

All-Too-Typical Email to IVUN

with Responses by Norma M.T. Braun, MD, FACP, FCCP

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Email: *I had polio at age 18 months and spent six months at Sister Kenny in Minneapolis, Minnesota, in 1948 and received hot baths there.*

Norma M.T. Braun, MD, FACP, FCCP:

Do you recall being in a device to help you breathe, as an iron lung? Is there any information from your parents or the records of physicians who cared for you?

Reply: *No, I do not recall being in an iron lung. No records exist from the General Hospital, nor from The Sheltering Arms for that time period. Mom and Dad never discussed my having had polio, as I grew up.*

Here are excerpts from the only letter I found.

“On October 12 or 13, 1948 you became ill and for three days you were listless, and for about four days you had a fever and Doctor Sisterman gave you 300,000 units of penicillin. Then it seemed you were getting better for you had better appetite and were active. At the supper table on Friday evening, Daddy and I noticed you had difficulty picking up your spoon with your right hand. Your fingers didn't grasp the spoon tightly and you tipped your back to the left and displayed some difficulty raising your arm to put the spoon on the table. ... you were taken to the General Hospital for a spinal tap to see if you had polio. (Polio is in the research stage.) Normally, there is 7-10 white corpuscles each cubic centimeter in the spinal fluid, but you had a count of 72. Soon as the doctor rechecked the laboratory report, you were admitted to the contagion ward.”

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Email: *My right side is smaller in circumference and length. My pelvis is twisted and I walk by throwing my left leg inward. I tend to turn in my right foot also, so I try to pay attention to this as I age, as my balance is not good anymore. I can stand on both feet and swing my right foot. The difference in length*

has never kept me from sports. I was never told I couldn't do anything, except contact sports.

Braun: This suggests that you had truncal muscle involvement which may be playing a role now. The twisting you describe can be from a combination of weak truncal muscles and proximal leg muscles especially the quadriceps muscles. There is clearly weakness in the right lower leg muscles as you are compensating by using other muscles to both turn the foot and move it forward.

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Email: *About 8 years ago, I was diagnosed with PPS by a neurologist and neurosurgeon in the state in which I now live.*

Braun: Were there any electro-physiological studies? How was this diagnosis made?

What did they recommend?

Reply: *No tests were done. No recommendations were made. My walk showed a limp to the right and I had shallow breathing. The symptoms I expressed over the years I had seen him as a patient led to his assessment.*

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Email: *Recently, on a trip to Duluth, Minnesota, to bury my mother, who had told me in the '80s that I snored, I shared a room with double beds with my brother who said I snored so loudly that no matter what he did during the night, he couldn't sleep. In a trip to Hawaii last December 2013, I stayed with friends, in the opposite end of their home with doors closed. They could hear me snoring in their bedroom!*

Braun: What is your age now? What is your height and weight and has the latter changed? When did it change?

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Reply: *I was 5'7" at age 19. In 2012, when I had a total left knee replacement, I found out I was 5'5" tall. I weighed 157 pounds in May of 2014. I then took prednisone for another condition and I gained 25 pounds.*

Braun: This weight gain, from prednisone likely, increases the stress on already weakened muscles and joints. The height loss of two inches may be from loss of water from the discs between the spine bones but may also be due to osteoporosis, made worse by reducing physical activity. If you have developed scoliosis, from the different degrees of weakness on each side, it might also contribute to height loss.

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Email: *This past September 2014, I saw an ENT who sent me home with a sleep apnea home study unit for three nights. The outcome was severe apnea (63 apneas per hour) and shallow breathing. I was told that I sleep with an 80% oxygen level in deep sleep. As of this date, approval by insurance for the sleep apnea equipment is pending.*

Braun: Home sleep studies are best for suspected classic Obstructive Sleep Apnea (OSA), not for patients with past polio or other disorders interfering with restful sleep. Carbon dioxide levels need to be measured and can be done noninvasively with end-tidal CO₂ levels. Most standard sleep labs do not monitor CO₂ levels and definitely not home study protocols. (Four months is too long to wait for insurance approval.) A plain CPAP unit may not solve your problems.

Your lung size is determined by your original height of 5'7" and so the loss of two inches "compresses" your lungs rendering them smaller. In addition, your truncal muscles weakness strongly suggests the need for pulmonary function tests (PFTs) with predicted from your original height. This is especially important given the sleep study results.

