



Life after lung surgery

This leaflet tells you about monitoring follow up after you have had lung surgery for different types of tumours:

- Lung cancer
- Carcinoid tumour (Neuroendocrine tumour/ NET).
- Thymoma or thymic cancer

After lung cancer surgery

It is common to find that after surgery you are not in the same place physically or emotionally as you were before. The thoracic surgery team, part of University Hospitals Birmingham NHS Foundation Trust, is based at the Queen Elizabeth hospital. We will support you in several ways after surgery:

Helping with parts of the Macmillan recovery package.

The recovery package has four main parts:

- Holistic Needs Assessment and Care Planning
- Treatment Summary
- Cancer Care Review
- Health and Wellbeing Events

These are conversations and plans aimed at improving your quality of life following treatment for lung cancer. Some parts of the recovery package are delivered by your GP (cancer care review) or Lung Cancer Nurse Specialists (health and wellbeing events).

After lung cancer surgery, support and monitoring is led by the Macmillan Thoracic Advanced Practitioners (AP). We can talk to you, over the phone or point you to other relevant support services. We can help with:

- Coping with after effects and symptoms of surgical treatment such as pain, shortness of breath and poor appetite
- General health and wellbeing: we can support you returning to your usual activities by referring you to rehabilitation such as an exercise programme. This aims to help you cope with being short of breath and improves your fitness levels. We can also help you with your efforts to quit smoking and remain smoke free and advise you on specialist support to improve your appetite and help with weight issues you may have
- Dealing with concerns: completing a Macmillan holistic needs assessment helps us to help you. We can also advise on support groups specifically for people diagnosed with lung cancer
- Monitoring you for lung cancer coming back

Monitoring

You may worry about the cancer coming back (recurrence). The chance of this varies with lung cancer stage but if it does happen you may still be able to receive further anti-cancer treatment. It is a good idea to talk about these concerns with us. We can tell you what to look out for and help you find ways of coping with your worries. We will go over the plan of how we monitor you over the coming years.

We usually monitor you by doing a CT (Computerised Tomography) scan of your chest, carried out every six months in the first two years after surgery and then annually up to five years. These scans are looking to see if the cancer has returned or if a new cancer has developed in the lungs.

After the scan it takes a few weeks for the radiologists (doctors who look at X-rays) to look at it in detail and write a report. Once this is done we will call you to give you the result, so it is important to ensure we have the correct telephone details for you. This result will be confirmed by a letter to you, which will be copied and given to your GP as well.

If the scan picks up something that has changed we may have to perform other tests. In many cases the changes on the scan may not be due to cancer so further tests are required to check if the cancer has returned. This will be discussed with the consultant doctors who are looking after you and we may ask you to attend an outpatient appointment at the hospital to discuss this with you in more detail.

Most CT scans are done without contrast dye. However, if your scan needs contrast dye you may need to have a blood test (urea and electrolytes) to check your kidney health at least one month before your CT scan. This is to check that your kidneys can safely remove the contrast dye used during the scan. A blood form will be posted to you with your result letter, in preparation for the next scan.

Please contact us on 0121 371 2000 and ask for Thoracic surgery secretaries, if you do not receive or have lost your blood form and we will send another out. Please also contact us if you have not received a CT scan results after 6 weeks.

What to look out for

Some people experience symptoms that may mean the lung cancer has returned. Most of the time these symptoms are not related to cancer, but if you are worried please ask us for advice. These include:

- A new cough that doesn't go away after 2 to 3 weeks or despite treatment
- Coughing up blood
- A long-standing cough that gets worse
- Unexplained weight loss
- New constant chest pain
- Chest infections that keep coming back
- Worsening tiredness or lack of energy

For more detailed information about symptoms please visit

www.nhs.uk/conditions/lung-cancer

You, your family or your GP can also contact us if you need support.

Your cancer monitoring plan. (Please fill in your operation and the timetable below. It is your plan and reminder of when your follow up scans are due. Please ask if you need help to complete it).

If your appointments are running late, please get in touch with the thoracic surgery team.

Your operation (side and type) _____

Your operation date _____

CT scan due dates following your operation	Blood test*	CT scan	Result received
6 months			
12 months			
18 months			
2 years			
3 years			
4 years			
5 years			

*Blood test for kidney health done at least 1 month before CT (only if contrast dye is being used)

Notes:

Monitoring Carcinoids (Neuroendocrine tumours NET)

You may worry about the carcinoid coming back (recurrence). The chance of this varies with carcinoid type and stage (if the carcinoid had spread). Lung carcinoid tumours tend to grow slowly, and they may not cause any symptoms for many years. If the carcinoid does come back, you may be able to have further treatment.

