

VENTILATOR-ASSISTED LIVING

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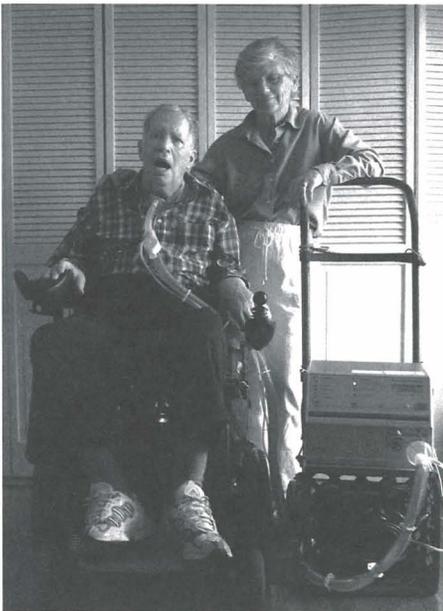
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Quality of Life: Profiles of Living with ALS

The decision by individuals with amyotrophic lateral sclerosis (ALS) to use assisted ventilation when their breathing muscles become weaker needs careful consideration. Some people do not choose to use any form of assisted ventilation. Others, who start early with noninvasive ventilation, may later face a decision about continuing with tracheostomy ventilation. Some may decide to refuse a tracheostomy. In March 2004, The ALS Association's Clinical Conference in Woodland Hills, California, focused on pulmonary care during each stage of the disease and emphasized early use of noninvasive positive pressure ventilation. Theresa Imperato, RN, Nurse Coordinator, ALSA Greater New York Chapter, a speaker at the conference, contacted two of her patients who wrote these profiles describing their use of assisted ventilation.

Herb Ingham, Long Island, New York (hingham@optonline.net)

I am 72 years old and was diagnosed with bulbar ALS in January 2000. Symptoms started with slurred speech and muscle twitches and progressed to difficulty with swallowing. I was mobile until recently and can stand for short periods of time with help. I can still use my hands on a limited basis and type on a LightWRITER communication device (www.zygo-usa.com). My wife Jackie and I took a course in sign language, but my signing ability has declined and signing my needs at night is difficult. Soon I will need a word-scanning system for my computer because it is becoming more tedious to type.



Herb and Jackie Ingham

In the last quarter of 2001, I experienced severe bouts of choking and gagging on mucus. I tried using BiPAP® (www.respironics.com) and CoughAssist® (www.coughassist.com), but neither was successful because of ill-fitting masks. My wife and I were aware that a tracheostomy could help alleviate the choking problem and discussed that prospect with the ALS clinic. The clinic staff was not encouraging because of the long-term ramifications of a tracheostomy — prolonging life with progressive ALS leading to complete paralysis. However, because I still had good limb mobility and was so uncomfortable with the heavy secretions, we were leaning toward the tracheostomy for suctioning, but not for ventilation.

Fate intervened. Hospitalized for an impacted bowel, I experienced such severe gagging that my pulmonologist ordered surgery for a tracheostomy. The tracheostomy eliminated the choking problem but introduced another — throat spasms. Initially these were frequent and severe, sometimes lasting for an hour. (A respiratory therapist told me that such throat spasms are uncommon.) Initially mucus was suctioned up to 20 times per day, and each time the suctioning triggered the spasms. We learned that partial inflation of the trach tube cuff helped to prevent secretions from dropping past the trach, and that, coupled with Lorazepam drops squirted against my inner cheek, helped to control the spasms. Spasms are now infrequent and less arduous. The CoughAssist® has been very effective in removing mucus from the airway and has virtually eliminated suctioning.

Home Mechanical Ventilation in Brazil Revisited

Luiz Gustavo Ghion, PT, and Walmar Augusto Miranda, MD
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Home mechanical ventilation (HMV) has been a reality in Brazil since 1994 when home care companies began in São Paulo (see *IVUN News*, Vol. 15, No. 4, Winter 2001, www.post-polio.org/ivun). Before that, only a few people used HMV, and the cost of the treatment was covered privately by the individual's family. If the person's family did not have enough money, the person remained in the hospital indefinitely, even with a stable clinical condition.

In Brazil home care is available only for people who have private insurance (about 28% of the entire population). Public programs to help less wealthy people using HMV are just beginning.

