



Stereotactic radiotherapy for paraganglioma using CyberKnife

This leaflet has been given to you to provide some written information about the treatment that is being planned for you, in addition to the explanations that you have received from your doctor. If you have any questions, please get in touch with the specialist radiographers (contact details can be found at the end of this leaflet).

What is a paraganglioma?

Paragangliomas are rare tumours, known as neuroendocrine tumours, that form in several regions of the body including around nerves and major blood vessels (carotid artery) within the head and neck. The nerve cells involved in paraganglioma are part of the peripheral nervous system, meaning the part of the nervous system outside of the brain and spinal cord. The majority of these tumours are benign. Some paragangliomas are associated with inherited genes, or hormone secretion. If you have questions regarding a possible cause for your paraganglioma please do ask your medical team.

What is stereotactic radiotherapy?

Radiotherapy is a treatment which involves precisely targeting high energy X-rays (ionising radiation) at a specific area, with the aim of destroying any abnormal cells there.

Some patients may benefit from having highly focussed and accurate radiotherapy known as stereotactic radiotherapy (SRT). If only one treatment is given, it is often referred to as stereotactic radiosurgery (SRS).

At the Queen Elizabeth Hospital Birmingham, we deliver stereotactic radiosurgery and stereotactic radiotherapy using a CyberKnife unit. This unit has a radiotherapy machine, which can generate high energy X-rays, mounted on a robot arm. This means that the treatment can be delivered from many different angles, so that the normal tissue around the area being treated receives a much lower dose than with conventional radiotherapy. It enables high doses of radiation to be delivered with sub-millimetre accuracy, as the CyberKnife has the ability to track the tumour's position throughout the treatment.

It is extremely important that you are not pregnant or become pregnant during your course of radiotherapy. Even a small amount of radiation may damage an unborn foetus so it is very important to let the radiographers know at once if you think there is even a possibility that you may be pregnant before any radiation exposures are given on the CT scanner or CyberKnife unit.

Having radiotherapy does not make you radioactive. There is no need to restrict your contact with other people, including children and pregnant women.

Why do I need to have stereotactic radiotherapy?

The decision to use radiosurgery or stereotactic radiotherapy will depend on several factors including location, volume of tumour and ability to clearly define the tumour on scans. This approach is generally preferred for small clearly defined tumours which are difficult to remove. Having considered your case, the team of doctors (surgeons, oncologists and radiologists) involved in treating paraganglioma have proposed stereotactic radiosurgery or radiotherapy as a treatment option. If you are unsure why this option has been suggested to you, please feel free to ask.

Are there any alternative treatments to stereotactic radiosurgery or stereotactic radiotherapy?

Treatment options to discuss with your doctor include:

- Medication
- Observation
- Surgery
- Radiotherapy

What are the benefits of stereotactic radiosurgery or stereotactic radiotherapy?

For most patients the aim of stereotactic radiotherapy is to stop the paraganglioma from growing to prevent further disability, and the need for surgical intervention in the future. This disability will depend upon the location of the paraganglioma. Your consultant will discuss this in more detail when you first see them. If you do decide to have stereotactic radiotherapy, you will be asked to sign a consent form, stating that you have been informed of the risks and benefits. This does not mean that you cannot change your mind about your treatment choices.

When is stereotactic radiosurgery or stereotactic radiotherapy given?

Stereotactic radiosurgery is given in a single treatment on a weekday and stereotactic radiotherapy can be delivered in either three, five or 25 daily treatments on consecutive weekdays. The treatment is delivered in the CyberKnife suite in the Radiotherapy Department in the Cancer Centre at the Heritage Building (Queen Elizabeth Hospital Birmingham).

What needs to happen before I start stereotactic radiosurgery or stereotactic radiotherapy?

