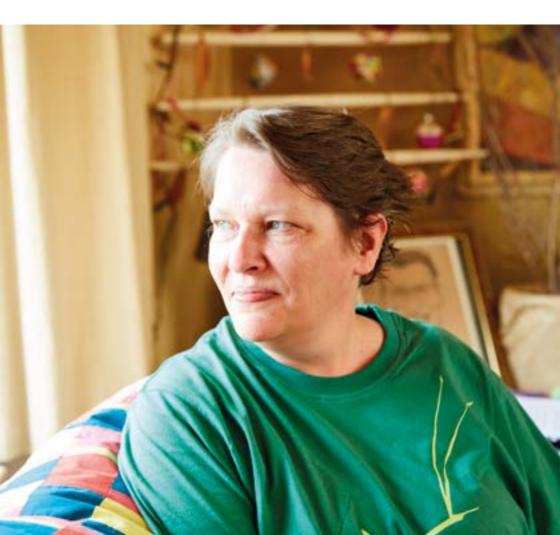


# Managing breathlessness





There are limitations because of cancer and the side effects of my medication. But I've taught myself not to be scared of adapting exercises. II

Clare, who had breast cancer and breathlessness

# About this booklet

This booklet is about managing breathlessness. It is for anyone who has breathlessness caused by cancer or its treatments.

The booklet explains the causes of breathlessness and the different ways to manage it. It has breathing and relaxation techniques. It also explains medicines to control breathlessness.

We hope it helps you deal with breathlessness and some of the questions or feelings you may have. Carers, family members and friends might find this information helpful too.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

## How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the <u>contents list</u> to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

At the <u>end of the booklet</u>, there are details of other organisations that can help.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

## Quotes

In this booklet, we have included quotes from people who have had breathlessness, which you may find helpful. These are from people who have chosen to share their story with us. This includes Clare, who is on the cover of this booklet. To share your experience, visit <u>macmillan.org</u>. <u>uk/shareyourstory</u>

# For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on <u>0808 808 00 00</u>, 7 days a week, 8am to 8pm, or visit <u>macmillan.org.uk</u>

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

We have some information in different languages and formats, including audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit <u>macmillan.org.uk/otherformats</u> or call <u>0808 808 00 00</u>.

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# The lungs and breathlessness

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# The lungs

The lungs are the parts of the body that we use to breathe. The body has 2 lungs – 1 on the right and 1 on the left. They supply oxygen to the organs and tissues of the body. The lungs are divided into areas called lobes. The right lung has 3 lobes and the left has 2 lobes.

The lungs are part of our respiratory (breathing) system. This system also includes the:

- nose and mouth
- windpipe (trachea)
- 2 tubes called the left and right bronchus, which branch from the windpipe and go into each lung.

When you breathe in, air passes from your nose or mouth through to the windpipe (trachea). The trachea divides into 2 tubes (airways) that go to each lung. These tubes are called bronchi. Bronchi is the plural of bronchus.

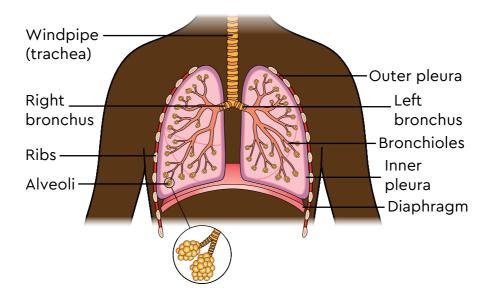
Air passes through each bronchus into the lungs through smaller tubes called bronchioles. At the end of the bronchioles, there are tiny air sacs called alveoli. This is where oxygen from the air you breathe in (inhale) passes into the blood. Then blood moves the oxygen around the body.

A waste gas called carbon dioxide passes from the blood into the air sacs. These are called the alveoli. You get rid of carbon dioxide when you breathe out (exhale).

Below the lungs is a dome-shaped sheet of muscle called the diaphragm. When you breathe, the diaphragm and the muscles between the ribs contract. This sucks air into the lungs. Then they relax. This pushes air out of the lungs. These are the main muscles used for breathing when you are relaxed. During heavy exercise, the muscles in your shoulders and upper chest can also help with breathing. These muscles are not meant to work for long periods of time, so they get tired easily.

The lungs are covered by a lining (membrane) called the pleura. The pleura has an inner and outer layer. The inner layer covers the lungs. The outer layer lines the ribcage and the diaphragm. The pleura produces fluid that acts as a lubricant. This allows the lungs to move in and out smoothly.

#### Upper airways and the lungs



# What is breathlessness?

Breathlessness is sometimes called shortness of breath. It is also called dyspnoea (pronounced dis-nee-a). It can be a symptom of cancer, or a side effect of treatment. Breathlessness may be caused by several things, such as:

- changes within or around the lungs
- low levels of oxygen in the blood
- other changes in the body, such as muscle weakness.

Breathlessness affects everyone differently. It may happen suddenly, but only last for a short time, for example hours or days. This is known as acute breathlessness. Or it can happen gradually and last for several weeks or more, or keep coming back. This is known as chronic breathlessness.

Signs and symptoms of breathlessness include:

- uncomfortable or fast breathing
- a tight chest
- using the neck and shoulder muscles to pull more air in
- feeling anxious or frightened.

#### Contact your doctor straight away if:

- breathlessness is a new symptom
- you have pain when you breathe
- the breathlessness gets worse quickly.

You may need urgent treatment. If you cannot speak to your doctor and your breathlessness continues to get worse, go straight to your nearest A&E (emergency department).

# **Causes of breathlessness**

There are different causes of breathlessness. Your cancer doctor will look at your symptoms to find out what may be causing your breathlessness. This will help them find the best treatment or <u>ways to manage it</u>.

Your doctor will usually:

- ask some questions about your health and how your breathlessness affects you
- examine your chest and tummy
- ask you to complete a <u>breathlessness scale</u> to measure your breathlessness.

You may have 1 or more of the following:

- chest x-ray
- CT scan
- lung function test
- blood test.

We have more information about different tests you may have at <u>macmillan.org.uk/tests-scans</u>

<u>Asthma and Lung UK</u> has more information on diagnosing the cause of breathlessness and the sort of questions your doctor may ask.

There are many different causes of breathlessness.

## **Cancer affecting the lungs**

This can be cancer that:

- started in the lungs this is called primary lung cancer
- has spread to the lungs from another part of the body this is called secondary lung cancer.

Treatments such as radiotherapy or chemotherapy may help shrink the tumour and relieve breathlessness caused by the cancer. We have information about different types of cancer and treatments you may have. Visit <u>macmillan.org.uk/cancer-types</u>

# Fluid build-up

If cancer cells irritate the lining of the lungs or tummy (abdomen), this can cause fluid to build up.

A build-up of fluid in the lining of the lungs is called a pleural effusion. It means there is less room for the lungs to expand.

