

How do I help the person I'm caring for manage COPD?

THE COPD CAREGIVER'S TOOLKIT







How do I help the person I'm caring for manage COPD?

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WHAT IS COPD? WHAT ARE ITS CAUSES AND SYMPTOMS?

Caring for someone with chronic obstructive pulmonary disease (COPD) might be new for you. COPD can be hard to understand and manage. The first step is to understand more about the condition.

COPD is a group of lung diseases including emphysema and chronic bronchitis, or both — that block airflow in the lungs. This makes breathing difficult for people living with COPD.

- **Emphysema:** the walls between air sacs in the lungs are damaged.
- Chronic bronchitis: the lining of the airway stays constantly irritated and inflamed, causing thick mucus to form.

Damaged lungs and mucus buildup make it hard for the lungs to spread oxygen to the rest of the body.

It is important to know the symptoms of COPD: shortness of breath, mucus expelled from the lungs, and coughing. The most common cause of COPD is smoking. Other causes of COPD include secondhand smoke (the mix of smoke and chemicals that come from a lit cigarette), indoor air pollution, chemicals, and dust at work. A rare inherited disorder, called alpha-1 antitrypsin deficiency, is also a cause of COPD.

There is no cure for COPD. However, COPD can be controlled and the life of the person you care for can be improved. To do this, you need consistent COPD care and regular communication with a doctor and other healthcare providers. The use of this toolkit will support you and the person you care for on this journey.



Important to know

- Someone with COPD may experience more frequent colds and other illnesses that impact breathing and can lead to a COPD flare-up. A COPD flare-up is an increase in symptoms, difficulty breathing, or shortness of breath and decreased airflow.
- People with COPD are more likely to experience mucus buildup and lung infections like pneumonia.
 These may occur because damaged lungs are not good at getting rid of mucus buildup.
- It is important to stay away from things that may irritate the lungs (for example, exposure to smoke) to decrease risk of COPD flare-ups.
- It is important that you and the person you care for speak with a doctor about the patient's symptoms and ways to reduce COPD flare-ups.





Shortness of breath



Mucus expelled from the lungs



Coughing



For more details on COPD, please visit <u>RHA's COPD section of the Lung Health Library</u>.

IS IT A SYMPTOM OF COPD — OR SOMETHING ELSE?

When the person you care for experiences COPD symptoms, it's good to know what might be a symptom of COPD and what might be symptom of a different condition.

In this section, we identify conditions that have similar symptoms to COPD. People living with COPD may also have these conditions. It is important to talk to your healthcare provider about these other conditions, because they may affect the management of COPD.



Bronchiectasis

Bronchiectasis is caused by damage in the lungs that leads to chronic infections in the airways, usually from bacteria. This can result in airway inflammation. People who develop bronchiectasis may have symptoms that can look like a COPD flare-up. These include:

- increasing shortness of breath;
- feeling tired and run down;
- coughing up mucus expelled from lungs.



Make an appointment to see the doctor, who will likely perform tests. The doctor will be better able to determine if the person you care for is experiencing bronchiectasis along with COPD. The doctor will also be able to select the best treatment, which may include antibiotics or mucus-thinning medication. Other treatments include chest therapy to help clear mucus from lungs and medications to treat inflammation.

Is the person you care for still smoking? Smoking can limit the effects of treating bronchiectasis. Talk with the doctor about how to help the person you care for quit smoking.



For more about bronchiectasis, visit NHLBI's Health Topics page.

For more about GERD, visit NIDDK's Health Information page.



Gastroesophageal reflux (GERD)

GERD is also called acid reflux or heartburn. It occurs when stomach acid or even stomach contents wash back into the esophagus. A symptom that overlaps with COPD includes coughing.

GERD is a common condition that can affect anyone occasionally without any harm. However, for people with COPD, GERD can actually cause COPD flare-ups. If the person you care for also has asthma, GERD can trigger asthma symptoms, too.

> What can you do?

It's important for people with COPD to treat any recurring GERD. While mild forms of GERD can be treated with overthe-counter medications, some people need stronger medication. Consult with your doctor to properly diagnose and treat the person you care for.

