



MANAGING YOUR RESPIRATORY DISEASE

A GUIDE TO NONINVASIVE VENTILATION THERAPY



Although the idea of assisted ventilation may seem overwhelming at first, it's important for you and your caregivers to understand how this will improve your condition.

THE RIGHT CHOICES WILL HELP YOU BREATHE A LITTLE EASIER

For some people, the routine process of taking air in and out is far from simple. Diseases that affect your lungs or respiratory muscles also challenge your quality of life and your overall health.

When your breathing is interrupted – either because your muscles are too weak to pull air into your lungs or because your airways are blocked – you may experience a variety of symptoms. Typical symptoms may include fatigue, shortness of breath and difficulty lying flat. When you wake up, you may have a headache or feel confused, disoriented and anxious. You may also lose your appetite and develop a weak cough.

To help, your doctor may recommend assisted ventilation. There are two types of assisted ventilation – noninvasive (NIV) therapy and invasive therapy (IV). NIV therapy is used with a mask and a device that assists your breathing. Invasive therapy requires a surgical procedure to create an opening through the neck into the trachea, or windpipe. A tube is placed through this opening to provide an airway and remove secretions from the lungs.

Although the idea of assisted ventilation may seem overwhelming at first, it's important for you and your caregivers to understand how this will improve your condition. Take a few minutes to get to know what options are available and discuss them with your health care provider to see what's most appropriate for you. The more you know now, the better you'll be able to avoid a respiratory crisis down the road.



A BRIEF REVIEW OF THE RESPIRATORY SYSTEM

Your lungs are vital organs that bring fresh oxygen into your body and remove carbon dioxide and other gases that your body does not need. This process, known as ventilation, takes place 12 to 20 times every minute.

The lungs, however, do not work alone. They depend on the muscles of your rib cage to help – especially the large, dome-shaped muscle called the diaphragm. When you breathe in, your diaphragm tightens and flattens, allowing you to take air into your lungs. When you exhale, your diaphragm and other rib cage muscles relax, and the air comes out of your lungs.

