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# Pituitary and Craniopharyngioma

Radiotherapy

A guide for patients and carers

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This information is for patients who are going to receive radiotherapy for pituitary adenoma or craniopharyngioma.

This leaflet will explain:

- What is radiotherapy?
- General information about side effects of treatment
- During treatment
- After treatment
- Long term side effects.
- Completion of radiotherapy and follow-up
- Who to contact when you need advice

## Radiotherapy

Radiotherapy is most commonly used for patients with cancer. Although patients with either pituitary adenoma or craniopharyngioma do not have cancer, radiotherapy may still be recommended to control the growth of the tumour and prevent it getting bigger.

Radiotherapy can sometimes result in shrinkage of the tumour, but this can take many months or years to happen.

You may have been referred for radiotherapy if:

- There is some tumour left following surgery
- The tumour is secreting a hormone that continues to be raised following surgery despite treatment with medication
- The tumour has been removed but the type of tumour means it has a high chance of coming back (recurrence) without the addition of radiotherapy
- The tumour has regrown after surgery

In any of these situations, the risk of recurrence (tumour continues to grow or secrete hormones) is reduced from over 50% at ten years to less than 3%.

## Radiotherapy for a Pituitary adenoma or Craniopharyngioma

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## Side effects from Radiotherapy

Radiotherapy can cause general side effects such as tiredness, but there are some effects which are specific to having pituitary radiotherapy.

Side effects can depend on the number of treatments you have and the dose of radiotherapy required. Most side effects are temporary but some may last for weeks or months after your treatment has finished. During your treatment your neuro oncology Clinical Nurse Specialist will review, assess and support your needs, it is important that you report any concerns or side effects that you may be having.

## Side effects during Radiotherapy treatment (short term side effects)

### **Tiredness**

It is common to feel more tired than usual during your treatment and for several weeks after your treatment has finished. It is important to rest when you feel the need to do but also continue to do some gentle exercise to balance your energy levels. You may need to ask your family and friends to help out when they can.

### **Headaches**

Radiotherapy treatment may cause the brain to swell slightly so you may develop signs and symptoms of raised pressure. It is important to discuss these reactions with your doctors or clinical nurse specialist so the right treatment and support can be given. These reactions are temporary and 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 do suffer from headaches you can also take painkillers such as paracetamol to help.

### **Loss of appetite/Nausea**

Occasionally radiotherapy can cause nausea (feeling sick). If it is going to happen, it usually occurs two to six hours after your treatment and usually settles within a couple of hours. If you have not felt sick with your first or second treatments, you are unlikely to be affected by the remaining treatments. You can help yourself



by trying to drink plenty of non-alcoholic drinks, trying to eat small meals four or five times a day.

Your appetite may increase or decrease during the course of treatment. It is important that you try to eat a healthy balanced diet during the radiotherapy to help you feel stronger and more able to cope with the treatment. It is also important to drink plenty of fluids.

If you do feel that you are struggling with poor appetite or nausea, please discuss this with your clinical nurse specialist, they will be able to offer self-help advice and discuss management options such as anti-sickness medication.

### **Hair Loss**

You may lose your hair in the treated area. Most hair loss is temporary and usually starts to grow back within two to three months of finishing treatment, but for some people this can be permanent. Whether or not you lose your hair depends very much on the dose of radiation and the number of treatments you are going to have. Sometimes hair can grow back a slightly different colour and texture than what it was before treatment. If you would like to discuss the option of a wig, your clinical nurse specialist can arrange for you to be given a voucher. Turbans, scarves, caps and hats are alternatives to wearing a wig.

## **Skin Reactions**

Skin reactions in the treatment area should be mild, with slight redness and itching, but can be affected by the dose and type of radiotherapy that your consultant has prescribed. It can also be dependent on your type of skin, any existing conditions such as diabetes and especially if you smoke. Some tips for looking after your skin during radiotherapy are: wash your hair very gently using a baby shampoo and lukewarm water, avoid washing your hair if your scalp becomes sore. Avoid using a hot hairdryer, do not expose your head to bright sunlight during treatment and for several months after treatment has finished – wearing a hat is advisable. If you feel your skin is becoming red, itchy or dry you can discuss this with your clinical nurse specialist or one of the radiographers who will be able to give you a gentle moisturising cream to use.

## **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 your treatment ends. If you, or your partner, are concerned, please speak to your consultant or clinical nurse specialist.





## Side effects after completion of radiotherapy treatment

### **Somnolence syndrome**

Feeling excessively tired, lethargic and sleepy in the weeks following completion of treatment. It is important to ensure that you have plenty of rest when needed. You may experience a particularly sleepy spell starting four to six weeks after treatment ends, continuing for two to six weeks or longer. You may feel that you have a lack of energy and cannot be bothered to do anything. This is a recognised reaction to the treatment and is not a cause for clinical concern, however if you are struggling please speak with your clinical nurse specialist who can offer advice and support.

