

# Living with COPD



[luchtpunt.nl](http://luchtpunt.nl)

# COPD



**If you are reading this leaflet, then you or somebody you know is probably living with COPD, and you would like to know more about this condition.**

**This leaflet will explain what COPD is, what you can expect with COPD and what you can do to live as well as possible with COPD.**



# What is COPD?



**COPD is a lung condition that causes shortness of breath and coughing. The condition is chronic and cannot be cured. However, with correct treatment you can live with the condition.**

COPD is the abbreviation for Chronic Obstructive Pulmonary Disease. It is a collective term for the respiratory tract conditions chronic bronchitis and pulmonary emphysema. These conditions cause chronic narrowing of the airways:

## **Chronic bronchitis**

In the case of chronic bronchitis, the bronchi (the branches of the airway leading to the lungs) are inflamed.

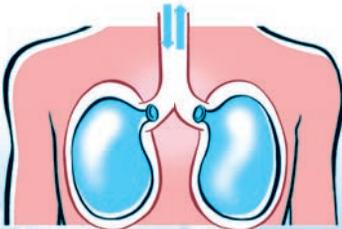
## **Pulmonary emphysema**

In the case of pulmonary emphysema or emphysema, the pulmonary alveoli are gradually lost.

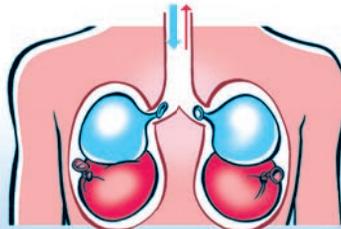
## **Traffic jam in the lung**

The result is that air remains behind in the lung when you exhale. The air that you breathe in is not all exhaled again. Effectively, the lung is pumped up a bit. This is called “air trapping” and causes shortness of breath.

**Normal breathing**



**Air trapping**



### **COPD examination**

The doctor will have to examine you to determine whether you have COPD. This examination consists of asking you questions (history), including questions about the symptoms that you have, how long these have been present and how these have changed over time. The doctor will also ask whether you are a smoker or have smoked in the past. In addition, a lung function test will be performed to measure how much air you can exhale in one second. This is called the 1-second value, or Forced Expiratory Volume 1 sec (FEV1) value. This value is expressed as a percentage of the volume that a person of the same age with healthy lungs can exhale. Your doctor will also perform a physical examination to listen to your lungs.

### **Categorisation according to severity of the COPD**

The severity of COPD can be divided into four groups, from A through to D. These groups are called the GOLD stages. Your doctor will determine the group in which your COPD can be categorised based on the lung function test, the limitations that you are experiencing as a result of your lung symptoms and the occurrence of sudden exacerbations that require treatment.

# Asthma or COPD?



**Asthma and COPD are sometimes confused. This is understandable, because the symptoms are very similar. However, there are some essential differences between asthma and COPD.**

Asthma occurs as a result of hypersensitivity to certain triggers (allergy) and the lung recovers if the trigger is removed. In the case of COPD, the lung is permanently damaged and the lung function does not return to normal. The exact differences are listed in the table on page 6.

If you suspect that you have COPD, then you could take the

GP, Den Bosch: *“If people come to me with symptoms such as a productive cough and shortness of breath, then I always ask about their history. Have they ever smoked? Or worked with irritating substances? If the answer is yes, then I immediately suspect COPD.”*

COPD test on [www.longfonds.nl](http://www.longfonds.nl). However, it is still best to present your symptoms to the doctor.

