

Understanding your small cell lung cancer



Introduction

If you or someone you care for has lung cancer and has just been told about small cell lung cancer, then it's almost certain that you will have a lot of questions.

We have produced this booklet in partnership with lung cancer experts and people affected by lung cancer to help you make positive, informed choices about your care and treatment. Use this booklet along with the information provided by your healthcare team.

Remember that most healthcare professionals are only too happy to answer questions and help you with things that may be unclear or causing you concern.

We hope that this booklet answers your questions about small cell lung cancer. If you would still like to talk to someone about this, call our free and confidential **Ask the nurse** service on: **0800 358 7200** or email: lungcancerhelp@roycastle.org

You can also contact one of the many support organisations listed in our *Living with lung cancer* booklet. Order a copy by calling us on **0333 323 7200 (option 2)** or look at the contacts on our website: www.roycastle.org/usefulcontacts



As well as affecting how you receive treatments and other healthcare services, the coronavirus (COVID-19) pandemic may also affect other aspects of your life such as visiting relatives, shopping, going on holiday or other activities. Your medical team and government websites will be able to give you information about how to keep yourself safe.

We would like to acknowledge Anne Hunt, who features on the front cover, for her support in helping us to produce this booklet.

Contents

○ Understanding your small cell lung cancer	4
What is small cell lung cancer	4
Assessing small cell lung cancer	5
○ Getting your test results	12
Staging small cell lung cancer	12
○ About your treatment and care	14
How doctors decide on treatment options	15
Making a decision about your treatment	15
○ Treating small cell lung cancer	17
Treatments by stage	20
What happens after first-line treatment?	22
○ During and after your treatment	24
After your treatment ends	25
What if your cancer comes back?	27
○ Living with small cell lung cancer	29
○ Outlook: further support and care	33
○ Questions to ask your doctor or lung cancer nurse	38

Understanding your small cell lung cancer

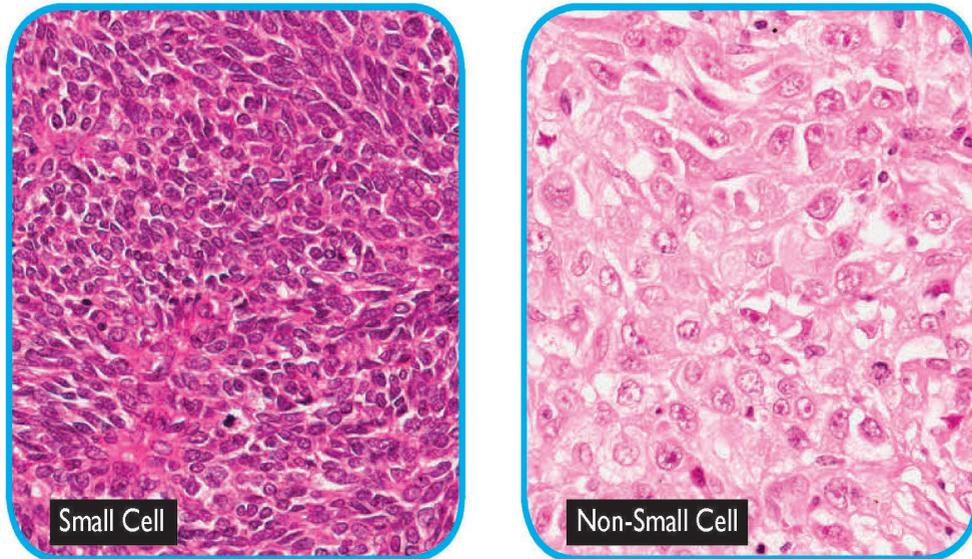
What is small cell lung cancer?

Lung cancer is a term used to describe abnormal cancer cells that start to grow inside the lung. These cells can grow to form a lump or *tumour*.

There are many different lung cancers that fall into two main groups:

- non-small cell lung cancer (NSCLC), and
- small cell lung cancer (SCLC)

SCLC is much less common and only 10-15% of people with lung cancer have it. It gets its name because, when the cancer cells are viewed under a microscope, they look small and are mostly filled with the cell's nucleus.



Courtesy of Prof AG Nicholson, Royal Brompton And Harefield NHS Foundation Trust.

There is a very rare form of lung cancer that combines SCLC and NSCLC. Less than 5% of lung cancers diagnosed are this type. The malignant tumour arises from transformed cells and contains a component of small cell lung cancer (SCLC) combined with one (or more) components of non-small cell lung cancer (NSCLC).

Compared to NSCLC, SCLC grows and spreads more quickly. This means it is rarely found early stage and may have been present and have spread further than NSCLC before people show symptoms and see a doctor.

Treatments are also different. While both may have chemotherapy, immunotherapy, radiotherapy and surgery as some of the available treatments, how they are used and when will vary. The treatments may also start very soon after diagnosis.

Your healthcare team will carry out a number of tests and procedures to assess and diagnose your cancer before recommending possible treatment options for you.

“Because my chemo was going to start the following week after my diagnosis, everything began to happen so quickly.

But my cancer nurse and my consultant were fantastic. They told me everything that was involved with the process. It was explained fantastically well to me.

Craig”

Assessing small cell lung cancer

Your chest or respiratory specialist will usually be the person who uses a range of tests and procedures to confirm you have lung cancer and what type of lung cancer it is.

