



Lynda Jackson Macmillan Centre
support & information at Mount Vernon Cancer Centre
... supporting 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.

Services offered at the LJMC include:

- Drop-in centre for support and information
- Telephone helpline
- Benefits advice*
- Complementary therapies*
- Relaxation classes
- Counselling*
- Look Good...Feel Better™ beauty workshops
- Self-help courses

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



The **Lynda Jackson Macmillan Centre** is situated between the Cancer Centre and Gate 3 (White Hill)

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

Mount Vernon Cancer Centre, Northwood, Middlesex HA6 2RN
Telephone Helpline: **020 3826 2555**
Website: **www.ljmc.org**



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a patient's guide

Radical radiotherapy/ chemoradiotherapy for lung cancer

Patient Information Series PI 80



East and North Hertfordshire **NHS**
NHS Trust



Contact details



Patient Label

My oncologist is:

Oncologist's secretary tel no:

Mount Vernon Hospital: 020 3826 2020

Cancer clinic nurses: 020 3826 2186

Lung cancer nurse specialist:

Julie Munson 07825 934210

..... 020 3826 2088

Lynda Jackson Macmillan Centre:..... 020 3826 2555

Nutrition & Dietetic department: 020 3826 2129

Physiotherapy department 01923 844430

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

This leaflet has been produced by professionals, patients and carers from Mount Vernon Cancer Centre who have expertise and experience in the topics covered by this publication. All our publications are reviewed and updated regularly. Details of the references used to write this information are available from the Information Team at the Lynda Jackson Macmillan Centre.

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 radiotherapy 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 radiotherapy. 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.

Radical radiotherapy/chemoradiotherapy for lung cancer

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Introduction

Your oncologist¹ has recommended that your cancer should be treated with a course of radiotherapy with or without chemotherapy at Mount Vernon Cancer Centre. This leaflet is a simple guide to your treatment. We hope it will answer some of your questions.

It should also be read with:

- Radiotherapy for lung cancer (Roy Castle Foundation)
- Managing Breathlessness (Macmillan Cancer Support)
- Managing Fatigue (Macmillan Cancer Support)
- HHC 229 - 'Living with Tiredness (fatigue)' (Lynda Jackson Macmillan Centre)

If you have further questions before, during or after your treatment, please contact one of your health care team. The contact telephone numbers are on page 2 of this booklet.

During your treatment there will be a team of oncologists, clinical nurse specialists (CNS), dietitians, physiotherapists, Lynda Jackson Macmillan Centre (LJMC) therapists, 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.

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

Personal record of how I felt

Session number: Starting date:

Fill in here the dates, starting with day 1 of session 7 of your chemotherapy

Side-effects as they happen to you																	

Please remember to bring this booklet with you to your next appointment

What happens before I start my treatment?

Before your treatment begins your oncologist will see you to explain your treatment plan.

If you are diabetic, and taking Metformin please call 020 3826 2622 as soon as possible. We may need to arrange for you to have a blood test before your planning appointment.

What happens at my planning appointment?

- The planning will usually take place in a computerised tomography (CT) planning room.
- The radiographers will explain in detail what these machines do and what is involved with your planning. If you have any questions, please ask.
- You will need to remove some clothing. We realise this may make you feel uncomfortable but we will maintain your dignity as much as we are able.
- You will be asked to lay on the bed in the same position as required for your treatment. Please tell the radiographers if you are uncomfortable as you may need to stay in that position for up to 30 minutes.

While you are having your scan you will be left alone in the room for a few minutes. During this time you are watched by closed circuit television, or 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 on your skin. Don't worry if these fade or wash off. You will also be given three tiny permanent dots (tattoo) on your chest which will never fade. This tattoo helps to ensure you are in the correct position each day for your treatment.

Please remember to bring this booklet with you to your next appointment

Side-effects as they happen to you																		

Fill in here the dates, starting with day 1 of session 6 of your chemotherapy

Personal record of how I felt

Session number: Starting date:

Your planning appointment may take between 1-3 hours. So expect to be at the hospital for most of the morning or afternoon on that day. You will see your specialist nurse, physiotherapist, dietitian and LMC therapists that day.

Your radiotherapy will usually start about 2-3 weeks after your planning appointment. This allows time for your oncologist, and planning physicist to calculate your treatment doses.

What treatment will I be having?

Your doctor has decided that you will have either:

- CHART
or
- Chemoradiotherapy
or
- Intensity Modulated Radiation Therapy (IMRT)

For more information about radiotherapy including CHART please read the Roy Castle Lung Cancer Foundation booklet “Radiotherapy for Lung Cancer” .

Your specialist nurse and radiographer will explain what this means, how often and when you have to attend for treatment.

