

# What is a Glomus Jugulare tumour?

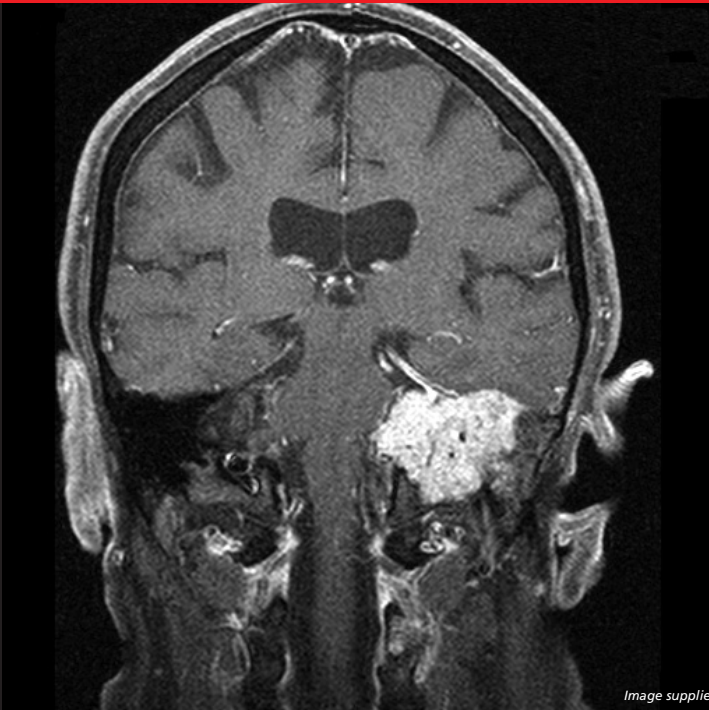


Image supplied by Andrea Wadeson



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You have been diagnosed with a glomus jugulare tumour (GJT), also known as a paraganglioma.

It is a slow-growing, benign (non cancerous) tumour that forms at the base of the skull, in an area called the jugular foramen. The jugular foramen is an opening where important nerves and blood vessels pass through the base of the skull.

The tumour arises from glomus cells. These cells line the blood vessels to respond to changes in your body temperature and blood pressure.

The tumour can affect the ear, neck, base of the skull, and the surrounding blood vessels and nerves.

Although uncommon, there is a small chance that the tumours may act more aggressively and spread to other parts of the body. This accounts for around 4% of cases.

Most GJTs will be sporadic (i.e. there is no known cause), however, around 10% occur due a genetic predisposition (ie. the tendency to form glomus tumours is inherited).

This will be discussed in more detail with you and you may be offered further testing. Patients who have a genetic predisposition are at risk of developing these tumours at other sites in the body as well.

Approximately 2% of these tumours can make chemicals called catecholamine hormones which can affect other parts of the body. This is explained more on the following page.

## Key facts

- 90% have unknown cause or risk factors
- Most commonly present between 40 and 70 years of age
- More common in females
- Rare - around 1 in 1.3 million people per year are reported

## Symptoms

- Hearing loss
- Hearing pulsations in the ear (pulsatile tinnitus)
- Difficulty swallowing (dysphagia)
- Dizziness / imbalance
- Hoarseness of the voice
- Weakness or loss of movement of the face
- Reduced tongue movement
- Pain

## Diagnosis

The first step is to perform a physical examination on your ears and throat, which can indicate if a tumour is present. The tumour may be visible in the ear or may be felt as a lump in the neck.

In order to confirm the presence of the suspected glomus jugulare tumour, the doctor will need to perform an imaging test such as magnetic resonance imaging (MRI).

A computed tomography (CT) scan may be requested to determine bone involvement.

## Further Investigations

Hearing tests (audiometry) can be performed to confirm any hearing loss and may also be useful to indicate the size of the tumour.

An imaging technique called cerebral arteriography can be used to look inside the arteries in and around the tumour to help with further management. This is performed by injecting a special dye inside the artery which is then identified by x-rays.

Genetic screening is appropriate for younger patients or those with a family history of paragangliomas.

A MRI of the neck, abdomen and pelvis and a second scan which includes iodine called an MIBG scan are often required to identify any other tumours elsewhere in the body.

