



COPD Caregiver Packet

A resource to help you care for loved ones with
chronic obstructive pulmonary disorder (COPD)

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Understanding COPD

The better you understand your loved one's condition, the easier it will be for you to help them lead a fulfilling, healthy life.

What is COPD?

Chronic obstructive pulmonary disease (COPD) is a disease that damages the lungs, making it difficult to breathe over time. It includes other chronic lung diseases such as emphysema and chronic bronchitis.

The main symptom of COPD is breathlessness. Some people with COPD also experience tiredness and chronic cough with or without mucus (phlegm). Let's break down this complicated name into smaller pieces so you can help explain it to loved ones:

C Chronic

COPD is not a disease that can be cured, but it can be successfully managed and treated. The symptoms of COPD often take years to develop, but with lifestyle changes and treatments, your loved one's quality of life can greatly improve and allow them to stay active.

O Obstructive

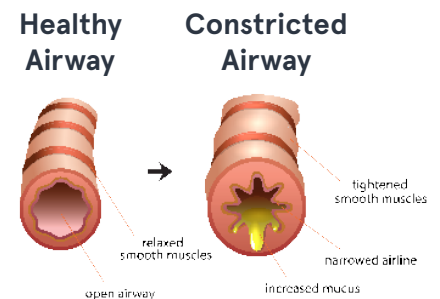
In COPD, airflow through the lungs is blocked (obstructed). Less air flows in and out which can be caused by swelling and extra mucus in the tubes inside the lungs.

P Pulmonary

Pulmonary means lung and is where this disease is located. When you breathe air in, it travels through your windpipe and into the airways in your lungs, called bronchial tubes. They look like the branches of a tree, with larger tubes leading to smaller ones. Each airway "branch" ends with alveoli, which are tiny air sacs where oxygen moves into the bloodstream. The alveoli can be thought of as the leaves on a tree. Chronic bronchitis affects the bronchi (the tree branches) while emphysema affects the alveoli (the leaves on the tree).

D Disease

COPD is a progressive disease which means lung damage gets worse over time and symptoms usually become more severe. But with the right treatment, your loved one's symptoms can be managed, and the progression of the disease can be slowed.



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Understanding COPD

What are the symptoms of COPD?

The symptoms of COPD can be different for each person. Your loved one's symptoms can also vary from day to day, with some days being worse than others. Common symptoms of COPD include:

- Shortness of breath, especially while doing everyday activities
- A frequent cough with or without mucus
- Wheezing (a whistling sound when breathing in or out)
- Chest tightness

Some of these symptoms are like those related to other conditions, such as heart problems, obesity, asthma, and allergies. If your loved one is experiencing any of these symptoms, it is important for them or you to contact their primary care provider.

Many people with COPD also have additional chronic diseases. These are called comorbidities, which means there is more than one disease or condition within the body at once. This term is important because it helps doctors and advanced practice providers (APPs)* understand and explain how different conditions might affect your loved one's physical and mental health, both together and separately. Talk to your loved one's primary care provider if they have other symptoms even if you think they are not related to your loved one's COPD.



There are many ways to treat and manage COPD. Your Village Medical care team will help you and your loved one figure out which medications, devices and lifestyle changes are right. Be sure to speak with your Village Medical team at the first sign of COPD symptoms so they can be managed to help improve your loved one's quality of life and overall health.

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*An advanced practice provider is defined as a nurse practitioner or physician assistant.

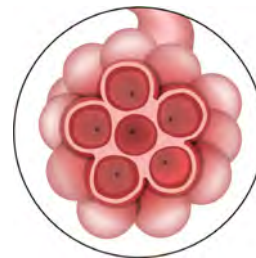
Medications for COPD

There are many medications available that can help improve your loved one's chronic obstructive pulmonary disease (COPD) symptoms. Let's learn more about the different types of COPD medications and how to help your loved one use them properly.

