Radiotherapy for craniopharyngiomas and pituitary adenomas

Radiotherapy Department
Patient Information Series No. 44
Introduction

This booklet has been written for patients who are receiving a course of radiotherapy for a craniopharyngioma or a pituitary adenoma. Radiotherapy is most often used for patients with cancer. However, patients with a craniopharyngioma or a pituitary adenoma do not have cancer.

The booklet describes:
- What is radiotherapy;
- Why you are having radiotherapy;
- How your treatment is planned and delivered;
- The side effects you may experience during and after treatment, and how best to cope with them.

We understand that this is a worrying time for patients and their families. You may feel that you have been given lots of information about what needs to be done in a short period of time. We hope this leaflet answers most of your questions and eases some of the worries you may have. If you still have any questions or concerns after reading this, please ask your doctor, specialist nurse or radiographer involved in your care. We are here to help.

If you are pregnant, or plan to become pregnant during your course of radiotherapy and up to four months afterwards, then it is advisable that you discuss this with your radiotherapy doctor, your specialist nurse or radiographer involved in your care.

What is radiotherapy?

Radiotherapy is the specialised treatment of cancer (and some other diseases) using high energy radiation beams. These can either be x-rays (also called photons), electrons or protons. X-rays and electrons are delivered from a machine called a linear accelerator whilst protons are delivered from a machine called a cyclotron.

From 2020 University College Hospital Trust will have a proton beam therapy (PBT) service. However, it is not appropriate to treat all kinds of cancers with proton beam therapy. This will be decided by your clinical oncologist and discussed with you.

Radiotherapy does not hurt, and it will not make you radioactive. You will be completely safe to be around family, friends and pregnant women. You will feel nothing from the treatment and the machine will not touch you. It is rather like having an ordinary x-ray. The most important thing is for you to lie very still for treatment.
Patients will normally receive their treatment as an outpatient, with a course of treatment lasting six weeks, treating daily excluding weekends. Your exact treatment schedule will be decided by your doctor and confirmed on your first visit to the radiotherapy department. Everyone’s treatment is different and is planned individually.

**Why am I having radiotherapy?**
In general, patients with a craniopharyngioma or a pituitary adenoma are referred for radiotherapy treatment if:

- They have evidence of persisting tumour following surgery.
- Their tumour is secreting a hormone that continues to be raised in blood tests following surgery, despite treatment with drugs.
- Their tumour re-grows (this would be some time after surgery, perhaps following a second operation).

**Planning your treatment**
Radiotherapy is a very precise treatment. In order to ensure treatment accuracy on a daily basis, your first visit will involve having a plastic mould (also called a mask or immobilisation shell) made of your head to ensure you are in the correct treatment position.

The mask has three purposes:
- To keep your head and neck immobilised during treatment
- To ensure you are in the same position every day for treatment
- To minimise the number of treatment marks on your skin

The mask is made from a sheet of thermo-plastic material called Posicast®. The sheet is hard when dry and is placed in warm water to allow it to soften. This is placed over your head and held in position, for five minutes, until it begins to dry and harden. Once the mask is made, your next visit will be for a radiotherapy computerised tomography (CT) planning scan.

**Having a radiotherapy CT planning scan**
You will be positioned on the CT scanner couch wearing your mask, with a support cushion under your knees. The radiographers will ensure you are straight and will then place some tape on your mask and draw marks on this tape. The scan will take about ten minutes, during which time you can breathe normally. Once the scan is complete, the radiographers will remove the mask and you will be free to leave the hospital. Before you go, you will be given an appointment card with the date and time for your next visit, which will be for your radiotherapy treatment.
Radiotherapy treatment
The radiotherapy treatment is daily, Monday to Friday. Your radiotherapy doctor will have already told you how many treatments you will be having. The treatment radiographers will explain the procedure to you and answer any questions you may have. For each treatment session, you will be lying on your back, on the treatment bed, wearing your immobilisation shell. The radiographers will ensure you are in the correct treatment position by aligning the marks on the shell with laser lights. They will then move the treatment machine and couch into position using your personal treatment plan.

When final verbal checks have been made, the radiographers leave the room. To give you the best treatment, you will be treated from several different angles. The linear accelerator will move around you, but will not touch you. You will not feel anything and you do not have to hold your breath. All we ask is that you keep still. The radiographers will be watching you at all times on a closed circuit television. Please check with your radiographers if you have any questions or concerns. Each treatment session takes about 30 minutes. Most of this time is spent getting you in the right position and taking images to ensure treatment accuracy. The treatment from each angle only takes a few minutes.

