



Living with squamous cell lung cancer

A guide for patients

ABOUT THIS BOOKLET

This booklet is designed to help you find answers to many of the questions you may have about squamous cell lung cancer (SqCLC). The main focus of the information is advanced SqCLC. The booklet contains questions relating to the features of this type of lung cancer, its diagnosis, symptoms, treatment options, and where you can find more information and support.

'Words to know'

If you see a word in ***bold and italics***, that means it is defined for you in the '**Words to know**' section at the end of the booklet.

This booklet has been developed by a group of medical experts with input from lung cancer patient advocacy groups.



The booklet has been endorsed by:



It should not replace the information provided by your health-care team.

Funding was provided by Lilly.



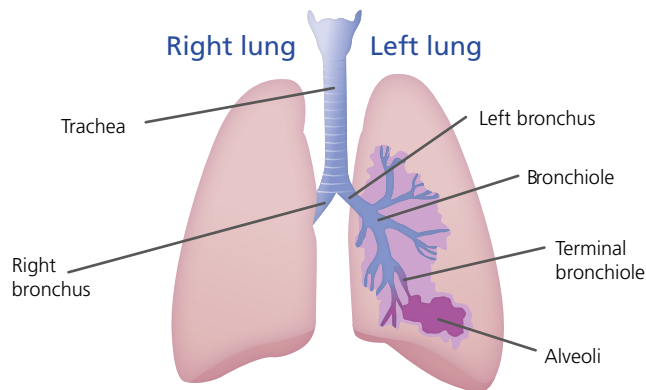
CONTENTS

Type of lung cancer	4
Diagnosis	10
Prognosis and symptoms	18
Treatments	22
Chemotherapy	28
Immunotherapy	37
Radiation therapy	39
Treatment monitoring and follow-up visits	41
Managing your health	44
Clinical trials, information, and support	48
Words to know	56

TYPE OF LUNG CANCER

What is SqCLC?

Squamous cell carcinoma of the lung or squamous cell lung cancer (SqCLC) is a common type of lung cancer. Around 25–30% of people with lung cancer will have SqCLC.



SqCLC often forms in the large airways (bronchi) that join the windpipe (trachea) to the lung. When the cancer starts, it is only in the lung. As it grows it may spread to **lymph nodes**, other parts of the lung (like the lining of the lungs), and other parts of the body. This is called metastasis.

Cigarette smoking is the most likely cause of SqCLC, with the risk of lung cancer increasing

Around 25–30% of people with lung cancer will have SqCLC

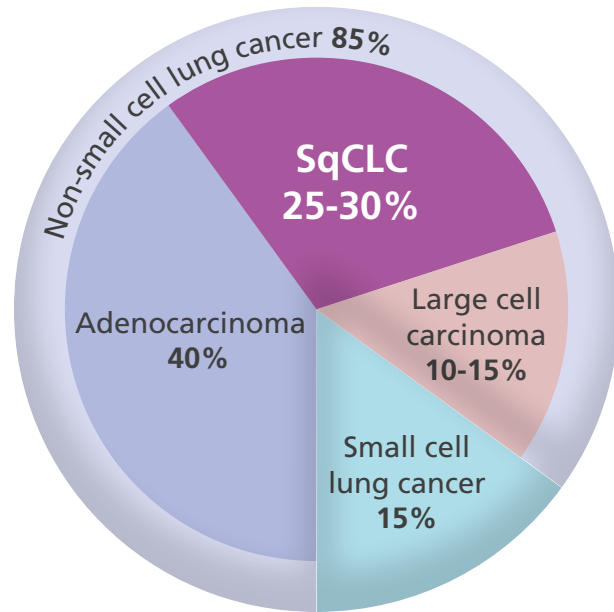


with the number of years a person smokes and the number of cigarettes smoked each day. Less common causes are breathing second-hand cigarette smoke, occupational exposure to asbestos or other cancer-causing agents, exposure to radon, previous treatment with **radiation therapy** or **chemotherapy**, and HIV infection.

What is the difference between SqCLC, adenocarcinoma, and small cell lung cancer?

Lung cancer can be divided into non-small cell lung cancer and small cell lung cancer. Adenocarcinoma and SqCLC are subtypes of non-small cell lung cancer. SqCLC, adenocarcinoma, and small cell lung cancer are the three most common types of lung cancer. The cancer **cells** and their arrangements look different under a microscope for each type of lung cancer. The different types are sometimes called histological subtypes. These lung cancer types

also show differences in their biology, where they form in the lungs, and how the cancer responds to particular treatments.



Types of lung cancer

Most SqCLC **tumours** develop from cells lining the bronchi, the air-conducting tubes of the lung, and often form in central parts of the lungs. Small cell lung cancer probably also derives from the same type of bronchial lining cells and this type of lung cancer grows very quickly. Adenocarcinoma of the

lung mostly develops from lining cells in the lung periphery, and so it is most commonly seen in the outer parts of the lungs.

If you have SqCLC it will determine the type of treatment you are offered. The treatment may be different from that offered to patients who have adenocarcinoma or small cell lung cancer.

Rarely, lung cancers have mixed histology, eg mixed squamous and adenocarcinoma. This diagnosis can be very difficult to make using tiny samples. Although very rare, if your tumour does have mixed histology, the treatment you are offered will usually be determined by the presence of an adenocarcinoma component.

What percentage of patients are diagnosed with SqCLC?

In Europe, 31–44% of all lung cancer cases in men and 17–24% in women are SqCLC. In the United States, 27% of all lung cancer cases in men and 18% in women are SqCLC. SqCLC is strongly linked to smoking and the percentage of patients with SqCLC in each country depends on the types of cigarettes smoked, including whether they have filters.

Why is it called ‘squamous cell carcinoma’?

