Radiotherapy for cancer of the head and neck area

Introduction

The Gloucestershire Oncology Centre at Cheltenham General Hospital is a specialist centre for the treatment of cancer, with patients coming here from Gloucestershire, Herefordshire, Worcestershire and Wales. We also have a Radiotherapy Unit at Hereford County Hospital treating patients from that region.

This booklet has been specially written for patients receiving radiotherapy for cancer of the head and neck area of the body. By giving you some idea of what to expect, we hope to ease some of the worries you may have.

This booklet is intended as a guide as effects of treatment may vary from one person to another. If you have any worries, however small, during or after treatment, please speak to your doctor, radiographer or specialist nurse, either at your visit or by telephoning the department, contact details can be found at the end of this leaflet.

When you arrive at the oncology department, it is important that you check in to the radiotherapy reception so that we know you are here. Please sit down and a radiographer or support worker will call you through for marking-up or treatment.

We have male and female staff working in our department and we also train students who are always supervised.

What is radiotherapy?

The machine used to give you your radiotherapy treatment is called a linear accelerator (Linac).

Radiotherapy is the use of carefully measured doses of radiation to treat disease, usually cancer.

The benefits of radiotherapy mean that many cancers can be cured. However, this is not always possible, but radiotherapy also plays an important part in controlling symptoms and increasing the quality of life of people with cancer.
The alternatives to having radiotherapy will be discussed with you by your consultant. Not having treatment may mean that your disease progresses.

Specially trained therapeutic radiographers will plan and give you your treatment.

Radiotherapy may be used as a treatment on its own or with other treatments such as chemotherapy and surgery. We treat the area where the cancer is, or has been removed from.

Our bodies are made up of many cells – these cells divide. Radiotherapy works by damaging cells when they are dividing. Cancer cells divide more rapidly than normal cells so are more sensitive to the damage caused by treatment and recover less easily. You will not be radioactive.

**Pregnancy**

If there is a possibility that you might be pregnant, please tell your doctor or radiographer when you arrive as there may be a risk to your unborn child.

It is important that you do not get pregnant during your course of treatment.

**Appointments**

Many patients receive their treatment as an outpatient and travel to the department for their appointment. Most patients arrange their own transport, either driving themselves or being driven by a friend or relative. When you start radiotherapy, a parking permit is available so you may park in the Oncology spaces free of charge for the duration of your treatment.

In some cases, hospital transport may be available for you, but we need to know in advance. If this applies to you, this will affect your appointment times.

For cancer of the head and neck, you may receive between 4 and 7 weeks of treatments. This will be Monday through to Friday. If a bank holiday falls during your treatment, we may need to treat you on a Saturday. Alternatively 2 treatments may be given in one day.
For some patients, it is necessary to make changes to their treatment after they have started. This may be because we can make the treatment area smaller as time goes on. Or it may be because we need to make a new mask if you lose weight during your treatment.

This would mean you need to have further planning appointments during your course of treatment. It can also alter the length of time your treatment takes at each visit. Your radiographers will explain this to you if it happens.

If you are using nutritional supplements, please bring a supply with you for each appointment and also any medications you will need.

Once started it is very important that you do not miss any treatments.

**Planning your radiotherapy treatment**

Before beginning radiotherapy, the treatment needs to be carefully planned. It is likely that you will need to have a mask made before the treatment starts. The mask helps you to keep still in the position needed and allows the marks for the treatment to be drawn on the mask rather than on your skin.

The mask is individual to you and made during your first appointment. A Computed Tomography (CT) scan will follow and will be used to plan your treatment. You will be required to wear the mask during your CT scan and for all of your treatments. Specialist Radiographers carry out all the planning and treatment appointments. A doctor may not be available at any of these appointments unless you have urgent issues to discuss, radiographers will do their best to answer any questions that you may have. Please bring a list of medications you are taking to this appointment.
Making a mask

The radiographers will explain in detail what is involved in making your mask when you arrive for your appointment.

