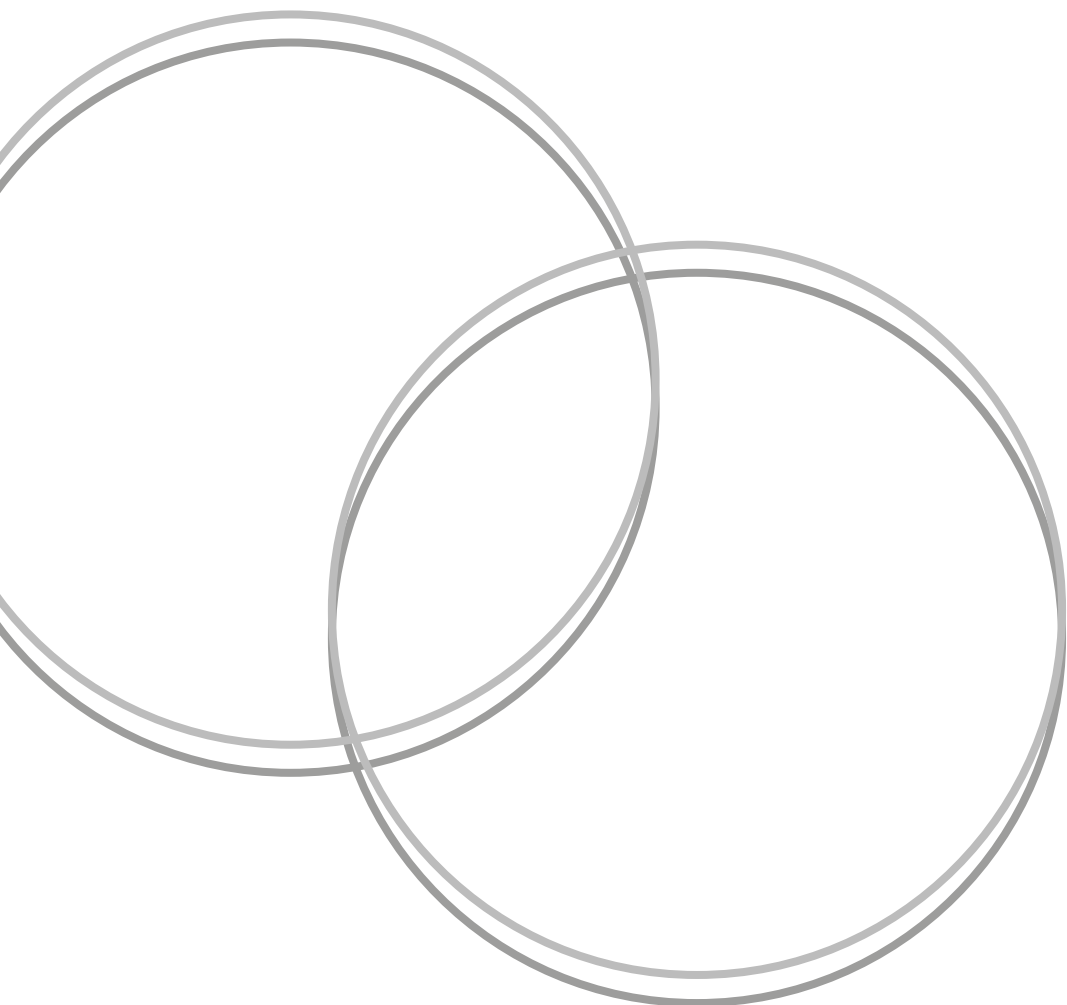




Oxford University Hospitals
NHS Foundation Trust

Vestibular Schwannoma

Information for Patients



You have been diagnosed with a vestibular schwannoma. This leaflet aims to provide further information on vestibular schwannomas 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

ENT Surgeon

- Mr Samuel MacKeith

Oncologists

- Dr Claire Hobbs
- Dr Meera Nandhabalan

Specialist nurses

We have a team of specialist nurses who are there to support you. Their contact details can be found at the end of the booklet.

