

## My Journey through the Basics of Post-Polio Breathing Problems

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Breathing was becoming problematic. For years I'd used a ceiling fan to stir the air in my room and give it a semblance of freshness, which made it easier to breathe. But sometimes I'd wake in the night with a start, feeling for a second that I couldn't get a breath, and this worried me. I'd seen the list of signs and symptoms that indicate it's time to consult a pulmonologist (preferably one who understands neuromuscular disorders) about getting an evaluation. Several of those signs were all too familiar. I made an appointment.

"You know, Nancy, you may need to use a ventilator to help you breathe one of these days," the pulmonologist said. His very words made it hard to take a breath. The thought of having to depend on a machine to breathe terrified me. My imagination ran wild – suddenly I felt vulnerable; a heavy weight closed around me. "I could never do that," I replied. "You'll change your mind when the time comes," he said.

### Signs and Symptoms of Underventilation

The presence of any one of these can alert polio survivors to the possibility of breathing difficulties:

- Weakness and fatigue, low energy, daytime sleepiness
- Air in the room seems somehow stale, claustrophobic
- Difficulty concentrating, impaired memory
- Irritability or anxiety or depression
- Morning headaches
- Waking in the night short of breath or with choking sensation
- Feeling unrefreshed upon waking in the morning
- Shortness of breath during the day
- Difficulty breathing when lying flat

### Underventilation

All pulmonary doctors treat lung disease. However, polio breathing difficulties (such as *underventilation* – also known as hypoventilation) are not caused by lung disease, but rather by problems outside the lungs that limit the amount of air entering the lungs with each breath – they do not get enough air to become fully inflated. Without proper ventilation to bring in oxygen-containing air and carry out the carbon dioxide made in the body, a buildup of carbon dioxide and a decrease in oxygen levels can occur. This is underventilation. Underventilation difficulties most often relate to *respiratory muscle weakness* or *scoliosis* or *sleep-disordered breathing*. Telling a pulmonologist about a history of polio is imperative.

**Respiratory muscle weakness** refers to muscles disabled by polio, such as the diaphragm or chest muscles, that affect breathing by causing smaller-than-normal breaths. If the breathing muscles of certain polio survivors were weakened by the initial virus, these individuals may have used an

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iron lung. They should be on the lookout for possible underventilation and seek treatment to avoid respiratory failure. Since even survivors who did not initially need an iron lung can develop underventilation, they, too, should be aware of troublesome signs and symptoms.

**Scoliosis** refers to a curvature of the spine that alters the space in the chest and compromises breathing or coughing.

**Sleep disordered breathing**, in this discussion, refers to *apnea* plus hypopnea (slow, shallow breathing.) *Apnea* is a Greek word meaning “without breath.” In sleep apnea, individuals literally stop breathing for as long as a minute or so during sleep, and possibly do this hundreds of times in a night. There are three types:

1. *Obstructive sleep apnea* happens when the airway becomes blocked, as when the soft tissue collapses at the back of the throat. It is possible for polio-weakened throat and neck muscles also to close off the airway during sleep.
2. *Central sleep apnea* happens when the brain “forgets” to tell the muscles to breathe.
3. *Mixed sleep apnea* is a combination of the other two.

In my case, bulbar polio affected the bulbar nerves and left me with weakness of the throat and neck muscles. Over the years it’s been increasingly difficult to get the necessary “lift” to keep the airway and throat open for breathing and swallowing. Finally my cousin made a “chin crutch” for me from the leg of a tripod (so its length can be adjusted) with a small rubber ball on the bottom (to anchor it com-

fortably) and a sheepskin-padded block on top that tucks under my chin. It’s always in place when I sleep and rest, and frequently during the day when I feel my throat closing, I grab the crutch.

### Incidence of Sleep Apnea

More than 12 million individuals in the United States general population have sleep apnea. It occurs more often in men, in those over forty, and in those who are obese, though anyone at any age can be susceptible. Polio survivors can have sleep apnea, too, sometimes along with any variety of other sleep difficulties pertaining to their polio conditions. Their polio histories should always be considered to ensure that polio-related symptoms are not mistaken for something else.

These sleep problems can be subtle, perhaps going unnoticed for too long. They can be life-threatening and therefore must be taken seriously.

### Diagnosis

All polio survivors might be better off having at least a *baseline pulmonary function test* to see if further investigation is warranted.

### Baseline pulmonary function tests

consist of several easily accomplished elements:

■ **Vital capacity (VC)** is usually measured by inhaling deeply and then blowing (one big, long breath to empty the air from the lungs) into a tube to see how much air is exhaled and how much remains in the lungs. When done as quickly as possible, this is called Forced Vital Capacity (FVC). VC should be measured in sitting, lying and other positions, as each of these may yield

Carter used many resources in writing this article. The Resource List is available at [www.post-polio.org/edu/pphnews/pph23-4res.pdf](http://www.post-polio.org/edu/pphnews/pph23-4res.pdf) or by calling 314-534-0475.

