NHS
East and North Hertfordshire
NHS Trust

a patient's guide

A short course of radiotherapy to the head, neck, mouth and throat

Patient Information Series PI 25

Patient Label

Mount Vernon
Cancer Centre

Contacts

My oncologist is: ....

Oncologist’s secretary
Please call Mount Vernon Cancer Centre switchboard
on 020 3826 2020
and ask for your oncologist’s secretary

Contact Centre Hub: 0333 332 5470

Mount Vernon Hospital: 020 3826 2020

Radiotherapy clinic radiographers: . 020 3826 2612 / 2613
or 07825 024058

Head and Neck specialist nursing team:
Audrey Scott, Hannah Millar, Xiaoying Wang & Sue Romeril

Mobile no: 07825 025499

Office no: 020 3826 2089

Speech & Language Therapy (SALT) department:

Mobile no: 07825 034934

Office no: 020 3826 2124

Dietetic department:................................. 020 3826 2129

24 hour Acute Oncology Service
Mount Vernon Cancer Centre: 07825 028855

Guide for patients having a short course of radiotherapy to the head, neck, mouth and throat

Contents

Introduction

It has been agreed by you and your oncologist[1] to treat you with a short course of radiotherapy at Mount Vernon Cancer Centre. The aim of this treatment is to control your cancer and ease your symptoms, so you feel more comfortable.

This leaflet is a simple guide to your radiotherapy. We hope it will answer some of your questions. If you have further questions before, during or after your treatment, please contact one of your healthcare team. The contact telephone numbers are on page 2 of this leaflet.

Radiotherapy is the treatment of cancer with radiation using x-rays. You will not feel the radiotherapy when you have your treatment. It is like having a normal x-ray.

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.

You could be seen by both male and/or female radiographers when you have your radiotherapy planning and treatment.

What happens in the planning appointment?

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. It will hold you in the correct position while you are lying flat. It will help you to keep still, and help ensure your treatment is accurate. The radiographers will show you an immobilisation shell and explain how yours will be made. There is a video that you can watch on the Lynda Jackson Macmillan Centre (LJMC) website. Please see page 13 for details.

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[1] In this leaflet the term ‘oncologist’ will refer both to your cancer specialist and any doctors working within his/her team

You will be asked to take off your clothes from above your waist. We will maintain your dignity at all times. After your shell is made, you will have a computerised tomography scan (CT) while you are wearing it.

While you are having your scan you will be alone in the room for 20–25 minutes. During this time you are watched through a window. The radiographers will tell you how you can let them know if you have any problems. You will not have any radiotherapy during your planning appointment.

You may have some pen marks drawn on your skin. Don’t worry if these fade or wash off. With your permission, the radiographers will make a tiny permanent mark on your chest (tattoo). This is very small and is done by pinpricking the skin with some special dye. The permanent dot is important as it enables accurate positioning and treatment delivery each day.

Your planning appointment may take between one to three hours, so expect to be at the hospital for most of the morning or afternoon on that day. You may find it helpful to bring a supplement drink with you if you are using them. If you take painkillers please ensure that you bring enough with you.

Your radiotherapy will usually start about two to three weeks after your planning appointment. This allows time for your oncologist and planning physicists to calculate your treatment doses.

Before starting your radiotherapy you will have a consultation with the head and neck specialist nurse. This session is a chance to ask about your treatment, your care and any other questions you have. This may be in person or by phone.

What will happen during my treatment?

On your first day, the treatment may take up to 20 minutes. After that your radiotherapy appointment normally lasts for about 10–15 minutes. The radiographers will get you in the correct position; it then takes about 5–10 minutes for your treatment to be given. You will be alone in the room during that time, but the radiographers can see you all the time by using closed circuit television. They will tell you how you can let them know if you have any problems while you are having the treatment.

The number of treatments you have depends on a few factors which the oncologist will discuss with you.

Your key worker during treatment is:

____

Your treatment will last:

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What side effects am I likely to have from my radiotherapy?

Radiotherapy kills cancer cells, but can also damage some normal cells causing side effects. The side effects you may have will depend on which part of your head, neck, mouth or throat is being treated.

Please remember not everyone will have every side effect. The most common side effects are listed in the tables on pages 8–10.