Audiology

- Ms Eleanor Mace

Specialised Physiotherapy

- Ms Kate Browne

Neuroradiology

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

Pathology

We work with a team of specialised pathologists.

What is a vestibular schwannoma?

A vestibular schwannoma is a benign (non-cancerous) tumour that arises from the cells that insulate the vestibular nerve as it travels between your inner ear and your brain. It is also known as an acoustic neuroma. 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.

How common is a vestibular schwannoma?

Vestibular schwannomas account for around 6% of all tumours inside the skull. Every year, approximately 20 people out of every million in the population are diagnosed with one. They are slightly more common in women than men, and in those aged between 30 and 60 years. They are rare in children.

What causes a vestibular schwannoma?

It is not fully understood what causes the majority of vestibular schwannomas. In approximately 95% of people the cause is unknown and they are described as sporadic. In a small minority of patients they are due to a genetic condition called Neurofibromatosis Type II (NF2). However this is not common, and your vestibular schwannoma will be a sporadic tumour unless your Doctor has mentioned that you may have this genetic disorder.

What are the symptoms?

Most commonly symptoms start with gradual hearing loss on one side. This is thought to be due to the tumour affecting the hearing nerve. Hearing loss often occurs even if there is no growth in the tumour. This means that worsening hearing does not necessarily mean your tumour has grown. Other common symptoms are tinnitus, a sensation of ringing in your ear, and dizziness/vertigo. Tinnitus affects approximately 70% of patients with vestibular schwannoma. Dizziness/vertigo affects approximately 50% of patients. Balance can be affected due to compression of the balance nerve by the tumour, but as vestibular schwannomas tend to grow slowly your body can often adapt and compensate for the change such that some people do not notice any change in their balance.

Other less common symptoms, which tend to occur with larger tumours include:

- numbness or pain on one side of the face
- problems with limb coordination on one side of the body
- weakness on one side of the face
- headaches with blurred vision
- in rare cases, changes to the voice or difficulty swallowing

Diagnosis

This is typically made by performing MRI (magnetic resonance imaging) of the brain. Once vestibular schwannomas are diagnosed, because of their relative rarity, patients are referred to a specialist team who are experienced in managing these tumours. That is why you were referred to the John Radcliffe Hospital in Oxford. Here we work as a multi-disciplinary team which is made up of many clinicians, including Neurosurgeons, ENT Surgeons, Oncologists, Radiologists and Specialist Nurses. We work together to ensure that the highest quality of care is delivered throughout.

Our webpage address www.ouh.nhs.uk/skullbase/default.aspx gives you further information on our team.

Treatment of Vestibular Schwannoma

Although a new diagnosis of vestibular schwannoma can feel daunting, many of these are small and at least 50% may not require any intervention. Treatment varies according to a wide variety of factors such as the size and position of the tumour, its growth rate, symptoms, overall health, and age.

When you meet us in clinic we discuss your tumour with you, the treatment options available and the risks and benefits of each, to help you come to a decision as to what treatment would be best for you. You might also find it helpful to talk to other patients and you could contact one of the organisations in the Useful Contacts section about any patient support groups that meet in your area.

In addition to the treatments below we can offer help and support with symptoms you may have from your vestibular schwannoma, at all stages. This includes help with your hearing, tinnitus, facial pain if you have this, and your balance (see Frequently Asked Questions on page 10).

Available treatment options are:

Active Surveillance

For small tumours this is typically our recommended option, and many patients do not go on to require treatment. We typically perform a scan 6 months after the original scan, and then yearly after that if the tumour remains stable. If the tumour is stable, scans are later spaced to every two years up to ten years from the initial diagnosis. The overall duration of follow-up varies between patients. As vestibular schwannomas are benign, and typically slow growing this is a very safe approach. Close monitoring will allow us to reassess your options at each given time.