Night												
PM												
Mid PM												
Mid Day												
Mid AM												
AM												
Reason												
Medicine and dose												

Your specialist nurse will complete this table with you. It will help you to remember when you need to take each of your medicines. It is important to take the medicines as advised, so you feel comfortable and are able to carry on with daily activities.

Medicine and dose	Reason	AM	Mid AM	Mid Day	Mid PM	PM	Night

What will happen if I am staying at Chart Lodge?

You will need to collect the keys from ward 11 on the Sunday evening before your treatment.

You will be treated three times each day starting on a Monday (week 1) for 12 consecutive days to Friday (week 2), which will include a weekend.

What will happen during my treatment?

On your first day, treatment may take up to 20 minutes. After that your radiotherapy appointment normally lasts for about 15-20 minutes. The radiographers will get you in the correct position. 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.

If you are having chemotherapy at the same time as your radiotherapy you will need to have blood tests and see the doctor more often.

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

Please read the booklet Radiotherapy for Lung Cancer (Roy Castle Lung Cancer Foundation) for information about side effects.

Everyone reacts and responds differently to treatment. Your health care 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.

The day for your review clinic is:

Please bring a list of any medicines you need and a new prescription will 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.

Notes:

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Your next appointments will be:

Day	Date	Time	Healthcare team member	Venue

How should I look after my skin?

Your skin in the area being treated 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 continue to use your usual soap. Pat your skin dry, using a soft towel.
- If you use a moisturiser on your skin in this area please carry on and use it to prevent your skin from becoming too dry.
- Do not expose the treated area to strong sunlight both during and after your radiotherapy. This is because your skin will be more easily sun burnt and will take longer to heal.
- In the future you must always protect this area from the sun and use a high factor sun cream.

Can I drink alcohol whilst having treatment?

Please discuss with a member of your health care team.

Everybody is different. Not everyone will get every side effect. If you are having difficulties with any of the following symptoms please tell one of your healthcare team.

Symptom	When will it occur?	How to manage it?	When will it get better?
Painful swallowing This happens because radiation has to pass through the oesophagus (gullet/food pipe) and lung.	About week 2-3	Avoid citrus/spicy food Soft moist food Use regular painkillers e.g. Oxetecaine Review by dietitian	Swallowing improves over 6 weeks after end of radiotherapy. Regular review by dietitian necessary.
Breathlessness Radiotherapy causes damage and inflammation of the lungs.	From about 4 weeks	Get into a comfortable position Controlled breathing Relaxation Sit near open window Fan therapy Regular morphine liquid Complementary therapy	May take up to 12 months Regular review by physiotherapist
Cough	From 2 weeks	Cough medicines Nebuliser - saline Complementary therapy	Over a few months after treatment Regular review by physiotherapist

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.

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

Useful national information

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 0800 226 237 www.cancerhelp.org.uk or www.cancerresearch.org.uk

Cancer Black Care - information and support to patients and carers from ethnic communities.
Contact 020 8961 4151 www.cancerblackcare.org

NHS Smoking Help line: (7am - 11pm)
Contact 0800 169 0169 www.givingupsmoking.co.uk

Roy Castle Lung Cancer Foundation
Contact: 0333 323 7200
www.roycastle.org

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 7.00 am onwards. If you have an afternoon appointment you need to be available from 12.00pm onwards. We cannot give an exact pick up time.

Am I entitled to financial help?

If you work, we advise you to inform your employer that you may need up to 6 months off work.

We know that this may impact upon your household income and we would advise you to contact the benefits advisor at the LJM (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.

Inflammation of lungs Pneumonitis symptoms - cough/shortness of breath.			Regular review by physiotherapist
Taste change - usually only with chemotherapy	During and after chemotherapy	Regular mouth wash	This will start to get better about 6 weeks after finishing treatment. Regular review by dietitian
Fatigue and tiredness	From week 2 onwards	Follow the nutrition plan from dietitian Plenty of rest during the day. Try to do some gentle exercise (short walks) when you feel able to. Plan your day so you can do things you want to do most	8-12 weeks after finishing treatment. Try gentle non-strenuous daily exercise, gradually increasing over the next few months, e.g. walking. It may take up to 12 months to fully recover. Regular review by a CNS, LJM therapists and physiotherapists.

You will be cared for by a multi-professional team which includes a CNS, physiotherapist, dietitian and LJM therapists. Each time you are seen in clinic you will see the relevant member of your health care team to help you cope with any symptoms you are experiencing at the time.

The information on pages 10-12 describes some of the side effects you may experience during and after your treatment has finished.

Will my eating and drinking be affected?

During your treatment you may find that you have a poor appetite. This is often due to the side effects mentioned on page 10. If you have any of these side effects, please discuss them with your clinic team.

