

Service: **Respiratory**

Living with a Chronic Lung Condition



Contents	Page
Coping with Breathlessness.....	2
The Active Cycle of Breathing.....	8
Pulmonary Rehabilitation.....	10
Coping with severe breathlessness.....	11
Practical Ideas for Living with a lung condition.....	13
Available Support.....	14
Benefits.....	15

Coping with breathlessness

We cannot cure your breathlessness but we can teach you methods to control and improve it. Practising these simple techniques can improve the efficiency of breathing and reduce the sensation of being breathless.

The more efficiently you breathe the less oxygen you use for the work of breathing.

Factors that can influence breathlessness include:

- Poor diet, being underweight or overweight
- Poor posture and changes to the shape of your chest
- Poor breathing pattern, over breathing
- Fear, anxiety and stress
- Sputum retention and chest infection
- Inappropriate use of medication/inhalers
- Tiredness/fatigue
- Different positions
- Lack of exercise, becoming unfit
- Past experience of breathlessness
- Lack of confidence

What happens when I breathe?

The whole process of breathing (respiration) is to take on board oxygen and to blow out carbon dioxide – the waste product produced as a result of using the oxygen.

Breathing in (inspiration)

The main muscle of respiration is called the diaphragm. This is a large dome shaped muscle, which sits underneath the lungs.

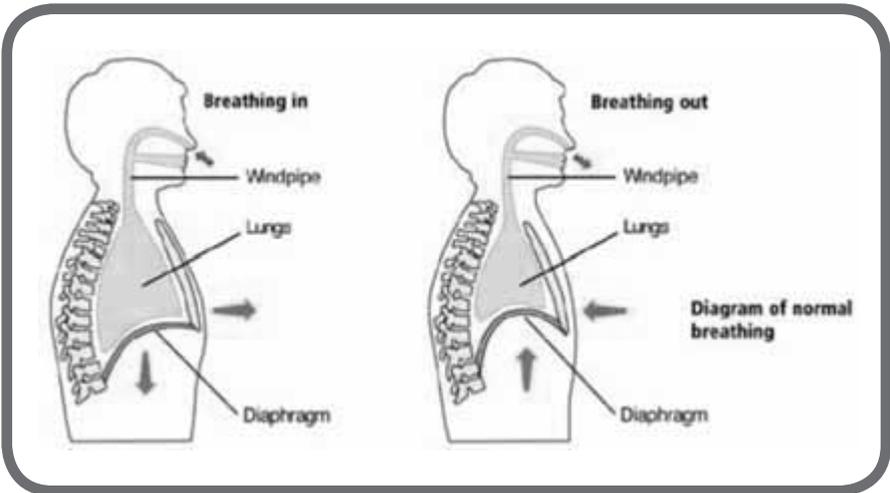
Breathing in, is an active process. This means that the diaphragm has to contract and shorten to move air from the lungs. This increases the volume of your lungs to take in the air.

As the diaphragm drops down in the chest, the stomach contents have to move forward to create space. Therefore, when you breathe in, you should see and feel the abdomen and lower chest rise.

Breathing out (expiration)

Breathing out should be passive. This means that no muscle activity is required for this process to happen. The air is forced upwards and out of the lungs due to relaxation of the diaphragm. As the diaphragm relaxes, it rises back up the chest cavity ending in a nice dome shape beneath the lungs.

As you breathe out the stomach contents will fall back into place and you should see and feel the stomach fall.



What happens when I'm breathless?

When you are breathless the diaphragm is unable to work as efficiently for a variety of reasons and therefore has assistance from the 'accessory muscles'. These muscles normally only work at times of increased demand. They are predominantly located around the upper chest, shoulders and neck.

Breathing with the upper chest is the most effortful and least productive way to breathe.

When these muscles are helping you breathe at rest it means there is less capacity for them to help when you are exerting yourself such as walking, dressing, climbing stairs etc and you may feel more breathless.

