Cambridge Skull Base Unit

Vestibular Schwannoma (VS)

Introduction

Addenbrooke’s Hospital in Cambridge has a specialist team (Skull Base) who deal with the rare inner ear tumour known as vestibular schwannoma. This condition is also known as acoustic neuroma. Our team aim to help you understand about vestibular schwannoma, its treatment and its effects on you.

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.

Who we are

We run a skull base meeting and clinic on the second and fourth Friday of each month, and smaller clinics on Monday and Tuesday afternoons. The meeting consists of different specialists, and you may meet more than one clinician at your appointment.

The Cambridge skull base team has a great deal of experience looking after patients with skull base tumours. It is one of the largest skull base units in Europe and is happy to share its research findings with you. Our website address is http://www.cuh.org.uk/skull-base-service

Most of your outpatient appointments will take place in Clinic 10, on Level two (ground floor) of the outpatient department. It is about 5 to 10 minutes walk from the main bus stop to the Addenbrooke’s entrance.

If you are parked in the main hospital car park and need assistance with transport to your appointment, a courtesy bus is provided every 10 minutes between 07:30 and 16:00. It stops outside the main entrance to the outpatient’s hall. It can accommodate one wheelchair at a time.

What is VS?

It is a benign tumour, not a cancer, which grows on the balance nerve. This nerve runs from the brain through a narrow channel in the bone of the skull to the inner ear (the internal auditory canal). These tumours originate inside the bony channel and grow into the space where the brain is situated. Once the tumour reaches a certain size, it can start to press on the brain. It does not grow into the brain tissue itself. The hearing nerve (or cochlear nerve) and the facial nerve are also present within this channel, and it is possible for them to be compressed by the tumour, which may cause you some symptoms.
What causes VS?

These tumours are caused by damage to the genetic material inside the lining of the balance nerve. The cause of this genetic damage is unknown. It is not caused by anything you have done and it cannot be caught from someone else. It is not passed on to your children.

This is slightly different in a rare condition called Neurofibromatosis Type 2 (NF2), where people may have multiple benign lesions. Only 5% of vestibular schwannomas are in people who have NF2, and the condition normally arises in teenagers or young adults. If we feel that you need any further investigation for this condition, we will discuss this with you at your outpatient appointment.

How common are VS?

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 VS grow?

Approximately 40% of vestibular schwannomas grow after diagnosis but the growth rate is usually very slow with an average growth rate of 1-2mm a year. They can occasionally grow faster and the pattern of growth is very variable. However, the rate of growth means that it is generally safe to plan treatment ahead of time.

What symptoms do VS cause?

Single-sided hearing loss is usually the most common symptom that people with vestibular schwannomas experience. Some people may lose their hearing altogether but the majority notice a gradual deterioration in their hearing on the affected side.

Tinnitus is also another common symptom, which is a ringing or buzzing sound in the ear. This can be quite troublesome but there are a number of effective therapies which can help. Some patients also experience imbalance or dizziness. Other symptoms include numbness of the face, aching of the bone behind the ear, twitching of the facial muscles and a feeling of fullness in the ear. Weakness of the muscles of the face is unusual but has been reported by some people with vestibular schwannomas. Some people have no symptoms at all, and the vestibular schwannoma is discovered 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.
If a vestibular schwannoma is allowed to grow very large, it can potentially be a life-threatening condition as the tumour can press onto parts of the brain that control breathing and heart rate. However, we monitor and treat these tumours to prevent this from happening.

**How can vestibular schwannomas be treated?**

There are three main ways of treating vestibular schwannomas. If the tumour is small, then many patients prefer to undergo a period of observation (known as active surveillance, ‘watch, wait and rescan’, or WWR). 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. We are able to offer this because 60% of vestibular schwannomas do not grow and cause only mild or manageable symptoms.

The other treatments are surgery and radiotherapy. If you have the tumour removed, it is usually possible to remove it completely, but as with any surgery there are risks to having an operation, such as facial weakness. Radiotherapy is very successful at stopping the tumour from growing, but it does not remove the tumour. In the few cases where it does not stop the growth, it can make any surgery needed much more difficult. The chances of complications with radiotherapy are generally less than those from surgery although in the long term there is a very small chance that the tumour could become cancerous. The risk of this is around 1% for each decade after treatment. Some people find it very difficult to decide whether surgery or radiotherapy would be best for them, and the doctors, nurse practitioners and radiographers can help you to make the right decision for you.

**Watch and wait**

**Why is my vestibular schwannoma being observed?**

You have a small tumour, which is not compressing the brain. This means that the tumour is unlikely to cause any problems in the short term. In this situation it is reasonable to observe the tumour rather than treat it by surgery or radiotherapy. The options for treatment will have been discussed with you and you have decided to undertake a period of observation to monitor your tumour.

**How often will I have a scan?**

At Addenbrooke’s, patients undergoing observation of their vestibular schwannoma are scanned six months after the original scan.

