Understanding your small cell lung cancer
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

“This booklet is the best explained information on small cell lung cancer that I’ve seen.”

Graham

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

What is small cell lung cancer?
If you or someone you care for has lung cancer, it may be useful to understand more. A diagnosis of lung cancer can be distressing. Lung cancer is a term used to describe a growth of abnormal cells inside the lung. These cells grow to form a lump that is often referred to as a tumour.

There are many different types of lung cancer, but generally the illness is split between two main ones: non-small cell lung cancer (NSCLC) and the less common small cell lung cancer (SCLC).

10-15% of people with lung cancer have small cell lung cancer. 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.

Combined SCLC/NSCLC is a rare form of lung cancer. Less than 5 out of every 100 lung cancers diagnosed are this type (5%). 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).
The treatment recommended will depend on the type and stage of your cancer. Different treatments are used for non-small cell and small cell lung cancer. Small cell lung cancer is usually treated with chemotherapy and radiotherapy initially. Surgery is rarely recommended for patients with small cell lung cancer.

“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

Your health care professional team

Who might be involved in my treatment care?

Your cancer doctor, usually a clinical or radiation oncologist, is the person who is responsible for prescribing and supervising your course of treatment. It’s useful to establish who you are talking to and to make a note of their name.

The treatment recommended for you will be one that offers the most benefits, keeps you well for longest and has lower risks or fewer side effects.

Your case may discussed by a group of health care professionals, known as a multidisciplinary team (MDT). They will talk through treatment options.

Your team will vary, depending on where you are getting treated. It will usually include a lung cancer nurse specialist, a chest physician, surgeon, medical and clinical oncologist (cancer doctor) specialising in lung cancer, radiologist, histopathologist, dietician and palliative care team.
Your chest or respiratory physician – what to expect
When you meet your chest physician at your hospital they will ask you about your general health and whether you’ve had any previous medical problems. They’ll also examine you and talk to you about what scans and tests they’d like to carry out.

If you haven’t already had a CT scan, they’ll arrange for one to take place to check for abnormalities such as inflammation, infection, scarring or growths. They may also ask you to give samples of your blood, urine, or other substance in your body which will be examined in a laboratory.

A sample of cells or tissue may be taken which will be examined under a microscope to check for signs of cancer. This is called a biopsy.
Your clinical 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 then 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 to you can contact them.

Oncologist
This is a doctor who provides non-surgical treatments for cancer including chemotherapy and radiotherapy.
Tests for lung cancer
Your chest specialist will use one or more of the following tests to help identify whether you have lung cancer and what type of lung cancer it is. The results of these tests are usually available within a few days, but sometimes it can take a couple of weeks before they come back. The actual diagnosis of lung cancer is made after looking at a sample of your lung cells under a microscope.

Medical and physical examination
Your doctor will ask about your medical history to learn about your symptoms and possible risk factors. You will also be examined for signs of lung cancer or other health problems.

If the results of your medical and physical examination suggest you might have lung cancer, you will have tests to look for it. These could include imaging tests and/or biopsies of lung tissue.

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. A number of tests may be done including:

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

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 10–30 minutes. You may be given a drink or an injection of a dye to help 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 a detailed image 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 rather noisy.

Because you have to lie in a long tube for about 30 minutes, you may find it a little uncomfortable. You will also have to complete and sign a checklist about whether any metal may be contained in your body. This will determine whether you can have the scan.

**PET (positron emission tomography) scan**

This scan gives pictures showing where there is active inflammation or cancer throughout the body. A PET scan should be used before lung cancer surgery and radical radiotherapy, to make sure that curative treatment is possible (a PET scan is more accurate than a CT for this). A PET 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 scan are usually combined with a CT scan which is performed at the same time – a PET-CT scan.

Source: Photo kindly supplied by The Christie.
Bone scan
This involves a small dose of a mildly radioactive substance being injected into your body. A radiographer then uses a scanner to pick up the substance and form images of abnormal areas of bone. A wait of two to three hours is usually needed between the injection and the scan taking place.

