

# Pulmonary rehabilitation

## Patient and healthcare professional perspective

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### The patient perspective

Jos Donkers, who was diagnosed with chronic obstructive pulmonary disease (COPD) in 1980 and completed a pulmonary rehabilitation programme in 2003.

I was diagnosed with chronic obstructive pulmonary disease (COPD) in 1980. Following this, I was prescribed 10 different medications, which I have always been really disciplined with taking correctly. However, over the years, I found that my condition declined.

In 2003, I was offered a place on a pulmonary rehabilitation programme at CIRO (Horn, the Netherlands). I was at the facility between 08:00 h and 17:00 h every day for 12 weeks. At first, I went through a physical and psychological assessment, which the team of specialists used to develop my personal plan. The service I received was excellent; the healthcare professionals spent a lot of time talking with me and reassuring me.

During the programme, we had to work really hard and do lots of exercises on the fitness equipment. Each day, we all started to feel the tasks getting easier, and we noticed that our wellbeing was improving. As everyone's condition varied, we found that we progressed at different levels, but we all supported each other and everyone was happy to be given the chance to be on the programme. There was a lot of time for us to talk to each other, and we became a small family during the 12 weeks.

After I completed the programme, I was so happy with the results. I was able to go for long walks again and travel to different countries with my wife. I was also able to play football and tennis with my grandchildren. I felt like myself again.

I have since become involved with Longfonds (the Dutch Lung Foundation) in the Netherlands.

In addition, I have spent 6 years on the board of clients for the hospital in Weert and, since 2010, I have been chairman of the board of clients at CIRO, so my colleagues and I talk to patients regularly at joint lunches or during evening recreation and keep up-to-date with the facilities on a weekly basis. As a former client at CIRO, I am keen to help those on the programme now and in the future as much as possible.

Since the programme, I have been campaigning for the Dutch government and health insurance companies to cover the costs of exercise for people following pulmonary rehabilitation. Currently, if someone is signed onto a pulmonary rehabilitation programme by a doctor, costs are covered by health insurance. However, if, after completing the course, they want to join local exercise classes to keep up their progress, reimbursement would depend on the degree of lung function impairment, with the consequence that some people have to pay for it themselves. Of course, people can exercise at home or go out for walks, but I find exercising with a group of other people to be more successful.

My lung function and physical condition are not good at the moment. During the past 3 years I have experienced other stressful situations that have affected my quality of life: my wife has been seriously ill and I also had my right eye surgically removed due to macular degeneration. I am currently experiencing shortness of breath and I get tired very quickly, both of which really affect my daily activities. For example, climbing a flight of more than 10 steps takes a lot of energy.

I have discussed this with my doctor. In my last assessment in July 2015, we talked about the possibility of me returning to pulmonary rehabilitation. I am happy with making this commitment; I know that a team of highly-skilled specialists will create a daily personal treatment plan for and with



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me, and that they will discuss my problems and needs with me and tailor my treatment, if necessary. Going through an intensive pulmonary rehabilitation programme is not easy; it is a harsh process. However, I know from my past experience that it will significantly benefit me and help to improve my quality of life.

I would recommend that anyone with a chronic lung condition experiencing symptoms talk to their healthcare professional about pulmonary rehabilitation. If you are offered the opportunity to do such a programme, grab it with both hands. It was a fantastic experience for me, and my condition really improved.

## The healthcare professional perspective

Dr Frits Franssen, Chest physician, CIRO, centre of expertise for chronic organ failure

My interest in pulmonary rehabilitation developed during my specialisation as a respiratory physician. What we can achieve through pharmacotherapy in chronic respiratory diseases is quite limited; we can treat symptoms, but a lot of people still encounter limitations in their daily life. I think that rehabilitation can sometimes be so much more effective. Pulmonary rehabilitation also allows people to be actively involved in their own therapy, which is important.

The pulmonary rehabilitation process involves a number of steps. When a person that seems to be a good candidate for the programme is referred to us, we invite them to the centre for a 3-day assessment. During this time, we run a number of physical and exercise tests to get an overall picture of the individual's health. They also have consultations with a dietician, physiotherapist, occupational therapist, psychologist and a respiratory doctor. We use this information to decide whether rehabilitation would be right for the person, and whether they should complete an inpatient or outpatient programme.

The programme consists of different modules. Everyone completes exercise training, but the level depends on the individual's physical condition and their needs. It could involve endurance training, interval training, neuromuscular electrical stimulation, and some people, especially those with musculoskeletal problems, will train in water.

Each service user has a respiratory nurse who manages their case, following up on their needs, helping with an exacerbation-management plan and checking their use of medication. Dieticians are available to help with weight loss or gain, and to advise on a healthy diet. We also offer psychological support for those with anxiety, depression or specific coping problems, and occupational therapy specific to the needs of the individual. There is also medical supervision throughout the programme from a respiratory specialist, a cardiologist and an internal medicine specialist, who closely collaborate.

After the programme, which normally lasts around 8 weeks, we repeat the tests performed at the beginning of the programme to track improvements and identify areas that need further attention.

A lot of people who complete the programme notice differences in exercise capacity and improvements in quality of life. Many change their lifestyles: they quit smoking and go to their physiotherapists after the programme finishes, but there are also those that do not respond. Some may need another intervention. And, for some, the rehabilitation period is the first time that they are confronted with their health issues; the lifestyle change may come afterwards. Getting ready for another, healthier lifestyle is often a goal of the programme in itself.

In general, anyone with chronic lung disease that is experiencing symptoms despite their pharmacotherapy is a good candidate for pulmonary rehabilitation. There are only a few contraindications – for example, among people that have an active malignancy, unstable cardiac disease or have had recent thoracic surgery. Most studies into pulmonary rehabilitation focus on COPD and asthma, but literature has been published recently on the benefits for people with lung cancer, sarcoidosis, interstitial lung disease and pulmonary hypertension. Pulmonary hypertension was formally thought of as a contraindication, and there are some safety issues to consider, but with the right medical supervision it can be really beneficial.

Many candidates for the programme also have other conditions alongside their respiratory issues, and everyone should be properly screened to ascertain whether high-intensity training would be safe for them. In addition, it is important to think about oxygen supplementation in among those with pulmonary hypertension and interstitial lung diseases.

It is important that candidates know what to expect from a pulmonary rehabilitation programme at the outset, and that we think about their goals with them in a clear and realistic way. Doing this before the programme begins can prevent dropouts and ensure that the people who complete the programme really benefit.

In the future, I hope that more people get the opportunity to try pulmonary rehabilitation; there are a lot of countries where it is not widely available, and there are issues with physicians not being aware of the programmes out there to refer their patients. I would also hope that rehabilitation services, although already quite personalised, can become even more precise and focus more on, for example, which exercise should be prescribed to whom.

CIRO is quite advanced and not a fair reflection of pulmonary rehabilitation centres. There is a lot of work to be done in other parts of the world, where facilities are less developed, and we are very willing to help develop centres in other countries. I believe that every centre, no matter what level it is at, has the power to really change the lives of people with chronic respiratory conditions.