

# A Patient's Guide to COPD

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# **A Patient's Guide to COPD**

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# **A Patient's Guide to COPD**

## **Introduction**

It can be upsetting to discover that you have a lifelong illness such as Chronic Obstructive Pulmonary Disease (COPD). The thought of having a long term disease can lead to feelings of hopelessness, anxiety and sometimes depression. You may worry that you will not be able to do all of the things you used to do, and may be frightened about the future. However, although COPD will always be with you, it can be managed effectively, and many patients find that they can still lead full and rewarding lives.

During the research for this book, we interviewed lots of people with COPD to find out how their illness affects them. The range of people covered both sexes and various age groups, and involved people with moderate to severe symptoms. This gave us a good insight into the disease from a patient's perspective. By looking at COPD in this way, we were able to see how COPD patients live their lives on a day to day basis,



and the strategies that they have developed in order to help them handle their condition. We have included a number of case studies in this guide so you can see how other people are affected by the disease and how they cope. Hopefully their stories will give you some inspiration.

You may sometimes feel isolated as doctors bombard you with medical terms that you do not understand, and the people around you don't know much about your disease either. In this guide we explain COPD in non-technical terms to help you understand more about your condition so you don't feel as overwhelmed by the medical jargon. As well as explaining what COPD is and its causes and treatments, we examine other people's experiences of the disease, which are illustrated in the above-mentioned case studies.

It is often comforting to know that there are people that you can share your concerns with, so we've included advice on how to discuss your illness with those close to you. We also introduce you to online communities where you can share your feelings, knowledge and tips relating to your condition with others in the same situation. Numerous patients benefit from becoming involved in a community of people who share the same illness as these are often the people who know best how to cope with that

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illness. COPD affects people in varying degrees, and those that have had the disease for a long period have often developed many techniques to improve their quality of life. To find out more about joining an online community for COPD, you could visit: [www.beebreathing.com](http://www.beebreathing.com), which has lots of information and advice.

As well as the help available through support groups, loved ones and online communities etc. there is a lot that you can do to help yourself. This includes taking the correct medication, avoiding trigger factors that may affect your health, breathing exercises and a whole host of other useful ideas, which we have covered in this guide.

It is also good to become more knowledgeable about COPD as many people are not diagnosed until the later stages when lung damage is irreversible. By getting an early diagnosis, patients and doctors can take steps to slow down the progression of COPD. Therefore, by becoming more aware of COPD you may be able to help others in the future.



Throughout this guide we place emphasis on having a positive outlook. That's why we've also given ideas for overcoming anxiety and depression. Although it can be challenging having COPD, it is important to bear in mind that it is not the end of the world. With correct diagnosis, treatment and management, you could be amongst the many COPD patients who are still able to live a full and rewarding life.

## **1) What is COPD?**

To help you understand what COPD is, we'll start by looking at how the lungs function normally. The lungs are situated in the chest, and control breathing. They are rather like a couple of sacks that fill with air when we breathe in through our windpipe (or trachea). Inside the lungs are a number of tubes, which branch out, and become narrower at the ends like

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the branches of a tree; these are called bronchial tubes, as shown in diagram 1. The narrower tubes are called bronchioles, and at the end of each one of these is a group of air sacs referred to as alveoli. Inside the alveoli the oxygen contained in the air we breathe is exchanged for carbon dioxide, which we breathe out. This oxygen then enters our blood stream via the heart and the oxygenated blood is utilized by the body.

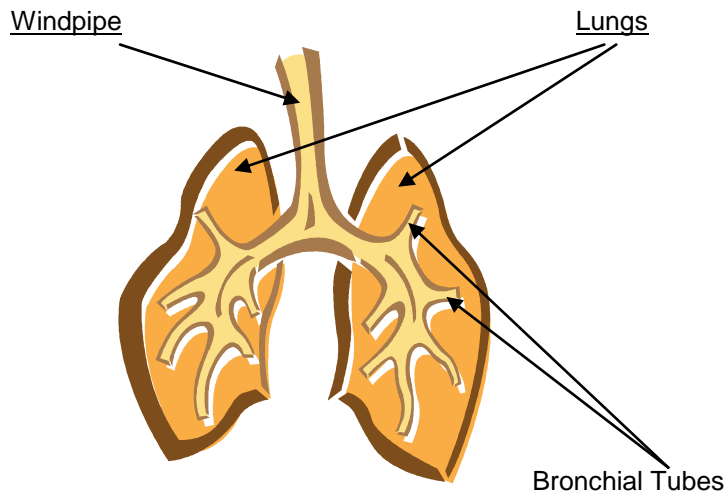


Diagram 1 - The Lungs

The bronchial tubes are covered in mucus and tiny hairs called cilia. Together they protect the lungs from any unwanted particles that try to enter. These particles are wafted by the cilia, and carried out of the lungs with the excess mucus.

With COPD the airways become damaged making breathing more difficult. This causes a blockage of the airways due to inflammation or too much mucus, and blockages can also occur in the small airways (bronchioles), and the air sacs (alveoli). As a result the lungs can lose their stretchiness and the airways can collapse causing air to become trapped in the lungs when exhaling. The disease is progressive, which means that it will get worse over time unless you take steps to prevent this i.e. by giving up smoking.

As the condition is long term, it is described as 'chronic', and covers a number of illnesses where the airways are obstructed. These include chronic bronchitis, emphysema and bronchiectasis, and some COPD patients could have more than one of these illnesses. The type of damage

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to the airways will depend on which type of illness the patient suffers from. These are as follows:

## **Chronic Bronchitis**

With bronchitis the bronchial tubes become inflamed, causing an increase in the production of mucus. This leads to phlegm which has to be coughed up by the lungs.

## **Emphysema**

With emphysema the air sacs (or alveoli) lose their elasticity causing the airways to narrow. This can lead to shortness of breath as the lungs are not as efficient at carrying oxygen into the body, so the patient has to breathe harder.

## **Bronchiectasis**

This is when the cilia are destroyed so the lungs cannot clear unwanted particles as effectively, causing a buildup of mucus and dust. The result is an accumulation of sputum at the back of the throat, which is mucus mixed with saliva. This can be very thick and difficult to cough up, and because sputum attracts bacteria, this can lead to infections in the lungs. These in turn can cause more damage to the airways, therefore leading to a repeated cycle of infections. As the airways suffer repeated damage, the tubes become enlarged. This damage can sometimes be caused by pneumonia or whooping cough.

## **2) The Causes of COPD**

The biggest cause of COPD is smoking, and most people develop the disease after they have been a heavy smoker for a number of years. Occasionally, COPD can be caused by other factors such as working in a dusty or heavily polluted atmosphere, or a certain genetic condition known as alpha-1-antitrypsin deficiency. However, it is very rare for someone to get COPD if they have never smoked.



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## **Damage Caused by Cigarettes**

Unfortunately it is not possible to reverse the damage caused to your lungs by cigarettes, but by stopping smoking you can prevent further damage no matter what stage of the disease you are at. If the disease is at an early stage then giving up cigarettes may be the only step you need to take to stop the disease progressing.

There are many substances in cigarettes which are harmful to the lungs. These include tar, and poisonous gases such as carbon monoxide and nitrogen oxide. Although some cigarettes have filters, their effect is limited. Therefore filters do not prevent poisons from entering your lungs.

Cigarette tar damages the airways in the lungs and can also cause lung cancer. As well as damage to the lungs, the toxic substances are released into your bloodstream causing damage to other organs, which can lead to severe illnesses such as heart attacks, strokes and cancer in other parts of the body.

Smoking is also harmful to other people, known as passive smokers, as they inhale the cigarette smoke that you breathe in and out, and they also inhale the smoke that is given off by the cigarette. The smoke that comes from a smoldering cigarette is not filtered so passive smokers inhale it directly, which can cause breathing difficulties for people with lung problems. It has also been shown that people who spend a great deal of time in smoky atmospheres are more likely to develop lung problems.

When you first give up smoking you may find that your cough gets worse for a few weeks. However, this merely means that your lungs are working to get rid of toxins, and the coughing will ease eventually. It is important that you are not tempted to start smoking again because of your cough. For tips on giving up smoking, please refer to the section, 'Giving up Smoking' in Chapter 3.

Although a few people do not suffer health problems through smoking, these are the exception to the rule. For the majority of people, their health will suffer, so it is not worth taking the chance. Please remember that once the damage to the airways is done, it cannot be reversed. However, there are still many benefits to giving up smoking, and it is never too late to try. Instead of focusing on the damage that you may have caused to your health, focus on the many benefits of quitting cigarettes.

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## **3) Who does COPD Affect?**

COPD mostly affects smokers, but it can affect people who have worked in environments where there is a lot of dust or pollution. Because COPD is a progressive disease, many sufferers are not diagnosed until later in life when the disease has reached a more advanced stage. Often they have been smoking for years and their chest problems have become steadily worse. It is common for the disease to affect the older generation who didn't fully appreciate the health risks when they began to smoke decades ago.

Therefore, by educating people about the causes and effects of smoking, and encouraging people to quit, we can prevent an increase in incidents of the disease in the future. Quitting cigarettes can also halt the progression of COPD in people who have already been diagnosed with the disease.

### **Giving up Smoking**

When you give up smoking, you will find that your breathing improves, because although damage to the airways is irreversible, the carbon monoxide will quickly disappear from your bloodstream. Therefore, you should soon find that you are feeling less short of breath.



Anyone who has ever tried to give up smoking will be aware of how difficult it is. Nicotine is very addictive and when your body doesn't receive its regular fix of nicotine, it begins to crave it. Nevertheless, because of the dangers of smoking there is a lot of help and support available to help people to quit.

Apart from the help available from the health service, there are a range of products that can help you to quit. Nicotine Replacement Therapy (NRT) is one of the options available and clinical trials have shown that using NRT can virtually double your chance of quitting smoking. The various products or therapies available to help give up cigarettes include:

- Nicotine Patches

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These are a form of Nicotine Replacement Therapy (NRT), and they deliver a dose of nicotine which is steadily reduced, helping you to withdraw gradually. You stick these to your skin and they release nicotine slowly over a 16 or 24 hour period. Some people find that they cause them to have weird dreams so they prefer not to use them at night, but this can lead to strong cravings early in the morning.