Home care provides the equipment, an auxiliary nurse 24/7, daily physiotherapy and respiratory care, and twice-weekly physician's visits. Home Doctor is one of the largest private home care companies in São Paulo with an HMV program. Currently the program follows 52 people, half adults and half children. Most of the people using HMV have neuromuscular disease; others are neurological and pulmonary patients.

Noninvasive ventilation (NIV) is used in Brazil by people with neuromuscular diseases and COPD, and sometimes during the weaning process. Home Doctor handles only a few NIV cases; most people use tracheostomy positive pressure ventilation. People with obstructive sleep apnea (OSA) use CPAP units, but they are not managed by home care companies.

Parents and caregivers are trained in suctioning and use of the ventilators, but with 24-hour nursing and daily

physical therapy, they usually do not perform the care themselves.

Due to cultural beliefs and intellectual levels, some of the families refuse to learn or to perform some procedures; they believe that a health professional should do it for them. Some families and caregivers prefer that their ventilator user remain in the hospital instead of at home, either because they do not want to provide any care or because they cannot afford the higher electrical bills and other expenses of home care.



Success for Twins

A year and a half ago, an insurance company contacted Home Doctor to assess a set of twins diagnosed with a nonspecific myopathy and dependent on tracheostomy positive pressure ventilation. At that time the twin boys, Matheus and David, were seven months old, and both were being ventilated with a Sechrist hospital ventilator in the Pediatric Intensive Care Unit (PICU). They also needed oxygen due to a recurrent atelectasis associated with pneumonia during their hospital stay.

The first step in going home was to start them with the LTV1000™ (Pulmonetic Systems, Inc., www.pulmonetic.com) during an adaptation period inside the PICU. At the same time an assessment in their home was performed, and electrical modifications were made to accommodate the electrical requirements of all the equipment the boys would need, including the ventilators, suction machines, oximeters, universal power system, etc. After two weeks, the twins' adaptation to the LTV1000 was judged a success

and they went home. Although the routine of the boys' parents completely changed, they are very happy to have their children home.

Now Matheus and David are 2 years and 4 months older. They use the LTV950™ ventilator, but they no longer need supplemental oxygen. During their time at home, the boys have required no hospitalization, and the parents are pleased with their sons' progress. ●

Homebound Exception Demonstration

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In a move that signals that the Centers for Medicare and Medicaid (CMS) has given priority to the implementation of the three-state (Massachusetts, Missouri and Colorado) demonstration that lifts the homebound requirement for permanently disabled beneficiaries, CMS has issued detailed systems directions to its contractors on how to implement the demonstration.

The demonstration will last for two years and essentially waive the homebound requirement for persons who otherwise qualify for Medicare home health under the following criteria:

- ◆ Their physician certifies that they have a permanent and severe, disabling condition that is not expected to improve.
- ◆ They are dependent in three activities of daily living.
- ◆ They require skilled nursing for life that is more than medication management.
- ◆ They require daily attendant care.
- ◆ They require an attendant or technology assistance to leave the home.
- ◆ They do not work for pay outside the home.

The effective date of the instruction is October 2004. Complete details are online at www.cms.hhs.gov/manuals/pm_trans/R3DEMO.pdf. ●

Retrofitting Ventilators for Power Chairs

Jerry Daniel, Vancouver, Washington (jerrydpd2000@aol.com)

When it comes to mounting a ventilator on the back of a tilt-and-recline power wheelchair, it is hard to find a good setup that doesn't throw the chair off balance or protrude too far in back. I constructed a scale model of a retrofitted LP10 ventilator to mount on the back of an Invacare Storm Series wheelchair. The retrofit makes it easier for a ventilator user, attendant or respiratory therapist to get at the control panel and settings. The easier it is to work with the ventilator, the easier it is to keep our caregivers happy and retain good attendants.

My one-fourth scale model LP10 takes the piston pump and circuit boards to minimum width configuration: 8¼" wide x 15½" deep. The piston pump assembly is placed with the motor in back and manifold in front. The cabinet saves space and allows the ventilator to ride across the back of the chair with minimum protrusion. The two (yellow) working panels on either end of the ventilator face up. Frequently used settings such as pressure monitoring, alarm indicators and reset, and power supply monitoring are easily visible and accessible from either side of the chair. The intake filter, external battery connection and external battery charge condition meter are also easily visible and accessible. The panels have clear plastic lids to guard against dirt and dust. The circuit/tubing output is mounted on a hard plastic turret that rotates 330° and therefore is not easily damaged.

