# Home oxygen for COPD

Trusted answers to common questions

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### We hear you.

Using home oxygen can be confusing and getting the oxygen equipment you need can be difficult.

In this report, we provide a list of questions we have heard that patients or their caregivers have about home oxygen and answers after talking with doctors, respiratory therapists, and discussions with CMS.

These answers should serve as a guide that you should use along with conversation with your doctors and additional resources from <u>the COPD Foundation</u> and the <u>American Association for Respiratory</u> <u>Care</u>. For urgent questions, call your doctor.

If you have additional questions about your home oxygen equipment we suggest you contact:

**Medicare:** 1-800-MEDICARE (1-800-633-4227) TTY users can call 1-877-486-2048

**COPD Foundation:** 1-866-316-COPD (1-866-316-2673) Leave a voicemail if there is no answer. Email them at info@copdfoundation.org

### American Association of Respiratory Care: 1-972-243-2272

If you have a question that is not answered here, you can submit a question by visiting <u>https://is.gd/Oxygen4COPD</u> or by pointing your phone's camera at the QR Code to the right. We will review them from time to time and update this document.



### Sources

This document contains common questions about COPD and their answers from two trusted sources:

### 1. Medicare Coverage of Durable Medical Equipment and Other Devices

Centers or Medicare & Medicaid Services

This official government booklet explains what durable medical equipment is; which durable medical equipment, prosthetic, and orthotic items are covered by Original Medicare; and where to get help with your questions.

Questions 33–35 on pages 11 and 12 and all of theme 7 on pages 14–17 are from this document .

### 2. Questions & Answers from a COPD education workshop

Held on February 17, 2018 in The Villages, Florida co-hosted by the University of Illinois at Chicago and the COPD Foundation. Answers to questions were reviewed and approved by the American Association of Respiratory Care.

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### Theme 1 General questions about COPD

### 1. What is respiratory therapy?

Respiratory therapy is a specialty that involves health-care professionals who receive 2-4 years of formal training at accredited institutions in evaluation and management of patients with lung disease, use of mechanical ventilation and equipment. For further information, please check out the website from the American Association for Respiratory Care (www.aarc.org).

### 2. How do I know the questions I should be asking if I'm new to this?

Write down all general problems, concerns, issues regarding oxygen therapy and discuss with your clinician. The COPD Foundation has a brochure <u>"Optimal Care for COPD"</u> and other single topic <u>Slim</u> <u>Skinny Reference Guides</u> that can help you decide what additional questions you should ask your healthcare professional.

### 3. How often should you be seeing your pulmonary doctor to be tested?

Regular visits with pulmonologist are recommended, this depends on how you do clinically and should be discussed with pulmonologist (if you have more or less symptoms/problems with your oxygen). Generally, a short term follow-up (within 1 month) is recommended after admissions for COPD exacerbations to ensure recovery and address any issues with oxygen. You should talk to your doctor about getting your oxygen needs retested around 3 months after you start oxygen.

### 4. What will medicine do to help us oxygen users?

The scientific community needs to do more research to answer this question.

### Theme 2 Ways to use oxygen

## 5. If you go on oxygen will you be on it forever and can you become dependent on it?

In general, patients remain on oxygen for a prolonged period of time, i.e. years, but in some patients, the oxygen level in the blood can increase to levels above the threshold to meet criteria for supplemental oxygen, e.g. when you are put on oxygen during a COPD exacerbation but recover afterwards, these patients sometimes can come off of oxygen.

Using supplemental oxygen as prescribed by your doctor won't lead to an addiction. However, supplemental oxygen helps the body maintain a level of oxygen in the blood necessary for your body to function, if your body is not able to do it by itself. In that sense, your body will depend on the supplemental oxygen.

6. Why do I need oxygen sometimes and not at other times? (Sometimes I'm on it and off it, when I'm in and out of the hospital) Please see the answer to the question above.

### 7. Why oxygen? Isn't there something I can do to stay off of it?

It is difficult to predict which patient will require oxygen during the course of their disease. Sometimes patients get started on oxygen for reasons other than COPD, like heart failure or pulmonary hypertension. General recommendations for your COPD care include: get regular check-ups with your pulmonologist, stop smoking, stay active, and get your vaccinations to stay as healthy as possible. These can help avoid COPD exacerbations and progression, all of which can cause you to need oxygen.

