

From Vent to Diaphragmatic Pacing System: Part II

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In Part I, I described all the factors I considered before deciding to become a Diaphragm Pacing Stimulation (DPS) System user. www.ventusers.org/edu/valnews/VAL_24-2Apr10p5.pdf



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After deciding that I want to become a DPS user, I took the next steps of contacting and meeting the surgeon to discuss my candidacy, obtaining necessary medical evaluations, and gaining insurance approval.

I met with Lawrence Lottenberg, MD, FACS, who performs surgery at Shands Hospital at the University of Florida in Gainesville. He thinks I'm a good candidate since I'm relatively young, healthy and quite motivated. Because I'm on a blood thinner, Dr. Lottenberg said I'll need to be hospitalized for at least two nights: one night preceding surgery to thicken my blood, and one night after surgery to thin my blood back to a "therapeutic" level to prevent blood clots.

I needed to have my heart pacemaker and my phrenic nerve evaluated. My heart pacemaker has a dead battery and will be replaced with a completely new pacemaker. It's a demand pacemaker that only kicks in if my heart rate falls below 60 beats per minute, which almost never happens. Consequently, there was some debate about whether I need the pacemaker, but since there's no interaction between the DPS and the pacemaker, why not have it as backup?

With that decided, I will have the pacemaker replaced by a cardiologist when I have the DPS surgery. The cardiologists said that it may take three days following surgery to get my blood back to therapeutic, and I'll probably need to stay in the hospital.

A successful phrenic nerve test helps secure insurance approval for the DPS surgery. The phrenic nerve is the body's natural way of stimulating the diaphragm for breathing. But

Dr. Lottenberg confirmed that the diaphragm's ability to be stimulated cannot truly be assessed until the surgeon gets inside, and that the phrenic nerve test often yields false negatives. It can yield a positive, which indicates that my diaphragm is capable of being stimulated, but a negative test doesn't eliminate the possibility for success with the DPS.

I had an appointment with a neurologist to test my phrenic nerve, but when he found out I had a heart pacemaker, he was not comfortable doing the test. Even though my pacemaker's battery is dead, he said, I still have leads going to my heart and he was concerned about stimulating my phrenic nerve under those circumstances.

After reporting that to Dr. Lottenberg and Dr. Raymond Onders, who pioneered the DPS, Dr. Onders said the neurologist could try stimulating my phrenic nerve only on my right side to avoid possible interaction with the pacemaker. But that became a moot point when I learned that my insurance company "has now passed protocol for the DPS, thus no prior authorization is needed." That statement was told to Dr. Lottenberg's assistant by the hospital's financial group, and I'm waiting to get written clarification. My understanding is that the surgery will cost more than \$20,000, and I don't want the hospital coming after me if my insurance doesn't pay for some reason.

Another insurance issue was trying to get my insurance company to state in writing that my level of nursing coverage would not be decreased when I become a DPS user. Currently I receive 44 hours per week of nursing coverage and my family covers the remaining 124 hours. For them to cover more would be quite difficult.

I wrote to my insurance company to explain that even as a full-time DPS user, I would still be dependent on a mechanical device to help me breathe, and the rest of my care would essentially remain unchanged. However, the insurance company replied that a “clinical review” would be necessary to determine the level of care I need after I get the DPS.

I wasn't pleased with that reply until I spoke with a Florida friend who has

the same insurance company and has been a DPS user for over five years. He told me that he receives 16 hours per day, 7 days per week, of nursing coverage, for a total of 112 hours. He also knows another DPS user with the same level of care and same insurance. Now I'm not concerned about a clinical review and might even be able to increase my nursing coverage. (For anyone who might have the same concern, Dr. Onders said that no DPS user has had his/her level of insurance coverage decreased, and it shouldn't be an issue for anyone.)

I don't have a firm surgery date yet, but I am hopeful it will be late June or early July. Stay tuned for Part III about the surgery. ▲

For more information about the DPS System, go to www.synapsebiomedical.com

Twin Vent Users

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leaving Sheila home. I had been trying to convince her to try the bilevel but she always found change difficult. After I went to Florida without her, she finally tried and succeeded with the bilevel. Since then we have both gone to Disneyworld together.

You would think living with a ventilator would be difficult, but it just becomes a way of life. You can choose to think of it as a burden or you can just enjoy each day as it comes. We are not saying that living on life support systems has not been challenging, but we have wonderful caregivers who like to have as much fun as we do.

Our summers are our time for fun! Last summer we traveled to Maine, Rhode Island, and many places in the

Boston area in our van. When traveling in the van, we wear our neck braces and chest straps. Our necks are very weak and floppy, so finding these neck braces (See Headmaster Cervical Collar™ details on p. 6.) was a great blessing and changed our lives.

We had a sine-wave inverter installed in our van so we could use our CoughAssist® when traveling as well as plugging in the bilevels anytime.

When we arrive at our destination, we turn on the HT50® ventilators on the backs of our wheelchairs and use them as we sightsee. People have told us we are like the Energizer bunny; we just keep on going! ▲