The ventilator can be worked from either side because some ventilator users function better with their attendant on the right side; others prefer

the left side. The ventilator tray does not move, and the working panels are visible in all positions of tilt and recline.

In tilt mode, the ventilator user can go to 45° without adjusting clothing or seating. In the reclining mode, the seat comes



close to the ventilator but does not touch it. The ventilator tray can be easily attached or removed from the Invacare base rails without tools.

At night, both the external and internal batteries can be charged by plugging the ventilator into the A/C module. This LP10 version does not carry the power transformer, reducing the weight by 5 lbs. No handling of the battery or external battery cords is necessary. In most cases, no special charger is needed.

An ideal situation for ventilator users would be to keep a large, durable and heavy piston-pump volume ventilator at the bedside and to mount a compact, lightweight and turbine-driven multi-mode ventilator on the wheelchair. However, the ventilator user would have to be flexible enough to switch from a piston-pump unit to a turbine-driven unit in the morning, and then back again at night.

Both Respironics Inc. and Puritan Bennett have received my design. They know that I am both a certified service technician and long-term ventilator user. I hope that my consumer input can move them to action. I am planning to build a prototype. ●



Preparing for a Respiratory Emergency

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People with respiratory muscle weakness due to a neuromuscular disease or condition that limits their breathing are at risk for respiratory infection.

They may go to a hospital emergency room (ER) with shortness of breath due to either infection or lung congestion caused by the inability to cough and clear increased mucus associated with a respiratory infection. Yet, their underlying respiratory problems may go unrecognized and they may not receive the appropriate respiratory support.

On initial evaluation in the ER, the symptoms may be associated with a primary lung disease, such as COPD. Although a lower respiratory tract infection is certainly a primary lung problem, congestion can result from inadequate cough strength to clear the increased secretions associated with the infection.

Respiratory health professionals who have considerable experience working with neuromuscular patients know that frequent and timely manual and/or mechanical cough augmentation therapy, supported by noninvasive ventilation, is key to relieving pulmonary congestion.

Healthcare providers unfamiliar with neuromuscular respiratory muscle weakness and cough augmentation therapy may provide supplemental oxygen, and use chest physiotherapy alone to clear pulmonary secretions.

Providing oxygen therapy without ventilatory support may depress the respiratory drive to breathe, causing a dangerous increase in blood carbon

dioxide levels that can lead to acute respiratory failure and even death.

The use of noninvasive ventilation with incorrect or inadequate bilevel positive airway pressures may also fail to provide the emergency support necessary to relieve shortness of breath associated with lung congestion.

Any delay in providing the correct and timely therapy may result in acute respiratory failure and the potential for assisted mechanical ventilation by invasive means such as intubation (the placement of a breathing tube down the throat).

This use of invasive mechanical ventilation may be necessary for short-term interim support, but the transition back to noninvasive ventilation can occur after acute respiratory failure is resolved.

People with respiratory muscle weakness due to neuromuscular disease should practice good self-management and pulmonary hygiene, and make preparations for a possible ER visit in order to decrease the potential for inappropriate or inadequate medical intervention. Good self-management means being aware of the symptoms of developing respiratory infection and possible complications.

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NORMA BRAUN, MD, St. Luke's-Roosevelt Hospital, New York City, suggests, "When and where possible take your equipment with you to the ER so that there will be no need to use the wrong piece of equipment with the wrong settings. The hospital may not have the type of equipment you use, and a substitute is difficult to adjust to, making anxiety worse, and delaying appropriate therapy. Your equipment may need to be adjusted only during the ER situation."

In the hospital, I started using tracheostomy positive pressure ventilation at night to rest fatigued breathing muscles and continued that for the past year at home with the LP10 ventilator (www.puritanbennett.com). I am certain that the trach and the ventilator have prolonged my life and kept me comfortable. In recent months I have been sufficiently short of breath to need to use the ventilator fulltime.