A build-up of fluid in the tummy is called ascites. The fluid pushes the diaphragm up and makes it harder to breathe properly.

<u>Pleural effusion</u> and <u>ascites</u> are treated by taking the fluid away. We have more information on our website.

# Low red blood cells (anaemia)

Red blood cells carry oxygen around the body. If the level of red blood cells in your blood is low, this is called anaemia. It can make you feel tired and breathless. There are many causes of anaemia. They include cancer or cancer treatments such as chemotherapy or radiotherapy. Your cancer doctor may recommend a blood test to check if you are anaemic. Some people may need a blood transfusion.

## **Chest infections**

A chest infection can cause phlegm (mucus) in the airways. This can make you feel breathless. Drinking plenty of fluid will make the phlegm easier to cough up. Contact your cancer doctor straight away if you have:

- a high temperature (above 37.5°C or 99.5°F)
- a chesty cough
- pain when you breathe.

They can prescribe you antibiotics, if needed.

## Weakened muscles

If the muscles used to breathe are weak, breathing can be more of an effort.

Your muscles may be weakened if you have advanced cancer. You may feel more tired (fatigued) and not able to do much physical activity. People with advanced cancer often do not feel hungry. This can mean they eat less and lose weight. Poor nutrition can cause muscles to become weaker. Breathing becomes more difficult, as the muscles have to work harder.

Your muscles may also be weakened by cancer or cancer treatments such as chemotherapy and radiotherapy. Weaker muscles are less efficient, and more effort is needed to do the same task, causing you to become breathless sooner.

We have more information about advanced cancer on our website. Visit <u>macmillan.org.uk/advanced-cancer</u>

# Pain

Pain can make it hard to breathe and move comfortably. If you have any pain, tell your doctor. They can make sure it is well-controlled. There are different types of painkiller that can help. We have more information at macmillan.org.uk/painkillers

# Blood clot in the lung (pulmonary embolism)

Cancer and some cancer treatments can increase the risk of a blood clot. Contact your cancer team or hospital straight away on the 24-hour number they have given you if you have any of these symptoms during or after treatment:

- throbbing pain, redness or swelling in a leg or arm
- suddenly feeling breathless or coughing.

#### Always call 999 if you have:

- chest pain
- difficulty breathing.

A blood clot is serious, but it can be treated with drugs called anticoagulants that thin the blood. Your cancer doctor, specialist nurse or pharmacist can give you more information about preventing and treating blood clots.

We have more information about blood clots and cancer on our website. Visit <u>macmillan.org.uk/blood-clots</u>

## **Other conditions**

Other conditions can cause breathlessness, such as:

- heart failure
- asthma
- chronic obstructive pulmonary disease (COPD)
- coronavirus (covid) and long covid.

If you have any of these conditions, talk to your doctor about the treatment you need.

# Smoking tobacco

Smoking makes breathlessness worse. The smoke irritates and inflames the airways. This means less oxygen is absorbed into the blood. If you want to stop smoking, there is help available. Ask your specialist nurse or cancer doctor for advice, or find out if there is a free <u>NHS Stop</u> <u>Smoking Service</u> near you.

We have more information about stopping smoking on our website. Visit <u>macmillan.org.uk/stop-smoking</u>

# **Anxiety and panic**

Feelings of anxiety and panic are common when you have a serious illness. They are natural reactions, but they can cause some people to have fast and shallow breathing. This can make you feel breathless, which can make you more anxious. <u>Breathing and relaxation</u> <u>techniques</u> can help break this cycle.

## **Cancer treatments**

#### Surgery

Surgery for lung cancer may involve removing part, or all, of a lung. Many people can breathe well after they recover from surgery, but some people may have long-term breathing problems.

#### Radiotherapy

Radiotherapy to the chest can cause inflammation of the lung (pneumonitis). This can lead to breathlessness. This is usually a short-term problem. But for some people it can last longer, and sometimes the problems do not go away. People who have intensive radiotherapy to the chest can sometimes develop hardening and thickening (scarring) of the lung. This can cause long-term breathlessness.

#### Chemotherapy

Some chemotherapy drugs can cause breathing problems or inflammation of the lungs. This includes some types of chemotherapy and some targeted or immunotherapy drugs. Your cancer doctor, specialist nurse or specialist pharmacist will explain if your treatment may cause this side effect and what symptoms to look out for.

#### Targeted therapy and immunotherapy

Some types of targeted and immunotherapy drugs, such as nivolumab, can also cause inflammation of the lungs. You will have tests to check your lungs. Your doctor may prescribe you steroids or other treatments to help with any inflammation.

"During radiotherapy I was so tired pretty much all of the time. And it took a lot more effort to do anything. Even a short walk or walking up the stairs made me a little breathless. "

Danielle, who had cancer and breathlessness

# **Breathlessness scale**

A breathlessness scale may be used to measure breathlessness. It can help your healthcare team understand how much breathlessness affects you.

Your healthcare professional will also talk to you about how you feel when you get out of breath. This can help them understand how much support you need.

## The MRC breathlessness scale

The Medical Research Council (MRC) breathlessness scale is used to measure breathlessness. It can give you a score for the level of breathlessness you feel doing an activity. The scale ranges from grade 1 to grade 5.

- Grade 1 means you are not troubled by breathlessness during your usual activities except when doing exercise that involves a lot of energy or effort.
- Grade 5 means you find it very difficult to leave the house because of your breathlessness.

Grade	Degree of breathlessness related to activity
1	Not troubled by breathlessness except during strenuous exercise.
2	Short of breath when hurrying on level ground or when walking up a slight hill.
3	Walks slower than most people on level ground, stops after a mile or so, or stops after 15 minutes walking at own pace.
4	Stops for breath after walking 100 yards, or after a few minutes on level ground.
5	Too breathless to leave the house, or breathless when dressing or undressing.
Used with th	e permission of the Medical Research Council and adapted for this publication

#### MRC breathlessness scale

You can complete the scale yourself, or your healthcare professional will ask you questions such as:

- How far can you walk before you get breathless?
- How fast can you walk on level ground or going up a slight hill?
- How quickly do you get breathless when you are walking?

If you have any questions about this, ask a healthcare professional.



# Coping with breathlessness

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# **Managing breathlessness**

Treatment for breathlessness will depend on <u>what is causing it</u>. Your GP or cancer doctor can refer you to services that can help you manage your breathlessness. Or they can prescribe medicines to help.

# What can I do to manage breathlessness?

There are some things you can do that may improve breathlessness, or help you cope with it. The following tips may be especially helpful if you have long-term (chronic) breathlessness.

#### Changing how you breathe

When you are breathless, you may try to take big breaths into the lungs. You may breathe faster and have tension in your upper chest and shoulders. Breathing in this way can make you more tired. This makes breathing uncomfortable and you can feel even more out of breath.

