

Managing lung cancer symptoms



Introduction

If you or someone you care for has just been diagnosed with lung cancer, then it's almost certain that you'll 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 about your care and treatment.

Remember that healthcare professionals are happy to answer your questions and help with things that are unclear or causing you concern.

We hope this booklet answers most of your questions about managing lung cancer symptoms and side effects. 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

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About lung cancer symptoms and side effects

Lung cancer is a serious illness that can significantly affect people's health and quality of life. Everyone is different, though. Some people may not have any symptoms, even when they are diagnosed. Others may only have vague feelings of not being well. For many, noticeable symptoms relating to their lungs or other parts of their body affected by the cancer prompt them to speak to their doctor.

Surgery, chemotherapy, immunotherapy, targeted therapies or radiotherapy, may be used to treat your cancer and reduce your symptoms. However, the treatments themselves may cause side effects that also need managed.

Following your treatment, and perhaps months or even years after your diagnosis, you may develop other related conditions that need to be treated and managed. Many of these symptoms and side effects are discussed in this booklet. They appear roughly in the order of most common to less common and more complex. Not all will be relevant to you so use the contents page to go to the information you need.

More common symptoms and side effects

Breathlessness

What is breathlessness?

All of us at some time in our lives have experienced shortness of breath, perhaps from over exertion, the after effects of a chest cold or when feeling particularly anxious or excited. Breathlessness causes you to increase the speed at which you breathe. This causes anxiety, tension and overuse of the muscles in your shoulders and upper chest.

All of this makes the effort of breathing harder, by involving more muscles and using more energy. Your breathing can also become shallower. This means that the lungs do not receive as much air, which adds to the feeling of breathlessness.

What causes breathlessness?

There are many reasons for breathlessness, sometimes referred to as dyspnoea (dis-nee-a) and you must **always** seek medical opinion to establish the cause and confirm the correct course of treatment. Below are common reasons for breathlessness:

- **Anaemia** – Low levels of red cells in the blood can be caused by the cancer or cancer treatments such as chemotherapy or radiotherapy.
- **Anxiety and panic** – Anxiety and panic can alter your natural way of breathing. When we are anxious, sometimes we breathe in a more rapid way, using less lung capacity. This reduces the amount of air available and can result in a stressful, fast breathing cycle.
- **Blockage** of an airway or artery in the lung.
- **Cancer treatments** – Some chemotherapy drugs can cause breathlessness. Radiotherapy may scar the treated lung causing mild to moderate breathlessness. Surgery, which may have removed part/all of the diseased lung, can sometimes cause shortness of breath.
- **Chest infection** – This can result in swelling and/or inflammation in the lung tissue which reduces your ability to breathe deeply and get as much air into the lungs as you normally would.
- **Heart conditions** such as angina.
- **Other lung conditions** such as asthma or chronic obstructive pulmonary disease (COPD).
- **Pain** – If your pain is not controlled, it can make it difficult to breathe comfortably.
- **Pleural effusion** – A build-up of fluid in the lining of the lung can be caused by the cancer or an infection.
- **Pulmonary embolism** – A blood clot on the lung.
- **Smoking makes breathlessness worse** and contributes to many current and/or potential health problems.
- **Tiredness/weakness** and generally being very run-down.

Are there breathing techniques that can help my shortness of breath?

Yes, while breathing is something we do all the time and seems automatic, with practice, you can learn to increase your control over it. You can help your breathlessness by:

- learning to control your breathing (see below)
- positions that may help you when short of breath (see page 7)
- breathing exercises (see page 8)
- learning to relax (see page 9)

Learning to control your breathing

The first step in learning to control your breathing is to become more aware of your breathing pattern generally. Exercise, talking too fast, stressful situations and even excitement can alter your breathing pattern, so try to correct it if it is too shallow or too quick. Pursed-lip breathing and diaphragmatic breathing will both help.

Pursed-lip breathing:

- Inhale through your nose for several seconds with your mouth closed, then exhale slowly through pursed lips for 4-6 seconds (like you are going to whistle).
- This helps to empty your lungs of old air and makes as much room in your lungs for fresh oxygen-rich air.

TOP TIP

Using an electric or handheld fan to direct a flow of air towards your face from about six inches away can help to reduce feelings of breathlessness, especially if you are in a stuffy room or perhaps on a plane or train.



Diaphragmatic breathing:

- Relax the top of your chest and shoulders.
- Place your fingers lightly at the front of your chest on your stomach.
- Give a little cough and the muscle that you feel under your fingers is the diaphragm.
- Breathe in and feel the expansion of the lower ribs and stomach rise under your fingers.
- Breathe out as gently as possible like a sigh, feeling the lower ribs come down and in.
- Try to repeat this exercise about five or six times.

Positions that may help you when short of breath

The most important thing is to be comfortable. Choose a position that will suit what you are doing and where you are. Try to be supported so that the upper chest and shoulders can relax. Your physiotherapist can help you if you are unsure.



Sitting leaning forward



Sitting upright



High side lying



Standing leaning forward

Standing leaning back or sideways



Breathing exercises

The aim is to allow the fresh air into the lungs and get rid of the old air. Try to imagine you are breathing out for twice as long as you breathe in. This will make room for the fresh air and also helps to slow down the speed of your breathing.

Keep your shoulders and the upper chest relaxed and easy. Feel as if the air is going down to your stomach and imagine that the breathing is taking place there.

Expansion of the lower chest:

- Place your hands on either side of your chest.
- Breathe out through your mouth, letting your ribs sink in as far as possible.
- Then, breathing in through your nose or mouth, feel your ribs expand outwards towards your hands.
- Gently breathe out to start again.
- Try to repeat the exercise about five or six times.

It is a good idea to practise this frequently throughout the day, so that they become a habit and can be used when you are feeling breathless.

