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MISSION POSSIBLE?

Converting to Noninvasive Ventilation

By Jean Dobbs

Dr. John Bach is on a mission: to close unnecessary tracheostomies. It may sound like an unusual calling, but Bach expresses complete faith in noninvasive ventilation for most people with spinal cord injury, post-polio sequelae or neuromuscular diseases.

"There are very few people who actually need to be trached," says Bach, a physiatrist who directs the Center for Ventilation Management Alternatives at University Hospital in Newark and Kessler Institute in West Orange, N.J.

Despite widespread dissemination of his pulmonary research findings, Bach says that recruiting followers in the medical community has been slow. "Nobody wants trach tubes," he says, "but doctors haven't always offered options." Fortunately, this is changing, he adds, and now more hospitals are trying to avoid tracheostomies. "There is a tremendous trend toward noninvasive ventilation as an initial treatment," he explains, but only a few doctors in the country convert people to other methods after they already have a trach.

Last year, Bach approached Christopher Reeve about switching to a Pneumobelt and mouthpiece ventilation, but the actor didn't want to do it. Why?

"It does require a lot of work to learn the new techniques, and I had the impression he was afraid of failing," Bach says. "Also, he still expects to recover. So he's thinking, `What difference does this intermediate action make if I'm going to be walking and breathing on my own?'

"It's unfortunate for other people with spinal cord injury whose doctors don't know about taking out trach tubes," Bach adds. "His example could have saved a lot of people a lot of complications."

The Complications

People with tracheostomies commonly report trouble with infections at the trach site, trachea damage, obstruction of the trachea, lung infections and pneumonia.

Bradley Smith, a 42-year-old vent user with ALS, battled a terrible case of pneumonia after his doctor recommended a tracheostomy. Smith, a Virginia-based counter-terrorism specialist for the State Department, says that one problem was that the vent life happened so quickly that he couldn't make an informed decision about equipment.

When his progressive condition started to cause breathing problems, Smith went to his local doctor for tests. His doctor said he needed a trach, to which Smith replied he wanted a second opinion from his neurologist in a couple of weeks. The doctor said, "You don't have a couple of weeks."

Smith got the trach. "It was a disaster," he recalls. He immediately came down with pneumonia and spent a month in the hospital, causing him to lose much of his remaining muscular ability. "Secretions were a big problem, and I was totally dependent because of the need for frequent suctioning."

Eventually though, he heard about Bach and drove to New Jersey to consult with him. "He said, `You don't need a trach. Here's an option for you.'"

The Options

Smith now uses a mouthpiece by day and nasal ventilation by night. This is a common arrangement, as the mouthpiece is more aesthetically pleasing for waking interaction but tends to fall out during sleep. A nasal mask with a good seal maintains ventilation all night, but most find it too distracting for day use.

One problem that may occur is facial irritation from the nighttime mask. Anne Marie Taddeucci, a 20-year-old C1-2 quad in Elmhurst, N.Y., switched to noninvasive ventilation after three months with a tracheostomy, but found the nighttime nasal mask caused irritation and scarring. She now uses mouth ventilation at night, but wonders if the mask's pressure is moving her teeth. The best idea, says Bach, is to have a mask custom-designed to fit the contours of your face.

A piece of gear that can replace or augment mouthpiece ventilation is the Pneumobelt, a positive pressure corset with a bladder inside that inflates and deflates, pushing the diaphragm up and down. Again, another technique is needed at night because the Pneumobelt isn't effective in the prone position.

One of the biggest changes that follows removal of the trach tube is that secretions no longer need daily attention. According to Lou Saporito, director of respiratory services for the Center, a trach tube actually stimulates secretions that must be suctioned. Ironically, the suctioning itself stimulates more secretions, locking people into a schedule of care that greatly reduces independence.

The average trached vent user, says Bach, needs eight suctions a day -- a job that legally must be performed by a licensed health care professional or family member (i.e., not an attendant). Because home nursing care is extremely expensive and most family members don't have time to do trach care, many people with tracheostomies must live in nursing homes. "If you can get trach tubes out, you can help get people home," Bach says.