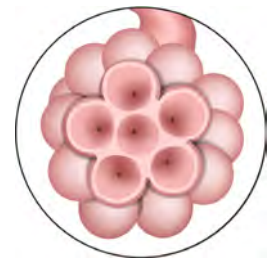
Medications for Daily Use

Long-acting medications are used every day to help prevent COPD symptoms. They do not work quickly. Often, your loved one may need to take long-acting medications for several days or weeks before noticing a change in their symptoms. These medications can include:

- **Inhaled Corticosteroids:** These medications help to reduce inflammation and swelling in the lungs. They decrease risk of a flare-up, but the change won't be noticeable right away.
- **Long-Acting Bronchodilators:** These medications help open up the airways over a longer period of time. They do not work immediately and should not be used for quick relief of COPD symptoms. These medications are used once or twice daily, every day. **Your loved one should not stop their long-acting medications when they feel well.**



Inflamed Air Sac
in Airway



Healthy Air Sac
in Airway

Medications for Flare-Ups (Exacerbations)



A COPD flare-up (exacerbation) occurs when your loved one's symptoms become worse suddenly, and they become sick. It's important not to delay starting rescue medications when a flare-up occurs.

If your loved one is having more shortness of breath and coughing than usual (COPD Action Plan **yellow zone**) or experiencing wheezing or chest tightness at rest (COPD Action Plan **red zone**), make sure they start taking the medications in their COPD Rescue Pack immediately.

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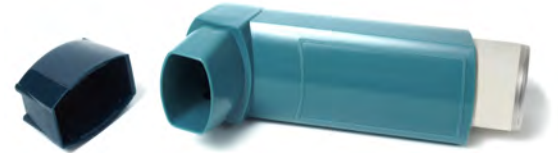


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Medications for COPD

Short-Acting Medications

Short-acting medications work quickly to help relieve COPD symptoms. Common short-acting medications—the ones used for quick relief—include short-acting bronchodilators such as albuterol or levalbuterol. These medications relax the muscles around the lungs' breathing tubes. They will help your loved one breathe easier and reduce coughing.



Oral Corticosteroids

Oral corticosteroids are medications that reduce swelling in the breathing tubes of the lungs. This helps make breathing easier. Oral corticosteroids, such as prednisone, are pills or tablets that are taken by mouth. These are not the same type of steroids that some athletes take to give them bigger muscles. These medications are only used for a short time during a COPD flare-up.

Antibiotics

COPD flare-ups are often caused by infections in the lungs. Your loved one's primary care provider may prescribe antibiotics to treat the infection such as amoxicillin, azithromycin, doxycycline, or levofloxacin. These antibiotics only work on lung infections caused by bacteria, such as bronchitis and pneumonia. These infections can make your COPD much worse.



It is important for your loved one to keep all of their medications refilled and to follow their medication schedule as directed by their primary care provider. If your loved one is having trouble affording medications, they should to their doctor, APP, care manager, or pharmacist.

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COPD Flare-up (Exacerbation)

A chronic obstructive pulmonary disease (COPD) flare-up (exacerbation) occurs when COPD symptoms suddenly become worse, leading to sickness. These flare-ups are usually caused by an infection in the lungs, changes in weather, increased air pollution, or exposure to smoke. Being run down or feeling stressed or anxious can contribute to a flare-up.

Warning Signs

The following signs and symptoms of a COPD flare-up may last 2 days or more and are stronger than usual symptoms. They may also get worse and not go away.

- Noisy breathing or wheezing sounds
- Coughing, sometimes with more mucus than usual or a change in mucus color
- Increased shortness of breath and trouble catching the breath
- Not being able to take deep breaths
- Fever
- Unusual tiredness
- Difficulty sleeping
- New or increased swelling in the legs
- Morning headaches
- Gray or pale skin
- Blue or purple lips or nail tips

If your loved one is having more shortness of breath and coughing than usual (COPD Action Plan **yellow zone**) or experiencing wheezing or chest tightness at rest (COPD Action Plan **red zone**), make sure they start taking the medications in their COPD Rescue Pack immediately.

What to Do

If your loved one has entered the **yellow zone** or **red zone**, make sure they **immediately begin to follow their COPD Action Plan**. This includes taking all medications prescribed by their doctor or advanced practice provider (APP)* for flare-ups (quick-relief inhalers, COPD Rescue Pack including steroids or antibiotics, anti-anxiety medicines, or medicine through a nebulizer). Your loved one should:

1. Start their COPD Rescue Pack if they have been prescribed one.
2. Call their doctor, APP, or care manager right away.
3. Continue use of existing prescribed medications.



