

THE POLIO PERSPECTIVE

APRIL, 2016

Millie Malone Lill, editor

Wilma J. Hood, publisher

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by Vicki McKenna

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Ageing with Disability

Old age doesn't come alone as those ageing with Post Polio Syndrome know....

"I dread to think what life will be like in my golden years and I really don't want to think of sitting in a wheelchair and unable to do anything for myself. It would drive me crackers if I have to ask others to do everything for me - I don't think I want to live that way."

"The main effect on my life is a fear of being older and unable to express oneself as well as being paralysed -especially when you are in the hands of people who don't understand the special needs of polios. "

"I live alone and do most things for myself and want to be as independent as I can. I do get very tired and frustrated. I used to cycle and walk for miles, which I miss very much as I have to go out in a wheelchair now. I think the medical profession should realise the difficulties of post polio. "

Clearly all of these people are understandably apprehensive and frustrated at the thought and reality of ageing with their disability. Its tricky enough coping with the challenges of PPS but as we age we are aware that further changes may well occur. And not only do we fear losing more of our already waning mobility but we also feel anxious at the thought of perhaps having to ask for help from carers and health professionals who do not fully understand the needs of polio survivors.

Daoism can help calm our apprehensions about old age by giving us a perspective that encourages confidence to handle this phase. Daoists hold the view that life is a cycle of changes and instead of seeing old age as a regrettable state as so many of us do in the 21st century, ageing is seen as an opportunity to accept things as they are, to slow down and cultivate inner strength and wisdom through self knowledge, self discipline and perseverance. Through acceptance we let go of the frantically busy world of our youthful lives, we let go of pushing ourselves beyond our limits and so preserve our energy. Letting go of pushing ourselves, preserving our energy –does this sound familiar? These are all lessons that we polio survivors have been studying closely for some time –nothing new here! So be confident that you have prepared well in advance and can accept and handle these up coming changes! But being confident in your ability to accept and handle this stage of your life does not mean denying feelings-- when you feel despairing, grieving, anxious, angry about worsening physical limitations the Daoist view encourages us to accept the mess of all our feelings whilst aligning with our inner strength and wisdom.

Zhuangzi was a Daoist philosopher who lived around the 4th century BC. His book is an ancient Chinese collection of wonderful anecdotes and fables and in one passage Zhuangzi describes how one character accepts his physical decline: "Why should I resent it?" replied Zi Yu. "If my left arm is transformed into a rooster, I'll just go looking for night's end. If my right arm is transformed into a crossbow, I'll just go looking for owls to roast. And if my butt's transformed into a pair of wheels and my spirit's transformed into a horse, I'll just ride away! I'd never need a cart again!" Here Zhuangzi humorously suggests we give up fearing changes and instead, by accepting them, we can start to see the opportunities in our changed circumstances. For example as we age with a disability such as PPS we might need to use a wheelchair or scooter to get about. If we take Zhuangzi's advice, instead of resenting our changed circumstances we can perhaps see this physical decline as an opportunity to find a way to continue to be mobile.

Ageing with a disability is an opportunity to go with the flow and work with the changes you are experiencing. Resistance is indeed futile and only leads to further exhaustion. Better to accept our circumstances and the opportunities therein. Now is the time to enhance health in any and every way -- clean up our diets, simplify our lives. Take on new hobbies, have fun with your grandchildren, get on your scooter and enjoy the park on a sunny day, learn Chi Gung from a wheelchair –whatever floats your boat! No longer run yourself ragged looking after everything –see that ageing is an opportunity to really firm up boundaries, learn to say No and prioritise your own needs. And cultivate a daily time to be still and quiet –twenty minutes meditation twice a day can be transformative in helping you to feel clearer and more energised.