Side effects during treatment
There will be some side effects that will gradually appear during your course of radiotherapy, although these will vary from person to person. The risk and severity of any side effects depends on the dose of radiotherapy given. Your radiotherapy doctor will discuss these fully with you. There are side effects that occur during treatment, some happen soon after treatment, and some can occur months or years after radiotherapy. The main side effects that occur during treatment are:

Skin changes
The skin in the area being treated may become red, flaky and itchy during the radiotherapy treatment. You may get some dry peeling of the skin on your head. The skin behind your ear or the ear itself (if this is included in the treatment field) may become sore and moist.

During treatment we advise that you wash normally using warm water and soap. Pat your skin dry with a soft towel. We advise that you wash your hair gently using warm water and a non-medicated shampoo. When drying, use a soft towel and gently pat the scalp dry. You may also use a hair dryer on a cool setting or leave the hair to dry naturally. Brush and comb your hair gently using a soft brush or a wide rounded-toothed comb.
To minimise the risk of skin irritation we would advise the use of any skin cream/emoillient of your choice. However, creams containing the following ingredients should be avoided:

- Sodium Laurel Sulphate (sometimes referred to as ‘SLS’)
- Alcohol
- Perfumes
- Metallics

Should you not use a regular skin cream we would advise the use of creams such as ‘E45’ or ‘Zerobase’.

If you are unsure as to which skin cream to use on your skin during radiotherapy please ask, and we will be able to review any products that are brought in to confirm their suitability.

Avoid exposing the skin in the treatment area to strong sunlight or extreme temperature changes during treatment. Always ensure you wear a hat/cap to protect your head if you are outside during strong sunlight. After treatment has finished we would always recommend that you use a high protection sun cream (Factor 50 or more) and wear a hat/cap in strong sunlight.

Hair loss
Hair loss usually occurs after three weeks of radiotherapy treatment, and this will be in the treatment area. The hair usually starts to grow back about three months after treatment. The new growth will often be slightly different in colour and texture. Your hair might not grow back completely in the areas that have had a very high dose of radiation. The doctors will advise you about this.

Feeling sick (nausea)
Feeling sick is unusual during this treatment, however, some patients may feel sick (nauseated) and vomit during treatment. Radiation can cause a temporary swelling of the treated area in the head. You will be prescribed regular anti-sickness medication to take during treatment. If you are still feeling sick, please tell us. We can refer you to a doctor for further medication.

Headaches
The radiotherapy treatment may cause the brain to swell slightly and so you may develop signs and symptoms of raised intracranial pressure, which can include headaches, nausea, vomiting or double vision. This is usually for a short period of time, but it is important to discuss these reactions with your doctor or specialist nurse so the right treatment and support can be given. These reactions are temporary and are usually relieved by steroids.
Steroids may be prescribed depending on your symptoms. The steroid dose is gradually reduced and discontinued when treatment is completed. If you have a VP shunt (a tube draining fluid from the brain to the heart or gut) and are experiencing headaches, it is important to seek advice from your doctor or specialist nurse. It may be an indication of a blocked shunt.

Changes in appetite
Your appetite may increase or decrease during the course of treatment. Some people lose weight due to a change in appetite, while others gain weight, usually due to the steroids they are taking. It is important that you try to eat a healthy balanced diet during radiotherapy to help you feel stronger and more able to cope with treatment. It is also important to drink plenty of fluids, between one to two litres a day. This can include water, squash or hot drinks.

If you are losing weight, try to supplement your eating with high energy calorie drinks. Eat what appeals to you. Have snacks handy to nibble on throughout the day. Liquids may be more tempting than solids. If you are worried about any weight loss please ask to see the dietitian who can give you advice. Weight gain due to steroids is generally unavoidable. Watch what you eat and try to eat healthy foods. Choose lower calorie, lower fat foods. Most people lose weight once they no longer need to take steroids.

The use of steroids in brain irradiation
Steroids are drugs used to reduce the swelling associated with brain tumours and their treatment. They can temporarily relieve symptoms, improve your neurological status and promote a feeling of wellbeing. Due to the swelling you may experience symptoms similar to your original presenting symptoms, such as problems with speech (dysphasia), limb weakness, headaches, and nausea. Steroids are given to patients having brain radiotherapy to treat the radiation-induced swelling and any associated symptoms. There are, however, potential side effects which require close monitoring. The more common side effects of steroid medication are:

Problems with sleeping (insomnia)
To reduce the effects of insomnia it is suggested that you take your tablets in the morning and/or early afternoon.

