



Guide for Patients having Radiotherapy to the head, neck, mouth and throat at Mount Vernon Cancer Centre

Patient Information Series No 13

Consent

It is a legal requirement to have a signed Consent Form from you before the start of your treatment.

If you have already been given one of these forms, please bring the completed form with you when you come for your first appointment.

If you have not been given a form, this will be discussed with you at your first appointment.

Pregnancy/fathering a child

Female patients must not be pregnant or become pregnant and male patients must not father a child during a course of chemoradiotherapy or for some months afterwards.

Please discuss this with your cancer specialist.

If you think there is a chance, however small, of you or your partner becoming pregnant during treatment, it is extremely important that you discuss this with your oncologist, radiographer or nurse as soon as possible.

Female patients will be asked to confirm their pregnancy status prior to chemoradiotherapy. This applies to all women between the ages of 12 - 55 years. This is a legal requirement.

Identification

Please note that it is a legal requirement for the staff to check your name and details against your treatment sheet every time you attend.

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A patient lying on a simulator couch wearing an 'immobilisation shell' during a radiotherapy planning session

Introduction

Your oncologist¹ has recommended that your cancer should be treated with a course of radiotherapy at Mount Vernon Cancer Centre. This leaflet is a simple guide to radiotherapy. While it does not deal with every issue, we hope it will answer some of your questions.

If you have any further questions before, during or after your treatment, please do not hesitate to contact one of the team treating you - there are some contact telephone numbers at the end of the leaflet.

During your radiotherapy there will be a team of oncologists, specialist nurses, dietitians, speech and language therapists (SALT), radiographers and other hospital staff caring for you.

Radiotherapy is the treatment of cancer with radiation using x-rays. You will not feel the radiotherapy when you are receiving it. It will be like a normal x-ray.

What happens before treatment can begin?

Before your treatment begins your oncologist will see you to explain your treatment plan. If you are having treatment to your mouth, you will have a dental assessment to see if you need any dental treatment or possibly some teeth removed. Your oncologist will discuss this with you and arrange this before the start of your radiotherapy planning.

The process of planning your treatment can take 2 - 3 weeks. Your treatment will be planned very carefully so that only the necessary area is treated.

¹ Throughout this leaflet the term 'oncologist' will refer both to your cancer specialist and any doctors working within his/her team

All patients having radiotherapy to the head, mouth or throat will need to have a special mask called an 'immobilisation shell' made. This shell is made specially for you, and will hold you in the correct position lying flat, helping you to keep still, to ensure accuracy during treatment.

A radiographer will show you an example of what it looks like and explain the process of making it. You should be given the factsheet 'Helpful Hints on Having an Immobilisation Shell made' (see page 20) which explains the procedure. Once your shell is made, the lines marking the treatment areas will be drawn on the shell.

You may have some pen marks on your skin. Don't worry if these fade or wash off. There will also be a tiny permanent dot (tattoo) which will never fade. This tattoo will be made at your first radiotherapy appointment to accurately plan exactly where the treatment is going to be applied.

What happens in the planning session?

Planning takes place in a simulator (a machine which allows the doctors to plan your radiotherapy). You will lie flat on a couch with your mask on and will be left alone in the room for short periods of time. During this time you are monitored constantly by closed circuit television, or through a window. You will not receive any radiotherapy during your planning session.

Planning sessions can last a long time, so be prepared to attend the hospital for most of the morning or afternoon.

See factsheet 'Helpful Hints on Having your Radiotherapy Planning' (see page 20).

What happens during treatment?

On your first day, treatment may take about 20 minutes but after that your radiotherapy appointment normally lasts for about 10 - 15 minutes. After positioning you, it takes about 5 minutes for the treatment to be given.

See 'Helpful Hints on Having your Radiotherapy Treatment' (See page 20). The number of treatment sessions you have depends on several factors which the oncologist will discuss with you.

Your treatment will last:

What are the common side-effects of radiotherapy?

Radiotherapy causes side-effects by damaging normal cells. The side-effects you may experience will depend on which part of your head, mouth or throat, is being treated, and are discussed in greater detail later in this leaflet.

The most common side-effects include soreness of the skin, dry and sore mouth, painful swallowing, taste changes, excess production of mucus (thick saliva) and possibly some hair loss in the area being treated. You may also experience extreme tiredness towards the end of, and after, treatment.

These side-effects develop gradually over the course of the treatment and can continue to develop for two weeks after your treatment is completed, after which they will gradually reduce over the following 6-12 weeks.

During your treatment, you will be reviewed weekly by your doctor, nurse, dietitian and if appropriate, SALT.

At these appointments you will be given medication to help you cope with side-effects. Please see page 18 for advice on obtaining a prescription medical exemption certificate.

