

Polio Perspective

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How Polio Survivors Can Avoid Tracheostomies

by John R. Bach, MD

How Polio Survivors Can Avoid Tracheostomies By John R. Bach, MD. Physical Medicine & Rehabilitation, University Hospital, University of Medicine & Dentistry of New Jersey, Newark, New Jersey Dr. Bach is in charge of the Center for Noninvasive Mechanical Ventilation Alternatives and Pulmonary Rehabilitation and has spoken and written extensively. (See "Management of Patients with Neuromuscular Disease" by Hanley & Belfus (2003).

Dr. Bach wrote "Respiratory Muscles Aids to Avert Respiratory Failure and Tracheostomy," which can be found at <http://www.ventusers.org/edu/ConfCall2013Bach.pdf>. His talk supported the premise that "polio survivors can virtually ALWAYS avoid tracheostomies even if continuously (noninvasively) ventilator dependent." However, If you can't speak or swallow, then you do need a tracheostomy. Dr. Bach describes his patients. My first patients were those who used ventilators since having had polio. Then, I started seeing patients who had used iron lungs but had weaned from them but now need to use noninvasive ventilation. There are also some people who never before needed assisted ventilation until recently. Dr. Bach on the first decision. First, it should be determined if polio survivors are

symptomatic for nocturnal under ventilation. It is also possible that there could be a second condition like lung disease (failure of oxygenation) especially if one was a heavy smoker. Most of the time, though, the symptoms are from muscle weakness (failure of ventilation) for which the treatment is nocturnal ventilation. This is most likely for the survivors of polio. The treatments are very different. For lung issues, the solutions include bronchodilators and oxygen. But, for muscle weakness the treatment is the use of respiratory aids which include noninvasive ventilation and mechanical coughing aids. If a patient has both problems, eg, lung problems due to smoking and neuromuscular weakness due to polio, a decision may need to be made as to which is the primary problem and treat it. Dr. Bach on breathing muscles. Inspiratory muscles assist with inhaling. Shortness of breath when lying flat (orthopnea) is a sign of a weak diaphragm (an inspiratory muscle). Many polio people use pillows to support their backs to prevent shortness of breath when they sleep, but the best solution for weak inspiratory muscles is intermittent positive pressure ventilation (air under pressure when inhaling) from a ventilator and via a nose interface. It takes about 20 ml of water pressure to ventilate someone who has severe muscle weakness. Expiratory muscles (mostly the abdominals) assist with coughing. If survivors get a cold, they may not complain of shortness of breath but of anxiety and difficulty sleeping due to high blood carbon dioxide levels. It is not helpful to use CPAP and only minimally helpful to use bilevel devices if breathing muscles are weak, because the air blowing in when we exhale is counterproductive. Bulbar (throat) muscles protect the airways. There isn't anything to be done for bulbar muscle weakness when it results in continuous aspiration of saliva into the lungs but in polio that almost never happens which is why tracheostomy tubes are unnecessary. Dr. Bach on weak coughing muscles. Weak coughing muscles keep one from getting rid of the bacteria, etc. in the lungs, which results in pneumonia risk. The first thing an ER physician normally would do is to give oxygen, and if the CO₂ is already high it will "go through the roof." This is why and how many polio survivors get intubated and, after the pneumonia clears up, many are trached. It is not necessary. If a person could speak and swallow at least a little before getting intubated he/she certainly does not need a tracheostomy. Do polio people have trouble swallowing? No. But, people with ALS have trouble swallowing and they can need tracheostomy tubes. Dr. Bach on CoughAssist (Philips Respironics). Some people who have a trach think that it is easier to suction mucus when they have a cold if they have a trach. The only people who think this are those who don't know how to use the CoughAssist through the nose and mouth. For that matter, it is also much better than suctioning the airways to use it via a trach tube too. It is best to use the CoughAssist with an abdominal thrust and at least 35 ml of water pressure in and out. A manually assisted cough will get most polio people a functional cough to help them through most problems, so a cough machine is not as necessary for everybody. Dimi Italia s.r.l., Seoil Pacific Group, B & D Electromedical and Siare Engineering International Group S.r.l. also manufacture cough devices. Dr. Bach on trach tubes. Four out of five people who get a trach will die because of the trach. Problems include mucus plugs, a fistula between the esophagus and trachea (windpipe), and granulations around the trach that bleed when the trach is changed. The tube itself can puncture the windpipe or trachea, or even an artery. People with trach tubes also carry many bad pathogens, so it is not surprising that people with trachs have a greater number of serious infections than those who use noninvasive ventilation. Trach tubes should be removed in those who can speak and swallow food and can cooperate and communicate. Dr. Bach on CO₂. Too much CO₂ in the blood causes acidity just like CO₂ causes acid rain. Some CO₂ is needed to trigger the brain to tell muscles to breathe. Most labs do not measure end tidal CO₂ but do painful arterial blood gases which make people hyperventilate from the pain. Painless end-tidal CO₂ is actually much more useful. Dr. Bach on oxygen use. It's a terrible mistake for polio survivors (without lung diseases) to use oxygen. Oxygen use turns off the drive to breathe, and causes the CO₂ levels to rise. Any polio survivor who has respiratory problems, sees a physician, and is sent home with oxygen will be back for treatment of pneumonia or respiratory failure sooner than if they had not been treated at all. The problems that polio survivors have are weak muscles and extra secretions, and there are solutions for both, ie, the treatment is either