IS IT A SYMPTOM OF COPD — OR SOMETHING ELSE? (continued)



Lung cancer

People diagnosed with COPD have an increased risk of developing lung cancer. Symptoms of lung cancer can be similar to those of COPD. They include:

- cough that won't go away or coughing up blood;
- · chest, back, or shoulder pain;
- shortness of breath or wheezing;
- fatigue;
- · weight loss.

For people who continue to smoke after being diagnosed with COPD, his or her chances of being diagnosed with lung cancer continue to increase.

> What can you do?

Medical tests will confirm whether someone has lung cancer. Work with the healthcare provider to determine a treatment plan to help the person you care for.

Quitting smoking is the single most important thing a person can do for his or her health. The majority of smokers want to quit, too. Although it may be difficult to quit smoking, every day many smokers quit successfully. If smoking is still an issue, speak with a healthcare provider about how to support the person you care for quit smoking.



For more about lung cancer, visit NCI's page.



Asthma

Asthma is a chronic disease of the lungs that includes airway inflammation (swelling) and airway restriction (squeezing of smooth muscle around the airways). This can cause wheezing, coughing, and chest tightness. A large number of adults, particularly those with chronic respiratory symptoms, may have asthma and COPD. This may be called Asthma-COPD Overlap Syndrome (ACOS) or Asthma-COPD Overlap (ACO). Several symptoms of asthma mimic the symptoms of COPD. Shared symptoms can include:

- · coughing;
- wheezing;
- chest tightness;
- increased respiratory infections.

> What can you do?

Your doctor can help determine if the person you care for also has asthma. The doctor will use additional testing and talk to the person you care for to better understand his or her symptoms and develop an appropriate treatment plan.



For more about asthma, visit NHLBI's Health Topics page and NHLBI's Learn More Breathe Better® page.

IS IT A SYMPTOM OF COPD — OR SOMETHING ELSE? (continued)



The heart and lungs work together to give the body the oxygen it needs to work. Since COPD makes it harder for oxygen to go into the lungs and then into the blood, the heart is forced to work harder. People with COPD are at an increased risk for some types of heart disease.

Heart failure is also known as congestive heart failure, or CHF. Heart failure means that a person's heart, which is a muscle that pumps blood to all parts of the body, is not working as well as it should and cannot pump as much blood as the body needs.

Some symptoms that look like COPD may actually be evidence of heart failure. These include:

- shortness of breath and cough;
- racing or skipping heartbeat (palpitations);
- difficulty sleeping;
- fatigue, weakness, and a reduced ability to exercise;
- lightheadedness;
- difficulty concentrating or staying alert.

People with COPD are also at a bigger risk for developing other types of heart disease, too. This may include increased blood pressure, heart irregularities known as arrhythmias, ischemic heart disease, and peripheral heart disease.



For more on CHF symptoms, visit NHLBI's Health Topics page.

> What can you do?

People with heart failure are best treated by a cardiologist. So it's a good idea to discuss the symptoms listed here with the doctor of the person you care for. Together you can decide if seeing a cardiologist is a good idea. Heart disease can often be managed with lifestyle changes and medications. Lifestyle changes include things like changes to diet, exercising, and quitting smoking.

Pulmonary rehabilitation is important for people living with COPD. These exercises can help the heart. This will help the person you care for stay more active and healthy.

WHAT ELSE SHOULD I BE LOOKING FOR?

People living with COPD may have other health conditions, too — an average of up to five other conditions in addition to COPD. It's important to understand these other conditions because they may impact the care you give.

Some of the most common health conditions among people living with COPD are:



Sleep apnea

Sleep apnea describes a condition in which someone experiences shallow breathing and pauses in breathing while sleeping. Breathing pauses may last from a few seconds to minutes. Pauses may occur as often as 30 times or more an hour. Typically, normal breathing then starts again, sometimes with a loud snort or choking sound. The pauses can cause significant interruptions in sleep.

As a result, people who have sleep apnea may wake up feeling tired and underslept, rather than rested. He or she may also experience daytime sleepiness and lack energy for daytime activities.

> What can you do?

It is important to talk with a doctor if you believe the person you care for has sleep apnea. Sleep apnea can impact heart health. The doctor may prescribe oxygen or a device called a CPAP to help the person you care for breathe more easily when asleep.