You will be asked to remove any clothing/jewellery from around your neck and shoulders. This is to make sure that the mask fits well and to prevent your clothes becoming wet.

The mask is made from a sheet of plastic mesh. This is immersed in warm water and then becomes soft. Once it is softened the radiographers will shake off the excess water and gently place it over your face and neck.

You will feel the radiographers gently moulding the mask to the shape of your face and neck. It is very important that you remain still while this is happening. Some people find it a strange experience but it doesn't hurt and you can breathe while wearing the mask.

The mask will take about 10 minutes to dry and set, during which we will stay in the room with you. If we need to leave the room we will let you know.

The next step is to mark up your mask ready for treatment. This will happen during your CT scan.
CT planning

Despite probably having had previous CT scans, we need to do a scan with you lying in the position needed for your treatment and with you wearing your mask. This scan is used specifically for the planning of your radiotherapy treatment and no results are available from it.

The radiographers will position you on the CT couch with you wearing your mask. The mask is attached to the couch top so if you need the mask to be taken off please raise your hand so the radiographers can remove the mask safely. It may be necessary to have an injection of contrast to help show up the area we are looking at.

The radiographers realise that wearing the mask can be difficult for some people and will be as quick as possible.

They will draw some marks on the mask and as soon as the scan has finished the mask is removed. This process may take up to 10 minutes.

After the CT planning scan is completed you will be given your appointment timetable for treatment if you have not already received it. If the appointments have not been arranged, you will be contacted as soon as possible. For this reason, it is important that we have your correct contact details. It is also important to bear in mind that sometimes it is necessary to make adjustments to your treatment plan. This may mean that your appointments could be changed.
What happens during treatment?

Your first treatment

Before your first treatment, a radiographer will explain your treatment and its side effects to you and answer any questions you may have. You can have a relative or friend with you for this.

We try to plan your treatment on the same Linac which means you will see the same team of radiographers on a regular basis allowing you to build up a relationship. There will be occasions when you are treated on another Linac but your treatment will be the same.

It may be necessary to remove or move some items of your clothing/jewellery from around your neck or shoulders so the mask fits correctly.

The radiographers will cover your body up whenever possible to make sure your dignity is maintained at all times.

You will lie on the treatment couch and your mask will be placed on you. The radiographers will then position the treatment couch and treatment machine. You will feel the couch moving as the radiographers’ line up the marks drawn on the mask with the treatment machine.

The radiographers will leave the room to switch the treatment on but a closed circuit television on the control desk means they can see you at all times during your treatment. There is also an intercom system where the radiographers can talk to you during your treatment and offer you some reassurance.
It is important for you to stay still during your treatment but the radiographers will tell you what to do if you need to cough, sneeze or move during your session. There is no need to hold your breath; you should breathe normally.

The radiographers may enter the room to move the machine to the correct position for the next part of your treatment, they will tell you when your treatment has finished and you can get off the couch.

The whole procedure will last 10 to 20 minutes and there is nothing to see or feel; you will hear a buzzing sound when the machine is on.

In the first week and regularly afterwards the radiographers will take X-ray images/scans to check your treatment positioning – these do not show how effective treatment is being. This involves the machine moving around you in a full circle. When this happens you may notice that you are in the room for a little longer. This is to allow the radiographers to check all the images before they treat you. You may also notice the bed move slightly when we make our adjustments. This is to make sure the accuracy of your treatment.

Each treatment is very similar so once you have your first treatment you will know what to expect each day.

**Chemotherapy**

Many head and neck patients will also have chemotherapy before, after, or alongside their radiotherapy treatment.

The chemotherapy is timed to coincide with your radiotherapy and you may be asked to come in on a Sunday night/Monday morning and receive both chemotherapy and radiotherapy the next day. This happens 2 to 3 times during your radiotherapy. You will be asked to phone the ward on the morning of chemotherapy but please do not call before 9:45am. If there is no bed for you, please do not worry – your chemotherapy will be given during that week.