Further tests to diagnose small cell lung cancer
Symptoms and the results of imaging tests might suggest that a person has lung cancer, but the actual diagnosis is made by looking at cells from your lung with a microscope.

Lung biopsy
In order to provide the best treatment, it is important to make an accurate diagnosis by examining a small sample of the tumour under the microscope.

The sample, called a biopsy, can be taken in various ways. It is commonly taken during bronchoscopy. It can also be taken by passing a fine needle into the tumour through the chest wall, during a CT scan.

Your doctor will explain which method is most appropriate for you and will ask for your consent before taking the sample.

Bronchoscopy
This involves a doctor passing a bronchoscope down your windpipe.

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 relieve any discomfort, 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 the use of a rigid bronchoscope is needed to get a better image of your lungs and airways.

If this is required, 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 involves a doctor passing a bronchoscope (see above) down your windpipe. The bronchoscope features a small ultrasound probe to create images of around your heart and lungs, and to show if any nearby lymph nodes are bigger than normal.

A needle may also be passed down the bronchoscope to take a sample of tissue. Your doctor will carry out the procedure under local anaesthetic and also be offered 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.

It is important to follow the directions of the technician and blow into machines via a mouthpiece as long and hard as you can.

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

**Getting the results**
Your doctor may ask you to go back to the hospital when your test results come through. But this is bound to take a little time, even if only a few days.

Contact your lung cancer nurse specialist if you have any concerns or questions or call our free and confidential Ask the nurse service on: 0800 358 7200 or email: lungcancerhelp@roycastle.org
Staging small cell lung cancer

Staging is the process that your doctors will use to describe the size and position of your cancer and whether it has spread. Having this information helps your doctors to decide on the best treatment for your cancer.

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 not just on tumour stage but a number of factors including your general fitness and any other medical conditions you may have.

**TNM staging**

It’s highly likely that your doctors will use the TNM classification system to stage your cancer:

T describes the size of the original (primary) **Tumour** and whether it has invaded nearby tissue.

N describes nearby (regional) lymph **Nodes** that are affected.

M describes distant **Metastasis** (spread of cancer from one part of the body to another).

When your doctor talks to you about the staging of your cancer, it can help you feel more in control of your situation if you fully understand what they’re telling you, so do ask questions to clarify things.

To help you have an idea of what you might be told, we’ve provided an overview of the TNM classification system staging overleaf.
<table>
<thead>
<tr>
<th>Stage 1</th>
<th>The lung cancer is a small tumour that has not spread beyond the lung and does not affect any lymph nodes.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage 1A</strong></td>
<td>the cancer is no bigger than 3cm in size.</td>
</tr>
<tr>
<td><strong>Stage 1B</strong></td>
<td>the cancer is between 3 and 4cm in size.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage 2</th>
<th>The lung cancer is more advanced but still involves only one lobe of the lung.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage 2A</strong></td>
<td>the cancer is between 4 and 5cm in size.</td>
</tr>
<tr>
<td><strong>Stage 2B</strong></td>
<td>the cancer is up to 7cm in size or has spread to involve the membranes covering the lung or heart, or has spread to involve the closest lymph nodes, or there may also be additional tumours in the same lobe of the lung.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage 3</th>
<th>The lung cancer is more locally advanced.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage 3A</strong></td>
<td>the lung cancer can be any size or has spread to involve the diaphragm, heart, great vessels, trachea (windpipe), nerve to the larynx, oesophagus (gullet) or vertebral bone, or has spread to involve any lymph nodes in the same side of the chest, or there may also be additional tumours in another lobe of the lung.</td>
</tr>
</tbody>
</table>

*continued...*
The lung cancer has developed metastases (secondaries).

Stage 3B – the cancer is at least 5cm in size and has spread to involve any lymph nodes in the same side of the chest, or the cancer is up to 5cm in size and has spread to involve any lymph nodes in the opposite side of the chest or lower neck.

