Introduction

The booklet provides information for patients completing a course of Chemo-radiotherapy or Radiotherapy for Head and Neck cancer at the Beatson West of Scotland Cancer Centre. Please remember this is a general guide and if you have any questions about any of the information contained within this booklet please do not hesitate to ask a member of the team here at the Beatson, your local hospital team or GP.

Contact Information

Radiotherapy Advice Line  0141 301 7432
(please note this is an answer machine only service and is not an emergency helpline).

Clinical Nurse Specialists (CNS)  0141 301 7588/7589
Dietitian  0141 301 7005

Secretaries to:
Dr James  0141 301 7069
Dr Rizwanullah  0141 301 7131
Dr Paterson  0141 301 7068
Dr Grose  0141 301 7070
Dr Schipani  0141 301 7027

Out of Hours NHS24  08454 24 24 24
What happens after my radiotherapy ends?

First Follow Up Appointment

- The follow-up clinics for head and neck cancer patients are both at your referring hospital, (with the surgical team who originally referred you to your consultant oncologist) and also here at the Beatson.

- Your first follow-up appointment is with the surgical team, usually 4-6 weeks after you have completed your radiotherapy and they will see you regularly thereafter.

- You will also be seen at the Beatson 3 months after completing your radiotherapy. Following that visit you will be seen here regularly for the first 2 years after completion of your treatment and then once per year for 5 years.

- The Clinical Nurse Specialists at the Beatson also have a telephone follow up clinic. They will call you about a week after you complete your treatment. They may continue to keep in contact with you in the coming weeks depending how you are recovering from your treatment.

If you have any concerns whilst you are waiting on your follow-up appointment please do not hesitate to contact any of the numbers above or you can let the clinical nurse specialists know when they call you.

How do I look after my skin when radiotherapy has ended?

District Nurses

If you needed dressings to your skin during radiotherapy, our out-patient nurses who have been carrying out these dressings
will arrange for your district nurse to continue this care after you have completed your radiotherapy.

- Often the skin reaction in the area which received radiotherapy can become worse 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 anti-biotics. Your GP can prescribe these for you.

- If the skin peels or discharges, it may be helpful to have dressings applied to this area. These relieve discomfort and help prevent infection. Your district nurse can do this and your own GP practice can arrange this for you.

If you need any further advice about this please call your clinical nurse specialist on the number above.

**Other Side Effects**

**Dry Mouth**

Dry mouth is very common after some types of radiotherapy treatment. We can provide information about the use of artificial saliva preparations available as well as general advice to help manage this side effect. Again please call the number above for your nurse specialists or contact your local clinical nurse specialist at your referring hospital.

There are several other side effects of radiotherapy treatment. These depend on the area of the head and neck treated.

As a general guide, to help reduce side effects it will help if you can:

- Drink plenty of non-alcoholic fluids.
- Make sure you are getting enough nourishment either
through food or supplement drinks/tube feeding.

- Get plenty of rest.
- Try not to smoke at all. If you can’t manage this please try to cut down as much as you can.

Again, please contact us on the numbers given earlier in this booklet, or your own GP if you have questions or concerns.

Feelings and Emotions

Sometimes people can feel very anxious or low in mood at this time. If you feel like this, please tell your GP as there is usually something which can be done to help you. There is a counselling service here at the cancer centre and Clinical Psychologists are also available. If you would like to be referred this can be done by contacting a member of staff using the details provided earlier in this booklet. We also have an Information Centre which holds a wide range of information about cancer, coping with effects and support services that may be available in your own local area.

Chemotherapy

If you have had chemotherapy as part of your treatment, remember that you may still be prone to infection for a few weeks after your last dose. So if you feel unwell, you need to contact your GP or out of hours service urgently. If you have a temperature and have recently had chemotherapy you must seek medical attention immediately.

What can I do to look after myself?

Diet and Nutrition

- It is vitally important that you get enough nutrition both
during and after your treatment.

- Monitoring your weight weekly can be useful as a guide to let you know if you are getting enough.

- To help maintain your weight and recover from treatment you may need additional nutrition:

  This can come from food fortification, which simply means adding extra calories to your food e.g. adding butter and cream to mashed potatoes or oral nutritional supplement drinks which are available from your GP.

- In some cases you may be unable to meet your nutritional needs with oral diet/fluids and will have been advised to supplement your intake with a feeding tube in your nose or stomach.

