

A Patient's Guide to the Head and Neck Aftercare Service at the Mount Vernon Cancer Centre

Your personalised care plan

Hospital label or:  
Name:  
Hospital number:  
Date of birth:

Diagnosis:  
.....

Treatment received:                  Treatment completion date:  
.....  
.....  
.....  
.....

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.

## A Patient's Guide to the Head and Neck Aftercare Service at the Mount Vernon Cancer Centre

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### Introduction

This leaflet is your personalised care plan with information for when you have completed your treatment for head and neck cancer.

It aims to answer some of your questions about the team who will be seeing you, where they will see you and how often you will be seen by the head and neck team. It also has details of the contact numbers you should use if you have any concerns between hospital visits.

*We hope the aftercare service will help you to adapt to the changes caused by your cancer and its treatments so you can achieve the best quality of life after treatment.*

### Who will see me at my After Treatment Review Clinic?

On some occasions it will be appropriate for you to be reviewed by your consultant and at other times you may be seen by the clinical nurse specialist and/or other health professionals.

Many members of the head and neck team can be part of your after treatment reviews, depending on your needs. This includes surgeons and oncologists, specialist nurses, dietitians and speech and language therapists. In addition, you can be seen by a lymphoedema therapist or physiotherapist if needed.

## Why do I need to attend the After Treatment Review Clinic?

The review clinic can help to improve the quality of your life. When you attend:

- ◇ You can go over any ongoing side effects from your treatment and receive advice on how these might be best managed.
- ◇ We will monitor any signs of recurrence of your cancer. You may need some tests from time to time; these will be discussed with you if they are necessary.
- ◇ We will provide an opportunity for you to discuss how you are feeling after your treatment and give advice and support if you are finding adjusting to life after cancer difficult.
- ◇ You can receive support to stop smoking if needed.
- ◇ We can give support to help you control your alcohol intake if needed and discuss any possible further referral.

## Can I bring my family to the After Treatment Review Clinic?

We encourage active involvement of family and welcome their attendance at the clinic. Addressing their concerns and need for information is an important part of the clinic's aim.

## After Treatment Review appointments

How often you are seen depends on your type of cancer and your individual needs. If you are having troublesome side effects from your treatment you may be reviewed every month. However, if things are going well, you may have a review every 3-6 months. Reviews will become less frequent as time passes over the next two to five years. Should you feel you need a more urgent appointment, we would be happy to give you an earlier appointment (usually within 1-2 weeks). You can also have telephone advice and support between visits by telephoning your keyworker – a head and neck cancer specialist nurse.

Keyworker: .....

Telephone: .....

The clinics take place in **Mount Vernon Treatment Centre** from 10am on Wednesday mornings:

Dr. Lemon, Mr. Gilhooly, Mr. Visavadia	Clinic 3
Dr. Goodchild, Mr. Farrell, Mr Tatla	Clinic 4

## Will my GP be informed about my appointments?

After you attend clinic your GP will be sent a letter to update them on how you are. This letter is usually sent out within a week of you attending clinic. You can also receive copies of your clinic letters - please mention this if no one asks you.

## **Restricted mouth opening (Trismus)**

During and after radiotherapy treatment, you may experience some discomfort and tightness when opening your mouth to yawn or eat. This may happen because the muscles around the jaw have become stiffer and less elastic.

It is helpful to keep stretching the mouth open for short periods regularly for at least three to six months after treatment. Continue to use the muscles responsible for chewing, talking and yawning as frequently as you are able. This is not only important for eating but also for dental hygiene and dental treatment.

If you feel that your mouth opening is becoming restricted, please contact your Speech and Language Therapist who will be able to measure your mouth-opening and advise on an appropriate treatment plan to maximise your jaw function.

## **When should I see my dentist?**

Regular dental care is an important part of your aftercare. You should make an appointment to see your dentist about six months after you have completed your treatment.

