



Royal Berkshire
NHS Foundation Trust

Radiotherapy to the head and neck

Information for patients beginning
radiotherapy treatment

What happens next?

In the clinic today, you and your doctor agreed that you are going to have radiotherapy treatment for your cancer. This booklet discusses what you can expect during and after your treatment and gives some general advice and information.

You will be given time to discuss any concerns with the radiographer (a person trained to give radiotherapy) at your planning appointment. You will be contacted by telephone to arrange an appointment for the CT scan which forms part of the planning of your radiotherapy treatment and which can take up to one hour. During this telephone call please mention if:

- You have not had a blood test taken in the last 6 weeks, as we may require you to take one prior to the planning scan date.
- You have any problems with travel or appointment times and we will do our best to help you.

At this appointment we will ensure you have completed any dental work required prior to radiotherapy.

If you have not been called by the Radiotherapy Planning Department within a week of today's appointment, then you can contact us on the number below, leaving a message on the answer phone if asked.

Telephone: 0118 322 7872, Monday-Friday 8.30am-4.30pm.

What are the benefits of radiotherapy?

Radiotherapy works by using high energy x-rays to kill cancer cells. Our bodies are made up of different cells, and all cells have the ability to divide and grow. If radiation hits a cell that is dividing, it will be damaged. Unlike normal cells, cancer cells are much less able to repair the damage which means that more of them will be destroyed.

When recommending radiotherapy, your doctor will have taken into account the risks and benefits of the treatment. Although there are risks and side effects, it is felt that the advantages for you outweigh the disadvantages.

Radiotherapy for head and neck cancer

Your oncologist (specialist cancer doctor) will discuss with you the number of treatments you need, and your treatment will be given daily Monday to Friday.

Chemotherapy

Your doctor may recommend some chemotherapy as well as radiotherapy. If you are having chemotherapy with radiotherapy, the chemotherapy will be given once a week for a maximum of six doses. You will have a chemotherapy pre-assessment appointment prior to starting treatment where the chemotherapy is explained, with the potential side effects and you will be given some information to take away with you.

Pregnancy and radiotherapy

Female patients must not be pregnant or become pregnant at any time during a course of radiotherapy as radiation can be harmful to the unborn child. It is important to let the radiographers know if you have missed a period or suspect that you may be pregnant, before you are exposed to any radiation. Female patients will be asked to confirm their pregnancy status prior to planning the radiotherapy and again on the first day of radiotherapy treatment. This applies to all women between the ages of 12-55 years and is a legal requirement.

Your planning appointment

At the start of your planning appointment you will have a chat with the radiographers who will explain what is going to happen, outline all the points specified on your consent form by your doctor and answer any of your questions. You can have the opportunity to meet the head and neck review radiographer who will be on hand to answer questions and support you throughout your radiotherapy treatment.

Your appointment is divided into two halves. For the first half we make a mask for your treatment and in the second half you have a CT scan wearing that mask, this scan helps us plan your treatment.

Making the mask:

It is very important that you keep as still as possible during the radiotherapy so we make a mask that helps keep you in place for your radiotherapy planning and treatment. We also put markings on the mask to help plan the treatment.

You will be asked to lie down on the couch on your back. We have a variety of different neck rests in order to support your neck so if it does feel uncomfortable please let the team know and we will try and change it.

Please remove any necklaces or earrings for your planning appointment.



The mask begins as a flat piece of plastic with lots of holes in it. This is placed in warm water and stretched over your head and neck. It then cools and sets into a personalised mask with plenty of air holes. This takes about eight minutes.



Sometimes, we may have to make a something called a 'mouthbite'. A mouthbite is a little tube with a gummy paste around it that you bite lightly on and is used for planning and treatment. If this is required this will be made before the mask. People may feel anxious or claustrophobic when wearing the mask. If you have concerns about this or experience these feelings please let the radiotherapy team or the head and neck cancer nurse specialists know; there is often something we can do to help.