Your doctor will carry out medical and physical examinations and ask about your medical history to learn about your symptoms and possible risk factors. They will be checking for signs of lung cancer or other health problems.

If these suggest you might have lung cancer, you will have further tests to look for it. Some of these are described below.

Imaging tests to look for lung cancer

Imaging tests use X-rays, magnetic fields, sound waves, or radioactive substances to create pictures of the inside of your body. These tests may include:

Chest X-ray

A simple X-ray of the chest which can sometimes show abnormalities such as inflammation, infection, scarring or growths, such as tumours.

CT (computerised tomography) scan

This scan is carried out by a radiographer and takes a series of X-rays to build up a 3D image of the inside of your body. This helps to find the exact area and size of a cancer and whether it's spread to other organs in your body, your lymph nodes (a key part of your immune system) or your blood vessels.

The scan is painless and should take around 10 to 30 minutes. You may be given a drink or an injection of a dye to help the scan highlight areas in your body more clearly. Once the scan is over, you'll probably be allowed to go home.



MRI (magnetic resonance imaging) scan

This test uses magnetism rather than X-rays to create detailed images of areas of your body.

Sometimes people are injected with a dye (*contrast medium*) to help make images show up more clearly.

The procedure, carried out by a radiographer, is painless but can be a bit noisy. Because you have to lie in a long tube for about 30 minutes, you may find it a little uncomfortable.



Source: Photo kindly supplied by The Christie.

You will also have to complete and sign a checklist about whether you have any metal in your body. Having something metallic in your body doesn't necessarily mean you can't have an MRI scan, but you should make sure you tell the radiographer if you have a metal plate, an artificial joint or a cochlear implant, for example.

If you have a pacemaker, it usually means you will not be able to have a scan of this type.

PET (positron emission tomography) scan

This scan gives pictures showing where there is active inflammation or cancer throughout the body. A PET scan is likely to be used to make sure that curative treatment is possible before lung cancer surgery and radical radiotherapy are considered as treatment options. A PET scan is more accurate than a CT for this.

This type of scan can also be used to investigate a suspected cancer if diagnosis has not been possible using other tests.

An injection containing a radioactive substance is given to highlight any active cancer cells. The scan is painless and quiet and you will not be fully encased during the examination. Modern PET scans are usually combined with a CT scan which is performed at the same time – a PET-CT scan.

Bone scan

This scan also involves an injection of a mildly radioactive substance to create images that show bone structures. A radiographer then uses these images to identify areas of bone that appear abnormal, possibly affected by cancer. There is usually a wait of two to three hours between the injection and the scan taking place.

Other procedures to diagnose and assess lung cancer

The results of imaging tests, along with your symptoms, may suggest to your chest physician that you have lung cancer. However, an actual diagnosis is made by examining a sample or cells from any suspicious areas in your lungs under a microscope.

Lung biopsy

The sample of cells used to identify the type of lung cancer you may have is called a *lung biopsy*. A lung biopsy may be taken in several ways, some of which are described below. Your doctor will explain which method is most appropriate in your case and will ask for your consent before going ahead.

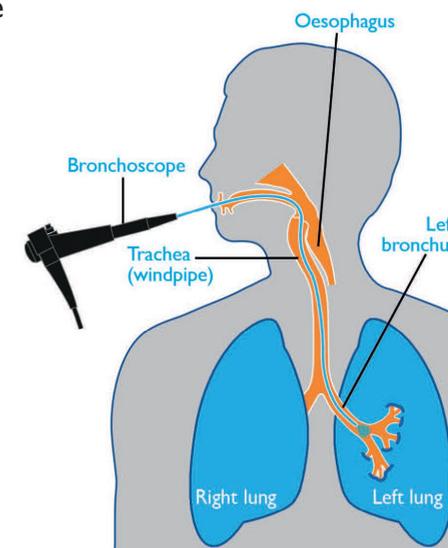
Needle biopsy

A needle biopsy is a procedure that uses a thin, hollow needle and a syringe to extract cells, fluid or tissue from a suspicious lump or other abnormal area of the lung. The material is then examined under a microscope or tested in the laboratory to determine its cause. This may be carried out during a CT scan to help guide the needle.

Bronchoscopy

This involves a doctor passing a flexible tube, called a *bronchoscope*, down your windpipe and into your lung near the suspected tumour. The procedure isn't painful but it can be uncomfortable, as the tube will be inserted down your nose or throat for a few minutes.

You will usually have this procedure as an outpatient, or day case. To help you relax, you may be given a mild sedative to help you relax. Once you are comfortable, a local anaesthetic will be sprayed in the back of your throat to make it numb.



Sometimes a *rigid* bronchoscope is needed to get a better image of your lungs and airways. If so, you'll be given a general anaesthetic, and there's a possibility that you might need to stay overnight in hospital.

Endobronchial ultrasound (EBUS)

This also uses a type of bronchoscope (see above). This one has a small ultrasound probe on the end that creates images of the area around your heart and lungs, and to show if any nearby lymph nodes are bigger than normal.

A needle may also be passed down this bronchoscope to take a lung biopsy. Your doctor will carry out the procedure under local anaesthetic and offer you a mild sedative to help you relax during the procedure.

It will usually take less than an hour, and you should be able to go home the same day.

Mediastinoscopy

This is a surgical procedure that's used to examine the lymph nodes under the breastbone (those closest to the lungs).

A doctor will make a small cut at the base of your neck, just above the breastbone, and insert a thin, flexible tube with a camera on the end of it. The doctor will then use a monitor to look out for anything that may need further investigation.

