

The Road to the RTX

Carol Purington, Colrain, Massachusetts

The journey started on June 1, 2012, when I received a letter saying that the machine that powers my Porta-Lung, the NEV-100, was being discontinued at the end of the year. I needed to find a replacement for something I use twenty or so hours a day. I was shocked. I'd been told that the NEV-100 was being phased out for some users but not for those, mostly polio survivors, who rented it directly from the distributor. Very bad communication on someone's part!

My primary care physician was sent a similar but not identical letter, in which two options were offered – switch to positive pressure ventilation (PPV) or use the Hayek RTX (www.unitedhayek.com/products), apparently the only negative pressure ventilator on the market that will operate the Porta-Lung. (Briefly, PPV blows air into the lungs through the nose or mouth via an interface or a trach. Negative pressure ventilation uses a chamber, e.g., iron lung, chestshell, Porta-Lung, to create a negatively pressurized area around the torso, causing air to be pulled into the lungs.) In my case, the NEV-100 is used to create the negative pressure.

I've used negative pressure ventilation for 60 years and didn't like the idea of changing to PPV. My primary concern is about having to use a mask or nose piece in the middle of a serious respiratory infection, when having air pushed through my throat sometimes irritates it so much that the airway temporarily closes, which is very frightening.

During this past year there have been occasions when I wondered whether I really would have to give up on negative pressure ventilation (NPV). PPV is now

much more widely used than NPV, which means it's what the medical community is familiar with and what manufacturers develop and sell. But so far converting to PPV hasn't been necessary.

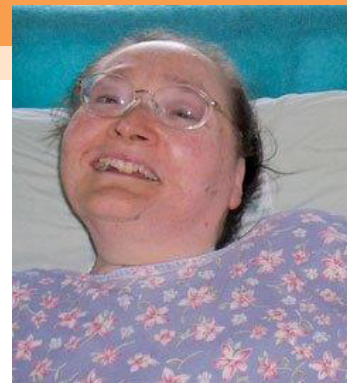
I began almost immediately to research the Hayek RTX after recalling an article in *Ventilator-Assisted Living* (October 2010, Vol. 24, No. 5). I also found another NPV ventilator that sounded promising, an Italian-made unit called the Pegaso V. No one seemed to know much about the Pegaso V because it is not available in the United States. (Note: Pegaso V is looking for a U.S. distributor having received permission to market in this country.)

Back to the Hayek. To get my hands on a trial RTX, I had to work through various medical and insurance forms. Completing that process took until November. In the interim and after several detours, I obtained the newer Porta-Lung, which is in short supply, too. I would have lost my way without much advice and assistance from family members.

Finally, on December 13, a Hayek respiratory specialist from Philadelphia brought an RTX to the house. He brought three sizes of the Hayek chest shells, none of which fit. It actually was a good thing because we discovered that the RTX can work with my familiar chest shell.

The RTX provides a different breathing rhythm, jerkier than I'm used to, but I knew I could adjust. I also tried the RTX with the Porta-Lung and found that it couldn't deliver the same readings that the NEV does. The specialist said that some RTX users find they do okay with the RTX producing lower readings than they are used to with NEV. This was not very confidence-inspiring.

The RTX is significantly louder than the NEV. That's a serious problem for me because I have a soft voice, and



Carol Purington

Carol Purington is an award-winning haiku poet who has published eight books of poetry. She is the seventh generation of her family to live at Woodslawn Farm, a dairy farm in the Berkshire Hills of Massachusetts. She contracted polio in 1955 at age 5 on her first day of grade school.



▷ also because I use a voice-recognition computer system that doesn't deal well with environmental noise.

We decided that before I made a commitment to the RTX, I needed to have tests done to compare oxygen and carbon dioxide levels with the RTX/ Porta-Lung and the NEV/Porta-Lung. Learning what equipment was needed, figuring out how it could be brought to the house, arranging to have a respiratory therapist involved, finding out how to get the information from the equipment to my pulmonologist's computer – all of these activities took until May. The tests were completed by mid-June, and I received my pulmonologist's assessment in July.

Briefly, the RTX ventilates me at least as well as the NEV. So now I know that I have to work with the RTX, at least for the immediate future. And, that I can!

Meanwhile, I will do my best to be flexible and patient. Many family members are thinking about solutions to the noise issue. Unfortunately, simple ways of reducing noise also impede the needed movement of cooling air through the unit, which can cause overheating problems.

I wish that the NEV will again become available, but I can't rely on that. I would like to network with other NEV users so we can compare our situations and solutions. Email me at carol.purington@gmail.com. ■

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