

GAYLORD PULMONARY EDUCATION MANUAL



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Introduction

The mission of Gaylord Specialty Healthcare is to preserve and enhance a person's health and function. Our hospital values, which guide all of our actions, are clinical excellence, compassion, integrity, respect and accountability. Our vision is to promote patient functionality through the best clinical services, most advanced and effective treatment protocols, and documented outcomes for our patients.

The Pulmonary Rehabilitation Program is one of the first and largest programs at Gaylord Specialty Healthcare. Rehabilitation after an exacerbation of a pulmonary disease is a process that the person and their support system work through together, with the assistance of an interdisciplinary group of professionals. This team approach is essential to maximize the physical, cognitive, linguistic, psychological, emotional, spiritual and social recovery. This education manual is dedicated to all our persons with pulmonary disorders, their families, and support system - the true core of every rehabilitation team.

 Gaylord Specialty Healthcare



www.gaylord.org

SECTION 1

Welcome to Gaylord's Pulmonary Rehabilitation Program

Different Levels of Care for Pulmonary Rehabilitation

People with Pulmonary Disease may be served by many people in the healthcare system. Recovery often follows a progression that is often defined by the term "**continuum of care.**" That means that a person with pulmonary disease may transition from an acute care hospital through progressively less medically intense levels of care. The first step in the continuum is the acute care hospital. Patients are stabilized, medications are initiated or their effect is maximized. Secondary complications related to the pulmonary disease and other medical problems are minimized.

Once someone is discharged from the acute care hospital, they go to the next level that is most appropriate for them. That could be locations anywhere along the continuum, based on each individual's needs, from home with outpatient therapy to a long term acute care hospital. The first step is often to a **long term acute care hospital (LTACH)**. An LTACH is an option for persons with pulmonary disease that have specific, complex medical needs. Gaylord is an LTACH. We are able to care for persons with pulmonary disease with medically complex problems and provide therapies that are equal to their needs to maximize their function and health. An LTACH average length of stay is 3-4 weeks based individually on each patient.

Another option along the continuum is a sub-acute facility or a **skilled nursing facility**. These are institutions where people with pulmonary disease have needs that can not be met at home from a medical or care standpoint. They continue to progress at a slower rate and are able to maximize their recovery prior to discharge. People can also transfer to an extended care facility as well, if home is not an option for discharge.

Following a stay at any facility, a person with pulmonary disease can discharge home with home care or go directly to outpatient therapy. Some people begin their therapy at home to maximize their function there or because they are unable to get to outpatient therapy and then transition to outpatient therapy.

Other times, people with pulmonary disease can also discharge from a facility directly into outpatient therapy. Outpatient therapy is typically more intensive than home care therapy. Outpatient therapy has the benefits of equipment and facilities not available in the home. Gaylord also has a large outpatient therapy department with a Pulmonary Rehabilitation program for persons with pulmonary disease on the Wallingford Campus.

SECTION 2

Role of Treating Team

Care Management:

The Care Manager coordinates health care services that a person with pulmonary disease requires through a collaborative multi-disciplinary team approach. It is the responsibility of the Care Manager to provide education and support to the person and their family as well as to hospital staff regarding community resources, managed care issues, or payment / payer issues. Discharge planning is initiated early on during the inpatient stay. The Care Manager develops and revises individualized discharge plans as indicated by the team's assessment, and the patient's response to treatment. Many factors including the psychosocial, physical, educational and cultural aspects are taken into consideration when developing a plan. It is the role of the Care Manager to ensure that the plan of care promotes a safe and timely discharge, and to evaluate the overall plan for effectiveness. The Care Manager involves both the person with pulmonary disease and family in the formulation of goals for a safe discharge. The Care Manager provides the link between provider and payer organizations, physicians and the community in the transition of your care through the health care continuum.

Food and Nutrition:

A Registered Dietitian (RD), upon nutrition consultation, will evaluate and monitor the nutritional status of the person with pulmonary disease and provide guidance for the person, family and team. Interventions may include education about healthy food choices to help manage chronic health conditions and assistance with managing poor appetite or addition of nutrition supplementation. The dietitian also assesses and may modify a tube feeding regimen as needed. The RD works closely with the Speech-Language Pathologist (SLP) when a modified consistency diet is needed due to swallowing problems. A representative from the Food & Nutrition department meets with patients daily for individual menu selections.

Before changing diet or taking any type of supplement, one should always check with their health care provider. Nutrition education may be provided in both group and individual sessions. Continued nutrition support and counseling may be recommended after discharge on an outpatient basis.

Medical:

The physician is the team leader. This professional is usually a specialist in Internal, Pulmonology, Critical Care, or Sleep Medicine. Since patients have survived a very severe and, in many cases, life threatening illness, continued management of medical complications beyond the acute care hospital is essential. Without medical stability, the person with pulmonary disease's full participation in a rehabilitation program would be impossible. The physician will assess many aspects of the ongoing health care needs. Both pre-existing and new medical problems will be evaluated, monitored, and managed. The medical team may also include a physician's assistant (PA) or a nurse practitioner (APRN), both of whom play key roles in managing the ongoing health care needs of the person with pulmonary disease.

Nursing:



A registered nurse is responsible for establishing a plan of care based on the needs of the patient as identified by the nurse. The ultimate goal of rehabilitation nursing care is helping people regain the control of and the responsibility for their lives. It is important to remember that the focus is on the person with pulmonary disease becoming more independent and less reliant on others as discharge approaches.

The nurse ensures that each person receives adequate nutrition and rest, administers medications and performs treatments ordered by the physician. Monitoring the person to prevent or correct problems such as skin pressure areas, infection, deformities and excess weight is very important. Physical, cognitive, social and emotional reactions are also observed and recorded. Nurses work closely with other team members in evaluating and helping the person with pulmonary disease practice on the unit the functional skills taught in other therapies. They address bowel and bladder training as needed.

Because the family is part of the team, education and participation in their relative's care is necessary. Correct techniques are taught to the family in the therapy departments and on the nursing unit and once learned, the family will be encouraged to help whenever they are present. Adequate family training not only makes the transition from hospital to home easier but often can mean the difference between the person with pulmonary disease being able to go home or to another facility.

Occupational Therapy:



The occupational therapist (OT) evaluates and treats areas which affect a person's ability to care for his or her self. The role of the occupational therapist is to assist the person in achieving the highest level of independence possible in activities of daily living (ADL's). This may include areas such as feeding, grooming, dressing, bathing, ability to get to and from the bathroom, and preparing meals. A person may need to re-learn how to perform these activities while pacing themselves, and may also need to learn to compensate for visual, perceptual, and cognitive deficits. The occupational therapist

may recommend adaptive equipment or modify the environment to assist the person with pulmonary disease with their ability to perform these tasks more independently while conserving energy. The occupational therapist also provides demonstrations and training to family members in the areas of self care and mobility in preparation for a safe discharge home.

Pastoral Care:

The chaplain is a person with specialized training who has been authorized by a formal religious body to minister to persons with pulmonary disease, families and staff in a healthcare setting. The goal of the chaplain is to help facilitate a person's use of his/her own faith, belief system, religious experience, or heritage during a crisis. The chaplain can help provide religious resources, act as a helpful liaison with various religious bodies or communities, or assist the person with pulmonary disease and family to use faith and spiritual values to gain emotional support or spiritual strength.

Physical Therapy:



The role of the physical therapist (PT) is to assist the person with pulmonary disease in attaining the highest level of mobility possible following hospitalization. The physical therapist will conduct an evaluation of movement in both legs comparing strength, sensation, tone and coordination. The therapist will also evaluate endurance, balance, as well as important mobility skills necessary for getting out of bed to walk, move from/to a bed or wheelchair (“transfer”), or use stairs. The therapist will also evaluate the amount of energy required to perform these tasks. After completion of the evaluation, an individualized treatment program is developed in consideration of both the person and family’s goals for rehabilitation.

Family education and training is an essential component to the recovery of the person with pulmonary disease. In consideration of a goal for a discharge to home, it may be advised for the appropriate family members to attend treatment sessions for training to assist the patient with safe mobility in the home environment. Recommendations for necessary assistive equipment and continued therapy services are made by the physical therapist prior to discharge.

Helpful Hint: Wearing loose and comfortable clothing, including sneakers and pants (no skirts) is recommended.

Psychology:

Psychology clinicians are available to assist patients and families involved in the inpatient and outpatient pulmonary programs. First a meeting of the patient and clinician will help identify treatment goals as well as review the patient’s current emotional state, adjustment to illness, and discussion of relevant health behaviors (e.g., smoking cessation). Psychological treatment may include individual, family and/or group talk therapies to aid in adjustment issues and coping with pulmonary disease. Treatment would include the patient, family members if desired, and other care providers. Upon discharge, resource information may be provided for further follow-up, as desired.

Respiratory:



The Respiratory Therapist (RT) plays a key role in the management of the person with pulmonary disease. The RT will initially assess for any and all respiratory needs including oxygen, medication therapies, airway clearance modalities and airway interventions. The RT works together with the interdisciplinary team to best coordinate all aspects of the care of the person with pulmonary disease. The Respiratory Therapist works with members of the interdisciplinary team to facilitate ambulation as soon as appropriate and aid in recovery and return to everyday activities. The RT staff will also work together with Speech Therapy to utilize a speaking valve to allow for communication, if a tracheostomy is in place. The RT staff will also provide education on breathing interventions to maintain optimal respiratory function. The Respiratory Therapist may also work with the patient to transition to an outpatient pulmonary rehabilitation program.

Speech-Language Pathology:



If appropriate, the person with pulmonary disease is evaluated by a speech-language pathologist (SLP). The doctor will order an evaluation of swallowing, communication and/or cognition (See each specific section for more information). Following the evaluation(s), an individualized treatment plan is developed. Goals are set by the person with pulmonary disease, family members or therapist, to assist with return to the highest level of function. Examples of speech therapy goals include: returning a patient to eating the least restrictive diet if he is nothing by mouth (NPO) or on a modified diet, using a speaking valve if a tracheostomy is in place, or remembering newly learned information. Treatment is given in individual speech therapy sessions and group therapy if appropriate. Families are encouraged to participate in treatment sessions to promote implementation of all skills/strategies learned.

Therapeutic Recreation:

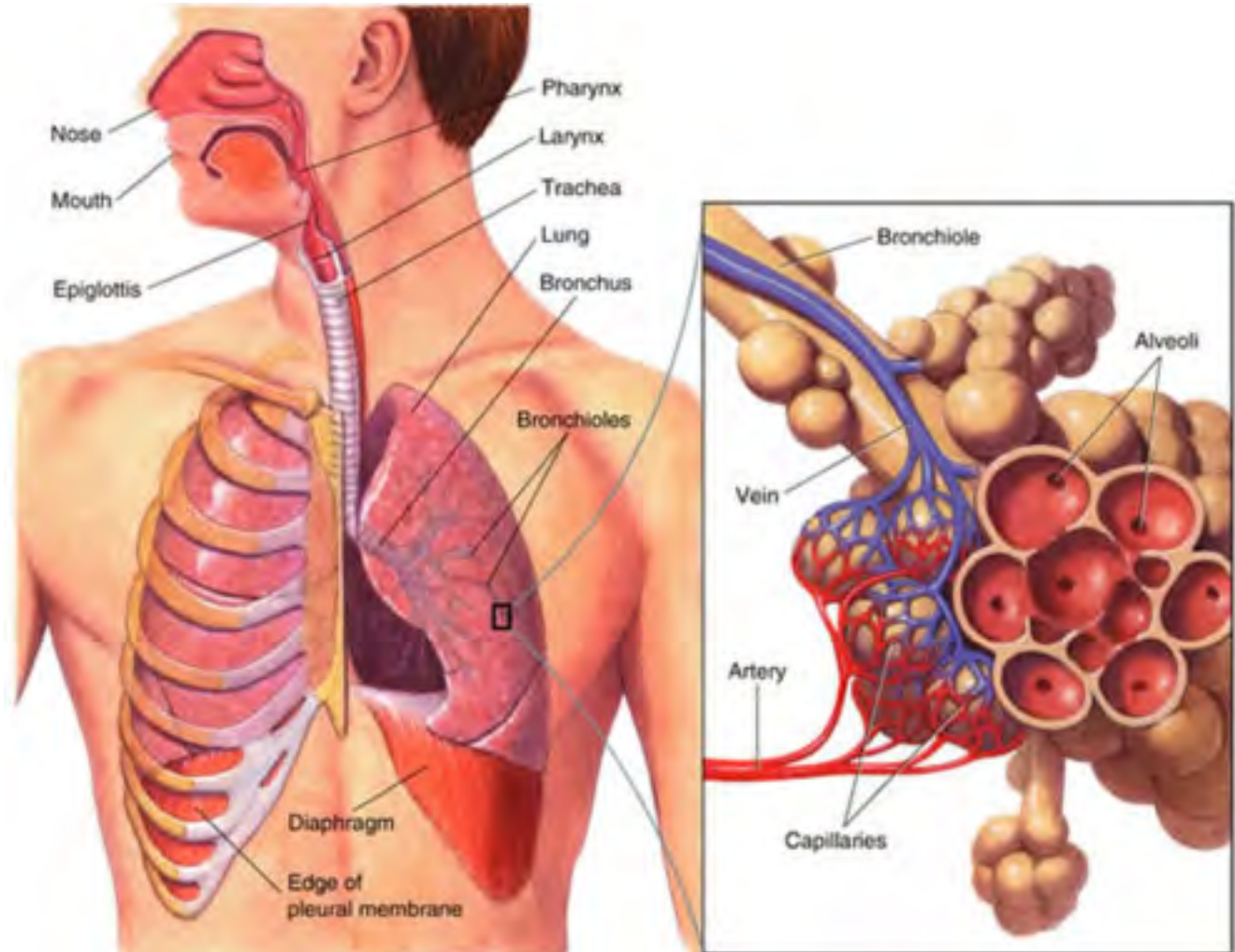


Therapeutic Recreation (TR), also called Recreational Therapy, uses leisure and recreation programs to improve an individual's quality of life and physical, cognitive, social and emotional function. Therapeutic Recreation helps to improve abilities, enhance independence and make participation in recreation possible. TR offers activities that address the physical, cognitive, social, emotional and creative needs through engaging in activities of interest to each individual. Some examples of activities may include: board games, cards, Wii or video games, arts and crafts, iPad use, sports and community re-integration. Leisure Education teaches or enhances recreation skills and attitudes that will be used throughout life. It can help one to discover new and exciting activities through interest exploration and to re-familiarize one with their community. Leisure Education also helps an individual continue to participate in activities of interest through adaptive equipment.

SECTION 3

About Your COPD

Lung Anatomy



Alveoli: Air sacs at the end of the bronchioles that are surrounded by tiny blood vessels call capillaries. This is where gas exchange takes place – oxygen is absorbed into the blood, carbon dioxide is removed into the lungs to be exhaled.

Bronchial Tube: The main airways of the lungs. The bronchial tubes are surrounded by smooth muscle and lined with a mucous membrane.

Bronchioles: Them smallest branches of the respiratory tree that end in the alveoli.

Cilia: Tiny hair-like cells that help to keep the lungs clean by “sweeping” mucous toward the major airways so it can be coughed out.

Diaphragm: The primary breathing muscle. It separates the chest cavity and the abdominal cavity.

Heart: A muscular organ that pumps blood to the lungs and throughout the body.

Intercostal Muscles: Thin sheets of muscle between the ribs that expand when air is inhaled and contract when air is exhaled.

Lungs: The two respiratory organs that extract oxygen from the air and expel carbon dioxide from the body. The right lung has three lobes and the left lung has two.

Larynx: Commonly called the voice box, is an organ in the neck of amphibians, reptiles, and mammals involved in breathing, sound production, and protecting the trachea against food aspiration. It manipulates pitch and volume.

Nasal Cavity: The internal area of the nose that is lined with mucous membrane to help clean, moisten air and warm the air that is breathed in.

Nose Hairs: Hairs at the entrance of the nasal cavity that trap large particles from the air to help keep the lungs clean.

Pulmonary Circulation: Blood vessels of the lungs have dual circulation:

- 1. Bronchial circulation:** supplies blood to the large airways of the lungs.
- 2. Pulmonary circulation:** pulmonary arteries carry deoxygenated blood from the heart to the lungs. Pulmonary veins carry oxygen rich blood back to the heart to be distributed to the body. Capillaries are the tiny blood vessels that surround the alveoli and allow gas exchange to take place.

Ribs: Bone that support the chest wall and protect the heart, lungs and other chest organs.

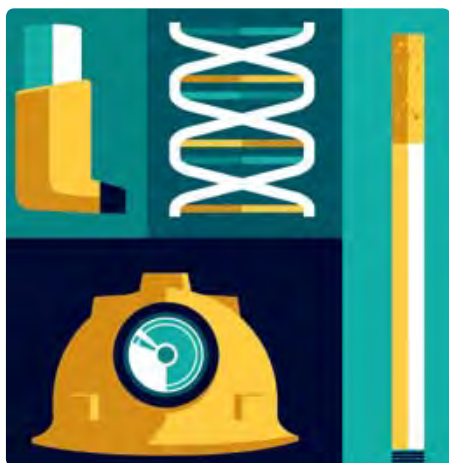
Trachea: The main airway in which air passes from the nose to the lungs. Also known as the wind pipe.

PATIENT PRIMER

By Valerie Neff Newitt

At Risk for COPD?

Find out if you should be screened by answering a few simple questions



CHRONIC PULMONARY obstructive disease, or COPD, is really more than a single disease. It is a group of lung diseases, including emphysema, chronic bronchitis, and asthma, that make it increasingly difficult to breathe. Symptoms may vary from person to person, but the most common signs are shortness of breath, wheezing, chronic coughing, and an uncomfortable tightness in the chest.

As the disease progresses, it impacts quality of life by making normal activities difficult, and it can even lead to severe illness or premature death. In fact, COPD has been pegged as the number three killer in the U.S., preceded only by heart disease and cancer. Early treatment is the best way to slow its progress and minimize symptoms, but too often COPD goes unrecognized in the earliest stages. That

is why it is important to understand your own risk for COPD and to seek medical assessment if you are a candidate for screening.

Are you at risk?

Your risk of developing COPD is about one in four, according to a study published in 2011. But there are certain factors that predispose a person to that endangered 25 percent. Here are questions to help you decide if you are at risk:

Do you or have you smoked? Between 80-90 percent of COPD patients are current or former smokers. All types of smoking count: cigarette, cigar, pipe, marijuana, and exposure to second-hand smoke. (You can still get COPD if you are a non-smoker, but it is not as likely.) The single most important step you can take to reduce your risk of COPD is to stop smoking.

Is your environment safe? Living or working around dust and fumes has been pegged to about a third of the COPD found in non-smokers, and about a fifth of the COPD found in smokers. It is estimated that about 15 percent of all COPD cases are work-related. People working in mining, manufacturing, and construction all carry a particular burden of risk. It has been determined that people exposed to heavy indoor smoke are twice as likely to be diagnosed with COPD. And more than a million people die of COPD each year due to exposure to indoor pollution caused by biomass fuels. For example, the smoke from a wood burning stove releases toxic gases and particle pollution. Particulate matter can be inhaled into the lungs where it can damage the cells. In addition, outdoor air pollution also poses

a risk so living near a congested traffic area or highway could pose a problem.

Do you have asthma? There may be a link between asthma and bronchitis and emphysema, although further research is needed to confirm the association. One study, however, concluded that people with asthma have about 12 times the risk of developing COPD as those who do not have it.

Is it in your genes? Research is finding genetic links to COPD and identifying certain groups of people who are more susceptible to the ravages of smoking and the likelihood of COPD. Individuals with a deficiency of a protective protein called alpha-1-antitrypsin (ATT) are at much greater risk of developing emphysema. ATT deficiency is most often seen in people of Northern European descent.

Are you in a target population? In general, any current or former smoker over age 40 or never-smoker with a family history of COPD, emphysema or chronic bronchitis, those with exposure to occupational or environmental pollutants, and those with a chronic cough, sputum (mucus discharged from air passages) production or breathlessness, should seek testing for COPD.

How can you find out if you have COPD?

Go to your doctor, who will ask you about your family history and whether you smoke or have been exposed to lung irritants. Your health care provider also will examine you and listen to your lungs. Your doctor will use a simple, painless breathing test called spirometry to confirm a diagnosis of COPD. You will breathe into a tube connected to a spirometer. When you breathe out, the spirometer measures how much air your lungs can hold and how fast you can blow air out of your lungs after taking a deep breath. Spirometry can detect COPD long before you have significant symptoms.

For more information about spirometry, check out a downloadable guide called "What Is Spirometry?" at: <http://respiratory-care-sleep-medicine.advancweb.com/Clinical-Resources/Patient-Primer/What-Is-Spirometry.aspx> ■

Information adapted from mayoclinic.com, copdfoundation.org, copd.about.com, patientlinx.com, asthmacopd.com, lungusa.com

DAVE PERILLO

EDITOR'S NOTE: Your doctor or therapist has given you this educational handout to further explain or remind you about an issue related to your health. It is a general guide only. Discuss specific questions with your doctor or therapist.

Look under the "Education" tab at advancweb.com/respiratory for more educational handouts.

Smart Thinking for Patients With COPD

Chronic obstructive pulmonary disease, like a force of nature, can't really be stopped. But if a hurricane was coming your way, you wouldn't just sit around twiddling your thumbs, right?

Odds are you would board up the windows, pack up the china, and so forth in your best effort to minimize the damage. It's to your benefit to approach COPD in the same way. You can take measures to reduce the risk of exacerbations — serious symptom flare-ups that can land you in the hospital and lead to debilitating or even fatal complications.

Knowing symptoms and triggers

For starters, you should know the symptoms of an exacerbation, so that you'll recognize when you're actually having one. Symptoms include increased or prolonged breathlessness, coughing, sputum (mucus) production, wheezing, chest tightness, and fever. Keep track of how many and how severe your symptoms are, and share this information with your physician. A simple breathing test called spirometry can help to determine if your lung function is declining.

In addition, you should become aware of what aggravates your COPD. Evidence suggests 80 percent of COPD exacerbations are infectious in origin, so practice good hand hygiene, and avoid people with colds or other respiratory illnesses.¹ Make sure you get your annual flu shot because the vaccine can decrease serious complications and death in COPD



DAVE PERILLO

patients by as much as 50 percent.² Ask your physician if you're a good candidate for the pneumonia vaccine as well.

Pollution is another major trigger of exacerbations for people with COPD, so minimize exposure to environmental irritants such as dust, chemicals, and secondhand smoke. Stay inside on high ozone days.

Healthy living

Proactive approaches like a balanced diet, a good night's sleep, and maintaining a healthy weight are good ideas for anyone, but they can be especially valuable to COPD patients who want to improve their quality of life. It's also wise to make an effort to keep your emotions in check, because depression and anxiety can lead to a higher frequency of exacerbations.³

Exercise in the form of pulmonary rehabilitation is suggested for people looking to avoid exacerbation relapse because pulmonary function declines after each

episode. Staying active can help strengthen the muscles you use to breathe.

But the most important lifestyle change you can make is to quit smoking to slow the progression of lung inflammation that causes COPD.

Managing therapies

Following the medication plan prescribed by your doctor is another simple way to manage your disease. Take your maintenance medications daily to keep symptoms under control and reduce your need for rescue medications. If you use supplemental oxygen, be sure that you're using the appropriate levels prescribed for periods of activity and rest.

Remember, despite your best efforts to prevent them, COPD exacerbations are common and can occur suddenly. Be sure to know how and when to use your rescue medications, and go to the emergency room if necessary. ■

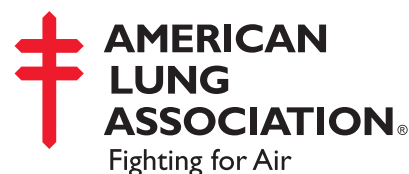
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MY COPD ACTION PLAN

It is recommended that patients and physicians /healthcare providers complete this action plan together. This plan should be discussed at each physician visit and updated as needed.



The green, yellow and red zones show symptoms of COPD. The list of symptoms is not comprehensive, and you may experience other symptoms. In the “Actions” column, your healthcare provider will recommend actions for you to take based on your symptoms by checking the appropriate boxes. Your healthcare provider may write down other actions in addition to those listed here.

Green Zone: I am doing well today	Actions
<ul style="list-style-type: none"> • Usual activity and exercise level • Usual amounts of cough and phlegm/mucus • Sleep well at night • Appetite is good 	<ul style="list-style-type: none"> <input type="checkbox"/> Take daily medicines <input type="checkbox"/> Use oxygen as prescribed <input type="checkbox"/> Continue regular exercise/diet plan <input type="checkbox"/> At all times avoid cigarette smoke, inhaled irritants* <input type="checkbox"/> _____
Yellow Zone: I am having a bad day or a COPD flare	Actions
<ul style="list-style-type: none"> • More breathless than usual • I have less energy for my daily activities • Increased or thicker phlegm/mucus • Using quick relief inhaler/nebulizer more often • Swelling of ankles more than usual • More coughing than usual • I feel like I have a “chest cold” • Poor sleep and my symptoms woke me up • My appetite is not good • My medicine is not helping 	<ul style="list-style-type: none"> <input type="checkbox"/> Continue daily medication <input type="checkbox"/> Use quick relief inhaler every _____ hours <input type="checkbox"/> Start an oral corticosteroid (specify name, dose, and duration) _____ <input type="checkbox"/> Start an antibiotic (specify name, dose, and duration) _____ <input type="checkbox"/> Use oxygen as prescribed <input type="checkbox"/> Get plenty of rest <input type="checkbox"/> Use pursed lip breathing <input type="checkbox"/> At all times avoid cigarette smoke, inhaled irritants* <input type="checkbox"/> Call provider immediately if symptoms don't improve* <input type="checkbox"/> _____
Red Zone: I need urgent medical care	Actions
<ul style="list-style-type: none"> • Severe shortness of breath even at rest • Not able to do any activity because of breathing • Not able to sleep because of breathing • Fever or shaking chills • Feeling confused or very drowsy • Chest pains • Coughing up blood 	<ul style="list-style-type: none"> <input type="checkbox"/> Call 911 or seek medical care immediately* <input type="checkbox"/> While getting help, immediately do the following: <input type="checkbox"/> _____

*The American Lung Association recommends that the providers select this action for all patients.

The information contained in this document is for educational use only. It should not be used as a substitute for professional medical advice, diagnosis or treatment. The American Lung Association does not endorse any specific commercial product.

For more information, visit www.Lung.org or call 1-800-LUNG-USA (1-800-586-4872)

MY COPD MANAGEMENT PLAN

It is recommended that patients and physicians/healthcare providers complete this management plan together. This plan should be discussed at each physician visit and updated as needed.



General Information	
Name:	
Emergency Contact:	Phone Number:
Physician/Health Care Provider Name:	Phone Number:
Date:	

Lung Function Measurements		
Weight: _____ lbs	FEV ₁ : _____ L _____% predicted	Oxygen Saturation: _____%
Date:	Date:	Date:

General Lung Care		
Flu Vaccine	Date:	Next Flu Vaccine Due:
Pneumonia vaccine	Date:	Next Pneumonia Vaccine Due:
Smoking status	<input type="checkbox"/> Never <input type="checkbox"/> Past <input type="checkbox"/> Current	Quit Smoking Plan
Exercise plan <input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Walking <input type="checkbox"/> Other _____ _____ min/day _____ days/week	Pulmonary Rehabilitation <input type="checkbox"/> Yes <input type="checkbox"/> No
Diet plan <input type="checkbox"/> Yes <input type="checkbox"/> No	Goal Weight: _____	

Medications for COPD			
Type or Descriptions of Medicines	Name of Medicine	How Much to Take	When to Take

My Quit Smoking Plan		
<input type="checkbox"/> Advise: Firmly recommend quitting smoking	<input type="checkbox"/> Discuss use of medications, if appropriate:	
<input type="checkbox"/> Assess: Readiness to quit		
<input type="checkbox"/> Encourage: To pick a quit date	<input type="checkbox"/> Freedom From Smoking® www.ffsonline.org	<input type="checkbox"/> Lung HelpLine 1-800-LUNG USA
<input type="checkbox"/> Assist: With a specific cessation plan that can include materials, resources, referrals and aids		

Oxygen		
Resting:	Increased Activity:	Sleeping:

Advanced Care and Planning Options				
<input type="checkbox"/> Lung Transplant	<input type="checkbox"/> Lung Reduction	<input type="checkbox"/> Transtracheal Oxygen	<input type="checkbox"/> Night-time Ventilator	<input type="checkbox"/> Advanced Directives

Other Health Conditions			
<input type="checkbox"/> Anemia	<input type="checkbox"/> Anxiety/Panic	<input type="checkbox"/> Arthritis	<input type="checkbox"/> Blood Clots
<input type="checkbox"/> Cancer	<input type="checkbox"/> Depression	<input type="checkbox"/> Diabetes	<input type="checkbox"/> GERD/Acid Reflux
<input type="checkbox"/> Heart Disease	<input type="checkbox"/> High Blood Pressure	<input type="checkbox"/> Insomnia	<input type="checkbox"/> Kidney/Prostate
<input type="checkbox"/> Osteoporosis	<input type="checkbox"/> Other:		

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■ PATIENT PRIMER

By Colleen Mullarkey

Getting With the COPD Management Program

A look at resources that can help you manage your COPD

MANY EMPLOYERS and health insurance plans now offer disease management programs for a number of medical conditions. You might have heard about some for weight management or diabetes care, but did you know there also are many to help you manage your chronic obstructive pulmonary disease (COPD)? More companies have been adding COPD disease management programs to their list of benefits, so let's take a look at what they have to offer.

A quick review

COPD disease management programs combine a number of ways to help you improve control of your COPD symptoms and lessen harmful effects. Disease management professionals use a team approach to care rather than just giving you directions. They work with you to improve your treatment plan, watch your progress, and often provide support after hours.

Some programs send a health care professional to meet with you regularly at your home and then follow up with phone calls or emails in between visits. Others don't require any face-to-face meetings. They might send you educational materials by mail and check your progress by phone or email.