### 8. How much oxygen should I use per minute?

This depends on determination of oxygen needs. Your clinician would usually do testing of your oxygen needs at rest, with activity, and with sleep.

Theme 2: Ways to use oxygen, continued

### 9. What number am I on and can I change it?

Similar to the #8 on the previous page. Please see the answer there.

If you have a pulse oximeter at home to measure your saturation levels throughout the day, you can discuss with your doctor and respiratory therapist about how to titrate your oxygen based on your saturation readings. That way, you can have an action plan on what to do in different situations.

An example of a guideline might be: if you find you often need to use more liters per minute than you were initially prescribed to maintain saturation you should call your doctor to make sure there isn't a bigger health concern that needs evaluation.

Don't wait until you "feel bad" to check your saturation or use your oxygen. Some patients will not feel short of breath but do in fact have a low saturation.

### 10. What times do you need to actually use this oxygen?

Similar to the question above. This depends on the determination of your oxygen needs. Clinician would usually do testing of your oxygen needs at rest, with activity, and with sleep.

### 11. When do I use oxygen?

Similar to question above. Please see answer there.

### 12. How do I know when I need daytime oxygen?

Similar to question above, this depends on determination of oxygen needs. A clinician would usually do testing of your oxygen needs at rest, with activity, and with sleep.

### 13. Is it possible to do too much?

Like any medicine, oxygen is a medical therapy and should be used at specific times and amount. Too much oxygen can be of no clinical benefit and even be potentially harmful. Please check with your healthcare provider to find out what the right prescription is for you. Theme 2: Ways to use oxygen, continued

### 14. What dictates increase/decrease?

Changes in clinical status, e.g. worsening of COPD (exacerbation) and/or underlying disease other than COPD that might warrant need for oxygen, e.g. heart failure, pulmonary hypertension etc. can change oxygen needs. Regular check-up with pulmonologist and primary care doctor and short-term follow-up after exacerbations of COPD are recommended.

#### 15. How is dosage determined?

See answers to questions #5, 6, 8, 10 and 12.

#### 16. They don't talk about titrating oxygen when you leave the hospital.

This might relate to a few different things. This might relate to lack of communication between different provider teams (Theme: Service issues and advocacy, question #69) or relate to the need to check for change of oxygen needs after hospital discharge (Theme: Ways to use oxygen, questions #5 and 14).

#### 17. Can I go out with oxygen?

Yes. It is encouraged to use oxygen the same way outside as when using it at home. If outside, you will need oxygen equipment that can be carried, e.g. compressed oxygen tanks, or portable concentrators. Your clinician and respiratory therapist can help determine which equipment is best fit for your needs.

### 18. What are limitations of activity with oxygen?

Similar to question above. In general, it is encouraged to use oxygen when determined if there are oxygen needs with activity. If used during activity, you will need oxygen equipment that can be carried, e.g. compressed oxygen tanks, or portable concentrators. Theme 2: Ways to use oxygen, continued

### 19. Do I have to sit up or lie down to use it?

You can use oxygen in any position (standing, sitting, lying down).

### 20. Are there patterns of numbers for how much oxygen to use?

There is no standard number of liters per minute of oxygen to use. It depends on your individual oxygen needs at a certain situation (at rest, with activity, and with sleep) but most patients are first prescribed between 2 to 4 l/min. The prescribed amount may increase over time. Your healthcare provider can help you determine your oxygen needs.

### 21. How do you know how much you're taking in on a pulse dose?

It is difficult to know how much amount of oxygen actually reaches the patient. In contrast to continuous flow, which provides a constant flow of oxygen, pulsed dosing only provides flow of oxygen when the patient takes in a breath. One way to test, if you receive an adequate amount of oxygen for your needs is to check your oxygen saturation with a pulse oximeter.

### 22. Can you swim with oxygen?

Some water activities may be possible, however swimming may not be feasible as the oxygen delivery device may not be waterproof. Please check with your DME provider. You can also read about other oxygen users' experiences with this topic on the <u>COPD Foundation's 360Social</u> free online social network.