This procedure is done under a general anaesthetic and will require you to have a short stay in hospital.

Lung function tests

If your treatment is going to involve radiotherapy or surgery, you may be asked by your doctor to do some breathing tests. These will help to determine how well your lungs are working.

A technician will ask you to blow into a machine through a mouthpiece. They will ask you to blow as hard and long as you can.

The machine will record how much air you can breathe in or out and how much oxygen your lungs absorb. The results help to predict how well your body would cope if part of a lung was removed or affected by radiotherapy.

Performance status

Treatments that may be available to you are also determined by your *performance status*. This is a widely accepted World Health Organisation (WHO) scale of how physically capable a person is, giving an indication of how well they may tolerate treatments. It is on a scale of 0 to 4:

- 0 – able to carry out all normal activity without restriction
- 1 – restricted in strenuous activity but ambulatory and able to carry out light work
- 2 – ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
- 3 – symptomatic and in a chair or in bed for greater than 50% of the day but not bedridden
- 4 – completely disabled; cannot carry out any self-care; totally confined to bed or chair

Your doctor will use the results of your tests and assessments to work out your performance status.

Getting your test results

Your chest or respiratory specialist may ask you to return to the hospital when your test results come through. Some test results may be available within a few days, but some can take a couple of weeks to come back. This can be worrying, so ask your doctor how long the results might take.

At your appointment, they will talk to you about what the results mean for you. If you have lung cancer, they will tell you about what happens next. This would typically be a referral to a cancer specialist (*oncologist*) who will be part of a larger team of health care professionals responsible for providing your treatment and care.

The results will be able to confirm if you have small cell lung cancer. They will also be able to help your cancer team see if your cancer is small or if it has grown and spread.



Staging small cell lung cancer

When doctors evaluate the extent of a person's cancer, they call it *staging*. Having this information helps your doctors to decide on the best treatment for your cancer.

Part of staging is the *TNM system*. In this system, T (followed by a number 1 to 4) refers to the size of the tumour, N (followed by a number 0 to 3) refers to any spread of the cancer to lymph nodes, and M (followed by 0, or 1a, 1b or 1c) refers to any spread of the cancer to other parts of the body, known as *metastases*.

Combinations of these letters and numbers identify the extent, or spread, of the lung cancer in stages 1 to 4. Stage 1 means the cancer is small and in one area of the lung (*localised*), while Stage 4 means the cancer has spread to another part of the body (*secondary or metastatic cancer*).

For small cell lung cancer, your doctors may also refer to a simplified stage grouping approach, based on the TNM system. They would typically put someone's SCLC into *limited-stage* or *extensive stage*. In very rare cases, they may class it as *early-stage* SCLC.

These stages are described below:

Early-stage

The lung cancer is a small tumour that has not spread beyond one lobe in a lung and does not affect any lymph nodes. It is very uncommon for small cell lung cancer to be diagnosed at this stage as it has most often already spread beyond the lung when it is found.

The TNM system would describe this stage in the range T1–2a, N0, M0.

Limited-stage

The cancer is larger but is still limited to one lung (no metastases). It may or may not be affecting nearby lymph nodes.

The TNM system would describe this stage in the range T1–4, N0–3, M0.

Extensive-stage

The cancer has spread outside the lung, for example to the other lung, or into the bones or brain.

The TNM system would describe this stage in the range T1–4, N0–3, M1a/b.

Generally, a lower stage of lung cancer is linked to a better outcome. However, cancer affects everyone in very different ways. The right treatment for you depends on tumour stage and other factors such as your general fitness and any other medical conditions you may have.

About your treatment and care

The key people involved in your care are likely to be a clinical or medical oncologist and a lung cancer nurse specialist.

If you are diagnosed with lung cancer, you may be introduced to a lung cancer nurse specialist (LCNS). They can help you understand and come to terms with your diagnosis and offer a wide range of support and information throughout your cancer journey.



“We’re there before diagnosis, if there’s a suspicion of cancer. And we’ll be there when there is a diagnosis. We’re also the patient’s key contact, and make referrals to other teams, as well as speak to family members.

It’s all about coordination and support, and being a constant contact throughout.

Lucy Scott,
Lung Cancer Nurse Specialist, Frimley Park Hospital



If you don’t meet a nurse, or you do but don’t have their details, you can call us free on our **Ask the nurse** service: **0800 358 7200** to find out who your local lung cancer nurse specialist is and how you can contact them.

The doctor responsible for your treatment and care will most likely be an *oncologist*. These are doctors who provide non-surgical treatments for cancer including chemotherapy (*medical or clinical oncologist*) and radiotherapy (*clinical oncologist*). An oncologist is usually the person responsible for prescribing and supervising your course of treatment.

How doctors decide on treatment options

Your oncologist will take your case to a meeting of a group of health care professionals, known as a *multidisciplinary team* (MDT). This team meets to consider most cases and talk through people’s treatment options.

MDTs are usually made up of several health care professionals including chest or respiratory physicians, lung cancer nurse specialists, medical and clinical oncologists (cancer doctors) specialising in lung cancer, surgeons and radiologists. The teams vary depending on where you are getting treated.

When considering treatment options for you, they will take into account the type of cancer you have, its stage and your performance status. SCLC is treated according to national guidelines (best practice) and your cancer team will follow these when planning your treatment.



