

Learning to Use a Speaking Valve

Jack Rushton interviewed by Julie Kobak, M.A., CCC-SLP/L, Vice President of Clinical Education, Passy-Muir, Inc., Irvine, California, JKobak@passy-muir.com

What circumstances led you to a tracheostomy and living with a ventilator?

Jack: August 1, 1989, I was body surfing with my son and his friends at Laguna Beach, California. I was riding a wave into shore when I hit my forehead on a submerged rock. I was immediately paralyzed, couldn't move my arms or legs to swim and could only see the swirling seawater all about me. I blacked out, but my son and his friend got me to shore, where lifeguards did CPR until the paramedics arrived.



Jack Rushton

Two hours later I woke up in the hospital surrounded by doctors and nurses. A nurse said, "Mr. Rushton, you have had a bad accident. If you understand what I am saying, blink your eyes once." I understood perfectly what was going on, blinked my eyes once, and heard a collective sigh of relief from everyone in the room. Tests revealed that my spinal cord had been severed between the second and third cervical vertebrae. From that day 21 years ago, I have been kept alive by a ventilator breathing for me.

How did you communicate immediately after you were trached?

Jack: For a month, not being able to move any part of my body and not being able to speak was a very frustrating and frightening situation. I felt extremely vulnerable not being able to communicate even my most basic needs. I wanted so badly to have my

teeth brushed and my glasses brought to me, for example.

One morning while still in the ICU, I was running a fever and feeling claustrophobic. I felt that if I couldn't get relief of some kind I would just die – in fact dying would have been a great relief from the misery I was in. Nurses walked by glancing at me, but not being able to communicate, I could not elicit their help.

Thankfully, a good friend came in, saw the panic in my eyes, felt how hot I was and immediately began to bathe my face and arms with ice water. The nurses realized the seriousness of the situation, and soon I was cooled down and feeling at peace once again. How dangerous it is to be in a hospital without the ability to communicate!

About a week after my accident, a good friend created a series of charts that helped a great deal. By pointing a finger at different items on the charts and my blinking once for "yes" and twice for "no," I was able to communicate my basic needs. The chart was so ingeniously put together that I could even indicate what books and Scriptures I wanted to have read to me.

When and how was the Passy-Muir Valve introduced to you?

Jack: After two weeks at the regional trauma center, I was transferred to Rancho Los Amigos Rehabilitation Hospital in Downey, California.

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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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Special thanks ...
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From Around the Network

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

Manufacturers' News

Covidien sold its CPAP and bi-level products (GoodKnight™ brand) to PH Invest, a privately held company in Luxembourg. The transaction is expected to be completed in September. The Adam™, Breeze™ and Dreamfit™ interface products will continue to be sold by Covidien. www.covidien.com

Newport Medical offers a free online training program for the HT50 on its website, www.ventilators.com. The excellent three-part program is a fully narrated class which teaches people HT50's clinical capabilities, setup (including circuit configuration), and special application considerations for children and others with airway leaks. It is easy to follow and can be done at any pace, started and stopped as needed, or skimmed through for specific information.

HT50 users who wish to access the training program may request a password through the website or contact Watsa Chaodee, Newport Medical, 800-451-3111, ext. 285, wchaodee@newportmedical.com.

IVUN members who want to learn more about the HT50 can receive a temporary password by clicking on the same link. Fill in the Contact Information box, and in "Comments/Requirements," type in "IVUN Member." (The program is also available on CD for those who have computers but no access to the Internet.)

Pediatric Home Care

"**Making Life Easier**" is the name of a series of educational videos featuring home care tips on children and home mechanical ventilation. Produced by Children's Hospital Los Angeles, it is available in both English and Spanish. Topics include discharge planning, education and home preparation for living at home with a ventilator, and diaphragm pacing for children. Go to www.YouTube.com, and enter "home mechanical ventilation" in the search box.

Home Care of Children on Ventilators: A Parent's Guide, a 55-page booklet, is available from the Pediatric Committee of the California Thoracic Society. The *Guide* is designed to answer frequent questions and help parents comfortably address the challenges of their child's respiratory needs. It includes checklists for discharge, home medical equipment services, safety checks, and establishing a home care routine. www.thoracic.org/chapters/thoracic-society-chapters/ca/publications/resources/respiratory-disease-pediatric/Vent_Dependant_Children_booklet.pdf ▲

Ask The Experts

QUESTION: The IVUN office has received several reports from families of users of noninvasive ventilation (NIV) who choke, get pneumonia or have major surgery, and end up trached, either in a skilled nursing facility or in a long-term acute care hospital. They are told they can't be discharged until they are weaned from the vent. Should complete weaning be the paramount goal, particularly when individuals have used NIV successfully in the past?