assisted ventilation and/or assisted coughing. Dr. Bach on testing. Pulmonary function testing is for lung disease, not muscle weakness. What polio people need is the measurement of vital capacity, which is the largest breath one can take both while sitting and lying down. The difference between the two should be less than 7%. Other important spirometric tests include measuring air stacking ability. The needed tests are not done in pulmonary function labs and include the measurement of cough flows, both assisted and unassisted. The assisted-cough flow is measured when an Ambu-Bag (manual resuscitator) is used to “air stack,” ie, retain consecutive volumes of air and hold it in the throat to attain the highest volume. Then pressure is put on the belly, if the abdominals are weak, to cause a cough, and the flow is measured. If the flow is more than 270 liters per minute a polio survivor has little chance to get pneumonia during a cold, but if less, any respiratory infection is likely to result in pneumonia. Sleep studies (polysomnography) were never meant to test for post-polio muscle weakness, but can be useful to rule out other problems, such as obstructive/central sleep apnea which is NOT the principal problem of polio survivors. If a pulmonologist sends someone for a sleep study and they have weak inspiratory muscles, they will treat the patient incorrectly. CPAP is useless for those with breathing muscle weakness, and BiPAP suboptimal particularly at the usual settings used (Inspiratory pressure of 10; Expiratory pressure of 5). Dr. Bach on oximeters. All polio survivors should have oximeters to assist with the protocol to prevent pneumonia. When sick, use the oximeter to be sure it never registers below 95%. If it does, it means one of two things. One, your CO₂ is high and ventilation is needed. Two, secretions are high and assistance with coughing is needed. If neither treatment is used, the situation worsens and when taken to the ER, oxygen is offered which often results in breathing arrest and emergency intubation, then unnecessary tracheostomy. Remember, if this happens, people can have the tube or trach removed and be successfully managed using noninvasive ventilation. (See Extubation of patients with neuromuscular weakness: a new management paradigm, Bach JR, Gonçalves MR, Hamdani I, Winck JC. Chest. 2010 May;137 (5):1033-9.) Dr. Bach on ventilators. Ventilator use rests a weak diaphragm and weak inspiratory muscles during sleep, and the result is feeling stronger, better during the day and blood gases are better, ie. CO₂ is more normal. The way to rest the muscles is to use a ventilator using pressures of 18-20 cm of water, not by using CPAP or BiPAP. Remember: It is not possible to turn off the expiratory pressure on a BiPAP machine and the user cannot air stack using it. Air stacking is important to stretch the lungs to full capacity, because if the vital capacity is 50%, that means that half of your lungs are not being used and they “close down.” Dr. Bach on what breathing device to use. Many polio survivors used negative pressure machines (iron lungs, chest cuirasses, pulmowraps) in the early days, but they caused obstructive apneas and the users experienced desaturations and high blood pressure. I don’t recommend negative pressure for anybody any more. I recommend the LTV Series (CareFusion), Trilogy Series (Philips Respironics), and Newport HT50, HT70 (Covidien) here in the United States. Dr. Bach on nasal masks. There are hundreds of nasal masks on the market, and I recommend that people try several. If someone has trouble with the nasal mask leaking, then try an oral/nasal device such as the Hybrid™ Universal Interface (DeVilbiss Healthcare) or the lip cover Oracle™ 452 (Fisher & Paykel Healthcare), and the oro-nasal Mirage Liberty™ (ResMed Corp). Dr. Bach on diaphragmatic pacers. A diaphragmatic pacer is completely useless for polio people because to use the device a person need a good phrenic nerve and a good diaphragm and if they had them they would need no help at all.

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THE POLIO VIRUSES LIVE ON AND ON . . .