- Other forms of NRT

These deliver nicotine in short, sharp doses rather than steadily over a period and include gum, lozenges, nasal spray, plastic cigarette inhalators and preparations for under the tongue.

- Bupropion Hydrochloride

This is a drug (also known as Zyban or Wellbutin) which is usually prescribed by a doctor in tablet form. It reduces cravings by controlling them in the brain, but can have side effects and isn't suitable for everybody. Your doctor will be able to advise if it is appropriate for you.

- Natural Remedies

Some people prefer to take a natural approach and, although the success of these alternative therapies hasn't been proven, some people claim that they have helped them to quit. These include: hypnotherapy, acupuncture, dummy cigarettes, herbal preparations and mouth washes.



If you are determined to give up smoking, it is best to fix a set date when you will stop rather than trying to reduce cigarettes gradually. It also helps to have a good network of family and friends who can encourage you, and even better if you can get somebody else to give up at the same time so that you can support each other.

Try not to focus on the negative aspects of giving up smoking such as putting on weight. Although smoking suppresses the appetite, you can avoid putting on weight by eating healthily and taking regular exercise. Focus on the positive aspects of giving up smoking; as well as the numerous health benefits, you will also find that you are much better off

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financially. Increasing numbers of people are giving up smoking and finding that they feel much better as a result.

## **4) Symptoms**

The symptoms of COPD vary depending on the severity of the disease. Sometimes symptoms can suddenly get worse and these are known as flare-ups or exacerbations. By learning how to manage your illness you will be able to recognize a flare-up when it occurs, and will know how to handle it. We give advice on this in chapter 7 under the section headed, 'Managing Flare-ups.'



### **Coughing**

One of the first signs of COPD is a cough, which may come and go at first, but then becomes more persistent as the illness progresses. The cough is accompanied by phlegm as the lungs will produce increasing amounts of mucus.

### **Breathlessness**

People usually become more concerned when they begin to become breathless. At first this may be only after exertion, during the winter, or after a cold, but as COPD becomes more severe you may feel breathless every day.

### **Wheezing**

The breathlessness will often be accompanied by wheezing.

### **Hyperventilation**

Many people become distressed when they have difficulty breathing and this can lead to hyperventilation. This is when somebody breathes too fast or too hard, causing an imbalance in the levels of oxygen and carbon dioxide in the body. The symptoms of hyperventilation can be quite

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alarming, such as pins and needles, and faintness. However, these symptoms will not cause any harm, and it is possible to retrain your breathing to reduce the chances of this occurring. Please refer to chapter 7 for tips on controlling your breathing.

## **Chest Infections**

COPD patients are also more susceptible to chest infections, because of the excess phlegm. When you have a chest infection, your coughing, breathing and wheezing will become worse and the phlegm will be a yellow or green color.

As COPD becomes more advanced you will find that you are becoming increasingly breathless and will find it difficult to take part in any physical activities. However, it is important to try to keep fit as people who never exercise will find that they get breathless even more easily. Later in the book we will look at how you can tackle an exercise regime, helping to improve your overall health.

When the symptoms of COPD are particularly bad, this is described as a 'flare-up.' These usually increase in frequency and severity as COPD progresses. Generally the more damaged the lungs are, the more severe the symptoms will be. The above symptoms are those most commonly associated with COPD, but you may also find that you suffer from:

## **Anxiety and Depression**

Many people feel anxious because they have difficulty breathing, and some can feel depressed because of their illness. Later in the book we will look at ways to cope with anxiety and depression.

## **Sleeplessness**

This could occur if you are waking up at night feeling out of breath or coughing.

## **Extreme Tiredness**

This is caused because your lungs are working harder to breathe in and out, and the amount of oxygen delivered to the muscles in your body is reduced.



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## **Weight Loss**

Breathlessness could also make it difficult for you to eat as well as usual. However, it is important to eat a healthy diet in order to maintain your overall health, so you should consult your doctor if you are losing weight because of your illness.

## **Coughing up Blood**

You should seek medical advice if you are coughing up blood.

## **Chest Discomfort**

You should also consult a doctor if you are experiencing discomfort in your chest.

## **5) Diagnosis**



A persistent cough with phlegm and shortness of breath can be indications of COPD, especially if the cough is becoming more persistent. It is important to see your doctor if you have these symptoms as the earlier COPD is detected the better.

When you visit your doctor he will ask you about your symptoms and how long you have had them, and may also ask if you are a smoker or if you have been previously. He will usually listen to your chest using a stethoscope, and will use a spirometer to check your breathing. This means that you will have to blow into a tube which is connected to a machine. The machine will calculate how much air you can blow out in one second in relation to the total amount of air that you blow out each time you exhale. If your measurement is low this indicates that your airways are narrowed. The doctor will use this measurement together with his other findings to diagnose whether you have COPD.

Asthma has similar symptoms to COPD, but differs as there is no permanent damage to the airways. With asthma the airways become inflamed, and the muscles tighten, causing the airways to narrow. Asthma

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responds to treatments that help to open up the airways, and symptoms come and go in varying degrees. It is also more common for non-smokers to develop asthma than it is for them to develop COPD.

## **6) Treatments for COPD**

Although COPD is incurable, there are a range of treatments available, which help to alleviate the symptoms. There are also other ways in which you can manage your condition, which we will look at later. In this chapter we will concentrate on the treatments that are available from your doctor or health service. These will depend on the severity of your illness and the type of symptoms that you have, and some people will have more than one treatment for their COPD. Treatments include:

- Inhalers
- Nebulizers
- Steroids
- Antibiotics
- Pulmonary rehabilitation
- Non-invasive Ventilation (NIV)
- Mucolytic medicines
- Oxygen therapy
- Surgery

Let's look at each of these in turn:

### **Inhalers**

These are also known as bronchodilators or puffers and are used to widen the airways to help with breathlessness. To deliver the medicine to your lungs you have to press the inhaler and breathe in at the same time. It's quite straightforward and you'll soon become used to it. However, if you're not sure if you are doing it correctly, it is best to ask your doctor or nurse to check your technique.

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- Spacers

Inhalers can also be used with a spacer, which is a large chamber that you attach to the inhaler. When you press your inhaler the medicine enters the spacer before you inhale it. These help if you want to inhale your medicine more gradually, or if you want to take larger doses of your medicine by pressing the inhaler several times. Some people find that the medicines used in bronchodilators can be harsh and cause oral thrush, but using a spacer can prevent this. It is important that you wash the spacer once a week in warm soapy water, then rinse it and leave it to dry. This will ensure that it continues to operate efficiently.

Bronchodilators can be short acting or long acting. Short acting bronchodilators work by widening the airways, and are broken down into two types:

- Beta Agonist Inhalers

These are fast acting inhalers such as salbutamol and terbutaline, which normally start working after 5 to 15 minutes, giving relief for 3 to 6 hours.

- Antimuscarinic Inhalers

The other type of inhalers that give relief for 3 to 6 hours is Antimuscarinic inhalers such as Ipratropium, which starts to work after 30-40 minutes.

These two inhalers work in different ways to widen the airways and can be used together for increased effectiveness. Some people with mild or intermediate COPD may find that they only need to use these inhalers to relieve symptoms of wheezing and breathlessness as they occur.



- Long Acting Inhalers

These inhalers include Beta Agonist and Antimuscarinic drugs. The Beta Agonist types are called Formoterol or Salmeterol, and the Antimuscarinic type is called Tiotropium. These also work by widening the airways but the effects last for 12 or more hours. They can be used in addition to a short acting inhaler if symptoms are more severe or more frequent.

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- **Steroid Inhalers**

These are used to prevent flare-ups and work in a different way to Beta Agonist and Antimuscrinic inhalers as they reduce inflammation of the airways. These can be used in addition to the other two types if symptoms are severe.

## **Nebulizers**

These are used to provide larger doses of drugs than inhalers. They are a large piece of equipment, which has a face mask or mouthpiece attached to a chamber, which the drug passes through. The other end of the chamber is connected to a compressor, which pressurizes the air in order to turn the drug into a fine mist (known as an aerosol). The three parts can be detached so that the mask and chamber can be cleaned, which we will discuss later in this section.

- **Compressors**

These are usually connected to mains electricity, but can also be portable with a rechargeable battery. There are also types that are operated with a foot pump, which can be a useful back-up, as they don't need an electricity supply.

Nebulizers can be used to deliver a range of medicines into the lungs, as follows:

- **Relievers**

These are the same drugs that are used in bronchodilators, such as salbutamol, terbutaline or ipratropium, but they are delivered at much higher doses. You would normally have to press your inhaler several times into a spacer to get the same effect.

- **Steroids**

As with relievers, the nebulizer is used to deliver high doses.

- **Saline**

This can help you to cough up sticky phlegm.

- **Antibiotics**

These are used to treat people with infections in the chest and lungs.

- **Morphine**

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This can be administered by a hospital via a nebulizer in cases of terminal care.

## Using a Nebulizer

Although nebulizers can deliver higher doses of reliever and steroid medicines than inhalers, they are a more expensive option. Also, whilst using a nebulizer you should take care not to inhale more than the prescribed amount of medication.

When you are allocated a nebulizer by your doctor or hospital, you will usually be taught how to manage your illness whilst using the nebulizer. You should be shown how to set up the nebulizer, how to put the medicine into it, the dose of medicine to use and how often to use it. You should also be able to recognize when your condition is getting worse, for example, if you need to take more frequent or higher doses of your reliever because of breathlessness, and what to do in an emergency.

Whilst using your nebulizer you will need to know how to take care of it so that it always performs efficiently. This will include cleaning it, and having it serviced and repaired. It is best to make sure that you are confident about all aspects of using your nebulizer before taking it home with you, so don't hesitate to ask if there is anything that you are unsure about. Here are some tips for looking after your nebulizer:



- Tap the nebulizer chamber each time you use it to dislodge any large drops of solution left at the bottom of the chamber from previous use.
- Put the compressor on a clean level surface and keep it off the floor so it doesn't get dust inside it.
- You should have the compressor serviced twice a year, and the chamber checked every two months, but the filters may have to be changed more frequently, usually when they become discolored.
- Ensure that you have a back-up if your nebulizer is being serviced or becomes faulty, either at home or through your doctor or hospital.