If this is stable, we then:

- scan yearly for three years (for example at 18 months, 2.5 years and 3.5 years)
- then every two years for the following six years
- then every three years after that

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 Addenbrooke’s so that your specialist can look at the scans carefully themselves. The MRI scan takes around thirty minutes and you may have an injection of dye in your hand. The scan is painless but it can be quite loud inside the scanner. Once the scan is done, the specialist will look at the scan and write to you with the result. If you e-mail skullbase@addenbrookes.nhs.uk to inform us that you have had your scan, we will be able to review the report and send it to you sooner. If you do not wish to contact us, you will still receive your results, but it may take longer.

**Will I need to be seen again?**

We will see you at two and five years after your first appointment to review your symptoms and your scans with you. If you remain well and the scan shows that the tumour has not grown then we do not need to see you after this. We normally request a repeat scan when we write to you with the result of your most recent scan and we will inform you when to expect this in your letter.

**What happens if my symptoms change?**

If there are any changes in your circumstances, we will be very happy to see you again and discuss any issues you may have. We will then be able to discuss the new situation with you and run through the treatment options available. Please contact the nurse practitioners on (01223) 348672 if you are concerned about a change in your symptoms.

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

If the scan shows there is growth of the tumour, then we will arrange for you to come to Addenbrooke’s so that we can show you the scan and discuss what should be done. If there is a small amount of growth and the tumour is not touching the brain, then it may be possible for us to continue observing the tumour. However, if the tumour is starting to compress the brain, then we would probably recommend either radiotherapy or surgery in order to treat the tumour. These forms of treatment will be fully discussed with you so that you can make an informed decision about which type of treatment you would like.

**What happens if I decide to have a different type of treatment?**

You can change your mind about what type of treatment you are having at any time. If you would like to change to a different type of treatment, then please contact us and we will be happy to see you at Addenbrooke’s in order to discuss the issue with you.

**Surgical removal of vestibular schwannoma**

Complete removal of the tumour at surgery is achievable in the majority of cases and only 1% of tumours not fully excised will start growing again. In patients who have small tumours and socially useful hearing (i.e. can use the telephone), an attempt can be made to preserve the remaining hearing on the affected side.

However, only around one in three of these patients will have any hearing at all in the affected ear after the operation.
In patients who have large tumours, or those who have no socially useful hearing, it can be assumed that hearing will be permanently lost on that side after surgery.

Your surgeon will discuss with you whether it is possible to attempt to save some hearing on the affected side. This affects the technical details of the operation and how we reach the area.

A hearing-preservation operation is described as a retro-sigmoid operation.

Most non-hearing preservation operations are carried out via a translabyrinthine approach. This is through the bone behind the ear.

Your surgery will be performed by a neurosurgeon and an ENT surgeon.

What is it like to have surgery?

Before your operation
You will usually be seen in our pre-admission clinic by a specialist nurse practitioner. At this clinic, we shall ask you for details of your medical history and carry out any necessary clinical examinations and investigations, such as audiology, ECG and blood tests.

This is a good opportunity for you to ask any questions about the operation, and please feel free to discuss any concerns you might have at any time.

You will be asked if you are taking any tablets or other types of medication – these might be ones prescribed by a doctor or bought over the counter. It helps us if you bring details with you of anything you are taking (for example, bring the packaging with you).

Most people who have had this type of operation will need to stay in hospital for approximately five to seven days. Sometimes we can predict whether you will need to stay for longer than usual. Your doctor will discuss this with you before you decide to have the operation. We recommend that you have someone at home with you for the first two weeks after the surgery.

Hair removal before an operation
For most operations, you do not need to have the hair around the site of the operation removed.

However, with this type of surgery we need to remove a small amount of hair from your head in order to see and reach your skin. We will do this by using an electric hair clipper, with a single-use disposable head, on the day of the surgery.

Please do not shave the hair yourself, or use a razor for hair removal, as this can increase the risk of infection to the site of the operation.

If you have any questions, please ask the healthcare team who will be happy to discuss this with you.
During the operation itself

This operation involves the use of general anaesthesia so you will not be awake or aware of your surgery. The operation will normally last all day.

For most operations, we make an incision behind the ear and remove a small amount of bone to give us access to the tumour. When we close the wound, we remove a small piece of tissue from the outer thigh (usually the right side) to seal up the bone of the ear. This is necessary to reduce the risk of cerebro-spinal fluid (the fluid surrounding the brain) getting into the ear and then draining out through the nose via the small tube that connects the two.

Occasionally, a small amount of capsule (covering of the tumour) will be left in place if it is attached to important structures, for example the facial nerve. This decision will be made if there is concern that removing all of the capsule will cause nerve damage. Surgery cannot restore function in nerves that have already been damaged or destroyed by the tumour.

After the operation

You will wake up in the recovery room after your operation. You might have an oxygen mask on your face to help you breathe more easily. You might also wake up feeling sleepy.

