

**Patient
 Information**

Radiotherapy to the Head and Neck

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Reference No.

GHP11692_10_21

Department

Radiotherapy

Review due

October 2024

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Introduction

Your oncologist has recommended that you have a course of radiotherapy. This leaflet gives you information about radiotherapy, what will happen during treatment and the side effects.

Please be aware that radiotherapy centres are training centres for doctors, nurses and radiographers. Students may be present in the department but they are supervised at all times. If you would prefer not to have students present during your treatment please let a member of staff know.

You may find it useful to write down some questions before you start your treatment. A space is provided towards the back of this leaflet for you to do so.

Useful contacts

Radiotherapy appointments: _____

Radiographers: _____

Clinical Nurse Specialist: _____

Dietitian: _____

Speech and Language Therapist:

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What is radiotherapy?

Radiotherapy is the use of radiation to treat a disease, most commonly cancer.

Your treatment will be divided evenly into a number of sessions (fractions), usually given once a day from Monday to Friday, with a rest at the weekend. Some departments work at weekends, or weekend treatments may be given around bank holidays or in the event of a machine breakdown.

The treatment delivered will be exactly the same every day. The number of sessions you have will vary depending on a number of factors. For this reason, each patient's treatment is specially tailored to them, and even those with the same type of cancer as you may receive different treatments.

The treatment will cause damage to the normal cells in the area too, but they can repair themselves much more effectively than the cancer cells. This damage is what causes the side-effects you are likely to experience during the treatment.

The radiotherapy will be delivered by a team of therapeutic radiographers who will see you every day and can answer your questions about radiotherapy, as well as help look after you during your treatment.

Who will I see during my treatment?

You may regularly see other professionals during your treatment, these may include:

- Specialist Therapeutic Radiographers
- Dosimetrists and Medical Physics Experts
- Mould Room Technicians
- Clinical Oncologists
- Oncology Doctors/Registrars
- Clinical Nurse Specialists
- Dietitians
- Speech and Language Therapists (SALT)
- Cancer Support Workers

There is a space at the front of this booklet to write down their contact numbers should you need them.

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Radiotherapy planning

There are a number of stages involved in getting you ready for your radiotherapy, and getting your radiotherapy ready for you.

Dental

If your jaw bone will be in the treatment area, you will need an X-ray and dental assessment before your radiotherapy planning can begin.

You may need to have some teeth removed before your radiotherapy planning; the dentist will let you know if this is the case.

Even if you do not have any teeth, you may still need an assessment to check for any remaining roots.

The swelling from any extractions will need to have settled before the next stage can begin.

Feeding tube (gastrostomy)

Having radiotherapy to the head and neck area may make swallowing very painful for you.

Your oncologist and dietitian may recommend that you have a gastrostomy tube inserted before your treatment begins to help support your nutrition. Not all patients will need one; your oncologist will discuss this with you.

A gastrostomy is a way of delivering food, fluids and medicines directly in to the stomach by inserting a thin tube through the skin and into the stomach. This procedure may involve an overnight stay in hospital. The tube can be hidden underneath your clothing but will require some daily care and attention.

Alternatively, if you are unsuitable for a gastrostomy or choose not to have one and it becomes too difficult to swallow during your treatment, it may be recommended that you be admitted to the hospital for the placement of a nasogastric tube (NGT).

A NGT is a soft tube that is placed through your nostril, down the back of the throat and into your stomach. It can provide nutrients and medication while you are finding swallowing difficult. It is less invasive than a gastrostomy but it can be seen and requires more care and attention.

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Mask - treatment planning appointment



A shell or mask will be made to help you keep your head still during treatment. You will be placed in the treatment position, usually on your back, with your arms by your sides. If you find this uncomfortable, please do not hesitate to tell one of the team as they may be able to change your position.

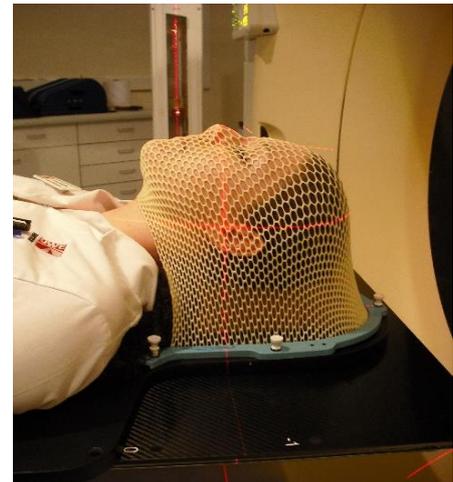
The plastic sheet of material used to make your mask will have been warmed in a water bath, so it becomes very flexible. It will then be laid across your face and neck and gently pressed into position around your facial features.