Coughing can be hard work and can increase breathlessness so, if possible, try to cough only when you are ready to spit out phlegm. Breathing exercises may help to move the phlegm, which will make it easier to spit it out.



For further information about breathing exercises and advice on breathlessness, ask your cancer doctor or lung cancer nurse specialist to refer you to a physiotherapist.

The Asthma and Lung UK website also has a section on breathlessness: www.asthma.org.uk

Learning to relax

Another common reaction to anxiety is increased muscle tension, such as hunched shoulders, clenched fists or feeling a knot in your stomach.

TOP TIP

Many cancer centres offer relaxation sessions to help you learn relaxation techniques. Restrictions introduced following the COVID-19 pandemic may mean face-to-face support is now more limited but there are many free relaxation resources online.

Learning to relax by letting go of this muscle tension can also be a useful method of controlling anxiety and breathlessness.



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



Are there any treatments that will help my breathlessness?

Yes, there are. Many cancer treatments and procedures can help reduce breathlessness. Treatments many include steroids, radiotherapy, chemotherapy or stenting. Your cancer doctor or lung cancer nurse specialist may suggest some of the treatments below:

- **Drug treatments** such as painkillers (*morphine*), steroids and sedatives help relieve anxiety and panic caused by breathlessness.
- **Bronchodilator drugs** relax the muscles in the lungs and open up the airways. Some types are taken to relieve breathlessness and others to help prevent it. These drugs are normally given through an *inhaler* or *nebuliser* (sometimes called a *puffer*).

Continued on next page...

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- **Oxygen therapy** increases the amount of oxygen in the lungs and the bloodstream. If your blood oxygen levels are low, getting more oxygen can help you breathe better.

An oxygen cylinder may be given if you only need oxygen for short periods of time. If you need oxygen for longer periods of time, an oxygen concentrator may be supplied. This is a machine that takes oxygen from surrounding air. It is usually given using a face mask or through small tubes that sit under the nostrils (*nasal cannula*).

- **Chemotherapy** drugs are carried by the bloodstream throughout your body. Chemotherapy may be used on its own or as part of a combined treatment.

It may be given after surgery – this is called *adjuvant* chemotherapy. It can also be given at the same time as radiotherapy – this is called *concurrent* chemotherapy.

- **Radiotherapy** is a type of cancer treatment that uses high energy X-ray beams. Cancer cells are able to grow and divide faster than healthy cells.

Radiotherapy works by killing cancer cells and is often used to treat lung cancer. It works by targeting the cancer cells and disrupting the cell growth.

- **Immunotherapy** drugs are carried by the bloodstream throughout your body. Immunotherapy may be used on its own or in combination with chemotherapy.

Immunotherapy drugs help the body's immune system find, attack and destroy cancer cells.

- **Targeted therapy** drugs are oral tablets taken daily that can block some of the processes that enable cancer cells with genetic mutations to grow and spread.

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- **Stenting** can be used to treat airway blockages to maintain an open airway and help you breathe better.

A stent is a tiny tube made of silicone or metal that your doctor may use to open an airway before or after other therapeutic treatments. Some stents are rigid, plastic tubes.

The type of stent used most often to keep an airway open is a wire mesh tube that expands outwards in the airway (an *expandable stent*).

TOP TIP

It may be that a well-ventilated room, using open windows or using an electric or handheld fan, will achieve the same effect as oxygen.

My breathlessness is causing me extreme anxiety. What should I do?

Feelings of extreme (*acute*) anxiety can sometimes happen suddenly. It is important to remember that these feelings will subside. While it might be tempting to avoid anxiety provoking situations, in the long term this can affect your self-confidence.

You can learn to manage anxiety experienced in such situations by facing up to them a little at time and using the breathing techniques mentioned.

For some people being breathless can be frustrating and at times even frightening. Some people report that breathlessness is commonly linked with anxiety and panic. Unfortunately, anxiety only makes breathlessness worse. It can therefore be useful to learn ways of controlling anxiety and panic.

Anxiety is a normal reaction to situations where we may feel frightened or threatened. The anxiety response involves changes in the body, and in the way you think and behave.

Some common bodily responses to anxiety include:

- fast breathing, chest tightness and shortness of breath
- muscle tension, trembling or shaking
- sweating, cold and clammy hands
- heart pounding/racing and palpitations
- light headedness, dizziness and feeling faint

Although you may feel anxious when breathless, try using the breathing techniques discussed and your breathing will naturally slow down as you regain control.

Sometimes it helps to focus on a pleasant image in your mind's eye or do something to take your mind off the breathlessness. Find out what works best for you, for example, relaxing music, comedy show or a scenic view.

Remember the fear will subside in time. If you are experiencing significant problems coping with anxiety, it may be useful to discuss with your cancer doctor or lung cancer nurse specialist about being referred to a clinical psychologist.

I get very breathless at the start of the day.

Is there anything I can do to help this?

When rising, take your time getting out of bed. Sit on the edge of the bed for a few minutes. Perhaps you don't need to get dressed immediately – you may feel better having a warm drink first.

When bathing or showering you may find that this takes up a lot of energy. Avoid having the water too hot and making the room too steamy.

Try opening a window or leave the door slightly open. After your bath it may help to let the water out first then to kneel before getting out. Sit down while showering, especially if you are prone to getting very tired or dizzy. Have a small grab-rail in the shower that you can put your hand onto if you require.

Following your bath or shower, sit down to dry yourself or wrap yourself in an absorbent towelling bathrobe. There is a whole range of bathing and showering equipment available to help (speak to your district nurse or occupational therapist for advice).

When dressing, give yourself as much time as you need. It may be easier to sit down and it is best to avoid bending as much as possible.