Even if your chemotherapy is delayed or not given, it is very important that you still receive your radiotherapy treatment as planned, especially on the first day that your treatment is due to start.
You will also be seen in the chemotherapy clinic the week before your chemotherapy.

**Side effects of radiotherapy**

Each patient may experience some or all of the side effects to differing degrees. Specific side effects will depend on exactly which area of the head and neck is receiving treatment. Your radiographer or specialist nurse will explain which side effects apply to your treatment.

We appreciate that this treatment can be very difficult and to offer you support, there is a specialist team looking after you. You will be seen each Monday in the review clinic to assess and manage your side effects and given the opportunity to ask questions and discuss any concerns you may have. This will be with a specially trained radiographer. You will also be seen on a Thursday by the Head and Neck team (specialist nurse, dietitian, speech and language therapist). If you need to see a doctor during your treatment this will be arranged for you.

**General advice for side effects**

**Tiredness**

Some patients may find that they feel more tired than usual during treatment (often after 2 to 3 weeks). Travelling to the department may also add to this.

You may find it helps to get plenty of rest and sleep during treatment (especially if you start to get tired).

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. We have an information leaflet designed to help you cope with Fatigue. Please ask a radiographer if you would like a copy of this leaflet.

**Skin**

Your skin in the treated area will become pink or red as your treatment progresses.
It is likely that the skin in the treated area will get very sore and may peel or blister which will become painful and uncomfortable. We recommend you moisturise the treated area twice a day with either your usual cream/lotion or if you are purchasing something new – one which does not contain sodium lauryl sulphate (SLS). Please ask your radiographers for further advice.

As your skin becomes more sensitive, it may feel dry, sore or itchy. The radiographers will advise you on how to care for your skin.

Please be reassured that the radiographers are able to help you with any skin reaction you develop and provide any advice, pain control, alternative creams, gels or dressings that may be needed.

You can bath or shower during treatment, but wash the treated area gently making sure the water is not too hot.

We recommend that you do not wet shave within the treatment area but use an electric shaver to reduce friction.

You may wish to wear looser cotton clothing next to your skin to minimise irritation.

While having treatment and for the foreseeable future, your skin within the treatment area will become very sensitive to the sun. Please avoid sun exposure to the treatment area where possible.

**Hair loss**

Depending on the radiotherapy treatment you are having, hair within the treatment area (usually towards the back of the scalp/beard area) may be lost. If this is the case, the radiographers will show you the area. This is not generally permanent and grows back in time.

Please discuss any side effects that you experience with the team of radiographers treating you. If you attend for treatment and are not feeling well or are concerned about side effects please inform your treatment team so that we can help you.
As well as the general side effects from this treatment, there will be particular side effects depending on the area of your head and neck we are treating with radiotherapy. Your radiographer will be able to tell you which side effects apply to you.

**Specific side effects**

**Dryness of the mouth (Xerostomia) and thick mucus**
Your mouth may become increasingly dry throughout treatment. We will advise you to sip water regularly throughout the day and to suck sugar free sweets/chew sugar-free gum.

Your saliva will become thicker and stickier leading to a dry mouth and throat. This can make eating, drinking, speaking and swallowing difficult. You may be offered an artificial saliva spray. During treatment, one of the most difficult side effects to deal with can be the production of thick mucus in the mouth and throat. We may offer you something called a nebuliser, which produces a fine mist to help manage the production of thick mucus. The thick mucus should go after treatment has stopped but is likely to worsen for the first 2 weeks before gradually settling. Having a dry mouth may continue and be permanent.