There is more information about multidisciplinary teams in our *Managing your lung cancer diagnosis* booklet that is part of our *Lung cancer – answering your questions* pack. You can order a copy by calling us on: **0333 323 7200** (option 2).

Making a decision about your treatment

Your cancer team will have considered the results of all your assessments and tests before deciding what they consider to be your best treatment options. The final decision about whether or not to go ahead lies with you so ask as many questions as you need to understand what is likely to happen.

Small cell lung cancer can spread quickly so there is likely to be little delay before you hear about your treatment options. It is still important for you to be confident that you’ve made the right choice, so do ask for more time to think about things if you need it.

Some of the treatments you may be offered are described below and when they might be used, depending on the stage of your SCLC. Cancer treatment can be complex so speak to your cancer team about things you don't understand.

You can ask for a second opinion about your treatment options if you are unsure about the treatment plan you have been offered. You also have the right not to go ahead with treatment for your cancer even if it has been offered to you.



This can feel like a very big decision with a lot of things that are difficult to understand. Weigh up for yourself the benefits and risks of treatment and consider possible side effects.

There are some questions you may want to ask your cancer team on page 38.

You do find some patients live from appointment to appointment. So it's important they do their living between appointments, such as a break or spending time with their family.

It helps to focus on something other than their cancer.

Anne

Treating small cell lung cancer

As mentioned earlier, the treatments you may be offered for your lung cancer will be determined by its stage and your performance status. Clinical trials have shown what works most effectively and these approaches are written into national guidelines that doctors follow.

Some of the main treatment options, such as chemotherapy, immunotherapy, radiotherapy and surgery are described below. These may be used at different stages of SCLC and the treatment options within each stage are on pages 20 to 22.

A first-line treatment is a treatment that is used before other treatments. Subsequent treatments may start if that first treatment stops working and these would be *second-line* or *third-line* treatments.

Your cancer team will speak to you about which treatments may be most suitable for you and answer any questions you may have. You may have more than one type of treatment.

Chemotherapy

Chemotherapy is often the first type of treatment for SCLC which can grow and spread quickly. Chemotherapy is a *systemic* treatment, meaning it is able to reach all parts of your body through your bloodstream. It can therefore reach and affect cancer that is no longer confined to one tumour in your lung.

SCLC can also respond well to chemotherapy. Treating it systemically can relieve symptoms such as coughing and breathlessness.

Chemotherapy drugs are usually injected into a vein. Treatment happens in a chemotherapy day unit and you will receive several *cycles* over three to four weeks. There will be days when you receive treatment, and days in between when you don't and can recover.

Treatment is given in cycles because it works by affecting cells that are growing or dividing. As not all cells are always doing this, staggering treatments in this way mean more cancer cells are affected (killed off) than if the treatment was given once.

The number of cycles you have will depend on how your cancer reacts to the treatment, but it's often four to six.



For more information, our *Chemotherapy for lung cancer* booklet can be viewed at: www.roycastle.org/ayqpack or you can order a copy by calling us on **0333 323 7200** (option 2).

Immunotherapy

Immunotherapy is a drug treatment used to treat some types of cancer, including lung cancer. These drugs help the body's immune system find, attack and kill cancer cells.

For previously untreated extensive-stage SCLC, the drug atezolizumab (Tecentriq®) may be used but only in combination with some chemotherapy drugs.

Immunotherapy drugs are injected into a vein. Treatment happens in a chemotherapy day unit and you will receive several treatments over several cycles every three to four weeks. There will be days when you receive treatment, and days in between when you don't and can recover.



For more information, our *Immunotherapy for lung cancer* booklet can be viewed at: www.roycastle.org/ayqpack or you can order a copy by calling us on **0333 323 7200** (option 2).

Radiotherapy

Radiotherapy uses high-energy radiation to target and kill cancer cells in the body. For small cell lung cancer, radiotherapy is used:

- concurrently (together) with chemotherapy
- following chemotherapy

Prophylactic cranial irradiation

Prophylactic cranial irradiation (PCI) is a type of radiotherapy sometimes used as a treatment for small cell lung cancer. PCI involves treating the whole brain with a low dose of radiation. It is used to treat undetectable cancer cells in the brain that may otherwise grow in the future.



For more information, our *Radiotherapy for lung cancer* booklet can be viewed at: www.roycastle.org/ayqpack or you can order a copy by calling us on **0333 323 7200** (option 2).

Surgery

If your cancer has been diagnosed at an early stage and has not spread outside of your lung, there may be a chance that it can be removed with surgery. Small cell lung cancer (SCLC) has usually spread to other parts of the body by the time it is diagnosed, so an early-stage SCLC diagnosis is not common.

There are different types of operation for lung cancer. Your surgeon will talk to you about which is best for you. The aim of the surgery will be to remove your cancer and the lymph nodes in your chest.

Surgery in these circumstances is very rare, especially as a treatment option following a diagnosis of SCLC. It may be the case that lung surgery is carried out because something suspicious has been detected on a scan and any tissue removed may then be found to be SCLC.



For more information, our *My lung surgery* booklet can be viewed at: www.roycastle.org/ayqpack or you can order a copy by calling us on **0333 323 7200** (option 2).

Treatments by stage

The treatment options described above may be used alone or in a combination that is best for your lung cancer depending on its stage and other factors such as your performance status.

Everyone's situation is different and your treatment may vary from these general guidelines.