These side effects develop gradually over the course of your treatment and for about two weeks following treatment. After this they gradually reduce over the following four to six weeks.

During your treatment, you will be reviewed weekly by your oncologist, nurse, dietitian and sometimes a speech and language therapist (SALT).

At these appointments you will be given medicines and advice to help you cope with side effects. Please see page 20 for advice on getting a prescription medical exemption certificate.

The day for your review clinic is:

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Please make a note of any medicines you need so that a new prescription can be given. Try to plan ahead so that you do not run out of medicines. You could leave your prescription at pharmacy and collect the next day. This helps to avoid long waits at pharmacy.

Everybody reacts and responds differently to treatment. Your healthcare team will advise you about what you should expect. The following pages will give some tips to help you manage your side effects.

It is **very important** you follow the advice about how to use your medicines and how to manage your side effects. If you have any difficulties following this advice please ask your health care team.

If you are having difficulties with any of the following symptoms please tell your head and neck specialist nurse. Not everyone will have every side effect.

Symptom	When will it occur?	How to manage it?	When will it get better?
Red/sore skin on neck, face, upper chest and shoulder (see page 11)	Redness - about week 2	❍ please discuss the use of creams with your healthcare team ❍ electric shave only ❍ avoid perfumes, make-up, talcs etc	Most reactions will have healed by about 2 weeks after finishing treatment.
Ulcerated mouth/throat/ lips (see pages 12–13)	About the start of week 2	❍ use your mouthwash as prescribed ❍ regular painkillers	Slowly settles over 3-6 weeks after finishing treatment.
Painful swallowing (see pages 12–13)	About week 2	❍ avoid citrus/spicy/ salty food ❍ soft texture food ❍ use regular painkillers ❍ review by dietitian ❍ review by SALT ❍ possible PEG tube support	After finishing treatment, swallowing improves and tube feeding is not needed. Regular review by a dietitian and SALT are necessary. This will also depend on what your swallowing function was like before radiotherapy.

Symptom	When will it occur?	How to manage it?	When will it get better?
Taste change	For some, this is about week 2 onwards	❍ regular mouth wash ❍ use of herbs, honey, sauces to flavour foods	There may be some improvements in taste, a few weeks to a few months after finishing your treatment. However for some patients their taste changes may never go away (they will be permanent).
Excess production of mucus (thick saliva) (see page 12)	About week 2	❍ regular mouth care ❍ drink plenty of fluids ❍ nebulised saline 6–8 times a day	4–6 weeks after finishing treatment. Some patients may have changes to their saliva for good (permanently), ie. sticky or thicker saliva.
Change in voice	Week 2–3	❍ review by SALT ❍ avoid straining to speak ❍ depends on location of tumour	4–6 weeks after finishing treatment. Some changes take many months to settle. Some stay for good (permanent).
Trismus (restricted mouth opening)	Week 3–4	This depends on where your cancer is. You will be given specific mouth exercises by your SALT.	This can be a long term problem. It is important to do regular mouth exercises to improve and keep your ability to open your mouth. These exercises are a lifetime activity.

Symptom	When will it occur?	How to manage it?	When will it get better?
Extreme tiredness (see page 14)	Week 2–3	❍ follow nutrition plan from dietitian ❍ plan rest periods during the day. Try to do some gentle exercise (short walks) when you feel able to	Starts to improve about 6 weeks after finishing treatment, but it can take months. Try gentle non-strenuous daily exercise.
Hair loss	Week 2–3 Facial hair loss Hair at side/ back of head	Electric shave. You may find you do not need to shave after a few weeks. Temporary - keep hair longer to hide if possible.	Usually re-grows within 3 months. For some people the hair may not grow back in the area that has been treated.
Dry mouth (see page 12)	Usually as soon as radiotherapy has finished	Water spray. Carry a bottle of water. Many saliva replacement products are available (your nurse will help to find the best one for you).	Some patients may notice an improvement 4–6 weeks after finishing treatment. For others this may stay for good (be permanent).
Lymphoedema (facial and neck swelling) (see page 15)	Sometimes this can occur towards the end of treatment. Usually occurs 8–12 weeks after finishing treatment	You will be shown how to massage the area by a lymphoedema nurse. Sometimes you may need a course of massage treatment.	This can take up to 6 months after finishing treatment to settle. You may need to carry on doing self massage for longer.

