

From Henry's Desk.....

Being on Life Support and the Quality of Life

This article will only apply to a few among thousands of polio survivors. If you had bulbar polio or weakened respiratory muscles along with restrictive vital capacity of your lung volume secondary to scoliosis, then this article might be of interest to you. What I am sharing is somewhat autobiographical, but my knowledge of maintaining a quality of life on life support has been enriched by sharing with others in similar situations or by reading the experiences of others who are no longer with us.

I had polio at age eleven in 1950. I was a victim of the worst polio epidemic in the history of the State of Virginia. My case was diagnosed on September 23, 1950 and on that day I was admitted to the polio isolation ward of the Medical College of Virginia Hospital. I was paralyzed from the neck down with greater severity of damage on the right side. I did not have bulbar polio as I was never in respiratory distress during acute polio. After spending three months in the hospital and being taught by a visiting teacher for a year I returned to public school wearing a long leg brace on my right leg which I still wear today and some residual weakness in my right arm and right side. During my adolescent growth period I developed scoliosis because the muscles of my back were weak on the right and strong on the left resulting in a spinal curvature. Despite the scoliosis I was quite active in every way that I could be. I could climb steps, ride a bicycle and drive a car when I was old enough to get a driving permit. I went four years to high school, four years to college and four years to medical school without missing a single day.

In 1966 I began a rotating internship at a large city hospital. I went through the surgery, medicine and ER rotations and when I was on OB, I developed pneumonia. My life was in jeopardy and I survived because I had a tracheostomy, was on a ventilator for two weeks and was gradually weaned off the ventilator. After missing a month during my internship I completed my last rotation on pediatrics and decided that I should enter a medical field that was less physically draining. Thus, I returned to the Medical College of Virginia and started a psychiatric residency. Dr. James Baker became my pulmonary doctor while I was in residency. He monitored my blood gases which included my blood levels of oxygen, oxygen saturation, carbon dioxide and my blood ph. As my oxygenation gradually reduced over the next year adding nasal oxygen was not a safe treatment because hypoventilation could still result in an increase of carbon dioxide in my blood. Thus, in June 1968 I was intubated with a naso tracheal tube and placed on a ventilator for three days which successfully reduced the carbon dioxide in my blood and increased my oxygen saturation. This worked for 18 months and once again I was fighting respiratory failure. The decision was

made to do a permanent tracheostomy which was done on January 15, 1970. Between that time and November 1971 I was hospitalized approximately monthly for two to three days at a time to prevent respiratory failure. With the tracheostomy in place I did not have to endure a painful intubation. Finally in November 1971 Dr. Baker convinced my health insurance company that it would be less expensive to provide me with a ventilator at home. With my wife Brenda's help I learned to connect to the ventilator at night via the tracheostomy tube in order to sleep safely. Thus, I was one of the earliest cases to demonstrate that continuous nocturnal ventilation was restorative for the next day. From November 1971 until Post Polio Syndrome began in 1991 I was not admitted to a hospital again for respiratory failure.

In 1991 I did not develop respiratory failure, but did experience increasing total body fatigue, central fatigue and gradual weakening of the muscles on the left side of my body which had been the least damaged by acute polio. In 1991 I acquired a scooter and a van with a scooter hoist to carry the scooter around. I felt better and continued to practice full time and was on the attending staff of three hospitals until 1996. In 1996 the immense fatigue that I was experiencing convinced me that I had a brain tumor or some other serious neurological condition. Tests proved that I did not have anything but the immense debilitating fatigue of Post Polio Syndrome. I quit working for six months and only resumed working on a part time basis in a home office. I gave up all hospital work. I felt defeated and that my career was essentially over.

In addition I was beginning to age and my respiratory function started to decline despite nocturnal ventilation. My oxygen saturation gradually got lower and breathing was becoming difficult except when I was on the ventilator. In June 2002 my pulmonary doctor told me that I would develop right heart failure and likely expire unless I used my ventilator 24/7. Fortunately over the years technology had improved and ventilators had become smaller in size and lighter in weight. It was also recommended that I get a power wheelchair. Thus, by early 2003 I had a power w/c with a basket on the rear which would hold my Newport HT50 ventilator. This little ventilator only weighs seventeen pounds and has an internal battery that can power the ventilator for up to six hours. It also can be charged by both AC and DC current. Also in 2003 I purchased a van with an electric ramp which made it possible to enter and leave the van in my power w/c. For the last six years I have been mentally alert, see some patients in a home office, supervise residents, teach medical students in small groups and have been more active in my church, professional organizations and enjoy a more joyous family and social life.

I actually have a good quality of life in my old age and look forward to every day. I believe this has all been possible because of Brenda, my wife of forty-four years who has saved my life on many occasions, having well trained doctors, the

progression of medical technology, the support of the Central Virginia Post Polio Support Group, the support of my family and friends and my faith.