We usually monitor you by asking for a CT (Computerised Tomography) scan of your chest without contrast dye, as follows:

Typical carcinoids: the first chest CT at 6 months, then annual chest CT for 10 years.

Atypical carcinoids or those patients with lymph nodes positive for carcinoid tumour: 6 monthly chest CTs for 2 years then annually for 10 years.

Patients with a history of carcinoid tumours in the abdomen (Gastrointestinal Tumours GIST, liver, or pancreas) who also had a lung carcinoid will need a chest and abdomen CT with contrast dye.

Your Monitoring Plan

CT scan due dates following your operation	Kidney Blood Test Yes/No	CT scan date	Result Received Yes/No
6 months initial			
1 year later			
18 months later			
2 years later			
3 years later			
4 years later			
5 years later			
6 years later			
7 years later			
8 years later			
9 years later			
10 years later			

***Blood test for kidney health done at least 1 month before CT due date (for CT scans with contrast dye only).**

What to look out for

Some people experience symptoms that may mean the carcinoid has come back in the lung.

- A new cough that doesn't go away after 2 to 3 weeks despite treatment. Or a long-standing cough that gets worse.
- Coughing up blood.
- Worsening shortness of breath.
- New wheezing.
- New chest pain

Some people have a set of symptoms (carcinoid syndrome) related to over production of hormones from a carcinoid, such as serotonin.

Symptoms of carcinoid syndrome can include:

- diarrhoea
- the skin on your face and upper chest turning pink or purple (flushing)
- wheezing which is like asthma
- tiredness (fatigue).

Thymoma

You may worry about the thymoma coming back (recurrence). The chance of this varies with tumour type and stage. Thymomas have a small risk of coming back later and rarely spread beyond the thymus. If a thymoma/thymic carcinoma does come back, you may be able to have further treatment.

We usually monitor you by asking for a CT (Computerised Tomography) scan of your chest without contrast as follows:

Initial CT 3-4 months after surgery.

Thymomas completely removed (R0) stage 1 or 2, annual chest CT for 5yrs then every 2yrs for 10 years.

Stage 3 or 4 thymomas or thymic carcinomas or incompletely removed tumours (R1 or R2), chest CT every 6 months for 2 years then annually for 10 years.

Your monitoring Plan

CT scan due dates following your operation	CT scan date	Result Received Yes/No
3-4 months initial		
1 year later		
18 months later		
2 years later		
3 years later		
4 years later		
5 years later		
6 years later		
7 years later		
8 years later		
9 years later		
10 years later		

If you have not received your result after a CT scan please contact the Thoracic Surgery Secretaries, the phone numbers are on the back of this leaflet.

What to look out for

Thymoma or thymic carcinoma recurrence may not cause early symptoms. If symptoms do happen, they may include:

- Chest pain
- A cough that doesn't go away
- Shortness of breath
- Difficulty swallowing
- Hoarse voice
- Swelling of the neck or face

Getting support with day-to-day concerns after a lung cancer treatment

Your local Lung Cancer Nurse Specialists are always there to support you; their telephone numbers are at the top of each thoracic surgery clinic letter.

Macmillan cancer support

Call the Macmillan support line free on 0808 808 0000, Monday to Friday, 09:00 to 20:00. If you would prefer to speak to Macmillan in another language, interpreters are available.

If you are hard of hearing, you can use textphone 0808 808 0121 or use Text 18001 followed by 0808 808000.

The Macmillan online community is a place where you can talk to others for help and support. You can also join groups related to your experiences, for example about a particular cancer type or life after cancer. www.community.macmillan.org.uk

Macmillan provides a range of information on cancer, treatments and side effects. They also have information about work, financial issues, diet, life after cancer and information for carers, family and friends. This is available online at www.macmillan.org.uk/information-and-support

Roy Castle Lung Cancer Foundation Support, information and the online community can also be found on The Roy Castle Lung Cancer Foundation website at www.roycastle.org You can also call 0800 358 7200 or email: lungcancerhelp@roycastle.org

Carcinoid tumours

Further information can be obtained from Macmillan (see above) and the NET Patient Foundation www.netpatientfoundation.org

ThymicUK

ThymicUK is a registered charity that supports patients with thymic cancers, including thymoma and thymic carcinoma. Website: www.thymicuk.org

Thoracic surgery Please visit the thoracic surgery website www.thoracicsurgery.co.uk for information on ways to recover well after lung surgery. You can also phone switchboard and ask for the thoracic surgery secretaries on 0121 371 2000.

Thoracic Surgery

Nuffield House
Queen Elizabeth Hospital
Birmingham

Accessibility

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