



ROY CASTLE
LUNG CANCER
FOUNDATION

Living with lung cancer



Introduction

If you have or someone you care for has lung cancer, you will probably have a lot of questions about how best to get on with life during or after treatment.

We wrote this booklet with the help of lung cancer experts, people affected by lung cancer, and others who support people with lung cancer to help you make the most of your health and wellbeing. The index on the opposite page will help you find the sections you want to read.

Use this booklet along with the information your doctors and nurses give you. You can also speak to them about things you are worried about or don't understand.

If you still have questions and want to talk to someone, 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 at the back of this booklet, or look on our website: www.roycastle.org/usefulcontacts

Contents

○ How does lung cancer affect people?	4
○ Getting organised	6
○ Money matters	8
Should I tell my employer I have lung cancer?	9
Am I entitled to benefits?	12
Work-related illness, benefits and compensation	17
○ Looking after yourself	19
Getting enough sleep	22
Helping yourself to relax	24
Taking a break or having a holiday	36
○ Eating well	38
I've not got much of an appetite just now – is this normal?	40
What kind of things should I be eating?	41
Other questions about food and eating	42
○ Getting active	45
Stretching exercises	48
Strength building exercises	50
Managing everyday activities	52
○ Stopping smoking	55
Why is smoking such a problem?	55
How will stopping smoking help me?	56
I see the benefits and want to stop – what will help me?	57
○ Help and support	62
Healthcare services	62
Information and networking	63
Other support organisations	67

How does lung cancer affect people?

Living with lung cancer can bring many challenges. It can affect people of all ages, though it still mainly affects older people. One part of living with lung cancer is the treatment and care given by medical and other professionals. The other is what you and those around you can do for yourself to maximise your health and general wellbeing.

Being proactive in this is important whether you have just been diagnosed, are already receiving treatment, have finished treatment, chosen not to have treatment or are on a clinical trial.

Lung cancer affects people in many ways, and its symptoms and lasting effects can have a significant impact on a person's quality of life.

One of the most troubling symptoms can be cancer fatigue. Fatigue means tiredness and lack of energy. For people with cancer this can be severe and last a long time.

Breathlessness, coughing, pain and poor appetite, among other effects, can also affect your mood and leave you tired. People's sleeping patterns can be disrupted and their physical capacities reduced. Medication, such as steroids, can also affect sleep patterns.

This combination of factors can leave you irritable and distressed, and some people experience depression or anxiety. People close to you may also be affected and feel emotional and struggle to know what to do for the best, and you may worry about this too.

We produce a range of booklets about managing lung cancer symptoms and the many treatments available. Knowing as much as you can about lung cancer means you are well informed when speaking to your doctors, or other healthcare professionals, such as your lung cancer nurse specialist.



It is also important to be realistic and honest about how your lung cancer may or may not progress, or return, over time and know what to look out for in terms of symptoms. If you are noticing changes, or are concerned about any symptoms, speak to your doctor.

Some lifestyle choices can also affect how well you do over time. Lower activity levels, poor diet, drinking lots of alcohol and smoking can reduce the effectiveness of treatment and slow down recovery. They can also reduce a person's quality of life and longer-term survival. Making positive lifestyle choices, even now, can really make a difference.

The information in this booklet focuses on some of the things you can do yourself to help manage the effects having lung cancer can have on your life. It suggests ways to manage changes to your appetite, weight, work and money matters, being less active, feeling stress and anxiety, as well as supporting you to make positive health choices.

Getting organised

Once someone has been diagnosed with lung cancer, or any other serious medical condition, one of the best ways they can support themselves is to get better organised.

When you first heard the words “you have lung cancer”, your head would probably have started to swim. At that point, you may well have stopped actually hearing what someone was saying to you, and even if you did hear, struggled to make sense of the words.

Very quickly you can start to feel overwhelmed with information, appointments to keep, and things to do. On top of any medical information, you may worry over your other personal business such as your bank accounts, gas and electricity bills, family and caring responsibilities, your mortgage or rent, driving and travel costs, already-booked holidays, and even perhaps not having written your will. People who work or run a business may also worry about how their lung cancer may affect their job.

While you get your head around attending to all of this, your free time can easily be consumed by hospital appointments, stressed, feeling unwell, or talking things through with your family and others close to you.

Because things can easily become overwhelming, it's a good idea to put systems and processes in place. Filing and planning can lift a huge weight off your mind when you know that you have things recorded, and you and everyone else knows where to go to find your important paperwork. Loose ends cause stress. If you don't feel up to doing it all yourself, ask a family member or friend to help you.

For your medical notes and appointments, your lung cancer nurse specialist may help you keep a diary or folder. If not, start your own. Get a decent sized, day-a-page diary and a good lever arch file with some coloured tab dividers and poly pockets. You may prefer to do this on your computer, and some online apps may be available for your phone.



Record all your appointments in one place, and have a separate section for information about treatments, test results, any medication you are given (including dates, dosage and side effects), your doctors' names and contact details, your lung cancer nurse specialist and any other important healthcare information.

This will save you and those around you time and effort along the way.



Cancer Research UK produce "*Your cancer treatment record*", a paper-based tool to help you track what's going on. For more information, watch a video about it at:

• www.cruk.org/your-cancer-treatment-record

You may already have everything in order relating to, for example, your mortgage, bank accounts, savings accounts, insurances, investments, car, gas and electricity.

If not, create folders or set up a filing cabinet where you can put everything in order so you, and anyone else you want to tell, know where you keep it. It's a good idea to have a system for your phone and internet provider information and for safely managing all your passwords.

Although it can be an emotive issue, some people decide the time is right to write or update their will and make funeral arrangements. They may also arrange other legal matters such as a power of attorney to make sure your wishes are carried out if you become unable to make your own decisions. A power of attorney maybe necessary to enable someone to access your bank accounts or mobile phone so they can pay your bills.

Money matters

Having lung cancer is likely to have an effect on your cash flow. If you were working at the time you were diagnosed, you may or may not have been able to continue to do the same work, or may have had to do fewer hours or even stop working altogether, temporarily or permanently.

While getting bombarded with information about lung cancer, having various tests and treatment options presented to you, thinking about money matters may be the last thing on your mind, far less actually feel able to do anything about it.

Retired or unemployed people are also likely to feel some financial pressure as everyone's expenses are likely to rise through travel costs, parking, heating and needing to buy new clothes.

If your income goes down, you may have savings or other sources of money to keep you going. There may be welfare benefits to which you are entitled, some of which are payable to you because of your illness and not because they assess your financial situation.

This may be a time to check any insurance policies you may have for any critical illness cover. If appropriate, you may want to evaluate your pension with your financial advisor.

Some banks and other financial organisations are gearing up their services to support people with cancer more sympathetically, including staff training about the impact cancer has.

They can offer more support, and allowances may be made around loan and mortgage payments, for example, while you are going through this illness. Speak to your lenders and to your own bank before you start to struggle financially to find out what they can do for you.

Should I tell my employer I have lung cancer?

Having been diagnosed with lung cancer, you may worry about whether or not to tell your employer. Some people decide to keep it all very private because that's their nature, others because they want to avoid any potential negative reactions from their employer or colleagues.

By law, you don't need to tell your employer about having lung cancer though it may be more practical for you to do so. Your employer may be able to support you and take your condition into consideration.

If you drive as part of your job, and you develop brain metastases, you will need to tell your employer. This is because you will no longer be allowed to drive (perhaps temporarily) and have to tell the DVLA.

Once someone is diagnosed with cancer, but not before, they are considered to have a disability and are covered under the Equality Act 2010 (Disability Discrimination Act 1995 in Northern Ireland). Your employer should not put pressure on you to resign because you have become disabled.

Dismissing someone simply because they become disabled is likely to be direct discrimination (which is unlawful).

Managers have a duty of care to their staff and must take reasonable steps to ensure your wellbeing. Having conversations about cancer can be difficult for them and for you, but if you do want to let them know, try to have a conversation early on.

You will also need to think about whether or not to tell your colleagues. Your managers may only tell people with your permission. Supportive employers and colleagues are more likely to understand and make allowances for any changes in your work routine or absences from work for treatment.

Once your employer knows about your situation, they may need to consider making reasonable adjustments to your work environment, such as providing equipment to help you do your job, a phased return, working from home or changing your working hours.

They may also allocate to another employee some tasks that you can no longer easily do. They will take into account your treatment schedules and fitness.



If the help you need at work isn't taken care of by any reasonable adjustments made by your employer, you may be able to get help from the Access to Work scheme:

- www.gov.uk/access-to-work
- www.nidirect.gov.uk/articles/access-work-practical-help-work

Recent experience with the COVID-19 pandemic has shown that employers also need to be prepared to make particular arrangements for your safety if you are in the category of being a clinically vulnerable person. This may include enabling you to work from home.