'Breathing Control'

When you feel short of breath you may have found that you do one or a number of the following:

- Use your shoulders and upper chest to help you breathe
- Increase your rate of breathing
- Have feelings of fear, anxiety, panic or general unrest

Although these are natural responses they can make your breathlessness worse. The aim of breathing control is to help steady and pace your breathing rate and pattern during these times.

Breathing control is designed to retrain you and your muscles to work more efficiently.

The technique is described below:

- Make sure you are in a comfortable position
- Make sure your head, neck and shoulders are not tense. Let your shoulders fall into their natural resting position.
- To recognise whether you are relaxed or tense, pull your shoulders up to your ears as far as you can and hold for a

count of 5 seconds and then let them relax. You should feel the difference between a tense and relaxed state.

- By relaxing your upper chest, the effort of breathing is reduced and you use less oxygen.
- Place a hand on the upper part of your stomach
- As you breathe in your hand should rise a little, as you breathe out it should fall.
- Try to feel the expansion of the lower ribs and upper stomach as air comes in.
- This will give you a feeling of breathing around the waist.
- Breathe in through your nose or mouth. The breath out should not require any effort.
- Some people find it easier to breathe out through pursed-lips. Only do this if you find it comfortable.

See photos.

This technique might feel odd to begin with and takes lots of practice.

To begin with you should practise it somewhere quiet when you are resting. Try to practise this regularly throughout the day. The aim is to get your body used to using this technique so it can be applied whenever you find it most useful.

‘Breathing is something we do 24 hours a day, every day – practising 10 minutes a day is not enough.’

You can then start to use this technique when you are feeling more breathless at rest or when you are exerting yourself, for example when walking, going up and down stairs or during other daily activities.

- Your rate of breathing increases when you are breathless.
- It is important not to panic.

- If necessary breathe in and out through your mouth, but using the technique described above. You will relax and gain control more quickly this way.

Positions to use when breathless

Sitting leaning forward

Sit leaning forward with your arms resting on your thighs and with wrists relaxed.



Relaxed sitting

Make sure your back is well supported.



Sitting at a table

Sit leaning forward from the hips with your upper chest and head supported on pillows or cushions.



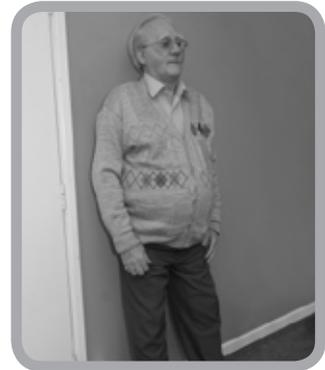
Standing leaning forward

Stand leaning forward from the hips, with your forearms resting on something the right height (e.g. window sills, kitchen work top, banister rails, back of arm chairs).



Standing leaning back

Stand leaning backwards against a wall, with your feet placed slightly apart, and about 12" out from the wall. Your shoulders should be relaxed with your arms hanging loosely by your sides.



High side lying

Lie on your side, rolled slightly forward with a slope of 4 or 5 pillows to raise the shoulders. Use an extra pillow to fill the gap between your waist and armpit to stop you sliding down the bed. The top pillow should be above the shoulder supporting the head and neck only. The knees should be slightly bent with the top leg in front of the one underneath.



The Active Cycle of Breathing

Technique (ACBT)

This guide is designed to teach you the 'Active Cycle of Breathing Technique' (ACBT). It is a set of breathing exercises designed to help you to loosen and clear phlegm from your lungs. Done regularly it can help to maintain your lungs in good condition and make it easier to breathe. Your physiotherapist or respiratory nurse specialist will be able to teach you the technique and give you specific instructions for your chest condition.

The ACBT is made up of:

Breathing control

This is normal relaxed breathing, with your upper chest and shoulders relaxed. This part of the cycle is very important to let you and your lungs rest between the deep breaths and huffing. Your physiotherapist or respiratory nurse specialist will teach you to judge how long to do this part of the cycle.

