FACTSHEET Hearing health



Acoustic neuroma (vestibular schwannoma)

An acoustic neuroma is a rare, non-cancerous growth or tumour that develops on the balance nerve between the brain and inner ear, usually causing hearing loss, tinnitus or balance problems. This factsheet explains the causes and symptoms of an acoustic neuroma, and what treatment is available.

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Medical disclaimer

The information given in this factsheet is not medical advice and, by providing it, neither Action on Hearing Loss nor our audiology specialists undertake any responsibility for your medical care, or accept you as a patient. Before acting on any of the information contained in this factsheet, or deciding on a course of treatment, you should discuss the matter with your GP (family doctor) or other medical professional who is treating you.

What is an acoustic neuroma?

An acoustic neuroma is a rare and non-cancerous growth or tumour between the brain and the inner ear.

The term acoustic neuroma is technically inaccurate. That's because the tumour doesn't grow on the acoustic (hearing) nerve, and doesn't form from nerve tissue (a neuroma is a growth or tumour of nerve tissue).

In fact, the tumour develops on the balance nerve (vestibular nerve), which sends information about your balance from the inner ear to the brain.

The tumour is formed when the body produces too many **Schwann cells** – cells that play an important part in helping the nervous system to function properly. So, the technically correct name for the tumour is a **vestibular schwanomma**.

However, as the tumour is more commonly known as an acoustic neuroma, that's the term we use in this factsheet.

Acoustic neuromas can grow slowly over several years. Many stop growing altogether or have stopped growing by the time of diagnosis. In rare cases, the tumour can grow large enough to press on the brain and cause more serious problems of the nervous system. Most, however, are identified and treated before they reach this stage (see 'How is an acoustic neuroma treated?' on page 4).

As the tumour is non-cancerous, it doesn't spread around the body.

How common is an acoustic neuroma?

Every year, around two in 100,000 people are diagnosed with an acoustic neuroma.

What causes an acoustic neuroma?

When the body produces too many Schwann cells, they form a swelling. The balance nerve is particularly prone to this happening. It's not known why it happens, and it doesn't appear to be related to lifestyle, other health issues or mobile phone use.

In a small number of cases (less than 5%), acoustic neuromas are caused by neurofibromatosis type 2, a rare, inherited condition that causes non-cancerous tumours to grow on nerve tissue in the body, particularly in the head and spine. People with this type of acoustic neuroma usually develop tumours on both sides, which means they are likely to have hearing problems in both ears.

What are the symptoms of an acoustic neuroma?

Small acoustic neuromas may not cause any symptoms and are often found when someone has a scan for other reasons.

The most common symptoms are:

- Hearing loss this is the most common symptom and usually develops gradually in one ear (on the side where the tumour is). Nine out of 10 people with an acoustic neuroma have hearing loss. For a small number of people, the hearing loss may be sudden or it may come and go. People who develop an acoustic neuroma as part of neurofibromatosis type 2 may have hearing loss in both ears.
- for hearing noises (such as ringing or buzzing) that don't have an external source. About 70% of people with an acoustic neuroma experience tinnitus in one ear. However, tinnitus is common and most people with tinnitus don't have an acoustic neuroma.

 Dizziness and balance problems – the tumour may cause problems with the balance system, including unsteadiness or vertigo (the sensation that you or the environment around you is moving or spinning). However, not everyone experiences this.

As the tumour continues to grow, later symptoms can include:

- numbness, tingling or pain on one side of the face
- facial weakness or twitching
- double vision
- an increase in pressure inside the head (hydrocephalus) – this is a rare, but more serious, complication of acoustic neuroma and may cause: headaches, blurred vision, nausea, problems with physical co-ordination (including walking), incontinence, confusion, drowsiness and even coma.

The symptoms of an acoustic neuroma may be more severe for some people than others.

If you experience any of the symptoms described above, see your GP.



To find out more about hearing loss, tinnitus and balance problems, see our **Hearing health** and **Tinnitus** factsheet ranges.

How is an acoustic neuroma diagnosed?