When applying for a job, it is unlawful (under the Equality Act 2010) for prospective employers to ask applicants about medical conditions until they have decided to offer you a job.

If you are self employed, it would also be your choice about whether or not to tell your clients about your illness.

The type and extent of your lung cancer may have an effect on your capacity to drive, lift, sit at a computer or concentrate in meetings, so you will need to make allowances for this, and think carefully about disclosing any information.

The section *Am I entitled to any benefits?* on page 12 has information about how you can check if you may be entitled to any welfare benefits if your income changes.

Taking sick leave

Some people are able to continue to work during their illness and treatment. Others may need to take time off. If you are unable to work because of your ill health for more than seven days, you will need to get a fit note from your GP.

If the fit note says that you cannot work, you should be allowed sick leave according to your company's policy. Your organisation should have clear information about sick leave entitlements.

Sick pay (statutory and company schemes)

As an employee taking time off, you may be entitled to sick pay. There are two types:

- *Statutory Sick Pay (SSP)* is the minimum amount you are legally entitled to.
- a *company sick pay scheme* is run by your employer and is usually more generous than SSP. Because having one of these schemes is not a legal requirement, employers can decide the terms under which their employees can get company sick pay.



Speak to your employer to find out more, or visit:

- www.gov.uk/taking-sick-leave
- www.gov.uk/statutory-sick-pay
- www.nidirect.gov.uk/articles/sick-pay-rights

Am I entitled to any benefits?

The benefits system can be confusing, especially if you have never been in a position before of needing to claim. Though you may initially feel reluctant to claim, a range of financial benefits is available to people affected by lung cancer.

Most cancer information centres can either help you to fill in the forms or pass you on to a welfare benefits advisor who will be able to help you. Macmillan Cancer Support also offer a financial benefits service, and have online benefits calculators.



These websites can help you find out more about welfare benefits:

- Disability benefits – www.gov.uk/browse/benefits
- Macmillan Cancer Support – www.macmillan.org.uk
- Citizens Advice Bureau – www.citizensadvice.org.uk

Your cancer doctor, lung cancer nurse specialist or GP may also be able to help you and provide more information.

Not everyone may be eligible, and benefits, eligibility criteria and payable amounts may change, so **always get expert up-to-date advice.**

We are not able to tell you if you will qualify for financial help.

More about welfare benefits

There are quite a few benefits that may be available to you.

Attendance Allowance

You can get Attendance Allowance if you're 66 or over and:

- you have a physical disability (lung cancer qualifies you here)
- your disability is severe enough for you to need help caring for yourself or someone to supervise you, for your own or someone else's safety

Carer's Allowance

This is the main benefit for carers. You must be looking after someone for at least 35 hours a week and earn £204 (or less) a week (after deductions) to be eligible.

It is not affected by savings, although the person being cared for must be receiving Attendance Allowance or the daily living component of Personal Independence Payment. You can backdate your claim by up to three months.

Employment and Support Allowance (ESA)

ESA can provide financial help if you are under state pension age and have a disability or health condition that affects how much you can work.

You also need to have both:

- worked as an employee or have been self-employed
- paid enough National Insurance contributions

You could get Universal Credit (see page 14) at the same time or instead of ESA. You won't get ESA if you claim Job Seeker's Allowance or Statutory Sick Pay.

Personal Independence Payment – PIP (Replaces Disability Living Allowance)

This benefit helps with some of the extra costs caused by long-term ill-health or disability.

How much you get is not based on your condition, but how your condition affects you. You'll need an assessment to work out the level of help you get. Your award will be regularly reviewed to make sure you're getting the right support.

PIP is made up of a daily living part and mobility part. Whether you get one or both of these and how much you'll get depends on how severely your condition affects you. It is not based on your income or savings.

Call the **Department for Work and Pensions (DWP)** to start your PIP claim. In Northern Ireland, call the PIP Centre on **0800 012 1573**.

Universal Credit

This is a payment to help with living costs and you may be able to get it if you are on a low income, out of work or you cannot work.

Whether or not you can claim it depends on your circumstances and it replaces some other benefits, including Child Tax Credit, Housing Benefit, Income Support and Working Tax Credit.





There is a different form for each type of benefit.

You can get the forms by phoning the **Disability Benefits Helplines** (see page 68) or at your nearest **Citizens Advice Bureau**.

If you're living with a terminal illness and your doctor or a medical professional has said you might have less than six months to live, you may:

- get benefits at a higher rate or get extra money
- start getting payments quicker than usual

Ask your GP, hospital doctor or lung cancer nurse to fill out an SRI form, or a BASRiS form if you're in Scotland, so you can get benefits quicker. You may also get benefits at a higher rate or get extra money. The SRI or BASRiS form will confirm your diagnosis and treatment plan.

They will send it to the Department for Work and Pensions (DWP) to support your benefit application, or you can send it yourself. The address is on the form.

As well as maybe getting some of these benefits, you may also be able to get help with paying your rent and/or council tax. You may be entitled if you are either working and have low earnings, or if you are not working and have a low income, pension and/or benefits.

Contact your local council for information on how to claim. You may also be able to get help with prescriptions, dental treatment, spectacles and the cost of travelling to and from hospital. Ask your lung cancer nurse specialist or benefits advisor about the Blue Badge Parking Scheme or Mobility Scheme.

Financial support

If you are struggling financially due to your diagnosis, there are organisations that can offer information, practical support, and advice.

Macmillan Cancer Support provides guidance on managing the financial impact of cancer, including help with understanding benefits, grants, and other forms of support that you may be able to apply for.

Cancer Research UK also offers information about financial support, including benefits and possible sources of help.

Other charities and local organisations may provide financial or practical support, depending on your circumstances and location.

Your lung cancer nurse specialist (LCNS), GP, or a hospital social worker can help you explore what support may be available and how to access it.



Work-related illness, benefits and compensation

Most lung cancers are not caused by working conditions. However, some types of lung cancer can be caused by coming into contact with asbestos or silica dust. A number of chemical agents including fumes from arsenic, benzene, nickel or tin (or their compounds), or fumes from a number of chromate compounds, also carry an increased risk of someone developing lung cancer.

People at risk include those who have worked as:

- ladders (and in trades involving heavy exposure to asbestos dust)
- dyers
- coke and gas plant workers
- metal smelters

Some people who come into contact with cancer causing chemicals at work may also have smoked. Smoking and exposure to these chemicals further increase your risk of getting lung cancer.

If you have lung cancer and have come into contact with any of the above cancer causing chemicals at work, you may also be entitled to Industrial Injuries Disablement Benefit. You may also be able to claim civil compensation.



Ask your cancer doctor or lung cancer nurse specialist if it is appropriate for you to apply.

For more information, contact the **Industrial Injuries Disablement Benefit Centre** on **0800 121 8379** or visit:

- www.gov.uk/industrial-injuries-disablement-benefit

To claim this benefit you will need to complete a form and send a report from your doctor or lung cancer nurse specialist giving details about your lung cancer.

To claim compensation, you should seek advice from lawyers who specialise in dealing with claims for occupational lung disease. Good lawyers should offer you a first interview at no cost to you.

“Find out what financial help is available as soon as you are diagnosed. We suffered in silence and used up all our savings before getting help.”

Phil



Looking after yourself

When living with a cancer diagnosis, it can be difficult to relax and you may have feelings of stress, worry, anxiety, anger, grief or even depression.

Being affected emotionally is normal for people living with a serious illness. It is important to bear this in mind and take time to think about how you will look after your mental health and wellbeing as well as your medical situation.

Some people may be used to many challenges in their lives and have tried-and-tested coping strategies. For others, this may be one of the first major things to affect their lives and feel a bit lost and out of their depth. This section will help you work out your best ways to look after yourself during what can be a difficult time.

On a day-to-day basis, it may help to talk about how you feel with a member of your family, a friend, or your lung cancer nurse specialist. Sometimes it's your friends and family who need to talk things over.



To speak to someone independent for support and advice, call our free **Ask the nurse** service on: **0800 358 7200** or email: **lungcancerhelp@roycastle.org**



Keeping up with social activity, hobbies and perhaps volunteering will help you to maintain a sense of routine and occupy your mind with something more positive, though you may struggle initially to get motivated.

Longer term, it is good to plan particular ways you can support yourself during this challenging time.

Other sections in this booklet will be helpful to you if you want to boost your mood.

For example, if you haven't already read it, the *Getting organised* section on page 6 will help you consider things that need to be done and other things you want to get done so you can plan ahead, pace yourself and save your time and energy for your health and wellbeing.

Life can be hectic, with dozens of things to do, bills to pay, appointments to keep, people to see, DIY, paperwork to complete and it can be easy to put things off for another day, or to stress around doing or not doing something.

