



with

# COPD

**Chronic Obstructive Pulmonary Disease** 

# **COPD Self Care Pack**



Name		
(please state the name you prefer to be known as)		
Date of Birth		
NHS Number		
Emergency Contact/ Carer's Details		
If found, please return this pack to:		

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We have tried to include as much information as possible in the pack. Wherever you see a website or email address there is a hyperlink to that page. If you are viewing this pack on a computer you can click on these links to view that web page.

As everyone's situation is different, you may find that there is information in this pack that doesn't apply to you. You may also want to use this pack to make notes, store appointments, and add letters, leaflets and anything else you may find useful.



### ... and what does it mean for me?

Looking after yourself in a healthy way, whether it's brushing your teeth, taking medicine when you have a cold, or doing some exercise, is really important to help to keep yourself as well as possible.

If you have a long-term condition, there are extra things you may need to consider, such as making changes to your diet, different types of exercise or different types of medication you may need to take.

It is important to stay active and do things that are important to you, such as gardening, seeing friends and family, going on holiday, or continuing to work where possible. Self care involves looking at what you can do and want to do, rather than what you can't do.

Living a healthy lifestyle is an important part of self care for everyone. You can take responsibility for your own health and wellbeing, with support from the people involved in your care.

When you talk to your doctor or nurse about your condition, you may want to discuss some of the things you need to do to stay well. Some of these will be things that you do yourself, such as eating healthily, exercising, or taking your medicines at the right time.

#### **NHS Choices**

There's lots of useful information about keeping well and healthy living. Look out for the Live Well section of the NHS Choices website. If you're living with a long-term condition, Your health, your way has advice on self care and taking control of your health.



www.nhs.uk

### What is COPD?

Chronic Obstructive Pulmonary Disease (COPD) is a collection of lung diseases including chronic bronchitis, emphysema and chronic obstructive airways disease.

If you have COPD, you will have difficulty breathing, primarily due to the narrowing of your airways, this is called airflow obstruction.



Typical symptoms of COPD include:

- Increasing breathlessness when active
- A persistent cough with phlegm
- Frequent chest infections

### What causes COPD?

#### **Smoking**

Smoking is the main cause of COPD. At least four out of five people who develop the disease are, or have been, smokers. The lining of the airways becomes inflamed and permanently damaged by smoking. This damage cannot be reversed. Around 10-25% of smokers develop COPD.

Research has shown you are up to four times more likely to quit smoking if you use the support of your local Stop Smoking service in addition to products such as patches or gum. They can offer support, advice and details of local support groups. For contact details of your local Stop Smoking service please refer to the 'Useful Contacts' section of this pack (page 27).

#### **Passive smoking**

Exposure to other people's smoke increases the risk of COPD.

#### Other factors

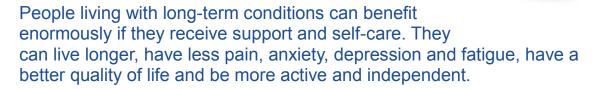
Some cases of COPD are caused by having worked in a damaging work environment, living in damp conditions, fumes, dust, air pollution and genetic disorders, but these are rarer.

# Living with COPD

COPD can affect many aspects of your life. However, there are some simple tips and techniques to help reduce its impact.

#### Self-care

Self-care involves taking responsibility for your own health and wellbeing with support from people involved in your care.



#### Take your medication

It's important to take your medication as prescribed, even if you start to feel better. Continuous medication can help prevent flare-ups. If you have questions or concerns about the medication you're taking or side effects, talk to your healthcare team.

It may also be useful to read the information leaflet that comes with the medication about possible interactions with other drugs or supplements. Check with your healthcare team if you plan to take any over-the-counter remedies, such as painkillers, or any nutritional supplements, as these can sometimes interfere with your medication.

#### Regular reviews

Because COPD is a long-term condition, you'll be in regular contact with your healthcare team. A good relationship with the team allows you to easily discuss your symptoms or concerns. The more the team knows, the more they can help you.

