PITUITARY RADIOTHERAPY

(From the Pituitary Foundation – www.pituitary.org.uk)

Radiotherapy is sometimes used as part of the overall treatment for pituitary tumours (also called pituitary adenomas).

The aim of radiotherapy treatment for patients with pituitary tumours is to control the growth of the tumour (or any remaining tumour after surgery) and prevent it enlarging. In some cases, radiotherapy also results in shrinkage of the tumour, but this can take many months or years to happen.

Although radiotherapy treatment is most often used for patients with cancer, patients with pituitary tumours do not have cancer; their tumours are benign.

Pituitary tumours grow very slowly and tend to respond to radiotherapy slowly as well. Because of this, if radiotherapy treatment is required, it does not need to be given urgently within days or weeks of surgery and can safely be given months after the operation.

What exactly is radiotherapy?

Radiotherapy uses X-rays to treat disease and it works by damaging the DNA in the nucleus of any cells that it passes through.

Although cells can continue to live for some time with damaged DNA, eventually cells either repair the damage and survive, or, if the damage is too great, the cell dies. This cell death happens some time after the radiation is delivered, often after the cell has divided a few times, many weeks, months or years after the treatment.

Normal body cells are better able to repair radiation damage than tumour cells and by delivering the radiotherapy using repeated small dose treatments; the chance of permanent damage to your own normal body cells is reduced. In addition, by giving many small treatments, the total dose that can safely be delivered to the tumour is higher, thus increasing the chances of success.

Radiotherapy is delivered using high-energy X-ray machines, called linear accelerators (Linacs) which are similar to CT scanners. They focus an X-ray beam onto the pituitary tumour and surrounding area, from several different angles, one at a time.

Because the radiotherapy source is external, it does not make you radioactive. It is perfectly safe for you to be with other people, including children, throughout your weeks of treatment (although not during the radiotherapy itself). External radiotherapy is usually given as an outpatient. It is planned and supervised by a Clinical Oncologist (a cancer specialist with training in radiotherapy treatment).

Why do I need to have it?

It is not always possible to remove the whole of the pituitary tumour during surgery without running the risk of damaging surrounding structures, such as the optic nerves (the nerves that come from the eye and enable us to see) or major blood vessels. This is particularly true of larger tumours. Although pituitary tumours are almost invariably benign, they do have a tendency to grow and if even a few cells remain after surgery, they can be the seed for a recurrence of the tumour in the same area.

Following surgery, patients undergo further scanning (MRI or CT) and blood tests. Their cases are then reviewed and discussed by the multidisciplinary team (including an endocrinologist, neurosurgeon and radiotherapist) looking after them. A consensus decision on each case is then made by the team and recommended to the patient.

In general, radiotherapy is considered for patients:

- Who have evidence of persisting tumour outside the pituitary fossa (the space where the pituitary gland sits) following surgery.
- Whose tumour is secreting a hormone that continues to be raised in blood tests following surgery despite treatment with drugs.
- Whose pituitary tumour re-grows (this would be some time after surgery, perhaps following a second operation).

Some patients, whose postoperative scan shows minimal persistent tissues within the pituitary fossa only, are not given radiotherapy after surgery. They are followed up with annual scans, blood tests and visual field checks.

How effective is radiotherapy?

When we look back on patients treated 20 years ago, radiotherapy is very effective.

- Re-growth of the tumour is prevented in nine out of ten patients (for similar types of patients who were not given radiotherapy following surgery, the tumour re-grew in over half of all cases).
- Half the patients whose eyesight has been affected by the tumour notice an improvement following surgery and radiotherapy.
- For those patients who are receiving radiotherapy in order to reduce hormone secretion, it is effective in nine out of ten patients, starting about two years after radiotherapy and continuously improving for ten to fifteen years.

What should I expect?

