

## What I Wish I'd Known Prior to Vent-Life

1. To explore non-invasive ventilation as an option
2. To pursue immediately financial options through Medicaid and Medicare as well as the establishment of a Special Needs Trust
3. To use devices that increase my overall health:
  - a. The Volkner Turning Bed Mattress Overlay, <http://www.volkner.com/products.html>
  - b. Cough Assist Mechanical Insufflation-Exsufflation Device, <http://www.jhemerson.com/coughassist.htm>
  - c. The Vest Airway Clearance System, [http://lungsforlife.org/news/vest\\_fda\\_approval.htm](http://lungsforlife.org/news/vest_fda_approval.htm)

### *Other Useful Devices*

- a. Noise Maker; vent users who can speak with a talking valve or by deflating cuffs on their trach tubes typically do not have the option to speak when they sleep; thus, if those of us physically dependent need a means to alert a caregiver should a problem develop; I use a remote sold by Radio Shack; it activates a device in an electrical outlet; that device, in turn, activates the radio I have hooked into it; when a problem I need addressed emerges, I activate the radio to wake my caregiver. What about power outages? The vent alarms with an electrical outage; however, it would be great to use a device independent of electricity.
- b. Urinal; to decrease the need to transfer in and out of bed, this device proves helpful.
- c. Wrap Skirts; to decrease the effort involved by a caregiver in transferring me to and from the toilet, I have found wrap skirts helpful; they can be left in the wheelchair, meaning the caregiver has one less thing to navigate in the successful transfer; obviously this works better for women than for men.

### *Caring for Devices*

Sterility and sanitation of course become even more important for frail bodies who naturally by-pass the body's defense mechanisms through procedures like invasive ventilation.

- a. Develop a reasonable schedule for cleaning washable device tubing, washable filters, yaunkers, suction canisters, nebulizers. First use soap and hot water, then move the items to soak in vinegar and water. Soak in each of these solutions for a half hour. Allow to dry thoroughly prior to re-use. Sometimes dishwashers prove effective for the canisters and yaunkers. We soak the washable components at least once a week. Some items undergo the process twice a week. The nebulizer itself and the Cough Assist tubing get rinsed with each use. Whenever the washing fails to clean the parts adequately (foul odors and discoloration suggest this), we discard the parts and replace them.
- b. Consider using Listerine or a like mouthwash not only for your oral hygiene (Studies show that Listerine is as great as dentists' clinical applications of other substances in controlling the growth of unhealthy bacteria in the mouth.) but also as the first substance in newly cleaned suction canisters. If possible,

however, use a clear mouthwash. Using green or blue mouthwash can make it harder to notice if yellow, green, or brown mucous is exiting your lungs, and it's best to notice those potential-infection signs as soon as possible. (Vent users and their caregivers can also examine daily, to monitor infections, the color of mucous around the stoma and on its drainage sponge as well as the odor and, for vent patients, the taste of mucous harboring infections.)

- c. Develop a reasonable schedule for exchanging sterile catheters like the contained multi-use Ballard suction catheters and for replacing non-washable filters on the vent and Cough Assist. (If you use Mucomyst, you may need to use new antibacterial filters with each nebulization. The sticky medication can otherwise cause vent malfunctions.) We change my Ballard every three days unless the protective outer plastic ruptures sooner. We change my non-washable anti-bacterial filters and LTV (Pulmonetics vent) circuits once a week.
- d. Follow closely directions for trach tube sterility. I only used an inner cannula the first week of my trach life. Since then I use a Bovina tube that lacks an inner cannula. I like this tube, but the entire tube must be removed and replaced when occlusions occur (or after 30 days of use – though I am not sure I've ever made it 30 days between changes). The Bovina we soak in vinegar and water, scrubbing it with a trach brush. Then it is taken for sterilization in an autoclave machine. After such sterilization it returns in a sealed, see-through bag. The tube inside can be re-used after such sterilizations as long as the structural integrity of the tube and its inflatable cuff hold. Before we take one trach tube from my trachea, we check the integrity of the new tube. It comes out of its sterile package, and we insure that the trach inflates and deflates without leaking. Some people inflate such cuffs with air; however, I use sterile saline.

### **What I Wish I'd Known Early in Vent Life**

1. Speaking, eating, drinking, and getting out of bed would remain an option.
2. Heavy edema would become a constant problem due to the positive pressure system the vent creates in the thoracic cavity, typically a low pressure system. Diuretics (80 mg of Lasix, 2 mg Bumex jointly once or twice weekly) so far tend to be what most helps me alleviate the pressure the fluid retention causes. I wish I had a better solution. Should you pursue this plan of care, it will require a physician's involvement; the day you take the diuretics, plan to have frequent help for your toileting routine. Also, hydrate extensively and consume potassium- and magnesium-rich food or supplements. Failure to do so can induce or elevate a fever and thicken secretions.
3. Using saline bullets during the suctioning process is an art and involves particularizing the process for your own lungs. In my case, bleeding from tissue irritation and extraction occurred with dry runs. With too much saline, I felt as much like I were drowning as I did with congestion from mucous. Most often I prefer 3 "runs" with the Ballard suction catheter per suctioning set/cycle. With the first two runs, using a 5 cc saline bullet, 2.5 cc of saline enters my lungs before the vacuuming begins. The third run is a dry run.