Most people with an acoustic neuroma will initially visit their GP with symptoms such as hearing loss in one ear, tinnitus in one ear or dizziness. If you have these symptoms, your GP should refer you to the ear, nose and throat (ENT) clinic of your local hospital, where a specialist will take a medical history and perform a hearing test.

If you have these tests and they suggest the possibility of an acoustic neuroma, the consultant will usually arrange for you to have a magnetic resonance imaging (MRI) scan. Only about 1–5% of these scans show an acoustic neuroma. If you are unable to have an MRI scan, a computerised tomography (CT) scan may be arranged instead.

MRI scan

This is the most common, and accurate, test for identifying acoustic neuromas. The scan uses a strong magnetic field and radio waves to produce a detailed picture of the inside of your head. It's a painless procedure that involves lying flat on a bed that slides into a narrow scanner.

You may be provided with earplugs or headphones if the scanner is very noisy. The whole process usually takes about 30 minutes.

Most MRI tunnels are quite narrow, so if you have severe claustrophobia (a fear of enclosed spaces), you may find the process unpleasant.

If you have any concerns, you should discuss them with the team arranging the scan.

CT scan

If you're not able to have MRI scans (for example, if you have a pacemaker or a metal surgical implant in your head), you may have a CT scan instead. This scan uses X-rays to produce pictures of the inside of your head. It is less sensitive than an MRI scan, so may not pick up small tumours.

CT scanners are much quieter than MRI scanners. The scan is painless and usually takes 10 minutes. The CT scanner is less narrow than the MRI and may, therefore, be more suitable for you if you have severe claustrophobia.

How is an acoustic neuroma treated?

Acoustic neuromas grow very slowly (or not at all in many cases), so there's no need for you to rush into a decision regarding treatment – you should consider all of your options carefully and discuss them in detail with your specialist.

The treatment options include:

- monitoring the tumour to check its growth (see page 5)
- stereotactic radiosurgery or radiotherapy to stop the tumour from growing (<u>see page 5</u>)
- microsurgery to remove the tumour (see page 6).

The treatment that's recommended for you will depend on your wishes and:

- your age and general health
- the size and position of the tumour
- results of scans and other tests.

Acoustic neuromas are assessed and treated in regional specialist centres, so you may have to travel for the treatment.

What is monitoring?

Small or medium-sized acoustic neuromas (usually less than 20mm) may be carefully monitored over a period of time with MRI or CT scans. This generally means having a scan once every 1-2 years.

If the tumour remains stable in size over a period of time (usually 5–10 years), further growth is very unlikely. You won't then need to attend any follow-up appointments. If the symptoms or tumour size change, more active treatment can be discussed.

What are stereotactic radiosurgery and radiotherapy?

Stereotactic radiosurgery and radiotherapy are highly specialised forms of radiotherapy that precisely target the tumour with high-energy X-rays.

Radiotherapy doesn't remove or shrink the tumour, but it is very successful at stopping further growth.

Stereotactic radiosurgery

Stereotactic radiosurgery is a surgical procedure that can be carried out in a single day, with no need to stay overnight in hospital.

After you have been given a local anaesthetic, a temporary frame or mask is used to keep your head still during treatment. You will also have an MRI or a CT scan, or both, before treatment.

The treatment itself is like having an X-ray. You lie flat in the radiotherapy machine and cannot see or feel the rays.

Depending on the type of machine used, treatment will last between 10 minutes and two hours. You may feel a little tired after the treatment, and most people take about a week off work. From the day after treatment, it's fine to drive, as long as you feel ok.

Stereotactic radiotherapy

Stereotactic radiotherapy, a similar treatment, is given as 25–30 small doses of radiation. You have to visit the radiotherapy department every weekday for 5–6 weeks.

Radiotherapy is generally used for small or medium-sized acoustic neuromas (less than 25mm). Occasionally, it is used for larger acoustic neuromas, in people who cannot or do not want to have microsurgery.

Side effects

For most people, stereotactic radiosurgery and radiotherapy have very few major side effects. They may cause tiredness, and any mild lightheadedness should settle over a few weeks. Tinnitus and imbalance may worsen following treatment and can come and go for a few months.

Your hearing may slowly reduce in the years after treatment, although this is also true of people who are having their acoustic neuroma monitored.