Reply: *The ENT does not believe a pulmonary test is necessary, because a sleep test proved I had sleep apnea.*

Braun: In reviewing your sleep study results, there is no doubt that you were viewed as a "standard" patient who snores. There were many more episodes where you were hypopneic (shallow) with desaturations, and you had five "central apneas," which means you stopped breathing.

There is no evidence of a physical exam excepting for your height, weight and neck size; giving you a BMI of 30, definitely greater than a healthy 25 or less.

Your neck circumference of 32 cm, which is less than 13", may not contribute to your snoring, depending on your upper airway anatomy.

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Email: *As I am a veteran, my counselor suggested that I stay overnight at sleep apnea unit at the VA Hospital. Two hours into the study, the technician said the monitors indicated I had sleep apnea and shallow breathing, and a machine was needed. She hooked me up to a "nose water ventilator" by Phillips.*

I said I couldn't get enough air so she increased the pressure, but after the second increase, I was told I just had "to get used to the machine." During the night, I had to grasp for air and was told to not breathe through my mouth. They diagnosed me with sleep apnea and issued a CPAP.

Reply: *The VA pulmonary physician does not think I need pulmonary function testing either. At present, the Sleep Apnea Section, has urged me to use the Philips Respironics Auto A-Flex machine with the Quattro Air for Her, full face mask. I cough and gag with it, along with gasping for air. They state that CPAP is what I need and tell me that it takes time to get used to CPAP.*

Braun: It is likely that you need a bilevel device. Why? They considered that you needed only a "little" pressure, but when you felt that you needed more air, i.e., a bigger breath, they increased it – "continuously" with the CPAP machine. The need for a bigger breath coupled with your description of your own lifelong

"I said I couldn't get enough air so she increased the pressure, but after the second increase, I was told I just had 'to get used to the machine.'"

shallow breathing strongly suggests that your breathing muscles, the diaphragm and other chest wall muscles have some impairment. This added to your weight gain and the height loss suggests the need for BiPAP – one pressure on inspiration and a lower pressure on expiration.

There is no such thing as getting “used to the machine” when you are that distressed. Your brain is smart and knows what it needs so if the settings are not right, it will be stressful. The unit must be adjusted to you and not you to the machine.

There are many mask types and sizes available now. You may do better with a nasal mask or even nasal pillows where the interface goes into the nostrils. If possible, try until one “fits” like shoes. Masks cannot be used unless comfortable.

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Email: *My concentration has been on snoring. I had not thought about having had polio and the residuals that I have had my whole life. I have shallow breathing and I have to take deep breaths several times a minute. I have this action in my mouth that is like sucking on a binky, that I have done my whole life. I have always been weak in my arms. I never thought about restrictions in doing things, until the last several years. Compromise and adjust. It is how I have handled most things.*

Braun: This suggests that you have compensated for the effects of polio with swallowing air into your lungs your whole life and thus not aware that you were different from others since you got polio at such an early age. You cannot swallow air when you are sleeping. It is also more difficult when you are lying down. Further, if swallowing leads to a bloated stomach, then your diaphragms are further “loaded” needing a greater amount of work to breathe.

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Email: *What do I do? What do you recommend for me to use to breath at night?*

Braun: I recommend a thorough physical exam of your throat, including soft palate mobility, swallowing, neck, chest wall and diaphragm movements and abdominal and back musculature along with assessment of any scoliosis. The asymmetry of limb muscles along with their strength need to be assessed as well your gait.

Pulmonary function tests are a must in both sitting and supine postures along with maximum static inspiratory and expiratory muscle force as well as a Maximum Voluntary Ventilation (MVV) which is the only test of breathing endurance that is highly correlated with daily function. An ABG (arterial blood gas) sitting and supine for five minutes is also necessary. Predicted PFTs need to be determined from your original height or current arm span.

You need to be seen by a pulmonologist, preferably one more experienced, who may be more willing to research and learn about the late effects of polio. Also, one who is trained in sleep physiology, so he/she might be familiar with more than ONE cause of sleep disordered breathing.

Besides an obstructed airway, sleep disordered breathing can be the consequence of any neuromuscular disorder that affects the proximal muscles. Metabolic disorders (thyroid, diabetes), other neurological disorders (Parkinson’s, dystonias, etc.), medications (prednisone and many others) can all interfere with restful sleep.

This is very serious and needs attention immediately. See *IVUN’s Resource Directory for Ventilator-Assisted Living* on www.ventusers.org. ■

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