COPD patient Bob Wiersma (49): *“As a carpenter, I have worked with wood all my life. Sometimes I would spend full days sanding or sawing wood. The workshop was quite small and we never wore protective masks. They simply did not exist. Now I know that all that dust was not good for my lungs. Unfortunately I am no longer able to work and I have to divide my days into three sections: I have to lie down for a while between each section. That is sometimes frustrating, because I used to be a person who couldn’t sit still even for two minutes.”*

	<b>COPD (chronic bronchitis and pulmonary emphysema)</b>	<b>Asthma</b>
<b>Age at which you develop symptoms</b>	Older than 40 years.	All ages.
<b>Cause</b>	History of smoking, prolonged exposure to irritating substances, air pollution, hereditary condition, pneumonia/lung disease.	Allergy or hypersensitivity, hereditary condition.
<b>Symptoms</b>	Shortness of breath, tight feeling in the chest, coughing, producing mucus.	Shortness of breath after exposure to triggers. Tight feeling in the chest, coughing, producing mucus.
<b>Course</b>	Chronic and gradually becoming worse, airways damaged beyond repair.	Responds favourably to medication, airways recover after an attack (if asthma is under control).
<b>Life expectancy</b>	Deteriorating, particularly if you do not stop smoking.	Normal.
<b>Lung function</b>	Continued deterioration, even with optimum treatment.	Normal with optimum treatment.

# Treatment of COPD



**Treatment of COPD has six official treatment goals. Their combined aim is to limit your symptoms as far as possible. In order to achieve this, your doctor will set up a treatment plan together with you that is tailored specifically to your needs.**

## Aims of COPD treatment

- ↪ reducing the symptoms
- ↪ improving the exercise capacity
- ↪ normalising the deterioration in the lung function (FEV1)
- ↪ preventing exacerbations
- ↪ delaying or preventing disability and incapacity to work
- ↪ improving the disease-related quality of life.

## Quitting smoking

The first point of attention in a treatment plan is smoking cessation. The damage to your lungs can no longer be repaired, but by quitting smoking you can prevent any further deterioration in your lungs.

There are many stories about quitting smoking, particularly that it is difficult. Nevertheless, anyone can stop smoking. You are not alone: your GP and practice support worker can assist you with

targeted support and medication. They can tell you, for example, whether nicotine patches are an option for you. They can also refer you to a smoking cessation outpatients' clinic of a hospital.

Do also have a look on the internet. You will find a whole world of possibilities on [www.longfonds.nl](http://www.longfonds.nl), [www.rokeninfo.nl](http://www.rokeninfo.nl) and [www.kwaliteitsregisterstopmetroken.nl](http://www.kwaliteitsregisterstopmetroken.nl). From simple tips for the do-it-yourself approach to professional guidance.

COPD patient Marianne van der Loos (61):  
*"When I was diagnosed with COPD, I had just started smoking again, because of my divorce. But when I was told that it would be better to stop smoking, I did so immediately. It wasn't hard, because I knew why I was doing it: for my health. In combination with medicines, I soon noticed an improvement and my condition became more stable."*

### Medicines

Medicines for COPD are aimed at reducing symptoms: more air and less coughing. These are almost always medicines that you can inhale. Breathing in these medicines provides the shortest route to where they need to be: in your lungs. It also prevents side effects from occurring elsewhere in the body.

### Bronchodilators

There are short-acting and long-acting bronchodilators. The short-acting ones are used at times when you feel more short of breath. The long-acting ones are for daily use and are a form of support: by keeping your airways open, they make it easier for you to breathe out. This means less shortness of breath, meaning that you are able to exercise or play sports for longer periods. And

that is important, because the fitter you are, the less you will be troubled by COPD.

### Anti-inflammatories

These can help to prevent exacerbations (sudden worsening of your symptoms) in the case of more severe COPD.

### Therapy compliance

It is very important that you use the prescribed medication exactly as instructed. This gives your lungs the maximum opportunity to continue to work normally.



If you feel that the medicines are not working as well as they were, then this usually means that your

lungs have deteriorated further. If you stop taking your medication this will often result in a worsening of symptoms. Therefore, do not stop taking your medication, but see your doctor first.

### Lung rehabilitation

Lung rehabilitation is a collective term for treatments that can reduce your symptoms and help to improve the quality of life. Examples include physiotherapy, breathing exercises, improving your physical fitness, dietary advice and often also seeing a psychologist: anything that can help to tackle COPD and make living with COPD easier.

