ADVICE FOR PEOPLE WITH POST-POLIO OR OTHER NEUROMUSCULAR DISORDERS

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If you have had polio or suffer from some other neuromuscular disorder and have weakness of the neck, upper trunk, or shoulders but are not on a respirator, you may want to evaluate your respiratory needs. Such a disorder may be polymyositis, muscular dystrophy, amyotropic lateral sclerosis, spinal muscle atrophy or spinal cord injury. As you grow older, your respiratory reserves will diminish. A potentially serious problem may develop whereby carbon dioxide is retained and oxygen is decreased in your bloodstream. These changes may be obvious but in most cases they are subtle. You can easily recognize weakness if you cannot pick your head up off the bed, raise your arms above your shoulders, turn over in bed by yourself, come to a sitting position or sit independently without a back support. However, it is difficult to recognize when the muscles of respiration (the muscles and rib cage that expand and contract your lungs) are not working adequately. When these muscles are impaired a restrictive respiratory problem results. This is different from obstructive pulmonary problems or disorders of the airways.

In the course of normal aging, our lungs and chest wall become less elastic. We do not breathe as deeply. Our vital capacity, the biggest breath we can take into our lungs and then push out, decreases by 30 cc per year (1 oz). Our cough is not as vigorous. Aging and neuromuscular disorder produce more serious changes. These changes are maximized by conditions such as kyphoscoliosis and airway obstruction or chronic bronchitis.

Symptoms which may be associated with failing respiratory reserves are numerous and for the most part non-specific. This means that other medical problems can cause them as well. However, they do serve to alert you to a possible respiratory problem. These symptoms include feeling more tired or becoming exhausted from ordinary activities, and reducing usual activities because of fatigue. Anxiety, inability to fall asleep, restless sleep, awakening during the night with nightmares and awakening in the morning with headache or slight confusion may occur. Brain functions are altered so depression, inability to concentrate, dizziness, sleepiness during the day and blurring of vision may be present. Vascular symptoms such as peripheral cyanosis or an abnormal sensitivity of the extremities to cold and the tendency to develop high blood pressure or a rapid heart beat may be caused by respiratory insufficiency. Breathlessness during activity including such a simple task as speaking may occur. Your voice may be lower than it had been. The breaths you take when you are awake may be very shallow and even more shallow when you are asleep. This is why early symptoms usually occur in sleep. Tranquilizers and sedatives will further depress your respiration and should not be taken especially at bedtime or during the night.

For many people, the first changes may be difficulty raising secretions and feeling congested with frequent colds. Difficulty raising secretions leads to a sealing off of lung tissue from the airways (atelectasis), or to infections of the lung tissue (pneumonia). The work of breathing becomes even harder and respiratory failure occurs more rapidly. With respiratory failure, the right side of the heart fails causing generalized edema and protein in the urine.

If you have any of the signs and symptoms described above, you should make an appointment to see your doctor. Your breathing can be evaluated by simple tests. One of these is measuring your vital capacity (the maximum amount of air that can be moved into the lungs and then forcibly exhaled). If your vital capacity is reduced but is still above 50% of a predicted value for your age and sex, it is unlikely that your symptoms are related to your diminished breathing capacity except in three situations; marked

obesity, partial obstruction of the throat during the night in sleep, and the presence of an intrinsic lung disease such as an old tuberculosis or emphysema. If your doctor consider it necessary, he will refer you to a pulmonary specialist.

The pulmonary specialist will do screening pulmonary function tests, more comprehensive pulmonary functions tests if he finds them necessary, and arterial blood gases. He may not find it necessary for you to have a ventilator but may wish to follow you on a regular semiannual or annual basis, or to see you immediately if you develop an intercurrent respiratory infection. If he suggests mechanical respiratory support, you need not be alarmed. Such support is an insurance policy for your well-being.

The respirator will help you sigh your lungs (stretching or range of motion). It will help you to cough, speak and even regain energy that had to be funneled into the increased work that you expended in breathing prior to the use of the respirator. For the most part, the respirators used today are small portable units that operate on either battery or wall current. They are silent, inconspicuous, and are used with a mouthpiece both day and night, unless the person has a weakness of the throat. In selected cases, respirators including the iron lung, rocking bed and chestpiece, which provide a person with expiration and inspiration are still in use. Some people prefer a special body respirator called the pneumobelt especially when they are sitting. This is an inflatable bladder held against the abdomen in a nonelastic corset and cycled with the portable ventilator which mimics the abdominal muscles. If the mouth and throat are weak, a tracheostomy can be considered and the ventilator is connected to a tracheostomy tube. With appropriate follow-up and mechanical ventilation you will increase your sense of well-being and longevity.

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