If you need dentures, we recommend that they are not made until six months after you have completed treatment. This is because the lining of your mouth needs time to completely recover from treatment and the shape your of gums may still be changing. If your dentist advises any extractions in the future, it is important this is discussed with your oncology team.

If you are experiencing a dry mouth due to your treatment, we would advise you to start using fluoride supplement products. These can be obtained from your dentist.

Dental implants are suitable for some patients. Please ask your Maxillofacial surgical team.

## **Lymphoedema**

At about eight to 12 weeks after radiotherapy you may notice a soft swelling around your neck, chin or face. This swelling can fluctuate in size and can appear bigger in the mornings. This is a side effect of having surgery and/or radiotherapy to your neck. If you find this side effect troublesome, we can refer you to the lymphoedema service where they will use special massage techniques to help drain this fluid away from the face and neck area.

You will be taught self massage techniques that you can use at home. For most people, this swelling will decrease slowly over the 12 months following treatment.

## **Taste and dry mouth**

Head and neck cancer treatment can cause your mouth to become dry. This can affect the pleasure you get when eating.

Your GP or cancer doctor can give you saliva replacement products to help your mouth feel moist. There are a range of different products available from gels to toothpaste to sprays. A simple water spray or sips of water can also be effective. Please let your doctor or nurse know if a dry mouth is causing you concern.

If the soreness in your mouth has settled, the helpful hints on dry mouth and taste changes on page 10 may be useful.

For some people these changes may be permanent and no recovery in saliva production is expected. For others it may be that at about two years after treatment you notice your mouth becomes more moist and your taste improves.

Please discuss any concerns with your head and neck team at your aftercare review.

## **Helpful hints on taste and dry mouth**

When mouth soreness has settled:

- ◇ Try rinsing your mouth with fizzy water before meals.
- ◇ Gently clean your mouth and teeth after meals, as good mouth care is essential.
- ◇ Avoid mouthwashes containing alcohol or strong flavours which may alter the taste of foods.
- ◇ Tell your doctor if you notice white patches in your mouth, or if you have a consistent 'bad taste' in your mouth which may indicate an infection.
- ◇ If food tastes bitter, it may be helpful to avoid red meat, sour juices, coffee, tea, tomatoes and chocolate.
- ◇ If food tastes too sweet, try cooking with lemon juice, herbs, vinegar or mint, although they may not be advisable if you have a sore mouth, or are receiving radiotherapy to the mouth and throat.
- ◇ Use marinades, soy sauce or ready made sauces to enhance flavour.
- ◇ Sweet flavoured drinks, carbonated drinks and ice-lollies can all help you cope with a change in taste.
- ◇ Add lots of seasoning, sugar or other flavourings to meals.
- ◇ Try leaving food to cool for five minutes, as very hot food may not taste as good if you have very little taste.
- ◇ Try different flavours, or foods you may not have previously enjoyed.
- ◇ Try eating small pieces of fresh pineapple - very refreshing.
- ◇ Concentrate on foods which taste good to you.

Remember: Your doctor can prescribe artificial saliva gel or spray.

## Physiotherapy

You may have been given exercises by a physiotherapist to improve movement in your shoulder and neck and to decrease the tightness of your scars. If you have any difficulties with this movement or concerns about your scars, please discuss this with your team at your review clinic. They will refer you to the physiotherapist if needed.

## Exercising after cancer treatment

“It’s often difficult enough for people without health problems to increase their physical activity. Following a cancer experience it’s likely to be a lot harder. You may feel you don’t have the energy or willpower to do exercise, that you don’t know where to start or that it’s too late. But it’s never too late to start.

“Inactivity causes our muscles to lose strength and work less well. It can also increase feelings of extreme tiredness (fatigue), stress and anxiety. Even a little regular exercise can build up your energy levels (stamina) and help you feel better. Exercise also helps people cope with treatment side effects and cancer symptoms.”

(Taken from Macmillan Cancer Support’s booklet ‘Exercise after Cancer Treatment’ and used with permission.)

