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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 craniopharyngiomas 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 daunting time for patients. 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 booklet answers some of your questions. If you still have any questions or concerns, please let your doctor, nurse or radiographer know. We are here for you.

What is radiotherapy?
Radiotherapy is treatment using high energy X-rays, aimed specifically at the site of the tumour. It is a quick and painless procedure. Radiotherapy has clear benefits since it is a localised treatment which can shrink the tumour, or reduce the risk of recurrence of the tumour. However, no treatment is completely risk free. In recommending your treatment, your radiotherapy doctor (Clinical Oncologist) has weighed up the risks and benefits. Please do discuss these issues with your doctor or a member of the radiotherapy team if you are worried.

Radiotherapy is planned to treat as little normal body tissue as possible and treatments are usually extended over a period of weeks. This allows normal cells to recover from the effects of the radiation. Common treatment prescriptions for treating benign tumours are between five and 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.
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
Before beginning radiotherapy, your treatment must be carefully planned. To ensure your treatment is accurate, you will have a personalized mask made of your head. You will wear the mask each day during your treatment. Your first appointment will be to have the mask made and to have a radiotherapy CT planning scan. You will need to attend the mould room in the radiotherapy planning department.

• The mask has three purposes:
  • To help you keep still during your treatment
  • To ensure you are in exactly the same position each day for treatment
  • To prevent having to draw treatment marks on you, as they are drawn on the mask instead.

You will be given a booklet called “A visit to the mould room”. When you come for your appointment the mould room staff will explain the process in more detail. After your mask has been made you will be taken to the CT scanner for a radiotherapy CT planning scan. This scan locates the exact area to treat in relation to surrounding normal tissue.
You will be positioned on the scanner couch lying on your back wearing your mask. The radiographers will mark lines on your mask. These will be used to ensure you are in the correct position each day for your treatment. The scan will take approximately five to ten minutes. You will feel nothing. All we ask is that you lie still and breathe normally.

After the scan is completed, 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 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. Your treatment will be on a machine called a Linear Accelerator. 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 mask. The radiographers will ensure you are in the correct treatment position by aligning the marks on the mask 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 15 minutes. Most of this time is spent getting you in the right position. The treatment from each angle only takes a few minutes.
Side effects during treatment

There will be some side effects which will gradually appear during your course of radiotherapy, although these will vary from person to person. The risk and severity of any side effects occurring depends on the dose of radiotherapy given. Your radiotherapy doctor will discuss this 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 the head. The skin behind the ear or the ear itself (if this is included in the treatment field) may become sore.

How to look after your skin
During treatment we advise that you wash your skin gently using warm water and a non-perfumed soap. Pat the skin dry with a soft towel. Do not rub the treatment area.

Aqueous cream, which will be given to you at the start of your treatment, may be applied to the treated skin. This is a simple, unperfumed moisturising cream to help prevent the skin from becoming too dry. The cream can be used from the start of treatment. Apply the cream two to three times per day. Smooth a little cream very gently onto the treatment area. Do not rub it in. If your skin becomes broken and sore do not use aqueous cream. You may be prescribed alternative creams by the doctor or referred to the nurses for advice.

Do not use any other creams or lotions in the areas being treated unless advised by a member of staff.
Avoid exposing the skin in the treated area to strong sunlight, both during and after your radiotherapy treatment. Ensure that you wear a hat, cap or head scarf at all times when outside to protect your head. Radiotherapy causes changes to the skin which makes it more sensitive to the sun. Your skin will damage more easily and take longer to heal. The treated area will be especially sensitive for the first twelve months and you should avoid exposing the treated area to strong sunlight. After this time you can gradually increase the sun exposure but we recommend that you always use a high protection sun cream (Factor 25 or more) in strong sunlight.

**Hair loss**
Hair loss occurs in the area being treated about two to three weeks after you begin your radiotherapy treatment. It is usually temporary but permanent hair loss over the area being treated can occur with higher doses of radiation. Your doctor will advise you of this. Your hair will begin to grow back several months after your radiotherapy treatment has finished, but the new growth might not be the same texture or colour as your original hair.

**Managing hair loss**
You may wash your hair gently, with warm water. Only use a mild shampoo such as an unperfumed and limit your hair washing to two or three times a week. When drying, use a soft towel and gently pat your scalp dry, do not rub vigorously. You may also use a hair dryer on a cool setting or leave your hair to dry naturally. Do not use any harsh hair treatments such as hot rollers, perm solutions, hair sprays or hair colours. Brush and comb your hair gently using a baby (or other soft) brush or a wide rounded toothed comb.