Osteoporosis

Osteoporosis is an illness that weakens a person's bones. A person can then be at a greater risk for falling and breaking bones. Some people with COPD have other risks related to osteoporosis. These risks are smoking, low vitamin D levels, and the use of steroids for treatment.

> What can you do?

Weight-bearing and strength exercises, offered through a pulmonary rehabilitation program, can help prevent breaking bones.



Depression/Anxiety

Many people living with COPD experience some degree of mental distress from their symptoms. He or she may have a difficult time adjusting to challenges caused by COPD, and this can put them at greater risk for depression or anxiety.

> What can you do?

Participating in a pulmonary rehabilitation program or a support group can help reduce physical symptoms related to COPD while providing social support for any mental health issues. A doctor or other healthcare provider might also prescribe antidepressant medication to address symptoms.



Diabetes

Diabetes and COPD might be related because both conditions involve chronic inflammation. Some research shows a connection between high blood sugar and either COPD flare-ups or changes to lung function.

> What can you do?

If the person you care for has diabetes, try to help him or her follow a healthy diet. Also encourage him or her to get enough exercise. Exercise is useful in helping prevent and manage both diabetes and COPD. A medical professional will make sure that the COPD medications and the diabetes medications do not interfere with each other.



For more on sleep apnea, visit NHLBI's Health Topics page.

WHAT MEDICATIONS WILL WE NEED? WHEN AND HOW SHOULD THEY BE USED?

There are many kinds of COPD medication. People who have COPD might need to take a number of them. It's important to know what the medications are, when to use them, and how to take them so that you can provide better care.

Doctors create medication plans based on a patient's needs and symptoms. COPD medication plans are an important part of an overall treatment plan. A COPD treatment plan usually consists of medication as well as non-medication therapies.

COPD medications help people manage their disease. Medications are used to:

- prevent and control symptoms;
- reduce the frequency and worsening of COPD symptoms;
- · improve breathing;
- improve the ability to exercise.

"Controller" medications

These are medications that are taken every day to help control and prevent the symptoms of COPD. These drugs help ease breathing. They help by preventing swelling and mucus build-up in the airways.

"Reliever" medications

These are sometimes called a "quick-relief" or "rescue" medication. They are taken during a COPD flare-up when a person is coughing, wheezing, or having trouble breathing. These drugs work to relax muscles in the airway to ease breathing.

COPD medication devices

COPD medications come in many different types of devices. These include: metered-dose inhaler, dry powder inhaler, and nebulizer.

Nebulizers are small air compressors used to administer medication. Users put a nebulizer mask on their face or use a mouthpiece to breathe in mists of air mixed with medication.

It is important to practice how to use COPD medications with a healthcare provider. We provide instructions on how to take COPD medication in this toolkit.

Other medications

The person you care for may be taking other medication. For example, if he or she had a recent flare-up, the person may be taking an antibiotic or an oral steroid. These medications are prescribed to work with the COPD management plan of the person you care for. Such medication can be used short-term or even longer term, depending on what the doctor thinks is best.

HOW TO USE AN INHALER WITH A SPACER

Most COPD medications are taken by inhaler. The instructions here show how to use a Metered Dose Inhaler (MDI), which gives puffs of medication in aerosol form. MDIs are used to give either "controller" or "reliever" medication — make sure you know which is which by writing down the name and color of each! A doctor may suggest that the person you care for use a spacer, too. A spacer is a plastic holding chamber designed to help more medication go deeper into the lungs.

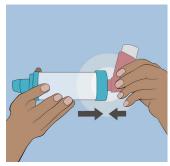
Ask the healthcare provider to demonstrate how to use and clean the MDI (and spacer, if one is being used). Review this technique at each follow-up visit. Always read and follow the instructions that come with the specific inhaler being used by the person you care for.

1 TAKE CAP OFF & SHAKE



Take cap off the inhaler. Check for any dust or fuzz. Shake for 5 seconds.

2 ATTACH SPACER



Attach the inhaler to the spacer. Take all food, candy and gum from your mouth. Stand up straight.

3 BREATHE IN & OUT



Take a deep breath, then breathe out all the air, away from the inhaler.

4 PUT IN SPACER & PRESS



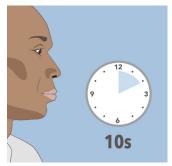
Put the inhaler in your mouth and seal your lips around the mouthpiece. Press down on the inhaler once.

