

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 on page 5.** 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 telephone 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.

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. This is the first point at which your doctor can properly assess how effective the treatment has been.
- 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 waiting for your first appointment, please do not hesitate to contact us for advice by telephone (see page 5 for contact numbers). If necessary, we can arrange an earlier clinic appointment.

District nurses

We may refer you 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.



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 one of the nurses listed on the first page.

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'.

A very common side effect of radiotherapy is a soft or firm swelling under the chin. This is nothing to worry about. You can discuss this with your doctor at your first follow-up appointment.

To help reduce side-effects:

- drink plenty of non-alcoholic fluids
- make sure you are getting enough nourishment either through food or 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 extremely important that you get enough nourishment during and after your treatment. This may be from soft or liquidised food or by drinking 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 number you have been given in your information pack.
- The Christie Hotline on **0161 446 3658**.

If you have had a tube inserted directly into your stomach (gastrostomy, RIG or PEG) and it falls out, it is essential that you seek help and get it replaced as soon as possible. Otherwise the hole may close over and the procedure to insert the tube will have to be done again.

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

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.
- 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 on the numbers shown on page or contact 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.

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 on page 5). 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 telephone the cancer information centre on **0161 446 8100**.

Maggie's centre

The centre provides a full programme of practical and emotional support, including psychological support, benefits advice nutrition and head care workshops, relaxation and stress management. Contact Maggie's on **0161 641 4848** or email Manchester@maggiescentres.org.

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 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.**

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 fibre-optic 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 most cases a scan is done about 3 months after the radiotherapy is completed.

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

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.

Why don't I have regular blood tests to monitor the cancer?

At the moment there is no blood test to check for head and neck cancer.

Further follow-up

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 two months 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.

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 the treatment area from the sun by wearing total sun block.

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 (contact **0161 446 8100**) or by contacting Macmillan Cancer Support on **0808 808 0000** (Freephone).

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.

0161 446 3000 and ask for bleep **12589** or mobile **07539 527907**

Debbie Elliott, Head and neck clinical nurse specialist

0161 446 8041 You can leave a message on this number and Debbie will call you back.

0161 446 3000 and ask for bleep **12610**

Bethan Harland, Macmillan head and neck clinical nurse specialist

0161 918 2424 You can leave a message on this number and Bethan will call you back.

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**

Dr McPartlin **0161 446 3354**

The Christie Hotline (24 hours) 0161 446 3658

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.

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.information@christie.nhs.uk

For information and advice visit the cancer information centres at Withington, Oldham or Salford. Opening times can vary, please check before making a special journey.

Contact The Christie Hotline for
urgent support and specialist advice
The Christie Hotline: 0161 446 3658
Open 24 hours a day, 7 days a week

