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 lung cancer, call us free on our nurse-led helpline: 0800 358 7200.

You can also contact one of the many support organisations available on page 58 of our *Living with lung cancer* booklet. Order a copy by calling us on 0333 323 7200 (option 2), or look 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, Graham Thomas and Craig Brydon for their support in helping us to produce this booklet.
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 SCLC 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, contains a component of small cell lung carcinoma (SCLC) combined with one (or more) components of non-small cell lung carcinoma (NSCLC).

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

Who might be involved in my treatment care?
A team made up of various health professionals should be involved in your care. This is sometimes called a multi-disciplinary team or MDT. The purpose of the MDT is to explore the best possible options for you. 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. The table on pages 18-20 of our Living with lung cancer booklet explains the role of each professional who may be involved in your care.

Your chest specialist – 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

At your hospital you may be introduced to a nurse called a lung cancer clinical nurse specialist (CNS). If you are diagnosed with cancer, your lung cancer specialist (CNS) will help you understand and come to terms with your diagnosis, and offer a wide range of information and support throughout your cancer journey.

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

Oncologist

Is a doctor who provides non-surgical treatments for cancer including chemotherapy and radiotherapy.
Tests for small cell 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 small cell 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:

“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
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 is painless and carried out by a radiographer. 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
A scan that gives pictures showing where there is active 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 purpose). 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.

**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. This 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.

**Fine needle aspiration**
This procedure involves a doctor inserting a fine needle into an area of abnormal swelling or lumps located under the skin such as a cysts (fluid-filled lumps), nodules or masses (solid lumps) and enlarged lymph nodes.
**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.

**Tests to find lung cancer spread**
If lung cancer has been found, it’s often important to know if it has spread to the lymph nodes in the space between the lungs (mediastinum) or other nearby areas. This can affect a person’s treatment options.

**Endobronchial ultrasound (EBUS)**
This involves a doctor passing a bronchoscope (see page 10) 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. You will 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.

**Endoscopic ultrasound (EUS)**
This is a procedure carried out by a doctor that’s similar to an EBUS but uses an endoscope (small, flexible tube), which is placed down the oesophagus to provide pictures of around the heart and lungs. It also identifies if lymph nodes in the central chest are bigger than normal. This test is rarely performed and only used in special circumstances.

**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.

**Blood test**
This can help in finding out about your general health and the possible spread of lung cancer. It can provide information on many aspects of health including:

• How well your kidneys and liver are working (Creatinine/LFT’s)
• If your body’s biochemistry is balanced (for example, does it have enough calcium and protein)
• Ongoing/vulnerability to infection (white cell count)
• Anaemia/lack of circulating oxygen (haemoglobin)
• Susceptibility to bruising/bleeding (platelets).
**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 result**

Your doctor may ask you to go back to this hospital when your test results come through. But this is bound to take a little time, even if only a few days. This is a very anxious time for most people. You contact your lung nurse specialist if you have any concerns or questions or call our **free nurse-led helpline on 0800 358 7200**.

“Don’t be afraid ask questions. There’s a lot of help out there from some amazing people. And try and keep on keeping on.”

Graham

Please see our *Understanding brain metastases and lung cancer* booklet for more information on brain scan. Call us **0333 323 7200 (option 2)** or email us at info@roycastle.org.
Staging of 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 below.

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Small cell lung cancer is a small tumour that has not spread beyond the lung and doesn’t affect any lymph nodes.</th>
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<tr>
<td></td>
<td><strong>Stage 1A</strong> – the cancer is no bigger than 2cm in size.</td>
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<td><strong>Stage 1B</strong> – the cancer is more than 2cm in size but no bigger than 3cm.</td>
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<td><strong>Sometimes called early or localised lung cancer.</strong></td>
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## Stage 2
Small cell lung cancer is divided into two sub stages.

**Stage 2A** – the cancer is more than 3cm in size but no bigger than 5cm.

**Stage 2B** – the cancer is more than 5cm in size but no bigger than 7cm.

The cancer may have also spread to the main airway of the lung (bronchus) or the membrane covering the lung (pleura), or made the lung partially collapse.

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## Stage 3
Small cell lung cancer can be any size and may have spread into:

- the main airway of the lung (bronchus)
- the chest wall
- diaphragm
- the covering of the lung (pleura)
- the covering of the heart (pericardium).

There may also be separate tumour nodules (a small mass) in the same lobe of a lung (the right lung has three lobes and the left lung two). In addition, the cancer may have made the lung collapse completely.

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## Stage 4
Small cell lung cancer can be any size. It may have spread to the lung on the other side and distant parts of the body through the bloodstream, such as the brain, bones and liver.