To break this cycle, try to focus on breathing out and relaxing the upper chest and shoulders. Learning breathing techniques such as relaxed tummy breathing (<u>breathing control</u>) can help.

#### **Breathlessness and anxiety**

Anxiety is a feeling of fear or worry that lasts for some time. It can be mild or severe. It may affect how you do your everyday activities.

Feeling breathless can make you feel anxious. You may worry whether you can control your breathing. Some people feel like they are having a panic attack.

Common symptoms of anxiety and panic are:

- heart palpitations (heart beats that suddenly become noticeable)
- feeling dizzy
- headaches
- breathlessness
- chest pains.

Anxiety may make you breathe too fast and take shallow breaths from the top of your lungs rather than your lower chest. Breathing in this way can make you feel more breathless, which can make you feel even more anxious.

Try talking to your healthcare professional, family or friends about how breathlessness makes you feel. This may help you recognise what triggers your anxiety. Talking through your thoughts may help those around you understand what you are going through. They may be able to help.

Some people may also need to <u>take medication to help them manage</u> <u>their anxiety</u>.

#### Make a plan

You may find it helpful to have an action plan for breathlessness. Write down a simple plan of what you will do when you are breathless. This could be using a <u>relaxation technique</u> that you have learnt. Or you could try <u>using a handheld fan</u> to cool your face. This can help calm and slow your breathing.

Have your plan nearby. Reading it can help reassure you of the steps you need to take to help you.

The <u>Cambridge Breathlessness Intervention Service</u> has more information on breathlessness and anxiety, including an example of an action plan. Search <u>cuh.nhs.uk</u> for 'thoughts about breathlessness'.



#### **Physical activity**

Breathlessness can be uncomfortable. You may want to avoid moving around so that your breathlessness does not get any worse. Family or friends may help you more which causes you to move around even less.

But physical activity can improve your breathing. It helps you be as fit as possible and can make you feel better. Even people with severe breathing problems can benefit from small amounts of physical activity.

Physical activity may not make you more breathless, especially if you go slowly and use <u>relaxed tummy breathing</u> as much as possible. You may get breathless, but over time you will be able to do more before you get breathless.

By slowly doing more activity you will become fitter, and your muscles will become stronger. Over time, you will be more confident in your ability to calm your breathing. You will also know when and how to do this. It can help to remember that breathlessness usually goes away in a few minutes.

If your breathlessness starts to get worse or gets worse quickly, make sure you see a doctor straight away. There may be a new cause for your breathlessness that needs treatment quickly.

#### Trying some physical activity

Start slowly by doing movements with your arms and legs while you are sitting down. Then set goals that are right for you. For example, you might aim to walk from room to room, to the front door or to the garden if you have one. Or you might aim to go for a short walk. You can slowly build up what you do.

When starting physical activity remember to:

- go slowly
- use relaxed tummy breathing
- match your breathing rhythm to your steps.

You may find you are able to do a bit more each time. This will help you manage your everyday activities more comfortably. A physiotherapist can give you advice on the correct type of physical activity for you. A pedometer or step counter can help you slowly increase the amount of walking you do each week.

Some hospitals, hospices and specialist palliative care units have breathlessness services or rehabilitation programmes. They also have different types of specialists who can help you manage your breathlessness. Ask your specialist nurse if there is one in your area. If there are no breathlessness services in your area, you can ask to see a physiotherapist or occupational therapist (OT) for advice on how to manage breathlessness.

We also have further information in our <u>Physical activity and cancer</u> booklet.

"The sooner you start being physically active, the easier it is to cope with the cancer and treatments. It worked for me and gave me a feeling of being in control of my body. It's 30 minutes of 'me' time.

Clare

# Relaxation

Learning and practising relaxation techniques can help you control anxiety and breathe more easily. We have described a technique you might like to try below.

It can take practice to become good at it. Try it for 5 to 10 minutes once a day to start with. Then you can try to do it for longer. Set aside time during the day to practise. It might help to ask someone to read these instructions to you.

# **Relaxation technique**

Try to find a quiet and peaceful place to do this exercise. If you notice any sounds around you, try not to let them distract you.

Make yourself comfortable. You can do this sitting or lying down. Make sure your shoulders, back and neck are well supported. You may want to try using a high-backed chair. Have your arms by your sides or rest your hands on your lap.

- 1. Close your eyes.
- Start by breathing out and then in, only as much as you need. Then breathe out slowly with a slight sigh, like a balloon slowly deflating.
- **3.** Do this again, as slowly as you can. As you breathe out, feel any tension in your body start to drain away. Then let your breathing go at an even, steady pace.
- 4. When you feel comfortable doing this, you can move on to the next stage.
- 5. Start to think about each part of your body, 1 at a time.

- 6. Start with your toes. Wiggle them, then let them relax. Let them feel heavy, and free of any tension.
- 7. Now think about your legs. Let your thighs relax and roll outwards.
- 8. Next, let your tummy muscles become soft and relaxed.
- 9. Make a fist with your hands, then let go. Let your fingers become limp and still. Let this relaxed feeling spread up your arms to your shoulders.
- 10. Let your shoulders relax and drop easily.
- **11.** Let your neck muscles relax. Your head is resting and supported. Enjoy this relaxed feeling.
- **12.** Let your face and expressions relax. Make sure your teeth are not clenched and let your jaw rest in a relaxed position.
- 13. Now, as your body feels relaxed, be aware of the all-over feeling of letting go. Be aware of the feeling of quiet, calm and resting. Enjoy this relaxed feeling. If you find your mind becoming busy again, think about where your muscles have tensed and then relax them.
- 14. Slowly bring your attention back to the room. Have a gentle stretch and open your eyes. Remember to get up slowly when you have finished. If you managed to fully relax, your blood pressure may have dropped. You may feel dizzy if you get up suddenly. Bending and stretching your arms and legs a few times before standing up should help.

When you feel comfortable doing the relaxation exercise, it can help to listen to some relaxing music while you do it. Imagine peaceful surroundings while you do the exercise.

You can listen to a recording of these instructions at <u>soundcloud.com/cuh\_nhs/body-relaxation-scripts</u>

## Other ways to relax

You may want to try other ways to relax:

- The <u>Cambridge Breathlessness Intervention Service</u> has videos and audios to help manage breathlessness. Search <u>cuh.nhs.uk</u> for 'breathlessness video'.
- Relaxation CDs may be available from your local library or cancer centre. Or you can download an app or listen to podcasts.
- Some hospitals, cancer centres and hospices offer breathing control and relaxation sessions. Ask your cancer doctor, specialist nurse or physiotherapist which sessions are suitable for you.
- Finding a complementary therapy that helps you relax may help you manage your breathlessness. Therapies such as acupuncture, aromatherapy and meditation may be helpful. Always tell your doctor if you are thinking of starting any new therapies. We have more information in our booklet <u>Cancer and complementary therapies</u>.

