

VENTILATOR-ASSISTED LIVING

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Flying – Part II

Role of the Airlines, Resources and Reporting Travel Problems and Solutions

Joan L. Headley, Executive Director, International Ventilator Users Network, St. Louis, Missouri, director@post-polio.org



Samples of stickers

In Flying - Part I Ventilator Users' Report and Manufacturers' Role, December 2012 *Ventilator-Assisted Living* (Vol. 26, No. 6), we reported on the responses from IVUN's Ventilator Users' Survey regarding flying, and the information collected from the manufacturers. The manufacturers remind users that equipment certified for flying has a sticker on it.

If that is not the case, check Manufacturers' Certification Letters.

Role of the Airlines

IVUN sent a brief survey to 54 airlines (Adria Airways to Virgin Airlines) asking about their policies regarding the use of a ventilator during flight, their policy on hooking up to the plane's power supply, and the use of oxygen during flight. The response was minimal.

IVUN has created a chart called "Links to Accessibility/Medical Policies of the Airlines" and uploaded it at www.ventusers.org/adv/issues.html. There has been a significant improvement in

the quality and amount of information available on each site to assist travelers. Airlines are not required to allow a plug in, but the good news is that the newer ventilators come with smaller and swappable batteries. In fact, even if an airline lets someone using a ventilator to plug in, they often require equivalent battery backup for the duration of the trip anyway. Remember, it is still true that the captain of the plane has the final word as to what happens on the flight.

Responses from Airlines

Scandinavian (SAS) sent the most comprehensive reply. Batteries must conform to the International Air Transport Association Dangerous Goods Regulations (IATA DGR chapter 2.3.4.8) and the ventilator must fit under the seat or in the hat rack. Plugging in depends on which aircraft type is used on the route. Passenger-owned oxygen containers must conform to IATA DGR chapter 2.3.4.1. SAS sent a print out of charts listing all the approved equipment and the approval condition for each.

British Airways allows all FAA-approved vents and oxygen concentrators on board. Power ports are not available in all cabins. If so, an adapter is required to connect to power and the ventilator must be switched off during takeoff and landing.

AIRLINE	PHONE #	Link to policies related to use of ventilators
Air Berlin	866-266-5588	Transporting medical equipment
Air Canada	888-247-2262	Customers with Special Needs
Air China	800-882-8122	Special Travel Needs
Air France	800-992-3982; 800-210-6508	Reduced mobility and other disabilities
Air Tran	800-247-8726	Medical Portable Electronic Devices, M-PEDs
Alaska	800-654-5669	Ventilators, Respirators, and CPAP Machines
Alltalia	800-223-5730	Traveller's care, No Barrier Travelling, Health on Board
All Nippon Airways	800-235-9262	Travel Assistance of Disabled Customers

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Product News

Trilogy series upgrades

Philips Respironics recently announced updates to the Trilogy ventilator series. These include increased pressure support (up to 40 cm H₂O) for mouthpiece ventilation, adjustable AVAPS (average volume-assured pressure support) to maintain targeted volume, AVAPS A-E to automatically adjust EPAP and to maintain a backup rate, waveform displays on-screen, “kiss” trigger for mouthpiece ventilation that detects when a vent user engages and disengages from the mouthpiece, a mouthpiece ventilation circuit support accessory, and sensitive auto-trak trigger for vent users with minimal inspiratory effort.

Send product news to
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With the exception of the mouthpiece ventilation and support system hardware, the updates are software related. Homecare providers can download the software from www.my.respironics.com and can easily update any Trilogy via SD card. This is not a mandatory update; many homecare providers will update the ventilators that are in the field at the next service interval. For more information, patients should contact their homecare provider. <http://trilogy100.respironics.com/versatility/default.aspx>

Flu outbreak

The H7N9 bird flu virus strain that has been reported recently in China and caused several deaths is being closely monitored by the World Health Organization (WHO). Because the birds do not show obvious signs of the virus and there have been no mass bird deaths, the virus is harder to track. Although the virus has not been passed between humans, there is still concern about a possible pandemic. The Centers for Disease Control and Prevention (CDC) is developing a vaccine. For more information, go to www.who.org and www.cdc.gov/flu/avianflu/h7n9-virus.htm.

Journal articles

“Postoperative respiratory muscle dysfunction: pathophysiology and preventive strategies” by Drs. Nobuo Sasaki, Matthew J. Meyer and Matthias Eikermann, was recently published in *Anesthesiology* 2013; 118:961–78. The article discusses the postoperative respiratory complications that can occur for a number of reasons that result in the inability of respiratory muscles to provide adequate oxygenation and ventilation. The role of the anesthesiologist is key in preventing many of these complications.