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- It is important to keep the nebulizer clean to ensure that it functions properly. The chamber should be washed daily and the face mask two to three times a week in warm water then rinsed and dried.
- The compressor should never be immersed in water. Instead you should wipe it with a damp cloth, but switch it off before doing so.



## **Steroids**

Steroids can be taken in tablet form for lung problems as well as inhaled. This is usually when there is a flare-up (or exacerbation) of symptoms, for example, due to a chest infection. A short course of steroid tablets help to reduce inflammation in the airways.

However, they have many side effects, so they are not recommended for long term use.

## **Antibiotics**

These can also be taken in tablet form in cases of infection. If you are coughing more than usual, and your phlegm is yellow or green in color, this indicates that you have an infection, so it is best to visit your doctor for a course of antibiotics as the infection will also worsen your other symptoms.

## **Pulmonary Rehabilitation**

The aim of pulmonary rehabilitation is to help COPD patients to cope better with their disease. If you are offered pulmonary rehabilitation you will be assigned a number of staff who will help you with your COPD. These will include doctors, nurses, psychologists, physiotherapists, occupational therapists, respiratory specialists and dieticians. Help is offered in three main areas, which are: education regarding COPD, physical training, and psychological/sociological support. These involve the following:

- **Education**

This can be provided in a number of ways such as lectures, demonstrations and handouts, and covers information about how the lungs work and how COPD affects the lungs. You will also receive advice on the range of treatments for COPD, how to

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manage your breathing, and the benefits of diet and exercise, as well as many other useful topics related to the disease.

- **Physical Training**

This consists of exercises for the ventilatory muscles, which are those muscles involved in inhaling and exhaling. This can improve respiratory muscle function, reducing breathlessness and make it easier to exercise. Pulmonary Rehabilitation can also include exercises for the lower body and the upper body, which can both be beneficial for COPD patients. Once you become fitter your muscles will require less oxygen to carry out day to day tasks. Your exercise routine will be developed specifically for you to suit your level of fitness.



- **Psychological and Sociological Support**

COPD patients often feel isolated, anxious and depressed about their condition. If you are affected in this way you could receive support through a patient education program, a stress management group or counseling. You could also be shown relaxation techniques and taught the importance of receiving emotional support from others.

You can find out about Rehabilitation Programs in your area by telephoning the American Association of Cardiovascular and Pulmonary Rehabilitation on: 608 831 6989 or contacting your local branch of the American Lung Association.

## **Non-invasive Ventilation (NIV)**

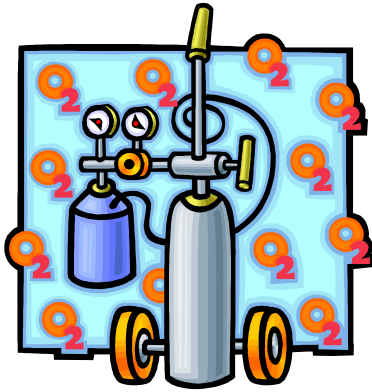
This is sometimes given to patients who are hospitalized to help them to breathe. It is usually administered by staff who have been specially trained to handle the equipment, and it works by pushing air into your lungs via a mask which you wear over your face.

## **Mucolytic Medicines**

These work by decreasing the thickness of phlegm so that it is easier to cough up, and can reduce the number of infections. Some of the mucolytic medicines available are carbocysteine or mecysteine. They are useful for

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people who have moderate to severe COPD, and people who take a mucolytic medicine often have fewer flare-ups.



## Oxygen Therapy

Oxygen is used for patients who have low levels of oxygen in their blood rather than for breathlessness, and most COPD patients do not need it. The oxygen is supplied via an oxygen cylinder or a machine called a concentrator, which can be used at home. The concentrator is electrically operated and works by taking oxygen from the air in the atmosphere. There will be a mask attached to the machine or narrow tubes that fit just inside the nostrils. These tubes are very long, enabling you to move about whilst you are using oxygen.

To test the levels of oxygen in your blood your doctor or nurse will carry out a test called a pulse oximetry. If your doctor decides to put you on long-term oxygen therapy, you will have to use it for 15-20 hours a day, but you will not be able to use it if you smoke as it is a fire hazard. People on long-term oxygen therapy may also be allocated a portable oxygen cylinder to use outside the home. These small cylinders last for several hours.

## Surgery

This option is only available for a small number of COPD patients. These are usually people who have the disease worse in the upper lobes of their lungs, and surgery may be offered if they are severely limited physically because of their illness. Surgery involves removing the section of lung that is no longer functioning to give the rest of the lung more capacity to work.

Unfortunately, the success rates for this type of surgery are not very high at the moment, but further research into lung transplantation is being carried out.

Whatever treatment you are offered by your doctor or nurse, it is important that you always take it regularly and at the prescribed dose. Many COPD medications are designed to work effectively through regular use.

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## **7) Managing your Condition**

There are so many things that you can do to ease your symptoms and make your illness easier to handle. These can range from keeping healthy through diet and exercise, to breathing exercises and knowing how to prevent flare ups. We have divided this chapter into several sections, each full of useful information and advice.

### **Alleviating Symptoms**

First we will look at what you can do to ensure that your symptoms are less frequent and less severe. The most obvious step is to stop smoking. Although we have already mentioned this, it is important at this point to re-iterate that giving up smoking is the single most effective way of helping yourself if you have COPD. Many of the tips given in this chapter will prove really valuable in helping you to manage your illness, but unless you give up smoking, your lung disease will become progressively worse. If you are still struggling to give up cigarettes then it may help to recap on some of the tips for quitting smoking that we gave in chapter 3.



If you become ill, for example, through a cold or flu, then this can cause more flare-ups, and you could be more susceptible to chest infections, which will worsen your symptoms further. It is therefore advisable to have a flu and pneumonia injection every autumn in order to protect yourself.

For many COPD patients one of the most alarming symptoms is breathlessness. It can be quite frightening when you are struggling to breathe, but there are a lot of ways in which you can avoid this. It helps to stay fit and active and to avoid chest infections. Later in this chapter we will give you advice on keeping healthy and show you how to build up your fitness levels gradually at a pace that suits you, as well as teaching you some useful breathing techniques. There are also ways in which you can adapt your routine so that you can perform your day to day tasks more easily. Here are a few ideas:

- Plan your day so that you can carry out physical tasks according to the amount of time and energy that you have.

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- If your energy is limited, prioritize so that you do the most importance tasks first.
- Try to incorporate some rest periods into your daily routine, especially before and after any activities that are physically demanding such as shopping.
- For tasks that require a lot of energy, sit down whenever possible, for example, when doing the ironing or washing the dishes.
- Don't be afraid to ask for help if you need it.



## Avoiding Triggers

Triggers are those things that can make your COPD worse and sometimes bring on an exacerbation. These can be colds and infections, or substances that you breathe in; therefore it is wise to avoid them. Although it is not always possible to avoid every situation that may bring on your symptoms, you will find that there are many ways in which you can minimize your exposure to triggers. This is particularly true in the home where the air could be polluted by gases, dust, moulds and chemicals. Here are some of the common triggers that affect COPD patients, together with advice on how you can avoid them.

- Colds and Flu  
As well as having your annual flu and pneumonia vaccination, it is best to stay away from people who have colds and flu, and asking them to stay away from you. In some situations this cannot be avoided, for example, in the work place, but takes steps to protect yourself such as using a mild disinfectant to wipe the mouthpiece of a shared phone.
- Exhaust Fumes  
Aim to avoid places that are heavily populated by traffic.
- Keeping Warm

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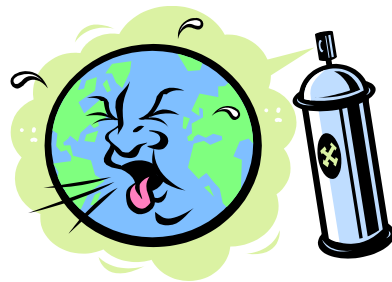
Try to ensure that your home and place of work are at a comfortable temperature, and if you go outdoors in the cold, keep well wrapped up and use a scarf to cover your nose and mouth.

- Smoky Environments

If your workplace is smoky or dusty you may consider asking for a move to another department or changing your job.

- Cleaning Products

Use natural cleaning products where possible, such as sodium bicarbonate, vinegar or lemon juice. If you have to use toxic cleaning substances, take steps to avoid inhaling them, such as wearing a mask and ensuring that the area is well ventilated.



- Cigarette Smoke

As well as not smoking yourself, ask people not to smoke around you, and avoid places where you know there will be a lot of smoke.

- Dust Mites

These are found in every home, but there are ways in which you can minimize them, for example, by regular vacuuming, using protective bedding and having wooden or laminate flooring rather than carpets.

- Pet Hair

This can cause a reaction in some COPD sufferers. If you are a pet owner, it is important to keep the home as free from pet hair as possible by vacuuming regularly or asking someone else to. Alternatively, you may consider keeping pets that don't give off as much hair such as fish.

- Mould and Mildew

These are produced when an area becomes damp, for example, through condensation, so it is important to keep the home well ventilated, whilst also ensuring that it doesn't get too cold.

## Fumes from Cooking or Heating Appliances

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Make sure that all appliances are professionally installed with an external vent where necessary, and regularly maintained, in order to prevent the release of toxic gases into the atmosphere.

- **Other Irritants**

Other substances that can affect the lungs are paint, perfume, aerosols, scented candles, and air fresheners.

## **Keeping Healthy**

### **Diet**

Eating a balanced diet and maintaining your weight at a suitable level are essential for anybody to keep healthy, but this is even more important for people with a chronic disease. This means that you should ensure that you are neither overweight nor underweight. If you are overweight it will be even more difficult for you to carry out physical tasks as your body will have to work even harder to carry the excess weight around. Medical staff can advise you regarding the correct weight for your height and frame or you can find information on the Internet.



Regular small meals will give you energy, strengthen your respiratory muscles and protect you against chest infection. You should avoid overeating as your stomach will become distended leaving less room for your lungs to expand. Stomach distension can also be caused by eating foods that cause your body to produce gas, for example, onions and cucumber. Different people are affected by different foods so you should stay clear of any foods that you know give you a problem. If you become constipated, this can also cause your stomach to swell, but a healthy diet and exercise should prevent this for most people. However, if this is a persistent problem, there are a variety of medicines which can help.