You can order our booklets and leaflets for free. Visit <u>be.macmillan.org.uk</u> or call us on <u>0808 808 00 00</u>.

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# **Breathing techniques**

Breathlessness can be hard to live with, but there are ways you can reduce how much it affects your life. Learning some breathing techniques can help.

It helps to practise these breathing techniques for the first time when you are not too breathless, if possible. Then you will find them easier to do when you are feeling breathless. Knowing there are things you can do when you feel breathless can help you feel more in control. It might help for someone to read the instructions to you the first time.

Try to remember to do these breathing techniques as often as possible. It can take some time to get used to them. Try not to force the exercises or expect instant results. Aim for a slow change from breathlessness to calmer breathing.

To start, it might help to ask your specialist nurse or GP if you can see a <u>physiotherapist</u> or <u>occupational therapist</u>. They can help you learn these techniques.

# Get into a comfortable position

When you feel breathless, get into a comfortable position that supports your upper chest muscles and allows your diaphragm and tummy to expand fully.

On the next few pages, we explain some comfortable positions that can help with breathlessness. Try different positions and find one that works best for you.

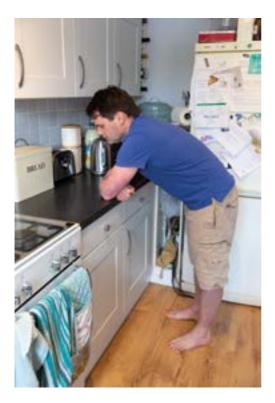
- Sit in a chair in an upright position, with your back supported.
- Keep your legs uncrossed and your feet on the floor.
- Let your shoulders drop and feel heavy, with your arms resting softly in your lap, or on the arms of the chair.
- Keep your head up or relax it back against the chair if you are sitting in a high-backed armchair.



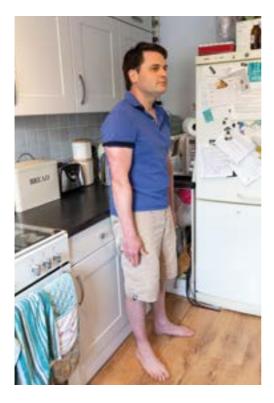
- Sit in a chair and lean forward from your hips.
- Rest your elbows and lower arms on your thighs, supporting your upper body.
- Have your legs uncrossed, your feet on the floor and your shoulders relaxed.
- Keep your knees shoulder-width apart and let your chest relax when you lean forward.



- Stand and lean forward on to a secure surface.
- Let your arms and elbows rest on the surface, so you are supporting the weight of your upper body.
- Keep your shoulders and chest relaxed by keeping your arms shoulder-width apart.



- Stand up and lean back against a surface that supports your weight, such as a wall.
- Let your arms drop to your sides and let your shoulders feel heavy and relaxed.



#### If you are in bed

- Try to sit up with your head and back supported by pillows. This allows you to expand and open your chest area.
- Let your head rest back gently on the pillow, so you can feel the tension leave your neck and shoulders.
- Rest your arms by your sides. You can support them with pillows if this is more comfortable.
- Some people find their breathing feels more comfortable if they lie on their side instead of their back.

# Relaxed tummy breathing (controlled breathing)

Breathlessness can make you breathe with your upper chest and shoulder muscles, rather than your diaphragm and lower chest. This causes fast and shallow breathing, which uses more energy and makes you tired.

An important part of managing breathlessness is learning relaxed tummy breathing. This is sometimes called controlled breathing. This uses your diaphragm and lower chest muscles to help you breathe more efficiently. Breathing from the lower chest and tummy can also help you relax.

If you practise this when you are not too breathless, you will find it easier to do when you are breathless.

- 1. Sit comfortably, with your neck, shoulders and back well supported.
- 2. Relax your shoulders and upper chest.
- **3.** If possible, breathe in gently through your nose. When you inhale, your tummy area and lower chest should expand. Your upper chest should stay relaxed.

- 4. If possible, breathe out slowly through your nose. Watch your tummy sink back down. Relax your shoulders and upper chest a little more each time you breathe out.
- 5. Pause slightly as you breathe out before the next breath begins.
- 6. Continue doing steps 1 to 5 until your breathing is calmer.

Practise relaxed tummy breathing at the following times:

- when you first wake up
- when you go to sleep
- throughout the day when you are resting.

To check you are breathing from the lower chest, put 1 hand on your tummy, just below your ribcage. As you breathe in, you should feel your hand rising. As you breathe out, your hand will sink back down. Your upper chest and shoulders should not move.

It may help to sit sideways next to a mirror. This is so you can see your lower chest moving in and out.

If you feel too breathless, try breathing in through your nose and out through your mouth. You may have to mouth breathe until your breathing settles enough to return to nose breathing.

If your nose is blocked, talk to your GP. They may be able to suggest things to help.

It may also help to take slightly longer, deeper, slower breaths in and out from the tummy. This will help to calm your breathing.

## **Pursed lip breathing**

Some people use pursed lip breathing to help ease breathlessness during or after an activity, such as walking. This technique involves breathing in through the nose and then out through pursed lips, as if blowing out a candle. Some people may find it easier to breathe in through their mouth instead, and then out through pursed lips.



# Using a handheld fan

Studies have shown that cooling the face with a handheld fan is a simple way of easing breathlessness. Many people usually notice a difference within a few minutes.

Carry a handheld fan with you to use whenever you need it. Or you can keep one by your bed to use at night. These fans are small and light, and easily fit into a handbag or pocket. A floor-standing fan or desktop fan can also be helpful.

The following tips for using a fan may help:

- Get into a comfortable position.
- Hold the fan about 15cm (6in) away from your face.
- Let the cool air blow towards the nose and mouth. Move it side to side so your cheeks are cooled.

Sitting in front of an open window with the cool air blowing over your face can also be helpful. Some people find putting a cool flannel on their face before using the fan increases the cooling effect.

You can watch a video on how to use a handheld fan on the <u>Cambridge</u> <u>Breathlessness Intervention Service</u>.

# Medicines and other help for breathlessness

There are different medicines and treatments that may help with breathlessness. You can talk to your GP, cancer doctor or specialist nurse at the hospital.

# Painkillers

Some types of painkiller can help relieve breathlessness. For example, morphine can be taken:

- as a tablet
- in liquid form
- by injection under the skin.

We have more information at macmillan.org.uk/painkillers

## Sedative drugs

Breathlessness makes some people feel anxious. Sedatives can help relieve anxiety. It is always better to try to learn some <u>relaxation</u> <u>exercises</u> to help with breathlessness, before trying sedatives.

People with anxiety may be prescribed sedatives if other treatments have not helped their breathlessness.

## **Steroids**

Steroids can help reduce inflammation in the airways of the lungs. This may help to reduce breathlessness.