A related editorial “Postoperative respiratory muscle dysfunction: only the strong survive” by Dr. Michael Gropper also appears in *Anesthesiology* 2013; 118:783–4. www.anesthesiology.org ■

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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 your newsletter.

The Adventures of Traveling With a Vent

Elaine M. Burns, Boston, Massachusetts

Traveling with a vent? No problem! I had done so successfully for over twenty years. I had a backup plan, should something stop working: I carried the phone number of the vent manufacturer I used. I had dealt with their customer service and repair departments and they were always helpful. Unfortunately, having their contact information did me very little good when a problem occurred when traveling 3,000 miles from home.

First, some background information. I had polio as a child and now am probably dealing with the late effects of polio and/or aging. I had used a volume ventilator for more than twenty years to keep my lungs clear of carbon dioxide when sleeping. I have had a series of ventilators, most of them heavy and awkward to transport.

When I was dating my future husband, although he enjoyed traveling as much as I did, he didn't enjoy lugging my PLV®-100 vent around or lifting it into the airplanes' overhead compartment. Then, Pulmonetic Systems (now CareFusion) introduced a compact vent, the LTV®900 series. Insurance was not going to pay for it, so we bought it outright from a dealer. This vent was fabulous for travel, much lighter and more compact. The problem was that although we bought it from a certified Pulmonetic dealer, he didn't continue to be one, leaving us on our own since Pulmonetic Systems, in most cases, would not deal with us. Fortunately, I do have a home health respiratory company, and they had it serviced for me.

I have always been blessed with travel opportunities, and along with my new vent, off I went. I made sure that I had the appropriate phone numbers with me, in case there was a problem. When I went to Europe, I had the phone numbers of contacts for each city. No problem, I thought.

Last June, we traveled to a wedding two hours north of San Francisco. On a Saturday morning I awoke to my vent malfunctioning. It would alarm, but stop when the reset button was pushed, then alarm again later. Using my Pulmonetic Systems contact numbers, I left a phone message and a repair person quickly returned my call. No, he had never heard of the problem that I was experiencing, and no, they could not provide me with another machine. Since the machine was undiagnosable, I had no idea how long it would continue to work, with intermittent alarming.

I called my home health respiratory company and the owner responded quickly. He and my respiratory therapist made many calls attempting to locate a company that would loan me a vent, but they were not successful. There was nothing to do but cut our trip short and return home immediately after the wedding. Fortunately the ventilator never stopped working. Once at home, I switched to my backup vent, and the malfunctioning vent was immediately shipped off to the manufacturer for repair.

This was quite a learning experience for me. The first lesson was that I should always travel with a copy of my prescription, with the settings for my vent. This is true for a volume vent, BiPAP or CPAP. I carried the vent settings for a medical emergency, but I didn't have an official prescription. Without a prescription, no one would loan me a vent even if they had one. I now do this. Second, my home health company



Elaine M. Burns

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Tell Me About a Trach Before I Need One

Joan L. Headley, Executive Director, International Ventilator Users Network, St. Louis, Missouri, director@post-polio.org

Over the years, IVUN has received numerous calls from families and users of noninvasive ventilation who experienced respiratory failure and to save their lives, received a tracheostomy. These calls, coupled with the extensive networking among polio survivors and other vent users, made us aware that many individuals fear the idea of having a tracheostomy. We were asked to provide factual information and invited Linda K. Dean, a Registered Respiratory Therapist (RRT), to present the topic on IVUN's Fourth Educational Conference Call on Jan. 23, 2013.

Before agreeing to a tracheostomy tube, Dean recommends that all vent users ask their doctors: "Is there anything else I can do to postpone it?" Dean explained that noninvasive ventilation and attention to airway clearance are both ways of avoiding a tracheostomy.

She also clarified that not all patients who receive a tracheostomy tube require help with their breathing. They may have a weak cough and need help clearing their secretions, or they may have a tumor or other obstruction blocking their trachea (windpipe). Other reasons why some people obtain a tracheostomy tube are the need for prolonged mechanical ventilation; noninvasive ventilation no longer meets the need; upper airway (above the voice box) obstruction; to improve patient comfort.

Linda K. Dean, RRT, Educational Consultant and Clinical Specialist, Passy-Muir, Inc., has more than 26 years of experience that ranges from critical care, clinical education and sub-acute provider, to clinical specialist for Passy-Muir Inc. She has provided in-service education, with a focus on the "art" of speaking valve placement in the ICU, throughout the United States, Canada, Thailand and Vietnam.