Deep breathing

These are 3-4 long slow deep breaths in and relaxed breaths out. It is these deep breaths that help to loosen up the phlegm from deep in your lungs.

Huffing

This is taking a medium size breath in and squeezing it out through an open mouth using your stomach and chest muscles, as if you were steaming up a mirror with your breath. This helps to move phlegm up and out of your lungs.

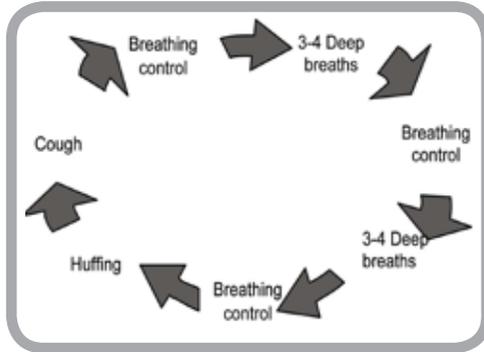
You should do 1 or 2 huffs at a time, but always have a period of breathing control between huffs.

Coughing

This should follow huffing. Cough only if you feel that phlegm

is ready to come.

The parts of the ACBT fit together like this:



To perform the technique you go round and round the cycle to coax up the phlegm. Never force a cough, but you may feel the need to cough after huffing. If the phlegm will not clear easily, be patient, go back to the beginning of the cycle and start again.

How long for?

You need to go around the cycle for at least 10 minutes each treatment or until your chest clears. Your physiotherapist or respiratory nurse specialist will give you guidance.

How often?

Usually 1-2 times a day, depending on the amount of phlegm on your chest. You may need to increase the amount and length of treatments if you have a chest infection.

When?

Whenever you find it most convenient to fit into your day. Mornings are the most common time to clear the lungs for the day and bedtime to have a good night's sleep. You may have a certain time of day that you start to cough. If you are taking inhaled or nebulised drugs, you need to time your breathing exercises with them, speak to your physiotherapist or nurse for advice.

Bronchodilators (e.g. Salbutamol (Ventolin), Ipratropium (Atrovent)) are best taken approximately 30 minutes before you do your ACBT, as they open up your tubes and help the phlegm to clear more easily.

If you are prescribed nebulised antibiotics (e.g. Colomycin (Coliston)) or nebulised / inhaled steroids (e.g. Pulmicort, Becloforte, and Becotide) these should be taken after ACBT.

In what position?

The ACBT works in any position, but you should be comfortable and relaxed. Your physiotherapist may suggest a specific way to sit or lie when you do your treatment, depending on your chest condition.

Pulmonary Rehabilitation

Pulmonary Rehabilitation is a supervised, personalised exercise and education programme that can help you to learn to manage your breathlessness and remain active. The programmes are usually run by physiotherapists or nurses, with involvement from other health professionals and can help improve your energy, strength and quality of life. Your doctor, nurse or physiotherapist will be able to refer you to a programme near you.

New evidence shows that it is both safe and highly effective to start Pulmonary Rehabilitation soon after an exacerbation of COPD. It is therefore now normal practice to be assessed at this time.

Coping with severe breathlessness

Sometimes people with chronic lung disease can develop severe breathlessness due to their deteriorating condition that cannot be relieved by the above methods, and significantly impacts on quality of life. The medical term for this is 'Intractable Dyspnoea' which means when a person's breathlessness does not improve with regular medication and techniques. The information provided here is a summary of the protocol used by your respiratory specialist team to help relieve your breathlessness.

Severe breathlessness treatment options

1. All possible treatable causes for your worsening breathlessness will be considered by your health care team, such as infection or anaemia, and treated appropriately.
2. An ongoing assessment for low oxygen levels will commence and be treated appropriately. Please see section below on oxygen therapy.
3. Some of the following may be suggested and taught:
 - Fan therapy – air flow across the face +/- a cool flannel on the face
 - Open windows – reduces 'air hunger'. Keep rooms cool and uncrowded but avoid over chilling.
 - Pace activities
 - Breathing control, positioning and chest clearance.
 - Psychological therapies – using music and relaxation. A referral to a psychologist for support can be arranged.
4. If oxygen levels remain above 90% and the above techniques have been tried your team will discuss with you a trial of medication called opioids. You may also be referred to the palliative care team if this is your wish to help manage your symptoms. Examples of medicines used are low doses

of morphine which can come in immediate release liquids or slow release tablets and can help relieve the sensation of breathlessness.