### **Bronchodilator drugs**

Bronchodilator drugs widen the air passages and increase airflow. You usually have them through an inhaler. If being breathless means you find it hard to use an inhaler, your GP or practice nurse may give you a spacer device. A spacer is a plastic tube that fits onto your inhaler mouthpiece. It helps make sure the drug from the inhaler reaches the lungs.

Bronchodilator drugs can sometimes be given as tablets.

The drugs can also be given through a small machine that turns the liquid drug into a fine mist. This machine is called a nebuliser. It lets you breathe the drug deep into your lungs. You breathe through a mask or a mouthpiece to inhale the drug.

## Sterile salt water (saline)

This can be given through a nebuliser to loosen sticky phlegm (mucus).

# Diuretics

Diuretics are medicines to help you pass more urine (pee). They can help if your breathlessness is caused by having too much fluid in or around the lungs. These drugs help you get rid of excess fluid. You may have them as tablets, or sometimes as a drip (infusion).

### **Oxygen treatment**

Oxygen is used to help with low oxygen levels. Oxygen treatment is only suitable for people with low oxygen levels in the blood.

If your oxygen levels are not low, <u>other ways to manage breathlessness</u> may work better.

You can have a simple test to measure the level of oxygen in your blood. This is called a pulse oximetry. A sensor will be placed on your fingertip or earlobe. If your oxygen levels fall below a certain level, your healthcare professional, such as your specialist nurse, will usually refer you to the home oxygen assessment and review service. You will usually be seen by an oxygen specialist in an outpatient clinic. Talk with your healthcare professional if you have any questions about this.

### Using home oxygen

The main ways of having oxygen treatment at home include:

- using a face mask over your nose and mouth
- through small tubes that sit under the nostrils (nasal cannula).

Try using a water-based lubricant like K-Y Jelly<sup>®</sup> to stop your lips or nostrils getting dry. You should not use petroleum jelly (Vaseline<sup>®</sup>) or any other oil-based lubricants or creams when using oxygen. This is dangerous and causes a fire risk.

<u>Asthma and Lung UK</u> has more information about home oxygen therapy. You can also search <u>nhs.uk</u> for 'home oxygen'. Oxygen may be supplied in:

- portable oxygen cylinders
- large oxygen cylinders
- an oxygen concentrator machine.

If you only need oxygen for short periods, your doctor may recommend a large oxygen cylinder. This is a storage cylinder filled with oxygen for you to breathe.

If you need oxygen for longer periods of time, they may suggest an oxygen concentrator. This machine is the size of a large home printer. It takes and filters oxygen from the air around you.

### An oxygen concentrator machine



If you want to go out but need oxygen, you can get a portable cylinder or a portable oxygen concentrator. If you use a wheelchair, you can have a bracket fitted to carry the cylinder. Ask the wheelchair service about this.

If you want to travel with oxygen, there are a few things to consider. You can find out more about this from <u>Asthma and Lung UK</u> or your local NHS service.

### Smoking

Smoking is not allowed in a house where there is home oxygen. This includes using e-cigarettes. If you or people you live with smoke, you cannot use oxygen at home. This is because of a serious risk of explosion and fire.

The NHS has a lot of information and support to help you stop smoking. Look on the <u>NHS website</u> for the country where you live. We also have more information about stopping smoking at <u>macmillan</u>. <u>org.uk/stop-smoking</u>

If you smoke, you need to tell the healthcare professional prescribing the oxygen.

<u>Asthma and Lung UK</u> has more information on using oxygen safely.





# Managing everyday life

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# Practical tips for daily activities

It is good to keep active, but when you are breathless, even normal activities can feel overwhelming. You can ask to see a <u>physiotherapist</u> or an <u>occupational therapist (OT)</u> for some expert help with this. Some of the following tips may also help.

# Prioritise

Save your energy for the things that need to be done most, or are most important to you. Before doing a task, think about whether you need to do it now. If it is not necessary, consider doing it at another time.

If it is a more active task, ask family or friends to help if you can. Do everything the easiest way possible. Give yourself extra time to do things, so you are not rushed or stressed. This should make you less likely to get breathless.

## Plan ahead

Some tasks may be easier if you plan ahead. For example, you could do your shopping online or ask someone to do it for you, if you can. Most supermarkets offer online shopping and home delivery.

You might also find tasks are easier at a certain time of day. It can help to <u>write a diary</u> to see any patterns. You might notice times during the day that you are less breathless, or have more energy. You can use this to plan ahead, and do the things you want to at times when you might find them easier.

### Pace yourself

Take breaks between being active and resting. You may also want to take breaks during activities. Do not rush an activity as this can make you more breathless.

The breathlessness had got better, but I still struggled with flights of stairs and hills. I started yoga classes at the Macmillan Centre which were great. They not only helped me to relax but also stretch and use muscles in ways I hadn't used them for a while.

Danielle, who had cancer and breathlessness

### Around the house

You may be eligible for grants to make changes to your house or for extra pieces of equipment that can help. An <u>OT</u> or <u>physiotherapist</u> can also give you practical help and advice. Here are some things you may want to consider:

- Think about ways to arrange your home to make tasks easier. For example, it might help to put a chair in a hallway or landing, so you can rest when walking between rooms.
- Sit down to do tasks like washing, dressing or preparing food.
- Arrange your kitchen so the things you use most often are at waist height. This means you do not have to bend or stretch to reach cupboards.
- Try to avoid bending from the waist down, as this can restrict your breathing. Instead, try bending your knees, while keeping your back straight. This keeps your chest upright and your shoulders back.
- When you bend down, you may find it helps to hold on to a secure piece of furniture. Some people find it helpful to use a grabbing stick or reacher (pick-up stick). An OT can give you advice on this.
- Try not to lift heavy items, as this can make you tired and short of breath. Laundry or shopping is easier to push in a trolley. When walking around a supermarket, you may feel less breathless if you lean on the trolley handle.
- Some people find they can walk further and feel less breathless when using a wheeled walking frame or walker. Some wheeled walkers come with baskets to carry things. A 4-wheeled walker may also have a seat so you can sit and rest.

- Keep your phone close by. Using a cordless or mobile phone is easier. It might help to tell people who call you often that they need to give you plenty of time to answer.
- Think about getting an intercom system. For example, a baby monitor lets you talk to someone in another room without having to shout or get up during the night.

### **Getting dressed**

- Sit down when you are getting dressed. Choose loose-fitting clothes, especially around the waist and chest. If you wear a bra, using a bra extender may help it feel less restrictive.
- Bring your feet up to put on socks, tights and shoes, as bending at the waist can make you breathless. Some people like to place their foot on a box or stool to help. Slip-on shoes are easier to get on and off.
- When you get undressed, do not hold your breath as you take clothes off over your head. Take your arms out first, then quickly slip the clothes over your head. This means your face is only covered for a short time.