Some people with COPD can be underweight as their body uses up a lot of energy breathing, and they sometimes struggle to eat because of breathlessness. Ways to encounter this are by eating small meals frequently, and making sure that you eat food that is high in protein and calories, but not fats.

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It is useful to have somebody who can share the cooking when you are feeling unwell, but if this is not possible, cook extra portions when you are well and freeze them. That way you can fix yourself a meal quickly when you are not feeling so well. You could also look out for quick, easy and nutritious recipes in books and magazines, so that you can cook healthy meals with minimum effort.

As well as eating healthily, you should drink plenty as fluids keep the lining of the airways moist and thin phlegm. It is best to drink plenty of water rather than drinks that will dehydrate you such as tea, coffee and alcohol.

## Getting your Sleep

Getting a good night's sleep will also help you to stay healthy as your body needs to rest in order to recuperate. You should have a regular bedtime routine that your body gets used to, for instance, having a warm drink or reading a book. Try to avoid anything that will stimulate your brain too much immediately before bedtime as this could make it difficult for you to get to sleep.



Ensure that your bedroom is at the right temperature so that you are comfortable and that your bedding is not too heavy. You will also find it useful to have your medication at your bedside so that you can take it immediately if your symptoms wake you. It might also be helpful for you to try different sleeping positions; some people find it more comfortable to sleep propped up on lots of pillows or to sleep on their sides.

## Exercise

Many people with COPD avoid taking exercise as they believe that it will make their symptoms worse. However, by exercising regularly you will help your body to become fit and therefore more able to meet the physical challenges of your illness. It is best to start with a less demanding exercise routine and then build it up gradually. Your doctor can advise you on the type and amount of exercise that will be suitable for you. For example, you could try going for a short walk each day. You will find it easier to walk at a slow, steady speed with your shoulders and chest relaxed, and your arms hanging loosely. Use your inhaler or nebulizer before going out and take back-up medication in case you become breathless.

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It will also help you with your exercise if you learn some breathing techniques and we will cover these later on in this chapter. If you wear some headphones so that you can listen to music as you walk, it may take your mind off your breathing difficulties.

During exercise your heart rate and your breathing increase, so your lungs will probably need to take in twice as much air. This is because the muscles that are being exercised need oxygen, so your brain will send signals to the muscles that control your breathing, causing you to take more breaths. The muscles use oxygen to produce energy by breaking



down the glucose from food. When you have COPD your lungs will have difficulty providing enough oxygen when you exercise. This will therefore result in you becoming breathless. However, as you become fitter and your lung muscles become more efficient, your body will find exercise less strenuous and will therefore not require as much air to breathe.

By taking regular exercise you can train your body to deliver more oxygen to your muscles. This therefore means that as you get fitter you should become less breathless when you exercise. This will also mean that you will feel better overall and will find it easier to carry out everyday tasks such as washing, cooking and cleaning.

If your illness is particularly bad you could begin by doing small arm and leg movements whilst seated, and eventually build up to a little walking. You could start by walking around your home, then around the garden, progressing to the end of the street and further. Make sure you take your exercise when you have time to take a rest afterwards.

## **Breathing Exercises**

For many people with COPD, shortness of breath is one of the most distressing symptoms. When you find it hard to get your breath, this can lead to feelings of panic when you begin to take shorter sharper breaths in quick succession to try to get some air into your lungs. Unfortunately, this can make you feel worse as it leads to an imbalance of oxygen and carbon dioxide and is called, 'hyperventilating' (or over-breathing). Hyperventilation can lead to dizziness, faintness and pins and needles, and unless you are aware of what it is, it can be quite alarming. However, hyperventilation will not cause you any harm. It is possible to learn

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breathing techniques that will slow down your breathing and can lessen the feelings of panic.

The following breathing techniques are not suitable for all COPD patients so you should check with your doctor before practicing them. These exercises concentrate on using the lower chest and the diaphragm whilst keeping your upper chest and shoulders relaxed. When inhaling you should place your hand on your tummy so that you can feel it expand as you breathe in. If you are finding it difficult to master the techniques you could ask your doctor to refer you to a physiotherapist who can show you how to practice the exercises. If you practice them daily they can help you become less breathless when carrying out physical tasks and can also help you when you have sudden bouts of breathlessness. When practicing the techniques make sure that you are in a comfortable position so that you are not tense when you are breathing. You could try some of the positions given below.

- Pursed Lip Breathing

With this technique you breathe in slowly and gently through your nose and then breathe out slowly and gently through your lips. Your lips should be pursed as though you are whistling. This method can slow down your breathing and can be used in conjunction with counted breathing, which you practice as follows:

- Counted Breathing

Try counting to four as you inhale then counting to four as you exhale. This will slow down your breathing, making it feel easier to breathe. Make sure that you are in a comfortable supported position with your shoulders, arms and hands relaxed, and focus on feeling more relaxed each time you exhale.

1, 2, 3, 4

- Activity Related Breathing

If you are doing something that requires some exertion, for example, walking up the stairs or stretching for something high on a shelf, breathe out during the most strenuous part of the action.

- Paced Breathing

This is also helpful when carrying out activities such as walking or going upstairs. Breathe in time with the steps you take. For example, as your foot lands on a step, inhale, and as you step up

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towards the next step, exhale. You may find it better breathing in for one step and out for the next. This will depend on what pace suits you.

## - **Breathing Positions**

These positions should help you to become less tense when you are practicing your breathing exercises so that you are not wasting energy by straining.

You will probably find seated positions the best as they use less energy. Leaning forwards with your forearms on your knee or a table is usually the most comfortable, but you should also make sure that your clothing is loose around your chest and abdomen. You could also try resting your head on a pillow on top of a table. Alternatively, some people find it better to lie down on their side propped up on lots of pillows whilst practicing breathing exercises. It's a matter of experimenting to find which position is best for you.

If you prefer to exercise when standing up, try leaning forward, bending slightly from the hips, with your forearms resting on an object such as a chair. The object needs to be at the right height so that you are only leaning forward slightly. If you are walking, put your hands on your hips or in your pockets so that your arms are supported. You could also try using a walking stick or a supermarket trolley when you are outside the home, so that you are in a comfortable breathing position.



In our chapter on Anxiety and Depression, we will look at the other symptoms of anxiety, apart from hyperventilation, and ways in which you can combat them.

## **Coughing Technique**

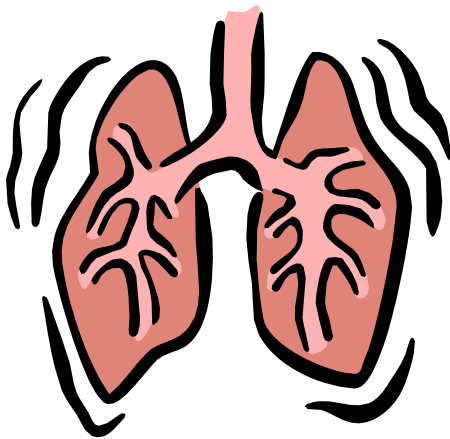
Coughing is your body's way of clearing your lungs of excess mucus, and any other substances that can work their way into your lungs, such as dust particles. However, as the mucus becomes thick and sticky, some COPD patients may find it difficult to cough up it up. This could lead to chest infections as the mucus mixes with saliva, which can attract bacteria. It is

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therefore helpful to use a technique that makes coughing more productive, helping to clear the airways of excess phlegm. The technique can take a short while to learn, but with practice you should soon become good at it.

When somebody with healthy lungs coughs they use the muscles in the chest and abdomen to build up pressure in the lungs. The brain then sends a signal to the body to release that pressure, resulting in a blast of air from the lungs that forces the phlegm out. Unfortunately, with COPD patients the muscles are weak and the airways are narrowed, therefore the required pressure is lacking. This means that the cough is less effective at clearing excess phlegm. It is possible for you to make your cough more productive by employing a method known as the Huff Cough technique.

## The Huff Cough



Instead of one big cough, the huff cough technique uses several small coughs. You have to first of all ensure that you get sufficient air inside your lungs, and this should penetrate deep into the lungs so that it is behind the phlegm. To do this you need to start by exhaling in order to clear the old stale air out of your lungs. When you inhale you do not need to fully inflate the lungs, but it should be a deep breath. To get rid of the old stale

air, slow your breathing down and do a long exhalation which should last for three or four breaths. Each time you breathe in again, only inhale to about 75-80% of a full breath, otherwise you will fill your lungs up again. This action will prepare the lungs and have a massaging effect on the bronchial tubes, making it easier to displace the phlegm when you perform the Huff Cough.

Next, take a slow deep breath, but do not fill your lungs to maximum capacity. Whilst doing this you need to keep your Glottis (voice box) open by opening your mouth into a loose 'O' shape. Now give a short sharp cough by quickly contracting your abdominal muscles. Try to contract the muscles in the centre of your abdomen and, if you are doing this correctly, it should result in a huffing sound, which is different from the barking sound of a normal cough. It is important that this is a short cough as any cough will cause a degree of bronchial compression, which will stop the

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phlegm from clearing. However, the degree of compression is not as much as with a normal cough.

As soon as you complete the Huff cough, inhale quickly but only partially, and try to feel the air being sucked into the bottom of your lungs, past the phlegm. This will help to open up the collapsed airways ready for the next Huff Cough. Next, repeat the Huff Cough immediately, but with a smaller breath, then take in a smaller partial breath and repeat the Huff Cough a third time. If you struggle to reach three Huff Coughs, just do two for now. Each Huff cough should be progressively smaller, and at the end of the series of Huff Coughs you should feel that most of the air is out of your lungs. This is because the deep breaths that you were taking in between the Huff Coughs were smaller each time. This will further increase the massaging effect on your bronchial tubes helping to clear the phlegm.



Next, take a forced deep breath into the bottom of your lungs, but don't inhale to maximum capacity. Follow this with a hard forced Huff Cough, keeping your Glottis open by forming a loose 'O' shape with your mouth. This should result in mucus being forced out of your lungs. In effect, by first of all taking two or three mini huff coughs you will have loosened mucus from the small bronchial tubes and carried it into the larger tubes. The larger forced huff cough will then have forced it out of the tubes altogether.