You may wish to consider other methods of putting on your socks or shoes. Try a sock aid or a long handled shoehorn, or perhaps a family member can help. Loose clothing is often simpler to put on and will let you breathe easier.

Are there any tips to help me manage tasks around the house?

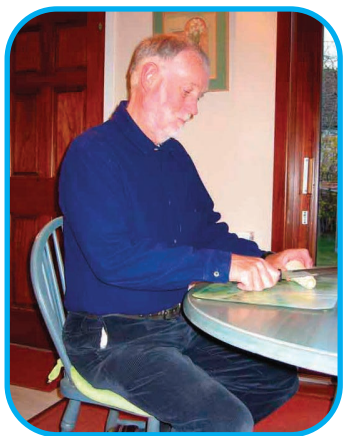
Avoid too much bending and stretching. It may be easier to sit on a stool when bending down to reach low plugs and switches or, for example, emptying your washing machine.

Another tip is to place shopping/washing baskets on a stool or table at waist level, when organising or emptying them. You may wish to consider using a pick-up stick or reacher – useful for picking up the letters from behind the front door.

Organise your house so that items you use frequently are kept within easy reach. Use your work surfaces or table to help you move your utensils or cup of tea around the kitchen — a kitchen trolley can be very useful to carry heavier objects from room to room.

Use a flask and a shoulder bag if a trolley is not available or suitable. This can help to carry drinks around and keep both hands free. Keep the phone nearby; a cordless or mobile may be useful. Ask your family and friends to give you plenty of time to answer. Ask your district nurse or occupational therapist for advice.

Sit down to do as much as possible, for example, peeling potatoes, drying dishes or waiting for food to cook. Your occupational therapist may be able to arrange for you to be supplied with a perching stool, which is ideal for working at worktop height. If you can, try to avoid climbing the stairs too many times during the day. Bring down everything you may need for the day when coming down in the morning.



Try to ensure that your bed or chairs are easy to get on/off. If chairs or the toilet are too low, you will waste a lot of energy struggling to get up.

Try to sit on a suitable height of chair.

A low toilet can easily be sorted by using a slightly raised toilet seat or perhaps a small grab-rail, strategically placed, on the wall.

TOP TIP Ask your district nurse or occupational therapist for advice on where you can get equipment that will help you.

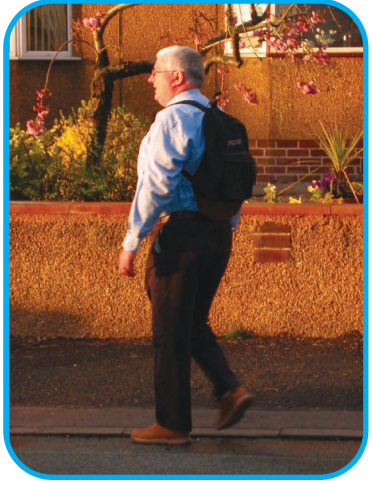
Can I still get out and about when I'm feeling breathless?

Remember to think ahead when you are planning an evening or a day out. If you are going somewhere unfamiliar, try to get information in advance, for example, make sure that lifts and parking/transport facilities are nearby.

If you have to carry heavy shopping, try to distribute the weight comfortably by using a shopping trolley or rucksack. A wheelchair may be useful to you. Ask your GP or occupational therapist if this would be of benefit to you. Your local shopping centre and supermarket may have wheelchairs available to borrow.

You may find that in certain atmospheres your mouth becomes dry or that you cough more. You may find that cold/damp weather or forced air/humid environments such as shopping centres can make you feel more breathless. It can be helpful to have a small bottle of water or some sweets handy.

If you are having difficulty breathing whilst performing day-to-day activities, such as walking, bathing or dressing, then you may qualify for some financial benefit from the government. You may also be entitled to a disabled badge for parking a car as a driver or passenger, or be able to claim travelling expenses.



Rather than carry a heavy bag to appointments, I bought a backpack so I don't have to carry anything and it keeps my hands free.

Tom

I want to keep active but I'm not sure if I should be exercising.

Would it help me?

It's natural to feel a little nervous about being too active and getting out of breath. However, light exercise can have real benefits to your wellbeing. Certain exercises that focus on breathing can prove helpful, for example, swimming, walking, yoga and Pilates.

Maintaining or improving your fitness level or performance status may also increase your treatment options and help you tolerate the treatments better.

Roberta

My breathlessness is affecting my sexual relationship.

What can I do to help this?

As with other activities, you may find that your breathlessness affects your sexual relationship. This in turn could lead to frustration between you and your partner at a time when you want to be really close.

It might help to set aside time when you can discuss your most intimate feelings with your partner and look at ways that you may overcome any problems.

You may find that certain sexual positions make you less breathless than others. If you have a reliever inhaler, it may be of help to use it before and after sexual relations. It might help to discuss any problems with someone not so close, but who is able to answer your questions, such as your GP, cancer doctor or lung cancer nurse specialist.

I am a smoker. Will quitting smoking help my breathlessness?

Although most health care professionals will advise you to quit, they will recognise that this is a very individual choice. If you do stop smoking, your breathlessness will improve. You will have better circulation and it will reduce the amount of poisonous chemicals in your body.

Continuing to smoke during treatment may reduce its effectiveness and can increase complications and side effects.

Research shows that cleaner lungs may also help your recovery from treatments, reduce the risk of the cancer returning and may increase your chance of survival. In the short term, stopping smoking can make you feel more emotional than usual, cause lack of concentration, difficulty sleeping (*insomnia*) and memory problems.



Contact details of the NHS Smoking Helplines can be found at the back of our *Living with lung cancer* booklet or visit our website: www.roycastle.org/usefulcontacts

Tiredness (*fatigue*)

Everyone has felt tired at some point but people with cancer often feel very tired and have lack of energy. This is also known as fatigue, which may be caused by the cancer, side effects of treatment, anaemia, side effects of other drugs (steroids or painkillers), anxiety or depression.