Cancers are called squamous cell carcinomas (or SqCLC) when the cancer **cells** show changes that are similar to those seen in normal squamous-type cells in the body, such as cells on the surface of the skin (the epidermis). A **pathologist** will check for these changes by examining the cells under a microscope. Squamous cell carcinomas are sometimes called epidermoid carcinomas.

Squamous cell carcinomas can develop in and from the normal squamous **tissues** in some organs of the body. Squamous tissue is not usually found in the lung, but may develop in the lung due to toxic damage. This tissue may then undergo cancerous change, leading to squamous cell carcinoma.

When did my cancer start?

It is difficult to know exactly when your lung cancer started. In people who smoke, the **bronchial mucosa** are exposed to tobacco smoke for many years. This first causes **precancerous lesions** that can later turn into cancer. However, it can take several years before the lung cancer becomes visible or causes symptoms.

Are my children at a higher risk for lung cancer?

Not directly because there is no known genetic pathway to pass this cancer on to your children. However, this type of lung cancer is generally caused by cigarette smoke. So, your relatives would be at risk if they smoke themselves or if they were breathing in cigarette smoke from other smokers for a long period of time (several years).



DIAGNOSIS

How is SqCLC diagnosed?

Diagnosis of SqCLC involves a number of steps:

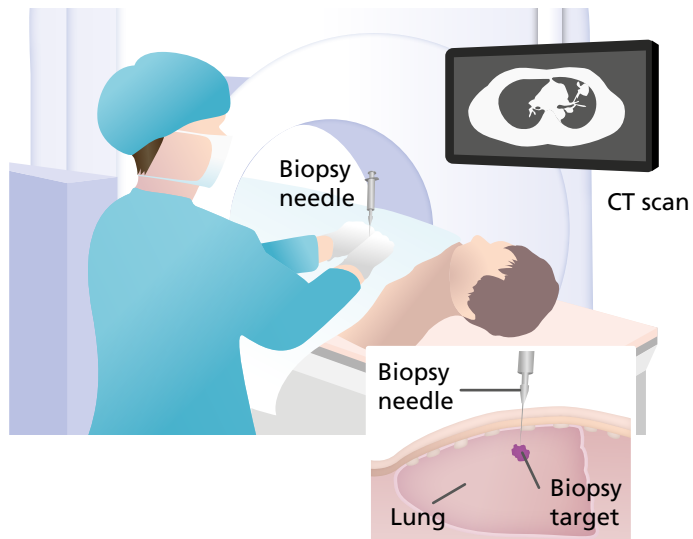
STEP 1

Usually, a mass is found on a chest x-ray or chest **CT scan**

STEP 2

The patient is referred to an **interventional radiologist**, a chest surgeon, or a lung specialist (pulmonologist) to obtain **tissue** samples (biopsies) from the mass

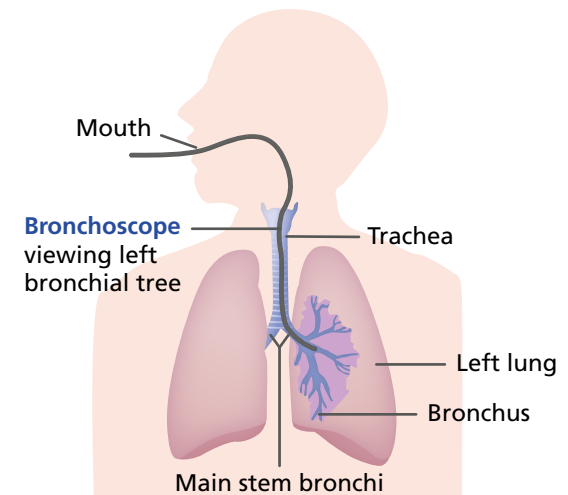
- Interventional radiologists obtain tissue samples using **CT-guided needle biopsy**



All types of lung cancer are diagnosed in a similar way



- Chest surgeons and pulmonologists obtain tissue samples using a procedure called **bronchoscopy**



STEP 3

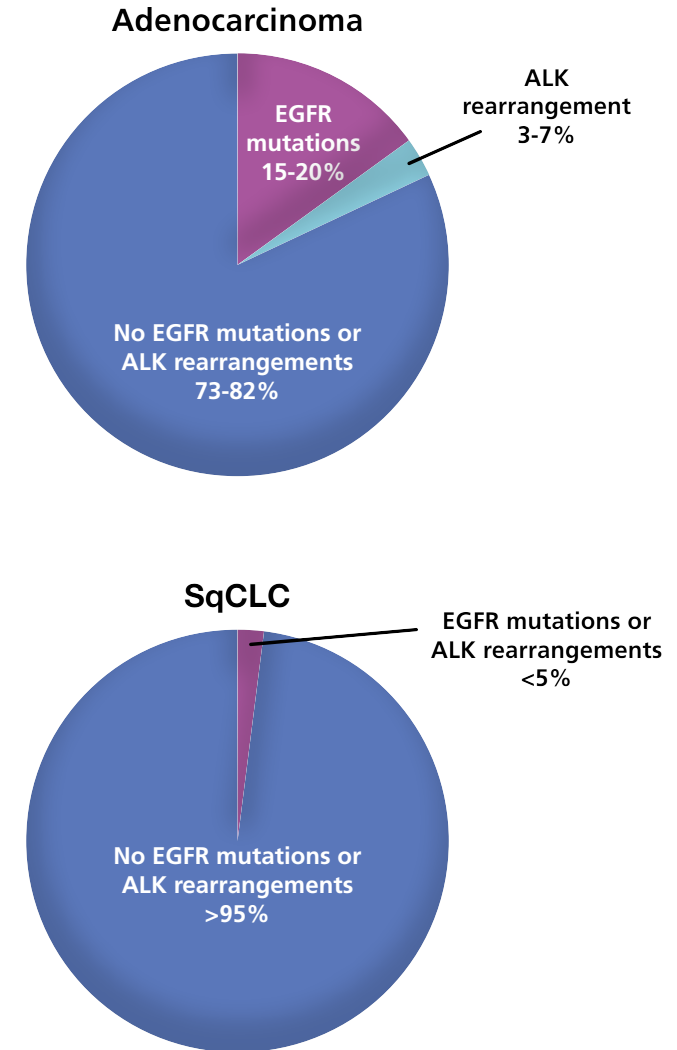
Lastly, a **pathologist** studies the tissue samples under a microscope. If the cancer cells have features consistent with squamous cell carcinoma, the pathologist will make a diagnosis of SqCLC.