CT scan

The CT scan takes place in the Radiotherapy Department, and the scan itself takes only a few minutes. You will be wearing your mask during the scan and once you are positioned correctly on the bed, we will take a few measurements, put some marks on the shell and also draw a small mark on your chest just below the mask. We will then let you know that we are leaving the room to start the scan but we are able to see you throughout the whole procedure. The scan takes two to three minutes, it does not hurt and it is very important that you stay very still during the scan. Once the scan is finished, we will come back in and remove the mask.

The final part of the planning procedure is to tattoo a little mark on your chest. This involves pricking the skin with a needle, which you may find a bit uncomfortable. This will produce a very small pinpoint sized permanent black mark which when used with the mask, will allow us to make sure you are in the same position for each treatment.

Contrast injection ('dye')

The doctor may have asked for you to have an injection of contrast for the scan. Not everyone will have this but for some patients it is helpful to show more detail in the head and neck area, acting like a dye.

You may have had an injection of contrast for scans before. It involves having a cannula, which is a flexible tube, inserted into your arm or

hand using a needle. The contrast (dye) is injected via this cannula. The timing of the injection is quite important and the contrast is injected just before the scan starts.

The contrast (dye) can give you a very warm feeling during and after the injection for about 20 seconds. This is often concentrated around the pelvis and groin area spreading down the thighs. This is common and goes away quickly. It may also give you a metallic taste in the back of your throat.

The cannula will be removed about 15 minutes after your CT scan is finished.

If you have had an allergic reaction to contrast dye before, you must tell the radiographers before your scan.

Once you have completed your planning appointment there will be a period of 3 - 4 weeks before your treatment will begin. This is because it takes time for the team to prepare your treatment plan.

Your first radiotherapy treatment

When you arrive for your treatment, please report in to the radiotherapy reception desk in the main radiotherapy waiting room. A member of the radiotherapy team will call you in for your treatment.

On your first treatment you will meet with one of the team of radiographers who will be treating you. He or she will:

- Check your details.
- Give you a list of the first week's appointment times.
- Discuss the treatment procedure.
- Outline the potential side effects.
- Tell you which day your doctor, review radiographer, clinical nurse specialist and dietitian will see you during the treatment.
- Answer any questions you may have.

The Berkshire Cancer Centre is a training centre, so you may meet radiography students who may be involved with the delivery of your treatment under close supervision.

What happens during treatment?

Radiographers operate the radiotherapy machines to give you the precise treatment prescribed by the doctor. Each time you attend the department for treatment we need to make sure that we are treating the correct person so when you enter the treatment room, you will be asked to identify yourself by telling staff your name, date of birth and first line of your address. The staff will check this information against the treatment sheet that has your radiotherapy prescription.

On each treatment visit they will ask you how you are feeling and ensure that you are coping well as the treatment progresses. The radiographer will help you on to the treatment bed, put your mask on you and adjust the bed and the machine to the exact positions that are needed. He or she will ask you to remove any clothing or jewellery including earrings that are in the area being treated.

All the measurements for your treatment will then be set and checked. This preparation may take quite a bit of time, and is often longer than the treatment itself. As part of this preparation, you will hear the radiographers calling out some numbers and measurements; this is how they check your position. You should breathe and swallow normally but try to stay as still as possible.

Once the radiographers are happy with your position, the machine will then be moved to the first treatment position. The treatment machine will not touch you.

Remember that it is very important to remain still and breathe normally during your treatment, as you did for the CT scan.

The radiographers will leave the room, take a short scan to check your position and then start the treatment. Although you are alone in the room, the radiographers are able to see you through closed-circuit

monitors. If you need a radiographer during the treatment, raise your hand clearly and a radiographer will stop the machine and come into the room.

The machine is controlled by the radiographers outside of the treatment room and it will move around you and give you treatment from different angles. You will not feel anything during the treatment, but you will hear a buzzing noise as the treatment is delivered.

Some people worry that they will be enclosed by the machine but this will not happen. The machine can move around you, but nothing will press down on you.

During your first three treatments a short scan will be taken to make sure that you are in the right treatment position. These are then repeated weekly or more frequently as required. There will not be any 'results' from these scans and they do not show us how the treatment is working; they are designed to confirm you are in the correct position for treatment.

The total time of your first treatment will be approx 30 minutes.

Subsequent treatments should take between 10 and 15 minutes.