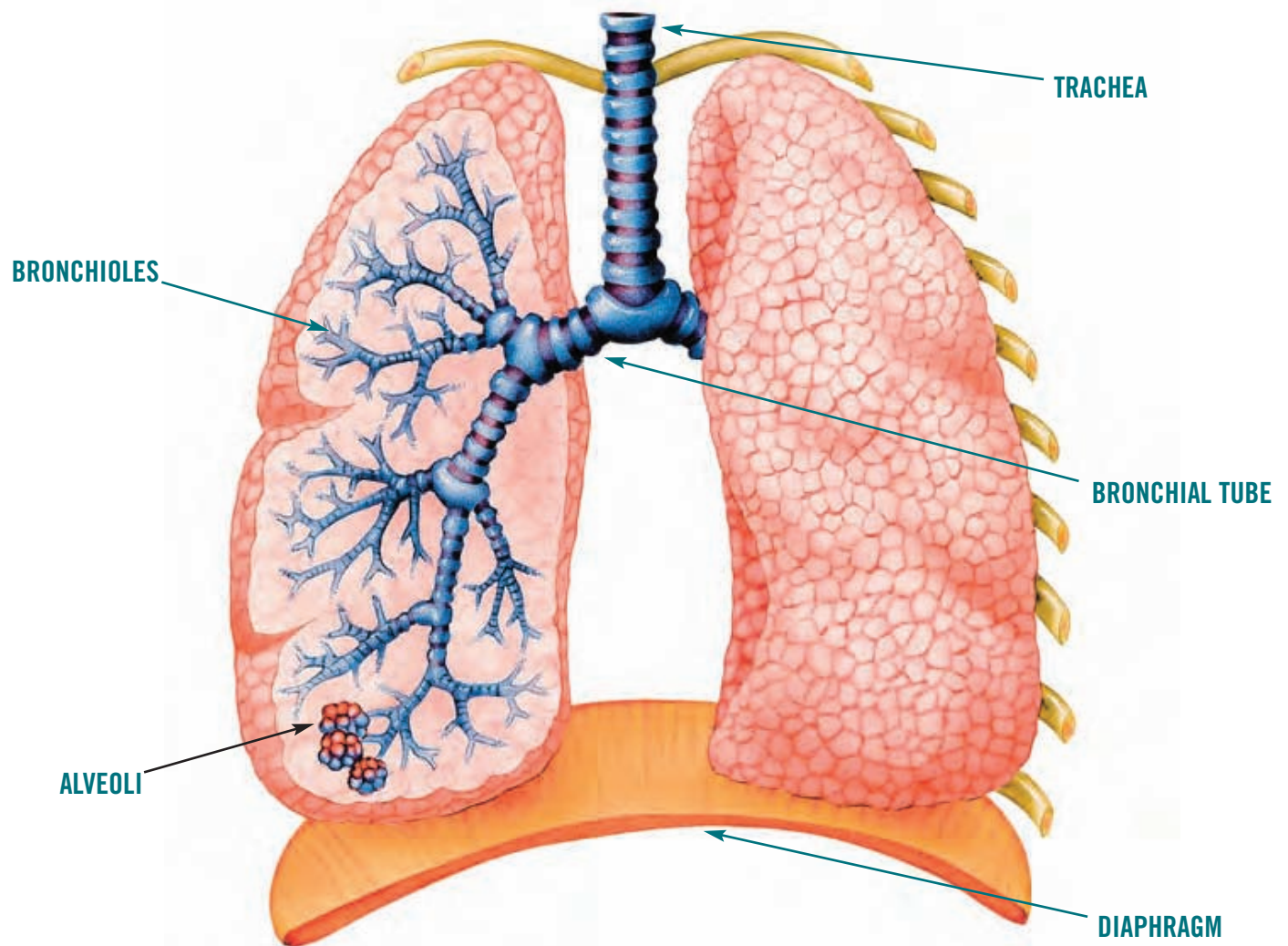
To get the oxygen you need, you inhale through your mouth and nose. The mucous membranes in your mouth and nose warm and moisten the air and filter dust and dirt before the air passes through the throat into the trachea, or windpipe.

From there, your airway gets increasingly smaller. The trachea is divided into two air passages called bronchial tubes. One leads to the left lung, the other to the right. The bronchial tubes divide into yet smaller air passages called bronchi, and then into bronchioles.

At the end of the bronchioles are tiny air sacs called alveoli that are clustered like bunches of tiny balloons. When you breathe in, the balloons expand as air rushes in. When you breathe out, the balloons relax and air moves out of the lungs. There are approximately 300 million alveoli in the lungs. Tiny blood vessels that surround each of these balloons transfer oxygen from the inhaled air to the blood, and also allow carbon dioxide and waste gases to be exhaled.

It's hard to imagine that this entire process is repeated continuously, every minute of your life. But sometimes, chronic conditions cause the respiratory system to fail, and you'll need to rely on respiratory equipment to help move air in and out of the lungs effectively.





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ALLEVIATING THE RESPIRATORY SYMPTOMS OF NEUROMUSCULAR DISEASE AND CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

Researchers have identified more than 40 different neuromuscular diseases, including ALS (commonly referred to as Lou Gehrig's disease) and Duchenne muscular dystrophy. The impact of these diseases can vary greatly from one person to the next, and symptoms that affect your breathing can start early or much later in the progression of your illness.

When neuromuscular disease affects the nerves that control the respiratory muscles, breathing becomes strained and weak. You may become short of breath when you exert yourself or while you're lying in bed. This "breathlessness" is an important indication of trouble. You may need to prop yourself up on pillows or even try to sleep sitting up in a chair. You might also find it's difficult to cough and to control swallowing. These symptoms can lead to infection or to blocked airways. It's important to contact your doctor as soon as you experience these symptoms so that further complications will not occur.