After this operation, most people will have a small tube in one of the veins in their arm. This might be attached to a bag of fluid, which hydrates you until you are well enough to eat and drink by yourself. You will also have a urinary catheter which involves inserting a small tube into your bladder to drain urine; and sometimes a thigh drain.

While you are in the recovery room, a nurse will check your pulse and blood pressure regularly. When you are well enough to be moved, you will be taken to a ward. If your operation is very long, you may stay in the neuro critical-care unit (NCCU) overnight so that you can be monitored closely.

Sometimes, people feel sick after an operation, especially after a general anaesthetic, and might vomit. If you feel sick, please tell a nurse and you will be offered medicine to make you feel more comfortable.

Eating and drinking: you can eat and drink when you feel ready, which is usually 24 hours after surgery. You may experience altered taste and a dry mouth. If this is causing you problems your GP can prescribe you artificial saliva.

The surgical site: at first, there will be a small dressing behind your ear, and you may have some steri-strips or stitches underneath. As the wound heals, you will have a scar but in most people this is very small and not particularly noticeable. You will also have two small wounds on your forehead due to the position you were held in for surgery.
For some patients we might do a lumbar puncture (withdrawing some cerebro-spinal fluid from your back by inserting a needle). This is to take the pressure off the operation site to give the wound a chance to heal.

**Getting around and about:** after this operation, we will try to get you up and walking as soon as we can, to help prevent complications from lying in bed and to help with balance. The physiotherapists will help you with advice and exercises in regards to balance and facial weakness should you have one.

**When you can resume normal activities including work:** recovery from this operation is slow and steady. It will take approximately eight to twelve weeks. You should not return to work until you have been reviewed in the outpatient clinic, which will be approximately six weeks after surgery.

It can take a long time to build up your energy levels and do not be tempted to go back to work too early as this is likely to cause you to become tired, very quickly. If you have a job that allows you to resume work on a part-time basis, then take this opportunity and gradually build up to your previous hours.

If you feel that you need adaptations to your workplace or your workplace would like further information on how to help you with your hearing loss, or if you are worried that you will not be able to return to work, then please speak to one of the nurse practitioners.

**Special measures you need to take after the operation:** you will be given more detailed information about any special measures you need to take after the operation. You will also be given information about things to watch out for that might be early signs of problems (for example, infection).

**Driving**
There is no need to inform the DVLA (Swansea) that you have had surgery, unless specifically instructed to do so by a medical team. However, our advice may differ if you have an HGV licence so please let us know if this is the case for you. The DVLA’s advice is that you do not return to driving until ‘fully recovered from the surgery.’ This varies enormously between patients and depends on your ability to perform an emergency stop, being able to glance in your mirrors and look right and left without feeling nauseous or dizzy. Once you feel able to do these, you are able to return to driving. To begin with, only drive short distances, and gradually increase the distance.

**Flying**
Travelling by aeroplane should be avoided for at least three months after vestibular schwannoma surgery.

**Check-ups and results:** you will be given an outpatient appointment to be reviewed by the neurosurgeon about six weeks after surgery. You will also be asked to attend an appointment to see the ENT surgeon 12 weeks after surgery. If the surgeons have been able to fully remove the tumour and you feel well, we will then review you at one year after your surgery (this may be via our telephone clinic), and again at two years following a final MRI scan to check for any residual tumour.
Serious or frequently occurring risks

The risks of any surgical operation:
- **Haemorrhage** - (less than 1%). Although the risk of bleeding is very small, when it occurs in a confined space, for example next to the brainstem, it can result in serious permanent neurological disability. This can include weakness or paralysis, difficulty in breathing or impaired swallowing.
- **Respiratory complications** – chest infections, which can usually be treated with antibiotics and chest exercises with physiotherapists.
- **Blood clots** – there is a risk of deep-vein thrombosis in the legs, which occasionally pass to the lungs (pulmonary embolism).
- **Wound problems** - including wound infection or leakage.
- **Heart** - for example, abnormal rhythm or heart attack.
- **Death** - (less than 1%)

The risks specifically related to the surgical removal of vestibular schwannomas:
- **Facial weakness**: the facial nerve (which is a nerve that supplies the muscles of facial expression) and the acoustic nerve (the nerve of hearing and balance) run very close together. Due to their anatomical position, the facial nerve is attached to the surface of the tumour and is at risk during tumour removal. There is a 5 - 30% risk of facial weakness after this operation depending on the size of the tumour and how tightly it is stuck to the facial nerve.

  With small tumours, it is nearly always possible to preserve the facial nerve anatomically (i.e. not seen to damage it ‘by eye’), but the facial muscles may be weak for a number of months afterwards due to bruising.

  With some large tumours, and even very occasionally with small tumours, it is not possible to spare the facial nerve. If the facial nerve is completely lost, or fails to recover after the operation, there are a number of plastic surgical operations that can be undertaken to restore some function (your doctor can discuss this with you).

