



The View From Here

Living with COPD as It Moves on

by I. Gene Schwarz, MD

In March of 2010, “Adventures of an Oxy-Phile II” by Thomas L. Petty, MD, FAARC, was published posthumously through the determination and dedication of Louise Nett, RRT, RN, FAARC, and her collaborators.¹ I was pleased to be asked to contribute my experiences of “Living with COPD” to the book as it gave me a way to honor a true pioneer in the field of oxygen therapy and to share how I wrestled my way through accepting the fact that I had COPD, which I hoped would be helpful to others.²

Anyone who is afflicted with chronic obstructive pulmonary disease will soon realize what “chronic” means in real living time. COPD is not going to go away, and the disease will gradually increase in severity over time. As a physician, I thought I understood and thoroughly accepted this fact. As a patient and mere human, I would soon find that I would be fighting the reality every inch of the way. Every time I needed to ask for help, I was reminded that I had lost something of my previous healthier self and needed to first acknowledge the loss of function and then find ways to compensate for it. This may be easier for some, but for me, I need to be in charge and have probably fooled myself into thinking I was in charge even when it was obvious I was not. The mind is a complicated, wondrous part of us and at times allows us to escape painful realities. To have something going on in my lungs without my permission was a tough one for me to swallow.

When my omniscient and omnipotent cover was blown, it enabled me to reach out to fellow COPDers and become part of the Colorado COPD Connection,³ a group made up of patients, health professionals, and suppliers as well as the Colorado COPD Coalition patient advocacy section.⁴ At this very moment as I’m writing, I almost lost my focus and started to tell you all about these organizations, the dedicated people who give their time so freely, and to continue on to describe some of the accomplishments of these groups. That is a here-and-now example of how powerful the pull is for me to avoid talking about the progress of this disease. So, I will be on my

guard and will try to keep focused on how COPD continued to move on within me, what I learned about myself, the ways I found to compensate for the loss in function, and how helpful people have been once I could allow them to help.

Denying early symptoms

I was living in the foothills just west of Denver at an altitude of 8,000 feet. This is where we lived for almost 40 years and where our three children grew up. In the year 2000, I closed my office in Denver and continued to see a few patients at an office adjacent to my home. I would drive into Denver once a week to teach or consult with colleagues; but most of the time I was leading a fairly active life, cycling around the foothills on a reclining trike, working out at the fitness center, attending yoga classes, cross-country skiing, and trying to keep up with all the activities my wife was active in.

I knew I had COPD; but since I had stopped smoking for almost 30 years, I was doing pretty well for someone in his 70s. Over the next few years, I noticed that I was getting short of breath while cycling and working out; but my gift of denial won out until one day a nurse/paramedic on the rescue team I was a board member of did not like the way I looked and suggested I let her check my blood oxygen saturation. It was low, even allowing for the altitude. I started deep diaphragmatic breathing, and it still was low. I added a small electric motor to my reclining trike and slowed down my speed on the treadmill, and it still was low. Eventually the better sense part of me took over and I went to see my primary care physician. She recommended that I start on supplemental oxygen at night and pursue an extensive evaluation of my pulmonary function.

Beginning treatment

That was my introduction to National Jewish Health Center where I had a thorough evaluation of my pulmonary function and got started on supplemental oxygen.

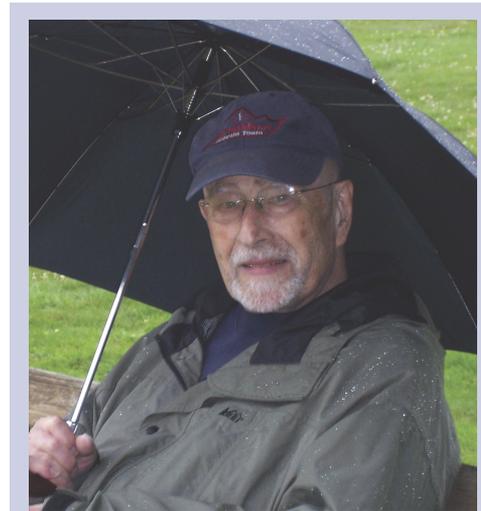
It is also where I joined a support group and met other patients with lung disease, which led to my involvement in patient advocacy and public awareness movements.

For me, using supplemental oxygen gave me the freedom to do almost everything I enjoyed while I slowly got used to the idea that I could not live an active life without it. It was the beginning of a balancing act that made the loss of lung function less incapacitating and allowed me a quality of life that was productive and gratifying. Getting used to wearing a nasal cannula in the grocery store was a piece of cake when I realized that other shoppers were more interested in reading food labels than they were in looking at me. I met people in the checkout line who were also on supplemental oxygen and often exchanged helpful information about portable oxygen equipment, medications, and tips on how to make better use of time and energy. It became important to know how much oxygen I would need to go to a meeting and get back home, as well as how much liquid oxygen my portable unit held and how long it would last at various liter flows. I always carried a pulse oximeter so I could monitor oxygen needs. I found it is not wise to rely solely on how I felt, because my oxygenation saturation had to fall quite low before I became short of breath or felt faint or dizzy.

