

Disabled Take Advantage Of Artificial Breathing Devices

by Jack Genskow, PhD



I'm only a representative of a much larger group, those of us who require artificial breathing aids in order to live. My role here is to share a bit of my personal experience of 28 years using a breathing aid.

We ventilator-dependent people are a group of individuals each with our own unique solutions to our life situations. I contracted polio at age 19 on my summer job, which was running a horseback riding stable. This was following my first year on scholarship at Yale. I spent 24 of the next 32 months in six different hospitals, including the National Foundation's Respiratory Centers in Omaha and Chicago. Initially, I was totally dependent on the iron lung and nearly totally paralyzed. It took me five months to get out of the lung. I still have quadriplegic involvement, and use a motorized wheelchair.

Much of my breathing is still voluntary; that is, if I were to pass

out or become unconscious I would essentially stop breathing. I now use a rocking bed to sleep on at night. On trips such as this, I use a portable chest respirator and a chest shell. For the first six years, I didn't know how to glosso pharyngeal, or "frog" breathe, so I carried a small positive pressure blower with me with a transformer in case I got tired or had to cough. If I needed to, I'd just plug into the nearest outlet to let the blower breathe for me.

But "frog breathing" has really been a life saver for me and has made my life much simpler. Without frog breathing I have a maximum vital capacity of 350cc's, but with frog breathing I have a maximum vital capacity of 2800cc's. As you may know, frog breathing is a method of pushing, or "swallowing," mouthfuls of air with the tongue into the lungs, which then inflate a mouthful at a time. My wife brought a book home from

work that showed me how to do it, and the first time I yelled at her she was delighted.

My wife and I met when she was a student nurse at my third hospital, and we started dating later when I was in the Chicago Respiratory Center. We have two children — Karen, 19, and Ken, 17. We've traveled as a family unit all over the country — from Florida and Maine to Texas and Colorado, usually driving, but sometimes flying. Lil and I spent our 1961 honeymoon in the Bahamas where her dad lived. When airlines wouldn't let me fly without a doctor's permission, we found a small island hopping boat that took us across the Gulf.

Respiratory disabilities haven't prevented opportunities from presenting themselves in my life either. I attended college with the support of what was then the Division of Vocational Rehabilitation Services, and the March of

Dimes National Foundation. Then I received fellowship support which led to a PhD in counseling and rehabilitation psychology. Illinois DVR hired me to develop and direct their Residential Evaluation Center and Service. Currently, I'm associate professor in human development counseling at Sangamon State University. (The vice president's comment on my employment interview was, "I guess it's what you have to say, not how loud you say it, that's important.")

Although we haven't gotten rich, I have paid more than \$70,000 in personal income taxes back into the economy since 1965.

One of the ironies of my life, which I think has implications for this conference, stems from my being turned down for rehabilitation services by an Illinois DVR counselor in 1957 because I was too severely disabled to benefit. The irony in that is that currently I'm appointed by Illinois Governor Thompson, as chairman of that state agency's Advisor's Council. Illinois and rehabilitation have come a long way.

Important factors in living my life with a disability included: 1) good medical care and planning in the early stages of recovery, especially by the National Foundation of Respiratory Centers; 2) ongoing support and respiratory equipment, provided, again, by the National Foundation and Life Care Systems; 3) an effective social support system, including first, my wife and family, and then of course, friends; and 4) an opportunity to live in the community as anybody else where I can have control of my own life.

The essential lesson to learn from that counselor 25 years ago is: Don't let your perception of the severity of a young person's disability today limit his or her potential for tomorrow.