The length and make-up of the program usually depend on the stage of your disease and the amount of time you're willing to commit. For some people, it might last a few months, while others choose to continue for a few years. As you progress, your health care providers will tailor the program to fit your changing needs.

Tests, tips, and techniques

Even though you'll find differences in how care is provided through these programs, you'll find they share the same basic ideas. The first step in any COPD disease management program is a general review of your health to figure out what level of care you need.



Health care providers will check basic vital signs and perform more specific tests to examine your lungs, breathing, exercise levels, and oxygen.

A simple test called spirometry measures how much air you can breathe in and out, and how fast you can blow the air out of your lungs. A finger probe called a pulse oximeter also can measure the oxygen levels in your blood.

They'll use these and other results to help you come up with goals and a personalized plan to recognize your symptoms and steer clear of risks like smoking, dust, and people who are not well.

This might include lifestyle changes like quitting smoking, a healthy diet, exercise, and flu shots every year. Overall, they'll teach you how to use your medications, how to stick with your treatment, and how to track and respond to your symptoms.

If you're looking for something a little more intense and hands-on, find out if your health insurance offers coverage for pulmonary rehabilitation programs. They incorporate similar lessons but provide more direct contact with medical professionals, usually through two to four visits at a medical facility each week.

Many resources are available to help you manage your disease. Regardless of which one you choose to use, working to get your disease under control is the first step to improving your health and quality of life. ■

Information provided by Jakki Grimboll, MA, RRT, AE-C, asthma and COPD program administrator at BlueChoice HealthPlan.



PATIENT PRIMER

By Colleen Mullarkey

Alpha-₁ Testing and Treatment

While many consider chronic obstructive pulmonary disease a smoker's disease, the truth is it can strike non-smokers too. A hereditary condition called alpha-₁ antitrypsin deficiency, often called "genetic COPD," is the most commonly known genetic risk factor for the lung disease.

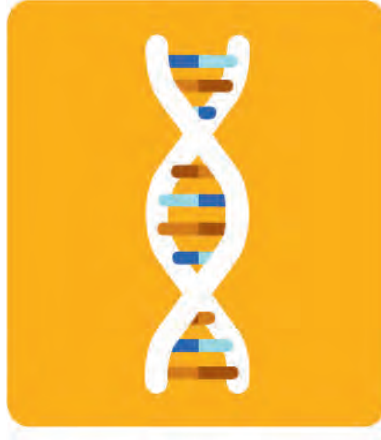
It occurs when there's a severe lack of alpha-₁ antitrypsin, a protein in the blood that protects the lungs from inflammation caused by infection and inhaled irritants. With early diagnosis and avoidance of risk factors like smoking, people with alpha-₁ may remain healthy throughout their lives.

Who should be tested?

You should be tested for alpha-₁ if you have emphysema, COPD, chronic bronchitis, or asthma that's not completely reversible after aggressive treatment. Common respiratory symptoms include shortness of breath, wheezing, chronic cough, phlegm production, and recurring chest colds. If you have unexplained liver disease, a family history of liver disease, or a blood relative that has been diagnosed with alpha-₁, you should get checked out too.

Talk with your health care provider, who will need to give you a prescription for the test. Medical insurance usually covers the simple and highly effective blood test used to diagnose alpha-₁, but other resources also can provide free and confidential testing.

Your results will be analyzed at a



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laboratory, and generally you can expect an answer within one to two weeks. If the test shows you have inherited one defective alpha-₁ gene, you are an alpha-₁ carrier. It's unlikely that you will have any symptoms or require treatment, but you could pass the abnormal gene onto your children. If you have inherited two defective genes, you'll need to talk with your provider to determine the best treatment plan to manage your condition and symptoms.

Treatment options

You'll most likely visit a pulmonary specialist at least twice a year with additional follow-up based on your individual condition. The specialist usually will measure your oxygen levels with a simple, painless device called a pulse oximeter. A series of

breathing tests called pulmonary function testing will determine how well your lungs are working. The doctor also may order lung X-rays and CT scans to take a closer look at your lungs' physical condition.

All of these tests will help to determine what kind of treatment you need. Smoking cigarettes is the biggest risk factor for lung disease and damage, so quitting is a must. In addition, your doctor may prescribe inhaled medications, antibiotics, or supplemental oxygen to treat your symptoms as needed.

Augmentation therapy, the standard treatment for alpha-₁-related lung disease is a weekly treatment that replaces the lacking protein through an IV. A professional can administer the treatment in your home, a clinic, or the hospital, or you can administer the treatment yourself. You should speak with your provider and your insurance company to determine the best option for you.

Receiving a diagnosis of alpha-₁ antitrypsin deficiency can be intimidating, but resources like the Alpha-1 Foundation can help by putting you in touch with health care professionals and other patients who understand your medical and emotional needs. [n](#)

Information provided by Bob Campbell, communications manager at the Alpha-1 Foundation and adapted from www.alphaone.org.



This Patient Primer was sponsored by:
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Ste. 302
Miami, FL 33133
(888) 825-7421
www.alphaone.org

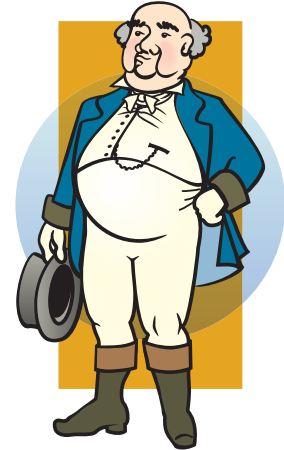


AMERICAN THORACIC SOCIETY

Patient Information Series

Obesity Hypoventilation Syndrome

Obesity hypoventilation syndrome (OHS), can be a serious, but treatable, complication of being obese.



What is Obesity Hypoventilation Syndrome (OHS)?

OHS is a breathing disorder in obese people that leads to low oxygen levels and too much carbon dioxide in your blood. Low oxygen and high carbon dioxide levels may develop because of a condition called hypoventilation during the day (daytime hypoventilation). Hypoventilation means you are not moving enough air in and out of your lungs very well. With OHS, you may also have difficulty sleeping because of obstructive sleep apnea (see ATS Patient Series to read more about *Obstructive Sleep Apnea* at <http://patients.thoracic.org/information-series/index.php>). The three main characteristics of OHS are: 1) obesity; 2) daytime hypoventilation (difficulty getting rid of carbon dioxide); and 3) sleep disordered breathing (such as obstructive sleep apnea).

OHS is also referred to as Pickwickian syndrome because persons with OHS may have symptoms like those described by Charles Dickens in his essay, *The Posthumous Papers of the Pickwick Club*.

What are the symptoms of Obesity Hypoventilation Syndrome?

The symptoms of OHS are usually caused by a lack of sleep and a lower than normal oxygen level in your blood. Symptoms can include daytime sleepiness, lack of energy, breathlessness (see ATS Patient Series on *Breathlessness* at http://patients.thoracic.org/information-series/en/resources/ATS_Patient_Ed_Breathlessness.pdf), headache and even depression.

Nighttime symptoms include: loud and frequent snoring during sleep and/or breathing pauses. Breathing pauses are when you stop breathing for

short periods of time. These may be concerning to your bed partner. Your bed partner may be the only one who sees or hears your nighttime symptoms.

Why is it important to know if I have Obesity Hypoventilation Syndrome?

It is important to know if you have OHS because OHS can be treated. If left untreated, OHS is potentially life threatening. When treated, your breathlessness, fatigue, daytime sleepiness, and depression may be reduced or relieved entirely. Treatment could improve your quality of life and decrease your chances of further health issues, including the need to be hospitalized from serious complications of having OHS. If left untreated, the lack of oxygen can put a strain on your heart (see ATS Patient Series on *Obstructive Sleep Apnea and Heart Disease* at <http://patients.thoracic.org/information-series/en/resources/osa.pdf>).

Do we know what causes Obesity Hypoventilation Syndrome besides obesity?

The cause (or causes) of OHS are not fully understood. OHS may be a combination of your brain's being unable to correctly manage your breathing, your excess fat producing hormones that cause you to breathe ineffectively and the extra weight placed on your chest that makes it much more difficult for you to breathe normally.

How is Obesity Hypoventilation Syndrome diagnosed?

Your health care provider diagnoses your OHS

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by taking a complete history of your symptoms, including your sleeping habits, evaluating your body mass index (BMI), measuring your oxygen and carbon dioxide levels, possibly taking a chest x-ray and a sleep study. Your height and weight are used to calculate your BMI. A BMI of 30 or over is considered obese. An online calculator for BMI is available at <http://www.nhlbi.nih.gov/guidelines/obesity/BMI/bmicalc.htm>. Your oxygen and carbon dioxide levels are measured by taking a blood sample from your artery, usually from an artery in your wrist. A pulse oximeter (a sensor lightly attached to the finger) can be used to get an estimate of the amount of oxygen (but not carbon dioxide) in the blood (see ATS Patient Series *Pulse Oximetry* at <http://patients.thoracic.org/information-series/en/resources/ats-patient-ed-pulse-oximetry.pdf>). Pulse oximetry however is not as accurate as a blood sample from your artery.

A chest x-ray may be taken to rule out any other causes of your breathing difficulty. You may be asked to have a sleep study called a polysomnography (see ATS Patient Series on *Sleep Studies* at <http://patients.thoracic.org/information-series/en/resources/sleep-studies.pdf>). The sleep study will determine if you have sleep apnea and what treatment may be needed. Although not necessary to diagnose OHS, a sleep study is usually ordered for patients with OHS to also find out how severe your sleep apnea may be. In addition, a sleep study is done (titration polysomnography) to guide treatment.

How is Obesity Hypoventilation Syndrome treated?

Treatment for OHS will include weight loss and treating your breathing disorder. Sometimes, weight loss alone corrects many of the other problems such as obstructive sleep apnea. Therefore, the first approach to treating your OHS is weight loss. Diet, exercise, and good sleep are important to weight loss. Because OHS can cause serious health problems, sometimes surgery is needed (e.g. gastric bypass surgery) to help with your weight loss.

To treat your breathing disorder, you will

probably need positive-airway pressure (PAP) support described in the ATS Patient Series on Obstructive Sleep Apnea in Adults. The types of PAP support include Continuous PAP (CPAP) or Bi-level PAP (BPAP). Both are devices that deliver air to you through a mask that you wear anytime you are sleeping or napping. CPAP delivers air at a constant pressure both when you breathe in and when you breathe out. BPAP on the other hand delivers higher pressures when you are breathing in, than when you are breathing out. When OSA is severe, and not controlled with PAP, a tracheostomy (surgical hole in the neck) may be needed to ensure that your sleep apnea is adequately treated.

Research is being done to find medications to treat OHS. So far, no medications are recommended for the treatment of OHS.

Authors: Vidya Krishnan MD, MHS and Pedro Genta MD

Reviewers: Suzanne Lareau RN, MS; Bonnie Fahy, RN, MN, CNS; Atul Malhotra MD

Rx Action Steps

- ✓ If you are obese and having symptoms of OHS, discuss this with your health care provider who may refer you to a Sleep Specialist.
- ✓ Weight loss alone may help your OHS, but your breathing pattern while sleeping must also be controlled.
- ✓ If your bed partner notices you have pauses in your breathing, contact your health care provider

Doctor's Office Telephone:

Resources:

National Institutes of Health:

http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001149/#adam_000085.disease.causes

Patient.co.uk:

<http://www.patient.co.uk/doctor/Pickwickian-Syndrome.htm>



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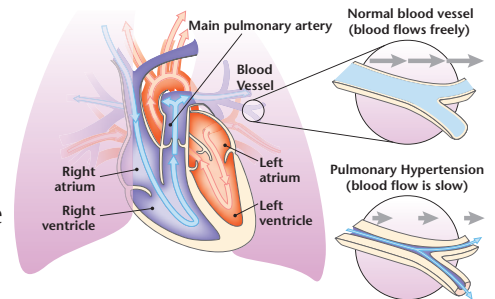
Patient Information Series

Pulmonary Arterial Hypertension



What Is Pulmonary Hypertension?

To understand pulmonary hypertension (PH) it helps to understand how blood flows throughout your body. While the heart is one organ, it works like two pumps that are connected to one another. There is a left side and a right side of the heart, each with two different jobs.



The left side of the heart (left atrium) takes oxygen-rich blood coming from your lungs and the left ventricle pumps this blood throughout your body. Since the left side of your heart has to pump blood such a great distance, the left side of your heart is designed to pump against a fairly high pressure. This pressure is easily measured with a blood pressure cuff and is called your blood pressure. When your **blood pressure** is too high, it is called **systemic hypertension** or simply, **hypertension**.

After your blood has delivered oxygen to the tissues of your body, the blood needs to come back to the lungs to get more oxygen. It does this by returning the blood to the right side of the heart (right atrium) and then the right ventricle pumps the blood into your lungs, so the process can start over again. The blood does not need to travel very far to get from the right side of your heart to your lungs. Therefore, the right side of your heart pumps against less pressure than the left side of your heart. The right side of your heart is therefore normally a *low-pressure* system. The pressure that the right side of your heart is pumping against is called your **pulmonary pressure**. When this pressure is too high, it is called **pulmonary hypertension** (PH). How the pressure in the right side of your heart is measured will be discussed in a later section.

Is There More Than One Type of Pulmonary Hypertension?

Yes, you may hear the terms pulmonary hypertension (PH) or pulmonary arterial hypertension (PAH). Both terms mean that the pressure on the right side of your heart is higher than normal. Pulmonary hypertension (PH) is a general term that means that the blood pressure on the right side of your heart is too high, but does not explain why it is high. The high pressure could be caused by a medical condition such as; chronic lung disease, blood clots in the blood vessels in your lungs, or the left side of your heart is weakened (causing a back-up of pressure on the right side of the heart). This type of pulmonary hypertension was called “secondary pulmonary hypertension” but is now referred to as PH, because the cause is known to be from lung disease, heart disease, or

chronic thromboemboli (blood clots).

Pulmonary Arterial Hypertension (PAH) used to be called “primary pulmonary hypertension”. PAH occurs when the blood vessels in the lung are directly diseased (unlike the other forms of PH where the increased pressure is due to another reason like chronic lung or heart disease) and become thick and narrow. The pressure on the right side of your heart increases as it tries to pump blood through these narrow blood vessels. In PAH the pressure that the right side of your heart is pumping against is usually a much higher pressure than in patients who have PH from other causes.

What Happens to the Body with Pulmonary Arterial Hypertension?

With PAH, the arteries become too narrow to handle the amount of blood that must be pumped through the lungs. This causes several things to happen: a backup of blood in the veins returning blood to the heart; an increase in the pressure that the right side of your heart has to pump against to push blood through your lungs; and a strain on the right side of your heart due to the increased work that it has to do. If this increased pressure is not treated, the right side of your heart can become overworked, become very weak and may possibly fail. Because the blood has difficulty getting through the lungs to pick up oxygen, your blood oxygen level may be lower than normal. This can put a strain not only on your heart, but also decrease the amount of oxygen getting to your brain.

What are the Symptoms of Pulmonary Arterial Hypertension?

There may be no signs or symptoms of PAH in its early stages. You might first notice that you become short of breath more easily. You might also notice you are more tired (fatigued) than usual. Some patients also may feel “light headed” or even pass out. Swelling (edema) of your feet and ankles is common with PAH and may progress to swelling of your belly (ascites). Chest pain may also occur and can be mistaken for a heart attack. You may feel your heart racing or pounding (palpitations). The oxygen level in your blood may become very low.

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How is Pulmonary Arterial Hypertension Diagnosed?

Because the different kinds of pulmonary hypertension are treated differently, it is important that your health care provider takes the time and orders the necessary tests to find out what kind of pulmonary hypertension you have. You can help your health care provider in diagnosing your condition by telling them what kind of symptoms you are having and if there is any worsening of these symptoms. For example, let your health care provider know if you notice any of the following:

- Increased shortness of breath
- Dizziness
- Feeling like you might faint
- Fainting
- Chest pain
- Heart palpitations (feeling like your heart is racing or pounding)
- Increased swelling of your feet, legs or belly
- Your lips and/or fingers turn blue

If your health care provider thinks you may have PAH, they will order tests to see if there is a strain on the right side of your heart. Usually the first test they order will be an ultrasound of your heart (echocardiogram). If the echocardiogram shows the pressure on the right side of your heart may be high, they may order a cardiac catheterization. During a cardiac catheterization, a rubber tube (catheter) is placed through a blood vessel into the chambers of your heart to measure the pressure in the right side of your heart (See ATS Patient Series at <http://patients.thoracic.org/information-series/en/resources/arterial-catheterization.pdf>). A cardiac catheterization is the best way to measure the blood pressure in the right side of your heart.

What Causes Pulmonary Arterial Hypertension?

The cause of PAH is often difficult to determine. Your health care provider will likely order several tests to see if they can find a cause. PAH can be from some known causes, such as inherited (called *familial*) PAH, or be caused by reasons that are never known (called *idiopathic* PAH). Other known causes of PAH (called *associated* PAH) are:

- Connective tissue diseases such as scleroderma or lupus
- Use of prescription amphetamines or diet pills
- Use of illicit drugs such as cocaine and methamphetamines
- Congenital heart defects
- Liver disease/cirrhosis
- HIV

Is There a Cure for Pulmonary Arterial Hypertension?

PAH is a serious disease that at this time has no cure but there are treatments available and new medications are in clinical trials. Every patient's disease is different and it is important that you discuss your care with your health care

provider. Early diagnosis and treatment are important to try to limit the progression of PAH.

How is Pulmonary Arterial Hypertension Treated?

If you have PAH, there are several types of treatment available. These include medicines you swallow (oral medications), medicines that you breathe directly into your lungs (inhaled) and medicines that are given continuously, directly into a vein or under your skin with a pump (infused). These PAH medications are given to open the blood vessels in your lungs, improve the blood flow through your lungs and reduce the strain on your heart. Most patients with PAH will need to take medicines (diuretics, also called "water pills") that remove excess fluid that tends to buildup in the body. You may also need to use oxygen if your oxygen level is low. Additionally, patients with PAH may be referred to a pulmonary rehabilitation program to help them become more active and breathe better. There are many new medications being studied and your provider may suggest or recommend these for the treatment of your PAH as part of clinical research trials.

Authors: Lisa Roessel FNP_BC, Karen A. Fagan MD, Mark Gillespie PhD

Reviewers: Suzanne Lareau RN, MS, Bonnie Fahy RN, MN, Linda Nici MD.

Resources:

National Heart Lung and Blood Institute (NHLBI) at
<http://www.nhlbi.nih.gov/health/health-topics/topics/pah/>
Pulmonary Hypertension Association at
<http://www.phassociation.org>

Rx Action Steps

If you have been diagnosed with PAH, it is important to find a health care provider who has experience in treating patients with PAH. Centers specializing in PAH (www.phassociation.org/Patients/FindADoctor) may be the best option as they have dedicated doctors, nurses, and other staff to assist in your care. You should see your health care provider regularly and contact them if you notice any change in your symptoms including the following:

- ✓ Increasing shortness of breath
- ✓ Swelling
- ✓ Feeling light headed
- ✓ If you have passed out.

Doctor's Office Telephone:

Overlap Syndrome

What is it?

Individuals who have an overlap of obstructive sleep apnea (OSA) and chronic obstructive pulmonary disease (COPD) are identified as having overlap syndrome.

Screening and diagnosis are important. COPD affects 20 million people in the US. Obstructive sleep apnea affects 4% of US men and 2% of US women. This suggests almost 10 million people affected.

Having one disorder increases your chance of having the other by more than 10%.

Patients with both COPD and OSA have two reasons that can cause nocturnal oxygen desaturation. This requires patients with overlap syndrome to carefully follow MD orders regarding nocturnal oxygen and/or CPAP.

Diagnosis of Overlap Syndrome

Diagnosis requires polysomnography (a sleep study) and an evaluation of symptoms and disease process. A pulmonary MD (pulmonologist) is the best physician to evaluate a patient that may have overlap syndrome. A patient who has either OSA or COPD and daytime hypercapnia and pulmonary hypertension indicates the need for an evaluation.

Treatment

Treatment is generally based on treatment of the component diseases. The goal of treatment is to maintain adequate oxygenation at all times and to prevent sleep disordered breathing. CPAP (continuous positive airway pressure) is the gold standard of treatment for OSA and is also the gold standard for those with overlap syndrome. CPAP alone may not correct hypoxemia and supplemental oxygen may be required.

Obesity Can Take Your Breath Away

The never-ending supply of holiday goodies finally has started dwindling, and once again, you are enlisting to fight in the battle of the bulge. That outfit from years ago has been calling your name, but you have an even stronger motivation to think about when planning your weight loss strategy — your lungs.

In addition to heart problems, diabetes, and a host of other health concerns, obesity also has been linked to respiratory diseases such as obstructive sleep apnea (OSA), chronic obstructive pulmonary disease (COPD), and asthma. A balanced diet and regular exercise can help you and your lungs get back into shape.

Obstructive sleep apnea

People with OSA awake several times a night because their airways can collapse or get blocked, causing them to stop breathing. Obesity is a well-documented risk factor for the condition — about 70 percent of those with OSA are obese. Some physical characteristics of obesity such as large tongue, large neck size, and narrow airways can worsen these airway problems.

See your doctor to discuss OSA if you experience feelings of choking or difficulty breathing during sleep, loud and habitual snoring, frequent awakenings at night, morning headaches, or daytime sleepiness. If your doctor suspects you have OSA, he will most likely refer you for further sleep studies, including a polysomnogram. Sleep specialists will use this test to observe your sleep patterns overnight with equipment to monitor your breathing and other vital signs.

If you have OSA, many treatment options can help to alleviate your symptoms. The most common treatment is a continuous positive airway pressure (CPAP) device. You will use a mask over your nose or mouth to gently blow air into your airways to keep them open at night. You can talk to your doctor about other options, including bariatric surgery, oral surgery, or an oral device to help keep your airways open.

COPD and asthma

An association between obesity and respiratory problems has emerged from numerous studies, dating back to the 1980s. Recent research suggests being overweight or obese increases the odds of developing asthma by 50 percent.

If you have chronic cough, excess mucus production, wheezing, or shortness of breath, talk to your doctor about the possibility of COPD and asthma, especially if you smoke or frequently are exposed to allergens. The doctor can perform pulmonary function testing with a small device called a spirometer. A quick, easy, and painless test will show the doctor exactly how your lungs are functioning.

While wheezing and shortness of breath are two key symptoms of COPD and asthma, you could be experiencing them because of the strain extra

weight has put on your lungs or a weakness in your respiratory muscles. That is why it is extremely important to get pulmonary function testing done to confirm a diagnosis.

Easing the burden

Weight loss can improve many of these respiratory symptoms and decrease your risk of developing respiratory complications or disease. You

may want to talk to your doctor, a nutritionist, or a dietitian about working with you to plan a weight loss program that includes a balanced diet, regular exercise, and good sleep habits. A healthy, active lifestyle can take a load off your mind, your weight, and your lungs. ■



Adapted from The National Sleep Foundation and “The effect of obesity on chronic respiratory diseases: pathophysiology and therapeutic strategies” by Magali Poulai, Mariève Doucet, Geneviève Major, Vicky Drapeau, Frédéric Sérès, Louis-Phillipe Boulet, Angelo Tremblay, and François Maltias.

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notes

Your doctor or therapist has given you this patient education handout to further explain or remind you about an issue related to your health. This handout is a general guide only. If you have specific questions, discuss them with your doctor or therapist.



HEALTHCARE
PROFESSIONAL
USER GUIDE



COPD Assessment Test

Expert guidance on
frequently asked questions

Issue 3: February 2012

Introducing the COPD Assessment Test™ (CAT)

The COPD Assessment Test (CAT) is a patient-completed instrument that complements existing approaches to assessing COPD, such as FEV₁ measurement. It has been designed to provide a simple and reliable measure of health status in COPD and assists patients and their physicians in quantifying the impact of COPD on the patient's health. The CAT does not replace other COPD disease management tools such as smoking cessation or rehabilitation programmes.

The CAT has undergone a rigorous, scientific development process and the first validation studies show that it has properties very similar to much more complex health status questionnaires such as the St George's Respiratory Questionnaire (SGRQ)¹ that are used in research studies. It takes only a fraction of the time to complete, however, making it suitable for routine use. It is being used in COPD studies in Europe, USA and Asia.

Throughout its development, we have understood from discussions with primary care physicians, pulmonary specialists and patient groups from around the world that the precise way the CAT will be used will vary by healthcare setting and country. However, we felt

that some guidance for healthcare professionals on how to use and interpret CAT scores would be helpful. As such we have developed and updated this CAT User Guide, which is based upon our current knowledge of the CAT. We have refined our method of grading impact of COPD by CAT scores and provide a simple outline of potential management considerations/actions. These recommendations will be developed further as more evidence becomes available and clinicians gain more experience with the CAT. The guide is presented in the form of frequently asked questions in order to make it as accessible and applicable to your everyday practice as possible.

We look forward to hearing about your experiences using the CAT in your practice in the near future!



Professor Paul Jones
London, UK

Professor Christine Jenkins
Sydney, Australia

Dr Otto Bauerle
Merida, Mexico

On behalf of the CAT Development Steering Group

The COPD Assessment Test™ (CAT) – the basics

What is the CAT?

The CAT is a validated, short (8-item) and simple patient completed questionnaire, with good discriminant properties, developed for use in routine clinical practice to measure the health status of patients with COPD¹. Despite the small number of component items, it covers a broad range of effects of COPD on patients' health. Studies have shown that it is responsive to changes in the disease and to treatment like rehabilitation.^{6,8}

Why has the CAT been developed?

COPD represents a major burden on patients and healthcare systems. Despite the fact that it is projected to become the third leading cause of death by 2030², communicating the impact of COPD can be difficult and this can contribute to under-management of COPD in a significant proportion of people who may suffer increased disability and reduced quality of life as a result.

The care of COPD patients can only be optimised if there is a reliable, standardised measure of the overall effect of disease on each patient's health. Unfortunately, commonly used lung function measurements such as FEV₁ do not reflect the full impact of COPD.

As a result, there is a need for a simple-to-use tool which can measure the effect of COPD on the patient's health and enhance understanding between patients and physicians of the disease's impact, in order to manage patients optimally and reduce the burden of disease as much as possible. The CAT was developed to meet this need.

Development of the COPD Assessment Test™ (CAT)

How was the CAT developed?

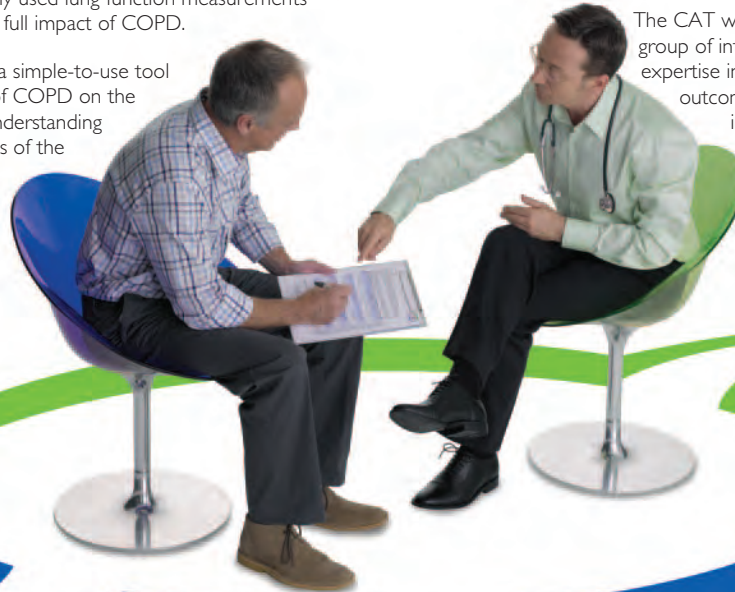
The development of the CAT has involved well accepted methodologies used to develop psychometric tools.^{1,3} The initial item generation process involved literature reviews, physician interviews and, most importantly, patient input.³ A structured, rigorous scientific approach was then used in the item reduction process to select the best items and generate the final 8-item questionnaire.¹

The CAT has been initially validated in prospective studies conducted in the USA and Europe¹ and in China⁴ but we believe that it is globally applicable.

The CAT has been translated and validated for use in more than 50 languages other than English. Only validated translations of the CAT should be used. For further details on validated translations please visit www.CATestonline.org.

Who developed the CAT?

The CAT was developed by a multidisciplinary group of international experts who have expertise in developing patient reported outcomes tools/questionnaires. The group included pulmonary specialists, primary care physicians and representatives from patient bodies. Patients with COPD were integral to the development and validation of the tool. The CAT development was commissioned and funded by GlaxoSmithKline.



Using the CAT in everyday practice: why, who and when?

Why should I use the CAT?

The CAT is a short, simple questionnaire which is quick and easy for patients to complete. It provides a framework for discussions with your COPD patients and should enable you and them to gain a common understanding and grading of the impact of the disease on their life. It should also help you to identify where COPD has the greatest effect on the patient's health and daily life. As a result you may be better informed when discussing and making management decisions with your patients and be able to ensure that his or her health status is as good as it can be.

Where and how does the CAT fit into the clinical assessment of COPD?

The CAT provides a reliable measure of the impact of COPD on a patient's health status.^{1,12} It therefore provides supplementary information to that provided by other aspects of COPD clinical assessment recommended by current management guidelines (i.e. assessment of exacerbation risk and degree of airway obstruction, assessed using spirometry).⁹

The CAT does not replace COPD treatments but can help you monitor their effects, e.g. rehabilitation programmes or recovery from an exacerbation.^{6,8}

For which patients is the CAT suitable?

The CAT is suitable for completion by all patients diagnosed with COPD.

Can the CAT be used in all COPD patients irrespective of disease severity?

Yes. The CAT has been developed and validated in COPD patients of all severities. Stable patients of all severities (defined by FEV₁) and exacerbating patients were included in the development population.^{1,3,6}

Does the CAT replace spirometry?