If this only succeeds in bringing the mucus part way up and you feel as though you will have a coughing attack, stay calm and try to suppress the coughing. Take slow, deep breaths, exhaling for long periods until you have got your strength back. It may help to do pursed lip breathing (as described above). Sometimes you will be able to control the urge to cough by taking a few sips of water. Once you have regained your strength, repeat the Huff Cough sequence until you are able to bring up the mucus. Don't forget that by drinking plenty of water you can keep the lining of the airways moist and this will help to thin the phlegm so that it is easier to excrete.

This technique can seem like a lot to digest at first but with practice you will soon get the hang of it. To help you remember the series of actions, let's recap:

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First, deflate the lungs by taking several breaths making sure that you only fill your lungs to 75 - 80% capacity when you breathe in.

Then, take a deep breath in.

Next, take your first Huff Cough, followed by a rapid partial inhalation.

Then, take your second Huff Cough followed by a smaller rapid inhalation.

Then, take your third Huff Cough followed by a deep forced breath in.

Finally - Take a final forced Huff Cough, which should expel the mucus.

Take a rest, then repeat the sequence if you are still having difficulty excreting the phlegm.

If after a few attempts you are still struggling to manage the Huff Cough technique, it may be worth asking your doctor or nurse to teach you how. Medical staff may also know other coughing techniques that they can recommend.

## **Managing Flare-ups**

As discussed previously in this book you can reduce the number of flare-ups or exacerbations by taking regular medication, stopping smoking, and taking other preventative measures such as having a flu jab. It also helps to avoid the trigger factors which we outlined earlier in this chapter. However, you will still find that there are some occasions when your symptoms become much worse and you need to know what to do in this situation.

To start with, you need to examine the phlegm that you cough up at least twice a day, especially first thing in the morning, as this is a good indicator of your state of health. By examining your phlegm regularly you will know what it looks like normally so that you can spot any changes in the volume, thickness or stickiness. If your mucus becomes opaque, yellow or green this could indicate that you have a chest infection. It is necessary to get



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treatment for your chest infection as soon as possible as it will cause an increase in the amount of flare-ups.

Other worsening symptoms to look out for are increased breathlessness, a temperature and increased difficulty with day to day tasks. If you spot any of these changes you need to take action straightaway. You may have already made arrangements with your doctor so that you have a supply of antibiotics in case of infection, or are able to telephone for an urgent prescription. If none of these arrangements are in place, you need to see a doctor as soon as possible.

## **8) Challenges of COPD**

If you have reached this point in the guide you should be feeling very confident in being able to manage your condition using the range of strategies that we have discussed. As with any chronic illness, however, you will be faced with challenges related to your illness on a day to day basis. By staying positive and meeting those challenges head on, you will be able to cope with whatever comes along and develop a routine that suits your lifestyle and your illness. Let's have a look at a few of the situations that you are likely to come across.

### **Adapting your Routine**

You may find that your life has changed a lot since you became ill. Perhaps you have had to change your job to something that is less physically or mentally demanding. If you are struggling in your current role then it may be worthwhile consulting an occupational therapist to explore other options that could be suitable for you. Your doctor might be able to put you in touch with an occupational therapist.



You may have had to give up a favorite hobby or pastime or you may even be in a situation where you have had to give up work and normal daily tasks are a challenge. In this guide we have included a number of case

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studies of people with COPD. Each of these people tells his or her story of living with the illness and how they have adapted their lives. Hopefully, by reading their stories you will find some encouragement to help you to tackle your own challenges.



In the previous chapter we looked at ways of alleviating your symptoms, for example by prioritizing your tasks and setting time aside for rest and recuperation. Throughout your illness you will find that you have good days and bad days. Some days you will have fewer symptoms and you might feel that things aren't so bad, but on other days it might be an effort just getting out of bed. The way to tackle this is to organize things around your illness, getting plenty of jobs done when you are feeling well and trying to get in front so that you can take it easy when you are not feeling so well. Although it is crucial to stay as active as possible to improve your overall health and fitness, it is also important to relax and conserve your energy. Here are some ways in which you can do this:

- When you get a little breathless doing something, stop and take a short rest before carrying on.
- Organize the space in your home so that everything is close to hand - maybe you could keep more things downstairs to reduce the number of trips upstairs.
- Always keep your medication close by in case you have a flare-up.
- Take things at a slow pace as rushing around is likely to make you breathless.
- Make routine tasks easier e.g. sit down to do the ironing, keep things at eye level so you don't have to bend down or stretch up towards them, and wear slip-on shoes so you don't have to struggle to fasten them.

Feeling anxious can also exacerbate your symptoms as it consumes energy, so try to avoid situations that make you stressed. In the next chapter we will look at how to deal with anxiety as well as depression, but

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first of all we will take a look at some of the other challenges that you may have to face.

## Going on Holiday

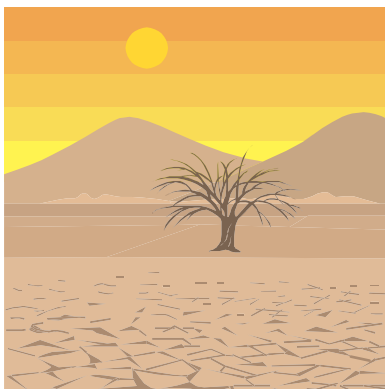
Getting away for a week or two is one of the most pleasant experiences in life for many people. However, if you have COPD there are many things that you have to take into account when going on holiday: will the climate suit you, will you be able to fly, what about your medication? These are all questions that may trouble you, but this doesn't mean that you have to give up your holidays. It simply means that you may have to adapt your holidays to take account of your illness.



The first thing to do is to find out if you are fit to travel by consulting your doctor. He may assess your suitability for travel by asking you to take some tests, especially if you are travelling a long way or flying. If you need to use oxygen, ask your doctor how you can manage this whilst going on holiday. You will also have to organize this with your oxygen supplier.

Before deciding where to go on holiday there are a few factors that you will need to take into consideration. It is important to plan well in advance to ensure that you have thought of everything. You will need to be realistic when planning where to go on holiday as it may be that places you visited in the past are no longer practical for you.

One thing to think about is the climate in the country or area that you are planning to visit. Because of your illness you will be more suited to a warm climate where the air is salty. If it is too hot, or the altitude is high with low oxygen levels, this could make it more difficult for you to get your breath.



The second consideration is whether the area you are visiting is hilly, because walking uphill usually causes people to feel more out of breath. If you are a wheelchair user, it will also make it more difficult to get around, and you should think about

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wheelchair access generally. There are some hotels that are adapted for wheelchair users, so it is worthwhile speaking to your holiday company.

Another thing to think about is the availability of transport. Can you hire a car whilst on holiday or is there an adequate bus or train service so that you do not have to walk too far? You need to take account of how far you are able to walk comfortably, and what types of transport are suitable for you. Many people with nebulizers find it easier to travel by car as they can plug a portable compressor into the electricity supply for a cigarette lighter. If you are not able to walk long distances, you may consider hiring a mobility scooter or wheelchair whilst on holiday, but make sure that there is somewhere where they can be stored and, in the case of a mobility scooter, recharged, whilst you are on holiday. There are many companies that specialize in hiring these; try typing 'mobility scooter hire' in an Internet search engine to see the range available.



When planning your holiday it is wise to shop around as different travel companies have different facilities for people with lung disease, so it is best to find one that caters for your condition. Don't be afraid to ask the travel companies any questions that may concern you as many of them are used to catering for special requirements. It will also help you to assess what you can expect from them.

Once you have decided where to go on holiday, there are other details that you will need to attend to, such as:

- Make sure that you have enough medicine for whilst you are away and take emergency supplies with you.
- Make sure that you are covered for your illness by your insurance company, and that the insurance will cover any medical equipment that you may need whilst away as well as other incurred costs. This could include the cost of a return journey by air ambulance if you become too ill to fly ordinarily. Some insurance companies charge an extra premium to cover pre-existing health problems and many will not cover you unless you have a note from your doctor stating that you are fit to fly.

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- If you are going abroad and need to take a nebulizer, get a letter from your doctor as you may need this to show the airline or customs.
- If you use a nebulizer, hire a battery operated portable compressor.
- If you are travelling abroad with a nebulizer, take an adapter so that you can plug in your compressor where you are staying.

You should also think about the method of transport that you will use to arrive at your holiday destination, and whether there will be suitable facilities for you. Here are some of the most common ones:

## Bus or Coach

If you are a wheelchair user you will find that facilities for wheelchair access vary from company to company. Some companies provide help with folding wheelchairs and even provide battery-powered wheelchairs. You will also find that some vehicles have a feature called 'kneeling suspension' to make boarding and alighting from the vehicle easier. Not all coaches have toilets, but some have toilet facilities that are level with the coach seating, making it easier for you. It is best to contact the coach or bus company to check the available amenities before booking your holiday. You should also check what the facilities are for using oxygen during your coach or bus journey.



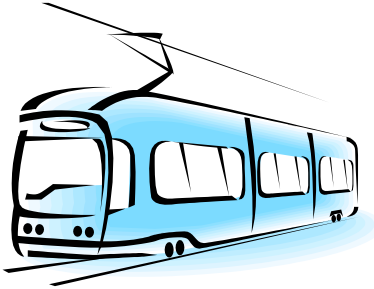
The Greyhound bus company, which is the biggest intercity bus company in America, provides a range of help for customers with chronic illness, which is termed a disability. They provide assistance for boarding and alighting from buses, help with luggage and retrieval of wheelchairs or other mobility devices.

For people travelling with oxygen or respirators, Greyhound permit you to travel with a maximum of four oxygen canisters (two in the baggage compartment, and two onboard the bus). These must not measure more than 26 inches in length and 4.5 inches in diameter. You must ensure that any canisters stored in the baggage compartment are in protective cases and have safety caps on the valves.

Greyhound gives the following recommendations to ensure that you get the help you require:

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- 1) Ring Greyhound at least 48 hours before your departure to inform them of your specific needs and your travel schedule. They have dedicated telephone support on: 1-800-752-4841.
- 2) During your trip Inform Greyhound employees of your needs.



## Train

Amtrak, the American passenger rail company allow you to take bottled oxygen, oxygen concentrators and nebulizers onboard their trains, but there are certain requirements regarding equipment. These are as follows:

- Your oxygen equipment must be able to operate for at least four hours without the need to use the electrical power onboard the train.
- Your equipment must be factory mutual (FM) listed or Underwriter's Laboratory (UL) listed.
- There is a total weight restriction of 120 lbs maximum for oxygen equipment.

