

Patients suffering from pulmonary fibrosis lack the kind of support cancer patients receive

Pulmonary fibrosis is an incurable lung disease, with a prognosis worse than most cancers. Action for Pulmonary Fibrosis is developing a national network of groups to support patients on their difficult journey.



Steve Jones
Chair of Trustees,
Action for Pulmonary Fibrosis

The idea of people affected by illness or loss coming together to form groups to help each other was spearheaded by Donald Macmillan, after losing his father to cancer in 1911. The society he formed grew into MacMillan Cancer Support. Donald Macmillan was a trailblazer who realised that peer support could hugely improve outcomes for patients.

Cancer support is now well developed across the UK, yet, for those suffering from many incurable diseases, there is little support available. Pulmonary fibrosis, a progressive lung scarring disease, affecting over 70,000 people in the UK, is one of those diseases. This is why the charity Action for Pulmonary Fibrosis (APF) is spearheading the development of

pulmonary fibrosis support groups across the UK.

Pulmonary fibrosis support groups are becoming more accessible

Working with healthcare professionals and patients, APF has helped grow the number of groups from five in 2013 to 65 today. It aims to have 100 support groups up and running by 2020, so that no pulmonary fibrosis patient will live more than an hour away from a support group.

Average life expectancy after diagnosis is three-years

To be diagnosed with pulmonary fibrosis, is devastating. The prognosis for idiopathic pulmonary Fibrosis (IPF), the most common form of the disease, is worse than for many cancers with an average life expectancy of only three years. As

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the disease takes hold, you become more and more breathless – unable to climb stairs or walk more than 50 or 100 metres on the flat, without resting. You become dependent on supplementary oxygen. Your world closes in on you and you feel isolated. Who can you turn to for help?

When your world is shrinking, you need support

I speak from experience in saying that the impact of support groups, for many patients, can be life-changing. I lived with IPF for many

years. Joining my local support group transformed my life. I met other patients and their families and felt less alone. I felt supported by other patients and could, in turn, support them. I learnt more about my disease and felt empowered to manage it better. In the end, I was extremely lucky and received a lung transplant. Sadly, few patients are so fortunate.

Although progress is being made in treating pulmonary fibrosis, we are a long way from really effective treatments or a cure. Patients must battle on in the knowledge that the best they can hope for is that current drug therapies may delay the inevitable. A support group can do so much to help them cope well with that reality.

One of APF's founding trustees was Wendy Dickinson whose father, Nottingham Forest Football Manager, Peter Taylor, who won two European Cups with his partner

Brian Clough, died from IPF in 1990. She says: "When I visit support groups, it is wonderful to see new people walk out of the room after a couple of hours with a smile on their face, even though they may have felt desperate when they walked in. Groups offer advice, information and friendship and, most importantly, the chance to talk to people who are sharing your difficult journey." ■

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How can you help yourself when living with pulmonary fibrosis?

HEALTHY LIFESTYLE

Have a healthy, balanced diet with plenty of fruit and vegetables. These contain antioxidants, which may be beneficial to your lungs as well as your general health. Try to keep your weight optimum, as you will feel more breathless if you are overweight.

PULMONARY REHABILITATION

Ask your doctor or nurse to refer you for a course of pulmonary rehabilitation. Originally set up for people with chronic obstructive pulmonary disease (COPD), many patients with pulmonary fibrosis benefit from this programme and it is recommended by NICE.

Typically, it involves a six-week course and includes exercise classes to improve muscle strength and fitness, advice on managing breathlessness and other aspects of living with the condition.

EXERCISE

Regular exercise is important for maintaining muscle strength, improving sleep and general well-being. But exercise can be difficult to do when you are breathless. Getting slightly short of breath when you exercise is safe; however, you must stop if you feel dizzy or have chest pains.

Start with gentle walking around the house or garden on a regular basis. As you feel stronger, you can increase the distance you walk. You may find it helpful to set yourself targets or discuss an exercise programme with your doctor or physiotherapist.

GET VACCINATIONS

People with lung disease are at an increased risk of infection. Having the seasonal flu vaccine may help to reduce your risk. Check that your pneumonia vaccine is up to date, too. Your GP or hospital doctor will be able to advise.

JOIN AN IPF SUPPORT GROUP

Join a pulmonary fibrosis support group and meet other people living with the disease. Support groups provide mutual support and helpful information about how best to live with pulmonary fibrosis. It can be invaluable for your physical and mental wellbeing. See the APF website to find your nearest group.

STOP SMOKING

If you smoke, the most important thing you can do is to stop. There are many resources available to help with smoking cessation. A good place to start is discussing this with you or GP or local pharmacist. For more information visit the NSH smokefree website¹.