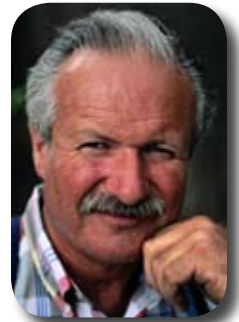


# Living

## with Asbestos-Related Illness



## A Self-Care Guide

CS107729



**ATSDR**  
AGENCY FOR TOXIC SUBSTANCES  
AND DISEASE REGISTRY

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## About this Guide

This guide will help you understand the illnesses asbestos may cause and how to take care of yourself if you have any of those conditions. Caregivers may also find the guide useful.

## Asbestos Exposure and Health

Asbestos is a naturally occurring mineral. It is made up of fibers that are so small that you cannot see them. Asbestos fibers may be released into the air when asbestos-containing material is disturbed during product use, demolition work, and building or home maintenance, repair, or remodeling. If asbestos fibers are in the air you breathe, you will get asbestos fibers in your lungs. This is the main way that people are exposed to asbestos. Asbestos fibers may remain in the lungs for a lifetime. In some cases, the fibers might damage the lungs or the pleura covering the lungs, leading to illness and even death.

Some people who worked with asbestos years ago are now getting sick. They may have brought asbestos fibers home on their clothes, shoes, and bodies. People who lived in those same households could have been exposed to asbestos, too. Some household members may now be sick because of this exposure.

## First Steps

If you think you might have been exposed to asbestos:

- **Tell your doctor.** Your doctor may take an exposure history and recommend a thorough physical exam, including a chest x-ray and lung function tests. Your doctor may need a specialist who is experienced in reading x-rays for asbestos-related illness to help interpret the results. Other tests may be necessary.
- **Quit smoking.** If you are a smoker, quit smoking. Smoking combined with asbestos exposure greatly increases the risk of getting lung cancer.
- **Get regular influenza (flu) and pneumonia shots.** Regular shots help reduce the chance of lung infections.

Being exposed to asbestos does not mean that you will develop health problems! Many things need to be considered when evaluating whether you are at risk for health problems from asbestos exposure. A doctor can help you find out if you have health problems from asbestos exposure.

## Asbestos-Related Illnesses

Asbestos has been widely used in the United States; nearly everyone has been exposed to asbestos at some time in his or her life. However, most people who become sick from asbestos are exposed to high concentrations of asbestos, are exposed for longer periods of time, and are exposed more often.

Most asbestos fibers that are inhaled are breathed out, but some can become lodged in the lungs and remain there throughout life. Because asbestos fibers attach to the membranes that line the chest cavity and cover the lungs, they cannot be coughed out or washed out. Fibers can gather and cause scarring and inflammation. As the lung tissue scars and thickens, breathing becomes more difficult.

Most people do not show any signs or symptoms of asbestos-related disease for 10 to 20 years or more after exposure. The most common asbestos-related illnesses are lung cancer, mesothelioma, and asbestosis:

### Lung cancer

- **Lung cancer** is a malignant tumor that invades and obstructs the lung's air passages. Cigarette smoking greatly increases the likelihood of a person developing lung cancer as the result of asbestos exposure.

Signs and symptoms of lung cancer include:

- ▶ coughing
- ▶ hoarseness
- ▶ wheezing
- ▶ labored breathing
- ▶ shortness of breath
- ▶ persistent chest pain
- ▶ anemia

Other symptoms can include weight loss, fever, chills, and night sweats. People who develop these symptoms do not necessarily have lung cancer, but they should consult



a physician for advice. Most cases of lung cancer in workers occurred 15 years or more after the person was first exposed to asbestos.

### Mesothelioma

- **Mesothelioma** is a very rare cancer of the lining of the chest or abdomen. Most mesothelioma cases are caused by exposure to asbestos and are diagnosed 30 years or more after the first exposure. By the time a person is diagnosed with mesothelioma, it is almost always fatal.

Signs and symptoms of mesothelioma include:

- ▶ shortness of breath or trouble breathing
- ▶ unexplained weight loss
- ▶ pain under the ribs
- ▶ pain, swelling, or lumps in the abdomen

### Asbestosis

- **Asbestosis** is a serious, progressive, long-term disease that causes scarring of the lungs. This scarring makes it hard for lungs to get oxygen into the blood. It restricts breathing and leads to smaller lung volume. Asbestosis is not a cancer.

Signs and symptoms of asbestosis include:

- ▶ shortness of breath (the primary symptom)
- ▶ a persistent and productive cough that expels mucus
- ▶ chest tightness
- ▶ chest pain
- ▶ loss of appetite
- ▶ a dry, crackling sound in the lungs while inhaling

Asbestosis generally progresses slowly, but the rate can vary greatly from one patient to another. Breathing can become more difficult as the symptoms progress over time. Lung tissues and the lining of the chest wall can change from the thinness and stretchiness of a balloon to the thickness and hardness of an orange peel.