A power chair with provision for a ventilator and oxygen is on order and should afford me more freedom. My wife rigged up a dolly with a milk crate containing a battery on top of which rests the ventilator. This is wheeled alongside my wheelchair when we go anywhere; two helpers are required. We had use of a small portable ventilator that could have been attached easily to any wheelchair but after two operating failures, we decided to use a larger ventilator with proven reliability so as not to risk another malfunction.

What is ALS?

Amyotrophic lateral sclerosis (ALS) is also known as motor neuron disease and Lou Gehrig's disease. It is a degenerative disease of the neurons (nerve cells) in the brain and spinal cord that causes progressive weakness of the voluntary muscles, eventually leading to total paralysis and death.

An important consideration in deciding to use assisted ventilation is long-term care costs. Ventilators, cough machines and associated supplies are expensive. Although I'm covered by Medicare, the copayment has to be paid by private insurance or out of my own pocket. With advancing ALS, a caregiver must be on hand all of the time to

respond to alarms warning of ventilator detachment, leaks or other malfunctions. We have an excellent live-in aide. Jackie takes over at night and weekends.

Quality of life issues continue to concern us. I am still able to communicate and do the simple things I enjoy: watching TV, working and playing at the computer, visiting with family and friends. The concern lies with the future as ALS progresses. Ventilator use, although prolonging life, has complicated that issue.

Jack O'Neil, New York City,
New York (Epko65@aol.com)

I am presently 69 years old and was first diagnosed with ALS in 1979. The prognosis was not good; I was told I would have about two years to live. This was an especially difficult time for me because I had just gotten married for the first time in 1978 when I was 43. My wife Eileen, a very smart and dynamic woman, is also a registered nurse with an EdD.

Everyone knows that they are going to die but if someone gives you a date, even an approximate one, it has a way of focusing your attention. Things went downhill very fast because I experienced weakness in my arms and legs, and had a low energy level, but after about six months I seemed to plateau, neither getting any better nor any worse. My mental state was in bad shape because I became very depressed while I worked on my exit strategy. Eileen made me visit a psychiatrist who succeeded in helping me focus on life instead of death.

When my two years left to live were up, I was weak, but I was still working and getting around with a cane and leg braces. My physical condition continued to decline, and I no longer had

enough energy to work. I stopped working in 1985 and used a scooter to get around.

New York is a great place to live and, despite my physical problems, Eileen and I enjoyed the theater, movies, concerts and restaurants. We also had a summer home on Fire Island. Our quality of life was good, although I suffered from aggravation and frustration which even healthy people experience.

The major change in my life came on Easter 1999, twenty years after the diagnosis. I woke up struggling for breath, in respiratory failure. Eileen called 911. I ended up in the ICU at Beth Israel Hospital, drifting in and out of consciousness, sure that I was going to die.

After a week in intensive care, I was feeling better and became aware that I was wearing a nasal mask connected to a BiPAP® (www.respironics.com) unit. The mask was very uncomfortable, and although I tried different types of masks, I couldn't find relief. After two weeks I was able to breathe about nine hours on my own.

The physicians did not think that I was going to survive and transferred me to the hospice program at Beth Israel. I had very mixed emotions about it, but the hospice unit prepared me to return home. By then, I could no longer move my arms or legs more than a few inches. I required help with all of the activities of daily living and acquired an electric wheelchair, Hoyer lift, BiPAP® unit and a variety of accessories.

Fortunately our large two-bedroom/two-bathroom apartment was able to accommodate all of this new equip-

ment. The hospice program also provided an aide for eight hours a day, weekly visits from a nurse and biweekly visits from a social worker. But after 14 months, I was kicked out of hospice because my health improved.

The first thing I did when I came home was to search for a comfortable mask and found one that caused the least discomfort — the Phantom® (www.sleep-net.com).

I have been using BiPAP® for more than five years and have three machines: one in our apartment, one on Fire Island and one in our van. I use BiPAP® at night and when it gets too hot or muggy. I am not thrilled with this arrangement, but I feel that it increases my chances of waking up in the morning by about 70%. I have a home health aide about eight hours a day that I pay for myself, and I see a nurse and a social worker during my visits (every three months) to the ALS clinic. ●

More about ALS ...

