

**Screening to find the early signs of lung cancer after treatment for Hodgkin lymphoma:  
Helping you decide**



A lung scan can detect the early signs of lung cancer before symptoms have developed

This leaflet has been written to help you decide whether or not to have a lung cancer screening test (a lung scan). It is entirely your choice whether to have the test. Please read the information carefully. You may want to discuss it with your family, friends or doctor before deciding. You can also contact your lung health check nurse.

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## Why should I think about lung cancer screening?

People treated for Hodgkin lymphoma have a higher chance of getting lung cancer than people in the general population who have not had Hodgkin lymphoma. This is because cancer treatments like radiotherapy and chemotherapy cause damage to cells in the lung.

Some treatments that increase the chance of getting lung cancer are:

- Radiotherapy to the chest area
- Chemotherapy for lymphoma.

At what time in my life do I have a higher chance of getting lung cancer?

People treated for Hodgkin lymphoma have a higher chance of getting lung cancer for at least 40 years after their diagnosis. The chance of getting lung cancer also gets higher as you get older.

Do I still have a higher chance of getting lung cancer if I don't smoke?

Yes, you have a higher chance of getting lung cancer even if you have never smoked or have given up. This is because of the cancer treatment you were given.

If you **have smoked**, this adds to your chance of getting lung cancer.

## How likely is it that I will develop lung cancer?

A study of more than 16,000 people treated for Hodgkin lymphoma when they were aged 15-39 in the UK found that:

5 out of 100 men treated for Hodgkin lymphoma develop lung cancer in the 35 years after treatment



4 out of 100 women treated for Hodgkin lymphoma develop lung cancer in the 35 years after treatment.

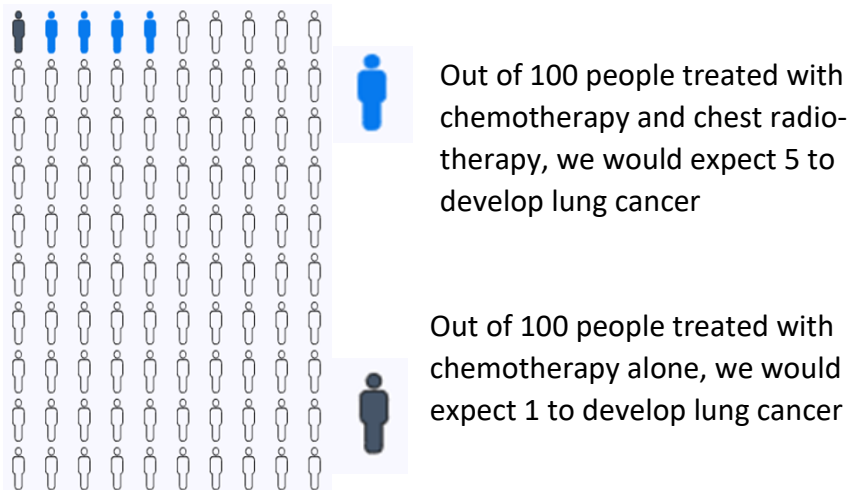


Other things to know about your chance of getting lung cancer:

If a close family member has had lung cancer, you have a higher chance of getting lung cancer.

If you had radiotherapy *and* chemotherapy, you are at higher chance than if you only had chemotherapy.

This is shown in the picture below.



How many people in the general population get lung cancer?

In the general population in the UK, which includes smokers, ex-smokers and people who have never smoked:

- 8 out of every 100 men will get lung cancer in their lifetime
- 7 out of every 100 women will get lung cancer in their lifetime

## What does lung cancer screening involve?

Lung cancer screening involves having a CT scan of your chest. The CT scan is looking for spots on your lung (called nodules). During the scan you will usually lie on your back on a flatbed that passes into the CT scanner. The scanner has a ring that rotates around a small bit of your body as you pass through it. During the scan you will need to lie still and follow simple breathing instructions for less than 10 seconds to make sure that the pictures are not blurred.

- The scan takes around 20 seconds to complete.
- You do **not** need to have an injection.
- You do **not** need to take your clothes off but you should avoid wearing clothes with metal such as zips, or jewellery, as these will need to be removed.
- After the scan you can eat, drink and drive as usual.
- You cannot have a CT scan if you are pregnant.