No. The CAT is not a diagnostic tool. Spirometry is essential for the diagnosis of COPD. The CAT and spirometry are complementary measures which can be used together in the clinical assessment of a patient's COPD to ensure that they are being optimally managed.

Can I use the CAT to diagnose COPD?

No. The CAT is a scientifically developed tool for measurement of health status. It is not a diagnostic instrument, unlike FEV₁ measurement - which is needed to confirm the diagnosis of COPD, as well as to assess the degree of airway obstruction.

Will the CAT help me make management decisions regarding any co-morbidities which my COPD patients may also have?

No. The CAT is a disease-specific tool to measure the impact of COPD on patients. It will not provide an assessment of co-morbid conditions or provide information to help guide any management decisions for co-morbid conditions.

How does the CAT compare with other health status measures used in COPD?

The CAT has very similar discriminative properties to the much more complex SGRQ which is often used in clinical trials showing that it will be able to measure the impact of COPD on individual patient's health. However, the CAT is much simpler and quicker to complete. This similarity enables us to describe what a patient's CAT score may mean and, more importantly, to interpret changes in CAT score.

Practical use of the CAT

When do I give the CAT to my patients to complete?

Experts involved in the development of the CAT recommend that you ask a COPD patient to complete a CAT questionnaire when they arrive for a check-up appointment for their COPD or immediately before attending. The CAT test can be completed and printed from the CAT website and takes only a couple of minutes. Patients could complete it whilst waiting to see you or at home prior to consultation. The completed CAT questionnaire can then provide a framework for your consultation.

Where can I access the CAT questionnaire?

You can download the CAT questionnaire from www.CATestonline.org

Will patients require much instruction to complete the CAT?

The content of the CAT questionnaire has been driven by COPD patients. It comprises 8 simple questions that most patients should be able to understand and answer easily. You should not need to assist patients to complete it. In fact it is much better if they complete this independently.

What is the scoring range of the CAT?

The CAT has a scoring range of 0-40.

What do CAT scores mean?

The implication of the CAT scores needs to be considered in relation to an individual's disease severity. Several studies have indicated that the relationship between lung function (FEV₁) and health status scores is generally weak.^{5,10} As recognised by the GOLD strategic document the lung function, exacerbation frequency and health status (CAT or mMRC) are complementary⁹ and all together help to define the severity of the disease in a particular patient.

How frequently should the CAT be used in patients?

The CAT Development Steering Group and the GOLD strategic document recommend that patients routinely complete the CAT questionnaire every 2 to 3 months to detect changes and trends in CAT score.⁹

What change in CAT score is meaningful?

Research is currently ongoing to define ranges of CAT score severity and to better understand the minimal clinically relevant change (often referred to as the Minimum Clinically Important Difference or MCID) in a CAT score from one visit to the next. There is a strong correlation between the CAT and SGRQ. Based on a minimal clinically important difference of 4 in the SGRQ, we believe that a difference or change of 2 or more suggests a clinically significant difference or change in health status.¹² We emphasise that this needs to be confirmed by further scientific studies, but we are confident that it is a reasonable indicative value of the MCID based upon current knowledge.

Can CAT be used to set a target score?

Since COPD is a progressive disease, a fixed target score for all patients cannot be set. In Practice, a target for improvement in individual patient CAT scores may be set, based on an holistic assessment of the patient. We believe a change of 2 units suggests a meaningful difference.

What if my patient's CAT score gets worse?

Based on the correlation with SGRQ the CAT score would not be expected to decrease by more than 1 unit per year.⁷ Worsening scores may indicate that patients are experiencing exacerbations that they have not reported to you. CAT scores may also worsen where a patient has stopped or is not taking their treatment effectively. Check inhaler technique as well as adherence to treatment. Where rapid disease progression is suspected, referral for specialist opinion may be required.

In addition, for each scenario, the CAT Development Steering Group has proposed some potential management considerations:¹¹

CAT score	Impact level	Broad clinical picture of the impact of COPD by CAT score	Possible management considerations
>30	Very high	Their condition stops them doing everything they want to do and they never have any good days. If they can manage to take a bath or shower, it takes them a long time. They cannot go out of the house for shopping or recreation, or do their housework. Often, they cannot go far from their bed or chair. They feel as if they have become an invalid.	<p>Patient has significant room for improvement In addition to the guidance for patients with low and medium impact CAT scores consider:</p> <ul style="list-style-type: none"> • Referral to specialist care (if you are a primary care physician) <p>Also consider:</p> <ul style="list-style-type: none"> • Additional pharmacological treatments • Referral for pulmonary rehabilitation • Ensuring best approaches to minimising and managing exacerbations
>20	High	COPD stops them doing most things that they want to do. They are breathless walking around the home and when getting washed or dressed. They may be breathless when they talk. Their cough makes them tired and their chest symptoms disturb their sleep on most nights. They feel that exercise is not safe for them and everything they do seems too much effort. They are afraid and panic and do not feel in control of their chest problem.	<p>Patient has room for improvement – optimise management In addition to the guidance provided for patients with low impact CAT scores consider:</p> <ul style="list-style-type: none"> • Referral to specialist care (if you are a primary care physician) <p>Also consider:</p> <ul style="list-style-type: none"> • Additional pharmacological treatments • Referral for pulmonary rehabilitation • Ensuring best approaches to minimising and managing exacerbations
10-20	Medium	COPD is one of the most important problems that they have. They have a few good days a week, but cough up sputum on most days and have one or two exacerbations a year. They are breathless on most days and usually wake up with chest tightness or wheeze. They get breathless on bending over and can only walk up a flight of stairs slowly. They either do their housework slowly or have to stop for rests.	<p>Patient has room for improvement – optimise management In addition to the guidance provided for patients with low impact CAT scores consider:</p> <ul style="list-style-type: none"> • Reviewing maintenance therapy – is it optimal? • Referral for pulmonary rehabilitation • Ensuring best approaches to minimising and managing exacerbations • Reviewing aggravating factors – is the patient still smoking?
<10	Low	Most days are good, but COPD causes a few problems and stops people doing one or two things that they would like to do. They usually cough several days a week and get breathless when playing sports and games and when carrying heavy loads. They have to slow down or stop when walking up hills or if they hurry when walking on level ground. They get exhausted easily.	<ul style="list-style-type: none"> • Smoking cessation • Annual influenza vaccination • Reduce exposure to exacerbation risk factors • Therapy as warranted by further clinical assessment.
5		Upper limit of normal in healthy non-smokers	

What effect does an exacerbation have on CAT scores?

We know from the first CAT validation study that CAT scores in patients with moderate-severe exacerbations are approximately 5 units higher than in those who have stable COPD.¹ In this study patients responding to treatment for their exacerbation reduced their CAT score by 2 units in 14 days, whilst patients who did not respond had no change in score.⁶ Research studies have also shown that it may take many weeks for patients to recover fully from a single moderate-severe exacerbation and some patients may never recover fully. Therefore another potential application of the CAT may be to assess the degree of recovery following an acute exacerbation by re-assessing the CAT score 2-3 months after the event.

Will I be able to assess response to therapy with the CAT?

We know that the CAT has good repeatability¹, which is similar to that for the FEV₁ and, based upon our current knowledge, we believe that the relative size of its response to therapy will also be similar to that of the FEV₁. In a study of patients undergoing rehabilitation, CAT scores decreased by 3 units over 42 days in patients reporting an improvement in their COPD. In patients who reported worsening of COPD over the same period CAT scores increased by 2 units.⁶ In assessing whether an *individual patient* has had a worthwhile response to a specific therapy, a thorough individual assessment taking a number of factors into account – including change in CAT score – will be required. However, the CAT *will* provide a measure of the individual patient's health that will be very useful in initial assessment and for following medium to long-term trends. It should also provide a prognostic measure of future health resource use in *individual patients*. The design of the CAT may also allow clinicians to readily identify areas of a patient's health that are more severely impaired than others, such as mood, daytime physical function or sleep.

Can I just use a few of the questions included in the CAT?

No. The CAT should be used in its entirety. The CAT was validated as an 8-item questionnaire and the questions should not be split up or used independently of each other which will reduce the integrity and measurement properties of the questionnaire. However, responses to the individual items can be used to provide you with an indication of the areas of the patient's health that are more affected than others. For example, one patient may have higher scores for cough and sputum, whereas another may have highest scores for the items about activity or sleep.

Is the CAT free to use?

Yes. The CAT is available and free to use globally (no charges will be associated with its use).

Do I need permission to use the CAT?

No. The CAT can be used for clinical or research purposes without permission, as long as you respect the integrity of the test. All trademark and copyright information must be maintained as they appear on the bottom of the CAT questionnaire. However for commercial use you should seek permission from GSK.

Is the CAT available in different languages?

Yes. The CAT is available in more than 50 different languages. Only approved translations of the CAT questionnaire should be used to ensure the validity and measurement properties of the questionnaire are maintained. For further details on validated translations please visit www.CATestonline.org.

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COPD Assessment Test

Improving COPD communication,
supporting care

www.CATestonline.org

Supported by an educational grant
from GlaxoSmithKline

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RECE/RESP/0018/12 Date of preparation: April 2012

Your name:

Today's date:



How is your COPD? Take the COPD Assessment Test™ (CAT)

This questionnaire will help you and your healthcare professional measure the impact COPD (Chronic Obstructive Pulmonary Disease) is having on your wellbeing and daily life. Your answers, and test score, can be used by you and your healthcare professional to help improve the management of your COPD and get the greatest benefit from treatment.

For each item below, place a mark (X) in the box that best describes you currently. Be sure to only select one response for each question.

Example: I am very happy (0) (1) (2) (3) (4) (5) I am very sad

			SCORE
I never cough	(0) (1) (2) (3) (4) (5)	I cough all the time	<input type="text"/>
I have no phlegm (mucus) in my chest at all	(0) (1) (2) (3) (4) (5)	My chest is completely full of phlegm (mucus)	<input type="text"/>
My chest does not feel tight at all	(0) (1) (2) (3) (4) (5)	My chest feels very tight	<input type="text"/>
When I walk up a hill or one flight of stairs I am not breathless	(0) (1) (2) (3) (4) (5)	When I walk up a hill or one flight of stairs I am very breathless	<input type="text"/>
I am not limited doing any activities at home	(0) (1) (2) (3) (4) (5)	I am very limited doing activities at home	<input type="text"/>
I am confident leaving my home despite my lung condition	(0) (1) (2) (3) (4) (5)	I am not at all confident leaving my home because of my lung condition	<input type="text"/>
I sleep soundly	(0) (1) (2) (3) (4) (5)	I don't sleep soundly because of my lung condition	<input type="text"/>
I have lots of energy	(0) (1) (2) (3) (4) (5)	I have no energy at all	<input type="text"/>
			TOTAL SCORE <input type="text"/>

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AMERICAN THORACIC SOCIETY

Patient Information Series

Sleep Studies

SLEEP MINI-SERIES #1

It can be normal to have trouble sleeping from time to time, but if you are having trouble sleeping most nights, you may have a sleep problem. Sleep problems can affect your quality of life, and some can pose a serious threat to your health if left untreated. If you think you might have a sleep problem, discuss your symptoms with your healthcare provider. After reviewing your sleep history, your healthcare provider may refer



you to a specialized sleep center/lab, where trained technicians will perform a sleep study. Sleep studies are tests that monitor your sleep, either overnight or during a series of naps during the day. These tests are painless and used to diagnose sleep problems such as insomnia, sleep apnea, or narcolepsy.

Why do I need a sleep study?

Your healthcare provider has determined that you are having health problems possibly related to poor sleep. Sleep studies will help your healthcare provider determine whether you have a sleep problem and the best treatment options for you.

What are some of the most common signs of sleep problems?

1. Snoring loudly during sleep
2. Stopping breathing during sleep
3. Sleeping in a fitful or restless manner
4. Feeling very sleepy during the day

If you have one or more of these signs, you may have a sleep problem. Examples of two common sleep problems are: obstructive sleep apnea, a condition in which you stop breathing during sleep due to a narrowed or closed airway, and narcolepsy, a condition in which you experience daytime sleepiness and may fall asleep at unexpected times, such as during work, school, or driving. These and other sleep conditions can cause serious health problems and poor quality of life and need to be properly diagnosed and treated.

What are the different types of sleep studies?

The evaluation of sleep problems is usually done in a specialized sleep center that can study your sleep during the day or at night. The sleep specialist will decide which

type of study is best to evaluate your sleep problem.

Studies conducted at night, called “overnight studies,” are:

- **Basic Polysomnography:** This study records several body functions during sleep including breathing, body movements, brain activity, and eye movements.
- **Continuous Positive Airway Pressure Trial:** This test is done to see how well you sleep while using nasal continuous positive airway pressure therapy (CPAP), a treatment for obstructive sleep apnea. As you sleep, CPAP delivers air to you through a mask placed over your mouth and nose or only over your nose. The air that flows into your lungs under slight pressure prevents the airways from narrowing or closing, allowing you to breathe normally and sleep well.
- **Split Night Study:** This study is a combination of the first and second studies listed above. In a split night study, you sleep part of the night without the CPAP to see what problems you may have. If you have sleep apnea, you will sleep with CPAP the rest of the night.

Studies conducted during the day include:

- **Multiple sleep latency test (MSLT):** This study is done to see how sleepy you are during the day. The MSLT is used most often to diagnose narcolepsy (inability to stay awake during the day) and see what might be causing your excessive daytime sleepiness.
- **Maintenance of Wakefulness Test (MWT):** This study is done to see how well you can remain awake when you are in a situation that makes it easy to get sleepy.

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What can I expect during my sleep study?

When you arrive at the sleep lab, a sleep technician will show you to a (usually private) room. The technician will tape or gel small metal discs on your head and body. Needles are NOT used. These discs are called electrodes and will measure your brain activity, eye movement, heart rate and rhythm, breathing rate and rhythm, snoring, and muscle movements in your face, chest, belly, and legs. Your oxygen, carbon dioxide, and amount of air flowing through your mouth and nose will also be measured. If you are going to have a CPAP study, the technician will help you select a mask most comfortable for you to wear during the study. After the electrodes are placed, you can relax until the technician is ready to have you go to sleep.

Your sleep and breathing will be monitored for the entire study. If you need to get out of bed to go to the bathroom, you can alert the staff and they will help you. Most centers will wake you after the study is complete.

The sleep center will provide you with a list of things to bring, depending on whether the study will be held overnight or during the day. They will also give you a list of what to do and not do.

The following are some **general examples** of what you will need and what you should and should not do.

What should I bring with me to the sleep study?

1. Loose fitting sleepwear if you're having an overnight study, or comfortable loose clothes for a daytime study.
2. Something to read or work on while awaiting the start of the test. Most sleep centers have televisions in the rooms.
3. Personal toiletry items and a change of clothes for the next day if you are having an overnight study.
4. Any medications you need to take.

How Do I Prepare For A Sleep Study?

1. Eat your regularly scheduled meals the day of your sleep study.
2. No alcohol or caffeine (coffee, tea, soda pop, chocolate) for at least 24 hours before your study.
3. Ask your healthcare provider if you should stop any medications before having your sleep study.
4. The night before your sleep study, go to sleep at your normal bedtime. DO NOT take naps during the day of the study.
5. Shower and wash your hair prior to the study.

6. DO NOT use make-up, lotion, powders, perfume, and cologne or aftershave on your skin, or conditioners, hair spray or gels in your hair. Oils, gels and sprays can interfere with the recording by the electrodes.

What happens after my sleep study?

Your sleep study will be read by a sleep specialist and a final report will be sent to your healthcare provider after the study. You should schedule a follow-up visit with your healthcare provider to discuss the results of your study and any treatment that is needed. If the sleep study shows that you do need additional treatment, your healthcare provider will order the equipment you may need, arrange training on how to use the equipment, and schedule any more tests that may be needed.

Authors: Rowley, J., Sockrider, M., Fahy, B., Lareau, S., Garvey, C.

Additional Resources:

American Academy of Sleep Medicine
www.sleepeducation.com

National Sleep Foundation
www.sleepfoundation.org

American Sleep Apnea Association
www.sleepapnea.org

**American Thoracic Society
Public Advisory Roundtable**
www.thoracic.org/sections/about-ats/par/index.html

Rx What to do...

- ✓ If you are having problems sleeping or staying awake, ask your healthcare provider if you should have a sleep study.
- ✓ Tell your healthcare provider if you have loud snoring, stop breathing while sleeping, have difficulty falling or staying asleep, or have trouble staying awake during the day.

Doctor's Office Telephone:



AMERICAN THORACIC SOCIETY

Patient Information Series

Circadian Rhythm Sleep Disorders

Circadian Rhythm Sleep Disorders (CRSDs) are sleep problems in which a person's internal sleep-wake cycle does not line up with the times in their schedule when they need to be asleep or awake. Unlike other sleep problems (such as sleep apnea), CRSDs do not affect the

quality of your sleep, but rather cause you to be sleepy when you need to be awake and awake when you need to sleep.

Are there different types of CRSD?

There are several types of CRSDs. They include delayed sleep phase, advanced sleep phase, jet lag, shift work disorder, free-running and irregular sleep-wake type. All types stem from the fact that our tendency to be sleepy or alert is to some degree regulated by a part of the brain that acts like a clock. This "clock" is reset on a daily basis by exposure to bright light and other regular activities such as meals or exercise. CRSDs occur when the sleep-wake cycle of our internal "clock" is different from the sleep-wake schedule we would like to follow.

If you have the **delayed sleep phase** type of CRSD, you are a "night owl". You have difficulty falling asleep at a "normal" bedtime but go to sleep late (2 AM or even later). Because you still need your normal amount of sleep, you end up sleeping until later in the day. This is common in teens and young adults, but can be seen in any age group. This type of CRSD is not considered a "disorder" unless your sleep schedule causes you problems like being late for work, school or social events.

The CRSD that is the opposite of the delayed sleep phase disorder is the **advanced sleep phase** disorder. If you have this disorder, you are an "early bird" or "morning lark". You prefer an early bedtime (6 to 9 PM) and wake up early in the morning, usually after a normal amount of sleep time. Advanced sleep phase is frequently seen in the elderly, but also occurs in younger age groups. In the elderly, this change in sleep timing is thought to result from age-related changes in the brain, while in younger individuals the tendency appears to be inherited. Just as in delayed sleep phase type, advanced sleep phase type is not considered a "disorder" unless it interferes with your desired or

required sleep-wake schedule.

Traveling from one time zone to another can cause **jet lag**. Jet lag occurs because your internal "clock" remains set to the sleep-wake cycle of your original time zone. The main symptoms of jet lag are difficulty falling asleep at a bedtime that is normal for the new time zone and sleepiness during the day of the new time zone. Jet lag lessens as your internal "clock" resets to the new times of day and night. On average, our internal "clock" can shift about 1-2 hours each day, but some people handle time zone changes better than others, a trait that may be inherited. Older individuals tend to suffer more from jet lag than those in younger age groups.

Changes in the timing of your work shift can cause a CRSD called **shift work type**. Work schedules that require you to be awake during your normal sleep time and asleep during the normal hours you are awake, may cause sleepiness and poor performance during your working hours and difficulty sleeping during your daytime sleep period. Like jet lag, individuals differ in their ability to adjust to shift work. If you keep the same work schedule over long periods of time, the solution is to follow the same sleep-wake times during days off as are required for the work shift so that your internal "clock" resets to this new schedule. This may be difficult due to family and social factors. Adjusting your internal clock is even more of a problem if you frequently rotate shifts.

The CRSD known as **free-running type** or non-24 hour sleep-wake disorder can occur for many reasons. The most common cause of non-24 is blindness, but other causes include changes in light sensitivity, environmental factors, and hormonal factors. With this problem, your preferred sleep period changes daily, usually shifting 1-2 hours later each day. For unknown reasons, your internal "clock" tends to maintain a 25-hour "day". With this disorder, resetting the "clock" does not happen unless attention is paid to



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other factors such as meals and other activities that can help reset the “clock.”

The last CRSD, **irregular sleep-wake** type can occur for several reasons. For example, irregular sleep-wake can occur when your exposure to bright light or daily activities vary (or are entirely missing), and when there are age-related changes in the brain (senile dementia). Without a set schedule, you may doze on and off throughout each 24 hour period. This problem is common in nursing home patients and for those with an extremely disorganized living pattern.

Why is it important for me to know if I have a circadian rhythm sleep disorders?

CRSDs make it harder for you to get high quality, refreshing sleep. Untreated CRSDs and increased sleepiness can increase your risk of accidents such as car crashes. They may also raise your risk of having heart attacks and diabetes (see *ATS Patient Series on Heart Disease and Sleep Apnea* at <http://patients.thoracic.org/information-series/en/resources/osa.pdf>). CRSDs may lead to poor work performance, social stresses and depression.

How do I know if I have a circadian rhythm sleep disorder?

You may have a CRSD if you find it hard to fall asleep during normal sleep times and you are sleepy at times when you should be awake. If your sleepiness is causing difficulties with work, school, or socially, you should be evaluated by a sleep specialist. Before seeing the sleep specialist, keep a detailed sleep history and a sleep log for 1 to 2 weeks. This will help the specialist determine if your sleep problem is from a CRSD or due to another sleep disorder or medical issue.

How are circadian rhythm sleep disorders treated?

Treatment varies depending on the specific CRSD. The goal of treatment is to fit your sleep pattern into a schedule that allows you to meet the demands of the lifestyle you want. Therapy usually includes several approaches:

- Allowing enough time for sleep
- Keeping regular bedtimes and wake up times (including days off)
- Adjusting your wake up time until you can fall asleep at the time you want
- Avoiding taking naps if you have difficulty falling asleep at your desired bedtime
- Sleeping in a dark, cool, quiet room
- Avoiding caffeine and alcohol within six hours of bedtime
- Taking melatonin (available over the counter) may be helpful in certain situations as recommended by your health care provider
- Using bright natural or artificial light soon after your desired wake up time, and scheduling meals and activities at regular times to help reset the

sleep-wake cycle but avoiding bright light near bedtime

Different combinations of these treatments are used for the different CRSDs. Having good sleep habits will improve your CRSD symptoms. It is very important to keep regular wake up times and bedtimes. Often, CRSDs can be treated with simple solutions that result in your being awake and alert when you wish and able to sleep when required. You should contact your health care provider for guidance if you think you have a circadian rhythm sleep disorder.

Things you might do to help evaluate your CRSD are:
Step 1. If you are having difficulty falling asleep or staying awake, consider whether this is due to “bad habits” or a situation that will resolve by itself (e.g. travel to another time zone)
Step 2. Review the treatments for CRSDs listed above
Step 3. Ask for a referral to a sleep specialist if these suggestions don’t work. It is especially important to get evaluated if your sleepiness is affecting your safety such as falling asleep while driving or you’re your ability to function (unable to stay awake at work)

Authors: Jay Balachandran, MD and Brian Cade, PhD

Reviewers: Suzanne C. Lareau RN, MS, Lee Brown MD, Bonnie Fahy, RN, MN

Resources:

American Academy of Sleep Medicine

<http://yoursleep.aasmnet.org/Hygiene.aspx>

National Institute of General Medical Sciences

http://www.nigms.nih.gov/Education/Factsheet_CircadianRhythms.htm

Rx Action Steps

It is especially important to get help from your health care provider if you have any of the following.

- ✓ find yourself sleeping when driving or using dangerous equipment
- ✓ fall asleep at times that are not normal (at work or school)
- ✓ unable to wake up in time for work, school, or other activities
- ✓ unable to fall asleep within 1 hour after going to bed

Health Care Provider’s Contact Numbers/ E-mail Address:



AMERICAN THORACIC SOCIETY

Patient Information Series

SLEEP MINI-SERIES #2

What Is Obstructive Sleep Apnea In Adults?

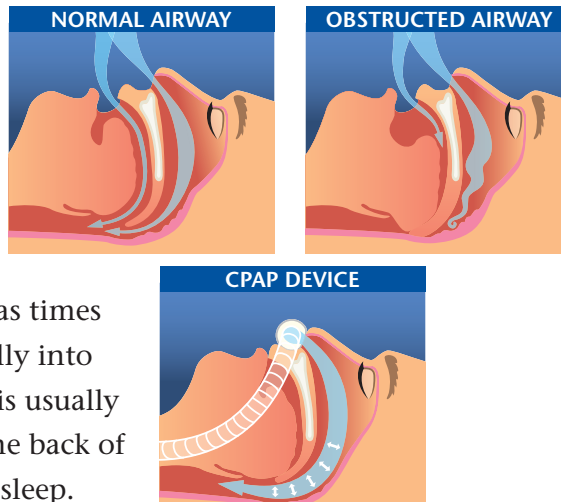
Obstructive sleep apnea (OSA) is a common problem that affects a person's breathing during sleep. A person with OSA has times during sleep in which air cannot flow normally into the lungs. The block in airflow (obstruction) is usually caused by the collapse of the soft tissues in the back of the throat (upper airway) and tongue during sleep.

Apnea means not breathing. In OSA, you may stop breathing for short periods of time. Even when you are trying to breathe, there may be little or no airflow into the lungs. These pauses in airflow (obstructive apneas) can occur off and on during sleep, and cause you to wake up from a sound sleep. Frequent apneas can cause many problems. With time, if not treated, serious health problems may develop.

OSA is more common in men, women after menopause and people who are over the age of 65. OSA can also occur in children. There are several groups of people who are particularly at risk for developing OSA. People who are overweight are more likely to develop sleep apnea. OSA can occur in people who have large tonsils or adenoids. OSA can also run in families of people of normal size and in people with certain types of jaw problems. People with these jaw problems have difficulty keeping the back of their throat open. Some of these conditions are called micrognathia (a small jaw) and retrognathia (a pulled back jaw).

What are the symptoms of obstructive sleep apnea?

There are many clues that tell your provider that you may have OSA. You may not be aware that you have OSA, but these symptoms may be more obvious to a spouse, other family member, or close friend.



Common symptoms you may have during sleep

- Snoring that is usually loud and bothers other people trying to sleep near you. Snoring can come and go through the night.
- Gasping or choking sounds
- Breathing pauses observed by someone watching you sleep.
- Sudden or jerky body movements
- Restless tossing and turning
- Frequent awakenings from sleep

Common symptoms you may have while awake

- Wake up feeling like you have not had enough sleep, even after sleeping many hours
- Morning headache
- Dry or sore throat in the morning from breathing through your mouth during sleep
- Sleepiness during the day
- Fatigue or tiredness through the day
- Personality changes, such as mood swings and difficulty getting along with others
- Problems with poor memory or inability to concentrate

Can OSA be dangerous?

Lack of sleep can cause you to fall asleep while driving and result in car accidents. Periods of stopping breathing can, with time, cause high blood pressure (hypertension), heart disease, stroke or early death.

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How do I know I have OSA?

The signs of OSA described above should make you seek help for an evaluation. Discuss your problems with your health care provider. They can sort through some of the problems you are having and determine whether you should be evaluated further at a sleep center.

OSA is diagnosed by a sleep study (or polysomnogram). A sleep study is generally done at a sleep center where you will be scheduled to sleep overnight. During this time, your breathing, heart rate, sleep state and oxygen levels will be monitored.

How is obstructive sleep apnea treated?

Sleep apnea can be effectively treated, and there are a number of ways to do so. The type of treatment recommended will depend on the reason for and severity of the sleep apnea. If your OSA is from being overweight, weight loss may cause the apnea to go away completely. You can avoid alcohol for at least 4 hours before going to bed. If you sleep on your back, you can use a pillow or some other strategy to force yourself to sleep on your side. Some people sew a tennis ball into their pajama bottoms to remind them not to turn on their back.

Continuous Positive Airway Pressure (CPAP) is a common device ordered to treat most conditions of OSA. CPAP is delivered by a compressor that blows air (with or without oxygen) into a mask that is worn snugly over the nose and or mouth during sleep. The flow of air acts like a splint to keep the upper airway from collapsing. This helps prevent obstruction and the apnea from occurring. The air pressure is adjusted to a setting that best controls the apnea. Often a person will also notice much less snoring when wearing CPAP.

There are devices and surgeries which can be done to treat OSA. The type of device or surgery will depend on what has cause the apnea. Some appliances or devices (called oral devices) that are worn in the mouth during sleep may keep your airway open. Most oral devices work by either bringing the jaw forward or keeping the tongue from blocking the throat. Oral appliances are most likely to help a person who has mild sleep apnea and who is not overweight. These devices are usually custom-made and fitted under the supervision of a specialized dentist or oral surgeon who works with these problems.

Surgery may be recommended in some cases. When the tonsils or adenoids are causing the throat to be blocked, a tonsillectomy may be recommended. Surgery may also be helpful for patients with jaw problems. Other surgeries for OSA either clear out the tissue from the back of the throat or reposition the tongue forward. These surgeries are not, however, as effective as CPAP to control your OSA and are usually reserved for patients who fail CPAP.

Authors: Rowley JA, McGowen C, Lareau S, Fahy B, Garvey C, Sockrider M

For more information contact the following websites:

American Thoracic Society

<http://www.thoracic.org/sections/education/patient-education/patient-information-series/resources/en/sleep-studies.pdf>

American Academy of Sleep Medicine

http://www.sleepfoundation.org/site/c.hu1XKjM0lxF/b.2417141/k.27D9/Home_of_the_Sleep_in_America_Poll.htm

American Sleep Apnea Association

http://www.sleepapnea.org/info/index.html?gclid=CJ7_l-qby5cCF5Jlagod1BNvRw

National Heart Lung and Blood Institute

<http://www.nhlbi.nih.gov/health/public/sleep/index.htm>

Rx Action Steps

- ✓ Talk with your health care provider if you have symptoms of obstructive sleep apnea
- ✓ Ask people who are around you when you sleep if they have heard loud snoring or saw you have apnea spells
- ✓ Ask your health care provider if you need a sleep study
- ✓ Exercise regularly and work to lose weight if you are overweight
- ✓ Avoid alcohol, particularly just prior to sleep

Doctor's Office Telephone:



AMERICAN THORACIC SOCIETY

Patient Information Series

Sleep Mini Series #5

Sleep Problems in Asthma and COPD

Good quality sleep is important for everyone. People with asthma and/or Chronic Obstructive Pulmonary Disease (COPD) may have sleep issues that can lead to nighttime awakenings and daytime sleepiness.

