

My Ventilator and I: Traveling Buddies

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Marie and Winnie the Pooh.

Two weeks with grandchildren, Mickey Mouse and Winnie the Pooh. What more could a grandparent ask? I thought the dream was out of reach.

I previously turned down opportunities to travel on the basis of the logistics, but my daughter-in-law finally enticed me to celebrate Christmas with them. In 2008, I was with my son and family getting on a Disney Cruise Line® ship, and when December 2009 rolled around, I was with them again. We also spent time at Walt Disney World® Resort in Orlando, Florida.

My experiences were “magical,” even when traveling with my “mechanical toys.” I carried a ventilator on my lap making room for my twin tubes – the tracheostomy and feeding tubes.

Disney has built accessibility into its planning and daily operations. The staff is prepared for people with all types of conditions and makes you feel happy and special, but never patronized or like an afterthought.

The accessible ground transportation was important to me. My daughter-in-law preplanned and reserved several themed dinners, such as a Polynesian Luau, all over the park. I could go everywhere on the accessible sidewalks and ride the monorail, the boat ferry and the busses. The rides with boats had an accessible boat onto which I could drive my wheelchair.

There was even room for my family to ride with me. Being able to participate with my family in all of the

activities captivated me. (The rides which require a transfer out of your wheelchair are identified.)

Boarding the “Disney Magic” cruise ship is barrier free. Once onboard, your room host will take care of your room and you for the duration of the trip. Cleanliness and safety are ship-wide priorities. Each time you enter a restaurant, they hand you a wipe to clean your hands, and the ship is washed down every night.

The ship’s medical center includes a physician. I did not make it a point to meet the doctor, but in hindsight should have just so he would know my situation. Before the ship sets sail, there is a mandatory fire/emergency drill, so you will know where to go in an emergency.

Mealtime is such a pleasant experience even though I eat totally through my feeding tube using a medically prescribed formula and don’t taste one bite of food. I think that fellowship is as important as food, so I don’t let the tube inhibit me from enjoying life.

You are assigned different restaurants for each evening meal, but the serving staff moves with you. They immediately learn your name and your preferences. For example, when they learned I had the feeding tube and

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needed warm water to flush the tube, they always brought hot water in a Styrofoam cup. It was easier to pour from than the formal cups.

Here are some hints to assist the "magic."

Plan ahead. Any trip takes preparation, but for me, preparation reaches a new level. By shipping supplies ahead to Disney's warehouse in Port Canaveral, Florida, and carefully marking them, my feeding tube formula and supplies were in my stateroom when I arrived. I also shipped formula and a suction pump to the resort.

Don't leave anything to chance. On one trip, the formula was not in my room. The person in guest services said since it was late, they would check on it in the morning. I told her it was an immediate need and why, and the formula was located and delivered within fifteen minutes.

Have your own travel agent. The ideal is to use an independent agent – one which does not charge you but is paid by Disney for the business (not a Disney agent). I use an exceptional problem-solver team from the Fort Worth area, JoAn & Clif Hale, Anthaume Group; 817-448-9404; selah50@sbcglobal.net.

Take advantage of Disney-related services.

Complete forms online. Disney has a number of required forms to be filled out and deadlines to be followed. Having them completed online makes boarding much smoother. For example, <http://disneycruise.disney.go.com/faqs/site-help/my-online-check-in/> medical-info-form/ is the link to a form that allows your physician to report any current medical condition(s) and medications and arrange for wheelchair access and/or lift, oxygen

More about Marie ...

Marie Latta is a survivor of bulbar polio she contracted during the 1949 epidemic when she was 8 years old. After a career in special education, she began an ADA (Americans with Disabilities Act) consulting business in 1992.

In 1993, she began using a wheelchair because her breathing no longer supported her walking. In 1994, she added a bilevel device, which she used until 2006, when she had a tracheostomy and feeding tube placed on Mother's Day afternoon. The permanent trach and the feeding tube have both been life changing, and she is stronger because of them. At that time, she was not using a ventilator, but was using a Passy-Muir speaking valve.

In April 2009 after attending the ventilator sessions at Post-Polio Health International's 10th International Conference in Warm Springs, Georgia, she added the LTV® 950 ventilator to her cache of mechanical toys.

Marie has lived alone since the death of her husband from a heart attack in May 1999. In a future issue, she will describe how she manages her tube and trach care and continues her consulting work part-time.

and/or special dietary needs. The form must be received at least 14 days prior to sail date.

I was relieved to know that the ship had four large diesels that power the engines and all the other electrical systems on the ship. If one fails, they can switch the load to another.

Purchase a transportation package.

When you check your luggage at your home airport, it will be tagged for your destination. I checked my luggage in Atlanta, and the next time I saw it was in my room at Disney's Contemporary Bay Lake Resort. The fee of \$69 was worth it not to go through baggage claims and lug baggage around.

Purchase travel insurance. I paid \$199.00 for insurance to cover emergencies, such as onboard illness or medical evacuation. Without insurance, an unexpected event would cost far more than "an arm and a leg."

Airport Security. I flew from Atlanta to Orlando, Florida, to meet my son and his family. I had not flown in ten years, but, at least for me, going through security has greatly improved. I carry my LTV®950 in my lap and it always triggers a search when going through the screening device. The security personnel always drag it out

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From Around the Network

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

Quality Control for Ventilators

Royal Brompton Hospital's Sleep and Ventilation Unit provides a respiratory support telephone hotline for home vent users to call. The unit followed 1,211 adults and children (using noninvasive ventilation primarily). Dr. Mark Chatwin and his team did an analysis of the phone calls between January and June 2006. They found that vent users had technical problems with the ventilators, some of which could be easily solved in the home or which required replacement or new parts. When no mechanical fault was found, the vent users were found to be unwell and/or needed hospitalization. The team also identified characteristics of vent breakdown: vents used for more than 16 hours per day; vents older than 8 years; and vents new on the market.

An accompanying editorial by Drs. Delguste and Rodenstein called for a quality control system for ventilators in Europe.

References

Chatwin M, Heather S, Hanak A, et al. Analysis of home support ventilator malfunction in 1,211 ventilator-dependent patients. *Eur Respir J* 2010; 35:310-316. M.chatwin@rbht.nhs.uk

Delgado P, Rodenstein, D. Home ventilation: Need a user support number? Editorial in *Eur Respir J* 2010; 35:243-244. rodenstein@pneu.ucl.ac.be

Medicare Rights Center

The Medicare Rights Center, with offices in Washington, DC, and New York City, is a national, nonprofit consumer service organization working to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives. Trained hotline counselors can respond to questions about available health plan options, rights and benefits, and appeals after Medicare denials. If you have Medicare questions, call 800-333-4114 (Spanish-speaking counselors available.)
www.medicarerights.org ▲

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of its bag, but I am ready to explain what it is, and now carry a copy of a letter from CareFusion, the company that purchased the maker of my ventilator, stating that my vent is in full compliance of RTCA/DO -160 F Section 21, Category s, Section 21, Category M and can be used during flight. (See IVUN's website – www.ventusers.org.)

Don't stay home! On the last cruise, I spoke with a woman whose family

was on a celebratory trip for Grandma, who used a wheelchair and oxygen. The only thing missing was Grandma. She was afraid she couldn't get around, so she stayed home.

What of my dream? I went to a fantasy world to find an accessible reality, a place where I could go with all my mechanical toys, breathe easily and play with my grandchildren! ▲