



Maidstone and
Tunbridge Wells
NHS Trust

Kent Oncology Centre

Radiotherapy for Heads and Neck Cancers: Side Effects and Management

We hope this leaflet will help you understand radiotherapy treatment to the head and neck; the side effects that may occur and ways to manage these effects. If you would like to speak to one of the radiotherapy team please feel free to contact them on the numbers given below:


Maidstone Hospital

Macmillan Head & Neck Radiographer  01622 220293

Macmillan Radiotherapy Specialists  01622 225094

Appointment enquiries  01622 225080

Kent & Canterbury Hospital

Macmillan Head & Neck Radiographer  01227 766877
Ext 722 2711

Appointment enquiries  01227 783010

What is radiotherapy?

Radiotherapy uses high energy x-rays and similar rays called electrons, to treat abnormal cells such as cancer cells. It is usually given as a series of short, daily treatments, Monday to Friday, in the radiotherapy department using a machine called a linear accelerator, also known as a 'Lin Acc'. The machine does not touch the body but you will be brought closer to it. You do not go 'into the machine' but it will move around you whilst you lie on the couch.

Treatment is individually planned for each person so even people with the same type of cancer may have different types of radiotherapy treatment.

Each treatment is called a 'fraction'. Giving the treatment in fractions ensures that normal cells are damaged less than cancer cells. The damage to normal cells is mainly temporary, but still causes radiotherapy side effects.

Radiotherapy **does not** make you radioactive so it is safe for you to be with people, including children, after each treatment. Radiotherapy is painless, although it may gradually cause some uncomfortable side effects which will be discussed later in this leaflet.

How will I feel after treatment?

Radiotherapy affects people differently; some find that they can carry on working, only needing time off for their treatment, while others find it too tiring and prefer to stay at home. If you have a family to look after you may find you need extra help.

Don't be afraid to ask for help, whether it's from your employer, family and friends, social services, or the staff in the radiotherapy department. As your treatment progresses, you'll have a better idea of how it makes you feel, so you can make any necessary changes to your daily life.

Giving your consent

Before you have radiotherapy your doctor will explain the aims of the treatment to you. You will be asked to sign a form saying that you give your permission (consent) for the hospital staff to give you the treatment; no medical treatment can be given without your consent. Before you're asked to sign the form you should have been given full information about:

- the type and extent of the treatment you are advised to have
- the advantages and disadvantages of the treatment
- any other treatments that may be available
- any significant risks or side effects of the treatment

If there is anything you don't understand let the staff know straight away so that they can explain. Some cancer treatments are complex, so it's not unusual for people to need repeated explanations. You do not have to make a decision when the treatment is first explained, you can always ask for more time to think it through.

Before you have your first treatment, staff will check again that you still give consent to have treatment and will ask whether you have any further questions. You are free to choose **not** to have the treatment, and the staff will explain what may happen as a result of that.

Pregnant?

Please tell the medical staff if you might be pregnant as radiotherapy can harm the developing baby.

Planning your treatment

Careful planning ensures that the radiotherapy is as effective as possible and that the radiotherapy rays are aimed precisely at the cancer, causing the least possible damage to the surrounding healthy tissues.

The treatment is planned by your clinical oncologist, a physicist and therapy radiographers. It is usually necessary to wait a number of days, possibly up to two weeks, for treatment to start because of the preparation required.

Treatment mask

You are likely to need a special device called a mask to help you hold your position very still during your treatment, making it as effective as possible. This will be made on your first visit. The mask is made of plastic mesh which has been softened in warm water and molded to your head and face. It hardens after a few minutes and is then ready to use. It will fit snugly so it may feel claustrophobic, but you will only wear the mask for a few minutes at a time. Please do not wear any hair products, e.g. hairspray, gel or wax on the day of planning as these can make hair stick to the mask during moulding.

CT planning scan

Once your mask has been made, you will then have a CT planning scan. A CT scan is a type of x-ray. You will be lying on a couch which will move through a wide ring so that many images from different angles can build up a three-dimensional picture of the area. The mask you are wearing will be fastened to the couch you are lying on. This session usually takes about 45-60 minutes.

In order to obtain very clear images, it may be necessary to inject a dye (contrast) into a vein. The radiographers will discuss this with you and ask for your consent. A cannula will be placed into your arm so that the dye can be given when you are in the scanner. This is for the planning scan only and not for treatment. We advise that you do not have anything to eat for two hours before this scan but we like you to have had plenty to drink.

Positioning

The CT couch will be identical to the one that you will lie on during treatment. The radiographers will explain what they are doing and will make you as comfortable as possible before leaving the room to take the scan which lasts a few minutes and is painless. They will watch you from outside the room. We need you to lie very still for a few minutes so that accurate measurements can be taken and your exact position recorded. Guidance marks can be made on the mask instead of on your skin. The measurements and the information from the scans are fed into a planning computer that is used to help your consultant plan your treatment precisely.

Having your treatment

Before your first treatment the radiographers will explain to you what you will see and hear. It's quite normal to feel anxious about having your treatment, but as you get to know the staff and understand what is going on it should become easier. If you wish, you can eat before your treatments.