### 23. Can I take a shower with oxygen on?

Yes, however some of the equipment may need to stay dry, especially if it has electrical components. Non-electronic devices are suggested for the shower. Please check with your DME provider. You can also read about other oxygen users' experiences with this topic on the <u>COPD Foundation's 360Social</u> free online social network.

## Theme 3 Symptoms to watch out for

## 24. How to determine whether you have a COPD exacerbation, the flu, a cold or are just plain sick?

This should not be done by patient and caregivers themselves but together with the clinicians, because the conditions are oftentimes difficult to differentiate. This would require more work-up and can be done in a clinic or at a hospital. One useful approach that your clinician can give, is an action plan with some specific steps and symptoms to look out for to be able to quickly recognize significant and life-threatening worsening of your condition. You can find one example of an Action Plan <u>here</u>. Take this or any Action Plan to your doctor to fill out and make a plan best fit for your needs.

## 25. If oxygen saturation goes below 88% for a short time, how much damage are you doing to your body?

It depends on the situation in which your oxygen is low (e.g. at rest, with activity or sleep) and for how long the levels are low. In general, it is preferred to avoid severely low oxygen levels at any situation (at rest, with activity or sleep) for a prolonged period of time.

### 26. What affect does oxygen have on other body functions?

Similar to question above, see answer there. All organs and body functions depend on adequate levels of oxygen in the blood. However, hyperoxia, i.e. from using too much oxygen, should be avoided in certain clinical situations, e.g. hypercarbic respiratory failure (high levels of carbon dioxide), etc. as this can worsen clinical outcomes.

### 27. What do I do if my oxygen levels are ok but my heart rate is way up?

Tachycardia, or elevated heart rate, might be due to multiple causes, e.g. cardiac problems, arrhythmias, deconditioning, anxiety, pains etc. We would recommend to check with your healthcare provider to determine if there are any other underlying medical problems.

## Theme 4 Oxygen safety

### 28. What are the dangers of having oxygen tanks around?

There are potential fire hazards when oxygen equipment and tubing is close to flames, fire smoke, and fire sparks. No one should smoke near oxygen delivery devices. Other hazards include fall risks when tripping over oxygen tubing, for example.

### 29. Can you light candles when you are wearing oxygen?

No. Open flames, fire smoke, and fire sparks should be avoided when using oxygen and a safety distance to any oxygen equipment and oxygen tubing should be maintained to avoid fire hazards.

### 30. How safe is oxygen?

Similar to question #28. Please see answer to that question. In general, it is safe when used appropriately but there are risks of oxygen therapy, e.g. fire hazards and fall risks when tripping over oxygen tubing. Please also see answers to: question #13 (Theme: Ways to use oxygen) and question #26 (Theme: Symptoms to watch out for)

## Theme 5 **Traveling with oxygen**

### 31. How can I travel with oxygen by air or sea?

You should plan travel in advance as you need to coordinate your travel plans with your DME company and airline. They may need special equipment for air travel and/or arrange delivery of equipment to the location of travel. It sometimes takes two weeks to get clearance from the airlines to fly with oxygen. Check with your airline as not all have the same policy for oxygen use during travel.

Your healthcare provider may need to provide additional information to the DME company or airline, which may require additional testing before you travel. The COPD Foundation has a Slim Skinny Reference Guide all about traveling, available for free download <u>here</u>. Click on Slim Skinny Reference Guides and then English to see the topic list including "Traveling with COPD."

### 32. Can I rent a small machine to travel by car for a few days?

You may be able to rent a small machine for travel. You should contact your DME provider to check what type of equipment they can provide. A respiratory therapist or your DME provider can better answer this question.

## 33. If I travel by plane, is my oxygen supplier required to provide a portable oxygen concentrator?

Your oxygen supplier isn't required to give you an airline-approved portable oxygen concentrator, and Medicare won't pay for any oxygen related to air travel. You may be able to rent a portable oxygen concentrator from your supplier. Also, rentals are available through online companies that work with most airlines. These companies can give the documentation needed for your travel.