Are any specialised or sophisticated techniques needed to diagnose this type of lung cancer?

No, all types of lung cancer are diagnosed in a similar way. After a physical examination, blood tests and scans, your doctor will decide on the best way to obtain adequate samples of **tumour tissue** to confirm the diagnosis.

Occasionally, if it is difficult to obtain tissue, you should consider being evaluated by a team of lung cancer specialists who will recommend alternative ways to obtain adequate tissue to establish a diagnosis. The tissue samples may have to be sent for extra tests to confirm what type of lung cancer you have, before a treatment plan can be decided.

For some types of lung cancer, such as adenocarcinoma or non-small cell lung cancer not otherwise specified, the samples can also be used to determine if the tumour has special features (mutations) that may affect treatment options. These tests are not usually performed for SqCLC because these mutations are very rare in this type of lung cancer.



Percentage of patients whose tumours have special features for different types of lung cancer

What type of specialists treat patients with my type of lung cancer?

SqCLC is managed and treated by cancer specialists, called oncologists. There are at least four types of physicians who manage SqCLC:

- **medical oncologists**,
- **surgical oncologists**,
- **radiation oncologists**, and
- pulmonologists (lung specialists).

You may need to see one or all of these types of specialists to treat your cancer, depending on the extent of your disease.



A multidisciplinary team made up of the types of doctors listed opposite, plus specialist nurses, **pathologists** and supportive care workers, will meet regularly to discuss your treatment and help ensure you receive the most appropriate therapy.

Do I need to have my tumour molecularly tested?

Generally, no. Molecular testing is not routinely recommended if your **tumour** is SqCLC. This is because the **molecular markers** (features) that can be specifically targeted by drugs are very rare in SqCLC. An exception to this recommendation is if you have SqCLC and you have never smoked.

If you are taking part in a **clinical trial**, your tumour may be tested to see if it has special features that mean you are likely to benefit from the drug being tested. This testing may be particularly important for **immunotherapy**.

If you have another type of lung cancer, such as adenocarcinoma or non-small cell lung cancer not otherwise specified, then your tumour should be tested, as the results will affect your treatment options.

What is the stage of my cancer? What does the stage of cancer diagnosis mean? Has my cancer spread beyond the lung?

Staging is used to describe the size, position, and how widespread your cancer is at the time of diagnosis. It helps your doctor plan suitable treatment.

Lung cancer can be staged in four main stages:

Stage	Description
Stage I	The cancer is small and is only in one part of the lung (localised)
Stage II and III	The cancer is larger and may have spread into surrounding tissues . Cancer cells may also be in nearby lymph nodes . The cancer remains inside the chest
Stage IV	The cancer has spread outside the chest to another part of the body (metastasised)

Can I seek a second medical opinion? If yes, when and from whom?

Yes, you should seek a second opinion. Ideally, it should be from a doctor at a larger hospital or treatment centre or who sees more patients with lung cancer than your current doctor.

This could be a University Medical Centre, a major academic centre, or a Comprehensive Cancer Centre. These centres are easily found by searching the internet or even asking your doctor who they would recommend you see for a second opinion.

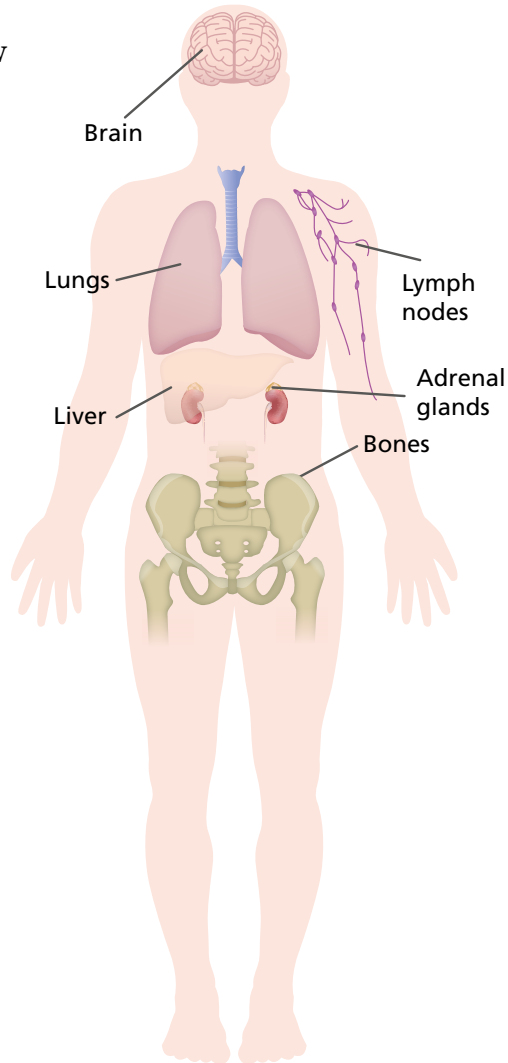


PROGNOSIS AND SYMPTOMS

Will my cancer spread to other parts of my body? If yes, where can the disease spread to?

How likely your cancer is to spread depends on how advanced your cancer is when you are diagnosed and how well it responds to treatment.

When SqCLC starts, it is only in the lung. As it grows it may spread to **lymph nodes**, other parts of the lung (such as the lining of the lungs), and later to other parts of the body, such as the other lung, liver, adrenal glands, bones, or brain.