Once you have started your course of radiotherapy treatment, we aim to continue it without any breaks or days off.

Staff on the radiotherapy treatment machine will give you times for your other visits on a weekly basis.

Treatment is usually given Monday to Friday. Sometimes, treatment is given once over a Bank Holiday weekend.

Due to servicing of the machines it may sometimes be necessary to treat you on a different machine. Please be assured that all the machines give the same treatment.

It is very important that you do not miss treatment days as this may make your treatment less effective. If you feel you are unable to attend for any reason please discuss the problem with a radiographer, or phone your head and neck cancer nurse specialists.

Each week while you are having radiotherapy, you will generally see a doctor, a head and neck cancer nurse specialist, the dietitian and a speech and language therapist if indicated. You will also be reviewed on a weekly basis by the head and neck review radiographer. The purpose of these visits is to support you through treatment and help with any side-effects that you may be having. If you feel you need to be seen at any other time, please speak to a radiographer who will help you.

After treatment

Radiotherapy does not make you radioactive and it is perfectly safe for you to be with other people, including children, after your treatment. You may experience some symptoms and side effects.

Side effects during and after your treatment

Not all of these side effects will happen to you – we will talk about this with you before you start treatment.

Radiotherapy side effects generally only happen in the area being treated and can vary in severity from person to person. Side effects tend to start towards the end of the second week of treatment and will be at their worst for 7-10 days after the course of treatment has finished. Most side effects are temporary; generally, people notice a significant improvement in side effects 6-8 weeks after the end of treatment. There are some side effects which may last for a few months after the end of treatment and some side effects which can be permanent.

- Sore mouth and throat

Your mouth and throat may become very sore and inflamed if they are being treated, and this can make swallowing very painful. You will be given painkillers and mouthwashes to help you cope with the soreness, but you may find it becomes painful to swallow.

If you normally pay for prescriptions you will be eligible for a prescription exemption card, if you do not have one please speak to the head and neck cancer specialist nurses. It is important to take the pain relief prescribed regularly; it can help to take your pain relief half an hour before meals. If you are using an anti-inflammatory painkiller such as ibuprofen or diclofenac (Voltrol) regularly we will prescribe you a stomach protecting tablet to take once daily.

Some pain relief can cause constipation (e.g. codeine or morphine); we will prescribe you laxatives to take regularly if you are using these medications. It is important to continue opening your bowels regularly, please let us know if you are not. You will be advised during your treatment about increasing or changing your pain relief as needed, to keep you as comfortable as possible. If you feel your pain is not being controlled and you are not due for a review, please let the radiographers know and they will organise for you to be seen by the doctor or head and neck cancer nurse specialists.

- Difficulty swallowing

Swallowing can become difficult due to pain in the mouth and throat and dryness, affecting your ability to eat. This may also increase the risk of food or fluids 'going the wrong way'. You will be seen by our speech and language therapist during and after treatment. They can help you with your swallowing and may recommend swallow exercises. Your weight will also be monitored weekly throughout your treatment. It is very important that you try to maintain your weight to allow the mask to continue to fit well and promote recovery. Weight loss due to poor nutrition can prevent healing of the area treated by radiotherapy. The dietician will see you each week during radiotherapy to give advice regarding this.

Using the following tips may be helpful:

- Eating small meals frequently known as 'the little and often' approach – eating five or six times a day even if you are not hungry.

- Eating soft, moist or liquid foods, such as porridge or Weetabix with plenty of milk, scrambled eggs, omelettes, mashed potatoes, soups, cottage pie, fish in sauce, milky puddings, yoghurts and mousses.
- Adding extra cream, cheese and butter to foods and using full fat products can be helpful to add extra calories if you are eating smaller amounts than is normal for you.
- Drinking extra fluids, especially milk. Try to aim for 8-10 glasses of fluid per day as a minimum.
- Using supplement drinks, such as Ensure Plus/Ensure Twocal. Your dietitian will be able to advise you on these if they are needed.
- Avoid very hot, spicy and sharp/tart foods and drinks, such as fruit or fruit juices, vinegar and tomato soups, as they may sting.
- Avoid crackers, toast and biscuits which can be dry and scratchy.
- Avoid alcohol, especially strong spirits. Alcohol may also make the side effects of radiotherapy worse and during treatment many people find it better to give up alcohol (especially spirits) completely until their mouth has healed.