However, sometimes I need an additional dry run or another set or two/cycle or two of 3 runs with more saline for the first two of those 3-run sets/cycles.

4. How to diagnose a trach tube occlusion; knowing signs of trach tube occlusion can prevent oxygen deprivation, lessen pneumonia symptoms, and ease the struggle of breathing.

*Signs of Trach Tube Occlusion*

- a. Increased difficulty in breathing
- b. Frequent vent alarms (low minimum volume or high pressure)
- c. Ability to Speak as if the trach tube were capped although it is not
- d. High congestion, heavy mucous production
- e. Feeling Resistance in or around the tube
- f. Requiring fewer CCs of saline or air to inflate the trach tube cuff

**What I'm Glad I Didn't Know Prior to Vent Life**

1. My respiratory collapse would happen much sooner than tests suggested to doctors: Sometimes I wonder what might be different if my doctors had diagnosed the severity of the situation or I'd have researched differently pre-respiratory collapse. I might have had non-invasive ventilation and greater health in light of respiratory failure, but I also could have had a living will denying intubation. I believe I likely would have chosen the latter if I had known how expensive it would be to support such a life (expensive on both a financial and physical burden level); my ignorance of this makes me most glad I accepted inaccurate assessments from the medical community. Although it could be devastating to not know how fiscally or logistically difficult it is to manage the situation and although I might have been better informed about the logistics of vent life, I also am glad that the burden of that did not immediately cloud my hope, my effort, my desire and will, my courage ... and not just mine but my husband's and that of others who help us.
2. How inexperienced and, thus, uninformed about living in the face of respiratory collapse/vent dependency my medical community of doctors, occupational and respiratory therapists, nurses, and social workers would be: In a city with a medical center/school, multiple branches of multiple hospital systems, and an MDA clinic, it surprised me that I had to educate myself and then them and petition for certain things I needed for my long-term care. Ideally I would have been better guided in terms of devices that could increase my health and in terms of arranging my long term care. It especially concerns me that among those I encountered social workers and case managers (insurance or facility or agency or public/civic program) could not advise me when I asked for help. I wished they were better educated on long-term care options.
3. How depleted I would grow physically and remain physically with the respiratory failure: My strength proved further compromised by hospital-acquired staph and pseudomonas (2 gram negative strains) infections and the subsequent (due to heavy antibiotic use) candida due to long-term heavy antibiotic use.

*Useful Things to Know*

- a. Vegetarians can rebuild strength, acquiring enough protein in their diets without meat.

- b. Anti-Candida Cookbooks and websites on candida control exist, so it is easy to learn the trigger foods to avoid.
- c. Different antibiotics work better for different people even with the same infection/diagnosis. Different doctors know and try different treatments. If one isn't working, get another opinion, if possible.

### **What I Most Wish Were Untrue, Other than the Degenerative Process Itself**

How complicated the current system makes it to live, long-term, at home as an adult married to a productive individual.

### **What I Most Miss As a Result of Vent Dependency**

The greater health and the freedoms that brings including more solitude, more independence, more energy, greater productivity, and easier mobility.

### **The Single Most Important Thing I Saw**

Reverence for life; my husband, many of my doctors and nurses, many physical therapists and respiratory therapists, many friends and relatives, and even acquaintances worked together to sustain my life. The tremendous outreach and then amazing dedication bolster me still. It does require a team effort to regain strength and then to remain out of an institutional setting. I am blessed thus far to have such a team. I am immensely grateful for every contributor.

I especially wish to thank my husband for his incredible strength. I am grateful that a person who so savors his autonomy can take on as graciously as he does this highly interdependent life my body demands and how supportive of my body but also of the me behind the body he has been, and I am grateful for how much he savors my presence despite the huge financial and emotional and physical expense of it. Certainly I had intimations of his strength and level of commitment time and again prior to my respiratory failure, but my fear of and concern with imposing this on him would have clouded my ability to see fully his amazing commitment to my life and the miracle of such love as he has for me, the trust I can place in him.

### **What I Would Hope My Respiratory Collapse Helps Demonstrate**

Sometimes I wonder if I appreciated the comparative ease of being in the world when one can breathe without mechanical support. I wonder if I'd had done more or, at least, chosen different activities in my pre-vent days if I'd known this collapse was on the horizon. Perhaps. In a way, though, it was a blessing not to know. I didn't live in fear of the months of incapacitation ahead of me. If there's a lesson there, it's that of any unanticipated "tragedy" (granted, my fate escapes the real tragedies on this planet): we all need to embrace life as fully as possible given our current opportunities.