

Vignettes... of Polio Survivors Using Ventilation Assistance

◆◆ In 1950, I was completely paralyzed by polio. I spent six months in the iron lung, but slowly through therapy I reentered life unable to lift my arms.

Post-polio respiratory weakness was a phrase I did not like to hear, thinking that my chest cuirass which I used at night would be adequate. I was wrong. I had heard speakers discuss positive pressure ventilation and masks at the G.I.N.I. conferences but as an active individual, teaching three grades in a private school, doing family things, going on vacations, participating in church activities, I just did not have time to think morbid thoughts about respiratory collapse.

The body can be pushed only so far and at 42, you are not what you were at 16 (even without polio). Push came to shove. I became weak so I pumped more vitamins and iron pills. After reporting dizziness one summer to our local physician, I was treated for inner ear problems, although my ears looked clear. Being an optimistic person, I refused to admit that there was a serious problem and knew I would be better in the fall when it was cooler. I was getting older, you know.

While visiting the dentist, I had to leave the chair and the building, because I was so claustrophobic and dizzy. I began to have trouble breathing when I brushed my teeth. Other things began to happen. I would actually fall asleep in the classroom helping the children with their work. They would scamper off to get me a cup of coffee to help me stay awake.

My Amish-Mennonite family of five sisters and five brothers came to my rescue. My sisters saw my dilemma better than I. They literally forced me to seek medical advice. I was referred to Dr. Edward Sivak who understood my problem and suggested a nasal mask over the phone. I tried to convince him that I only needed a better fitting cuirass. He very patiently listened and made an appointment for me. (Edward Sivak, MD, is now at SUNY Health Center in Syracuse, New York.)

I will never forget the first time I tried the BiPAP® System and the mask. I was afraid of it. I immediately jerked the mask off my face when I felt the air. In my heart I knew it was either this or a tracheostomy. I did not want a trach.

Once I quit fighting the mask, and accepted it as a friend, it began working. Now I look forward to putting it on at night. I just let the air enter my nostrils and soon I am asleep. This took at least two months to happen though.

I no longer have those severe headaches at the base of my neck in the morning, no abnormal sleepiness during the day, no swelling of the ankles. My color is very good, and my strength is back. I have a zest for life. *Vera Overholt, Minerva, Ohio*

◆◆ I had polio in August, 1949, and was completely paralyzed. Within hours after admission to the hospital I was placed in an iron lung where I remained for two and

one half months. After recovering with weakness, I did not have any other breathing problems until I had surgery in 1984, and after that I had yearly exams by a pulmonologist. In 1990, following surgery, I went into respiratory arrest. Since that time I have used the BiPAP® S/T at night with a Sullivan Bubble Mask. It lowered my CO₂ and made it possible for me to return to the working world.

I have had some problems with a pressure sore on the bridge of my nose. When the pressure becomes too bad I use ADAM nasal pillows by Puritan-Bennett for a week and then go back to the mask. I find the pillows uncomfortable, and do not like the rush of cold air going up my nose. If I have any air leaks around the mask, I just put some cotton under the leaking area. A mask that fits comfortably is important in adjusting to BiPAP® System. Also, don't fight it — try to relax and let it help you breathe — you will feel so much better. *Sheila Stuckey, Cincinnati, Ohio*

◆◆ My three-month hospital stay in 1952 included six weeks in an iron lung. I have complete paralysis of one arm and weakness in the other, plus some additional weakness in the shoulders and upper back, but I had no respiratory problems until 1980. Beginning with IPPB treatments using Provental on a Bennett AP-5, I had to add night-time ventilation — first with an Emerson Poncho Wrap and then in 1987 with a Bear 33. I use a custom-made, acrylic face mask that has no straps or bands. It is held in place on my face by a bite-wing type mouthpiece. (The mask was made at Dallas Rehab Institute by Sue Sortor Leger, RRT, now in Lyon, France.) I can get in and out of it independently despite the limited use of my arms. I sleep on my back or side and can move comfortably at night.