Occasionally some patients need to be admitted to the hospital to be fed through a nasogastric tube (a thin tube which goes down your nose and into your stomach) because they are finding it too difficult to swallow food and fluids. This may mean staying in hospital for the duration that feeding support is required; if the team feel you might struggle with managing the tube at home. Once you are able to eat and drink enough in the normal way the tube can be removed.

Sometimes a gastrostomy feeding tube (PEG) is recommended by the doctor. This is a thin tube which will be inserted directly into your stomach just before or in the first two weeks of radiotherapy treatment. This is because we think that you are more likely to need support with your eating and drinking. We will provide you with information if you need a gastrostomy feeding tube and you will be seen by the PEG

nurse. This type of tube can be looked after at home but does mean a short stay in hospital of 2-3 days while it is fitted.

- Dry mouth and throat

The radiotherapy treatment can often make your mouth and throat feel dry and your saliva feel thick and sticky, especially if you're having your salivary glands treated. Sipping drinks can help and most people carry a bottle of water with them when going out or coming for treatment.

If your secretions are particularly difficult to cough up and clear, breathing in warm steam when you are in a steamy bathroom or kitchen can be helpful. You could also try breathing in steam from a bowl of warm water with a towel over your head. This needs to be done regularly to be effective. Try to aim for 10-15 minutes at least four times a day or more often if able. The warm steam can help loosen thick secretions.

Some people have great difficulty clearing thick secretions, which can cause gagging and potentially lead to nausea or vomiting. In this case we may recommend a nebuliser which is organised via your GP surgery. A nebuliser sends moist air through your airway to help loosen the thick secretions and make it easier to cough and clear.

Oral thrush can be common when your mouth is dry. You may notice a white patchy coating in your mouth and increased soreness. If this happens it can be treated with anti-fungal medication, so please let one of the team know if you notice any symptoms of oral thrush.

- Mouth care

It is very important that you keep your mouth clean and moist using regular mouthwashes, particularly after meals. Salt water mouthwash can be made at home using 1 teaspoon of salt to 1 pint of warm water. You can use salt water mouthwash as often as you want. It is important to brush your teeth at least twice a day, ideally after each meal and before you go to bed. As your mouth becomes more sore

using a children's toothpaste can help reduce any stinging and a children's toothbrush will be gentler.

- Voice changes

Your voice may become hoarse or weaker for a time, so 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, but do not whisper. Give your voice rest throughout the day. If your treatment includes your voice box (larynx), you may lose your voice completely towards the end of your treatment. Your voice will gradually return, in the meantime if necessary you may find it useful to carry a pen and paper to write messages.

- Taste changes

You may find that your sense of taste is altered. Some people lose their sense of taste or feel that everything tastes the same. A common complaint is that food tastes saltier than usual. Some people also say that they have a metallic taste in the mouth. It can take some months for the sense of taste to return and there can be some permanent changes. It can help during treatment to think of food and fluid as medicine, particularly if eating and drinking are no longer enjoyable. Drinking plenty and eating well are very important when going through radiotherapy treatment.

- Difficulty with mouth opening

Radiotherapy can cause tightening of the muscles that open your mouth, which can mean your jaw feels tighter and your mouth is more difficult to open. This is called trismus. Being able to open your mouth to 'three fingers' width is widely considered normal. If you notice your mouth opening is reducing it is important to practice jaw opening exercises for as long as possible during treatment and when you feel comfortable enough to do so after treatment. Our speech and language therapist can help you if you have any concerns about mouth opening.

- Skin reaction

The skin in the treated area can at first become pinker or darker depending on your skin colour. Your skin may feel more dry, sensitive, itchy and sore and further into treatment your skin may become moist, blister or peel. If your skin becomes moist and broken it may produce a yellow or bloody discharge. It is important to keep these areas clean and dry and not use any cream until these areas have healed. We will monitor your skin reaction and, if necessary, advise you on using dressings on broken areas for your comfort. Your skin will generally be healed about four weeks after treatment. If the skin has broken, healing may take a little longer than this.