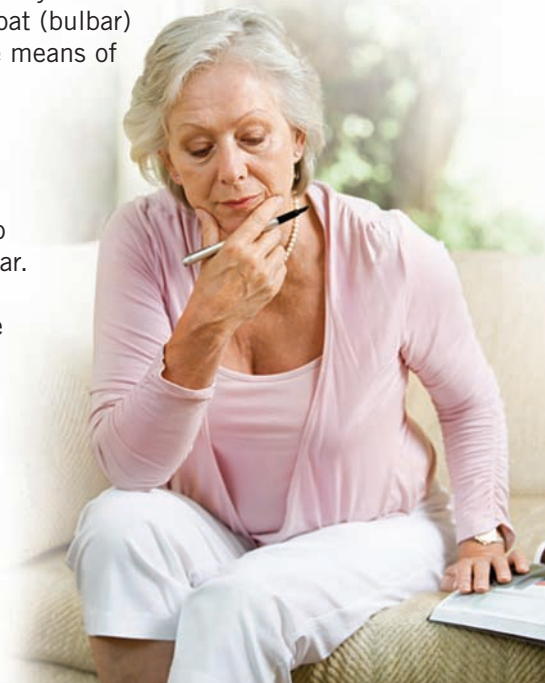
COPD refers to a group of lung diseases (such as emphysema and chronic bronchitis) that obstruct air from easily entering and exiting the lungs. Patients with COPD struggle to breathe and often have a chronic cough that produces sputum. Medication, oxygen therapy and pulmonary rehabilitation are treatment options used to reduce and control the symptoms of COPD. In the latter stages of this disease, some patients have greater difficulty eliminating carbon dioxide, and physicians may recommend a machine to assist with their breathing.

VENTILATORY ASSISTANCE

When a disease weakens a person's breathing ability, you have two options to assist the breathing process – noninvasive and invasive ventilation. With NIV, a machine delivers a preset amount of air into the lungs via a mask, nasal pillows or a mouthpiece. In the beginning, you will probably use this machine only at night, when the body's urge to breathe is naturally reduced. Later, you may need to use it during the day as well. With invasive ventilation, the volume of air is delivered through a tracheostomy, a minor surgical procedure that inserts a tube into the trachea (windpipe). Some people with neuromuscular diseases ultimately need a tracheostomy because of the weakness of the mouth and throat (bulbar) muscles. Invasive ventilation is thought to be a more reliable means of delivering air to the lungs when the disease is advanced.

COUGH THERAPY

When respiratory muscle strength decreases, it's important to be able to cough effectively in order to keep your airways clear. Certain devices are available to help strengthen a patient's coughing mechanism and clear mucus from the lungs. These are especially important if you have had a cold or other upper respiratory infection that's producing excess mucus.



UNDERSTANDING YOUR THERAPY OPTIONS

Ventilation equipment is smaller, lighter and more effective than ever before. It's a good idea to find out a little more about the different equipment used for NIV before you begin treatment. Your respiratory therapist can recommend the device that would be best for you, and help you become familiar with both the mask and the operation of the equipment.

BI-LEVEL THERAPY DEVICES

A blower within the device delivers a prescribed amount of air through a mask into your lungs. The level of pressure will be higher when you inhale and will decrease as you exhale.

- Bi-level S (spontaneous) responds when you start to inhale and exhale. There is no automatic delivery of a breath if you do not inhale.
- Bi-level S/T (spontaneous/timed) responds when you start to inhale and exhale. If you do not start inhaling within a set time, the device automatically delivers a breath.
- Respiration Average Volume Assured Pressure Support (AVAPS) feature guarantees a desired volume of air to the lungs.

PRESSURE- OR VOLUME-CONTROLLED VENTILATOR

Pressure- or volume-controlled ventilators deliver a preset pressure or volume of air when you inhale. These ventilators can deliver higher volumes and pressures than bi-level units. They also have additional alarms and internal batteries. If a patient requires continuous ventilation, a pressure or volume ventilator is recommended. These types of ventilators usually require the use of a tracheostomy tube.

