

ON THE ROAD WITH TED P.

THE SUPPORT OF FAMILY AND OXYGEN GET HIM WHERE HE WANTS TO GO

I've always led a busy, active life—enjoying careers in both finance and real estate, and taking cruises and other trips with my wife. When I started feeling short of breath, I went to my family physician complaining about it. From 1997 through 2003 he never found anything wrong. Even though he ordered stress tests, they all came back saying I was OK.

In late 2003 my doctor recommended that I have chest x-rays.

After reviewing the images, he then referred me to a pulmonary specialist who confirmed that I had pulmonary fibrosis, or IPF. The specialist said that there was no cure, and that I could expect to live only another three to five years.

Early in 2004, I was fortunate to join an investigational program at the University of Virginia Hospital. This means that every two or three months my loving wife and I drive five hours up to the hospital for an evaluation. The staff are all just great there, particularly the nurse who administers the program. We almost look forward to making those long drives!

I also exercise, though sometimes keeping to the routine is hard. I am lucky to have a slowly progressing illness, although I can tell that my breathing has diminished. I acquired an oxygen meter that measures my oxygen intake and heart rate. Although I was initially very negative about using oxygen, now I look on it as a very good friend.

Other than that, our lives haven't changed that much. Instead of flying or taking cruises, we load up the car with tanks of oxygen and go wherever we need to. During football season, we go to all the games—home and away—of our local college team, Appalachian State University. In the past 30 years we have missed only five games. Although it's sometimes hard to climb the stadium steps, the satisfaction of being there in person makes the effort worthwhile.

I try to live one day at a time. I'm grateful for 76 good years, a caring wife, our five terrific children, and our seven grandchildren. One of the positives of my illness is that my children and grandkids beat a continuous path to our door to visit.



ONE BREATH AT A TIME

An introduction to oxygen therapy

The amount of oxygen in the air you breathe is one of the things that determine how much oxygen gets into your blood. Lung diseases like IPF make it harder to get oxygen from the air into your blood where it is needed.

Low oxygen levels in the blood usually make you feel short of breath. If the oxygen level in your blood is too low, it can be increased by adding extra oxygen to the air you breathe. An oxygen tank can deliver the extra (supplemental) oxygen needed.

Although some people don't like the idea of having to use an oxygen tank, the benefits you can receive from supplemental oxygen are extremely important. Receiving supplemental oxygen can help to improve your quality of life greatly by:

- Reducing your shortness of breath
- Increasing your ability to be active
- Improving your quality of sleep
- Enhancing your mood and sense of alertness
- Enabling your body to carry out normal functions



Today's oxygen delivery systems are designed for flexibility. While you may use a continuous-flow tank at home for exercise or sleep, smaller systems let you benefit from oxygen therapy with a more discreet device that you can take with you.

Ask your doctor if supplemental oxygen might be right for you. He or she can evaluate your needs and help you determine the best systems. You may find that a prescription for a little extra "O₂" can have a big impact on your ability to participate in activities you enjoy.

Please visit www.fightipf.com for additional information and resources.

IPF Diagnosis and Tracking

To find out whether there is enough oxygen in your blood, your doctor might perform one or both of these tests:

Arterial blood gas: By taking a blood sample from an artery in your arm, your doctor can directly measure the pressure of oxygen in your blood

Pulse oximetry: Using a probe attached to your fingertip, earlobe, or forehead, an indirect measure of blood oxygen saturation can be made

Although reviewed by an editorial team of healthcare professionals, this newsletter is for informational purposes only. It is not intended to replace your doctor's advice. Talk to your doctor regarding your condition, appropriate medical treatment, and activities.

To access previous newsletters and additional resources for people who have IPF and their caregivers

VISIT WWW.FIGHTIPF.COM

NETWORK EXCHANGE

Learning about clinical trials

At this time, there are no approved drugs available to treat IPF. The good news is that new medications are under investigation in clinical studies. These studies help determine the safety and efficacy of potential new therapies.

People who participate in clinical trials may benefit in many ways, whether they receive the experimental drug or the inactive drug (*placebo*) to which it's compared. Some of the potential benefits may include:

- Close monitoring at regularly scheduled visits
- Expert medical care at leading healthcare facilities
- Helping others by contributing to the understanding of their disease

If you have considered asking your doctor about a trial in your area, or if you're simply curious about what is involved, visit the links below.

www.clinicaltrials.gov

A service of the US National Institutes of Health; includes basic information as well as details on all trials currently in process.

www.centerwatch.com

An open resource for patients and healthcare professionals. Includes up-to-date listings of more than 40,000 clinical trials.

www.lungusa.org

Official site of the American Lung Association.

www.coalitionforpf.org

Official site of the Coalition for Pulmonary Fibrosis.

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