- If soreness in your mouth or throat is stopping you eating or drinking, you may need to take stronger painkillers. Please ask your GP about this.

- If you have been discharged from our ward in the cancer centre and now feel you need further advice on any of these issues, please contact your dietitian in the community or at your clinic appointment in your local hospital.

- If you are unsure how to contact a dietitian ask your GP practice or the dietitians at the Beatson on the contact number at the beginning of this leaflet.

**How long should I stay on painkillers?**

- Painkillers are not part of the treatment as such; they are there to help reduce the pain or soreness caused by the radiotherapy treatment. So 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 so please take them regularly.

• As the reaction to your treatment settles down in the weeks after you finish radiotherapy, you will be able to reduce the painkillers you are taking. If you need advice on reducing or stopping your painkillers please consult your GP. If you take a morphine based painkiller you must see your GP before reducing or stopping it.

• If the pain or soreness gets suddenly worse, it may mean you have an infection. This can normally be treated with a short course of antibiotics from your GP. They may ask for you to be seen earlier at the out-patient clinic.

• If you have been prescribed Antacid and Oxcetecaine during your treatment, your GP and community pharmacy should be able to continue to supply this for you. Information about this is on the sheet provided by the team during your radiotherapy. Sometimes it can be difficult to get further supplies outwith the Beatson so if you have problems please contact or ask your local pharmacy to contact the Oncology Pharmacist on 0141 301 7409.

**Dental Health**

This is important to all patients whether you have your own teeth or wear dentures. You can be more prone to dental problems after radiotherapy to the head and neck area so if you need advice on routine brushing and hygiene, please see your dentist.

• It is important to brush your teeth even if you are not eating or are unable to swallow.

• If you have your own teeth you must have a dental check
up at least every 6 months and tell your dentist you have had radiotherapy.

• Your dentist will try to avoid removing any teeth if at all possible. If you really need this, he or she may carry this out or may refer you to a dental hospital. Antibiotics may be given if dental work is carried out.

• If you have dentures you must have these checked regularly to make sure they still fit correctly.

• Osteonecrosis or osteoradionecrosis is a rare late complication of radiotherapy and surgery. This is damage to the jaw bone. This was discussed with you by the team at the Beatson before you began your radiotherapy treatment. If you develop pain or discomfort in the bone of your jaw please seek advice from your GP or Surgeon. This complication may simply require antibiotics or pain killers to treat it. Very occasionally surgery may be required to remove the damaged bone.

**What will happen at my clinic appointments?**

As we explained earlier, your follow up appointments will take place at your referring hospital (usually where you had your cancer diagnosed) and also at the Beatson. You may see a member of the oncology team or the surgical team. Both teams remain in close contact regarding your progress.

At your follow up appointments your care team will ask about how you are feeling generally and whether you have any new problems to let us know about. Please remember to bring a note of your current medication to the appointment.

• We will also weigh you and ask about what you are managing to eat and drink. A dietitian will be available to you if necessary.
We may also ask you about the following:

- Voice quality
- Tiredness
- Dry mouth

This information allows us to assess how you are recovering from your treatment.

We will also ask about smoking. **It is vital that you stop smoking** as you are otherwise at risk of complications from the treatment as well as developing further cancer(s). Help and advice with stopping smoking is available from your GP practice.

**How do we know if the cancer has gone?**

At your follow-up appointments, your doctor will examine the area where the cancer was originally. This may involve looking into you mouth, throat, nose or ear. In some cases we may do this using a ‘scope’.

We will also examine your neck. This is to check that any lymph glands that were enlarged have gone and no new glands have appeared.

**Will I have a scan?**

In most cases the questions and examinations described above are the best way of assessing whether there is cancer present and a scan is not generally needed. If at any time your consultant thinks a scan is required this will be arranged.

**Further Follow-Up**

In general you will be asked to attend the Outpatient Clinic regularly. It is important that you attend these appointments.
If you are not able to attend you should contact the number provided on your appointment card and make an alternative appointment.

The normal length of follow-up is five years. At this point a decision will be made if you need to continue to be followed up. If you are cancer free we may discharge you.

A Final Word

This leaflet is a general guide to what to expect after radiotherapy and how best to cope. Please remember it is important to let us know how you are coping and feeling, and if there are any sudden changes that concern you. It’s also important to know that all the staff caring for you are happy to answer any further questions or concerns, so please get in touch with us if you need to.

Leaflet developed by M. Thomson and C. Paterson

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