### Pursed lip breathing

There is a clever trick that can help when you are feeling short of breath: the so-called pursed lip breathing technique. You breathe in through your nose and then breathe out gently through pursed lips. This places slight pressure on the air in your lungs when you breathe out. This extra air pressure prevents the smallest airways from collapsing. If you

breathe out very slowly like this, you will notice that you can get much more air to flow out of your lungs than when you exhale normally.

### Oxygen therapy

Extra oxygen can help if you are very short of breath. The lungs do not have to work as hard to absorb sufficient amounts of oxygen. People who receive extra oxygen in addition to their treatment find it easier to exert themselves and to relax.

**COPD patient Marianne van der Loos (61):**  
*'When I am getting dressed, I sometimes need to sit down. Washing my hair is also difficult. So I do everything slowly. I just need to make sure that I take plenty of time. However, I do try to participate in everything. For example, if we want to go cycling with friends on a weekend, then my husband and I will rent a tandem bicycle. This allows me to cycle with them.'*

# What can you do yourself?



## Accept that you have COPD

Those who accept that they have COPD will find it easier to live with the accompanying limitations and lifestyle rules. This is why a visit to a psychologist can be very useful. After all, if you are mentally stronger, you will find it easier to deal with the limitations.

It may sound obvious, but for COPD it is also important that you approach your condition with a positive attitude. Try to focus on what you can still do. You may not always be able to play football with your grandchildren, but you could build kites with your grandchildren instead.

## Avoid triggers for COPD

Some triggers in your surroundings can provoke shortness of breath or coughing. Therefore, it is important to ensure that you avoid these triggers as much as possible, both at home and at work. The table below provides a list of the most well-known triggers. Try to keep a diary to track which triggers you are sensitive

## Triggers for COPD

- ↪ pets
- ↪ tobacco smoke
- ↪ wood fires
- ↪ combustion gases from a gas stove or a geyser without extraction
- ↪ cooking smells
- ↪ perfume and air fresheners
- ↪ candles
- ↪ the smell of chlorine, polishing wax, white spirit or other cleaning products
- ↪ strong smells such as hair spray, strong perfume and aftershave.
- ↪ car exhaust fumes
- ↪ mist, wind, rain, humid weather, large temperature fluctuations, cold air
- ↪ colds and flu

to. Next, it is important to avoid these triggers or even remove them from your surroundings.

In the case of tobacco smoke, this not only means that you should quit smoking, but also avoid smoky environments.

It is better to avoid large temperature fluctuations. Of course you cannot influence the weather. But perhaps you do not have to go outside when it is raining or freezing cold. Keep the heating in your house as steady as possible: 21 degrees during the day and 18 degrees at night. And on a warm summer's day, try to avoid supermarkets that have the air conditioning on high.

### Flu shot

Then there is the flu shot. As a COPD patient, it is wise to get this shot each year, not only because you are more susceptible to flu, but also because flu can make symptoms such as shortness of breath and coughing much worse. The latter also applies to the common cold. Unfortunately there is no vaccine available against the common cold. Avoid people who have a cold and wash your hands frequently.

### Make it easy for yourself

"If you can't do it the way it should be done, do it the way it can be done." If there is one expression that applies to COPD, then it is this one. Often a small adjustment is all that is necessary to allow you to continue leading your own life.

COPD patient Marianne van der Loos (61):  
*"Sometimes I see someone my age walking quickly up the stairs. Then I think: I could have been able to do that. That does confront you with the facts. But I usually try to be happy with what I can still do. Even if it means that - for example - I have to take it easy or use a wheelchair when going for a walk."*

Therefore, it is wise to focus on the things that are going well, both in work and in your private life. And leave the things that are difficult to others or adapt them.

For example, think about changing the layout of your house. A stair lift can be fitted in almost every house. And do you really need to go up and down the stairs for everything?

