



*PULMONARY REHABILITATION AND
OXYGEN MANAGEMENT FOR THE
IDIOPATHIC PULMONARY FIBROSIS PATIENT*

Helping You Make the Most of Every Day



Education. Support. Hope.

LIVING LIFE TO ITS FULLEST

For the idiopathic pulmonary fibrosis (IPF) patient, managing symptoms of respiratory distress can make even the simplest activities of daily living a challenge. Not only does IPF gradually rob you of your ability to breathe properly, but low oxygen levels in your bloodstream can leave you feeling weak, tired and uncomfortable, and compromise your quality of life. You may find yourself curtailing activities that previously brought you pleasure, from walking around the block or visiting the supermarket to attending family outings or enjoying concerts, plays and movies.

Yet if you are an IPF patient, there is no need to put your life on hold. Pulmonary rehabilitation and oxygen therapy are two patient resources designed to help people with chronic lung disease become more active and vibrant while better understanding how your body uses oxygen. Through pulmonary rehabilitation, you can build your strength and endurance – resulting in a richer, more enjoyable life experience. And with supplemental oxygen therapy, you can supply your body with the oxygen it needs and possibly avoid the risk of future cardiac (heart) stress.

Pulmonary rehabilitation and oxygen therapy can help you live life to its fullest. Make it a point to discuss these options with your physician. Why observe life from the sidelines when you can again be an active participant?

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WHAT'S GOING ON IN YOUR LUNGS?

Approximately 83,000 Americans are living with IPF, and more than 31,000 new cases develop each year. This debilitating condition involves scarring of the lungs. The lungs' air sacs develop scar—or fibrotic— tissue, gradually interfering with the body's ability to transfer the oxygen you breathe into the bloodstream, and preventing your vital organs and tissue from obtaining enough oxygen to function normally.

What happens when your lungs lose the ability to transfer oxygen into the bloodstream? The following symptoms can result:

- Shortness of breath, particularly during or after physical activity
- Spasmodic, dry cough
- Gradual, unintended weight loss
- Fatigue and weakness
- Chest discomfort
- Clubbing, or enlargement of the ends of the fingers (or sometimes the toes) due to a buildup of tissue

As you can imagine, these symptoms can greatly impact the quality of life. Fortunately, both pulmonary rehabilitation and oxygen therapy can help minimize lifestyle-altering effects of IPF.

PULMONARY REHABILITATION: BRINGING BACK LIFE'S PLEASURES

Pulmonary rehabilitation programs are designed to help you be as active and functional in your daily life as possible while living with IPF. Most programs include medical management, exercise training to improve endurance and strength, breathing retraining, education, emotional support and nutritional counseling. Physicians, physical therapists, exercise physiologists, nurses, respiratory therapists, psychosocial professionals and nutritionists work together to help you reach your functional goals.

The most important component of pulmonary rehabilitation is exercise, which helps reduce the effects of inactivity, increases your exercise capacity, and allows you to maintain activities of daily living. Emotions associated with IPF— including depression and anxiety — may interfere with your daily activities. Psychosocial counseling and emotional support are also key components of pulmonary rehabilitation and can help alleviate these feelings.

Pulmonary rehabilitation also addresses nutritional issues, as severe lung disease may cause weight loss. Nutritionists can teach you how to eat properly and evaluate your oxygen saturation level during meals. Finally, education will help empower you – teaching you how to get the most out of life while living with IPF.

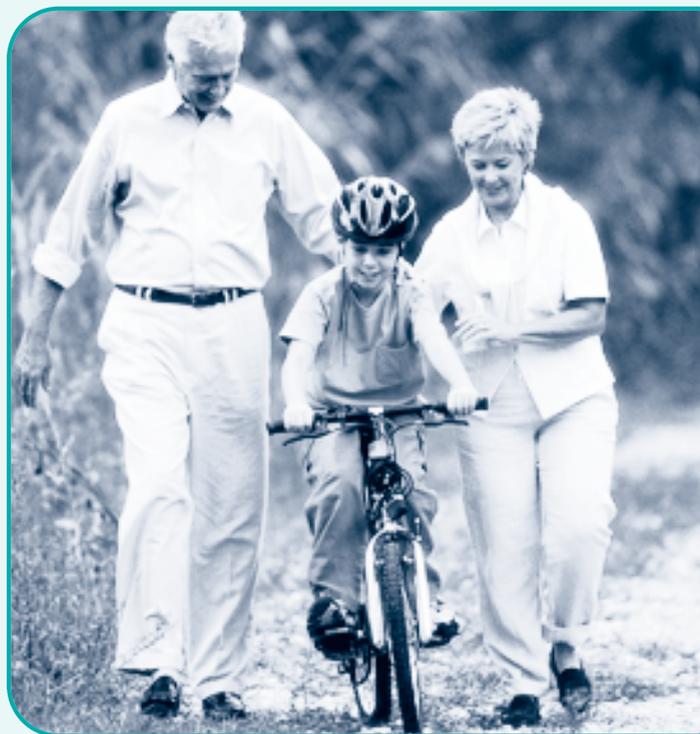
Pulmonary rehabilitation programs are designed to help prolong life, reduce disability and raise your level of physical and social functioning to the highest possible level. Since each individual with IPF presents unique challenges, pulmonary rehabilitation programs are individually tailored to your needs. You will receive individual assessment and instruction, as well as an opportunity to take part in group activities.

ARE YOU A CANDIDATE FOR PULMONARY REHABILITATION?

