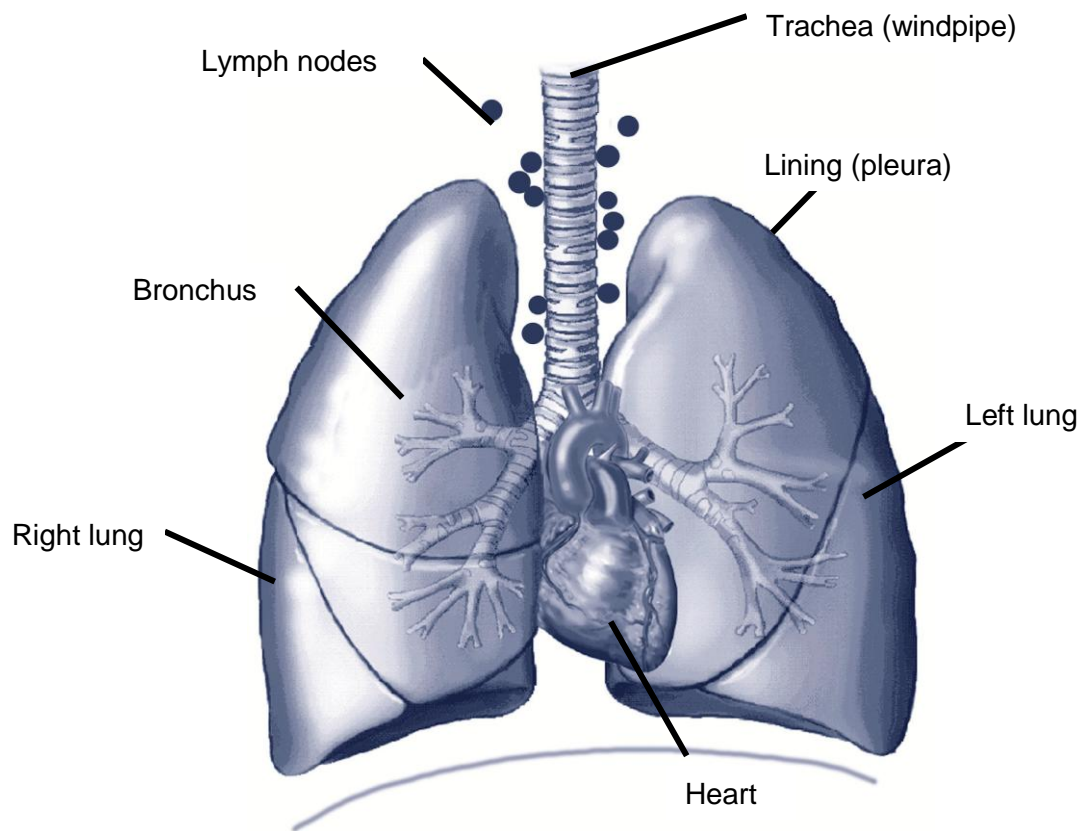


Follow-up after treatment for lung cancer

Information for patients, relatives and carers



Introduction

This booklet gives information about your follow-up care for lung cancer or mesothelioma. It aims to answer some of the questions you may have about your appointment at the hospital, who will see you and who to contact about your condition if you have any concerns between hospital appointments. We hope it will answer some of the questions that you or those who care for you may have at this time.

This booklet is not meant to replace the consultation between you and your medical team, but aims to help you understand more about what is discussed.

After treatment – follow-up

After your treatment has finished, your condition will continue to be monitored either at the hospital or in the community. Regular check-ups at the hospital will be offered, but if you prefer we can arrange for your follow-up to be with your local GP or community nurse(s).

Your questions answered

Who will see me at the check-up appointments?

At the hospital check-ups you will be seen by a specialist doctor, who is a member of the lung cancer team or the clinical nurse specialist (CNS)/key worker, and sometimes both.

Your check-up appointments are meant to help you cope with your symptoms and pain resulting from cancer and its treatment, and help you with your social, spiritual and emotional needs to live as comfortably and fully as possible.

What happens at your appointment?

Your doctor and nurse will talk with you about how you are getting on. This is a good time to discuss any problems or new symptoms you may have. Having lung cancer or mesothelioma can impact on many aspects of a person's life, causing physical symptoms such as breathlessness, cough or pain. It can result in practical problems to do with financial issues, transport or family concerns. It can bring with it changes in your emotions as you learn to live with your condition.

Can I bring my family or carer to my appointments?

