Patient Information Sheet

Radiotherapy and Chemoradiation to the face and neck area

The Beatson
West of Scotland Cancer Centre

1053 Great Western Road,
Glasgow G12 0YN
This leaflet is for patients attending the Beatson West of Scotland Cancer Centre for radiotherapy treatment to the head and neck area. It describes the radiotherapy planning and treatment. It also explains the effects you may experience during and after treatment, and how best to cope with them.

The effects of treatment vary from one patient to another, therefore the information given here is intended as a general guide. Your healthcare team within the hospital will explain specific aspects of your treatment. If necessary they will give you separate leaflets on brachytherapy or chemotherapy.

After seeing your doctor from the Beatson Cancer Centre you will be sent a list of your appointments. This will include a visit to the Mould Room and CT simulator as well as your treatment room appointments.

If you have any of your own natural teeth, you must have a dental check up before starting any treatment.

**Preparation for treatment**

Before you can start your radiotherapy treatment it will need to be planned. This is done by visiting the CT simulator or simulator. You will need to have a ‘beam directional shell’ or ‘mask’ made in the Mould Room before your planning begins.

**Mould Room**

You will visit the mould room once or twice before your treatment is planned. This will depend on the kind of mask you need. The Mould Room is where the ‘mask’ or ‘beam directional shell’ (BDS) is made. This mask is usually used when the face & neck area is treated and it is made just for you. The shell keeps your head still during treatment and the radiographers use the marks on it to give your treatment to exactly the same area each day.

The process of making the shell will be explained to you in detail by the Mould room team when you go for your appointment. Ladies may find it easier to wear a crop-top or vest, as you will need to
take off your outer clothing down to your waist. This process can be a little messy. If necessary for your treatment, you may also be asked to use a ‘mouth bite’ which holds your jaw steady and helps protect your mouth from some of the effects of radiation.

If necessary, you will have a second visit to the mould room to check that the shell fits snugly and is not uncomfortably tight anywhere.

Your shell is only worn during treatment and planning, not at home.

Gentlemen with a beard or moustache are advised to shave it off before coming to the Mould Room as it is important that your skin is smooth before we start to make your mask.

**CT or MRI Scans**

It is sometimes necessary to have more scans to help us to plan your treatment. It may be necessary to wear your shell for these scans.

**CT Simulator**

The planning of your treatment will begin with a visit to the CT simulator (scanner). This is a special X-ray machine used to take images with you lying in the position you will be in when you are having your treatment. You will need to wear your ‘mask’ for this. The scan does not take long, usually 10-15 minutes. You must stay very still for this but you can breathe and swallow as normal. During the scan digital images will be taken. Your doctor will use these images to decide the correct treatment for you.
Simulator

Before your treatment starts you will also visit the simulator. This X-ray machine will take more images to check that your treatment plan is correct. The area to be treated will be marked on your mask and used by the radiographers on the treatment unit to give you your treatment. Some patients have their treatment in phases. If this is the case, you will be asked to go back to simulator during your treatment for replanning.

The number of treatments you get depends on your particular type of cancer. Your doctor will have given you some idea of the number of treatments at your first visit.

Your treatment can take from 4-7 weeks to complete, as radiotherapy is usually only given once a day, Monday to Friday.

Radiotherapy treatment

Your treatment will be given on an x-ray machine called a linear accelerator.

When you attend for your first treatment, the radiographers will explain what will happen and answer any questions you have. Each day you should ‘check in’ at the hospital reception and again at your treatment room.

In the treatment room you will be asked to lie on the couch/bed with your ‘mask’ on. The radiographers will help you into the correct position for your treatment. The room lights are put off and red laser lights are used to position you. Once the radiographers are satisfied that the machine is set up correctly, the lights will be put back on, they will leave the room and start your treatment. You will hear a humming noise from the machine and a ‘trip-switch’ alarm being set as the radiographers leave the room each time.
You must lie still during your treatment, but you will be able to breathe and swallow normally at all times. You will be watched on TV cameras at all times by the radiographers, so if you raise your hand they will see that you need help. Usually, the radiographers have to come back into the room a few times to adjust the treatment machine. Although you may be in the room for about 10-15 minutes, you will only be on your own for a minute or so each time, as the radiographers are in and out, resetting the machine and checking you. There is nothing to feel while the treatment is given – radiotherapy is totally painless.

**General Advice during treatment**

There is no reason to change your lifestyle completely during treatment. However it may help to:

- Try to get plenty of rest and sleep, especially when the treatment begins to make you tired. It is important to try to continue your normal daily activities and interests. A sensible balance between rest and activity may be best.
- Accept offers of help from family and friends if you need help around the house. This also allows them to feel involved in caring for you during this time.

