Sandra Rock

IDIOPATHIC PULMONARY FIBROSIS

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I would like you to try something for me. Think of five of your friends or family members. Now imagine all of them passing away in the same year. Would you be heartbroken? This is what it's been like for me for the last 15 years, except I lose approximately 10 support group members a year to a devastating disease that has no cure.

Idiopathic pulmonary fibrosis robs you of the ability to transport oxygen so you lose energy, stamina and the ability to do everyday activities. I used to work, shop, travel, swim, maintain my house, do laundry, but now I can't work, and the rest I do on a very limited basis.

In pulmonary rehabilitation, I learned how to climb stairs using proper breathing technique, how to breathe and bend over to empty the dishwasher or dryer, and how to get in and out of bed or the car. These are all things you never think about when you can breathe normally.

I started using oxygen at night because my breathing was so slow I wasn't getting enough oxygen when I slept. It then transitioned to at night and during exercise. Now it's at night, during exercise, or any kind of exertion. Next it will be 24/7.

IPF affects the entire family. My daughters are constantly telling me to stop and rest. I can't run and play with my granddaughters. Jim, my loving husband of 45 years, has now become my caregiver. I can't dance with Jim without using oxygen, so I put it in a backpack and strap it on my back. Swing dancing is a little tough!

Darlene, my wonderful rehab therapist, introduced me to another IPF patient Kathy, and we started a support group in 2002. Unfortunately, Kathy passed away from her illness four months after we started the group.

Three years ago I had to give up the support group because of my health. I'm lucky, though, and for some reason I've lived longer than predicted. Most patients are expected to live three to five years after diagnosis.

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Pulmonary fibrosis (PF) describes a group of lung diseases in which thickening of the walls of the air sacs (called alveoli) caused by scarring (fibrosis). Scarring in alveoli prevents oxygen from passing into blood vessels. This can result in coughing, shortness of breath, fatigue, and low blood oxygen levels. The scarring also makes the lungs "stiff" and difficult to inflate, which means they hold less air than normal lungs.

- The diagnosis is idiopathic pulmonary fibrosis (IPF) when the cause of the PF is unknown.
- The amount of scarring can increase with time, making the lung even stiffer, further limiting its filling capacity, and limiting the ability of oxygen to pass through air sac walls.

Learn more: ATS Patient Education Series. "Idiopathic Pulmonary Fibrosis (IPF)" New York, NY. 2011. thoracic.org/patients

When I ask other patients how IPF has changed their lives, answers include loss of income or loss of intimacy, inability to play sports, dance, do yard work, garden, go camping or traveling. Many people with IPF are also learning to live with oxygen and the fatigue that comes from a continuous cough. It's like your whole world being turned upside down.

One member whose husband has been on the transplant list for months says their strategy is not to plan ahead as they don't know what the future brings. They live each day as best they can, enjoying the simple pleasures in life. For me, it's a good meal or an evening with family and friends. Every extra day is precious.

Last year two medicines were approved by the Food & Drug Administration to help stop the progression of IPF. For many patients living with the disease and unable to take the drug or ineligible for a transplant, there's only anticipation of future research catching up to them, such as new medicines to stop the scarring and possibly even reverse it.