Having lung cancer is going to take up a lot of your time and energy so doing as much as you can to get on top of tasks, and asking for help is recommended.

Also, when people notice they are losing weight, have little or no appetite or struggle to eat, it can be a great worry. Understanding a bit about nutrition and how lung cancer and its treatments can affect your eating, can help you and those who may care for you plan shopping, look at the best meal options for you, and so help you stay more positive.

The *Eating well* section on page 38 is full of information and ideas.

Even just completing some stretching exercises mentioned in the *Getting active* section on page 45 you are very likely to reduce your stress and feel better. Building this and other activity into your day is also good to help you work through anxious and stressful times, as well as potentially improve your outcomes during and after treatment.

There is long-established evidence of the harms smoking can cause and links with lung cancer. If you do smoke, stopping it can reduce future risk of many cancers and other health issues.

However, while some people swear by the apparent relaxing effects of a deep puff on a cigarette, research suggests that a smoker's perceived anxiety relating to everyday pressures may actually be largely down to the withdrawal that increases before the next fix.

Nicotine is a stimulant, not a relaxant. If you are a smoker, the [Stopping smoking](#) section on page 55 can help you look at the health benefits of stopping as well as perhaps motivating you to try to quit.

It is crucial for people to look after themselves in every aspect of their lives – sleep, diet, exercise, relationships, work – and to remove negative life aspects if at all possible.

Phil

The information about work, money and other sources of support may also help you feel like you can manage things better and break up your list of things to do into manageable chunks.

There are many websites around that have tips and techniques for relaxing, and supporting your wellbeing. The NHS Choices website (www.nhs.uk), for example, has a section called 'Moodzone' that helps people deal with stress and difficult emotions.

If you are finding things hard, feeling anxious or depressed, talk it through with your cancer doctor, lung cancer nurse specialist or GP. They may be able to put you in touch with a counsellor, or arrange for some medication that may help.

Getting enough sleep

Many people affected by cancer can have difficulty sleeping. Some medication, such as the steroids prednisolone and dexamethasone, can cause insomnia. There may be side effects linked to your cancer and its treatment such as nausea, pain, hot flushes and frequent trips to the toilet. Side effects may happen during your treatment or appear some time after your treatment stops.

These can all disrupt a good night's sleep.

Sometimes the emotional effects of lung cancer, for example worry, anxiety or depression, can also mean you lose sleep. If you spend time in hospital, that can be challenging for sleep because of the noise and many interruptions. It's not the bed you are used to sleeping in either. Even your own bed at home may be uncomfortable after surgery, for example, so you may need to try different sleeping positions and use extra pillows to prop yourself up.

Sleep is important to everyone, not just those with cancer. It is restorative both physically and emotionally. It is a time when your body reproduces and repairs cells, helping it heal. It helps boost your immune system, particularly important for people on some chemotherapy drugs.

If you are running short of sleep, it can affect your mood and how you interact with those around you. If you are feeling a bit negative, it will influence how you choose and respond to treatment options, and how open you may be to support and suggestions offered by your loved ones and medical team. Rest can help you think more clearly and positively.

Sleep is good for us all, and is very important in improving our quality of life. Many people simply put up with the lack of sleep. They consider it a minor issue, don't want to trouble anyone, or think there is nothing that can be done to help.

There are things you can do to try and improve your sleep, including:

- having a regular bedtime routine
- avoiding electronic gadgets like TVs and mobile phones (they give off more blue light than natural daylight and can affect sleep patterns)
- relaxing before bed: light stretches, relaxation CDs or reading
- being more physically active during the day
- making sure your bedroom is not too hot/cold/light or noisy
- having a snack before bed, but avoiding caffeine, sugar and alcohol

If worry and anxiety are keeping you awake, talking to someone may help. Writing down your worries a few hours before bedtime can help clear your mind. Breathing and relaxation exercises may also be useful to reduce these feelings.

Some medicines used in the treatment of cancer can affect your sleep. Your doctor or nurse can give you advice on coping with this.

You may be able to take sleeping tablets to help. These can have side effects, so they are usually prescribed for only one to two weeks. There are also some behavioural therapies that can help. Your GP can tell you if these are suitable for you.



Find out more about getting better sleep by searching for “bedtime routine” at:

- www.nhs.uk/Livewell

I have been lucky in mostly sleeping well. In the earlier days, my breathing was poor at night and I found a collapsible back rest in the bed raised at night to be a great help rather than lying flat.

Graham

Helping yourself to relax

Relaxation may be helpful as you train the mind to relax the body. This may help to reduce any stress or anxiety you feel. It can also help you with memory, concentration and fatigue.

The first stage in learning relaxation is becoming more aware of which particular parts of your body tense up when you feel uptight. The most commonly affected areas are the neck, shoulders and back. Below are exercises that are intended to help you learn how to relax.

To begin with, start by practising these exercises at least once a day. Either do these exercises in a comfortable armchair that gives good support for your head and shoulders, or propped up in bed. Do the exercises somewhere you won't be disturbed and you can concentrate fully. It may be helpful to get someone to read out these exercises to you initially.

Relaxation exercises and techniques include:

- breathing exercises
- progressive muscular relaxation
- guided imagery
- visualisation

Breathing exercises

Learning a breathing technique in itself can help you relax, and reduce stress and anxiety. It can also support you when doing physical activity (see page 45) as you may need to breathe more deeply to get more oxygen.

Breathing is something most people take for granted, but having lung cancer usually reduces how well your lungs work, sometimes greatly. Speak to your medical team about help with breathing if you are finding it hard.

It is important not to give up – if you aren't used to exercise (with or without lung cancer), it's natural to breathe more heavily. Only by improving your fitness will this improve.

Groups of muscles in your chest and abdomen attach to your ribs and spine to work like bellows around the lungs, enabling a breathing action. The rib cage increases in size when breathing in (inspiration), and reduces in size when breathing out (expiration).

As with all muscles, these work better when exercised.

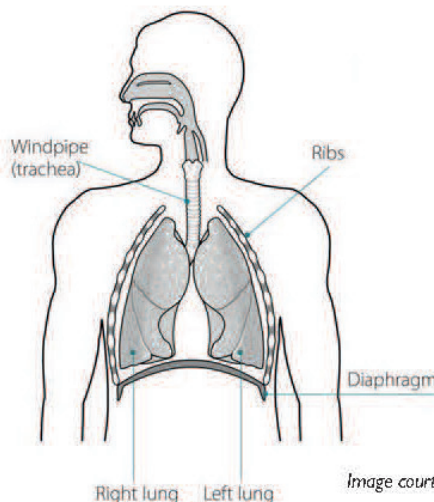


Image courtesy of Irish Cancer Society.

Diaphragmatic breathing

The diaphragm is a key muscle used in the process of breathing.

It is dome-shaped and attaches to the ribs and spine around the bottom of the chest (see page 25). When it contracts, the diaphragm flattens and pulls the lungs down, making them draw in air.

Diaphragmatic breathing helps you breathe more efficiently, allowing you to shift more air in and out of your lungs without tiring your chest muscles as much.

When the diaphragm becomes weak, people compensate when breathing by using the shoulders and other muscles to help them breathe.



To practise diaphragmatic breathing:

- Sit or standing up straight and relax the top of your chest and shoulders.
- Place your fingers lightly at the bottom of your chest on your tummy.
- Give a little cough and the muscle that you feel under your fingers is the diaphragm.
- Breathe in slowly through your nose and feel your lower ribs expand and tummy rise, noticing your fingers move outwards. Allow your diaphragm to lower and lungs to inflate as far as they can.
- Purse your lips and breathe out as gently as possible like a sigh, feeling your lower ribs come down and in, emptying your lungs.
- Notice your tummy button pressing towards your spine as you push more and more air out.
- Breathe in again slowly, and repeat the exercise.
- Try to do it about five or six times.

Do this exercise several times a day. It will help you strengthen your abdominal muscles, and regulate your breathing if you become short of breath, particularly during an activity.

Progressive muscular relaxation

This technique involves tensing and relaxing muscle groups throughout your body. It can be deeply relaxing. You should tense the area of the body and muscle group described for a few seconds before relaxing it. Try to concentrate on the difference between feeling tense and relaxed.

For maximum benefit, tense and relax each muscle group twice before moving on to the next one. Before starting the exercise, shut your eyes and establish a slow, steady pattern of breathing. Begin to notice how every time you breathe out, you start to feel more relaxed.

Face: Pull your eyebrows tightly together and close your eyes, as if making a frown, and hold that tension for a few seconds, then – relax. Now try clamping your teeth together, feeling the tension in your mouth and jaw. Push your tongue against the roof of your mouth and hold that tension for a couple of seconds and – relax. Repeat.