A very reasonable goal for a neuromuscular disease patient on a ventilator following acute failure to breathe adequately could be maintenance with NIV. Unfortunately, many physicians consider liberation from mechanical ventilation to be the only acceptable goal. This is due, in large part, to lack of training experiences in managing patients with long-term chronic ventilation needs. Most pulmonary and critical care physicians are trained to manage acute illness in patients for whom complete weaning from mechanical ventilation is the appropriate goal. Unfortunately, when a patient previously managed successfully with NIV is admitted to the ICU, the previous successful experience with NIV may be forgotten and a tracheostomy-based ventilator strategy becomes the main goal.

How can we change this? Education of pulmonary and critical care physicians in chronic non-invasive ventilation is crucial. A greater understanding of the home options for ventilatory assistance patients is equally important. These clinical training experiences are difficult to come by but can make all the difference in a physician's comfort level in managing such patients.

Charles W. Atwood, Jr., MD, FCCP, University of Pittsburgh Medical Center, VA Pittsburgh Healthcare System, Pittsburgh, Pennsylvania. atwoodcw@upmc.edu

The paramount goal definitely should not be to wean the patient entirely from the vent, but rather to return the patient home at the highest level of functioning possible. Especially if the patient had been a successful user of noninvasive ventilation previously, I would attempt to wean the patient from invasive ventilation back to NIV. I have done this many times, and the main considerations are to postpone the transition until the underlying process (pneumonia, for example) has responded to treatment, and secretions are manageable. Using devices like the cough inextufflator can be very helpful during this transition.

Mask ventilation can be started with the trach plugged and NIV sessions gradually lengthened as tolerated until the patient can be supported entirely noninvasively, at which point the trach can be removed.

Sometimes patients acquire problems with swallowing and severely weakened cough and are not good candidates for returning to NIV. In this case, it is still sometimes possible to discharge patients home in the absence of weaning, but there has to be much more caregiver support available than is the case with NIV. If the patient is capable of eating and speaking, then part of the rehabilitation should focus on preserving these functions while providing breathing assistance.

Some patients are so ill they cannot wean from tracheostomy ventilation or be sent home, but this situation is acceptable only if weaning to NIV and transfer to home have been seriously considered and proved impossible.

Nicholas S. Hill, MD, FCCP, Chief, Pulmonary, Critical Care & Sleep Medicine, Tufts Medical Center, Boston, Massachusetts, NHill@tuftsmedicalcenter.org ▲

Do you have a question about ventilator-assisted living?

Are you a health professional with a question for ventilator users? Send it to info@ventusers.org, and IVUN will find experts to answer it.



Marie B. Latta

Living Independently with Twin Tubes

Marie B. Latta, M.Ed., Atlanta, Georgia, latta@mindspring.com

A survivor of bulbar and respiratory polio during the 1949 epidemic, I have quipped that I can't breathe and can't swallow, but other than that I'm OK! Today my life with PPS includes the use of multiple mechanical helps. In addition to my power wheelchair, I have a permanent tracheostomy tube and a feeding tube. I do no eating orally and use a ventilator when sleeping. With all that, I live alone.

On Mother's Day 2006, I had surgeries to place a tracheostomy and a feeding tube, both permanent. (I joked that the hospital had a two-for-one Mother's Day special.) Ten days later, I was sent home with minimal written instructions.

Since the surgeries had not been planned at the time of admission, I knew very little about what I was getting ready to live with. Home health had been arranged, but there were several initial serious bumps in the road.

I knew that I would have to take charge and learn fast even though I was extremely weak. The hospital respiratory case worker recommended transitioning to a rehab center, but my pulmonologist knew I could manage at home. After the first few challenging months, my "new normal" life fell into a routine.

It was soon clear that I had two main jobs: The first was to understand my twin tubes and how they were operating for me. The second was to know how to maintain and keep them clean.