There is a small risk of damage to the nerves around the tumour, particularly the nerves that control the sensation and movement of the face.

Finally, all radiotherapy to the brain slightly increases the risk of a stroke and the development of another tumour. However, with this very precise treatment, these risks are very small and occur decades after the original treatment.

After treatment, the medical team arrange monitoring and follow-up scans for a number of years. There is a small chance that the acoustic neuroma will continue to grow after radiotherapy treatment. If it does, other treatment options will be considered, including surgery, monitoring or further radiotherapy.

What is microsurgery?

Acoustic neuromas can be removed through microsurgery, carried out under general anaesthetic. A neurosurgeon and ENT surgeon, often working together, will perform the surgery.

Several different surgical techniques may be used to remove an acoustic neuroma. The technique chosen will depend on:

- the size of the tumour
- its location
- whether hearing in the affected ear is still good
- the surgical team's experience and preference.

Acoustic neuromas can usually be removed completely. If the tumour is large, the surgeon may leave a small part behind to minimise the risk of damaging surrounding areas, such as the facial nerve.

If a small part of the tumour is left behind, it can be monitored with scans or treated using stereotactic radiotherapy (see page 5), if necessary.

Recovery from microsurgery

People recover at different rates.
Following microsurgery to remove an acoustic neuroma, people usually need 5–10 days in hospital to recover. You should, normally, be able to return to work after about two months. Full recovery from surgery may take up to six months, and any facial weakness can continue to improve over two years.

Risks of microsurgery

Microsurgery to remove an acoustic neuroma is a major procedure. In each case, the surgical and anaesthetic team will make a careful assessment in order to minimise any potential risks. The major risks of microsurgery are fortunately very low. The serious risks of damage to the nervous system, through a stroke, infection or bleeding, and even risk to your life, are very low (less than 1%).

Hearing loss

Microsurgery almost always affects any remaining hearing in the affected ear – which usually results in complete hearing loss.

For smaller tumours, it may be possible for the surgeon to save some of the hearing in the affected ear, depending on the surgical technique used. For larger tumours, it's more than likely that all hearing in the affected ear will be lost.

Hearing in the 'good' ear is not affected by surgery and most people are able to hear well in most situations. It may be more difficult to work out where sounds are coming from, and to hear a conversation if there's a lot of background noise.

Various hearing aids are available that may help to improve hearing in the affected ear or transmit sound to the unaffected side. The ENT consultant or audiologist will advise you on the most suitable options.



For more information, see our leaflet *Getting hearing aids* and our factsheet *Boneconduction hearing aids*.

Facial paralysis

Microsurgery for an acoustic neuroma can lead to facial weakness, because the facial nerve is very close to the tumour. Even slight injury to the facial nerve can lead to temporary or permanent problems, causing the face to droop or sag.

Although the facial nerve is carefully monitored during surgery, it may not be possible to avoid injury.

These symptoms often improve over the 6–12 months following surgery. However, some damage to the facial nerve may be permanent. Weakness of the eyelid may make it difficult to close your eye when blinking. You may need lubricants and eye-drops to keep your eye moist.

In the long term, some people may need to have an operation to help them close their eyelids when blinking. Weakness of the face and at the corner of the mouth may cause leakage from the mouth when eating and drinking.

If this does happen, you may be able to discuss options for managing the condition with a facial plastic surgeon. Facial paralysis may also have a cosmetic effect. The specialist team can provide the necessary support to help you manage the condition.

How common is facial nerve damage?

The likelihood of facial nerve damage depends on the size of the acoustic neuroma and the technique used to remove it. In cases where the tumour is small, around 10% of people will have their facial nerve affected after treatment.

For large tumours, 30-40% will have some degree of weakness after surgery, although this often improves with time. Around 10-20% of patients may have more permanent or severe weakness.

Cerebro-spinal fluid leak

Cerebro-spinal fluid (CSF) is a clear, watery liquid that surrounds the brain. After surgery for acoustic neuroma, this fluid may leak out from the skin wound or ear canal, or drip from the back of the nose. This can occur in up to 30% of cases.