The following advice may help minimise the skin reaction:

- You can bath or shower during treatment, avoiding very hot or very cold water on the area being treated.
- wash the skin gently with products you would normally use; the area being treated should be rinsed, using lukewarm water, then patted dry with a soft towel and not rubbed.
- Use a moisturiser sparingly, apply gently with the fingertips and apply in the direction of hair growth. To help reduce irritation a moisturiser that is sodium lauryl sulphate free would be best. If your moisturiser irritates your skin, please talk to your treatment team and stop using it.
- Avoid or reduce shaving if possible. Men are advised to use an electric shaver rather than wet shaving. Avoid wax/creams for hair removal.
- Avoid wearing make-up, perfume or after-shave on the treatment area only.
- Avoid friction to the area being treated, such as tight clothing, and use natural fabrics when possible, like cotton, silk or soft wool, which are soft and let your skin breathe.
- Avoid rubbing the area.
- 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 cream or lotion on the area during treatment. After your treatment is finished and your reaction has healed, you should use a total sun block while in the sun for at least a year. It is important that you continue to protect your skin from the sun during this time.

- If your skin is not broken you may swim, however please stop if swimming irritates your skin. Shower after swimming to wash off the chlorine and apply your moisturiser.
- When your skin is no longer red or itchy you can go back to washing and shaving normally.

- Hair loss

Any hair, including facial hair, that is in the treatment area and where the x-rays leave the body, will fall out. Any part of a beard or moustache that is in the treatment area will stop growing during radiotherapy and is likely to never grow again. However, hair lost where the radiotherapy beams leave the body will normally grow back after treatment. You can wash your hair with a mild baby shampoo, rinsing off with lukewarm water and patting dry.

- Tiredness

Radiotherapy can make you feel tired, as can anxiety and travelling for the treatment. Tiredness may start whilst you are having treatment and continue for a number of weeks after the treatment has finished. If needed you should allow extra time for a rest, for example an afternoon nap. If possible spread your chores out over the week. There is no reason you shouldn't continue with your usual daily activities if you feel able. Once you have finished treatment and are starting to recover gentle exercise can help improve energy levels.

- Nausea (feeling sick)

Nausea can sometimes happen during treatment and we will prescribe anti-sickness tablets to help control this. If you do feel nauseous it may help to take the anti-sickness tablets half an hour before meals.

Also eating little and often can be helpful. If you are struggling to control the nausea or are vomiting please let us know. Sometimes people feel nauseous or vomit due to gagging or retching on thick/sticky secretions. If this happens it may help to follow the advice for loosening secretions in the dry mouth section.

Important advice

Smoking while you are having treatment may cause some side effects to develop earlier and possibly be even worse. We strongly suggest that you give up smoking and we will be able to advise and support you with this. Please talk to the head and neck cancer specialist nurses if you want advice about stopping smoking.

Alcohol may also make the side effects of radiotherapy worse and during treatment many people find it better to give up alcohol, especially spirits, completely until their mouth has healed.

Long term side effects

There are some possible late side effects which your doctor will discuss with you. These can occur months or even years after treatment, and will depend on what part of the head and neck was treated by radiotherapy.

- **Mouth and dental problems**

After treatment it can take a long time (up to six months or more) for saliva production to return to normal. If the salivary glands were in the area being treated by radiotherapy, dryness of the mouth may be permanent. There are a variety of saliva substitutes available that you can be prescribed which some people find useful, we can discuss this with you after treatment. It can help to eat foods with plenty of sauce or gravy. Generally, people find frequently sipping water the best way to manage the dryness.

If you are experiencing a dry mouth you will also be at increased risk

of tooth decay as the teeth are no longer protected by saliva. Keeping your teeth clean and in good condition can help – brush with a fluoride toothpaste at least twice a day, floss daily and use a non-alcohol fluoride mouthwash. It is advisable to visit your dentist regularly, every 3-4 months and make sure any dentist you see knows you have had radiotherapy in the head and neck area. If you need any dental work completing and your dentist is not happy to complete it please let us know, and we will make a referral to the hospital Maxillofacial Team or the Restorative Dentistry Service based in Oxford.

