

Pflex[®] (my new friend) and More ...

Carol Wallace, MEd, Certified Rehabilitation Counselor, Austin, Texas, contact at info@ventusers.org

I contracted polio in 1951 at age 5. Acute and rehabilitation hospitalization totaled two-and-a-half years with six months of iron lung treatment. Both of my upper extremities were and are paralyzed with only partial and weak right-hand motor function. As an adult, my forced vital capacity averages 48 percent. I require noninvasive mechanical ventilation whenever supine.

The Philips Respironics Pflex Inspiratory Muscle Trainer is an exercise device that my pulmonologist, who conducts a neuromuscular clinic once a month, prescribed for respiratory muscle strengthening. Pflex has six levels of inhalation resistance with setting 1 giving the least resistance and setting 6 giving the greatest resistance. Breathing only through the mouth, training starts at the setting that requires the patient “to work hard but not to the point where it is exhausting.”



Carol Wallace is shown using the Philips Respironics Pflex Inspiratory Muscle Trainer as part of her respiratory exercise program.

The instructions also say to inhale as deeply and forcefully as possible for approximately two seconds and exhale normally. During the first week, limit training to 10-15 minutes per day gradually increasing to 20-30 minutes per session or two 15-minute sessions per day. When your training gets easy, begin the process again for whatever length of time is tolerated at the greater resistance setting and gradually increase the duration of exercise as before.

I began using Pflex in mid-November 2012. I began at setting 1 and in a few days progressed to setting 2. I do two 15-minute Pflex sessions separated by about a 10-minute break every evening while watching TV news. When I tried setting 3 for only a few seconds, it felt so extraordinarily difficult that I questioned whether I would ever achieve it.

In the meantime I had noticed that, for me, the hardest part of the training was the first few minutes and the easiest was the last 15 minutes of 30. Because of this, when I began setting 3, I started by substituting setting 3 for setting 2 at the end of that session and gradually increased the minutes of setting 3 while decreasing the equivalent number of minutes of setting 2. This process continued until I reached two 15-minute sessions of setting 3.

Similarly, when I tried setting 4 for a few seconds, I felt I would never be able to do it. However, following the same above procedure of starting with the last few minutes of the second 15-minute setting 3 session and gradually increasing,

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Fisher & Paykel's
Pilairo™ nasal pillows

Product News, Masks

Pilairo™ nasal pillows are new from Fisher & Paykel – a very light interface, weighing only 1.83 ounces. The Pilairo features a self-inflating AirPillow™ Seal and minimal headgear for more freedom of movement. One size fits all. For use with bilevel and CPAP units up to 25 cm H₂O pressure. www.fphcare.com/products/pilairo-nasal-pillows-mask/

Eson™ nasal mask also from Fisher & Paykel features unique RollFit seal, ErgoFit headgear and low profile for a clear line of vision. Small, medium and large sizes. For use with bilevel and CPAP units up to 25 cm H₂O pressure. www.fphcare.com/products/eson-nasal-mask/



Fisher & Paykel's
Eson™ nasal mask

Consumer Health Information

Now that everyone seems to be using the Internet to obtain medical information, it's important to know which websites to trust for accurate, up-to-date and reliable information. The Medical Library Association has compiled a list of consumer health sites that it considers most useful and trustworthy. These include websites for major diseases such as cancer, diabetes and heart disease. www.mlanet.org/resources/userguide.html

Other reliable websites include:

MedlinePlus, sponsored by the National Institutes of Health, for disease definitions, explanations and symptoms, and medications. www.nlm.nih.gov/medlineplus

Centers for Disease Control and Prevention, for vaccination recommendations, traveler's health, epidemiological data and disease outbreaks. www.cdc.gov

Competitive Bidding Update

For background, go to www.ventusers.org/edu/valnews/val_26-5oct12pAll.pdf

The Centers for Medicare and Medicaid Services (CMS) competitive bidding program to cut costs for durable medical equipment, prosthetics, orthotics and supplies (DMEPOS) is about to enter Round 2 on July 1, 2013, covering 91 additional geographical areas.

The CMS Ombudsman office handles inquiries and complaints about how the program is working for consumers and suppliers in the Round 1 areas. People who use bilevel units and their home health companies may be affected. If you have a complaint, please call 800-633-4227 or email CompetitiveAcquisitionOmbudsman@cms.hhs.gov. However, CMS records only the complaints that are passed to a higher level. If the complaints to the tollfree number are resolved, they are not considered a complaint. Please let IVUN know about your complaints and how they were handled; email www.info@ventusers.org.

A market pricing alternative to competitive bidding, H.R. 6490, was introduced in Congress last year, and if passed, would take effect in July 2013. www.ventusers.org/edu/valnews/val_26-3jun12p2-6.pdf ■

Send product news to
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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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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.

