Follow-up information after radiotherapy for head and neck cancer

This leaflet describes the follow-up procedures following radiotherapy treatment for head and neck cancer. This is a general guide and you may have a slightly different follow-up routine from that described. Please ask your Christie doctor or nurse if you have any questions about your own case.

Sometimes problems can develop in the first few weeks after radiotherapy. We encourage you to contact us with any concerns on the numbers below. You can be seen at a clinic at The Christie if you are having problems at any stage during your recovery. Please phone us to arrange this on the numbers below.

There is also advice in the booklet ‘Radiotherapy to the head and neck’. You were given this booklet before you started your radiotherapy.

Contact numbers
If you have any queries or concerns about any aspect of your treatment or condition, please contact us on the numbers below.

Kathleen Mais, head and neck nurse clinician
0161 446 3428 You can leave a message on this number and Kathleen will call you back.
Or call: 0161 446 3000 and ask for bleep 12589
Mobile: 07539 527 907

Debbie Elliott, head and neck nurse specialist
0161 446 8041 You can leave a message on this number and Debbie will call you back.
Or call: 0161 446 3000 and ask for bleep 12610

Claire McVey, Macmillan head and neck nurse specialist
0161 918 2424 You can leave a message on this number and Claire will call you back.
Or call: 0161 446 3000 and ask for bleep 12828

Secretaries
Dr Garcez 0161 446 3331
Dr Lee 0161 446 8581
Dr Sykes 0161 446 3354
Dr Thomson 0161 446 3361

The Christie Hotline (24 hour number) 0161 446 3658

Research nurses
If you have been taking part in a clinical trial you can contact the Research Nurses:
Kim Denton and John Baron 0161 446 8102 or 0161 446 8518
First follow-up appointment

- Your first follow-up appointment is usually about six weeks after completion of your treatment. This allows time for the reaction to settle down.
- Sometimes, especially if you have had a particularly severe reaction to the treatment, we may ask you to come back to The Christie earlier than six weeks to check how you are recovering.
- Your follow-up appointment will either be at The Christie or back at your referring hospital.
- At The Christie, you may see the head and neck nurse clinician at your appointment or a doctor.

If you have any concerns while you are awaiting your first appointment, please do not hesitate to contact us for advice by telephone (see page 1). If necessary we can arrange an earlier clinic appointment.

District nurses
If you wish, you can be referred to the district nursing service on completion of your radiotherapy. These nurses, who liaise with your family doctor, can visit you at home to give advice on dressings, pain control and other symptoms.

Community Macmillan nurses
These nurses are specially trained in the care of patients with cancer. They can give you and your family general support and can advise you on control of the symptoms resulting from your treatment and/or your cancer. Ask the staff caring for you at The Christie or your GP about a community Macmillan nurse referral.

Skin reaction

- Sometimes the skin reaction can be at its worst just after the radiotherapy treatment has ended.
- If there is a discoloured or offensive-smelling discharge from the skin this may mean an infection is present which requires antibiotics. Your family doctor can prescribe these for you.
- If the skin peels or discharges, it may be helpful to have dressings applied to the sore area. These relieve discomfort and help to prevent infection. Your district nurses can arrange to do these dressings. Alternatively contact Kathleen, Debbie or Claire on the numbers provided.

Other side effects
There are several other possible side effects of radiotherapy treatment, depending on the area of the head and neck treated. These are detailed in the booklet ‘Information about radiotherapy to the head and neck’.

To help reduce side effects:
- drink plenty of non-alcoholic fluids
- make sure you are getting enough nourishment either through food or the supplement drinks
- don’t smoke
- you may have an alcoholic drink but don’t drink to excess
- contact us or your GP if you have any queries or concerns
Chemotherapy
If you have received chemotherapy as part of your treatment, remember that you may still be prone to infection for a few weeks after the last dose, so if you feel unwell you will need to ring The Christie Hotline on 0161 446 3658.

Nutrition
- It is important that you get enough nourishment during and after your treatment.
- This may be from soft or liquidised food or by drinking the supplement drinks (eg Ensure, Fortisip, Calshake). If you are concerned that you are not getting enough calories, please contact us or your GP. He/she can arrange for you to see a dietitian to advise you on eating.
- If soreness in your mouth or throat is stopping you eating or drinking, you may need to take stronger painkillers to help for a while. Please ask your GP about this.

Feeding tube
Some patients have a feeding tube inserted during their treatment. If you have a feeding tube and have any problems with it please contact: The Christie Hotline on 0161 446 3658.

If you have problems related to the feed itself, please contact your community dietitian.

You may need the help of a speech and language therapist. They help decide whether it is safe for you swallow without the tube. It is important to try to stop using the tube as soon as possible after radiotherapy. This helps to reduce the chance of swallowing problems in the future. It is not always possible to have the tube removed. If you have concerns about this, please contact us (see page 1).

