

Traveling with PH: Medication and oxygen management

Portland, Ore. 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 are 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. Panelists will also discuss how to know how much oxygen to wear when traveling on an airplane or when functioning at higher altitudes. The session will also give an overview of the High Altitude Simulation Test (HAST) which can be helpful in determining oxygen requirements during their travel planning.

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
- Understand what a High Altitude Simulation Study is (HAST), what the purpose is and how the test is performed.

Overview

Discuss your travel plans with your doctor well in advance. Tell him or her where you want to go, what you plan to do, how you plan to get there and how long you plan to stay. Ask him or 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 troubleshoot all of your equipment or travel with a capable, trained companion.
- Be up-to-date with your immunizations.
- Obtain travel/evacuation insurance if traveling internationally.
- You should search online for PH specialists at your destination – and along your route if you are driving. Keep their contact information in case you have an emergency. You can find PH specialists by:
 - Asking your health care team
 - Accredited PH Programs: www.PHAssociation.org/PHCareCenters/Accredited-Centers
 - All Physicians Connected to PHA (have not necessarily been reviewed by the PH Care Centers Program): www.PHAssociation.org/Patients/DoctorsWhoTreatPH
- You need to be responsible for making your own travel arrangements.
- Patience, perseverance and planning/preparation are key.

Specific Vacation Plans

- Discuss your travel plans with your doctor. Are there certain activities that should be avoided?
 - Swimming
 - Contact sports

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- High impact activities
- Plan activities to avoid dehydration, long lines (standing) and temperature extremes.
 - If traveling to an amusement park, be familiar with park's rules.
 - Plan your meals to avoid eating snacks or restaurant foods high in sodium.
- 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.
 - 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. You can also ask your PH care team or provider the name of a PH specialist in or around your travel destination.
- 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 checked 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. Make sure you include all doses, routes and how often you take your medication. If you are on a pump medication please know the dose and not just the pump rate.

- 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. It is also recommended that you count your medications and days you will be away from your pharmacy if they do not ship. You may need to request a "vacation" disbursement of medication.
 - 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 the dosing sheet from specialty pharmacy.
 - Vial concentration (Remodulin®)

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- 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 health care 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.
 - Request the "bulkhead seat" whenever possible when taking an airline flight. The bulkhead seat is usually the seat that separates first class from economy class. There may or may not be additional cost. This seat usually has more room and close to bathrooms (If you are traveling with a portable oxygen concentrator, it will need to be stored under the seat in front of you so you will not be permitted to sit in this row.).

Oxygen: Why Do I Need It?

Lower oxygen levels can cause further narrowing of the blood vessels in the lungs, 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, passing out and/or fingers and lips turning blue), 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.

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 who need it 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 safely 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.

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- 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.
 - The Travel Company
 - Once you know your travel plans, it is recommended that you check to see what the requirements are for your specific air or cruise line, train or bus as their rules and regulations vary. This information is usually available under the “accessibilities: area on their websites.
 - Most companies appreciate at least a 48 hour notice of travel with POC - a phone call is best.
 - The Oxygen Company:
 - Request a **FAA approved** portable oxygen concentrator (POC) for the trip. There is usually a fee (may be covered by insurance). There is usually high demand for POCs, so get the request in early!
 - Have a back-up POC and battery (150% of the duration of your flight, plus ground connection time).
 - Leave home with fully charged batteries and keep plugged in whenever possible. Power source may or may not be available in the plane, train or bus.
 - Arrange for oxygen tanks delivery if needed to be sent to your destination, are available on the cruise or at intervals during land travel.
 - The company can help you arrange for oxygen pick-up or delivery from another source at your destination, if needed.
 - Ask for an oxygen supplier at your destination in the event you have a malfunction or other oxygen emergency.
 - You could ask for a referral to a company at your final destination or cities along your route and give them permission to share information if necessary.
 - Many cruise lines will provide oxygen while others will allow you to bring your own oxygen. If you're bringing your own, you'll want to calculate how much backup oxygen

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- to bring for the duration of your trip. If not, you should arrange for oxygen pick up at various ports.
- The physician's office:
 - You must have a physician consent form (obtained from company website or printed on physician's letterhead) to travel by plane, train or ship. Keep this letter on your person during travel. This letter is to include:
 - Capability to operate the POC: Recognize and respond appropriately to its alarms.
 - When the POC use is necessary (taxi, take-off, in-flight, landing).
 - The maximum flow rate corresponding to the pressure in the cabin under normal operating conditions (cabins are pressurized to an altitude of 8,000 feet).
 - Often your oxygen prescription may be different during air travel than when "on the ground." if land travel to a place of higher altitude. Please verify exactly what you doctor recommends prior to travel
 - Keep a current oxygen prescription with you for emergencies.
 - Other considerations:
 - If you are on BiPAP or CPAP, you should bring your machine and associated supplies with you in your carry-on luggage
 - It's important to store your oxygen out of direct sunlight and away from any heat sources.
 - No one should smoke near oxygen in use or stored

How do you know how much oxygen to use when traveling on an airplane or at higher altitudes?

What is a HAST study?

- High Altitude Simulation Test
- Diagnostic test that calculates a patient's oxygen needs for traveling or while being at a high altitude
- Determines if supplemental oxygen is needed
- How much oxygen is needed at rest and with exercise

What is the purpose of a HAST study?

- To identify patients at risk of developing low blood oxygen levels during airplane flights, or who may become at risk due to functioning at higher elevations
- Is additional oxygen needed above the current oxygen level?
- Why airplane cabins are pressurized
- Airplanes usually travel at around 30,000-40,000 feet.
- Cabins are pressurized to around 8,000 feet.
- HAST test simulates being at 8,000-9,000 feet.
- The higher the altitude, the lower the oxygen percentage.
- 8,000 feet = approximately 15% oxygen.

How is a High Altitude Simulation Study Performed?

(It is performed using a 15% oxygen mixture that simulates being at approximately 8,000 feet)

- The baseline oxygen level is recorded.
- Baseline oxygen saturation and HR is recorded.

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- A baseline Arterial Blood Gas (ABG) is drawn.
- A 15% oxygen, 85% nitrogen mixture is breathed in for 20 minutes.
- Along the way, a decrease in oxygen saturation is monitored and adjusted (by adding oxygen) to keep it above a certain level.
- At the end of the 20 minutes, another ABG is drawn.
- For 10 minutes the patient exercises and is monitored again for decreases in oxygen saturation and the supplemental oxygen is adjusted accordingly.
- The final oxygen level needed at rest and with exercise at high altitude is recorded.
- Most airlines have a list of approved portable oxygen concentrators by the FAA.

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:

- <https://www.thoracic.org/patients/patient-resources/resources/oxygen-therapy.pdf>
- https://www.faa.gov/about/initiatives/cabin_safety/portable_oxygen/