If you answer yes to any of the following questions, you may be a candidate for pulmonary rehabilitation:

- Is your shortness of breath compromising your lifestyle?
- Do you want to learn more about your disease and improve your self-care?
- Do you want to discover ways to improve your breathing?
- Do you want to increase your exercise endurance?
- Do you want to maintain your activities of daily living?

Through breathing retraining, regular exercise, proper nutrition, psychosocial support and ventilatory therapy, you can dramatically improve your breathing ability – and your ability to make the most of every day.



SUPPLEMENTAL OXYGEN THERAPY: ANOTHER VITAL TOOL

Another vital tool that can help people with IPF lead fuller, more active lives is supplemental oxygen therapy. Oxygen, which can be provided by a local medical equipment company for home use, allows you to be more active in your life.

Supplemental oxygen can:

- Decrease your shortness of breath – especially with exercise.
- Increase your activity.
- Improve your quality of life.
- Increase life span by decreasing the extra work your heart is doing because of low oxygen saturation levels.

Oxygen is a gas that you can't see, taste or smell, yet it is in the air all around us and is necessary in order to survive. Why is oxygen so important? Oxygen is vital in the production of chemical energy in the cells of your body that all organs and tissues need to function optimally. Reduced levels of oxygen in your body can injure cells and may cause cell death. Indeed, this lack of oxygenation has been shown to decrease life span by making your heart work too hard.

The amount of oxygen in the air is always the same – 21%. This is enough for people with normally functioning heart and lungs to thrive. However, a person with IPF often benefits from breathing air with a higher concentration of oxygen because the scarring that occurs in IPF patients can slow the movement of oxygen into the bloodstream, requiring the lungs to work harder. Supplemental oxygen helps increase the amount of oxygen that is available to be transferred from your lungs' air sacs into the bloodstream. This is why you and your doctor should discuss supplemental oxygen as part of your treatment plan.



Photo courtesy of National Jewish Medical and Research Center, Denver, CO.

WHO NEEDS SUPPLEMENTAL OXYGEN?

If you are unable to maintain the necessary amount of oxygen by just breathing room air, you may require supplemental oxygen. To determine if you need oxygen, your doctor will order the following tests:

Arterial Blood Gas – This may be evaluated by drawing blood from an artery in your wrist, which directly measures the amount of oxygen in your blood.

Pulse Oximetry – This is a test performed by placing a probe attached to your fingertip, ear lobe or forehead that is attached to an oximeter to indirectly measure the amount of oxygen in your bloodstream.

If your results breathing room air oxygen at rest, with exertion or with sleep are:

$PaO_2 \leq 55$ mm HG measured by arterial blood gas

$SaO_2 \leq 88\%$ on room air measured by pulse oximetry

you will require supplemental oxygen therapy. Once your doctor has your test results, a prescription for supplemental oxygen will be written. Oxygen is extremely important to your quality of life, and should be thought of as one of your medicines.

PORTABLE AND CONVENIENT

There are many types of oxygen supply systems, and several of the newer type are smaller, lighter, and more efficient – allowing you to benefit from oxygen therapy both at home and while traveling. Newer portable “pulse-dose” liquid oxygen systems give patients great flexibility and mobility, allowing them to breathe easier and enjoy life again. IPF patients may only need supplemental oxygen support during activity or sleep, but patients most often benefit from a continuous oxygen delivery system that helps maintain your oxygen saturation levels at all times. Your pulmonary doctor will help you determine the appropriate amount of supplemental oxygen necessary to support your needs.

Of course, oxygen use also requires heightened awareness of safety issues. For example, oxygen itself is not flammable, but it will support fire. That means that if anything nearby the oxygen source should ignite, it will flame quickly. Consequently, no one should smoke near you while you are on oxygen therapy. In addition, you should keep oxygen 10 feet away from sources of ignition such as gas stoves, candles, fireplaces or space heaters.

TALK TO YOUR DOCTOR

Both pulmonary rehabilitation and oxygen therapy require a prescription from your doctor. If you are an individual with IPF, make it a point to discuss these options with your physician upon your next office visit. In most instances, both “prescriptions” are covered by insurance, and both can help enhance the quality of your life.

There is absolutely no need to suffer with shortness of breath or dramatically decreased activity when such valuable and effective therapeutic options are available. Be proactive and find out more from your physician. And make the commitment to enjoy every single precious day.



ADDITIONAL RESOURCES

American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR)

www.aacvpr.org

401 North Michigan Avenue, Suite 2200

Chicago, IL 60611

312-321-5146

aacvpr@sba.com

American Association of Respiratory Care (AARC)

www.aarc.org

9425 N. MacArthur Blvd. Suite 100

Irving, TX 75063-4706

972-243-2272

info@aarc.org

Breathin' Easy

www.oxygen4travel.com

225 Daisy Dr.

Napa, CA 94558

888-699-4360

National Home Oxygen Patients Association

www.Homeoxygen.org

5454 Wisconsin Avenue, Suite 1270

Chevy Chase, MD 20815-6920

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The following publications were referenced by the authors in developing this educational material:

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About the Coalition for Pulmonary Fibrosis

The Coalition for Pulmonary Fibrosis (CPF) is a 501 (c) (3) nonprofit organization dedicated to advocating on behalf of all those affected by IPF. The CPF's nonprofit partners include the Mary D. Harris Memorial Foundation, The Pulmonary Paper, the Caring Voice Coalition, Second Wind Lung Transplant Association, the Autoimmune Related Diseases Association, and more than 30 leading IPF treatment and research centers nationwide. For more information on CPF, please visit www.coalitionforpf.org or call (888) 222-8541.

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