Specialist Radiotherapy

This is an effective technique that uses highly targeted doses of radiotherapy with the aim of stopping the tumour from growing any more. Growth control rates with this form of treatment are up to 95%. This is usually offered to patients with small but growing tumours, as an alternative to surgery. This can be delivered in one dose (radiosurgery) or several doses (radiotherapy). What type is offered, and whether this is a safe and appropriate option, depends on the size and shape of your tumour. Most of our patients wishing to be treated with specialist radiotherapy will have this in Oxford, at the Churchill Hospital. This will be discussed with you in more detail if required/appropriate by your Doctor.

Surgery

Surgery may be indicated for a wide range of reasons. Typically surgery is considered for patients with larger tumours, and young patients with growing tumours. It is a widely offered treatment option, which aims to remove the tumour completely or significantly reduce its size. Surgery cannot however restore function in nerves that have already been damaged by the tumour. Again this will be discussed with you in more detail if required/appropriate by your Doctor.

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 Specialist Nurse:

Oxford Neurosciences Department

John Radcliffe Hospital

Tel: 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.

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

Other useful contacts

BANA - British Vestibular schwannoma Association

Website: www.bana-uk.com/

Tel: 0800 652 3143

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 Tinnitus Association

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

Acoustic Neuroma Support Oxford

Email: a.mayhead@btinternet.com

Facial Palsy

Website: www.facialpalsy.org.uk

Frequently Asked Questions

What about Gamma Knife / Cyberknife?

Gamma Knife and Cyber Knife are alternative ways of delivering radiosurgery.

My hearing is worsening. What does it mean?

Unfortunately hearing loss in the affected ear is common with vestibular schwannomas. Worsening hearing does not necessarily mean your tumour is changing. In fact, hearing can deteriorate even if your tumour remains small and stable in size over many years. We can help with this by means of a hearing aid (see below).

My hearing level has suddenly worsened. What should I do?

Occasionally patients with vestibular schwannomas develop sudden hearing loss. If this occurs it is important to get an urgent repeat hearing test to confirm. Whilst again this does not mean anything has necessarily changed with your tumour, we would advise being referred to the on-call ENT team in your area for consideration of oral steroids which may improve the chances of some recovery.

Will having treatment improve my hearing?

Unfortunately, none of the treatment options will improve your hearing and most have a risk of worsening your hearing. A hearing aid is the most appropriate treatment for hearing loss from vestibular schwannomas. The type of hearing aid required will depend on how severe your hearing is and your ability to understand speech in the affected ear. We can refer you to the appropriate team to assess your hearing levels with a hearing test and then discuss the options for helping with the hearing loss you have.

My balance is poor and I am unsteady. How can this be helped?

For the majority of patients with vestibular schwannomas, especially those with small tumours, the reason for balance problems is weakness of the inner ear balance system on the affected side. The treatment for this is balance therapy (vestibular rehabilitation) with regular focussed exercises. This can be provided in Oxford by our balance physiotherapy department or locally if available. If you have a sudden or significant change in your balance it may be necessary to be reviewed in clinic. We can refer you for specialist physiotherapy if you are struggling with your balance.

Are there any lifestyle changes I should make?

There are no specific lifestyle changes recommended for patient's with vestibular schwannomas.

Can I drive?

There are no restrictions on driving for patients with a diagnosed vestibular schwannoma, and you do not need to inform the DVLA, unless you suffer with uncorrected double vision, or sudden and disabling dizziness. If you are in doubt please consult your Doctor for advice. If you have a bus, lorry or coach you must inform the DVLA if you have vestibular schwannomas on both sides, or if you suffer sudden and disabling dizziness.

For further advice please see: www.bana-uk.com/resources/practical-information/dvla-and-acoustic-neuroma-guidance/

Can I travel?

Yes, there are no travel restrictions, but we would recommend that you inform your insurance company of the diagnosis.

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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Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information



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