

Cetuximab and radiotherapy to the head, neck mouth and throat

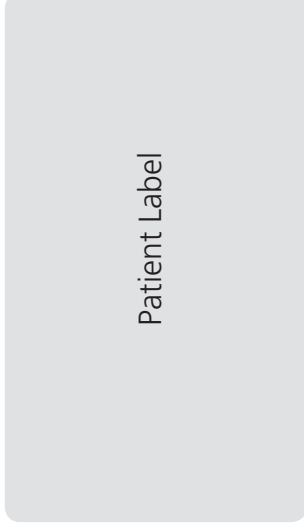
Patient Information Series PI 13b



NHS
East and North Hertfordshire
NHS Trust



Contacts



Patient Label

My oncologist is:

Oncologist's secretary tel no:

Mount Vernon Hospital: 020 3826 2020

Cancer clinic nurses: 020 3826 2186

Macmillan specialist nurse (keyworker): Audrey Scott
..... 020 3826 2089 / 07768 237522

Radiotherapy support nurses: 07825 025499

Speech & Language Therapy (SALT) department:
tel no: 01923 844457

Dietetic department:
tel no: 020 3826 2129

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

Cetuximab and radiotherapy to the head, neck, mouth and throat

Contents

Contacts	2
Introduction	4
What is cetuximab and radiotherapy treatment?	4
What happens before I start my treatment?	5
What happens at my planning appointment?	6
What will happen during my treatment?	7
How are the treatments combined?	8
What side-effects could I have from Cetuximab?	8
What side-effects am I likely to have from my radiotherapy?	10
How should I look after my skin?	15
How should I look after my mouth?	16
How will my taste be affected?	17
What can I eat or drink?	17
How will my mouth feel?	18
Will I lose my hair?	19
What should I do if I need to visit the dentist?	19
Can I have dentures or implants?	20
What will happen if I smoke?	20
Will I lose my voice?	21
What if I have a laryngectomy?	21
What can I do to help myself?	21
How will I feel once my treatment has finished?	22
Where can I get help?	23
Will I need to have physiotherapy?	25
What is lymphoedema?	25
When will I see the oncologist after my treatment has finished?	26
How can I get to hospital?	26
Am I entitled to financial help?	28
Useful national information	29
Other help and support	30
If you normally pay for NHS prescriptions	30
Consent	31
Identification	31
Pregnancy/fathering a child	31

Introduction

Your oncologist¹ has recommended that your cancer should be treated with a course of cetuximab and radiotherapy at Mount Vernon Cancer Centre. This leaflet is a simple guide to your treatment. 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 health care team. The contact telephone numbers are on page 2 of this leaflet.

During your treatment 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 is cetuximab and radiotherapy treatment?

Cetuximab and radiotherapy is the combined use of a drug and radiotherapy to treat people with head and neck cancer.

Cetuximab is a type of drug known as a monoclonal antibody. It is **not** chemotherapy. A monoclonal antibody is used to stop cancer cells from growing and dividing. It causes little harm to normal cells. As a monoclonal antibody, cetuximab works in a different way from chemotherapy and therefore has different side effects. Cetuximab makes the cancer cells more sensitive to radiotherapy and this is why the treatments may be used together.

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.

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

By combining these treatments, the cetuximab can make the radiotherapy more effective at controlling your cancer and improving your survival.

There are two types of radiotherapy given to patients with head and neck cancers: conventional radiotherapy and intensity-modulated radiation therapy (IMRT). Your oncologist will decide the most suitable type of radiotherapy for you. Both of these types of radiotherapy are carefully planned and shaped to match the part of you that needs treatment. This helps to reduce any side effects you may have.

What happens before I start my treatment?

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 some teeth removed. Teeth are removed before treatment to prevent or reduce the risk of dental problems and infections after your treatment has finished.

The number of teeth to be removed will depend on the condition of your teeth. If they are in a poor condition, some or all teeth may need to be removed. Teeth that are heavily filled or crowned may also need to be removed.

Your oncologist will discuss this with you and arrange this before your radiotherapy planning.

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?

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 ensure your treatment is accurate.

The radiographers will show you an immobilisation shell and explain how yours will be made. There is video that you can watch on the Lynda Jackson Macmillan Centre (LJMC) website. Please see page 24 for details.

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 CT scan (Computerised Tomography) while you are wearing it. You may need an injection of a special dye during this scan. This will be explained to you if it is needed.

While you are having your scan you will be alone in the room for about 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 1-3 hours, so expect to be at the hospital for most of the morning or afternoon on that day. Your radiotherapy will usually start about two to three weeks after your planning appointment. This allows time for your oncologist, and planning physicist to calculate your treatment doses.