Treating early-stage SCLC

Small cell lung cancer can grow and spread quickly. This means that it is very rare for it to be found when it is still early stage. If you are found to have early-stage SCLC, your doctors may offer you surgery to remove the cancer, and this may be followed by chemotherapy.

This is because the cancer would still be contained within one tumour and not have spread, and a surgeon could try to remove it all. Some early-stage SCLC may not be operable, and another treatment option may be more suitable.

Treating limited-stage SCLC

Limited-stage SCLC has several treatment options. The main first-line treatment is likely to be 4 to 6 cycles of chemotherapy, most commonly *etoposide* combined with *carboplatin* or *cisplatin*, a drug that contains platinum.

If you have kidney problems, and a performance status of 2 or higher (less able) with other health conditions, you may be offered combination chemotherapy of *etoposide* with *carboplatin*.

You may be offered twice-daily radiotherapy with *concurrent* chemotherapy (*chemoradiotherapy*) if you have a good performance status (0 or 1) and your SCLC is not bigger than an area that can be treated by radical radiotherapy. These two treatments run in parallel. Your radiotherapy would start during your first or second cycle of chemotherapy. This could be twice a day though may be once a day if you choose that or your cancer team think that twice a day would be too much for you.

Some people may not be well enough for concurrent chemoradiotherapy. If this is you, you may be offered radiotherapy *after* chemotherapy if your lung cancer has responded to it.

For people with a performance status of 0 to 2, and whose SCLC has not got worse during their first line treatment, prophylactic cranial irradiation may be offered. Alternatively, your doctor may suggest ongoing monitoring, with regular head scans.

Treating extensive-stage SCLC

There are two main first-line treatment options if you have extensive stage SCLC.

One possible first-line treatment option, if you have a performance status of 0 or 1, is immunotherapy using *atezolizumab* (Tecentriq®) with combination chemotherapy of *etoposide* and *carboplatin*.

The other possible first-line treatment, if immunotherapy is not suitable for you, is platinum-based combination chemotherapy if your doctors assess you as being fit enough to receive it.

You could receive up to six cycles of this treatment depending on how well your cancer responds to it and if side effects are under control. Your doctors would assess your fitness to continue with treatment before each treatment cycle. If you are not strong enough for this, your doctor may choose to use single-agent chemotherapy such as carboplatin.

If the cancer in your chest area or other parts of your body has responded partly or completely to the combination chemotherapy, you may be offered radiotherapy to your chest area along with prophylactic cranial irradiation (see page 19). Alternatively, your doctor may suggest ongoing monitoring, with regular head scans.

What happens after first-line treatment?

First-line treatment can often be effective at reducing and managing SCLC but there is a high likelihood of it coming back. If this happens, your cancer doctor will meet with you to talk about options you may have.

If you are still well enough to have chemotherapy, re-treatment with your original chemotherapy may be considered suitable, especially if it has been more than three months since your last chemotherapy finished. If re-treatment with the original chemotherapy is not planned, different chemotherapy drugs may be used as further (second- or third-line) treatment, and these include:

- a combination of cyclophosphamide, doxorubicin (Adriamycin®) and vincristine, in what's known as the 'CAV' regime
- topotecan, used on its own and taken as a tablet, if you are not being offered re-treatment with your first-line chemotherapy and the CAV regime is not suitable for you
- to manage or shrink tumours in other places

You may also be offered radiotherapy as a palliative treatment to help manage some symptoms you may have such as pain, a cough or breathlessness. When first-line treatments do not work at all, and the cancer keeps growing, it means that second-line treatments are also unlikely to work. Your cancer team will make sure you understand what options you have if this is the case for you.

Clinical trials

Clinical trials are an essential part of medical research. They can find out if new treatments are better than current best practice. On some clinical trials, your condition may be monitored more regularly than with standard care. This may include more blood tests, CT scans or other cancer tests. You may also spend more time with your doctor or nurse.

This could mean that any changes in your health, whether or not they are related to the treatment you are having, are frequently picked up and acted upon earlier than if you were not in a trial.

It is important to keep in mind that the drug trial or research study on a new treatment is only carried out to find if the new option is better than what is currently offered. It may be the same, or it may be worse. Drugs tested in trials may also not be made available to everyone on the NHS after the trial ends.

Ask your cancer doctor about any clinical trials. Getting into a trial is not automatic and often based on being able to meet some very specific criteria. Your cancer doctor will be able to tell you if you are eligible.



To check what clinical trials are available, visit:

UK Clinical Trials Gateway: www.bepartofresearch.nihr.ac.uk

Cancer Research UK: www.cancerresearchuk.org/about-cancer/find-a-clinical-trial

During and after your treatment

Your healthcare team can give you the contact details of a professional you should call if you have any physical problems or notice any new symptoms between appointments. This key worker is often a lung cancer nurse specialist, but it may also be a doctor or other health professional.

It is important that you contact them as soon as you have any concerns, or if you struggle with the ongoing side effects, such as breathlessness.

Between appointments you may also begin to struggle emotionally. People often feel abandoned or isolated after the end of their treatment because they have much less contact with the doctors and nurses who cared for them for so long.

How you can help yourself during treatment

There are a number of things you can do to help make your treatment as successful as possible, speed up recovery, reduce side effects of treatment and prevent cancer returning.

If you are a smoker, the most important thing you can do is to give up smoking. We know that this can be particularly difficult. But even trying and not achieving your goal is better than not trying at all. Stopping smoking can help reduce side effects from treatments, increase their effectiveness and improve your quality of life.