Stage 3C – the cancer can be any size and has spread to involve any lymph nodes in the opposite side of the chest or lower neck.

Stage 4 – The lung cancer has developed metastases (secondaries).

Stage 4A – there are separate secondary tumours in the opposite lung or on the membranes covering the lung or heart (sometimes causing fluid to accumulate in these areas) or in a single site elsewhere in the body.

Stage 4B – there are multiple secondary tumours elsewhere in the body.

IMPORTANT – The TNM 8th edition, 2017 is the staging classification for both non-small cell lung cancer and small cell lung cancer.

Stage grouping system
For treatment purposes, most doctors will use an older, more general classification system to stage your cancer.

Limited stage – cancer is in one lung and (maybe) nearby lymph nodes.

Extensive stage – cancer has spread outside the lung, such as the other lung, brain or bones.
Treating small cell lung cancer

Making treatment decisions
Before deciding on the best treatment options, you will be assessed by a thoracic oncologist, this should include a discussion about your medical history, on whether you have smoked, a physical examination, a complete blood count, liver and kidney test and CT scan.

Because small cell lung cancer spreads rapidly, your doctors may decide quickly on the best treatment for you, or present you with a number treatment options. Although speed is of the essence, it’s important you feel confident that you’ve made the right decision for you, so do ask for more time to consider your options, if you need it.

What will probably help you most when making decisions about your treatment is having high-quality information. That’s why it’s very important you understand everything your doctors tell you about your different treatment options.

After they’ve initially spoken to you don’t be worried to ask your doctor some of the following questions to clarify things:

• What do you think is the best type of treatment for me?
• What may happen after I start this particular treatment?
• How will this treatment affect my everyday life?
• What are the side effects of this treatment?
• What clinical trials are available to me?
It’s also worth noting that you can ask for a second opinion about your treatment options, if you feel it will be beneficial. Plus, you also have the right not to accept any treatment for your cancer. You need to weigh up for yourself the benefits of treatment versus possible side effects.

The treatment recommended to you will depend on the stage of your cancer and your general health and fitness.

If your cancer is very small, 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.

Chemotherapy is an effective first line treatment for more than 8 patients in 10, leading to tumour shrinkage and improved symptoms.

This may be followed by sessions of radiotherapy to kill cancer cells; or if you’re fit enough, you may receive radiotherapy at the same time as your chemotherapy, which is called chemoradiation.

If your cancer is very advanced, your doctor’s aim is then to recommend treatment to reduce symptoms and improve quality of life.

This is often called palliative care or supportive care, and is provided in people’s homes and hospitals and may be provided over days, weeks, months or even years (see page 32 for more information about palliative and supportive care).

You may also find it helpful to ask your doctors for statistics about different treatments.

However, while statistics can give you an idea of what may happen in the future, your doctors won’t be able to say for sure what your outcomes are likely to be.
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

If you’re diagnosed with small cell lung cancer, it is likely you’ll be offered the following treatments.

**First-line therapy** – this is the initial chemotherapy given to treat your small cell lung cancer. Doctors have usually identified it as the best course of treatment for your particular type of cancer and the stage it is at.

**Thoracic radiotherapy** – this should be considered after chemotherapy if there has been a complete response at distant sites and at least a good partial response within the thorax.

**Prophylactic cranial irradiation** – this type of radiotherapy is used to prevent small cell lung cancer from spreading to the brain. It is usually only offered to people whose cancer has not progressed following first-line treatment.

**Second-line therapy** – if your first-line treatment doesn’t work at all, works but then stops, or causes you serious side effects, your doctors may suggest a second-line therapy if you’re well enough to receive it. This will normally involve you receiving a different chemotherapy.

Retreatment with the same regimen is recommended if there has been no progression for more than six months. If relapse occurs earlier or the disease is primarily chemoresistant, an alternative regimen may be offered.
Chemotherapy

Chemotherapy is usually the first type of treatment you receive. This is because SCLC can grow and spread quickly, and has often spread outside the lung when the lung cancer is detected, and responds well to chemotherapy.