Before starting your radiotherapy you will have an appointment at Mount Vernon Cancer Centre with the head and neck specialist nurse. It is **very important** that you attend this appointment so that you can be given the mouthwash to use during your radiotherapy. This session is also a chance to ask about your treatment, your care and any other questions you have.

Many people find it helpful to attend the Head and Neck Cancer Support Group before starting their treatment. This is a chance to meet people who have had similar treatments and can share useful information and advice (see page 23).

Your key worker during treatment is:

Your treatment will last:

What will happen during my treatment?

On your first day, the treatment may take up to 30 minutes. After that your radiotherapy appointment normally lasts for about 10-30 minutes. The radiographers will get you in the correct position; it then takes about 10-20 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.

How are the treatments combined?

Radiotherapy is given each day of the week from Monday to Friday for six or seven weeks.

Your first dose of cetuximab will be given the week before your first radiotherapy. After this first dose, you will receive cetuximab once a week as an outpatient at Mount Vernon Cancer Centre. It is a colourless liquid and is given over one hour as a drip usually in the chemotherapy suite. One hour after your cetuximab you will receive your radiotherapy. Please prepare to be here most of the day on your cetuximab treatment day.

What side-effects could I have from cetuximab?

Each person's reaction to a cancer drug is different and some people will have very few side effects, while others may experience more. Any side effects you have can often be managed with medication.

Allergic reactions

You will be monitored closely during your treatment. It is important to tell your nurse if you have any signs of an allergic reaction to cetuximab. Signs of an allergic reaction usually appear in the first two hours of treatment and can include skin rashes and itching, a feeling of swelling in the tongue or throat, irritation of the nasal passages, wheezing, a cough or breathlessness. You may be given certain drugs (antihistamines) before the infusion starts to help prevent a reaction.

Skin changes

An acne-like rash can appear on the head, chest or back during treatment with cetuximab. (This can occur after the first dose.) This is a common reaction and may be more troublesome in the area of skin being treated with radiotherapy. Less commonly, your skin may become dry, itchy or feel tender and peel.

Tell your oncologist or nurse if you have any changes to your skin as they may be able to prescribe medication to reduce the rash and moisturising creams for any dry and itchy areas. If the skin in any area becomes broken they will provide dressings to help the area heal.

Breathlessness

You may feel short of breath more easily while on cetuximab. If you notice any increase in breathlessness it is important that you tell your nurse or oncologist.

Feeling sick (nausea) or being sick (vomiting)

You can receive medication to help prevent or greatly reduce any feeling of nausea or vomiting. Please let your nurse or oncologist know if you are feeling sick or vomit whilst taking the medication. Everyone is started on the same anti sickness medicine but the same medicine does not work for everyone. Your anti sickness medicine may need to be changed to be more effective.

Diarrhoea

If you are opening your bowels and passing loose or watery stools more than four times per day, tell your nurse or oncologist so that they can prescribe some medication to help. It is important to drink plenty of fluids especially if you have diarrhoea.

Fever and chills

If you feel unwell or develop a fever (temperature above 38 °C) or shaking chills it is important to call a member of your health care team at Mount Vernon Cancer Centre **immediately**. If this is during the night or at the weekend please call the 24 hour Acute Oncology Service (see page 2).

Sore eyes

Tell your oncologist if your eyes become red, itchy or sore. This is known as conjunctivitis and eye drops can be prescribed.

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 12-14.

These side-effects develop gradually over the course of your treatments and for the two weeks following treatment. After this most will gradually reduce over the next 6-12 weeks. But some changes may never go (may be permanent). These will be discussed in more detail by your oncologist or specialist nurse.

During your treatment, you will be reviewed weekly by your oncologist, nurse, dietitian and sometimes SALT. At these appointments you will be given medicines and advice to help you cope with side-effects. Please see page 30 for advice on getting a prescription medical exemption certificate.

The day for your review clinic is:

Please bring a list 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.

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.