A small percentage (around 2%) of glomus jugulare tumours release chemicals called catecholamines.

Catecholamines are hormones that prepare the body for physical activity. Screening for catecholamines can indicate the presence of these tumours and is done through a blood and/or urine test.

These investigations usually need onward referral to a specialist (called an endocrinologist) who manages the body's endocrine system. This is the system that controls the body's hormones. This will be discussed with you in more detail in clinic.

## Salford Royal's Skull Base Team

The skull base team at Salford Royal NHS Foundation Trust is made up of:

3 Consultant neurosurgeons

**Professor Andrew King**  
**Mr Scott Rutherford**  
**Miss Charlotte Ward**

2 ENT (ear, nose and throat) surgeons

**Mr Simon Freeman**  
**Mr Simon Lloyd**

3 Clinical Oncologists

**Dr Catherine McBain**  
**Dr Gillian Whitfield**  
**Dr Rovel Colaco**

and a clinical nurse specialist,  
**Sister Andrea Wadson**

They also have specialist fellows working with them who are undergoing subspecialty training in this type of surgery.

There is a wider multidisciplinary team who may be involved in your treatment including radiologists and radiographers.

Together they work with other disciplines and ward staff to ensure that the highest quality of care is delivered to you during your stay with us.

Salford is one of the largest neuroscience centres in Great Britain. It receives referrals nationally and internationally due to its expertise in managing glomus jugulare tumours and other similar conditions.

Our web page address is featured at the end of the leaflet for further information on our team.

## Treatment for Glomus Jugulare tumour

You are now at the stage where treatment options will be discussed with you. Your surgeon will have discussed the findings on your MRI with a team of specialists. Treatment for your glomus jugulare tumour will depend upon many factors including:

- Your age; Though each case will be assessed on an individual basis, it is generally a safer option to monitor patients with slow growing tumours especially as older patients may have other health factors to take into consideration which may make surgery more risky
- Your overall health; if your health is poor it may not be advisable to perform surgery and another option may be considered
- The size and configuration of your tumour; larger tumours tend to be managed with surgery, although this is highly dependent on other factors. There are certain other characteristics of the tumour

which may influence this decision (for example if the tumour contains cysts, or if there is involvement with important nerves and other surroundings)

- The growth rate of the tumour; if your tumour does not appear to be growing or it is growing at a slow rate then you may be observed with periodic scans and clinical follow ups. If your tumour appears to be growing faster, your surgeon is likely to advise an active form of management
- Your symptoms; the amount of nerve involvement and its associated symptoms is a major factor in deciding the most appropriate form of treatment

It is important that you discuss in detail any questions that you may have at this stage. Your surgeon will decide with you which option would be the most appropriate for you depending on the factors above.

## Watch, wait and rescan

As the vast majority of GJTs are indolent or slow growing, we often suggest active surveillance and follow a 'watch, wait and rescan' approach.

No active treatment will be required until clear tumour growth is demonstrated, as seen in further scans at a six to twelve month interval.

If your tumour remains static or if the growth rate is very slow and your tumour still small, your surgeon may simply suggest continued monitoring with MRI and clinical follow ups. This may also be the case with older patients with health issues.

It may seem like nothing is being done for you, however, as glomus jugulare tumours are benign and often do not pose any immediate risk to you, the risks of surgery or other treatment options may outweigh the benefits at this point.

The close monitoring would enable the team to reassess your options at any given time. It is important that you inform the specialist nurse of any new or worsening symptoms in between hospital visits.

## Surgery

Surgery aims to deal with this condition by completely removing the tumour. There are cases where it is not possible to remove the entire tumour, typically due to adherence to vital nerves or blood vessels.

If this is the case, it is safer to leave a small portion of the tumour to preserve function, rather than risk permanent injury.

By achieving total or near-total removal of the tumour, surgery offers a 90% chance of successfully dealing with your tumour. A small number may need further treatment. In either instance you will be monitored after your surgery to assess the unlikely occurrence of a re-growth.

The operation will involve an incision behind the ear on the affected side, and may extend down to the upper neck.