Supportive treatments can help to manage your symptoms and any side effects



What are the specific symptoms that I am most likely to experience during the evolution of my disease? How will these symptoms change during treatment?

Lung cancer symptoms vary and depend on where the cancer is growing. Many people have shortness of breath and a cough. Some people cough up blood, but this is uncommon. If the cancer spreads to the bones and some other organs it can cause pain. Many people lose weight and are tired whenever the cancer is growing. Supportive treatments will be available to help manage your symptoms and any side effects you may experience as a result of your treatment.

If a treatment is working, your lung cancer symptoms will usually decrease. The side effects of **chemotherapy** and **radiation therapy** can

also cause symptoms like tiredness, nausea, and sometimes hair loss. Overall, if treatment is working, you are likely to feel better than without treatment.

If your lung cancer progresses, or starts to grow even with cancer treatment, your symptoms may get worse. The symptoms vary and depend on where the cancer is growing. Hopefully, a different cancer treatment will control the cancer and improve your symptoms.

How does the prognosis of SqCLC compare with the prognosis of other types of lung cancer?

The **prognosis** for all lung cancers depends on how widespread the cancer is when you are diagnosed, your general health, and how well your cancer responds to treatment. Your doctor should discuss all these points with you.



TREATMENTS

How is SqCLC treated?

Treatment for SqCLC depends on how widespread your cancer is and your general fitness.

- **Surgery:** for early stages of lung cancer, if your **lung function** is good enough, surgery to remove part of a lung may offer a chance for cure.
- **Radiation therapy** may be used to treat the lung cancer itself, including **lymph nodes**, or to control symptoms if the cancer has spread (metastasised).
- **Chemotherapy** may be used alone, with radiation therapy, or after surgery for lung cancer.
- For advanced SqCLC, adding a **monoclonal antibody** treatment to chemotherapy may help you live longer compared with chemotherapy alone. Also, a new type of treatment called **immunotherapy** can be used for some patients.

Your doctor will discuss which treatment is most suitable for your stage of disease and let you know what treatments and drugs are available in your area.



Treatment for SqCLC depends on how widespread your cancer is and your general fitness

Does SqCLC require specific treatment and management compared with other types of lung cancer?

Yes, treatment of advanced SqCLC is different for several reasons. **Chemotherapy** is the most effective initial treatment for most patients.

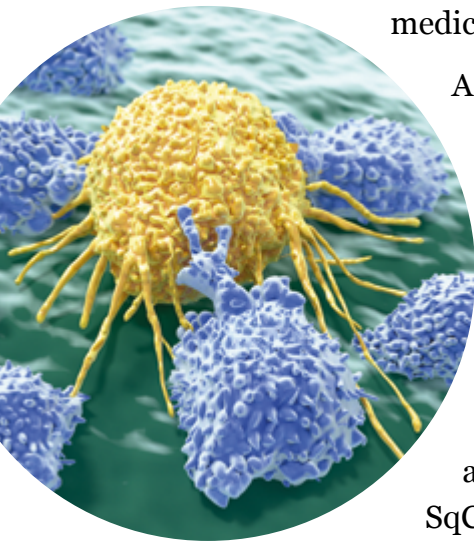
Unlike adenocarcinoma, where **molecular markers** sometimes allow us to treat you with a **targeted therapy**, usually a well-tolerated pill, in SqCLC these markers are very rare. On the other hand, adding a **monoclonal antibody** treatment to chemotherapy may help you live longer compared with chemotherapy alone. Also, some patients with SqCLC can be treated with **immunotherapy**.

Your doctor will discuss which treatment is most suitable for you and let you know what drugs are available in your area.

What treatments are effective for this disease?

For advanced stage SqCLC, the main treatment options are **chemotherapy** and **immunotherapy**. These treatments have been shown to help people live longer.

Chemotherapy may include a combination of medications that include carboplatin, cisplatin, paclitaxel, nab-paclitaxel, gemcitabine, docetaxel, and vinorelbine. Usually, either cisplatin or carboplatin is given with one of the other medicines in the list.



A **monoclonal antibody** treatment can be added to chemotherapy to treat advanced SqCLC. These drugs may help you live longer compared with chemotherapy alone.

Immunotherapy is a new approach to treat advanced SqCLC in suitable patients.

Immunotherapy drugs work by activating the immune system to fight the cancer.

Your doctor will discuss which treatment is most suitable for you and let you know what drugs are available in your area.

Why can I not receive treatment in the form of a pill as some other patients do?

For advanced lung cancer, only patients whose **tumours** have special features (called **EGFR mutations** or **ALK rearrangements**) can receive a pill as their first treatment.

These features are very rarely seen in SqCLC, so if you have advanced SqCLC you are likely to receive treatment with **chemotherapy** or **immunotherapy**.

If you cannot tolerate chemotherapy or your lung cancer grows after receiving chemotherapy, pill therapies that target the EGFR pathway may provide modest benefits and may be an option.

Your doctor will discuss whether a pill treatment would be suitable for you and let you know what drugs are available in your area.

Will I need supplemental oxygen?

You may need to use supplemental oxygen if your lungs are unable to extract enough oxygen from the air. SqCLC **tumours** are often located centrally in the chest and can make it more difficult for you to breathe. If you have SqCLC, you are also more likely to experience a partial lung collapse (atelectasis) and pneumonia than people with adenocarcinoma.

If you have other diseases as well, such as heart or lung disease (for instance chronic obstructive pulmonary disease [COPD]), you may experience further breathing issues and need supplemental oxygen.

Can the tumour be removed (definitively or partially) by surgery?

Surgery to remove the **tumour** only benefits patients with early stage lung cancer. Sometimes, surgery is still possible if the lung cancer has only spread to nearby **lymph nodes**. Some patients may be given **chemotherapy** after surgery (adjuvant chemotherapy) to reduce the risk of the cancer returning.