**Early effects of radiotherapy treatment**

We are all individuals so the effects of treatment may vary. By following advice given to you by staff, you can help minimise side-effects. Please tell us how you are feeling, so we can help you if necessary. You will have a weekly appointment with a member of the Head and Neck team while you are on treatment. It is in your best interest that you are seen each week so please ensure you are reviewed. If you have particular problems, the Head & Neck nurse will arrange to see you more often.

**Chemotherapy and Radiotherapy**

Many patients having radiotherapy are also given drug treatment (chemotherapy). The chemotherapy increases the activity of the radiotherapy against cancer cells.
If you are getting chemotherapy drug treatment in the ward during your radiotherapy course, you will be more prone to side effects discussed in this leaflet. We may ask you to come for extra blood tests and check ups to make sure you are well.

**Skin Care**

You are most likely to experience dryness and redness of the skin. Like the sun, which we all react differently to, we can’t accurately predict how your skin will be. We can give you some advice:

- You may bath and shower during treatment, avoiding very hot or very cold water on the area being treated.
- You may use unperfumed soap or we’ll give you aqueous cream to wash the treatment area with. The area being treated should be rinsed, using lukewarm water, then patted dry with a soft towel and not rubbed.
- Only use the creams prescribed and given to you by our staff. Any creams given should be gently applied with the fingertips and not rubbed in, even if it says so on the tube. However soothing you may think other creams may seem, they may contain substances which could react with the radiotherapy and make your skin worse.
- Gents are advised not to use a wet shave, but instead to use an electric razor. Any part of your beard /moustache growth that is in the treatment area will stop growing some time after starting radiotherapy. After treatment ends, it may eventually come back, if a little less strongly.
- You are asked not to wear any make-up, perfume, after-shave etc (on treatment area only)
- Try to avoid friction to the area being treated, such as tight clothing, and do use natural fabrics when possible, like cotton, silk or soft wool, which are soft and let your skin breathe.
- Avoid exposing the area you are having treated to the sun. Lightly cover the area with a soft silk scarf, wear a wide brimmed hat or stay in the shade. Do not use sun screen/
lotion on the area during treatment. After your treatment is finished and your reaction has healed you should use a total sun block (factor 25) while in the sun for at least one year. It is important that you continue to protect your skin from the sun during this time.

- Do not go swimming, because of the chlorine, until after your treatment is over and your skin is back to normal.

When your skin is no longer red or itchy you can go back to washing and shaving normally.

**Hair Loss**

Your will only lose hair from the area being treated, where the radiation goes in and out of your body. Whether on your head or your beard, this hair loss is only temporary for most people, although for a very small number of people this loss may be permanent. You may wash your hair with a mild baby shampoo, rinsing off with lukewarm water and patting dry.

**Mouth, Throat and Gullet**

While you are on treatment a severe ‘sunburn’ type reaction will occur on and around the treatment site where the radiation goes in and out of your body. This also happens on the inside of your mouth, throat and gullet. This reaction may cause soreness, ulceration, redness, cracks and bleeding. We will give you mouthwashes, gargles and pain killers to treat these effects. Remember, only use the medication given to you by the Beatson staff.

You may also find that your saliva becomes thicker and there is less of it. There is a separate leaflet called ‘Caring for your Mouth’, which discusses in detail how to look after your mouth and teeth during and after treatment. If you are not given this leaflet, please ask for it or pick one up and let us know if you have any worries about your mouth.

These symptoms should clear up and go away within 6-8 weeks of finishing treatment.
Swallowing will frequently become uncomfortable and painful. When this happens we will give you medicine to take before meals to help you swallow and the appropriate painkillers for your pain. Contact your GP to have any medicines you already take changed to a liquid or soluble form. It is very important to continue with all your medicines. You must let us know if you are having difficulties.

**Soft Diet**

It may be more comfortable to take a *softer diet* eg scrambled eggs, soups, puddings etc, which slip down the throat more easily. Try using more gravies and sauces and avoid food that is too hot, too cold or spicy. You can increase the nourishment in your food by adding more milk and cream to porridge, soups etc. and adding cheese and butter to mashed potatoes. There is a separate booklet called ‘Food boosters’ which contains helpful tips. Please pick one up or ask a member of staff for a copy. It is recommended that you try to drink as much as possible during your treatment. At least 8-10 glasses of fluid a day is ideal.

**Weight**

You will be weighed at the start of treatment and every week thereafter before you see a member of the H&N team. If you lose weight or need advice, our dietitians will help you. They may prescribe food supplements or recommend that a feeding tube may be helpful. This will be explained to you in detail if it needs to be done. You may need to be admitted to the ward for a short time so we can explain how to look after your feeding tube at home.

**Taste**

Your sense of taste may change or be lost completely for some time. A common complaint is that food tastes more salty than usual. This usually improves but can take several months. Very few people lose their sense of taste forever.
Smoking & drinking

Smoking and drinking alcohol are both likely to make the side effects of radiotherapy even worse. We will be happy to offer any help with giving up smoking or you can contact Smokeline yourself. During treatment, many people find it better to give up alcohol, especially spirits, completely until their mouth has healed.

