



Judy & Bob Luther

Idiopathic Pulmonary Fibrosis

About 20 years ago, my husband, Bob was diagnosed with a hiatal hernia. He had struggled with acid reflux and chronic cough. He was put on GERD medicine. However, his chronic cough, chest pain, and shortness of breath did not desist. Our family physician ordered cardiac testing, which showed normal results. As his symptoms persisted, he underwent cardiac evaluation approximately every two years for many years. Finally, our family physician ordered pulmonary function testing which showed restrictive lung disease with 40 percent lung capacity. We were referred for a CT scan, and Bob was found to have interstitial pneumonitis which eventually became idiopathic pulmonary fibrosis. In addition, the left side diaphragm was barely working which just compounded his struggle with breathing. The doctor informed us in the kindest way that Bob had three years at most to live. He was evaluated by the lung transplant department but found to be a poor candidate.

Bob was a fit man. Before he became sick, he would run two miles, five days a week. In the beginning of his illness, he continued to walk on the treadmill, obviously at a slower pace and less distance. He would keep his pulse oximeter on his finger. I would stand beside him, watch his oxygen levels and breathing, and run to the living room to turn up his oxygen as needed. We were advised by all the doctors and pulmonary rehab to keep exercising as long as he could tolerate it. But what was also important was to keep Bob's frame of mind positive, and exercising was an important activity before the illness. He needed to feel a sense of himself.



With chronic lung disease, come restrictions in public activities. Exposure to illness can quickly compromise lung function. As a result, we were not able to go to church as often, walk around the mall, or go out to dinner with friends. Our friends would have us over for dinner instead of going to crowded restaurants, or they would come to our house for a visit. Every day we took a two-to-three-hour drive in the car. We would drive in the country or around town, often stopping in front of the church for a short prayer. There was such joy for Bob in these drives. He felt freedom from the house and escape from his disease.

As his disease progressed, Bob became almost childlike. He did not want to be without me close. When he could not catch his breath, he would lean forward and point to his back. I was the only one who could talk him down from panic. If he lost his breath, he would become panicked and breath faster and faster. I would hold his hand, look in his eyes, and say, "Smell the rose. Blow out the candle." He would watch and follow my breathing. His best compliment was to tell our girls, "You know your mom is my angel."

Bob had to take many medicines and restrict his salt and fluid intake. I had a medicine and an intake chart recording all day. A typical schedule looked like:

- Woke up three times a night for bathroom, requiring oxygen to be turned up. Once he was back in bed, I had to turn his oxygen back down.
- I would help him shower, and dress.
- He would relax in living room for couple of hours so I could handle laundry, house cleaning, and quick errands, if possible.
- At noon, we'd start our daily two- to three- hour drive by stopping at McDonalds for a chicken snack wrap.
- Once home, he'd walk on the treadmill. I would watch his oximeter and adjust his oxygen.
- I'd get him back to living room and settled, so I could cook dinner.
- I'd clean the kitchen and join him to watch T.V., all the while watching him breathe, and adjusting his oxygen levels.
- I'd take him to bed and get him settled, and he would keep his cell phone so he could call if he needed me, which he usually did at least once.
- Once he was asleep, I'd take some time for me out in living room before going to bed myself.



As you can imagine, this took its toll on my body. Trying to keep weight on him meant higher calorie meals, and our schedule did not allow time for me to exercise. My sleep became fragmented and shallow. Eventually, I had to hire visiting nurses to help. My body could not keep up with demands of disease progression.

We have the most amazing group of friends. If I needed anything, they were there. Our girls, Kari and Dana, called often and came for visits. Both girls lived on the east coast and could not be with us constantly. Our grandson, Trent, came to live with us while he was completing college at Eastern Illinois University.

He helped with chores around the house, and his youthful presence lifted our spirits. He would also take his grandpa for drives sometimes to give me some time to myself.

“In Bob’s case, there was no limit to his oxygen needs. He would be up to 10 liters per minute by the end. He was tethered to a concentrator with yards and yards of tubing. It was never difficult to know where he was in the house.”

Bob had very good medical care from all the medical staff. He used to say that he spent years exercising, eating properly, not drinking because he was worried about his heart, but that it would have been better if it had been his heart because there had been so much research and problem solving for the heart. He wanted research to continue for lungs as it had for the heart.

In conclusion, I want to give advice to families caring for loved ones suffering from chronic illness.

- Make lists and charts. When you stay organized with all the medications, fluid intake, sodium intake, or other information you need to manage, you can manage your day with a clear head. You will be less flustered if you can reference your notes throughout the day instead of trying to just remember all the small details.
- Engage a formal palliative care program early in the illness instead of creating your own patchwork system. This will help to keep loved ones out of the emergency department or hospital and support your decisions regarding care.
- Take advantage of your family and friends' offers of support and do NOT feel guilty for asking for help. It is paramount for your wellbeing. Respite care is important for all involved in patient care. ●

Idiopathic Pulmonary Fibrosis

Pulmonary fibrosis literally means scarring of the lungs. Over time, fibrosis can worsen to the point that patients may need supplemental oxygen to raise low blood oxygen levels, relieve shortness of breath, and improve exercise ability. Other facts about Pulmonary Fibrosis are:

- Pulmonary fibrosis can happen for many different reasons, including autoimmune disorders, environmental/occupational exposures, as a side effect of certain medications, and other causes. In many cases, despite extensive evaluation, the cause is unknown; we call such cases idiopathic.
- IPF is usually diagnosed in people between the ages of 50 - 80 years. IPF is very uncommon in people under the age of 50 years.
- Most people with IPF will have shortness of breath, exercise limitation, and cough as the disease progresses. Many people will require oxygen at some point in their life.

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