Increased appetite leading to weight gain
You may experience cravings for sweet foods and an increased appetite. Try to eat a healthy balanced diet, although some weight gain may be unavoidable. Please ask to see a dietician if you are having difficulties managing your weight.

Changes in mood
Please be aware that steroids may affect your mood as they affect your body’s natural hormone balance. The effects could include irritability, mood swings, agitation and depression.
It may be helpful to discuss these effects with your family or carer. If you feel the need to talk about your feelings talk to your specialist nurse, the radiographers, nurses or your doctor. They are here to help you and can refer you to other health professionals for further advice and support.

**Irritation of the stomach lining**
Steroids can cause stomach irritation and symptoms similar to acid indigestion or heartburn. Take your tablets with food. Inform your nurse or doctor if you are experiencing any symptoms as you can be prescribed medication to manage these symptoms.

**Facial swelling**
You may develop a puffy, “rounded” face after several weeks of taking your steroid medication. This may mean that the mould you wear for your treatment can become tight and uncomfortable. Please speak to the radiographers if this is a problem as adjustments may have to be made.

**Steroids should never be stopped suddenly**
Do not change your dose unless the doctor tells you to do so, and when the steroids are stopped, they must be gradually withdrawn on a schedule prescribed by your doctor.
You will be given further advice and information regarding your steroids and their management by your specialist nurse.

**Hearing problems**
You may experience temporary hearing difficulties. There may be swelling in the inner ear due to the radiotherapy which can cause fluid to accumulate in the ear. You may also experience a hardening of the wax in your ears if your ears are in, or near, the area being treated. Please speak to your specialist nurse if you are anxious about this.

**Decreased sex drive (libido)**
Your desire for sexual activity may be lowered due to your hormone levels being affected, stress, or because you are just too tired. Share your thoughts with your partner. Explain that this is a side effect of treatment, not a change in your feelings. Your sexual desires will return to normal once treatment ends. If you or your partner are concerned, please speak to your doctor or your specialist nurse.

**Tiredness**
Tiredness is a very common side effect of radiotherapy. You may feel more tired than usual and have less energy, both during and after treatment. Do not worry, this is normal. It is usually a combination of travelling to hospital every day, the side effects of treatment, coping with a diagnosis of cancer and continuing with normal life.
We recommend that you listen to your body. Do as much as you feel you can and rest when you need to. However, gentle exercise has been found to improve fatigue levels in patients and we would recommend walking as a good form of exercise. Please let someone know if you are finding things difficult, as they may be able to offer practical advice.

There might be a particularly sleepy spell starting four to six weeks after treatment ends and going on for two to six weeks or even longer. This is called somnolence syndrome and has been described as excessive sleepiness, drowsiness and lethargy. You may feel that you have a lack of energy and cannot be bothered to do anything. Please contact your specialist nurse or your medical team if you are experiencing excessive tiredness.

**Who can I discuss my side effects with?**

At your first treatment appointment the radiographers will discuss the treatment with you and explain any possible side effects you may experience. They will see you every day and ask how you are and how you are feeling.

During treatment you will be assessed on a weekly basis by your clinical nurse specialist who will monitor your side effects and review your progress.

**Late side effects of radiotherapy**

Late side effects incurred during treatment can appear to develop many months or years after radiotherapy has finished. They are the hardest to accurately predict and, unfortunately, when they do occur they are usually permanent. Your doctor will discuss the possibility of these late side effects with you, at the time you sign your treatment consent form. Possible late side effects may include

**Hormone imbalance**

If your pituitary gland was in, or near, the treatment area you may experience changes in your normal hormone levels. This is called pituitary-hypothalamic dysfunction and can lead to problems with your thyroid, sugar metabolism, fertility, or ability to process water.

You will be regularly monitored by the neurology and radiotherapy doctors, and your specialist nurse when you attend for follow-up appointments. If you are experiencing any problems or have any worries please do not hesitate to ask for help.

**Cognitive (memory and thinking) problems**

In a very small proportion of patients, you may experience such problems due to changes in the brain caused by long term radiotherapy effects. The small blood vessels in the brain can be affected by the radiotherapy many years after treatment. Effect on the small blood vessels is similar to the changes that occur within the brain as it ages. Symptoms can be mild, moderate or severe, depending upon the area of brain affected and the extent of the damage to normal brain cells. You may experience:
• Problems thinking clearly
• Difficulty with managing tasks you previously found easy
• Poor memory
• Confusion
• Personality changes

If you are experiencing such symptoms please report these to your medical team. Neuropsychology assessments can be undertaken, and strategies to help manage any memory problems you may be experiencing can be suggested.