Ask your cancer team about smoking cessation support services that may be available locally. Other things you can do to help yourself include:

- eating a healthier diet
- exercise at a level you find comfortable (it could just be walking to the shops)
- learning some relaxation techniques to ease any anxiety



Please see our *Living with lung cancer* booklet for more information. See page 2 for details on how to get a copy.

After your treatment ends

After your treatment ends, you will receive a *treatment summary* and your cancer team will work with you to develop a personal *follow-up care plan*.

The treatment summary describes the treatment you had. It will include information about side effects or possible late side effects of your treatment (side effects that may begin after your treatment has finished), as well as any symptoms you should look out for and tell your specialist about.

The plan for your follow-up care will include:

- the dates of your follow-up appointments
- information about future tests or investigations you might need
- the contact details for your cancer team

It will tell you how your health will be monitored over the coming months and years, including regular check-ups at your hospital or with your GP or community nurse.

How often these check-ups happen will depend on the treatment you've had and how well it has worked. You will usually have your first check-up two to six weeks after treatment has ended.

You will then begin to have appointments at regular intervals after this, for example, every three months. These will then become less frequent as time goes by.

It's important you always attend your check-up appointments because they help professionals to check whether your cancer has come back, and an appointment may involve tests that can spot recurrence early.

I did go on holiday and I'm planning more holidays for the future. I'm trying to plan things to look forward to and not worry too much.

Although at the back of your mind you are always thinking your next follow-up appointment is coming up.

Anne

Follow-up is also important because it gives you an opportunity to talk about any long-term and late side effects you're experiencing. Your doctor may help to manage these side effects themselves, or they may refer you to a service that can.

In addition, follow-up appointments also give you an opportunity to ask any questions you have to talk about any worries. Getting answers to these questions from a professional who knows your individual circumstances can provide great reassurance and help you feel more in control of your situation.

You should also have a *holistic* needs assessment. You and your cancer team will talk about any needs or concerns you have about your physical, emotional and spiritual health, as well as your work and family life.

Every assessment will result in a personalised care plan being created. This is a summary of the issues and concerns you mentioned and the help they suggested, or support that is already in place.

Ideally, you should receive a copy of this plan, as you may wish to update it at follow-up appointments. Your GP should also have a copy.

Your doctor or lung cancer nurse specialist will take the time to discuss your treatment summary, and your GP should receive a copy. If you're not given a copy, you can ask your hospital team for one.

How you can help yourself after your treatment ends

After finishing your treatment, it is important to prioritise and focus on your health and wellbeing. Enjoying yourself can be highly beneficial.

If you feel well enough, try to spend quality time with family and friends, do activities you enjoy, or try something you've always wanted to do but never have. This can be great for the mind, body and soul.



If you would still like to talk to someone about this, call our free and confidential **Ask the nurse** service on: **0800 358 7200** or email: luncancerhelp@roycastle.org

What if your cancer comes back?

Small cell lung cancer is very difficult to remove entirely from your body. This means it's likely that your cancer will return at some point after your initial treatment.

This could happen weeks, months or even years after your original diagnosis. The cancer may show up again in your chest or another part of your body.

Although this is likely to be a very frightening time for you and your loved ones, your healthcare team will be there to support you, just like they did throughout your original treatment.



You will be assessed by the thoracic oncologist. This may involve restaging tests and a re-biopsy to plan further treatment. They will decide with you all of your treatment options depending on:

- the type, size and location of the cancer that has returned
- your overall health
- the type of treatment you originally received and how well it worked
- any adverse effects you've experienced after your original treatment
- how long it has been since your treatment finished

Your doctors may suggest a second-line therapy if you're well enough to receive it. This will normally involve you receiving a different type of chemotherapy to your first-line therapy, or radiotherapy to control symptoms.

The most effective treatment options will be discussed with you by your doctor. If your disease has not responded to first-line treatment, there is very limited evidence that second-line chemotherapy will be of benefit.

Emotionally, you may even find that the return of your cancer is more upsetting than your original diagnosis. You may also have doubts about your original treatment, but it's important to remember that you and your doctor based your choices on all of the information available to you at the time.

If you do begin to struggle with emotions such as shock, fear or anger, or a feeling you're losing control, it's important that you talk to your healthcare team or GP about this. They will be able to support you or direct you to services that can help.

Living with small cell lung cancer

Being diagnosed with lung cancer can be distressing for you and your family. It can turn your world upside down.

It's highly likely that you and your family will be affected by a wide range of emotional, practical and financial issues, during and after treatment.

In this section we look at some of the main problems you may face and who can help you cope with them. This will mainly be members of your healthcare team, but there are many other excellent support services you can access which may feel right for your particular situation.

In addition, we also have lots of helpful information that you can read at: www.roycastle.org/living-with-lung-cancer

Emotional and practical issues

It's not unusual for people diagnosed with small cell lung cancer and their loved ones to react to the diagnosis in many different ways. It's also common for people to experience and struggle with different emotions at different times during their own cancer experience.

Some of the emotions you and your family may experience include shock, fear, denial, anger, guilt, resentment, sadness and a desire to be left alone.

To cope with these feelings, you may find it helps to speak to family and friends.



If this isn't the right option for you, or you feel you need professional support as well, don't be worried about asking members of your healthcare team for additional support. They will be able to help you manage difficult emotions or direct you to specialist help such as counselling.

