

Follow up for lung cancer

A patient's guide

Introduction

Moving from active treatment for lung cancer to routine follow-up is an important milestone.

Many people look forward to finishing their initial hospital-based treatment (surgery, radiotherapy, chemotherapy/immunotherapy). However, some people find this an anxious time as they are uncertain as to what happens next. This leaflet aims to help you, and your family / carers understand why follow-up is so important and what it involves.

Follow-up is part of your ongoing care and after lung cancer treatment this is usually over a five-year period. There are no national guidelines to identify exactly when a patient should be seen, what imaging is required and how long they should be followed up for. This is dependent on several factors:

- The type and stage of your lung cancer.
- The treatment you have had.
- Local hospital arrangements.

Follow-up will:

- Identify your progress following your main treatment.
- Detect recurrence or new cancers to enable timely and appropriate management.
- Talk about any concerns or questions you may have.
- Monitor your physical and psychosocial supportive needs.
- Co-ordinate care between all providers to ensure your individual needs are being met.
- Assist you to greater independence and self-management of your health and wellbeing.

Contact Sheet

Healthcare professional involved with your care

Healthcare professional	Name	Contact details
Lung cancer nurse specialist/keyworker date of change		
Nurse consultant secretary		
Chest physician secretary		
Thoracic surgeon secretary		
Oncologist secretary		

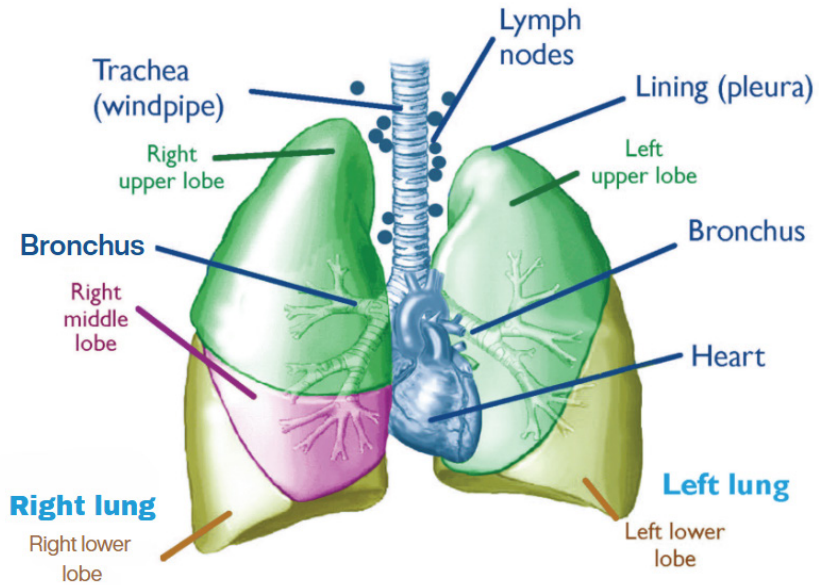


Image courtesy of the Roy Castle Lung Cancer Foundation used with permission.

Your diagnosis and stage of cancer before treatment

T (tumour)

N (nodes)

M (metastases)

Cell type_____

Stage_____

Date completed	Treatment received	Consultant
	Chemotherapy + immunotherapy prior to surgery (Neo-adjuvant treatment)	
	Surgery / operation Stage after surgery pT N PL R Cell type Stage	
	Radical radiotherapy / SABR	
	Chemotherapy and radiotherapy	

Follow up

Follow-up may be in various ways:

- Face to face in clinic with a member of your health care team.
- By telephone – with your health care team.

Telephone clinics are now a very common and effective type of follow up care. They can help you avoid journeys to hospital and possible waits in hospital clinics.

- A combination of face to face and telephone.

Do let your health care professional know which is most beneficial to you.

Below is an example of a follow-up schedule you could fill in your appointments with your Health care professional.

First 24 months following initial treatment

Months	3	6	9	12	15	18	21	24
Clinic F2F								
Telephone FU								
Chest X-ray								
CT scan								

25-60 months

Months								
Clinic F2F								
Telephone FU								
Chest X-ray								
CT scan								

What is a cancer recurrence?

Lung cancer that has come back in a person who was thought to be cancer free, is referred to as cancer recurrence. Despite the best efforts to get rid of the cancer completely, some cancer cells (micro metastases) have remained. These cells are too small to see on any imaging but may travel via the bloodstream or lymphatic system and over time form new visible tumours.