#### **Keeping well**

Everyone with a long-term condition such as COPD is encouraged to get a yearly flu jab each autumn to protect against flu. They are also recommended to get an anti-pneumococcal vaccination, a one-off injection that protects against serious infection caused by pneumococcal bacteria.



#### Long-term oxygen therapy

If the oxygen level in your blood is low, you may be advised to have oxygen at home through nasal tubes (also called a nasal cannula) or through a mask. This should be prescribed by your doctor or oxygen assessment service and monitored by the oxygen assessment service. Oxygen is not a treatment for breathlessness, but it is helpful for some patients with persistently low oxygen levels in the blood.

You will probably be referred for more detailed assessment to see whether you might benefit from long-term oxygen therapy. The aim of long-term oxygen therapy is to extend your life.

Do not smoke when you are using oxygen. The increased level of oxygen produced is highly flammable, and a lit cigarette could trigger a fire or explosion.

#### Check the weather

Check the forecast as the weather can have an adverse effect on COPD symptoms. Cold spells lasting at least a week and periods of hot weather and humidity can cause breathing problems. Try and avoid exposure to cold air to minimise your symptoms.



#### Watch what you breathe

To reduce symptoms of COPD and chances of a flare-up, there are certain things that should be avoided if possible, including:

- Dusty places
- Fumes, such as car exhausts
- Smoke
- Air freshener sprays or plug-ins
- Strong-smelling cleaning products, unless there is plenty of ventilation
- Hairspray
- Perfume

### **COPD Wrist Bands**

Medical alert wrist bands that allow ambulance staff to quickly identify patients with COPD are now available from Breathe Easy Portsmouth South.

The group has already had 200 bands made for people with COPD and is selling them for £2.50 plus postage costs.

The bands have been approved by South Central Ambulance Service, which has circulated a picture of the bands to first responders and paramedics. Front line staff have said that the bands are easily recognised and clearly marked, allowing them to identify a person with COPD.



If someone is alone and has an exacerbation of COPD, they can often find it difficult to speak. Wearing the medical alert band could speed up the time it takes for a paramedic to give treatment.

If Breathe Easy groups would like to purchase bands to sell to members or other people with COPD, email Eric Compton at:



eric.compton@btinternet.com

You could also wear an SOS medical band. There are numerous designs and styles available which can be purchased online.

### **Health and Wellbeing**

#### **Exercise**

People with COPD who exercise or keep active regularly have improved breathing, less severe symptoms and a better quality of life.

For most people with COPD who are disabled by their breathlessness, a structured programme of pulmonary rehabilitation provided by experienced healthcare professionals does the most good.



Getting breathless is unpleasant but it isn't harmful. Every patient should exercise as much as they can, however limited that may be, twice a day. Even chair-bound people can do some arm and upper-body movements.

Research shows that pulmonary rehabilitation improves exercise tolerance, breathlessness and health-related quality of life. It results in people seeing doctors less often and spending less time in hospital.

#### Maintain a healthy weight

Carrying extra weight can make breathlessness worse. Therefore, it is a good idea to lose weight if you are overweight. This can be difficult because the breathlessness caused by COPD can make it hard to exercise.

However, some people with COPD find that they lose weight. Eating food high in protein and taking in enough calories is important to maintain a healthy weight.

Research has shown that people with COPD who are underweight will have fewer COPD symptoms if they increase their weight.

#### Talk to others

If you have questions, your doctor or nurse may be able to reassure you. You may find it helpful to talk to a trained counsellor or psychologist, or someone at a specialist helpline. Your doctor's surgery will have information on these. Some people find it helpful to talk to other people who have COPD, either at a local support group or in an internet chat room.

#### **Health Trainer Service**

If you want to improve your health, be less stressed, or reduce your weight you can also see a health trainer. They can provide free and confidential one to one support to:

- Eat healthier
- Get fit
- Manage your weight
- Feel happier
- Reduce stress
- Access new groups
- Make any lifestyle or behaviour changes to improve your health and wellbeing

You can refer yourself to a local NHS trained Health Trainer, or ask your doctor to make a referral.