  You may experience problems with a dry mouth and dry eye after surgery. Your doctor can prescribe you artificial saliva for your mouth. You should use regular eye drops and ointment at night, and may need to tape your eye closed at night to prevent corneal damage.

- **Loss of hearing on the affected side**: 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.
- **Tinnitus**: some patients experience tinnitus (for example a ringing noise) in the affected ear. Even when hearing is lost completely after surgery, it is possible that you will still have tinnitus. Even if you had no tinnitus before the operation, it may develop afterwards. However, it is unusual for tinnitus to be dramatically worse after an operation.

- **Cerebral-spinal fluid (CSF) leak**: CSF bathes the brain in fluid. When the tumour is removed, the CSF 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 leakage is around 4%. The majority of leaks will settle down over a few days if a drainage tube is placed temporarily in the spinal fluid pathways in your back. However, around one in three leaks will require a second small operation to repair them.

- **Infection**: the operation to remove a vestibular schwannoma is long, and the ear can contain micro-organisms that can get inside the head. These can infect the cerebro-spinal fluid and cause either a local wound infection or meningitis. If there is a leakage of cerebro-spinal fluid after surgery (see above) this can cause infection. The majority of infections can be treated with antibiotics. Very occasionally, there can be serious and longstanding problems from infection inside the head. Your doctor can discuss this with you on request.

- **Problems with balance**: in many cases with vestibular schwannoma, the balance nerve would have been slowly destroyed by the growing tumour. As the tumour grows slowly the brain has been able to compensate for the reduction in information it receives about balance by relying on the other ear. The tumour can only be removed by cutting through the nerve of balance in the affected ear. Therefore, if before the operation there was some function in the nerve, you will feel dizzy and unsteady after the operation until your brain gets used to it. Your balance may be tested before the operation to see how likely this is to happen and your surgeon will discuss with you the likelihood of you being unsteady or dizzy after surgery. In addition, we will need to temporarily displace the cerebellum (the balance part of your brain). There is a very small risk that this part of your brain could be injured during removal of the tumour which might result in permanent unsteadiness.

- **Difficulty swallowing**: in large tumours (generally those more than 3cm), the nerves that control swallowing and supply the vocal cords might be stuck to the tumour. If this is the case, these nerves might not function after the tumour has been removed. This can result in difficulty swallowing and hoarseness of the voice for a number of months after surgery. Very occasionally, problems of this kind are permanent.

- **Stroke/major neurological impairment**: there is a very small (around 1%) risk of major neurological impairment following surgery. The greatest risk is if there is any bleeding into the cerebellum or around the brainstem after surgery.

  A further small risk is of bleeding from the important blood vessels supplying the brainstem and cerebellum, which can become quite stuck to the tumour, particularly if it is of a large size.
- **Headache and neck pain:** as we need to gain access to the bone behind the ear during surgery, we need to disturb some of the neck muscles in this area. This will cause some neck pain and stiffness. It is common to experience a headache after operations on the head, particularly for the first few days. This will be controlled with painkillers.

- **Numbness of the face:** with large vestibular schwannomas, the trigeminal nerve (the nerve which is responsible for feeling/sensation on the face) can also become stuck to the tumour. If this nerve is damaged during the operation, you can experience numbness on that side of the face. Our greatest concern here is if the surface of the eye becomes numb. If you are not able to feel the surface of the eye, you would not be able to tell if grit or dirt gets into the eye, and this 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. If this is necessary, you will be taught how to do this. This will involve regular use of eye drops and ointments, and taping your eye closed at night.

**Further information**

If you require more information, please contact the nurse practitioners and they will be able to advise you or direct you to further sources of information.

**Radiotherapy treatment to vestibular schwannoma**

**What is radiotherapy?**

Radiotherapy is the use of very focussed high energy x-rays to treat tumours. It can be delivered as a single or small number of treatments and this is normally called stereotactic radiosurgery or SRS. Alternatively it can be divided into 30 treatments (fractions) which are given daily (Monday to Friday) for several weeks; this is called fractionated radiotherapy (RT). Both forms of radiotherapy treatment can be given at Addenbrooke’s in the Oncology Centre on an outpatient basis where you do not have to stay in hospital overnight. To decide which form of radiotherapy is best for you involves an outpatient appointment to see you, look at your MRI scans and to assess the size of your tumour, its location and also to consider your own personal preference.

**What is the aim of SRS or fractionated radiotherapy?**

Radiotherapy aims to stop your tumour growing and for some patients the lesion may shrink in the years following treatment but it will not disappear completely and radiotherapy will not remove your tumour. Radiotherapy for vestibular schwannoma is very successful and control rates (stopping growth) for either form of radiotherapy are better than 95% at 5 years. Radiotherapy will not improve the symptoms you already have from your lesion (e.g. hearing loss will not improve).
Stereotactic radiosurgery (SRS)

How is SRS treatment planned?
To allow the radiosurgery to be delivered very precisely and accurately and also to help you keep as still as possible a device called an immobilisation mask will be made for you. Once this has been made, you will also need to have some scans to allow your doctor and the radiotherapy planning team to plan the radiosurgery. Normally the immobilisation mask and scans are done on the same day. Another patient information leaflet describes the planning process and the immobilisation mask in more detail and is available if you decide to opt for SRS or want to know more about it. Please let your treatment team know about any concerns you may have about claustrophobia as there are strategies to help with this.

