



Coping with breathlessness

Breathlessness can be a very frightening and distressing symptom of pulmonary fibrosis. It is important that you learn how to minimise, cope and manage this symptom. Learning to manage and live with breathlessness can make a big difference to your quality of life.

We know that there are many things that can cause breathlessness and it is important to have your breathlessness assessed by your local healthcare team to make sure that there is no other medical cause. Your doctor or nurse might want to do a breathing test, a chest x-ray, blood test or check your oxygen levels with pulse oximetry; this is a finger or ear lobe clip that painlessly records your oxygen levels.

We know that our emotions can affect our breathing – relaxation helps reduce breathlessness

Many of us will have experienced a nervous or anxious situation in the past and may remember how they felt breathless or were unable to speak due to breathlessness. Being anxious about our breathlessness can make our breathing worse.

Relaxation is useful for relieving anxiety. Being able to relax is important for managing breathlessness so try to find what relaxes you. It might be listening to a relaxation tape, listening to classical music, reading a book. It might be just being with your family and friends.

Distraction is also a useful tool to help people relax and forget about their breathlessness. By getting absorbed in something that you enjoy is a good way of switching off.

Over-exertion

It is likely that you will experience breathlessness in pulmonary fibrosis on exertion which means that when you do anything physically active you might get breathless. If you are sitting or doing nothing you will feel fine. With pulmonary fibrosis the scar tissue which is laid down in the alveoli of the lung slows down oxygen entering into the blood. Oxygen is the fuel for our muscles so when our muscles sense that they are not getting the fuel that they need they send a message via the nervous system to our brains, which in turn sends a message to our lungs telling them to breath faster and work harder to get more oxygen.

This is what makes us breathless. Ultimately, we get breathless whilst doing exercise because the muscles are not getting the oxygen they need. This will give you a big clue as to how to control breathlessness on exertion. The first thing to do is to stop and you will notice that, your breathing will slow down and you will recover quickly. It is important to remember this, as this means that you will be able to exert some 'control' over your breathlessness.

You will learn very quickly which activities will make you breathless and which you can manage. This will mean that you will need to decide which activities you can no longer do and need to delegate to others and which activities you still need to be able to do so that you can carry on with a normal life.

So for example: you may get breathless, but have always cut the 6ft. hedge that surrounds your garden, but it has to be done. You might also enjoy and

still want to be able to walk your dog each day. Whilst you have always cut the 6 foot hedge, you need to be realistic about what you can and what you cannot do, what you need to do and what you enjoy doing. It might be sensible to delegate cutting the hedge to someone else. You can then start to work out how you will continue to do the things that you need to do and those that are still important to you and that you want to do.

Having already worked out that if you STOP then your breathing settles quickly, the next lesson to learn is to SLOW DOWN.

Learning to slow down

If you start out slowly and do not rush, you will be able to do more before you start getting breathless.

Unfortunately, some people mistakenly think that if they rush and do things quickly before the breathlessness kicks in that they are likely to be able to achieve more. Sadly this is not the case and there is always a lag in the development of breathlessness and it will always catch up with you in the end. If you start out slowly, then you can sense your breathlessness developing, a bit like a seaside wave building up as it travels into the shore.

Learning to sense the wave building up gives you a chance to remain 'in control'. If you STOP at this point and allow your breathing to settle, then you can start up again as soon as you feel comfortable. If you feel 'in control' of your breathlessness you are less likely to panic which is often the result if you try to rush and 'beat' the breathlessness. Many people with pulmonary fibrosis learn to 'pace' themselves by STOPPING and STARTING.

Unfortunately, we are often used to doing things in a rush, but if you want to continue doing things you must learn to do things more SLOWLY and STOP and

START. This way you will remain 'in control' of your breathlessness and it will not control you!

Other things that can help breathlessness is oxygen. Your healthcare practitioner will be regularly assessing you to see whether you might benefit from oxygen (read section on oxygen). Sometimes people find that by using a walking aid such as a rollator is helpful.



A rollator with basket

A rollator can help as it can support your body weight as you walk. There are several different models; try one with a seat so you can have a rest if needed and a basket so you if you need oxygen you can place it in the basket. Many people find that they can walk further if they are supported. Experiment by using a supermarket trolley and see if this helps you. Sometimes adopting a different position can help breathlessness. By leaning on a wall or resting your elbows on pillows while sitting.

Some people find that opening a window and having cool air circulating can help breathlessness. Likewise a fan can help to move air and feel refreshing

around the face. There is some evidence that using a hand held fan can help reduce the unpleasant sensation of breathlessness.

Drugs can also help reduce the sensation of breathlessness. They will not take it away, but in the same way that drugs can reduce the feeling of pain, drugs can also reduce the feeling of breathlessness. Some of these drugs include small doses of morphine which can also have side-effects of constipation. Some drugs work by reducing anxiety brought on by breathlessness. Talk to your doctor or nurse about drugs that might reduce the sensation of breathlessness.