The plastic will feel warm and damp against your skin, but it should not feel uncomfortable. Your mouth and nose will be covered but you will be able to breathe normally through the holes in the plastic.

A well-fitting shell can be difficult to make if you have long hair, a beard or a moustache, so you may be asked to tie your hair back. You may also be asked to shave any facial hair before your planning appointment.

Once the shell or mask has been made, you will then have a CT scan while wearing the shell. This scan is used to plan your treatment accurately.

Depending on the area being treated, you may also need a 'mouth bite'. This is a mould of your teeth with a tube through the middle that you can breathe through. This is to keep your mouth open and your tongue in the same place every day while you have your treatment.



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Scan

To plan your treatment, a CT scan is needed. This is usually done on the same day that the mask is made. Depending on the area being treated, the radiographers may need to inject a dye (contrast) into a vein in your hand or arm that shows up on the scan.

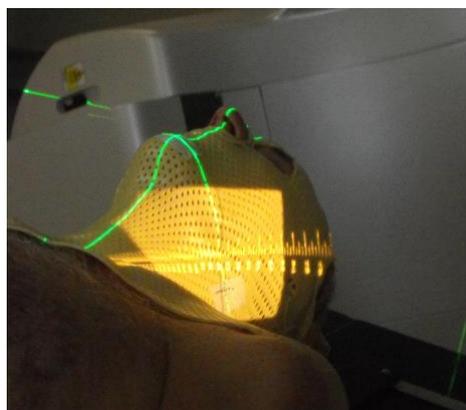
The radiographers will get you in the same position as when you had your mask made and take a scan. This scan is for the sole purpose of planning your radiotherapy, and there will not be any results available.

Please bring a list of any medicines you are taking to this appointment.

Radiotherapy treatment

The first day of treatment is usually a little longer than the others, as the team has to do extra checks to make sure that everything is correct.

The radiographers will place you on the treatment couch in the same position you were scanned in. They will put your mask on, which is then clipped to the bed in the same way as when you were scanned.



Your mask may be a little tighter than it was originally as it can shrink slightly as it sets in the days following it being made.

If you feel you need to come out of the mask at any time, wave your hand.

Once you are in the correct position, the radiographers will check some measurements and then leave the room, where they will operate the machine from outside. They are watching you at all times on CCTV cameras.

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Over the course of your treatment, X-rays will be taken regularly to confirm your position, and to evaluate any potential weight loss or change in shape that may affect your treatment plan.

When the machine is on you may hear some noises coming from it, but the treatment itself will be painless.

Side-effects of radiotherapy to the head and neck

The majority of side-effects from radiotherapy are predictable, expected and temporary (short term side effects), while other side-effects can be chronic (long term). Everyone is different and so you may find you experience some or all of these symptoms. Likewise, you may recover very quickly or it may take a while longer.

Short-term side-effects

The radiotherapy has a delayed effect; this means that you usually do not notice any side effects until the end of the second week of treatment. Side effects usually start off mild and slowly build up during the course of your treatment. They most commonly include:

- **Tiredness/fatigue**
Some patients may find that they feel more tired than usual during treatment (often after 2 to 3 weeks). Travelling to your radiotherapy appointments may also add to this. It is important that you continue with your normal activities and routines as much as possible. Try to find a sensible balance between rest and activity.
- **Sore skin in the treatment area**
Your skin in the treated area will become pink or red as your treatment progresses. It is also likely that the skin will get very sore and may peel or blister which will become painful and uncomfortable. Please read the 'Self-care during radiotherapy' section for information on how to care for your skin.

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- **Hair loss in the treatment area**

Hair loss is anticipated during most types of radiotherapy to the head and neck area. This usually happens after 2 to 3 weeks of treatment. Hair regrowth usually begins a few weeks after treatment. Sometimes, new hair can be different in colour or texture than it was before. Occasionally, hair loss can be permanent.
- **Dry mouth**

If all your salivary glands have been treated with radiotherapy there is a risk of a permanently dry mouth. Most people find sipping water and chewing sugar-free gum can help. Dryness can increase the risk of developing oral thrush, so it is important to keep the oral cavity moist. Other products to help relieve dryness are available; speak with your radiographers or specialist nurse for further advice.
- **Mouth ulcers/sore throat**

The radiotherapy treatment will make your mouth and throat very sore and you may develop ulcers. This can be relieved with pain medication but the team looking after you will monitor and advise you.
- **Difficulty swallowing/oesophagitis**

Radiotherapy to the head and neck area often causes swelling and soreness of the throat. This can make swallowing, and therefore eating, more difficult and painful. Your radiographer or specialist nurse will be able to arrange pain medication for you to help with this. You will have support from a specialist Speech and Language Therapist (SLT) and dietitian who can advise and help you. It is important to use your swallow as much as possible during treatment to help reduce the chance of long term problems.
- **Sticky saliva/excess mucus**

Your saliva will become thicker and stickier leading to a dry mouth and throat. This can make eating, drinking, speaking and swallowing difficult.
- **Oral thrush**

During treatment you will be at risk of developing an oral infection (thrush). Your mouth will be regularly checked for this but you must tell a radiographer if you notice any changes.