Surgery does not help if the cancer has spread to the other lung or outside of the chest to another part of the body (metastasised). This is because surgery at one site will not stop the cancer growing at other sites in the body to which it has spread. Only removing part of the cancer does not help, as the remaining tumour will continue to grow.

How important is endobronchial treatment for SqCLC?

Endobronchial treatments involve using a **bronchoscope** to enable the treatment to be

applied directly to the lung cancer. They are used for both early stage and late stage SqCLC to treat a **tumour** that has not spread beyond the airway wall or to remove or decrease the size of tumours blocking the airways.

There are many different endobronchial treatments. Some treatments are used to remove blockages from the airways and provide immediate symptom relief. These include electrocautery, argon plasma coagulation (APC), and laser therapies. Other endobronchial treatments, such as cryotherapy, photodynamic therapy (PDT), and intraluminal irradiation therapy or brachytherapy, work more slowly and are mostly used to treat small, early stage tumours.

For early stage SqCLC, although surgery is often considered, there are some advantages to endobronchial treatments over surgery in suitable patients. The advantages include fewer complications after treatment. Most importantly, patients who receive endobronchial treatments often do as well as patients who are treated with surgery.



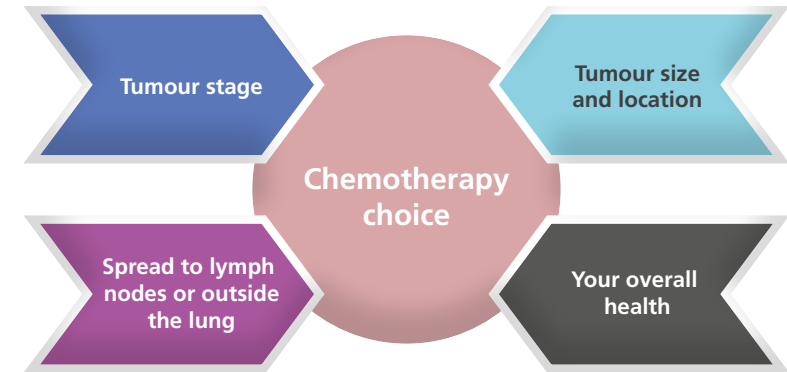
For later stages of SqCLC, when surgery is not possible, endobronchial treatment may provide relief from symptoms such as breathlessness by opening up the airway.

Chemotherapy

Which chemotherapy should I undergo and how will I know which is the best option for me?

Chemotherapy may be recommended for any stage of SqCLC. Many factors are considered when deciding if chemotherapy (alone or in combination with **radiation therapy**) is right for you. These include the stage of your **tumour**, the tumour's size and location, whether or not the cancer has spread to your **lymph nodes** or outside of the lung (metastasised), and your overall health. Your doctor is more likely to recommend chemotherapy if your cancer has a high chance of recurring.

For advanced SqCLC, some options are carboplatin or cisplatin combined with either nab-paclitaxel, gemcitabine, docetaxel, or paclitaxel. Your doctor will discuss the specific type of chemotherapy that they think will be the best option for you.



Factors influencing choice of chemotherapy

Where will I receive chemotherapy treatment for my cancer?

If you receive **chemotherapy**, it is usually given in an outpatient clinic. You will have blood tests to check your laboratory values, such as haemoglobin, platelets and white blood cell counts, before receiving chemotherapy. Most therapies are given as an intravenous infusion, which is a method for delivering medicine into your bloodstream through a vein. It is often referred to as an IV.

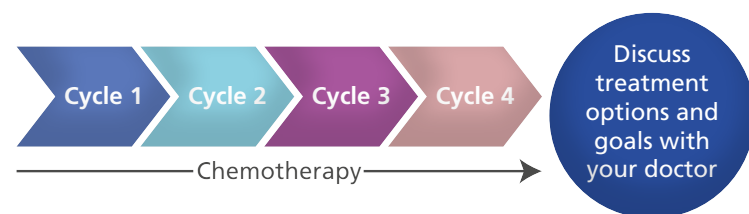
Treatment can take different amounts of time – from a few hours to a whole day. This is because you may also need to have medications to prevent side effects of the chemotherapy (like extra fluids to rinse your kidneys).

If you are receiving a **monoclonal antibody** drug as well as chemotherapy, you can receive it on the same day.

How long do I need to take medicine or be in therapy?

Most patients with advanced SqCLC who receive **chemotherapy** as their first treatment will receive two chemotherapy drugs (carboplatin or cisplatin plus another chemotherapy drug). You will usually receive four cycles of chemotherapy.

If you experience severe side effects or the cancer continues to grow, your doctor may stop the treatment and change to a different one.



An overview of first chemotherapy treatment for advanced SqCLC

After four cycles of chemotherapy, if your cancer has responded to treatment you have several options, such as having a treatment break or continuing to receive a chemotherapy drug. To help you decide, talk to your doctor about what your goals are and how any side effects are affecting your life.

I am over 70 years old. Is chemotherapy still useful at my age?

Chemotherapy is just as effective for your cancer but you may experience more side effects. Your doctor will discuss which specific chemotherapy they would recommend for you to minimise the side effects of treatment. This may be an adapted treatment, such as one chemotherapy drug instead of a combination of drugs.

Older people, and/or people who smoke or used to smoke, may be more likely to have other diseases as well, such as heart or lung disease, decreased kidney function, or diabetes. Patients with other diseases may experience more side effects from chemotherapy.

What are the side effects of chemotherapy?