For more information drop in to the Lynda Jackson Macmillan Centre for a copy of this booklet, or visit [www.macmillan.org.uk](http://www.macmillan.org.uk).

## What other services are available?

One of the most difficult things to cope with after treatment is the feeling that cancer and its treatment have taken control over your life. There are many small things that can help to make each day easier, but there may be times when you are too tired to think about them.

Recovery from head and neck cancer can be a slow process. Getting a better understanding of head and neck cancer, its treatment and ways to manage side effects can lead to an improvement to life after treatment.

Over time, side effects will lessen and become easier to manage. However, if you are feeling overwhelmed by thoughts or fears for the future it is important to let your doctor or nurse know. It may be that you are experiencing depression which is very treatable.

The following services are available to you and or your family/carer any time following your treatment:

### Counselling

This is available through the Lynda Jackson Macmillan Centre (LJMC). Your doctor or nurse can refer to this service but you can also refer yourself at the LJMC.

Counselling may help you understand your experience and feel more in control and able to cope. Sessions are by appointment only.

## Head and neck support group

do you have **head & neck cancer?** do you need help.



why not come along to the **head & neck cancer support group**



**Opportunity** to share your experience with other people affected by head & neck cancer.

**Explore** and discuss issues and concerns relating to coping, adjustment & relationships, with health professionals informally.

**Receive** practical advice on issues such as swallowing, communication, nutrition, finances etc. & get answers to questions about treatments & side-effects.

This support group, run by your Head & Neck Team at Mount Vernon Cancer Centre, is for anyone affected by head and neck cancer (including carers) - for further details please contact either: Sandra (Macmillan Head & Neck Specialist Nurse) on 01923 844078 or the Lynda Jackson Macmillan Centre (LJMC) on 01923 844014

Group meets  
2nd Tuesday  
of every month  
4pm  
at the LJMC

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## “Moving on from head and neck cancer” course

moving on from **head & neck cancer**



Join us on this free 5 week self-help programme



➔	Routine follow-up & investigations - to explain what you may expect during your follow-up visits / Future treatment strategies & developments in head & neck cancer / A discussion & presentation with a Consultant Oncologist
➔	Food for the future - importance of a healthy diet & advice on how to overcome side-effects
➔	Swallowing and communicating - information on tackling treatment side-effects
➔	Relationships - a discussion on adjusting to changes in relationships within & outside the home. A patient and carer's reflection on a long-term experience of head and neck cancer
➔	Survivorship - facing the future with confidence

The next course starts:

This self-help programme, run by your Head & Neck Team at Mount Vernon Cancer Centre, is for anyone affected by head & neck cancer (including carers). For further details please contact either: Sandra (Macmillan Head & Neck Specialist Nurse) on 01923 844078 or the Lynda Jackson Macmillan Centre (LJMC) on 01923 844014

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Patients' comments about the "Moving on from head and neck cancer" course.

"As a whole I found the course very interesting and extremely helpful. I'm so glad I made the effort. It made me realise that everyone is different and there is a light at the end of the tunnel."

"This five week course has been very interesting to me, as it has shown me that we are not in this alone, and that there is plenty to discuss for the present and also about the future."

### What concerns or symptoms should I contact the hospital about?

Some symptoms and changes are expected after treatment. The tables on the following pages are a guide to help you in managing expected symptoms. It will also help you to identify unusual symptoms that you will need to contact your head and neck team about. (Please see the tables on pages 16 and 17.)

This is not an exhaustive list. Please contact your head and neck specialist nurse about any other concerns.