***by INTERNATIONAL POST-POLIO TASK FORCE International
Centre for Post-Polio Education and Research PostPolioInfo.com***

thought I'd repeat this 2009 release about a US man with a WEAKENED IMMUNE SYSTEM who died when he was infected by an unknown person who had been shedding the ORAL vaccine strain of poliovirus for at least nine years.

POLIO KILLS IN THE U.S. - Minnesota Death Gives "Nipp It Year" New Emphasis

TUESDAY APRIL 14, 2009: THE ASSOCIATED PRESS TODAY REPORTED THE DEATH OF A PERSON INFECTED WITH THE LIVE POLIOVIRUS USED IN THE ORAL VACCINE THAT WAS DISCONTINUED IN THE U.S. NINE YEARS AGO. The health department says the patient died with polio symptoms, but it's not known to what extent polio contributed to the death. The patient also had a WEAKENED IMMUNE SYSTEM and multiple health problems. **THE MINNESOTA DEPARTMENT OF HEALTH SAYS THE PATIENT MOST LIKELY BECAME INFECTED FROM SOMEONE WHO HAD RECEIVED THE LIVE-VIRUS VACCINE BEFORE ITS USE WAS STOPPED IN 2000.**

"For reasons we don't understand, the live poliovirus remained inside this person for fifteen years, mutated and became virulent, then contributed to the person's death," said Dr. Richard Bruno, chairperson of the International Post-Polio Task Force. "This death is the latest sad reminder that polio may be forgotten in the U.S., but that it is far from gone."

ALARMING DROPS IN POLIO VACCINATION IN US BORDER STATES AND PORTS OF ENTRY

Unfortunately, rates of polio vaccination have decreased in the US in spite of six other U.S. polio cases since 2005 -- five of them in Minnesota, where a woman with a weakened immune system harbored the poliovirus for years and infected her own children -- and in spite of polio breaking free of vaccination efforts last month in Africa, with Kenya and Uganda reporting their first polio cases and deaths in twenty years.

"The latest Centers for Disease Control data show drops in polio vaccination in twenty states and in ten large U.S. cities," said Dr. Bruno, who is also director of the International Centre for Polio Education. The CDC estimates that more than one million U.S. toddlers are unvaccinated. "Even Minnesota has had a decrease in polio vaccination, which is obviously disturbing," said Dr. Bruno. "It is frightening that states with the largest drops lie next to Mexico and Canada, across whose borders the poliovirus is believed to have been imported into the U.S. since 1997." Seventy percent of the states that border Canada had drops in polio vaccination as did Arizona, Texas and New Mexico.

CITY CHILDREN HAVE LOWEST POLIO VACCINATION RATES

Dr. Bruno is also concerned about cities that are major points of entry into the U.S. -- New York, Philadelphia, Houston and Seattle -- where drops in polio vaccination were also reported.

"Toddlers living in poverty have the lowest polio vaccination rates -- below 87% in Boston, Indianapolis, Memphis and Phoenix, and below 85% in Detroit, Houston and Seattle -- rates lower than in Western Pacific countries that include Cambodia, Mongolia and Vietnam," said Dr. Bruno. "I'm worried that those who recently had polio in the US are canaries in the mine shaft."

"NIPP IT YEAR" UNDERSCORED BY MINNESOTA DEATH

The International Post-Polio Task Force proclaimed 2008-2009 "National Immunization for Polio Prevention in Infants and Toddlers -- or 'NIPP IT' -- YEAR," to prompt parents, healthcare professionals and state health officials to ensure that all American children receive four doses of the injectable, inactivated polio vaccine by age two.

"'NIPP IT YEAR' is intended to raise awareness of the need for polio vaccination, to stop state legislatures from allowing parents to refuse vaccinations for their children because of a "philosophically objection" to vaccines, and hopefully 'nip' America's next polio epidemic in the bud," said Dr. Bruno. "The polio vaccine has been a victim of its own success. Young parents do not vaccinate because they have not experienced the devastation, death and disability caused by diseases vaccines eliminated."

Nor are people unaware that polio remains a scourge transportable from Africa, Pakistan and

Afghanistan.

"With the ease of air travel, what will happen when a polio-infected individual lands in one of America's potential polio pockets, like New York City, and passes poliovirus to the estimated 24,000 infants and toddlers in that city who are not immunized?" asked Dr. Bruno "We must do more to vaccinate America's children against this deadly and disabling disease. America's next polio epidemic could be just a car or plane ride away."

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AGING GRACEFULLY?

By Millie Malone Lill

When I was four, I had polio, or infantile paralysis as it was called then. I doubt if I did anything gracefully at that tender age and I'm positive I've done nothing gracefully since then, either. So, maybe I could give aging gracefully a shot. Where do I start?