### Theme 5: Traveling with oxygen, continued

## 34. What if I'm away from home for an extended period or I move to another area during the 36-month period?

If you travel away from home for an extended period of time (several weeks or months) or permanently move to another area during the 36-month rental period, ask your current supplier if they can help you find a supplier in the new area. If your supplier can't help you find an oxygen supplier in the area where you're visiting or moving to, visit Medicare.gov/supplierdirectory or call 1-800-MEDICARE (1-800-633-4227). TTY users can call 1-877-486-2048.

## 35. What if I'm away from home for an extended period or I move to another area after the 36-month period?

If you travel or move after the 36-month rental period ends, your supplier is responsible for making sure that you have oxygen and oxygen equipment in the new area. You can't be charged for oxygen equipment after month 36 even in these situations.

If you use either an oxygen concentrator or equipment used to fill portable tanks in your home, you may have to pay a maintenance and servicing payment every 6 months if the supplier comes to your house to inspect and service the equipment. The supplier can't charge you for this service unless they come to your home to inspect and service the equipment.

Your supplier may arrange for you to get oxygen and oxygen equipment from a different supplier in your new area. For more information, visit Medicare.gov/supplierdirectory or call 1-800-MEDICARE.

## Theme 6 **Companion treatments**

### 36. Do all people use an inhaler and use oxygen, too?

Patients with COPD are often on inhalers besides oxygen therapy. Depending on the underlying severity of the COPD or other diseases that might require oxygen therapy, e.g. pulmonary hypertension, patients are usually also treated with inhalers, medications, and other therapies.

### 37. What are the latest surgical procedures available?

You should discuss indications for surgical therapy as well as risks and benefits with your healthcare provider. Surgeries, e.g. lung volume reduction surgery in patients with COPD, are generally high-risk therapies and may improve outcomes in few, selected patients only.

### Theme 7 Oxygen equipment + Medicare

## 38. How does Medicare pay the supplier for oxygen equipment and related supplies?

If you have Medicare and use oxygen, you can rent oxygen equipment from a supplier for as long as you have a medical need, but payments for the equipment stop after 36 months of continuous use. After 36 months, your supplier must continue to provide oxygen equipment and related supplies for an additional 24 months. Your supplier must provide equipment and supplies for up to a total of 5 years, as long as you have a medical need for oxygen.

### 39. What do I pay the supplier? What does the rental payment cover?

The monthly rental payments to the supplier cover your oxygen equipment, and any supplies and accessories, like tubing or a mouthpiece, oxygen contents, maintenance, servicing, and repairs. If you use portable oxygen equipment, there is a separate monthly payment made in addition to the general monthly payment, which also ends after 36 months. In both cases, you pay 20% of the Medicare-approved amount after you pay your Medicare Part B deductible for the year. Medicare pays the other 80%.

### Theme 7: Oxygen equipment + Medicare, continued

## 40. What happens with my oxygen equipment and related services after the 36 months of rental payments?

Your supplier must continue to maintain the oxygen equipment (in good working order) and furnish the equipment and any necessary supplies and accessories, as long as you need it until the 5-year period ends. The supplier can't charge you for performing these services.

If you use oxygen tanks or cylinders that need delivery of gaseous or liquid oxygen contents, Medicare will continue to pay each month for the delivery of contents after the 36-month rental period. The supplier that delivers this equipment to you in the last month of the 36-month rental period must provide these items, as long as you medically need them, up to 5 years. The supplier owns the equipment during the entire 5-year period.

If you use either an oxygen concentrator or equipment used to fill portable tanks in your home, you may have to pay a maintenance and servicing payment every 6 months if the supplier comes to your house to inspect and service the equipment. The supplier can't charge you for this service unless they come to your home to inspect and service the equipment.

### Theme 7: Oxygen equipment + Medicare, continued

### 41. What happens to my oxygen equipment after 5 years?

If your medical need continues past the 5-year period, your supplier no longer has to continue providing your oxygen and oxygen equipment, and you may choose to get replacement equipment from any supplier. A new 36-month payment period and 5-year supplier obligation period starts once the old 5-year period ends for your new oxygen and oxygen equipment.

