

Never Give Up! Never!

By Vijai P. Sharma, Ph.D, a yoga teacher, psychologist and a person with emphysema (In that order of priorities)

"Never give up! Never!" This was the best promise I offered to myself in 1994. However, my promise does need reminders and prompts from me. How about you? What is your promise to yourself? If you haven't made one, now is a better time than ever time to make a similar promise to yourself. You deserve it! I would like to share some personal details of my emphysema/COPD journey with you in the hopes that it provides you something helpful in your own journey, my fellow travelers!

From Despair to Hope

I had noticed out of the ordinary breathlessness since my teenage years. Retrospectively, it appears that my subconscious way of dealing with breathlessness was to do less of whatever made me breathless. I didn't participate in any sports. Whenever I was roped into informal group games requiring swift motion or physical activity, I would get out as soon as I could. I thought I got out of breath because I had a weak heart. Other than the exertion related excessive breathlessness, I felt and looked healthy.

In 1994, I was becoming quite anxious, finding myself becoming increasingly breathless even during mild exertion. So, I decided to build my stamina. "What could be a better way to build stamina than jogging," I told myself. The following morning, I went out to jog. I couldn't do even light jogging for five minutes without feeling uncomfortably out of breath. I would stop to rest a bit, and start again. Subsequently, I attempted this on several occasions with no significant improvement. I could walk but I couldn't jog. That's when I got an appointment to get my first lung function test.

Here I was; at age 53, diagnosed with emphysema, which had been hiding under my nose and progressing steadily for who knows how many years. They said because of the destruction of air sacs (alveoli) and airways obstruction, my lungs were as if I were a 76 year old man. It was quite a come down for someone who is used to hear, "You look like you are not over 40" to be told, "Your lungs look like you are 76."

In an attempt to soften the blow, I asked if the destruction in the air sacs was primarily in one lung. They said it was in both lungs. I tried again, "Is this obstruction and alveolar destruction in the top of the lungs, middle or bottom?" They said, "It is everywhere, all over the lungs." I asked, "Could it be an error, like a wrong reading of results or a lab error or some sort?" Pointing to the x-ray plates on the table, the doctor told me, "It's right there on the X-ray plates. It's visible to the naked eye."

Many questions such as these came up as I left the doctor's office: "What can they do to recover my lung function?" "Is there anyway to build the air sacs back?" "Can we clear up the airways obstruction?" "Should I visualize growth of new air sacs as cancer patients visualize destruction of cancer cells and get cancer free? Is there an herbal "Roto Rooter" for cleaning up the gunk in my airways?"

It dampened my spirit to hear "Your Emphysema (or your COPD) is a horribly progressive disease! With treatment, you can slow the progress of the disease. Keep your airways clear to maintain and protect your lung function."

Soon, my usual optimistic attitude surrendered to pessimism. Pessimism turned into depression. From 2 or 3 puffs twice or thrice a day, my use of bronchodilators had increased to 3 to 4 puffs 4 times a day. On a bad day, I used them as much as 5 times a day. I was getting sometimes breathless from just moving about the house. Cold, heat, humidity, dryness, pollen or anything even slightly disagreeable in the environment was bothering me more than before. The airways had become pretty "hyper responsive."

I had to constantly deal with my psychological "demons," depression, anger, frustration, worries, anxiety or feeling a loss of control and lowered self-esteem. Being a psychologist, I could recognize that my negative emotions directly affected my breathing and tried to handle them.

Fortunately, two friends of mine, trained as respiratory therapists came to visit us. As they were leaving, they said, "Think lung rehabilitation." Those three words coming from friends reverberated in my head continuously and became the turning point in my life. In addition to the treatment I received, I found an additional source of help, ME! I have finally recruited me to help myself, and now it has assumed the leadership role in my treatment and rehabilitation team!