How is SRS treatment delivered?
The treatment is normally scheduled for about 2 weeks after the planning day and is delivered using a machine called a linear accelerator. You will be positioned in your immobilisation mask on the treatment couch and marks on the mask are used to align you in the correct position. You will be on your own in the room while the SRS treatment beams are delivered but you will not feel anything and the treatment radiographers will be watching you the whole time on CCTV. Normally the whole process from entering the room to leaving it takes 40 to 45 minutes but you are only on your own for a very short time and the radiographers come in between beams to move the machine.

What are the side effects of having SRS?
SRS does not make you radioactive and there is no need to take any special precautions for the safety of others. The SRS treatment is unlikely to make you ill and you will be well enough to travel but you are advised not to drive yourself home after treatment. Side effects vary from person to person and not everyone will experience the side effects that are listed below.

SRS acute side effects
These are the side effects that may occur in the first days to weeks after SRS. You will be prescribed some medication to take on the day of treatment and the day after to reduce the risk of you having any immediate side effects following SRS. If you are in paid employment we would recommend you take a couple of weeks off after SRS to allow any acute side effects to settle. Side effects that you may experience include:

- Nausea & vomiting - you will be prescribed some anti-sickness tablets that aim to reduce the risk of nausea or sickness.
- Headache - generally mild and settles with simple painkillers.
- Around 1 in 6 patients may develop transient dizziness or notice their balance gets slightly worse
- Fatigue / lethargy - this is a common side effect after any radiotherapy treatment. Generally it is mild and daily gentle exercise can be beneficial.
SRS transient side effects (6-9 months)
In the initial months after treatment the lesion may increase slightly in size as it responds to treatment. The majority of patients do not experience any side effects as a result of this but a few do report some new or worsening symptoms.

These include:
- Worsening balance / dizziness
- Headache - generally mild and settle with simple analgesia
- Nausea - may require some anti-sickness medication
- New or worsening cranial nerve symptoms this includes facial numbness or change in sensation, facial weakness or facial spasm

Late side effects (> 12 months)
These are the side effects that may occur many months to years following SRS.
- Trigeminal nerve neuropathy: around 5%-8% patients may develop some trigeminal nerve symptoms. If it does occur it is normally either a transient (not constant) facial numbness or paraesthesia (change in sensation) with a < 1-2% chance of a permanent neuropathy expected.
- Facial nerve neuropathy: around 5% of patients may experience some facial nerve symptoms and these can vary in nature from a mild spasm to extremely rarely a complete, permanent facial weakness (facial palsy).
- Hearing loss: poorly defined risk. SRS does not guarantee preservation of your hearing and in general patients report a gradual hearing loss over years following SRS. Rarely a sudden acute hearing loss may occur after SRS.
- Tinnitus: there is a (poorly defined) risk of worsening, more intrusive tinnitus but patients have also reported some improvement. Referral to the tinnitus clinic may be beneficial to help you manage tinnitus.
- New and persistent dizziness or worsening balance: rarely balance / dizziness problems following SRS can be permanent and are reported in around 2% - 4% patients following SRS. For some patient SRS may improve balance in the long term. Referral to a balance clinic (vestibular assessment and rehabilitation) can be helpful if this occurs.
- Occasionally tumour swelling causing hydrocephalus and requiring VP shunt (risk < 2%)
- Risk of carcinogenesis (causing another tumour to form) in treated area: estimated variously at around 0.1%-1% per decade following treatment, including an extremely small risk of malignant transformation of the neuroma.
- Small increase in the risk of stroke following radiotherapy, mainly after several decades.
- Very rarely other symptoms of brain necrosis e.g. dysarthria, dysphagia.
Fractionated radiotherapy (RT)

How is fractionated radiotherapy planned? Before the radiotherapy can be delivered, it is important to make an immobilisation mask that keeps your head very still and also makes sure that the position you lie in is the same for each visit. Another patient information leaflet is available that describes the process of having the mask made in more detail. You will also need to have some scans to plan precisely where the radiotherapy needs to go. This normally means having an MRI scan (not wearing the mask) and also a CT scan wearing the mask. We try to do all the planning on the same day but occasionally this is not possible and a couple of visits may be required. The planning is usually done about three weeks before the RT treatment begins. Please let your treatment team know about any concerns you may have about claustrophobia as there are strategies to help with this.

What is it like having fractionated radiotherapy?
The treatment is given in one of the radiotherapy treatment rooms. At each treatment you will lie on the treatment couch wearing the mask and the radiographers will place you in the correct position.

During the treatment the radiographers will leave the room but are watching you closely via a TV monitor. You will not feel anything during treatment but may be aware of a buzzing sound.