Or could you do some things downstairs too? Ensure that the home is cool in the summer by installing a fan or portable air conditioner. Or keep the curtains on the sunny side of the house partly closed. Perhaps you can arrange

*COPD patient Truus Braakman (57): "I am a grandmother to two energetic grandchildren. I sometimes struggle to keep up now that they no longer nap during the day and are on the go the whole day. They are very sweet though, they understand that granny sometimes feels a little tired. But I really regret not being able to horse around with them."*

the contents of the kitchen cupboards so that you do not have to bend down all the time. Shopping may be easier at times when the store is less busy. And of course gardening is fun, but it might be better to leave heavy chores like mowing the lawn to a neighbour. And as a COPD patient you may - in some cases - be eligible for a household assistant.

These are merely examples. The point is that you start looking at

your home and working environment from a different angle. If you are no longer very strong, you have to be clever!

### **Be clear about your COPD**

A common complaint by COPD patients is that people do not understand their condition. Why don't you come to that family barbecue? And why is the air conditioning in your workplace slightly cooler? Understandable questions, and often very easy to answer by explaining what COPD is.

COPD is not a visible condition. People don't see many reasons to be considerate of your condition. They then feel disappointed when you prefer to wait for the next bus rather than run for this one. And people who are aware of your COPD can face another dilemma: should they help you with your limitations or not? It is best to be as clear about your COPD as possible.

Be open about your COPD. Being a slow starter in the morning is

not a problem, as long as your spouse knows that it is due to night-time shortness of breath and not sudden laziness. It is very normal to ask people not to smoke near you. Most people would rather go outside than cause shortness of breath for a COPD patient. A short break during a long walk shouldn't be a problem, as long as the other walkers know the reason.

*COPD patient Harry Walker (66): 'I sometimes need to take it easier when doing chores. I no longer dig up the garden in one go, I split it into three sections. And if I see the bus approaching whilst I am still on my way to the bus stop, I don't run, I simply wait for the next one.'*

*COPD patient Marianne van der Loos (61): "It isn't easy for my husband either that I have COPD. He is a fantastic support, but it does mean that he constantly needs to adapt his rhythm. So I stimulate him to go and do his own thing. For example, he recently travelled to Canada with a friend. He didn't really want to leave me alone. But I convinced him to go, because it is good for him not to be involved with my COPD all the time."*

# COPD and health



**With COPD it is particularly important to maintain your overall health. The better your health, the more energy you have. If you feel physically stronger, you will enjoy life more. You will also be less susceptible to shortness of breath and coughing fits. Exercise and a healthy diet are vital in managing COPD.**

## Get exercising

With exercise, it does not matter whether you can outperform others; what matters is to challenge yourself. If you were able to walk for half an hour last week and three quarters of an hour today, then you have already gained a small victory. It does not happen on its own. But you can make it easier for yourself. A few tips are provided here:

Do not exercise alone but in a group. You will keep each other occupied and you will keep enjoying it. Set realistic challenges. Don't go out and buy a racing bicycle, just go for a gentle cycle every day. You can even use an electric bicycle for this. Ever been on a tandem bicycle? Give it a try. Frequency is more important than the exact achievement: it is

better to do your shopping on your bicycle every day than to try to make an impressive effort a few times a month.

Select an activity that you want to keep doing for six weeks. This is a manageable period, in which you will really notice the effect of your efforts. This will stimulate you to continue.

Take your prescribed treatment exactly as instructed, as this will offer optimum dilation of your airways and make it easier for you to exercise. This will train your body more quickly and you will notice a greater effect.

If you want to take a more professional approach you could talk to a physiotherapist. He or she can set up a tailor-made exercise pro-

gramme for you. A physiotherapist can also answer your questions and take away any concerns that you may have about exercise and exertion.

The most important thing is that you make exercise a permanent part of your life. Take the stairs instead of the lift. Use a bicycle instead of the car for your shopping. Create an oversight of what exercise you take and what benefits it provides. Many people enjoy recording their activities and achievements in a diary. Then you can see what you have done and what effect you have achieved. This will really motivate you to continue.