### Having a bath or shower

- Bathrooms can get warm and quickly fill with steam. When you are having a bath or shower, open a window or leave the door slightly open.
- Keep the water warm but not too hot, as this can make you breathless.
- To get into the bath, sit at the side and slowly lift in one leg at a time. After your bath, you may find it easier to kneel up first and rest for a few moments before standing up.
- If you are having a shower, try to keep the spray away from your face. Some people find it helps to turn the water off while they soap themselves, and then turn it back on to rinse off. If there is enough space in the shower, sit safely on a seat or stool.
- A bathrobe or big towel wrapped around you will help you get dry without lots of rubbing and patting. Sit down while you dry yourself. Bring your feet up, so you do not have to bend to dry them. Remember to keep breathing from your tummy, relaxing the upper chest.

## Going to the toilet

- If you find it hard to get to the toilet, it can help to use a urine bottle or commode (portable toilet seat and bowl). A community or district nurse can arrange this for you. Your hospital or GP can arrange for you to have a community nurse.
- Aids such as grab rails, a raised toilet seat, bath board or bath lift can make going to the toilet and bathing easier. An <u>OT</u> can visit you and suggest adaptations to your home to make things easier.
- If you are constipated (have problems pooing), get this treated quickly. Constipation and straining can make breathlessness worse.

# Diet

You may find that breathlessness can cause problems with eating. If you are not managing to eat enough, you can add calories to your food with high-protein powders. You can also try adding nutritious, high-calorie drinks. Your GP or dietitian can prescribe these for you. They are also available from most chemists. You can ask to be referred to a dietitian at your hospital. If you are at home, your GP can arrange this for you.

Here are some other tips:

- If you can, sit up at a table to eat as breathing may feel less restricted.
- Smaller meals on a smaller plate are easier to manage.
- Eat slowly and take smaller mouthfuls.
- Try to avoid chewy food.
- Try adding sauces or gravies to make food easier to eat.
- Take sips of fluid often. This helps keep your mouth moist. It also helps stop phlegm getting sticky, which makes it easier to cough up.
- Drink at least 11/2 litres (3 pints) of fluid a day, if you can.
- On days when making food feels too difficult, ready meals can help.
- Having a small alcoholic drink like sherry or brandy before a meal can help your appetite.

## **Dry mouth**

Being breathless can make you breathe through your mouth more than your nose. This can make your mouth and tongue dry, which can leave a bad taste.

Here are some things that might help:

- If your tongue is 'coated', it may make your food taste unpleasant and put you off eating. If this happens, talk to your healthcare team for advice.
- Drink sips of fluid often. You may find fizzy drinks more refreshing. Keep water by your bed and take water with you when you go out.
- Try sucking ice cubes or ice lollies. You can make lollies by freezing fresh fruit juice in ice-cube trays or in special lolly containers with sticks.
- Keep your food moist with sauces and gravies.
- Avoid chocolate and pastry, as they can stick to the roof of your mouth.
- Tell your doctor about your dry mouth. They can prescribe mouthwashes, lozenges or saliva-like sprays or gels to help.
- Use lip balm for dry lips. But do not use lip balm if you are having radiotherapy to the head or neck area.
- If you need to moisten your lips and you have been prescribed oxygen, use a water-based lubricant, such as K-Y Jelly<sup>®</sup>. Do not use petroleum jelly (like Vaseline<sup>®</sup>) or other oil-based lubricants or creams. These are a fire risk when used with oxygen.

# Going out

If you are planning a day out somewhere you have not been before, it may help to get some information before you go. You might want to find out about lifts, parking, transport links, and how far you will have to walk.

The air may be drier if there is air conditioning or if it is a cold, dry day. This can cause a dry mouth or coughing. Taking a small bottle of water with you can help. You could also keep a <u>handheld fan</u> with you to help if you get breathless.

Some people find that when the air is cold outside, it can help to put a light scarf across their nose and mouth. This warms the air they breathe and adds moisture to it.

When you are walking outside, go slowly and use <u>relaxed tummy</u> <u>breathing</u>. It may help to match your breathing to your steps. You can do this by:

- breathing in on 1 step
- breathing out on the next 2 steps.

A walking stick, walking frame, wheeled walkers or wheelchair can be useful when you are outside, particularly for longer trips. Your <u>nurse, physiotherapist or OT</u> can arrange these for you. You can also hire wheelchairs from the <u>British Red Cross</u>. There is a charge for this service. Your local shopping centre or supermarket may also have wheelchairs you can borrow while you are there.

The Shopmobility, Motability and Blue Badge schemes may be able to help. Ask your nurse, OT or social worker for details.

# Keep a diary

You may find there are certain times of the day when you need more energy, such as in the morning when you are getting dressed. Or you may find there are certain things that make your breathlessness worse, such as feeling stressed.

It can help to write down:

- when your breathlessness is difficult
- activities that make it worse
- times of day that you have more energy
- what techniques you use to deal with it.

You can also use a diary to plan activities for times of the day when you feel better. And it can remind you to practise controlled breathing and relaxation techniques.

Over the last few years, my breathing has deteriorated significantly. I am now the proud owner of a Blue Badge. Remaining active and going to the gym twice a week has been my saviour both physically and emotionally.

Paul, who had throat cancer and breathlessness

# Sex and breathlessness

You may be worried about how being breathless can affect your sex life. If you have a partner, they may also be thinking about this. Sex takes energy and is tiring for the heart and lungs. It is important to recognise this and make some changes. Here are some tips that may help:

- Be open with your partner about your worries and what might help. This can help you both enjoy a fulfilling sex life.
- Talking, hugging and touching are all important parts of intimacy that do not take too much energy.
- Try to have sex when you are feeling rested, and your breathing is at its best.
- You might find it easier to have sex at a certain time of day, such as early evening rather than late at night.
- Some positions use less energy. You may need to try different positions to find what suits you best. <u>Asthma and Lung UK</u> has illustrations of suggested sexual positions for people with breathlessness.
- Make sure you are as relaxed as possible and take things slowly.
- A cooler room may help your breathing to feel easier.
- Sex after a big meal or alcohol might be more difficult, as your stomach will be full. Alcohol can also affect your sexual function.
- If you have oxygen at home, it may be helpful to use it before, during and after sexual activity.
- If you feel breathless while having sex, pause and take a few deep, slow breaths from your lower chest. Do this rather than completely stopping.
- Speak to your GP or specialist nurse if you want more advice. They can refer you to a sexual health counsellor.

# **Your feelings**

Your feelings may change over time. Some days you may feel well and relaxed. Other days you may feel scared, angry and sad. These are normal responses to breathlessness, cancer, treatment and any fears you have about the future. There is no right or wrong way to deal with these feelings, but accepting they are normal will help.

Sometimes you may feel you need to be alone. Other times you may want to be with people. Do what feels right for you at the time. You may have family and friends who find your changing emotions hard to understand. But try talking together about how you all feel. This can help you understand each other better and be able to cope with the problems more easily.