For fractionated radiotherapy the treatment is divided into several parts, called fields. The treatment machine is positioned slightly differently for each field. Each treatment field takes about a minute and the radiographers will come into the treatment room between fields. The whole treatment takes about 15 minutes.

What are the side effects of having radiotherapy?
Radiotherapy does not make you radioactive and there is no need to take any special precautions for the safety of others. The radiotherapy will not make you ill and you will be well enough to travel.

Many patients carry on their normal daily activities before and after the daily treatment session. However sometimes it can cause you to have some side effects.

Fractionated radiotherapy

Acute Side Effects (during treatment and for a few weeks after)
Not every patient will experience all of the side effects and if they do happen, the team looking after you will be able to provide help and advice.

Acute side effects that you may experience include:

- Nausea and vomiting - generally any nausea is mild and is helped by eating small amounts regularly. Anti-sickness tablets can be prescribed if this happens to you. It is very rare to actually be sick.
- Headache - generally mild and settles with simple painkillers.
• Around 1 in 6 patients may develop transient dizziness or notice their balance gets slightly worse - this will be more likely if your balance is already affected by the lesion.

• Fatigue / lethargy - this is a very common side effect after any radiotherapy treatment. Generally it is mild and daily gentle exercise can be beneficial.

• Skin erythema. This means the skin just in the area being treated may become pink and a bit dry. This is normally very mild, not permanent and will settle about three weeks after treatment finishes.

• Hair loss. This is just in the treated area (normally a very small area) and for the majority of patients the hair will grow back normally three to four months after treatment has finished.

• Increase in tinnitus. Sometimes the noises you hear in your ear may appear to grow louder or change in tone.

• Irritation of the treated ear canal. You may experience some redness and irritation of the ear canal on the side being treated. This may also mean that your hearing seems worse and you feel like your ear is blocked. This should settle a few weeks after treatment finishes.

Fractionated radiotherapy transient side effects (6-9 months)

In the initial months after treatment the lesion may increase slightly in size as it responds to treatment. The majority of patients do not experience any side effects as a result of this but a few do report some new or worsening symptoms. These include:

• Worsening balance / dizziness

• Headache - generally mild and settle with simple analgesia

• Nausea - may require some anti-sickness medication

• New or worsening cranial nerve symptoms this includes facial numbness or change in sensation, facial weakness or facial spasm

Fractionated radiotherapy late side effects (> 12 months)

These are the side effects that may occur many months to years following radiotherapy.

• Trigeminal nerve neuropathy: around 5%-8% patients may develop some trigeminal nerve symptoms. If it does occur it is normally either a transient (not constant) facial numbness or paraesthesia (change in sensation) with a < 1-2% chance of a permanent neuropathy expected.

• Facial nerve neuropathy: around 5% of patients may experience some facial nerve symptoms and these can vary in nature from a mild spasm to extremely rarely a complete, permanent facial weakness (facial palsy).

• Hearing loss: poorly defined risk. Radiotherapy does not guarantee preservation of your hearing and in general patients report a gradual hearing loss over years following radiotherapy. Rarely a sudden acute hearing loss may occur after treatment.
- Tinnitus: there is a (poorly defined) risk of worsening, more intrusive tinnitus but patients have also reported some improvement. Referral to the tinnitus clinic may be beneficial to help you manage tinnitus.
  - New and persistent dizziness or worsening balance: rarely balance / dizziness problems following radiotherapy can be permanent and are reported in around 2% - 4% patients following radiotherapy. For some patients, radiotherapy may improve balance in the long term. Referral to a balance clinic (vestibular assessment and rehabilitation) can be helpful if this occurs.
- Occasionally tumour swelling causing hydrocephalus and requiring VP shunt (risk < 2%)
- Risk of carcinogenesis (causing another tumour to form) in treated area: estimated variously at around 0.1%-1% per decade following treatment, including an extremely small risk of malignant transformation of the neuroma.
- Small increase in the risk of stroke following radiotherapy, mainly after several decades.
- Very rarely other symptoms of brain necrosis e.g. dysarthria, dysphagia.

**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 schwannoma does not show evidence of further growth. It is common in the 1st couple of years after radiotherapy to actually see a slight increase in the size of the lesion as a response to treatment. Normally this will have settled and we would expect the tumour size to be stable from year three onwards.

After each MRI you will also have an appointment to review your symptoms and this can either be a telephone consultation or a face to face appointment in our skull base clinic.

If you have useful hearing before radiotherapy we will ask you to have hearing tests at two and five years following treatment.

**Can I drive during and after my treatment?**

Please refer to the separate patient information leaflet about driving for more information about this. To summarise the DVLA guidelines state that for a vestibular schwannoma you may drive and need not notify the DVLA unless you experience sudden and disabling giddiness. If you are a group 2 licence holder (bus and lorry) you would need to inform the DVLA about your condition if you have bilateral (affecting both sides) vestibular schwannomas. For SRS we advise that you do not drive yourself home after treatment.