As we age with disability a great deal of anxiety is generated at the prospect of having to ask for help from carers and health professionals –many of whom often seem not to fully understand the needs of polio survivors. In the past we have sometimes been our own worst enemies by pushing past our limits in denial of our disabilities to prove that we can keep up with or surpass those who are “able bodied”. And then we have perhaps been rewarded by hearing friends or strangers say “I don’t see you as disabled!” Sometimes those words might have felt like an accolade for all our efforts to keep up. But, eventually, exhausted, although acknowledging that the friend or stranger’s comments are meant kindly, we finally realise that we need to let go of resisting our reality and instead our disability needs to be seen, acknowledged and accepted –especially by ourselves. We cannot expect anyone else to acknowledge our limitations if we ignore them ourselves! Now as we become older it is a time like no other to learn to be kind towards ourselves, admit our limitations and ask for help.

Asking for help is even more important as we age. Now especially we may need more help in the house or help getting out and about shopping and socialising. Do not expect others to anticipate your needs - you need to explain them clearly and firmly. Allow others to help and give them recognition and thanks for doing so. Sometimes this is hit and miss –we all have experienced medics or carers who haven’t a clue how to help our particular needs but my advice is to persist and keep looking for the health professionals and carers who do recognise the particular needs of those of us with PPS. Support groups (such as Dr Bruno’s Post Polio Coffee House) on social media are often a great source of good advice with people sharing names of individuals or organisations found to be helpful. And if you are worried that at some time in the future you may lack mental capacity or may no longer wish to make decisions for yourself then give someone you trust the legal authority to make decisions on your behalf via Power of Attorney. Setting this up as you go into older age can give you peace of mind.

Let us never romanticise old age. It can be a painful and challenging time especially if you are disabled. But we do not need to suffer through it. See ageing with your disability as an opportunity to accept your limitations (again!), learn to enjoy new activities and use any assistive aids that will help you to stay mobile but rested. And always accept help when it is offered – do not struggle stoically! Most of all remember that this is a time to find that quiet and calm centre within and enjoy stillness and silence so that you may accept and handle with confidence all the changes that life brings .

see more articles at <http://balancedway.simplesite.com/>

for a copy of Vicki's e book see see http://www.postpolioinfo.com/balanced_way.php

Everything About Polio Survivors Not Using Oxygen, Retaining Carbon Dioxide And Not Getting Their Throats Cut...
by Richard Bruno and Michael Watson LCMHC

How Polio Survivors Can Avoid Tracheostomies...

John R. Bach, MD, Physical Medicine & Rehabilitation, University Hospital, University of Medicine & Dentistry of New Jersey, Newark, New Jersey, 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.

www.doctorbach.com/

Lemonade *by Millie Malone Lill*

Some people call it being a Pollyanna, after the little girl in the story who always saw the bright side of every situation. I call it making lemonade out of the lemons life sometimes hands us. Most of my friends are disabled, elderly or poverty stricken. In other words, all God's chilluns got problems. You can choose to bite into your lemons and keep a sour face at all times or you can squeeze the heck out of them, add water, ice and sugar, kick back and enjoy a frosty glass of lemonade.

One of my dear friends, an elegant woman who now uses a power chair full time, decided to focus on pretty shoes. She mentioned that now she can wear any kind of impractical shoe she wants. No, she

can't walk in them but duh...she can't walk! Her feet are now decorated in the latest style. If she wears boots, she looks very trendy. Stilettos look sexy. Ballet shoes make her look like a retired dancer. It's all good.

Another friend frequently falls. When he does, he announces a gravity check to the rest of us, assuring us that gravity is in fine working order and that the test pilot has survived to test it again at a later date. When my friend Susan's chair hit the curb at an alarming rate of speed, tossing her up and out of it, she told us that was the first time she had actually stood up straight in a long while. True, it only lasted a nanosecond while she was airborne and her efforts at landing were neither graceful nor painless, but for that tiny segment of time, she was fully upright.

I've been asked if I ever take anything seriously. No, I try not to. Life is far too grim to be taken seriously. We are not going to get out of it alive, so we may as well enjoy the time we have here. I've been handed a nice little basketful of lemons myself. My mother always found me a disappointment and an embarrassment, but my own children benefited from my knowledge of how that felt. They always knew that I loved them unconditionally. If they were disciplined, they knew that once that was over, the incident was forgotten. On to the next adventure. With three sons, I can assure you, there were plenty of adventures!

