What You Need to Know About End-Stage COPD

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What to Expect From End-Stage COPD or Stage IV

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It is estimated that approximately 65 million people worldwide have moderate to severe chronic obstructive pulmonary disease (COPD) – and this number will only continue to rise over the next 50 years.

In the United States, approximately six percent of our population carries a diagnosis of COPD – this equates to approximately 15 million Americans. As many as 12 million Americans may have COPD and not know it. It is a costly disease – it costs the U.S. approximately $30 billion in healthcare dollars annually.

What Is End-Stage COPD?

COPD is a chronic, irreversible lung condition. Its hallmark symptom is breathlessness. It is an umbrella term for the following progressive lung conditions: emphysema, chronic bronchitis, and refractory asthma.

- **Emphysema** affects the tiny sacs of the lungs (alveoli). The alveoli become damaged and stretched out; thus the lungs become larger making air exchange more difficult. “Old” air gets trapped in the alveoli, and “new” air is unable to be exchanged.
- **Chronic bronchitis** causes inflammation to the breathing tubes (bronchial airways) of the lungs. This happens because the cilia, the tiny hair-like structures that line the airways, are unable to sweep the mucus. The lungs become swollen with mucus, and airflow becomes obstructed.
- **Refractory asthma** is a specific type of asthma that is unresponsive to asthma medications. During a typical asthma attack, certain medications can be used to open the airways when the bronchial airways are tightened; with refractory asthma, the airways do not respond to these medications.

COPD is typically a combination of these chronic lung conditions. When COPD reaches stage 4, it is also termed “end-stage.” We will discuss the symptoms and the stages of COPD later in the article.

Symptoms of End-Stage COPD

Symptoms of end-stage COPD are similar to that of COPD in general but intensified. These symptoms are more frequent and more severe – and are more likely to require treatment from a healthcare professional.

Common symptoms of COPD include:

- A chronic cough
- Shortness of breath that makes it difficult to perform activities of daily living, such as finishing a meal
- Phlegm production
- Worsening exacerbations

- Low blood oxygen levels without supplemental oxygen
- A need for supplemental oxygen
- Confusion due to low oxygen levels

Symptoms of end-stage COPD may include:

- Rapid heartbeat
- Swelling in the upper and lower extremities
- Weight loss
- A loss of musculature
- An increased difficulty breathing and speaking
- Cyanosis – a blue tinge to the lips and nail beds
- A loss of mental alertness

Stages of COPD

As with other chronic conditions, physicians stage COPD to determine the severity of the condition. This helps because then any provider who cares for you will know what your baseline functioning is.

There are two ways to stage COPD – the **GOLD Staging System** and the **BODE Index**.

The Global Initiative created the GOLD Staging System for Chronic Obstructive Lung Disease; it utilizes the forced expiratory volume in one second (FEV1) measurement from a pulmonary function test, then places you in stages. Other symptoms are also considered.

The **BODE Index** stands for the following: **B**ody mass, **O**bstruction of airflow, **D**yspnea, and **E**xercise capacity. The BODE Index is used to evaluate the effect on everyday living and the severity of symptoms.

The general stages for COPD are as follows:

1. Stage 1 (mild COPD) – an FEV1 about 80 percent or more of normal. People with mild COPD may not even realize that they have COPD yet, but slight symptoms are beginning to develop, such as a cough and phlegm development.
2. Stage 2 (moderate COPD) – an FEV1 between 50 and 80 percent of normal. An increase in cough and mucus production has developed. At this stage, people begin to seek assistance with their symptoms.
3. Stage 3 (severe COPD) – an FEV1 between 30 and 50 percent of normal. Symptoms begin to worsen and begin to impact daily living. Fatigue begins to develop, have difficulty exercising, and require increased medications to function.
4. Stage 4 (end-stage COPD) – an FEV1 lower than stage 3, or those with a stage 3 FEV1 and low blood oxygen levels. Flare-ups of COPD can become life-threatening. Oxygen therapy may be required.

Treatment for End-Stage COPD

There are a variety of medications that can be used to treat COPD:

- **Bronchodilators** are inhaled and work by relaxing the muscles of the airways. They make breathing easier. There are short-acting bronchodilators that are used when symptoms are acute or before activities or long-acting bronchodilators that are used daily (tiotropium, salmeterol, formoterol).
- **Inhaled steroids** reduce inflammation of the airways. They also prevent exacerbations. They are extremely helpful for people who have frequent COPD exacerbations. However, there are more frequent side effects with inhaled steroids, such as bruising, hoarseness, and oral infections. Examples include fluticasone and budesonide.
- **Combination inhalers** combine bronchodilators and inhaled steroids, thus have the benefits of both types of medications. Examples include salmeterol and fluticasone and formoterol and budesonide.

Next page: More treatment for end-stage COPD options, information on end-stage COPD and end-of-life care, and more.

