

## From Vent to Diaphragmatic Pacing System: Part I

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I am paralyzed from the neck down and use a ventilator due to a high-level (C1-2) spinal cord injury that I incurred in August 1997. I had heard about diaphragmatic pacing systems as an alternative to ventilators and learned of the NeuRx Diaphragm Pacing System (DPS)™ several years ago, but I didn't think this method of ventilation could do much to improve my quality of life and might even decrease it. But I decided to consider the benefits and drawbacks of the DPS to determine whether it might work for me.

The biggest benefit would be growing comfortable enough with the DPS to remove the ventilator and vent tray from my wheelchair. I would like to get a chair that can stand me up which would provide weight-bearing for my bones and let me view the world from my natural height. I also have speaking engagements and plan to teach at the community college level upon completing my Master's degree. Wouldn't it be cool for a quadriplegic to be able to stand up when speaking?

Not having a ventilator on my wheelchair would also enable me to maneuver in tight spaces more easily. And I could drive my wheelchair while standing – I'd love to roll upright across the stage when I graduate.

Another benefit of the DPS is improved speech quality in bed, because it would be like using a Passy-Muir speaking valve all the time. I don't currently use a speaking valve in bed because the valve tends to dry out my airway; I re-humidify my airway while I'm in bed.

The DPS should allow me to either cap my trach or use a small speaking valve, either of which would make getting dressed a bit easier and wearing certain clothes MUCH easier. Now, the vent circuit attached to my trach makes wearing a tie quite difficult. Also, I could wear a turtleneck or mock-turtleneck, which I cannot do currently, and they could hide my trach altogether. (I'm not self-conscious

about my trach or general appearance, but that would obscure a sign of my disability, which is good because I try to not let my disability define what I can do.) Some DPS 24/7 users have had their trachs removed entirely.

DPS users report that senses of taste and smell both improve, though I cannot imagine certain foods tasting any better than they do now. I can smell fairly well when I actively try to take air in through my nose, and selective smelling can be a good thing! These improvements would be of minimal benefit to me.

For me, the main drawback about the DPS is that it doesn't allow the user to initiate breaths. My voice is my primary link to the world; the better my speech, the better my quality of life. Using a Passy-Muir speaking valve, I have almost continuous speech while receiving 13 breaths per minute (BPM) at a volume of 900 cc (just less than half of a 2-liter soda bottle).

However, sometimes I run out of air to speak with before I finish my thought and have learned to use my neck muscles to initiate a breath. That shortens the pause in between scheduled breaths so I can continue speaking. A simple fix with the DPS is to increase the breath rate to 14-15 BPM which should work during the day when I'm speaking but can be lowered for sleeping.

continued, page 7



Bill Miller

C1-2 Quadriplegic with a 221 High Bowling Game

Co-founder of Manufacturing Genuine Thrills Inc. d/b/a MGT

My blog:  
<http://powerwheelchairusers.blogspot.com>

Business website:  
[www.ikanbowler.com](http://www.ikanbowler.com)

Personal website:  
[www.lookmomnohands.net](http://www.lookmomnohands.net)

# Ask The Experts

**QUESTION:** “I read about new ventilators in *Ventilator-Assisted Living* and would like to get one. I spoke with my current home health care company for durable medical equipment (DME), and they said that if I wanted the Trilogy100 or the Puritan Bennett 540™, I’d have to switch home health care companies because they don’t carry them. How do I find a local home health care company that provides the newer vents? Does it make a difference if I have private insurance or coverage by Medicare or Medicaid?”

**ANSWER:** First of all, you will need to have a prescription from your physician and agreement from him or her that the new equipment you desire is the best for you.

If you want to get the Trilogy100, call Philips Respironics at 800-345-6443 and ask for Customer Service. Tell them that you would like to find a DME supplier that rents or sells the Trilogy100 in your neighborhood.

You can do the same if you are interested in the Puritan Bennett vent but please be aware that Puritan Bennett products are now sold by their parent company, Covidien Ltd. Call 800-635-5267 to connect with one of the manufacturer’s representatives in the United States.

The health insurance that each supplier accepts varies. Most accept Medicare as the primary insurance carrier. Not all accept Medicaid as the primary carrier but may accept it as the secondary carrier. Private insurance offers a vast array of plans, both in-network and out-of-network.

Check with the supplier to determine your coverage. ▲

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## **Do you have a question about ventilator-assisted living?**

Are you a health professional with a question for ventilator users? Send it to [info@ventusers.org](mailto:info@ventusers.org), and IVUN will find experts to answer it.

## **From Vent to Diaphragmatic Pacing System: Part I** continued from page 5

I was also leery about having only battery power for the DPS. It’s comforting to know I have unlimited vent time when plugged in to a standard outlet, as well as vent batteries that provide about 12-14 hours on a full charge, and charge simply by being

plugged in. However, a friend who has used the DPS essentially 24/7 for more than five years hasn’t had any issues with the batteries.

After thoroughly investigating the system and with the issues resolved in my mind, I decided to proceed in converting from conventional assisted ventilation to the DPS. Stay tuned for Part II. ▲

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**Bill Miller**  
[www.ventusers.org/edu/valnews/val14-2.html#nob](http://www.ventusers.org/edu/valnews/val14-2.html#nob)

**Diaphragm Pacing System**  
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