The day for your review clinic is:

Please bring a list of any medications you need and a new prescription will be given

We all react and respond in different ways, so your team treating you will advise you about what you might expect. The following pages will help to explain your side-effects.

How should I look after my skin?

Your skin may become red and itchy during your course of radiotherapy. We suggest you follow these instructions to help you cope with the skin reaction.

- Wash the treated area very gently using tepid water (warm but not hot) and a simple unperfumed soap, then pat your skin dry, using a soft towel.

- Do not use make-up, creams, perfumes, lotions or aftershave in the area being treated.
- Whenever possible, let the area being treated get as much air as possible. Avoid wearing tight collars.
- You will be given some aqueous cream to put on your treated skin to prevent it from becoming too dry. Some patients find it more soothing if the cream is cool, so you could store it in your fridge.

Please use this cream 4 times a day from the start of treatment. Do not wait for the skin to get dry. Do not put anything else on your skin in the treated area unless your oncologist has recommended it. If you are in any doubt, the team treating you will be pleased to advise you.

- There may be a point in your treatment when you get breaks in your skin, and aqueous cream is not appropriate, in which case dressings may be required. Your skin will heal in about two weeks after you have completed your treatment, and the redness will fade over the next few weeks.
- Men wishing to shave should use an electric razor, and once the skin becomes pink or darker toned you should stop shaving. You will find that your beard stops growing at this stage.
- Facial and head hair may stop growing if it is included in the area you are having treated. Your oncologist will tell you whether the lost hair is likely to regrow, as this will depend largely on the dose of radiation you have received.

- Avoid exposing the treated area to strong sunlight both during and after your radiotherapy. This is because your skin will be more easily damaged and take longer to heal.

The radiographer or nurse will advise you about using a sun block cream after treatment.

- In the summer, we recommend that you wear a wide brimmed sun hat to shade you from strong sunlight.

How should I look after my mouth?

- Brush your teeth with a soft toothbrush after food. You may find this difficult as your treatment continues. If so, stop brushing your teeth and use mouthwashes.
- Brush dentures after food and soak them overnight in denture cleaning solution.
- Rinse your mouth with mouthwash after food and drink. As your treatment progresses and your mouth/throat becomes sore, rinse your mouth hourly.
- Do not use mouthwashes which contain alcohol.
- Apply Vaseline frequently to your lips.
- Avoid hot spicy foods.
- Do not drink any alcohol. If you feel this is difficult please speak with a member of the team treating you.
- Do not smoke. If this is a problem please discuss it with a member of the team treating you.
Smoking during treatment will make your side-effects worse, and make your recovery time longer. Smoking will also affect how your cancer responds to treatment.

- If advised, do your 'jaw opening' exercises regularly. If this becomes painful please ask the speech and language therapist (SALT) for advice.

What can I eat or drink?

It is important that you are well nourished throughout your treatment. The hospital dietitian will inform you of the best ways of maintaining your nutrition.

If you have a feeding tube, the dietitian will advise you on how much prescription feed and fluids you will need.

You may have difficulty chewing and swallowing your food because of the pain. A SALT will be able to offer advice on consistencies and textures of food. See the factsheet 'Helpful hints on Chewing and Swallowing problems' (see page 20).

How will my mouth feel?

When you are about half way through your treatment you will begin to produce thick mucus and saliva. There are no drugs or medicines available to prevent this side-effect from occurring. However frequent rinsing of the mouth can help prevent a build-up of mucus forming.

Nebulised saline (salt water) or steam inhalations can help to clear this mucus and make you feel more comfortable. Your medical team will lend you a Nebuliser machine if one is available. Please return it as soon as you no longer need it.

Spraying water (from a water spray bottle) can help to loosen the mucus. When you have excess saliva or mucus you may need to rinse your mouth more frequently (i.e. every 10 - 15 minutes).

The radiotherapy can affect the salivary glands if they are in the area being treated. Your mouth may become dry and you may find frequent sips of water helpful.

Improvements in dryness can happen up to two years after treatment, but in some cases a degree of dryness remains.

Do not drink alcohol during this time as it will increase the dryness in your mouth, and it will also be painful to swallow.

How will my taste be affected?

Your sense of taste will change. Please see the factsheet 'Helpful Hints on Taste Change' (See page 20). It will improve after your radiotherapy treatment has finished but this may take several months and in some cases changes may remain.

What if I need to visit the dentist?

Following radiotherapy, you will be more prone to tooth decay. It is very important to tell your dentist about your radiotherapy, and any other treatment you have had.

Once your treatment is finished, it is important to brush your teeth 3 times a day after meals with a fluoride toothpaste and a fluoride gum tray may be used (this can be obtained from your dentist /hygienist).