Fatigue can cause a feeling of having no energy and no strength to do anything – even getting out of bed can be a challenge. Fatigue can affect the way you think and feel.



It is important to speak to your cancer doctor or lung cancer nurse specialist as the symptoms of fatigue can often be helped.

Will I be able to carry out everyday activities?

You may find that at times, particularly during periods of treatment, you feel more tired than usual. You may need to adapt your everyday activities to help overcome this.

What kind of changes may I need to make?

When activities are carried out in the easiest, most efficient way, less strength is used and tiredness or pain is prevented. This means that you will have more time and energy to cope with other activities.



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

What sort of activities may I find more tiring?

Usually you will find that more physically demanding activities, for example, climbing stairs, gardening, shopping or perhaps bathing or showering are more tiring. Some specialist equipment or minor adaptations may help you remain independent and reduce how much of your energy you need to use to carry out activities. For example:

- use a stool to sit on when gardening
- check your bed and chairs are high enough for you to get on and off easily
- a high toilet seat can be ordered if your toilet is too low
- a grab-rail beside the bath, shower or toilet, or an extra handrail on your stairs, will help you be steadier on your feet

Ask your occupational therapist for advice on where you can get equipment that will help you.

I find it tiring to prepare and eat food. What will help me?

If possible, get someone to help you to prepare your food for the day. It may also be useful to make several portions of meals and freeze them for use on days when you don't feel able to cook.

Choose soft foods that are easy to chew, for example, egg dishes, soups, puddings, crustless bread with toppings of banana, Greek yogurt, cream cheese, meat or fish paste. It may also help to mash or liquidise foods.

Is there anything that will help me to get a good night's sleep?

If you have difficulty sleeping at night, a few simple changes might help:

- Try to limit daytime naps so you are tired when it is bedtime. Here are some things to help you get a good night's sleep:
- Avoid caffeine in drinks (coffee, tea, fizzy drinks) before bedtime and try herbal/camomile tea.
- Drinking alcohol in the evening may prevent you having a restful night's sleep.
- Try to relax before going to bed – have a bath (not too hot), read or listen to music.
- Relaxation techniques may also help you at bedtime.
- Making sure the bedroom is not too hot or cold can help.

“Try aromatherapy oils, such as lavender, applied to your pillow or room diffuser, or use sleep spray.”
Janette

Coughing

Why am I coughing?

Coughing is a common and distressing symptom for lung cancer patients. It can often be a symptom of lung cancer which affects many areas of life. It can affect your sleeping pattern causing severe tiredness, loss of appetite, pain, anxiety and sometimes can cause loss of control over passing urine. Your cough may be dry (called *non-productive*) or you may cough up phlegm (called a *moist* or *productive* cough).

This phlegm (*sputum*) should be clear or white in colour. If it becomes discoloured (yellow, green or bloody), please inform your cancer team. They may want to take a sample for the labs to see if treatment is required. Your coughing may also be caused by other health conditions such as COPD or an infection.

What can be done to help my cough?

Your cancer doctor or lung cancer nurse specialist will assess how often you are coughing and if there are situations or times of the day when your cough is worse. Treatments to help your cough will depend on many factors.

Tips to help your cough:

- If you have a dry cough, try to increase the amount of fluids you drink, especially water.
- Drinking warm honey and water and sucking on sweets or lozenges will also help.
- Try breathing in steam from hot water – add some herbal drops to the water, such as eucalyptus oil or Olbas oil.
- A *cough linctus* or *cough suppressant* can be prescribed by your GP.

What can help me when I am coughing up phlegm?

If you are coughing up phlegm, sitting in an upright position will help you cough better. Coughing will only move phlegm from your upper airways.

It can be difficult to clear it from your lungs. Ask your nurse or physiotherapist for advice on breathing techniques or if a nebuliser would be helpful. This is a portable machine that produces a vapour that can help clear sticky or thick phlegm from your chest and airways.

If you are dehydrated, the phlegm in your lungs may become sticky and can be difficult to cough up. You should drink around 6 to 8 glasses of water a day. If you dislike drinking water try adding diluting juice (cordial) to flavour the water.

I have coughed up some blood in my phlegm. What does this mean?

Some patients with lung cancer will cough up blood. This is called haemoptysis (he-mop-ti-sis) and can be very distressing. It can be caused by a bleed in the blood vessels in the lung, an infection or clot in the lung.

It is important to tell your cancer doctor or lung cancer nurse specialist about this and further investigations or treatment can be given.

Pain

I am experiencing pain. Is this normal?

Pain usually occurs when there is damage to your body and can be a sign that you have an illness or injury.

Not everyone but some people will experience pain with lung cancer. Pain is a symptom of illness or injury and is well understood and easily managed by health professionals. Therefore, please let them know if you have pain so they can help treat this symptom quickly.

There are many reasons for pain and in order for your pain to be managed effectively you need to accurately assessed by your cancer doctor.

Some people experience pain after treatments for cancer and understandably worry that it is a sign that the cancer has come back or has spread. This is not necessarily the case as many people experience pain, not caused by cancer.



If your pain is because you have had surgery for lung cancer, see our *My lung surgery* booklet for more information. See page 2 for details on how to get a copy.



Assessment of pain

There are a variety of ways to assess pain, your cancer doctor will discuss the one that best suits you. A verbal self-rating tool which involves your cancer doctor or lung cancer nurse asking you to rate your pain severity on a scale of 0 to 10, with 0 being no pain and 10 being the worst ever pain experienced. There can be many reasons for pain and in order for your pain to be managed effectively, you need to be accurately assessed by your cancer doctor.