5 BREATHE IN



Take a slow, deep breath in.

6 HOLD FOR 10 SECONDS



Hold your breath for 10 seconds, then breathe out.

7 RINSE WITH WATER



If you are using a controller medication (inhaled steriod), rinse your mouth with water, and then spit the water out.

HOW TO USE A DRY POWDER INHALER (DPI)

The instructions here show how to use a dry powder inhaler (DPI). This type of inhaler contains pre-set doses of medication in powder form.

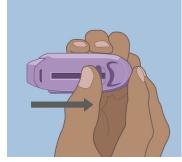
Ask the healthcare provider to demonstrate how to use and clean the DPI. Review this technique at each follow-up visit. Always read and follow the instructions that come with the specific inhaler being used by the person you care for.

1 OPEN THE INHALER



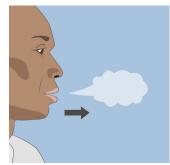
Open the inhaler with the mouthpiece facing you.

2 LOAD THE MEDICATION



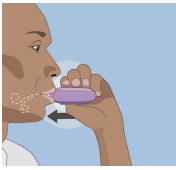
Slide the lever away from you until it clicks. This means the medication has been released. Be careful not to tip the inhaler or slide the lever again — or the medication will fall out, and it will be wasted.

3 BREATHE IN AND OUT



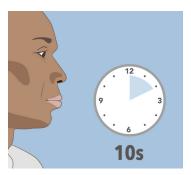
Take a deep breath. Then breathe out all the air, away from the inhaler.

4 BREATHE IN



Place the inhaler in your mouth. Seal your lips tightly around it and take a quick, deep breath in.

5 HOLD FOR 10 SECONDS



Hold your breath for 10 seconds, then breathe out.

6 RINSE WITH WATER



Rinse your mouth if using a controller medication (inhaled steriod). Spit the water out.

HOW TO USE A NEBULIZER

These instructions depict using a nebulizer. This machine delivers a fine, steady mist of medication, which is accessed using a mask or mouthpiece.

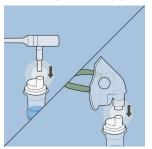
Always read and follow the instructions that come with the nebulizer being used by the person you care for.

1 WASH YOUR HANDS



Wash your hands before using the nebulizer.

4 ATTACH THE CUP



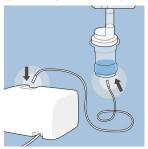
Attach either a mouthpiece or mask to the end of the medication cup.

2 FILL MEDICATION CUP



Open the medication cup and fill it with medication.

5 ATTACH THE TUBING



Hook one end of the tubing to the medication cup and the other end to the nebulizer.

3 PUT THE CAP ON



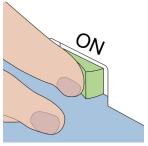
Tighten the cap.

6 PUT IN/ON YOUR MOUTH



If using a mouthpiece, seal your lips tightly around the mouthpiece. If using a mask, place mask firmly on your face.

7 TURN THE NEBULIZER ON



Turn on the nebulizer.

8 BREATHE



Breathe normally through the mouthpiece or mask until you no longer see the medication mist OR until the medication cup is empty (about 10 minutes).

9 RINSE AND CLEAN UP



Rinse your mouth if using a controller medication (inhaled steriod). Wash your face if you used a mask.

ARE THERE OTHER MEDICAL TREATMENT OPTIONS?

In some cases a person with COPD may want to think about other treatment options. It is best to have an understanding of the options for treatment in order to prepare for a discussion with a doctor. Your doctor will be able to help decide which, if any, other treatments are right for the person you care for.

Ventilatory support

Noninvasive ventilation is used to treat COPD flare-ups. Examples include Continuous Positive Airway Pressure (CPAP) machine and Bi-level Positive Airway Pressure (BiPAP) machine. Ventilatory support is usually not used for those with severe COPD. People with severe COPD might need more support.

Bullectomy

Bullectomy is a procedure for patients with bullous emphysema — lungs with severe emphysema that contain air- and/or fluid-filled pockets. These pockets can cause further obstruction and increase pressure in the lungs. In carefully selected individuals, this procedure is effective in short-term reduction of shortness of breath and improvement in lung function.