Neck: Press your head backwards, either against the bed or chair and feel the tension. Hold that tension for a couple of seconds and – relax. Repeat.

Shoulders: Bring your shoulders up as high as you can. Hold the tension and then – relax. Allow your shoulders to drop back down and again feel the difference between the tension and the feeling of relaxation. Concentrate on how your shoulders, arms, wrists and hands now feel relaxed and heavy. Repeat.

Arms: Bend your arms, bringing your hands up towards your shoulders and again, notice the tension. Try to make the muscles tight for a few seconds and – relax. Repeat.

Hands and wrists: Tense your hands by squeezing your hands into fists. Feel the tension and – relax. Notice the difference between tension and relaxation. Repeat.

Chest and stomach: Push your chest out arching your back and hold that position for a couple of seconds and – relax. Notice how the muscles in your chest feel relaxed. Continue to breathe regularly and evenly. Next, pull your stomach in tightly and hold the tension for a couple of seconds and – relax. Repeat.

Legs: Point your toes away from your head and stretch your legs. Feel the tension for a couple of seconds and – relax. Repeat.

For a few moments, continue to breathe gently and regularly, enjoying the feeling of relaxation. Try to imagine a pleasant image in your mind's eye.

Once you are ready to move, count backwards from three to one and open your eyes. Get up slowly and try to keep that state of relaxation for as long as possible.



Guided imagery

Before imagining or listening to this scene, close your eyes and take three deep breaths. Breathe slowly and steadily, in through your nose and out through your mouth.

Now picture a happy, pleasant time, a time when you have had little or no problems or worries about your health.

Fill in the details of that time:

Look at the surroundings. Is it indoors? Outdoors?

Who is there? What are you doing?

Listen to the sounds. Even those in the background.

Are there any pleasant smells? Feel the temperature.

You are happy. Your body feels good.

Just enjoy the surroundings.

Fix this feeling in your mind and you can return to it any time you like just by picturing this happy time.

When you are ready, take three more deep breaths.

With each breath, say the word “*relax*”.

Imagine the word written in warm sand or clouds.

Now open your eyes – remain quiet for a few minutes before slowly returning to your activities.

Visualisation

One way to use visualisation is to think about pleasant scenes from your past or create new scenes in the mind. It allows you to create more of your own images than the guided imagery technique does. For example:

Try to remember every detail of a party that made you happy.
Who was there? What happened? What did you talk about?

You can do the same sort of thing by remembering a special holiday.

Another form of visualisation involves using the mind to think of symbols that represent the discomfort of pain felt in different parts of the body.

For example, the tightness in your chest may be red or have a constricting band around it. After forming these images, you can then try to change them. The red colour may fade until there is no more colour, or the constricting band will stretch and stretch until it falls off.

Visualisation is a useful technique to help you set and accomplish your personal goals. After you have set these goals take a minute to imagine doing your exercises, taking your medications, or taking a walk. Here you are mentally rehearsing the steps to achieve your goals successfully.



There are many examples of breathing exercises online, and many are audio files that you can download. You may find helpful information and audio files here:

- Maggie's Centre – www.maggies.org
- Macmillan Cancer Support – www.macmillan.org.uk have a relaxation CD you can order or download
- Asthma + Lung UK – www.asthmaandlung.org.uk
- NHS trust websites also give downloadable exercises

Complementary therapies

Sometimes also known as alternative therapies, complementary therapies may help to control your symptoms and enhance your quality of life. They may be used alongside conventional cancer treatments. They work using the healing power of nature, stimulating the body's natural healing ability.

The treatments aim to work with the whole person including the physical, spiritual and social being. Some complementary therapies can be helpful in reducing symptoms such as pain, however it is important to stress that there is no conclusive scientific proof that such treatments can reduce (shrink) or cure cancer. You can ask your therapist if their approach has any proven benefit to someone in your situation.

There is a huge variety of complementary therapies advertised on the open market. Many are well known and proven to be helpful. However, there are also some therapies that have doubtful or unproven benefits.



It is important to also check with your doctor before starting any complementary therapy as it may interfere with some treatments or other medication you may be taking and affect how well they work.

Cancer Research UK (www.cancerresearchuk.org) often has news articles about alternative treatments whose benefits are not clear, including cannabis oil. Trust information from reputable sources and be wary of links shared on social networks claiming miracle cures. Your hospital or GP practice may have a complementary therapy service.

I have used acupuncture, Reiki, Emotional Freedom Technique (EFT), massage, kinesiology, yoga and Pilates. These have helped with my mind and with side effects.

Katie

Therapy	what is it?
<i>Acupuncture</i>	Part of a system of Chinese medicine that depends on the balanced functioning of the body's energies and involves very fine needles being inserted at specific points on the body's surface.
<i>Aromatherapy</i>	Uses massage and inhalations combined with essential plant oils, to promote health and healing of the body.
<i>Bowen technique</i>	A light tissue manipulation thought to help balance the body's energies.
<i>Hypnotherapy</i>	Uses the hypnotic state to overcome limitations by controlling the body and mind.
<i>Massage</i>	Uses gentle to vigorous contact to stimulate the blood flow around the body, helping a person to relax.
<i>Reflexology</i>	A form of ancient Chinese medicine involving treatment using massage to reflex areas found in the feet and hands.
<i>Reiki</i>	Uses life energy being passed by gentle touch, through the practitioner to the person receiving this relaxation treatment.
<i>Spiritual healing</i>	Channels healing energy from a spiritual source to the patient through the healer's hands.
<i>Tai Chi</i>	Tai chi combines deep breathing and relaxation with flowing movements. Originally developed as a martial art in 13th-century China, tai chi is today practised around the world as a health-promoting exercise.

Be very wary of unusual (possibly illegal) and often costly therapies advertised in the media such as the internet, or newspaper adverts. If you are in any doubt, speak to your GP or hospital team about whether it may be of any particular benefit to you.

Taking a break or having a holiday

Something most people look forward to is a holiday, time away from the routine and a chance to take a break from our everyday pressures. While there are some obvious benefits to being away, it would also mean that all the people and services you rely on at home won't be at your fingertips so you will need to think ahead.

For many, going on holiday or travelling with lung cancer will have little or no impact on how well you are. However, it can also be tiring, and the further and longer you travel, the more you could be affected, particularly if your health isn't too good.

It's very important for you to speak to your doctor or lung cancer nurse specialist before making any travel plans if you want to go away for a short break or a longer holiday.

They can tell you whether your cancer or treatment may make travelling unsafe. They can also tell you what you might need to consider when travelling abroad.

Will I be able to get travel insurance?

Getting travel insurance can be difficult, but there are specialist insurance companies that cover people with cancer.

The UK Global Health Insurance Card (GHIC) lets you get state healthcare in Europe at a reduced cost or sometimes for free. If you have a UK European Health Insurance Card (EHIC), it will be valid until the expiry date on the card. Once it expires, you'll need to apply for a GHIC to replace it.

To be sure you are covered for any medical problems while abroad, you will need a policy that covers you after fully disclosing your lung cancer diagnosis, lung cancer status and treatment history.

Will I be allowed to take my medicines abroad?

If you are taking regular medicines, make sure that you have enough to last you the whole trip, even if your return is delayed by a couple of days. Also remember that some countries limit the amount of certain drugs that can be taken into the country. You may want to take a copy of your prescription with you in case your return travel is delayed longer than your supply.

Check with the high commission or embassy of the country you're travelling to about any restrictions they have. If you are using a travel agent, they may be able to confirm what is needed in writing.

It's a good idea to carry all medicines, covering letters and licences for controlled drugs in your hand luggage, as customs officers will usually need to see them. It may be advisable to keep medicines, including inhalers, in a see-through bag. Also try to keep medicines in their original packaging so they can be easily identified.

If I often get breathless, can I still travel?

If you are affected by breathlessness, sometimes it can be helped by taking some oxygen with you, particularly if flying. Having to wear a face covering may make breathing more difficult, and you may find it helps to have a battery-powered hand-held fan.

Planes fly at over 30,000ft and the pressure inside the cabin is lower than at ground level. This causes oxygen levels in people's blood to drop.

If you don't get enough oxygen into your blood, you may feel unwell. This condition is called hypoxemia, and symptoms include headaches and feeling sick. It is important to speak to your GP or lung consultant well in advance of your trip to find out if you will need extra oxygen.

Some medical centres may do a hypoxic challenge (fitness-to-fly) test. The test simulates the reduced oxygen levels that you would normally experience during a flight and helps work out if you would need extra oxygen.

“ We have been to Thailand and Italy,
along with some UK breaks.
The holidays gave me and my husband some quality time
away together, away from hospitals.”