Treating it systemically with chemotherapy usually leads to relief of symptoms and longer survival. Radiotherapy may be given after chemotherapy to try to stop the cancer coming back.

Chemotherapy drugs are usually injected into a vein, or sometimes taken orally. Treatment happens in cycles (typically over three to four weeks).

This means you usually take drugs for a few days, have a rest period for your body to recover, and then begin to take the drugs again. The number of cycles you have will depend on how your cancer reacts to treatment, but it’s often four to six.

There are different types of chemotherapy drugs for small cell lung cancer. The most common first line treatment is a combination of etoposide and one containing platinum (cisplatin or carboplatin).

Other drugs that may be used as further treatment (second or third line) after initial chemotherapy, include Topotecan, Cyclophosphamide, Doxorubician (Adriamycin) and Vincristine.

Topotecan, is used on its own, and the other three are used together in what is known as the ‘CAV regime.’

For more information about these drugs visit: www.medicines.org.uk/emc

For more information, our Chemotherapy for lung cancer booklet can 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 kill cancer cells in the body. For the treatment of small cell lung cancer, radiotherapy is used:

- concurrently with chemotherapy.
- following chemotherapy.
- to manage/shrink tumours in other places.
- to reduce risk of cancer spreading to brain.

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 surgery is an option for your cancer, your surgeon will discuss your operation with you. Its aim will be to remove your cancer and the lymph nodes in your chest.

The nodes will be examined for cancer cells to see if your cancer has spread and whether you need further treatment.

You may also be asked to attend a pre-operative assessment clinic. This will involve you having tests to check how well your lungs are working and your general health. These tests will determine if you’re fit enough to have surgery.

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).
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 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
Difficulties between appointments
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 this key worker 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
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 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.

On top of this, 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.
Living with small cell lung cancer

I’ve just been told that I have small cell lung cancer – how will I cope?

Being diagnosed with lung cancer can be a deeply distressing event for you and your family.

Being told you have cancer can feel like your world has been turned 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 about living with lung cancer 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 help you cope with these feelings, you may find it helpful 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 still 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 your healthcare team should be able to help you with include:

*physical conditions*, such as tiredness and breathlessness, which 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 a number of benefits and other financial support you and your carers can claim to help ease the financial pressure caused by your diagnosis.

Because 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 what you’re entitled to.

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 you will have a lot to think about in terms of weighing up the immediate benefits against the long term consequences for your family.

If you have problems with your mortgage, insurance and pension, the advisors from your trade union or Citizens Advice Bureau can help you.

For more information, about all these topics, please see our *Living with lung cancer* booklet (see page 22).

**Family impact**

If you have children or grandchildren aged under 18, you may find it difficult to find the right words to talk about your cancer and treatment, and what may happen to you in the future.

Usually, being honest and open about what’s happening is 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 this.

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

You’ll also find helpful information on the NHS Choices website: [www.nhs.uk](http://www.nhs.uk)

Simply search ‘Talking to children about cancer’ in the search box.
The holistic needs assessment should involve you talking to a member of your healthcare team 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 which is already in place.

Ideally, you should receive a copy of this plan, as you may wish to update it at follow-up appointments and shared with your GP.

The treatment summary describes the treatment you had and what to expect now that treatment has finished.

This will include information about possible side effects or late effects of your treatment, as well as any symptoms you should look out for and tell your specialist about.

The treatment summary will also include the dates of your follow-up appointments, information about future tests or investigations you might need, and the contact details for your cancer team.

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.
**Follow-up care**

After your treatment has finished, your doctor will work with you to develop a personal follow-up care plan.

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

How often these check-ups occur will depend on the treatment you’ve had and how well it has worked. Usually, though, you will 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 on.

“I did go on holiday last year, and I’ve been on holiday this year. 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 discuss 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.

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
What if your cancer comes back?