New CoughAssist Model Approved

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

In January 2013, Philips Respironics received clearance from the FDA to market the next generation CoughAssist model – the CoughAssist T70. (Outside the United States, it's called the CoughAssist E70 and comes with an oscillation feature.)

The CoughAssist, earlier known as the In-Exsufflator developed by the J.H. Emerson Co. in the 1990s, provides a noninvasive secretion clearance alternative to suctioning. Individuals who have a trach can use the CoughAssist with an adapter, and those who use noninvasive ventilation can use it with a mouthpiece or facial mask.

The unit works by gradually applying positive air pressure to the airway (inspiratory phase) and then rapidly shifting to negative air pressure (expiratory phase). The shift in pressure creates a high outward flow that simulates a deep, natural cough. Each cough cycle is composed of an inspiratory, expiratory and pause (20-30 seconds) phase, for a typical sequence of four to six cycles. Treatments can be performed several times per day, as needed.

The new model is much lighter, weighing less than 9 lbs., with smaller dimensions (9.1”H x 11.5”W x 7.5”D). The Cough-Trak feature provides a unique trigger with automatic sensitivity to allow individuals to initiate therapy and synchronize treatment with their own breathing patterns. Up to three settings can be saved to provide different therapies, such as for routine use, mucus plug removal and lung volume recruitment.

The large color screen display is user-friendly. Tidal volume, peak cough flow and oxygen saturation levels can be effectively monitored with data management software (SD card) that is the same used for the Trilogy100. One of the most innovative features is the ability to operate the CoughAssist hands-free with a foot pedal.



Philips Respironics' CoughAssist

The CoughAssist also has a detachable lithium-ion battery that can support up to four treatments on a single charge. Accessories include an SD card, hose clip, air filter, patient circuit, adult mask, carrying case and AC power cord. The unit has been FAA-approved for air travel.

The cost of the new model is about the same as the previous model. Vent users who have the older model and want to “upgrade” should work with their physician, DME home care company and insurance provider to determine eligibility for the newer model.

The CoughAssist is an invaluable device for people with neuromuscular conditions who do not have a strong enough cough to remove secretions and vital to the success of noninvasive ventilation. The use of this mechanical device during respiratory infections may minimize the risk of mucus plugs that could lead to pneumonia and possible emergency hospital admission. ■

For clinical references and reimbursement information:

<http://coughassistt70.respironics.com/resources.html>
<http://coughassiste70.respironics.com>

For background:

www.ventusers.org/edu/valnews/val7-1a.html#the
www.ventusers.org/edu/valnews/val12-1.html#ass

Making a Smooth Transition and Adding Mobility

Joan L. Headley, Executive Director, Post-Polio Health International, St. Louis, Missouri, director@post-polio.org

Ronda Bradley MS, RRT, FAARC, Spiritus Consultants, and representing CareFusion, presented the third lecture in IVUN's series of educational sessions for users of long-term ventilation.

Bradley's talk provided useful information for users needing to switch from obsolete machines, such as the LP10s and PLVs, while focusing on the LTV®1100 and LTV®1150 ventilators (CareFusion).

The LTV1100 and LTV1150 are portable volume and pressure mode ventilators that can be used invasively or noninvasively by children (>5 kg) and adults.

LTV® Series ventilators weigh 14 pounds and have approximately one hour of internal battery. The company offers other transport battery options. (See photos.) The LTV vents are approved by the Federal Aviation Administration for military use, which is a higher standard than for commercial flights.

Alarms

The flow in the LTVs is generated by a turbine, giving the ventilator the capability of delivering higher pressure and volumes

than comparable ventilators. The sound is different, and Bradley recommended that time be spent just getting used to the white noise.

The following alarms are possible:

- Apnea with apnea backup (for rates <4 or for pressure support only). The FDA requires this alarm to be on, but it has an adjustable time from 10-60 seconds. If a rate is not set, the vent will give 12 breaths per minute until it recognizes an effort at breathing.
- Low pressure is the “disconnect” alarm.
- High pressure alarm serves as “pop off”/pressure release. A nice feature is the high pressure delay, which helps weed out false high pressures such as a cough. This feature, when set, will delay the alarm for one or two breaths that exceed the high pressure threshold.
- Low minute ventilation can be turned off, but it can be used as a secondary disconnect alarm. For example, if the circuit gets lodged in blankets there could be a buildup of pressure even though there is a disconnect.
- High RR (f), i.e., high frequency respiratory rate (with time delay for the first 60 seconds from startup).
- High PEEP/Low PEEP.
- Low peak pressure, low minute ventilation, PEEP alerts and high respiratory rate alarms can be disabled, but a wide configuration of settings provides safety without nuisance alarms.