Jane

If your doctor does say you should take oxygen when flying, you should speak to the airline before you book your holiday. Each airline has a different policy on carrying oxygen and whether they charge a fee or not.

Speak to your doctor, lung cancer nurse specialist or oxygen supplier about who can supply you with oxygen for the flight and what arrangements can be made for when you are away if you need oxygen throughout your holiday.

The air travel section of the European Lung Foundation website has information about the oxygen policies of different airlines (www.europeanlung.org).

Most airports and train stations have facilities to help you get around and avoid getting too breathless, such as wheelchairs or mobility buggies.



For more information, check out:

- Civil Aviation Authority – www.caa.co.uk/passengers
- World Airport Guides – www.worldairportguides.com
- World Travel Guide – www.worldtravelguide.net

TOP TIP

A hand-held electric fan can be effective in cooling you down and help you breathe more easily when you are travelling. They are simple to operate, and batteries are widely available across the world. Keep it in your hand luggage when flying.

Do I need to take extra care in the sun?

Some cancer treatments can make your skin more sensitive to sun damage. Speak to your doctor or lung cancer nurse specialist about what extra care you should take if you are travelling to a sunny destination.

Ideally use products with a sun protection factor (SPF) of at least 30 and wear a sun hat, staying out of the sun during the hottest part of the day.

Our *Travelling, going on holiday and lung cancer* booklet gives more information about going on holiday.

It also has a section on getting travel insurance that lists some travel insurance companies and brokers recommended by people who have been affected by lung cancer.



You can view this booklet online at:
www.roycastle.org
or call us free on
0333 323 7200 (option 2)
to order a copy.



Eating well

People with lung cancer can often experience a loss of appetite as well as difficulty with chewing and swallowing, and some treatments can cause side effects that may make eating enough food difficult.

We eat food for energy, protein and for the vitamins and minerals we need, so it is really important to try to eat as varied and nourishing a diet as you can. Our practical tips may help mealtimes become a little more manageable – and enjoyable.

People with lung cancer may experience weight loss to some extent, and most of our advice recommends eating high calorie (energy) and high protein (building blocks) food.



As a result of some treatments, others may gain weight. If this applies to you, eat a healthy, balanced diet and speak to your healthcare team.

The key is trying to get a varied and nutritious diet, including fruit and vegetables.

If you are struggling to do this, please talk to your dietitian or other healthcare professional for advice. They may prescribe nutritional supplements that can help improve your overall intake.



Nutritional supplements can be added to everyday foods such as milkshakes, soups, juices, yogurts and puddings. They can be consumed on their own as an addition to your usual diet, or they may be used to replace a meal when you are not managing to eat.



There is a range of nutritional supplements available including milkshake style, juice-tasting style, yogurt style, soups, puddings and powdered drinks.

Your doctor, nurse or dietitian will prescribe these for you and will give you guidance on the recommended quantities.

Remember if you have any concerns, your healthcare professionals are there to help and can provide details about local organisations that offer support.

Does sugar feed my cancer?

All our body cells, whether cancerous or not, use sugar (glucose) for energy. Giving more sugar to your body won't speed up the growth of cancer cells. Depriving yourself of sugar won't slow their growth either.

If you are going through treatment, remember that your healthy cells need energy, especially during this time. There is insufficient evidence that avoiding sugar and carbohydrates completely helps treatments, however, it could leave your healthy cells low in energy.

It is worth noting that sugar only provides calories and no other valuable nutrients like vitamins or minerals and fibre. Better sources of energy would be from foods that contain natural sugar such as fruit, dried fruit as well as starch carbohydrate like bread, cereals, rice and potatoes. These will also add interest and variety to your daily diet.

I've not got much of an appetite just now – is this normal?

Weight loss and loss of appetite or taste are very common in people with lung cancer, and there can be many reasons for it – the cancer itself, your treatment or medication, or through worry or anxiety.

When a person has limited breathing capacity it can feel quite scary to “use it up” by the effort of chewing and swallowing. However, it is vital to keep going as much as you can.

Start to concentrate on eating foods that will give you more energy and protein. Smaller meals can be less of a challenge than a big plateful of food. Try three smaller meals with extra snacks and nourishing drinks in between. Using a smaller plate too can help.

You are more likely to get the nutrients you need if you eat little and often. It is a good idea not to drink a lot of fluid before your meal as this may make you feel fuller and reduce your appetite.

You may find it easier to try softer, moist foods such as nourishing soups, scrambled eggs, pasta in cheesy sauce, vegetable bakes, soft stews, fish or mince with mashed potatoes.

If your appetite is better at a particular time of day, plan to eat then even if it's not your usual time to eat a meal. Some people find that a small glass of alcohol, sherry, for example, can help perk up their appetite. Just check with your doctor or pharmacist that it doesn't affect your medication.

Fresh air can help stimulate the appetite so try to go outside wherever possible or, if you are not very mobile, sit by an open window before mealtimes.

What kind of things should I be eating?

You can add extra calories to foods by adding butter, olive oil, grated or cream cheese, or cream to savoury foods. Puddings and fruit can be enriched with cream, evaporated milk, ice cream, dried fruit, honey, jam or syrup. For snacks, try some biscuits or cake with a cup of tea, cheese and biscuits, crisps or nuts, a bowl of cereal or a creamy yoghurt.



Using mayonnaise and salad dressings, and drizzling olive oil through soups or on bread can be good ways to add calories to your meals.

Try to have good protein sources at each meal and some for snacks. Protein-rich foods are eggs, meat, fish, soya, Quorn, milk and dairy products, beans, pulses, nuts, nut butters, seeds and quinoa.

Can I drink alcohol while getting treatment?

If you are undergoing cancer treatment and you are considering having some alcohol, talk to your doctor about it first. Drinking alcohol may not be a problem so long as it is within recommended amounts.

If you are getting chemotherapy, speak to your doctor about how it may or may not affect your treatment. Radiotherapy can make you tired, and alcohol may add to this.

Other questions about food and eating

“I can’t face eating at all just now – what should I do?”

If you aren’t able to eat at all, try a nourishing drink. Fortified milk is good for this. Just add three or four tablespoons of skimmed milk powder to a pint of full fat milk. You can then use this in hot drinks or blended with milkshake powder, fruit or ice cream. Keep it in the fridge and use within 24 hours.

Speak to your health care team about some suitable oral nutritional supplements.

“I feel too tired to cook – what would help?”

It is quite common to feel tired and not have the energy to cook and prepare meals. If you do feel like cooking, do more than you need and freeze the extra portions for quick, easy meals when you feel less able.

Homemade soups can be a good option. Friends and relatives can often want to help by bringing meals in for you, so take them up on the offer.

Let the supermarkets do the hard work and take advantage of their convenience foods and ready-made meals. Always have a few in the fridge or freezer.

If you, a friend or family member can go online, most supermarkets will pick, pack and deliver your food order, sometimes at no extra cost if your order is over a certain amount. It can also be a good idea to keep a supply of tinned and packet foods in your cupboards.

Supermarkets and other food suppliers now have many delivery options. Frozen meal companies can also be very helpful, and a great way to get quick, tasty and nourishing meals delivered to your door.

“I struggle to eat sometimes as I feel sick – what can help?”

Feeling sick (*nausea*) can be difficult to manage, whether it's because of treatment or medication. There are anti-sickness medicines (also called *anti-emetics*) that can reduce this feeling, and your cancer doctor or lung cancer nurse will be able to help you find one that is suitable for you.

Other things to try to help include:

- eating cold or room-temperature food to reduce some food smells, and avoiding greasy food
- eating little and often throughout the day
- trying foods or drinks that contain ginger – ginger tea, ginger beer, ginger ale or ginger biscuits
- sucking boiled sweets, fruit sweets or mints
- trying other carbonated drinks such as lemonade, cola or flavoured sparkling water



What can I do if I have a sore mouth or throat?

Some people receiving treatment, such as radiotherapy, chemotherapy, immunotherapy or targeted therapies get a sore mouth or throat.

Other infections, such as thrush (white patches over the lining of your mouth or your tongue), or problems with your teeth or dentures can make things worse. Speak to your GP or hospital and they may prescribe a mouthwash or other medication to help.

Having good oral hygiene is important. Keep your mouth clean and fresh, regularly brushing your teeth or dentures with a soft brush. It may be a good idea to visit your dentist for a check-up before starting treatment.

Some ideas that may help:

Milkshakes and smoothies: These are a great way to get fruit and veg into your diet if you are having trouble chewing and swallowing, drinks.

Avoid very hot food: Let it cool down to a temperature you find works best for you. This might be room temperature or straight from the fridge.

Avoid rough or textured food: Cereal or crackers, for example, can catch in sore areas.

Go for milder foods: Avoid curry, chillies, citrus fruit and vinegar.

Blended, creamy foods: Soups really work for some people, but just remember to let it cool a bit before eating.