The ALS Association provides an excellent set of manuals entitled *Living With ALS*. Volume 6 discusses "Adapting to Breathing Changes." All are available to people with ALS, either online (www.alsa.org) or in hard copy through the chapter offices.

"Disparities in perceptions of distress and burden in ALS patients and family caregivers" by E.E. Adelman, S.M. Albert, J.G. Rabkin, et al. appears in *Neurology* 2004, 62, 1766-1770 (www.neurology.org). The conclusion: "However, patients and caregivers each overestimated the psychosocial impact of the disease on the other."

IN MEMORIAM

Ira Holland, 1939-2004

IVUN's long-time friend and supporter Ira Holland died suddenly on March 16, 2004. Ira bequeathed \$15,000 to IVUN "solely to disseminate information about portable ventilators." Ira's fascinating biography, which can also be read as a history of noninvasive ventilation and the independent living movement, is online at www.post-polio.org/netwkg_peo.html#ira.

Ira was a true visionary in promoting independent living for people with disabilities and ventilator users. Concepts of Independence, the program that he established in New York City, enabled people with disabilities to direct and manage their personal care and empowered countless individuals to live interdependently within their communities. In the last few years, his work as a consultant provided an invaluable perspective for home health agencies and ventilator equipment manufacturers.

Ed Litcher, a good friend of Ira's, said, "The lessons we can draw from Ira's life will depend upon the parts we see. He was a disabled man living and loving in the community. He was an advocate who cared about the independence and empowerment of people with disabilities. He was a friend, a neighbor and a mentor to many, but I think that the basic lesson we can all draw from his life is that life is to be lived. Find your path and attack. As Ira himself said, 'All things are possible.'"



Respironics and IVUN's Ventilatory Equipment Exchange

Need a scooter? Need orthotics?

PHI has \$1,000 (\$500 maximum per person) available to assist ventilator users in purchasing scooters or orthotics (leg, arm and back bracing and custom-made or modified shoes).

For details and application, contact 314-534-0475 or ventinfo@post-polio.org.

In response to ventilator users of iron lungs who cannot make the transition to alternative noninvasive equipment, Respironics Colorado issued a statement on May 10, 2004. "In an effort to continue to support these patients as long as possible, Respironics Colorado will put all returned iron lungs through a comprehensive Quality Assurance check, and providing the device meets standards, it will be held in a rental pool in the event one is needed in an emergency situation by those opting to remain on the iron lung. Returned devices, which do not pass the overall QA check, will be held as parts resources. The reality, however, is that this may only provide a limited and unpredictable source of replacement product and repair parts and the best long term resolution for patients may be to transition to an alternative therapy." The complete statement and a statement by the manufacturer of the iron lung,

J.H. Emerson Co., is available online: www.post-polio.org/ivun/val_18-1h.html#res. For more information, contact Wendy Yates, Privacy and Compliance Leader, Respironics Colorado, Wendy.Yates@respironics.com, 800-659-9235, ext. 3414.

IVUN is working with Respironics Colorado in facilitating the exchange of equipment.

People wanting to donate ventilatory equipment and aids can advertise their offerings on IVUN's website by connecting to "Can You Help: IVUN's Ventilatory Equipment Exchange" (www.post-polio.org/netwkg_ivun.html).

People can view available offers and make arrangements to obtain equipment and/or they can submit a description of equipment needs along with their contact information. ●

ResLink™ from ResMed (www.resmed.com) records data on as many as ten different parameters, including oximetry on the AutoSet Spirit™, S7 Elite and VPAP III Series bilevels for 10 hours each night (30 days continuously). ResLink also collects a summary of up to one year of data stored in each flow generator. Data collection includes tidal volume, leak, apneas, hypopneas, minute ventilation, flow limitation, snore, oxygen saturation, pulse and breath rates, etc. The module fits on the back of the bilevel units. Physicians, home health care equipment suppliers and the individual using the unit can all review the data to fine-tune the settings and troubleshoot.

OSA/CPAP users can find more information on these websites — www.healthysleep.com and www.myresmed.com.

Medicaid Waivers. The website of the National Association of State Medicaid Directors (NASMD) explains the different Medicaid waivers — 1915 (b), 1915 (c), 1115 — and lists those available in each state: www.nasmd.org/waivers/waivers.htm.