**Swallowing**
You may find it difficult to swallow and your radiographer or nurse will be able to provide you with pain medication to help with this. Taking regular pain medication is important to allow you to continue swallowing. We also have a specialist speech and language therapist who can advise and help you. It is very important that you try to swallow regularly and frequently even if it is just sips of fluids. You will also receive specialist support from a dietitian to support you with continued eating and nutritional advice during your treatment.

**Voice change/ loss of voice**
Your voice may change and lose some of its strength while having treatment. It can also become painful to speak.
Taste changes
Many patients suffer from changes in taste sometimes alongside a metallic taste in their mouth.
This may lead to you not enjoying certain foods as much as you usually would. We can advise you on how to manage this. 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.

Loss of smell
Your sense of smell will be affected and any loss or change may be permanent. Your nose may feel ‘bunged up’ and you may have nose bleeds.

Ear problems
Hearing can change while having treatment. This includes loss of hearing and can take a couple of 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 calm down. Some patients also experience a ringing in the ears (tinnitus), this usually follows chemotherapy.

Pituitary and hypothalamus function
The pituitary gland and hypothalamus are areas at the front of your brain which very occasionally can be affected by your radiotherapy treatment. This can affect certain hormone levels. Your doctor will arrange regular blood tests to check your hormone levels if necessary.

Tracheostomy
A tracheostomy is an opening created at the front of the neck so a tube can be inserted into the windpipe (trachea) to help you breathe.
If you have a tracheostomy tube fitted, you will be given a plastic one to wear instead of metal before your radiotherapy starts.
Soreness inside the mouth
The radiotherapy treatment will make your mouth very sore and you may develop ulcers. This will happen gradually. This can be managed by pain medication and you will be monitored closely to make sure that this is under control. The team looking after you will advise you on how to manage this.

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

Sore lips
Your lips may become sore and dry; you will be given a product to apply which will help. Sipping water regularly will also help keep your lips moist.

Stiffness of the jaw (trismus)
Some patients who have this treatment suffer from scarring of the muscles and joints which support the jaw. To help prevent this, you must try to move your jaw and stretch the muscles on a regular basis. If you haven’t already seen a speech and language therapist regarding exercises to help this, please ask.

Finally, it is important to stress that the side effects mentioned are possible effects and that you may not experience all of them. Also, areas other than where the cancer is situated may be affected by the treatment, for example if you are receiving treatment for cancer of the throat (larynx) you may experience side effects in your mouth. Your radiographer will tell you if this applies to you.

Oral hygiene
It is vital to keep your teeth, mouth and gums as clean as possible. At the start of your radiotherapy you will be given a mouth rinse called Caphosol®. It is recommended that you use this regularly while having treatment as it will help to reduce the severity of oral side effects.
If you are unable to tolerate Caphosol you may wish to use a salt water rinse instead (1 tsp in 200ml water) every 4 hours.

You should already have seen a dentist to assess your teeth. If not, please discuss this with the team looking after you. If you have been given other mouthwashes, please also discuss this with the head and neck and review team when they see you.

If you wear dentures, they will need to be thoroughly cleaned after every meal or every 4 hours with a brush and water. Soak the dentures in Milton® 1% solution and throw away the solution every day.

Clean around your mouth every 4 hours with either Caphosol or salt water. If your mouth or gums begin to get sore you will be advised to leave your dentures out when possible.

You may notice the shape of your gums change and you may need new dentures to be fitted at a later date.

**Eating**

During your treatment, you may find that you are having difficulty eating or with maintaining your weight. Our dietician will be able to advise you. You may also be provided with some food supplements that will be easier to swallow. Some general advice for your diet while you are having treatment:

- Try to keep drinking non–alcoholic fluids
- Eat as well as you can; with higher calorie foods such as full fat milk and creamy yoghurts
- Sipping fluids often and eating small frequent meals may be easier than large meals
- Softer/moister foods may be easier to eat

Some patients will already have a feeding tube placed before the start of radiotherapy. When the time comes to use this, your dietician will advise you and support you fully on how to use this tube. They will also create a nutritional feeding plan for you.