Yes. You are welcome to bring a friend or a member of your family. We can answer their questions and discuss their concerns as well as yours.

What help can we offer?

Your doctor and nurse are interested in all of your concerns and wish to help you to cope.

They may:

- Offer specific advice about troublesome symptoms such as pain or shortness of breath if they occur
- Provide information about your condition and treatments such as chemotherapy, radiotherapy or biological radiotherapies
- Discuss potential clinical trials if you wish to be involved
- Assist with family worries including advice on practical help at home, transportation or financial matters

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- Offer emotional and psychological support in helping you and your family adjust to the changes in lifestyle your illness may cause
 - Refer you to support services such as community nurses to visit you at home, social workers or a counsellor

Your check-ups may involve having tests from time to time such as chest x-rays if needed, but CT scanning is not part of routine follow-up for lung cancer or mesothelioma.

How often will I have check-ups?

How often you have appointments depends upon your needs. If you have troublesome symptoms, you may need to be assessed frequently. However, if all is going well for you, appointments may be less frequent, such as every three to six months and even yearly. Our approach is flexible and we aim to offer support which meets your needs. You will be offered regular appointments; but if you feel you need an appointment sooner, we will bring your appointment forward.

This means you can telephone and make an appointment at short notice (usually within a week or two). You can also get advice and support between appointments by telephoning your lung CNS/key worker or Macmillan/community nurse and GP.

Will I have any more treatments for my cancer?

The lung cancer team (oncologist, surgeon, chest physician etc) work closely together and you will be offered further treatment if appropriate.

Will my GP and community nurse know about the appointments?

After you attend, your GP will be kept up to date on how your hospital follow-up is going. Your GP will normally be sent a letter within a week of your attendance at the clinic and can always contact your consultant if necessary. We also liaise with any communities or professionals involved with your care (district nurses etc).

What if I am worried?

Your lung CNS/key worker is here to support you. It may also help to see a psychologist or a counsellor, both professional trained in emotional wellbeing. Asking for help does not mean that you are not coping. If you would like to talk to a professional psychologist or counsellor, let your doctor or lung CNS/key worker know and they will arrange for you to see one.

What if I am too ill to come to the appointment?

For some people there comes a time when attending clinic appointments becomes too difficult. Under these circumstances, it is possible to refer your care to the community teams. If attending your appointment becomes a struggle, please talk to your lung CNS/key worker.

Who do I call if I have problems in between appointments?

Learning to live with lung cancer or mesothelioma may be difficult and patients tell us they often worry about symptoms. Knowing who to call, and when, can be difficult, especially as various healthcare professionals will give you their telephone numbers.

On pages 5 and 6 of this booklet is a list of problems patients with lung cancer or mesothelioma can develop and who to call. While this is a good guide, it is not absolute and if you are concerned or confused about who to call, please call your clinical nurse specialist/key worker.

My personal treatment record summary

Your diagnosis is:	
The treatment you have had:	Aim of your treatment:
Ongoing services or treatment you will be receiving:	

Management and support plan

Following your first assessment, you have identified the following concerns, care needs or goals that you would like to see addressed, improved or achieved:

1
2
3
4

As an outcome of the discussion it was agreed:

1

2

3

4

Suggestions on services available for you and health advice:

Follow-up arrangement/monitoring/date of next review:

Assessment completed by:

Name	
Title	
Signature of professional	
Contact details	

Your concerns and who to talk to

Common medical problems	
Normal cold or flu-like illness	Contact your GP
A cough with green or brown phlegm	
Something to do with another existing medical condition, for example high blood pressure or diabetes	

Gradually worsening symptoms	
These are common problems related to lung cancer and mesothelioma and may change over days to weeks	
An existing dry cough that is getting worse	<p>Contact your lung CNS/key worker or GP</p> <p>Monday-Friday 9:00-17:00</p>
Increasing breathlessness that is not related to a recent cold or flu	
Streaks of blood in the sputum	
Feeling more tired than usual	
Weight loss, loss of appetite	
Side effects from treatment or medicines you are taking for your lung cancer treatment)	
Pain in the back or chest area, or any pain that persists	
Hoarse voice not associated with cough/flu/sore throat	

Rare symptoms that need assessment urgently	
Tingling/numbness in fingers or toes	Please ring this number 020 3311 7866 (24/7)
Severe or worsening back pain	
Weakness in your legs or arms	
Coughing up blood	If these occur during office hours, contact your lung CNS/key worker
Troublesome swallowing, especially liquids	
A sudden swelling of an arm or a leg	Out of these hours or if you cannot get hold of your lung CNS please contact your GP or visit the A&E Department at Charing Cross or St Mary's Hospital
Drowsiness or feeling more sleepy than usual	
Bad headaches that do not improve in a day or two	
Vomiting not related to a recent stomach bug	
Facial swelling/bulging neck veins	
Breathing unusually loud and high pitched	