The radiographers will advise you where to lie on the couch, gently fitting your mask on you before raising the couch to a higher position. Your positioning is very important so the radiographers may take a little while to get you ready (they may call this 'setting up'). The room may be in semi-darkness while this is happening and the radiographers will be talking to each other and calling out measurements.

As soon as you are positioned correctly the staff will need to leave the room to prevent them from being exposed to any unnecessary radiation.

During treatment you will be alone for a few minutes but there will be a radiographer watching you during this time on a monitor camera. To protect your privacy, nobody else will be able to see you. If you have any problems you can raise your hand to attract the radiographer's attention and they will come in to help you. The radiographers may come into the treatment room to re-position equipment in the middle of your treatment.

Most radiotherapy machines can rotate around your body, giving treatment from several different directions. This and the sound of the machine can be unsettling at first. Some treatment rooms have CD players so that you can listen to music to help you relax while having your treatment and there may be a screen you can see which will display pictures.

The radiographers may tell you on some days that they are 'taking pictures'. Over the course of treatment you may lose a little weight and this regular check ensures that the treatment still matches the original plan. Occasionally small changes sometimes have to be made to your treatment plan; the radiographers will explain any changes, and their reasons, to you.

Side effects of radiotherapy to the head and neck

Some side effects may occur, usually towards the end of the course of treatment and also during the first few weeks after treatment has finished. Treatments given over several weeks give more side effects than a short course of treatment.

These side effects can be upsetting and may require you to make some adjustments to your normal life, but most are temporary and will gradually disappear after a few weeks. However, some side effects may continue for, and some may only become apparent after, months or years following treatment.

It is important to discuss these with your consultant as help may be available

Short term side effects

You will be monitored throughout your treatment by the radiotherapy team. Please let them know if you experience any of the following problems:

Tiredness

You may find that you become more tired as your treatment continues. This is very common with radiotherapy and is caused partly by the travelling back and forth to hospital, and partly by the treatment itself. Rest if you need to but try to get some exercise each day, however gentle.

Loss of appetite

Some people lose their appetite as an effect of radiotherapy. A sore, dry mouth can also make eating difficult. If you struggle to eat much, it is a good idea to supplement or replace your meals with nutritious high-calorie drinks, which can be supplied initially by our dietitian and are subsequently available on prescription.

Occasionally radiotherapy can make you feel sick (nauseous). This can often be helped by drinking more fluids. If this becomes troublesome please tell the radiotherapy team as you can be given medication to help with this.

Loss of taste

If part or all of your mouth is treated, then your sense of taste will quickly change during radiotherapy. Some people lose their sense of taste completely while others find that everything tastes the same as each other (usually rather metallic, salty, or like cardboard). Although your sense of taste will recover, it may take six weeks or more for it to return to normal after the treatment.

Dry mouth

You may not produce as much saliva as before treatment. The lining of your mouth and throat may become dry, making eating and speech difficult. You may also notice a feeling of sticky mucous in the throat, as radiotherapy can make the saliva thick and stringy. Steam inhalation may help along with regular sips of water. To reduce the dry feeling, you may also find it helpful to use an artificial saliva spray which we can supply to you.

Although you may start to produce some saliva again within a few months of treatment, it is important to be aware that the problem might continue for some time. If your mouth, throat or the upper part of your neck is being treated, your mouth may become permanently dry. We can give you advice about coping with the long term effects of a dry mouth.

Skin changes

The skin over your face and neck is very likely to gradually redden or darken and become itchy and sore (like sunburn). Sometimes the skin will peel or flake resulting in a sore and weepy skin reaction. You will be prescribed painkillers to help until your skin heals.

Your skin reaction can be affected by the dose and type of treatment that your consultant has prescribed. It can also be dependent on your type of skin, your shape, any existing conditions such as diabetes and especially if you smoke.

Tips for helping your skin include:

- Wash the skin gently using soap or aqueous cream and gently pat dry
 - To reduce irritation to the treatment area you may use a moisturiser (your Macmillan radiographer can advise on this)
 - Do not use any perfumes, make up, pre-shave and/or aftershave on the treated area
 - Avoid heating and cooling pads/ice
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- Men wishing to shave their face are advised to only use an electric razor or not to shave at all whilst on treatment as wet shaving can further irritate the skin
 - Avoid wearing collars and ties; loose, natural fibre clothing is more comfortable
 - If your skin peels, dressings may be provided to aid comfort
 - Ensure the treated skin is covered when out in the sun; your skin may be more sensitive to the sun especially in your first year after treatment so it is advisable to apply a high factor sun screen

After finishing treatment you may be aware of your skin reaction becoming worse for up to another two weeks. Continue with the suggested skin care tips, returning gradually to your usual skin care regime when your skin has returned to normal.

Sore mouth and throat

Your mouth and throat will probably become sore and inflamed and you may develop some mouth ulcers. Your voice may also become hoarse. You may become sensitive to very strong flavours and/or extreme heat and cold. Eating food may become difficult and swallowing painful.

