

IVUN's mission is supported by its Membership.

Highly Dependent on Power!

Audrey King, MA, Toronto, Canada

A massive winter storm hit the eastern United States and southern Canada just before Christmas last year, causing major inconvenience to millions of people. Power outages in some locations caused further complications, and to some, like Audrey King, created a life-threatening crisis for nearly four days.

I have lived in Toronto for 30 years, on the third floor of a condominium mainly occupied by empty nesters, older folk who enjoy the quieter lifestyle and amenities nearby. Although the building is five stories high and lacks an emergency generator, living here has suited me well.

My apartment has been renovated to meet the needs of an “independent” quadriplegic lifestyle — counters and sinks I glide under in my wheelchair, taps I can easily reach and turn on with a touch, ceiling tracks in bedroom and bathroom so I can electrically hoist myself and transfer between wheelchair, bed, toilet or bath. A remotely operated door opener enables me to let people in and out of my apartment. Battery chargers power my wheelchair and floor heaters cater to my impaired circulation. Even my Ultramatic bed enables me to shift position frequently during the night. Of paramount importance is the ventilator I am dependent on during the night, and often during the day to keep me breathing. I am highly dependent on power!

Every weather related power failure since the four-day power failure 10 years ago has prompted me to do what I can to keep emergency supplies on hand and to advocate for establishment of a vulnerable persons registry, but there has been little interest or initiative.

Obviously, I was worried about the ice storm forecast.

When the icy rain started I was happy to be comfortably in bed, having made it safely back from a family Christmas party in another town. The ventilator alarmed about 1:30 am and switched to its internal battery mode — good for two more hours. Hopefully, the power will return by then, I thought. At 3:30 am as it alarmed again I woke my weekend attendant and switched to the back-up ventilator. This one had six hours of internal battery life. I slept lightly for a little longer.

As the light of dawn broke, one glimpse of the beautiful devastation out of the window made it crystal clear the situation was serious and likely to persist for some time. Neither land line nor cell phone worked ... for several days as it turned out. I could listen to radio reports, sparingly, on my cell phone but could not call for help. No batteries could be recharged.

Staying alive, breathing, was essential! The first priority was to find a source for recharging the ventilators and enabling at least eight hours of further breathing support. The superintendent located a working telephone at a neighbor's down the hall. Phone calls to my book club friends at the church across the street led to the church turning on their generator

continued on page 6



World Health Organization Releases International Perspectives on Spinal Cord Injury

Joan L. Headley, Executive Director, International Ventilator Users Network, St. Louis, Missouri

It was through my colleague David Gray, PhD, Professor of Occupational Therapy and Neurology, Washington University, St. Louis, Missouri, that I joined the advisory committee for a major project of the World Health Organization about perspectives on spinal cord injury. The document is written for the world in which every year between 250,000 and 500,000 people suffer a spinal cord injury, with road traffic crashes, falls and violence as the three leading causes.

People with spinal cord injury are two to five times more likely to die prematurely. I had the opportunity to review chapters looking for information about the option for ventilator use and to pass along the opinions of users of home mechanical ventilation. IVUN was specifically asked, "Do you think attendants of ventilator users should be required to have some medical training and should there be a method of certifying them?" We asked the question in February 2012 via internet posting to two ventilator user listserves. Respondents were those who used a ventilator as a result of disabilities such as SCI, post-polio, ALS, muscular dystrophy, etc.

Long-term ventilator users responded, with the following comments:

"How to train a new attendant/caregiver is a tough question. I'm sure you will get many answers. Most often, the old attendant trains the new one. A family member may be available to train."

"Some of us vent users can and do train the new person. As far as what specific training to give the new person, just train for the specific person's needs, and don't overwhelm the attendant with stuff that's irrelevant."

"Of course an RN or LPN would be nice, but too expensive and some training with the vent might be needed. Everybody needs to be flexible because there is no international standard."

"The agency that provides two of my caregivers provides specific ventilator training followed by a competency exam. My privately hired caregivers receive their training here by my most experienced caregiver. I personally believe certification is not necessary."

"The training and licensing of a personal assistant regarding ventilator use can well be false security regarding competence and ability to meet the needs of a ventilator user. I nearly died once because a so-called 'qualified and licensed' nurse decided I was just anxious and did nothing when I was having difficulty breathing. It was my long-time personal assistant (who had been shown how to suction at the hospital before discharge)



VENTILATOR-ASSISTED LIVING

February 2014

Vol. 28, No. 1

ISSN 1066-534X

Editor: Gayla Hoffman, info@ventusers.org

Designer: Sheryl R. Rudy,
webmaster@ventusers.org

©2014 Post-Polio Health International (PHI).
Permission to reprint must be
obtained from Post-Polio Health
International (PHI).

