

Always Having Hope

by Jo-Von Tucker

No one should be without hope, ever!

Receiving a diagnosis of chronic obstructive pulmonary disease is a daunting thing. We soon learn that we are afflicted with a so-far-incurable illness that is usually progressive, and one that has several probable components, such as emphysema, chronic bronchitis and bronchial asthma. It is a disease that will alter our lifestyles by severely limiting physical abilities, and adding fatigue and shortness of breath.

We may hear all or none of this information at the point of diagnosis. Some people are just left to fend for themselves. Most doctors – even pulmonologists – do not have the time or inclination to function as educator of their patients. So people are left with huge holes in their knowledge about COPD and how to best manage it.

By far the worst item left out of diagnosis is hope. We are rarely ever advised that we have a right to hope for the best with COPD. While we cannot expect recovery, *we can, and should, aim for stability.* There are basic steps that we can take to keep the disease from getting worse... to prevent us from spiraling downward into more and more disability.

This doesn't mean that we should expect our doctors to take on the monumental task of educating us about COPD. But they should encourage us to learn about it any way we can! By reading about it, researching it on the Internet, and by participating in an active and vital support group, we can learn from one another!

Still, physicians are the ones we turn to most often when we are seized by fear of the unknown. The big questions usually come awhile after the initial diagnosis, after the shock of being on the receiving end of a diagnosis of a chronic illness. After the shock wears off a bit, we find ourselves desperately in need of an understanding of what we, and our families, are facing.

I would like to see all pulmonary physicians add a few more pertinent facts to their 10-minute visit allocation... to add words of hope by making the patient aware that their life is not over, just because they have COPD; by encouraging patients to become active in the management of their illness, and by letting them know that there is such a thing as stability of the disease.

If you allow yourself to be helpless in the face of COPD, you may become resigned to being a victim. And being victimized can lead only to frustration and more loss of health. It will also cause discomfort for those around you... spouses, caregivers, close relatives, etc.

We have lung disease that is chronic and usually progressive... but we can choose to live our lives in ways that may allow us to become stabilized. By following our doctor's treatment program, eating nutritious and healthy diets, keeping a steady exercise regimen, conscientiously pursuing social contacts, avoiding exposure to viruses and other harmful bugs, and aggressively maintaining a positive outlook, we are following the basic ground rules to stability!

Learn from doing. If you feel helpless and like a victim of the disease, or if you feel hope slipping away, take control and battle those “H” words, *helplessness and hopelessness*, for all you're worth. Pull your coping skills up out of their holsters and take aim! You'll feel better for having blasted the hell out of those head-hanging blues.

Recognize when you are feeling helpless, and take positive steps to fight your way back to better control of your life. How, you say? We can begin by finding alternative ways to accomplish our goals if we are prevented in doing so by compromises in our physical strengths. Or alter the objective, if you can. If we cannot do "X", we may be perfectly capable of doing "Y". For example, if we can no longer pursue a previously loved hobby (in my case it was active and journalistic photography), we may be successful in acquiring skills in the same hobby but less physically demanding ones. I'm now trying to learn to transfer my skills in field and travel photography to Cape landscapes and studies – more sedate than the shots I captured riding elephants in the jungles of Nepal, but somehow just as fulfilling for me now.

Everyone deserves hope! It is a ladder to hold onto. It is a reason to get up in the morning. It gives us reason to smile. It lets us reach out to offer help to other people. It helps us sleep at night. Hope provides us with inspiration, encouragement, and strength, and gives us insights into what is most important in our lives.

Even if a doctor suspects that the patient in front of him may have a poor prognosis, I believe that the person is entitled to hope... that it should never be taken away. In my own case, I was diagnosed with COPD and advised that I had between two and five years of life left. That was fourteen years ago! Even though I was prescribed supplemental oxygen 24/7 for the rest of my life, and I have compliantly been on O₂ all these years. I am still around... still kicking, still working every day, still very much alive... and glad of it!

But I had to find my own hope.

Part of it I have done by my active involvement as an advocate for COPD'ers. Part of my own hope came from my quest for information about this illness. Part of it, I found by writing my book about living with chronic lung disease. Part of it, I stumbled on by observing that there were others who were worse off than I was. And part of it, by having faith in my own ability to overcome obstacles... even chronic illness.

And, although my case is complicated by the "other" health problems, it is important to note that I continue to learn about COPD almost every day, and that I am determined not to give in to it. Nor will I give up my fondest hope... that they will find a cure for obstructive lung disease... or at least, something that will generate new tissue growth in the lungs. And hope, too, that stability remains within my grasp... and yours!

*Jo-Von Tucker passed away in late 2003 from complications following surgery. Her book, *Courage and Information for Life with Chronic Obstructive Pulmonary Disease*, is available in the BBLW Bookstore on this website. Her advice on starting and running a support group can be found in the chapter on lung support groups in *Breathe Better, Live in Wellness: Winning Your Battle Over Shortness of Breath*, also available in our online bookstore.*