The LTV uses a non-vented mask or interface, so no hole/exhalation port in the mask or whisper swivel is needed. Vent users can continue to use whatever interface that they use now with their PLVs and LPs. However, there is a wide choice of masks, nasal pillows, mouth pieces or dental straw devices. Users will not experience extra air blowing out of



The Freedom Vent Carrier (www.freedomvent.com/carefusion.html) is shown here with the SprintPack™ Battery Lithium-Ion Power System.

the mask and if using a humidifier, water will not shoot out of the vent from the mask either.

Making the Transition

Bradley emphasized that users should follow any transition protocol written by the physician with additional recommendations from the respiratory therapist (RT) at the durable medical equipment company (DME) office.

Although all ventilators are slightly different, the LTV1100 is designed to meet the transitional needs of those who have long utilized a pressure-trigger ventilator (the older vents). The LTV1100 sensitivity is triggered by flow or pressure.

The bias flow (a small amount of constant air flow) on the LTV1100 can be turned off, which is why Bradley recommends it to vent users trying to switch from the PLV-100s and LP10s – they have no bias flow. With the LTV1100, a user also can turn on or off leak compensation.

She recommends close communication with the physician on determining settings, then working with the RT to determine if additional features such as triggering options, bias flow, leak compensation or “sigh” are helpful. (The LTV1100 offers a big breath or “sigh” every 99 breaths.)



Upcoming Educational Conference Call

Wednesday, February 27, 2013
at 1:00 pm CT

John R. Bach, MD, Physical Medicine & Rehabilitation, University Hospital, University of Medicine & Dentistry of New Jersey, will present “How Polio Survivors Can Avoid Tracheostomies.”

Reservations are required to be on the call. To reserve your spot, contact info@ventusers.org or call 314-534-0475. Reservations are on a first-come, first-served basis.

Past presentations are online at www.ventusers.org/edu/confcalls.html#pas

Do you have suggestions for other topics? If so, please send them to info@ventusers.org.



The PowerPoint at www.ventusers.org/edu/IVUN-TransitiontoLtv.pdf pictorially shows how to set up a circuit and how to operate the vent.

Points to Remember

- Ask for help: a local CareFusion representative or clinical support person is available at 800-754-1914.
- These are the three major choices to be made:
 - Choosing flow or pressure triggering
 - Turning off bias
 - Turning off leak compensation
- Once set up, the settings will be locked in and ready when the ventilator is turned on.

Portable ventilators improve mobility, and the LTV can be carried on a wheelchair in several ways. The LTVs have been improved over the years but the basic size has not changed, and consequently, devices to hold the vents have been developed. ■

The black box in this photo is the PowerTech Vent Power Center by Richardson Products. It is designed to provide stable power to the ventilator from the power chair battery (www.richardsonproducts.com/Electronics.pdf). Because the vents use a small amount of power, users of this system report that a battery that would get 16 hours of power can run for 15 hours while using the vent. People who use 24/7 ventilation like this option, because they can be out all day. More options and bedside set-ups are described in the PowerPoint (www.ventusers.org/edu/IVUN-TransitiontoLtv.pdf).

continued from page 1

within a week I was able to complete two 15-minute sessions at setting 4.

The benefits of Pflex for me include a noticeable decrease in shortness of breath during certain activities, most notably during aquatic exercise. For 22 years, three times per week, I've been walking in a rehab pool of 92-degree water for general health and to maintain balance and lower extremity and respiratory muscle strength. Included in my aquatic exercises are 20 minutes walking against water just above breast level and 20 minutes just below breast level. I exercise in the deeper level to achieve the greater water resistance against my respiratory muscles for strength maintenance.

***Ventilator-Assisted Living* asked Norma M.T. Braun, MD, FACP, FCCP, to review and comment on Carol Wallace's use of the Pflex® Inspiratory Muscle Trainer. Here is her response:**

I read with interest Carol Wallace's experience with learning to use a Pflex device for respiratory muscle training and it is accurate for her. In polio survivors there is wide variability in what muscles were affected and how severely as well as compensations/losses over time. She had growth on her side. The fact that she needed an iron lung so early guaranteed her need for ventilation at some time in the future. There are no good data, especially longer term, to describe the potential benefits of respiratory muscle training for patients with neuromuscular disorders and some in patients with post-polio syndrome: it is very much individuated.

Her approach is "scientific" as she edged into the task, assessing herself and her reactions to each incremental step. She back tracked or altered the pattern when fatigued or when perception of the task was too great, learned her pattern of responses and limitations and then "tested" herself in the pool, a translated real-life task. It would be useful to have parallel pulmonary and respiratory muscles function testing before, early and later to use as a measure that might reflect the extent of her improvement and what was of benefit and how long it may last. Kudos to her. Finding that fine line between enough and too much in respiratory or other muscle training is as pertinent in non-polio subjects as in polio survivors. It is just that the margin is so much smaller for polio survivors.