You may find it helpful to talk to other people who are going through similar experiences. There may be <u>support groups</u> in your area. You can also share your experiences of breathlessness with other people on our Online Community at <u>macmillan.org.uk/community</u>

## Feeling depressed

Many people feel sad because of their cancer and difficult symptoms such as breathlessness. This is natural, but if these feelings get worse, you may become depressed.

Depression can happen slowly and may be hard to recognise. If you are depressed, it may be harder for you to follow your treatment plan or your healthcare professionals' advice.

Depression can usually be successfully treated. The first step to feeling better is getting the right help. If you or your family or friends think you may be depressed, talk to your GP. They may recommend an antidepressant drug for you. Or they may refer you to a doctor or counsellor who specialises in helping people cope with emotional problems.

## **Feeling isolated**

People with breathlessness can sometimes become isolated if it is hard for them to go out and meet family or friends. Talking in a big group of people can also be tiring.

You may feel you would rather avoid these types of social situation. If you do feel isolated, talking to family and friends can help. Tell them how you feel and how much you can do. Together, you can find a way to see each other that is less tiring for you.

Sending messages or using social media can also be a good way of feeling more connected to people without using much energy.

Studies have shown that singing regularly as part of a group can help reduce feelings of isolation. Singing is also good for people living with long-term breathlessness. It can help you:

- breathe more deeply and slowly
- have more control over your breathing
- improve your posture.

<u>Asthma and Lung UK</u> has more information on singing and lung health, including how to find a group in your area.

# Looking after someone with breathlessness

Looking after someone with breathlessness can cause many different feelings. The person looking after you may feel anxious to see you breathless. They will want to know how to help. They may feel isolated as they are spending more time looking after you.

It is important that the person looking after you takes time to look after themselves so that they can better support you.

We have more information about looking after someone, including information about having a carer's assessment to see what help you might need. Visit <u>macmillan.org.uk/carers</u>

The organisation <u>Supporting Breathlessness</u> has more information for family, friends and carers of people with breathlessness.



# Who can help?

It is important to know who to contact if you need information or support with breathlessness.

Ask your cancer doctor or specialist nurse:

- who you should contact
- how to contact them, including at night, on bank holidays and at weekends
- when you should call for help or advice.

## **Clinical nurse specialist (CNS)**

A clinical nurse specialist gives information about cancer, and support during treatment. They can refer you to other members of the healthcare team, to help you manage your breathlessness in the best way. They can also help you find support groups in your area.

## **Physiotherapist**

A physiotherapist gives advice about exercise and mobility. They can help you learn breathing techniques and relaxation. They can also show you new ways of doing daily activities.

## **Occupational therapist (OT)**

An occupational therapist gives information, support and aids to help people manage their everyday activities, such as washing and dressing. They can help you find ways of doing things at home safely and without getting too breathless. They can arrange for you to have equipment, such as a grabbing stick, to make tasks easier. OTs can also offer expert advice on relaxation and how to pace your daily activities.

## Dietitian

A dietitian gives information and advice about food and food supplements. They can give advice to make eating easier when you are breathless. They can also suggest changes to your diet. They may recommend supplement drinks if you find it hard to eat enough.



## **Social worker**

A social worker can help sort out practical and financial problems. They are also trained in offering emotional support. A social worker may sometimes be called a care manager. If you are in hospital, you may be referred to a hospital social worker, care manager or assessment officer if you need help with:

- preparing meals
- personal care such as washing and dressing
- your finances.

If you are at home, you can request help yourself by contacting your local social services department. Find your local council on the <u>GOV.UK website</u>.

## **Community support**

Different people can offer support in the community. District nurses (also called community nurses) give advice and support to people by visiting them at home. They work closely with GPs.

Specialist nurses called palliative care nurses help with symptom control. They are sometimes called Macmillan nurses. They can offer you practical and emotional support. They can also visit you at home and support you and your family. Some palliative care nurses are linked to the local hospice. Your GP can usually arrange for you to be seen by a specialist nurse at home. If you have a local cancer centre, they may also have a hospice or a community specialist palliative care team that can offer you specialist help with your breathing. Team members can include the following:

- a physiotherapist
- an occupational therapist
- a dietitian
- a social worker.

Some hospitals have a specialist team for managing breathlessness.

<u>Marie Curie</u> nurses give palliative care and support to people by visiting them at home. They give nursing care during the day and overnight. You can talk to your district nurse or GP about whether a Marie Curie nurse is suitable for you.

## **Breathlessness clinic**

Some hospices and hospitals have special clinics to help you manage your breathlessness. Your GP or someone from your cancer team can let you know if there is a service in your area. They will be able to refer you. Some services may offer you a video outpatient appointment so that you can attend from home. Talk to your healthcare professional for further information.



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# **About our information**

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

### Order what you need

You may want to order more booklets or leaflets like this one. Visit <u>be.macmillan.org.uk</u> or call us on <u>0808 808 00 00</u>.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

### **Online information**

All our information is also available online at <u>macmillan.org.uk/</u> <u>information-and-support</u> You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

### Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille

- interactive PDFs
- large print
- British Sign Language
- translations.

easy read booklets

Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at **informationproductionteam@macmillan.org.uk** or call us on <u>0808 808 00 00</u>.

### The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit <u>macmillan.org.uk/ourinfo</u>



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

### Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

### **Macmillan Support Line**

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Call us on <u>0808 808 00 00</u>. We can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on **18001** 0808 808 00 00, or use the Relay UK app.

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

### **Macmillan Information and Support Centres**

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at <u>macmillan.org.uk/informationcentres</u> or call us on <u>0808 808 00 00</u>.

### Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

### **Financial guidance**

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

### Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit <u>macmillan.org.uk/financialsupport</u> to find out more about how we can help you with your finances.

### Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

### **Macmillan Grants**

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to changes needed to your home.

Call us on <u>0808 808 00 00</u> to find out more about Macmillan Grants.

### Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit <u>macmillan.org.uk/work</u>

### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on  $0808\ 808\ 00\ 00$  to speak to a work support adviser.

# Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

### Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting <u>macmillan.org.uk/</u> <u>selfhelpandsupport</u>

## **Online Community**

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at <u>macmillan.org.uk/community</u>

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support adviser or an information and support adviser any questions you have.

# Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

# Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

# Support for breathlessness

# Asthma and Lung UK

### Helpline **0300 222 5800**

### www.asthmaandlung.org.uk

Supports people with any type of lung disease. Has a range of resources to help people understand, manage and live well with a lung condition. Provides information on support groups including singing and music groups.

# Cambridge Breathlessness Intervention Service (BIS)

www.cuh.nhs.uk/our-services/breathlessness-intervention-service/ A service that operates from the Cambridge University Hospitals website. Has videos and a range of fact sheets with information on managing breathlessness. Also has audio clips for relaxation.