Stereotactic radiotherapy requires appropriate preparation and must be carefully planned. Firstly, you will have an appointment with a clinical oncologist in an outpatient clinic who will explain the details of the planned therapy and obtain your consent. After this appointment, we will organise some imaging which you will need to have done, in addition to any previous imaging you may

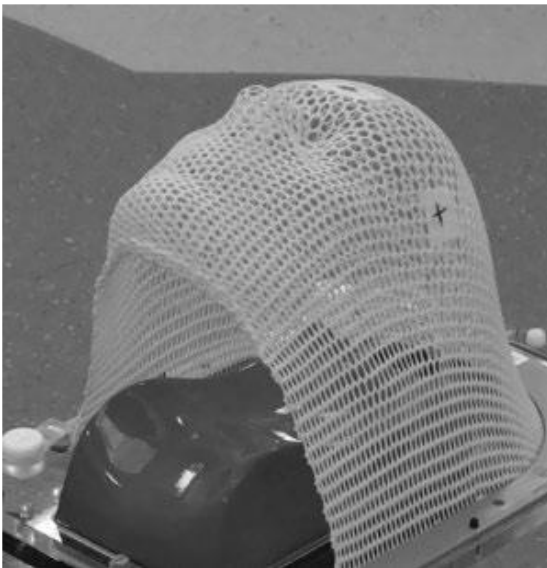
have had. This will include a planning CT scan which is done within the Radiotherapy Department and an MRI scan.

What needs to happen for my stereotactic radiosurgery/stereotactic radiotherapy to be planned?

Your first visit to the radiotherapy department is to the Mould Room where a mask is made. This mask is made several days or weeks prior to starting radiotherapy. It fits over your head and is attached to the treatment couch. The mask is needed to ensure that you are in the same position as you were for your planning CT scan so that the treatment can be given very precisely to the correct area.

Making the mask involves warming a sheet of a thermoplastic material so that it softens and can be gently draped over your head and moulded to you. The mask then needs to stay in position for about ten minutes whilst it hardens and sets. The plastic is warm and feels a little like having a warm flannel over your face. The plastic has small holes in it so that you can still breathe easily. The mask must be a close fit in order to be effective, but it should not be painful.

After the mask is made, you will have a CT scan which is done with the mask on. The radiographers will put some marks on the mask so that when you return for your radiotherapy treatment it will be possible to have you lying in the same position. It is important that if you are uncomfortable or struggling with the position, you tell the radiographers.



After your CT scan, the radiographers will give you the details of your first radiotherapy treatment appointment and show you where the CyberKnife suite is.

The radiographers will ask if you prefer a morning or afternoon appointment for your treatment and they will pass this onto the treatment radiographers. Please be aware that although the treatment radiographers will always try their best to give you appointments around your preference, it may not always be possible to accommodate these requests. If you require hospital transport for your treatment, please discuss this with the CT radiographers.

In between having your CT scan and starting treatment a lot of work needs to be done, by your doctors and the team of radiographers and physicists, to plan and check your treatment.

Use of steroid tablets

Often you will be given a short course of steroids to help reduce the effect of any swelling from the tumour, which can be made temporarily worse with stereotactic radiotherapy. This is most commonly in the form of Dexamethasone.

The prescription will be given to you before you leave from your CT appointment and the radiographers will explain when to start taking it.

What happens when I come to the CyberKnife unit?

Your treatment will be on a weekday. This appointment normally takes between one and one and half hours. The radiographers will explain what is going to happen and show you the CyberKnife unit. The machine moves around the room and can make some noises. The radiographers will position you in the same way you were for your planning CT scan. The radiographers will then move you into the correct position.

The radiographers will then take some X-ray images to confirm your position before they start the treatment. They may come in and out of the room and adjust your position slightly. The treatment machine will then move around you so that the treatment can be delivered from lots of different angles. The machine will only be on for brief periods before moving to the next position.

You will not feel anything whilst you are having radiotherapy, but you may see CyberKnife moving around you.



Whilst you are on the treatment couch, the radiographers will continue to take and assess X-ray images during your treatment to ensure your position remains perfect. Assessing these images may take some time and necessitate discussion with other members of the team such as physicists and doctors.