Dr. Braun is Ombudsman, Clinical Professor of Medicine, Columbia University College of Physicians & Surgeons, Department of Medicine, Pulmonary/Critical Care/Sleep Division, St. Luke's-Roosevelt Hospital, New York, New York.

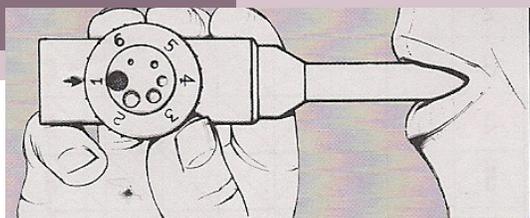
When I return after missing a few sessions in the pool, the difficulty is even greater for the first few minutes. In the last two to three years, breathing while walking through that deeper level has become more difficult and I've wondered if in a year or so whether I'd be able to continue. Immediately after starting setting 4, I had to miss a few weeks at the pool. As soon as I returned and entered the deeper level, I was immediately shocked at how much easier it was to breathe. This was my first deep water walk since beginning Pflex setting 4. My guess is that my breathing exertion at this deep level has improved to about the same as it was two to three years ago!

I will most certainly continue to use the Pflex trainer and intend to try setting 5 soon. Although I haven't had pulmonary testing since beginning Pflex, my clinical experience is encouraging enough for me.

"As soon as I returned and entered the deeper level [of the pool], I was immediately shocked at how much easier it was to breathe."

Note: I altered my Pflex training a bit from the instructions. Using the recommended nose clip caused me some panic, so I don't use it. I am disciplined to breathe only through my mouth without a nose clip because I've done so for years with my ambu bag exercise. I also stray from the instructions which say to "try to train at least 3-5 times per week." I found that when I skip a day the next day's sessions are noticeably harder. To avoid a more difficult session, I train every day but only for one 15-minute session once or twice a week.

The other piece of my respiratory exercise program is that every evening for a number of years, I stack breaths with an ambu bag to maintain chest wall flexibility as recommended by my pulmonologist. As I understand it, anatomical changes of normal aging result in a stiffening, and a decrease in size, of the thoracic cage. Since I cannot



Pflflex has six levels of inhalation resistance with setting 1 giving the least resistance and setting 6 giving the greatest resistance.

squeeze the ambu bag with my hand, I use a slightly longer hose and squeeze the bag between my knees. I stack breaths for maximum – but safe – chest wall expansion and hold it for about 50 to 55 seconds. One time I felt some pain in a rib at expansion, so that became a guideline for what to avoid. I do this stretching of my chest wall five times once a day, although ideally I should do it at least twice a day.

This is my management/exercise program for maintaining and improving my chest wall flexibility and respiratory muscle strength. ■

MORE on www.ventusers.org

Airway Clearance and Lung Volume Recruitment
Ventilator-Assisted Living, Vol. 25, No. 4
www.ventusers.org/edu/valnews/val_25-4aug11p1etc.pdf

MARCH 19-21. Medtrade Spring.

Mandalay Bay Convention Center, Las Vegas, Nevada.
www.medtrade.com/medtrade-spring

MARCH 23-29. Ventilator-Assisted Children's Center (VACC) Camp.

Miami, Florida. Contact Bela Florentin, VACC, Miami Children's Hospital, 305-662-8222, bela.florentin@mch.com, www.vaccamp.com.

APRIL 11-13. "A Breath of Fresh Air," Canadian Respiratory Conference.

Québec City Convention Centre, Québec City, Québec, Canada.
www.lung.ca/crc/home-accueil_e.php

APRIL 11-13. Sleep and Breathing.

European Respiratory Society and European Sleep Research Society. Berlin, Germany. www.sleepandbreathing.org

APRIL 26-28. Parent Project Muscular Dystrophy West Coast Connect Meeting.

San Diego Marriott Mission Valley, San Diego, California.
www.parentprojectmd.org

MAY 9-11. Spring FOCUS on Respiratory Care, Sleep Medicine, and Critical Care Nursing Conference.

Gaylord Opryland Hotel, Nashville, Tennessee. www.foocus.com

MAY 17-22. American Thoracic Society Annual International Conference.

Philadelphia, Pennsylvania. www.thoracic.org

JUNE 12. "Interdisciplinary Perspectives on Spinal Muscular Atrophy: Defining Your Role," SMA Research Group.

Disneyland Hotel, Anaheim, California. www.fsma.org

JUNE 13-16. FSMA Annual Conference.

Disneyland Hotel, Anaheim, California. www.fsma.org

JUNE 27-30. Parent Project Muscular Dystrophy Annual Connect Conference.

Baltimore, Maryland. www.parentprojectmd.org

SEPTEMBER 7-11. European Respiratory Society Annual Congress.

Barcelona, Spain. www.ersnet.org

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