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significantly different results if respiratory muscles are weak.

■ **Maximum Inspiratory Pressure (MIP) and Maximum Expiratory Pressure (MEP) tests** measure diaphragm muscle power by breathing forcefully in and out into a mouth tube.

■ **Peak cough flow** is measured to test the effectiveness of a cough. Weak respiratory muscles can mean a weak cough impeding secretion removal, and can lead to respiratory infections and pneumonia.

I was told that people who did not have polio sometimes improve their VC scores with repeated tries at forceful breathing. Not so for polio survivors like me with respiratory muscle weakness, as I learned the first time I was tested. I may have reached my peak in the initial attempt, and after that not only were my efforts less productive, my excessive huffing and puffing caused me to seriously overwork those muscles, leaving me, by that night, in pain and with difficulty breathing. I should have known enough to stop after the first several breaths.

■ **Sleep studies** may be suggested when a pulmonologist determines that additional tests are needed. These studies are usually done overnight in a specially equipped laboratory and include ECG (electrocardiogram), EEG (brain wave), eye movements, snoring, and measurements of airflow, apnea and shallow breathing events, and blood oxygen saturation, among other tests. Polio survivors may want to ask if a lab uses an end-tidal CO<sub>2</sub> monitor, since this device is meant to detect underventilation. In some cases a breathing machine, such as a BiPAP®, may be tried for a few hours in order to analyze its effectiveness.

■ **An Arterial Blood Gas (ABG)** is done by drawing blood from the artery on the underside of the wrist, testing levels of oxygen, carbon dioxide and pH in the blood and evaluating pulmonary gas exchange. Since in underventilation carbon dioxide increases, pushing out oxygen in the blood, an ABG can be a good diagnostic tool. Pulse oximetry is a noninvasive measurement of oxygen saturation in the blood, but it is less precise than an ABG.

### Assisted Breathing

Because underventilation results from too little oxygen and too much carbon dioxide in the blood, some polio survivors (and perhaps even a few in the medical community) may make the mistake of believing that oxygen is the way to treat the problem. It is not. Mechanical ventilation is essential. Polio survivors with respiratory muscle weakness who are developing progressive respiratory failure risk death if their underventilation is not treated with proper ventilation.

Depending on the breathing difficulty, pulmonologists will recommend the breathing machine best suited to a survivor's needs. These can be used in the home:

■ **CPAP (Continuous Positive Airway Pressure)** – Air flows continuously through a breathing mask into the airway. It is used mainly to treat obstructive sleep apnea because of its ability to use positive air pressure to keep airway open. Some units work automatically to provide the right level of pressure. CPAP delivers a single preset level of pressure in both the inspiratory and expiratory phases. A CPAP is not a ventilator.

### For more about ventilator-assisted living –

International Ventilator Users Network (IVUN) is the premier source of information about living independently with a ventilator. An affiliate of PHI, IVUN has its own website ([www.ventusers.org](http://www.ventusers.org)), quarterly newsletter (*Ventilator-Assisted Living*), and its *Resource Directory for Ventilator-Assisted Living*. IVUN's Home Ventilator Guide ([www.ventusers.org/edu/HomeVentGuide.pdf](http://www.ventusers.org/edu/HomeVentGuide.pdf)) provides details about the numerous breathing machines.

■ **Bi-level Positive Airway Pressure** – Air flows continuously through a breathing mask into the airway, but the inspiratory and expiratory pressures can be adjusted separately. It is used mainly to treat sleep apnea and under-ventilation that occur simultaneously. Certain bilevel devices function similar to a ventilator because they have a backup rate.

■ **Volume Ventilator** – A device that delivers more air (measured by volume) and thus deeper breaths through a breathing mask into the airway. Air does not flow continuously, but rather is delivered in the right amount with each breath, with the correct breathing rate and the exact inspiratory flow speed. This ventilatory support is sometimes necessary for those with respiratory muscle weakness and underventilation when a bilevel device cannot deliver sufficient pressure.

■ Newest on the scene are **multi-mode ventilators** that provide volume control, pressure support and control, and bilevel device and CPAP modes. They are smaller, weigh about 13-20 pounds, and cost more than other breathing machines.

■ **Negative pressure devices** are still used by the occasional polio survivor. Vacuum-like intermittent negative pressure devices used on the chest and abdomen include iron lung, chest shell and body jacket, though they are considered less effective than positive pressure machines.

■ **Rocking beds** exist but have given way to more effective solutions.