You are strongly advised to see your dentist and oral hygienist every 3 - 6 months.

Your oncologist will always be pleased to answer any queries from your dentist. This can be arranged through your oncologist's secretary even after your treatment is finished.

What if I wear dentures?

If possible avoid wearing dentures during your course of radiotherapy. If this is not possible, then be sure to keep your dentures clean, brush them after all food, and soak them in denture cleaning solution, preferably overnight. We do not advise you to use denture adhesive.

Depending on how much of your mouth is treated, you may not be able to wear dentures for a few months after treatment.

Usually new dentures should not be made until 6 months after your treatment, to allow time for your gums to heal and for any changes in your mouth to settle.

What if I smoke?

Your oncologist will discuss this with you and will recommend that, ideally you give up smoking altogether. Above all, do not smoke during the period of your treatment or whilst you are experiencing any soreness in your mouth or throat as smoking increases the reaction.

Nicotine replacement treatments are now available on prescription. Your hospital doctor or GP will be able to prescribe them for you.

Giving up smoking will ensure that you give yourself the best opportunity to recover from cancer. If you find it difficult to stop smoking, please speak to a member of the team treating you.

Leaflets to help you give up smoking are freely available from the Lynda Jackson Macmillan Centre (LJMC). You can also contact the NHS smoking helpline (see page 21).

What if I lose my voice?

If you are having radiotherapy to your throat, it is quite likely that you will lose your voice at some stage. Your voice may also become hoarse.

Rest your voice as much as possible during your treatment, don't strain to make it louder when it is quiet and don't over-talk when it seems stronger.

When your treatment is finished, it may be a few weeks before your voice starts to recover, and even then it may remain husky. The SALT will be able to offer advice and support.

If you have had a Laryngectomy and are using a speaking valve you will not be able to wear your HME base plate during treatment, as it will irritate the skin around your stoma. We would advise you to wear a stoma button and a special bib. You will need to nebulise regularly (4-6 times per day) to keep your secretions loose and easy to clear.

How will I feel once my treatment has finished?

Within 6 - 8 weeks of completing your radiotherapy, your side-effects will mostly have settled. You will continue to improve over many months, but some changes may remain.

You may have ongoing difficulty chewing and swallowing your food. If this happens a SALT will be able to offer advice on consistency and textures of food, and will suggest swallowing techniques which may be more suited to you. See factsheet 'Helpful Hints on Chewing and Swallowing Problems' (See page 20). The dietitian will advise you about the best ways of maintaining your nutrition.

Most patients feel tired and lethargic at some stage during and after their radiotherapy. This is quite normal, so try to pace yourself realistically and try not to overdo things. See factsheet 'Helpful Hints on Dealing with Fatigue' (See page 20).

It is unwise to become sunburnt on any part of your body. Do not expose the treated area to the sun whenever possible. It will be necessary to apply a high protective factor sun cream to the treated area for the first year after your treatment if you cannot avoid exposing it.

Please ask your oncologist or specialist nurse for advice on how to deal with these long-term symptoms.

Physiotherapy

We advise patients who have had surgery and/or radiotherapy to attend for physiotherapy. You will be given instructions on exercises to improve neck and shoulder movement. Your doctors will refer you to the physiotherapist.

Lymphoedema services

Once the initial side-effects of treatment have eased, some patients may notice swelling around the neck area or under the chin. This happens because the drainage of fluid from the head and neck area may be affected by the surgery and / or radiotherapy.

If this happens to you please let your oncologist or nurse know and we will arrange for you to be seen by a lymphoedema therapist who will use special massage techniques to improve the circulation of fluid in these areas. This usually settles over time.

Follow-up for head and neck cancer patients

Depending on the type of treatment and your side-effects, you may be seen at Mount Vernon Cancer Centre weekly for about 6 - 8 weeks after your treatment is completed. Your specialist nurse or radiographer will advise you when you will be seen.

Once your side-effects have settled you will be referred back to your original hospital to see your oncologist, surgeon, SALT, dietitian and nurse.

If you have been treated for head and neck cancer, you will be seen monthly, and as time progresses these appointments will become less frequent i.e. every 2 - 6 months. The reason for these appointments is to check that your side-effects have settled and that your cancer is not returning.

You should be contacted with a date for the first of these appointments within two weeks of your last appointment at Mount Vernon. If you have not heard from us, please contact your consultant's secretary (see Contacts on page 21).

Getting to hospital

We would recommend that people provide their own transport to hospital. This may mean that you start your treatment sooner and that you do not have long waits for your transport to take you back home. You might like to be accompanied by a friend or relative.

