

Chapter 5

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Living with COPD

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Perhaps the title of this chapter should be, “Accepting You Have Chronic Obstructive Pulmonary Disease, and Learning to Live With It.” That was the difficult part for me. As a clinical professor of psychiatry at the University of Colorado Health Sciences Center and a former director of The Denver Institute for Psychoanalysis, I should have seen the psychological issues coming. But in many respects, I didn’t.

It all started right after I turned 65 and joined the Medicare rolls. My primary care physician announced he was retiring and referred me to a young colleague, telling me I would be better off with someone who most likely would outlive me.

This young doctor was very thorough, and one of the questions he asked me was, “Do you smoke?” I said, “No.” He then asked if I had ever smoked, and I could sense a bit of irritation arising in me, which I managed to ignore. I gave him a short, quick affirmative response, which seemed to propel him to delve into my smoking history.

He finally dragged out of me the fact that I had my first cigarette at age nine and my last at age 49. He thought 40 years of smoking warranted a more thorough evaluation of my pulmonary function and took me into another room where he had a portable spirometer.

The results of this simple test indicated that I had COPD. I had no symptoms of this disease and was living a healthy life, with exercise and good nutrition all while living at an altitude of 8000 feet. I could ski, ride a bike, and do moderate workouts. So I had COPD. So what?

## Down the river of denial

I never told my wife or family about my visit with my new doctor, and I managed to avoid seeing him and any other doctor for the next seven years. I did not consciously decide to keep this diagnosis secret or not to go back to the doctor. It just happened. It is as if after leaving his office I left all that he told me behind.

This young man was a discerning diagnostician, but I don't think he fully appreciated the impact of being told you have a serious progressive disease. After 50 years in psychiatry, I can spot massive denial a mile away. I just couldn't see it when it was under my nose.

At age 72, I developed a fulminating pneumonia, and for the first time I can remember, I was very, very sick. I would like to say when I recovered I finally acknowledged I needed to have my pulmonary function evaluated, but it took another bout of pneumonia the following year to break through this powerful state of denial.

In retrospect, even at age 65, I had symptoms of a compromised pulmonary function that I managed to ignore. My wife tells me she also ignored the moments I had shortness of breath, and in a sense was colluding with my denial of there being something wrong going on in my body. She didn't want me to be sick, and neither did I.

You might think this is the old story of, what you don't know or won't acknowledge, won't hurt you. It's really the story of how painfully frightening it is to have something going on in your body that you can't control, and one way of dealing with that fear is to pretend that everything is normal and okay. No wonder I was annoyed with the young doctor who was practicing medicine the way it ought to be practiced.

## Coping with oxygen

This is not the end of the story. Denial takes some time to fade away. At least for me it did. I went through a similar process when it came to taking medication and initiating doctor's appointments. I have seen, in my own practice, how irrational thinking can cloud the judgment of people who usually function on a reasonably rational level in their everyday life. One

has to overcome the irrational idea that if you have to take medicine it means you are sick, and accept the fact that you have a disease and there are medicines available to help manage it and improve your quality of life.

This is especially the case with the use of supplemental oxygen. It is difficult to overcome the idea that the less oxygen you use the less sick you are. What was helpful to me was meeting other people with pulmonary disease who were most willing to share their experiences with the use of supplemental oxygen.

I soon learned that almost everyone I met carried their own small pulse oximeter. They would monitor their oxygen saturation and came to know how many liters they needed when they were at rest, walking, or engaged in exercise. Most had encountered providers that didn't approve of their monitoring their oxygen saturation, but soon found what was helpful to them didn't always coincide with what the professional thought would be helpful.

I monitor my oxygen use, which is currently 2 liters at rest, 6 liters walking at my usual pace, and 6 to 9 liters when I work out on the bike. All are continuous flow. I had a TTO in November 2009 and feel much stronger and also have my voice back.

### Me, a “patient”?

You may have noticed I have avoided use of the word, “patient.” I must say that I haven't noticed any of my fellow COPDers get their dander up when someone refers to them as a patient. Part of my problem has to do with being a provider of care who is now on the receiving end. But I also think it has to do with the uneven playing field between the health professional and the patient, and the loss of autonomy that being labeled may imply.