Many of us were somewhat isolated because of our having had polio. So was I, but now as a result of that, I am very inclusive. My party guest lists look like the phone book because I never want anyone to feel left out. As a result of having pain, we can become more compassionate. Because it is difficult to do some things, we learn an easier way to do it. We can share that with our able bodied friends as well as those of us who are not in that enviable state.

Life is one continual learning curve. As long as we look at it that way, we can get through most things with a smile on our faces. Making lemonade out of lemons. I am visualizing a huge party with all of my beloved friends, sitting on a sunny beach under beach umbrellas, enjoying tall, frosty glasses of lemonade, while laughing and chatting away. I think some of them put a little bit of vodka in theirs! Cheers

Web Corner

If I've had shingles, do I still need the shingles shot?

<http://well.blogs.nytimes.com/2016/04/15/ask-well-do-i-need-the-shingles-vaccine-if-ive-had-shingles/?ref=todayspaper&r=0>

PPS Pain and Fatigue

<https://lindaonwheels.wordpress.com/2010/10/05/pps-pain-and-fatigue/>

A short animated video about the switch from oral polio vaccine to another type of vaccine:

<https://www.youtube.com/watch?v=dZbp-q2SJA4>

Reported cases of a polio-like illness

<https://myelitis.org/reported-cases-polio-like-illness-relationship-transverse-myelitis/>

Amazing new design for crutches

<https://www.facebook.com/intvidsorg/videos/1023687171058669/>

Watch your co-pays, your pharmacy may be overcharging you

https://www.washingtonpost.com/national/health-science/watch-your-co-pays-your-pharmacy-may-be-overcharging-you/2016/04/18/a6c4a2c0-ff54-11e5-9d36-33d198ea26c5_story.html

Why dietary supplements are suspect

<http://www.health.harvard.edu/staying-healthy/why-dietary-supplements-are-suspect>

Nine essential questions to ask before hiring an in-home care giver

<https://seniorcareadvice.com/9-essential-questions-to-ask-before-hiring-an-in-home-caregiver.htm>

How to turn your oven into a dehydrator

<http://www.cnet.com/how-to/dont-have-a-dehydrator-use-your-oven/?ftag=CAD9f89b0c&bhid=20495407614517753760105414858186>

Sixteen years ago, a doctor published a completely made up study and it made us all sicker

<http://www.upworthy.com/16-years-ago-a-doctor-published-a-study-it-was-completely-made-up-and-it-made-us-all-sicker?g=2>

A Little Bit of Humor

A father walks into the market followed by his ten-year-old son. The kid is spinning a 25-cent piece in the air and catching it between his teeth. As they walk through the market someone bumps into the boy at just the wrong moment and the coin goes straight into his mouth and lodges in his throat.

He immediately starts choking and going blue in the face and Dad starts panicking, shouting and screaming for help.

A middle-aged, fairly unremarkable man in a gray suit is sitting at a coffee bar in the market reading his newspaper and sipping a cup of coffee. At the sound of the commotion he looks up, puts his coffee cup down on the saucer, neatly folds his newspaper and places it on the counter. He gets up from his seat and makes his unhurried way across the market. Reaching the boy (who is still standing, but only just) the man takes hold of the kid and squeezes gently but firmly. After a few seconds the boy coughs up the quarter, which the man catches in his free hand.

The man then walks back to his seat in the coffee bar without saying a word.

As soon as he is sure that his son was fine, the father rushes over to the man and starts effusively

thanking him.

The man looks embarrassed and brushes off the thanks.

As he's about to leave, the father asks one last question. "I've never seen anybody do anything like that before - it was fantastic - what are you, a surgeon or something like that?"

"No" the man replies, "I work for the IRS, getting people to cough it up is my business