"Is there anything else I can do to postpone it?"

Advantages

The advantages of a tracheostomy are that it can save lives; improve quality of life, e.g., frees up face/hands for eating, etc.; may decrease the need for continuous ventilation; makes available direct access to vent users' lungs to assist with secretion removal and to provide mechanical ventilation and medications.

Disadvantages

What are the disadvantages of a tracheostomy? It requires a surgical procedure, and there is an increased risk of infection, bleeding and development

of scar tissue. There are emotional and psychosocial issues, such as an altered body image and changes in ways to communicate. The ability to swallow may be altered,

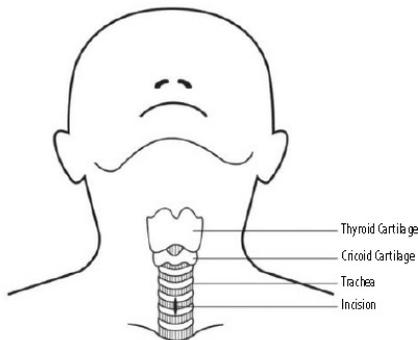
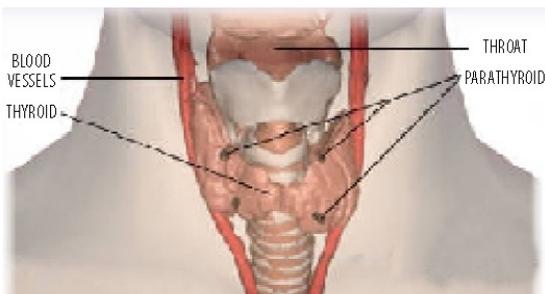
and the sense of taste and smell can be lost. There is loss of the natural warming, humidification and filtering of air that usually takes place in the nose and upper airway. Lastly, there is a greater need for home health services/skilled caregivers due to increased equipment needs, which results in more expensive cost of care. Dean stated that it is up to each vent user to decide which of the advantages and disadvantages are the most important factors in making a decision.

Tracheostomy or Tracheotomy? The terms tracheotomy and tracheostomy are used, but which is which? Tracheotomy refers to the surgical opening of the trachea. Tracheostomy also refers to a surgical procedure – the creation of a stoma (hole) at the skin surface – but most often the term is used to reference the tube itself. Sometimes the word is shortened to "trach."

How Is A Tracheotomy Performed?

A percutaneous one is performed at the bedside, usually while a patient is in critical care. An “open” tracheotomy takes place in an operating room with a surgeon, who is usually an ENT.

The tube itself is usually made of plastic or silicone, but all of them curve slightly to conform to the trachea in which they are inserted. The tube is inserted between the rings (usually 3-4 or 4-5) of cartilage of the trachea, just below the larynx (voice box). The tube is secured in place with stitches and a “trach tie” of some sort. The stitches usually come out in one week.



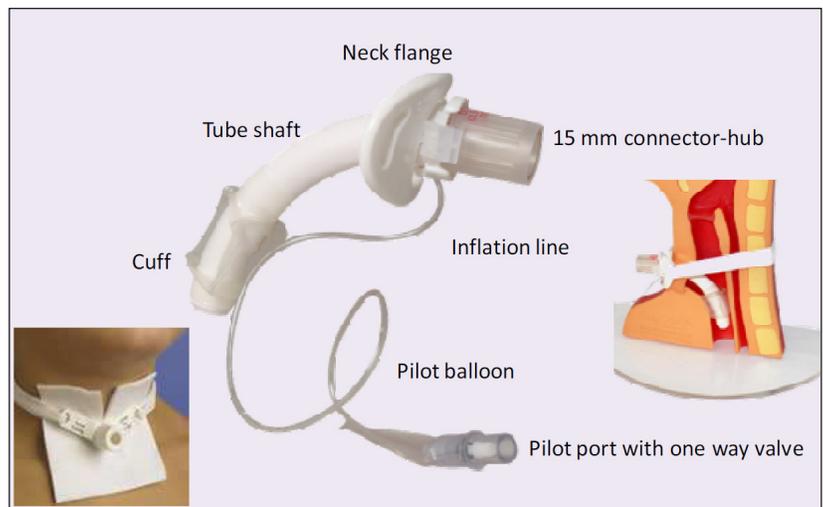
Surgical Tracheostomy

There are many brands and models of tracheotomy tubes. Shiley®, Bivona® and Portex® are the most common tubes available in the USA. (These names can be found in the handouts under the definitions pages at the end of Dean’s presentation at www.ventusers.org/edu/ConfCall2013Trach.pdf.)