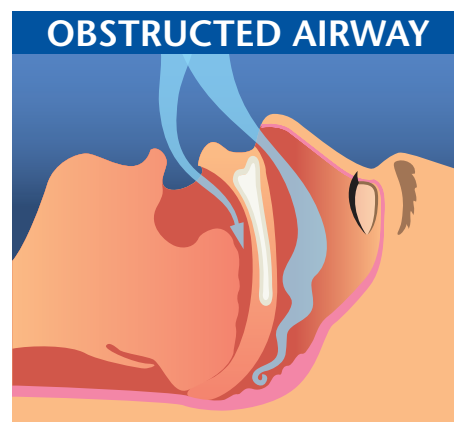
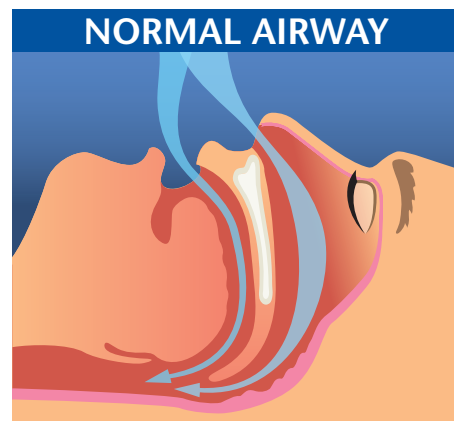
This may worsen their symptoms of asthma or COPD. There are a number of steps people with asthma and/or COPD can take to improve their sleep.

What kind of night disturbances can I get with asthma and/or COPD?

Waking up at night, also called nighttime arousals or nighttime awakenings, can happen if you have asthma or COPD. These arousals interrupt your sleep and may result in feeling groggy in the morning and/or tired during the day. Symptoms of COPD and asthma that may cause you to wake up at night include coughing, wheezing, chest tightness and breathlessness. People with COPD and/or asthma may also be at increased risk for sleep apnea and may awaken from symptoms of this sleep problem.

What is sleep apnea and why can I get sleep apnea with asthma and/or COPD?

Sleep apnea is a condition that causes you to have periods when you stop breathing during sleep. These pauses in breathing usually last 10 seconds or longer. It is not clear why sleep apnea may occur more often in people with asthma and/or



COPD, but you are more at risk if you have severe asthma, are overweight, have nasal congestion, acid reflux and/or use high doses of inhaled corticosteroids. (Also see *ATS Patient Series on Obstructive Sleep Apnea in Adults* at <http://patients.thoracic.org/information-series/index.php>).

How do sleep problems affect my asthma and/or COPD?

People with asthma and/or COPD who have a frequent problem waking up at night often have worse respiratory disease. They are also at risk for complications from their asthma or COPD. Sleep apnea can worsen asthma symptoms throughout the

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day, increase your need for rescue inhalers, and worsen your quality of life. If you have COPD, the pauses in your breathing and low oxygen levels with sleep apnea can make your COPD worse, increase your risk for exacerbations and reduce your survival. Sleep apnea can be a serious condition by itself. In those with moderate to severe sleep apnea who do not get treatment, their risk for hypertension, heart disease and stroke is increased (see ATS Patient Series on Heart disease and sleep apnea).

What can I do to help myself sleep better?

The first step is to make sure that your asthma and/or COPD is under good control. You may have to visit with your health care provider to be evaluated, see that you are getting the right medical treatment and develop a series of steps you can take, to control your asthma/ COPD and guide you through an episode of sudden breathlessness. Your provider will instruct you when to use your rescue inhaler (albuterol) or pursed lip breathing, and what questions to ask yourself about your condition, should you experience any sudden breathlessness. Also, talk to your health care provider if you have nasal congestion or get heartburn, to get them under better control. If you smoke, quitting smoking will not only help your asthma or COPD control, but the quality of your sleep will also improve. Tell your health care provider if you think you may have sleep apnea so that you can be evaluated. Sleep apnea is a treatable condition!

Authors: Jay Balachandran, MD and Mihaela Teodorescu, MD

Reviewers: Suzanne C. Lareau RN, MS and Chris Garvey FNP, MSN, MPA

References:

American Thoracic Society (ATS) ATS Patient Series on COPD at

<http://patients.thoracic.org/information-series/index.php>

Sleep Foundation

<http://www.sleepfoundation.org/article/sleep-related-problems/chronic-obstructive-pulmonary-disease-and-sleep>

Rx Action Steps

If you have asthma and/ or COPD, you may be at increased risk for sleep apnea if:

- ✓ You have more frequent asthma/ COPD symptoms, you are overweight, smoke, experience nasal problems, heartburn, or use higher doses of inhaled corticosteroid
- ✓ You are sleepy during the day, even after you have slept all night
- ✓ You snore or make choking noises while you sleep
- ✓ You have been observed to have breathing pauses during sleep
- ✓ You wake up in the morning with headaches

Doctor's Office Telephone:



Uncovering OSA in Women

The demands of work and family life can be exhausting, but a potentially deadly condition could be another reason why some women feel as if they're running a marathon day after day.

Two percent of women in the U.S. aren't getting enough shut-eye because of obstructive sleep apnea (OSA). Not only does it disrupt your beauty sleep, but it could contribute to serious health problems such as heart failure, stroke, high blood pressure, and diabetes.

Don't lose any more sleep worrying about the risks; visit your doctor who can recommend sleep testing and treatment so you can get the rest you deserve.

What is OSA?

OSA is a sleep disorder which interrupts breathing briefly and repeatedly during sleep. People with OSA awake several times a night because their airways collapse or get blocked, causing them to stop breathing. Other symptoms include feelings of choking and loud, habitual snoring. People with OSA may experience daytime sleepiness, fatigue, and morning headaches as a result.

Many women and doctors overlook OSA as a potential problem because some women don't exhibit the typical symptoms. For example, women with OSA are less likely than men to report pauses in breathing or loud snoring. Instead, they're more likely to have a history of depression or a problem with insomnia.

Hormonal Havoc

These symptoms may appear or worsen if you're experiencing hormonal changes, such as pregnancy or menopause. One-third of women who have never snored will begin snoring during pregnancy. Some of these women will develop OSA as the pregnancy progresses. The condition is more likely to surface if you had a high body mass index (BMI) before the pregnancy. It's imperative to seek treatment because severe sleep apnea can decrease oxygen levels and affect your baby's growth.

Even long after the pitter-patter of little feet,

OSA can arise. The rate of OSA is three times higher in postmenopausal women. Some doctors suggest postmenopausal weight gain may be a factor, but many also think it's connected to lower estrogen levels.

Pay attention

Don't ignore your sleep deprivation. Evidence indicates that women tend to underreport their symptoms, which contributes to underdiagnosis. If you experience any OSA warning signs — whether you're welcoming a new baby, experiencing menopause, or anywhere in between — bring them to your physician's attention.

He or she will most likely refer you for a sleep study, which is called a polysomnogram. Sleep specialists will use this test to observe your sleep patterns overnight with equipment to monitor your breathing and other vital signs.

If you have OSA, many treatment options can help ease your symptoms. The most common

and well-established treatment is a continuous positive airway pressure device, also known as CPAP. You will use a mask over your nose or mouth to gently blow air into your airways to keep them open at night.

Other treatment options include oral surgery which removes excess tissue in the throat or mouth to widen the airway. You also could consider wearing oral devices nightly. Similar to an orthodontic retainer, these small appliances reposition your jaw or tongue to help prevent your soft throat tissues from collapsing.

Maintaining a fit lifestyle is another key treatment component. Cigarette smoking, alcohol use, obesity, and weight gain can contribute to or hasten OSA. Eliminating these factors will put you on the path to good health and a good night's sleep. ■

Adapted from <http://sleepeducation.com> and the Trover Health System.

Colleen Mullarkey is assistant editor of ADVANCE. She can be reached at cmullarkey@merion.com.

notes

Your doctor or therapist has given you this patient education handout to further explain or remind you about an issue related to your health. This handout is a general guide only. If you have specific questions, discuss them with your doctor or therapist.



Spirometry

It's painless. It's quick. But what is it?

SPIROMETRY IS A TEST to measure your lung function. A device called a spirometer measures how much air you can breathe out of your lungs and how fast you can do it. These measurements are recorded and compared to predicted normal values based on your age, gender, height, weight, and ethnicity.

By looking at test results, your health care provider can diagnose and monitor certain types of lung diseases, such as asthma, chronic bronchitis, chronic obstructive pulmonary disease (COPD), emphysema, or pulmonary fibrosis, as well as distinguish one from another. The test can detect very small changes in lung function even before you recognize them yourself.

The Test

You will be seated, and directed to breathe through a mouthpiece while wearing a soft nose clip, and then to blow the air fully out of your lungs. (You may be asked to exhale for 10 seconds, or more.) You also may be asked to inhale a short-acting medication that opens up your airways, and to repeat the breathing exercise. Usually, it will be performed three times to ensure accuracy. That's it.

The Results

The test will reveal two measurements:

- The amount of air that can be expelled following a deep breath, called forced vital capacity (FVC)
- The amount of air that can be forcibly exhaled in one second, called forced expiratory volume in one second (FEV₁).

Your lung functions will be recorded on graphs which will be compared to graphs of normal function (normal FVC and FEV₁ values) for people of your age, gender, height, weight, and ethnicity.

While you may want to "read" your spirometry test yourself, it is complicated and in-depth training is required to interpret the results properly.

Your health care provider can use the ratio of FEV₁ to FVC to evaluate you for airflow



Getting Ready

Follow your doctor's orders for test preparation.

They are likely to include:

- Avoid eating a heavy meal within 30 minutes of test time.
- Avoid vigorous exercise within 30 minutes of test time.
- Avoid using specific medications such as a short-acting rescue inhaler within 4 to 8 hours of test time (unless you specifically need it), a long-acting bronchodilator within 12 hours of test time, and others. Your health care provider will give you instructions on these and other medications.
- Bring a list of all of your medications and the times you last took them.
- Bring your rescue inhaler, if you have one.

obstruction or reduced lung volume. Generally speaking, any value less than 85 percent of normal predicted values is considered abnormal and indicative of a lung function problem.

If your numbers are lower than they should be for your demographic (age, height, weight,

etc.), you may be referred for additional lung function tests to find out why.

Information adapted from National Heart, Lung, and Blood Institute, GOLD Guidelines, Maine Health, PennMedicine.org, and copd.about.com



Name: _____

Today's Date: _____

ASTHMA CONTROL TEST™

The ASTHMA CONTROL TEST™ is a quick test for people with asthma 12 years and older. It provides a numerical score to help assess asthma control.

- INSTRUCTIONS:**
1. Write the number of each answer in the score box provided.
 2. Add up the score boxes to get the TOTAL.
 3. Discuss your results with your doctor.

1. In the past 4 weeks, how much of the time did your asthma keep you from getting as much done at work, school or at home?						SCORE
All of the time [1]	Most of the time [2]	Some of the time [3]	A little of the time [4]	None of the time [5]	
2. During the past 4 weeks, how often have you had shortness of breath?						
More than once a day [1]	Once a day [2]	3 to 6 times a week [3]	Once or twice a week [4]	Not at all [5]	
3. During the past 4 weeks, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?						
4 or more nights a week [1]	2 or 3 nights a week [2]	Once a week [3]	Once or twice [4]	Not at all [5]	
4. During the past 4 weeks, how often have you used your rescue inhaler or nebulizer medication (such as albuterol)?						
3 or more times per day [1]	1 or 2 times per day [2]	2 or 3 times per week [3]	Once a week or less [4]	Not at all [5]	
5. How would you rate your asthma control during the past 4 weeks?						
Not controlled at all [1]	Poorly controlled [2]	Somewhat controlled [3]	Well controlled [4]	Completely controlled [5]	

If your score is 19 or less, your asthma may not be as well controlled as it could be. No matter what your score is, share the results with your healthcare provider.

TOTAL:

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This material was developed by GlaxoSmithKline.



AMERICAN THORACIC SOCIETY

Patient Information Series

Pulmonary Function Tests

Pulmonary function tests (PFT's) are breathing tests to find out how well you move air in and out of your lungs and how well oxygen enters your body. The most common PFT's are *spirometry* (spy-RAH-me-tree), *diffusion studies* and *body plethysmography* (ple-thiz-MA-gra-fee). Sometimes only one test is done, other times all tests will be scheduled, often on the same day.



Lung function tests can be used to:

- Compare your lung function with known standards that show how well your lungs should be working.
- Measure the effect of chronic diseases like asthma, chronic obstructive lung disease (COPD), or cystic fibrosis on lung function.
- Identify early changes in lung function that might show a need for a change in treatment.
- Detect narrowing in the airways.
- Decide if a medicine (such as a bronchodilator) could be helpful to use.
- Show whether exposure to substances in your home or workplace have harmed your lungs.
- Determine your ability to tolerate surgery and medical procedures.

To get the most accurate results from your breathing tests:

- Do not smoke for at least 1 hour before the test.
- Do not drink alcohol for at least 4 hours before the test.
- Do not exercise heavily for at least 30 minutes before the test.
- Do not wear tight clothing that makes it difficult for you to take a deep breath.
- Do not eat a large meal within 2 hours before the test.
- Ask your health care provider if there are any medicines that you should not take on the day of your test.

What is spirometry?

Spirometry is one of the most commonly ordered

lung function tests. The spirometer measures how much air you can breathe into your lungs and how much air you can quickly blow out of your lungs. This test is done by having you take in a deep breath and then, as fast as you can, blow out all of the air. You will be blowing into a tube connected to a machine (spirometer). To get the "best" test result, the test is repeated three times. You will be given a rest between tests.

The test is often repeated after giving you a breathing medicine (bronchodilator) to find out how much better you might breathe with this type of medicine. It can take practice to be able to do spirometry well. The staff person will work with you to learn how to do the test correctly.

It usually takes 30 minutes to complete this test.

What should I know before doing a spirometry test?

- You may be asked not to take your breathing medicines before this test.
- Instructions will be given on how to do this test. If you do not understand the instructions, ask the staff to repeat them.
- It takes effort to do this test and you may become tired. This is expected.
- If you become light-headed or dizzy during this test, immediately stop blowing and let the staff know.

What are diffusion studies?

Diffusion tests find out how well the oxygen in the air you breathe into your lungs moves from your lungs into your blood. Like spirometry, this test is done by having you breathe into a mouthpiece

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connected to a machine. You will be asked to empty your lungs by gently breathing out as much air as you can. Then you will breathe in a quick but deep breath, hold your breath for 10 seconds, and then breathe out as instructed. It usually takes about 15 minutes to complete this test.

What should I know before doing a diffusion test?

- Do not smoke and stay away from others who are smoking on the day of the test.
- If you are on oxygen, you will usually be asked to be off oxygen for a few minutes before taking this test.

What is body plethysmography?

Body plethysmography is a test to find out how much air is in your lungs after you take in a deep breath, and how much air is left in your lungs after breathing out as much as you can. No matter how hard you try, you can never get all of the air out of your lungs. Measuring the total amount of air your lungs can hold and the amount of air left in your lungs after you breathe out gives your health care providers information about how well your lungs are working and helps guide them in your treatment. This test requires that you sit in box with large windows (like a telephone booth) that you can see through. You will be asked to wear a nose clip and you will be given instructions on how to breathe through a mouthpiece. If you have difficulty with being in closed spaces (claustrophobia), mention this to your provider ordering the test. This will avoid any misunderstanding and discomfort to you. It usually takes about 15 minutes to complete. Some PFT labs will use other tests instead of plethysmography to measure the total volume of air in your lungs.

What should I know before doing a phlethsmography test?

- Some laboratories will use other tests instead of plethysmography, to measure the total volume of air in your lungs.
- If you are on oxygen, you will usually be asked to be off oxygen during this test.
- Let the staff know if you have difficulty in closed spaces.

What are normal results for lung function tests?

Because everyone's bodies and lungs are different sizes, normal results differ from person to person.

For instance, taller people and males tend to have larger lungs whereas shorter people and females have smaller lungs. A person's lungs grow until they are in their mid-twenties and then after that, lung function falls slightly every year.

There are standards that your health care provider uses that are based on your height, weight, age, and gender. These numbers are called the predicted values. Your measured values will be compared to the standard values to determine whether they are in these standard values. Your own lung function can be tracked over time to help see if you have had a change.

Authors: Bonnie Fahy, RN, MN; Marianna Sockrider, MD, DrPH; Suzanne Lareau, RN, MS.

Updated: Marianna Sockrider MD, DrPH

Reviewer: Brian Graham MD

Additional Lung Health Information

Canadian Lung Association

https://www.lung.ca/diseases-maladies/help-aide/spirometry-spirometrie/index_e.php

National Lung Health Education Program

<http://www.nlhep.org/Pages/Spirometry.aspxWebMed> <http://www.webmd.com/lung/lung-function-tests>

New York Times

<http://health.nytimes.com/health/guides/test/pulmonary-function-tests/overview.html>

Rx *Action Steps*

- ✓ Ask questions if you do not understand the instructions for the lung function test.
- ✓ If you have a cold or flu, let the test center know because they may want to reschedule your test.
- ✓ If you have difficulty with closed spaces (claustrophobia), let the test center know in case one of the tests involves being enclosed
- ✓ Ask if there are any medicines you should stop taking before being tested and for how long you should stop it.
- ✓ After your pulmonary function testing is over, you can return to your normal activities.

Health Care Provider's Office Telephone:

Pulmonary Function Tests in COPD

COPD MINI-SERIES #4

Pulmonary function tests (PFTs) are breathing tests to find out how well you move air in and out of your lungs and how well oxygen enters your body. The most common PFT's are *spirometry*, *diffusion studies* and *body plethysmography* (ple-thiz-mä-gra-fee). Sometimes only one test is done, other times all tests will be scheduled, often on the same day.

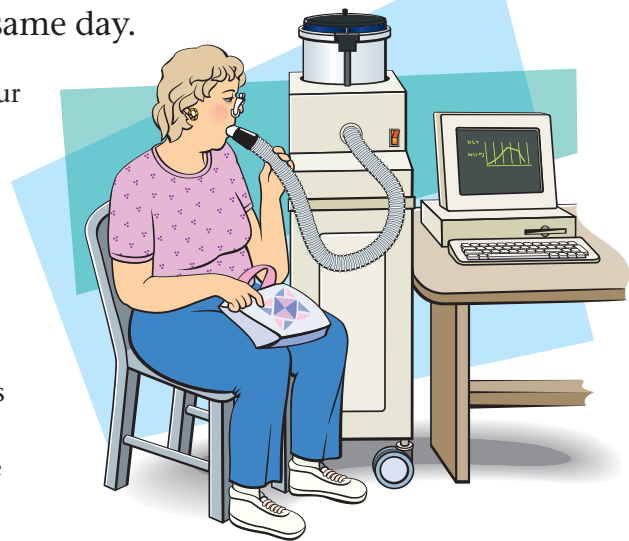
To get the most accurate results from your breathing tests:

1. Do not smoke for at least 4 hours before the test.
2. Do not drink alcohol for at least 4 hours before the test.
3. Do not exercise 30 minutes before the test.
4. Do not wear tight clothing that makes it difficult to take a deep breath.
5. Do not eat a large meal 2 hours before the test.

What is spirometry?

Spirometry is the most commonly ordered test to find out if you have Chronic Obstructive Pulmonary Disease (COPD). The spirometry test is often repeated after giving you breathing medications to find out how much improvement you get with these medications. This test is done by having you take in a deep breath and blow hard into a tube connected to a machine.

This machine measures the amount of air you can move in and out of your lungs. It usually takes 30 minutes to complete this test.



What should I know before taking this test?

- You may be asked not to take your breathing medicines before the test.
- It takes effort to do the test and you may become tired. This is expected.
- Instructions will be given on how to do the test. If you do not understand them, ask the technician to repeat them.
- If you become light-headed, or dizzy during the test, immediately stop blowing and let the technician know.
- To get the best results, the test will be repeated 2-3 times.

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What are diffusion studies?

Diffusion tests find out how well the oxygen in the air you breathe moves from your lungs into your blood. This test is done by having you breathe into a mouthpiece connected to a machine. You will be asked to empty your lungs by gently exhaling out as much air as possible. Then you will breathe in a quick but deep breath, hold your breath for 10 seconds, and breathe out as instructed. It usually takes about 15 minutes to complete this test.

What should I know before taking this test?

- Do not smoke and stay away from others who are smoking for at least 4 hours before this test.
- If you are on oxygen, you will usually be asked to be off oxygen for a few minutes before taking the test.

What is body plethysmography?

Body plethysmography is a test to find out how much air is in your lungs after you take in a deep breath and how much air is left in your lungs after breathing out as much as you can. No matter how hard we try, we can never exhale all of the air from our lungs. With COPD, the amount of air left in your lungs is often more than normal. Measuring the total amount of air your lungs can hold and the amount of air left in your lungs after you breathe out gives your health care providers information about your COPD and helps guide them in your treatment. This test requires that you sit in an enclosed plastic box which you can see through. You will be asked to wear a nose clip, and instructions will be given on how to breathe through a mouthpiece. It usually takes about 15 minutes to complete this test.

What should I know before taking this test?

- If you are on oxygen, you will usually be asked to be off oxygen during the test.
- Let the technician know if you have difficulty in closed spaces.

Sources:

1. P. Meek, S.C. Lareau, B. Fahy, E. Austegard. ATS/ERS Standards for the Diagnosis and Management of Patients with COPD, Patient Section. www.thoracic.org/COPD/pdf/copdpatient.pdf
2. ATS/ERS Task Force: Standardization of Lung Function Testing. Eds. V. Brusasco, R. Crapo & G. Viegi. www.thoracic.org/adobe/statements/pft1.pdf

Additional Lung Health Information

American Thoracic Society

www.thoracic.org/COPD/patients.asp

National Lung Health Education Program

www.nlhep.org

Global Initiative for COPD

www.goldcopd.com

Rx Key Points

- ✓ Ask questions if you do not understand the instructions for the test.
- ✓ If you have a cold or flu, let the test center know because they may want to reschedule your test.
- ✓ If you have difficulty with closed spaces (claustrophobia), let the test center know in case one of the tests involves being enclosed.
- ✓ Ask if there are any medications you should stop before being tested.

Doctor's Office Telephone:



PATIENT PRIMER

By Colleen Mullarkey

Arterial Blood Gas Testing

Needles and blood tests are sore subjects for many people. This guide will give you some painless tips to prepare for your arterial blood gas test and learn the ABCs of ABGs.

The basics

An ABG test measures the acidity (pH) and levels of oxygen and carbon dioxide in your blood. It's used to check how well your lungs can move oxygen into the blood and remove carbon dioxide from it.

Your health care provider might order an ABG test for several reasons. It can detect the severity of breathing problems in lung diseases such as asthma, cystic fibrosis, or chronic obstructive pulmonary disease. Or it can tell you how well a lung disease treatment is working.

If you use supplemental oxygen, it can determine if you're getting the right amount or if you need extra oxygen or a ventilator to help you breathe. If you have heart failure, kidney failure, uncontrolled diabetes, a sleep disorder, or severe infections, your provider also might want to use a ABG test to measure the acid-base level in your blood.

Getting ready

Before the test, tell your provider if you've had bleeding problems or if you take blood thinners such as aspirin or warfarin. Tell him about all medications you're taking



TOM WHALEN

and those that you're allergic to, especially if you have reactions to anesthesia.

If you use oxygen therapy, your oxygen may be turned off 20 minutes before the ABG. This is a room air test — if you can't breathe without the oxygen, then it won't be turned off during the test. Avoid smoking and exposure to secondhand smoke, carbon monoxide, or strong fumes before the test because these factors can affect your results.

Easy as 1-2-3

Your ABG test may be performed at a doctor's office, a hospital, or a commercial pulmonary function laboratory. A health care professional will take a sample of blood from an artery, usually on the inside of

your wrist. If you have poor circulation in your hands or there's a problem with the artery, an artery in another part of the body might be used.

The test will hurt a bit because arteries are protected by nerves and are deeper than veins. You'll probably feel a brief, sharp pain as the needle enters your artery.

If you're concerned about the pain, tell your provider for a local anesthetic before the test. It can eliminate or reduce the pain from the needle puncture and blood collection.

The test usually lasts five to 10 minutes. After the blood has been collected, a bandage will be placed over the puncture site. Apply firm pressure to the area for five to 10 minutes afterward.

Don't exercise or lift heavy objects for at least 24 hours after the test. Be sure to tell your provider if you notice bleeding, bruising, numbness, tingling, or discoloration around the puncture site.

Your results may be ready in minutes or your sample may be sent to a laboratory for analysis. Your provider will assess your lungs based on the ABG results and recommend treatment such as oxygen therapy if necessary. It's important to remember that the information this test provides can help save your life.

Adapted from Healthwise Inc. and University of Maryland Medical Center. ■

EDITOR'S NOTE: Your doctor or therapist has given you this patient education handout to further explain or remind you about an issue related to your health. It is a general guide only. If you have specific questions, discuss them with your doctor or therapist.

BY KRISTEN ZIEGLER

patient primer

Pulmonary Rehab for Beginners

Starting a pulmonary rehabilitation program is like going to school. The “classes” address subjects such as administering medications, stress management, and smoking cessation. The “teachers” are a multidisciplinary team of health care professionals.

But you don't have to be a whiz kid for pulmonary rehabilitation to help manage your symptoms and slow the progression of your pulmonary disease. While results vary, the goal is to increase your independence, decrease your hospitalizations, and improve your quality of life.

What to expect

The structure of pulmonary rehab programs varies; the majority of programs are held as group classes, but some are done individually. Most programs encourage family or friends to attend with you.

Before you begin, a pulmonary rehabilitation team member will talk with you about your chronic lung disease and its physical and emotional effect. They will determine whether you need testing such as pulmonary function tests and chest X-rays. They also may have you take a short quiz about lung diseases and ask you to set goals for your progress.

For your first class, wear comfortable clothing and walking shoes. Make sure to bring your fast-acting inhaler, supplemental oxygen equipment, and other prescribed medications.

A staff member will measure the distance you are able to walk in six minutes while a device called a pulse oximeter determines the oxygen saturation in your blood through a clip on your finger or a forehead sensor. The test results will help the rehabilitation team assess your functional exercise capacity and develop an exercise program tailored to your abilities.

Exercise training

As your weeks of pulmonary rehabilitation

progress, you will practice a regimen of stretching, aerobic activities like walking, and strength exercises using free weights and resistance bands. A typical exercise prescription emphasizes endurance training for 30 to 40 minutes repeated at least three times weekly, but preferably five to seven times a week.

It's important to exercise at home as well. This “homework” includes walking, bicycling, swimming, or other activities recommended by your rehabilitation team. Keep up this routine even after completing rehabilitation to ensure its long-term effectiveness. Patients who discontinue exercise

following rehabilitation typically return to their previous state of health within 12 to 18 months.

The rehabilitation team also will show you how to conserve energy and pace yourself during exercise and daily activities. They will demonstrate strategies to help reduce your shortness of breath.

Increasing Awareness

A comprehensive pulmonary rehabilitation program will teach you to pay attention to your body. You'll learn to prevent respiratory infections by avoiding crowds, getting flu or pneumonia shots, and using antibacterial wipes or gels.

Most pulmonary rehabilitation programs include 40 to 80 hours of sessions. Program costs vary greatly by location, but many therapies are covered by insurers. Check with your local pulmonary rehabilitation provider for further information.

With a little effort, you're sure to graduate pulmonary rehabilitation with flying colors. Just don't forget the homework. ■

Information provided by Lana Hilling, RCP, FAACVPR, pulmonary rehabilitation coordinator of John Muir Health in Concord, Ca. and adapted from National Lung Health Education Program guidelines.

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TOM WHALEN

notes

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Fit for Life

Keeping up with pulmonary rehabilitation exercises at home

Fitness buffs will tell you their workouts don't end after they leave the gym. Staying in shape means making changes at home too. The same goes for pulmonary rehabilitation. A home exercise routine can help to maintain your lung function and improve your overall well-being.

Think of your pulmonologist, respiratory therapist, and primary care physician like a team of personal trainers. A pulmonary rehabilitation program is a great place to learn how to do the proper exercises with a health care professional's guidance and expertise. They'll create an at-home exercise plan and suggest lifestyle changes to reach your long-term goals after your formal pulmonary rehab sessions end.

Talk with your pulmonary rehab team about your living situation and surroundings. Perhaps you already have a treadmill, stationary bike, or light free weights to use at home. If you don't, they can suggest resources in your area such as a community or senior center that has exercise equipment.

They also can recommend simple strategies to fit in the recommended 20 minutes of continuous walking a day. You could do laps at a local mall or high school track, stroll around your block or apartment building, or even just walk the length of your hallway a few more times.

While aerobic exercise focuses on your cardiovascular endurance, strength training keeps your upper body in shape. Some people like to use light free weights or resistance bands; others use items from their pantry like soup cans or water bottles. Your pulmonary rehab team will advise you on the ideal amount of weight, type of exercise, and number of repetitions to improve your strength and muscle tone.

When you leave a formal pulmonary rehab program, you may miss the social support and motivation that it offered. Signing up for a gym membership, finding a workout buddy, or making an arrangement with a family member can increase the chances that you'll stick with the routine.

Safety first

While a regular exercise routine is important, be careful not to overdo it. Your pulmonary rehab team will identify stretching and warm-up



exercises that start at a low intensity and then gradually increase. It's important to slow your pace for five minutes to cool down.

Watch for signs of a possible exacerbation. The pulmonary rehab program can help you become more aware of your breathing levels and what to do if you experience a change in your breathing.

If you use long-term supplemental oxygen, your pulmonary rehab team will determine which oxygen flow rates you should use during periods of rest and exercise. They may recommend using a fingertip pulse oximeter at home to occasionally check your oxygen level.