Where does lung cancer recur?

Lung cancer can recur in the same place it was originally located, or it can move to other parts of the body. Recurrence is divided into three categories:

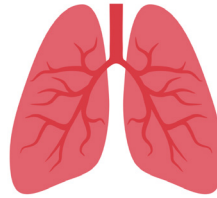
Local recurrence. The cancer reappears in the same place it was first found or very close by. The cancer hasn't spread to the lymph nodes or to other parts of the body.

Regional recurrence. The cancer recurs in the lymph nodes near the site of the original tumour.

Distant recurrence. The cancer has spread to an area away from the site of the original tumour. The most common sites for the spread of lung cancer are the other lung, the brain, bones, adrenal glands or liver. This is called 'metastatic cancer'.

A new 'primary' lung cancer

In rare instances a patient may develop a new "primary" cancer that is completely unrelated to their first cancer. This is referred to as a second primary cancer.



Lungs



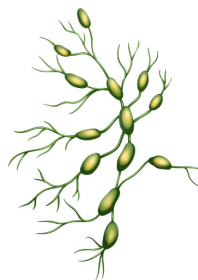
Adrenals / kidneys



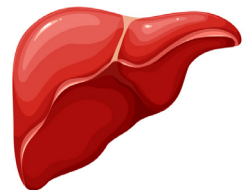
Bone



Brain



Lymph node



Liver

How is cancer recurrence diagnosed

Health care teams may suspect a cancer recurrence, or a new primary cancer based on

- Signs and symptoms
- The results of routine follow up tests (chest X-ray, CT scan).

Making the diagnosis of cancer recurrence or a second primary will be guided by where the cancer has recurred.

Undergoing the medical tests and investigations for a second time may be difficult as all the emotions experienced when first diagnosis may return.

Symptoms and signs to discuss with your healthcare team

When it comes to identifying changes in your health and new symptoms you are the most reliable source of information.

Some symptoms you should watch out for are listed below.

By letting your health care professional know changes to your health, they will decide if further tests or investigations are needed.

- A new persistent cough or worsening cough
- Coughing up blood
- Increase in shortness of breath
- Hoarse voice
- Unexplained dizziness, headaches and or visual disturbances
- Unintentional weight loss
- Persistent tiredness
- Unexplained pain that persists for more than three weeks

Can cancer recurrence be cured?

If it is suspected that a lung cancer has recurred, health care professionals will usually discuss your case in a multidisciplinary team meeting (MDT) and an appropriate plan will be made for ongoing care.

This is based on several factors:

- Length of time between the original diagnosis and recurrence
- Type of cancer
- Where it has recurred
- How well initial treatment was tolerated
- Overall health status / fitness
- Personal values and wishes

The cancer team will discuss with the patient and their family the most appropriate course of action.

The goal of treatment may be to:

- Cure the cancer although this is less likely when a cancer has recurred.
- Control the cancer by shrinking the cancer and slowing down the cancer's growth.
- Make you more comfortable by addressing your symptoms.
- These treatments aim to improve quality of life and prolong life expectancy.
- Clinical trials may be available. The goal of the clinical trial and how it is going to help you will be discussed with you and your family.

Occasionally people might wish to get a second opinion, to feel that they have made the best decision.

Emotional needs

Coping with a cancer recurrence can be difficult, as all the emotions of the original diagnosis may return. For some people, the disappointment can be overwhelming and lead to

depression and anxiety over a battle they thought they had won.

If your feelings and worries are interfering a lot with your day-to-day life and you are finding it difficult to cope, there are many ways to access help and support. Please consider talking to:

- Your lung cancer nurse specialist or another member of your cancer team.
- GP
- A national or local charity (eg The Roy Castle Foundation, Macmillan Cancer Support)
- Local support group
- A private counsellor
- A family member or trusted friend

Feeling upset and angry about the cancer coming back is completely normal. We are all unique individuals so our feelings and thoughts and response to a cancer coming back will be different.

Remember that there may be a number of treatment options to consider, chemotherapy, radiotherapy, targeted therapy, immunotherapy surgery or a combination of these. Some people experience a good quality of life for many years following a recurrence of lung cancer.

General communication

Date and comments

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Date and comments

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