Keeping your weight stable and your muscles strong can help you cope with your treatment better.

If you find you are eating less, try to increase your calorie intake by:

- eating small regular meals 5-6 times per day
- you may find it easier to eat soft, moist meals
- adding foods such as cream cheese and butter can add energy into your meals

It is a good idea to avoid spicy or acidic foods as they may cause soreness when you swallow. Your dietitian will advise you when you are seen in clinic.

Are there any exercises I should do to help my breathing?

If you are having severe breathlessness, difficulty in getting rid of secretions from your chest or need help regarding exercise, please ask for advice when you attend your clinic appointment.

Your specialist nurse, physiotherapist or LJMCT therapists will be able to help you.

What will happen if I smoke?

- 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.

How can I get 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 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-related Employment and Support Allowance
- the Guarantee Credit part of Pension Credit
- or if you have an HC2 or HC3 certificate
- Universal credit.

If you are eligible, the Patient Affairs Department will pay your travelling expenses. 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. Patient Affairs is located at the main hospital reception near the Oak Tree restaurant.

Department of Work and Pensions (DWP) rules state that we cannot refund taxi fares. Your lung nurse (CNS) 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.

Listed below are some of the titles in our which you may find helpful:

- Swallowing problems
- Living with tiredness (fatigue)
- Loss of appetite
- Relaxation and Breathing techniques

For information about local support groups and organisations ask in the LJMC for a copy of the lung cancer contact list: HHC207 or download the information from the website: www.ljmc.org

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

You will be seen at Mount Vernon Cancer Centre weekly for about 6-8 weeks after your treatment has finished. This will depend on the type of treatment and the side effects you have. Your specialist nurse or radiographer will advise you when you will be seen.

As soon as your side-effects have settled you will be referred back to your original hospital or clinic to see your oncologist.

To start with you will be seen monthly. As time passes these appointments will be 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 call your consultant's secretary (see Contact details on page 2).

- Your oncologist will discuss this with you and will recommend that you give up smoking both during treatment and afterwards.

Giving up smoking will ensure you give yourself the best chance to recover from cancer. This is because nicotine in cigarettes causes the blood vessels to shrink (vasoconstriction) and this may make your treatment less effective.

You may want to consider not re-starting to smoke after your treatment has finished. If you do smoke there may be an increased risk of some long term side effects. If you want more information, please ask your oncologist or nurse.

Nicotine replacement treatments are now available on prescription. Your oncologist or GP will be able to prescribe them for you. Please ask at the LJMC for leaflets to help you give up smoking. You can also contact the NHS smoking helpline - see end of booklet for details.

What can I do to help myself?

You will be given medicines to help manage some of your side effects. These will include painkillers to help you feel comfortable while eating and drinking. It is usual for patients to be on strong painkillers by the end of treatment and for some weeks after treatment as the tissues heal. Your health care team will discuss how to take painkillers regularly so that they are most effective, helping to keep any pain under control.

Please use your painkillers as advised and tell one of your health care team if you are having any side effects from them. These side effects can be managed so that you stay comfortable and able to carry on with daily activities.

The diary at the back of this leaflet may be helpful in monitoring how well your painkillers are helping you. (see page 22).

Make sure you attend the weekly review clinic on the correct day during your treatment. You will be seen by the oncologist, specialist nurse, dietitian, LJM therapist and physiotherapist.

Your LJM therapists will show you tools and techniques to help you manage your side effects and keep you feeling well as possible.

If you have any concerns or questions talk to your health care team.

How will I feel once my treatment has finished?

Side effects last for several weeks. Many will start to settle by about 8 weeks after you have finished your radiotherapy.

By 12 weeks of finishing your radiotherapy, most of your side-effects will have settled. Some will continue to improve over many months, but some changes may stay.

You may have ongoing difficulty swallowing your food. If this happens a dietitian will talk to you about what foods to eat so that you get the right nutrition to help you recover from your treatment.

Most patients feel tired and lethargic at some stage during and after their radiotherapy. This is to be expected. For some patients this can last many months or even years. Try to pace yourself and not do too much. Some gentle exercise can help with tiredness. See the LJM factsheet 'Living with tiredness (fatigue)' (see page 16).

It is unwise to become sunburnt on any part of your body. Try not to expose the treated area to the sun at any time.

You will need to apply a high protective factor sun cream to the treated area for the first year after your treatment if you cannot keep it covered when you are in the sun.

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

Where can I get help?

Often people who have had cancer say that during their illness they have a range of emotions, expected and unexpected. Many people find it a stressful, anxious and confusing time, for themselves and their family and friends.

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 member of your health care team.

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

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

The LJM also produces a series of factsheets on a variety of topics including side-effects of radiotherapy.