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- **Change/loss of sense of taste**
Many patients suffer from changes in taste sometimes alongside a metallic taste in their mouth. Your taste should gradually return, but this can take 6 to 12 months after treatment has finished. Occasionally, your taste never completely returns to normal.
- **Change/loss of voice**
Your voice may change and lose some of its strength while having treatment. It can also become painful to speak. It is important to keep well-hydrated to protect your voice. Please make sure that you sip water regularly throughout the day.
- **Change/loss of hearing**
Hearing can change while having treatment. This includes loss of hearing and tinnitus, which can take several months after treatment to return. Soreness, inflammation and swelling of the ear and in some cases weeping may happen if it is within the treatment area. This will take a few weeks after treatment to improve.
- **Sore/watery eyes**
You may develop sore, inflamed or watery eyes if the treatment area includes or is close to the eye(s). Let the treatment team know if you notice any changes.
- **Nasal crusting**
Your nose may become sore, dry or develop crusting if it is in or near the treatment area.
- **Lymphoedema**
Radiotherapy to the head and neck area may cause a build-up of fluid (lymphoedema) in the area being treated. If you notice any swelling it is important that you inform the radiographers or your specialist nurse. You may be referred to a lymphoedema specialist. Following the skin care guidance later on in this leaflet can help minimise and manage any lymphoedema.

The side-effects you experience will depend on the dose, area being treated, and whether you have had or are having chemotherapy and/or surgery. Your oncologist, radiographers and specialist nurse will go through what you can expect in more detail.

**Patient
Information****Long-term side-effects**

Some side-effects may occur months or years after treatment has finished. These are less common, but often permanent and may include:

- Tiredness/fatigue – this may take up to a year to fully recover
- Dry mouth – saliva production may never fully recover
- Thick oral secretions
- Difficulty swallowing, including an increased risk of food or drink 'going the wrong way' (aspiration)
- Aspirating – food or fluid pass into the lungs rather than stomach
- Damage to the jaw bone
- Trismus – difficulty opening your mouth
- Changes in the skin
- Lymphoedema – fluid build up
- Cataracts
- Brachial Plexopathy – damage to the nerves leading to the arm

As the treatment involves using radiation, there is a very rare risk that it may cause another cancer within the area treated in the future.

Self-care during radiotherapy**Skin care in the treatment area**

- Moisturise frequently; gently smooth it onto your skin until it is absorbed. Do not rub.
- Continue to use the moisturiser you prefer and like to use – if you do not currently use one, speak with the radiographer or your CNS and they will be able to suggest some options.
- Do not apply moisturiser immediately before treatment.
- If a moisturiser is causing irritation, stop using it and discuss it with a radiographer or your CNS.
- If your skin blisters or peels, stop using moisturiser in that particular area and seek advice from a radiographer or your CNS.
- Avoid sun exposure in the treatment area – wear a brimmed hat and/or cover up with clothing.

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- **Please avoid rubbing the area, using sticky tape, wet shaving, wearing make-up and using wax, hair removal cream or lasers.**

Health and wellbeing

- Keep well hydrated – aim to drink 2 litres (4 pints) of water a day, or put through your feeding tube.
- Avoid drinking alcohol.
- Eat a nutritionally well-balanced diet. If you are struggling to eat, a dietitian can help to advise you on how to add extra nourishment to your food, adapting the texture of your diet and high energy and high protein options. They can also arrange a prescription for nutritional supplements, such as high calorie drinks to help keep your weight up.
- It is important to try to maintain your weight during treatment. This will help to make sure that your mask fits well and should minimise any interruptions to your treatment.
- Keep active if you can – activity helps to improve outcomes and help you cope better with side-effects.

Mouth care

- Brush your teeth and gums regularly with a soft tooth brush - you may need to use high fluoride toothpaste, this will be provided for you if needed. Once treatment is complete, you will need to get this toothpaste from your dentist or GP on repeat prescription. The high fluoride toothpaste is likely to be required for life.
- You may be provided with mouth wash or mouth care products – use these regularly to help keep your mouth moist and clean.
- Pay attention to what is happening in your mouth; let your treatment team know if you begin to get ulcers or notice any changes.

Smoking

- Smoking can reduce the effectiveness of your treatment and make your side-effects worse. It is advised that you try to stop smoking before your treatment. If you would like help with this, please speak to your treatment team who can put you in touch with your local support.