How should I look after my skin?

Your skin may become red and itchy during your radiotherapy. You should follow this advice to help you cope with any skin changes:

- Wash the treated area very gently using tepid water (warm but not hot) and a mild unperfumed soap. Pat your skin dry, using a soft towel.
- Do not use make-up, creams, perfumes, lotions or aftershave in the area being treated.
- Try to let the area being treated get as much air as possible. Avoid wearing tight collars.
- Use a moisturiser. Do not put anything else on your skin in the treated area unless your oncologist has recommended it. If you are in any doubt, ask your health care team.
- Men wishing to shave should take extra care.
- Facial and head hair may stop growing if it is included in the area you are having treated. This hair is likely to regrow once the side effects of your treatment have settled.
- Do not expose the treated area to strong sunlight both during and after your radiotherapy. This is because your skin will be more easily sunburnt and will take longer to heal.
- In the summer you should wear a wide brimmed sun hat to shade you from strong sunlight.
- In the future you must always protect this area from the sun and use a high factor sun cream.
- If you have any area of skin that has already developed a wound due to your cancer, your specialist nurse will advise you which dressings are best to use during radiotherapy. It is important that you do not use any tape on your skin in the treatment area.

How should I look after my mouth?

- Having a cancer in the mouth or throat can cause mucus or thick saliva that is difficult to swallow. Radiotherapy temporarily makes this mucus worse.
  Using a mouthwash regularly, every couple of hours, can help to control this mucus. You will be given Tellodont mouthwash which will loosen mucus and refresh your mouth. You can use this as often as you need.
- Brush your teeth with a soft toothbrush after food. You may find this gets more difficult after a number of treatments.
  If so, stop brushing your teeth and use mouthwashes.
- Do not use mouthwashes which contain alcohol.
- Brush dentures after food and soak them overnight in denture cleaning solution.
- Avoid hot spicy foods, citrus and tomato based foods.
  Also avoid dry foods (moist foods are easier to manage).
- Try to avoid drinking alcohol, especially spirits. Please speak with a member of your health care team if you feel this will be difficult.
- Do not smoke. If this is a problem, please discuss it with a member of your health care team.
  Smoking during treatment will make your side effects worse, and make your recovery time longer. Smoking will also reduce the effect of your treatment on your cancer (see page 14).
- If you have been told to do jaw opening exercises, it is important you do these. If this becomes painful please ask the SALT for advice. These exercises will help to prevent future problems with mouth opening.

What can I eat or drink?

It is important that you are well nourished and do not lose weight during your treatment. The dietician will talk to you about the best ways of helping you to eat healthily.

If you have a feeding tube, the dietician will advise you on how much prescription feed and fluids you will need. It is important to follow their instructions.

You may have difficulty chewing and swallowing your food. A SALT will be able to offer advice on consistencies and textures of food. See the LJMC factsheet ‘Chewing and swallowing problems (HHC224)’ (see page 19).

What if I wear dentures?

If possible, avoid wearing dentures during your radiotherapy. If this is not possible, you need to keep your dentures clean.

You must:

- brush them after each time you eat
- soak them in denture cleaning solution overnight if possible
- if possible do not use denture adhesive

Head & neck cancer: What can I tell you?

The Head & Neck Patient Support Group at Mount Vernon Cancer Centre has produced a series of short videos about treatment of and recovery from head and neck cancer.

View these on **www.ljmc.org/information/head-neck**

What will happen if I smoke?

Your oncologist or specialist nurse will discuss this with you. We recommend that you **stop** smoking completely during the period of your treatment and while you have any soreness in your mouth or throat. This is because smoking increases any side effects you get.

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

If you find it difficult to stop smoking and would like advice, please speak to a member of your healthcare team. Leaflets to help you give up smoking are available from the Lynda Jackson Macmillan Centre (LJMC). You can also contact the NHS smoking helpline (see page 20).

How will I feel once my treatment has finished?

Within four to six weeks of finishing your radiotherapy, most of your side effects will have settled.

