

## Shared Decision Making – chronic obstructive pulmonary disease (COPD)

Next clinical review date March 2018

### Deciding what to do about COPD

This short decision aid is to help you decide what treatment, or combination of treatments, to choose if you have chronic obstructive pulmonary disease (or COPD for short).

The main treatment options for COPD are:

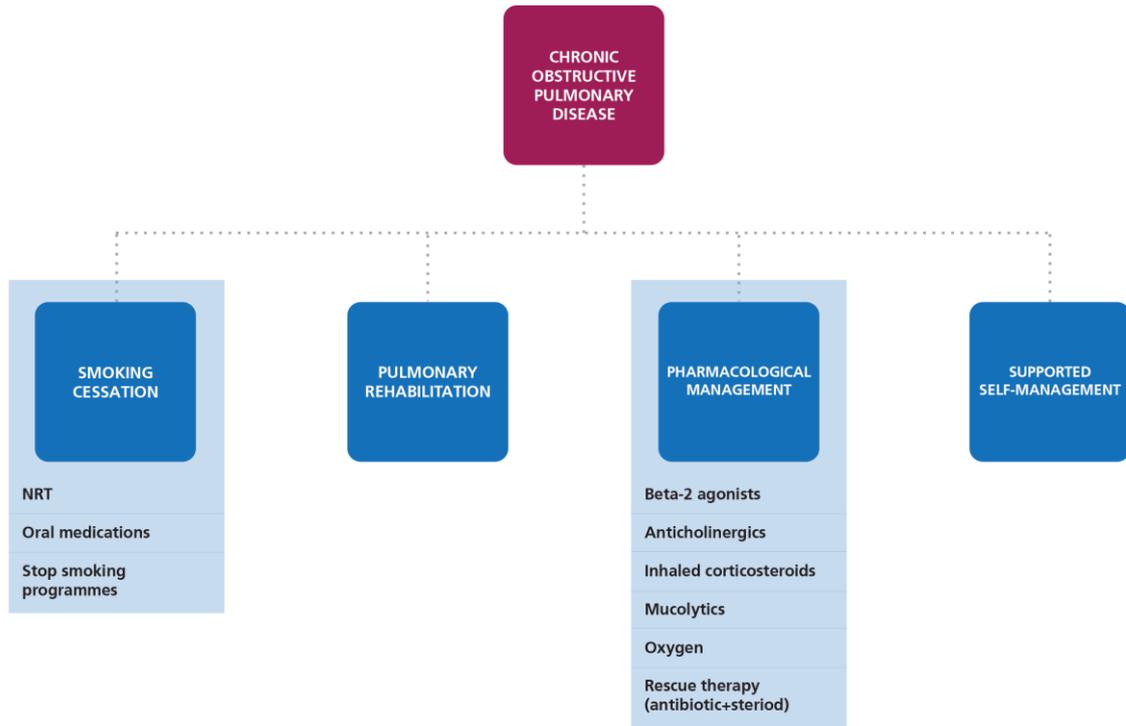
- If you're a smoker, stopping smoking
- Taking medicines (drugs) to improve your symptoms
- Self-management programmes, which means learning about how to manage your COPD yourself
- Pulmonary Rehabilitation, which includes learning exercises to help improve your breathing.

You don't have to choose just one of these options. You can choose to have a combination of treatments. Your choices may depend on many things, including how much your symptoms bother you, how damaged your lungs are, and whether you smoke.

The types of decisions people with COPD are making include:

- I'm a smoker. What treatments can I try to help me stop smoking?
- Get out of breath easily doing everyday things like getting dressed. Should I try an exercise programme, or is it best to start taking medicines first?
- My symptoms are getting worse. What should I try next - different medicines, a self-help programme, or both?