### 42. My oxygen equipment doesn't allow me to move around like I want to inside and/or outside my home. What should I do?

If your doctor determines that your oxygen equipment doesn't meet your needs, he or she may notify the oxygen supplier with a new letter of medical necessity. The letter should explain your mobility needs both inside and outside your home. If you switch from using stationary oxygen to portable oxygen, a new 36-month payment period and a new 5-year supplier obligation period begins once the 5-year contract for the stationary oxygen expires.

### 43. What happens if the equipment I have is no longer effective for me?

If your doctor decides that your oxygen equipment is no longer effective for you, he or she may notify the oxygen supplier with a new letter of medical necessity for different equipment. The oxygen supplier must give you equipment that fits your needs. *Theme 7: Oxygen equipment + Medicare, continued* 

## 44. What if my oxygen supplier tells me they'll no longer provide liquid oxygen?

If your supplier tells you they'll no longer provide your prescribed therapy, and you haven't completed your 5-year contract, you should:

- Get the oxygen supplier to put their intentions in writing.
- Call 1-800-MEDICARE (1-800-633-4227) to file a complaint. TTY users can call 1-877-486-2048.

## 45. Can my oxygen supplier decide to change the terms of my contract for my equipment or the number of tanks I get each month?

Your supplier can't change the type of equipment or number of tank refills you get unless your doctor orders a change. Your oxygen supplier must provide all your oxygen equipment and supplies, including all necessary tank refills.

46. If I travel by plane, is my oxygen supplier required to provide a portable oxygen concentrator?

See #33 on page 11

## 47. What if I'm away from home for an extended period or I move to another area during the 36-month period?

See #34 on page 12

### 48. What if I'm away from home for an extended period or I move to another area after the 36-month period? See #35 page 12

## 49. What if my supplier refuses to continue providing my oxygen equipment and related services as required by law?

If your supplier isn't following Medicare laws and rules, call 1-800-MEDICARE. A customer service representative will refer your case to the appropriate area.

### Theme 8 Equipment issues and maintenance

The questions in this section are best answered by a respiratory therapist, DME provider or other healthcare professional in your community. You can also view some similar questions and conversations with peers at <u>www.copd360social.org</u>.

### 50. How can widespread confusion on oxygen equipment be corrected?

This is a complex issue and one way to address it includes tailored oxygen teaching and education specific to a patient's needs. Different advocacy and research groups, including ours, are working on development of tools to assist in better teaching, management, and prescription of oxygen therapy and oxygen equipment. Would also recommend to look at further resources and educational material that is provided by the COPD Foundation (www.copdfoundation.org).

### 51. How and when should I use equipment?

Similar to question above and relates to what type of oxygen equipment should be used. Please see answer above.

### 52. How do I order home oxygen?

Your DME company can arrange for delivery of oxygen or equipment. Your clinician and respiratory therapy can assist with contacting the DME company. Learn more about oxygen coverage and rights <u>here</u>.

### 53. Why can't I get a reading with my pulse oximeter?

There are multiple reasons for why a pulse oximeter may not be able to read your oxygen level, e.g. oximeter malfunction, nail polish, movement, decreased blood flow to fingers where measurements are taken etc. We would recommend to bring the oximeter to your healthcare provider to demonstrate how you take measurements at home and make sure no other underlying medical problems are going on.

### Theme 8: Equipment issues and maintenance, continued

## 54. How can I learn which oxygen equipment companies and machines are best?

We do not want to make company and machine recommendations as each case is different and not the same fit for all. The important thing is to get devices appropriate for your needs with correct settings. Check with a respiratory therapy or advocates from the COPD Foundation. Depending on the area where you live, there may be only certain DME companies available due to the competitive bidding program. Your primary care physician or pulmonologist, should be able to provide information on oxygen equipment.

### 55. How often should home oxygen equipment be serviced?

The frequency of service depends on your device. Contact your device manufacturer and ask how your device should be serviced. A technician may be able to visit your house, depending on the service your DME provider offers. Ideally, they would come out every month or as needed. CMS has some information about equipment maintenance: <u>https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/Home-Oxygen-Therapy-Text-Only.pdf</u>

### 56. How often should you change your cannula? When it gets rigid? Every month? When you get sick or have an infection?