How long should I stay on painkillers?
- Painkillers are not part of your treatment as such. They are to help reduce the pain or soreness caused by the radiotherapy treatment. You need to stay on them as long as you have pain or soreness.
- It is important that you have adequate pain relief to make you feel comfortable and to allow you to eat and drink.
- As your radiotherapy reaction settles down in the weeks after treatment finishes, you will probably be able to reduce the painkillers you are taking. If you need advice on reducing or stopping your painkillers, especially if you are on painkilling patches or any other type of morphine, contact us or your GP.
- If the pain or soreness gets suddenly worse, it can mean that you have an infection. This can normally be treated with a short course of antibiotics from your GP.

Many patients take The Christie paracetamol mixture. This can be difficult to get at other pharmacies. If you need a repeat prescription, contact us via the numbers on the front page of this information. Alternatively you can take soluble paracetamol tablets, available from your GP or from your local pharmacy.

Remember - you can only safely take 4 grams (8 tablets) of paracetamol in any 24 hour period. This is 40mls of The Christie paracetamol mixture.

If you have any queries or concerns about your painkillers, please let us know.
Feelings and emotions
Sometimes patients can feel very anxious or low in mood at this time. If you feel like this, please tell us or your GP. There is usually something we can do to help. There are specially trained doctors, nurses and counsellors here at The Christie who can offer psychological support. If you would like to be referred, ask your doctor or nurse at The Christie. (See contact numbers page 1). Local cancer centres often offer counselling and you can find the address and telephone number of a centre near you in The Christie booklet ‘Where to get help’ or phone the cancer information centre on 0161 446 8100.

What will happen at my clinic appointments?
At your follow-up appointments we will ask you how you are generally and whether you have any pain. Please remember to make a note of the names and dose of any painkillers or other new medicines you are taking.

You will also be weighed and we will ask about what you are managing to eat and drink.

We may ask you about other things, such as your voice quality, tiredness and whether you have a dry mouth. All these questions give us an idea about how you have recovered from the treatment. Please tell us about any symptoms that are bothering you or that you think might be important.

If you are or were a smoker, we will also check whether you are still smoking. People who continue to smoke after the treatment remain at risk of complications from the treatment as well as other diseases including cancers.

Dry mouth - Many people have a dry mouth after radiotherapy. We can give you advice about this. Useful preparations to replace the saliva include Biotene mouth gel and Saliva Orthana. Please note Glandosane spray can be harmful to your natural teeth (but not to dentures).

How do we know whether the cancer has gone?
At your appointment, the doctor or nurse clinician will examine the area where the cancer was originally. This may involve looking into your mouth, throat, nose or ear. In some cases we may do this by performing a fibreoptic nasendoscopy, sometimes known as a ‘scope’ or an ‘FOL’. This is often the best way to see areas such as the voice box or the back of the throat or nose. We will also examine your neck. This is to check that any lymph glands (or nodes) that were enlarged have gone and that no new lymph glands have appeared.

Will I have a scan?
In some kinds of head and neck cancer a scan is the only way of telling what has happened to the cancer. In these cases, scans can be done regularly.

For most people, the questions and examinations described above are the best way of assessing whether there is cancer present and a scan is not generally needed. However, if your consultant thinks that a scan is needed at any time one will be arranged.

Why don’t I have regular blood tests to monitor the cancer?
In some diseases, such as cancer of the bowel or the prostate, there are blood tests that can help us to check for the cancer. At the moment there is no such test for head and neck cancer.
You will have had a blood test before you started the radiotherapy treatment. This, like most of the blood tests we do, are to check your general health including your kidney and liver function. During and after radiotherapy, blood tests are not normally required.

Patients who have had chemotherapy will have more frequent blood tests to check for side effects of the chemotherapy. Once the chemotherapy treatment has finished, regular blood tests are not normally required.

Further follow-up
In general you will be asked to attend the outpatient clinic regularly. The frequency of your appointments will depend on the original cancer and the treatment you have had. Many patients are asked to attend clinic every six to eight weeks for the first year.

The normal length of follow-up is five years. If you have been clear of cancer during this time, you will probably be discharged.

Again, please remember that for some people the follow-up procedure will vary. If this applies to you, your doctor or nurse will discuss follow-up with you.

Can I travel abroad after radiotherapy?
Usually this is not a problem once the reaction in your mouth or throat has settled down. If you wish to travel please discuss it at your next clinic appointment. You should always protect the skin within your treatment area from the sun by wearing total sunblock.

It can be difficult to get travel insurance after a cancer diagnosis. Information about insurance companies who are usually helpful is kept in The Christie information centre on 0161 446 8100 or by contacting Macmillan Cancer Support freephone on 0808 808 0000.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact patient.info@christie.nhs.uk

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.