You may have ongoing difficulty chewing and swallowing your food. If this happens a SALT will give you advice on consistency and textures of food. They will suggest swallowing techniques which may be easier for you. The dietitian will talk to you about what foods to eat so that you get the right nutrition to help you recover from your treatment. See the LJMC factsheet ‘Chewing and swallowing problems (HHC224)’ (see page 19).

Most patients feel tired and lethargic at some stage during and after their radiotherapy. This is to be expected. Try to pace yourself and not do too much. Some gentle exercise can help with tiredness. See the LJMC factsheet on ‘Living with tiredness (fatigue) (HHC229)’ (see page 19).

What is lymphoedema?

When the initial side effects of treatment have eased, you may notice swelling around the neck area or under the chin. This happens because the fluid from the head and neck area may not be able to drain away from the tissues in that area. This is an effect of surgery and/or radiotherapy. It is called lymphoedema.

If this happens to you please tell your oncologist or nurse. They 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 will usually settle over time.

When will I see the oncologist after my treatment has finished?

You will be seen weekly after you have finished your radiotherapy. The number of weeks will depend on the treatment you had and your side effects.

As soon as your side effects have settled you will be referred back to your original hospital or clinic to see your oncologist, surgeon, SALT, dietitian and nurse.

The purpose of these visits is to assess your side effects, and also your response to the radiotherapy. If you have any worries or concerns in the meantime, please contact your specialist head and neck nurse, or your oncologist's secretary to bring your hospital appointment forward (see page 2).

How can I get to hospital?

If possible patients should provide their own transport to hospital. This may mean that you start your treatment sooner and that you do not have long waits for transport to take you back home. You might like to have a friend or relative come with you.

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
- Universal Credit
- 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. You will need to bring proof that you receive one of the benefits, your travel receipts and your appointment letter. Patient affairs is located at the main hospital reception near the restaurant and is open Monday-Friday, 8.30am–4.30pm.

Department of Work and Pensions (DWP) rules state that we cannot refund taxi fares. 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 health care team if you need transport. If 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 7.00am onwards. If you have an afternoon appointment you need to be available from 12.00 noon onwards. We cannot give an exact pick up time.

Car parking at the hospital

A Pay & Display parking scheme operates 24 hours a day. Cancer patients have a £1 concessionary parking rate but must register for this.

Registration forms are on the back of appointment letters or are available at the Cancer Centre Reception desk.

On your first visit, take your registration form to one of the following offices (Monday–Friday), where you will be given a yellow Concessionary Parking Pass:

- **Facilities Office**: 8.00am–4.00pm
- **Car Parking Office**: 8.00am–1.00pm and 2.00pm–4.00pm
- **Post Room**: 8.30am–12.00pm and 1.00pm–4.00pm

Buy a Concession ticket for £1 at the Pay and Display machine and display this and your yellow pass on the car dashboard. Your yellow pass can be used in any car.

Blue Badge holders do not need to register or pay. Please display your Blue Badge on your dashboard and make sure you park in a parking bay.

Am I entitled to financial help?

Your specialist nurse will be able to give you advice on Macmillan grants (see page 20).

Other help and support

People who have cancer often say that, during their illness, they experience a range of emotions. Many find it to be a stressful, anxious and confusing time.

If you have any questions or concerns about cancer and your treatment, are struggling to cope or need some support, please visit the Lynda Jackson Macmillan Centre (LJMC). Please feel free to drop in before, during or after any of your visits to the Cancer Centre.

The team at the LJMC works as part of the overall team caring for you to provide help, support and information in a relaxed setting to help you better cope with cancer and its treatment. Your family and friends are also welcome to visit the centre or call the Helpline.

A range of support services are available at the centre. These include complementary therapy, relaxation sessions, counselling and financial advice. Please ask for more details.

You do not need an appointment to visit the LJMC which is located next to the Chemotherapy Suite by Gate 3. If you are unable to get to the LJMC, you can call the Helpline on 020 3826 2555.

Please see the back page of this leaflet for more information.

Some patients find it helpful to meet and discuss their experiences with other patients who have been through similar treatment. Details of support groups are below or, if you would like us to arrange for you to meet another patient, please speak to a member of your healthcare team.