5. In addition or as an alternative if your breathing is making you feel very anxious you can try some medication to help with the anxiety. The most common medicine used for this is Lorazepam which is dissolved under the tongue.

6. In severe cases or where tablets can no longer be tolerated there is an alternative to these medicines in injection form. At this time you would be under the care of a community nursing team if you were at home or a specialist team in hospital.

Oxygen therapy

If your oxygen levels are low you will be offered a referral for a formal Long Term Oxygen Therapy (LTOT) assessment.

If your oxygen levels are normal but you remain very breathless despite the above treatments then there is no evidence to support the use of home oxygen therapy. However, oxygen can be tried, to assess if it helps reduce anxiety and the need for hospital admission. If it does not help you it can be removed but if you find it beneficial it can continue either via nasal cannula or a face mask. A face mask can make it difficult to eat, drink and talk so nasal cannula are more commonly used. There is a separate detailed patient information leaflet on oxygen therapy.

Nebuliser therapy

Most people can manage their inhalers effectively and there is little benefit from a nebuliser. However, for some people with very severe breathlessness having your airway opening medication such as Salbutamol through a nebuliser can help. In addition, if you are on oxygen or a mouth breather you may find saline nebulisers can improve comfort levels when taken between your other inhalers.

Personal wishes and beliefs

It is important when you are reaching the final stages of your illness that you have thought about what treatment you would like and that your family and carers are aware of this. We understand it is difficult and upsetting to talk and think about this but planning ahead can help ensure your wishes are followed. Your health care team will support you in these decisions and help you access any further support you or your family may need.

Practical ideas to help those with lung conditions

Physiotherapy and Occupational Therapy Services

Your physiotherapist can assess your ability to move and make recommendations to help you maintain and restore maximum movement and functional ability. They can offer advice regarding various aids such as a rollator (walking frame) or walking sticks that may be helpful for those who have difficulty walking. They will be able to give you specific exercises to help improve your physical fitness, and can advise regarding chest clearance, postural care and managing breathlessness.

The occupational therapist's focus is to enable a person to carry out their everyday routine. Breathlessness and fatigue are common symptoms of respiratory conditions which occupational therapy can help to address in practical ways. An occupational therapist's role can include; assessment of activities of daily living such as personal care, equipment provision, home environment modification and advice regarding energy conservation techniques.

Physiotherapy and occupational therapy services can be accessed through your local health centre via your GP.

Available Support - Care Direct provides information about care services, other types of support and welfare benefits such as:

- Help to look after yourself at home
- Advice, aids and adaptations to help people continue living at home
- Support for carers
- Help after leaving hospital
- Meals delivered to your home
- Advice on benefits
- Residential and nursing care, advice on very sheltered housing
- Piper lifeline

Tel: 0117 9222700 www.bristol.gov.uk/adultcare

Benefits:

The Benefit Enquiry Line is a telephone advice and information service, before you have made a claim. You can call if you are sick or disabled or if you are caring for someone and acting on their behalf.

Telephone: 0800 88 22 00, 8.30 am to 6.30 pm Monday to Friday. www.direct.gov.uk

www.direct.gov.uk/en/DisabledPeople/FinancialSupport/Introductiontofinancialsupport/DG_065148

Attendance allowance is a tax free benefit. You may be entitled to Attendance allowance if you are over 65 and need help with personal care. The allowance is based on the help you need – not the help you actually get.

