

From Vent to Diaphragmatic Pacing System: Conclusion

Bill Miller, Leesburg, Florida, www.LookMomNoHands.net



Bill Miller

Ultimately our trip for my surgeries was successful, though not as successful as hoped. The primary successes were: replacing my cardiac pacemaker, getting x-rays of my chest and neck that I was given to view on CD and having actual outpatient surgery for my procedures (no overnight stay required, which limited my chances for infection). I'm now more than two months post-surgery, and I've healed well with no infections.

Missing from that success list is implementation of the NeuRx Diaphragm Pacing System™ (DPS). Even when inside my chest, with the electrodes placed on my diaphragm, my diaphragm wouldn't fire when stimulated by the DPS. My surgeon, Dr. Michael Cheatham, tried everything – even calling DPS inventor Dr. Raymond Onders (who trained Dr. Cheatham to do the DPS) for additional suggestions. It wasn't meant to be.

Dr. Cheatham indicated that my diaphragm apparently has zero innervation, as it was completely atrophied and much thinner than he typically sees. Even if it had fired, he was a bit apprehensive about placing electrodes into my diaphragm because it was so thin and he didn't want to damage anything.

Though I could have received several benefits from the DPS, I stand by my statement that I already have a high quality of life, and I'm not limited by the vent in the most important ways: speech quality and infections.

For a quadriplegic like me, my ability to talk well is of extreme importance.

And if you've heard me talk in person or via phone, I think you'll agree that I speak well and typically clearly, at an appropriate volume (when well hydrated) and with little pause between breaths. Only having a brief pause is thanks to a speaking valve, and also the ability to initiate another breath sooner than programmed, and also receiving fairly large breaths.

With the DPS, I was concerned about matching that quality because breaths cannot be initiated with the DPS, and the size of breath is smaller than what I receive via vent (quite possibly 30 percent smaller for me). That could have been mitigated by increasing my breath rate on the DPS, but only doing it could answer that question.

Also, my lack of significant respiratory infections for a vent user is fairly uncommon, and is represented by zero respiratory-related hospitalizations in the 13.5 years since I was discharged from my initial hospitalizations and rehab. I'm certainly not saying that my number of infections would have increased on the DPS (it could have,

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International Ventilator Users Network's mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.

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From Around the Network

Judith R. Fischer, MSLS, IVUN Information Specialist, info@ventusers.org

Product News

Ventilator users interested in changing their interface and/or ventilator should discuss the change with their pulmonologist and home health care provider.



Mirage™ FX (left) is the newest nasal mask in ResMed's FX series. The lightweight mask utilizes the Spring Air™ cushion for an even distribution of pressure and extra softness on the bridge of the nose. www.resmed.com/uk/products/mirage_fx/



S9 VPAP™ ST, based on ResMed's S9™ series for sleep-disordered breathing, provides bilevel support

with a backup rate. The EasyBreathe motor technology distributes airflow more evenly throughout the motor to reduce noise. The Climate Control humidification system provides vent users with a ClimateLine™ heated tube. Integrated oximetry is an optional feature. Many data management options are also available. www.s9vpap.com



LTV® 1100 (left) is the latest portable ventilator in the LTV series from CareFusion. It is designed for vent users who need volume ventilation with pressure support; it does not provide pressure control. www.carefusion.com

OPAP, the oral interface described in *Ventilator-Assisted Living*, December 2010, aroused interest in ventilator users, but they experienced some difficulty in contacting the manufacturer. The OPAP Healthcare site – www.opaphealthcare.com – is being updated, but it provides the basic information on how the device works. Direct contacts are Larry Twersky, Ltwersky@1800snoring.com, 800-818-0598, and Scott Veis, Vice-President of Sales and Marketing, Appliance Therapy, scottv@appliancetherapy.com, 800-423-3270, ext. 4590.