Take home messages:

1. If you notice shortness of breath while performing mild to moderately challenging activities, ask for a lung function test. We must "catch" the disease before substantial impairment occurs. If you know a friend or relative in a similar situation, encourage them to get tested.
2. Upheaval of negative emotions such as depression, anger, frustration, worries, anxiety or feeling of loss of control and lowered self-esteem are natural. We don't need to be embarrassed by them. They are quite common. Don't hesitate to seek help.

On the Road to Self-Empowerment

There was no pulmonary rehabilitation program near where I lived, so I read everything regarding lung rehabilitation and exercises from libraries, Internet and patient associations.

I increased the duration of my walking. I selected specific exercises to strengthen my arms, legs, abdomen and chest. I especially focused on making my diaphragm and ribcage more flexible and strong. I began to do yoga postures and breathing exercises that I had given up

some years ago due to exertion avoidance. I lifted light weights. I joined the gym at the local YMCA where I could have access to different types of treadmills and muscle strengthening machines.

Don't let me give you an impression that it all flowed smooth and nice. It was a tough road. The first day I went on treadmill, it was the longest three minutes I have ever spent. My legs were feeling tired and jammed and I was feeling short of breath. I made my goal of staying on it for 5 minutes and to go as slowly as I needed. In just a few days, 5 minutes were stretched to 15 and in a couple of months I could go on up to 30 or 35 minutes. I made an interesting discovery about endurance and stamina. Having followed a regular exercise routine for a few months, I discovered that the first 5 minutes were the hardest, then next 5 minutes were easier and next 5 minutes were still easier. However, it required careful attention of the breath and know when and knowing how much to slow down so as not to run out of breath. I call it "breath awareness" and "breath management." We will discuss it later in detail.

I performed a different set of exercises on each day of the week and thus covered a wide variety of light to moderate exercises during the span of the week.

At the same time I studied extensively to understand my disease, medication and treatment options. For example, I learned the most efficient way of using bronchodilators so I could get the most from my puff. I learned to recognize the beginning of an acute exacerbation of COPD symptoms and seek medical treatment as soon as possible.

As I developed more understanding of the disease and available treatment, I began to feel I had some control over how I spent my day. Even on a bad day, I get to choose. I realize it's my choice: I could spend the day being sick and complaining or focus on trying to get better. I like to choose the latter. On a bad day, I spend most of my time on regulating my breathing, doing light stretching and lots of relaxation exercises to get some relief from symptoms.

I rarely get depressed now. I am no longer angry about why I had to get emphysema and over the things I failed to do in taking better care of myself. To a large extent, I have accepted my disease. I know the word "acceptance" sounds scary, but I don't want to waste my "breath" yelling and screaming inside myself. Someone said it so beautifully, "What is, is! Now it's up to me!"

Translation: Now that I have it (my emphysema) I want to focus on doing everything I can to take care of it. I am past the stage of questioning. I spend my energy looking for answers and solutions to practical problems of everyday life.

I am working on reducing my emotional reactivity to frustrations and obstructions in my way. "Obstruction!" That's a loaded word. Obstructions are not found in the lungs only; they are everywhere!

In the serious vein, I have come to realize how much my emotions affect my breathing. I am learning to regulate my emotions. It's a constant work. I am an anxious person by temperament, but by doing muscular relaxation, breath relaxation and mental relaxation, I don't let the anxiety get out of hand. Breath related anxiety has lessened quite a bit. There is

a little self-confidence growing that eventually I will be able to get the breathing back to my normal. Fortunately, I don't have other medical problems like heart disease, high blood pressure, diabetes, etc. to additionally complicate the breathing problem; mine is only the pulmonary obstruction.

Take home messages:

1. You yourself have to pave the road to self-empowerment. It's hard work! However, you will receive ample rewards for your hard work!
2. The road to self-empowerment is paved by knowledge, intelligent action and persistence. The raw material used for paving is books on your illness, treatment, self-help books and relevant Internet sites, exercise machines and all the self-help tools you can find.
3. Emotional regulation, stress management and relaxation skills can provide significant relief for breathlessness and other breathing discomforts.