It's important not to wait too long to start rescue medications. If you think your loved one may be having a flare-up but are not sure, contact their doctor, APP, or care manager right away.

When the Doctor, APP or Care Manager Should Be Contacted Right Away

If your loved one is having a flare-up (exacerbation), their symptoms do not get better or their symptoms keep getting worse, your loved one should call their doctor, APP, or care manager immediately.

Call 911

If you need immediate help, please call 911.

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Five Tips for Self-Care as a COPD Caregiver

So much caregiving happens outside the walls of our Village Medical practices. That's why we're working with the COPD Foundation to empower patients and caregivers with educational resources.

Being a caregiver can be overwhelming, exhausting, and stressful. No matter how strong you are, the stress caused from caregiving responsibilities can do serious harm to your well-being.

But caregiving can be an incredibly rewarding experience – one that brings you closer to your loved ones. Here are five tips to take care of your own health while caring for friends and family with COPD.

Make sure your loved one has the resources to understand and manage their COPD.

Empowering your loved one in their own health is one of the most important things you can do as a caregiver. When your loved one understands their condition, how to manage it, and the resources available for them in emergencies, they will live a more fulfilling, healthy life. That will reduce your stress as their caregiver.

The caregiver packet provides two key pieces of information for anyone looking to manage COPD: **the COPD Action Plan and Medication List**. The COPD Patient Packet contains comprehensive information about COPD, specifically for patients. Ask your primary care provider for a copy of the COPD Patient Packet to discuss with your loved one.



You are not alone. Talk to others about your experience.

If caregiving becomes overwhelming, don't hesitate to ask for support from family, friends, or a mental health professional. Talking to family and friends can be a great way to put your experience into context. Even if it's just for a short walk or a quick cup of coffee, make time each week to visit with someone you trust.

Take advantage of resources, such as classes, faith groups or support groups, available for caregivers in your community and online, such as www.COPD360social.org. It's stress-relieving to talk about the problems you are facing with people who are willing to listen closely, and support groups can provide encouragement through difficult times.

Maintain healthy relationships with loved ones by respecting their independence.

Many people find themselves in a caregiving role for their parents as they age. For most of our lives, our parents had the responsibility of caring for us, and the role reversal can be jarring. Tension can result when we interrupt their sense of independence as they manage COPD.

It is important to be patient with your loved ones – they may not be able to take care of themselves like they used to, but that doesn't mean there aren't things still in their control. Maintaining a healthy relationship with those you care for will help lower stress. Be sure to help your loved one maintain their independence. Encourage them to participate in the tasks that they can complete. Have them:

- Plan meals
- Track exercise
- Monitor their medication plan
- Fold laundry
- Participate in shopping
- Cook and clean where possible



Allow others to help.

For us to be the best caregivers, it is important we stay in good health. Sometimes that means taking breaks and allowing others to step in and help. Here are some options to consider:

Take advantage of in-home services in your area. You can find health care aides to come to your home to provide nursing services and even simply spend time with your loved ones. For example, in several areas our Village Medical at Home program brings comprehensive primary care directly to our patients. You might also find caregiving services such as rides, meal delivery, or house cleaning to take additional responsibilities off your plate.

Find nearby adult care centers and programs. You may have places in your area that provide care for older adults during the day. Some of these centers also care for young children and provide opportunities for kids and older adults to spend time with each other.

Consider a short-term nursing facility. If you need a short-term break from caregiving, there are short-term nursing facilities, assisted living homes, and memory care homes that can help take care of your loved ones.

Check-in with your primary care doctor.

Talk to your doctor or advanced practice provider about what you are feeling and experiencing as a caregiver.

By discussing any worries or symptoms, such as trouble sleeping, fatigue, or irritability, your primary care provider can help you with treatment options.

It's also important to stay up to date on your vaccines and health screenings to avoid the added stress of dealing with illnesses and worsening conditions of your own.