**Feeling sick (nausea)**
Feeling sick is unusual during this treatment. However, some people may feel sick and vomit during their course of treatment. If you are experiencing any symptoms please speak to a member of staff who can refer you to a doctor for further medication. Please ask for a copy of the leaflet “Coping with nausea”.
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 and 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. Please ask for the leaflet “Eating hints for patients”.

Headaches
The radiotherapy treatment may cause the brain to swell slightly and so you may develop signs and symptoms of raised pressure, which can include headaches. 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.

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.

Side effects after treatment
As well as side effects that occur during treatment, there may also be side effects of radiotherapy treatment that occur several weeks after the treatment has finished. Please ask your radiotherapy doctor about the chances of such side effects occurring. These include:

Somnolence syndrome
Somnolence syndrome is described as excessive sleep, drowsiness and lethargy. The majority of patients undergoing radiotherapy to the pituitary experience some degree of fatigue and drowsiness during their treatment. Allow yourself to get plenty of rest and set your own pace.

However, many patients do not have a problem with tiredness and you are encouraged to lead as normal a life as possible.

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. You may feel that you have a lack of energy and cannot be bothered to do anything. This is a normal reaction to the treatment but the long duration and sometimes the severity of the symptoms can cause anxiety. Please ask for the leaflet “Coping with fatigue and tiredness”.

Hormone imbalance
Radiotherapy may cause changes in your normal hormone levels. If your pituitary gland was in, or near, the treatment area you may experience changes in your normal hormone levels. There is an increased chance that you may need pituitary hormone replacement therapy in the years following radiotherapy.
This is called pituitary-hypothalamic dysfunction and can lead to problems with your thyroid, sugar metabolism, fertility, or ability to process water. 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 twenty or more years to appear. You will be regularly monitored by the Neurology, Endocrinology 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 effected by the radiotherapy many years after treatment. The 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. Neuropsychological assessments can be undertaken, and strategies to help manage any memory problems you may be experiencing can be suggested.
Strokes
Patients with pituitary tumours have a slightly higher risk than the general population of having a stroke. This may be partly to do with the radiotherapy treatment, and partly to do with the pituitary tumour and the effect of raised pituitary hormones.

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.

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 nurses. 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 in two weeks time. This will either be at University College London Hospital, or The Hospital for Neurology and Neurosurgery at Queen’s Square. You will have a baseline postradiotherapy CT 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 department, your specialist nurse, the nursing staff or the Macmillan information radiographer if you are worried. You could also contact your GP or call outpatients to request an earlier follow-up appointment. 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: braintumourunit@uclh.nhs.uk

Macmillan Information and Support Radiographer
Mark Williams
Direct telephone: 020 3447 3711
Main switchboard: 0845 155 5000
ext 73711
bleep 1458

Alternative switchboard: 020 3456 7890
ext 73711
bleep 1458

Email: mark.williams@uclh.nhs.uk

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 13:00  
Email: helpline@pituitary.org.uk  
Website: www.pituitary.org.uk

**Brain Tumour Action**
Main/Befriender Helpline: 01314 460236  
Telephone: 01506 436164  
Evenings and weekends  
Email: chair@braintumouraction.org.uk  
Website: www.braintumouraction.org.uk

**British Brain Tumor Association**
National Information Line: 01519 293229  
10:00 to 16:00  
Fax: 01519 293229

**Samantha Dickson Brain Tumour Trust**
Telephone: 0845 130 9733  
Email: enquiries@sdbtt.co.uk  
Website: www.braintumourtrust.co.uk

**Brain and Spine Foundation**
Freephone Helpline: 0808 808 1000  
Website: www.brainandspine.org.uk
**Carers UK**
Freephone: 0808 808 7777
Wednesday to Thursday
10:00 to 12:00 and 14:00 to 16:00
Email: info@carersuk.org
Website: www.carersuk.org

**National Library for Health**
Covers all aspects of health, illness and treatments
Website: www.library.nhs.uk

**NHS Direct**
Telephone: 0845 4647
Available 24 hours
Website: www.nhsdirect.nhs.uk

**Patient UK**
Comprehensive, free, up-to-date health information
Website: www.patient.co.uk

**NHS 24**
Telephone: 0845 424 2424
Website: www.nhs24.com

**NHS Choices**
Website: www.nhs.uk

**Health Talk Online**
Website: www.healthtalkonline.org
Space for notes and questions