People with asbestosis may require aggressive medical care, including frequent use of antibiotics when warranted, for any respiratory infection. As the disease progresses, shortness of breath becomes worse. After awhile, a person may require supplemental oxygen to carry out daily activities. The end result of the disease is lung and heart failure.

## Treating Asbestos-Related Illness

A doctor can help manage asbestos-related symptoms, but no cure is available. Treatment involves preventing further complications of the disease and treating its symptoms.

For information about treating asbestos-related cancer illnesses, contact the National Cancer Institute's Cancer Information Service. Their toll free number is 1-800-4-CANCER (1-800-422-6237).

## Taking Care of Yourself

If you have an asbestos-related disease, the following self-care tips and techniques will help you take care of yourself and live more comfortably:

### Food, Rest, and Exercise

- Taking care of your body will help you breath easier:
  - ▶ Eat healthy foods, including lots of fruits and vegetables. Good eating habits help maintain muscle mass and body functions.
  - ▶ Limit your salt intake.
  - ▶ Drink lots of fluids—at least six glasses of water daily, unless your doctor tells you differently.
  - ▶ Sleep 7 to 8 hours every night.
  - ▶ Take several short rests during the day. Conserve your energy and avoid getting too tired.
  - ▶ Exercise to increase the strength and endurance of your heart and lungs.

### Cleanliness

- Make an effort to prevent infection:
  - ▶ Wash your hands often to lower your risk of colds and flu.
  - ▶ Wash your hands before taking your medication or handling your oxygen equipment.
  - ▶ Avoid situations, like large crowds, that might expose you to respiratory infections.



## Annual Shots

- Get flu and pneumonia shots every year (offered between September and December).
- To protect your health, caregivers and all household members also should get flu and pneumonia shots every year.

## Keeping a diary

- Keep a diary of when you have trouble breathing. Note how often you have trouble, how bad it is, and what you were doing that may have triggered the trouble. The diary will help you recognize and avoid events that trigger breathing trouble.

## Avoiding Bad Air

- When air pollution and pollen counts are high, stay inside. An air-filtering machine can improve the indoor air quality.
- Avoid breathing pollutants that can trigger shortness of breath. This includes traffic fumes, smog, aerosol sprays, and chemical vapors (from products such as paint, kerosene, and cleaning agents).
- In cold weather, breathe through your nose. Cover your mouth and nose with a scarf.

## Productive Coughing

- People with chronic lung diseases are more at risk for respiratory infections because their lungs are already damaged. One of the most important preventive measures is a “productive” cough. This is a cough that is moist and brings up mucus from the lungs and air passageways. This helps clear the air passages.

An unproductive cough reduces airflow and causes respiratory muscle fatigue. If mucus and other foreign bodies remain in the respiratory tract, they can pool in the airways. This makes it difficult to expel bacteria and increases the risk of infection.

Very dry air increases shortness of breath and thickens the mucus in your lungs. Your doctor may recommend a humidifier, breathing therapies, and chest percussion (pounding or clapping the chest to loosen secretions). These steps loosen and thin out bronchial secretions, allowing them to be expelled by the cough.

## Avoiding Smoke

- Stay away from smoke and smokers.
- If you smoke, now is a good time to quit. Smoking can increase the rate at which a disease gets worse. It can also increase the risk of lung cancer. Even if you have been smoking for years—or you already have lung disease—quitting smoking now will greatly improve your health. Your blood vessels will relax, allowing the blood to flow normally; your heart will not have to work as hard. Your lung tissue will become healthier and you will breathe easier.
- If you smoke, a structured stop smoking program may help you kick the habit. The use of nicotine patches and antidepressants along with counseling may also be helpful.



## Taking Care of Yourself (cont.)

### Respiratory Therapies

- Participate in respiratory therapies (such as bronchial drainage) as recommended by your doctor. Your doctor might recommend using an ultrasonic mist humidifier to help clear secretions from your lungs.
- You might also learn postural drainage; the positioning of a person to drain and remove secretions from particular areas of the lungs.
- Clean and maintain respiratory therapy devices to limit their risk of causing infection. Though you may need proper training to do that, the following are general recommendations:
  - ▶ Clean all reusable respiratory therapy equipment twice a week. That includes ventilator circuitry, nebulizers, aerosol tubing, and peak flow meters. Consult your provider about cleansing routines for respiratory equipment.
  - ▶ Completely air dry all cleaned devices before putting them back together. Moisture trapped in the devices can allow bacteria, viruses, and fungi to grow.
  - ▶ All ventilator filters should be cleaned and changed as often as the manufacturer recommends.