The Bear 33 has a deep-breath sigh cycle which has been most beneficial. Having an AP-5 in my school classroom and a Monaghan with cigarette lighter adapter for in-car IPPB treatments has allowed me to keep teaching and attending workshops, etc. Since I drive 35 miles a day to school, I "rest" on my Bear 33 with a pipe mouthpiece, again using the cigarette lighter adapter for power while traveling. (I steer the car with my left leg by placing it in a yoke and moving my leg to the left or right as needed.)

Jean Graber, Pretty Prairie, Kansas

◆◆ I contracted polio in August, 1953, and was in an iron lung for approximately four months. I was left with severe paralysis of both arms and a drop foot on the right leg.

I began using a Thompson Maxivent, a negative pressure unit with a fiberglass/plastic shell over my chest in January, 1984, after a bout of pneumonia. This unit did the job, but was uncomfortable, difficult to travel with, and required constant adjustment of the padding on the shell to keep it sealing properly.

I converted to a Respirationics BiPAP® System in March of 1992. I use the standard Respirationics silicone contour mask, size medium small, without the mask support ring

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and with a number 6 spacer. I use the unit with the humidifier placed on a small heating pad every night while sleeping and sometimes during the day when I lie down.

For pressure sores on the bridge of my nose, I tried many different masks, finally going back to the original. I now cut most of the adhesive ends off a band-aid and put it on the bridge of my nose every night. This, combined with careful tightening of the mask and routing the air hose up over my forehead seems to keep the pressure sores at bay. Routing the hose over my forehead also seems to stop air leaks around my eyes without having to tighten the mask excessively.

My mouth and nose were very dry in the morning, but the humidifier has reduced the problem. My problem with a runny nose has become less severe, but I still have to blow my nose a lot for the first hour after I get up. Periodic diarrhea, possibly due to ingested air, is still a problem. Since I never know when it may occur, I take an Immodium pill the day before important activities and cross my fingers.
Allan Gouldburn, Whitby, Ontario

◆◆ **I had polio in 1952**, was hospitalized for three months, partially paralyzed in one arm and one leg. I also was left with kyphoscoliosis, but no pulmonary difficulties. In 1981 I had a spinal fusion with Harrington rods. In 1984 I began having noticeable pulmonary problems (in hindsight), but did not recognize them until pulmonary failure hospitalized me again in 1985.

I have been on nocturnal ventilatory assistance for sleeping since then. I progressed from chest shell to pulmowrap to intermittent positive pressure using LIFE CARE's PLV-100 and a Respironics nasal mask. The early Respironics masks leaked badly and abraded the bridge of my nose. I used one inch surgical Microfoam tape on my skin for a seal and cushion.

After the G.I.N.I. conference in 1989, I had my dentist make a fitted hard mask with a bite plate, which I used for several years, but it always leaked badly around the swivel fitting because I need such high pressures. It finally became unsatisfactory.

After the G.I.N.I. conference in 1994, I began using the newer Respironics fitted mask with cushion, which is OK, but using the Microfoam tape with it is even better. I have not been able to adapt to a lipseal for oral use, nor could I use nasal pillows. I expect to try a custom mask in the near future. I find that respiratory therapists do not know how to find optimum settings for a ventilator or mask, and use trial and error. I had a sleep study in 1993 which should be part of any evaluation of the late effects of polio.

Alan D. Fiala, PhD, Falls Church, Virginia

◆◆ **Since contracting paralytic polio at age two** and being hospitalized for nine months, I have had slight scoliosis, a slightly shortened left leg, and a totally flaccid right arm. About ten years ago, I developed profound muscle weakness in my left arm. Not having had bulbar polio, I never expected to have respiratory difficulties. However, about two years ago, at age 45, increasing upper body weakness made sleeping, speaking, and even breathing dif-

ficult. A Respironics BiPAP® S/T for night-time ventilatory assistance has given me considerable relief.