There is a great deal of help and support available, including:

The Swallows Head and Neck Cancer Support Group
www.theswallows.org.uk
24/7 support line, tel: 07504 725 059

Head and Neck Cancer 'What can I tell You?' videos are a series of short videos developed by the head and neck patient group at Mount Vernon Cancer Centre. They give an insight into some concerns you may have before, during or after treatment. There are links to these videos in the Head & neck cancer section on www.ljmc.org/information.

Lynda Jackson Macmillan Centre (LJMC)
A range of support and information services is available for patients and their families at the LJMC. The centre is located next to the Chemotherapy Suite by Gate 3. The staff at the LJMC work as part of the team caring for you.
Please feel free to drop in before, during or after any of your visits to Mount Vernon Cancer Centre to find out more about the LJMC services that you may find helpful.
Services include complementary therapy, counselling, relaxation sessions and financial advice. You can drop in without an appointment or call the LJMC helpline on **020 3826 2555**. More information is on the back of this leaflet.

Where can I get more information?

At the Lynda Jackson Macmillan Centre there is an extensive range of leaflets on all aspects of cancer and its treatments. Please feel free to drop in before, during or after any of your visits to Mount Vernon Cancer Centre to ask any questions you may have.

The LJMC website also has links to many sources of information and support. Follow the links to the Head & neck cancer section from **www.ljmc.org/information**

We have produced a range of factsheets that you may find helpful. These are available from the LJMC and can also be downloaded from the website.

- ❍ Chewing and swallowing problems (HHC224)
- ❍ Living with tiredness (fatigue) (HHC229)
- ❍ Loss of appetite (HHC214)
- ❍ Managing taste changes (HHC244)

Useful national sources of information

Changing Faces - national charity offering written information and telephone support for people who have disfigurements of the face.
Contact 0300 012 0275   www.changingfaces.org.uk

Macmillan Cancer Support - information and support services to patients and carers. Includes benefit advice.
Contact 0808 808 0000   www. macmillan.org.uk

Cancer Research UK - information for patients and carers.
Contact 0808 800 4040   www.cancerresearch.org.uk

Cancer Black Care - information and support to all members of the community, who are affected by cancer.
Contact 020 8961 4151   www.cancerblackcare.org.uk

NHS Smoking Help line
Contact 0300 123 1044   www.nhs.uk/smokefree

If you normally pay for NHS prescriptions

People undergoing treatment for cancer do not have to pay NHS prescription charges if they have a valid medical exemption certificate. To get an exemption certificate, ask your GP for an application form.

Mount Vernon Cancer Centre is committed to ensuring that patients receive the best quality of care regardless of their gender identity or sexual orientation.

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.

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.

Pregnancy/fathering a child

Patients must not be pregnant or become pregnant, or father a child, during a course of treatment or for some months afterwards. **Please discuss this with your cancer specialist.**

If you are of child bearing capacity we ask that you inform a member of staff. It is our duty of care to enquire whether individuals may be pregnant or breastfeeding. This information will be kept in strict confidence.

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

This publication has been produced by the Information team at Mount Vernon Cancer Centre. Contributors include health professionals, patients and carers who have expertise and experience in the topics covered by this publication. All our publications are reviewed and updated regularly. If you would like any details of the references used to write this information please contact the Information team on 020 3826 2555.

Notes:

Notes:

Questions or concerns about cancer and treatment? Struggling to cope? Need some support? Need to talk?

Drop in to the Lynda Jackson Macmillan Centre
or call the support & information helpline

We will listen to your concerns, answer your questions
and guide you to further information
and services to help you

cancer treatment
side effects of treatment
day-to-day living with cancer
benefits advice
counselling
someone to talk to
emotional support
complementary therapy
relaxation services

practical support
headwear workshops
exercise
diet and nutrition
health and wellbeing
talking to family and friends
Look Good Feel Better
self-help courses
life after cancer

The Lynda Jackson Macmillan Centre is situated between the
Cancer Centre and Gate 3 (White Hill)
Opening hours: Monday–Friday 9.30am–4.30pm
020 3826 2555
www.ljmc.org

Supporting people affected by cancer
from diagnosis, through treatment and beyond

QUALITY assured information
Lynda Jackson Macmillan Centre

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