The right choice for you may change over time. This short decision aid aims to help you make the right choice for you now, but you may wish to change your mind as your COPD or your life changes





## What are my options?

	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<b>What is the treatment?</b>	<p>Most people who smoke find it easier to stop smoking if they get professional help or advice. This can be from a doctor, pharmacist, nurse, or trained counsellor. You can have treatment to help you stop smoking at the same time as having other treatments for COPD.</p> <p>The main treatments to help people stop smoking are nicotine replacement therapy (NRT) and drugs to help you stop</p>	<p>A range of drug treatments are used to improve COPD symptoms. Some are taken with an inhaler so you breathe in the drug as a powder or spray. Others are taken as a tablet. The right treatment will depend on your symptoms, and how much your lungs have been damaged. Some people take a combination of drugs.</p> <p>The main drugs used to treat COPD are Beta-2 agonists, anticholinergics, inhaled corticosteroids and mucolytic drugs. Inhaled</p>	<p>Self-management means learning more about your illness, how you can manage your symptoms, and when to get help to prevent a flare-up of COPD. You can find out about how to manage your illness from your nurse, GP, or your specialist hospital team. You can do this on your own or as part of a group.</p> <p>Self-management programmes are courses designed to support you to manage your own condition.</p> <p>You can follow a self-management programme while you are having other treatments for COPD, such as stopping smoking,</p>	<p>Pulmonary rehabilitation is a programme designed to help improve your breathing so that you feel healthier and more able to do normal everyday things.[1] During pulmonary rehabilitation you will usually learn more about your COPD and how to control your breathing. You will also learn to do exercises for your lungs and learn techniques to help your breathing.</p> <p>You can have pulmonary rehabilitation</p>

	<p>smoking. These drugs are called bupropion and varenicline.</p> <p>Other treatments are hypnosis, electronic cigarettes, and self- help guides. These are aids and devices that may help you get over your cigarette cravings.</p>	<p>corticosteroids should only be used in combination with long acting beta-2 agonists. You may also need rescue medication (oral steroids and antibiotics) for a flare-up of COPD, or oxygen if you have severe COPD and damage to your lungs that hasn't been helped by other drugs.</p>	<p>taking COPD drugs, or having pulmonary rehabilitation.</p>	<p>n while you are having other treatments for COPD, such as stopping smoking, taking COPD drugs, or following a self-management programme. You can choose to have a combination of all these options if you prefer.</p>
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	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<p><b>What is the effect on how out of breath you feel?</b></p>	<p>Stopping smoking may make you feel less out of breath. If you don't get out of breath at the moment, but you continue to smoke, there is a higher chance that you will get out of breath in the future. In one group of</p>	<p>Taking drugs for COPD may make you feel less out of breath.[9] People with COPD taking a type of drug called a beta-2 agonist (which relaxes the muscles in the lungs) said their breathlessness improved by one</p>	<p>Following a self-management Programme may make you feel less out of breath.</p> <p>People with COPD who followed a self-management Programme had about a one-point improvement on</p>	<p>Having pulmonary rehabilitation may make you feel less out of breath.</p> <p>People with COPD who had pulmonary rehabilitation had about a one-point improvement on a seven point</p>

	<p>people with COPD who gave up smoking, about <b>19 in 100</b> had breathlessness after five years, compared to about <b>24 in 100</b> of those who carried on smoking.[8]</p>	<p>point on a five-point scale of breathlessness, compared with those not taking the drug.[9]</p>	<p>a 12-point scale of breathlessness, compared with those who had other treatments.[10]</p>	<p>scale of breathlessness, compared with those who had other treatments.[11]</p>
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	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<b>What is the effect on how well your lungs work?</b>	Your lungs are likely to work better and for longer if you stop smoking.[12] People with COPD who stop smoking have lungs that work about one-and-a-half times better after five years of stopping than people who carry on smoking. Stopping smoking is one of the most important things you can do to prevent your lungs from getting worse.[9]	Your lungs are likely to work better and for longer if you take drug treatments for COPD.[9]	Your lungs are likely to work better if you follow a self-management programme.  People with COPD who follow a self-management programme have an average FEV1 (a measure of how well your lungs work) of about 54 percent, compared to about 46 percent in those who don't follow a programme.[13]	We are not sure if having pulmonary rehabilitation will improve how well your lungs work. Very few studies have looked into this. However, many people find that their breathing improves and that they can take part in more everyday activities after having pulmonary rehabilitation.