Daily care routine: My morning routine includes daily care and cleaning of both my tracheostomy and my feeding tube – as important as brushing my teeth. After showering, I use cotton swabs and gauze with saline and a small amount of hydrogen peroxide for another cleaning around both tubes. Careful drying is critical to preventing fungus infections. The warm moist areas around the stomas

(holes) can quickly turn into fungus folly. One of my prevention and intervention tools is Nystop®, an anti-fungal powder.

I had assumed that care of the trach would be the biggest challenge. So wrong. The trach is the good twin. Initially there was a huge amount of secretions in my trach. The suction pump provided by my home health agency allows me to clear my trach adequately. Even though the level of secretions has become manageable, the suction pump will be a lifelong companion to clear my airways.

For 13 years before my surgeries, I used a BiPAP (bi-level positive airway pressure). After my trach surgery, I did not use ventilation, but in 2009, when my chest began feeling tired just from breathing, I began using an LTV®950 (nighttime and naps), which has increased my stamina and strength.

Back to the daily routine: After the lengthy personal care time comes morning nutrition, which I get totally though the feeding tube, a Kimberly Clark Mic Gastronomy Feeding Tube. It was surgically placed directly into my stomach just to the left of my belly button.

I attach a 60 cc syringe to the tubing and pour the formula in. Initially I used a plunger to push the formula through, but when I began damaging my hands using the plunger, I switched to letting the formula flow in by gravity. With the help of my occupa-

In this article, Marie, who lives alone, describes how she manages her trach and feeding tube care. In the April 2010 issue of *Ventilator-Assisted Living*, Marie wrote about taking a cruise last year with her family and her "mechanical toys."

www.ventusers.org/edu/valnews/val_24-2apr10p1.pdf

tional therapist, we rigged a stand designed to hold hairdryers to hold the syringe. The base slides under my legs when I am in my wheelchair. (See photo at right.)

My physician prescribed five cans per day of FiberSource HN to provide 1500 calories (at least 100 percent of nutritional needs) that allow me to maintain a stable weight. I have two cans at breakfast and at lunch, and one in the evening. Taking in adequate water in between is essential.

Thankfully, I can do all my own personal care. My county senior service provides two hours per week house-keeping services, and a teenaged friend comes two hours per week to help me with anything I need. I have kept my lift-van even though I no longer can drive. Sometimes friends drive me to errands or appointments, and other times I use our public transit's Paratransit services.

Emergencies: In the two years after my tube placements, I became well acquainted with the emergency room to replace failed feeding tubes. Initially the medical folks were over-inflating the balloon that keeps the tube from falling out, causing the balloon to rupture.

Preparedness: I have learned to replace both my tubes. After having my clinical respiratory therapist teach me, I began changing my trach tube at home with a home health RT standing by. (They are not allowed by law to do in-home changes.) Recently I found I could also successfully change my feeding tube when it fell out an hour before I was to leave for an evening function. I always keep a spare.

I always carry with me supplies that allow me to eat or hydrate. In addition, I carry extra trach tubes, feeding tubes and supplies for emergency use. When I travel, my ventilator and portable suction pump go with me.

Eating out: Even though many tube users emotionally can't handle being

at the table with everyone else eating, I enjoy the fellowship. And I eat! I have developed a discreet system for feeding, by acting like it is normal, and no one has ever objected.

My biggest social challenge is that I cannot swallow anything – including my own saliva. At home I have the suction pump. But I determined early that my limitations and mechanical toys would not control my life. So when I go out, I carry paper cups which I call my portable suction. I use a stack of three (for stability) opaque paper cups into which I excrete my saliva, looking as if I were drinking. My friends and family know what I am doing, but others often have no idea. One advantage of being in a wheelchair is that I use my knees as a tool, wedging the cups between them and covering them with a lap cloth.

Quality of life: My respiratory and swallowing needs are simply one part of my life. I want to remain as independent as possible. I am clearly aware that we each have varying levels of limitations and needs. But having an independent spirit is a choice that we each can make. I have felt the sting of hospital providers wanting to make me dependent. Fortunately my pulmonologist believes in me, and my home health agency thinks my independence is great. My respiratory therapist tells me they have no other patients who change their own trachs and no other ventilator users who live independently.

