

Jo-Von Tucker's life as she knew it came to a screeching halt when, at age 52, she was told that she had COPD. Her doctor also told her that she would have to wear oxygen 24-hours a day for the rest of her life, and that she only had less than five years to live.

Did she go home and give up? No way! Jo-Von was a fighter and she went on to help herself and others by starting a much-needed breathing support group. She also wrote a book and published a newsletter for pulmonary patients and families. In addition, Jo-Von worked with various organizations to improve oxygen delivery and availability. Everything she did, she did with gusto and that no-nonsense Texas / Manhattan style, sometimes very bluntly saying, "We just have to get off our duffs and fix this!"

I met Jo-Von for the first time in late 2003 at the first national COPD conference in Arlington, Virginia. Just one month later she passed away unexpectedly from complications following surgery.

I share with you now some of her wisdom; and I'm sure she would be very pleased that she is helping, her words and her spirit still working to improve the lives of people with COPD everywhere.
JMM

Defying the Laws of Gravity, or Holding on to Stability! by Jo-Von Tucker

key words:

- **Exacerbation** – a flare-up / episode with difficulty breathing that may last for hours or days
- **FEV₁** -- a lung function number that indicates the degree of obstruction. It stands for Forced Expiratory Volume in one second. This is the amount of air you can blow out in the first second of your exhalation.
- **Spirometry** -- medical test in which you breathe into a machine that measures your lung function
- **de-conditioning** – developing weak muscles due to inactivity

My number one mission, and I am sure it is the same for many other COPD patients, has been a commitment to maintain stability of my lung disease. Yes, I too, find myself walking that often slippery path, and have to work on preventing further progression of obstructive lung disease.

I have been very fortunate over the past fourteen years or so to have maintained a relatively stable condition. In spite of a few exacerbations, I've managed to avoid the steady downward spiral that can happen to patients with COPD. My FEV₁ has remained mostly the same (until recently), with small amounts of slippage notable on spirometry tests.

It has taken a lot of commitment to my treatment program, and to staying as conditioned and active as I possibly can. That slippery slope of stability has seemed to me like defying the laws of gravity! Like a skilled trapeze artist, I had been able to ward off most lung infections, keeping my state of stability in the air at least temporarily, from one stretch to the next.

But like all good things, I suppose, that combination of maneuverability and luck had to come to an end sometime! Kerplow! That's the sound I seemed to hear as my doctor reported the latest results of my spirometry tests. Gravity 1 -- Jo-Von, 0. My numbers had slipped precariously from 60% to about 45% of lung function, within a short period of time.

What do we attribute this deterioration to? Several factors, probably... my age, since I was diagnosed fourteen years ago, my busy-ness and exhaustion, which go hand-in-glove. A general de-conditioning that has occurred since I was so very sick and hospitalized for a couple of weeks with ulcerative colitis last fall. Altogether, a deadly combination that has definitely pulled me down to earth!

I share my personal experience with you because I don't want to see it happen to the rest of you! I know how hard we all work to hang on to our stability. My example must help others realize their own mortality and vulnerability, and to take steps accordingly to preserve their quality of life they have established.

Why is this stability status so important? Because it is almost impossible to repair the damage to re-establish the same level of stability that we previously had! Once lost, it is extremely difficult to rebuild. Stamina and energy can be improved with the proper steps of illness management and treatment. We must do this because, remember, our lungs do not regenerate. New replacement tissue will not grow. New functioning alveoli (air sacs where oxygen exchange takes place) will not appear...at least not yet, as science continues to work toward this elusive goal.

Therefore, stability is precious! It is worth expending the effort to hold you at your level of COPD. You will naturally lose a tiny bit with time, even if you are successful at holding the disease at bay.

So, here are my thoughts to pass along to you to help balance your COPD life with maximum stability. I hope that you will heed them, and that the suggestions will help in your own battle with this monster called chronic obstructive lung disease.

- Listen to your doctor! Understand the treatment program prescribed for you, and follow it. Take your medications exactly as prescribed, including the use of supplemental oxygen.
- Be consistent with your exercise. If you haven't taken a pulmonary rehabilitation course, talk with your doctor about a referral. If you are a graduate, consider taking a refresher course, or at the very least, continue your exercises and physical activities -- every day.
- Be an active participant in your breathing support group. Knowledge is power, and you will do much better if you know what you are up against, and understand how to deal with it. And spending time with others who have similar concerns really does help.
- Maintain social contact with the outside world. Avoid isolation! Do not let this disease rob you of enjoyment and interaction with friends, family, loved ones, and neighbors. Isolation leads to depression, and depression can lead to further debilitation.

- Pay attention to nutrition. Provide your body with the right foods and nutrients to fuel it for maximum benefit. Your body needs protein and a well-balanced diet of fruits, vegetables, meats and dairy products. Take a multi-vitamin every day. If you have lost weight and are too thin, talk with a dietician about increasing your calories. Some people with COPD use a lot of calories just to breathe -- more than they are able to take in.
- Avoid exposure to viruses and cold germs. Remember to get the flu vaccine each year. Washing your hands with good old warm water and soap can keep germs from bugging you! Get a pneumonia vaccine every five to seven years.
- And most importantly, find the time to give your body the rest that it needs. Do not push yourself to exhaustion. If you need an afternoon nap, take one. Listen to your body and pay attention when it tells you it needs rest.

Even if you take all of the pro-active steps and measures, you may find it hard to attain stability and to maintain it. But it is well worth the effort involved. You can extend your life by trying to keep your COPD on an even keel.

It's best to remind yourself that no one can manage your illness for you! It is something you'll have to do for yourself. Even if you have a loving, caring spouse, there are things about your own illness that only you can know. That's why it is a really good idea to keep a journal to write down your notes and thoughts about your experiences. It can serve as a reminder whenever you go through a similar situation. Besides, keeping a journal is a terrific way to express yourself, to allow yourself to write about emotions that you may be reluctant to share with even your close family.

The search for stability goes on... with all the ups and downs of those "good days/bad days" that seem to come with COPD. It is important not to let the down times discourage you. Keep your chin up and your focus firmly attached to whatever it takes to level off your disease.

It may seem to you, too, as though you are trying to defy the laws of gravity. But remember, I managed to accomplish stability for fourteen years. It took a series of extraordinary negative circumstances to boot me off of that tightrope. And I'm going to give it all that I have to find my way back to a stable status.

It's the very least I can do for myself!

Jo-Von Tucker's 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.