General risks include reduced hearing on the side of surgery, imbalance, facial weakness, swallowing problems, change in strength of voice, reduced tongue movement and reduced shoulder movement.

All are relatively low risk and will be discussed with you in more detail by your consultant. Should such issues arise there are multiple specialist therapists and clinicians who have an interest in managing such symptoms and many patients will get good function back in time.

Surgery can also have other rare complications, and this includes a tiny risk to your life (<1%), a tiny risk of stroke (<1%), bleeding inside the head or infection.

After surgery you can expect to stay in hospital for approximately 5- 7 days though a small minority of patients require a slightly longer stay.

We advise that you have someone at home when you are discharged as you will be tired and possibly dizzy for a few weeks after surgery.

There may also be swelling around the neck area which should settle in time and is generally normal. You may have some headaches which should become intermittent as you recover and it is very common to be tired after this surgery for many weeks.

## Radiotherapy or Stereotactic Radiosurgery (SRS)

Stereotactic radiosurgery (SRS) is a technique that uses a single highly targeted dose of radiotherapy to arrest the activity of the tumour and prevent further growth.

There are several different machines capable of delivering "radiosurgery", and the differences in these relate to

the targeting mechanisms and the radiation source, rather than the principle by which the radiotherapy is delivered.

In other words, the "Gamma Knife", the "Cyber Knife" and "Linac" just refer to different machines rather than different treatment modalities.

Some patients may be offered radiotherapy in multiple doses over several weeks rather than a single dose, dependant on the size and position of the tumour. This is called fractionated radiotherapy. This will be discussed with you if appropriate.

Most of our patients wishing to have radiosurgery will be treated in The Christie radiotherapy satellite centre at Salford Royal NHS Foundation Trust. This satellite centre is equipped with two modern high precision linear accelerators ("linacs") which are specially designed for radiosurgery.

*continued page 9*

The tumour control rate of radiotherapy rivals that of surgery, where approximately 90% of tumours are successfully controlled. However, radiotherapy does not remove any tumour and rarely causes much shrinkage.

Depending on the size of tumour, its relationship to surrounding nerves and its blood supply, radiotherapy may offer an advantage in terms of a lower risk of complications compared to surgery.

Radiotherapy treatment (either fractionated or SRS) is usually very well tolerated. The main side effects at the time of treatment are tiredness, and possibly a sore throat and some hair thinning or loss, which will regrow.

There is a small chance of long term side effects from radiotherapy. As for surgery, there can be hearing loss or facial weakness on the affected side, imbalance, swallowing

problems or change in strength of voice, but the chances of these side effects are generally rather lower than with surgery. Again, the therapists and clinicians who specialise in such symptoms would be involved in treating you, but if such symptoms do occur after radiotherapy, they can be permanent.

There is a very small chance that the x-rays involved in having SRS or fractionated radiotherapy may cause a benign or malignant (cancerous) tumour in later life. In each decade after treatment, around 1 in 1000 people may suffer this complication.

There is a small increased risk of future strokes. If the tumour is large, then there is a small risk of developing serious chronic infection in the surrounding bone. These risks increase decades after treatment so are much less of a concern with older patients.

Radiosurgery or fractionated radiotherapy does not involve a surgical incision. The treatment is delivered by focusing x-rays on your tumour. You will have a custom mask made to fit you, to hold your head still during each stage of your planning and treatment.

To plan your treatment, you will have a CT scan wearing this mask. You may also have another MRI scan, but you will not need to wear the mask for this.

These scans will allow the Clinical Oncologist and team of experts preparing your treatment to locate the position of the tumour and to prepare a plan to target the radiation dose, so that the tumour is irradiated with minimal dose to surrounding structures.

If you are having SRS, you will return to the Christie at Salford on a subsequent day for the treatment. This is normally about two-three weeks after the CT scan visit.

The SRS treatment is painless and should last approximately 30-40 minutes. You will be lying on your back on a table that moves into the radiation unit, similar to having a scan, during your treatment.

You will be able to speak to the radiographer at any time and are observed on a camera. You can go home as soon as the treatment is done.

You may have some mild headaches immediately after the treatment though this should quickly subside. Many patients resume normal activities the following day.