Be wary of alcohol: Though a glass of sherry before a meal can help some people's appetite, alcohol can irritate sore mouths, so avoid it until your mouth feels better.

Getting active

Being active and exercising is beneficial to people's health and wellbeing. If you have lung cancer, as well as perhaps COPD or asthma, there are many benefits too.

In general, taking regular exercise is beneficial because it can:

- increase strength and muscular endurance
- help regulate your breathing
- lower blood pressure
- reduce the risk of some health conditions, including heart disease, stroke and type 2 diabetes

During cancer treatment, people may become less active due to side effects of the treatment. However, exercise has also been shown to help people better tolerate, respond to and recover from lung cancer treatments, such as chemotherapy, radiotherapy and surgery.

Exercise can also help you:

- manage cancer fatigue
- reduce stress and anxiety
- boost your mood and energy levels
- relax
- improve your sleep

It can also reduce the risk of depression, as well as increase your appetite and confidence.

Being active during treatment is generally safe too. While it's natural to feel a little nervous about being too active and getting out of breath, light exercise can have real benefits to your wellbeing.

*“ Do something that you enjoy.
Just walking helps if it gets you outside.
It lifts your spirits as well to be out in the fresh air.”*

Graham

Increasingly, exercise is being recommended as part of prehabilitation programmes – a range of services and support given to someone between their diagnosis and the start of any treatment. It can help reduce possible complications from those treatments, and to improve physical and mental health outcomes.

While some activity and exercise may be a solitary activity, like vacuuming or gardening, walking with family or friends can be a good way to socialise.

Exercise when you can, even once or twice a week, building up to every day if possible. Light exercises that fit into everyday life include:

- going for a walk
- doing some gardening
- taking your children or grandchildren to the park
- walking up stairs instead of taking the lift
- strolling around a museum, gallery or shopping centre (many of which are indoors, flat and have seating areas)

If you were active before your diagnosis, you may need to be patient and be realistic about how much you can do now compared to before. Lung cancer reduces strength and endurance no matter how fit you have been.

Because of how lung cancer affects people, it is always important for you to spend some time concentrating on breathing (pages 25 to 27) and stretching (pages 48 and 49). See them as exercise in themselves, and have them as part of any plan to get active.

Putting together a suitable programme of breathing, walking, stretching and strength training will help you with your illness, and develop your energy and endurance. There may be suitable locally organised exercise programmes you can join. Speak to your lung cancer nurse specialist or physiotherapist about whether these would be suitable for you and how can access them.

So, whether you want to just walk around your garden, do some housework, cycle or swim, speak to your lung cancer doctor, lung cancer nurse specialist or physiotherapist. They can help with what is realistic and best for you, and, if you get treatment, what will help you most before, during and after it.



These websites may also give you useful information about exercise and fitness:



- NHS Choices
www.nhs.uk/livewell/fitness
- Maggie's
www.maggies.org/cancer-support/managing-practically/exercise-and-cancer/
- Roy Castle Lung Cancer Foundation
www.roycastle.org/about-lung-cancer/living-with-lung-cancer/getting-active/

Stretching exercises

By doing regular stretching exercises for your upper body you will improve the mobility in your chest and back. This helps your lungs and diaphragm move more freely. The stretches below are only some that you may want to do after talking with your healthcare professional.

Stretching the different areas helps to keep the chest muscles loose and encourage deeper breathing. It will also help your general flexibility and improve your range of movement. It helps with circulation and this supports the body to heal.

You may also enjoy the more structured stretching of yoga or Pilates, in an organised class or online. Yoga is an ancient form of exercise that focuses on strength, flexibility and breathing to boost physical and mental wellbeing.

Pilates aims to strengthen the body in an even way, with particular emphasis on core strength to improve general fitness and wellbeing. Both have something to offer people of all ages and levels of ability and fitness.

Shoulder stretch

This stretch, done standing or sitting, helps to loosen your shoulder joint and around your shoulder blade.

Reach one hand and wrist over the opposite shoulder, pushing it at the elbow with your other arm. Hold the stretch for around 20 seconds, then relax.





Triceps stretch

You can do this stretch standing or sitting. It stretches the muscles at the back of the arm as well as encouraging movement in your chest and shoulders.

Bend and lift the arm to be stretched over your head and reach your hand between your shoulder blades. With the other hand, grasp the elbow and push it back and down until you feel the stretching at the back of your upper arm. Hold the stretch for around 20 seconds, then relax.

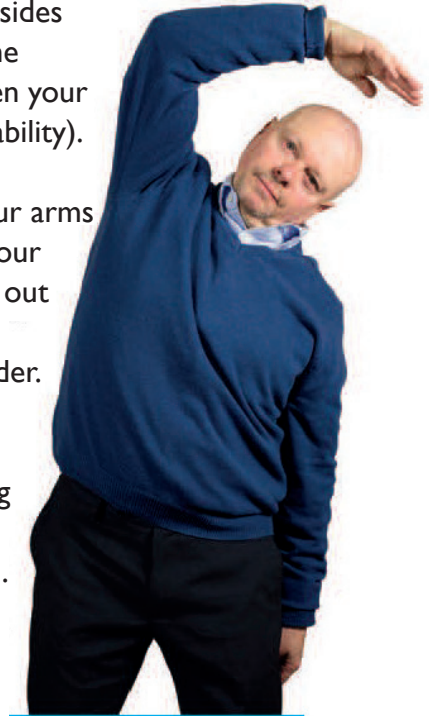
Standing side stretch

The standing side stretch helps to open the sides of your body, focusing on the rib cage and the intercostal muscles (the muscles run between your ribs that help with breathing and rib cage stability).

Stand with your feet hip-width apart and your arms relaxed by your sides. Breathe in and raise your left arm straight up over your head. Breathe out and lean over to the right, keeping your hips facing forward and your buttocks tucked under.

Lengthen your neck and stretch over to the side as far as you can without compromising spinal alignment. Hold the pose for a few breaths, focusing on expanding your rib cage.

On an out breath, return to standing and repeat on the opposite side.



Strength building exercises

People with lung cancer may benefit from exercises for strength because they can build up muscles that were weakened from symptoms and anti-cancer treatments. If you spend a lot of time just sitting, this can affect muscle mass which will decrease.

A good way to start to exercise is in small increments of ten minutes at a time depending on your level of tiredness. Increase exercise levels slowly, set reasonable goals, and be mindful of the effect that exercising can have on your body – remember, it may take time to improve your fitness level.

At first, you might feel more tired and might only be able to exercise for a short period of time. Gradually increase your exercise session each day as you feel able.

By becoming stronger, you will be able to do more day to day. Strength training can also help improve your balance, posture, and increase bone strength.



Bicep curls

Stand with your arms hanging down.

Hold a tin, or weight in each hand and turn your palms forward.

Bend and then straighten your elbows.

Repeat 10 times.

Knee bends

Stand with your feet about hip width apart in front of a table or chair and hold on with both hands.

Slowly bend your knees, keeping your back straight and heels flat.

Hold for just two or three seconds. You should feel the stretching in your buttocks and the front of your thighs.

Straighten the knees, and return to your starting position. Repeat 10 times.



Heel raises

Stand with your feet about hip width apart in front of a table or chair and hold on with both hands.

Slowly bend your knees, keeping your back straight and heels flat.

Hold for just two or three seconds. You should feel the stretching in your buttocks and the front of your thighs.

Straighten the knees, and return to your starting position.

Repeat 10 times.

Managing everyday activities

What we enjoy doing or need to do each day varies from person to person. What might be important to one person may not be to another. Everyone is unique.

You may find that at times, particularly during periods of treatment, you feel more tired than usual. When carrying out certain activities, your breathing might be difficult. Finding ways to adapt some daily activities may help this. Also, your ability to breathe may be affected by hot, humid or cold conditions outdoors.

When necessary, your doctor will also provide medication or treatment to help you. When activities are carried out in the easiest, most efficient way, less strength is used, so you should find it easier. There are some simple guidelines below that can help you to cope with any difficulties you may experience.

Try to remember the following four **P**s:

**Problem solve. Prioritise.
Plan ahead. Pace yourself.**

Problem solve: Often it's not what you do, it's how you do it that makes the difference. Look at your daily habits and routines – does your body complain when you do certain things? If so, how could you do them differently that would help?

Prioritise: Think about what is important for you. You may find that you can't pack as much into each day as you would like, so you may wish to save your energy for specific activities or events. It may be helpful to leave some tasks, particularly heavier ones, to friends or family.

This will give you more energy for the things that are more important to you. Let someone else take care of the laundry if it allows you to go on a short stroll with the dog.