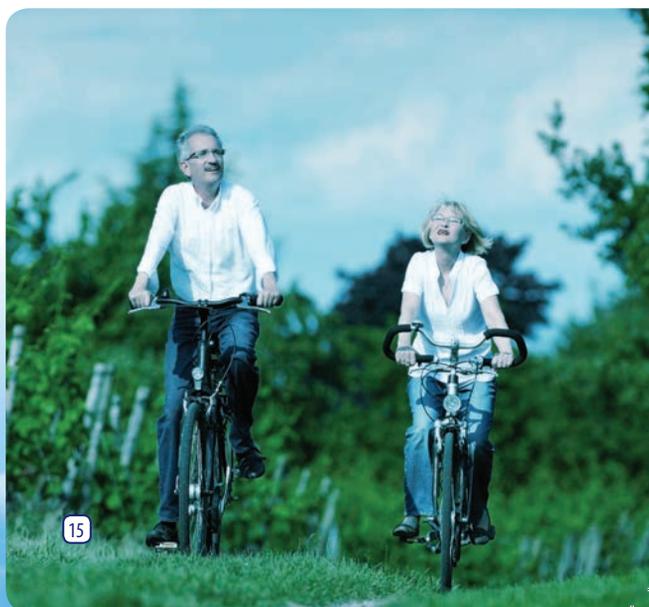
### Good food

COPD makes certain requirements of your diet. After all, you need to work relatively harder to do the same tasks. And the inflammatory processes in your airways also take a toll on your body. Therefore, many COPD patients lose weight. Sometimes that goes unnoticed. This makes it impor-

*Physiotherapist, Utrecht: 'Movement increases muscle strength and fitness, including that of your lungs. So keep moving.'*

tant to keep a careful eye on your weight. And to re-examine whether you eat a healthy diet.

Dieticians can assist you in this. They have many recipes that give you exactly the building blocks and energy that you need, without feeling like you are on a diet.



COPD patient Harry Walker (66): *'I have a dog that I take for a walk every day. I am luckily still able to do this. Exercise is very important, it keeps you in shape and keeps you fitter. And this is my way of exercising.'*

Some COPD patients struggle with excess weight. As you can imagine, this makes life unnecessarily hard: dragging around extra weight with a reduced lung capacity. This is not good. Being overweight also makes you more susceptible to additional diseases and other discomforts. All the more reason to speak to a dietician if you have excess weight. Your GP can recommend someone to you.

Of course you can also take a look at your menu yourself. There are many websites about tasty and healthy food. Even [www.longfonds.nl](http://www.longfonds.nl) has a page dedicated to food. A very complete source of knowledge and recipes is available on [www.voedingscentrum.nl](http://www.voedingscentrum.nl).

Make cooking as easy as possible for yourself. Select easy recipes; there are plenty available. And divide the cooking into manageable phases: first make sure you have all the equipment and ingredients ready, so that you do not have to walk back and forth or bend down for each new pan. Work in an upright position. If you cannot raise the counter, put a raised chopping board on it. That will make a big difference. And if cutting, washing and rinsing a whole pack of spinach is too much effort, buy frozen or pre-cut vegetables. There is nothing wrong with that.

One final tip: ensure that cooking vapours are kept to a minimum. Have the extractor fan checked or buy a better one. Cooking in a microwave, pans with inserts or pressure cookers is also a very efficient way of reducing symptoms.

# Measuring is knowledge



**Measuring is knowledge. This also applies to triggers that cause extra shortness of breath. Therefore, try keeping a diary. Then you do not need to guess at the causes of shortness of breath; instead you will gain insight into triggers, the effects of exercise, medication and weather conditions. That gives you peace of mind and makes taking adequate measures a lot easier.**

A diary can also help you to take your medication on time. If you keep your diary on a daily basis, then the risk is much lower that you will accidentally take too much or too little of your medication.

There is a handy app available on [www.luchtpunt.nl](http://www.luchtpunt.nl). This allows you to record how you are feeling on a weekly basis. The app closely matches the questions asked by your care provider at a check-up, so that can be very handy. But of course a simple paper booklet works fine too.

This activity schedule originates from the Luchtpunt Bewegingsplan.