NEV®-100 has been discontinued by Philips Respironics. (www.ventusers.org/edu/faqNEV-100mar11.pdf) People who have been using the unit to power the Porta-Lung are advised to use either the Hayek RTX Respirator, www.unitedhayek.com, 866-361-4839, or Pegaso V from Dima Italia, www.dimaitalia.com, distributed in the USA by Porta-Lung, Inc., 303-288-7575.

Home Care Workers

Jim Lubin, who uses a vent and hires his own attendant care workers, recommends an excellent website from the Home Care Referral Registry of Washington State. The site provides useful resources. “Hiring and Supervising Your Home Care Worker” is available as both a print download and YouTube video. www.hcrr.wa.gov/Consumers2010/videos_guides.html

Vent Users in Taiwan

In February, polio survivors in Taiwan demanded that the Bureau of National Health Insurance (BNHI) cover home respiratory equipment. Joined by representatives of the opposition political party, they want the qualifications for reimbursement of home respiratory support changed. Currently home ventilators are provided free to those who have undergone 21 consecutive days of tracheotomy or intubation. It is estimated that there are approximately 1,800 people in the government-funded home respiratory support program annually.

The annual cost of home respiratory support, including respiratory equipment, maintenance fees and a therapist to provide regular check-ups, is estimated at NT\$500,000 (USD \$15,625), but the cost is too high for individuals and families. The BNHI will evaluate and review the reimbursement plan. ▲

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because I’m breathing through three filters on the vent and would have had one filter at most on the DPS) but it’s hard to beat zero in 13.5 years.

I’m not disparaging the DPS; I have two friends in particular who are benefiting significantly from the DPS, and I wanted to try it and potentially benefit from it. But I don’t want anyone reading this to think that life with a ventilator is a necessarily bad.

If my diaphragm had fired when stimulated by the DPS, I would’ve continued to embrace the challenge of becoming a successful DPS user.

But that is/was a very significant challenge that included learning and teaching my caregivers different ways of providing for my needs. For example, it would’ve placed a port on my stomach where the DPS connected that would’ve required care and careful bathing around it, etc. The point being, I think that we, as a team, are already good at life with a ventilator and largely see it as not that big of a deal.

No worries and God bless! ▲

MORE on www.ventusers.org

For more on Bill’s pursuit of the NeuRx Diaphragm Pacing System™, see:

Part I
www.ventusers.org/edu/valnews/val_24-2Apr10p5.pdf

Part II
www.ventusers.org/edu/valnews/val_24-3Jun10p4-5.pdf

Part III
www.ventusers.org/edu/valnews/val_24-5Oct10p4-5.pdf

Ask The Experts

QUESTION: My friend in Hawaii has spinal muscular atrophy, Type 3 (SMA3), uses a ventilator, and is in a motorized wheelchair. Her husband is her sole caregiver since they have no insurance or money for private care. She is not old enough for Medicare and his income (on paper) does not qualify them for Medicaid. How do other ventilator users obtain attendant care?

ANSWER: Deshae Lott, deshaelott@hotmail.com

Your friend's situation sounds quite familiar to me. There are a few things I can suggest, though none of them offers an immediate resolution to this difficult and depressing situation that I, too, have faced and do face.

First, SMA3 should qualify her for SSI (Supplemental Security Income) or, if she has paid into Social Security for 10-plus years of work, for SSDI (Social Security Disability Income). Signing up for Medicare, despite a wait, eventually will alleviate some health care expenses. This will and can supplement any other insurance she has and reduce the burden of medical expenses that Medicare approves, which will not be hourly skilled long-term caregiving, but still will help with overall finances so that more funds of her own can be directed into caregiver costs.

Second, they should check with the state Medicaid office or an independent living center to see if there are any waiver programs for caregiving. These services often have long wait lists. I've been waiting on a list in Louisiana since 2004; however, if I am alive when my slot opens, perhaps within two to three years, that program will begin to assist us tremendously. After the 1999 Olmstead decision, which ruled that Title II of the Americans with Disabilities Act prohibits the unnecessary institutionalization of persons with disabilities, most states have initiated such programs. Some states have a much swifter service record than Louisiana.