Finally, listen to your instincts. If something doesn't feel right, stop doing it immediately, and call your primary health care provider. You may need to limit your activities until the problem is resolved.

Regular exercise has many benefits. The stronger your muscles become, the more efficiently you use oxygen. Staying fit also can help lower blood pressure, improve mood, and manage stress. Keep up the progress you made in pulmonary rehab by following an exercise routine that is convenient and

Information provided by Peter J. Rising, MS, manager of the pulmonary function laboratory at Temple University Health System

Staying Active With COPD

Simple tasks like getting up from a chair can leave people with chronic obstructive pulmonary disease breathless. So they may think exercise is out of the question.

On the contrary, it's important for even those with advanced lung disease to stay active. When you exercise, your muscles get stronger. Strong muscles need less oxygen. Therefore, exercising actually makes it easier for you to breathe.

Get started

It's important to start slowly. Some people may begin with a few minutes a day, while others are able to do more. Remember to speak with your doctor before beginning an exercise program. He or she can help you decide what level is right for you.

Setting goals helps you stick with your program. Be sure your first goal is one you know you can meet, and then gradually work up to higher goals. Eventually, you'll want to be able to exercise for 20 to 30 minutes, two to four times a week. But if you try to do that much in the beginning, you might give up.

A pulmonary rehabilitation program can help you get the most out of exercise. In addition to physical training, rehab programs offer nutrition counseling and education. Plus, programs offer support and supervision for those who aren't confident exercising on their own.

Get going

Always begin exercise with a warm-up period. While simple stretching warms up your muscles, pursed-lip breathing warms up

through your mouth with your lips pursed. It's important to exhale twice as long as you inhale so you get all the air out of your lungs. Practice the technique for 10 minutes. Once you get the hang of it, you can do pursed-lip breathing during exercise as well.

After warming up, perform your main low-impact aerobic activity such as swimming and walking. If you need oxygen therapy during exercise, a treadmill or stationary bike is your best bet. Pick activities you enjoy, and alternate them so you're more likely to stay motivated.

Resistance training (lifting a light weight with your arms or legs) is important for making muscles stronger and increasing endurance. This can help you reduce fatigue and reverse deconditioning.

Finally, be sure to end your workout with a cool-down activity, which can be stretching, or walking or swimming at a slower pace.



SCOTT DERBY

Rewards

Even the smallest amount of exercise is better than no exercise at all. An active lifestyle increases your physical capacity even though impaired lung function continues to persist after exercise training.

An exercise regimen will give you more confidence and independence, and daily activities like shopping and cooking soon will be easier.

Editor's Note: Information adapted from the American Association for Respiratory Care, the American College of Sports Medicine, and the University of Pittsburgh Medical Center.

notes

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This Patient Primer was sponsored by



Pacing & Energy Conservation

Help Prevent Fatigue and Breathlessness

Plan your day

- Do the most important activities while you have the most energy. Don't do high-energy activities back-to-back. Use lightweight pots and pans for cooking. Keep frequently used dishes out rather than putting them away.

Plan rest periods

- Plan about 5-15 minutes between activities. Sit while performing tasks, such as washing dishes, bathing, brushing your teeth, etc. Use a shower stool.

Use a cart

- To move objects around the house. Push or slide objects instead of lifting them. Let dirty dishes soak—don't scrub them. After washing dishes, let them air dry.

Gather your clothes together

- Before getting dressed. Sit down while dressing. Don't bend over to put on shoes and socks. Instead, bring your feet up or use a long-handled shoehorn to put on shoes.

Keep items you use often at waist height

- To avoid having to reach, bend or lift. Consider home modifications or renovations that reduce effort or strain.

Put everything you need in one spot

- Before starting an activity. You won't have to get up as often.

Reduce shopping stress

- Keep grocery bags light and easy to carry. If you have someone to carry them for you, consider buying nonperishables in bulk. You won't have to shop for them as often.

10 Tips for Energy Conservation

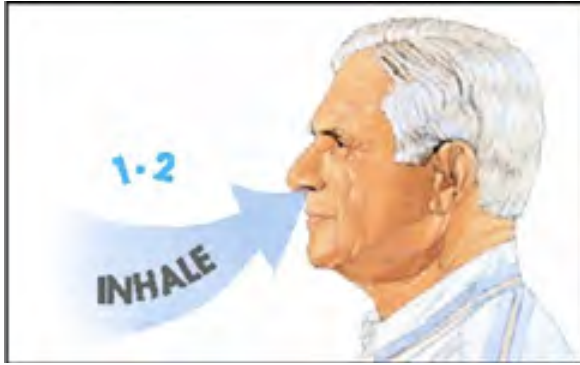
- 1.** Sit as much as possible when doing activities (sit on a shower chair when showering, sit at the kitchen table to prepare a meal.)
- 2.** Arrange your kitchen so the most commonly used items are easy to reach.
- 3.** Lay your clothes out the night before.
- 4.** Wear slip on shoes or use a foot stool to put on shoes and socks. Avoid bending over, it takes a lot of energy and makes breathing more difficult.
- 5.** PACE YOURSELF! Spread chores out during the day and week.
- 6.** Stop and rest after an activity (sit on the edge of the bed after you dress)
- 7.** Spend time every day to just relax! Listen to relaxation tapes, practice your pursed-lip breathing techniques, or do a low energy hobby you enjoy.
- 8.** Line oven pans with aluminum foil for a quick clean up.
- 9.** BE ORGANIZED! This can help save steps.
- 10.** Lastly, it is OK to let others/family help. You are the boss. Delegate chores.

SECTION 7

Exercise

Breathing Exercises - Pursed Lip Breathing

- Helps open up airways and slow breathing.
- Pursed-lip breathing helps you exhale more fully so that you can take in more oxygen-rich air when you inhale through your nose.
- You should use pursed-lip breathing anytime you start to feel short of breath.
- Pursed-Lip breathing should also be used to prevent shortness of breath when you exert yourself.
 - o Exercising
 - o Walking
 - o Climbing stairs
 - o Bending over
 - o Lifting
 - o Reaching
- With regular practice, this technique will seem natural to you.
- Practice every day so you will know how to breathe.
- This technique helps open up airways and slow breathing. It also helps air trapped in the lungs escape, letting in fresh air. Follow these steps:
 1. Breathe in slowly through your nose, keeping your mouth closed. Hold your breath for about 3 seconds. (It's not necessary to take a big breath –a normal breath is fine).
 2. Purse your lips as if you were going to whistle.
 3. Breathe out slowly through your pursed lips for about 6 seconds. You should make a soft whistling sound while you breathe out. In general, breathing out should take 2-3 times longer than breathing in.



Remember

- Smell the roses and blow out the candles
- DO NOT breath forcefully – take relaxed but full breaths.
- Always exhale twice as long as you inhale
- Always exhale during exertion or the most difficult part of an activity
- NEVER hold your breath

Breathing Exercises - Diaphragmatic Breathing

• Diaphragmatic breathing can help prevent shortness of breath by increasing the movement of the diaphragm so that you can get more air in and out of your lungs.

- o The diaphragm should contract when you inhale
- o The diaphragm should relax when you exhale
- o This is the technique:
 - o Lay down on your back with a pillow under your head. Bend your knees (or put a small pillow under them) to relax your stomach.
 - o Put one hand on your stomach, just below your rib cage. Put your other hand on your chest.
 - o Slowly breathe in and out through your nose using your stomach muscles. If you do the right, the hand on your stomach will rise and fall as you breathe in and out. The hand on your chest should hardly move. Time your breathing so that you can breathe out for about twice as long as you breathe in.



Remember

- Your hand on your chest should not move- if it is moving you are using your chest muscles for breathing
- Work on pursed lip breathing as you perform this exercise
- Always exhale twice as long as you inhale.

- Once you are able to do this, you can practice this technique while sitting, standing, walking or eating and with pursed-lip breathing. You can also use it while you meditate. Over time, your muscles may become stronger and your breathing easier.

Exercise

Exercise can help your body better use oxygen, strengthen muscles, and improve your state of mind. Consult your health care provider before starting an exercise program. Ask about medications. Your health-care provider may prescribe oxygen therapy or increase your flow rate. He or she may also prescribe medication to take before exercising so you can breathe more easily.

Warm up before exercising.

- You could do breathing exercises and walk at a slow pace for about 5-10 minutes, for example. Then you could do some stretching. (Do not stretch first. This can damage muscles that are not warmed up).

Set goals you can reach.

- Set your goals higher as you get stronger. Reaching goals, even small ones, will give you a sense of success.

Choose activities you enjoy

- If you are bored with your exercise program, you are less likely to stick with it. Consider activities like walking and gardening.

Exercise with a friend.

- It will push you and give you a chance to talk and laugh.

Don't overdo it.

- Set a pace that is comfortable for you.

Cool down when you are done.

- Like the warm-up, you should stretch, practice breathing exercises and/or move at a slower pace for 5-10 minutes.

Reward yourself.

- Do something nice for yourself after you reach a goal. This can keep you on track to reach your next goal.

Stop and rest if you have a problem.

For example, stop if you get dizzy or short of breath, or if you are in pain. Seek medical help right away.

How to Measure Exertion

Modified Borg Rating of Perceived Exertion Scale (RPE)

- This is a subjective rating scale to measure the intensity of exertion.
- The numbers range from 0 which means “Nothing at all” to 10 which means “Very, very hard.”
- Often individuals are advised to keep their exertion between “Fairly light” and “Somewhat hard.”
- There is a high correlation between RPE scores and heart rate.
- Often monitoring heart rate is an effective method of measuring exertion. However, an individual’s heart rate will not increase as much with exertion if an individual is taking beta blockers. Therefore, it is better to measure exertion with the RPE scale.

0	Nothing at all
1	Very Light
2	Fairly Light
3	Moderate
4	Somewhat Hard
5	Hard
6	
7	Very Hard
8	
9	
10	Very, Very Hard

RPE SCALE

Use this scale to judge how hard your activity is when planning out your day; this will help with conserving energy.

SECTION 8

Stress

Stress Management

Anxiety is a common side effect of many pulmonary disorders. Anxiety and breathing difficulties can interact in a way to keep you from meeting your goals.

Progressive Muscle Relaxation

- This involves tensing and relaxing muscle groups one at a time. Begin with your facial muscles. Frown hard for several seconds and then relax. You should feel a difference between tense and relaxed muscles. Move on to other muscle groups, such as your shoulders, arms, chest and legs until you have tensed and relaxed your entire body.

Visualization

- Give yourself a “vacation” by closing your eyes and imagining a relaxing scene, such as a sandy beach. Picture yourself there. What do you see? What do you hear? What do you smell? Focus on the scene for about 15 minutes.

Meditation

- Close your eyes, breathe deeply into your abdomen and think about a calming thought, word or object. If you have trouble staying focused, try repeating a word or sound over and over. (Some people find it helpful to play soft music while meditating.)

Breathing Exercises

- These are great ways to improve your breathing. But they can also help beat stress.

Don't give up! You may need to practice a technique for a few weeks before you begin to feel the benefits

TIPS

- No matter which technique you choose, start by finding a quiet spot where you can sit or lie comfortably. It might be a favorite chair, your bed or even a park bench.
- Some strategies work better for one person than another, so pick one that most appeals to you. Then practice when you feel okay as well as when you feel stressed to get better control of the technique.
- Anxiety is treatable. Developing strategies help to distract from anxiety or pain while relaxing your mind and body is the best place to start.

Smoking Cessation

Why quit?

Smoking Facts:

- Tobacco smoke contains more than 7000 chemicals and chemical compounds which reach your lungs every time you inhale. These poisons are then carried to all parts of your body through your bloodstream.
- Second hand smoke causes an estimated 50,000 deaths each year mostly from lung cancer and coronary heart disease. Smoking also leads to heart attacks and stroke.
- Smoking causes over 393,000 deaths per year. Smoking causes or worsens many lung-related diseases including cancer and COPD (chronic obstructive pulmonary disease), which includes emphysema and chronic bronchitis. Smoking also makes asthma symptoms among children and teens worse.
- Quitting smoking provides both immediate and long-term benefits to your health, reducing or eliminating the risks for many of the diseases caused by smoking.
- Within 5 years of quitting, your chance of cancer of the mouth, throat, esophagus, and bladder is cut in half. If nobody smoked, 1 of every 3 cancer deaths in the United States would not happen.

- Smoking Cessation is not one size fits all. There are several options. These include nicotine replacement therapies (NRT) gum, NRT patch, NRT lozenge, NRT inhaler, NRT nasal spray. Prescription medications such as Bupropion and Varenicline and individual counseling, group counseling, phone counseling.

Smokers save money when they quit:

- Smokers can save approximately \$1300-2500 annually by quitting a pack per day habit. Heavy smokers can save even more by quitting.
- Some health insurance companies and life insurance plans give discounts for non-smokers. By quitting, a smoker may be able to save significantly on premiums.
- Minor expenses related to smoking can add up: cleaning and maintenance costs for houses, cars and more frequent dry cleaning and other personal expenses.

Call 1-800-QUIT NOW (784-8669) for more information. The resource list section has additional websites listed.

■ PATIENT HANDOUT

By Lauren Greaves

Diet & COPD

Help manage symptoms with healthy eating habits

MAINTAINING A HEALTHY AND BALANCED LIFESTYLE is a good idea for everybody, but if you are an individual with Chronic Obstructive Pulmonary Disease (COPD), you need to be especially attuned to how your choices, particularly when it comes to diet, affect your health and COPD symptoms.

COPD encompasses a range of progressive lung diseases, such as emphysema, chronic bronchitis and non-reversible asthma. It is characterized by increasing breathlessness, frequent coughing, wheezing and tightness in the chest. It's estimated that 24 million Americans have COPD, and half of those cases are undiagnosed.

Most COPD patients are aware of the environmental factors and personal choices that can exacerbate symptoms. Such triggers include air pollution, hot and cold weather extremes, and smoking. However, fewer individuals are aware that eating and drinking habits can also affect breathing. Knowing what's good and bad for your body will allow you to make smart and healthy food choices that will keep you breathing easy.

Your first step should be to talk to your care provider about food preferences, your daily eating and exercising habits, and any dietary restrictions. This is a good starting point for creating a food plan that is specific to your needs. A registered dietician (RD) who specializes in COPD or a respiratory therapist (RT) will be able to direct you towards the right foods.

There are many components involved in a dietary regimen. Here are several you should keep in mind and discuss with your care provider so you can be sure you are eating right for the management of your COPD:

Calories. The amount of calories you consume translates to how much energy you have. And believe it or not, people with COPD can burn 10 times as many calories breathing as a healthy person does. Do you lose weight easily? Or do you find yourself gaining weight? This is a good starting point for gauging whether you are taking in the proper amount.

Protein. Your muscles get their strength from protein. As somebody with COPD, it's important that you consume protein at least twice a day in order to strengthen your respiratory muscles. Some excellent sources of protein include dairy products, meat, poultry, seafood, nuts and legumes such as dried lentils and peas.

Fluids. It's important to drink lots of water, which helps to keep mu-



cus thin and can decrease inflammation. Aim for six to eight glasses of water a day, and remember that healthy liquids, like teas, can count towards your fluid goals.

Sodium. Sodium can counteract the benefits of proper hydration. It can cause irritation, inflammation and swelling. Talk to your doctor about how much you should be consuming, and be leery of cooking with store-bought spice blends that tend to have a lot of excess salt.

Fats. The amount of fat each person should consume can vary, but if your RT advises you to increase your fat intake, make sure it's the polyunsaturated kind. Polyunsaturated fats contain no cholesterol, and include liquid vegetable oils, soft margarines and mayonnaise made from plant oils. Avoid trans-fat whenever possible.

Meals. Eat four to six small meals a day, instead of two or three large ones. After you've eaten a large meal, your stomach presses up against the space under your diaphragm and can keep you from taking deep and full breaths. Try to rest before a meal, and avoid gassy foods such as broccoli, carbonated drinks, cauliflower and beans which can cause added discomfort.

Weight. Weigh yourself regularly, and if you notice a continual increase or decrease while you are following your recommended diet, consult your care provider.

Every person with COPD is different, and certain nutritional guidelines will be effective for some and not for others. Pay attention to your body before and after you eat, and be sure to consult a nutritionist or RT so you can develop a plan that will work best for you.

Information provided by the American Lung Association. Visit www.lung.org.

EDITOR'S NOTE: Your doctor, therapist, or sleep technologist has given you this patient education handout to further explain or remind you about an issue related to your health. It is a general guide only. If you have specific questions, discuss them with your doctor, therapist, or sleep technologist. Look under the "Education" tab at advanceweb.com/respiratory for more educational handouts.



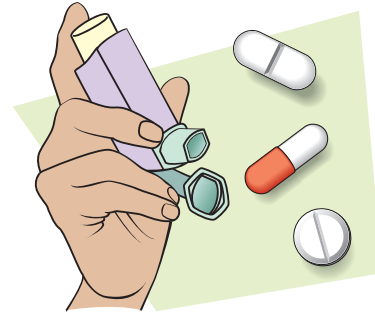
AMERICAN THORACIC SOCIETY

Patient Information Series

Medicines Used to Treat COPD

COPD MINI-SERIES #3

The most common medications for treating chronic obstructive pulmonary disease (COPD) are bronchodilators and steroids. Both make breathing easier, but do this in different ways.



BRONCHODILATORS

Bronchodilators are medications that relax the muscles that wrap around your breathing tubes, allowing the tubes to become larger and easier to breathe through. Each bronchodilator is different, based on 1. the chemical make up, 2. how fast it works and 3. how long it lasts. Your health care provider will work with you to decide which of these medications or combinations work best for you.

Types of bronchodilators:

- beta₂-agonists
- anticholinergics
- theophyllines

Beta₂-Agonists

Inhaled beta₂-agonists can be fast-acting (start to work within 3 to 5 minutes), or slow-acting (take 20 minutes to work). These medications can also be short- or long-lasting. Short-lasting beta₂-agonists (albuterol, pirbuterol, salbutamol, terbutaline) last for 4-6 hours, while long-lasting (salmeterol, formoterol) can last for up to 12 hours. Indacaterol and vilanterol last up to 24 hours. Albuterol and terbutaline are available in both inhaled and pill forms. The pill form can cause more side effects than the inhaled form.

Beta₂-agonists that are fast-acting are also known as reliever medicines because they bring quick relief for breathlessness, but do not last long enough to provide 24-hour relief. Using your reliever medication before an activity that you know makes your breathing worse (exercise, showering, or going out into the cold air) may help lessen or prevent your breathing difficulty.

Long-lasting beta₂-agonists are taken every 12 to 24 hours, providing more convenient treatment of COPD than short acting drugs.

Common side effects when taking beta₂-agonists

Beta₂-agonists can cause fast heartbeat (and other heart problems), shakiness, and cramping of the hands, legs, and feet. Often this combination of fast heartbeat and shakiness can cause anxiety and worsen breathlessness. This can happen when the medicine is overused. These side effects can last for a few minutes after taking the medicine, and may totally go away after a few days of regular use. If the side effects do not go away, talk to your health care provider, who may stop or reduce the dose, or change to another type or brand of beta₂-agonist.

Anticholinergics

Anticholinergic bronchodilators are inhaled medicines. They can be short- or long-lasting. The short-lasting form (ipratropium) works in about 15 minutes and lasts for 6-8 hours, and is usually taken 4 times a day. The long-lasting forms take about 20 minutes to begin working and last 24 hours (tiotropium, umeclidinium) or 12 hours (aclidinium). Because of the slower onset of action of anticholinergics, they are not to be used for quick relief (reliever medicine).

Common side effects when taking anticholinergics

Anticholinergic bronchodilators do not have as many side effects as beta₂-agonists. The most common side effects are dry mouth and difficulty passing urine (urinary retention).

Why am I taking two bronchodilators if they both do the same thing?

Understanding why you are taking two different bronchodilators may be confusing. You may be given a beta₂-agonist with an anticholinergic because the two work better than just one alone. Another common combination is to take a fast-acting bronchodilator with a long-lasting bronchodilator. This combination gives fast action and long-lasting relief.

Theophylline

Theophylline is no longer commonly used for COPD in the U.S. Theophylline is usually taken by pill. Inhaled forms of theophylline are not available.

When taking theophylline, a blood test must be done to check your theophylline level. The amount of theophylline you take needs careful supervision since your theophylline blood level can change just by starting a new medicine or stopping smoking. Common side effects are shakiness, but very serious side effects that may occur are severe nausea, vomiting, heart irregularities, and seizures. If you experience any of these, get medical care immediately.

STERIODS

Steroids, also known as corticosteroids, are medications used to reduce swelling in the breathing tubes. These drugs are not the same as anabolic steroids (misused by athletes) to build muscles.

Steroids are usually taken by inhaler or pill. The inhaled steroid may be combined with a bronchodilator. Inhaled steroids can be given in small doses, resulting in fewer side

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effects. They do not work quickly, however, and may take a week or more before you notice the benefits. Pills can act faster (within 24 hours) than inhaled steroids, but can cause more side effects.

Common side effects when taking steroid medications

Side effects depend on the dose, length of use, and whether taken by pill or inhaled. The most common side effects of inhaled steroids are a sore mouth, hoarse voice, and infections in the throat and mouth. You can avoid or reduce these side effects by rinsing your mouth after taking an inhaled steroid. If using a spray inhaler, also use a spacer/chamber to reduce the amount of steroid landing in your mouth and throat.

Taking steroids by pill in high doses, or taking low doses for a long time, may cause problems including bruising of the skin, weight gain, weakening of the skin and bones (osteoporosis), cataracts, increased blood sugar, mood changes, muscle weakness, and swelling of the ankles or feet. Patients who use inhaled steroids may have a higher risk of pneumonia. While many of these unwanted effects can be troublesome, not taking steroids when they are needed can lead to severe, life-threatening breathing problems. You should discuss any concerns about taking steroids with your health care provider.

OTHER MEDICATIONS

Antibiotics for bacterial infection, mucolytics to thin mucus (phlegm or sputum), and oxygen to treat low oxygen levels (www.thoracic.org/patiented/adobe/oxytherapy.pdf), are also used to treat COPD. Other medications that have not been mentioned have not as yet been proven to be effective in the treatment of COPD. For people with frequent exacerbations despite being on bronchodilators and steroids, two medications are sometimes used. Roflumilast is a new medication that may decrease the number of exacerbations you have. Long-term use of the antibiotic azithromycin, may also decrease the number of exacerbations you have. Both can have side effects so it is important to discuss the risks and benefits with your health care provider.

What is the Difference Between Generic and Brand Name Medicines?

Most medicines have two names, a generic and a brand name. The generic name describes the main chemical in the drug. The brand name is decided by the maker (or makers) of the medicine. Therefore, if several manufacturers are making the same generic drug, then the drug may be known by several brand names. Brand names and generic names can be different from country to country. Usually there is no major difference between brands of the same medicine.

Delivery Devices for Inhaled Medicines

Bronchodilators and steroids are usually taken by inhaling the medicine. These inhaled medicines have recently been developed in a dry powder form as well as liquid spray. This has resulted in new designs for inhalers. These inhalers can be hard to use correctly. If not taken properly, you may not be receiving the full dose of the medicine. Bring your inhalers

and spacer/chamber to your clinic visit and review your medicines and the way you use them with your health care provider.

Examples of bronchodilator actions and common side effects:

	Beta ₂ -agonist	Anticholinergic	Theophylline
Short-lasting (4-6 hours)	albuterol, pirbuterol, salbutamol, terbutaline	ipatropium	✓
Long-lasting (12-24 hours)	Indacaterol, formoterol, salmeterol, vilanterol	aclidinium, tiotropium, umeclidinum	✓
Fast-acting (5 minutes)	albuterol, formoterol, salbutamol, terbutaline		
Slow-acting (20 minutes or more)	salmeterol	ipatropium, tiotropium	✓
Side Effects:			
Shakiness	✓		✓
Dry mouth		✓	
Fast heart rate	✓		✓
Nausea/ Stomach upset			✓
Muscle Cramps	✓		✓

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Additional Lung Health Information

American Thoracic Society

<http://patients.thoracic.org/information-series/en/resources/chronic-obstructive-pulmonary-disease-copd.pdf>

Canadian Lung Association

<http://www.sk.lung.ca/drugs/pages/copd.html>

Rx Key Points

- ✓ Know the names of your medicines and what they are supposed to do and not do.
- ✓ Review how you take your medicines with your health care provider.
- ✓ Tell your health care provider everything you are taking (medicines for other conditions, over-the-counter medicines, herbs, medicines from relatives, etc).
- ✓ Overuse of medicine can result in side effects.
- ✓ Call your health care provider promptly if you have any serious side effects.

Health Care Provider's Contact Numbers/ E-mail Address:

Making the Switch

If you've been food shopping recently, you might have noticed green products aren't just in the produce section anymore. Each aisle offers you more environmentally friendly choices — from organic chips to nonabrasive drain cleaners. Pharmacy shelves have been making some changes, too, starting with the albuterol inhaler's green makeover.

After the Food and Drug Administration's Dec. 31 deadline, pharmacies won't supply albuterol metered-dose inhalers containing ozone-depleting chlorofluorocarbons (CFCs) anymore. Instead you'll find the same medication in an inhaler using hydrofluoroalkane (HFA), a propellant that won't harm the environment.

This guide will help you to get friendly with your new ozone-friendly inhaler.

Getting started

First, make sure your prescription is up to date. You won't be able to get a new HFA inhaler using your CFC prescription. If your inhaler doesn't say "HFA" on it, make an appointment with your health care provider to get a new prescription. It's better to do this sooner rather than later so you don't end up without medication in an emergency.

You and your provider will choose one of the four reliever HFA inhalers on the market. Each brand is a little different, so talk together about which one might be right for you. Some topics to discuss are side effects, insurance coverage, and whether you need



an inhaler that counts your doses. This is a good opportunity to review whether your asthma is properly controlled.

A new routine

An HFA inhaler releases smaller particles that are easier to inhale deep into your airways. Its softer, gentler spray may feel and taste a little different than your old inhaler's. The most important thing to remember is that the medicine in your HFA inhaler is just as effective. Reviewing your symptoms and peak flow readings after taking the medicine will help you decide if your symptoms are better controlled after using the new inhaler.

Even though its effectiveness won't change, its maintenance routine will. You need to prime HFA inhalers before the first use to get the right amount of medication. That means you have to release a certain number of sprays into the air before you use it. You also will have to repeat the priming if it's been a while since the medicine was last used. Priming instructions for each brand vary, so read all of the directions to make sure you're using your inhaler safely and effectively.

Regardless of the brand, cleaning is a

top priority. It's especially important to keep the exit port clear. That's the tiny hole inside the mouthpiece where the medicine comes out. HFAs are a little stickier than CFCs, and they tend to clog the exit port. Check your inhaler's package insert for cleaning instructions. One important tip: Don't expose the canister to water because it can damage your HFA inhaler.

Dollars and sense

Going green may cost more green at first. Depending on your insurance coverage, the HFA inhalers cost from \$30 to \$60, compared with \$5 to \$25 for a generic CFC inhaler. Generic albuterol HFA inhalers won't be on the market until at least 2010.

Don't worry; plenty of financial resources can help to ease the strain. Many pharmaceutical manufacturers have discount coupons and financial assistance programs for HFA inhalers. Ask your doctor about free samples or phone numbers for national assistance programs.

Change isn't always easy, but you can work with your doctor to make a smooth transition to your new inhaler. Pretty soon you'll know the ABCs of these HFAs, and you'll feel good about taking care of your asthma and the environment too.

Adapted from the Asthma & Allergy Network Mothers of Asthmatics. ■

This Patient Primer was sponsored by:



5 Latour Ave., Ste. 1600
Plattsburgh, NY 12901

(800) 833-9653 www.monaghanmed.com

▼ **NOW ONLINE** Critical differences exist between the CFC and HFA metered-dose inhalers. Visit www.advanceweb.com/respmanager to see a webcast about the new inhalers and hear one family's experience with the transition.

Rescue vs. Controller Medication-Know the Difference!

Rescue Medications

- Rescue medications, also called quick-relief or fast-acting medications, work immediately to relieve worsening breathing symptoms when they occur. They are often inhaled directly into the lungs, where they quickly open up the airways and relieve symptoms such as wheezing, coughing, and shortness of breath, often within minutes. But as effective as they are, rescue medications do not have a long-term effect.
- **Important Safety Information-** Overuse of any inhaler, particularly rescue inhalers can have deleterious side effects. Using a rescue inhaler too often or too much can cause dizziness, nervousness, tremors, trouble sleeping, and palpitations along with other side effects. The risk of severe heart problems and sometimes death may be increased with overuse.
- The most-prescribed rescue medications are quick-acting bronchodilators (usually given through an inhaler or a nebulizer), which loosen the tightened muscles around inflamed airways. The most common of these, beta2-agonists, are related to adrenaline and usually work within minutes to provide relief of symptoms.
- If a bronchodilator alone doesn't resolve a severe flare-up, other medications may be given by mouth or injection to help treat it.

Controller Medications

- Controller medications, also called preventive or maintenance medications, are slower in onset of action and work over a longer period of time to reduce airway inflammation and help prevent symptoms from occurring. They may be inhaled or swallowed as a pill or liquid
- Because airways can be inflamed even in between flare-ups, controller medications are often needed. Some of the slower-acting controller medicines can take days to start working, but when they do, they help prevent airway inflammation.

- There are a variety of controller medications, but inhaled corticosteroids are most common. They're usually given through an inhaler or nebulizer.
- Long-acting bronchodilators also can be used as controller medications. These relax the muscles of the airways for up to 12 hours, but cannot and should not be used for quick relief of symptoms because they don't start to work immediately.
- They must be taken regularly (even when you don't have symptoms) in order to be completely effective.

Respiratory Inhalers

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Allergy & Asthma Network (AAN) is a national nonprofit organization that provides award-winning patient education, advocacy and community outreach services.