	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<b>What is the effect on how often you have chest infections?</b>	Stopping smoking means you are likely to have fewer chest infections within five years of stopping	Taking drugs for COPD is not likely to make much difference to how often you get a chest infection.	Following a self-management programme is not likely to make much difference to how often you	We are not sure if having pulmonary rehabilitation will make you less likely to get chest infections. Very

	smoking. [14]		get a chest infection.	few studies have looked at this.
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	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<b>What is the effect on how likely you are to have a flare-up of COPD?</b>	We don't know for sure if stopping smoking means you are less likely to have a flare-up. Flare-ups are often caused by chest infections. Stopping smoking can reduce your chance of having chest infections, which may mean you have fewer flare-ups.[8]	You are less likely to have a flare-up if you take drugs for your COPD than if you don't.[15] All drugs for COPD reduce your chances of getting a flare-up.[15]	<p>Going on a self-management programme may help you to spot when your symptoms are getting worse so that you can treat them earlier. This may mean you have fewer flare-ups.</p> <p>People with COPD who go on a self-management programme take fewer doses of rescue drugs for flare-ups than those who don't go on a self-management programme.[16]</p>	You are less likely to get a flare-up that requires going into hospital if you have pulmonary rehabilitation than if you don't. About <b>seven in 100</b> people with COPD who have pulmonary rehabilitation after being in hospital for a flare-up will go back to hospital with another flare-up within three months. This is about <b>33 in 100</b> in those who don't have pulmonary rehabilitation.[17]

	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<b>What is the effect on how tired you get?</b>	<p>We don't know whether stopping smoking has an effect on how tired you get.</p> <p>Coughing less, being less out of breath, and having fewer colds and chest infections may mean you are less likely to be tired.</p>	<p>Taking drugs for your COPD can make you feel less tired than if you don't take drugs for your COPD.</p> <p>In one group of people with COPD, those who took a beta-2 agonist drug (which relaxes the muscles in your lungs) for seven or more days got less tired than those who didn't take the drug.[9]</p>	<p>Going on a self-management programme can make you feel less tired than if you don't go on a self-management programme. In one group of people with COPD, those who followed a self-management programme scored better on a questionnaire about tiredness than a group who didn't go on a programme. [13]</p>	<p>Having pulmonary rehabilitation can make you feel less tired than if you don't have pulmonary rehabilitation. In one group of people with COPD, those who had pulmonary rehabilitation had a one point improvement in their tiredness on a seven-point scale, compared with another group who had other treatments.[11]</p>

	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<b>What is the effect on how you feel?</b>	<p>Some people with COPD who stop smoking feel less anxious or sad.[18]</p>	<p>People with COPD symptoms that are well managed with drugs have an improvement in their mood of</p>	<p>People with COPD who learn how to self-manage their COPD feel better about their disease and less</p>	<p>People with COPD who have pulmonary rehabilitation feel healthier, happier with life, less</p>

		<p>about four points on a 100-point scale.[19] An improvement of four points is the minimum doctors look for when they weigh up if a treatment is actually improving your mood.</p> <p>People with COPD who have well-managed symptoms when they take long-acting beta-2 agonists with inhaled steroids say they feel happier.[20]</p>	<p>bothered by their symptoms.[16]</p> <p>People who go on a self-management programme feel more in control of their disease and feel more confident about avoiding breathing problems when exercising or doing physical activities. [13]</p>	<p>anxious or depressed, and more confident in controlling their disease.[21] [22][11] After pulmonary rehabilitation, people with COPD have a six-point improvement on a 100-point scale of how healthy they feel compared to those who have other treatments.[11]</p>
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	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<b>What is the effect on how likely you are to need to go into hospital?</b>	<p>If you stop smoking you are less likely to need to go into hospital.[23] You are likely to have fewer colds and chest infections if you stop</p>	<p>If you take drugs for COPD you are less likely to need to go into hospital. People with COPD who take a long-acting beta-2 agonist,</p>	<p>If you follow a self-management programme you are less likely to need to go into hospital. In a group of people who had to go to hospital</p>	<p>If you have pulmonary rehabilitation you are less likely to need to go into hospital because of a flare-up than if you don't have pulmonary rehabilitation. Around <b>7 in 100</b></p>