Third, check into a special needs trust. The rules vary state-to-state. However, this is a way the government allows you to receive its benefits (or remain eligible to stay on wait lists for services) but also to have a means to supplement your care costs for things the government does not cover. Such a trust can fund medical expenses not already covered by other means (private insurance, Medicare, and/or state Medicaid insurance) but cannot fund basic daily living expenses (housing, food, clothing) that SSI or SSDI and other government assistance programs are designed to support.

The trust requires using a specialized attorney, and that can cost \$1,500 to \$7,000 – a considerable expense. However, if there are friends or relatives who have an interest in supporting your

Are you a ventilator user or health professional with a question about home mechanical ventilation?

Send it to info@ventusers.org, and IVUN will find experts to answer it.

friend's health costs, it's vital to have a trust. Direct gifts to the individual are forbidden if one is to receive or to qualify for government support. But gifts can be given to a trust. The caveat is that neither she nor her husband can serve as trustee. They will need a trusted friend, relative or a bank representative to serve, and this may involve financial compensation for their time. So, this is an option, but again it has its limits.

I have had to cultivate a peace with the high cost of my life. This entailed a grief process, but in the end, I looked at the facts straight on, knowing mostly I'd be facing Hobson's choices. It's humbling to wish to be self-reliant and then to conclude that a vast array of a community's resources will be required to sustain one's life.





Finding peace with this daunting situation has been a matter of deciding whether I feel purposeful in staying embodied, and – as a person of faith – whether I feel it is God’s will that I do so. As long as I can say “yes” to purpose and a sense that God still wishes my soul to inhabit its current physical form, then I opt to do the best I can. It involves re-enthusing one’s self for and re-committing to the journey each day. And then I problem-solve and navigate my dynamics as best I can, step by step.

Please let me know if you have questions about what I’ve shared. I am not fully informed about various state regulations or specific situations, but I can share more of my experience.

ANSWER: Audrey King, king.aj@rogers.com

If you lived in the province of Ontario, Canada, and are considered “competent” (able to hire, fire, manage, direct and pay your attendants in accordance with Ontario’s Employment Standards and Regulations), you qualify for Direct Funding. Funding for up to six hours a day at \$15 per hour is deposited directly to you by the Ministry of Health and Long-Term Care. If you use a ventilator 24/7 you may be granted nine or more hours per day. You would become an employer or “self manager” and would be expected to take on the responsibilities and liabilities entailed as well as keep records and provide a quarterly report to the government (via your local center for independent living).

In addition to “hours” there are also provisions for contingency situations and an option for flat-rate overnight situations. This is very low – \$30 to \$50 – and is based on the premise that somebody sleeps over just to be “on call” if needed. Many significantly disabled ventilator-assisted people have found this program sufficient to establish a successful “live-in” caregiver situation. The great thing is the flexibility and choice in choosing your own attendants, in how and where and when you use these hours and what you can train them to do for you, e.g., any routine procedure like suctioning and catheterization and/or driving. The down side is the small size of the program and the lengthy waiting list. Approximately 500 people are still waiting to get on to the program.

Alternatively, you would be eligible to receive up to a maximum of 14 hours per week from your local Community Care Access Centre. This medically assessed service is only for personal care, simple meal assistance and to tidy up your home. You are likely to receive care from a variety of workers and at times not necessarily convenient to you. Also, the service is usually burdened with policies and procedures that limit you further, e.g., no nail cutting, registered nurse (RN) must train the worker in using your lift, two workers must be present during lift transfers, only RNs can do “invasive” procedures such as suctioning, catheterization, injections and medications. ▲

Deshae Lott, PhD, teaches at Louisiana State University in Shreveport. She serves as President of CMMS Deshae Lott Ministries Inc, a nonprofit offering support for those interested in spiritual studies whose Outreach Program offers quality-of-life grants and scholarships to persons with severe physical disabilities. Diagnosed with limb girdle muscular dystrophy at an early age, she is a ventilator user and has used attendant care for 18 years.