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.

How to contact IVUN

Executive Director Joan L. Headley, MS
info@ventusers.org

4207 Lindell Blvd., #110
Saint Louis, MO 63108-2930 USA
Phone: 314-534-0475
Fax: 314-534-5070
info@ventusers.org
www.ventusers.org



Like us on Facebook.

International Ventilator Users Network (IVUN)

To be sure you receive email updates from PHI and IVUN, set your spam filters to allow messages from info@post-polio.org and info@ventusers.org.

Moving? Change of address?

Notify IVUN before you move by calling 314-534-0475 or email info@ventusers.org, and tell us your old and new addresses.

Away temporarily?

Send us your second address and dates you will be there and we'll do our best to send you our newsletter.

who arrived, encountered difficulty, and in front of the nurse picked up the phone and called 911. As it turned out, a huge granuloma was blocking the airway below the trach tube. I could have died!”

“I look for maturity, interest, basic intelligence and an ability to listen and take directions, well before I even consider any credentials, references or experience with ventilator users. If anything, credentials are a red flag to me and I redouble my efforts to determine the qualities of character I need before hiring a new attendant.”

“As for training a new personal assistant, it’s a combination of having my experienced attendant showing them what to do and my also directing. The interplay between me and a trusted, experienced personal assistant during this teaching process gives the new employee a ‘loud and clear message’ that this is a team effort.”

“Absolutely NO to certification for home care workers. It goes against all tenets of consumer direction for people with disabilities and will force many into institutional settings. I live in a state where we have consumer-directed attendant services (Colorado). We get to screen, hire, train, fire (if necessary) our attendants. We set their duties and decide on their qualifications. In my state it is impossible for a home vent user on Medicaid to find adequate home health services through the agency system. The staff simply is not there. If it wasn’t for consumer direction, we would all be living in acute care hospitals.”

“I can only speak from my experience. I can’t speak for the parent of a non-verbal child who is vent-dependent. I’m fairly independent, with the use of a scooter, limited walking, and I drive a van. I’ve had personal assistants in the past and none were certified, they were trained by me to do simple tasks.”

“I’ve had medical doctors tell me how to suction, adjust my vent settings, even force an adult trach into my pediatric stoma, so I can say the qualifications don’t always match the competency. Personal assistants are just that — personal, not professional. A good relationship with the person is all that is needed.”

“As a resident of California, I have had the responsibility of training my attendants to perform my daily necessary attendant care tasks. Personally, I wouldn’t have it any other way. If I should ever hit a snag regarding ventilator training, (which has never happened in 31 years), I have a very competent RT available to help me. I also rely on a type of training using a more experienced attendant helping to train a new attendant with my oversight. This system has always worked really well for me. I believe if it ain’t broke, don’t fix it.”

“Yes, of course, they need training! I would want them to know what to look for if the vent alarmed, without panicking, how to reset the vent, how to talk my son through breathing off the vent until other help could arrive, if necessary, etc.”

“‘Medical professionals’ always have a tendency to assume that disabled people are naive, ignorant or just plain stupid. They always seem to undermine our knowledge and skill about knowing what our needs are, and how to attend to them.”

“That is a very hard question. I’d say it all depends on the competency of the caregiver. My son is on a vent 24/7, and I can take care of him very well even though I am not a nurse. He does have RNs and LPNs caring for him now. If I could not find a nurse and had to rely on a personal assistant, I would want them to have training. The question is: Where would they receive it? I don’t know of any place here in New York that does such training (which doesn’t mean there isn’t, just that I don’t know about it).”

My personal opinion is that I think personal attendants (PAs) are “the hands” that people with significant disabilities can’t use. The person with the disability instructs those hands to do what they want done when they want it done. I suspect that the relationship/understanding between the two parties, ultimately, is more important than certification.

The vent user understands that the PA comes with some training and skills and the PA understands that the vent user is unique and has certain ways of doing things and should honor that.

My observation has been that new vent users (including families) need and want the attendants initially trained about vent use (e.g., use/care of the vent and the interfaces [masks], trach care, and how to trouble shoot and handle emergencies) by the professionals. For those who use a vent 24/7, it is a matter of life and death.

But, veteran vent users have acquired practical knowledge that most professionals have not had a chance to acquire. It makes perfect sense that they train their own attendants and have past attendants train the new ones. The general fear (in developed countries, too) is that if the task is “medicalized” too much, vent use will become too costly and unavailable as an option. Paying an RN for 24-hour care is prohibitive for most, and in many cases unnecessary.” ■

[Access the full 247-page report ...](#)

[Access a summary and key findings ...](#)



Roger Goldstein, MBChB, FCCP, when presented with the Margaret Pfrommer Memorial Award in Long-term Mechanical Ventilation.

