

Bilevel Ventilation

Rick Van Der Linden, Editor, *The Southern California PPS Manager Newsletter*,
ppsman@aol.com

A polio survivor from the class of 1953 at age five, I was diagnosed with bulbar polio. The doctor advised my mother that she should not be surprised to find me in an iron lung some day, but I never was put in the “can.” The most apparent effect of the disease shows in my pectoral muscles.

I started experiencing the late effects of polio – mainly pain, weakness and fatigue – during the late ‘80s. That prompted an all-out effort to rebuild strength. My weapon of choice was long-distance bicycling. Within a few years, I was able to ride 75 to 100 miles per week and rode the occasional century (100 or more miles in one day) while training to ride from California to Virginia.

During months of preparation I noticed that, in spite of strict attention to diet and a carefully planned training schedule, I was dropping behind my older training partner. The first hint of breathing weakness came when I discovered that I could reduce burning in my leg muscles by using my abdominal muscles to increase ventilation. Then I noticed reduced performance at elevations over 3,000 feet.

One day, on a casual ride near my home, I came across a lady walking slowly along the roadside. As soon as I saw the braces on her legs, something clicked, so I stopped to talk. Yes, she had had polio and worn braces as a child, but then had forgotten all about it – until now. They were new braces. I concluded I had better watch out for polio’s late effects. The bicycling phase of my life soon tapered off.

For the next few years, I experienced breathing and sleep problems that included sleepless nights, waking up in a sweat, “drowning” dreams, memory and concentration problems, poor judgment, high blood pressure and chronic fluid in my lungs. (Asthma runs in my family, I have allergies, and I smoked for 10 years.) I was

unaware that breathing assistance could solve my problems.

I sold my business, signed up for Social Security Disability Insurance, started using leg and back braces, and moved to a lower elevation. Later, after pulmonary function tests (PFTs), Jacquelin Perry, MD, Rancho’s famous polio doctor, brought up the idea of using a machine to help me breathe. That scared me, so I put it out of my mind for a while.

I had three more PFTs, two home sleep studies, and two overnight lab sleep studies over a period of two or three years. A pulmonologist who does not believe in post-polio syndrome determined that I was not significantly impaired and that the findings were “borderline.” He prescribed a CPAP unit and then a basic bilevel unit – both of which I struggled with using over the next year.

Finding the appropriate ventilator has been a lengthy learning experience for me. By the time I got a basic bilevel unit (S – spontaneous – mode means you can initiate your own breaths), I was so bad off that I needed to recover some physical and, most importantly, mental function before I could start to

recognize the individual reasons for my underventilation and mixed sleep apnea problems. It was then that I realized that the spontaneous mode didn't address all my problems.

When I explained my need for a bilevel machine with a backup rate (ST – spontaneous and/or timed – mode means if you can't initiate a breath on your own, the machine can be set to do it for you), my doctor agreed but said I would be in for a long battle with my HMO.

I made the decision to switch to Medicare Direct, found a durable medical equipment company experienced in neuromuscular breathing/sleep problems and noninvasive ventilation (they tested my vital capacity in the supine position), and obtained a VPAP® III ST.

Even though my self-initiated breaths have increased, I will always need the timed function to start a breath for me. Reason: If I overdo during the day, I go to bed too tired to start each breath. Over time I get into a deficit situation, and it begins to snowball. Without a backup rate, recovery can take days or weeks depending on my general life situation at the time. With the timed feature, I can recover quickly.

I've been using VPAP® III ST with built-in humidifier for more than a year with an Ultra Mirage® II nasal mask (both from ResMed; www.resmed.com). The VPAP is so quiet that I forget I am using it.

I'm fortunate to be able to set the machine myself. The smaller IPAP (inspiratory positive airway pressure) and EPAP (expiratory positive airway pressure) increments of .2 taught me that my polio-weakened diaphragm

and intercostals are more sensitive to the pressure setting than I previously thought. Since I don't have the classic obstructive sleep apnea problem in which the upper airway needs to be kept open, I prefer 3 or even 2 (lowest EPAP setting on VPAP III is 4).

A lower EPAP setting also makes it easier to start a breath, increasing the percentage of self-initiated breaths.

Understanding the way the machine settings need to balance has helped me visualize my exact breathing needs and make corrections accordingly for a greatly improved quality of life. ▲

Custom masks.

Matt Singer of Silicone Ocular & Singer Prosthetics in Memphis, Tennessee, specializes in maxillofacial prosthetics. He has recently made a unique custom facial mask (retained by dental appliances) for respiratory polio survivor Deborah Cunningham (Deborah@mcil.org). The mask design is similar to Deborah's old mask made by Sue Sortor and her team at Dallas Rehabilitation Hospital many years ago.



Singer's masks are made of vacuform plastic with a removable silicone gasket, either soft or firm. Total cost is \$2,800 (covered by most insurance carriers) with a turn-around time of two days. Masks are estimated to last

for several years, providing the person does not lose or gain a significant amount of weight and the person's teeth remain essentially the same.

To contact Matt Singer, phone 901-405-4440 or email msinger@flexiglasseye.com.