The most common side effects of **chemotherapy** are:

Temporary decreases in white blood cells, red blood cells, and platelets

This can increase the risk of complications and might require treatments such as antibiotics or transfusion of red blood cells

Vomiting and nausea	This can be effectively controlled by supportive medications
Fatigue	Weakness, tiredness, and lack of energy may occur in between treatment courses
Obstipation (severe constipation)	Usually resulting from a blockage in the intestines. It is caused by some drugs and supportive therapies. It is important to monitor how often you pass bowel movements, particularly if you have received opioid drugs
Neurotoxicity	A few patients may experience numbness, tingling, and pain. It is important to tell your doctor if you already have a neuropathic condition or have these side effects because it might be necessary to modify your chemotherapy dose or change your chemotherapy drugs

Ask your doctor for more information on other side effects.

Can I do something to prevent or reduce possible side effects?

Yes, there are several things that you can do.

1	Your doctor will prescribe medication to prevent vomiting and nausea – it is important that you take this medication as instructed
2	Physical activity will help you manage side effects like nausea
3	You may experience a loss of appetite and may not be able to follow your usual eating habits. Introducing lighter meals and eating smaller amounts more often might help
4	Talking with other patients and having regular contact with a support group will ease the psychological burden of chemotherapy and may help you overcome the discomfort of treatment

Am I going to lose my hair?

Some **chemotherapy** drugs cause hair loss (alopecia) but others do not. Some patients experience hair thinning without losing their hair.

Several of the **chemotherapy** drugs available to treat SqCLC do not cause hair loss. Please discuss the best chemotherapy option for you with your doctor.

Will I be able to work while I am undergoing chemotherapy?

It depends on the type of work you do, your desire to work, and how well you think you can do your work during this time. If continuing to work is important to you, discuss your options with your doctor and employer.

You may feel that a work absence is the best way to maintain your quality of life during **chemotherapy**.

A discussion with both your doctor and your employer will help you make the best decision for your own situation.



Can I socialise with other people while I am undergoing chemotherapy?

In general, yes. It is important to maintain your quality of life and part of this involves socialising. It is also important to maintain as active a schedule as you can manage. This includes social interactions as well as exercise and good eating and sleeping habits.

At times your blood counts may be low and socialising may not be advisable because of an increased risk of infection. Tiredness may also be an issue. Check with your doctor to see when you are able to be around other people to minimise your risk of infection.



Will I be able to have children after treatment with chemotherapy?

Yes, it is possible to have children after **chemotherapy**. However, chemotherapy drugs could harm a developing baby. You and your partner should not try to become pregnant during the entire time you

are receiving chemotherapy and not until at least 70–90 days after your last chemotherapy treatment.

If you plan on having children after cancer, speak with a fertility specialist to discuss your options and the risks that may be involved. This is particularly important if you are a woman.

If my chemotherapy does not work, what is the next step? Can I go home without further treatment?

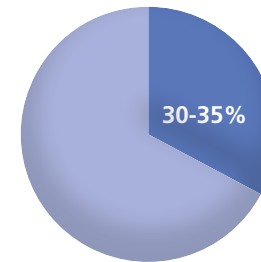
If your **chemotherapy** does not work, there may be other chemotherapy drugs to try. There are also new **immunotherapy** drugs for SqCLC that are very promising.

You can also ask your doctor if you could take part in a **clinical trial** for a new treatment. Information on where you can find out more about clinical trials is included in the ‘[Clinical trials, information, and support](#)’ section of this booklet.

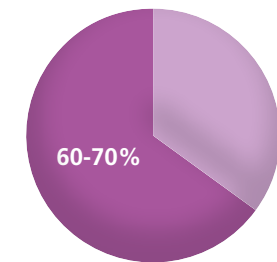
What will happen if I refuse chemotherapy?

If you are considering refusing **chemotherapy**, please speak with your doctor to discuss the best treatment option for your personal situation.

Patients who respond to chemotherapy



Patients who experience symptom improvement



Percentage of patients with advanced SqCLC who respond to chemotherapy or experience improvement in their symptoms

For advanced SqCLC, around 30–35% of patients will respond to chemotherapy and around 60–70% will experience improvements in their symptoms. However, if your SqCLC is left untreated, your symptoms will usually get worse and your health will deteriorate. Refusing chemotherapy may shorten how long you live and your quality of life is unlikely to improve.

Immunotherapy

Does immunotherapy work for the treatment of SqCLC?

Yes. Some **immunotherapy** drugs, called anti-PD-1/PD-L1 agents, have shown promising results in advanced lung cancer in certain situations.

These immunotherapy drugs may reduce the size or extent of the lung cancer and help some people live longer. SqCLC was the first type of lung cancer to show benefit from immunotherapy.

Your doctor will discuss whether immunotherapy would be suitable for you and let you know what drugs are available in your area.

What are the possible side effects of immunotherapy?

The side effects of **immunotherapy** drugs are different from, happen less often, and are less severe than **chemotherapy** side effects. These side effects are normally easy to manage, especially if detected early. Your awareness of these side effects will greatly assist in identifying any problem.

The most common side effects of immunotherapy include weakness and lack of energy, tiredness, lack of appetite, nausea, and diarrhoea.

In about 10% of patients, excessive stimulation of the immune system with immunotherapies can cause damage to normal organs and can result in side effects related to the immune system, such as rash, and problems with the lungs (pneumonitis), intestines (colitis), or hormone-making glands (endocrinopathies).

The symptoms for pneumonitis include shortness of breath, dry cough, fever, chest tightness and/or pain, and general malaise. For colitis, the main symptoms are diarrhoea and abdominal pain. Symptoms of endocrinopathies are often less specific and can include nausea, headache, fatigue, and vision changes.

Contact your doctor/nurse if you experience any of these symptoms.

Radiation therapy

Will radiation therapy be part of my treatment?

Radiation therapy uses high-energy radiation to shrink **tumours** and kill cancer **cells**. It may be recommended for any stage of SqCLC.

If you have surgery, you may also have radiation therapy afterwards to reduce the risk of the cancer returning. Radiation therapy may also be used as a treatment for early stage tumours if your cancer is not suitable for surgery.