Ventilator-Assisted Individuals; Integrating Across the Spectrum of Care

Dr. Roger S. Goldstein, Director Respiratory Medicine and Senior Scientist, West Park Healthcare Centre, Toronto, Ontario, Canada

Between 1850 and 1950, negative pressure ventilators, rocking beds, cuirass shells and iron lungs were developed. The latter proved lifesaving during the polio epidemics in the mid-1950s. Subsequently positive pressure ventilators (invasive and noninvasive) as well as interfaces (tracheostomy, face mask, nasal pillows) came into being. The growing prevalence of long-term mechanical ventilation (LTMV) is associated with increased survival following a life-threatening episode, increased technology in the intensive care unit (ICU) and greater awareness of individuals whose underlying condition progresses naturally to cardiorespiratory failure so that elective ventilatory support may be initiated.

The spectrum of care for ventilator-assisted individuals (VAI) varies from the ICU (highest acuity of illness and highest intensity of care), to home (lowest acuity and lowest intensity of care). Between these two points there are non-acute assisted ventilatory care units, in-patient rehabilitation units, skilled nursing facilities and assisted living centers, each of which is designed to offer a safe setting for the VAI, preferably with a rehabilitative environment to promote autonomy and self-directed care.

It is now appreciated that the best chance of successful rehabilitation begins in the ICU, with a series of steps to enable those who cannot be fully weaned from the ventilator to be **successfully fully weaned from the ICU**. Of these steps, perhaps the most difficult for some is the psychological separation to a less intense environment.

Long-Term Assisted-Ventilatory Care Units (LTAVCU), either free standing or attached to a hospital, require a multi-

dimensional continuum of service by an interdisciplinary team. The preferred patient is medically stable, mentally alert, understands that ventilatory assistance is long term, is prepared to participate in comprehensive training and is prepared to relocate with appropriate support. Assisted-living units have a lower staffing ratio and skill level than do the LTAVCU. The VAI is encouraged to be more autonomous and so the setting is much less like a hospital and closer to the community.

In 1995, we interviewed 100 VAIs ventilated for almost five years¹. Two points in particular stood out: the first was that the ability to cope with ventilation changed with time. Whereas 52% of respondents indicated initial difficulty coping, only 11% felt this way five years later. Although only 5% indicated that overall they had no difficulty coping, this had increased to 37% after five years. The second point was that when asked if they had made an informed choice when starting ventilation or when long term ventilation was being considered, the group responded yes (37%), no (54%) and unclear (7%). Being more attentive to these points requires ongoing education of the healthcare professionals, patient and family, when ventilation is being initiated or identified as becoming prolonged. We have also developed a more **formal training regimen for VAIs and their caregivers**, in order to reduce the issues and concerns that arise regarding care of the VAI especially in the first few weeks.

It is possible to have an accelerated transition from the ICU to a more appropriate environment if the host and rehabilitation teams jointly identify the discharge setting and support

requirements early in the process of ongoing ventilation. They also need to introduce the idea of leaving the ICU after a training program as well as facilitating discharge plans that link institutional with community care, primary care, homecare and housing. The extent of caregiver training will vary with the mix of family care, private care and community support.

The importance of follow-up, especially with a measure of transcutaneous carbon dioxide tension, has become more apparent. VAIs stable for many years will sometimes require adjustments to their ventilator in response to changes in their medical condition. Age transition from the pediatric to the adult age group also requires a regular reassessment of ventilation, interface, mode of ventilation and the ventilator settings.

A few years ago we undertook semi-structured interviews with VAIs who had neuromuscular conditions (NMD), to learn which things they considered impacted on their health-related quality of life². They spoke about the physical and psychological adjustment to ventilation and the positive effect that a physician, who believes in the effectiveness of their treatment, had on their sense of well-being. They also spoke of the support they received from other VAIs. Their situation was made more difficult by the trauma of the ICU, especially if they had been unable to communicate, and made easier when they were able to share in the decision making. They spoke of the frustration of requiring personal attendants, the public stigma of using equipment, the need for legislation to regulate who could suction, manually ventilate and perform tracheostomy care as well as the energy spent scheduling multiple inter-related healthcare and social services. When asked for recommendations that might improve their lives, they made many, [summarized here](#).