If you intend to take oxygen equipment onboard an Amtrak train you need to inform the company at least 12 hours before your departure, and make your reservations in advance. You can contact them on: 1-800-872-7245.

Amtrak also offer assistance for people travelling with wheelchairs. For boarding and alighting trains they can provide a bridge plate across the gap between the platform and the train. They also have some station-board lifts to provide level boarding. For trains that are bi-level Amtrak can provide a wheelchair ramp to help you board the lower level.

The company will allow you to remain seated in your wheelchair throughout your journey, but you must use a wheelchair lockdown for safety. If one of these is not available then they ask that you apply your brakes. Some of the trains have seats that are accessible for wheelchair users, enabling you to store your wheelchair nearby during your trip.

Amtrak can accommodate most wheelchairs, including manually operated and battery powered, but they advise that accessible space is limited so it

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is important to make a reservation as far in advance of your trip as possible. There are some restrictions regarding wheelchairs, which are as follows:

- The wheelchair should measure no more than 30 inches wide by 48 inches long, and should not exceed 2 inches of ground clearance.
- The wheelchair alone should weigh no more than 600 pounds.

Amtrak also ensure that most of their train stations are accessible to people who may be in a wheelchair or who may have difficulty walking.



You can check the accessibility of a particular station prior to your journey by telephoning: 1-800-872-7245.

When you contact the train company, tell them your requirements, where you are travelling to and from, the dates of your journey, and how you will be travelling to and from the station. On the day of your trip, arrive at the station at least one hour before your journey time to give the staff sufficient time to assist you. You may have a short wait if there are a lot of customers requiring assistance at that particular time. However, Amtrak staff will be able to help you to and from restrooms, and provide courtesy wheelchairs and wheelchair lifts at most stations.

Another facility offered by Amtrak is with regard to meals. You will be able to either have your meal delivered to your set or eat in the lounge car when possible, but they ask that you transfer to and from the Lounge Car at station stops if you are in a wheelchair.

### Ship or Ferry

As with bus and coach travel, the facilities on offer will vary from company to company, so it is worthwhile shopping around to check out the amenities on offer. Many cruise companies have lifts and wheelchair facilities, and some can provide wheelchairs at terminals. Some even have special cabins for people who are in wheelchairs, and will make special provisions for people with breathing problems. If you are travelling on a drive-on ferry, some give priority loading and



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allocate special parking spaces for disabled vehicles, which could apply to you if you are wheelchair-bound. Again it is essential to ask for assistance from the crew before you travel as arrangements may need to be made in advance.

## Car

Many COPD patients prefer to travel by car because of the sense of freedom it gives them. They can pack all of their essentials, including sufficient medication, compressors or oxygen tanks, and can even plug a portable compressor into the cigarette lighter socket inside the car. Also, they can travel at their own pace and take a break whenever they need to. Furthermore, a lot of patients don't like to draw attention to themselves or feel that they are making a fuss when asking for assistance from staff on public transport.

Again you will need to plan in advance. By planning your route, and accommodation ahead of the journey, you can ensure that you take sufficient rest breaks. You can also check to make sure that the accommodation and destination is suitable for you, following the guidelines that we gave earlier in this chapter. Certain motoring organizations can help you to plan your journey and some have details of facilities for people with a medical condition. You will also need to consult your doctor before going on holiday so that he can give you a letter and medical supplies in case of emergency.



Make sure that you have your car serviced before you go away, and check your insurance requirements. If you are a blue badge holder and are driving to another country, you will need to check with that country's embassy that your badge is valid in that country.

## Airplane



This is perhaps the most challenging mode of transport for someone with lung disease, but it is still possible even if you need oxygen. You need to check with your doctor first of all that you are well enough to travel by plane. Air travel can affect a

## A Patient's Guide to COPD

small number of people with lung disease, because of the reduced air pressure inside aircraft cabins. If you have had a collapsed lung, your doctor will probably tell you not to travel by airplane for some time. Generally, if you can walk 100 meters on a flat surface without feeling breathless or needing oxygen, you will probably not have a problem with the reduced air pressure on an airplane. However, if you cannot do this, your doctor is likely to carry out some tests to check whether your blood oxygen level is likely to cause you breathing difficulties when flying. You should also visit your doctor before flying if you have had problems flying in the past, if you have been in hospital recently with lung problems, or if you have ever suffered from blood clots in your legs, veins or lungs. It is best to get a letter from your doctor detailing your condition and your medication, and keeping this in your hand luggage.

If the doctor's tests show that air travel could be a problem, you may still be able to fly if you are provided with oxygen. You will also need permission from the airline if you need to take any electrical equipment on board in relation to your medication, such as a nebulizer. It must be battery operated and you will not be able to use it during take-off or landing. However, you will be permitted to use an inhaler.

Once your doctor gives you the go ahead, you need to check with the airline company to make sure your requirements will be met. Many airlines have a medical officer or a helpline dedicated to disabled passengers, and you will be able to find guidelines on the company websites. Airlines can arrange to supply oxygen for you, but many charge, at varying amounts, so it is best to check this out beforehand. You need to make arrangements for oxygen with your travel company at least a month before travelling, otherwise they may not have sufficient supplies on board. They will usually ask you how much oxygen you need and how often, how long your flight is, your route and whether you are travelling alone or accompanied.

When you contact the airline company it is best to find out what facilities are available at the airport as well as on the airplane. Here are some things that you will need to find out before you book your flight:

- What is the company's policy regarding oxygen? Some companies will not allow oxygen on the airplane at all whereas



# **A Patient's Guide to COPD**

others are very accommodating.

- How long is your flight and are there likely to be any delays.
- Does the airline need a letter from your doctor before you fly, or will you have to fill in a special medical form? Some ask for your doctor to verify this form or some ask for it to be verified by the airline's medical staff.
- What amenities are there at both airports including availability of oxygen, help with luggage and boarding the airplane, and wheelchair availability? Bear in mind that at some airports there is a very long walk to the departure gates.

Once you are happy that your needs will be met, and you have booked your flight, there are a few other things that you should bear in mind:

- Make sure that you put your reliever medication in your hand luggage rather than in the hold.
- Try to exercise your legs on the airplane and move about to reduce the risk of Deep Vein Thrombosis (DVT).
- Drink plenty of non-alcoholic drinks during the flight.

## **Coping with Illness Abroad**

When you visit your doctor prior to your holiday, you should ask him to check to make sure you do not have a chest infection. If you do have the misfortune to contract a chest infection whilst abroad you should obtain antibiotics to treat the infection as soon as possible. Some countries sell this type of medicine over the counter at pharmacies, but in some countries you will have to visit a doctor. It is best to find out beforehand with your travel company regarding the arrangements in the country you are visiting.

Another thing to check out is the possibility of obtaining oxygen abroad should you need it. If you are on oxygen medication, it is best to speak to your oxygen supply company before you travel to find out what arrangements are in place.

It may seem that you have to go to a lot of trouble before going on holiday but it is always best to be prepared. Once you are sure that you have taken care of everything, you will be able to relax and enjoy your holiday.

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## Getting the Most from your Doctor



Another challenge for COPD patients is to ensure that their doctor understands their illness so that they can receive the right treatment. COPD affects people in varying degrees and each COPD patient will have his own needs, which may change as the disease progresses. When you are first diagnosed with COPD you will probably have numerous questions that you want to ask. By finding out as much as possible about your

illness and how it affects you as an individual, you will be able to manage it better. Here are some ideas for questions that you could ask your doctor about your diagnosis.

- 1) How severe would you class my illness?
- 2) In what ways will the disease affect me and how rapid will its progression be?
- 3) What are the best medications for me and what affect will they have on my symptoms?
- 4) Are there any side effects with these medications?
- 5) Will I have to use a spacer or nebulizer and can you or an assistant show me how to use it?
- 6) What should I do if my symptoms haven't improved once I have been taking the medication for a while?
- 7) What tests will be taken to monitor my condition (e.g. x-rays, pulmonary function studies (PFT's), and arterial blood gas (ABG's)), and how often will these be repeated?
- 8) Can you explain the purpose of these tests?
- 9) What steps can I take to stop the disease progressing further?
- 10) Can you recommend any exercises or vitamin supplements that could help me?
- 11) How do I manage flare-ups?

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12) If I am having a flare-up, under what circumstances should I contact my doctor's surgery or the hospital?

13) How do I spot if I have a chest infection, and can you give me antibiotics to take if I become ill on a weekend or on holiday?

14) When can I have a flu injection?

If you are one of those patients that have multiple illnesses, you may want to ask your doctor about the effects of each disease and how the diseases affect each other.



When you have COPD you will probably find that you have to visit your doctor's surgery regularly if your symptoms worsen or so that he can check on your progress. You're probably familiar with the situation when you come away from a doctor's visit feeling that you haven't managed to convey exactly how you are feeling, and therefore haven't got the answers you wanted. By preparing for your visit beforehand, you should ensure that you come out of the doctor's surgery feeling satisfied that your problems have been dealt with. Here are some tips that should help:

- Think about what you need to tell the doctor beforehand, including all your symptoms, how long you have had them, how they are affecting you and how you feel.
- Think about what you want to get out of your doctor's visit in terms of medication or advice.
- If you don't understand what the doctor is talking about, be sure to ask him. He may also be able to provide further information for you in the form of leaflets or booklets.
- Take a friend or relative into the surgery with you if you feel you would benefit from their support.

Some people feel apprehensive about visiting their doctor and can feel confused by the terminology that doctors use. As well as making sure you ask the doctor if there is anything you do not understand, you will also find that the more you find out about your illness, the more confident you will be when speaking to medical personnel about it.

# **A Patient's Guide to COPD**

## **9) Dealing with Anxiety and Depression**

It is common to feel anxious or depressed about your COPD. You may feel stressed by your symptoms, or you may be worried about the future. This can lead to feelings of anxiety or depression. In this chapter we will look at anxiety and depression in turn and discuss how to deal with them.