Changing lifestyle

As time moved on and I required a higher liter flow, the establishment of a routine for living became more important. This involved what the professionals call “activities of daily living,” such as taking a shower, getting dressed, and all the activities I never gave a second thought to — they all had to be altered to allow for an adequate supply of oxygen. I also had to have the cooperation of my oxygen supplier in order to have the equipment to support the changes in my condition. When I learned to stop and think before acting, I became more efficient in the use of my time, which made it easier to monitor my oxygen use. In 2005, we moved down to Denver, the mile-high city, and the difference of 3,000 feet of altitude helped, but not as much as I hoped. Vacations at sea level were a real gift as I did not need supplemental oxygen and I could increase my activity level. It was tempting to think about moving to the coast, but it would have meant leaving family and friends while not being able to predict how long it would be before I needed supplemental oxygen. As it turned out, in 2007 I needed two to four liters of oxygen at sea level and four to six in Denver.

As my oxygen needs increased, I turned to one of my COPD friends, Lynn Cole, who has an incredible knowl-



ABOUT THE AUTHOR

I. Gene Schwarz, MD, passed away shortly before the publication of this story. He was clinical professor of psychiatry in the department of psychiatry at the University of Colorado Health Sciences Center, as well as a former director of the Denver Institute for Psychoanalysis. For the last 50 years, he divided his time between the practice of psychoanalysis and psychotherapy and the education and training of medical students and graduate mental health professionals, both locally and nationally. Dr. Schwarz had a special interest in the law and conducted seminars for lawyers and judges. He was the first psychiatrist to serve on the Colorado Supreme Court Grievance Committee. He promoted understanding of the impact of living with COPD and was working on his third novel for publication. ■

edge of portable oxygen equipment and is someone the manufacturers often ask to test and evaluate new devices.⁵ She and another COPDer, Mike McBride,⁶ have come up with creative ways to use portable devices to be able to do 10Ks, marathons, and other strenuous feats I would not have thought possible. Lynn and Mike had transtracheal catheters, which allowed them to receive supplemental oxygen directly to the lungs and not have to use a nasal cannula. This was not only a more efficient pathway for the use of supplemental oxygen, but also it offered a way to increase the liter flow by using both a nasal cannula and transtracheal oxygen (TTO) when they were climbing mountains or doing 10Ks.

Although my liter flow requirements were gradually increasing, I did want to be able to continue exercising and maintain muscle tone and strength. I consulted with John R. Goodman, BSRT, RRT, a respiratory therapist who

is an active member of the COPD Connection and has an enormous amount of knowledge and experience in all aspects of transtracheal oxygen therapy.⁷ He encouraged me to explore the possibility of having a TTO procedure and introduced me to a hands-on pulmonologist, Michael Schwartz.⁸ Michael proved to be a real-deal physician, a rare find in modern day medicine.

In November of 2009, I had the TTO procedure done. It was a team effort, with the pulmonologist, surgeon, and respiratory therapists all familiar with the procedure and follow-up care. With the help of the team, in two weeks I learned how to clean and replace the catheter. It helped reduce the liter flow of oxygen I needed at rest — but not when I was active. The only times I know there is a catheter in place is when I remind myself that it is time to clean it. Having the TTO allowed me to lead a more active life as well as start an exercise program at pulmonary rehabilitation.⁹ At this point I would not be able to get enough oxygen without the TTO and a nasal cannula.

Wishing for “do-overs”

As time moved on, so did my COPD; and as it slowly progressed, I not only needed more oxygen, I needed more help at home, eventually becoming homebound. The more I needed help, the more Joan, my wife of 58 years, stepped up to be there. We both thought it important for Joan to be able to continue all the important activities she has devoted so many years to. Since neither one of us drives, we found a helper who drives Joan wherever she needs to go. It is important to take care of the caregiver.

I could not even estimate the times I have asked people I was working with in therapy to tell me what they were feeling. I know how difficult it is to describe and get into feelings in any depth, but I never realized just how difficult it was until I started to ask myself that same question about how I feel about dying. It is easier to talk about my thoughts, to prepare a living will, shred confidential records, and take care of all the paperwork to make it easier for my wife and even share in dark jokes about death. Humor helps. I became aware that I was thinking more about what I had done with my life, what I accomplished, could have done, should have done, people I helped, and people I owe an apology to for the way I handled a relationship. There are a lot of “do-overs” I think about while at the same time realizing I might have made the same choices if I had a second chance.

I have thought a good deal about a concept that Dr. Donald W. Winnicott, an English pediatrician and psychoanalyst, proposed and expanded on far beyond my

use of it here: the concept of being “good enough.”¹⁰ I use it here to recognize my humanness and my wish that I have been a “good enough” husband to my loving wife — “a good enough” father to three wonderful children — regret that there is not time enough to be “a good enough” grandfather to my five grandchildren. I hope I have been a “good enough” physician and human being and sincerely apologize to anyone I have unintentionally hurt.

Appreciating the pioneer researchers

I would probably not be here today if it were not for the research and teaching of Tom Petty and Louise Nett. I know that I would not have been able to manage these years so easily if it were not for the people who have been so helpful and have given freely of their time as advocates for COPD. I am particularly grateful to Edna Fiore, a COPDer with an enormous base of knowledge, which makes her an effective advocate both locally and nationally.¹¹

I hope my personal account will be helpful to those with COPD who are looking for ways to manage and live a productive life as this disease advances. ■

EDITOR'S NOTE

Our AARC Times editors thank the family of I. Gene Schwarz for allowing us to publish this story for our readers. It is also available for viewing on the AARC's patient education website YourLungHealth.org.

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