Lung Volume Reduction Surgery (LVRS)

LVRS is a procedure in which damaged parts of the lung(s) are removed to improve lung function. This procedure helps alleviate symptoms for a short time and should only be recommended in carefully selected individuals with severe COPD.

For more details on other COPD treatment options, please visit RHA's Lung Health Library.

Endobronchial valve treatment (EBV treatment)

Some patients with COPD may benefit from bronchoscopic lung volume reduction with endobronchial valves, also known as EBV treatment. Like LVRS, EBV treatment works to remove the damaged parts of the lung, but EBV treatment is a less-invasive alternative. It has been shown to improve lung function and capacity for exercise, as well as enhancing quality of life.

Lung transplantation

Lung transplantation (including singlelung transplants) for appropriately selected individuals has been shown to improve quality of life. Specific guidelines are followed when selecting candidates for lung transplantation in severe COPD.

ARE THERE OTHER, NON-MEDICAL TREATMENTS FOR COPD?

Oxygen therapy

Oxygen might be necessary if the person you care for experiences any of the following:

- low blood oxygen level as identified by a doctor;
- shortness of breath, more than normal;
- harder time exercising, more than normal;
- tiredness or dizziness.

Oxygen is a main treatment for people with severe COPD. Changes occur in the lungs of COPD patients. These include narrowing of the airways and the destruction of lung tissue. These changes can make it harder to breathe. Therefore, the amount of oxygen that reaches the blood is not enough to meet the body's needs. Oxygen therapy can help control this problem.

> Benefits

Oxygen therapy can improve a person's ability to exercise. It can also affect sleep and thinking skills.

> What's involved?

Talk with the doctor to decide if oxygen therapy is right for the person you care for. Oxygen therapy is prescribed based on one of a few different tests. The doctor will decide which tests to take to see if oxygen therapy is a good fit.

There are several types of oxygen devices. The doctor can help decide which device is right for the lifestyle of the person you care for.



For more information on oxygen therapy or pulmonary rehabilitation, please visit RHA's Lung Health Library.

Pulmonary rehabilitation

Pulmonary rehabilitation is a great way for a person with COPD to learn how to better manage symptoms. This can reduce pressure on a caregiver, too. Through pulmonary rehabilitation, someone living with COPD may become more independent and meet other people who have COPD. Pulmonary rehabilitation helps control the impact of COPD through exercise, education, and support.

> Benefits

There are many benefits to pulmonary rehabilitation. The primary benefits are reduction in COPD symptoms and flare-ups, support for depression and anxiety, and increased physical and emotional participation in everyday activities.

It can be hard to be physically active with COPD. Yet exercise — one component of a pulmonary rehabilitation program — can strengthen the body, including the muscles used to breathe; improve overall endurance; and may also help with sleep.

> What's involved?

Programs vary, but they may include: physical exercise, breathing exercises, nutrition tips, and disease education. Programs may be covered by health insurance. For those on Medicare, visit Medicare's webpage for information about coverage.

Palliative care

The goal of palliative care for someone with advanced COPD is to prevent pain and provide relief in ways that improve the quality of life at end-stage disease.

Speak with a doctor and the person you care for about palliative care options and how these options might fit one's needs.

WHAT SHOULD I KNOW ABOUT COPD AND SMOKING?

Eliminate exposure to smoke in the home to reduce COPD symptoms. Knowing the benefits of being smoke-free will help you give better care.

You've probably heard this advice before, but if the person you care for still smokes, it's best for him or her to quit. Quitting smoking — even after a COPD diagnosis — is the best thing a person can do for one's health.

You or the person you care for may have tried to quit smoking before. Quitting smoking is hard. It often takes multiple attempts before quitting for good. Don't be discouraged. There are many resources to help you. Talk to your doctor or healthcare provider about your options for quitting smoking, including quit smoking medications.

What about e-cigarettes?

E-cigarettes are not approved by the FDA to help people quit smoking. An e-cigarette is a battery-powered device that produces an inhalable vapor. It does so by heating a liquid that usually contains nicotine. But e-cigarette vapor is not just water vapor. E-cigarettes may contain chemicals including known carcinogens.



To find more information to quit smoking, please visit RHA's Quit Smoking Page.



My mom, dad, and grandma all have some form of COPD. And all have inhalers that they have to use because of smoking.