Disability Living Allowance (DLA) is a tax free benefit for people under 65. If you are not already receiving DLA you can no longer apply for it. This has now been replaced by Personal Independence Plan (PIP) For people aged 16 to 64.

Industrial Injuries Benefit: Industrial Injuries Disablement Benefit (IIDB) is for people who are disabled because of an accident at work or who are ill or disabled as a result of a disease such as asbestosis or mesothelioma caused by work.

Carers Benefit: you may be able to get carers allowance if you are aged 16 or over and are caring for someone for more than 35 hours a week who are receiving attendance allowance, or DLA at middle or higher rate for personal care. The Carers Allowance Unit can send you a claim form.

Write to:

The Carers Allowance Unit, Palatine House, Lancaster Road,
Preston PR1 1HB

Tel: 0845 608 4321

8.30 am - 5.30 pm Monday - Thursday,

8.30 am - 4.30 pm Fridays

Email: cau.customer-services@dwp.gsi.gov.uk

Pension credit is an income related benefit for pensioners living in Great Britain. It is made up of 2 parts, Guarantee Credit and Savings Credit.

You can call The Pension Service on 0800 99 1234, 8.00 am to 8.00 pm Monday to Friday. www.direct.gov.uk/en/Pensionsandretirementplanning/PensionCredit/DG_10018692

Care and Repair: a non-profit making organisation with charitable status.

Services are available for homeowners in Bristol, South Gloucestershire and North Somerset who are over 60 or are disabled. They can advise regarding adaptations to your home, or general repairs and inform you of government grants and other organisations who may be able to help financially.

Bristol & South Gloucestershire

Tel: 0117 9542222 Mon to Thurs 9.00 am - 5.00 pm,

Friday 9.00 am - 4.00 pm

www.bristolcareandrepair.org.uk

North Somerset Tel: 01275 858518 Mon to Thurs 9.00 am - 5.00 pm, Friday 9.00 am - 4.00 pm

Travel

Blue Badge

The Blue Badge scheme allows drivers of passengers with severe mobility problems to park close to where they need to go. Depending upon your locality, application forms can be obtained as follows;

South Gloucestershire: Forms can be collected and submitted at any of the one-stop shops in Kingswood, Patchway, Thornbury or Yate .

You can also email: **contravel@southglos.gov.uk** Tel: 01454 868004

Bristol: Forms can be requested by calling 0117 922 2600, or emailing parking.permits@bristol.gov.uk.

North Somerset: Download and complete the disabled parking permit application (pdf) and return to;

Disabled Parking Permits, North Somerset Council, PO Box 53, Town Hall, Weston-super-Mare, BS23 1ZX Tel: 01275 888 801 Fax: 01275 884 258

<https://www.n-somerset.gov.uk/Transport/Parking+and+access/disabledparking-faq.htm#1>

Community Transport and Dial a Ride

Dial a ride provides door-to-door transport services to disabled and older people who are unable to use public transport because of mobility or communication impairments. Services vary so please contact your local office for further details;

Bristol area

Tel: 0845 130 1875 www.bristoldialaride.org.uk

Kingswood area

Old School House, Kingswood Foundation, Britannia Road, Kingswood, S Gloucestershire BS15 8DB

Tel: 0117 961 6016 www.kingswoodct.org.uk

Yate, Sodbury & District Community Transport (including Frampton Cotterell Enterprise Group)

(Group hire, Ring and Ride & voluntary car)

The Yard, 390 North Road, Yate, South Gloucestershire, BS37 7LW

Telephone: Ring & Ride 0845 241 0985

Office Tel: 01454 228706

www.accessible-transport.com

Filton, Patchway, Stoke Gifford, Thornbury and Bradley Stoke.

Four towns and Vale Link Community Transport

Norman Scott Park, Coniston Road, Patchway, South Gloucestershire BS34 5JR

Tel: 01454 868 529 www.accessible-transport.com

North Somerset Tel: 01275 885176

Portishead Porters Tel: 01275 855552

Nailsea & District Community Transport Tel: 01275 848190

www.accessible-transport.com

Other Organisations

British Lung Foundation (BLF)

The BLF is a charity that promotes lung health and supports people affected by lung disease. It campaigns to raise public awareness of lung disease and the impact it has on peoples' lives.