## Activiteitschema

Start dag en maand:	Welke activiteit:						
Week: <input type="text"/>	maandag	dinsdag	woensdag	donderdag	vrijdag	zaterdag	zondag
Medicatie ingenomen							
Heb zelfs meer activiteiten gedaan							
Heb de activiteit gedaan							
Het lukte met gemak							
Het lukte zonder teveel moeite							
Het lukte met veel moeite							
Het lukte niet							
Notities:	<input type="text"/>						

# Happy holidays



COPD does not have to prevent you from going on vacation. If you want, you can even opt for adapted vacations. Stichting MEE has more information about this. However, if you wish to go your own way, do not go on a humid sunny vacation on the Dutch coast; rather, head for the cool dry mountains, or a dry and warm climate such as Spain, Portugal or Turkey. Cities that are hot and polluted are also not a sensible choice. Nor are holiday homes with pets, smoking and dust. De-

pending on the severity of the COPD, it is also good to think about the presence and quality of hospitals and medical care in the vicinity of your holiday location.

When travelling on an aeroplane, remember that the oxygen concentration at high altitude in a plane is lower than at sea level. Perhaps you would like to take oxygen with you. You will need to arrange this with the relevant airline in advance.

Anita Jutte (49), wife of COPD patient Chris Jutte (62): *'We went on holiday to Switzerland. Chris had one day when he was very short of breath, but other than that we had an excellent vacation. We may also rent a cottage closer to home some time. It is always nice to get away for a few days.'*

## Checklist

- Medical passport (make a copy)
- Extra medicines, in suitcase AND hand luggage
- Medical declaration from doctor about medicines. Compulsory in some countries.
- Your doctor's telephone number.
- Phrase book (check the medical section and supplement if necessary)
- Ask your oxygen supplier about options for delivery to your holiday address and about light weight tanks.

# More information



## Luchtpunt

You can find more information about COPD on [www.luchtpunt.nl](http://www.luchtpunt.nl). Luchtpunt is an objective information platform focusing on asthma and COPD. The website contains all sorts of information about this and you can download or order, free of charge, the leaflets *What is COPD*, *Living with COPD*, *What is asthma* and *Living with asthma*. Other useful organisations and websites:

### MijnLuchtpunt

Section of Luchtpunt, allowing you to record how you feel on a daily or weekly basis. The questions closely match those asked by your care provider at a check-up.  
[www.mijnluchtpunt.nl](http://www.mijnluchtpunt.nl)

### National Association "de Zonnebloem"

Adds colour to the lives of people with physical limitations due to disease, handicaps or advanced age. Organises outings and adapted vacations, among other activities.

Tel. (076) 564 63 62  
[www.zonnebloem.nl](http://www.zonnebloem.nl)

### MEE Nederland

Organisation for support on living with a disability.

Tel. (030) 236 37 07  
[www.meenederland.nl](http://www.meenederland.nl)

### Ik kan stoppen (I can quit)

The information platform that offers extra support for stopping smoking.

[www.ikkanstoppen.nl](http://www.ikkanstoppen.nl)

### Longfonds (Lung Fund)

Champions the interests of people with lung diseases.

Telephone advisory line:  
0900 – 227 25 96 (on working days between 10:00 AM and 02:00 PM)  
[www.longfonds.nl](http://www.longfonds.nl)  
[www.astmakids.nl](http://www.astmakids.nl)  
[www.hebikcopd.nl](http://www.hebikcopd.nl)

### Welder

Welder is a national foundation that aims to guide and empower people in the subjects of health, work and participation.

[www.weldergroep.nl](http://www.weldergroep.nl)

### Quitting smoking

As former smokers, pulmonologists Pauline Dekker and Wanda de Kanter are striving to make the Netherlands smoke-free.

[www.nederlandstopt.nl](http://www.nederlandstopt.nl)

### NISB

Nederlands Instituut voor Sport en Bewegen (Netherlands Institute for Sport and Exercise).

[www.nisb.nl](http://www.nisb.nl)  
[www.sportiefbewegen.nl](http://www.sportiefbewegen.nl)

NL/SPI-141708a



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