**Sometimes called metastatic or secondary lung cancer.**
IMPORTANT

The TNM staging will be done in accordance with the 8th edition of guidelines produced by the Union for International Cancer Control (UICC). If you wish to, you can ask your doctor which edition they are using.

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

Limited stage – the cancer can only be seen in one lung and maybe nearby lymph nodes.

Extensive stage – the cancer has spread outside the lung to other areas, such as the other lung, brain or bones.

Questions to ask health professionals
To help you feel prepared for meetings with doctors and other health professionals, we’ve compiled a list of questions you may want to ask on page 34.
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.

“My friends and family have been amazing. They have supported me throughout my treatment, and Jill, my sister, has been a tower of strength, accompanying me to all my appointments and treatments.”

Anne

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 – see the ‘Useful organisations’ section on page 58 of our Living with Lung cancer booklet.

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

You can also speak to one of our specially trained nurses about how you’re feeling. They’re available on 0800 358 7200 (Mon–Thu, 9am to 5pm, and Fri, 9am to 4pm).

Or you may find that what you really want to do is 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 our ‘Useful organisations’ section on page 58 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. There are about 15 people who go every month, and you’re amongst people that are in the same bracket as you. There’s even two people now who have exactly the same as me: small cell lung cancer that’s spread to the liver and lymph nodes. 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.

For details of who can help with practical issues, please see our Useful organisations section on page 58 of our *Living with lung cancer booklet*.

**Financial and benefit issues**

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.
**Work and employment**

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 managing your mortgage, insurance and pension, the advisors from your trade union or Citizens Advice Bureau can help you. For further information on these topics, please contact Macmillan Cancer Support, Citizens Advice and GOV.UK. Also see page 58 of our *Living with lung cancer booklet* for more information or organisations which can provide helpful advice about benefits and other financial support.

**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 query box.
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 of 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 doctors 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 30 for more information about palliative & 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.

Maintaining your health and fitness can help you cope with treatment. If you are a smoker, giving up is important to maintain your health and make treatment effective. Support is available, as this can be challenging and difficult habit to break. If your family smoke, giving up together may help alot of you.

“You do find some patients live from appointment to appointment. So I do encourage them to get something ready for the time between chemotherapy sessions, such as a break or spending time with their family. It’s important they do their living between appointments, and it helps to focus on something other than their cancer.”

Anne
Small cell lung cancer treatment options
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 – for patients with extensive-stage disease SCLC, thoracic radiotherapy 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 is a type of radiotherapy that 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 type of chemotherapy to your first-line therapy, or radiotherapy to control symptoms.

Chemotherapy
Chemotherapy uses drugs which travel in your bloodstream and through your body to destroy cancer cells. This is why it’s the main treatment for a fast-spreading cancer such as SCLC.

The use of chemotherapy usually leads to longer survival for SCLC patients and can improve symptoms such as chest pain, breathlessness, a cough and coughing up blood. It may also be used if SCLC has returned after initial treatment.

Chemotherapy drugs are usually injected into a vein, or sometimes taken orally as tablets. 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 many different chemotherapy drugs, but the most common used for SCLC are cisplatin or carboplatin, which contain platinum, in combination with etoposide. Other drug combinations which may be used include cyclophosphamide, doxorubicin, vincristine and topotecan. You can find detailed information about these drugs at www.medicines.org.uk/emc.

You may find it useful to visit our website to view our information booklet called *Chemotherapy for lung cancer* at www.roycastle.org/ayqpack, or you can order a physical copy by calling 0333 323 7200 (option 2).

“Often people feel quite a bit better after one to two cycles of chemotherapy. But they may well have to cope with extra tiredness, a lowering of their blood count, and having to have injections to boost that. So they might have to contend with a lot of extra things as they go along their cancer journey.”

*Therese Partridge-James, Macmillan Lung Cancer Nurse Specialist, Frimley Park Hospital*
Radiotherapy
Radiotherapy uses high-energy radiation to kill cancer cells in the body. For the treatment of small cell lung cancer, radiotherapy is used as follows:

- Concurrently with chemotherapy
- Following chemotherapy to control symptoms
- To manage/shrink tumours in other places
- To reduce risk of cancer spreading to brain.

Because radiotherapy has to be extremely precise to avoid damaging healthy cells, your treatment will be very carefully planned. This will involve you having a radiotherapy planning CT Scan, which allows 3D images to be obtained of the area being treated in order to create individualised radiotherapy plans. You may also have to lie inside a special X-ray machine called a simulator. It simulates the treatment that will be given to you to make sure the area of your body that needs treatment is effectively treated.