I had not paid much attention to this until I found myself identified as the “patient” and being related to, by some, as if who you are plays second fiddle to what you got. Perhaps all health care providers ought to have a go at being a patient.

When I sit in a waiting room and hear an 80-year-old being beckoned by a youngster who looks like he just got out of high school, and who calls the patient by his first name without asking and talks to him in a tone as if

he was talking to a young child, I think how infantilizing and un-empowering this is. On the surface it may seem to create a more friendly and intimate atmosphere, but on a deeper level it reinforces the loss of independent functioning as a competent adult.

This is not a trivial matter. With illness comes the inevitable loss of function. People with a chronic progressive disease, such as COPD, must learn to cope with profound loss of function to be able to deal with the feelings of depression, which can become crippling.

### Sharing experiences

While there is no way to predict how any particular individual will react to being told he has a chronic disease, I can share some of my own reactions and observations. Whenever I think I've gotten past the initial denial of my illness, I am quickly reminded that denial dies hard, especially when I think I can manage some task or activity without planning ahead as to my oxygen requirements. It always is a hard reminder, and it is always a relief to know that I can manage most things with an adequate supply of oxygen.

I found the feeling of helplessness can be the cloud that overshadows every aspect of my life, or it can be the propellant to action. It can be the force that pushes one to learn as much as one can about the disease and to find out what you can do to slow it down and maintain an enjoyable quality of life, while minimizing the downtimes.

There is a wealth of information available on COPD on the Internet. However, the most helpful source of information and support for me came from other people who have COPD and who have found unique ways of living a quality and productive life. In a very real sense they empowered me to move on and to join the growing group of advocates for the study and treatment of COPD. What I was finding out firsthand was how willing people are to share their experiences and knowledge.

In talking and being with other people who have a pulmonary disease, I found that I am not the sole proprietor of denial. There's a lot of that going around. Most people get through their denial with support from family and fellow COPDers. It also seems there is consensus that the major self treatment for bouts of depression is to find ways to empower yourself, to beat the demons of helplessness and loss. None of this would be possible without

the availability of a supply of portable oxygen and the groundbreaking work of Dr. Tom Petty, who dispelled some of the myths of oxygen therapy.

### **Overcoming stigmas**

So now we come to the enormous help support groups, health care professionals, and family can provide in overcoming the stigmas, both imagined and real, in using portable oxygen in everyday living. To some the use of oxygen is a sign of weakness, proclaiming to all that there is something wrong with you and that you brought this on yourself by contaminating your lungs with smoke.

What it boiled down to for me was, there is no more denying that I am mortal and have a chronic disease. The first time I ventured out to shop for groceries while wearing my oxygen, I was self conscious, but it didn't take long to realize people were more interested in picking out the ripe melon than looking at me. In fact, I met some interesting people on the grocery line who were also on supplemental oxygen, and discovered the good feeling that comes with the sharing of information and experiences.

I have the good fortune of being able to be part of a group that is working to inform the public and health professionals about COPD. This is a group made up of health care providers, representatives from the health care industry, and yes, patients like me. As part of this group, I have met some extraordinary people who are using supplemental oxygen and are making an enormous contribution to understanding and living with COPD. Most of us were influenced by the work of Dr. Petty, who was the pioneer in the use of portable supplemental oxygen, and know how much he advocated for the sensible and adequate use of oxygen to enable people with pulmonary disease to live a quality life. In being part of this group I was able to meet and know both Dr. Petty and his collaborator, Louise Nett, who together built the foundation upon which the use of portable oxygen evolved.

### **Empowering leap**

I hope my personal account of the psychological impact of having COPD will be helpful to those of you who are at the beginning of this process, and helpful to the health care professional who will work with you to manage this disease. As I look back on my personal odyssey, the hardest

part of the journey has been hurdling the massive denial of my illness. Making this leap allowed me to empower myself and regain some sense that I could be helpful to others. The feelings of helplessness and depression faded as I joined my fellow “patients” to help other “patients” to empower themselves.



*“Fish come and go, but it is the memory of afternoons on the stream that endure.”*

E. Donnell Thomas