What can help my pain?

Pain can usually be managed with a variety of different treatments and this will depend if the pain is mild, moderate or severe. For mild pain, you may be prescribed a mild painkiller (an *analgesic*) such as paracetamol or a non-steroidal anti-inflammatory drug such as aspirin, ibuprofen or diclofenac sodium.

For moderate pain, you may be prescribed a weak opioid drug like codeine or tramadol. For severe pain, you may be prescribed a strong opioid painkiller like morphine, oxycodone, fentanyl or diamorphine. It is important to speak to your doctor if you intend to drive while taking some painkillers as they may impair your capacity to drive. This may be illegal, even if the drugs are prescribed.

Drugs to help manage pain can cause side-effects and it's important that you tell your cancer doctor or lung cancer nurse specialist. Common side-effects can include constipation, feeling sick or being sick, drowsiness, feeling tired and dry mouth. Some people with cancer will need to take painkillers regularly to control the pain. It's important not to let pain build up until it's severe.

Other treatments to help manage pain can include chemotherapy or radiotherapy, or perhaps complementary therapies such as acupuncture and relaxation techniques.

TOP TIP

Keeping a diary may help you to know when you have pain. Show this to your cancer doctor or lung cancer nurse specialist so they can help you to manage your pain.

Will I have to take morphine?

You might feel frightened about taking morphine as it is sometimes thought of as being linked to death and addiction.

This is not true – it is a very useful painkiller and can also help reduce breathlessness. You should still be able to carry out most day-to-day activities such as driving.

However, morphine can at times make you drowsy, especially when you first start taking it. Do not drive if you feel at all drowsy.



How will I cope with the pain?

Getting medical help to control your cancer pain is very important. The best thing you can do is let your healthcare team know you are in pain. Feelings of fear, anxiety, depression and lack of sleep can increase pain and add to your suffering.

Talking about your pain can help. Don't be afraid to let the people close to you know that you are in pain. Having strong emotions about your pain is normal and is to be expected.

If you're having a good day, enjoy it and if you're having a bad day, think of the good days.

Ann

You may feel angry about having pain and how it affects your quality of life or anxious that the pain won't go away. Once your pain has been managed many of these feelings will go away.

Your cancer doctor or lung cancer nurse specialist may be able to refer you to counselling services, to help you to feel more in control and help you to cope.

The main thing is that you don't feel alone. Even if you don't have close family and friends around to help you, other people can help. Let your lung cancer nurse specialist know if you need support.

Constipation

Constipation is a common condition where you have difficulty opening your bowels. It affects many people who have cancer or are having cancer treatment.

Whilst everyone's normal bowel pattern is different, if you have not had a bowel movement for three days, you should speak to your GP, cancer doctor or lung cancer nurse specialist. The signs and symptoms of constipation can include:

- having less frequent bowel movements
- straining when passing stools (*faeces*)
- your stools becoming harder
- feeling bloated and experiencing wind
- pain in your stomach or back passage

Constipation can be caused by medications, chemical imbalances in the blood or even a change in diet. Being less mobile or lack of fluid (*dehydration*) can cause or worsen constipation.

What can be done to help relieve constipation?

Try not to feel too embarrassed to discuss this issue. The health professionals involved in your care will assess you and will be able to give advice. They may prescribe *laxatives* to help relieve your constipation.

Although you can buy many laxatives over the counter at the chemist, speak to your lung cancer nurse specialist before taking them to ensure you are taking ones to help you. Laxatives can come in many forms – tablets, capsules, syrups and powders to be added to water. If the constipation is severe, you may be prescribed enemas or suppositories to be inserted into your back passage.

Tips to help with constipation:

- Have plenty of fibre in your diet. Foods rich in fibre include fresh fruit and vegetables, brown rice, wholegrain cereals, kidney beans, lentils and chickpeas. When eating bread choose wholemeal, wholegrain, granary or multi-seed bread.
- Drink plenty of fluids. Try to drink at least 6 to 8 glasses per day.
- Try to limit the amount of caffeine, alcohol and fizzy drinks you consume.
- Don't ignore the urge to go to the toilet. When you do go, some people find that leaning forward and relaxing will help them open their bowels more easily.
- Exercise can affect your bowel habits. Try gradually increasing the amount of exercise you do. Walking, swimming and cycling each day will help to keep your bowels moving. It will also leave you feeling healthier and improve your mood, energy levels and general fitness.

Weight loss and loss of appetite

I have lost weight recently. Why is this?

It is common for people with lung cancer to lose weight. There are many reasons for this; you may be eating less than you normally do or your body may not be absorbing enough of the food you eat. Continuous weight loss can be very upsetting and worrying, and it can be a constant reminder of your illness. Your healthcare team will monitor your weight and can refer you to a dietitian for advice on eating a balanced diet.

Tips to help you with weight loss:

- Try eating small frequent meals rather than three large meals a day.
- Eat meals that are small in portion size but high in calories.
- Add ingredients such as cream, cheese, full fat milk, butter, yoghurt whenever possible.
- Keep nutritious snacks handy, eat when you feel able and treat yourself to foods that you particularly enjoy.
- Try not to drink too much tea, coffee or water as these are low in energy and can fill you up.
- Try full fat milk, milky coffee or supplement drinks such as *Complan* or *Build-up*.

I have lost my appetite. Is there anything that can help me?

Loss of appetite can affect many people who are affected by cancer and can be due to the cancer treatments or how your body is responding to the cancer.

Other symptoms such as breathlessness, pain and constipation can all affect your appetite. Your GP or hospital doctor may prescribe a short course of steroids to increase your appetite, food intake and feeling of wellbeing. The dietitian can advise which foods would be best for you and suggest food supplements to help you.