It may take some time for the lining of your mouth and tongue to heal; you may continue to have painful ulcers while this is happening.

- Dry cough

As the radiotherapy reaction settles a dry tickly cough can occur, this will ease over time. It may help to sip drinks or try a simple cough medicine. If you find you are coughing when you are eating and/or drinking please let us know. Please also inform us if your cough is persistent and does not settle.

- Weight loss

You may find it difficult to get back to your normal weight after treatment, even when your appetite has improved and you are eating well. We will weigh you at each outpatient appointment and monitor your weight. It is quite common for people to struggle with weight gain after treatment. The dietitian will continue to be available during follow-up, providing advice and support for maintaining your weight.

- Skin colour changes

You will always be sensitive to the effects of the sun; especially during the first year after your treatment in the area that's been treated.

Protect yourself with total sun block and a hat. Skin in the treatment area can become darker than your normal skin colour (generally or in patches) and you may notice patches of small blood vessels near the surface of the skin, but this is quite rare.

- Tight neck and throat – swallowing problems

Sometimes radiotherapy can cause a tightening of the inside of the throat which can make swallowing more difficult. If this is a problem, you will be seen by our speech and language therapists. You may also notice that the muscles in the neck feel firmer and tighter, which is generally more noticeable if you have also had surgery. If you experience any difficulty with neck/shoulder movement with or without pain, please let us know and we can make a physiotherapy referral for you.

- Damage to bones or cartilage

The jawbone can sometimes be affected by radiotherapy and become more brittle, this is another reason why you need to let your dentist know you've had head and neck radiotherapy. If you need to have any dental extractions post-treatment, there is a risk the jaw bone could become damaged. If due to dental work or for any other reason (for example: infection or jaw surgery) the jaw bone becomes damaged and cannot heal this is called osteoradionecrosis.

If you have had radiotherapy to the voice box there is a risk of cartilage damage, this is very rare but may be more common in patients who smoke during treatment.

- Hearing changes

In some people there is a risk that radiotherapy may affect your hearing, this is more commonly seen in people having radiotherapy for nasopharyngeal cancer. Hearing changes can be temporary and improve after treatment but in some cases long term hearing changes can develop.

- Underactive thyroid gland

If the thyroid gland is exposed to radiation during treatment, there is a risk it may become underactive months or years later. If we are concerned that this may happen we can monitor your thyroid gland with blood tests. An underactive thyroid gland is very treatable with daily medication.

- Cancers caused by treatment

A very rare side effect of the radiation is that it can cause a further cancer in the future. Although this is a serious possible side effect 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 be assured that we believe the benefits of your treatment for your current condition outweigh the longer term risks involved.

After treatment

Once you have finished your course of treatment you will be sent a follow-up appointment in the post to come back for review. We normally see people back in the ENT clinic four weeks after the end of treatment. During those four weeks you will receive a weekly phone call from either the head and neck cancer specialist nurse or the dietitian. This is to review how you are getting on and give you advice for managing your side effects. If you have any urgent concerns between these telephone calls please ring us on the numbers at the end of this leaflet, rather than wait for your review phone call. We will give you a prescription to top up any medications you are using for managing your side effects in the last week of treatment. If you run out of any medication please ask your GP for further supplies.

Contact details.

Head & Neck Cancer Clinical Nurse Specialists: 0118 322 8827

Speech and Language Therapists: 0118 322 5205

Dietetic team: 0118 322 7116

Berkshire Cancer Centre: 0118 322 7888 (9am-5pm)

Radiotherapy Assistants: 0118 322 7872 (8:30am-4:30pm)

Head and neck review radiographers: 0118 322 8869 (8:30-5pm)

Macmillan Cancer Information Centre: 0118 322 8700

Useful information / support

- Macmillan Cancer Support
0808 808 2020 www.macmillan.org.uk
- Heads2gether – Head and Neck Cancer Support Group
www.heads2gether.net 0800 0234550 to speak directly to a heads2gether supporter.
- Patient Relations
0118 322 8338 or email talktous@royalberkshire.nhs.uk

For more information about the Trust, visit our website at www.royalberkshire.nhs.uk

This document can be made available in other languages and formats upon request.

Notes

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