The Clinical Oncologist will see you in the oncology clinic. The radiotherapy treatment will be explained to you and side effects outlined (see below). You

will be asked to sign a consent form in order to receive the treatment. Your treatment will be carefully planned by a Clinical Oncologist, who will be assisted by a physicist and radiographers (who operate the machines that give you your treatment). The actual radiation is delivered in small daily doses (called fractions) over a period of five to six weeks (usually Monday to Friday only, with a rest at the weekend).

Because radiotherapy has to be very precise to treat exactly the right area of your body, it is essential your head and neck are kept as still as possible during treatment. Before your treatment begins, you will attend the clinic on two or three occasions to have a special mask or fixation device made, with generous holes for your eyes, nose and mouth to allow you unrestricted breathing. You will need to have scans or X-rays taken whilst wearing the mask or fixation device so that the treatment can be planned and the accuracy of the planned treatment confirmed. Some centres show you pictures to explain this.

A linear accelerator, a machine which generates high voltage X-ray beams, is used to deliver the treatment. You will lie on a treatment couch for approximately 15 minutes each day for the positioning and delivery of the therapy. The therapy itself takes about two minutes.

Radiation beams are shone from the linear accelerator from multiple directions, usually entering the head at the hairline of each temple (above or in front the ears) and the hairline of the forehead. They meet at the point within the pituitary gland where treatment is needed.

How is the fixation device or mask used?

There are a number of ways of ensuring that your head remains immobile during the treatment.

A clear plastic mask is often used. You visit the mould room where a cast of your head is made. Once this is done, and after you have left, clear plastic is moulded into the cast to form the mask, which fits your head and neck snugly. You attend again to have the mask fitted and then to have the scans and X-rays needed to plan the radiotherapy.

During treatment the mask is placed over your face and then attached to the treatment couch. You need the fixation device to immobilise your head during treatment, enabling very accurate treatment. This enables the dose of radiation to be concentrated in the exact area, reducing the risk of damaging the tissues the radiation passes through on its way to the pituitary gland.

More recently, some departments are using thermoplastic masks. This uses a special sheet of plastic with holes in it. Once warmed it becomes very flexible and can be pulled down over your face and fixed to the baseboard that you are lying on. Scans for planning the radiotherapy can be carried out on the same day using this system.

Finally, some departments use a stereotactic system. This involves having a special impression made of the upper teeth and back of head. These are attached to a ring, which fits on to the head and is pulled tight using Velcro straps over the top of the head. The ring is then clipped to the treatment couch.

Whichever system is used, the staff in the mould room will explain it fully to you before you start. However, if you have questions or concerns, you should feel free to ask any member of the team before treatment. In general, with the mask system, it is best for men to shave off beards and moustaches to ensure the snuggest fit throughout treatment.

Will I have any side effects?

Radiotherapy is painless and you will not feel anything. You will leave the treatment room having sensed nothing of the X-ray beam therapy. However, some patients find that they have an altered sense of taste and smell but these should return to normal within about two months. During the course of the treatment, patients do feel increasingly tired and may need to sleep longer at night or in the afternoon. This usually wears off after a month or two. Some patients feel queasy during the radiotherapy and occasionally patients are sick. Eating small meals frequently usually helps this. Your oncologist will give you medication to reduce nausea if necessary.

After three weeks of treatment, the skin at the point where the beam passes into and out of the head in the temples, the high forehead and the nape of the neck will become pink, perhaps sore and itchy. Hair at these places will start to fall out. But, in most cases, this will re-grow within three to six months. Your oncologist will give you medication to reduce soreness if necessary.

Are there any permanent side effects?

There are some side effects; however the majority are easily helped. It is important for you to weigh up the chances of the treatment helping you against the risk and seriousness of possible side effects.

- There is an increased chance of requiring pituitary hormone replacement therapy in the years following radiotherapy. About half of patients who are not already taking hormone replacement tablets when the radiotherapy starts will eventually need to take them. This need can take five to 20 or more years to appear. Patients are usually given male or female hormones using a gel, injections, tablets, and steroid and thyroid hormones via tablets. Please see our leaflet *The Pituitary Gland: Its Disorders and Hormones Explained*.