Less common symptoms and side effects

There are other less common symptoms and side effects that people who have lung cancer also experience. Some are quite rare. These are described on the following pages.

Symptoms can often be reduced with the use of medicines, treatments and practical changes to the way you live your everyday life.

This is called *symptom management* by your healthcare team.



Fluid in the lining of the lungs (*pleural effusion*)

My doctor says I have fluid on my lungs. What is this?

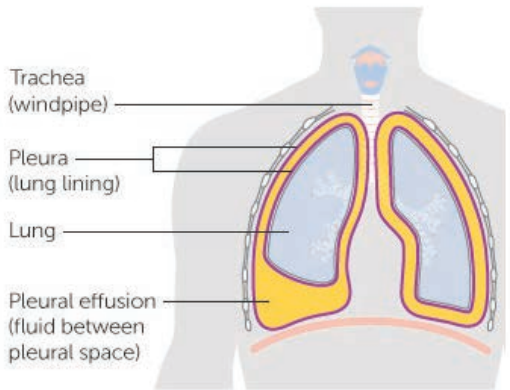
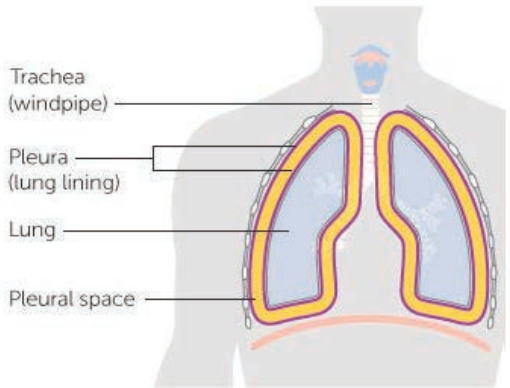
In some patients with lung cancer, fluid can build up between the sheets of tissue (*pleura*) that cover the outside of the lung and the lining of the chest cavity. This is called a *pleural effusion*.

The fluid stops the lung from fully expanding when you breathe. As it builds up, the collected fluid can cause shortness of breath, coughing and some chest pain.

Treatment

Your hospital doctor will drain the fluid by inserting a tube, called a chest drain, into your chest. You will be given a local anaesthetic which will help to relieve any pain and discomfort.

Your hospital doctor will then make a small cut in the chest and insert the chest drain into the space where the fluid is collecting.



Cancer Research

While the procedure is taking place you must let the nurse know if you are having any pain and you can have painkillers at any time. An ultrasound scan will be used to help guide the tube into the correct position. The chest drain is then attached to a bag or bottle to collect the fluid.

The fluid will be drained off slowly, to avoid complications as your lungs re-expand. You may feel dizzy, sick or light-headed. If you do, let your nurse know.

You will be given an X-ray to check that your lung has re-expanded. The length of time the drain stays in varies from person to person.

The doctors will let you know when drain can be removed. You will usually need to stay in hospital for a couple of days after the procedure. For some people with less fluid build-up, this procedure may be carried out as an out-patient without the need to stay in hospital.

To stop the fluid from building up again, a procedure called a *pleurodesis* (plu-roe-dee-sis) can be performed. This procedure is done while the chest drain is still in but when the fluid has drained to almost dry.

The hospital doctor will inject a sterile talc solution through the drainage tube, into the space between the tissues covering your lungs.

Again, the nurses will give you painkillers if you need them, so do not put up with any discomfort. Sometimes the fluid does come back making you short of breath again and you will need to have it drained again. This would mean repeated drainage with a new tube each time it collects, which can be uncomfortable and mean many trips to the hospital.

Sometimes, a permanent drain will be necessary to drain fluid from around the lungs. This is called an *indwelling pleural catheter* and will avoid the need for repeated chest tube insertion every time the fluid collects.

Hoarse voice

Why do I have a hoarse voice?

Some people with lung cancer can develop a hoarse voice. It may be caused by the cancer pressing on a nerve in the chest called the *laryngeal nerve*. If this nerve is squashed, one of the vocal cords in your throat can become paralysed, leading to a hoarse voice.

If your vocal cord is not working properly, you may also find it more difficult to swallow effectively and there is a risk that food and drink could be inhaled into the lungs (see *Swallowing difficulties* on page 33).

Having a hoarse voice can affect everyday social tasks, as you often have to use your voice. The impact can be significant for some people, both on a practical and an emotional level. It can also be very tiring to talk, as it takes a lot of effort to be heard and understood, particularly over the phone.

Is there anything that can help it?

The hoarseness of voice should be fully assessed by your cancer doctor or lung cancer nurse specialist.

Treatment will depend on the cause of your hoarse voice. Sometimes, if the cancer reduces in size, the pressure on the nerve may be released. Treatments such as steroids, radiotherapy and chemotherapy can help to improve your voice.

Referral to the speech and language therapy team (SALT) may be needed to assess swallowing and to advise if speech therapy would help. In some cases, it may be useful to ask for an assessment by the ear, nose and throat team (ENT), to see if any intervention such as vocal cord injections would improve your voice.

How can I help to protect and care for my voice?

Be conscious of background noise. Raising your voice over background noise, even of low intensity, may lead to strain and discomfort. Rather than avoiding places that are noisy, such as pubs and parties, try to talk only when you are somewhere quieter.

Speak clearly so that your lips can be read and speak more slowly.

Remember to turn off or mute the television and radio before speaking. Reduce unnecessary background noise whenever possible.

Rather than raising your voice, get closer to the person you are speaking to. If the listener has a hearing impairment, make sure that you are facing them when you speak and that background noise is minimal.

Use other noise makers that you have arranged beforehand to attract attention, for example, whistles or claps. You can use a mini voice amplifier to make your voice louder. This can be purchased or in some cases borrowed from a speech and language therapist. You can also use this device when making telephone calls.

