

On the go: Traveling with oxygen and PH medications

St. Paul, Minn. 2017 PHA on the Road



Session Description:

Patients with PH need careful planning to have a wonderful travel experience. This session will discuss how to prepare for travel to have a safe trip. Oxygen therapy and safe medication management is essential for many PH patients who are considering travel and long trips away from home. Panelists will review practical considerations during travel as well as determining oxygen requirements for travel and how they can be met with various devices.

Learning Objectives:

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

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

Overview

Discuss your travel plans with your doctor well in advance. Tell him/her where you want to go, what you plan to do and how long you plan to stay. Ask him/her if there are any potential problems with your plans.

- Request a letter from your doctor explaining your medical condition and need for specialty medications including need for infusion pumps, nebulizer devices and oxygen use during travel as well as your specialty pharmacy contact numbers for emergency assistance
- You need to be able to trouble shoot all of your equipment or travel with a capable, trained companion
- You need to be responsible for making your own travel arrangements
- Patience, perseverance, and planning are key

Specific Vacation Plans

- Discuss your travel plans with your doctor. Are there certain activities that should be avoided?
 - Swimming
 - Contact sports
 - High impact activities
- Plan activities to avoid dehydration, long lines (standing) and extremes of temperature.
 - If traveling to an amusement park, be familiar with park's rules.
- Plan for a stroller or wheelchair with ample cargo space to manage your equipment.

Important Considerations

Planning Ahead

- Contact your specialty pharmacy.
 - You can never be too early!
 - Notify your pharmacy of your destination, and ask for assistance
 - Carry your specialty pharmacy toll-free number with you at all times
 - Carry emergency instructions; e.g. how to use pump

On the go: Traveling with oxygen and PH medications

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- If you are traveling out of the country, you may be able to get an extended supply of medications (more than a month supply) to avoid shipping issues
- Keep MD name, coordinator, and phone number on hand
- Look up PH centers or tertiary care hospitals close to your vacation spot or along your travel route
- Wear medical alert jewelry
- Inform and provide your traveling partners of your emergency contact information
- *Pack your PH meds in your carry-on, not your check-in bag!*
- Consider having a partner separately carry extra critical medicines
- Carry your meds in their original pharmacy bottles with your doctor's letters

Success with PH Medications – What Can You Do?

Always keep an accurate, written list of all medications that you take and provide for all healthcare professionals involved in your care.

- Include prescription, over-the-counter and herbal or dietary health supplements
- Consider using medication boxes to help with organization of dosage regimens
- Write down travel questions and bring to your clinic visits
- Keep a log of any problems or possible side effects that you may have experienced
- Anticipate refill needs; alert your healthcare provider in advance if you need to have prescriptions renewed while traveling to avoid missing doses
- Make sure you can get your medication while traveling
 - Call your specialty pharmacy if you need your prescriptions shipped to a different address
 - If medication will be delivered to your home, be sure to arrange for a family member or neighbor to take the package inside for you
- Advanced therapies (prostacyclins):
 - Keep copy of dosing sheet from specialty pharmacy
 - Vial concentration (Remodulin®)
 - Pump used; IV or SQ
 - Dosing weight, dose, final concentration, base solution (e.g., normal saline vs. other), rate
 - Maintain back-up supplies (e.g., cassettes)
 - Letter from healthcare provider regarding supplies when traveling (airlines)
 - Try to call the airline well in advance to determine what their regulations are for traveling with medication and what documentation they require
 - Give the doctor's office fair time to get this information to you and the airline

Oxygen: Why Do I Need It?

Lower oxygen levels can cause further narrowing of the pulmonary arteries, leading to increased pulmonary artery pressure and increased work for the heart. While there can be many signs and symptoms of low oxygen levels (shortness of breath, fatigue, chest pressure, leg cramps, lightheadedness, dizziness, fingers and lips turning blue and passing out), it is important to know that a person may have no obvious signs or symptoms while their oxygen level is low. Wearing oxygen can help by decreasing the pressure in the arteries and improving symptoms. If oxygen is needed, it is just as important as any of the medications that are used to treat PH.

