

A Story of Two Women... or...

Why I Wrote *Live Your Life with COPD: 52 Weeks of Health, Happiness and Hope*

I didn't choose to write this book. It chose me.

When I was writing my first book in 1999, I heard about a yet-to-be published book, *Courage and Information for Life with Chronic Obstructive Lung Disease*. I was excited to learn of this new book about COPD – especially one written by a patient – a lady named Jo-Von Tucker. As soon as it was available for sale I bought it.

As I read it I was struck by Jo-Von's honesty in telling what it was like for her to fight the day-to-day battle for health and breath. The emotional issues in life with COPD can be brutal. In her writing Jo-Von talk about them, courageously baring herself to readers, revealing her fears, her demons, her failings, her triumphs – her hopes.

She wrote about the very issues – the emotional struggles – I'd seen in my own patients. On the road they traveled, sometimes my patients would stumble and fall; at times it was as if they were swallowed by a sinkhole. More often than not, though, they'd pick themselves up and march on, even stronger than before. But every time, every single time – by just being assured they were not alone – they were inspired.

I, myself, don't have COPD, but from my experiences working with people (at that time it had been for nearly 20 years) I knew more than anything that this information about life with COPD, must come to light. That's why I decided to write my first book; so folks with COPD who were doing well, those who'd faced the issues and conquered them, could help others. And thanks to Jo-Von I'd found even more insight.

I was in awe of this woman, Jo-Von Tucker, who had not only beaten the odds to live on – and live well – with COPD but had written a comprehensive guide to living with COPD. After all, she was a successful businesswoman, who, at age 52 was diagnosed with COPD and told she had two to five years to live. Undaunted, she marched on to become a well-known advocate for people with COPD, a support group leader, speaker and writer.

So, with a leap of faith I contacted her through email, not sure if she'd open the note in the first place, give me another thought if she did, let alone write back. But she did. We soon became friends and supported each other in both our writing and in the often challenging process of publishing. When others were writing about things like medications and nutrition, yes, we were writing about that – but so much more. We wrote about what was in the hearts and minds of people with COPD. Jo-Von and I were kindred spirits in that regard; pretty much the only ones back then writing about the emotional issues associated with COPD.

Jo-Von added me to the mailing list for her Cape Cod Support Group newsletter. I looked forward each month to seeing what was going on with her group because I, too, ran a support group in my hometown. But without a doubt, the first piece I'd look for was her

editorial. So often I'd think, "Boy, she hit the nail on the head with this one! Real people feel this way, but they just don't talk about it. And here she is, putting it down on paper."

Our friendship grew. Jo-Von introduced me by phone to a colleague of hers, Dr. Austin "Bill" Kutscher who organized COPD symposiums at Columbia University Hospital in New York City. In November of 2003 I finally met both Jo-Von and Bill in person at the first national COPD Coalition Conference in Arlington, Virginia. I first came upon Jo-Von who was sitting in a wheel chair in front of her presentation in the poster room. I met Bill later that night. He was a wiry man in his eighties; not as tall as I, but with an energy and intensity that was ferocious. I was honored to be in their company and it struck me then – there was so much for me to learn.

Barely a month later I was shocked and saddened to learn that Jo-Von passed away unexpectedly from complications following surgery. In corresponding with her over three years through email, I'd always looked forward to meeting her someday but also to working with her. That latter hope, of course, was now gone. Or, was it?

The following June I was invited to speak at a COPD symposium organized by Bill at Columbia University Medical Center in New York City. The focus was "Volunteerism in COPD." Bill had asked me to present two papers; one I'd written, and the other written by Jo-Von, one she had planned to present. At the close of the first day of the event, Bill handed me a stack of papers held together by a rubber band.

"Jane, these are Jo-Von's editorials. You should have them."

"Um...okay...thank-you," I answered, not really understanding what he meant by giving them to me, nor knowing what he wanted me to do with them.

That night in my hotel room, I read them, one after the other, spreading them out on my bed. I was overcome again by the wisdom in those forty-some editorials within 150 pages of her writings. It was a joy to see Jo-Von's words, the entire collection here in front of me – these open, positive, hopeful expressions of a wise woman. It was a delight to read with a fresh eye her experiences, her advice, her insight, her questions, as she shared her mind and heart and spirit – and doing it with gusto and that no-nonsense Texas / Manhattan style. I knew that night – somehow this work must be shared so Jo-Von's legacy could live on.

The next day at the symposium I approached Bill. "I read the editorials."

His piercing eyes met mine. "Yes."

I thought, "Jane, you've got an awful lot of nerve, but you have to say what you believe. I came right out with it. "They should be in a book."

He smiled. "I was hoping you'd say that. And you're the one to do it."

I was stunned; first, by Bill's trust in me, and a moment later, with the weight of this responsibility. That was 2004. Now, six years later, I've completed the job. I've done what Bill asked me to do and what I'm sure Jo-Von, also, would have wanted. I regret I never had the honor to work with my friend directly, but in working with her editorials – her thoughts, her words – I finally did. It's been a joy and an honor. Here and now, I humbly pick up the torch I was given, and together, we go on.