Treatment for End-Stage COPD

- **Oral steroids** are useful on a short-term basis for moderate and severe exacerbations because they can prevent worsening of COPD. Long-term use of oral steroids should be weighed heavily before prescribing because there are many side effects, such as weight gain, osteoporosis, diabetes, increased risk of infection, and cataracts.
- **Theophylline** is a low-cost medication, but it can also be fraught with side effects. It works by improving breathing overall and preventing exacerbations. Common side effects include tremors, nausea, headaches, and tachycardia. A low dose should initially be prescribed and increased as needed. When side effects are experienced, it is typically because the dosage is too high.
- **Phosphodiesterase-4 inhibitors** is a newer drug class that is specific to people with severe COPD. These drugs improve airway inflammation and relax the airways. Weight loss and diarrhea may be experienced. This medication is called roflumilast (Daliresp).
- **Antibiotics** are used when a lung infection is present. They are not used as a mainstay treatment for COPD. However, according to *WebMD*, "a recent study shows that the antibiotic azithromycin prevents exacerbations, but it isn't clear whether this is due to its antibiotic effect or its anti-inflammatory properties."
- **Oxygen therapy** can also be prescribed for people who need it. Oxygen therapy is used when there is not enough circulating oxygen in the blood. Some people who require supplemental oxygen need it just for sleep, while others will need it all the time. Oxygen therapy can improve quality of life – it extends life for people who need it.

End-Stage COPD and Palliative Care

It is important to understand that COPD is irreversible. It is a leading cause of mortality worldwide.

Unfortunately, the *European Respiratory Journal* stated in 2008 that, "Despite the high morbidity and mortality associated with severe COPD, many patients receive inadequate palliative care. There are several reasons for this. First, patient-physician communication about palliative and end-of-life care is infrequent and often of poor quality. Secondly, the uncertainty in predicting prognosis for patients with COPD makes communication about end-of-life care more difficult."

Many people associate the term "palliative care" with "end-of-life" – for some people, this may be the case. However, palliative care does not necessarily mean "hospice." The World Health Organization defines **palliative care** as "patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice."

The World Health Organization defines **end-of-life care** as "care concerning the final stage of life and focuses on care of the dying person and their family."

Perhaps palliative care and end-of-life care may overlap – but they do not need to initially. By definition, palliative care does envelop end-of-life care, but it also depends on your goals.

Defining your goals for treatment is important. These goals should also be outlined early in the course of your illness so that you have better quality for your end-of-life care.

Tips for Living with End-Stage COPD

Without a doubt, the process will be overwhelming and emotionally draining. Consider these tips for making the best of your experience.

- **Get educated** – When emotions run high, jumping to conclusions is typical, but try to avoid it. Get information from your doctor or other reputable sources about what your diagnosis means. Stage IV is a wide window of time for many people. Even if the information seems frightening, seek it out. It will provide a framework for your future choices and decisions.
- **Set and accomplish goals** – Having a terminal diagnosis does not mean that life simply stops. Life goes on for you and the people around you. What do you want to do with the time you have left? If there is something that you always wanted to do or a place you always wanted to go, go for it. Even though your limitations are likely severe at this point, there may be ways to achieve these goals. Don't let sadness convince you that you should be resigned to spending all day on the couch. Setting goals is a great way to avoid further regrets.
- **Grieve and mourn** – Grieving is a passive experience that is a reaction to a terminal diagnosis. You cannot force yourself to grieve but you can allow yourself time and the emotional resources needed. You are filling your brain with distractions and diversions delays grieving. Mourning is more active. An example of mourning would be setting aside time to think about aspects of death and dying. Making a list of feelings or fears about dying is an appropriate mourning exercise. These processes are never completed so continue doing what you can to move towards acceptance; with acceptance comes peace.
- **Be selfish** – The loss process needs to be selfish. You are going through something that others will not understand. Give yourself the freedom to do, think and feel what feels best for you. Assertively communicate your needs to your support system to establish a team approach. As long as your selfishness is in moderation, it will be a positive.
- **Be selfless** – Now that you have explored being selfish, change gears. Your family, friends, and supports are experiencing changing feelings and thoughts triggered by your stage IV diagnosis. Take time to consider their experience and feelings through empathy. Ask if there are goals or accomplishments they would like to complete. They might feel too uncomfortable to mention it on their own for fear that they would upset you. Remember, death is for the living.

Exercise Can Help

It may sound counterintuitive, but exercise can be very helpful. According to the Cleveland Clinic, utilizing a pulmonary rehabilitation program can "help you learn how to breathe easier and improve your quality of life. It includes breathing retraining, exercise training, education, and counseling." Ask for a referral to a pulmonary rehabilitation program if you have one locally.

Regular exercise – specifically aerobic exercise, which gets your heart pumping – is beneficial:

- Helps your body use oxygen more efficiently.
- Improves COPD symptoms in general.
- Improves energy levels overall.
- Strengthens the cardiovascular system.
- Lowers blood pressure.
- Increases endurance.
- Improves musculature, flexibility, and balance, which can lessen body weight.
- Improves sleep.
- Mental health benefits, such as reduction in stress, anxiety, and depression, as well as improved self-esteem.

Other Things You Can Do Today

The Centers for Disease Control and Prevention also recommend the following:

- Quitting smoking if you have not done so already.
- Avoiding exposure to secondhand smoke.
- Reviewing the air quality daily. You should stay indoors when the air quality is predicted to be bad.
- Following your physicians' recommendations for vaccinations – specifically influenza and pneumonia, which can be detrimental to someone with end-stage COPD.

- Take your medications as prescribed. If you’re having a difficult time affording your medications, you should speak with your physician to see if there are alternatives.

The Bottom Line…

Understanding that there are different stages to COPD, as well as the various COPD treatment options, is extremely important. If you have COPD, you should have a frank conversation with your loved ones, as well as your healthcare provider, about your wishes. Doing so can help extend your life, but also ensure that you have the best quality-of-life possible.