### Breathing Techniques

- Breathing techniques can help you control your respiratory rate and breathing pattern. That will help you breathe easier and more efficiently, and make you feel like enough air is getting into your lungs. Breathing techniques and correct posture also can improve the function of respiratory muscles and effectiveness of coughs.
- You can also do exercises to help you breathe more easily. Practice the exercises daily so that when shortness of breath occurs, you will do them naturally and not panic. Some of the exercises are the following:
  - ▶ **Pursed-lip breathing:** Pursed-lip breathing will slow down your breathing so that it is more efficient (breathing fast only worsens shortness of breath). You can do this kind of breathing anywhere.
    - Breathe in slowly through your nose. Hold your breath for 3 seconds.
    - Purse your lips as if you are going to whistle.
    - Breathe out slowly through your pursed lips for 6 seconds.



- ▶ **Abdominal/diaphragm breathing:** Abdominal breathing also slows down your breathing and helps relax your entire body.
  - Lie on your back in a comfortable position with a pillow under your head and knees.
  - Rest one hand on your abdomen just below your rib cage. Rest the other hand your chest.
  - Slowly breathe in and out through your nose using your abdominal muscles. The hand resting on your abdomen will rise when you breathe in and fall when you breathe out. The hand on your chest should be almost still. Repeat three or four times before resting.
- ▶ **Active Cycle of Breathing Technique (ACBT):** ACBT is a series of breathing techniques that help clear secretions and improve air delivery to your lungs. ACBT can be done sitting up. This technique combines breathing exercises with the “huff” cough and has three components in a set cycle. The huff cough involves holding a deep breath for a few seconds and then exhaling forcefully. The cycle is repeated until the huff becomes dry or nonproductive, or when 20 minutes have passed. Ask your doctor for guidance and instructions on this therapy.

## Pulmonary Rehabilitation

- Talk to your doctor about taking part in a pulmonary rehabilitation program. Pulmonary rehabilitation uses different therapies for persons with pulmonary disease. The goal of pulmonary rehabilitation is to help patients reach and maintain their maximum level of independence and ability to function in the community.
- Pulmonary rehabilitation is becoming a crucial part of therapy for many patients. It offers the best treatment option for patients with chronic respiratory illnesses. It helps people increase their exercise capacity and endurance and improves their health-related quality of life. The treatment also helps people breathe easier and results in fewer hospital admissions, even among patients with the most severe degree of lung disease.
- Patients with advanced lung disease may have emotional disorders, mainly depression and anxiety. In addition to appropriate medical therapy for these disorders, exercise as part of a pulmonary rehabilitation program can help lessen these feelings.
- The goals of a pulmonary rehabilitation program are to:
  - ▶ make breathing easier
  - ▶ improve pulmonary function
  - ▶ ease shortness of breath
  - ▶ increase efficiency of energy use
  - ▶ correct nutrition deficiencies

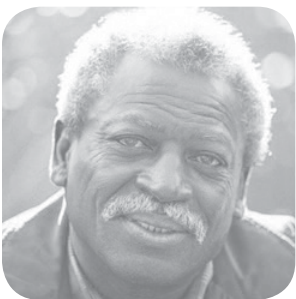
## Taking Care of Yourself (cont.)

- ▶ improve exercise performance and daily activities
  - ▶ restore a positive outlook
  - ▶ improve emotional state
  - ▶ decrease health-related costs
  - ▶ improve survival
- If you are interested in pulmonary rehabilitation, ask your doctor to help you design a program that will work for you.

## Your Doctor is Your Health Partner

Work with your doctor to help manage asbestos-related symptoms:

- Follow your doctor's instructions on taking your medicines, oxygen therapy, and chest physiotherapy.
- Make an effort to prevent infection.
- Do not try to treat yourself. Over-the-counter cold remedies might worsen the problem. Do not use them unless your doctor says it is okay.
- Get regular chest x-rays to help screen for cancers associated with asbestos exposure.
- Call your doctor if any of the following signs occur:
  - ▶ Fever
  - ▶ Increased wheezing, persistent coughing, or difficulty breathing
  - ▶ Changes in mucus (mucus is thicker; either more or less mucus is present than usual; mucus has a foul odor; or mucus is green, yellow, brown, pink, or red)
  - ▶ Stuffy nose, sneezing, or sore throat
  - ▶ Increased fatigue or weakness
  - ▶ Weight gain or loss of more than 6 pounds within a week
  - ▶ Swollen ankles or feet



## Travel

Living with asbestos-related illness should not keep you from traveling. This section will help you understand how to take care of yourself during travel.

## Oxygen Use

If your doctor has prescribed oxygen, you will have a liquid oxygen unit, an oxygen tank, or an oxygen concentrator. You will breathe the oxygen through either a mask or nasal cannulae (two short prongs that fit just inside your nostrils). The system will also have a humidifier to warm and moisten the oxygen.

As a precaution, also keep a small portable oxygen tank available in case of power failure.