Toll-Free Hotline for Airline Disability-Related Problems. U.S. Department of Transportation, Aviation Consumer Protection Division. 7 a.m.-11 p.m. EST, daily. 800-778-4838 voice; 800-455-9880 TTY.

The Association for Respiratory Technicians and Physiologists is the British equivalent of the American Association for Respiratory Care (the U.S. organization for respiratory therapists). The ARTP's website — www.artp.org.uk — posts a comparison of noninvasive ventilators (mostly pressure support and bilevel units used at night).

Chin/Neck Support. Some people with ALS and post-polio syndrome need help keeping the head and neck upright and straight. One option is the Chin-Neck Bandage made by Caromed (distributed by Byron Medical, 800-777-3434, www.byronmedical.com). It is made of stretch fabric that comfortably supports the head.

Rolling On: The Story of the Amazing Gary McPherson

by Gerald Hankins profiles ventilator user and respiratory polio survivor Gary McPherson, currently executive director of the Canadian Centre for Social Entrepreneurship in Alberta, Canada. The black and white photos are superb, supporting a well-written text that chronicles the polio epidemic in Canada, Gary's life and his drive for independent living. Paperback, 216 pp., black and white photos. Available from the University of Alberta Press, \$24.95 (USD) plus shipping and handling.

Contact Laraine Coates, University of Alberta Press, locates@ualberta.ca, www.uap.ualberta.ca/UAP.asp?lid=41&bookid=546. Also available through Michigan State University, 517-355-9543, toll free fax 800-678-2120, or msupress@msu.edu.



Early intervention is essential in minimizing the impact of an infection. Individuals should contact their pulmonary physician to determine whether antibiotic therapy is necessary, and they should increase cough augmentation therapy to relieve congestion and shortness of breath. These measures will help avoid hospitalization.

Having a good understanding of one's medical condition and respiratory support needs is important, but the best contingency plan is to have:

- ❖ A comprehensive medical note from one's pulmonary physician that includes the neuromuscular disease diagnosis, latest pulmonary function test results indicating respiratory status (vital capacity,

maximum inspiratory and expiratory pressures, peak cough flow, etc.).

- ❖ A list of current medications.
- ❖ A list of ventilatory equipment and the settings used.
- ❖ The pressure settings, if mechanical cough assist therapy — CoughAssist® — is used.
- ❖ The type of interface (nasal/ facial mask or nasal pillows) used.

This is vital information. Indicating the types of respiratory support equipment without specific setting information may either delay urgently needed support in the ER or result in inadequate support. Individuals and/or their caregivers/attendants should carry this medical information at all times in order to immediately inform medical staff of the specific condition and the appropriate respiratory therapy in case an ER visit is necessary.

Medical Alert cards can detail an individual's specific neuromuscular condition, medications, allergies, physician information, and a photo. An ER directive that alerts medical staff about how to care for neuromuscular patients with respiratory insufficiency should also be readily on hand. Both are available at www.doctorbach.com.

Wearing a medical identification bracelet or medallion (American Medical Identification, Inc., Houston TX, www.americanmedical-id.com, 800-363-5985) can also be beneficial in alerting medical staff to one's diagnosis, respiratory status, and respiratory support needs. ●

Letter to the Editor

We noted with interest the sidebar entitled "Talking with Tracheostomy Ventilation" in *Ventilator-Assisted Living*, Vol. 17, No. 4, Winter 2004. We heartily endorse Dr. Oppenheimer's reassurance that people will be able to speak with cuff deflation (or use of a cuffless tube) when tracheostomized.

But we would like to add that there are simple adjustments to ventilator settings that offer attractive alternatives to a one-way valve (such as a Passy-Muir valve). These include lengthening inspiratory time and applying 5 to 10 cm H₂O of positive end-expiratory pressure when using volume-controlled ventilation. The advantages of such adjustments are that they can produce speech that is just as good as the one-way valve, but with greater safety and at a lower cost. Another way to improve speech with invasive ventilation is the use of bilevel positive pressure ventilation; however, this form of ventilation is only approved for in-hospital use in the United States.

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Journées Internationales de Ventilation à Domicile (JIVD),
Lyon, France. JIVD (+33 4 78 39 08 43).

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