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 ulcerated skin on neck, face, upper chest, shoulders and acne type rash on face, chest, upper back. (see page 15)	Redness - around week 2-3 Ulcerated/sore - around week 4 onwards	<ul style="list-style-type: none"> <input type="radio"/> please discuss the use of creams with your health care team <input type="radio"/> electric shave only <input type="radio"/> avoid perfumes, make-up, talcs etc <input type="radio"/> dressings daily when skin is ulcerated <input type="radio"/> you may be given antibiotics 	Most reactions will have healed by about 2 weeks after finishing treatment. Any redness or darkening of the skin will get better over the next 8-12 weeks.
Ulcerated mouth/throat/lips (see page 16)	About week 3	<ul style="list-style-type: none"> <input type="radio"/> use your mouthwash as prescribed <input type="radio"/> regular painkillers 	Slowly settles over 6-10 weeks after finishing treatment.
Painful swallowing (see page 16)	About week 2-3	<ul style="list-style-type: none"> <input type="radio"/> avoid citrus/spicy/salty food <input type="radio"/> soft texture food <input type="radio"/> use regular painkillers <input type="radio"/> review by dietitian <input type="radio"/> review by SALT <input type="radio"/> possible PEG tube support 	After finishing treatment, swallowing improves and tube feeding is not needed. Regular review by 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?
Extreme tiredness (see page 22)	Week 4-5	<ul style="list-style-type: none"> ○ follow nutrition plan from dietitian ○ plan rest periods during the day. Try to do some gentle exercise (short walks) when you feel able to 	8-12 weeks after finishing treatment. Try gentle non-strenuous daily exercise, gradually increasing over the next few months, e.g. walking, swimming. It may take up to 12 months to fully recover.
Hair loss (see page 19)	Week 5 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.	Hair may not grow back in the area that has been treated. Usually re-grows within 3 months.
Dry mouth (see page 16)	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 will have some dryness for up to 2 years after finishing treatment. For others this may stay for good (be permanent).
Lymphoedema (facial and neck swelling) (see page 25)	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 usually gets better between 6-12 months after your treatment has finished. You may need to carry on doing self massage for longer than 12 months.

Symptom	When will it occur?	How to manage it?	When will it get better?
Taste change (see page 17)	For some, around week 2 onwards	<ul style="list-style-type: none"> ○ 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 treatment. However for some patients their taste changes may never go away (they will be permanent).
Excess production of mucus (thick saliva) (see page 18)	About week 3	<ul style="list-style-type: none"> ○ regular mouth care ○ drink plenty of fluids ○ nebulised saline 6-8 times a day 	8-12 weeks after finishing treatment. Some patients may have changes to their saliva for good (permanently), ie. sticky or thicker saliva.
Change in voice (see page 21)	Week 3-4	<ul style="list-style-type: none"> ○ review by SALT ○ avoid straining to speak ○ depends on location of tumour 	8-12 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.

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
- there may be a time in your treatment when your skin becomes ulcerated and sore. If this happens you will need dressings which will be given to you by your head and neck specialist nurse
- your skin will heal about two weeks after you have finished your treatment. The redness will fade over the next few weeks. District nurse support can be arranged for after your treatment, to help you with the dressings
- men wishing to shave should take extra care. Once the skin becomes pink or darker toned you should stop shaving. You will find that your beard stops growing at this stage
- 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 summer, we recommend that you 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

How should I look after my mouth?

- you will be given 'Tellodont' mouthwash which will loosen mucus and refresh your mouth. You can use this as often as you need
 - if your mouth is being treated you may also be given 'Caphosol' mouthwash. This will help to prevent ulcers from developing. It **must** be used four times a day from the first day of radiotherapy. If your mouth starts to ulcerate your oncologist or nurse will advise you to increase up to eight times a day. After rinsing you must not eat or drink for 15 minutes
 - 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
 - if possible do not use denture adhesive
 - use your painkillers as this will make your mouth feel more comfortable. They work better if you take them regularly. The specialist nurse will give you advice and support (see page 21)
 - avoid hot spicy foods, citrus and tomato based foods. Also avoid dry foods (moist foods are easier to manage)
 - do not drink any alcohol. 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 20)

- 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

How will my taste be affected?

Your sense of taste will change. Please see the LJMC factsheet 'Managing taste changes', (see page 25). It may improve after your radiotherapy has finished but this may take several months. For some patients these changes in taste may never return to how they were before starting treatment.

What can I eat or drink?

It is important that you are well nourished and do not lose weight during your treatment. Your treatment mask is fitted closely. Weight loss can cause the mask to become loose and may mean that your treatment needs to be re-planned. This can cause a delay in your treatment.

The dietitian will talk to you about ways to keep your weight the same to help avoid any delays in treatment. If you have a feeding tube, the dietitian will advise you on how much prescription feed and fluids you will need. Following their instructions will help you not to lose weight.

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 LJMC factsheet on 'Chewing and swallowing problems' (see page 25).

It is very important that you continue to swallow during the treatment and the recovery period, even if it is only small sips of tepid water or milk. This keeps your ability to swallow, and helps with the rehabilitation of your speech and swallowing. Please talk to a SALT for further advice, if you are having problems.