SECRETION MANAGEMENT

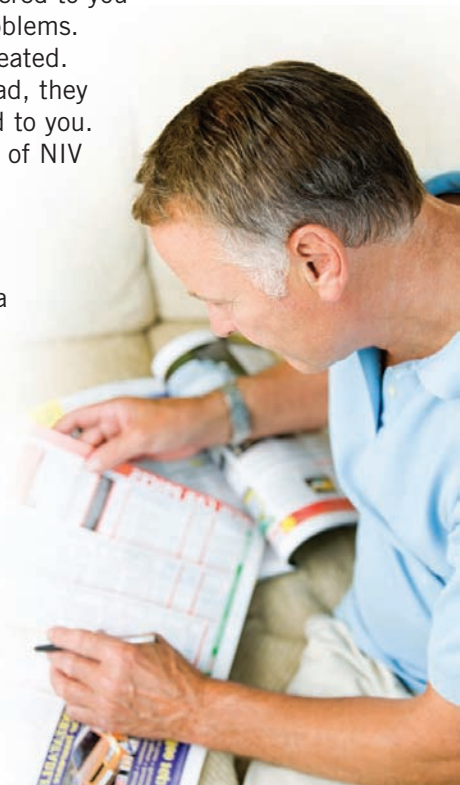
Secretion management therapy, such as the use of CoughAssist® from Respiration, can supplement your ventilation therapy to increase the effectiveness of your cough and clear secretions from your lungs and trachea. This small electrical machine first delivers a large volume of air, then quickly reverses air flow to pull out secretions. This will keep your airways clear and help reduce the chance of respiratory infection.

HUMIDIFICATION

A humidifier adds moisture to the air that is being delivered to you from your ventilator. It can help alleviate most nasal problems. There are two types of humidification – heated and unheated. Heated humidifiers do not actually “heat” the air. Instead, they increase the moisture content of the air that is delivered to you. Humidifiers can help to reduce some of the side effects of NIV therapy, such as dry nasal passages.

MASKS

A mask delivers air from the therapy device to you. It's a key component of your daily treatment. There are many styles of masks, and it's important to find one that fits you comfortably and can accommodate your lifestyle.





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THE BENEFITS OF NIV THERAPY

Although your respiratory muscles might be severely weakened, there are ways to maintain or improve your quality of life.

Noninvasive ventilation can help patients to be more independent with activities of daily living and less likely to be hospitalized for breathing-related episodes. Many ALS patients, for example, go to school or work, travel and enjoy the company of friends. In fact, ALS patients who use NIV to treat the respiratory insufficiency caused by ALS have significantly better survival advantage than other patients who received standard care.¹ What's more, even patients with severe impairment of the muscles that control swallowing enjoyed an improved quality of life.

When you use NIV according to the instructions of your doctor and respiratory therapist, you can help to:

- rest your respiratory muscles
- decrease the work of breathing
- reduce daytime sleepiness and morning headaches
- improve sleep quality
- maintain or improve the oxygen/carbon dioxide levels in the blood
- inflate the lungs more fully
- enjoy a better quality of life

DECIDING ON NIV AND INVASIVE VENTILATION OPTIONS

It's important to consider the options for ventilation in advance so you will feel prepared and in control. Deciding to use NIV is a different level of decision-making from that of deciding to have a tracheostomy and invasive ventilation. NIV allows you to try this type of assisted breathing without committing to a more permanent option. Consulting with your physician and home respiratory therapist will allow you to try NIV and make further decisions based on your experience at home.

Ventilation through a tracheostomy, however, may become indicated at some point. You should consider if assistance would be available from family, friends and other resources as well as the possibility of care in a long-term skilled facility.

When deciding on the appropriate level of respiratory support, there is no right or wrong decision. It's a personal choice. Your health care team can help you and your family plan as your needs change.



¹Kleopa, KA, et al Bipap improves survival and rate of pulmonary function decline in patients with ALS. *J Neurol Sci* 1999;164,82-88.



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Respironics Europe, Africa, Middle East: +33-1-47-52-30-00
Respironics Asia Pacific: +852-3194-2280
www.respironics.com

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