Try to keep the air clear and of a high quality. Household dust and pollen are irritants that cause the air passages to become inflamed and dry. This may affect voice pitch and quality. Try to make sure the house is as clean as possible and avoid doing major repair work which can cause further dust. Drink more fluids if the air quality is poor.

Inhalers are available that can help. If you have an inhaler, ensure that you follow the directions carefully. As you inhale, open your throat as wide as you can to ensure that all the inhalant is breathed in and as little as possible touches the vocal cords. Have a drink afterwards.

Tips to help a hoarse voice:

- Give your voice a rest or speak quietly, especially if you feel tired.
- Drink plenty of water to keep your vocal cords or throat hydrated, especially when you are talking.
- Breathing in steam will help moisten your voice box (*larynx*) and vocal cords.
- Your voice may be stronger at certain times of the day, so it may help to plan your day when your voice is stronger, for example, meeting people or making telephone calls.

“ If you have a hoarse voice,
try sucking on a soothing throat lozenge.”

Amy

My voice problems are causing me anxiety. How will I cope?

The voice is a reflection of how you feel. Vocal strain can be the result of emotional tension. For example, when you are afraid, your breathing rate increases, your heartbeat accelerates, your larynx rises and your vocal folds tighten causing the pitch of your voice to rise and your voice to sound tense.

Some people avoid social contact, but if at all possible continue to see your family, friends and meet people because it will improve your wellbeing. Talk over any worries or problems you might have with someone who is a good listener.

Consider seeking professional help such as talking to a psychologist or counsellor.

Swallowing difficulties

Why am I having trouble swallowing?

Some people with lung cancer can have difficulty in swallowing. This is called *dysphagia* (dis-fay-gia). Swallowing certain foods or liquids may be difficult. This can lead to loss of weight and dehydration, and can be very distressing.

It can be caused by cancer, infections (thrush, for example) or side effects from treatments such as radiotherapy. It can appear as if the food will not go down or sometimes the swallowed food will then be brought back up. Occasionally pain or a burning sensation can be experienced when swallowing.

Some people who have radiotherapy to the centre of the chest can experience difficulty or soreness in swallowing. This is usually a temporary side effect.

What can be done to help my swallowing problems?

If you are having difficulty swallowing, contact your GP or lung cancer nurse specialist for advice. They will carry out an initial assessment and may refer you to another healthcare professional for further tests and treatment. Sometimes, if the tumour reduces in size with cancer treatments, the pressure on the food pipe may be reduced.

There are some medicines that may help such as antacids and other stomach medications. These should only be used if prescribed by your healthcare team.

If swallowing problems continue, speak to your GP or lung cancer nurse specialist immediately. It may be necessary to change your diet to ensure you are receiving enough nutrition and fluids. Your hospital may refer you to a dietitian for advice.

Tips to help with swallowing:

- Make sure you are sitting upright, preferably in a hard backed chair. Try to stay sitting for at least 30 minutes after eating or drinking.
- It is safer to eat soft foods that you could mash with a fork. Avoid mixed consistencies like soup with bits, or hard cereals with milk.
- Take your time. Rushing or gulping food down will lead to more problems.
- Try not to talk and chew or swallow at the same time. Ensure that each mouthful has been swallowed before the next is taken.
- If the food sticks in the mouth or throat, take alternative swallows of food and a drink to help 'wash the food down'. Fizzy drinks can help with swallowing and eating.
- If swallowing is difficult, use a chin tuck: Sip, chin down and swallow. Stop eating and drinking if you are tired, if you start coughing or your voice becomes gurgly.
- If drinks make you cough or choke, speak to your GP or lung cancer nurse specialist. Try a thicker drink such as a smoothie or ask your GP for a thickener.



My doctor says I have acid reflux. What is this?

Acid reflux is sometimes known as *gastro-oesophageal* reflux. This is felt as a burning in the throat, heartburn or an acid taste in the mouth and is a common cause of throat problems. You may become aware of these symptoms during or after eating.

Tips to help with acid reflux:

- Avoid excessively large meals – have larger snacks between meals.
- Have your last meal at least two hours before lying down.
- If you think you have reflux, see your GP or lung cancer nurse specialist. Prescribed antacids are more effective than over-the counter medications. Your GP or speech and language therapist will be able to give you information on how to help reflux.

High calcium (*hypercalcaemia*)

High blood calcium is known as *hypercalcaemia* (hi-per-cal-cee-mia). It is a disorder that can sometimes affect patients with advanced lung cancer.

There are a number of causes of this disorder. Occasionally if the cancer has spread to the bones, the calcium in the blood can be high. The common signs and symptoms that may be experienced are:

- feeling sick (*nausea*), being sick (*vomiting*) or not eating
- constipation
- thirst and increased passing of urine
- dehydration
- drowsiness
- confusion

What will help me?

Your cancer doctor or lung cancer nurse specialist will assess the calcium levels in the blood. If you have mild hypercalcaemia you may just need monitoring and increase your oral fluid intake.

If it is more severe, you may require rehydration, usually by fluids and calcium lowering drugs (*bisphosphonates*) given by a drip called an *intravenous infusion*.

Sometimes the hypercalcaemia can come back. Look out for any signs or symptoms and get your blood calcium level checked. Some patients will require medication to keep the blood calcium within normal limits.

Low sodium (*hyponatraemia*)

Low sodium level in the blood is called *hyponatraemia* (hi-po-nat-ree-mia) is a potential problem for patients with lung cancer, more commonly small cell lung cancer.

Commonly, a mild low sodium level may not give any signs or symptoms at all. However, some signs that may be experienced are:

- concentrated urine (dark colour)
- muscle weakness and lethargy
- feeling sick (*nausea*) or being sick (*vomiting*)
- drowsiness and confusion
- risk of convulsions

What will help me?