These images are taken to ensure that you are in the correct position; they cannot be used to assess how well the treatment is working. These images involve a very small additional dose of X-rays. However, these images are essential to ensure accurate treatment and overall serve to reduce the risk of side effects.

The radiographers will ask you to stay as still as possible so that the treatment can be given to the correct place. The radiographers cannot stay in the room with you whilst the machine is on, but they are operating the machine and watching you all the time via cameras. If for any reason you need the radiographers, just raise a hand and they will immediately stop the treatment and come in.

CCTV use

The treatment rooms are monitored during your preparation, positioning and treatment delivery by television cameras. This is part of ensuring the accuracy of your treatment, and your safety and wellbeing in the room at all times. We assure you that the camera image feed is live, and it is not possible to make a recording. The images are viewable on screens situated in the machine control areas. The control areas are only accessed by authorised radiotherapy staff, some of whom may not be directly involved in your care at the time. If you have any concerns about your privacy or dignity, that you have not already discussed, then please do not hesitate to highlight your concerns during the information discussion with the radiographers at your first appointment.

What side effects may occur during my stereotactic radiosurgery or stereotactic radiotherapy treatment?

Stereotactic radiosurgery and stereotactic radiotherapy aim to have fewer side effects than conventional radiotherapy as less healthy tissue is exposed to high doses of radiation. However, you may still experience some side effects particularly related to structures, such as nerves, in the immediate vicinity of the tumour.

Side effects may not happen or be the same for all people and will depend upon the location of the paraganglioma. Short term side effects may include tiredness. The tumour can swell after treatment which may result in some deterioration in nerve function such as balance problems, reduced hearing, tinnitus, facial nerve twitching, spasm, weakness, voice problems or swallowing problems temporarily. Generally, the swelling passes after about six months. Sometimes you can get a pain associated with this or discharge from the ear. There could also be a small risk of later or permanent side effects that your doctor will discuss with you. These will also be detailed on the consent form.

Your consultant will discuss the possible side effects in more detail before you consent to treatment and these will be detailed on your consent form, which you will be given a copy of. If you are unsure about any of these side effects, please ask to discuss them further with your consultant (oncologist or neurosurgeon). Any exposure to ionising radiation carries some risk of causing cancer in the future, but this risk can be minimised by ensuring that the dose you receive is optimised as much as possible. We ensure that the benefit to you of the procedure outweighs any additional risk introduced by the use of radiation.

When you come for treatment, you will be seen by the radiographers, and you will be given the CyberKnife radiographers telephone number. If you have any concerns or questions, please speak to the radiographers.

Driving after treatment (DVLA guidelines)

Please speak to the CyberKnife radiographers/clinician to check how long you should not be driving for after treatment.

What happens after my treatment?

You will have a follow up appointment with the oncology consultant (radiotherapy doctor) or the Cyberknife/SRS consultant radiographer in around four to six weeks after treatment. They will organise a follow up scan; the first of which is normally carried out about six months after your treatment.

Other information

Car park D is directly opposite the doors to the Cancer Centre on the hospital drive. Please park here and bring in the ticket you have taken to access the car park with you. The radiographers in the treatment room will exchange this for a prepaid ticket so that you can exit the car park without paying. **You will need to provide your car registration number to get the pre-paid ticket.** This free car parking arrangement has been negotiated for patients who are attending for radiotherapy planning or treatment appointments only. The radiographers will not be able to give you a ticket if you are attending for a follow up appointment.

Contact details

CyberKnife radiographers' telephone: 0121 371 5060

CyberKnife/SRS consultant radiographer telephone: 0121 371 7703

If you cannot get through to a radiographer, please leave a message so one of the radiographers can call you back. This telephone will be checked regularly throughout the week but is not checked at weekends.

CyberKnife website: www.uhb.nhs.uk/services/radiotherapy/cyberknife/

Radiotherapy

Queen Elizabeth Hospital Birmingham

Heritage Building, Mindelsohn Way, Edgbaston
Birmingham B15 2TH

Future appointments

Date	Time	Procedure	Location

Accessibility

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