You might find yourself in the role of caregiver without any warning and feel unprepared. Remember to be patient with yourself because it is not easy. As you take on these new responsibilities and strive to be the best caregiver you can be for your loved ones, know you are not in it alone.

COPD Action Plan

Your COPD (chronic obstructive pulmonary disease) Action Plan is created by you and your primary care doctor or advanced practice provider (APP). It explains how to handle your symptoms as your condition changes and is tailored specifically for you. We recommend you review your COPD Action Plan with your doctor every 6 months.

Good Day

A normal day for me includes:

- Normal activity level
- No shortness of breath
- Usual amount/color of phlegm
- Good appetite
- Sleeping well at night

Next Flu Vaccination: _____

Stay Well

Continue:

- Taking all prescribed medications
- Avoiding all inhaled irritants & bad air days
- Keeping all routine doctor appointments
- Maintaining a regular exercise/diet plan

NOTES: _____

Next Pneumococcal Vaccination: _____

Bad Day

If you are experiencing 2 or more of the following symptoms:

- Noisy breathing or wheezing sounds
- Change in color, thickness, odor or amount of mucus
- Increased shortness of breath or coughing
- Unusual tiredness or difficulty sleeping
- Fever
- New or increased swelling in the legs

Take these steps:

- Continue daily maintenance medication(s)
- Use short-acting (rescue) inhaler or nebulizing solution
- Use pursed-lip breathing
- Start your Rescue Pack (if prescribed) if you experience an:
 - Increase in phlegm that is getting darker, yellow, or green and
 - Increase in shortness of breath
- Call your doctor, APP*, or care manager right away

NOTES: _____

EMERGENCY

Call your doctor/APP if you are experiencing ANY of the following symptoms:

- Wheezing or chest tightness at rest
- Unable to perform daily activities
- Unable to sleep due to difficulty breathing
- Fever or shaking chills
- Blue or purple lips or nail tips

Doctor/APP Phone Number: _____

CALL FOR HELP

Call 911 if you are experiencing:

- Unrelieved chest pain
- Coughing up blood
- Feeling confused or very drowsy

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COPD Action Plan

My Care Team

Doctor/APP: _____

Doctor/APP Daytime Phone: _____

Care Manager: _____

Pulmonologist: _____

Social worker: _____

Pharmacist: _____

After Hours Phone: _____

Phone: _____

Phone: _____

Important Reminders

Take your medications every day.

- Always carry a list of your medications with you and bring all your medicines and inhalers to your office visits. Ask your doctor, APP or care manager to list what each medication is for, how to take it and how often if you're not sure.
- Keep your short-acting (rescue) inhaler and spacer if needed with you at all times. Make sure you know which of your medications to use when you're suddenly feeling short of breath. Ask for instructions on how and when to use your inhaler and spacer if you're unsure.

Activity Check

Think about your ability to perform the activities below on a typical "green" day. Discuss with your doctor/APP how difficult it is to do that activity now.

- Sleeping
- Cooking
- Showering/Bathing
- Exercising
- Brushing Teeth
- Working
- Climbing Stairs
- Cleaning
- Making Bed

Important Reminders

- **Medication.** Always carry your short-acting (rescue) inhaler and spacer if needed with you.
- **Breathing techniques.** Use the pursed-lip breathing technique below:
 - Breathe in slowly through your nose for two counts, keeping your mouth closed.
 - Pucker or "purse" your lips as if you were going to whistle or gently flicker the flame of a candle.
 - Breathe out slowly and gently through your pursed lips while counting to four.
- **Exercise.** Being active will improve energy levels and strengthen muscles so you can do more.
- **Balance rest and activity.** Try to balance rest periods with activity each day.
- **Healthy eating.** Eat a well-balanced diet including protein, carbohydrates, and healthy fats for energy. Ensure your portions are well balanced.
- **Pulmonary rehabilitation.** Discuss the benefits of participating in pulmonary rehab programs with your doctor, APP or care manager.
- **Oxygen.** Follow your doctor/APP's instructions on when and how to use oxygen if it has been prescribed for you. Don't stop therapy or make changes on your own without first talking with your care team.

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