DOSE = DOSE COUNTER
A = ASTHMA
C = COPD
***** = BUILT-IN SPACER

Short-acting bronchodilators

relax tight muscles in airways and offer quick relief of symptoms such as coughing, wheezing and shortness of breath for 3-6 hours

ProAir[®] HFA albuterol sulfate **A** **DOSE** 

Proventil[®] HFA albuterol sulfate **A** **DOSE** 

Ventolin[®] HFA albuterol sulfate **A** **DOSE** 

Xopenex[®] HFA levalbuterol tartrate **A** **DOSE** 

Arcapta[®] Neohaler[®] indacaterol inhalation powder **C** **DOSE** 

Foradil[®] Aerolizer[®] formoterol fumarate inhalation powder **C** **DOSE** 

Serevent[®] Diskus[®] salmeterol xinafoate inhalation powder **A, C** **DOSE** 

Long-acting bronchodilators

relax tight muscles in airways and offer lasting relief of symptoms such as coughing, wheezing and shortness of breath for at least 12 hours

Flovent[®] Diskus[®] 50 mcg, 100 mcg, 250 mcg fluticasone propionate inhalation powder **A** **DOSE** 

Flovent[®] HFA 44 mcg, 110 mcg, 220 mcg fluticasone propionate **A** **DOSE** 

Pulmicort[®] Flexhaler[®] 90 mcg, 180 mcg budesonide inhalation powder **A** **DOSE** 

QVAR[®] (HFA) 40 mcg, 80 mcg beclomethasone dipropionate **A** **DOSE** 

Inhaled corticosteroids

reduce and prevent swelling of airway tissue; they do not relieve sudden symptoms of coughing, wheezing or shortness of breath

Aerospan[®] 80 mcg fluticasone **A** **DOSE** ***** 

Asmanex[®] Twisthaler[®] 110 mcg, 220 mcg mometasone furoate inhalation powder **A** **DOSE** 

Alvesco[®] HFA 80 mcg, 160 mcg ciclesonide **A** **DOSE** 

Breo[®] Ellipta[®] 100/25 mcg fluticasone furoate and vilanterol inhalation powder **C** **DOSE** 

Advair[®] HFA 45/21, 115/21, 230/21 fluticasone propionate and salmeterol **A** **DOSE** 

Dulera[®] 100/5, 200/5 mometasone furoate and formoterol fumarate **A** **DOSE** 

Symbicort[®] (HFA) 80/4.5, 160/4.5 formoterol fumarate and budesonide **C, C** **DOSE** 

Combination medications

contain both long-acting bronchodilator and inhaled corticosteroid

Advair Diskus[®] 100/50, 250/50, 500/50 fluticasone propionate and salmeterol inhalation powder **C, C** **DOSE** 

Combivent[®] Respimat[®] ipratropium bromide and albuterol **C** **DOSE** 

Atrovent[®] HFA ipratropium bromide **C** **DOSE** 

Anoro[™] Ellipta[®] umedclidium and vilanterol inhalation powder **C** **DOSE** 

Spiriva[®] Handihaler[®] tiotropium bromide inhalation powder **C** **DOSE** 

Tudorza[™] Pressair[™] acclidium bromide inhalation powder **C** **DOSE** 

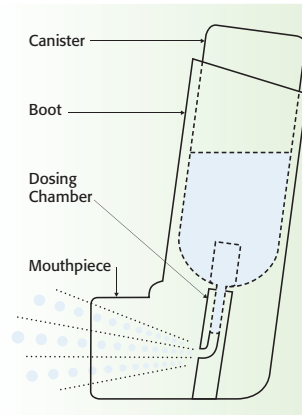
Anticholinergics

relieve cough, sputum production, wheezes and chest tightness associated with chronic lung diseases



Using Your New Inhaler With HFA Propellant

If you have a lung disease such as chronic obstructive pulmonary disease (COPD) or asthma, you are probably using an inhaler. There are several different types of inhalers, all of which deliver medicine into your lungs. However, if you have never been taught to use your inhaler correctly, then you may not be getting the full benefit of your inhaled medicine. At your next visit with your health care provider, bring your inhaler(s) and ask them to check that you are using them correctly.



Using Your Metered Dose Medication Inhaler (MDI)

A metered dose inhaler (MDI) is a small device used to deliver medicine that you breathe into your lungs. A dose of medicine comes out with each spray (puff). It can be hard to coordinate taking a breath into your lungs and activating the spray at the same time. In fact, using the best technique, you may only get 15% of what comes out of the inhaler into your lungs. Your healthcare provider may recommend that you use a device called a spacer/chamber, which stores the puff in the chamber until you breathe it in, giving you a better chance of getting the medicine into your lungs. Some spacer/chambers can increase the amount of medicine that comes out of the inhaler into your lungs to 20-25%, but not all spacers can increase delivered dose to this percentage. When choosing a spacer/chamber, ask for one that has a one-way valve, which keeps the medicine in the chamber until you breathe it in. You should get fewer side effects from the medicine if it goes into your lungs and does not get sprayed into the back of your throat or on your tongue.

What is an HFA inhaler?

There are several substances in the inhaler in addition to the medication. The substance that causes the medication to spray (the propellant) has been *chlorofluorocarbon* (CFC) until recently. Since CFC's have been found to damage the ozone layer, they are banned from production. The new propellant in your inhaler will be *hydrofluoroalkane* (HFA). HFA is not your medication but helps deliver your medication.

Which inhalers will have HFA?

Any inhaler discharging a liquid such as *albuterol*, *levalbuterol*, *salmeterol* and *beclomethasone* (in liquid form) now use HFA. Devices that have medication in powdered form such as *formoterol*, *salmeterol*, *tiotropium*, and most combination inhalers, do not require a propellant.

Will my inhaler work the same way with the HFA propellant?

MDI's using HFA will actually improve your chances of

getting a good dose of the medicine.

HFA propellant comes out of the inhaler in a softer manner and the medicine particles are smaller in size. The finer the spray, the smaller the particles in each puff and the better the chance of getting medication into your lungs. Although you may also not feel the same "kick" you received from your CFC inhaler and may wonder if you're getting enough medication, it's likely that you are. You should also note that if you can "see" the spray, the particles are too large to get into your lungs.

Using a Spacer/Chamber Device

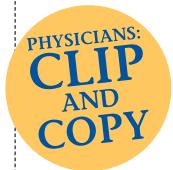
A spacer/chamber device should be used with all MDI's (inhalers that spray liquid, not inhalers with dry powder) to increase the amount of medication that gets into your lungs. If you are inhaling a steroid medication by MDI, it is even more important that you use a spacer/chamber. This will lessen the amount of drug that lands in your mouth. If you do not have a spacer/chamber, use the technique ("open" or "closed" mouth) that works best for you.

How to use your MDI with and without a spacer/chamber.



Using Your Metered Dose Inhaler WITH a Spacer/Chamber

1. Put the metal canister of your MDI into the "boot" or holder (see drawing). Shake well.
2. Remove the cap from the mouthpiece of both the MDI and the spacer/chamber.
3. Insert the MDI mouthpiece in the soft opening of the spacer/chamber with the canister in an upright position.
4. Breathe out to the end of a regular breath.
5. Place the mouthpiece of the spacer/chamber into your mouth. Close your lips around the mouthpiece. Make sure your tongue is below the mouthpiece. (If you use a spacer/chamber with a mask, position the mask over your nose and mouth. Be sure the mask has a good seal against your cheeks and chin).



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6.	Press down on the top of the metal canister one time to release the medicine into the spacer/chamber. Breathe in deeply and slowly through your mouth. If the spacer/ chamber whistles, you are breathing in too fast. You should not hear a whistle.
7.	Hold your breath for 5 to 10 seconds.
8.	Breathe out slowly.
9.	If you are instructed to take more than one spray (puff) each time you use your MDI, wait a minute or more before repeating steps 4-8.
10.	Replace the cap on the mouthpiece after you have finished.
11.	If you are inhaling a steroid, rinse your mouth out with water or a mouth-wash, and then swallow some water.
12.	You can use one spacer/chamber with all of your MDIs.



Using Your Metered Dose Inhaler WITHOUT a Spacer/Chamber

1.	Put the metal canister into the "boot". Shake well.
2.	Take the cap off of the mouthpiece.
3.	Breathe out to the end of a regular breath.
4.	Hold the inhaler in its upright position with the mouthpiece at the bottom. Place the mouthpiece between your teeth while keeping your lips open (see pictures).
5.	While breathing in deeply and slowly through your open mouth, fully press down on the top of the metal canister of your inhaler one time.
6.	Hold your breath for 5 to 10 seconds.
7.	Breathe out slowly.
8.	If you are instructed to take more than one spray (puff) each time you use your MDI, wait a minute or more before repeating steps 3-7.
9.	Replace the cap on the mouthpiece after you are finished.
10.	If you are inhaling a steroid, rinse your mouth out with water or a mouth-wash and then swallow some water.

Priming Your Metered Dose Inhaler (MDI)

The first time you use a new MDI you will need to prime your inhaler. If you have not used your inhaler for several days or weeks, you may need to prime your inhaler again. To prime your MDI, remove the cap, shake the inhaler, and then spray it once away from you. The instructions that came with your inhaler will tell you when your MDI needs to be primed and how many times the MDI needs to be shaken and sprayed when being primed. Each inhaler may recommend a different number of times to shake and spray away from you and how often you need to do this.

How to Tell When Your Metered Dose Inhaler (MDI) Is Running Out of Medicine

If you want to know how long your MDI should last, count how many puffs you take each day. Then look at the label on your MDI and see how many doses (puffs) are in the canister. Most canisters have 200 puffs (samples you get from your provider may be less than 200).

Divide the number of puffs you use in one day into the number of puffs in the canister. For example, if you use 8 puffs per day (2 puffs 4 times a day) and the inhaler has 200 puffs,

the inhaler will last 25 days. If you take a total of 4 puffs a day, your inhaler will last 50 days. Floating the metal canister in water or listening as you shake it are not the best ways to see how much medicine is left in your MDI. Be sure and check the expiration date on your MDI. The expiration date will be on the label of the metal canister or on the box it came in.

Cleaning Your Metered Dose Inhaler (MDI) and Spacer/Chamber

Because the spray from the HFA inhaler is so fine, the hole where the medication comes out of may clog. Check the hole where the medication comes out and wash the "boot" regularly with soapy water, then rinse, and let air dry before you put the canister back in the holder.

Spacer/chambers should also be cleaned once a week. Check the directions that come with your spacer/chamber for cleaning instructions. Do not put the spacer/chamber in the dishwasher as the heat will cause the valve to become brittle and remain in the open position. Replace your spacer/chamber whenever the rubber valve stiffens or becomes brittle.

Authors: Chris Garvey, FNP, MSN, MPA, Bonnie Fahy RN MN, Suzanne Lareau RN MS, Sidney Braman MD, Beth Laube PhD.

For more information contact the following websites:

American Thoracic Society

<http://www.thoracic.org/clinical/copd-guidelines/index.php>

American College of Chest Physicians

<http://www.chestnet.org/patients/guides/inhaledDevices.php>

UptoDate inc.

http://patients.uptodate.com/topic.asp?file=al_asthm/5100

Rx Taking Action

Bring your MDI and spacer/chamber with you each time you see your health care provider and show them how you use it.

If you can, use a spacer/chamber each time you use your MDI.

Breathe in through your mouth (and not your nose) when using your MDI.

The new HFA propellant may feel different to you. This does not mean you are not getting the medication in your lungs

Keep your MDI boot and spacer/chamber clean and dry. If using more than one kind of inhaled medicine, usually the quick acting medication (*albuterol, levalbuterol, Combivent*) are used first.

Get a new spacer/chamber whenever the valve stiffens or becomes brittle.

Prime your MDI when new and as instructed in the package insert.

Doctor's Office Telephone:

PATIENT PRIMER
By Colleen Mullarkey

Clearing the Way

Airway clearance therapy isn't just for CF

Our airways are a lot like a highway system with major roads and side streets that branch off. In certain diseases and conditions, thick mucus causes a traffic jam, which can lead to repeated infections, trouble breathing, and other health issues.

Along with inhaled bronchodilators and antibiotics, various airway clearance techniques can get the mucus moving smoothly again. These are standard treatments for cystic fibrosis (CF), but they can help with many other diseases and conditions too.

Bronchiectasis

In bronchiectasis, the airways become dilated, inflamed, and can collapse easily. This creates pockets of pus and mucus that can lead to recurring infections. It can occur on its own or with other airway diseases such as CF or chronic obstructive pulmonary disease (COPD). The techniques and devices are similar to those used in CF.

A respiratory therapist might advise coughing or breathing exercises, positive expiratory pressure (PEP) therapy, or high frequency chest wall oscillation (HFCWO). PEP systems include a mask or mouthpiece that's attached to a resistor. You breathe in normally and breathe out a little harder against the resistance.

HFCWO vests inflate and deflate rapidly, applying gentle pressure to the chest wall. An air pulse generator also sends vibrations to the vest. This loosens and thins mucus to move it toward the larger airways, where it can be cleared by coughing or suctioning.

COPD

Some COPD patients produce excess mucus in addition to having obstructed airflow. This dangerous combination can lead to repeated lung infections such as pneumonia and more frequent flare-ups. These patients typically use coughing exercises, PEP therapy, or oscillating PEP devices.

With oscillating PEP therapy, the patient blows through a device that vibrates the airways. This thins, dislodges, and moves the mucus. Some COPD patients also find HFCWO vests to be helpful.

Neuromuscular conditions

In addition, airway clearance can break up trapped mucus in many



neuromuscular conditions and injuries, including cerebral palsy, muscular dystrophy, amyotrophic lateral sclerosis, spinal muscular atrophy, and spinal cord injury.

With these conditions, respiratory muscles that aren't working well make it hard to take a deep breath and clear the airways. Weakened swallowing muscles can increase the risk of accidentally inhaling food, drinks, and stomach contents into the lungs.

PEP devices aren't recommended in these cases because they don't help externally to move the muscles. These patients often use an insufflation-exsufflation device, which is a small machine connected to a facemask or mouthpiece. It applies positive pressure then quickly shifts to negative pressure to mimic a natural cough. The inflation and deflation of some HFCWO vests also can help these patients.

Taking the next step

If excess mucus is making it hard for you to breathe, talk with your doctor about the possibility of using airway clearance. He might recommend you see a respiratory specialist who can teach you some manual breathing exercises and help you choose the best device or technique for you and your lifestyle. The therapist also can help you to figure out insurance coverage and pricing.

Keeping up with an effective airway clearance routine can improve your breathing, prevent or reduce infections, cut down on medical costs and hospitalizations, and enhance your quality of life. And freeing up your airways will free you up to do more things you enjoy. ■

Information provided by Michael Cantine, BS/AST, RRT, CPFT, AE-C, lead respiratory care practitioner at Morristown Memorial Hospital in Morristown, N.J., and adapted from the Cystic Fibrosis Foundation.

TOM WAHLEN

EDITOR'S NOTE: Your doctor or therapist has given you this patient education handout to further explain or remind you about an issue related to your health. It is a general guide only. If you have specific questions, discuss them with your doctor or therapist.



AMERICAN THORACIC SOCIETY

Patient Information Series

Oxygen Therapy

Patients with lung disease can have low levels of oxygen in their bodies and some need to use extra (*supplemental*) oxygen to bring their oxygen levels up to a healthier level. Adults and children with lung diseases such as chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, cystic fibrosis (CF), or bronchopulmonary dysplasia (BPD) may require this therapy. Extra oxygen protects their bodies from the effects of low oxygen levels, helps them to function better, and allows them to stay more active.



Why do some patients need oxygen therapy?

Oxygen is a basic need for all humans. The air we breathe contains about 21 percent oxygen. This amount is enough for people with healthy lungs and many with lung disease. However, some people with lung disease are unable to gather enough oxygen through normal breathing, so they require extra oxygen to maintain normal bodily function.

How do I know if I need oxygen?

A healthcare provider will figure out if you need oxygen therapy by testing the presence of gases in your blood. This test is called an arterial blood gas (ABG) and involves taking a blood sample from an artery (usually in the wrist). A healthcare provider can also measure your oxygen level (*oxygen saturation* or *O2 Sat*) with a small device called a *pulse oximeter* that can be clipped painlessly on to your finger, toe or earlobe. With this device, your oxygen levels can be checked over a period of time, for example, during sleep or exercise. The general treatment goal is to keep your oxygen at a level that meets the body's need for oxygen, usually 88% or above.

How much oxygen should I take?

Oxygen is a medical treatment that requires a prescription by a healthcare provider. Once the amount of oxygen needed is decided, the provider will prescribe an oxygen setting or flow rate. There may be a different setting or flow rate for different activities, for example during exercise, rest, and sleep. It is very important that you use the setting range exactly as it has been prescribed. Using too little may starve your brain and heart of oxygen, resulting in fatigue, memory loss or changes in the heart. Too much oxygen can also be a problem, especially for the lungs.

Will I need oxygen when I sleep?

During sleep, people slow down their breathing. Patients who have low oxygen levels while they are awake usually have low levels during sleep. In some cases, patients who may not require oxygen while awake may need extra

oxygen while sleeping. The healthcare provider will determine if and how much oxygen you should take at night.

Will I need oxygen when I am physically active?

During any physical activity people use more energy and therefore need more oxygen. To find out how much oxygen is needed during activity, the provider will have you do an *exercise stress test* or a *walk test* while measuring your oxygen saturation. Young children and infants can be observed during play activities and feeding.

How many hours a day will I need oxygen?

In some cases, patients only need to use oxygen when they are active or while sleeping. However, in most cases, oxygen should be used as close to 24 hours a day as possible.

Will I always need to use oxygen?

Most patients who require extra oxygen to treat their chronic illness will need to continue their oxygen therapy. Some patients may need to use extra oxygen during a disease flare-up or infection, but may be able to reduce or stop its use if their condition improves. You should never reduce or stop oxygen therapy on your own. Talk with your health care provider if you think a change in your oxygen therapy is needed.

What are the different kinds of oxygen systems?

Oxygen can be delivered from three types of sources: oxygen concentrator, liquid system or oxygen pressurized in a metal cylinder. The right choice for you depends on how much and when you need it, and your daily activities. You may also need to take into consideration where you live, costs, or insurance restrictions.

What are oxygen concentrators?

An oxygen concentrator produces oxygen by

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concentrating the oxygen that is already in the air and removing other gases. The concentrator is powered by electricity.

What is liquid oxygen?

Liquid oxygen is made by super-cooling oxygen gas, which changes it to a liquid form. When in liquid form, the oxygen takes up much less room and can be stored in special thermos.

What are oxygen cylinders?

Oxygen is compressed into a metal cylinder under high pressure. Oxygen may be stored in either large or small cylinders.

What is a nasal cannula?

A nasal cannula is a two-pronged tube attached to the oxygen device for delivering oxygen through the nose.

What are oxygen conserving devices?

Oxygen conserving devices make the delivery of oxygen more efficient, and reduce the amount of oxygen that is wasted. There are three types of oxygen conserving devices: the on-demand device, reservoir cannula and transtracheal oxygen.

What is an on-demand device?

On-demand oxygen delivery devices deliver a small amount of oxygen when the patient begins to inhale (breathe in). The delivery device is connected to the oxygen source by the nasal cannula. Young children do not usually use this device.

What are reservoir cannulas?

A reservoir cannula works by storing oxygen in a small chamber during exhalation (breathing out). When the patient is ready to inhale, they get the stored oxygen. This allows patients to use lower oxygen flow setting while still receiving the same amount of oxygen.

What is transtracheal oxygen?

Transtracheal oxygen is oxygen delivered through a thin tube inserted through the neck into the trachea (windpipe). Patients are able to talk with the tube in place. Transtracheal oxygen requires education for proper use.

What should I watch for while I am on oxygen?

Either too little or too much oxygen can be a problem. If you have symptoms of drowsiness, morning headaches, fatigue or breathlessness, you need to contact the doctor. If your child or infant on oxygen seems tired, less active, is breathing harder, or has blue lips or nail beds, call the child's doctor.

Do I have to worry about oxygen exploding or burning?

- Oxygen alone will not explode and does not burn, but oxygen will make a flame hotter and burn more vigorously.

- Never smoke while using oxygen. Your nose, hair, and clothing can catch fire.
- Keep oxygen at least 6 feet (2 meters) away from an open flame.
- Stabilize all cylinders by placing carts in a safe area or by securing them to a wall.
- Remember: oxygen is safe and therapeutic if used as instructed.

What do I need to do when I travel?

You can maintain a lifestyle that includes travel even if you are on oxygen. However, travelling with oxygen requires careful planning well in advance of your trip. Check with your transportation company (airline, train, bus, boat) about its policies for travelling with oxygen. Contact your oxygen company to coordinate your oxygen supply during each phase of your trip. Make sure that you have plenty of oxygen with you in case of delays or emergencies. Keep a copy of your oxygen and medicine prescriptions with you. Finally, you should keep emergency numbers handy (healthcare provider, oxygen supply company, and names of local doctors and hospitals) just in case.

Source: ATS/ERS Standards for the Diagnosis and Management of Patients with COPD, <http://www.thoracic.org/COPD/20/oxygen.asp>

Additional Lung Health Information

American Thoracic Society

www.thoracic.org

ATS Patient Advisory Roundtable

www.thoracic.org/aboutats/par/par.asp

National Heart Lung & Blood Institute

www.nhlbi.nih.gov/index.htm

American Lung Association

www.lungusa.org



Your healthcare provider has prescribed oxygen therapy for your lung condition

- ✓ Oxygen is a medical treatment
- ✓ Use your oxygen exactly as prescribed by your health care provider
- ✓ If you have any of these symptoms: breathlessness, morning headache, fatigue, drowsiness, contact your health care provider
- ✓ Oxygen used properly is safe. Do not smoke near oxygen, or keep oxygen near open flames, or other sources of heat or flames

Doctor's Office Telephone:

The ATS Patient Information Series is a public service of the American Thoracic Society and its journal, the AJRCCM. The information appearing in this series is for educational purposes only and should not be used as a substitute for the medical advice one one's personal health care provider. For further information about this series, contact J.Corn at jcorn@thoracic.org.

Housekeeping for Your Home Oxygen

You tackled that mountain of dishes and the last load of wash — finally you've finished the housekeeping, but are you keeping up with your home oxygen system?

Whether you're using liquid oxygen, compressed oxygen, or an oxygen concentrator, you need to maintain your equipment and accessories regularly to avoid contamination and ensure optimal health benefits. This guide includes tips to keep your system sparkling and sanitary.

No matter which system you're using, it's important to wash and disinfect your oxygen equipment in a clean environment. Avoid cleaning your system and accessories under an open window, in dusty, dirty, or smoking areas, or after vacuuming.

Keeping up with your concentrator

If you're using a humidifier bottle, empty and refill it with fresh water at least once a day. Wash it with soap and warm water, rinse, and refill with sterile or distilled water to the fill line. Don't use tap water because it can damage your equipment. Screw the humidifier bottle back onto the lid tightly to prevent leaks.

Once a week, remove your concentrator's filter and wash it in warm water and non-lotion detergent. Rinse well, gently squeeze water out, pat dry with a clean towel, and reattach.

Check your concentrator's alert buzzer weekly. Turn off the unit, unplug it, and push the power switch to "on." If the alarm buzzer doesn't sound to tell you there's no power supply, use a different oxygen source and call the oxygen company. Never use an extension cord or an outlet controlled by a switch with your concentrator.

Refilling your liquid oxygen

Because liquid oxygen evaporates within 24 hours, if you're not using your portable unit, it's best to fill it just before use to avoid waste. When you're ready to refill your portable liquid oxygen unit from the stationary reservoir, wipe the filling connectors on each device with a clean, lint-free cloth.

Turn off the portable unit's flow control knob, and attach the unit to the reservoir's filling connectors. Once you open the fill valve, you will hear a hissing noise while the unit is filling. Always stay with the unit while filling it, which should take about two minutes.

When the unit's full, slowly close the fill valve, and remove the unit from the reservoir. If the liquid oxygen continues to flow out of the stationary unit, don't attempt to reconnect the portable unit. Back away from the unit, and call your oxygen supply company.

Caring for your compressed oxygen cylinders

Always store cylinders in a well-ventilated space, and secure them in an upright position in a base or cart. Open and close the cylinder valve slowly, and aim it away from you and other people. Turn the supply valve off when you're not using the tank.

The oxygen is stored under extreme pressure, and if damaged, the cylinder can act like a missile and shoot off at a high rate of speed that could cause serious injury.

Call your oxygen supply company if you drop or damage your oxygen container — don't use it. If you hear a loud hissing noise, get away from the cylinder immediately.

Stay prepared

Check your system's contents indicator or pressure gauge often to make sure you have enough oxygen. Order a new supply of oxygen two to three days before you need it.

If there's a holiday or bad weather coming up, order extra in advance, and always keep a backup supply in case of an emergency. ■

Adapted from the American Lung Association, HealthTouch® Online, and Apria Healthcare.

Colleen Mullarkey is assistant editor of ADVANCE. She can be reached at cmullarkey@merion.com.

notes

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TOM WHALEN

■ PATIENT PRIMER

Preparedness for Oxygen Users

Assess needs, gather supplies, get support

ICE STORMS, EARTHQUAKES, FLOODS, PANDEMICS, bioterrorism — disasters of all types disrupt electrical power, gas, and water. If you regularly use supplemental oxygen, you need more than canned goods, a flashlight, and a first aid kit to survive.

This guide offers valuable tips to help you get ready.

Assess needs

Preparing for all disasters is best, but knowing the emergencies that have occurred in your area can help prioritize planning. For example, if you live in an area prone to wildfires, be aware that smoke and fire debris raise the risk of respiratory distress.

Also, consider the physical structure of where you live. Apartment dwellers should know if emergency generators power living quarters or only the main corridors. Find out how to exit the complex when elevators are not operating.

If you live in a house, make sure your backup generator provides adequate power, and safely store fuel to support equipment, lighting, and appliances for 72 hours. Identify escape routes and the safest places to stay during disasters.

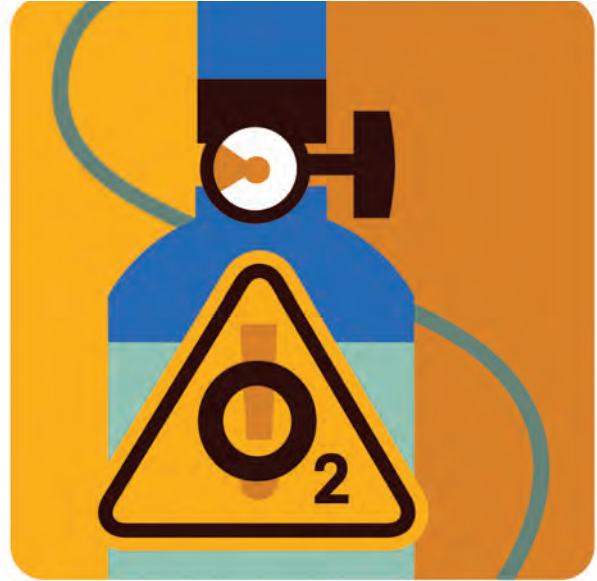
Keep emergency numbers and a charged cell phone handy. If cell towers are down, try land lines, email, or two-way radios.

Gather supplies

General checklists are available for basic disaster survival kits, but you'll need "must-have" items specific to your condition. Store a full backup oxygen cylinder that will last at least 48 hours in a location where it cannot topple and block access to any rooms.

Contact your oxygen supplier to find out how they will provide refills during a crisis. Ask where you stand on their prioritized list of deliveries. Home oxygen delivery trucks may be delayed or unable to travel, so this should not be your only plan.

Consult your physician to determine flow rate adjustments that can be made to stretch oxygen supplies. Record the reduced numbers on the equipment for easy reference. Another approach: a



battery-powered home pulse oximeter to titrate and conserve oxygen.

Always have a two-week medication supply on hand; store each medication appropriately and rotate it out before it expires. If you use stationary nebulizers for breathing treatments, ask your physician about using a metered-dose inhaler as a substitute. Purchasing a portable, battery-powered nebulizer is another option.

Assemble copies of important documents: vital care information, updated prescriptions, equipment make and serial numbers, a living will, medical power of attorney, and insurance cards.

Establish support

Identify a universal support team by contacting the utility company, police and fire departments, and local emergency management office. Let them know you are power-dependent. Often, first responders are neighbors and co-workers, so add them to your support team. Look for people who are strong, calm, dependable, and good communicators. Teach them how to operate and repair your equipment. Attach simple instructions to equipment to aid them.

Consider, too, evacuation plans. Identify at least two sites where you could relocate and store backup equipment. Check to see if your community has a medical shelter that can provide supervised care to pre-registered people with specific medical needs.

Wherever you go, make sure to take supplies, important papers, and extra clothing. If possible, notify your medical equipment provider in advance so that oxygen refills can be redirected there.

Once you have a preparedness plan in place, review and practice it regularly. ■

DAVE PERILLO

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PATIENT PRIMER

By Valerie Neff Newitt

Noninvasive Ventilation

An easier path to breathing help in the ICU and beyond

HEALTHY INDIVIDUALS rarely stop to think about breathing; it is a simple matter of in-and-out. But when patients are unable to pull adequate air and oxygen into their lungs, respiratory distress or failure may occur.

Thanks to evolving technology, help is available. Machines called ventilators can pump life-preserving air into a patient's lungs. And even better news for the patient is the fact that sometimes this can be accomplished without the use of internally placed airways.

What is noninvasive ventilation?

Noninvasive ventilation (NIV) is a term that refers to the use of external breathing support. NIV provides oxygen through a mask over the patient's face or nose. In comparison, invasive ventilation is delivered via tracheostomy or endotracheal tubes. While invasive ventilation can be a lifesaving technique, complications can occur, including injury to the trachea and larynx, speech and swallowing disabilities, ventilator-associated pneumonia, and more. Noninvasive methods may be just as — or even more — effective and present less risk when used in appropriately chosen patients.

NIV is considered a first line of therapy in many critical care hospitals. For example, it may be used during surgery when a patient is under general anesthesia that can disrupt normal breathing. It is also used to treat acute exacerbations of chronic obstructive pulmonary disease and asthma, congestive heart failure-related respiratory issues, pneumonia, postoperative respiratory distress or failure, neuromuscular respiratory failure, cystic fibrosis, and other conditions.

