

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

Patient Information Series No 24

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 months afterwards.

Please discuss this with your cancer specialist.

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.

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.

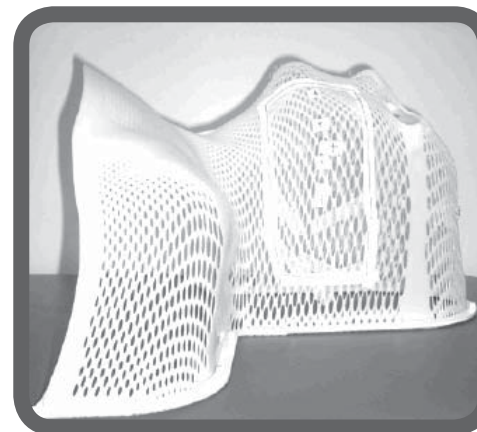
Identification

Please note that it is a legal requirement for the staff to check your name and details against your treatment sheet and your hospital name band each time you attend. You must wear your name band at all times whilst in hospital.

Guide for Patients having Chemoradiotherapy to the head, neck, mouth and throat

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An 'immobilisation shell'
(also known as a 'mask')



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

Photographs by the LJMC Information Team © 2006

Introduction

Your oncologist¹ has recommended that your cancer should be treated with a course of chemoradiotherapy at Mount Vernon Cancer Centre. This leaflet is a simple guide to chemoradiotherapy. 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 chemoradiotherapy there will be a team of oncologists, specialist nurses, dietitians, speech and language therapists (SALT), radiographers and other hospital staff caring for you.

What is chemoradiotherapy?

Chemoradiotherapy is the combined use of chemotherapy and radiotherapy.

Chemotherapy is the treatment of cancer with drugs.

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.

By combining these treatments, the chemotherapy makes the radiotherapy more effective.

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

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 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.

All patients having radiotherapy to the head, mouth or throat will need to have a special mask made called an 'immobilisation shell'. 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 your 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 22) 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.

Before you can have chemoradiotherapy you will need some blood tests and a kidney function test. This involves having an injection which is then followed by a blood test two and three hours later. These will need to be done at Mount Vernon Hospital.

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 22)

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 factsheet 'Helpful hints on Having your Radiotherapy Treatment'. (See page 22)

How are the treatments combined?

Radiotherapy is given each day of the week from Monday to Friday for six and a half weeks.

The chemotherapy is planned to be given to you as an inpatient for one day in the 1st, 4th and 7th week. You will be in hospital on each occasion for one night.

You will be an outpatient during weeks 2, 3, 5 and 6 when you will have only radiotherapy.

	Chemotherapy	Radiotherapy	Inpatient (1 night only)	Outpatient
Week 1	✓	✓	✓	
Week 2		✓		✓
Week 3		✓		✓
Week 4	✓	✓	✓	
Week 5		✓		✓
Week 6		✓		✓
Week 7	✓	✓	✓	

What are the common side-effects of chemotherapy?

The details of the chemotherapy drug you will be receiving, along with its specific side-effects will be discussed with you at your clinic visit.

Before each chemotherapy treatment you will usually have a blood test.

This is a routine check as these drugs affect blood cells, particularly the 'white cells' which protect our bodies from infection. If the number of blood cells becomes too low, your chemotherapy treatment may need to be delayed for up to a week, just to allow the blood cells to recover.

While you are receiving chemotherapy, if you feel pain or stinging at the cannula site, tell the nurse straight away. If at any time throughout your chemotherapy treatment you develop a fever or become unwell, please contact the ward or your specialist nurse immediately (see page 23).

Before starting treatment, please read 'A Patient's Guide to Chemotherapy at Mount Vernon Cancer Centre', available from the Lynda Jackson Macmillan Centre.

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 or 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 about six weeks, 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, dietician and if appropriate SALT. At these appointments you will be given medication to help you cope with side-effects. Please see page 20 for advice on obtaining an 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 any 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 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 'Tellodont' 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 may 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 become 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 about the best ways of maintaining your nutrition.

If you have a feeding tube, the dietician 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 22)

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 frequently (i.e. every 10 - 15 minutes).

The radiotherapy can affect the salivary glands depending on the site being treated. Your mouth may become dry, so 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 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 22) 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. 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, it may be better to 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 six 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 and would like advice, 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 23).

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. You will need to nebulise regularly (4 - 6 times per day) to keep your secretions loose and easy to clear. We would advise you to wear the special bib provided.

How will I feel once my treatment has finished?

Within 8 - 12 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 22) 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 22).

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.

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 service

Once the initial side-effects of your 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

Depending on your treatment and side-effects, it is usual for you to be seen at Mount Vernon Cancer Centre weekly for about 6 - 8 weeks after your treatment is completed. Once your side-effects have settled you will be referred back to your original hospital to see your oncologist, surgeon, SALT, dietician and nurse.

Initially 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 your side-effects have settled and 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 22).

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 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-related 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.

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. You can get the HC1 claim form from your local DWP office or Patient Affairs. 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. Should you wish to cancel your transport, please give as much notice as possible.

If you have a morning radiotherapy appointment you will 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 - 9 months off work.

We understand that this will impact upon your household income, and would advise you to contact the benefits advisor based at the Lynda Jackson Macmillan Centre (LJMC). 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 on page 23).

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 or cancer clinic.

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, who may refer you for counselling.

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 Lynda Jackson Macmillan Centre (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
- ◇ A patients guide to Chemotherapy
- ◇ Chewing and swallowing
- ◇ Fatigue
- ◇ Giving up smoking
- ◇ Having an immobilisation shell made
- ◇ Loss of appetite
- ◇ Preventing weight loss
- ◇ Radiotherapy planning
- ◇ Radiotherapy treatment
- ◇ Taste change

Please drop in to the LJMC for a copy of any of these or download them from the LJMC website: www.ljmc.org

For more information call:

Macmillan Benefits Helpline: 0808 808 0000

NHS Smoking Help line: (7am - 11pm) ... 0800 022 4332
www.smokefree.nhs.uk

Contacts

Marie Curie Ward: 01923 844225 [Mon 7.30am-Fri 8pm]

Ward 10 (mainly for men) 01923 844042 [24 hours]

Ward 11 (mainly for women) 01923 844043 [24 hours]

**Out of hours (9pm - 8am) you may also call
01923 826111 and ask for bleep 113**

Cancer Clinic Nurses tel no : 01923 844267
weekdays 9.00am - 5.00pm

Specialist Nurse is:

tel no:

Radiotherapy Support Nurse is:

tel no:

Speech & Language Therapist (SALT):

tel no:

Dietician:

tel no:

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.



Lynda Jackson Macmillan Centre

for cancer support & information

... working to improve the lives of people affected by cancer...

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.

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