In some circumstances you may be advised not to take anything by mouth and be dependent on tube feeding. Your team will discuss this with you.

How will my mouth feel?

This depends on how much of your mouth is receiving radiotherapy.

When you are about half way through your treatment you will begin to produce thick mucus and saliva. There are no medicines available to stop this side-effect happening. Some people may also feel sick (nauseous) due to the thick mucus. Sometimes patients find that rinsing your mouth can help prevent the mucus building up and reduce some of these side effects.

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).

Nebulised saline (salt water) or steam inhalations can help to clear this mucus and make you feel better. Your health care team may lend you a nebuliser machine if one is available. Please return it as soon as you no longer need it. We do not always have a nebuliser machine available. Sometimes we may need to advise you to buy one.

The radiotherapy can affect the salivary glands if they are in the area being treated. If your mouth becomes dry, you may find regular sips of water helpful.

Do not drink alcohol during this time as it will increase the dryness in your mouth, and it will also be painful to swallow. Many patients will always have some dryness in their mouth. However some patients find this gradually gets better for up to two years after they finished their treatment.

Will I lose my hair?

Some of the hair on your face may stop growing. This will depend on the exact area you are having treated. For some people this hair may not grow back (hair loss may be permanent).

Some people may lose hair at the back or side of their head. This hair usually starts to grow back a few months after finishing treatment.

Your oncologist will tell you whether you will lose any hair, and if it is likely to regrow after the treatment has finished. This will depend on the dose of radiation you will receive.

What should I do if I need to visit the dentist?

After your radiotherapy, you may 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 three times a day after meals with a fluoride toothpaste. A fluoride gum tray may be used. You can get this from your dentist/hygienist.

You are strongly advised to see your dentist and oral hygienist every three to six months. In the future if you need any dental work to the treated jaw area, the bone may not heal properly and this may cause other problems. For this reason it is important that you ask your oncologist before having any dental treatment to this area.

After your treatment has finished your oncologist will be pleased to answer any queries from your dentist. Please give your dentist your oncologist's secretary's phone number (see page 2).

Can I have dentures or implants?

You may not be able to wear dentures for a few months after treatment. This will depend on how much of your mouth is treated. Usually new dentures should not be made until six months after your treatment. This is to allow time for your gums to heal and for any changes in your mouth to settle.

Dental implants are not suitable for all patients. You will need an assessment by a head and neck (maxillofacial) surgeon to find out if implants are suitable for you.

What will happen if I smoke?

Your oncologist or specialist nurse will discuss this with you. We recommend that you stop smoking completely. This is because smoking increases the ulceration and pain.

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.

Make every effort not to re-start smoking 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. **If you smoke your cancer is more likely to return.**

Nicotine replacement treatments are 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 page 29).

Will I lose my voice?

If you are having radiotherapy to your throat, it is likely that your voice will get hoarse. You may also lose your voice completely at some stage. Because of this it is best to:

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

After your treatment has finished, it may be a few weeks before your voice starts to recover. It may remain husky for some time. The SALT will offer advice and support.

What if I have a laryngectomy?

If you have had a laryngectomy and are using a speaking valve, you will not be able to wear your base plate during treatment. This is because it will irritate the skin around your stoma. We advise you to wear a stoma button and a special bib.

You will need to nebulise regularly (six to eight times per day) to keep your secretions loose and easy to clear.

It is important you always wear the special bib provided to help keep your secretion moist and airway clear. You may also find it easier to use suction to clear your secretions. Your head and neck specialist nurses will show you how to do this.

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.

- **attend the weekly Monday review clinic** during your treatment. You will be seen by the oncologist, specialist nurse, dietitian and SALT. This may mean you are in the clinic for a few hours
- follow your nutrition plan from the dietitian. If you need more advice please ask
- it is very important that you follow the advice for looking after your mouth. Regular mouth care will help with your comfort and the prevention of infection
- if you have any concerns or questions talk to your health care team

How will I feel once my treatment has finished?

Within 8-12 weeks of finishing your radiotherapy, most of your side-effects will have settled. Some will carry on to improve over many months, but some changes may stay.

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.

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 25).

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.