Some people can’t use a standard tube, so measurements are taken and a custom tracheostomy tube is made and ordered.

Parts of a Tracheostomy Tube

Dean explained some medical terminology related to a tracheostomy tube. The neck flange, or neck plate, will rest on the skin of your neck. The only part that will be visible is the front of the neck flange and the hub of the tube. The neck flange front contains important printed information that tells caregivers the brand, size and cuff information about a specific tube. The hub may stick out slightly, but is necessary to attach ventilator circuits, emergency resuscitation devices and speaking valves.



The shaft of the tube will be centered inside your trachea or windpipe. The tube you receive may or may not have a cuff on the end. The cuff is used to seal the trachea during mechanical ventilation. If the tube has a cuff, there will be a pilot line, or inflation line, that leads to a spring loaded pilot balloon – this is where you put the air in, or take the air out of the cuff. Care should be taken to use the least amount of air possible to inflate the cuff once it is inside the trachea. If you do not require mechanical ventilation, you will receive a tube without a cuff, or cuffless tube.

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Choices of Tubes and Cuffs

Tracheostomy tubes may have a single lumen or double lumen cannula. (Lumen refers to a channel within the tube – one channel is a single lumen – 2 channels is a double lumen.) The single lumen tube is coated with material that helps keep secretions from sticking and clogging the inside of the tube should secretions be coughed up into the tube. It is usually changed and/or removed to clean weekly. Double lumen means there is an inner cannula that fits inside the tube. This inner cannula is changed and/or cleaned several times per day to make sure the opening remains free and clear of any secretions that may accumulate inside it. Some inner cannulas are disposable; some are re-usable and are cleaned and then put back inside the tube.

Another variation is that some companies offer water-filled cuffs instead of air-filled ones. They are referred to as TTS, or tight to the shaft, because when the cuff is deflated, the material hugs the shaft of the tube and virtually disappears. This streamlines exhalation around the tube during speaking valve use, and makes it easier to tolerate.

After describing a tracheotomy and the tracheostomy, Dean explained the care required if one has a trach, including the importance of compiling personal information and regular assessment to maintain safety.

How Will I Communicate?

Another concern is speaking. Dean who works for Passy-Muir, a maker of a speaking valve, commented that there



The Passy-Muir speaking and swallowing valve can be used while using a ventilator, as well as applied directly to the tube if not. The company sells three colors of valves. The aqua valve is most often used with the ventilator tubing. The purple valve is most often used on the trach tube while you are in the hospital, or a transitional facility. The clear valve is favored for use in the home care environment for patients who wish the valve to be less obtrusive.

Dean's presentation is online at www.ventusers.org/edu/ConfCall2013Trach.pdf and pages 5, 6 and 7 detail the problem of swallowing for people with a trach (the risk for aspiration can be as high as 85 percent). Additionally, the importance of humidification of air is addressed, since breathing through a trach bypasses the nose, our natural humidifier. She also outlines suggestions for trach care, trach changes, oral care, stoma care and personal hygiene.

If you do not have access to the Internet, email or call us for a copy of the presentation and the addendum of "Definitions," "Trach Safety" and a list of "Equipment Recommended for Home."

are countless communication devices and techniques. From simple tricycle horns to expensive electronic devices, so there should be no reason to be left without a voice.

Some people choose to use leak speech. Leak speech is when you partially (or fully) deflate the cuff on the tube and allow some of that ventilator breath to come up through the vocal cords to speak. Sometimes the volume of the breath is increased considerably to allow talking and ventilation to happen at the same time. The disadvantages to leak speech are that too much volume can be harmful to the lungs, and that a person must learn to talk during inspiration, not naturally during exhalation. ■



The valve can go directly onto the hub of the tracheostomy tube like the photo on the left. Or, it will fit into standard disposable ventilator tubing like the photo above.

The Passy-Muir valve is a one-way valve, and when it is attached to the trach or placed in line with the ventilator tubing, it re-directs exhalation past the vocal cords and out the mouth and nose. This redirected exhalation restores voice, improves swallowing, restores physiologic PEEP (the air in the lungs that never completely exhales), improves secretion management by restoring the natural cough, improves oxygenation, can be used as a ventilator weaning and decannulation (take the trach tube out) tool, may decrease the risk of aspiration, and improves smell and taste to make eating more pleasurable.

Photo credits: Linda Dean, Passy-Muir Inc.

