



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"