Plan ahead: Forward planning can help you to achieve what you want to do, without becoming over-tired or breathless. Think ahead when planning outings, for example, give yourself extra time when going to an appointment or choose a restaurant that has good parking. This will help you to feel more relaxed and enjoy your outing.

Pace yourself: Try to pace yourself during the day by balancing periods of activity with periods of rest. You may also find that you wish to have a rest during an activity to avoid becoming breathless. Sit down for as many activities as possible. Try to use slow, relaxed movements and avoid rushing and getting flustered.

Some people try too hard and overdo things, so be guided by your own body. Better to rest if you feel “below par” rather than carry on regardless and cause a setback to your recovery. Aim to pick up again as soon as possible.

An occupational therapist or physiotherapist can give you more information about managing everyday activities.

“*Sometimes you do push yourself
but you have to listen to your body.
If it's telling you to rest for a couple of hours, you rest.*”

Michele

Even though your lung capacity may have been affected, exercise can help you improve your quality of life, reduce fatigue and low mood, and improve muscle strength. Here are some tips:

Set limits: Remember that you may not be able to exercise at the level you have been used to. Listen to your body and start “low and slow”, for example, with a few five- or ten-minute sessions of light walking or easy cycling a few times each day, and build up gradually.

Set targets: Use a pedometer, mobile phone app or wearable activity tracker to count your steps and keep an eye on your exercise. These are great motivators too. Maybe you can persuade others to get involved in your exercise and keep you company. Write down your steps for a week, then slowly set goals from there, increasing the number of steps over time.

Watch your posture: Sitting down all day at a desk or driving can make your posture worse. Better posture is linked to better breathing and lung capacity. Think about keeping your shoulders and chin back, and opening your body to encourage deeper breathing.



Stopping smoking

We know that thousands of the people diagnosed each year with lung cancer have never smoked or gave up smoking many years ago. For those who do still smoke, or who start smoking after diagnosis, it is worth thinking about stopping.

Finding out you have lung cancer can be very distressing. If you do smoke, there are real benefits to stopping. For example:

- cancer treatment is safer for you
- you can expect to respond better to your treatment
- in the longer term, you will reduce your chances of having your cancer come back

Why is smoking such a problem?

Tobacco smoke is the most poisonous material to which people are regularly exposed. Even low levels of smoking, as well as breathing in second-hand smoke, is particularly harmful to you if you have lung cancer, both during treatment and after.

Smoke includes more than 7,000 toxic chemicals and these poisons get into your system very easily through your lungs. Some of the poisons include arsenic, butane (cigarette lighter gas), formaldehyde (used to preserve bodies), acetone (nail varnish remover and paint stripper) and methanol (rocket fuel). Nicotine is also a highly addictive substance.

There is no safe level of exposure, and smoking tobacco is very harmful in any form, including cigars, pipes, or shisha through a waterpipe.

How will stopping smoking help me?

Stopping smoking is good for anyone. It's even more important to stop if you have lung cancer and are starting treatment, such as surgery, chemotherapy and radiotherapy.

Smoking directly damages DNA (deoxyribonucleic acid), the genetic blueprint that controls our development and body function.

Tobacco smoke also contains high levels of carbon monoxide. In combination with some of the other chemicals, this can increase breathlessness, make you feel sick and stop you getting a good night's sleep.

It also narrows blood vessels, and this reduces the amount of chemotherapy drug reaching the cells. Carbon monoxide replaces oxygen in blood, and this can slow down any healing, and reduce the effectiveness of treatments such as radiotherapy.

Many of the drugs used to manage the side effects of treatments and cancer symptoms don't work as well because of it and the many other chemicals in tobacco.

So, treatment is safer and works better for those who have been able to quit smoking.

More generally, symptoms are improved and quality of life is improved by stopping smoking even when the lung cancer is more advanced.

Having lung cancer and getting treatment may be very emotional and stressful for you. It also puts extra stress on your body and this can increase your risk of heart attack and stroke, and serious lung infections are also more likely. Stopping smoking will help reduce these risks too.

Time from stopping	Health benefits
3 hours	Heart rate and blood pressure are lower, reducing the strain on your heart.
12 hours	Blood carbon monoxide level drops to normal increasing blood's capacity to carry oxygen.
4 weeks	Surgical wounds heal better reducing by 90% the chance of having a wound infection.
12 weeks	Circulation improves and the chance of heart attack and stroke start to reduce.
1-9 months	Coughing and shortness of breath decrease reducing the risk of lung infections.
1 year	Risk of coronary heart disease is about half of a smoker's.

I see the benefits and want to stop – what will help me?

Find out as much as you can about the options. Think about other ways of getting nicotine that don't involve burning tobacco, avoid your usual smoking triggers, and set achievable daily goals.

There are many more smokers who have been able to stop than who keep smoking. It can be done!

The people close to you and others who care for you and about you, including your doctors and nurses, will certainly help and encourage you.

Most smokers are dependent in some way on the nicotine in the smoke. Nicotine is as addictive as heroin and cocaine. As well as this, the tobacco industry adds chemicals to increase nicotine uptake, and flavours such as honey, sugar, caramel and menthol to keep people smoking (and spending more on it).

It's not all about nicotine. The process of smoking becomes a habit, or routine. You may notice a greater urge to smoke in certain places or with certain people, or when doing certain things. When trying to stop, it's a good idea to have a plan:

Be strong: Try not to smoke at home or in your car. Tell your friends and family not to offer you a cigarette or smoke near you.

Don't tempt yourself: Always arrange to meet up with friends in places where smoking is not allowed.

Use the support you have: Tell your friends and family that you are stopping smoking to help with your treatment and that you would like their support and encouragement.

Strength in numbers: Suggest people stop smoking with you. Having a stop-smoking buddy will help your motivation.



Advice from your lung cancer team may be all you need, with or without, for example, nicotine replacement patches or chewing gum. If you are already using electronic cigarettes, tell your medical team as you may need to adjust how you use them during your treatment.

Speaking to a specialist health advisor or counsellor may help you more, particularly if you have tried to stop in the past without success. Some medicines can also help with smoking cravings. Ask your doctor or nurse about what could be best for you.

The medication includes nicotine replacement therapy (such as patches, gum, lozenges, microtabs, inhalators, and mouth and nasal sprays), and prescription drugs used to tackle smoking addiction, such as varenicline and bupropion. Some are available over the counter, and others you may get on prescription from your doctor.

Stopping smoking abruptly may appear to be the toughest approach, but studies suggest it is more likely to lead to lasting abstinence than cutting down first. Overall, the most effective smoking cessation approach is a combination of multi-session intensive behavioural support and medication.

Counselling and group support to help you stop smoking may be available in your area. You might get a short series of one-to-one or group-based specialist counselling sessions. This may or may not be followed up with telephone support. Ask your medical team about local services.

These can all help you with motivation and keep you on track with your efforts to stop smoking. More and more online and social media networks and forums are also there to help.

Electronic cigarettes are an increasingly popular way for people to stop smoking. They deliver nicotine through inhaled vapour, not smoke, hence the name “vaping”. This way, e-cigarettes appear to be able to reduce craving and withdrawal associated with smokers who stop.

Although e-cigarettes still contain the addictive nicotine, some studies put the risks of vaping at 5% of those of smoking. Research is ongoing to understand the risks and benefits of using e-cigarettes as a stop-smoking tool and they should be used with caution as a way of reducing, but ultimately stopping smoking, not as a substitute or alternative, until more information is known.

Online support to help you stop



Our online forum lets you share your experience through blog posts and questions with other people trying to stop:

- www.healthunlocked.com/quitsupport



Should I tell my doctor that I am smoking?

Many people worry about this. However, doctors and nurses know how addictive smoking is, and how much it has been promoted. They won't blame you for having lung cancer that may have been caused by smoking or for the fact that you have not yet been able to stop smoking.

Lung cancer medical specialists and nurses, and other professionals involved in your treatment and care, treat everyone equally. If they ask you if you smoke, or if you have smoked, this is not to judge you. It is because they may need to do extra tests to make sure that you get the best treatment.

By telling them that you are still smoking, or have started smoking again, they will be better able to support and treat you, and, with your permission, can refer you to a smoking cessation specialist.

I ask all my patients whether they smoke because it gives me clues about their type of cancer and possible treatments, not because I am judging them.

If patients are still smoking at their time of diagnosis, I try as hard as I can to help them stop because we know that stopping, even at that point, makes treatments easier and more effective.

Tom Newsom-Davis
Consultant Medical Oncologist

Contact details of Stop Smoking Support and Helplines can be found at the back of the booklet.

Help and support

Healthcare services

Everyone has different needs when it comes to lung cancer support. Lung cancer nurse specialists offer a variety of support to people affected by lung cancer.