If you are also receiving **chemotherapy**, sometimes chemotherapy may be continued during radiation therapy.

You may need to have radiation therapy to relieve pain if your cancer has spread to your bones, to relieve shortness of breath if you have an obstruction of major airways, or to treat your cancer if it has spread to the brain.

Your doctor will discuss whether radiation therapy is a suitable treatment option for you.

Can radiation therapy cause other cancers?

The risk of a second cancer caused by radiation is low in patients with lung cancer.

In early stage (stage I) non-small cell lung cancer, the likelihood of a second lung cancer in patients who undergo surgery (not **radiation therapy**) is around 3–5%. Similar rates have been seen after patients received radiation therapy for stage I non-small cell lung cancer.

For advanced SqCLC, radiation-induced tumours are very uncommon at this stage of disease.

Treatment monitoring and follow-up visits

How will I know if my treatment is being effective?

You will have repeat **CT scans** to see how your cancer is responding to treatment. When treatment is effective, the cancer will either get smaller or stay the same size.

What is included in a typical follow-up visit for SqCLC? When do I have to attend follow-up visits?

The frequency of follow-up visits and tests depends on your stage of SqCLC.

Early stage or locally advanced SqCLC

You will generally be seen every 3–4 months for the first 2 years after treatment completion, every 6 months in the third year, and once a year after that.

Each visit will include:



a physical examination



questions about your health



blood tests



a chest *CT scan*

Advanced SqCLC

You will usually see your doctor every 3–4 weeks.

Each visit will include a physical examination, questions about your health, and blood tests.

You will have a chest CT scan before you start treatment and then after every 2–3 treatment cycles.



MANAGING YOUR HEALTH

Should I quit smoking following my diagnosis of SqCLC? Is quitting of potential benefit even if I have advanced stage disease (eg stage IV)?

Yes, you should definitely stop smoking if you have been diagnosed with SqCLC of any stage. This is because people who stop smoking tend to live longer and can have reduced complications from lung and heart disease, and so lessen the side effects from treatment.

Stopping smoking is also the best way to reduce your risk of a second lung cancer.

If you would like help to stop smoking, please speak to your doctor about joining a suitable programme.

What do I need to have in my home to manage my health?

Useful things for you to have available at home include:



a good thermometer



a list of the medicines and treatments you are taking in case of emergency



It is important to look after your health after a diagnosis of SqCLC



the phone number of the pharmacy you use, in case you call a doctor outside of normal hours and need a prescription



a list of common lung cancer symptoms and side effects of **chemotherapy** plus information on how you can help manage them at home. See the '[Prognosis and symptoms](#)' and '[Chemotherapy](#)' sections of this booklet.

How can I change my diet to best fight my SqCLC?

You may experience a loss of appetite, a feeling of fullness after eating small amounts, as well as side effects from **chemotherapy**, such as nausea or vomiting, constipation, and changes in how things taste.

If you notice these symptoms, it is good to eat small amounts more often. If you find that specific foods don't taste right or don't appeal to you, don't force yourself to eat them. You might find that lighter foods are more appealing and cause less feeling of fullness. If possible, try to eat foods that contain high amounts of protein and calories.



CLINICAL TRIALS, INFORMATION, AND SUPPORT

What is a clinical trial?

A **clinical trial** is a research study in which people volunteer to test new drugs or devices. They help doctors learn whether a new treatment works and is safe.

Clinical trials often compare the effectiveness and safety of one treatment with another. If you take part in a clinical trial of this type you will either receive an experimental treatment or the current standard of care treatment for SqCLC. Your disease may be more closely monitored during a clinical trial to allow the doctors to assess the effects of the new treatment.

How can I learn about clinical trials for my type of cancer?

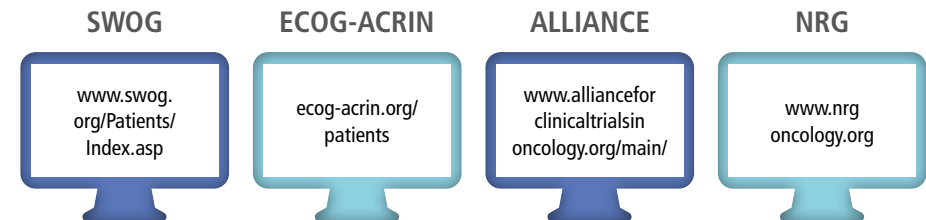
You can obtain information about **clinical trials** from several places:

- Your oncologist
- Your hospital's clinical trial website
- Clinical trial registration websites:
 - clinicaltrials.gov/
 - www.clinicaltrialsregister.eu/ctr-search/search

Clinical trials are an important part of developing new drugs



- Websites of groups that run clinical trials, such as:



- Websites of pharmaceutical companies who may sponsor clinical trials.

Do I qualify for SqCLC clinical trials?

It will depend on the specific **eligibility criteria** for each **clinical trial**. Eligibility criteria are mainly linked to disease characteristics, such as the type or stage of cancer, and the presence of other pre-existing diseases. These criteria are used to ensure new treatments are tested in the types of patients who are supposed to benefit from them.

Even if you don't qualify for one trial, you may well qualify for others.

You can usually find these criteria on the websites listed above.

Where can I find credible information about my disease that is presented in a way that I will be able to understand?

Learning about lung cancer and its treatment can help you feel less anxious and more prepared. Some treatment centres offer booklets, leaflets, and other sources of information.