When will I get the results?

You will be told the scan results by letter and a copy will be sent to your GP.

## What could the scan show?

The scan could be normal, or it could show a spot (a nodule) that needs further investigation.

What are the chances of having a clear scan?

Around 90 out of 100 people will have a normal scan

What are the chances of a spot (nodule) being found?

Around 10 in every 100 people will have a spot on their lung seen on their scan. Of these 10 people, most will **not** have lung cancer. They will need another scan in 3 months to check on the spot. It is possible that some of these 10 people will need more tests straightaway to find out if a spot is lung cancer or not.



We think that 90 out of every 100 people screened will have a normal scan



We think that 10 out of every 100 people screened will need more tests to rule out lung cancer

Because lung screening has not been tested in people treated for Hodgkin lymphoma, we cannot be certain of these numbers. They are our best guess.

What happens if the scan is clear?

If the scan is clear, you do not need another lung scan at this time. If you smoke you will be offered support to give up should you wish.

What happens if the scan result is uncertain?

Sometimes it is not clear whether a small spot on the lung is cancer or not. In this case, another CT scan is advised 3 or 12 months later to check on the spot. We can arrange these scans for you.

What happens if a possible lung cancer is seen?

If a possible lung cancer is seen, you will be referred to a lung clinic at your local hospital. You should be seen in the clinic within 2 weeks of the referral being made. The lung clinic will arrange more tests.

What else might the scan show?

The CT scan can also find problems that are not cancer. Chest radiotherapy and some kinds of chemotherapy can cause problems like weakness of the heart muscle or lung scarring. If the scan showed a problem that needed tests or treatment, we would write to you and your GP.

How often can I have a lung scan?

In this study you can have the first lung scan and another lung scan in 3 and / or 12 months if it is needed. After this, you will not be offered any more lung scans within this study.

## What are the benefits of having a lung scan?

A lung scan can find lung cancer early, before it causes symptoms. Early stage lung cancer is smaller and has not spread to other areas of the body. When lung cancer is found at an early stage, it can be cured.

Early stage lung cancer is often treated with an operation where a section of lung containing the cancer is removed. Sometimes, radiotherapy is used instead of surgery. Occasionally, chemotherapy is used after surgery.

Around 7 out of every 10 lung cancers **found through screening** are early stage.

A very large study found that people who had lung cancer screening tests were between 20% and 26% less likely to die of lung cancer compared to people who did not have the test. The people in this study were current or ex-smokers who had not had Hodgkin lymphoma.

We think that people who were treated for Hodgkin lymphoma could also benefit from lung cancer screening, but there has not been a large study to prove this yet.

## What are the disadvantages of having a lung scan?

### Radiation

A CT scan exposes you to a small amount of radiation. The CT scan used for lung cancer screening uses less radiation than a standard scan. In fact, the amount of radiation used in a screening lung scan is about the same as the radiation you are exposed to naturally in 1 year in the UK.

The chance of getting cancer *because of the low-dose CT scan* is very low (between 1 in every 10,000 and 1 in every 100,000 people who have the scan).

You can find more information about radiation by visiting:

- [www.xrayrisk.com/calculator/calculator-normal-studies.php](http://www.xrayrisk.com/calculator/calculator-normal-studies.php) and select CT scan, then Chest CT (Low dose Screening)
- [www.radiologyinfo.org](http://www.radiologyinfo.org) and select 'Safety'

### Extra scans and false positives (false alarms)

Around 10 out of 100 people who have a lung scan need another CT scan to monitor an abnormality that turns out not to be cancer. Some people could be told they have cancer on their scan, but it turns out not to be cancer after extra tests. This is known as a false positive.

We understand that needing extra scans or having a false positive scan can make people feeling anxious or worried. If you feel this way at any point, there are a number of ways you can access support listed later in this booklet.

### False negatives

Sometimes, tiny cancers are not seen on the scan. This can mean that a person is given a clear scan result but goes on to develop lung cancer. This is uncommon (around 1 in every 250 people who have the scan.)