My message: Have an independent spirit. Do whatever you can for yourself, and get help with the rest. Remain in charge of your care. It's your life. Some people I encounter wrinkle their face in a "poor you" expression. I am quick to say, "Don't feel sorry for me. My tracheostomy and feeding tube have been life-changing. I am healthier and better nourished because of them. Some folks equate trachs and feeding tubes with a death sentence. Not so! Mine have given me new life." ▲



Marie pouring formula into her feeding tube.

Excellent information about home tube feedings:

www.oley.org

More about my Shiley trach:

<http://respiratorysolutions.covidien.com>

Click on "Airway Management" and then "Tracheostomy Tubes"

More about my ventilator:

www.carefusion.com/products-and-services

Click on "Ventilation" and then "LTV®950"

Learning to Use a Speaking Valve

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Immediately upon arriving, the doctor in charge of the spinal cord injury unit deflated my cuffed trach, and I was able to speak my first words. How encouraging that was to me and my family!

After several weeks the trach was no longer cuffed, and I thought I was speaking pretty well, even though there were long pauses between my words which was frustrating. If it never gets better than this, I thought, I will just learn how to deal with it.

After I had been at Rancho almost two months, a speech pathologist and a respiratory therapist introduced me to the Passy-Muir Valve. They said that it would help me to speak much better and without long pauses.

Was it easy to use the first time you tried it?



Jack enjoying a moment with his wife and granddaughter.

Jack: The first time I used the Passy-Muir Valve was a very frustrating experience. It was like having a hurricane in my head. The valve forces you to exhale through your nose or mouth. Without the valve in place, you can be totally passive and the respirator will inhale and exhale for you. It is so easy and comfort-

able that one is tempted not to try anything else that requires effort.

My doctor, sensing my initial frustration, told me not to worry about it and that my life could be okay without the Passy-Muir Valve. The speech pathologist and respiratory therapist, as well as my family, encouraged me to use it. They knew, and I came to know, how much better I could speak when the valve was in place.

I was making so many other adjustments at that time that the Passy valve was not a high priority for me. When I left Rancho after six months, I was only using the Passy valve periodically.

At home, however, my family and friends really pushed me to use the valve. They encouraged me to increase my daily time using it, and I did. The day finally came when I had the Passy valve in all day without even realizing it. Since that day, more than 20 years ago, the Passy valve has been an important part of my life. I do a great deal of teaching and motivational speaking, as well as spending hours each day on my computer using voice recognition software. The thing I enjoy most is that I am able to interact and carry on conversations with my wife, children and grandchildren. I shudder to think what my life might have been like without it.

What do you find are the most significant benefits to using the Passy-Muir Valve?

Jack: The greatest benefit is to be able to speak in a fluid and powerful way. I also have learned that with the Passy valve in place I have fewer secretions and don't need to be suctioned as frequently. I believe it helps my general health because it forces me to exhale through my nose, and through the years, I have not had any sinus infections.

You write a series of "Observations" in which you provide insight and perspectives into important life issues. What advice do you offer people for living with a trach in regard to communication?

Jack: First, my "Observations" are posted on <http://apps.facebook.com/blogged/blogs/observations-by-jack-rushton/>.

▷ It is a frightening thing to have a trach and not know what your future ability to communicate will be. My advice to anyone who has this procedure is to go forward with faith and confidence that with the Passy valve you will be able to communicate in a normal and natural way. I'm a slow learner and perhaps others can adapt to the valve more quickly than I did.

I think it's so important not to give up in the beginning, but to be persistent. By using the Passy-Muir Valve, you will find that it gets better and better. In fact, it will get so good that you won't even realize you are using it until you try to get along without it. ▲

Calendar

September 18-22. European Respiratory Society 20th Annual Congress, Barcelona, Spain. www.ersnet.org

October 30–November 4. CHEST, American College of Chest Physicians Annual Conference. Vancouver, British Columbia, Canada. www.chestnet.org

November 21, 9:00am–2:30 pm. Breathing & Sleep II. Salk Institute for Biological Studies, La Jolla, California. www.salk.edu/breathingandsleep or contact Gladys Swensrud, 858-271-9288, swensrud@pacbell.net

IVUN invites you to promote your meeting in future issues of Ventilator-Assisted Living, IVUN Membership Memo and on www.ventusers.org/net/calendar.html. Send the details to info@ventusers.org.

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