Your cancer doctor or lung cancer nurse specialist will assess the sodium levels in the blood. To increase the sodium level, your cancer doctor may suggest your oral fluid intake is restricted to a certain amount. Sometimes drugs can be prescribed to help raise the sodium level. The sodium levels may not return to normal until the cancer is treated.

Superior vena cava obstruction (SVCO)

Lung cancer, particularly tumours in the right upper lobe of the lung, can sometimes block a large vein that carries blood from the brain, head and arms back to the heart. The vein is called the *superior vena cava*, and when it is blocked or squashed (*obstructed*), it is called a *superior vena cava obstruction (SVCO)*. This causes a build-up of pressure so that fluid seeps out of the blood stream and collects in the tissues.

The signs and symptoms that patients may experience can be very distressing. They can develop gradually or happen very quickly and could include:

- swollen arms, neck and face, particularly around the eyes
- purple, dilated veins on the skin's surface of the chest, neck and upper arms
- headaches or fullness in the head, particularly on bending or lying down, or dizziness

Superior vena cava obstruction (SVCO) is a medical emergency. You should contact your GP or healthcare team immediately if you experience any of these symptoms. Your doctor or nurse may want you to go to hospital for a chest X-ray and CT scan.

What will help me?

This condition should be fully assessed by your cancer doctor. Treatments aim to reduce the blockage of the vein and reduce the side effects it causes.

They can include steroids to reduce any swelling or painkillers for headaches or any pain. Sometimes a stent can be inserted to try to keep the vein open. Other treatments will depend on the type of lung cancer you have and may include radiotherapy and chemotherapy.

Metastatic spinal cord compression (MSCC)

The spinal cord is where nerves travel and carry signals between your brain and your body. Lung cancer that has spread to the bones in the spine can cause pressure on the spinal cord. This is called *metastatic spinal cord compression (MSCC)*.

Your doctor will tell you if you have an increased risk of this happening.

MSCC can cause a variety of symptoms:

- Pain in your back or neck – this may be mild to begin with but becomes severe. The pain may feel like a ‘band’ around the chest or abdomen and can occur in the lower back, the buttocks or legs.
- The pain can also spread down the arms. Quite often this pain can affect sleeping and is worse when lying down. It may also be worse when you cough, sneeze or go to the toilet.
- Mobility problems – you may experience feeling unsteady on your feet, have difficulty climbing stairs or walking, legs being weaker or just suddenly giving way.
- Problems with sensation – numbness, tingling or pins and needles.
- Problems controlling or emptying your bowel or bladder.
- Visual changes.
- Increasing breathlessness.

Metastatic spinal cord compression (MSCC) is a medical emergency. You should contact your GP or healthcare team immediately if you experience any of these symptoms. Your doctor or nurse may want you to go to hospital for a chest X-ray, and a CT or MRI scan.

What will help me?

This condition should be fully assessed by your healthcare team. Treatment should be started as soon as possible after diagnosis with the aim of minimising any permanent damage to the spinal cord.

Treatment will also help to reduce pain by shrinking the tumour and relieving the pressure on the nerves. The type of treatment depends on several factors including the type of cancer, the area of the spine affected and your general fitness.

Treatment may include one or more of these: steroids; lying flat to reduce movement; pain control; radiotherapy; surgery; chemotherapy.



Please see our *Understanding bone metastases and lung cancer* booklet for more information. See page 2 for details on how to get a copy, or view it online at: www.roycastle.org



Secondary cancer of the brain

Lung cancer that has spread to the brain is called *brain metastases* (me-tass-ta-sees) or secondary cancer of the brain. This can cause a variety of symptoms. Signs that cancer may have spread to the brain include:

- frequent headaches
- blurring of vision
- weakness or numbness in the arms or legs
- confusion
- behavioural changes
- fits (*seizures*)
- feeling sick
- visual changes
- increasing breathlessness

They may be able to prescribe steroids to reduce any swelling in the brain and help other symptoms. Steroids occur naturally in the body and help to control many body functions.

If you have had a fit or seizure, you may be prescribed anticonvulsant drugs to help prevent them happening again or reduce your symptoms.

Because brain metastases are unpredictable in terms of the effects they can have on a person's capacities to do things, any driver diagnosed with them should stop driving to minimise any risks to themselves or others.

There is a legal responsibility for driving licence holders to tell the DVLA about certain medical conditions that could affect their driving, and brain metastases is one of them. You may have to surrender your licence.

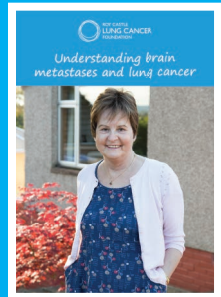
Reapplying for your licence could be after one year, usually two, and only if you are clear of brain metastases and your cancer is controlled, or if you are receiving immunotherapy or a targeted therapy and your brain metastases are stable or improving.

However, some people may decide there and then to stop driving for good and surrender their licence to the DVLA.

Other treatments for people with brain metastases can include chemotherapy, radiotherapy or surgery. Your cancer doctor may also recommend a targeted radiotherapy treatment called *stereotactic radiotherapy*, also sometimes called *stereotactic radiosurgery (SRS)*.



For more information about this and other aspects of lung cancer brain metastases, get in touch with us to ask for our booklet *Understanding brain metastases and lung cancer* on our website: www.roycastle.org or by calling us free on: **0333 323 7200** (option 2).



About our lung cancer information

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

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

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

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



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

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

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

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ROY CASTLE
LUNG CANCER
FOUNDATION

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

Supporting people living with lung cancer

Working closely with lung cancer nurses, we provide information, run lung cancer support groups and offer telephone and online support.

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

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booklets and support,
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