After months of experimentation I have settled on a couple of different masks, alternating them for comfort. Most of the time I use a triangular, soft rubber Sullivan Bubble Mask with 2-3 foam rubber spacers at the temple. Two wire twisters from plastic sandwich bags help secure the soft bubble portion of the mask to its hard plastic shell eliminating annoying air leaks when I turn my head.

Occasionally, especially if I want to read in bed, I use the T-shaped Healthdyne mask with nasal pillows since it covers less of the face and obscures less of my vision. I am troubled by mouth and nasal dryness even though I use the Respironics humidifier. Putting a heavy cream moisturizer inside my nose at bedtime and using the Sullivan mask certainly reduce the dryness problem. Despite the nagging inconveniences of the BiPAP® System and its accessories, I am highly enthusiastic about having it and use it faithfully, even when I travel. I view it as an orthotic or brace for my respiratory muscles, thus prolonging their ... and my ... life. *Patti Strong, California*

◆◆ **At the onset of polio in 1953**, I was totally paralyzed, and have remained a quadriplegic since that time. My first six months were spent in an iron lung, followed by using a rocking bed for three months. I used no respiratory aid for 14 years, during which time my respiratory functions gradually deteriorated resulting in severe underventilation, and, eventually, respiratory failure, which landed me in intensive care. Then it was back on the rocking bed for about 12 hours a day, supplemented by using a Bennett AP-4 IPPB (intermittent positive pressure breathing) with a mouthpiece at regular intervals the rest of the time. This arrangement worked well until about 10 years ago when I again began to notice symptoms of nocturnal desaturation.

For the past seven-plus years I have been successfully using LIFE CARE's PLV-100 with a Respironics silicone contour nasal mask at night. By placing a small piece of chamois with hypoallergenic tape over the bony part of my nose, I have avoided any problems with pressure soreness. The headstrap required some experimentation and I use a hybrid. It consists of two velcro-fastened straps — the top one goes around my forehead, the bottom one below my cheekbones — attached to a soft piece of flannelette to pad the back of the head. Using a satin pillowcase enables me to turn my head easily during the night without shifting or dislodging the mask.

During the day, I use a mouthpiece with either my PLV-100 or my old Bennett AP-4 as frequently as is necessary to breathe comfortably. If I am going to be away from home more than 4-5 hours, I take my PLV-100 with me. The auto lighter cable, which provides a power source while driving, is invaluable for traveling! *Yvonne Hudson, Winnipeg, Manitoba*

◆◆ **The equipment firm** seemed unaware that one has to use a humidifier with the BiPAP® System, and I had painful problems with cracked nostrils until another polio survivor figured out why.

The firm's respiratory therapist didn't tell me that the ADAM circuit nasal pillows by Puritan-Bennett came in

various sizes. Again, I found this out on my own and experimented until I found the right size.

Barbara Carter, Granada Hills, California

◆◆ I used the lip-seal type mouthpiece which was initially totally unsatisfactory and eventually caused me to permanently lose closure of my front teeth. Now I use ADAM nasal pillows by Puritan-Bennett.

I have become very familiar with the controls of the ventilator so that I can make adequate adjustments in air flow in order to compensate for occasional small leaks. These can be frustrating and difficult to isolate in the middle of the night. *Richard Thamm, Wilmington, Delaware*

◆◆ For pressure sores from the two nasal masks I alternate every few days, I toughen the skin under my nose by applying alcohol, and avoid creams and lotion that soften the skin in areas affected by pressure sores. The BiPAP® System and nasal mask have created sinus problems and increased the amount of mucus. I perform nasal irrigation to release the mucus and prevent it from dripping into my lungs and causing upper respiratory infections (acupuncture treatments help when the mucus secretion is severe). I also use a humidifier and a vaporizer and make sure my filter and tubing are kept clean. To adjust to the air flow and claustrophobic feeling, I use a variety of relaxation techniques, visualize the air flow into my lungs, and hold the top of the mask for brief periods to reinforce my own sense of control. *Linda Bieniek, Chicago, Illinois*

◆◆ Three steps — getting used to the mask, being able to fall asleep, and then being able to remain asleep, against the background of getting the right mask and getting all of the machine settings right — pretty much describes the process of adaptation in my case.