Other healthcare services are available that can give you extra support to help you overcome or adapt to some of the effects of lung cancer and its treatment, such as muscle weakness, problems walking, or difficulties with speaking, eating or swallowing:

Physiotherapy

This can help you maintain or improve your strength, mobility, balance and co-ordination through exercise and other advice. Physiotherapy can also help you with breath control, and coughing and chest clearing techniques.

Occupational therapy

If you are struggling with some everyday activities, like getting up stairs, bathing or cooking, an occupational therapist will look at equipment or adaptations that can be made to help. They can also help you deal with fatigue or poor sleep, as well as some aspects of going back to work.

Speech and language therapy (SALT)

This is a specialist team that helps people who find speaking clearly or loudly enough difficult, or who are not able to eat and swallow properly.

If you are finding it harder to get around or are having difficulty doing some of the things you are used to doing, speak to your lung cancer nurse specialist, consultant or GP. They may be able to refer you to the services you need.

Nutritionists and dietitians

These specialists assess, diagnose and treat dietary and nutritional problems, and help you make the right choices about what you eat.

Information and networking

There are many other types of support for people affected by lung cancer available around the UK:

- support from Roy Castle Lung Cancer Foundation
- online support
- cancer information centres
- carers' centres

Support from Roy Castle Lung Cancer Foundation

If you or someone you know needs support, we have a range of one-to-one, group, face-to-face and online services that can help.

One-to-one support

Our *Ask the nurse* service is a nurse-led helpline offering advice on:

- where to get help on side effects
- ways of managing how you, your family and friends are affected by lung cancer
- understanding treatment decisions/options
- any other issues around diagnosis and treatment



Please call our experienced team of nurses free on:
0800 358 7200 or email:
lungcancerhelp@roycastle.org

Our *Keep in touch support service* is a free and confidential telephone service for people with lung cancer and their carers, primarily if you are socially isolated and would like some extra contact.

A member of our support team will call at an agreed time, fortnightly or monthly (your choice). The calls will be mainly general conversation and to check on your wellbeing. If you need clinical or practical support you would be put in touch with other services, with your permission.



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

Groups and online support

Our lung cancer support groups take place around the UK. These groups meet regularly and are organised by local lung cancer nurse specialists.

The groups aim to provide you with the opportunity to meet other people affected by lung cancer, get support through sharing experiences and learn more about lung cancer and looking after yourself. You can find details of your local lung cancer support group at:

www.roycastle.org/supportgroups

We also run online support sessions and lung cancer information days across the UK for people affected by lung cancer.

You will have the opportunity to meet other people affected by lung cancer with whom you can share your experiences.

The information days and some online sessions are also attended by lung cancer healthcare professionals including oncologists, thoracic surgeons and lung cancer nurse specialists whom you can ask questions. Find out more by calling: 0333 323 7200 (option 2).

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

Other online support

There are many other cancer-related, website-based discussion forums. They provide an online community for people to ask questions, share knowledge and experiences, exchange ideas and support each other.

Social networks, such as Facebook, have groups where people in similar situations can connect and share information and experiences. These are often closed groups, meaning that membership is controlled, and usually restricted to people affected by the condition or situation covered by the group description.

They can also be international and you can connect to people all over the world with a vast range of experiences, many similar to yours.

Be aware though, that many may not be moderated (where posts and information is checked and screened) by healthcare professionals or experts.

Cancer information centres

Most cancer treatment hospitals have an NHS or charity funded cancer information centre. Most of these centres have a team of experts and trained volunteers on hand to answer your questions.

You can also access booklets, leaflets and other sources of information free of charge. Some centres also offer other services, including self-help and support groups, and complementary therapies.

Carers' centres

All around the UK carers' centres offer a wide range of local support services to meet the needs of carers in their own communities.

This includes information and advice about all issues affecting carers, including benefits, breaks, respite and support services, carer assessment procedures, and home aids and adaptations.



For details of your nearest support group, cancer information centre, carers' centre or lung cancer nurse specialist, please call us on **0333 323 7200 (option 2)**, or email: **info@roycastle.org**

Other support organisations

There are many different organisations working alongside the NHS to provide valuable information and support to people affected by lung cancer. Here are the contact details of some organisations that may be of help to you:

Asthma + Lung UK

Provides information and support to people affected by lung conditions.

Helpline: 0300 222 5800

Website: www.asthmaandlung.org.uk

Cancer Research UK

Funds cancer research and clinical trials throughout the UK.

Helpline: 0808 800 4040

Website: www.cancerresearchuk.org

Care Information Scotland

Telephone and online service available in Scotland for people seeking information about community care services for older people.

Helpline: 0800 011 3200 (Monday to Friday, 9.00am to 5.00pm)

Website: www.careinfoscotland.scot

Carers Trust

Provides carers' centres all around the UK offering a wide range of local support services to meet the needs of carers in their own communities.

Helpline: England: 0300 772 9600

Helpline: Scotland: 0300 772 7701

Helpline: Wales: 0300 772 9702

Website: www.carers.org

Carers UK

Provides expert advice, information and support on all matters to do with caring for someone.

Carers Wales: 0292 081 1370

Carers Scotland: 0141 445 3070

Carers Northern Ireland: 02890 439 843

Carers UK Advice line: 0808 808 7777

Website: www.carersuk.org

Citizens Advice Bureau

Provides free, independent, advice on your rights and responsibilities.

Wales: 0800 702 2020

England: 0800 144 8848

Scotland: 0800 028 1456

TextRelay: 0800 144 8884

Website: www.citizensadvice.org.uk

Disability Benefits Helplines

Provides advice or information about a claim you've already made.

Personal Independence Payment: 0800 121 4433

Attendance Allowance: 0800 731 0122

Disability Living Allowance (born before 8 April 1948): 0800 731 0122

Disability Living Allowance (born on or after 8 April 1948): 0800 121 4600

Website: www.gov.uk/disability-benefits-helpline

Gene mutation positive lung cancer

Provide information and support to people with gene mutation positive lung cancers.

ALK positive: www.alkpositive.org.uk

EGFR positive: www.egfrpositive.org.uk

ROS1 positive: www.ros1cancer.com

GOV.UK

The official source of information on benefits.

Website: www.gov.uk/browse/benefits

Macmillan Cancer Support

Provides practical, medical and financial support and advice.

Helpline (freephone): 0808 808 0000

Website: www.macmillan.org.uk

Maggie's Centres

Provide a community of support in some parts of the UK, to anyone affected by cancer.

Helpline: 0300 123 1801

Website: www.maggies.org

Marie Curie

Cancer Care Runs hospice centres throughout the UK, and a community nursing service to support cancer patients and their carers in their homes.

Helpline (freephone): 0800 090 2903

Website: www.mariecurie.org.uk

Mesothelioma UK

A national resource centre, dedicated to providing mesothelioma information, support and improved care and treatment.

Helpline (freephone): 0800 169 2409

Website: www.mesothelioma.uk.com

NHS Inform

This is the national health information service for Scotland.

Helpline (freephone): 0800 22 44 88

Website: www.nhsinform.scot

Neuroendocrine Cancer UK

Provides support and information for people diagnosed with neuroendocrine tumours and their families.

Helpline (freephone): 0800 434 6476

Website: www.neuroendocrinecancer.org.uk

NHS Choices

The official website of the National Health Service in England. It offers a multi-channel service for those seeking health and social care information.

Website: www.nhs.uk/nhs-services/services-near-you

Stop Smoking Helplines

NHS Smokefree Helpline: 0300 123 1044 (England)

Website: www.nhs.uk/better-health/quit-smoking

Smokeline: 0800 848 484 (Scotland)

Stop Smoking (Northern Ireland)

Website: www.stopsmokingni.info

Help Me Quit (Wales)

Helpline: 0800 085 2219

Website: www.helpmequit.wales

Tenovus Cancer Care

Offers support, advice and treatment for people affected by cancer in Wales. Mobile cancer support units provide treatment closer to home, in the community. Also provides information on financial support/benefits, cancer prevention and funds cancer research.

Support line (freephone): 0808 808 1010

Website: www.tenovuscancercare.org.uk

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

Published: TBC

© Roy Castle Lung Cancer Foundation

Registered charity number England and Wales 1046854 - Scotland SC037596 - Isle of Man: 1277

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, including photocopying, recording or otherwise, without the prior permission of Roy Castle Lung Cancer Foundation.



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

Head Office

Cotton Exchange Building,

Old Hall Street,

Liverpool, L3 9LQ

Email: foundation@roycastle.org

Information and Support Services

5th Floor, Baltic Chambers

50 Wellington Street

Glasgow G2 6HJ

Email: info@roycastle.org

Expect Better



[Roycastlelungcancer](https://www.facebook.com/Roycastlelungcancer)



[@Roy_Castle_Lung](https://twitter.com/Roy_Castle_Lung)