Small cell lung cancer is an aggressive cancer that spreads quickly, it’s very difficult to remove all cancer cells from your body. This means it’s likely that your cancer will return at some point after your initial treatment.

If your cancer does come back, it could happen weeks, months or even years after your original diagnosis and involve cancer returning to 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:

- what type of cancer has returned, where in the body it is and the size of it.
- your overall health.
- the type of treatment you originally received and how well it worked.
- adverse effects you’ve experienced following your original treatment.
- how long it has been since finishing treatment.

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.
You need to be aware that 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.
Palliative care

Sometimes called supportive care, this helps you manage the side effects of your illness. The care suggested is designed to help you manage better and maintain your quality of life, rather than treating your cancer.

You may be referred to your palliative care team at any stage following your diagnosis. This will mean a palliative care assessment and plan is agreed with you and put in place when you need it.

Early support can help you manage during and after anti-cancer treatment.

If your cancer has spread you may also receive palliative care to help you manage as your health changes, including if and when you need end of life care.

Palliative care services can help you manage symptoms. This can involve services to help you manage pain, side effects such as breathlessness or any other physical symptoms.

The team will also be able to assist you and your family if you are struggling with the emotional and practical impact of your cancer, including if you have advance stage disease that cannot be cured.

The assessment will look at what support you need emotionally and spiritually as well as to help you and your family cope practically.

If you have complex health care issues you may also be referred for a palliative care assessment. Specialists will work with you to organise the right kind of care for you.

This may include input from physiotherapists, occupational therapists and social workers.
The team involved in your care may include your GP, community nurses, social worker and spiritual care professionals.

Where you are cared for will depend on what is right for you over time. This may include home or community support, some hospital based services or care in a hospice or care home.

**Hospice care**

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
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.

If this is a situation, you, or someone you care for finds themselves in, it can help to prioritise activities that matter 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.

First think about how knowing them will affect you. Research, early diagnosis and treatments continue to improve.

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

**How you can help yourself**
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.
Questions to ask your doctor or lung cancer nurse

Prior to an appointment with your doctor or lung cancer nurse specialist, you may want to prepare some questions to ask. These may help you better understand your diagnosis, treatment plan and overall care.

We have suggested some questions below that you may wish to ask. But please add additional questions that are important to you.

What kind of lung cancer do I have?

Where exactly is the cancer? Has it spread beyond where it started?

What is the stage of my cancer, and what does that mean in my case?

Will I need any other tests before we can decide on treatment?

Do I need to see any other doctors or health professionals?

What are my treatment options?
How quickly do we need to decide on treatment?

What treatment do you recommend and why?

What can I do to prepare for treatment and reduce the chance of side effects?

Will I need to change my lifestyle in any way?

How long am I likely to live, based on my diagnosis?

Are there any clinical trials I could potentially benefit from?

If you have any questions or concerns in between appointments, remember that you can 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
My contacts

My GP
Name: ____________________________
Phone number: ______________________
Other contact details: ______________________

My lung cancer nurse specialist
Name: ____________________________
Phone number: ______________________
Other contact details: ______________________

My chest specialist
Name: ____________________________
Phone number: ______________________
Other contact details: ______________________

My lung cancer doctor/s
Name: ____________________________
Phone number: ______________________
Other contact details: ______________________
Name: ____________________________
Phone number: ______________________
Other contact details: ______________________
About our lung cancer information

All of 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 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

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

Our information is accredited by The Information Standard, which makes sure that it is trustworthy, easy to read and reliable. It also must be based on the best clinical evidence that is available.

The information is evidence based and follows national clinical guidelines for the management of lung cancer. You can find references to sources of information within this booklet at www.roycastle.org/evidence

Published: February 2019
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We value your feedback
If you would like to tell us what you think about this information booklet or would like to join our Reader Panel and review our lung cancer information, please e-mail us at info@roycastle.org
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

Expect Better
Roycastleningcancer  @Roy_Castle_Lung

Health & care information you can trust
The Information Standard Certified Member