### **Anxiety**

Anxiety can be an illness in itself with a wide range of symptoms. Unless you are aware of these symptoms it can be difficult to distinguish some of them from the symptoms of COPD. This can lead to further feelings of anxiety as you worry what is happening to your body. The first step to coping with anxiety is to learn to recognize the signs. These can typically include:

- Taut muscles (including a tight chest)
- Palpitations
- Hot sweats
- Feelings of panic
- Feeling faint or dizzy
- Dry mouth
- Increased need to empty the bladder or bowels
- Feelings of fear
- Constant worrying
- Lack of concentration
- Irritability
- Tiredness
- Sleeplessness
- Chest pain
- Nausea
- Quick, shallow breathing
- Poor appetite
- Headaches
- Butterflies in the stomach
- Flatulence
- Trembling
- No interest in sex
- Pins and needles in the hands, limbs or around the mouth

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## What Causes the Symptoms?

In order to tackle anxiety it is helpful to understand what causes it, and then to take steps to alleviate it.

Anxiety is the body's way of coping with a perceived threat of danger. When the human brain senses that there is imminent danger, it equips the body to deal with that danger in one of two ways; either by running from the danger or by tackling it. This is what is known as 'fight or flight'. In order to deal with the danger the body becomes extra efficient by producing an increased amount of adrenalin: oxygen is pumped around the body more quickly to prepare the muscles, ears are more receptive to sound and eye sight is keener. When we have to tackle difficult situations such as an examination or interview, this preparation can enable us to be very alert in order to improve our performance. Once the difficult situation has passed, these feelings usually subside.



Unfortunately, with people who suffer high levels of anxiety, their bodies can be constantly on high alert. If the perceived danger doesn't pass then the feelings of anxiety continue to build up. This can become a vicious cycle as you worry about the feelings, causing you to feel even more anxious. COPD can bring on feelings of excessive anxiety because of the worry concerning your illness or the uncertainty regarding your future. If you have had a particularly bad flare-up where you have struggled to breathe, you may worry that it could happen again. Some medicines can also make you feel anxious.

Having COPD doesn't necessarily mean that you will be anxious, but many patients do experience anxiety at some point. Also, if you suffer from anxiety you may find that you do not experience the full range of symptoms, but only some of them. One of the common symptoms for COPD patients is hyperventilation. If you are having problems with breathlessness you may sometimes panic and take rapid gulps of air. This leads to hyperventilation which is not a very pleasant sensation. However, by learning to slow down your breathing, you can avoid these feelings. Take a look at the [breathing exercises](#) in chapter 7, 'Managing your Condition', which should help you to control your breathing.

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There are other ways of dealing with your anxiety symptoms and we give tips for these below:

## Relaxation

This can be practiced in conjunction with breathing exercises, and involves sitting quietly whilst relaxing the muscles in the body and clearing the mind of all thoughts. There are many books and DVD's on relaxation techniques, and your doctor may also be able to give you details of any group relaxation therapy in your area. Relaxation can also involve taking more time for yourself instead of rushing around trying to do too many things at once, which can lead to more stress.



## Talking

It often helps to talk to someone about your feelings. This could be a family member, close friend or a counselor trained to help with anxiety. Please see chapter 10, 'Getting Support with your COPD'.

## Exercise

As well as being good for COPD, exercise is good for anxiety. It can take your mind off your anxious thoughts, and use up the extra adrenalin that your body produces when it is on high alert, therefore causing the anxiety to subside. Taking exercise can also help you to sleep better.

## Alcohol

Most doctors will advise you to avoid alcohol as too much can make anxiety worse and it could interfere with your medication. However, some people find that an occasional glass of wine can help them eat or sleep. It is essential that you don't overdo it, and it is also advisable not to make this a regular habit. It is best to check the instructions with your medication to make sure that it is all right to drink whilst taking it.

## Medication

If your anxiety becomes a big problem, you can have medication from your doctor to control it, which will usually be in the form of an anxiolytic or an antidepressant. However, these drugs are not recommended for long-term use as it can be difficult to stop using them.

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## **Complementary Therapies**

There are a range of complementary therapies that you may find useful for anxiety. These include hypnosis, massage, acupuncture and herbal remedies. However, it is best to consult your doctor before taking any herbal remedies to make sure that they are suitable for you and that they will not interact with any of your other medication.

The important thing to remember with anxiety is that although some of the symptoms can be distressing, they will not cause you any harm. It is just your body's way of dealing with stressful situations. Once you begin to understand more about anxiety, you will find ways to alleviate it.

## **Depression**

Some people with COPD can feel depressed because they cannot do the things they used to be able to do; they may have difficulty sleeping, eating or staying active and this can lead to feelings of hopelessness. A number of patients may suffer from depression as well as anxiety.



Many of us can feel a bit down or fed-up from time to time, but with depression, the feelings are more long-term, and extreme. Depression can be triggered by upsetting events in life such as being diagnosed with a chronic illness, but sometimes it can begin for no apparent reason. If you have had to give up work because of your illness, then this could be an additional trigger.

Depression is an illness where the sufferers can find themselves trapped in a cycle of negative thought, and it can be associated with chemical changes in the brain. If you feel depressed it is important to get help rather than soldiering on in the hope that the feelings will pass. Therefore, it is essential that you know the signs to lookout for. These include:

- Feeling sad most of the time over several weeks
- Disrupted sleep patterns
- Little or no interest in social life or activities
- Lethargy

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- Your appetite has either increased or decreased
- Poor concentration
- Feelings of worthlessness and hopelessness
- More tearful than usual
- Irritability
- Feelings of guilt
- Sensitivity to criticism
- Suicidal thoughts

It may be that you do not display all of these symptoms, but if you have more than five symptoms on this list, you should speak to your doctor or other medical staff about your feelings.



## Coping with Depression

There are many ways in which you can combat depression, and some of these will be similar to those recommended for anxiety. This is because when you feel anxious it may stop you from doing things that you would normally do, and this lack of activity can lead to depression. Some of the methods for coping with depression include:

## Breathing Exercises

Please refer to chapter 7 for breathing exercises which are recommended for COPD patients. These are also helpful for depression and anxiety.

## Exercise

We also looked at exercise in chapter 7. Exercise is good for depression as well as COPD because it can trigger the release of serotonin. This is a mood boosting chemical which is released by the brain. Even doing small activities such as walking around the garden or walking to the shops can help to lift your mood and take your mind off any depressing thoughts. Aim to do something each day at a time when you are feeling at your best.

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## Relaxation

We looked at relaxation in our section on anxiety and this can be good for depression too. Apart from relaxation and breathing exercises, you could try relaxing by having a bath, or going for a walk.

## Support Groups

As well as checking out local support groups, you could also look into joining an online community such as [www.beebreathing.com](http://www.beebreathing.com), which is dedicated to people with COPD. We will discuss the importance of support for your condition in the next chapter.

## Do Things you Enjoy

You shouldn't feel guilty about doing things that make you feel good about yourself. This could be a night out with friends or treating yourself at the shops. This could take your mind off any negative feelings and it will help you to talk to other people.



## Medication

Your doctor may prescribe some antidepressants if he feels that they are suitable for you. When deciding which antidepressants to prescribe for you your doctor will take into consideration your symptoms, any other illness you have, what medication you are already taking and whether you have suffered from depression in the past.

Antidepressants usually take a few weeks before they start to work. You may find that they will make you tired as soon as you start taking them and this can help to get your sleep patterns back to normal. However, their mood boosting affects won't be felt for several weeks as the drug starts to build up in your body. In order to benefit from them it is important to take them regularly. If you don't feel any improvement in your mood after taking them for several weeks, your doctor may increase the dose or try a different antidepressant.

Some antidepressants can cause side-effects so it is best to read the leaflet with the tablets so you know what to expect. It is best to speak to your doctor if these become troublesome. When you decide to finish taking antidepressants, you should withdraw from them gradually so that you do not experience withdrawal symptoms such as anxiety or agitation.

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Your doctor will help you to decide when you are ready to stop taking them.

## **Avoid Alcohol**

It is best to avoid alcohol if possible as it is a depressant, so although it may make you feel better at the time, you will feel much worse afterwards. Also, if you are on medication for depression, you should not drink at the same time.

## **Positive Thinking**

A successful method for dealing with depression is to turn negative thoughts into positive thoughts. Health professionals employ a method known as 'Cognitive Behavior Therapy'. This works by first of all identifying negative thoughts and writing them down. Then you are encouraged to counter that thought by coming up with something positive, which you write in a column next to the negative thought. With practice your automatic negative thoughts should become positive thoughts.



It is easier to apply this method with the help of a health professional and your doctor may be able to refer you for a course of cognitive behavior therapy. However, if you cannot access a course, you can practice this technique yourself. There are many self-help books available on the subject as well as information on the Internet.

Try to stay positive about your COPD by reminding yourself that you can still live a full life. In chapter 11 we will give more suggestions for, 'Living Life to the Full', but first we will look at ways that you can get support with your disease.

## **10) Getting Support with your COPD**

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When you are diagnosed with COPD you can start to feel isolated, and may tend to bottle your feelings up, leading to a spiral of anxiety and depression. These negative feelings can make your symptoms seem worse, but with the right amount of emotional care and support you will be able to cope better with your illness.



It is sometimes difficult to ask for help, but there are many who are willing to provide support. For most people this is part of our nature and being able to help others gives us a great deal of satisfaction; so you mustn't be afraid to ask.

We will look at the range of ways in which you can get emotional support:

## Family and Friends

You might tell yourself that your family and friends don't understand how you are feeling, or that you don't want to be a burden on them. However, the people closest to you are those that care about you and will want to share the burden with you. Getting support from your family and friends can help to relieve any anxiety and depression that you may have concerning your illness. They will need to know more about your illness so that they understand its limitations and how to help you. It will also help them to come to terms with their feelings about your state of health.

Your partner or close family will also feel anxious about your condition, and it is therefore a good idea to confide in each other about your worries. You may find that your partner will be over-protective and want to do everything for you so it might help if you gently explain the benefits for you of remaining as active as possible.



## Making a Care Plan

One of the things you may consider for managing your condition is to have a care plan. Not only will this enable you to ensure that your illness is managed effectively, but it will also tell your family what to do if you become very ill and are unable to look after

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yourself. A care plan is a written agreement between you and your doctor or health professional regarding how to manage your health. If your doctor does not provide this service then perhaps it would be a good idea to make your own care plan. The document should include the following:

- Details of your medication
- Dietary requirements
- Exercise plan
- Any goals that you want to work towards e.g. returning to work
- Details of your support services and who is responsible for medical care
- Emergency numbers to contact in case you become very ill

If your doctor is involved in your care plan, ask him for your own copy to take home.