Family members are essential to achieving a sustainable environment for the VAI to live safely at home. Informal caregivers underestimate the care burden especially the combination of underlying NMD and invasive ventilation. Prompted by having encountered several episodes of caregiver burnout, we recently interviewed 21 informal caregivers of 12 VAI with neuromuscular disease³. We were humbled by their tremendous sense of duty.

Many did not regret their decision seeing the satisfaction of their loved one (“If he wasn’t at home, he would not be here today.”). All had been deprived of leisure time (“I am a prisoner in my home, of my own will. I don’t regret it, but this is the way I feel.”).

Those receiving direct funding commented on its positive impact on their lives. The physical and emotional burdens were keenly felt, especially when they could not speak fluently with their loved ones (“Even at night when you sleep, you are sleeping with one eye open.”).

As far as training and education were concerned many caregivers did not know who to turn to for unexpected issues, especially in the first few months (“It was hard to come home even though we got trained. You don’t know what to expect.”). The importance of paid support was linked to the development of burnout.

In summary: There is a broad spectrum of care for the VAI, from ICU to home. The best chances of success occur when training is started early in the ICU. The VAI and caregivers’ ability to cope requires a formal training program that also includes follow-up, as well as early coordination among the various healthcare professionals, home support services, VAI and family. Support from other VAIs and a physician who confidently believes in long-term ventilation has a positive impact. Caregivers are essential to the success of home ventilation. It requires a substantial commitment from family caregivers even in the presence of outside supports. An awareness of the potential for caregiver burnout means that attention needs to be paid to their needs and to the opportunities for respite care for the VAI as well as close integration between the hospital and the community. ■

References:

1. Chest 1995 Home Ventilation: Demographic and User Perspectives. Goldstein RS, Psek J, Gort EH. *Chest* 1995;108 (6):1581-6
2. User Perspectives on Issues that influence the Daily Quality of Life in Ventilator Assisted Individuals with Neuromuscular Disease. Brooks D, King A, Tonach M, Simson H, Gould M, Goldstein R. *Canadian Respiratory Journal* 2004;11 (8) :547-54
3. Family Caregiver Perspectives on Caring for Ventilator Assisted Individuals and Home. Evans R, Catapano, Brooks D, Goldstein R, Avendano MA. *Canadian Respiratory Journal* 2012;19 (6) 373-9

continued from page 1

periodically so Rebecca, my amazing attendant, could transport my ventilators up and down the pitch-black stairwell and back and forth across the icy street to recharge its batteries.

The superintendent and property manager regularly checked on our status. One neighbor brought hot water, another



candles. Yet another 84-year-old neighbor drove Rebecca to get supplies and food, until he too was evacuated by his family. As the building emptied, it became even more frightening and difficult to be alone. I was getting exhausted and feeling helpless,

huddled in my down duvet, unable to even open the door.

On the second day, other long time attendants arrived unannounced, with hot water bottles and thermos. One stayed with Rebecca and me. Given the situation, it was now a two-person job.

Phone calls to my city councillor and the Ontario Premier's office triggered urgent pleas from them to call 911 and get myself to a warming center. But this was no solution. Warming centers had power and heat but not the resources to handle dependent quadriplegic persons such as myself. Going to a hospital was no solution either. Already overwhelmed emergency room staff would not welcome a "non-sick" person to clutter up their halls and protocol.

As my out-of-town family became increasingly aware of my plight, they too pitched in by arriving in person. One niece and her family appeared on Christmas Eve with a hot turkey dinner, which we ate bundled up in blankets and coats by candlelight! Another arrived early Christmas morning with breakfast before her own children had even awakened to open their stockings!

By Christmas Eve, with the delivery of backup ventilator batteries from Kingston's Ventilator Equipment Pool in just a few short hours as well as the help and caring of so many people, I went to bed feeling more secure and believing I might actually survive.

Early Christmas morning, as I lay completely cocooned (head and all) under my extra thick duvet and blankets, feeling snug, warm and safe with the hose from my ventilator delivering breaths from outside the blankets I felt akin to a miner trapped underground yet safe and warm in my little womb cave — "umbilical cord" and all. I listened to incredibly beautiful Christmas music via the earbuds and radio receiver buried with me. The pure pristine words of "Away in a Manger" and then "Rejoice" (Handel's "Messiah") transported me to yet another realm of the soul. I felt I was experiencing, seeing, absorbing the light and warmth of that Bethlehem scene so very long ago.

It was indeed a Christmas to remember — four days of destruction, fear, helplessness and terror. Yet, in the midst of it all, it was a "true" Christmas, one of genuine giving, unselfish caring and coming to the aid of someone in need. ■



Audrey King is a psychologist and internationally known writer, speaker and advocate on disability issues.