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Treatment reviews

You will be reviewed regularly throughout your treatment. This may be by your oncologist, dietitian, speech and language therapist, clinical nurse specialist or radiographer. The frequency of reviews will vary.

Your progress will be monitored to ensure you have everything you need to get you through the treatment.

You DO NOT need to wait for these appointments to report any problems, please keep your radiographers updated of any issues.

After radiotherapy

Radiotherapy has a delayed effect in which the side-effects will continue even after your treatment has finished. They tend to reach their peak around 7 to 14 days after your last radiotherapy session, so don't be alarmed if they worsen.

Recovery times vary from person to person, but side-effects should gradually improve over the following 6 to 12 weeks.

Your skin may develop a shiny appearance, sometimes with the appearance of broken blood vessels (telangiectasia). It is likely to be drier than it was before treatment so continue to moisturise regularly.

Your skin in the area treated will be more sensitive to the sun than it was previously. Make sure that you keep the area covered or use SPF 50+ sun screen for at least a year after treatment.

In the weeks following your treatment, you will be reviewed by the specialists that have been looking after you. This will vary depending on your diagnosis and treatment regimen, but you will be advised on this by your treatment team.

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Although all patients are glad to have finished their course of radiotherapy, it is quite normal to feel anxious as to what happens next. Please do not feel abandoned; if at any time between appointments you are concerned about anything, please contact your clinical nurse specialist, the radiotherapy department or your GP. They will be able to advise about any concerns you may have or arrange to see you if needed.

If you need urgent help out of normal working hours please contact NHS 111 for advice.

Questions

Please use this space to write down any questions you have, to help you remember to ask them at your first radiotherapy appointment.

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Radiotherapy summary

This page is intended for your health care professional to use when they talk to you about your radiotherapy. It is not an official document or consent, but to help summarise everything in one place for you.

You are having radiotherapy delivered to:

Your radiotherapy consultant is:

Treatment intent

<input type="checkbox"/> Radical radiotherapy – aiming to give long term benefits and cure in some patients – and may be in combination with chemotherapy given before, during or after the radiotherapy	<input type="checkbox"/> Palliative radiotherapy – aiming to improve symptoms. Whilst a cure is not likely palliative radiotherapy may also prolong life
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You will be having ____ treatments' over ____ days, not including weekends.

Side-effects

The ticked boxes below are potential side-effects that will arise from your radiotherapy treatment. This is to be taken as a guide, and will not be experienced by all patients.

**Patient
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- Fatigue
- Dysphagia (Difficulty swallowing)
- Lymphoedema
- Tinnitus / hearing loss
- Sore mouth / ulceration
- Altered taste
- Sticky saliva or excess mucus or dry mouth
- Oesophagitis
- Skin irritation – similar to sun burn
- Hair loss in the treated area
- Nasal crusting / bleeding / soreness
- Watery eyes / conjunctivitis

Long term side-effects

These may occur many months to years after treatment:

- Lasting fatigue / somnolence (sleeping more than usual)
- Xerostomia (dry mouth)
- Trismus (difficulty opening the mouth)
- Osteoradionecrosis (death of bone tissue due to radiation)
- Reduced hearing / tinnitus
- Lymphoedema, skin fibrosis / scarring
- Oesophageal stenosis / narrowing
- Permanent hair loss in treated site
- Delayed skin healing in treatment site
- Brachial Plexopathy
- A radiation induced malignancy (very rare)

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Further information

Further information is readily available online, we would recommend beginning with:

Macmillan Cancer Support

Tel: 0808 808 0000

Website: www.macmillan.org.uk



Cancer Research UK

Website: www.cancerresearchuk.org

The following QR codes will direct you to further resources relating to your radiotherapy treatment. You can use your smartphone camera to scan the codes:

Macmillan: Understanding Radiotherapy

Website: www.macmillan.org.uk/cancer-information-and-support/stories-and-media/booklets/understanding-radiotherapy



**Patient
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Website: <https://be.macmillan.org.uk/be/p-25106-managing-the-late-effects-of-head-and-neck-cancer-treatment.aspx>

**The Society and College of Radiographers: Radiotherapy Skin Reactions**

Website: [www.sor.org/getmedia/e091da21-6dc8-47fb-9e08-094a0cb3135e/5056 - sor design doc a patient infosheet - skin care a5 leaflet llv2-1 2.pdf](http://www.sor.org/getmedia/e091da21-6dc8-47fb-9e08-094a0cb3135e/5056_-_sor_design_doc_a_patient_infosheet_-_skin_care_a5_leaflet_llv2-1_2.pdf)



Further support will be available locally, please speak to your oncology team who can advise what local charities are there to help you, and which support groups are available near you.

Your data

All personal images and photographs taken during your radiotherapy will be used in accordance with the local Trust policy on the protection and use of patient information.

Content reviewed: October 2021