■ **Tracheostomy** is a surgical opening into the trachea for creation of artificial airway. This invasive method is sometimes indicated and in certain cases may not be avoided. It provides

#### **PRACTICAL SUGGESTIONS:**

- Adopt a healthy lifestyle, avoiding that which makes breathing more difficult, such as obesity, smoking, alcohol intake.
- Be aware – avoid unnecessary oxygen therapy, sedatives, humidity, extremes of temperature and excessive fatigue.
- Get flu and pneumonia vaccinations at the right time and stay away from people with respiratory tract infections.
- Plan well before surgery, especially anesthesia use, avoiding general anesthesia whenever possible in favor of local or regional anesthesia. Avoid unnecessary surgery.
- Carry out chest or lung expansion and assisted coughing exercises and other therapies recommended by the doctor.
- Use small, home devices for monitoring, such as a peak flow meter or an incentive spirometer or a portable oximeter to assess stability, especially during respiratory infection, if your doctor agrees.

direct access to the airway for ventilation and secretion management. Because of its potentially serious complications, many patients prefer to avoid or delay tracheostomy in favor of noninvasive methods, unless it is a matter of life or death.

#### **Interfaces**

All breathing machines deliver air through tubes going from the machine to the person using them. These tubes connect to an individual by an interface such as a face mask or nose mask or nasal pillows or mouthpiece. Numerous styles of interfaces exist. Through trying several of them, a comfortable one that doesn't leak can be found (or can even be custom-made).

Getting my ventilator and mask took some experimenting. At first I was sent home with a BiPAP® machine and a Respiratory Therapist (RT) to get me started. She adjusted the controls according to the doctor's orders, placed the mask over my nose, and turned on the machine. I was immediately hit with a blast of air the likes of which I hadn't felt since I stuck my head out of the car window as a kid when my dad was driving down the highway. There was no way I could take a breath with all that air coming at me. It was frightening not to be able to inhale – especially when I was using a machine designed to help me

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#### **Reminder:**

It's flu season ...  
*be sure to get your  
flu shot.*



### Excerpts from a Letter to Post-Polio Health International

*Ann O'Meara, New Jersey, called one day to talk about her brother and his recent death. She is committed to telling his story to encourage family members of other polio survivors to be alert. The excerpt below is only part of the story. The full story can be found at [www.post-polio.org/edu/pphnews/pph23-4ann.pdf](http://www.post-polio.org/edu/pphnews/pph23-4ann.pdf)*

My brother John was stricken with polio at seven years of age. He spent nine months in the hospital in an iron lung and lost the use of his right arm.

Over the past few years, John had recurring bouts of bronchitis. He often had trouble sleeping and would get out of bed and sit in a chair to finish the night. We thought the interrupted sleep was causing his fatigue. He began to fall asleep more and more during the day. Then his speaking became softer and slower, as if he didn't have enough air. His incredibly sharp mind and even quicker wit sometimes drifted into randomness during conversations.

John was under the care of a cardiologist who asked him to wear a 24-hour EKG, which he did. Eleven days later, the cardiologist's office called and told him to "go to the emergency room." There John experienced an "event" in which he stopped breathing. He was moved to Intensive Care, placed on a respirator, and later given a pacemaker.

During the hospital stay John realized how sick he had been. He came to understand our concern. I was hopeful that he would be a stronger advocate for himself. I contacted Post-Polio Health International and ordered the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* so that I could learn more.

John returned home and seemed well for a week or so. Then, again, I began to notice the slowing of his responses. He was bereft of energy. He returned to sleeping in the chair. It was in the chair that he died in the early hours of an April morning. I received the *Handbook* I'd ordered. As I read, through my tears, I was stunned to see the symptoms that were exactly John's experience.

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breathe. I asked the RT to change the settings. She said she could not. Clearly my breathing problems were not meant to be solved by BiPAP® at those settings.

Later I was given a PLV®-100 volume ventilator to try. With settings determined by my pulmonologist, this gentle machine gives me the predetermined amount of air I need at the predetermined moment when I need it. In a sense, it breathes for me. It's easy to care for: every morning I rinse the nose pillows and mask tubing in delicately soapy water, and once a week I soak them in a vinegar and distilled water solution. I also change the longer disposable tubing and filter weekly.

Since my weak neck muscles have trouble handling any weight at all above the shoulders, and I cannot tolerate a band around the back of my head, I decided to adapt a nose pillow mask to my needs. I simply discarded all the paraphernalia holding the mask onto the head and attached the front

mask piece to a light plastic dime store headband with duct tape. No leaks, only a couple of ounces of weight – AND my pulmonologist approves.

### A Final Word

What was I thinking all those years ago when I was resisting mechanical ventilation? I was so afraid to let go. I thought if I could just hang tight to my life the way it was and not allow anything more to slip away from me, not cave in to another limitation, everything would be fine. I fought for this. I did not want the risk of change. It seemed impossible that the hideous green machine now residing in my bedroom could bring me freedom – but it has.

While I sleep, my polio-weakened muscles get to rest, and I awaken refreshed, free to go about my day feeling more energetic and alive. I've found a serenity in all of this that I never dreamed of.

There's great value in acceptance. ▲