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

At Addenbrooke’s, we are able to offer other services that you may require after diagnosis or treatment for a vestibular schwannoma.
Hearing tests
We may offer you hearing tests called a PTA (pure tone audiogram) and SDS (speech discrimination score) on your arrival in Clinic 10 prior to seeing you in your outpatient appointment. This enables us to see how your hearing is being affected by the tumour, and how you are able to communicate with other people. If appropriate, we may offer you further assessments with our audiologists.

Hearing aids
- Audiology reception desk: Tel: 01223 217 797
- Audiology fax: 01223 586 912
- Email audiology: audiology@addenbrookes.nhs.uk

If you are identified with a hearing loss in the skull base clinic we will discuss your suitability for NHS digital hearing aids and assistive listening devices. We will see you for a full assessment to discuss your individual hearing needs.

NHS hearing aids are usually fitted behind the ear, and we will show you what is appropriate for your particular loss. You may be fitted here at Addenbrooke’s or at your nearest audiology department if you prefer.

Unilateral hearing loss clinic
A hearing loss which affects primarily or solely one ear tends to bring a particular set of hearing difficulties, typically with difficulty hearing sound from one side but also increased difficulty hearing amidst background noise and impaired ability to tell where sound is coming from. The audiology department has a dedicated clinic for this particular pattern of hearing loss.

Tinnitus
For patients with vestibular schwannomas who are troubled by tinnitus (an umbrella term for perceiving any sounds which are not genuine external sounds), there are various approaches which may be employed with the aim of reducing the impact that the tinnitus may have. We can arrange appointments to explore this if your doctors feel this is appropriate.

Vestibular assessments
Some people with vestibular schwannomas find that they have problems with their balance due to how the tumour can affect your hearing, balance function and eyesight. In order to investigate your balance further, we can arrange for a vestibular assessment in which we conduct a range of tests which thoroughly assess different aspects of your balance.

Vestibular rehabilitation
Any changes to balance function such as those caused by a vestibular schwannoma can result in sensations of imbalance or dizziness on movement. The aim of a vestibular rehabilitation appointment is to design some exercises which retrain the balance system to make the best use of remaining balance function. Strategies for dealing with difficult environments for balance can also be discussed.
Facial palsy/reanimation
The facial reconstruction service provides a number of modalities for the correction of the facial weakness that can sometimes occur with these types of tumour or following surgery. Depending upon how you are affected, you may be offered a number of treatments to help protect your eye, and to reposition the face if it falls. In some cases these treatments will allow you to actively move your face, in others they will simply reposition the face. In either event, we expect to be able to help you with your facial appearance and function.

Raised ICP and pulsatile tinnitus
Patients can occasionally experience headaches and a pulsating noise in the ear that is caused by a rise in pressure inside the head. This is often irritating but not life threatening. We have a team dedicated to the management of these conditions.

The skull base team

- Mr Patrick Axon MD FRCS (ORL), Consultant Skull Base and Hearing Implant Surgeon
- Mr Neil Donnelly MSc (Hons) FRCS (ORL-HNS), Consultant Skull Base and Hearing Implant surgeon
- Mr James Tysome FRCS (ORL-HNS), Consultant Skull Base and Hearing Implant Surgeon
- Professor Manohar Bance, (MB ChB, MSc, FRCSC (Canada-Otolaryngology-HNS), ABOto (American Boards), Professor of Otology and Skull Base Surgery
- Mr Richard Mannion PhD FRCS (SN), Consultant Neurosurgeon
- Mr Robert Macfarlane MD FRCS, Consultant Neurosurgeon
- Mr Adel Helmy, Consultant Neurosurgeon
- Dr Sarah Jefferies, Consultant Oncologist
- Dr Huiqi Yang, Consultant Oncologist
- Kate Burton, MSc (Hons), DCR(T), Consultant Radiographer
- Mr Richard Price, Consultant Plastic Surgeon
- Indu Lawes RN, MSc, Skull Base Nurse Practitioner (Neurosurgery)
- Juliette Buttimore RN BA (Hons) MSc, Skull Base & NF2 Nurse Practitioner
- Nicola Gamazo RN BA (Hons), Skull Base and NF2 Nurse Practitioner

Contact numbers
If you have any questions please contact one of our nurse practitioners:

Juliette Buttimore
Skull base & NF2 Base Nurse Practitioner (Department of Otolaryngology)
Telephone: 01223 348672 (direct line)
E-mail: juliette.buttimore@addenbrookes.nhs.uk
Nicola Gamazo  
Skull base & NF2 Base Nurse Practitioner (Department of Otolaryngology)  
Telephone: 01223 348672 (direct line)  
E-mail: nicola.gamazo@addenbrookes.nhs.uk

Indu Lawes  
Skull base Nurse Practitioner (Department of Neurosurgery)  
Telephone: 01223 245151 (main switchboard)  
Bleep: 154-175  
E-mail: indu.lawes@addenbrookes.nhs.uk