A CSF leak increases the risk of meningitis (an infection of the protective membranes that surround the brain and spinal cord) in the future.

In cases of CSF leak, the surgical team will recommend bed-rest for a few days after surgery and raise the head of the bed slightly. Some CSF may be drained off using a spinal catheter (a flexible tube) placed in the lower back in order to reduce pressure and help to stop the leak. In some cases of persistent CSF leak, a further operation may be needed to repair the leak.

Balance

After microsurgery, some people have balance problems caused by damage to the balance organ (in the inner ear) on the side affected by the tumour. These problems will continue until the balance organ on the unaffected side, and the brain, readjust. Sometimes, this can be a slow process, taking several months.

People who experience balance problems may need to ask their GP for a referral to a specialist in balance disorders.



For more information about balance disorders, see our factsheet *Dizziness and balance problems*.

Where can I get further information about acoustic neuromas?

Action on Hearing Loss Library

Our library has specialist publications ranging from academic journals to books for children. It is the largest library in Europe on deafness and hearing loss.

330-336 Gray's Inn Rd London WC1X 8EE

Telephone/textphone: **020 7915 1553**

Email: rnidlib@ucl.ac.uk

Website: actiononhearingloss.org.uk/ how-we-help/information-and-resources/

action-on-hearing-loss-library

Other organisations

Brain & Spine Foundation

A charity providing information and support for people with brain and spine conditions.

Brain & Spine Foundation LG01, Lincoln House Kennington Park 1–3 Brixton Road London SW9 6DE

Telephone: 0808 808 1000

Email: <u>helpline@brainandspine.org.uk</u>

Online contact form:

brainandspine.org.uk/helpline-contact-

<u>details</u>

Website: <u>brainandspine.org.uk</u>

British Acoustic Neuroma Association (BANA)

A charity providing information and support for people with acoustic neuroma.

Tapton Park Innovation Centre Brimington Road Chesterfield Derbyshire S41 OTZ

Telephone: **01246 550011**Email: admin@bana-uk.com
Website: bana-uk.com

Let's Face It

International support network for people with facial disfigurement, their families, friends and professionals.

Let's Face It 1 Victoria Place 90 Westgate Bay Avenue Westgate on Sea Kent CT8 8NG

Telephone: **01843 491 291**Email: chrisletsfaceit@aol.com
Website: lets-face-it.org.uk

Changing Faces

A charity working to help people who have a disfigurement find a way to live the life they want.

Support, information and advice Telephone: **0300 012 0275**

Email: support@changingfaces.org.uk

Website: changingfaces.org.uk

Skin camouflage service Telephone: **0300 012 0276**

Email: skincam@changingfaces.org.uk

General enquiries

Telephone: **0345 450 0275**

Email: info@changingfaces.org.uk

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The Information Standard certifies us as producers of high-quality, evidence-based information.

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For a list of references for this factsheet, please email references@hearingloss.org.uk

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Our expert information covers everything you need to know about:

- hearing loss and deafness
- tinnitus
- ear problems and treatments
- hearing aids and cochlear implants
- useful products and technology
- communication tactics and support
- benefits and grants
- your rights.

Visit our website <u>actiononhearingloss.org.uk</u> or call our Information Line (<u>see last page</u>) for information, support and publications. You can also find out about services in your area, our hearing research, and how you can get involved.

Please help us support others

We provide our leaflets, factsheets and Information Line service free of charge to anyone affected by deafness, tinnitus or hearing loss in the UK. We rely on the generosity of our supporters to help us do this. We would be very grateful if you would consider making a donation – of as little or as much as you can afford.

Please send a cheque, payable to Action on Hearing Loss, to:

Freepost RTLX-CZKX-BTTZ
Action on Hearing Loss
1-3 Highbury Station Road
London N1 1SE

(No stamp needed)

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M 0203 227 6185

Thank you.

Our purpose is to help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way.

To find out more about what we do and how you can support us, go to actiononhearingloss.org.uk

Action on Hearing Loss Information Line

Telephone: **0808 808 0123**Textphone: **0808 808 9000**SMS: **0780 000 0360**

(standard text message rates apply)

Email: information@hearingloss.org.uk

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