make facial expressions and the way you eat and drink with that side of your face.

In the immediate and short-term period after the operation a higher number of patients do have facial weakness due to the technique involved in removing the tumour. In the long term (several months after surgery) most patients have normal or near-normal facial movement, as the nerve recovers from this. You will be given a more accurate idea of the risks of surgery to your facial nerve for your specific tumour by your surgeon.

Hearing loss:

Most vestibular schwannomas are diagnosed after the patient experiences a loss of hearing, which can be partial or total. Following surgery, the majority of patients will lose their hearing completely in the affected ear. We will review your hearing tests and look at the appearance of the tumour on the scan. With this information, we can advise you as to whether an attempt can be made to preserve your remaining hearing in that ear. This will be discussed in detail with you before the operation. Hearing rehabilitation options can be discussed again after surgery.

Tinnitus:

Some patients experience tinnitus (hearing a noise such as a high pitch noise or ringing sound) in the affected ear. Tinnitus usually occurs together with hearing loss which means tinnitus can be present even when you have no hearing in the affected ear after surgery. Even if you had no tinnitus before the operation, it may develop afterwards. For most patients tinnitus becomes less intrusive over time, however, if it persists we can provide support for managing this symptom.

Facial numbness:

Often patients with large tumours have numbness or pain in their face before their operation, due to compression of the trigeminal nerve which supplies sensation to your face. For those larger tumours this may not recover, and in some patients due to the adherence of the nerve to the tumour it can worsen. Again the specific risks of this happening will be discussed with you before your operation. If your trigeminal nerve is impaired, then if grit or dirt gets into your eye you might not be able to feel it, which can lead to damage and later infection. If you have facial numbness, particularly in combination with facial weakness, you will need to take particular care to ensure that your eye is protected. We can advise you on this if needed.

Damage to other cranial nerves:

Sometimes surgery can be complicated by damage to other cranial nerves. Other nerves that can be affected are those that control eye movements, leading to double vision, or the nerves involved in swallowing and speech. These are rare. If they do occur you will be supported by the appropriate therapist.

Cerebral spinal fluid (CSF) leak:

CSF bathes the brain in fluid. When the tumour is removed, the cerebro-spinal fluid pathways around the brain are opened. CSF can leak out either through the entry wound or into the ear and then down the nose. The risk of this leakage is around 4%. If a drainage tube is placed temporarily in the spinal fluid pathways in your back, the majority of leaks will settle down, but around one in three leaks will require a second operation to repair them.

Hydrocephalus:

Hydrocephalus is a build-up of the CSF on the brain which can occur before or after surgery as a consequence of the tumour or its treatment. If this occurs you may require a temporary or permanent drain (shunt) placed into the brain.

Infection:

There is a risk of infection which can be of the skin/wound, or less commonly brain fluid (meningitis). The majority of infections can be treated satisfactorily with antibiotics.

Problems with balance:

Patients often experience dizziness/balance problems immediately following surgery. This usually improves over days to weeks. Persisting balance problems can be helped with dedicated balance physiotherapy.

Headache and neck pain:

It is common to experience headache and neck pain after operations on the head, particularly for the first few days. This will be controlled with painkilling medication and improves with time.

Stroke/major neurological impairment:

There is a very small risk (less than 1%) of significant bleeding or injury at the site of surgery which can result in loss of life or stroke with significant disability including paralysis.

General Anaesthetic Risks:

As with any long operation there is a risk of developing a clot in the leg or lung (pulmonary embolus), a chest infection or heart problems.

What is it like to have surgery?

Before your operation, in addition to meeting your surgical team, you will undergo hearing tests if you have not already had them and you will also have a pre-operative assessment.

You usually come into hospital the night before your operation or the morning of it. The operation usually takes all day, and you can expect to be in hospital for 5-7 days after the operation. After your operation you may stay overnight in the intensive care unit for close monitoring before returning to the ward. You will be cared for by a team of staff who are very experienced in looking after patients recovering from this type of surgery. You may also require input from other health professionals such as physiotherapists, speech and language therapists, dieticians, pharmacists and ophthalmologists. We usually try and get you up as soon as you can from your operation to prevent complications from lying in bed and to help with recovery of your balance.

If you have a facial weakness after your operation you may be seen by our ophthalmology team while you are an inpatient, and our facial palsy team who will then continue to support you when you have been discharged. The same applies for our physiotherapy team, and any other members of our team that may be of help to you in your recovery in hospital, and on discharge home.

We advise that you have someone at home when you are discharged as you will be tired and possibly unsteady for a few weeks after your operation. Recovery from this operation is slow and steady. It will take approximately six to twelve weeks. Some people may take longer. Tiredness is common, and you will find immediately after your operation that you feel exhausted even after activities like getting washed and dressed, going to the shops, watching television, or talking with friends.

If you drive you can continue to do so after your operation and you do not need to notify the DVLA with this type of tumour. We would advise a period of recovery, normally four weeks, prior to returning to driving. If you develop severe giddiness or other complications such as hydrocephalus this may change so consult your Doctor or specialist nurse for further advice. If you work, return to work will depend on what sort of work you do and when you feel able.
We advise that you can fly approximately two months after your surgery provided of course you feel well enough to do so at that point. You should inform your insurance company of your surgery before you travel.

You will be initially followed up by the specialist nurse via telephone, approximately two weeks after your operation, although of course you are welcome to contact us at any time if you have concerns related to your surgery or recovery. Your consultant will see you in clinic approximately eight weeks after your surgery. The timing of your follow-up scans will depend on how much tumour has been removed. Your surgeon will discuss this with you after your operation and at follow-up.

Who to contact?

Many questions can and do arise and we are here to help you. We advise that if you have any questions, however small, or you are concerned about a change in symptoms, to contact our specialist nurses in the first instance who will be able to help. If you call and we cannot answer the phone, please leave your name, date of birth and contact number and we will get back to you as soon as we can.

Skull Base Surgery Specialist Nurses:

Oxford Neurosciences Department

John Radcliffe Hospital

01865 231427

Email: skullbasenurses@ouh.nhs.uk

Your specialist nurse is available to advise in office hours Monday to Friday by e-mail or telephone. Out of hours and at weekends you should contact your GP. If the GP has concerns then they should contact the on call neurosurgeons via the Oxford Acute Referral System on oars.ouh.nhs.uk. If you are unable to see your GP and you have urgent concerns then please contact the ward via the switchboard on 01865 741166 and ask for the ward coordinator for the Neurosciences Ward.

Our webpage contains further information on our team and service and can be found at: www.ouh.nhs.uk/skullbase/

Other useful contacts

BANA - British Vestibular schwannoma Association

Website: www.bana-uk.com/

Tel: 0800 652 3143

Acoustic Neuroma Support Oxford

Email: a.mayhead@btinternet.com

Hearing Link, UK Hearing Loss Organisation

Website: www.hearinglink.org

Contact their helpdesk by asking a question on an online Helpdesk form.

Tel: 0300 111 1113

SMS: 07526 123255

Email: helpdesk@hearinglink.org

Action on Hearing Loss Information Line:

Tel: 0808 808 0123

Textphone: 0808 808 9000

SMS: 0780 0000 360

Email: informationline@hearingloss.org.uk

Action on Hearing Loss Tinnitus Information Line:

Tel: 0808 808 6666

Textphone: 0808 808 9000

SMS: 0780 0000 360

Email: tinnitushelpline@hearingloss.org.uk

British Tinnitis Association

Website: www.tinnitus.org.uk/about-tinnitus

Facial Palsy

Website: www.facialpalsy.org.uk

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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