

# PH and Preparing for an Emergency



Be prepared for potential emergencies. Use these tips to create a plan to stay a step ahead of an emergency.



## When to Seek Emergency Care

If you experience any of these symptoms or situations, seek emergency help or dial 911.

- Chest pain.
- Loss of consciousness.
- Coughing up blood.
- Worsening shortness of breath.
- Dislodged line/damaged or non-functioning catheter.
- Pump has stopped.
- You ran out or are about to run out of medication for your pump.

It's important to know your normal range of oxygen saturation. If your oxygen saturation drops below your normal range, you may notice:

- Unusual shortness of breath.
- Dizziness.
- Rapid heart rate.
- Headache.
- Blue lips, fingernails or earlobes.

**Oxygen saturation (O<sub>2</sub> sats) range:** \_\_\_\_\_. If you experience the symptoms listed above, and your oxygen saturation is below normal for you, this is an emergency.



## Infusion Medication and Oxygen Tips

- Take your temperature if you have a fever or sweats, which could indicate infection.
- If you have an infusion pump, keep your backup pump and all supplies in your emergency kit. Always bring backup supplies to the hospital.

- If you have a central IV line (catheter), keep your site cleaning and dressing supplies with you when you're away from home or if you need to leave home for an emergency. Supplies include gloves, mask, alcohol pads, dressings and tape.
- Power outages are dangerous for those on infusion medication and those who use oxygen. Contact your power company about your health condition so it lists you as high priority in a power outage. Work with your health provider to complete/submit paperwork to ensure your power stays on in an outage.
- Consider investing in a generator, and learn how to use it.
- Set aside a small portable cooler and freeze some large ice packs to keep your epoprostenol (Flolan) cool for several hours. Make sure your cooler holds several ice packs and your medicine. In case of a power outage, fill a cooler with ice to keep your epoprostenol cold.\*\*
- Keep a copy of your oxygen prescription/dosage in your medicine bag.
- Pack a bag with batteries and supplies you would need if you have to leave home. Include an extra section of oxygen tubing connectors.

\*\* Applies only to Flolan or generic epoprostenol, **not** for Veletri or treprostinil (generic or branded Remodulin).



## COVID-19 Public Health Emergency Planning

It is important to create and discuss an emergency plan with your PH care team in case you have symptoms of COVID-19 that need medical attention. Symptoms include cough, shortness of breath beyond your typical PH experience, difficulty breathing, fever, chills, muscle pain, sore throat, new loss of taste or smell, nausea and vomiting or diarrhea ([www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html](http://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html)). Your PH specialist might give you a specific number to call to determine whether you should go to the emergency room. Make sure your caregiver(s) know your COVID-19 emergency plan.

During the COVID-19 public health emergency, it is especially important to follow the Centers for Disease Control and Prevention (CDC) guidelines to prevent getting sick. Find the updated guidelines here: [www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/index.html](http://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/index.html).

The CDC website is the best resource on how to create a plan to protect yourself and your household from COVID-19 and what to do if you or a loved one gets sick. Visit [www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/get-your-household-ready-for-COVID-19.html](http://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/get-your-household-ready-for-COVID-19.html).

## Severe Storms and Natural Disasters

Natural disasters – hurricanes, fires, floods, severe storms and tornadoes – can happen with little warning, so make sure you and your family are prepared. That means having supplies and information on hand, as well as knowing the procedures to follow.





## Emergency or Disaster Preparation Tips

- Refer to power outage tips above for if you are on infusions and/or oxygen.
- Stock up on necessities, especially drinking water, food, first aid kits, flashlights and batteries.
- Keep a supply of extra distilled water for inhaled therapy devices or CPAP machines.
- Ask your PH care team if you can get extra medication and/or supplies (cassettes, syringes, etc.). Some insurance companies will allow early refills for emergency/disaster assistance.
- If you use oxygen, contact your oxygen company to have your tanks filled to avoid running short. Also ask about extra batteries.
- Keep a list of all your medications with you at all times. For infusion patients, state that your infused medication should never be interrupted or discontinued.
- Always keep a list of contact numbers, including your specialty pharmacy, PH doctor/clinic and emergency contacts with you.
- Keep a copy of your electrocardiogram (EKG) in case you need to go to the local emergency room so the emergency professionals can see your “normal” heart rhythm.
- Be sure you have a safe place to go and a way to travel if you need to evacuate. If you are driving, obtain a full tank of gas as soon as you learn of an impending storm.
- If you are running low on medication, need to change your medication shipment address or have another therapy access concern, contact your specialty pharmacy. Find pharmacies open in disaster-affected areas at [www.healthcareready.org/rxopen](http://www.healthcareready.org/rxopen).

### Specialty Pharmacy contact information:

Accredo/Express Scripts: 866-344-4874

Cigna Tel-Drug: 855-326-7463

CVS/Caremark: 877-242-2738

Humana Specialty Pharmacy: 855-478-8405

OptumRX: 855-856-0536

AllianceRx Walgreens Prime: 888-347-3416

- Keep your insurance cards with you when you leave home.
- If you are a member of a PHA support group, exchange numbers with the leader and other members to keep in touch during unexpected events.
- Connect to PHA and local PHers on social media. It’s a fast, easy way to convey information in crisis.
- If you have pets and need to evacuate, make sure you identify pet-friendly hotels. Most shelters don’t accept pets. Check with your local vet about shelters, and learn more on the CDC website: [www.cdc.gov/disasters/petshelters.html](http://www.cdc.gov/disasters/petshelters.html).



## Other Resources

- 2-1-1 National help line to locate local public resources: [www.211.org](http://www.211.org).
- Assistance after a natural disaster: [www.usa.gov/disasters-and-emergencies](http://www.usa.gov/disasters-and-emergencies).
- Making a plan and building a kit: [www.ready.gov](http://www.ready.gov).
- Centers for Disease Control Emergency Resources: [www.emergency.cdc.gov](http://www.emergency.cdc.gov).
- U.S. Department of Health and Human Services information for special populations: [www.sis.nlm.nih.gov/outreach/specialpopulationsanddisasters.html](http://www.sis.nlm.nih.gov/outreach/specialpopulationsanddisasters.html).



## Emergency Preparedness Checklist

- I keep a current list of emergency contact information including a health care provider and personal caregiver (See contact list on the EMS checklist).
- I maintain a current list of all my medications with doses and infusion rates.
- I have discussed an emergency plan with my PH provider.
- I let my PH center know if I have a planned vacation so it can identify the best hospital for me in case of an emergency.
- I keep my specialty pharmacy's 24/7 emergency number with me.
- I have a three- to seven-day supply of all my medications, oxygen and supplies (including distilled water if needed), depending on how soon I can refill my prescriptions based on my insurance plan.
- I have my pump, inhalation device, oxygen devices and/or CPAP machine, as well as batteries and appropriate power chargers for any machines I need ready to go in case of an emergency.
- I have an emergency kit with backup medical supplies.
- I keep important devices charged, including my cell phone. I always carry a cell phone and/or let people know where I am going if I am traveling alone.
- I wear a medic alert identifier to convey critical health information.
- For oxygen and/or infusion medication users: I have completed a power saving or sustaining form with my health care provider and submitted it to my power company.