The use of NIV has reached beyond hospitals to the pre-hospital emergency medical system arena. Specific patients whose lungs are filled with fluid, including those with acute congestive heart failure and acutely ill dialysis patients, can find great benefit. This pre-hospital use of NIV often results in the patient avoiding invasive ventilation.

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Look under the "Education" tab at advanceweb.com/respiratory for more educational handouts.



Terms you may hear

If you or a family member need ventilatory assistance, you may hear words that are new to you. However, there is no need to feel intimidated once you understand what they mean:

- Hypoxemia is when there is too little oxygen in the blood.
- Hypercapnia is when there is too much carbon dioxide in the blood.
- Oxygen therapy is the process of providing oxygen-enriched gas to a person.
- Ventilators are machines that support breathing. They can help people breathe easier, or perform the breathing activity for people who cannot breathe on their own.
- Ventilation enhances oxygen delivery to the lungs and helps to remove carbon dioxide from the body. Carbon dioxide is a waste gas that can be toxic.
- Interfaces serve as the connection between patient and ventilator, delivering gas to the patient through a set of flexible tubes called a patient circuit, and through a mouthpiece, nasal mask, orofacial mask, full face mask, nasal pillows, or a helmet. Usually, the smallest mask that provides a proper fit and prevents gas leakage is the most effective. This varies from patient to patient.
- Monitors measure pressure, volume, and flow, and provide alarms if measurements are out of the proper range.

The good news

For patients, NIV presents real advantages. NIV results in lower cost when compared to invasive ventilation. Patients who use NIV usually spend less time using the ventilator and have shorter hospital stays due to fewer complications. Patients also report greater ease of interaction and communication, and they generally have an improved patient experience. ■

Information adapted from www.nhlbi.gov, www.draeger.com, www.info.kyba.com, and www.jama.com.

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PATIENT PRIMER

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Making CPAP Work for You

By Debra Yemenijian

You just have been diagnosed with obstructive sleep apnea, and your physician has prescribed continuous positive airway pressure therapy to treat your symptoms. But the idea of sleeping with a mask and tubing is frightening. What do you do?

If you don't comply with treatment, it can lead to complications of OSA, such as fatigue, confusion, hypertension, heart disease, decreased productivity and falling asleep at inappropriate times. By finding ways to make CPAP more comfortable and use it on a regular basis, your OSA will be manageable. You'll be able to get the sleep you need and improve your quality of life.

MASK FIT

A variety of mask designs and materials are available to enhance your CPAP experience. Some masks include an adjustable pad that rests on the forehead. Others may use a soft foam or gel-like material that molds to your facial contours for a more comfortable fit.

Proper mask fit is essential for CPAP compliance because it will minimize air leaks, which can be large enough to disrupt your night's rest. Use adjustable headgear to properly position your mask. Headgear should be snug enough for a good fit in all sleeping positions. Straps that are too loose allow air leaks, and straps that are too tight can break the mask's seal and cause discomfort.

You may be able to use quick-release straps that allow for easy removal of the mask. They also keep the straps in place so you don't have to adjust them each time you use the mask.

If you breathe through your mouth at night, an adjustable chin strap can keep your mouth closed. Another option is to try a full face mask or oral mask instead of a nasal mask.

Nasal pillows are a choice for patients who prefer not to use a mask. They can insert into their nostrils two small oval-shaped prongs that are attached to a plastic adapter connected to the CPAP tubing. The pillows may solve the problem of allergies to mask material and claustrophobia complaints.

DESENSITIZATION

It's natural to need time to adjust to CPAP therapy. Instead of using the device immediately, familiarize yourself with your mask and machine. Then, ramping your CPAP at a low pressure setting, hold the mask loosely against your face for brief periods of time while sitting up. Do this until you can breathe while holding the mask in place for a minute or more.

Once you're used to having the mask in place, strap the mask on, making sure that it's not so tight that it hurts or so loose that air leaks irritate your eyes. The ramp will increase the airway pressure to your prescribed setting. When you're ready, lie down as you would when you sleep.



If you have difficulty sleeping with the mask on your face, acclimate yourself to the mask outside of the

bedroom. With the exhalation port open, wear the mask around the house for an hour or two each day while doing something relaxing like watching television. Using CPAP for short naps also may be helpful.

HUMIDIFICATION

Humidification can help improve CPAP conditions and make adjusting to your therapy easier, but little information is available on just how well humidification will increase compliance. Cold or heated humidification works by relieving upper airway drying and inflammation when your nasal airway is unable to maintain sufficient warmth for the increased air flow of CPAP.

No matter which methods you choose to comply with CPAP, make sure you inform your physician of your progress so that he or she knows how well treatment is working for you. ■

Editor's note: Information adapted from the American Sleep Apnea Association, the American College of Chest Physicians, and SleepQuest.

Debra Yemenijian is assistant editor of ADVANCE.

ILLUSTRATION BY JANICE WALCK



NOTES

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Series of horizontal lines for taking notes.

Choosing the Right CPAP Interface

By Debra Yemenijian

Finding the right continuous positive airway pressure interface is like buying a new pair of shoes. You don't want your interface to be uncomfortable to wear, and it must have good style. Because everyone's preferences are different, a variety of interfaces are available for you to choose from.

CPAP MASKS

Most CPAP masks are triangular in shape and worn over the nose, or over the nose and mouth. Many masks have a plastic body and a softer silicone seal that touches the face. If you have a silicone allergy, try a mask made with synthetic rubber or vinyl.

Several masks are made with a gel-like material that molds to the patient's face in order to alleviate pressure points. A variation of the gel-type mask has a soft, flexible shell and gel cushion. A pliable wire molded into the shell allows the mask to be shaped to each patient's liking.

A mask also may include an adjustable forehead pad, or it may have an inflatable seal that activates when the CPAP device is turned on. Some triangular masks have two connection ports so that oxygen can be used with CPAP if necessary.

A mask that fits properly is essential to overcoming common CPAP compliance obstacles. Choosing a mask that's larger than you need may require you to pull your headgear too tight, causing discomfort. If your mask leaks, causes irritation on your skin, or leaves pressure marks on your nose, it may not fit correctly.

When checking for a proper fit, make sure that the top of the mask sits at the bridge of your nose. The bottom of the mask should rest at the bottom of your nose and top of your upper lip. The sides of the mask should fit close to the sides of your nose without actually touching it. Generally, the smallest mask that fits you is the way to go.

It's possible to have your mask custom-made, so ask your doctor or home care company representative about this option.

NASAL PILLOWS

For patients who prefer not to use a mask, nasal pillows are another option. Nasal pillows are two small flexible pieces that you insert into the nostrils. These pieces are attached to a plastic adapter that's connected to CPAP tubing.

Patients with beards or moustaches may prefer nasal pillows to a mask. Although some masks are made with facial hair in mind, it can compromise a mask's effectiveness. The pillows also may help avoid allergic reactions to mask materials and prevent the feeling of claustrophobia sometimes associated with wearing a mask.

Patients requiring higher CPAP pressures are more likely to experience discomfort with nasal pillows.

OTHER INTERFACES

A newer interface that looks like a large nasal cannula has two tubes that fit securely in the nostrils. The tubing loops from the nose around the ears and joins together near the chest where it attaches to the CPAP

device. The device doesn't require headgear because a strap goes behind the head to keep the tubing in place.

Another option combines an oral appliance and pressurized air. The oral appliance is connected to CPAP tubing so that pressurized air is delivered through the nose via nasal pillows or through the mouth via the appliance. The oral appliance also can be used alone as part of sleep apnea therapy.

No matter which interface you choose, you need to be happy with it in order to maximize your therapy. At the first signs of discontent, work with your physician to find an interface you can use comfortably and correctly. ■

Editor's note: Information adapted from the American Sleep Apnea Association and the Canadian Lung Association.

Debra Yemenijian is assistant editor of ADVANCE. She can be reached at debray@merion.com.



TOM WHALEN



Troubleshooting Tips for CPAP Use

notes

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You're under the sheets, pajamas on, alarm set, and continuous positive airway pressure mask firmly secured — wait a minute, is that a hissing noise? Why do your nose and eyes keep burning? You've finally started using CPAP and with these nuisances, getting adequate sleep is still a nightmare.

Don't lose hope. This guide will address common problems CPAP users experience. With these troubleshooting tips, you'll be back to dreamland in no time.

Mask leaks/skin irritation/blisters

The strap adjustment may be too loose or too tight. Readjust the headgear straps. You'll want your mask to be as loose as possible while still creating a seal. If you can't seem to get it quite right, consult a sleep professional for a mask fitting. He may suggest an alternative type of interface such as nasal pillows or a full face mask.

Your mask could be dirty or worn-out. Inspect it for stiffness, cracks, or breaks and replace it, if necessary. Also, wash your mask daily and face nightly.



TOM WHALEN

until it reaches the right level. Some CPAP machines offer an auto-adjusting feature. This helps patients whose pressure levels need to vary during the night according to their stage of sleep or position.

You also could ask about bilevel positive airway pressure or proportional positive airway pressure. These modes aim to lessen the effort it takes to breathe during exhalation.

If the discomfort feels more like a choking sensation, you may be breathing through your nose and mouth at the same time. When you place the mask on your face or nasal pillow in your nose, close your mouth and place your tongue firmly against the roof of your mouth as soon as the air starts flowing.

Noisy CPAP unit

Blocked air intake can cause a ruckus. Make sure the air filter is clean and not blocked by outside items. Add a length of hose to the CPAP unit, and place it farther away from the bed if it's too close.

Give it time

Getting accustomed to CPAP may take a little while for you and your bed partner. You might experience some discomfort in the first few weeks or months until you get used to it. Edu-

cate your bed partner about the benefits of CPAP. Always consult a professional before making any changes to your CPAP treatment, and make sure to communicate any problems you experience.

When used correctly, CPAP can improve your sleep, breathing, energy level, general health, and overall quality of life. You may hit a few roadblocks in the beginning — but don't quit. Work with a professional to make your treatment as comfortable as possible, and you'll be on the road to better sleep.

Dry nose or throat/nasal congestion

Try using nasal saline spray before bedtime and when you wake up. Ask a professional about using heated humidification, which can help alleviate dryness by adding warmth and humidity to the air before you breathe it.

Sore, dry, irritated, or swollen eyes

A mask leak could be the culprit. Try reseating the mask on your face. Inspect it for stiffness, cracks, or breaks. Replace if necessary. It's possible that your mask is too tight; readjust the headgear straps.

Chest discomfort/difficulty exhaling

Ask a professional if your pressure requirement needs adjustment. She might suggest using a pressure ramp, which starts the machine at a very low level of air pressure and then slowly raises it

Information adapted from the American Sleep Apnea Association and the West Valley Sleep Disorder Center. ■

Colleen Mullarkey is editorial assistant for ADVANCE. She can be reached at cmullarkey@merion.com.



PATIENT PRIMER
By Colleen Mullarkey

That's the Ticket

Traveling with portable oxygen by land, air, and sea



It's often hard to find time to breathe when you're getting ready for a trip, but it should be your No. 1 priority if you're dependent on oxygen. Fortunately, you can travel almost anywhere with a portable oxygen concentrator (POC), provided you plan ahead.

If you need some help, find a travel agent who specializes in trip planning for travelers with special needs. This guide covers some basic tips for oxygen travel, but you should contact your travel provider's special services or medical department to get their specific requirements ahead of time.

On the road

In your own car, you can easily power your POC using a DC adapter. If traveling by bus, give at least 48 hours notice, and if you're planning to catch the train, provide a minimum of 12 hours notice.

Oxygen equipment, including oxygen concentrators, cannot rely

solely on train-provided electrical power, according to Amtrak. Any device brought on a train must be able to operate a minimum of four hours without available onboard electrical power.

Up in the air

Provide the airline with a physician's statement specifying your oxygen needs. It should describe your medical necessity for oxygen during all or only portions of the flight, your flow rates, your ability to understand and respond to device alarms, and the POC's model name or number.

Be sure your POC meets the airline's requirements and is approved by the Federal Aviation Administration. (See box.) Call the airlines at least 48 hours prior to departure, ask if they offer seats near a power outlet, and pack extra batteries in your carry-on bag along with power adapters.

Allow extra time for security and the flight crew to screen your POC. On the plane, use your POC in accordance with the directions in your physician's statement. Turn off and properly stow your POC during unauthorized times.

CLEARED FOR TAKE-OFF

The FAA has approved the following POCs for in-flight use:

- AirSep FreeStyle
- AirSep LifeStyle
- Delphi RS-00400
- DeVilbiss iGo
- IBC Lifechoice
- Inogen One G2
- Invacare XPO2
- OxLife Independence
- Respirationics EverGo
- Sequal Eclipse

Out at sea

If you're heading for the high seas, make sure to get approval from your cruise line four to six weeks in advance. Bring a letter from your physician that states your needs, a brief medical history, and approval for travel. You'll provide your own oxygen equipment so find out if it must follow any specific rules.

You can plug your POC into an outlet in your cabin, relying on battery power for activities outside of your room. Ask the cruise line to identify electrical outlets in the ship's dining and entertainment areas so you can save on battery power.

If you keep these tips in mind, your next getaway will be smooth sailing. ■

Information adapted from the National Railroad Passenger Corp., Federal Aviation Administration, Greyhound Lines Inc., and Breathin' Easy.

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PATIENT PRIMER

By Valerie Neff Newitt

Flying With a Ventilator

Advance travel planning keeps skies friendly for vent users

DON'T SAY NO to your spirit of adventure just because you're using a ventilator. Improvements in technology and portability, teamed with the Air Carrier Access Act, are your passports to world travel. With a letter from your physician assuring that you're "fit for travel" and advance planning, a trip to a distant location can come off without a hitch.

In May 2009, the Air Carrier Access Act went into effect, requiring U.S. aircraft (and foreign aircraft operating in the U.S.) with 19 or more seats to allow passengers to bring aboard and operate ventilators, respirators, positive airway pressure machines, and portable oxygen concentrators (POCs). All must meet Federal Aviation Administration requirements and display a manufacturer's label to that effect.

Equipment clearance

While POCs are commonplace on aircraft, ventilators are not. Air carriers may need advance notice to clear your device to meet regulatory emissions safety standards before you can fly. Call the airline directly—and early—to notify them of your travel plans. Find out if your equipment is on their list of approved ventilators before you purchase your ticket. Be prepared to provide vital info: name of the ventilator; model number; complete specifications; manufacturer's name, address, telephone number, and website. Request written documentation of the airline's approval.

Making reservations

Inform your ticketing agent that you will be traveling with a vent. Ask if they have an agent trained in handling ticketing for individuals with a disability. Tell your agent you must be seated near the front, a bulkhead, or next to an empty seat if your vent will not fit under the seat. Inquire about a courtesy bump-up to first class to accommodate your vent. Some airlines do this free of charge. (Important: If your vent is bulky, you may be required to



purchase an extra seat.)

Keep in mind that airlines have differing capabilities. Many do not have electrical outlets for passenger use and require sufficient dry- or gel-cell battery power for 150 percent of the flight duration (to cover delays).

Prepare for repairs

Know your ventilator's setting and operation in case any fixes are required (for example, if a knob is turned during handling). Also, carry detailed, written information on the ventilator's operation. This may be requested by the airline, and it could become vital should your machine malfunction in a country where your equipment may not be well known.

Bring along a few spare parts, such as extra

tubing, if you are planning a long trip out of the U.S. Pack a travel kit with small tools, an extension cord, surge protector, and electrical adapter plug suitable for the power platform in the country you will be visiting.

At the airport

Arrive early! It may take extra time to be sure you are cleared and screened properly. Bring a letter from your doctor explaining why you need this device. (Tip: Have the letter translated into the language of the country you will be visiting.) Some airlines require this medical documentation for boarding. Keep handy your clearance letter from the airline.

At the screening area, inform the security officer if your equipment cannot be safely disconnected. Only you can disconnect yourself to allow for equipment to be X-rayed. An alternative to X-ray screening will be provided if you cannot be disconnected. Ventilators do not count as carry-on items. All airlines are required to have a complaints resolution officer immediately available to resolve any disagreements between passengers and airlines.

Want more information?

This primer is adapted from information provided by Mobility International USA (www.miusa.org), International Ventilator Users Network (www.ventusers.org) and the Transportation Security Administration (www.tsa.gov). Their websites offer a wealth of information and specific airline requirements and capabilities.

Remember: Regulations do change, so make sure you double-check with airlines on policy changes. However, be sure to know your rights and assert them. ■

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Look under the "Education" tab at advanceweb.com/respiratory for more educational handouts.

SCOTT DERRY

SECTION 13

Tracheostomy Care & Education

Suctioning Your Tracheostomy

Suctioning keeps your trach tube clear of excess mucus. Suction as instructed by your health care provider. Follow these guidelines and any others you're given.

1. Collect Your Supplies

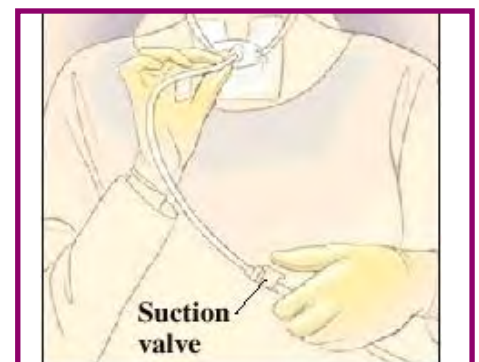
- Find a clean, well-lighted space near a sink or mirror.
- Collect your supplies: a suction machine, a clean suction catheter (a long, flexible tube that attaches to the suction machine), and a small bowl of distilled water.
- Wash your hands with soap and warm water.
- Put on clean, disposable, powderless gloves.

2. Prepare to Suction

- Turn on the suction machine to _____mmHg.
- Attach the suction catheter to the suction machine.
- Dip the catheter tip into the distilled water.
- Do the following only if your health care provider tells you to: Put a small amount of sterile saline solution into your trach tube. This will help loosen mucus.

3. Insert the Catheter

- Take a few deep breaths to fill your lungs with oxygen.
- Gently insert the catheter into your trach tube. While you insert the catheter, do not suction. Stop inserting the catheter when you start to cough.



4. Suction for 5 to 10 Seconds

- Apply suction. (To do this, cover and uncover the suction valve on the catheter.) At the same time, slowly pull the catheter out of your trach tube. Move the catheter tip in a circle as you pull the catheter out.
- The catheter should be out of your trach tube within 5 to 10 seconds. If you need to suction more, relax and breathe for a few minutes before you start again.
- When you have finished suctioning, turn off the suction machine. Discard the used catheter and gloves.

Helpful Hints

- While you suction, you may have a gagging feeling. Know this is normal. Try to relax.
- Use sterile, distilled water for suctioning if your health care provider tells you to.
- **DO NOT** suction for more than 5 to 10 seconds at a time. Suctioning longer pulls too much oxygen out of your lungs.
- If you use supplemental oxygen, use it before and after you suction.
- Warm, moist air helps loosen your mucus. Use a vaporizer or humidifier if your health care provider suggests it. Clean it daily.

When to Call Your Doctor

Call you doctor right away if you have any of these problems:

- Red, painful, or bleeding stoma
- Swelling around the trach tube
- Fever over 101° F
- Pain while suctioning
- Yellow, smelly, bloody, or thick mucus
- Shortness of breath
- Vomiting that doesn't go away

Call 9-1-1 (emergency) right away if you ever have trouble breathing.

Special Instructions:

Cleaning Your Tracheostomy

Clean your trach tube and the skin around it at least once a day. Cleaning helps prevent infection. Follow these steps and any other guidelines you are given.

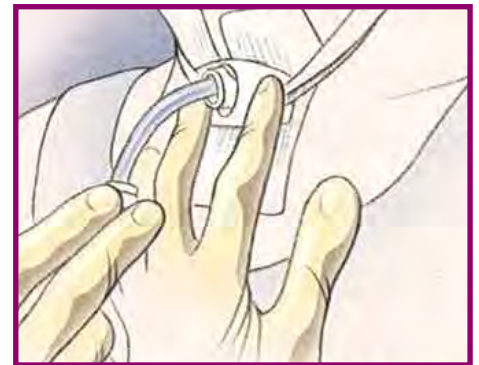
1. Collect Your Supplies

- Choose a clean, well-lighted space near a sink and mirror. Collect your supplies: lint free bandages, cotton swabs, a trach tube brush, and a bowl filled with distilled water and hydrogen peroxide in equal parts.
- Wash your hands with soap and warm water. Put on clean, disposable, powderless gloves.



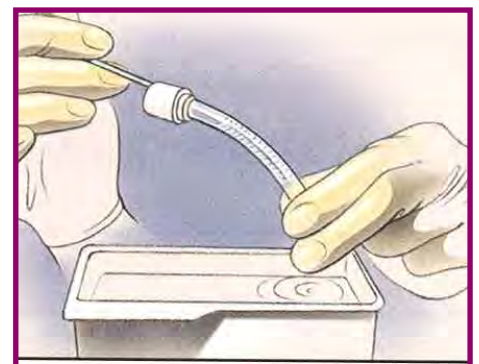
2. Remove the Inner Cannula

- Hold the neck plate with one hand. With the other hand, unlock the inner cannula (tube). Gently remove the inner cannula.
- DO NOT remove the outer cannula.



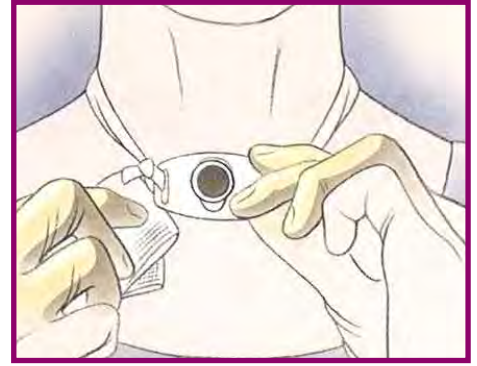
3. Clean the Inner Cannula

- Soak the inner cannula in the bowl of distilled water and hydrogen peroxide.
- Clean the inner cannula with a trach tube brush. DO NOT use a toothbrush. Rinse the inner cannula with distilled water.
- Put the wet inner cannula back into the outer cannula. Lock the inner cannula in place.



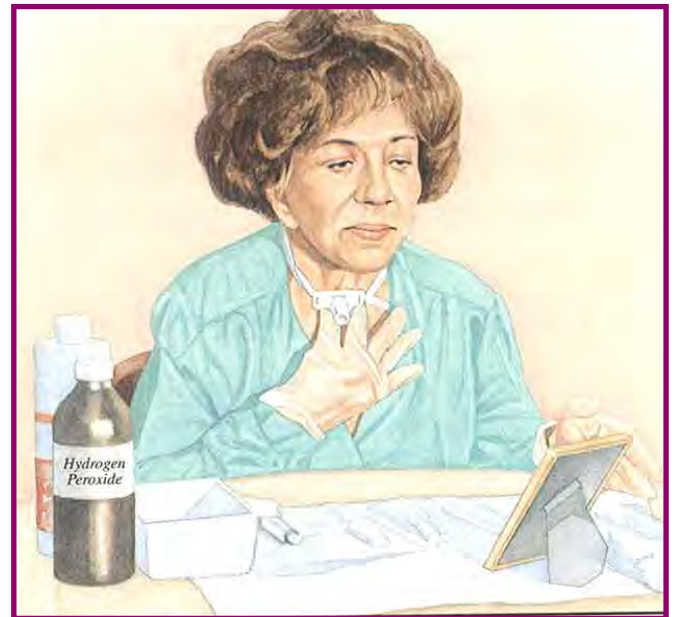
4. Clean Your Neck Plate and Skin

- Remove the soiled gauze from behind the neck plate. Clean the neck plate and the skin under it. Use a clean gauze pad or a cotton swab dabbed in distilled water. Gently pat the skin dry.
- Put a clean, precut gauze pad under the neck plate. This pad protects your skin.



Tips for Cleaning

- Spend 10 to 20 minutes cleaning your tracheostomy. Don't stop until you are done. This helps keep your hands clean.
- Each time you clean your tracheostomy, suction it first.
- Dispose of your gloves after using them.
- Buy cleaning supplies, such as a trach tube brush, at a medical supply store or pharmacy.
- Use sterile, distilled water if your health care provider suggests it.
- **DO NOT** use any cleaning agent other than hydrogen peroxide and water to clean your tube. **NEVER** boil the tube.



Ask others not to disturb you while you are cleaning your tracheostomy.

When to Call Your Doctor

Call your doctor right away if you have any of these problems:

- Red, painful, or bleeding stoma
- Swelling around the trach tube
- Fever over 101° F
- Pain while suctioning
- Yellow, smelly, bloody, or thick mucus
- Shortness of breath
- Vomiting that doesn't go away

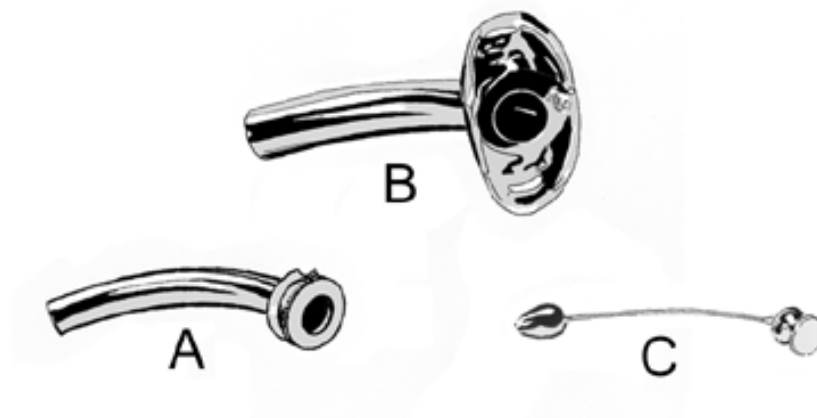
Call 9-1-1 (emergency) right away if you ever have trouble breathing.

Special Instructions:

Cleaning of Jackson Metal Trach

The Tracheostomy Tube

Most Jackson tracheostomy tubes have 3 parts (see below). The parts may not be used with another tube. The obturator is used to insert the outer cannula into the trachea. The obturator is removed after inserting the tube and should be kept handy for use should the tube come out. The outer cannula maintains the neck opening. The inner cannula is inserted into the outer cannula and locked into place and should only be removed for cleaning.



Parts of the Tracheostomy Tube: A. Outer Cannula. B. Inner Cannula. C. Obturator

Hand Washing/Cleaning Supplies

Because your hands may spread germs, you must wash your hands before and after all cares. Clean supplies must be used.

Cleaning the Inner Cannula

To ensure that the inner cannula does not become plugged, it must be cleaned.

1. To unlock and remove the inner cannula, turn it until the notch area is reached and slide it out.
2. Use a small brush or pipe cleaners to clean the inner cannula. Sterile water can be used to rinse the inner cannula.
3. Look through the inner cannula to make sure it is clean and free from any obstruction. Shake the inner cannula to remove excess moisture.
4. Reinsert the inner cannula and lock in place.

Emergency Situations and Use of Resuscitation Bag

In a medical emergency, caregivers can help a patient breathe using a squeezable bag with a face mask called the resuscitator bag. The bag can also be used when connected directly to the tracheostomy tube.

The resuscitator bag has a squeezable bag and a one-way valve. Compressing the bag opens a valve, forcing air through a mask or artificial airway into the lungs. Releasing the bag closes the valve and exhalation occurs passively through the exhalation port. During exhalation, the bag automatically refills with room air or oxygen. The cycle continues until spontaneous breathing occurs or breathing is mechanically supported by a breathing machine.

How to Use the Bag via a Tracheostomy Tube

- If oxygen is needed, attach the long tubing to the oxygen tank and turn the supply up to 10 to 15 liters/minute.
- Disconnect the ventilator tubing and attach the bag to the trach.
- Squeeze the bag as the person breathes in and allow it to reopen to let the person breathe out.
- Give breaths at about the same rate as the ventilator, if using the bag for ventilation in emergency, give 10-12 breaths per minute.

Replacing Trach Ties and Skin Assessment

Changing the Tracheostomy Tie

1. Different ties can be used, such as twill tape, bias tape, or Velcro tube holders.
2. Change the tie when wet, dirty, or frayed. Plan to do this when you have someone to help you.
3. The clean tie should be in place before soiled tie is removed.
4. If using a Velcro tube holder:



Tracheostomy Velcro Tube Holder

- a. Thread narrow Velcro tabs through opening in the neck plate.
- b. Adhere tabs to soft material on the band.
- c. Adjust and secure to fit your neck.
- d. Cut off excess band

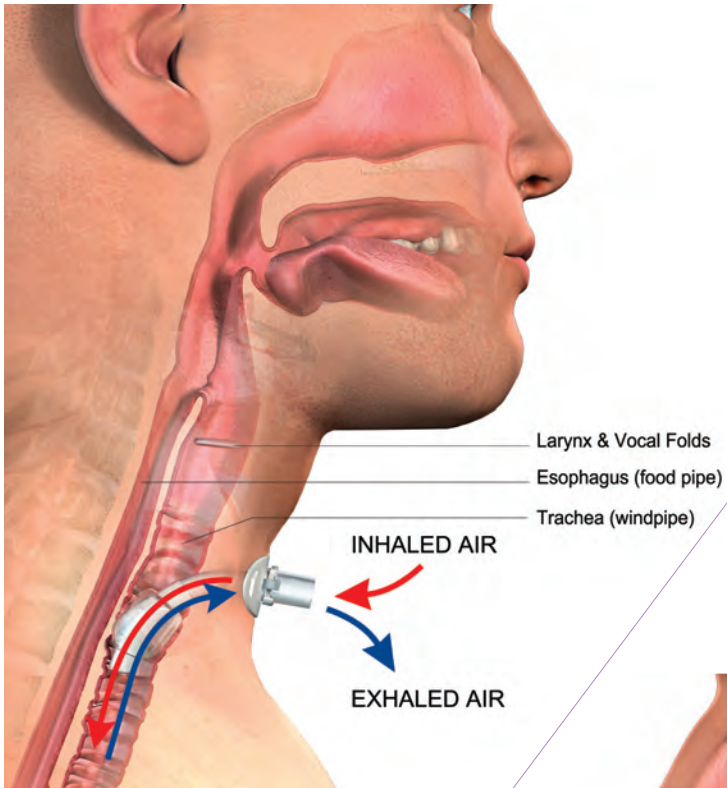
Regardless of if the tracheostomy is secured with velcro or twill tape, you want to make sure that the tracheostomy tube is secure and tight to the neck. A good guideline is that you should only be able to fit two fingers between the skin and the trach tie. If a trach tie is too loose, it will allow the tracheostomy tube to flop in and out of the tracheotomy site and potentially fall out.