Controlling Symptoms and Maintaining Lung Function

Coping with the disease is a process of learning. When I was told I had emphysema, I knew nothing about it. I had heard the name and thought it was a disease suffered by elderly people in nursing homes.

In the beginning, I didn't want to know about it or was too scared to learn how bad it can be. In last few years, I have been more determined to learn everything I can to handle my disease. I can now identify what has helped me in controlling my COPD symptoms and preserving my lung function.

Here are the things that have benefited me. Maybe they might be of help to you as well.

1. I have to put in a lot of time and effort in keeping better health. I spend about 3 to 4 hours every day on different self-help tools such as walking, breathing exercises, flexibility and strength training, weights and meditation. However, when my symptoms worsen, I spend as much time as it might require.
2. I have worked out a plan for the bad days; that is, the days when symptoms are aggravated. It gives me a sense of control and satisfaction that I am doing something about it and not just taking it "lying down." I spend the entire day (and even hours at night) working on opening my chest, slowing my breathing, relaxing the mind and body, visualizing the symptoms dissipating and meditating to slow down the heart and so on. I don't mind spending the time. What else is there to do? After all, when you can't breathe, nothing else matters.
3. I practice "24/7 pro-active breath management," rather than trying to manage it when my breathing begins to go haywire. I am constantly aware of how I am breathing. By closely monitoring and promptly correcting any irregularity in the breathing pattern, I can avoid severe breathlessness. At such times, I try to stay calm, relax and try to breathe

slowly. I work on stabilizing my breath. It has really served me well to recognize a "breathing attack" before it starts to escalate.

4. I have learned the hard way that I must treat a COPD "flare" (acute exacerbation of symptoms) aggressively and immediately. Earlier I had a stoic approach and a fond hope that symptoms would clear up. Sometimes I was foolish enough to believe that the symptoms were getting better, while the infection was slowly brewing in the silent areas of my lungs. Once I found out that I might be harming my lungs by delaying the treatment, I began to get to the doctor right away. Don't lose valuable time! Treat a COPD flare right away.

5. Relaxation exercises are mandatory for me: I do mini-relaxation sessions, 5 minutes each time, at least three or four times a day. I do at least two full sessions, 15 to 20-minute relaxation sessions a day. In relaxation sessions, I physically and mentally relax for 10-15 minutes and then do 5-10 minutes of smooth, relaxed, slow and deep breathing. I try to relax physically and mentally when resting. At night, when I can't sleep, I stay in bed and try to do my relaxation session as long as needed until I fall off to sleep. Sometimes, I can't fall off to sleep, then relaxation is an all night affair with me.

6. When I pace my breathing I can perform an activity longer. I exert according to how strong or weak I feel at the time. I call it my "exertion strategy." While performing an activity, exercising, walking or engaging in any other type of exertion and effort, I modulate my speed and breathing so I don't make myself breathless but still work at a moderately challenging level .

7. I have a tendency to stress out easily, so I do stress management all the time. I have realized that in order to regulate my breath, I have to regulate my emotions and manage my stress level. Anxiety, worries, panic depression, anger or any type of excitement can easily disturb my breathing, so I constantly work on it.

Summary

I pay relaxed attention to my breathing. Practice 24/7 pro-active breath management. Maintain breath awareness at all times. The moment I notice even a slight unwelcome change in my breathing, I start regulating it gradually and steadily. Constant awareness of breathing helps me to promptly adjust and adapt to the demands of different situations.

I struggle and try to get on top of my illness. It's not easy and I don't always succeed. "Never Give Up! Never!" It is a promise I made to myself. I try to keep it as much as I can, but I often need reminders and promptings from my loved ones.

If you haven't made already made a promise to yourself, this is the best time to do it.

If you have already made a similar or better promise, now is the best time to remind yourself and remember to give yourself many reminders and prompters to keep the "fire" burning!