On the go: Traveling with oxygen and PH medications

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

Levels of needed oxygen and guidelines for your oxygen regimen will vary from one individual to another. While some people need to wear it throughout the night, others may just need it during an exercise. *It is a spectrum*, but most need to wear it 24/7.

- Oxygen flow rates can range from 1-6 liters per minute. Some people even require oxygen as high as 15 liters per minute.
- Often the oxygen flow rate needs to be increased with exercise. A pulmonary rehabilitation program is a perfect venue in which to determine exactly how much supplemental oxygen you need.
- A pulse oximeter helps determine when and how much oxygen is needed. The goal is to keep the oxygen saturation level greater than 90%.

Medicare and Oxygen:

Insurance companies typically follow the Medicare guidelines, which state that:

- Oxygen saturation level must be 88% or less to qualify for oxygen. The test is performed with the person sitting still without supplemental oxygen.
- If the oxygen saturation is 88% or lower while at rest, oxygen is then added to bring the patient's saturation level to 90%. In this case, the patient would require supplemental oxygen at all times (rest, exertion, and sleep).
- If the oxygen saturation level still remains greater than 88% without supplemental oxygen while at rest, two further tests should be done – oximetry during exertion and an overnight pulse oximetry. The oxygen saturation level must drop below 88% for more than 5% of the test time to qualify for supplemental oxygen during sleep.
- Once the oxygen saturations are obtained, a prescription is sent to an oxygen company along with clinical notes from the visit and insurance information. The oxygen company then sends forms back to the provider to sign. After that is received, the oxygen can be delivered. *All information needs to be with the oxygen company within 30 days of the date of testing or the process starts over.* Only a few oxygen companies have the Medicare contract, which may change on a yearly basis.

Types of Oxygen Therapies:

- Most who use supplemental oxygen will have a concentrator at their home, and usually a large oxygen cylinder to be used if there is a power outage.
- Portable oxygen comes in cylinders, liquid oxygen containers and as portable oxygen concentrators.
- Cylinders come in several sizes and some may be filled at home by the patient.
- Oxygen is provided by either constant flow or a “pulsed-dose” with the use of a regulator that helps to conserve oxygen. Not everyone can maintain their oxygen levels high enough with the pulsed-dose devices, especially those on more than 4 liters per minute.
- Portable oxygen concentrators come in a variety of sizes and flow capabilities. They run on batteries which must be recharged frequently.

Traveling with Oxygen:

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.

- This process should start at least 6 weeks prior to the date of travel.

On the go: Traveling with oxygen and PH medications

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- Patients need to call the oxygen companies to request a portable oxygen concentrator (POC) for their trip. This is usually available for rent for a fee. There is usually high demand for the POC, so get the request in early.
- Often your oxygen prescription may be different during air travel than when “on the ground.” Please verify exactly what your doctor recommends prior to travel
- Keep a current oxygen prescription with you for emergencies.
- Sometimes, a different oxygen company needs to be used. If this is the case, oxygen qualification may need to be performed again.
- If traveling by plane or on a cruise, the airlines and cruise company need to be contacted early in case they have specific forms that require your provider’s signature. Allow time for your provider to complete the forms (~two weeks).
- If you are on BiPAP or CPAP, you should bring your machine and associated supplies with you in your carry-on luggage.

Tips for Wearing Oxygen:

- Humidification can help with nasal dryness, sore nose, and nose bleeds. A humidification bottle can be added to your home oxygen system.
- Saline nasal gel can be applied frequently in and around the nose. It may also help sore areas behind the ears.
- A rolling backpack can help with carrying heavy oxygen tanks and supplies.

Take Away Message:

Plan in advance to travel, do your research and get the letters and forms filled out early. Be prepared for emergencies when traveling. Being on oxygen should not stop anyone from traveling, but advanced preparation is a necessity!

Additional Resources (links and handouts will be available online also):

- <https://www.thoracic.org/patients/patient-resources/resources/oxygen-therapy.pdf>
- https://www.faa.gov/about/initiatives/cabin_safety/portable_oxygen/
- [Traveling with Oxygen PDF](#)
- [Chestnet.org article to read](#)