### Overdiagnosis

Some lung cancers that are found on a lung scan would never have caused problems. This means people could have unnecessary treatment such as surgery, chemotherapy and radiotherapy.

Can having a lung cancer screening test stop me getting lung cancer?

No, a lung scan cannot stop you getting lung cancer.

If you smoke, the best way to decrease your risk of lung cancer is to stop smoking.

For help to stop smoking, speak to your GP or visit:

[www.nhs.uk/live-well/quit-smoking/nhs-stop-smoking-services-help-you-quit/](http://www.nhs.uk/live-well/quit-smoking/nhs-stop-smoking-services-help-you-quit/)

What are the benefits and disadvantages of not having the lung scan?

If you do not have the lung scan, you will not be exposed to the risks associated with it.

If you do not have the lung scan and you have an early stage lung cancer that is not causing you symptoms, the cancer could become advanced before it is diagnosed. 7 out of every 10 lung cancers that are diagnosed **without screening** are diagnosed at an advanced stage when they cannot usually be cured.

## What are the common symptoms of lung cancer?

- having a cough most of the time
- having a change in a cough you have had for a long time - it may sound different or be painful when you cough
- getting out of breath doing the things you used to do without a problem
- coughing up phlegm (sputum) with blood in it
- having an ache or pain in the chest or shoulder
- chest infections that keep coming back or a chest infection that doesn't get better
- losing your appetite
- feeling tired all the time (fatigue)
- losing weight

If you have any of these symptoms it is important for you to speak to your GP.

### Making a decision

To help you decide whether to have a lung cancer screening test, you should think about which of the benefits and disadvantages matter most to you.

Pros of having a lung cancer screening test	Cons of having a lung cancer screening test
Lung cancer could be found at an early stage before symptoms develop	You might need more CT scans or a biopsy for a spot that turns out not to be cancer
If lung cancer is found early, treatment is more successful	False alarms or extra scans could cause anxiety
You are less likely to die from lung cancer	A lung cancer could be diagnosed that was never going to cause you any problems
If advanced stage lung cancer is diagnosed, you can access treatments and support	Exposure to a small amount of radiation

We understand that a lot of information has been given to you. You might find it helpful to follow these steps to help you make a decision about having a lung cancer screening test:

- Read the information in this booklet as many times as you need to
- Speak to your family or friends
- Speak to your GP, lung health check nurse or lymphoma doctor.

- We have provided a worksheet on the last page of this booklet where you can write down the pros and cons that are important to you. You can also write down any questions that could would like to discuss.

### **How to get in touch**

If you have made a decision about the screening test or wish to discuss it, you can contact your lung health check nurse using the phone number provided during your lung health check or in your follow-up letter.

## Information and Support

Where to find more information about the issues discussed in this booklet:

For more information about lung cancer:

<https://www.cancerresearchuk.org/about-cancer/lung-cancer>

For more information about lung cancer screening:

The Roy Castle Lung Cancer Foundation have produced a video about lung cancer screening. You can find it by going to YouTube and searching 'Roy Castle Lung Cancer Screening'. Because it is designed for people who have smoked, some of the figures are different to those in this leaflet.

To find out more about the late effects of treatment for Hodgkin lymphoma:

Lymphoma Action have produced a section on their website:

[www.lymphoma-action.org.uk/about-lymphoma-side-effects-treatment/late-effects-lymphoma-treatment](http://www.lymphoma-action.org.uk/about-lymphoma-side-effects-treatment/late-effects-lymphoma-treatment)

We understand that thinking about cancer can upset people and cause anxiety. If you are feeling worried or anxious after reading this booklet, you can access support and counselling by:

Speaking to your GP, lung health check nurse or lymphoma doctor.

Contacting Lymphoma Action:

via their website <http://lymphoma-action.org.uk>

or their free helpline 0808 808 5555 Monday to Friday 10am-3pm

a live chat option is available via the 'Contact Us' section of the website.

## Worksheet

Write down the pros of having a lung cancer screening test that are most important to you:

Write down the cons of having a lung cancer screening test that are most important to you:

Use the space to write down any questions you have about lung cancer screening