## **What to Tell the Children**

You may find it difficult to talk to your children or grandchildren about your illness as you don't want to worry them. It is best to be honest with them though, because otherwise they may imagine the worst. Take time to answer their questions and reassure them about their future, trying to focus on positive aspects e.g. 'Grandma will still be able to come on holiday with you'.

## **Support Groups and Communities**

For those of you who don't have anybody close that you can confide in, there is a lot of support available from outside sources. Check to see if there are any support groups for lung disease in your area, or for anxiety or depression if you suffer from these. By finding sources of support it will help you to feel more in control of your illness, and you will be able to share your feelings with others who are in a similar situation, and can therefore empathize with you. Also because these are people with the same illness, you will find that many have developed coping strategies, so you will be able to share ideas on managing your illness.

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Your doctor may also be able to put you in touch with sources of support such as counseling, psychotherapy or patient groups. Therapy can take the form of group sessions, or one to one counseling. Your doctor may even refer you for pulmonary rehabilitation, which will help you with the psychological effects of COPD as well as the physical effects - details of these courses was given in chapter 6, 'Treatments for COPD'.



As well as groups that you can physically attend, there are many online communities that offer support. These have the advantage of accessibility from within the home so that you can continue to get help and advice even when you are too ill to leave the house. The website: [www.beebreathing.com](http://www.beebreathing.com) is an online community for people with COPD. Here you will find advice about your disease, as well as tips on dealing with stress and depression and other topics. You could also try typing 'COPD Support' in an Internet search engine to see what groups are available.

For those of you who are religious, you may find that your local church is an invaluable source of support and practical help.

## **11) Living Life to the Full**

In chapter 8 we looked at how you can still enjoy holidays despite your disease. There are also other ways to ensure you don't let your illness stop you from getting the most out of life, and we will look at these in this chapter.

### **Exercise**

Exercise is another area that we have explored. In chapter 7 we introduced you to the idea of taking a little exercise to help manage your condition. If you have followed our suggestions and managed to improve your overall fitness levels, you may be ready to try other types of exercise. As well as helping with your illness, many people get a great deal of enjoyment from exercise, but you will need to speak to your doctor before taking up any new activities. The following are recommended for COPD

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patients, but they won't be suitable for all stages of the disease; your doctor will be able to advise you further:

- Swimming

This is a good exercise for COPD as it helps to strengthen the lungs, and use oxygen more efficiently. Try swimming a little at first, and stopping for breath at intervals. If this is too strenuous you could maybe walk up and down the pool to start with.

- Dancing

This gives you a cardiovascular workout like swimming, so it will also enable your body to use oxygen more efficiently. Many people find dancing a very enjoyable activity so it could help to lift your mood as well.



- Aerobics

If you are well enough to attend an aerobics class, this will also give you a cardiovascular workout as well as increased muscle strength. Don't worry if you don't have the stamina for a class though as walking, climbing stairs and slow jogging are all types of aerobic exercise.

- Stretching

Stretching can relax you, and you should also stretch your muscles before and after exercise to warm them up and prevent cramp.

- Resistance Training

This will help you to build up muscle strength. When the muscles in your upper body are stronger, it makes it easier for your respiratory muscles to function.

## Hobbies

You do not have to give up hobbies because you have a chronic illness. You may find ways to adapt so that you can still get involved in the same hobbies but in a different way.

Alternatively, you may find new hobbies to try. There are many things you



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could do that are not too physically demanding such as painting or learning to play a musical instrument. Try checking out what evening classes may be available at your local college. This could also help you to meet new friends and take your mind off any feelings of anxiety or depression.

One COPD patient called Danny had always been an avid fisherman and won many fishing tournaments. He used to take his fishing tackle in a trailer and then offload it into the boat.

As his disease took hold he found it increasingly difficult to participate in his hobby; even loading the boat was a challenge. He found that he eventually had to drop out of competition fishing, but although he is on oxygen therapy, he still manages to fish. He does this by adapting his pastime to fit in with his illness. He goes fishing with his son and his son's friends and helps them to spot fish, and gets help with loading the boat. Danny also has to ensure that he has his oxygen tank and concentrator with him when he goes fishing. Despite having to adapt to fit in with his illness he still gets a lot of pleasure from his hobby and even manages to drive the boat at 70mph when it suits him.

We have included the stories of several COPD patients in this guide, many of whom have found their own ways to adapt their own activities and pastimes. We hope that by reading their stories it will give you the determination to get the best out of life despite your illness.

## **Sex Life**



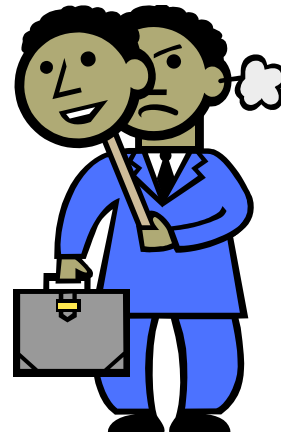
Many people with lung disease find that their sex life suffers. This is because they can feel tired, anxious or depressed, or they may get out of breath or have coughing spasms during sexual activity. Additionally, some types of medication can affect your sex drive. For a lot of people sex is an important part of their lives, so you shouldn't let your illness stand in the way. If full intercourse leaves you exhausted, there are other ways that you can express your feelings such as kissing, hugging and caressing. The following tips should help you continue to have a fulfilling sex life:

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- Check your medication to make sure that it isn't affecting your sex drive.
- Take it slowly, and try to conserve your energy.
- Pick a time when your symptoms aren't too bad, and you are feeling relaxed.
- Avoid having sex after a heavy meal as it can make you feel bloated and therefore more breathless.
- Use your reliever medication prior to sexual activity to stop you getting as breathless, or if you take oxygen, use it before and after sex.
- Talk to your partner about what type of sexual activity suits you and try to take account of your partner's wishes as well.
- If you become short of breath, pause to get your breath back or use your reliever medication, then continue your enjoyment.
- Try a range of positions. Some require less energy than others on your part and it will suit you better if your chest and diaphragm are not weighed down.
- Speak to your doctor or nurse if your illness is causing problems with your sex life.

## **Staying Positive**

We've already looked at the importance of positive thinking in previous chapters. This is fundamental in coping with your illness, and you should take whatever steps are necessary to make you feel better about yourself. This could be getting involved in a hobby, taking some light exercise or even treating yourself every day to give yourself a boost. Bear in mind that although your illness is debilitating and you will no doubt have some bad days, it isn't the end of your life and you can still have many good days too. The following ideas should help.



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- Take control of your condition and tackle it head on rather than letting it control you. Find out as much as you can and get involved in your treatment by telling your doctor what works best for you. Don't be afraid to ask questions if there is anything you are unsure about.
- Find the right doctor to treat your condition. If you are not getting satisfaction from your doctor, don't be afraid to change to another who may know more about your specific illness.
- Explore all the options when it comes to treatment, taking account of any side effects. Different combinations of medications may be the most suitable for you.
- Get all the help and support you can either from family and friends or support groups. We looked at these in chapter 10.
- Stay optimistic. Instead of asking, 'Why me?' decide that you will make the best of what life has to offer.
- Try not to feel guilty. Although it can be a difficult time for your family too, you are not to blame.

Lastly, don't forget to keep positive. There are new advances in medicine all the time. Stay receptive to any new medication that your doctor might want to try you with as it might make a vast improvement to your health.

## 12) **The Outlook**

As we have shown within this guide, your future outlook can be extremely positive, despite the drawbacks of having a chronic disease.

Nevertheless, whilst throughout this book we have discussed the many ways in which you can manage your illness and still live a full life, we appreciate that for some COPD patients it may be too late to halt the spread of the disease. A few of you may be in the advanced stages of COPD and be facing the final stages of life.

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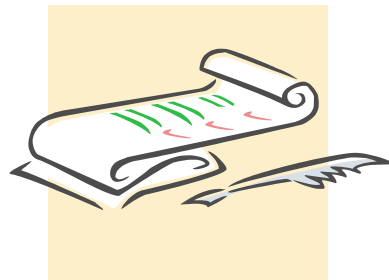
## **The Final Stages**

You may notice that your breathing becomes gradually worse and that after each flare-up your lungs don't work quite as well as they did before. As the disease develops you may notice other symptoms such as fluid retention in the legs and abdomen, and a congested liver due to low levels of oxygen in the blood. These later symptoms may reoccur over several years or they may be only short-term. In the last few days you will notice several other changes which can include:

- Reduced appetite due to difficulty swallowing
- Sleeping most of the time
- Changes in breathing patterns, and an increased build up of mucus
- Increased reliance on oxygen
- Changes in the color and temperature of the skin
- No desire to talk

## **Your Choices**

This is a very sad time for you and your family, but unfortunately it is a situation that we all must face at some time.



In facing that situation you have a number of options relating to the final stages of your care. Although it may be immensely difficult to discuss this subject with your loved ones, by making it clear to them what your wishes are, it will help them in the event of your departure. If you and your family find it too distressing to talk about, then perhaps you could write down your wishes to give to your next of kin, with the stipulation that they are to be referred to if you become too ill to act for yourself. Here are some points worth considering:

- 1) Would you like to die in your own home or in hospital?
- 2) Would you like medical professionals to try all means possible to keep you alive, such as non-invasive ventilation, life-support or resuscitation, or would you prefer to die without any intervention?
- 3) Do your loved ones know what to do if your illness becomes severe? (Your care plan could help with this, which we discussed in chapter 10).

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- 4) Do you have someone who could act as your advocate if you become too ill to take care of things yourself?
  
- 5) Have you made a will, appointed a power of attorney or completed an advanced directive?

Despite ending this guide on a gloomy note, please don't be drawn into feelings of negativity. Remember, death is inevitable for all of us. Just because you have a chronic illness doesn't necessarily mean that you will die before your peers. What it does mean is that you will probably know when your time is near, and will be able to make the necessary preparations. In the meantime, don't forget to stay optimistic and to carry on getting the best out of your life.



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