The Adventures of Traveling With a Vent

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suggested that on future trips they act as a concierge for me. I tell them our destination, and they identify a company there that will work with me in case of a machine malfunction. I then contact the company and confirm that they will be available in case of an emergency and that they do have a vent similar to what I am using. This has given me huge peace of mind. To date, we have only used this

back up plan in the United States, but I hope it will also work in Europe.

I consider myself fortunate to have traveled as often as I did with no problems, but from this point on, unless our destination is within driving distance of home, I will have a backup company in place and prescription in hand. ■

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Hawaiian Airlines states they do not have power ports. Approved portable oxygen concentrators may be used during flight, with restrictions, and personal oxygen is not accepted.

SkyWest Airlines (operates as United Express, Delta Connection and US Airways Express) reports that RTCA (Radio Technical Commission for Aeronautics) approval documents are required to use a ventilator during flight. None of their aircraft have power outlets for personal use. Oxygen and other devices can be used if they are on the approved list, which they attached.

Delta referred us to a great deal of information at www.delta.com/content/www/en_US/traveling-with-us/special-travel-needs/disabilities.html

United assured us that they are in full accordance with FAA safety regulations and the guidelines set forth in Part 382 of the Air Carriers Act and referred us to www.united.com, and under the "Travel Information" tab, click on "Special Travel Needs."

Reporting Travel Problems and Solutions

Our survey asked for comments from users of home mechanical ventilation who have flown. The comments could be categorized as "About the airlines" and "Regulations."

About the airlines:

"I will not fly any other airline but Southwest. SWA tries hard in every way; however, in spite of the Permobil rep working with SWA in Dallas, they still cannot seem to protect our power chairs in flights."

"I discussed my needs with Delta Airlines. I was told by their Manager for Disabilities that there was no problem with using my BiPAP and battery on any Delta flight. The flight attendants were very helpful and understanding. In fact, it was the same crew both directions and they remembered me."

"Besides the refusal of Air France. I was also refused by Turkish Airlines. In the case of Turkish Airlines I was allowed to fly using the vent one way but not back. They took my equipment away, sealed and stored it. I was forced to ventilate myself manually with a bag for four hours."

"Traveling with cheaper priced airlines is virtually impossible because these companies don't allow for exceptions, (which is why they are cheap)."

Regulations:

"TSA is our greatest challenge. They don't recognize the equipment and then evaluate it (and have left necessary 'pieces' of the circuit/system out of the bag after examining it). We have also arrived at our destination with broken/cracked components after examination."

"I have never been refused to fly because of my ventilator but because my wheelchair was 'too big.'"

"It is reasonable to require a vent to have battery power in the event of onboard power failing, so I do not think it is necessary to require airlines to provide power. The first step should be to require the airlines to allow vents and make a clear path to get vents approved."

"If airlines have electrical outlets for computers, then why can't an oxygen or ventilator device be used?"

Report Experiences (Good and Bad)

IVUN has developed a way to collect the travel experiences of ventilator users on its website. The form collects not only information about flying, but about train travel, cruise ships and road travel. Share your experiences. Enter the good and the bad. IVUN will make these experiences available to other vent users and researchers. Look for the orange "Travel" button on www.ventusers.org.



▶ Links to Governmental Policies and Resources

Laws and Regulations

- U.S. Department of Transportation, 14 CFR Part 382, Nondiscrimination on the Basis of Disability in Air Travel
- European Union Commission guidelines regarding Regulation (EC) No. 1107/2006 and the rights of disabled persons and persons with reduced mobility when travelling by air
- U.S. Department of Transportation, Passengers with Disabilities: About the Air Carrier Access Act

Medical Information

- Transportation Security Administration: Travelers with Disabilities and Medical Conditions
- Managing passengers with stable respiratory disease planning air travel: British Thoracic Society Recommendations, *Thorax*, September 2011, Volume 66, Supplement 1
- Centers for Disease Control and Prevention: Your Survival Guide to Safe and Healthy Travel

Consumer Protection

- U.S. Department of Transportation, Aviation Consumer Protection, File a Consumer Complaint
- Association for Airline Passenger Rights (AAPR): Section for Passengers with Disabilities
- International Air Transport Association (IATA), All Passengers This Way

General Travel Information

- Transportation Security Administration: TSA Cares (855-787-2227) is a toll free helpline to assist travelers with disabilities and medical conditions. TSA recommends that passengers call 72 hours ahead of travel for information about screening policies, procedures and what to expect at the security checkpoint.
- U.S. Department of Transportation: Air travelers who experience disability-related air travel service problems may call the hotline at 800-778-4838 (voice) or 1-800-455-9880 (TTY) to obtain assistance. ■

Not yet a Member?

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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 .

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