There are also several reliable internet sources where you can find up-to-date and accurate lung cancer information:



International Association for the Study of Lung Cancer (IASLC) Patient Resources:
www.iaslc.org/about-lung-cancer



Patient Resource Cancer Guide – Lung Cancer:

www.patientresource.com/userfiles/file/Lung2013.pdf



European Society for Medical Oncology Resources for Cancer Patients:

www.esmo.org/Patients



Lungcancer.org:

www.lungcancer.org/



American Cancer Society – Lung Cancer:

www.cancer.org/cancer/lungcancer/



National Cancer Institute:

www.cancer.gov/types/lung



Cancer.Net:

www.cancer.net/cancer-types/lung-cancer-non-small-cell

You may find useful information on these links to international and European organisations:



IASLC Patient Advocacy Partners:

www.iaslc.org/patient-resources/advocacy-partners



Global Lung Cancer Coalition (GLCC):

www.lungcancercoalition.org/



Bonnie J Addario Lung Cancer Foundation:

www.lungcancerfoundation.org/



LUNgevity:

www.lungevity.org/



Women Against Lung Cancer in Europe (WALCE) educational booklets:

www.womenagainstlungcancer.eu/?lang=en



Lung Cancer Europe (LuCE):

www.lungcancereurope.eu/

Are there advocacy groups devoted to SqCLC? How can I find out about any support groups? What kind of support do these groups offer?

Numerous patient advocacy groups exist for lung cancer, which help patients who have all types of lung cancer diagnoses. These groups help patients and their families to navigate the lung cancer landscape. They can be local, national, or international and they work to ensure lung cancer patients receive appropriate and timely care and education. They assist with patients' participation in support groups, offer psychological and financial assistance when needed, and advocate for patients' rights.

These groups could give you the tools you need to better understand your disease, help you learn how to cope with your diagnosis, and live the best quality of life you can.

You can ask your health-care team about the support groups in your area. Additionally, you can access information from these lung cancer advocacy organisations:



International Association for the Study of Lung Cancer (IASLC) Patient Advocacy Partners: www.iaslc.org/patient-resources/advocacy-partners



Global Lung Cancer Coalition (GLCC): www.lungcancercoalition.org/



Bonnie J Addario Lung Cancer Foundation: www.lungcancerfoundation.org/



LUNgevity: www.lungevity.org/



Women Against Lung Cancer in Europe (WALCE): www.womenagainstlungcancer.eu/?lang=en



Lung Cancer Europe (LuCE): www.lungcancereurope.eu/



WORDS TO KNOW

ALK rearrangements	A special feature (rearrangement) of a specific part of a cancer cell that can be targeted by drugs called ALK inhibitors
Bronchial mucosa	A tissue layer that makes up part of the wall of the large airways in the lung (the bronchi)
Bronchoscope	A long, thin, flexible device with a lighted viewing tube that is used to see the inside of the airways and lungs
Bronchoscopy	A procedure used to look at the inside of the airways. A bronchoscope is inserted through your mouth or nose and then moved down to the airways in the lung. Before the bronchoscopy, your throat is numbed and you will receive sedation. During the procedure, your doctors can obtain tissue samples from the mass in your lung
Cell	The smallest functional unit of a living thing. Cells are the building blocks of the body
Chemotherapy	This treatment uses drugs to treat your cancer by killing cancer cells directly. Different chemotherapies are sometimes used in combination with other drugs, surgery, or radiation. Often referred to as chemo

Clinical trial	Studies in which people volunteer to test new drugs or devices. They often compare one treatment with another. Clinical trials help doctors learn whether a new treatment works and is safe
CT-guided needle biopsy	A way of obtaining tissue samples from a mass in the lung. A radiologist uses a CT scan to identify the best site to obtain the sample. The skin is numbed and a fine needle is inserted through the chest wall into the mass in the lung and used to take samples
CT scan	This is short for computed tomography scan. It combines the images from a series of x-rays taken at different angles to generate 3D pictures of the part of the body of interest
EGFR mutations	A special feature (mutation) of a specific part of a cancer cell that can be targeted by drugs called epidermal growth factor receptor tyrosine kinase inhibitors (EGFR TKIs)
Eligibility criteria	The requirements that a person must meet to be included in a clinical trial. They usually include factors such as the patient's age, type and stage of cancer, general health, and previous treatment

Immunotherapy	A type of treatment that activates the body's natural defences (immune system) to fight the cancer
Interventional radiologist	A doctor who performs medical procedures using guidance from imaging techniques (eg CT scans) to diagnose and treat diseases
Lung function	How well your lungs work. It includes how much air you can take into your lungs, how much air you can blow out of your lungs and how fast you can do it, and how well your lungs put oxygen into your blood
Lymph nodes	Part of the immune system. There are hundreds throughout the body. They work as filters for harmful substances and contain cells that help fight infections
Medical oncologist	A doctor who specialises in treating cancer using chemotherapy and other medications
Molecular marker	A special feature of a cancer cell (a mutation) that can be targeted by specific drugs called targeted therapies. Targeted therapies are only likely to work if your tumour has one of these mutations

Monoclonal antibody	Also called a biologic therapy. It is a type of drug made from living cells and attaches to specific structures on cancer cells. It works by blocking the pathways that cancer cells use to grow
Pathologist	A doctor who studies samples from patients (eg blood or tissue samples) and helps to accurately diagnose diseases
Precancerous lesions	Made up of precancerous cells, which are abnormal cells that could undergo more changes and turn into cancer cells
Prognosis	A prediction of the likely or expected development of a disease or of the chances of getting better
Radiation oncologist	A doctor who specialises in treating cancer using radiation therapy
Radiation therapy	This treatment uses high-energy radiation to shrink tumours and kill cancer cells
Surgical oncologist	A surgeon who removes the tumour and nearby tissue during an operation. He/she may also perform procedures to obtain tissue samples

Targeted therapy	A drug that works by targeting specific parts of cancer cells to stop the growth and spread of cancer. Unfortunately, the cancer cell targets for most of these drugs are very rare in SqCLC
Tissue	Groups of cells in your body that perform specific functions
Tumour	An abnormal mass of tissue. Tumours are formed when cells grow more than they should or do not die when they should