Health Trainer Service 01274 777527



healthtrainers@bdct.nhs.uk

# **Ways To Get More Active**

- Start small and build up check with your doctor or healthcare team
- Be realistic about your goals set yourself realistic goals that are specific, measurable and achievable
- Make exercise part of your day. Plan a time to do some physical activity that fits in with the rest of your day and try keeping an activity diary to help monitor your progress and success. If you miss a day, don't worry - just make sure you start again the next day
- Keep moving and make it fun! Remember, everyday activities count, so look out for opportunities to be active during the day. For example, use the stairs instead of the lift, or walk to the local shop rather than taking the car. Choose activities that you enjoy, to help you achieve your goals and keep you motivated. Vary your activity and try involving family and friends
- Reward yourself recognise when you achieve your goals. Think
  of things that you could reward yourself with, like a copy of your
  favourite magazine

When doing regular physical activity becomes a habit, and you're looking for new challenges, increase little by little.

# **Breathing**

#### Watch what you breathe

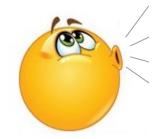
To reduce symptoms of COPD and chances of a flare-up, there are certain things that should be avoided if possible, including:

- Dusty places
- Fumes, such as car exhausts
- Smoke
- Air freshener sprays or plug-ins
- Strong-smelling cleaning products, unless there is plenty of ventilation
- Hairspray
- Perfume

#### **Breathing techniques**

There are various breathing techniques that some people find helpful for breathlessness.

These include breathing control, which involves breathing gently, using the least effort, with the shoulders supported. This can help when people with COPD feel short of breath.



Breathing techniques for people who are more active include:

- Relaxed, slow deep breathing
- Breathing through pursed lips, as if whistling
- Breathing out hard when doing an activity that needs a big effort
- Paced breathing, using a rhythm in time with the activity, such as climbing stairs

### Relationships

Having a chronic illness such as COPD can put a strain on any relationship. Difficulty breathing and coughing can make people with COPD feel very tired and depressed. It is also inevitable that their spouse, partner or carer will feel anxious or frustrated about their breathing problems. It is important to talk about your worries together.

Being open about how you feel and what your family and friends can do to help may put them at ease. But do not feel shy about telling them that you need some time to yourself, if that is what you want.

It is important that you discuss any worries or problems you have with your doctor or nurse if you feel unable to talk to your family. Many people do not want to burden those closest to them with their worries.

Your doctor or nurse will be able to advise you and arrange support. You may also find it helpful to join a support group where you can talk to other people with lung conditions whose circumstances are similar to yours.

You can contact the British Lung Foundation to find out about support groups in your area.



**British Lung Foundation** 

03000 030 555



www.blf.org.uk



helpline@blf.org.uk



#### **Family Support**

Being diagnosed with any health condition may affect the whole family. Family and friends may be worried, or having to take a caring role. It is important to get support before things become stressful so talk to your healthcare team about any worries you may have.

As COPD progresses, the increasing breathlessness can make it difficult to take part in activities. The breathlessness may occur during sexual activity, which may mean your sex life can suffer.

Communicate with your partner and stay open-minded. Explore what you both like sexually. Simply touching, being touched and being close to someone helps a person feel loved and special.

You might want to talk to someone from Relate. They offer advice, consultations, sex therapy, relationship counselling, workshops and support face-to-face and by phone. Counsellors are experienced relationship experts and are specially trained to work with families to help people resolve their problems.