**Effects after radiotherapy**

Your doctor will have discussed with you the possibility of potential long-term side effects happening after your treatment has finished.
The advantage of receiving radiotherapy is believed to outweigh the risks of long term problems.

All the side effects discussed above can take a number of weeks to settle down and may worsen for a few weeks after treatment finishes.

Tiredness can continue for up to eighteen months. It is important to remember that the full benefits of the treatment can take a number of weeks to be felt.

Any skin reaction should begin to settle down within a few weeks of treatment finishing but may take a while to go completely, depending on how severe it is at the end of your treatment.

You will always need to make the skin in the treated area is protected from sun exposure as it will be more sensitive. Once the skin reaction has settled we recommend using a factor 50 sunscreen.

You may continue to have difficulty swallowing, sometimes up to 6 to 12 months after treatment stops. Please carry on following any dietary advice you have been given, for example softer foods, supplements and fluids. In some cases, swallowing may not recover completely after radiotherapy and there may be some long term problems with swallowing. If all your salivary glands have been treated with radiotherapy there is a risk of a permanently dry mouth. Most people find sipping water can help.

The thick mucus and ulcers can also continue for a while so please continue with any advice and products you have been given until these settle.

**After treatment has finished**

On the day of your last treatment, the radiographers will give you specific advice on what to do now your treatment has finished, how to manage any side effects and what to expect.

If you are having dressings for your skin or taking regular medication you will be receive a short supply at the end of your treatment. You may need to continue these for a number of weeks and your practice/community nurse and GP will take over your care.
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 you have any worries regarding your treatment or side effects, you can phone the radiographers or specialist nurse who treated you. You can also contact your GP if you have any other worries concerning your disease or treatment.

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

You will be given the date and time of your first follow up appointment before you finish your radiotherapy. This appointment will be with your Head and Neck specialist nurse about 2 weeks after treatment finishes.

Your consultant will also see you 4 to 8 weeks after treatment finishes. This time is given to allow the treatment to continue working and any side effects to begin to settle and for you to recover.

You can contact your specialist nurse if you have any queries or are in need of any support.

Contact information

Radiotherapy Reception
Tel: 0300 422 4147
Monday to Friday, 8:00am to 5:00pm

Radiotherapy Appointments
Tel: 0300 422 4471
Monday to Friday, 10:00am to 3:00pm

Your treatment machine:

__________________________________________

Telephone number:

__________________________________________
Your treatment team:

________________________________

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Further information

FOCUS Cancer Information Centre
Oncology Outpatients Department
Cheltenham General Hospital
Tel: 0300 422 4414
Monday to Friday, 8:30am to 4:30pm

As well as information on treatments and support groups, the Centre advises on how you can obtain wigs and can supply a list of companies who may be able to help with holiday insurance. They also sell herbal sweets for nausea.

Aromatherapy, massage and reflexology are available to patients and carers. Appointments can be booked through the information centre.

Maggie’s Cancer Caring Centre
The local Maggie’s Cancer Caring Centre is located close to Cheltenham General hospital and offers support services. For further information visit the website, call or pop in to see them.

Maggie’s
The Lodge
Cheltenham General Hospital
College Baths Road
Cheltenham
GL53 7QB
Tel: 01242 250 611
Website: www.maggiescentres.org
Cancer Information and Support Service

Macmillan Renton Unit
Hereford County Hospital
Tel: 01432 355444 ask for ext. 5459
Monday to Friday, 9:30am to 4:30pm
Email: hereford.cancerinfoandsupport@nhs.net

The service offers confidential one-to-one support as well as information on all aspects of living with cancer and its treatments to anyone affected by cancer. This includes information on diet and nutrition, coping with hair loss and alternative headwear and benefits advice. Free internet access is available.

Many of the resources are available in different languages and formats and are suitable for people with special needs.

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