### **Hormone imbalance**

As the pituitary gland is in or near the radiotherapy treatment area you may experience changes in your normal hormone levels which can lead to problems with your thyroid, sugar metabolism, fertility, or ability to process water. There is an increased chance that you may need 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 can take five to twenty or more years to appear. You will already be under the care of an Endocrinology team and they will be kept updated following your treatment. If you have any questions regarding hormone imbalance or treatment, please speak with your clinical nurse specialist who will be able to advise further.

## **Cognitive (memory and thinking) problems**

A very small proportion of patients may experience cognitive 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. Symptoms can be mild, moderate or severe depending up the area of brain affected and the extent of damage to normal brain cells. If you are concerned about a change in your memory or thinking or wish to discuss this through further, please let your Consultant or clinical nurse specialist know.

## **Stroke**

People with pituitary tumours, undergoing radiotherapy have a slightly higher risk than the general population of having a stroke. This is believed to be due to a combination of radiotherapy treatment and the effect the pituitary tumour may have on hormone secretion. If you wish to discuss this further please let your Consultant or clinical nurse specialist know.

## **Eye problems**

The development of cataracts (mistiness of the lenses of the eye) can occur because of unavoidable radiation to the eye. If a cataract does occur, surgery to remove the cataract may be needed in later years. The location of the pituitary gland and tumour means that inevitably your eye nerves (optic nerves and optic chiasm) will receive some radiation. The radiotherapy dose to these structures will be minimised to as low as possible but there will be a small risk of damage to your vision long term.



## Monitoring and follow up

You will be monitored weekly during your radiotherapy treatment by the neuro oncology clinical nurse specialists. They will assess you clinically and ensure they manage any supportive needs that you may have during your treatment. They are also able to offer advice prior to starting treatment.

Following on from treatment you will have a telephone review with the clinical nurse specialist 2 weeks from completion of treatment, if you feel you would like a review prior to this appointment please let the clinical nurse specialist know and they will arrange this with you.

You will then have a follow up with your Consultant Clinical Oncologist 6 weeks following completion of treatment. At this point you will have the opportunity to ask questions and discuss any worries or concerns that you may have.

If you are well following radiotherapy and your Consultant feels it is safe to do so, you will then be referred back under the care of your neurosurgical and endocrinology teams.

## Driving Information

The DVLA state that during radiotherapy for a pituitary tumour a person must not drive. They may recommence driving once they have recovered from treatment provided you do not have a visual problem.

You do not have to inform the DVLA of this if you are having radiotherapy as a stand alone treatment.

## Urgent symptoms to report

If you experience any of the following symptoms please urgently inform your clinical nurse specialist or seek medical advice from the 24 hour hotline number which is provided below.

- Severe headaches
- Vomiting
- Visual changes or loss
- Drowsiness and confusion
- Excessive thirst
- Passing excessive volumes of urine

## Meet the team

### Consultants

**Dr Chloë May** - Consultant Clinical Oncologist

Specialist in neuro oncology, skull base tumours and pituitary tumours

**Dr Aditiya Shenoy** - Consultant Clinical Oncologist

Specialist in neuro oncology, head and neck and ocular tumours

**Dr Shaveta Mehta** - Consultant Clinical Oncologist

Specialist in neuro oncology and breast cancer treatment



## **Clinical Nurse Specialists**

**Jill Sokratous** - Neuro Oncology Clinical Nurse Specialist

**Jan Holding** - Neuro Oncology Clinical Nurse Specialist

**Helen Rogerson** - Neuro Oncology Clinical Nurse Specialist

## **Secretaries**

**Jane Richards** - Secretary to Dr Shenoy and Dr Mehta

**Jane Williams** - Secretary to Dr May

## **Contact details**

### **Neuro Oncology Nurse Specialists**

Voicemail - 0151 556 5850

### **Neuro Oncology Nurse Specialists**

Email - [ccf-tr.neuro.oncologynurses@nhs.net](mailto:ccf-tr.neuro.oncologynurses@nhs.net)

### **Jill Sokratous**

Work mobile - 07899877593

### **Jan Holding**

Work mobile - 07900737796

### **Helen Rogerson**

Work mobile - 07880005438

### **Clatterbridge 24 hour hotline number**

0800 169 5555

## Helpful resources

### **Clatterbridge Cancer Centre “Radiotherapy to the brain” booklet**

[https://www.clatterbridgecc.nhs.uk/application/files/3915/0150/1982/Radiotherapy\\_to\\_the\\_brain\\_-\\_vn3.0\\_a5.pdf](https://www.clatterbridgecc.nhs.uk/application/files/3915/0150/1982/Radiotherapy_to_the_brain_-_vn3.0_a5.pdf)

### **The Pituitary Foundation**

<https://www.pituitary.org.uk/>

### **Macmillan Cancer Support**

<https://www.macmillan.org.uk/cancer-information-and-support/brain-tumour/pituitary-gland-tumours>

<https://www.macmillan.org.uk/cancer-information-and-support/brain-tumour/craniopharyngioma>

### **DVLA driving regulations**

<https://www.gov.uk/guidance/neurological-disorders-assessing-fitness-to-drive#pituitary-tumour>





## How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

**If you have a comment, concern, compliment or complaint, please call 0151 556 5203.**

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