When you’re actually given a dose of radiation, it will be in the radiotherapy department of a hospital or cancer centre. A radiation therapist will use a machine called a linear accelerator to deliver it. This usually takes around 10–15 minutes and is painless. Radiation treatment will not make you radioactive.

Clinical trials
Clinical trials are an essential part of medical research. They are a way finding out if new treatments are better than current best practice.

On some clinical trials, your condition may be monitored more regularly than standard care. This may include more blood tests, CT scans other cancer test. 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.
Trials of new drugs and treatments test how they will work. In some situations they may improve treatment, or they may not work, or cause side effects. How well the treatment or drug works in the trial will affect if it is recommended for NHS use and which patients it is used for.

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.

If you would like to check what clinical trials are available, look at

- UK Clinical Trials Gateway – www.ukctg.nihr.ac.uk/home
- Cancer Research UK – www.cancerresearchuk.org

**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.

If you have any questions or concerns in the lead up to your surgery, ask to speak to your surgeon again, or talk to another member of your healthcare team. You may also find it helpful to read our *My lung surgery* booklet which can be viewed at [www.roycastle.org/ayqpack](http://www.roycastle.org/ayqpack) or you can order a physical copy calling 0333 323 7200 (option 2)

**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’s important that you contact this key worker as soon as you have any concerns, or if you struggle with ongoing side effects such as breathlessness.

Between appointments you may also begin to struggle emotionally. People often feel abandoned or isolated 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.

For information on stop smoking services in your area, and details on our forum for people trying to give up smoking, visit [www.roycastle.org/stop-smoking](http://www.roycastle.org/stop-smoking).

On top of this, other things you can do to help yourself include:

- eating a healthier diet
- doing exercise at a level you find comfortable (it could just be walking to the shops)
- learning some relaxation techniques to ease any anxiety.
After your initial treatment for lung cancer ends

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.
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 feel like this and want to talk about any feelings or concerns you have, you can call our free nurse-led helpline on 0800 358 7200.

“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, and as it gets nearer you worry a little bit more about whether it will be alright.”

Anne

What if my 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 begin to 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.

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, 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 painful, it is helpful to talk to your friends, family and clinical team about end-of-life care, to ensure that your preferences are addressed. 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. The ways you plan will vary depending on where you are in the UK. Local advice services are available from care organisations such as MacMillian, Marie Curie and your local hospices. See page 58 of our Living with lung cancer booklet for more contacts.

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. Support services and groups are available to help and adjust. Grief and bereavement affect people in different ways at different times and using professional, community and family support can help you to manage. There are also specific resources to support children and young people who are facing the loss of a close family member.
Outlook

The success of your treatment depends on the stage of your small cell lung cancer; see page 13-15. for more detail. Too often SCLC is already advanced when it is diagnosed. If you are in this situation, your treatment options many 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 many need emotional and practical support and there are organisations that can help.

If this is 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.
My contacts

My GP
Name: ........................................................................
Phone number: ................................................................
Other contact phone number: ............................................

My lung cancer nurse specialist
Name: ........................................................................
Phone number: ................................................................
Other contact phone number: ............................................

My chest specialist
Name: ........................................................................
Phone number: ................................................................
Other contact phone number: ............................................

My lung cancer doctor
Name: ........................................................................
Phone number: ................................................................
Other contact phone number: ............................................

Name: ........................................................................
Phone number: ................................................................
Other contact phone number: ............................................

Name: ........................................................................
Phone number: ................................................................
Other contact phone number: ............................................

Name: ........................................................................
Phone number: ................................................................
Other contact phone number: ............................................
Questions to ask

Questions to ask your doctor or lung cancer nurse specialist
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.

Also, please remember that you can always call our free nurse-led helpline on 0800 358 7200 (Mon–Thu, 9am to 5pm, and Fri, 9am to 4pm) if you have a question or concern between appointments.

- 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?

You may find it helpful to write down your own questions before an appointment. Please use the following blank pages to do this, or use them to take notes during appointments.
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.

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.

This booklet was produced in partnership with

* Our funding policy ensures that sponsors of our lung cancer information products do not have any editorial control.

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

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 email us at info@roycastle.org

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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 please call our free nurse-led helpline on 0800 358 7200 or visit our website at www.roycastle.org

Head Office
Roy Castle Lung Cancer Foundation
Enterprise Way, Liverpool L13 1FB
Email: foundation@roycastle.org

Information and Support Services
Roy Castle Lung Cancer Foundation
98 Holm Street, Glasgow G2 6SY
Email: info@roycastle.org

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