Relate Bradford 01274 726096



Relate Keighley & Craven 01535 605047

#### **Support for Carers**

If you have a carer and they need help or advice, please contact:



Carers' Resource 01274 449660 / 01756 700888



Carers' Connection 01274 323323

## **Taking Care of Yourself**

#### Tips on taking care of yourself:

- Keep any inserts from repeat prescriptions with this pack so that you remember which medication is important to take
- Check the weather Check the forecast as the weather might have an effect on COPD symptoms. Cold spells lasting at least a week and periods of hot weather and humidity can cause breathing problems
- Regularly check with your pharmacist or doctor to ensure you are taking the right medication
- It is important to have a health check each year. Remind your doctor if it has been longer than a year or you feel your health has changed
- The free annual flu jab can reduce the risk of getting seriously ill in winter months and is available to over 65 year-olds and those with serious medical conditions. Ask your doctor for details
- You should also contact your doctor if you haven't had the pneumococcal vaccine, routinely offered to over 65s, and the shingles vaccine, currently given to those aged 70 and 79 year olds
- Contact your doctor or District Nurse to get a Falls Risk Assessment. These are carried out by individual practices or District Nursing teams
- Manage your stress. Make sure you make time to relax and unwind. Take things more slowly if you are feeling tired, and don't take too much on

#### **Depression**

Depression is more than simply feeling unhappy or fed up for a few days. We all go through spells of feeling down, but when you're depressed you feel persistently sad for weeks or months, rather than just a few days.



It's important to seek help from your doctor if you think you may be depressed. Many people wait a long time before seeking help for depression, but it's best not to delay. The sooner you see a doctor, the sooner you can be on your way to recovery.

Depression is a real illness with real symptoms, and it's not a sign of weakness or something you can "snap out of" by "pulling yourself together."

Depression affects people in different ways and can cause a wide variety of symptoms ranging from lasting feelings of sadness and hopelessness, to losing interest in the things you used to enjoy and feeling very tearful. Many people with depression also have symptoms of anxiety.

There can be physical symptoms too, such as feeling constantly tired, sleeping badly, having no appetite or sex drive.

The good news is that with the right treatment and support, most people can make a full recovery.

Sometimes there is a trigger for depression. Life-changing events, such as bereavement, losing your job or even having a baby, can bring it on. People with a family history of depression are also more likely to experience it themselves. But you can also become depressed for no obvious reason.

Depression is quite common and affects about one in 10 of us at some point. It affects men and women, young and old.

Treatment for depression involves either medication or talking treatments, or may involve a combination of the two. The kind of treatment that your doctor recommends will be based on the type of depression you have.

Many people with depression benefit by making lifestyle changes such as getting more exercise, cutting down on alcohol and eating more healthily. Self-help measures such as reading a self-help book or joining a support group are also worthwhile.

# **Taking Care of Yourself**

#### **Appointments**

It is important to pay attention to any changes in your health, and to stay up to date with your health checks.



Filling in this page and sharing it with people who support you can help.

	Date of last check up	Appointments	Notes
General Health Check			
Flu Jab			
Dentist			
Hearing Checks			
Other Checks			

It is important to let your health or social care provider know you have asthma so that they can offer any extra support you may need.

### **Planning For The Future**

#### Work

People with COPD often have to give up work because their breathlessness stops them from doing what they need to do for their job. This can cause financial pressure.

There are several benefits for which people with COPD may be eligible:

- If you have a job but cannot work because of your illness, you are entitled to Statutory Sick Pay from your employer
- If you do not have a job and cannot work because of your illness, you may be entitled to <u>Employment and Support Allowance</u>
- If you are caring for someone with COPD, you may be entitled to Carer's Allowance
- You may be eligible for other benefits if you have children living at home or if you have a low household income

#### Want to know more?

The British Lung Foundation website has a section on financial support



www.blf.org.uk/Page/Financial-support

For information on benefits and allowances you, and/or your carer (if you have one) may be entitled to check out the following websites, or speak to your local Citizens Advice Bureau:



**Bradford & Airedale** 

Citizens Advice Bureau

0844 245 1282



www.gov.uk

#### **Driving**

You need to make sure that you are well enough, and that your condition does not affect your ability, to drive.