Alternatively, for patients under the care of Mr Donnelly and Professor Bance please call:  
Bianca Saunders, secretary to Mr Donnelly and Professor Bance on:  
Telephone: 01223 586638  
E-mail: bianca.saunders@addenbrookes.nhs.uk

For patients under the care of Mr Axon and Mr Tysome please call:  
Steve Potts, secretary to Mr Axon and Mr Tysome on:  
Telephone: 01223 256051  
E-mail: steve.potts@addenbrookes.nhs.uk

For patients under the care of Dr Jefferies and Dr Yang please call:  
Telephone: 01223 586705  
E-mail: carolyn.langham@addenbrookes.nhs.uk

For patients under the care of Mr Macfarlane please call:  
Havva Yilmaz, secretary to Mr Macfarlane on:  
Telephone: 01223 254693  
Email: havva.yilmaz@addenbrookes.nhs.uk

For patients under the care of Mr Helmy please call:  
Susan Birtles, secretary to Mr Helmy on:  
Telephone: 01223 256694  
Email: susan.birtles@addenbrookes.nhs.uk

For patients under the care of Mr Mannion please call:  
Maria Harrington, secretary to Mr Mannion  
Telephone: 01223 586858  
Email: maria.harrington@addenbrookes.nhs.uk

Speaking to your family about your diagnosis

If you need advice or support on how to talk to your family or children about your diagnosis, then please contact one of the nurse practitioners.

Patient representatives (patient and public involvement/ PPI)

If you have views about how we provide our service, the information that we give to people with vestibular schwannomas, or the facilities and environment of the hospital then we would welcome your views in person, via post, fax, phone or email.  
You do not have to be a patient to be a representative for the skull base service.
We are keen to hear what you have to say about the service and where possible wish to involve you in service development so that we can provide the best patient-focused care possible. Please inform the nurse practitioner if you are interested in this role.

**Transport and help with finances**

You can get help with travel costs for NHS treatment if you receive Income Support, Income-Based Jobseeker’s Allowance, Income Related Employment and Support Allowance, Pension Credit Guarantee Credit, or if you are named on an NHS Tax Credit Exemption Certificate. You may be able to get help with health costs if you are on a low income by completing an HC1 form (available online, from your GP, Jobcentres or the transport reception in outpatients). If you would like further information, please ask one of the nurse practitioners or contact the Citizens Advice Bureau.

**Support groups**

**AMNET**

AMNET (The Acoustic Neuroma and Meningioma Network) is a support group for people who have been diagnosed with skull base tumours such as Acoustic Neuroma (Vestibular Schwannoma) or Meningioma in the East of England.

AMNET offer support during the processes of diagnosis, shared decision making, management and treatment. Many of their members have had their treatment or continue under surveillance, and find that meeting with others is an invaluable help to them, and their families, in managing symptoms and making adjustments in lifestyle or in the workplace.

AMNET hold regular meetings and produce their own newsletter, AMNET news. They can offer someone to talk to, booklets, and a range of information to help people through this unsettling time. Please contact them through their website.

Website: [www.amnet-charity.org.uk](http://www.amnet-charity.org.uk)

**BANA**

The British Acoustic Neuroma Association (BANA) was formed in 1992 and registered as a Charitable Incorporated Organisation in 2016. BANA is organised and administered by people affected by acoustic neuroma and exists for mutual support, information exchange and listening.

British Acoustic Neuroma Association
Tapton Park Innovation Centre
Brimington Road, Chesterfield, Derbyshire
S41 0TZ, United Kingdom
Tel: 01246 550011
E-mail: admin@bana-uk.com
Website: [http://www.bana-uk.com/](http://www.bana-uk.com/)
Action on Hearing Loss
Action on Hearing Loss (formerly the RNID) aim to make day-to-day life better for people who are deaf or who are hard of hearing. Their website includes lots of useful information on communication equipment, your rights and help with benefits and services.

Website: [http://www.actiononhearingloss.org.uk/](http://www.actiononhearingloss.org.uk/)
Information line telephone 0808 808 0123 (Freephone)
Information line textphone 0808 808 9000 (Freephone)
Email information@hearingloss.org.uk

Brain and Spine Foundation
The Brain and Spine Foundation provide support and information on all aspects of neurological conditions. They aim to reduce uncertainty and anxiety by providing clear and accurate information on topics such as dizziness and balance, migraine and brain scans. This can be found at their website.
Website: [www.brainandspine.org.uk](http://www.brainandspine.org.uk)
Helpline: 0808 808 1000

Privacy & Dignity
Same sex bays and bathrooms are offered in all wards except critical care and theatre recovery areas where the use of high-tech equipment and/or specialist one to one care is required.

We are a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language or audio, please contact Interpreting services on telephone: 01223 256998, or email: interpreting@addenbrookes.nhs.uk For Large Print information please contact the patient information team: patient.information@addenbrookes.nhs.uk

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