

Kent Oncology Centre



Radiotherapy Side Effects and Management: Pituitary adenoma and craniopharyngioma

Information for patients

This booklet has been written for patients who are receiving a course of radiotherapy for pituitary adenoma or craniopharyngioma. We hope this leaflet will help you understand the side effects that may occur when having external radiotherapy to the brain. It also explains the best management of these side effects. If you would like to speak to one of the radiotherapy team please feel free to contact them on the numbers given below:



Maidstone Hospital

Macmillan Radiotherapy Specialists
Appointment enquiries

 01622 225094
 01622 225080

Kent & Canterbury Hospital

Macmillan Radiotherapy Specialists

 01227 766877
Ext 722 2711
 01227 783010

Appointment enquiries

You will be given a copy of our leaflet 'External Beam Radiotherapy' which we advise you to read alongside this leaflet; it provides general information about radiotherapy and useful contact numbers. If you have not been given a copy please ask. Our leaflets can also be found on the **Kent Oncology Centre website:** www.kentoncologycentre.nhs.uk

Why am I having 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 if:

- There is evidence of persisting tumour following surgery
- The tumour is secreting a hormone that continues to be raised following surgery despite treatment with medication
- The tumour regrows (this would be some time after surgery, perhaps following a second operation)

In these situations the risk of recurrence is reduced from over 50% at ten years to less than 3%

Side effects from radiotherapy

There will be 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 depend upon the dose of radiotherapy given. Your radiotherapy doctors will discuss this fully with you. Some side effects may occur, usually towards the end of the course of treatment and also during the first few weeks after treatment has finished.

These side effects can be upsetting and may require you to make some adjustments to your normal life, but most are temporary and will gradually disappear after a few weeks. However, some side effects may continue for, and some may only become apparent after, months or years following treatment. It is important to discuss these with your consultant as help may be available. Radiotherapy does not make you radioactive; it is safe to be with other people, including children, throughout your treatment.

Pregnant?

Please tell the medical staff if you might be pregnant; radiotherapy can harm the developing baby.

Short term side effects

You will be monitored throughout your treatment by the radiotherapy team. Please let them know if you experience any of the following problems:

Tiredness

Radiotherapy can make you tired so you may need more rest than usual, especially if you have to travel a long way for treatment every day. It is good to try to get some exercise each day, however gentle.

Loss of appetite

Your appetite may increase or decrease during the course of treatment. Some people lose weight due to a change in appetite whilst others gain weight, usually due to the steroids they are taking. It is often better to try to eat little and often. 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 e.g. water, squash, fruit juice, milk and soup.

If you are losing weight, it is a good idea to supplement your meals with nutritious high-calorie drinks. These are available on prescription or can be bought from the chemists. Please discuss this with the radiotherapy team.

Occasionally radiotherapy can cause nausea (feeling sick). This is often helped by drinking more fluids but medication can be prescribed if necessary.

Headaches/seizures

Radiotherapy treatment may cause the brain to swell slightly 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 doctors or specialist nurse 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.

Hair loss

You will lose your hair in the treated area. Most hair loss is temporary, usually starting to grow back within two to three months of finishing treatment, but for some people this can be permanent and is dependent on the dose of radiotherapy you receive. Hair only falls out where the x-ray beam enters and leaves the body. Sometimes hair can grow back a slightly different colour and texture and perhaps not as thickly as before. You can be referred for a wig consultation; please ask about this.

Skin changes

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, your shape, any existing conditions such as diabetes and especially if you smoke. Advice can be provided to help you stop smoking.

Tips for helping your skin include:

- Wash your scalp and hair gently with lukewarm water and a baby shampoo and pat dry.
- If required, moisturise skin across the forehead and around the ears with a moisturiser. Please ask the radiotherapy team if you are unsure which moisturisers to use
- Avoid exposing the area to extremes of temperature such as hair dryers (unless on a cool setting), heat pads, saunas or ice packs during treatment.

The skin on your head is sensitive so it is best not to over-expose it to the sun or cold winds. Try wearing a soft cotton or silk scarf or hat to cover the area when you go outside.

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 your ears. 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 your treatment ends. If you, or your partner, are concerned, please speak to your doctors or your specialist nurse.

Please note: if you are having radiotherapy to your brain the DVLA require that you do not drive through treatment.

Side effects after radiotherapy treatment

As well as the side effects that occur during treatment there may be side effects that occur in the months to years after treatment has finished. Please ask your radiotherapy doctors about the chances of such side effects occurring. These include:

Somnolence syndrome

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

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 normal reaction to the treatment but the long duration and sometimes the severity of the symptoms can cause anxiety.

Hormone imbalance

As the pituitary gland is in or near the radiotherapy 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. 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 regularly be monitored by the Endocrinology doctors when you attend for follow-up appointments. If you experience any problems or have any worries please do not hesitate to ask.

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. 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 up the area of brain affected and the extent of damage to normal brain cells. You may experience:

- Problems thinking clearly
- Confusion
- Difficulty managing tasks your previously found easy
- Poor memory
- Personality changes

If you experience such symptoms please report these to your medical team who can suggest strategies to help manage memory problems.

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, usually developing five to six years after treatment. If cataract occurs, surgery to remove the cataract may be needed in later years. Fortunately cataract surgery today is very straightforward and successful.

Second cancer

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 if the risk is relevant to you.

Contact details

Kent Oncology Macmillan Cancer Information Centre, Maidstone Hospital

Offers support and information to anyone who has concerns about cancer (patients, relatives, friends or carers).

☎ 01622 227064

Macmillan Cancer Support

Provide practical, medical and financial information

☎ 0808 808 0000 (Freephone)

Website: www.macmillan.org.uk

Cancer Research

This charity provides information about cancer, treatment and clinical trials.

☎ 0808 800 4040

Website: www.cancerresearchuk.org

Patient Experience Teams (PALS) for East Kent patients

Kent and Canterbury Hospital

Desk at the outpatient's entrance of the hospital

Queen Elizabeth the Queen Mother Hospital

Office at the main entrance of the hospital (Ramsgate Road)

William Harvey Hospital

Desk at the main entrance of the hospital

☎ 01227 783145 or 01227 864314

Email: ekh-tr.patientexperienceteam@nhs.net

Please use this space to write any notes or questions you may have.

MTW NHS Trust is committed to making its patient information accessible in a range of languages and formats. If you need this leaflet in another language or format please ask one of your clinical care team or the Patient Advice and Liaison Service (PALS). We will do our best to arrange this.

Maidstone and Tunbridge Wells NHS Trust welcomes all forms of feedback from our service users. If the standard of service you have received from the Trust does not meet your expectations, we want to hear from you. Please speak with the ward manager or the nurse in charge in the first instance, or you can contact the **Patient Advice and Liaison Service (PALS)** on:

Telephone: ☎ 01622 224960 or ☎ 01892 632953

Email: mtw-tr.palsoffice@nhs.net

or visit their office at either Maidstone or Tunbridge Wells Hospital between 9.00am and 5.00pm, Monday to Friday.

You can be confident that your care will not be affected by highlighting any areas of concern or making a complaint. The Trust will retain a record of your contact, which is held separately to any medical records. If you are acting on behalf of a patient, we may need to obtain the patient's consent in order to protect patient confidentiality. More information on PALS or making a complaint can be found on the Trust's website: www.mtw.nhs.uk or pick up a leaflet from main reception.

Issue date: February 2017
Database reference: RWF-ONC-RAD-LEA-PAT-1

Review date: February 2020
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