Anyone who drives and has a medical condition that may affect their ability to drive must inform the Driver and Vehicle Licensing Authority (DVLA) who will assess every case individually

It is a criminal offence not to inform the DVLA of your diagnosis

Check with your insurance company to make sure you are still covered following your diagnosis

#### **Travel**

If you have COPD and are planning to fly, go to your doctor for a fitness-tofly assessment. This involves checking your breathing using spirometry (a spirometer is a machine you will be asked to breathe into) and measuring your oxygen levels.

Before travelling, remember to pack all your medication, such as inhalers, in your hand luggage.

It's important that you have up to date, recognised relevant vaccinations for insurance purposes.

If you are using oxygen therapy, tell your travel operator and airline before you book your holiday, as you may need to get a medical form from your doctor. If you are using long-term oxygen therapy, make sure you take enough oxygen with you for your journey and arrange for oxygen at your destination. Oxygen in the United Kingdom can be arranged through your oxygen supplier.

The British Lung Foundation have a number of booklets to help you prepare for travel, which can be downloaded from their website, including:

- Going on holiday with a lung condition booklet BK6
- Air travel with a lung condition information sheet IS1
- Airline oxygen policies information sheet IS2
- Travel insurance information sheet IS31



#### Safe and Sound

Safe and Sound is a service that may be able to support you by quickly putting you in contact with someone should anything happen at home, such as a fall, at the time you need it, whether you live alone, with the family, care for someone else or have a disability. A response team is available in an emergency to help assess the situation, take the appropriate action and advise what needs to be done.

Equipment is installed which may be connected to your telephone line, usually with a pendant which can be worn round the neck or on the wrist, which has a button to press so that you can call in an emergency, even if you can't get to your telephone. Safe and Sound may provide other equipment which will either call your carers rather than the control centre, or remind you to take your medication. You can also be assessed for equipment such as smoke alarms, fall detectors, heat sensors and medication dispensers.

Safe and Sound service is available to anyone of any age who is assessed as needing help to feel safer, more protected and independent in their own home.

#### This includes people:

- With health problems
- Who have had falls
- Who are struggling with frailty or illness
- Who have dementia who live alone
- Who have just come out of hospital
- Who care for someone else

Access to the service is by self referral, via your doctor, hospital, district nurse, social worker or occupational therapist.

To find out more, call the number(s) below and someone will answer your questions, or find out the answers and get back to you.



01274 435400 office hours or 01274 434994 out of hours



safe&sound@bradford.gov.uk

### **Benefit Checks**



Many people don't claim the benefits they are entitled to. People with COPD often have to give up work because their breathlessness stops them from doing what they need to do for their job. This can cause financial pressure.

There are several benefits for which people with COPD may be eligible:

- If you have a job but cannot work because of your illness, you are entitled to Statutory Sick Pay from your employer
- If you do not have a job and cannot work because of your illness, you may be entitled to Employment and Support Allowance
- If you are caring for someone with COPD, you may be entitled to Carer's Allowance
- You may be eligible for other benefits if you have children living at home or if you have a low household income

You are entitled to a benefits check to ensure you are receiving the right amount. The organisations listed below can help you with this:

Disability Advice Bradford	01274 609895
Bradford and Airedale Citizens Advice Bureau	0844 245 1282
Department of Work & Pensions	0845 60 60 265
British Lung Foundation	03000 030 555

### **Planning For The Future**

#### **End of Life Care**

As with other conditions that cannot be reversed or cured, it is important to receive good care at the end of life. Talking about this and planning it in advance can be helpful. This is called palliative care.

It can be difficult to talk about dying with your doctor and, particularly with family and friends, but many people find that it helps. Support is also available for your family and friends.

It may be helpful to discuss which symptoms you may have as you become more seriously ill, and the treatments that are available to reduce these.

As COPD progresses, your doctor should work with you to establish a clear management plan based on your and your carer's wishes. This will include whether you would prefer to go to hospital, a hospice or be looked after at home as you become more ill.

You may want to discuss drawing up an advance decision, also called a living will, which sets out your wishes for treatment if you become too ill to be consulted. This might include whether you want to be resuscitated if you stop breathing, and whether you want artificial ventilation to be continued.