I rushed into the transition from a chest cuirass to a BiPAP® System, trying to force my way during a holiday break. It turned into a major ordeal and after a couple of weeks of uncertain ventilation, mounting sleep deprivation, and erratic progress, I retreated to a modified cuirass for several months. Then I renewed my efforts to make the shift, this time using a gradual approach in which I would typically start a night's sleep with the mask but switch back to the cuirass after a few hours. I used afternoon naps to gain experience adapting to the mask.

The first step is to get used to the mask by spending time on it as well as get the right mask and the right size. My physician recommended that the vendor provide a variety of masks for me to try. Perhaps a "beginner's package" should be made at a beginner's price. I encountered a tendency among therapists to fit me with masks that were too small, whereas a bit too large may be preferable. I have settled on the Sullivan Bubble Mask.

The second step is to fall asleep with the mask. Part of this is just sticking with it. For me, it was also a matter of getting the right settings on the machine. While I had good, general guidance, I had to do the refinements on my own through a lot of trial and error. After making several trial adjustments, one night I slightly changed one setting and immediately had my first good night's sleep. I gather than many physicians and therapists prefer, if not insist, that they determine the settings. My experience may imply that

physicians and therapists are essential advisors and collaborators but polio survivors should take an active role in figuring things out, even if by trial and error, a point my physician agrees with.

I continue to have a difficult time with "parched mouth syndrome," an extreme dryness in which my lips, gums, tongue, roof of my mouth, and the front of my throat are all stuck together, and no saliva is flowing. I constantly wake up and never get a full night's sleep. I have experimented with many things, such as I am now sipping water from a bicyclist's Camel Bak. *David Ronfeldt, Manhattan Beach, California*

◆◆ In 1948, at age 13, polio got me. I went into a two-week coma waking up in an iron lung with a tracheostomy learning that I had the chicken pox and double pneumonia. I was weaned from the iron lung and the trach by March 1949. Life seemed normal to me until 1982 when I noticed breathing difficulties especially while mowing the lawn.

After visiting a pulmonary specialist, I tried several non-invasive breathing devices. The chest cuirass could not be fitted to my scoliotic chest and facial masks were too claustrophobic. My blood gases never normalized on supplementary oxygen. I ended up in an emergency room and was trached.

Getting used to the ventilator was hard at first, but now I fall asleep quickly. Being able to go without the vent for a day allows me to take "vacations" once or twice a month. To help my chronic back pain, I started a neuromuscular re-education/myofascial release program with my doctor's consent. A side benefit has been an increase in breathing capacity allowing for more frequent "vacations."

A.J. Nadeau, St. Louis, Missouri

◆◆ I contracted polio in 1953. Within 24 hours of entering the hospital I was given a tracheostomy and placed in a tank respirator. I graduated from the tank to a hospital bed, using a cuirass. Ten months later I was free of any ventilator, my tracheostomy was closed. For the next eight years I used no mechanical ventilator, but then my CO₂ began to rise slightly, and I used a Thompson Zephyr for chest stretching and cough augmentation. A few years later I returned to using a Monaghan and cuirass at night.

In 1984 I experienced a sharp drop in my pulmonary capacity, no doubt due to the late effects of polio. After trying several noninvasive mouthpiece/nasal options with little success, I made the decision to have another tracheostomy. My upper extremity strength is limited, and I could never manage to put on or remove the cuirass by myself, nor the mouthpiece/nasal apparatus with its many straps and snaps. Using trach positive pressure, I can connect and disconnect the ventilator, and get in and out of bed by myself. *Richard Daggett, Downey, CA*, excerpted from *I.V.U.N. News*, Fall 1994 (Volume 8, Number 2) □

Readers: If you would like to network with any of the individuals who related their experiences in this article, please contact IPN. David Ronfeldt, of Manhattan Beach, CA, sent an extensive description of his experience of adapting. With his permission, we will share this with anyone who asks.