Cavernomas
Following radiotherapy to the brain, some patients may develop a small benign abnormality. These abnormal areas in the brain are due to a small tangle of blood vessels and are called cavernous haemangiomas, or cavernomas for short. In most cases, they cause no problems, but are detected on a routine follow-up MRI scan. Very occasionally, cavernomas may be discovered on a scan performed to investigate symptoms which might be due to tumour recurrence, but in fact have been caused by the small abnormal blood vessels bleeding. Cavernomas may appear some months or many years after radiotherapy, typically after about three years. The risk of developing a troublesome cavernoma is very low, only about one per cent.

Cataracts
The development of mistiness of the lenses of the eye can occur because of unavoidable radiation to the eye. This usually develops five to six years after treatment. In many cases this will not have an effect on your vision. However, in a small number of cases, some people may require surgery to remove the cataract in later years. Fortunately cataract surgery today is very straightforward and successful.

Strokes
Patients who have radiotherapy to the brain have a slightly higher risk (less than five per cent) than the general population of having a stroke. If you have any worries about this, please discuss it with your doctor.

Second malignancy
Very rarely, people who have received treatment for one particular tumour may develop another type of tumour in the treated area some years later. The radiotherapy doctors will discuss this risk if it is relevant to you.
Support
This booklet deals with the physical aspects of your treatment, but your emotional wellbeing and that of your family is just as important.

Having treatment can be deeply distressing for some patients. Within the radiotherapy department there will be access and support from your specialist nurse, the Macmillan information and support radiographer, the treatment radiographers and the radiotherapy review team. However, if you feel you require further medical or emotional support you can be referred to a variety of health professionals who can help with any worries or difficulties you may be having.

All the staff are here to make sure your treatment goes as smoothly as possible and to support you through this difficult period. We will try to help you with any questions or problems you may have.

After your radiotherapy has finished
Once you have finished your radiotherapy treatment, you will be given a follow-up appointment to see the radiotherapy doctors four to six weeks' later. This will be at University College Hospital, Queen’s Square. You will have a baseline post-radiotherapy MRI scan six to eight weeks after your radiotherapy has ended. This scan will not show how effective the treatment has been, but it will be used to compare with any future scans you may have.

The side effects you may have experienced will continue after radiotherapy treatment has finished. It is common to experience a worsening of the skin reactions for about 10 to 14 days after radiotherapy. Please feel free to contact the radiotherapy department or the brain tumour office if you are worried about your treatment side effects. However, most of the side effects should resolve after you have finished treatment. Before you finish your course of treatment, please ask for a copy of the leaflet “Finishing treatment”.

Useful contact numbers
Local
Contact your Clinical Nurse Specialist (Key Worker) via the Brain Tumour Office at The National Hospital for Neurology and Neurosurgery.

Name of Clinical Nurse Specialist:

Telephone: 020 3448 8830

For general enquiries, contact The Brain Tumour Unit
Telephone: 020 3448 8830
Email: uclh.braintumourunit@nhs.net
Macmillan Information and Support Radiographer:
Direct line: 020 3447 3711
Email: mwilliams21@nhs.net

Radiotherapy Review Team
Telephone: 020 3447 3700/3701

Out of hours oncology advice number
Mobile: 07947 959020

National

The Pituitary Foundation
Admin Line: 0845 450 0376
Support Line: 0845 450 0375
Endocrine Nurse: 0845 450 0377, Mondays 17:30 to 21:30pm and
Thursdays, 09:00 to 13:00
Email: helpline@pituitary.org.uk
Website: www.pituitary.org.uk

The Brain Tumour Charity
Support and Info Line: 0808 800 0004
Website: www.thebraintumourcharity.org

Brains Trust
Telephone: 01983 292 405
Support Line: hello@brainstrust.org.uk
Website: www.brainstrust.org.uk

CLIC Sargent
Freephone helpline: 0300 330 0803
Website: www.clicsargent.org.uk

Macmillan Cancer Support
Cancer Line Freephone: 0808 808 0000
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Cancer Research UK
Information Line: 0808 800 4040
Website: www.cancerresearchuk.org
Carers UK
Adviceline: 0808 808 7777
Email: adviceline@carersuk.org
Website: www.carersuk.org

NHS Choices
Website: www.nhs.uk

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