



## Oxygen Access and Management in PH

2018 PHA on the Road – Milwaukee

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### Session Description

Supplemental oxygen is a drug, just like other PH medications. Panelists will review the basics and benefits of prescribed oxygen and how it works as an important medical therapy for PH patients. In addition, they will discuss how the need for supplemental oxygen is determined; access and safety concerns; and the different delivery modes. Panelists will also share tips for traveling with oxygen.

### Objectives

At the end of this session the participant will be able to:

- Understand why oxygen is an important part of PH management
- Discuss how the need for oxygen is determined and what options are available
- Describe oxygen safety, tips and tricks to living with oxygen therapy
- Understand issues related to traveling with oxygen and PH medications

### Oxygen: Why Do I Need It?

Wearing supplemental oxygen can help by relaxing the blood vessels in the lungs, decreasing the blood pressure in the lungs and improving PH symptoms. Shortness of breath, fatigue, and dizziness are all signs of low oxygen level; however a person can have low oxygen levels with no obvious symptoms. If oxygen is recommended by your PH team, it is just as important as any of the medications that are used to treat PH.

### How Do You Decide How Much Oxygen I Need and When I Need to Wear It?

- Each person's oxygen needs and guidelines for use are unique.
- Ideally, your oxygen saturation level, measured with a pulse oximeter, should stay above 90%.
- Oxygen flow rates can range from 1-15 liters per minute and often need to be increased when you exercise.
- A pulmonary rehabilitation program is a safe venue to determine exactly how much supplemental oxygen you need and when. It can teach you ways to preserve oxygen consumption, improve your circulation and help the body better use oxygen.

### Types of Oxygen Therapies

- Oxygen delivery systems can be stationary or portable. Portable oxygen comes in cylinders, liquid oxygen containers and as portable oxygen concentrators. Your PH team will help you determine which oxygen delivery system best meets your needs.
- Oxygen is provided by either constant flow or a "pulsed-dose" with the use of a regulator that helps to conserve oxygen. However, not everyone can maintain high enough oxygen levels with the pulsed-dose devices.

### Tips for Wearing Oxygen

- Humidification may help with nasal dryness, sore nose and nose bleeds; a humidification bottle can be added to your home oxygen system
- Saline nasal gel or spray can be applied frequently in and around the nose and may help sore areas behind the ears; avoid petroleum-based products.
- Eyeglass cushions are a great way to help ease ear irritation. They can be purchased just about anywhere - Walmart, Meier, Walgreens, Target.
- A rolling backpack may help carry heavy oxygen tanks and supplies
- Always take an extra tank/battery with you even if you don't feel you'll need it.
- Place a sign in your home and car window notifying others that you have oxygen in use.

- Take a small bag with extra cannula, regulator, and key when you leave the house.
- Ask your oxygen company for swivel connectors to help keep your tubing from tangling.
- Keep a copy of your oxygen prescription on hand.
- If you have Medicare, do your research before selecting an oxygen supplier. You can only switch every 5 years.

### **Safety and Oxygen Therapy**

- Always keep oxygen cylinders secure.
- Do not allow smoking in your home.
- Notify your utility providers and local fire department that you are using oxygen in your home; they can put you on a “top priority listing” in case you lose power.
- Keep the service number for your oxygen equipment nearby in case something breaks.
- Make sure your smoke detectors work properly and replace batteries every six months.
- Make a quick escape plan in case of a house fire to prevent panic and confusion.
- When not in use, store your oxygen equipment far from sources of heat.
- Lastly, make sure your electric company knows you are on oxygen. Ask to be put on a priority list if your power goes out so your service is returned quicker. Most companies will accommodate this request.

### **Plan Ahead for Travel**

Part of the goal for the treatment of PH is to help a patient become more active and able to enjoy activities such as traveling. Wearing oxygen requires extra steps in preparing to travel.

- Begin planning at least six weeks prior to your departure date; discuss travel plans with your doctor, including where and when you want to go and how you plan to get there.
- Complete necessary letters and forms from your doctor early; request a letter from your doctor explaining your medical condition and need for specialty medications.
- Always carry contact information for your doctor and coordinator, including name and phone number; provide travel partners with your emergency contact information.
- Look up PH centers or tertiary care hospitals close to your vacation spot or along your travel route. PHA’s website lists PH Care Centers across the country at [www.PHAssociation.org/PHCareCenters/Accredited-Centers](http://www.PHAssociation.org/PHCareCenters/Accredited-Centers).
- Always carry an up-to-date list of your medications and oxygen prescription when traveling; if on an infused medication, make sure that list includes a note to contact your PH doctor before stopping (for example: “Short half-life - DO NOT DISCONTINUE before contacting [Insert PH Team Contact Information Here]”).
- Carry-on your PH medications; DO NOT put them in your checked baggage.
- Consider having a partner separately carry extra critical medicine.
- Carry your medications in their original pharmacy bottles with your doctor’s letters.
- Learn how to troubleshoot your equipment or travel with a capable, trained companion.

### **Treatment Access:**

Your oxygen supplier must provide the primary oxygen system (e.g. liquid canisters, portable concentrator etc.) prescribed by your doctor. If you having trouble getting access to the equipment you need, work with your PH care team to make sure that your letter of medical necessity is current and specific enough. If you continue to have problems:

- Medicare recipients contact 1-800-MEDICARE and ask for the durable medical equipment ombudsman
- Oxygen users with commercial insurance, contact your state’s Department of Insurance