Audrey King, PhD, is an instructor, researcher and advocate on disability issues at university, government and community levels. A psychologist by profession, she played a key role in establishing Ontario’s attendant services – supportive housing, outreach services and the Direct Funding program. King, a ventilator user who was disabled by polio at age 9, has used purchased attendant support for the last 25 years.



First CPAP, 1988-1989,
Sullivan branding



S9 Elite™ CPAP, 2010



BiPAP® ST, 1990



BiPAP® AVAPS™, 2007

Sleeping (and Breathing) Better: 30 Years of Progress

Judith R. Fischer, MSLS, IVUN Information Specialist, info@ventusers.org

Thirty years ago, the April 18, 1981, issue of *Lancet*, a renowned British medical journal, contained an article entitled “Reversal of obstructive sleep apnoea by continuous positive airway pressure applied through the nares.”¹ Written by lead physician and researcher Colin E. Sullivan with his colleagues in Sydney, Australia, it described the first use of what we now know as continuous positive airway pressure (CPAP) therapy to treat obstructive sleep apnea (OSA) noninvasively. Before CPAP, the treatment for OSA was an invasive tracheostomy.

In OSA, people experience a cessation of breathing (apnea) during sleep because the muscles of the throat collapse to block the airway. The CPAP therapy works by forcing a continuous flow of air down the airways to keep them open during sleep to prevent episodes of apnea. The individual wears a nasal, full or partial face mask, or nasal pillows connected by tubing to a CPAP unit.

Beginning in the 1950s, sleep medicine pioneers Nathaniel Kleitman, Elliot Weitzman, William Dement and Christian Guilleminault discovered and identified sleep stages that became the basis for understanding the influence and effects of sleep on breathing in the late 1970s.² (The Association of Sleep Disorders Centers was founded in 1976.)³

Sullivan expanded on those discoveries and characterized the pathophysiology of adult sleep apnea, later studying the use of noninvasive ventilation during sleep to manage respiratory failure. He helped develop the technology of CPAP and a variety of mask interfaces for ResMed,⁴ established and headquartered in Australia in 1989.

Taking CPAP a step further, Mark Sanders and Nancy Kern published an article in *CHEST*⁵ in 1990 describing the use of noninvasive ventilation at two different levels of pressure:

higher for inspiration, lower for expiration. Commercially developed by ResPironics,⁶ Inc., in Pittsburgh, Pennsylvania, this method of bilevel positive airway pressure was patented as BiPAP®. Although originally intended for people with OSA, this form of bilevel ventilation became widely used by people who needed nighttime ventilatory assistance. It offered an alternative to the volume and pressure ventilators that have alarms and more safety features for 24-hour use and are more expensive. Many companies in many countries around the world have since developed their own versions of the original devices.⁷ ResMed later developed its own bilevel units.

CPAP and bilevel use has skyrocketed in the past 30 years. CPAP's rise can be attributed to the high incidence of OSA in the general population, estimated at 12 percent. Auto-titrating, or automatic, positive airway pressure (APAP) units have been developed that are more sensitive in adjusting to individual breaths. The use of bilevel units as a first step in treatment that improves sleep and breathing in people with neuromuscular disorders such as ALS, muscular dystrophy and post-polio, and in children with CCHS, has gained widespread acceptance. The availability of bilevel units in developing countries that cannot afford volume or pressure control



▷ ventilators for home care has also contributed to its increasing use.

It is not an understatement that CPAP and bilevel units have improved the sleep and breathing of countless thousands of people and, in the process, have saved lives. ▲

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