If you would like to talk to someone about this, call our free and confidential **Ask the nurse** service on: **0800 358 7200** (Monday to Thursday, 9am to 5pm, and Friday, 9am to 4pm) or email: lungcancerhelp@roycastle.org

However, you may really just want to talk to other people affected by lung cancer about how you're feeling.

Speaking to people who really understand what you're going through, and who may have had similar treatment, could make a big difference to your emotional wellbeing.

If you're interested in joining a lung cancer support group or chatting to people affected by lung cancer online, please see the 'Help and support' section of our *Living with lung cancer* booklet.

I tend not to do things like go to a support group, but the first time I went, I loved it. You're amongst people that are in the same bracket as you.

It's lovely just to sit and talk to them.

Craig

Throughout your cancer journey there may be a number of practical issues you need to consider. Your health and social care team, and more often than not your lung cancer clinical nurse specialist, will be able to help you with these or direct you to someone who can meet your needs.

Practical issues that your healthcare team should be able to help you with include:

- **physical conditions**, such as tiredness and breathlessness, that make everyday tasks difficult
- **specialist equipment** to help in your home and with your everyday needs
- **support at home** so you receive the care you need and your carers get a break from their caring role
- **transport**, including getting help to attend medical appointments and applying for the Blue Badge Scheme, which allows people with mobility problems to park closer to where they want to go
- **body image concerns**, including hair loss, scarring and weight loss or gain

Money and work

There may be welfare benefits and other financial support you and your carers can claim to help ease the financial pressure caused by your diagnosis.

The benefits system can be confusing. You may find it helpful to speak to an expert, such as a welfare rights adviser, to make sure you receive all the financial support to which you are entitled.

To find out where your nearest adviser is located, speak to your clinical nurse specialist or another member of your health and social care team.

You may discover one operates from the hospital where you're being treated, a local cancer support centre or a location in your community.

If you are thinking about retiring on the grounds of ill health, weigh up the immediate benefits against the long-term consequences for you and your family.

Advisors from trades unions or the Citizens Advice Bureau can help you if you have problems with your mortgage, insurance and pension.

For more information, about all these topics, please see our *Living with lung cancer* booklet (see page 2).

Family impact

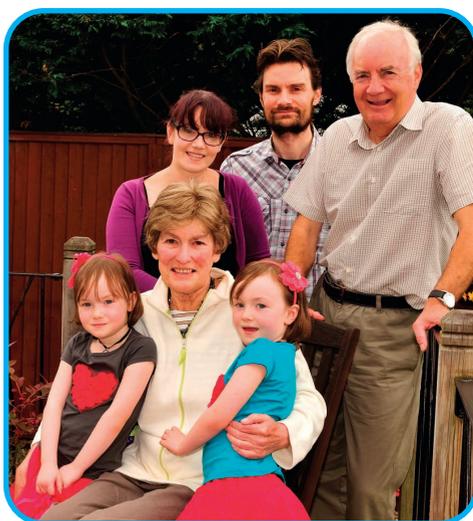
You may find it difficult to find the right words to talk to your family, including your children or grandchildren, about your cancer and treatment, and what may happen to you in the future.

Being honest and open about what's happening is usually the best option.

To help you have this conversation, you may find it helpful to talk to other adult members of your family about what you want to say and the best way of saying it.

Or you could speak to your lung cancer clinical nurse specialist for advice.

You can also search for "Talking to children about cancer" on the NHS Choices website: www.nhs.uk



Outlook: further support and care

The success of your treatment depends on the stage of your small cell lung cancer. Too often SCLC is already advanced when it is diagnosed.

If you are in this situation, your treatment options may be limited. It can be difficult to adjust knowing your cancer cannot be cured and may mean you have less time than you had thought.

You may need emotional and practical support and there are organisations that can help. It can help to prioritise activities that matter to you and help you feel well. Good support can also help you manage any side effects of the cancer.

If you are considering looking at or asking about survival statistics, be aware they are not specific to your situation and your treatment. Think about how knowing these statistics will affect you.

While they may help you understand your illness, they may also cause unnecessary anxiety. Remember too that research, earlier diagnosis and treatments continue to improve.

Being realistic and hopeful is an approach many people find useful in living well with advanced cancer.

Supportive and palliative care

Supportive and palliative care is an umbrella term for a range of services that help you, your family and other carers cope with your lung cancer and any treatment.

It should be given equal priority to other aspects of your care and begin even before your lung cancer has been confirmed.

This range of services includes:

- social support
- symptom control
- psychological support
- information giving
- self-help guidance

Palliative care is an aspect of supportive care. This is a term used for the range of services available to you if your lung cancer is advanced and progressing, and a cure is not possible. This type of care aims to:

- provide relief from pain and other distressing symptoms
- support your psychological and spiritual needs
- help you to live as actively as possible, and help you, your family and other close to you cope over time
- work alongside treatments, such as chemotherapy and radiotherapy, intended to reduce your symptoms and slow your cancer's progression



Lung cancer is often diagnosed when already quite advanced, so palliative care may be introduced from the start of any investigations or treatment.

The team involved in your care may include:

- your GP
- community nurses
- social workers
- spiritual care professionals
- physiotherapists
- occupational therapists

Using hospice services

You and your family might feel that hospice care is best placed to look after all your needs. The aim of hospice care is to improve the lives of people who have an incurable illness.