Only your doctor can decide how much oxygen you need. You should never change the flow rate without instructions from your doctor. The medical supply company will show you how to set the flow rate and how to care for the equipment. Keep the supplier's telephone number handy in case the system does not work properly.

Sometimes it is hard to tell whether oxygen is flowing through the tubes. If you have doubts, check to be sure that the system is turned on and the tubing does not have any kinks. If you still are not sure, place the nasal cannulae in a glass of water with the prongs up and watch for bubbles. If no bubbles appear, oxygen is not flowing through the tubes and you need to call your supplier.

Oxygen is very flammable. Keep your oxygen unit away from open flames and high heat, including lit cigarettes, burning candles, log fires, gas stoves, space heaters, or kerosene heaters.

## Traveling With Oxygen Locally

When traveling around town, be sure to plan for an adequate supply of oxygen and know how much time you can safely travel between refills. Always allow for a 20%–25% safety margin to cover any unexpected delays. When traveling, keep the oxygen container upright and secure at all times.

## Planning a Longer Trip

Before planning a longer trip:

- Discuss your travel plans with your doctor to be sure it is all right for you to travel and to find out how long your trip can safely be away on your trip.
- Contact your oxygen supply company about your travel plans. The company will recommend the equipment you need and help determine the time you can safely travel between refills. Get the oxygen equipment with which you will travel ahead of time so you can become familiar with how to operate it. Your supplier can also arrange to have oxygen supplied to you at your destination.

## Planning a Longer Trip (cont.)

- Check with your insurance company. You may have to pay in advance for equipment and submit the insurance claims after you return home. Be sure to keep your receipts.
- Always keep your prescription with you throughout the trip.

## Traveling by Bus

Bus lines do permit travel with oxygen equipment. However, to prevent any unexpected problems, check in advance. Most bus companies permit you to take one E (M-24; 680 L) cylinder onto the bus. Empty tanks can be checked as baggage. You must be able to put your tank on and take it off by yourself.

## Traveling by Train

In the United States, Amtrak requires at least 12 hours notice in advance of your train's boarding time of your need to bring oxygen aboard. Portable oxygen containers must meet the following requirements:

- Power source: Oxygen equipment cannot rely solely on train-provided electrical power
- UL or FM listed: Oxygen equipment must be Underwriter's Laboratory (UL) or Factory Mutual (FM) listed
- Weight limits: Each tank and its associated equipment may weigh no more than 50 lbs (22.7 kgs) per unit
- Configuration: Amtrak permits only one of the following:
  - ▶ a two-tank system (maximum of 50 lbs [22.7 kgs] per tank), or
  - ▶ a six-tank system (maximum of 20 lbs [9 kgs] per tank), but only if the tanks can be separated and handled individually

## Traveling by Ship

Cruise line regulations differ and are subject to change, so you must contact the cruise line regarding current rules. Some cruise lines permit you to travel only with oxygen cylinders and limit the number you may bring on board.



- Be prepared to supply the following information from your doctor:
  - ▶ a prescription stating the quantity of oxygen and the flow rate
  - ▶ a letter describing your diagnosis, and a statement that you are approved for travel

## Traveling by Plane

Regulations vary from one airline to another and are subject to change.

- Always call ahead of time to inquire about current rules. Some airlines will not permit passengers to use oxygen. Other airlines are willing to provide oxygen if you make advance arrangements, but you must use their oxygen supply. Airlines do not allow passengers to bring oxygen on board the plane.
- Always bring your own nasal prongs: some airlines use only simple oxygen masks, which allow carbon dioxide buildup. Also bring a universal nipple adapter that fits various sizes of tubing.
- You must make reservations 2 to 5 days in advance, depending on the individual airline's rules. Be sure to ask what documents you will need to supply. Airline documentation requirements are similar to those of cruise lines. Some airlines also have special forms that must be filled out by your doctor. You might have to sign a liability statement. In a few cases, you are required to bring a companion with you on the flight. Additional charges vary, but expect to pay about \$50 extra.
- Allow at least 1 hour between connecting flights. Remember that you must arrange for oxygen for the time between flights. Local oxygen suppliers will provide this service for layovers between flights. Whenever possible, use small airports because they usually have fewer delays and their boarding gates are closer together.

## Lodging

Hotels and motels are usually very accommodating about special needs. Someone is usually available to transport your oxygen tank.

- Contact your local supply company about arranging for a supply company at your destination to set up the equipment in the room before you arrive.

## Conclusion

We hope this guide has provided you and your family with the skills and information to help you live with asbestos-related illnesses.

For more information on asbestos exposure and your health, call 1-888-42ATSDR (1-888-422-8737), or visit our Web site at [www.atsdr.cdc.gov/asbestos](http://www.atsdr.cdc.gov/asbestos).

## Resources

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