And their health improves. Taddeucci, for instance, hasn't had a single infection or cold in the two years since she made the switch.

Smith says that when he does get sick, he now can clear his lungs independently with a machine called the In-Exsufflator, by the J.H. Emerson Company. This device, modeled after the polio-era Cof-flator, dislodges secretions by applying positive pressure to the airway and then quickly reversing the flow, causing a cough.

This cough machine has gained a following among many who've switched to noninvasive ventilation, but manually assisted coughing may be sufficient if you don't have scoliosis, says Bach.

Finally, says Bach, quality of life can't be ignored when discussing noninvasive ventilator options. In a 1993 Chest article, he reported that among 168 vent users who switched from tracheostomy to noninvasive methods, 100 percent preferred the latter. Most cited health reasons, but also significant were increased ability to talk, swallow and taste.

"You can't taste or smell when you have a trach because the air isn't passing through the nose," Bach explains. "Eighty percent of taste is smell. If you close your nose, you can't tell the difference between bananas and mustard."

The point, he emphasizes, is to return to life with as much independence and opportunity for joy as possible. "Removing the trach tube should be a part of rehabilitation," he says. "If it's not, you're not being rehabilitated."

>Keeping the Trach

Not everyone agrees with Dr. John Bach. Many people with tracheostomies don't experience frequent complications and say, "If it ain't broke, don't fix it."

Jerry Daniel, a 49-year-old polio quad who runs a vent service business out of Vancouver, Wash., says: "The debate over the trach versus [noninvasive methods] has gotten out of proportion because people make it sound like a trach is the worst thing in the world."

Daniel, who has had a trach since he was 10, is comfortable with suctioning and prefers it to the cough machine, which he tried when he first had polio.

Steve Lambert, 30, has taken yet another approach. After he shattered seven cervical vertebrae in a motorcycle accident at 16, he had a tracheostomy, but later discovered he could use a Pneumobelt. He opted to wear it about 18 hours a day and attach the trach tube at night.

"The main reason for the Pneumobelt is aesthetics," he says. "I cover the hole with a bandanna during the day. That's how I want to present myself to the public."

Lambert, who works for the Trauma Foundation out of San Francisco General Hospital, says his technique has also kept him very healthy: He hasn't been hospitalized or suctioned in 13 years.

>Manufacturers

* Aequitron Medical (Jerry Daniel's vent maker; invasive and noninvasive positive pressure products), 14800 28th Ave. N., Minneapolis, MN 55447; 800/497-4979.
* Healthdyne Technologies (noninvasive positive pressure products), 1850 Parkway Place, Marietta, GA 30067; 800/421-8754.
* J.H. Emerson Co. (cough machine and negative pressure products) 22 Cottage Park Ave., Cambridge, MA 02140; 800/252-1414.
* Lifecare International (Steve Lambert's vent maker; invasive and noninvasive positive pressure products), 1401 W. 122nd Ave., Westminster, CO 80234; 800/669-9234.
* Newport Medical Instruments (invasive and noninvasive positive pressure products), 760 W. 16th St., Building M, Costa Mesa, CA 92627; 800/451-3111.
* Respironics (noninvasive positive pressure products), 1001 Murry Ridge, Murryville, PA 15668-8550; 800/345-6443.

>Resources

* International Ventilator Users Network: publishes bi-annual newsletter ($12/year); provides information and referrals. 4201 Lindell Blvd., #110, St. Louis, MO 63108-2915; 314/534-0475; E- mail: gini_intl@msn.com
* Pulmonary Rehabilitation: The Obstructive and Paralytic Conditions, by Dr. John Bach. This $69.95 book is geared toward medical professionals but easily understandable by lay readers, according to Bach. Hanley and Belfus, 210 S. 13th St., Philadelphia, PA 19107; 800/962-1892.