Hospice care will ensure that you are treated with dignity and respect. You will receive personalised care ensuring that your physical needs as well as your emotional, social practical, psychological and spiritual needs are looked after. Looking after all these aspects is often referred to as holistic care.

During your care, you can sometimes take break from hospice care if your condition has become stable and you are feeling well.

End-of-life care and bereavement support

The possibility of dying is frightening, but it is important to consider your priorities, needs and preferences well in advance. For example, you might prefer to die at home, if this is possible.

Although it can be a difficult subject, it may help you to talk to your friends, family or clinical team.

Some patients may want to set up a formal Lasting Power of Attorney or an Advance Directive. Others will want to set out plans for their own funeral, to lighten the burden on their family. Your clinical nurse specialist or Macmillan nurse will be able to support you in this.

If you have been caring for someone and are bereaved, it can be an emotional and difficult time. Practical issues in planning for a funeral can take time and energy.

Grief and bereavement affect people in different ways at different times and professional, community and family support can help you manage.

There are also specific resources to support children and young people who are facing the loss of a close family member.

You can get more information and support from:



- **Macmillan Cancer Support:**

www.macmillan.org.uk 0808 808 00 00

- **Marie Curie:**

www.mariecurie.org.uk 0800 290 2309

- **Hospice UK:**

www.hospiceuk.org 0207 520 8200

Where can I get more support?

If you or someone you know or care for needs more support, Roy Castle Lung Cancer Foundation's services can help.

We have one-to-one services:

Our **Ask the nurse** service is a nurse-led helpline offering advice on all aspects of lung cancer including diagnosis and treatment. Please call our experienced team of nurses free on: **0800 358 7200** or email: lungcancerhelp@roycastle.org

Our **Keep in touch support service** offers confidential telephone contact for people with lung cancer and their carers. This service is primarily if you are socially isolated and would like some extra contact. You can have a fortnightly or monthly call over an agree timescale.

We have a range of group support online, by telephone and face to face: Our **lung cancer support groups** and **information days** take place around the UK. These groups meet regularly when restrictions relating to COVID-19 permit and are organised by local lung cancer nurse specialists.

Our **Lung Cancer Connect** services offers online and phone programmes as well as video content to help you adjust to diagnosis, treatment and managing with lung cancer.

Our online lung cancer community lets you share your experience through blog posts and questions with other people affected by lung cancer. You can join free and anonymously at: www.healthunlocked.com/lungcancer

For information on our services please call our Information and Support Team on: **0800 358 7200**, or email: info@roycastle.org

Questions to ask your doctor or lung cancer nurse

Before an appointment with your doctor or lung cancer nurse specialist, it is a good idea to write down a list of questions to ask. These may help you better understand your diagnosis, treatment plan and overall care.

Here are some suggestions and add others that are important to you:

1. What kind of lung cancer do I have?
2. Where exactly is the cancer?
3. Has it spread beyond where it started?
4. What is the stage of my cancer, and what does that mean in my case?
5. Will I need any other tests before we can decide on treatment?
6. Do I need to see any other doctors or health professionals?
7. What are my treatment options?
8. How quickly do we need to decide on treatment?
9. What treatment do you recommend and why?
10. What can I do to prepare for treatment and reduce the chance of side effects?
11. Will I need to change my lifestyle in any way?
12. What can I expect, given my diagnosis?
13. Are there any clinical trials I could potentially benefit from?

About our lung cancer information

We follow established quality standards and production principles to make our information trustworthy and easy to read. It is evidence based, following national clinical guidelines and best practice for managing lung cancer.

We believe information that is clear, accurate, evidence based, up to date and easy to use allows people to become better informed and more involved in their health and care.

Our information is written either by our information team or by lung cancer experts. We have a panel of lung cancer experts made up of doctors, nurse specialists and other health professionals involved in the treatment and care of people affected by lung cancer. These people help us on a voluntary basis. You can find out about our Expert Panel at www.roycastle.org/expertpanel

This booklet has been published in partnership with Lung Cancer Nursing UK.



Our information is also reviewed by members of our Reader Panel (made up of people who have experience of lung cancer). This makes sure our lung cancer information meets their needs. You can find out about our Reader Panel at www.roycastle.org/readerpanel

You can find references to sources of information within this booklet at www.roycastle.org/evidence

If you have suggestions for new publications or additions or improvements to our existing range of booklets and factsheets, please let us know at info@roycastle.org

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ROY CASTLE
LUNG CANCER
FOUNDATION

Roy Castle Lung Cancer Foundation is the charity that gives help and hope to people affected by lung cancer. The charity has two aims – supporting people living with lung cancer and saving lives.

Supporting people living with lung cancer

Working closely with lung cancer nurses, we provide information, run lung cancer support groups and offer telephone and online support. Our patient grants offer some financial help to people affected by lung cancer.

Saving lives

We fund lung cancer research, campaign for better treatment and care for people who have lung cancer, and raise awareness of the importance of early diagnosis. Our lung cancer prevention work helps people to quit smoking and encourages young people not to start smoking.

Contact us

For more information, call our Lung Cancer Information and Support Services:
0333 323 7200 (**option 2**)
or visit our website: www.roycastle.org

Head Office

Cotton Exchange Building,
Old Hall Street,
Liverpool, L3 9LQ
Email: foundation@roycastle.org

Information and Support Services

98 Holm Street,
Glasgow, G2 6SY
Email: info@roycastle.org

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