- Patients with pituitary tumours have a slightly higher risk than the general population of having a stroke. This may be partly to do with radiotherapy and partly to do with the pituitary tumour and effect of raised pituitary hormones.
- There are some very rare side effects. In less than one in 100 patients, the eyesight may become worse following radiotherapy. By 20 years following radiotherapy, two in 100 patients will have developed a further brain tumour. This is slightly higher than would be expected for people who have not had radiotherapy.

AFTER CARE

Your after care will continue to be monitored on a regular basis and this will be shared between your endocrinologist and GP. Because pituitary conditions are relatively rare, you might find that you will be the only patient with a pituitary condition that your GP is treating and they may find it helpful to have a copy of our *Pituitary Disease Fact File for General Practitioners*.

RADIOTHERAPY QUESTIONS & ANSWERS

Q *Will I be able to attend my local hospital for treatment?*
A Linear accelerators, the machines needed to deliver a course of radiotherapy, are usually situated in large cancer centres. These machines are sophisticated and expensive and require specially trained staff. So you will probably have to travel to your nearest specialist cancer (oncology) centre.

Q *Will I be able to drive myself to and from the hospital?*
A This will depend a little on how tired you become. If at all possible, try and have someone with you who can share the driving or take over if you are very tired. If you have to travel to and from the hospital on public transport, talk to the hospital staff as they might be able to time your treatment each day to fit in with bus and train timetables. You should inform the DVLA of your diagnosis and the treatment you are receiving.

Q *How long is it before the treatment is fully effective?*
A The effects of radiotherapy are gradual and cumulative over a period of several years.

Q *Will I be able to work? To look after my children?*
A Radiotherapy affects different people in different ways. Many patients are able to continue working throughout their course of treatment while others do find they get very tired, especially towards the end of the course. If you do experience tiredness, listen to your body and allow yourself extra time to rest. Try and maintain a healthy diet and drink plenty of fluids.

Q *I'm claustrophobic – will I be able to cope?*
A Tell the oncologist and radiotherapy staff of your concerns. It is quite normal to feel anxious about having your treatment but as you get to know the staff (who will probably be the same every day) and the procedure, it should become easier. Do try and relax and don't be afraid to express your fears to the staff as they are there to help you. Don't be afraid to ask questions if there is anything you do not understand. This is especially important when you start your treatment.

PATIENT STORY

I had been warned of the possibility that I might need radiotherapy (RT) after my surgery, as my tumour was very large, but, even so, was somewhat dismayed when the need was confirmed. After a short wait I headed off to the local cancer centre to see what was in store. More unknowns!

The specialist was really interested in pituitary tumours and took great care in explaining what was going to happen, in particular all the preparation that would be needed. I was concerned about my eyesight but was reassured that the beams would not affect that area. Soon I was having my mask made. The technician was brilliant. He explained exactly what was happening, and at the times when I needed to lie still and close my eyes kept talking to me. He put pink gunge over my face, allowing space for my eyes, nose & mouth and I had to lie very still while this set, making a mould of my face. I found it quite pleasant: as the gunge warmed up, I tried to imagine I was having a very expensive beauty treatment; but I'm sure many others would find it claustrophobic.

When the transparent plastic mask was made (did I really look like that?) I had several more visits for fittings. At these my post-surgery MRI scans were used to identify exactly where the beams needed to hit the mask which became marked with an assortment of lines and crosses until it was ready.

My five and a half weeks of treatment went very quickly. It took much longer to get everything set up than it did to receive the treatment. I hated the sound of the screws fixing me down – the metal screeching against the plastic! The radiographers were careful to explain everything and I had a chance to talk to the consultant at various times. I became quite sore above my ears and at the top of my forehead and some hair fell out – about the size of a 2p piece - where I was sore. It grew back quite quickly. I did get tired, perhaps the RT or perhaps the daily journey.

For several years after I still needed to take medication to keep my growth hormone levels under control, but now I don't need it.