Breathe Easy groups are run by members, with help and support from British Lung Foundation regional teams when it's needed. There are more than 230 Breathe Easy groups across the length and breadth of Britain, so you should be able to find one near you wherever you live.

Groups typically meet once a month and members arrange all kinds of things for their meetings, from talks on local patient services and advice from health care professionals, to arts and crafts and trips to the theatre or the seaside.

There are currently 2 Bristol groups:

New Brunswick Church, Wigton Crescent, Southmead

Linda Tel: 07837 256708

2.00-4.00 pm

2nd Monday each month

The Park, Daventry Road, Knowle

Sandra Tel: 0117 9773902

2.00-4.00 pm

3rd Tuesday each month

For confidential advice and support, and for answers to questions you might have about living with a lung condition, call the BLF Helpline on 03000 030 555 (Mon to Fri 10 am to 6 pm).

They offer information and support on a number of subjects including Travel & Transport, Oxygen, Equipment, Welfare Benefits, as well as many issues relating to over 40 lung conditions.

Alternatively, you can write to:

British Lung Foundation

73-75 Goswell Road

London EC1V 7ER

Or call the BLF head office on Tel: 020 7688 5555. Website:

www.lunguk.org

Age UK is the new force combining Age concern and Help the Aged

Age UK publishes a large number of free Information Guides and Factsheets on a range of subjects including money and benefits, health, social care, end of life, legal, employment and equality issues.

Age UK Advice

Visit the Age UK website, www.ageuk.org.uk, or call Age UK Advice free on 0800 169 65 65

British Red Cross

Provide short-term loans of medical equipment, such as wheelchairs, for people with a disability or illness.

83 Tower Road North, Bristol, Avon BS30 8XP

Tel; 0117 301 2600 Monday to Friday 9.00 am-4.00 pm

Carers UK

National network of free and independent advice centres. Depending on available resources may offer benefits check and help with filling in forms.

Tel: 020 7833 2181 (for local contact details only – not telephone advice) Website: www.adviceguide.org.uk

Well Aware

A guide to health, wellbeing and community services in Bristol, South Gloucestershire and Bath & North East Somerset.

“Well aware” have an A-Z of all the services to find support for

a friend, family member, client or patient, or for yourself. They can offer advice regarding personal health services, a lunch club or social group, help round the home or in the garden, dentistry, counselling or any other form of support for carers or particular disabilities.

www.wellaware.org.uk Tel: 0808 808 5252 (freephone)

SSAFA - Soldiers, Sailors, Airmen and Families Association

As one of the UK's leading Armed Forces charities, SSAFA support around 50,000 people each year. SSAFA Forces Help provides financial, practical and emotional assistance to anyone that is currently serving or has ever served in the Army, Navy or RAF, and their families.

www.ssafa.org.uk or call the Central Office on Tel: 020 7403 8783 for your local office details

References

Hough, A. (2000) *Physiotherapy in Respiratory Care: an evidence based approach* (3rd edition)

Oxygen Therapy – NBT leaflet

NHS Gloucestershire (2013), *Intractable Dyspnoea*

NHS Constitution. Information on your rights and responsibilities. Available at www.nhs.uk/aboutnhs/constitution

**PATIENT
APPROVED** 



www.nbt.nhs.uk/respiratory

If you or the individual you are caring for need support reading this leaflet please ask a member of staff for advice.

© North Bristol NHS Trust. This edition published June 2019. Review due June 2021. NBT002328

Take Part
Be Involved
In research

Research is everyone's business

Learn more about the wide range of research that takes place here every day

www.nbt.nhs.uk/research



southmeadhospitalcharity.org.uk

Southmead Hospital Charity raises funds for departments and wards throughout the Trust, meaning you can support an area close to your heart