You can go back to work as soon as you feel well enough and there are no specific restrictions on daily activities. You may feel tired after treatment but this should only last a few days.

Occasionally patients have some small patches of hair loss, which should regrow.



If you are having fractionated radiotherapy, this will usually be a six week course of daily treatment as an outpatient, Monday to Friday. This can be done at the Christie at Salford, or at The Christie's main site in Withington, south Manchester.

Each treatment lasts around 20-25 minutes. As for SRS, you will be lying on your back on a table that moves into the radiation unit and are able to speak to the radiographer at any time and are observed on a camera.

You can go home as soon as the treatment is done. During the treatment and for a few weeks afterwards you may feel slightly tired, but many people carry on working. Some people feel slightly nauseous or have mild headaches or a sore throat, for which you can be given medication.

You may have some patches of hair thinning or hair loss towards the end of treatment, which should all regrow within a few months.

## Aftercare

Aftercare of patients with a glomus jugulare tumour depends largely on the treatment given. If you are on the "Watch and Wait" list then you are likely to be observed for the rest of your life at intervals determined by your team.

You will be given a contact number for the skull base specialist nurse in case of any questions or worries you may have.

Despite a stable tumour, some patients who are being managed with periodic scans may see a change in their symptoms. This is usually nothing to be alarmed about but you should discuss any change of symptoms with the Specialist Nurse.

If you have surgery you will be cared for on a neurosurgical ward. Each ward has highly experienced staff that are familiar with the complex needs of patients following removal of a glomus jugulare tumour.

You may also need to have input from other disciplines such as speech and language therapists, dieticians, physiotherapists, audiology and ophthalmology.

You are likely to be tired for some weeks after surgery and we advise that you gradually increase your levels of activity in order to recover at a safe pace.

You will initially be followed up by the specialist nurse via telephone. If you are unable to use the phone then there is an option to communicate via email or via a nominated person. This takes place approximately 2 weeks after discharge for surgery.

The consultant will see you in clinic around 4-8 weeks after discharge and then you will be seen again after one year. You will be scanned periodically over the coming years.

Following SRS or fractionated radiotherapy you will usually be scanned periodically for the rest of your life. You are not likely to need any further treatment for you glomus jugulare tumour and should be able to return to a normal daily routine.

You will also be seen periodically in clinic by the skull base team to check on your symptoms.

## Who to contact?

Many questions can arise after diagnosis of a glomus jugulare tumour. There is always someone here who can help you.

We advise that if you have any questions, no matter how small, or if you have any changes in your symptoms, to contact the skull base specialist nurse:

### Andrea Wadeson

Skull Base Specialist Nurse

 **0161 206 2303**

 *andrea.wadeson@srft.nhs.uk*

or

### Jane Riley

Secretary to Mr Rutherford

 **0161 206 0119**

### Alison Dapoto

Secretary to Professor King

 **0161 206 5541**

### Melanie Hellawell

Secretary to Miss Ward

 **0161 206 8340**

### Kim Madden

Secretary to Mr Freeman & Mr Lloyd

 **0161 206 5754**

Or see your GP.

If the issue is more urgent, attend your local Accident and Emergency Department.

If your query is related to radiosurgery carried out at The Christie at Salford you can contact the oncologist's secretaries as below:

### Katie Royle

Secretary to Dr McBain

 **0161 918 7197**

### Lauren Brown

Secretary to Dr Whitfield and Dr Colaco

 **0161 918 7197**

Search our Website:

 **<http://www.srft.nhs.uk/about-us/depts/neuro-skull-base/>**

## Notes

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**If you need this interpreting please telephone**

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Urdu

اگر آپ کو اس ترجمانی کی ضرورت ہے تو مہربانی کر کے فون کریں۔

Arabic

إذا كنتم بحاجة الى تفسير او ترجمة هذا الرجاء الاتصال

Chinese

如果需要翻译，请拨打电话

Farsi

اگر به ترجمه این نیاز دارید ، لطفاً تلفن کنید

**0161 206 0224**

Email: [InterpretationandTrans@srft.nhs.uk](mailto:InterpretationandTrans@srft.nhs.uk)

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