Diaphragm Pacing Can Be Bridge to Independent Respiration

A new study published in the *Journal of Trauma and Acute Care Surgery* finds that diaphragm pacing (DP) stimulation in spinal cord-injured patients is successful not only in weaning patients from mechanical ventilators but also in bridging patients to independent respiration, where they could breathe on their own without the aid of a ventilator or stimulation.

The Diaphragm Pacing System (DPS) is a technology providing electrical stimulation to nerves running through the diaphragm, the major muscle involved in breathing. When stimulated, the diaphragm contracts, allowing patients to breathe more naturally than having air forced into their lungs as a mechanical ventilator would do. The system is implanted through minimally invasive laparoscopic surgery.

“DP is a major step in improving the quality of life for patients who have spinal cord injuries and cannot breathe without the help of a ventilator,” said Dr. Raymond Onders, MD, of Case Medical Center, one of the inventors of DPS and an author of the new study. “Based on testimonials that I’ve received from patients who have been in the clinical trials, DP provides patients with a freedom of mobility that they never imagined.”

Read more at www.redorbit.com/news/health/1113067438/diaphragm-pacing-in-spinal-cord-injury-successful-in-weaning-patients-from-ventilators/#rs40ELvdIucuFLXg.99 ■



New Product From ResMed

ResMed’s new **AirFit P10 nasal pillow system** weighs just 1.6 ounces and has color-coded cushion sizing, with small, medium and large sizes in the standard AirFit P10 system, and extra-small, small and medium sizes in the AirFit For Her system, which features headgear designed for women. It includes a new soft and stable QuickFit™ headgear and new mesh vent called QuietAir™ so the AirFit P10 is 50 percent quieter than its predecessor. ■

Not yet a Member?

Join **IVUN** for just \$30 a year (Subscriber Membership) and receive your own copy of *Ventilator-Assisted Living* via email six times a year (February, April, June, August, October and December), plus six *IVUN Membership Memos* via email. For \$55 (Subscriber Plus Membership), join IVUN and PHI and also receive *Post-Polio Health* in print four times a year (February, May, August, November) and eight *PHI Membership Memos*.

You can join online at <http://shop.post-polio.org> or send or fax (314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. Questions? 314-534-0475 .

\$30 Subscriber

Ventilator-Assisted Living (bi-monthly via email)

\$55 Subscriber Plus

Both *Ventilator-Assisted Living* (bi-monthly)
AND *Post-Polio Health* (quarterly)

Name _____

Affiliation _____

Address _____

City _____ State/Province _____

Country _____ Zip/Postal Code _____

email _____

Phone (include area/country code) _____

I am enclosing a check for \$ _____ made payable to “Post-Polio Health International.” (USD only)

Please charge \$ _____ to this credit card:

VISA MasterCard Discover

Card No. _____ Exp. Date _____

Name on Card _____

Signature _____

 **CareFusion** 866-752-1438, www.carefusion.com

The LTV® Series ventilator product portfolio from CareFusion gives patients portable advanced care ventilation in the home and at a post-acute care facility.

At 14.5 pounds and roughly the size of a laptop computer, the LTV Series ventilator features complex ventilation configured for convenience and mobility. CareFusion also offers the ReVel™ ventilator for portable ventilation on the fly. Weighing only 9.5 pounds and used for pediatric (> 5 kg) to adult patients in the home and hospital setting, this ventilator provides powerful technology to support you through the continuum of care.



CareFusion LTV Series Ventilator

RESMED 800-424-0737, www.resmed.com

The S9 VPAP™ ST-A with iVAPS (intelligent Volume-Assured Pressure Support) provides personalized non-invasive ventilation therapy. It offers all the comfort features of the S9 device such as climate control, along with iVAPS that automatically changes pressure support based upon the therapy pressure required to reach the set therapy target. Combined with the lightweight Quattro Air full face mask, ResMed delivers a complete therapy solution designed for performance and comfort.



S9 VPAP™ ST-A with iVAPS



800-634-5397, www.passy-muir.com

The Passy-Muir® Swallowing and Speaking Valve is the only speaking valve that is FDA indicated for ventilator application.

It provides patients the opportunity to speak uninterrupted without having to wait for the ventilator to cycle and without being limited to a few words as experienced with "leak speech." By restoring communication and offering the additional clinical benefits of improved swallow, secretion control and oxygenation, the Passy-Muir Valve has improved the quality of life of ventilator-dependent patients for 25 years.



PMV® 007 (Aqua Color™)



Meet Us in St. Louis!

May 31 – June 3, 2014
Hyatt Regency St. Louis at The Arch

www.ventusers.org