

Starving for Air

by Lori Palermo

Have you ever been in the company of a person with COPD/Emphysema while they are trying to get a breath of air? Have you found yourself trying to breathe with them? Have you wondered what it must be like to struggle to get that air into your lungs?

Try this: Hold your nose and breathe through a straw. How did you feel? Did you feel that you could not get enough air into your lungs, like the feeling of being suffocated?

My dad, who passed away of COPD/Emphysema December 2003 was *starving for air* for many years, but would not let *us, his family*, know. He did not share with us the continuing loss of his ability to breathe. He tried to hide it from my sister and I, even my mom, who was with him 24 hours a day.

Dad did not know much about his Respiratory Disease, so he did not understand or know how to deal with the many affects Emphysema had on his body.

As the years went by and the disease destroyed more of the air sacs, blood vessels and support tissue in the lungs and caused airway blockages, Dad's shortness of breath became increasingly worse. Dad became scared knowing he was losing his *quality of life*. He began staying home more, afraid to go out, afraid of going into respiratory distress. When he would take my mom to the store, he would sit in the car and wait for her. He began having more anxiety, and more stress. With anxiety, you breathe faster, and your breathing muscles tire easily. It all seemed to be a vicious circle. Dad would become anxious with his inability to breathe, which made him not able to sleep at night, which then would make him tired the next day and not want to eat and get the nutrients which were needed for his muscles and overall bodily requirements, then leading to less energy, more shortness of breath – and finally to depression. Dad was rushed to the hospital many times in respiratory distress. Once at the hospital, they would give him oxygen and he would feel safe again.

I love my dad with all my heart but I have to say he was a very stubborn man. Honestly, he did not try to help himself. I say that also with some mixed emotions, because Dad did not know what to expect with emphysema; he did not want to discuss it with anyone and sometimes I think he felt he was the only one trying to cope with this debilitating disease. So there is where my heart really went out to him, because he kept so many emotional feelings inside of him. You never actually knew what Dad was thinking about his life with COPD/Emphysema.

He had been involved in a Pulmonary Rehabilitation Program about three years before he passed away. He was thrilled with it, but the therapist told him, "If you don't use it, you'll lose it." Well, Dad did not keep up with his therapy, which did in time make him weaker and put more stress on his lungs and his heart.

Dad also had a very hard time with using his nasal cannula, and he refused to wear it around the house (he was embarrassed). Several months before he passed away, he had to use it more often – he had no other choice. And of course he would not take or even use his oxygen outside of the house. He would try to use the oxygen at night to help him sleep, but again, he said it was uncomfortable. He got tangled up in it and would have every excuse he could find not to use it.

After my dad passed away, I called his Pulmonary Doctor and requested Dads' records from the past few years. I just felt I had to try to understand what Dad was feeling by reading how bad his disease really was. I found this report interesting, but very sad. I realized that Dad was in the severe stages of Emphysema for at least three years before he passed away.

Here are just some of the details on his report: My dad had developed a high hemoglobin level which made his blood thick with red cells. About a year before Dad passed away, he would under go periodic phlebotomy (taking blood out) to help his breathing and keep his hemoglobin and hematocrit down. Before undergoing the phlebotomy he would go through severe periods of shortness of breath. Dad would experience exertional hypoxemia, meaning that with any type of exertion, the oxygen level in his blood went even lower. Hypothyroidism, where his thyroid was working at a lower than normal level, was also a problem.

Several months after Dad passed away mom my sister and I had a very emotional talk. Mom told us how Dad had really felt for all of those months. The first thing she said is that Dad had once even talked about suicide. And then she went on to tell us why he could not live with this disease any longer. He could not lift his arms to fully dress and undress himself. He got to the point where he could not walk up the basement steps. He had to crawl up on his hands and knees. He could not talk, or even eat, without getting out of breath. He would walk a few feet and have to lean over on a chair or table, whatever was there, for him to rest on. With Dad realizing that he was losing his *quality of life* he became very depressed. He would tell my mom he honestly could not live like this any longer. He *did not want* to live like this any longer.

I have learned so much about COPD/Emphysema since Dads' death. I now know that everything he went through is very normal in the life of a COPD patient. I also learned that there are breathing techniques to help with anxiety, that exercise keeps your muscles and body strong and puts less stress on your lungs for breathing, and that the foods you eat are so very important. I guess what surprised me the most is that millions of people have COPD. And here my Dad thought he was all alone. We can only imagine how depressing that must be and how hard it is to lose the one thing that is so important to live...Your Breathing Lungs.

I do regret that I did not learn this all then to help my Dad cope with his disease, but I realize I cannot go back. I can only go forward and help others who struggle with these problems – help them to learn and cope and have the best *quality of life* they are able to have.

Dad was a very proud man and loved his family dearly. So that is why on that cold and icy morning of December 26th 2003, my mom, sister and I had to make the hardest decision of our lives, but one that we knew dad would have wanted us to make. We had to take him off the ventilator and let him go.

Dad is now in heaven as our "Angel" where he has no stress, no depression and no anxiety. He has all of the air he needs to breathe.