If you provide your own transport, you can get help with your travel costs (bus, train or car mileage) if you are getting any of the following benefits:

- Income Support
- Income-based Jobseeker's Allowance
- Income-based Employment and Support Allowance
- the Guarantee Credit part of Pension Credit
- or if you have an HC2 or HC3 certificate.

If you are eligible, the Patient Affairs Department will pay your travelling expenses, and they will also provide you with a token for the car park. You will need to bring proof that you receive one of the benefits, your travel receipts and your appointment letter. They are located at the main hospital reception near the restaurant.

Department of Work and Pensions (DWP) rules state that we cannot refund taxi fares. However your head and neck nurse can apply for a Macmillan grant which can be used towards travel costs. This is means tested.

If you are on a low income, or travelling long distances but not getting any of the above benefits, you may still be able to get some help. Get the HC1 claim form from your local DWP office or Patient Affairs Department. This grant is means tested.

If you are unable to provide your own transport, hospital transport can be requested but 48 hours notice is required. Please speak to a member of your treatment team if you require transport. Should you wish to cancel your transport, please give as much notice as possible.

If you have a morning radiotherapy appointment you would need to be ready for pick up from 8.30 am onwards.

If you have an afternoon appointment you need to be available from 12.30pm onwards. Unfortunately we cannot give an exact pick up time.

Finances

If you work, it is advisable to inform your employer that you may need up to 6 months off work.

We understand that this will impact upon your household income, and would advise you to contact the benefits advisor at the LJMC (see back cover). Advice is also available on benefits for carers.

Your specialist nurse will be able to give you advice on Macmillan Grants and give you information about Macmillan's benefits service (see Contacts page 21).

If you normally pay for NHS prescriptions

From 1st April 2009, people undergoing treatment for cancer do not have to pay NHS prescription charges if they have a valid medical exemption certificate.

Apply for an exemption certificate by collecting an application form from your GP.

Additional help and support

People who have had cancer will say that throughout their illness they experienced a range of emotions, expected and unexpected. Many find it to be a stressful, anxious and confusing time, both as individuals and within relationships.

Some patients find it helpful to meet and discuss their experiences with other patients who have been through similar treatment. If you would like us to arrange for you to meet another patient please speak to a team member.

The Head and Neck Cancer Support Group meets on the second Tuesday of each month at 4pm at the Lynda Jackson Macmillan Centre (LJMC) and offers a chance for patients and carers to share their experiences, discuss concerns and receive practical advice.

'Moving on from Head and Neck Cancer' is a five week self-help course for patients and carers. Please ask for more information about this.

Some patients find it harder to make decisions or to face up to things, feeling overwhelmed and unable to focus on positive aspects within their lives. If you have difficulty making sense of your feelings or can relate to any of these experiences, you may find it helpful to talk to a trained health professional. They can refer you for counselling if you feel you would find it helpful.

The LJMC provides support and information. It offers a range of services including counselling, complementary therapies and relaxation sessions. There are more details about the LJMC on the back of this leaflet.

The LJMC also produces a series of helpful hints on a variety of topics including side-effects of radiotherapy.

Listed below are some of the titles in our 'Helpful Hints' series which you may find helpful:

- Alcohol issues
- Chewing and Swallowing Problems
- Fatigue
- Giving up smoking
- Having an immobilisation shell made
- Loss of appetite
- Preventing weight loss
- Radiotherapy planning
- Radiotherapy treatment
- Taste change

LJMC also has a range of leaflets from other organisations, or can give you advice about further information. Please drop in to the LJMC for a copy of any of these or download them from the LJMC website: www.ljmc.org

This leaflet forms part of a series of publications produced by the Lynda Jackson Macmillan Centre (LJMC).

If you would like further information about any aspect of cancer and its treatments, please drop in to the centre or call the Helpline.

The LJMC is staffed by healthcare professionals and trained volunteers and is part of the Mount Vernon Cancer Centre.

- Drop-in centre for support and information
- Telephone Helpline
- Benefits Advice *
- Pre-treatment visits
- Complementary therapies *
- Relaxation classes
- Counselling *
- Support groups
- Look Good...Feel Better™ beauty workshops

* These services are available to patients under the care of an NHS oncologist based at Mount Vernon Cancer Centre.

This leaflet has been written in collaboration with oncologists, health professionals, patients and carers at Mount Vernon Cancer Centre.

If you have difficulty reading this size of print, a version of this leaflet or any of our leaflets can be produced for you in a larger print.

Opening hours: Mon - Fri: 9.30am - 1.00pm & 2.00 - 4.30pm

Lynda Jackson Macmillan Centre
situated between the Cancer Centre and Gate 3 (White Hill)
Mount Vernon Hospital, Northwood, Middlesex HA6 2RN
Telephone Helpline: **01923 844014**
www.ljmc.org