If this happens, painkillers, mouthwashes and protective gels that coat the lining of the mouth can be provided to help ease the symptoms. You will be advised to eat soft food and to avoid smoking, drinking spirits and eating hot or spicy foods. Drinking plenty of bland, cool fluids e.g. milk or water will help to keep your mouth moist.

You will be able to discuss any problems with a speech and language therapist and/or a dietitian.

If you have had a PEG (feeding) tube inserted before starting radiotherapy you will be seen regularly by the dietetic team and/or our nurse who can advise about the management of the PEG and when to start using it.

Once the course of radiotherapy has finished, your mouth will gradually heal. Some people can return to eating their usual diet a few weeks after treatment has finished, while others may take longer. If you have a PEG it will remain in place until you are able to return to your usual diet.

Dental care

Your saliva normally acts as a protective film. If you have a dry mouth, your teeth will be much more prone to tooth decay so you will need to take special care. Please follow the dental hygiene advice that you are given, such as brushing regularly with a soft toothbrush. If you need any dental extractions these should be carried out before starting radiotherapy.

Hair loss

Hair only falls out where the x-ray beam enters and leaves the body. The radiotherapy team will advise you where you are likely to lose hair and if it will be permanent. Men may lose their beard permanently in those areas of skin that become red or dark and sore during treatment.

Stiff jaw

Treatment and procedures to the back of the mouth and throat can lead to stiffness of the jaw. You will be given exercises to do in order to prevent this from becoming a permanent problem. If the radiotherapy is to the back of your throat (nasopharynx), the muscles used to open and close your mouth can also become stiff. You will be shown mouth-opening exercises that you should do at least twice a day. There are also specialist aids available to help exercise your jaw. Your speech and language therapist can give you advice about exercises and where to get an exercise aid.

Bad breath

This can develop during treatment and may be helped by regular mouth care and mouth washes. Your Macmillan radiographer or nurse will be able to advise you on how to do this effectively. You may also be prescribed an antibiotic medicine that can help.

Still smoking?

Smoking during treatment could reduce the success of your treatment and cause some side effects to be worse.

Please ask for help if this is a problem for you.

Long term side effects

These side effects, some of which can be permanent, can include:

- Dry mouth – saliva is often decreased permanently; artificial saliva products can help
- Swallowing difficulties – may occasionally require long term use of a feeding tube
- Discoloration of skin in the treated area - this may be improved by the use of moisturisers
- Hardening of the underlying tissue in the treatment area (fibrosis)
- Underactive thyroid – this can easily be treated with medication
- Difficulty opening mouth - your speech and language therapist will encourage you to do jaw exercises to help with this
- Increased chance of dental decay/infections
- Damage to bone in treated area – this can be treated but is best avoided, so our team takes precautions to reduce the risk

It is important to remember that treating your cancer is the priority. However, your radiotherapy specialist team will do all they can to reduce the risk of any long term side effects. They will discuss any possible side effects with you before you agree to have treatment.

Further information and advice

Kent Oncology Macmillan Cancer Information Centre, Maidstone Hospital

Offers support and information to anyone who has concerns about cancer (patients, relatives, friends or carers).

☎ 01622 227064

Macmillan Cancer Support

Provide practical, medical and financial information

☎ 0808 808 0000 (Free phone)

Website: www.macmillan.org.uk

Cancer Research This charity provides information about cancer, treatment and clinical trials.

☎ 0808 800 4040 Website: www.cancerresearchuk.org

Patient Experience Teams (PALS) for East Kent patients

Kent and Canterbury Hospital

Desk at the outpatient's entrance of the hospital

Queen Elizabeth the Queen Mother Hospital

Office at the main entrance of the hospital (Ramsgate Road)

William Harvey Hospital

Desk at the main entrance of the hospital

☎ 01227 783145 or 01227 864314

Email: ekh-tr.patientexperienceteam@nhs.net

Please use this space for your notes.

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*The information in this leaflet has been taken from information provided by Macmillan Cancer Support.

MTW NHS Trust is committed to making its patient information accessible in a range of languages and formats. If you need this leaflet in another language or format please ask one of your clinical care team or the Patient Advice and Liaison Service (PALS). We will do our best to arrange this.

Maidstone and Tunbridge Wells NHS Trust welcomes all forms of feedback from our service users. If the standard of service you have received from the Trust does not meet your expectations, we want to hear from you. Please speak with the ward manager or the nurse in charge in the first instance, or you can contact the **Patient Advice and Liaison Service (PALS)** on:

Telephone: ☎ 01622 224960 or ☎ 01892 632953

Email: mtw-tr.palsoffice@nhs.net

or visit their office at either Maidstone or Tunbridge Wells Hospital between 9.00am and 5.00pm, Monday to Friday.

You can be confident that your care will not be affected by highlighting any areas of concern or making a complaint. The Trust will retain a record of your contact, which is held separately to any medical records. If you are acting on behalf of a patient, we may need to obtain the patient's consent in order to protect patient confidentiality. More information on PALS or making a complaint can be found on the Trust's website: www.mtw.nhs.uk or pick up a leaflet from main reception.

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