### Mesothelioma UK

### Helpline 0800 169 2409

### www.mesothelioma.uk.com

Provides up-to-date information for patients with mesothelioma and their carers through its helpline. Gives information on treatment, financial help, support services and support groups.

### The Roy Castle Lung Cancer Foundation

### Helpline **0333 323 7200**

### www.roycastle.org

Provides financial and emotional information and support to people with lung cancer. Also runs support groups and campaigns for lung cancer patients.

### **Supporting Breathlessness**

### www.supporting-breathlessness.org.uk

Provides help and advice for the family and friends of people with breathlessness.

# NHS stop smoking services

### England

Smokefree National Helpline **0300 123 1044** www.nhs.uk/better-health/quit-smoking

### **Northern Ireland**

www.stopsmokingni.info

### Scotland

Quit Your Way Helpline **0800 84 84 84** <u>www.nhsinform.scot/healthy-living/stopping-smoking</u>

### Wales

Help Me Quit Helpline **0800 085 2219** <u>www.helpmequit.wales</u>

# General cancer support organisations

## **Black Women Rising**

### www.blackwomenrisinguk.org

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

### **Cancer Black Care**

### www.cancerblackcare.org.uk

Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

### **Cancer Focus Northern Ireland**

### Helpline **0800 783 3339**

### www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

### **Cancer Research UK**

### Helpline 0808 800 4040

### www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

### **Cancer Support Scotland**

### Tel 0800 652 4531

### www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

### **Macmillan Cancer Voices**

### www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

# Maggie's

### Tel 0300 123 1801

### www.maggies.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

### **Penny Brohn UK**

### Helpline 0303 3000 118

### www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

# Riprap

### www.riprap.org.uk

Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

### Tenovus

### Helpline **0808 808 1010**

### www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

# General health information

# Health and Social Care in Northern Ireland

### www.northerntrust.hscni.net

Provides information about health and social care services in Northern Ireland.

### NHS.UK

### www.nhs.uk

The UK's biggest health information website. Has service information for England.

### NHS 111 Wales

### <u>111.wales.nhs.uk</u>

NHS health information site for Wales.

# **NHS Inform**

Helpline **0800 22 44 88** <u>www.nhsinform.scot</u> NHS health information site for Scotland.

## **Patient UK**

### www.patient.info

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

# Counselling

# British Association for Counselling and Psychotherapy (BACP)

### Tel 0145 588 3300

### www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

### UK Council for Psychotherapy (UKCP)

### Tel 0207 014 9955

### www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

# Emotional and mental health support

# Mind

### Helpline 0300 123 3393

www.mind.org.uk

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

# Samaritans

Helpline **116 123** Email **jo@samaritans.org** 

www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

# Financial support or legal advice and information

# Advice NI

Helpline 0800 915 4604

www.adviceni.net

Provides advice on a variety of issues including financial, legal, housing and employment issues.

# **Benefit Enquiry Line Northern Ireland**

### Helpline **0800 232 1271** Textphone **0289 031 1092**

www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

### **Carer's Allowance Unit**

Tel 0800 731 0297

Textphone **0800 731 0317** 

www.gov.uk/carers-allowance

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

# **Citizens Advice**

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

# England

Helpline **0800 144 8848** www.citizensadvice.org.uk

# Scotland

Helpline **0800 028 1456** <u>www.cas.org.uk</u>

### Wales

Helpline **0800 702 2020** www.citizensadvice.org.uk/wales

### **Disability and Carers Service**

### Tel 0800 587 0912

Textphone 0800 012 1574

<u>www.nidirect.gov.uk/contacts/disability-and-carers-service</u> Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

### GOV.UK

### www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

## Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details online by visiting:

### England

www.gov.uk/find-local-council

# Scotland

www.cosla.gov.uk/councils

### Wales

www.gov.wales/find-your-local-authority

# Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233** 

### **NI Direct**

### www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

## Unbiased.co.uk

### Helpline **0800 023 6868**

### www.unbiased.co.uk

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

# Equipment and advice on living with a disability

## **British Red Cross**

### Tel 0344 871 1111

### www.redcross.org.uk

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

# **Disability Rights UK**

### Tel 0330 995 0400 (not an advice line)

### www.disabilityrightsuk.org

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

# LGBT-specific support

# **LGBT Foundation**

### Tel 0345 330 3030

### www.lgbt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

### **OUTpatients**

### www.outpatients.org.uk

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

# Support for carers

### **Carers Trust**

### Tel 0300 772 9600

### www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

### **Carers UK**

### Helpline 0808 808 7777

### www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

# Advanced cancer and end-of-life care

### **Hospice UK**

### Tel 0207 520 8200

### www.hospiceuk.org

Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

## **Marie Curie**

### Helpline **0800 090 2309**

### www.mariecurie.org.uk

Marie Curie nurses provide free end of life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

# **Bereavement support**

### **Cruse Bereavement Support**

### Helpline 0808 808 1677

### www.cruse.org.uk

Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

## Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

### Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Dr Viv Lucas, Consultant in Palliative Care.

With thanks to: Joanne Currie, Clinical Nurse Specialist; Diane Jones, Specialist Physiotherapist and Member of the Cambridge Breathlessness Intervention Service; and Dr Kent Yip, Consultant Clinical Oncologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **informationproductionteam@macmillan.org.uk** 

### Sources

Below is a sample of the sources used in our breathlessness information. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk** 

European Society for Medical Oncology. Management of breathlessness in patients with cancer: ESMO Clinical Practice Guidelines. 2020. Available from www.esmo.org/guidelines/guidelines-by-topic/ supportive-and-palliative-care/management-of-breathlessness-inpatients-with-cancer [accessed March 2023].

Sparathis A, Booth S, Moffat C et al. The Breathing, Thinking, Functioning clinical model: a proposal to facilitate evidence-based breathlessness management in chronic respiratory disease. NPJ Primary Care Respiratory Medicine. 2017;27:27 Available from 10.1038/s41533-017-0024-z [accessed April 2023].

# Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

# 5 ways you can help someone with cancer

1. Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

### 2. Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

### 3. Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

### 4. Raise money

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

### 5. Give money

Big or small, every penny helps. To make a one-off donation see over.

# Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

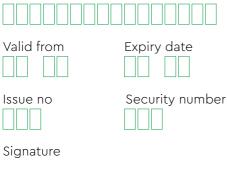
Email

Please accept my gift of £ (Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support OR debit my:

Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number



Date /

# Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to macmillan.org.uk/donate



Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This booklet is about managing breathlessness. It is for anyone who has breathlessness caused by cancer or its treatments. There is also information for carers, family members and friends.

The booklet explains the causes of breathlessness and different ways to manage it. We hope it helps you deal with breathlessness and answers some of the questions you may have.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call <u>0808 808 00 00</u> or visit <u>macmillan.org.uk</u> Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit <u>macmillan.org.uk/otherformats</u> or call our support line.



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