Skin Care

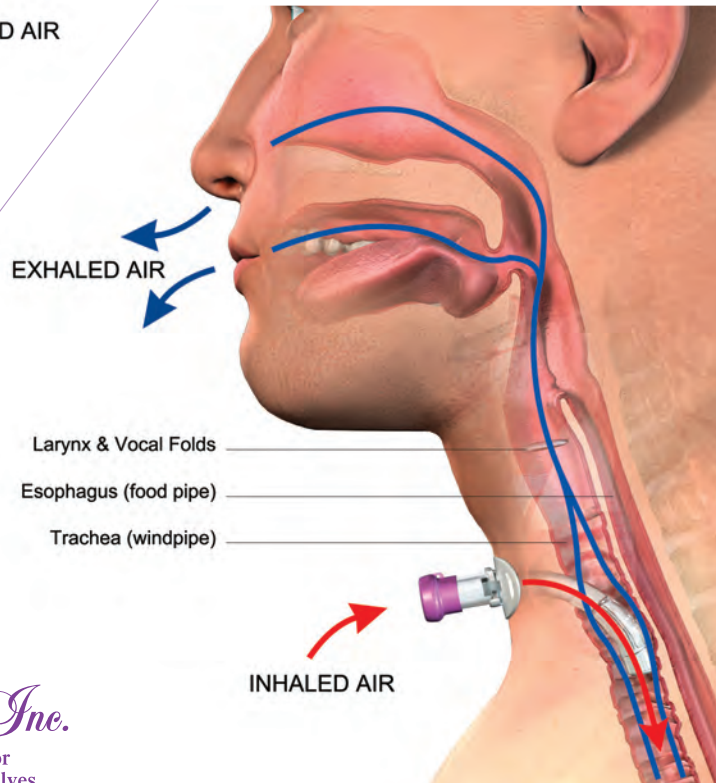
Skin around the tube should be kept clean and dry.

1. Q-tips or a damp washcloth may be used to gently clean around the neck opening.
2. Gauze may be placed under the ties next to the skin. Hold the tube while changing the gauze.
3. Change the gauze if it becomes wet, dirty, or frayed.
4. Look for redness or skin breakdown.

Airflow with open tracheostomy tube



Airflow with Passy-Muir® Valve



Passy-Muir Inc.
Tracheostomy & Ventilator
Swallowing and Speaking Valves

Clinical Information & Instructions for the Passy-Muir® Valve

How does the Passy-Muir® Valve work?

The Passy-Muir Valve is a closed position one-way valve. It opens when you breathe in through the tracheostomy tube. When you are finished breathing in, the valve closes, and all of the air is breathed out through your vocal cords, mouth and nose.

How do I put the Passy-Muir® Valve on?

- If your tracheostomy tube has a cuff, make sure that the cuff is **completely deflated**.
- While you are holding the neck-plate of your tracheostomy tube with one hand, place the Passy-Muir Valve on the tracheostomy tube with a gentle twist in a clockwise direction.
- Use the same motion to remove the valve.
- If you are using a ventilator, your therapist will instruct you on the proper placement of the valve in the ventilator circuit.



What are the benefits of using the Passy-Muir® Valve?

- Improved voice and ability to communicate
- Improved swallowing
- Improved sense of smell and taste
- Increased cough strength to clear mucous
- Helps to keep lungs inflated
- Helps to wean from ventilator and/or tracheostomy tube

Passy-Muir Inc.

Visit www.passy-muir.com for more information
If questions, call 800-634-5397

To order more patient instruction sheets visit:
store.passy-muir.com or call 800-634-5397

What if I am having trouble breathing when using the Passy-Muir® Valve?

Remove the valve immediately and try the following:

- Check that the cuff is **completely deflated**
- Make sure you are in a comfortable upright position
- Check the position of the tracheostomy tube
- Suction your airway and mouth so that they are clear of secretions
- Try to relax if you are feeling anxious

If you have tried these suggestions and still have difficulty, contact your physician or therapist so that they can help you.

How do I clean the Passy-Muir® Valve?

Clean the Passy-Muir® Valve daily.

1. Swish the Passy-Muir Valve and accessories in pure fragrance-free soap and warm water, or soak for 10 minutes in 6-8 oz. of warm water with one Passy-Muir cleaning tablet (to order visit store.passy-muir.com or call 1-800-634-5397).
2. Rinse thoroughly in warm water.
3. Allow valve to air dry thoroughly before storing in closed container.

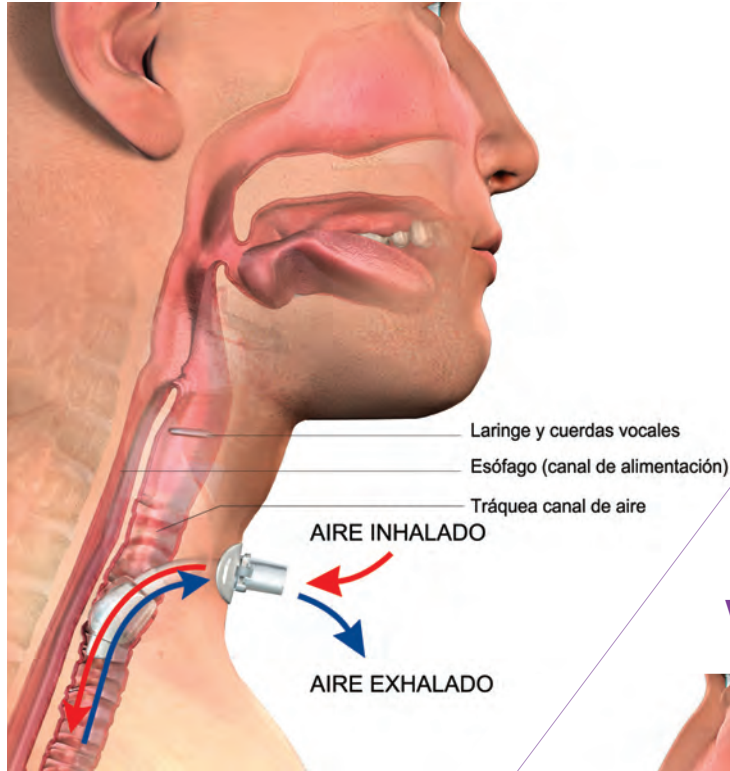
DO NOT use hot water, peroxide, bleach, vinegar, alcohol, brushes, or cotton swabs. Do not autoclave or apply heat to the valve.



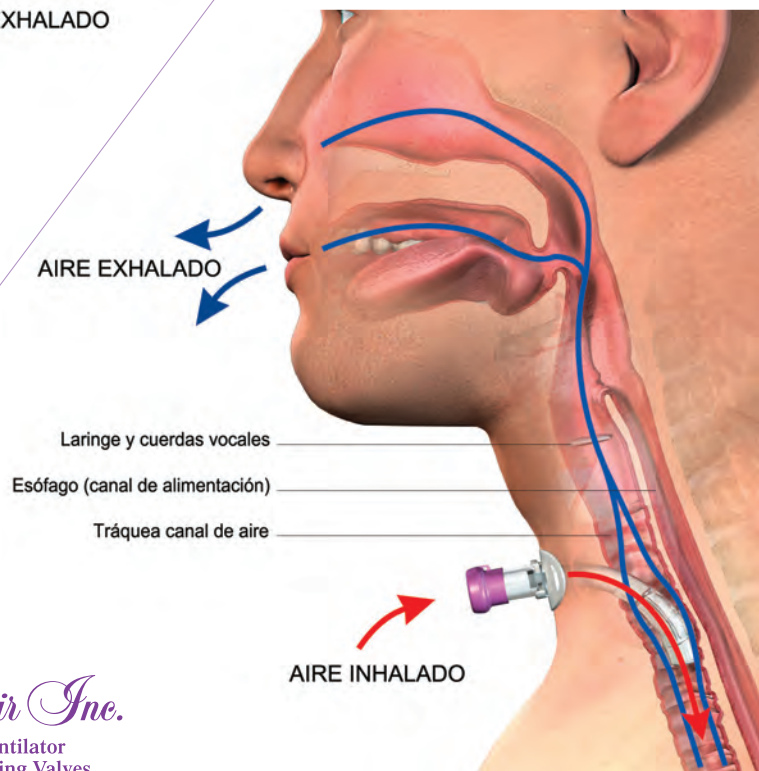
Special Instructions:

Doctor/Therapist Contact Information:

Flujo de aire con la cánula de la traqueotomía abierta



Flujo de aire con la Válvula Passy-Muir®



Passy-Muir Inc.
Tracheostomy & Ventilator
Swallowing and Speaking Valves

Información clínica e Instrucciones para el uso de la Válvula Passy-Muir®

¿Cómo funciona la Válvula Passy-Muir®?

La Válvula Passy-Muir es una válvula unidireccional, con un sistema de cierre automático. La válvula se abre cuando usted respira a través de la cánula de traqueostomía. Cuando termina la respiración, la válvula se cierra y todo el aire a ser exhalado pasa a través de las cuerdas vocales, por la boca y la nariz.

¿Cómo se coloca la Válvula Passy-Muir®?

- Si su cánula de traqueostomía tiene un balón, compruebe que el balón mismo esté **completamente desinflado**.
- Mientras usted asegura la porción externa de la cánula de la traqueostomía (neck-plate) con una de las manos, acople (coloque) la Válvula Passy-Muir® en la cánula de traqueostomía con un leve movimiento rotatorio en sentido horario.
- Realice el mismo movimiento para retirar la válvula.
- Si usted está usando un respirador (ventilador), su terapeuta le indicará la forma correcta de acoplar (colocar) la válvula al circuito del ventilador.



¿Cuáles son los beneficios que usted obtiene al usar la Válvula Passy-Muir®?

- Mejora la voz y la capacidad de comunicarse
- Mejora la deglución.
- Mejora el sentido del olfato y del gusto
- Promueve una tos más eficaz, que limpia los pulmones del moco
- Ayuda a mantener los pulmones inflados
- Ayuda en el proceso del destete del ventilador y/o la cánula de traqueostomía

Passy-Muir Inc.

Para obtener más información
visite la página www.passy-muir.com

Si tiene preguntas, llame al 1-800-634-5397

Para solicitar más folletos de instrucciones
para los paciente, visite:

www.store.passy-muir.com o llame a 1-800-634-5397

¿Qué pasa si estoy teniendo problemas para respirar cuando uso la Válvula Passy-Muir®?

Remueva la válvula inmediatamente y haga lo siguiente:

- Verifique que el balón este **completamente desinflado**
- Asegúrese de que usted se encuentre en una posición cómoda y vertical
- Verifique que la cánula de traqueostomía este en la posición correcta
- Aspire las vías respiratorias y la boca para que queden libres de secreciones
- Si usted se siente ansioso, trate de relajarse

Si usted ha seguido estas sugerencias y todavía tiene dificultad, entre en contacto con su médico o terapeuta para que le puedan ayudar.

¿Cómo puedo limpiar la Válvula Passy-Muir®?

Limpie la Válvula Passy-Muir® diariamente.

1. Lavese la Válvula Passy-Muir y sus accesorios en una solución jabonosa de agua pura, inodora y tibia (no utilice agua caliente), o enjuáguela por 10 minutos en 200 ml de agua tibia con una pastilla de limpieza de Passy-Muir (para ordenar las pastillas de limpieza visite a www.store.passy-muir.com o llame al 1-800-634-5397).
2. Enjuague bien con agua tibia (no utilice agua caliente).
3. Deje que la válvula se seque por completo antes de colocarla en el contenedor de almacenamiento. No aplique calor para secar la válvula PMV®.

NO utilice agua caliente, peróxido, blanqueador, vinagre, alcohol, cepillos o hisopos de algodón. Para limpiar la válvula PMV®; tampoco la esterilice en autoclave.



Instrucciones especiales:

Información y contacto para su médico y terapeuta:

Impact of Tracheostomy/Ventilator Dependency

Swallowing

What is dysphagia? Dysphagia is a Greek word meaning disordered eating. Dysphagia is difficulty eating as a result of disruption in the swallow process.

What is a “normal” swallow? When we put food/liquid in our mouth, we first mix the food with saliva to form a bolus. The tongue then works the bolus to the back of the mouth, at which point a rapid series of events occurs. First, the soft palate rises to protect the nasal cavity from food/liquid, the laryngeal muscles then move upward and forward and the vocal cords move together, and the epiglottis folds backward to protect the airway. The tongue pushes backward and downward into the throat to push the food down, which is assisted by the throat walls which move inward in a wave-like motion from top to bottom. The bolus is then passed into the esophagus to be transferred for digestion.

Implications of Tracheostomy/Ventilator Dependency on Swallow

Function

- Weight of trach affects ability of throat muscles to elevate and protect airway.
- A “hole” in the system, i.e. open trach, may not allow adequate pressure to build which is required to push food down the right way.
- Decreased sensation, due to lack of air movement through nose and mouth, can result in decreased coordination between breathing and swallowing and can also impact senses such as smell and taste.

What might patients complain of if they think they have a swallow problem?

“It feels like food is sticking to the back of my throat or upper chest after I eat or drink”

“The food just won’t go down”

“I have to clear my throat or cough a lot after I eat or drink”

“I feel like I have to swallow a lot after each bite and sip”

Signs and symptoms of dysphagia during or after meals may include:

- Coughing or choking with swallowing
- Difficulty initiating swallowing
- Food sticking in the throat
- Unexplained weight loss
- Change in dietary habits
- Recurrent pneumonia
- Change in voice or speech (i.e., “wet/gurgly” vocal quality)
- Nasal regurgitation
- Spiking fevers
- Decrease in O₂ sats during meals
- Pocketing food in mouth
- Regurgitation of food/evidence of food/liquid coming out of trach site

Communication

How do we produce speech? In the most basic form, the process of speaking begins with the air from our chest escaping from our lungs and moving through our throat to vibrate our vocal cords and out of our mouth into the open air. The articulators, or parts of our mouth involved in speech production, manipulate the air to produce various speech sounds.

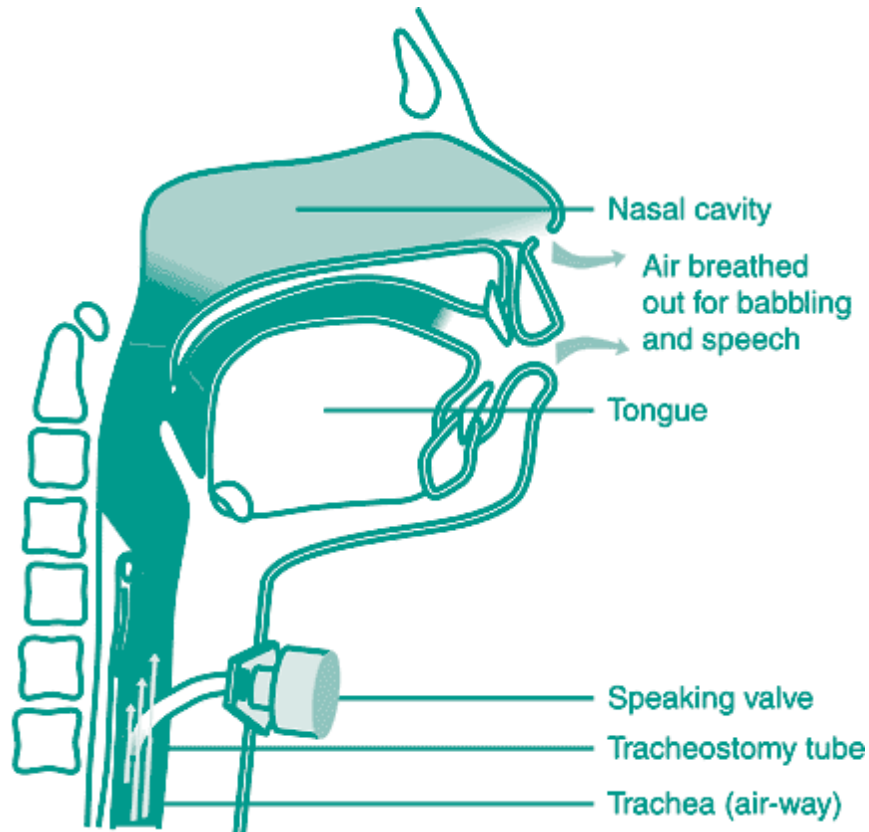
Implications of Tracheostomy/Ventilator Dependency on Communication

- Airflow to vocal cords can be impeded
- No airflow = no voice

Communication in the Trach/Vent Patient:

- Mouthing words
- Writing
- Gesture
- Electrolarynx
- Voice amplification
- AAC (Augmentative and Alternative Communication) devices including low-tech (i.e. communication boards) to high-tech (i.e. computer systems)
- Alternate trach tubes such as speaking trachs and fenestrated trachs

- Speaking valves, i.e. PMV (Passy Muir Valve)
 - A speaking valve is a valve that is placed on the end of a tracheostomy tube or in-line with a ventilator.
 - Allows air intake through the tube on inhalation. As the exhalation process begins, the valve closes and air is forced up through the vocal tract thus vibrating the vocal cords to produce speech.
 - Speaking valves may also be indicated to improve swallow function.



Types of Swallow Studies

1. *Bedside Swallow Assessment*

The Speech-Language Pathologist (SLP) looks at one's mouth movements, levels of alertness and participation and ability to follow directions. Food is presented in various consistencies and amounts. Variations of the bedside assessment may include the food/liquid colored blue in order to determine presence of aspiration if removed from airway. The SLP then looks for clinical signs that a patient may be aspirating. Recommendations are made for most appropriate food consistencies, compensatory strategies/swallowing maneuvers and/or need for further tests.

2. *Modified Barium Swallow Study (MBS)*

An instrumental assessment completed under x-ray. The patient is presented with various consistencies of food/liquid mixed with barium (agent visible under x-ray). This allows the SLP to observe penetration or aspiration, even when it is silent. SLP can assess ability to use strategies to decrease risk of aspiration, if needed, and determine possible etiologies.



3. *Fiberoptic Endoscopic Evaluation of the Swallow (FEES)*

An assessment tool used to evaluate the pharyngeal stage of swallow via a flexible laryngoscope at the patient's bedside. The laryngoscope is presented transnasally and is designed to assess anatomy and physiology of structures in view, evaluate swallowing of food and liquid for prolonged lengths of time without the fluoroscopy, and assess one's response to therapeutic intervention i.e., chin tuck posture, double swallow during repeated trials.

Safer swallowing can be achieved by following some basic swallow guidelines, including:

- Small bites and sips
- Eating slowly
- Maintaining upright posture (as close to 90 degrees as tolerated) and remain sitting upright for 45-60 minutes after meals

In addition to above, the pt may be presented with throat and mouth strengthening exercises, changes in diet texture, and/or positional changes/ swallowing maneuvers, at the discretion of the therapist.

SECTION 14

Tough Decisions

Thinking About Having A Chronic or Progressive Pulmonary Condition

When first told that you have a chronic pulmonary disorder, many questions may come to mind. Initially these may focus on gathering information:

- What can I do to keep symptoms under control?
- How can I try to minimize setbacks or worsening?
- How do I know when to seek medical attention?
- How will this disease affect my lifespan and quality of life?

Questions such as these are important to ask of your healthcare providers to allow you to best manage your illness and minimize anxiety. Such diagnoses may also lead you to have new thoughts about your future and your family's future:

- How will this disease affect my ability to do things that I love?
- How should I readjust my life's priorities?
- Have my thoughts about medical interventions that I want to undergo changed?
- Have I discussed my wishes about end of life with my loved ones?

The answers to these questions have no simple answer that fits for everyone, and the answers may change over time. These questions are important to think about and discuss with loved ones and healthcare providers. Though it can be uncomfortable initially to think about and discuss illness and death, it can make sure your wishes are honored and reduce some uncertainty for you, your healthcare team, and your family when medical decisions need to be made.

Attached is a guide to help you think through your answers to some of these questions. Discussions with your loved ones and psychology staff members here can also be helpful.

Your Conversation Starter Kit

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We know that no guide and no single conversation can cover all the decisions that you and your family may face. What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.

the conversation project



Created by The Conversation Project and the Institute for Healthcare Improvement

This Starter Kit doesn't answer every question, but it will help you get your thoughts together, and then have the conversation with your loved ones.

You can use it whether you are getting ready to tell someone else what you want, or you want to help someone else get ready to share their wishes.

Take your time. This kit is not meant to be completed in one sitting. It's meant to be completed as you need it, throughout many conversations.

Step 1: Get Ready	1
Step 2: Get Set	3
Step 3: Go	6
Step 4: Keep Going	9

Step 1: Get Ready

There are a million reasons to avoid having the conversation. But it's critically important. And you can do it.

Consider the facts.

60% of people say that making sure their family is not burdened by tough decisions is "extremely important"

56% have not communicated their end-of-life wishes

Source: Survey of Californians by the California HealthCare Foundation (2012)

70% of people say they prefer to die at home

70% die in a hospital, nursing home, or long-term-care facility

Source: Centers for Disease Control (2005)

80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care

7% report having had an end-of-life conversation with their doctor

Source: Survey of Californians by the California HealthCare Foundation (2012)

82% of people say it's important to put their wishes in writing

23% have actually done it

Source: Survey of Californians by the California HealthCare Foundation (2012)

One conversation can make all the difference.

Step 2: Get Set

Now, think about what you want for end-of-life care.

What matters to me is _____.

Start by thinking about what's most important to you. What do you value most?

What can you not imagine living without?

Now finish this sentence:

What matters to me at the end of life is _____.

Sharing your "What matters to me" statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what's worth pursuing treatment for, and what isn't.

Where I Stand scales

Use the scales below to figure out how you want your end-of-life care to be.

Circle the number that best represents your feelings on the given scenario.

As a patient...

1	2	3	4	5
I only want to know the basics				I want to know as much as I can
<hr/>				
1	2	3	4	5
Ignorance is bliss				I want to know how long I have to live
<hr/>				
1	2	3	4	5
I want my doctors to do what they think is best				I want to have a say in every decision

Look at your answers.

What kind of role do you want to play in the decision-making process?

How long do you want to receive medical care?

1 I want to live as long as possible, no matter what	2	3	4	5 Quality of life is more important to me than quantity
<hr/>				
1 I'm worried that I won't get enough care	2	3	4	5 I'm worried that I'll get overly aggressive care
<hr/>				
1 I wouldn't mind being cared for in a nursing facility	2	3	4	5 Living independently is a huge priority for me

Look at your answers.

What do you notice about the kind of care you want to receive?

How involved do you want your loved ones to be?

1	2	3	4	5
I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable at first				I want my loved ones to do what brings them peace, even if it goes against what I've said

1	2	3	4	5
When the time comes, I want to be alone				I want to be surrounded by my loved ones

1	2	3	4	5
I don't want my loved ones to know everything about my health				I am comfortable with those close to me knowing everything about my health

What role do you want your loved ones to play? Do you think that your loved ones know what you want or do you think they have no idea?

What do you feel are the three most important things that you want your friends, family and/or doctors to understand about your wishes for end-of-life care?

1. _____
2. _____
3. _____

Step 3: Go

When you're ready to have the conversation, think about the basics.

Mark all that apply:

Who do you want to talk to? Who do you trust to speak for you?

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> Mom | <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Dad | <input type="checkbox"/> Minister/Priest/Rabbi | <input type="checkbox"/> Caregiver |
| <input type="checkbox"/> Child/Children | <input type="checkbox"/> Friend | <input type="checkbox"/> Other: _____ |
-

When would be a good time to talk?

- | | | |
|--|--|---------------------------------------|
| <input type="checkbox"/> The next big holiday | <input type="checkbox"/> Before my next big trip | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> At Sunday dinner | <input type="checkbox"/> Before I get sick again | |
| <input type="checkbox"/> Before my kid goes to college | <input type="checkbox"/> Before the baby arrives | |
-

Where would you feel comfortable talking?

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> At the kitchen table | <input type="checkbox"/> On a walk or hike | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> At a cozy café or restaurant | <input type="checkbox"/> Sitting in a garden or park | |
| <input type="checkbox"/> On a long drive | <input type="checkbox"/> At my place of worship | |
-

What do you want to be sure to say?

If you wrote down your three most important things at the end of Step 2, you can use those here.

How to start

Here are some ways you could break the ice:

- “I need your help with something.”
- Remember how someone in the family died—was it a “good” death or a “hard” death? How will yours be different?
- “I was thinking about what happened to _____, and it made me realize...”
- “Even though I’m okay right now, I’m worried that _____, and I want to be prepared.”
- “I need to think about the future. Will you help me?”
- “I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I’m wondering what your answers would be.”

What to talk about

- When you think about the last phase of your life, what’s most important to you? How would you like this phase to be?
- Do you have any particular concerns about your health? About the last phase of your life?
- Who do you want (or not want) to be involved in your care? Who would you like to make decisions on your behalf if you’re not able to? *(This person is your health care proxy.)*
- Would you prefer to be actively involved in decisions about your care? Or would you rather have your doctors do what they think is best?
- Are there any disagreements or family tensions that you’re concerned about?
- Are there circumstances that you would consider worse than death? *(Long-term need of a breathing machine or feeding tube, not being able to recognize your loved ones)*
- Are there important milestones you’d like to meet if possible? *(The birth of your grandchild, your 80th birthday)*

- Where do you want (or not want) to receive care? (*Home, nursing facility, hospital*)
 - What kinds of aggressive treatment would you want (or not want)? (*Resuscitation if your heart stops, breathing machine, feeding tube*)
 - When would it be okay to shift from a focus on curative care to a focus on comfort care alone?
 - What affairs do you need to get in order, or talk to your loved ones about? (*Personal finances, property, relationships*)
-

This list doesn't cover everything you may need to think about, but it's a good place to start. Talk to your doctor or nurse if you're looking for more end-of-life care questions.

Remember:

- Be patient. Some people may need a little more time to think.
- You don't have to steer the conversation; just let it happen.
- Don't judge. A "good" death means different things to different people.
- Nothing is set in stone. You and your loved ones can always change your minds as circumstances shift.
- Every attempt at the conversation is valuable.
- This is the first of many conversations—you don't have to cover everyone or everything right now.

Now, just go for it!

Each conversation will empower you and your loved ones. You are getting ready to help each other live and die in a way that you choose.

Step 4: Keep Going

Congratulations!

Now that you have had the conversation, here are some legal and medical documents you should know about. Use them to record your wishes so they can be honored when the time comes.

- **Health Care Planning (ACP):** the process of thinking about your wishes—exactly what you have been working on here.
- **Advance Directive (AD):** a document that describes your wishes.
- **Health Care Proxy (HCP):** identifies your health care agent (often called a “proxy”), the person you trust to act on your behalf if you are unable to make health care decisions or communicate your wishes. In some states, this is called the Durable Power of Attorney for Health Care. This is probably the most important document. Make sure you have many conversations with your proxy.
- **Living Will:** specifies which medical treatments you want or don’t want at the end of your life, or if you are no longer able to make decisions on your own (e.g. in a coma).

You can find more information about these documents from the link in the “Keep Going” section of the website Starter Kit at www.TheConversationProject.org.

Remember, this was the first of many conversations.

You can use the questions below to collect your thoughts about how your first talk went, and then look back to them when you prepare for future conversations.

Is there something you need to clarify that you feel was misunderstood or misinterpreted?

Who do you want to talk to next time? Are there people who should hear things at the same time (like siblings who disagree about everything)?

How did this conversation make you feel? What do you want to remember? What do you want your loved ones to remember?

What do you want to make sure to ask or talk about next time?

We hope you will share this Starter Kit with others. You have helped us get one conversation closer to our goal: that everyone's end-of-life wishes are expressed and respected.

SECTION 15

Resources

Websites and Organizations

- American Lung Association- **<http://www.lungusa.org>**
- American Lung Association of CT- **<http://www.alact.org>**
- American Association for Respiratory Care- **<http://www.aarc.org>**
- Your Lung Health- **<http://www.yourlunghealth.org>**
- The Breathing Space- **<http://www.thebreathingspace.com>**
- National Lung Health Education Program- **<http://nlhep.org>**
- National Heart, Lung, and Blood Institute Lung Information- **<http://nhlbi.nih.gov/health/public/lung>**
- Emphysema Foundation for Our Right to Survive (EFFORTS)- **<http://www.emphysema.net>**
- National Institute of Health-Medline- **<http://nlm.nih.gov/medlineplus/encyclopedia.html>**
- Better Breather's Support Group - **<http://betterbreathers.freesevers.com/>**
- Smoking Cessation-
 - **www.smokefree.gov**
 - **www.cdc.gov/tobacco/data_statistics/fact_sheets/cessation/quitting/index/htm**
 - **www.lung.org**
 - **www.everydaychoices.org**.
 - American Lung Association- “Freedom from Smoking Online” at: **www.ffsonline.org**
 - Nicotine Anonymous
 - Toll-free number: 1-877-879-6422
 - Website: www.nicotine-anonymous.org

This educational resource was assembled through the dedication of our excellent clinical team. It started as a desire to share the best educational ideas and grew to a much bigger resource because of the dedication of the following people:

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Lorraine Trow, MD
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Christine Yantz PhD, ABPP
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Jack McGoldrick
Laura Phipps
And countless others...

Our program is as strong as our staff, and we have a wonderful care team!

 Gaylord Specialty Healthcare

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