Practical worries or concerns	
Emotional worries	<p>A number of professionals can help you with these worries or concerns. Please speak to your lung CNS/key worker or GP who can put you in touch with a:</p> <ul style="list-style-type: none"> - Community nurse - Social worker - Physiotherapist - Dietitian - Local counsellor/psychologist
Worries about taking your medicines	
Worries about managing at home	
Financial and family worries	
Advice about diet and exercise	
Problems getting to the hospital for appointments	

Helpful local contacts when dealing with lung cancer or mesothelioma

Contact	What they do	
GP	This is your family doctor	Name: Tel:
Oncologist	This is the doctor who sees you in the follow-up clinic and monitors your lung cancer or mesothelioma	Name: Tel:
Lung CNS/key worker	Specialises in lung cancer care and is your point of contact during your illness	Name: Tel:
Respiratory physician	This is a doctor specialised in the diseases of the chest and the breathing system	Name: Tel:
Community nurse	Visits you at home to provide nursing care and practical advice	Name: Tel:
Macmillan nurse	Usually visits you at home and provides advice on managing symptoms and coping with cancer	Name: Tel:
British Lung Foundation	This charity provides information, newsletters and support groups to anyone affected by a lung condition (not just cancer)	Tel: 030 0003 0555 www.blf.org.uk/
Mesothelioma UK	This national resource is dedicated to providing specialist mesothelioma information and support to anyone affected by the disease.	Tel: 080 0169 2409 www.mesothelioma.uk.com/
Macmillan Cancer Support	There is a free line for people affected by cancer who have questions about cancer, need support or just someone to talk to (interpretation service available).	Tel: 080 8808 0000 www.macmillan.org.uk/
The Roy Castle Lung Foundation	This UK charity funds lung cancer research, provides information and support and helps people to quit smoking.	Tel: 080 0358 7200 www.roycastle.org/

Local sources of information

Macmillan Cancer Information and Support Service at Charing Cross Hospital

The information centre provides vital emotional and practical support to anyone affected by cancer, every step of the way. Our highly skilled and dedicated Macmillan information specialist is here to answer your questions about cancer. He/she can also direct you to other ways of getting the support you need. The service is set in a warm, friendly and confidential environment and is located on the ground floor of the Charing Cross Hospital. The centre is open (except bank holidays):

- Monday and Friday 09:00-17:00
 - Tuesday, Wednesday, Thursday 09:00-16:00
- Telephone: 020 3313 0171

We are all individuals and cope in different ways and need different lengths of time to adjust to a cancer diagnosis. Your medical team is here to support you. You may want to discuss your worries or concerns with your lung CNS/key worker who can provide help and advice.

Maggie's Cancer Caring Centre

Maggie's is a cancer charity that provides emotional, practical and social support that people with cancer may need. The centre combines striking buildings, calming spaces, professional experts offering professional support, and the ability to talk and share experiences with a community of people who have been through similar experiences. Maggie's West London is located in the grounds of Charing Cross Hospital but please note it is independent of our hospital. The centre is open Monday – Friday, 09:00-17:00. For more information please call 020 7386 1750.

There are many other sources of support and help available. Please speak with your lung CNS/key worker if you need further information about any aspect of living with your condition.

Your notes

How do I make a comment about my treatment?

We aim to provide the best possible service and staff will be happy to answer any questions you may have. If you were pleased with your care and want to write to let us know we would appreciate your time in doing so. However, if your experience of our services does not meet your expectations and you would like to speak to someone other than staff caring for you, please contact the patient advice and liaison service (PALS) on 020 3313 3322 for Charing Cross, Hammersmith, and Queen Charlotte's and Chelsea Hospitals or 020 3312 7777 for St Mary's and Western Eye Hospitals. You can also email PALS at pals@imperial.nhs.uk. The PALS team will listen to your concerns, suggestions or queries and are often able to solve problems on behalf of patients.

Alternatively, you may wish to express your concerns in writing to:

The chief executive
Imperial College Healthcare NHS Trust
Trust Headquarters
The Bays, South Wharf Road
London W2 1NY

Alternative formats

This leaflet can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on 020 3312 5592.

Oncology
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