	<p>smoking.[14] This may mean you have to see your doctor less often.</p>	<p>a long-acting anticholinergic, and an inhaled steroid together are less likely to need to go into hospital in one year compared to people who take a long-acting anticholinergic on its own. [19]</p>	<p>because of a flare-up of COPD, around <b>27 in 100</b> people with COPD who followed a self-management programme needed to go back to hospital or died within one year of starting the programme, compared to around <b>49 in 100</b> who didn't follow a self-management programme. [24]</p>	<p>people with COPD who have pulmonary rehabilitation after being in hospital for a flare-up will go back into hospital within three months with another flare-up, compared to around <b>33 in 100</b> who don't have pulmonary rehabilitation.[17]</p>
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	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<p><b>What is the effect on how long you will live?</b></p>	<p>You are likely to live for longer if you stop smoking tobacco than if you carry on smoking. In one group of people with COPD, those who stopped smoking after using nicotine replacement therapy or counselling</p>	<p>We're not sure if taking drugs for COPD will make a difference to how long you will live. Different studies that have looked at this have shown different effects. [25]  People with COPD whose</p>	<p>You are likely to live for longer if you successfully complete a self-management programme for COPD than if you don't go on a self-management programme.  Around <b>27 in 100</b> people with COPD who</p>	<p>You are likely to live for longer if you have pulmonary rehabilitation after having a flare-up than if you don't.[27]</p>

	were more likely to be alive 15 years after stopping than people with COPD who continued smoking.[12]	symptoms are controlled by drug treatments may live longer than those whose symptoms are not under control.[26]	successfully completed a self-management programme went to hospital or died within one year of starting the programme.[24] Around 49 in 100 people with COPD who didn't follow a programme went to hospital or died within one year.[24]	
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	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<b>What is the effect on your cough?</b>	Stopping smoking may mean you cough less. If you don't have a cough now, but you continue to smoke, there is a higher chance that you will get a cough in future. A study of people with COPD who didn't have a cough found that, after five years, about 15	Some drug treatments for COPD may help improve your cough. Mucolytic drugs make the mucus (phlegm) in your lungs thinner, looser, and less sticky. These drugs can help if you have lots of phlegm when you cough.[9]	We are not sure if going on a self-management programme will improve your cough, unless you have other treatments as well. Going on a self-management programme and giving up smoking may help you cough less.[10]	We are not sure if pulmonary rehabilitation will improve your cough. Having pulmonary rehabilitation and giving up smoking may help you cough less.

	<p>in 100 of those who stopped smoking got a cough for more than three months in one year. This compared to about 23 in 100 of those who carried on smoking.[8]</p>			
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	Stopping Smoking	Drug Treatments	Self-Management Programme	Pulmonary Rehabilitation
<p><b>How likely is the treatment to cause unwanted side effects or complications?</b></p>	<p>You may have a cough that gets worse for a few weeks after stopping smoking. This is a sign that your lungs are healing. It should get better over time. You should speak to your doctor if your cough doesn't go away after stopping smoking.</p> <p>You may also put on weight after stopping smoking because you</p>	<p>Different types of drugs for COPD can cause different types of unwanted effects. Between 17 and 19 in 100 people with COPD who take long-acting beta-2 agonists or long-acting beta-2 agonists with inhaled steroids get side effects.[28] Most of these side effects go away naturally or they can be</p>	<p>Learning to self-manage your COPD isn't likely to cause you any unwanted effects.</p>	<p>Having pulmonary rehabilitation isn't likely to cause you any unwanted effects.</p>

	<p>may eat more. Eating healthily can help you control your weight.</p> <p>Treatments to help you stop smoking can have unwanted effects, including difficulty sleeping, dry mouth, and feeling sick (nausea).</p>	<p>treated if they don't.</p>		
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## What are the pros and cons of each option?

People with COPD have different experiences about the health problem and views on treatment. Choosing the treatment option or combination of treatment options that are best for the patient means considering how the consequences of each treatment option will affect their life.

Here are some questions people may want to consider about treatment for COPD:

- Are they very upset by feeling out of breath and coughing?
- How important is it for their treatment to increase the chances that they will live longer?
- How important is it to slow down the worsening of their symptoms?
- How important is it to be able to enjoy life more after treatment than they do with their symptoms as they are now?
- Do they want to learn more about how to manage their condition themselves before considering medical treatment?
- Do they want to be able to take part in more everyday things (like walking, household activities, or washing and dressing) than they can do at present?
- If they are a smoker, are they willing to try giving up smoking?
- Are they willing to try a treatment that has a big risk of unwanted effects?

## How do I get support to help me make a decision that is right for me?

People using this type of information say they understand the health problem and treatment choices more clearly, and why one treatment is better for them than another. They also say they can talk more confidently about their reasons for liking or not liking an option with health professionals, friends and family.

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