Your Voice

Your voice may become hoarse or weaker for a time, avoiding smoking and smoky places will help this. Your throat may become sore and uncomfortable when talking and your voice will become tired. Speak quietly and gently, giving your voice rests throughout the day. Our Speech Therapist will be able to give you further advice if you need it.

If you have a tracheostomy (breathing tube in your throat) or have had a laryngectomy (voice box removed) the head and neck nurse will offer any extra advice you need to cope with this during your treatment. It is sometimes necessary to add extra moisture to the air you breathe, to balance any drying effect of the radiotherapy. There are many ways to do this, including the different stoma protectors and a nebuliser.

Tiredness

You may get tired or fatigued as your treatment progresses. This tends to start a few weeks after starting your treatment and can last for several months after treatment has finished.

Exercise and Swelling

After neck surgery, if any of your glands have been taken away, your neck and chin area will swell slightly. This will get worse while you are having treatment but will improve slowly when treatment is completed. You will have been given exercises by the physiotherapist, after your surgery. You should continue doing these exercises moving your face and neck muscles gently, through their full range of movement, to prevent stiffness and
reduce any swelling. This should not be painful, so please let us know if you are having difficulties as we will arrange for you to see a physiotherapist.

### After radiotherapy

Your body will take some time, often 4-6 weeks before gradually returning to normal. Indeed, some people feel worse physically and mentally, when treatment is finished. You will be seen by your Beatson doctor and your surgeon at your local hospital, roughly 6-8 weeks after your treatment has finished. It is important to keep in touch with us if you feel worse, as we can see you earlier if necessary.

### Possible later effects of treatment

Effects vary from person to person depending upon the area being treated. Your doctor will explain particular issues that are likely to affect you.

- Due to the effect of radiotherapy, you may have a smaller amount of saliva, or it may become thicker. There are saliva substitutes available in both spray and gel form, some with fluoride. You will also be at increased risk of tooth decay. To prevent this, if you have your own natural teeth, they should be kept in good condition. Brush with fluoride toothpaste twice a day, floss daily, use a low or non-alcohol fluoride mouthwash and see your dentist/hygienist every 3-6 months.

- You will always be sensitive to the effects of the sun, especially during the first year after your treatment on the area you have been treated. Protect yourself with total sun block and a hat.

- We spend a long time planning your treatment and shielding areas we don’t want treated. However, the head and neck area contains a lot of important structures. The brain, spinal cord and eyes can be affected by radiotherapy, but only if they are in the area being treated.
- A very rare but potential effect is that radiation can cause tumours. Although this is a serious possible consequence of your radiotherapy, it is important to bear in mind that it is extremely rare. If it does happen it is likely to be many years after treatment has ended. Please do remember that we believe the benefits of your treatment for your current condition outweigh the longer-term risks involved.

**Where can I get help?**

*Information and support*

This leaflet deals with the physical aspects of your treatment but your emotional wellbeing is just as important to us. Being diagnosed with cancer can be a deeply distressing time for you and those closest to you. Within the department we have a counselling/support and clinical psychology service to help you if necessary. If you think this may be helpful to you, please ask staff to put you in touch.

- **Head & Neck Specialist Nurse:** 0141 301 7588/9
  - Macmillan Information

- **Radiographer & counsellor:** 0141 301 7423

- **Information and Support Radiographer:** 0141 301 7427

The Beatson Cancer Centre has a Radiotherapy Advice Line available for patients who have completed treatment. This is an answer machine service which is run by experienced Radiographers from Monday to Friday. Please leave your name and telephone number and you will be called back as soon as possible.

**Tel:** 0141 301 7432
There are also voluntary organisations providing information and support. These include:

**Cancerbackup**: 0808 800 1234  Offers counselling and also provides information booklets on particular cancers which are free to anyone affected by cancer.

**Macmillan Cancer Support**: 0808 808 2020  Develops services to provide specialist care at every stage of illness. Provides an information line and financial help through grants.

**Tak Tent**: 0141 211 0122  Offers support to people with cancer.

**Changing Faces**: 0845 4500 275  Offers help, advice and information for anyone with facial disfigurement.

**Let’s Face It**: 01843 833724  Provides supportive links for people with experience of facial disfigurement, especially facial cancer.

**Cancer Laryngectomy Trust**: 01422 205522  Advice and help after laryngectomy.

**National Association of Laryngectomy Clubs**: 020 7730 8585  Encourages the formation of clubs, to assist rehabilitation.

**Smokeline**: 0800 848484  Offers help to give up smoking.

**Alcoholics Anonymous & Al-Anon family Groups**: 0845 769 7555  Offers help to reduce alcohol intake, also providing support for families in local groups.

Leaflet reviewed by L. Brown