COPD Caregiver



Get help to quit

- Talk to your doctor or healthcare provider to quit smoking.
- Take a quit smoking medication this can double or triple your rate of success!
- Join a quit smoking group or one-on-one counseling.
- Get support from loved ones to stay smoke-free.
- Visit Smokefree.gov or call the Quit Line at 800-QUIT-NOW (800-784-8669)

WHAT VACCINES HELP MANAGE COPD?

Vaccines are important for successfully managing COPD and helping avoid flare-ups in the person you care for.

Two vaccines are important for successfully managing COPD. Influenza (flu) and pneumococcal (pneumonia) vaccines will reduce the chances of getting and spreading one of these diseases. If the person you care for gets the flu or pneumonia, his or her COPD symptoms can get worse or can even cause a COPD flare-up.

Adults can get vaccines at doctors' offices, pharmacies, community health clinics, and other locations. To find a place near you to get a vaccine, visit the CDC's web page.

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COPD and other chronic lung diseases can make a person more likely to get severely ill from COVID-19. Talk to your healthcare provider about getting the COVID-19 vaccine, for you and the person you care for.

For more information on COPD and vaccines, visit COPD and Vaccines: What You Should Know.

Learn more about these vaccines and talk to the doctor about adding them to the COPD management plan of the person you care for. Most health insurance plans cover doctorrecommended vaccines.



To find more information about the flu, please visit RHA's Lung Health Library.



Be proactive about vaccinations

- Talk to the doctor about vaccinations for flu and pneumonia for the person you care for.
 Ask about the best time to receive each vaccine.
- Protect the person you care for: Talk to the doctor about the vaccinations for yourself or other family members who come in contact with the person you care for. This may include children and grandchildren with whom you interact. This will help reduce the chance that you will get or spread vaccine-preventable diseases.
- Keep a record of the vaccination history, so you know when the person you care for is due for the next vaccine. Use the <u>Vaccine</u> <u>Tracking Sheet</u> to help you keep track.

HOW ARE COPD AND EATING RIGHT RELATED?

When a person has COPD, breathing can make physical activity hard to do. It's necessary to eat the right amount of calories and nutrients to stay strong.

For people with COPD, breathing requires more energy. The muscles used in breathing when living with COPD require more calories than usual. Think of food as a fuel needed to perform everyday activities and most importantly breathing.

The person you care for will need more calories to help maintain his or her energy. Good nutrition also helps the body fight infections. This can prevent some hospitalizations. Talk to the doctor about a nutrition plan for someone with COPD.



Eating right with COPD

Monitoring weight

Encourage a weigh-in once or twice a week. Track those numbers. If you see an unexplained weight gain or loss (2 pounds in a day or 5 pounds in a week), contact the doctor. The doctor may want to change daily food or fluid intake to better manage the condition of the person you care for.

Encourage drinking plenty of fluids

Help the person you care for drink at least 6 to 8 eight-ounce glasses of water a day. This keeps mucus thin and easier to cough up.

Include high-fiber foods

Add vegetables, fruits, beans, and wholegrain foods like bran cereals and brown rice to the daily diet of the person you care for. Fiber helps move food along the digestive tract, helps control blood glucose levels, and might reduce the level of cholesterol in the blood.

Help control salt intake

Eating too much salt causes the body to keep or retain too much water, causing breathing to be more difficult. Read food labels and avoid foods with more than 300 mg sodium per serving.

Encourage calcium and vitamin D intake

These keep the bones of the person you care for healthy. Good sources include foods made from milk (for example, cheese and yogurt) and foods fortified with calcium and vitamin D. Maintaining a healthy weight and exercising will also help keep bones healthy.

Encourage the use of nasal cannula

If continuous oxygen is prescribed for the person you care for, keep this on while eating. Eating and digestion require energy, so his or her body will need the oxygen.

Avoid overeating

A full stomach or bloated abdomen can make breathing uncomfortable. Avoid the foods that cause gas or bloating. For some people, this may include: carbonated beverages; fried or heavily spiced foods; beans and legumes; and some fruits and vegetables like apples, avocados, melons, broccoli, cabbage, cauliflower, corn, and cucumbers.



For more information, go to <u>Cleveland Clinic's page</u> on nut<u>ritional guidelines for people with COPD</u>.