Symptom	Who should I contact?	When contact them?
Change in voice	Head and Neck Specialist Nurse, Speech and Language therapists	Within usual working hours 9-5pm Mon-Fri
Unexplained rapid weight loss	Head and neck specialist nurse, Dietitian	Within usual working hours 9-5pm Mon-Fri
PEG/ RIG tube becomes blocked	District Nurse	Within usual working hours Mon-Fri. However, if this happens over the weekend please attend your local accident and emergency department.
PEG/ RIG feeding tube falls out	District Nurse (If the district nurse is unable to attend in 30-60 minutes following the tube falling out than you must attend your local A+E)	Within usual working hours Mon-Fri. However, if this happens over the weekend or during the night please attend your local accident and emergency department.
Swelling under chin and around neck and face.	Head and neck specialist nurse	Within usual working hours 9-5pm Mon-Fri

Symptom	Who should I contact?	When contact them?
Difficulty with swallowing, or coughing on swallowing liquids or foods	Head and neck specialist nurse, Speech and Language therapists	Within usual working hours 9-5pm Mon-Fri, or if this occurs at the weekend please attend your local accident and emergency department.
Change in breathing. Feeling short of breath or breathing becomes noisy.	Head and neck specialist nurse (If unable to contact attend your local A+E.)	Within usual working hours 9-5pm Mon-Fri.  However, if this happens over the weekend or during the night please attend your local accident and emergency department.
Lump in neck that feels hard.	Head and neck specialist nurse	Within usual working hours 9-5pm Mon-Fri
Persistent pain in neck or ear or mouth.	Head and neck specialist nurse	Within usual working hours 9-5pm Mon-Fri
Shoulder stiffness	Head and neck specialist nurse, Physiotherapist	Within usual working hours 9-5pm Mon-Fri
Feeling low in mood	Head and neck specialist nurse. Lynda Jackson Macmillan Centre	Within usual working hours 9-5pm Mon-Fri See back page.

Fill out this chart each day then bring this booklet with you each time you see the doctor and nurses at your review clinic. It will help you to remember accurately how you felt and enable the team treating you to try to ease your side-effects.

This is an example of how to fill in your personal chart. Please list the side effects that concern you.

(1) Not at all (2) A little (3) Quite a bit (4) Very much

(EORTC QLQ-C30)

Side-effects as they happen to you	21 Nov	22 Nov	23 Nov	24 Nov	25 Nov	26 Nov	27 Nov	28 Nov	29 Nov	30 Nov	1 Dec	2 Dec	3 Dec	4 Dec
Best days							✓	✓				✓	✓	✓
Worst days				✓	✓	✓								
Depression				3	3	3								
Face swelling					2	2	1							
Fatigue		4	3	3	3	2	2	2	2	2	2	1	1	
Dry mouth				3	3	3	2	2	2	2	2			
Shoulder stiffness												3	3	

Fill in the dates

	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	
Side-effects as they happen to you																						
Best days																						
Worst days																						

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

Fill in the dates

	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	
Side-effects as they happen to you																						
Best days																						
Worst days																						

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

Fill in the dates

	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	
Side-effects as they happen to you																						
Best days																						
Worst days																						

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Fill in the dates

	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	
Side-effects as they happen to you																						
Best days																						
Worst days																						

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Fill in the dates

	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	
Side-effects as they happen to you																						
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Worst days																						

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	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	
Side-effects as they happen to you																						
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Side-effects as they happen to you																						
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Fill in the dates

	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	
Side-effects as they happen to you																						
Best days																						
Worst days																						

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

## Helpful Contact Numbers

Head and Neck Specialist Nurse: ..... 01923 844078  
Dr Lemon's secretary Clinic 3: ..... 01923 844293  
Dr Goodchild's secretary Clinic 4: ..... 01923 844254  
Speech and language department: ..... 01923 844457  
Physiotherapy Department: ..... 01923 844430  
Dietetic department: ..... 01923 844366  
Lymphoedema clinic: ..... 01923 844369  
Lynda Jackson Macmillan Centre: ..... 01923 844014  
(including Benefits Adviser)  
Northwick Park Hospital (see below): ..... 0208 864 3232

If your consultant is Dr Gilhooly, Dr Visavadia or  
Dr Amin then please ask switchboard for the:  
**On Call Maxillofacial SHO**

If your consultant is Dr Farrell or Dr Tatla then  
please ask switchboard for the:  
**On Call ENT SHO**

# 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](http://www.ljmc.org)