#### **Further information**



British Lung Foundation have a helpful leaflet entitles 'Coping with the final stages of a chronic lung disease':



www.blf.org.uk/Publication/Detail/Coping-with-the-final-stages-of-lung-disease

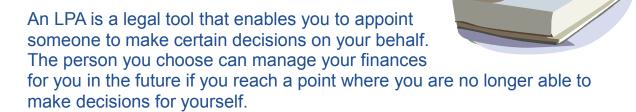
The NHS also have an End of Life Care Guide:



www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care

#### **Lasting Power of Attorney**

When planning for the future, it is a good idea to think about a Lasting Power of Attorney (LPA).



There are two types of LPA:

- Property and Affairs
- Health and Welfare

For more information on LPA's visit:

Notes				

www.gov.uk/power-of-attorney/overview

# **Important Contacts**

Use this page to list people whose numbers you may need to keep handy, for example: doctor, social worker, etc.

Name	Contact Number	Details

### Where To Find Support

#### **Services**

Look at what services may be available to you. Even if you don't need them now, they may be useful in the future.

By using the services that you are entitled to you can ensure that those closest to you don't have to take on all the responsibility for helping you.

- Find out what services can be arranged through your doctor or consultant
- Find out what kinds of services and support are provided by local voluntary organisations. Your local Citizens Advice Bureau, or Social Services can advise about this
- Connect to Support Bradford is a website to help people seeking social care or support in the Bradford District, with everything you need to help you with your support, from local to national products and services, information, advice and more



#### www.connecttosupport.org/bradford



### Welcome to Connect to Support Bradford District

Connect to Support is a new website for people needing care or support in Bradford District. You can find everything you need to help you with your support here, from local to national products and services, plus information and advice and much more.

Providers, sign up now Register today











 Contact your local social services department for details of services that they can arrange. Find out about getting a community care assessment to assess your needs. Social Services departments are listed in the phone book under the name of the local authority

## **Useful Contacts**

Name	Contact Number	Details
Emergency Services	999	To call in case of fire, medical emergency or if you urgently need the Police.
111	111	NHS 111 is a fast and easy way to get the right help, 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.
British Lung Foundation	03000 030 555  www.blf.org.uk/Home helpline@blf.org.uk	Support for people affected by lung conditions
Champions Show The Way	01274 321911 champions@bdct.nhs.uk	CSTW supports people's Health and Wellbeing by providing social activities and walking groups which are run by Volunteer Community Health Champions. These free activities are aimed at anyone who has a long term health condition/has recently been discharged from hospital or is over 50.
Health Trainers	01274 777527	Health Trainers can support you to make lifestyle changes and improve your health.
Carers' Resource	01274 449660 01756 700888	The Carers' Resource provides support for carers, no matter what their age, race, religion or needs.
	www.carersresource.org	

## **Useful Contacts**

Name	Contact Number	Details
Carers' Connection	01274 323323	Carers' Connection offer an advice and support service to carers on any matter of interest to them, such as: health and social care, residential care, holidays, equipment, leisure and wellbeing.
Connect to Support Bradford District	www.connecttosupport.org/ bradford	A website to help people seeking social care or support in the Bradford District. Everything you need to help you with your support, from local to national products and services, information, advice and more.
Stop Smoking Service	01274 437700  www.nhs.uk/smokefree  stopsmokingservice @bradford.gov.uk	Support and advice on stopping smoking as well as details of local groups and services.



Airedale, Wharfedale and Craven Bradford Districts Bradford City











Based on the RNIB Living Well with Diabetes Folder developed by Elaine Appelbee in collaboration with local communities and health service providers.

Special thanks to the British Lung Foundation for their contribution to the COPD Self Care Pack.

The wording in this publication can be made available in large print or Braille. Please call 01274 437963.

Self Care is committed to working in collaboration across Bradford CBMDC, Bradford City CCG, Bradford Districts CCG and Airedale, Wharfedale and Craven.