Grace...the word brings up a vision of long legs, elegance, maybe flowing garments. Ideally the legs should match, I suppose. Mine don't. They aren't long, either. Elegance is a bit difficult to achieve when you are sort of squatty and um...well cushioned. I did try flowing garments once. I had this beautiful sage green dress with a full gauzy skirt. I wore it to my son's barbecue just up the street from where I lived at the time. I should say I wore it halfway to my son's house. The full gauzy skirt somehow got wrapped around the wheels of my wheelchair and tore off of the bodice of the dress. Not elegant. Nope. Not even a little bit. So much for flowing garments. They should not flow under the wheels of my power chair.

Well groomed and well put together, that's another thing about gracefulness. Beautifully coiffed hair, meticulously applied makeup, maybe a designer outfit? Not me. My hair does what it wants to do and after all this time, I have quit arguing with it. It hangs straight down, limp as two week old celery. Makeup? Not very much of it on my face because I have a little dog who loves me and gives me kisses. If there are any little kids or dogs in the area that want to jump on my lap, give me kisses or hugs, I want to be ready. I don't want to worry about my makeup or my outfit. Besides, I am a card-carrying member of the Snug Wad Society. We are not tightwads, but our wads are extremely snug. We are not likely to buy the expensive lotions, potions and stuff just in a mostly vain attempt to be beautiful.

Can I at least not fall on my face while chasing this elusive graceful thing? That depends. If I'm walking, which I can still do for short distances, I have my head down watching for things that will trip me. You know, dips in the sidewalk, my shadow, stuff like that. Not exactly elegant. If I'm using my power chair, I won't fall down. I may back over the odd foot now and then, but I can do that gracefully. As long as I don't run over the hem of my own skirt, at least.

So here's the deal. I'm going to grow old, one way or another. Probably not gracefully, but at age 75, I have pretty much already arrived at Old. Maybe I'll just live one day at a time, do as little damage as possible to the toes of the people behind me, think positive thoughts and just enjoy this stage of my life. Gracefulness is overrated anyway.

Web Corner

What Fasting Does to the Brain and Why Big Pharma Won't Study It

<http://www.collective-evolution.com/2015/12/11/neuroscientist-shows-what-fasting-does-to-your-brain-why-big-pharma-wont-study-it/>

Cooking With a Disability

<http://www.thekitchn.com/cooking-with-a-physical-disability-171416>

Around the World in a Wheelchair

http://europa.eu/youth/hu/article/39/26039_en

Fifteen things you need to know about hepatitis vaccines

<http://all.privatehealthcarereports.com/15-things-you-need-to-know-about-hepatitis-vaccines>

The End of Polio and Collateral Damage

<http://www.hbo.com/vice/episodes/04/48-the-end-of-polio-and-collateral-damage/index.html>

Good, Bad and Fake News on Vaccines

<http://www.tampabay.com/opinion/columns/another-voice-good-bad-and-fake-news-on-vaccines/2313907>

Beach Access Made Easy

<http://www.wjhg.com/content/news/New-Mobimats-make-beach-access-easy-414097983.html>

Wheelchair Ramps: Do you Know Your Rights Under ADA?

<http://accessadvocates.com/wheelchair-ramps-know-rights-ada/>

First They Got Sick, Then They Moved Into a Virtual Utopia

<https://backchannel.com/first-they-got-sick-then-they-moved-into-a-virtual-utopia-1dc6c165f3e9#.2yg477orv>

Understanding Medicare

<https://medlineplus.gov/ency/patientinstructions/000945.htm>

Other Polio Newsletters

Post Polio Health

<http://polioplacement.org/living-with-polio/articles-post-polio-health>

Post-polio Oz

<https://www.poliohealth.org.au/>

Pennsylvania Polio Network

<http://www.papolionetwork.org/>

Atlanta Post-polio Association

<http://www.atlantapostpolio.com/>

A Little Bit of Humor

Old is When

"Old" is when...

...your sweetie says, "Let's go upstairs and make love," and you answer, "Honey, I can't do both!"

...your friends compliment you on your new alligator shoes and you're barefoot.

...a sexy babe catches your fancy and your pacemaker opens the garage door nearest your car.

...you remember when the Dead Sea was only sick.

...going bra-less pulls all the wrinkles out of your face.

...you don't care where your spouse goes, just as long as you don't have to go along.

...when it takes longer to rest than to get tired.

...when you are cautioned to slow down by the doctor instead of by the police.

..."getting a little action" means I don't need to take any fiber today.

..."getting lucky" means you find your car in the parking lot.

... an "all-nighter" means not getting up to pee!