This depends on the brand of cannula and how often you use it. You can change it once it becomes stiff or uncomfortable for you to wear. Generally, patients exchange the cannula according to their healthcare providers instruction. You might need to change it more often when you have an infection. You can find more resources from the COPD Foundation (www. copdfoundation.org) and the American Association For Respiratory Care (www.AARC.org).

### 57. How often should you change oxygen tubing?

Check with your manufacturer for recommendations. In general, most people change it every 3 to 6 months.

### Theme 8: Equipment issues and maintenance, continued

### 58. Can oxygen tubing be maintained?

Check with your manufacturer for recommendations. Tubing should be washed every week and replaced as discussed above. Some patients use a mixture of white vinegar and sterile water to disinfect tubing.

Some of the equipment may need to stay dry, especially if it has electrical components. Be sure not to get water inside the tubing as it may be hard to dry and could cause mold.

## 59. What is the cost of home oxygen equipment? What are the advantages of different types of equipment that can be purchased?

The costs of the oxygen delivery devices vary depending on the brand, model and other factors. The more sophisticated, the more it costs. One advantage of having an oxygen concentrator with home transfill system is not depending on cylinder tanks being delivered in order to have oxygen. The cost of getting oxygen depends on your location and the company that provides your oxygen. Further resources for independent guidance on the different types of oxygen delivery devices include the COPD Foundation (www. copdfoundation.org) and the American Association For Respiratory Care (www.AARC.org).

### 60. Do you need to wait 5 years before you can get a new one or do you have to buy one?

It depends on the type of insurance you have. For example, for patients with Medicare it may be difficult to change oxygen equipment between years 3 and 5 as Medicare will not pay additional money to the DME company for new equipment.

### Theme 9 Service issues and advocacy

### 61. Can my pulmonologist advocate for me?

Yes. Your pulmonologist is your advocate, together with the rest of your healthcare team including nurses and respiratory therapists. Other resources include advocacy groups like the COPD Foundation.

### 62. Who do I call if I am not getting proper service?

You should contact your DME company and healthcare provider. You can also contact your insurance company or the Medicare patient line (1-800-MEDICARE). The COPD Foundation is a great place to report your issues as well. They are collecting information in order to inform CMS about the problems and advocate for change. Call 1-866-316-COPD (2673).

## 63. How can I prevent information from getting lost between my primary care doctor and pulmonary rehab center?

This question seems to be related to problem of lack of closed-loop communication between primary care physicians and pulmonary rehab across healthcare systems. Unfortunately, there are no standard solutions so far, but we identified this as a problem that should be addressed. Some research groups, including ours, are working on designing solutions to improve communication and transfer of information across and within healthcare systems.

### 64. How can I know what home oxygen equipment Medicare will cover?

Coverage will vary based on your needs and the type of insurance you have. You can learn about your rights within traditional medicare <u>here</u>. Private insurances generally have similar coverage to Medicare and Medicaid.

Theme 9: Service issues and advocacy, continued

### 65. Who should you call if you have problems with Medicare?

You can contact Medicare directly (1-800-MEDICARE) to report problems. You can also contact your healthcare providers in assisting to advocate for you as they may have more experience dealing with payers. You can report your issues to the COPD Foundation at 866-316-COPD (2673).

## 66. I was surprised to learn my oxygen provider limited my oxygen tanks. How can I know what I'm entitled to?

You should discuss with your DME provider and if you have any remaining questions, the Medicare patient line may be able to provider additional answers. Additional resources include the COPD Foundation (1-866-316-COPD). Learn more about oxygen coverage and rights <u>here</u>.

Theme 10 Other

## 67. There is no independent and neutral review of oxygen equipment and companies.

The scientific community needs to do more research to answer this question.

We agree that this is a gap in what currently exists. Some resources that may be helpful are the COPD Foundation (phone # 1-866-316-COPD) and the AARC (phone # 972-243-2272). The UIC team is looking at some options and more information will be provided when it is available.