Further support/information available:

- the **Head and Neck Cancer Support Group** meets on the second Tuesday of each month at 4pm at the Post Graduate Centre at Mount Vernon Hospital. You do not need to book, just turn up. It offers a chance for patients and carers to share their experiences, discuss concerns and get practical advice. A head and neck specialist nurse is always at this group
- go to www.ljmc.org and follow the links to information for patients with cancer to the head, neck, mouth or throat
- website: Moving on from Head and Neck Cancer Facebook page: Moving on from Head and Neck Cancer. These have been developed by our patient support group to help inform and support you

- **‘Moving on from Head and Neck Cancer’** is a two day self-help workshop for patients and carers. We recommend that all our patients attend. Carers are also welcome. You will be given important information about living well after head and neck cancer treatment, and how to cope with any side-effects. Please call the head and neck nurses on 020 3826 2089 for more information about this workshop

- **Head and Neck Cancer ‘What can I tell You’ videos.** This is 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 and after treatment. Go to www.ljmc.org and follow the links to information for patients with cancer to the head, neck, mouth or throat

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

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

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

- Alcohol issues
- Chewing and swallowing problems
- Living with tiredness (fatigue)
- Loss of appetite
- Managing taste changes

LJMC also has a range of leaflets from other organisations, and 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

Will I need to have 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, specialist nurse or SALT will refer you to the physiotherapist.

What is lymphoedema?

When your 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 the surgery and/or radiotherapy. It is called lymphoedema. It may happen 6-12 weeks after finishing radiotherapy.

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 for about six to eight 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, surgeon, SALT, dietician and nurse.

To start with you will be seen four to six weekly. As time passes these appointments will be less frequent i.e. every two to six 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 page 2).

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 restaurant and is open Monday - Friday, 8.30 - 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 7.00 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 six 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 (see page opposite).

Useful national information

Let's Face it - an organisation for people with facial disfigurement. It offers telephone support, a link to people in similar situations, dietary and medical advice, social activities, resources and a newsletter. It also provides information on camouflage make-up.

Contact 01843 833 724 www.lets-face-it.org.uk

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 0800 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

Other help and support

The Lynda Jackson Macmillan Centre (LJMC) offers information and support to patients and their families and is located next to Chemotherapy Suite by Gate 3. The staff at the LJMC work as part of the overall team caring for you.

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. Please feel free to drop in before, during and after any of your visits to Mount Vernon Cancer Centre to find out more about the LJMC services that you may find helpful.

The volunteers and healthcare professionals at the LJMC provide help, support and information in a relaxed setting to help patients cope with cancer and its treatment.

LJMC services include a range of complementary therapies, 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.

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.

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

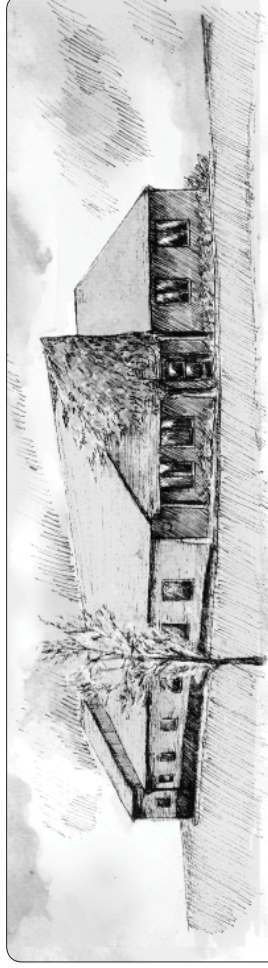
Female patients must not be pregnant or become pregnant and male patients must not father a child during a course of radiotherapy or for some months afterwards. **Please discuss this with your cancer specialist.**

If you think there is a chance, however small, of you or your partner 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 radiotherapy. This applies to all women between the ages of 12 - 55 years. This is a legal requirement.

This publication has been produced by the Information team at the Lynda Jackson Macmillan Centre. Contributors include 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. If you would like any details of the references used to write this information please contact the LJMC on 020 3826 2555.

Lynda Jackson
Macmillan Centre



Lynda Jackson Macmillan Centre

... supporting people affected by cancer...

- ① Drop-in centre for support and information
- ① Telephone helpline
- ① Complementary therapies*
- ① Counselling*
- ① Benefits advice*
- ① Relaxation classes
- ① Look Good...Feel Better™ beauty workshops
- ① The Way Ahead headwear workshops
- ① Self-help courses

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

Please drop in or call to find out how we may be able to help you

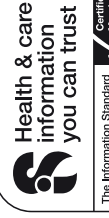
Opening hours: **Monday–Friday: 9.30am–4.30pm**

Mount Vernon Cancer Centre, Northwood, Middlesex HA6 2RN

Telephone Helpline: **020 3826 2555**

Website: **www.ljmc.org**

* Service only available to NHS patients under the care of an oncologist based at Mount Vernon Cancer Centre



© LJMC 2018

P113b [green] published 07/18
review date 07/20