



Peter and Bonnie M.

Chapter 3

Caring For a Loved One with IPF

by Bonnie M., Caregiver/Spouse

My name is Bonnie and I am the caregiver of an idiopathic pulmonary fibrosis (IPF) patient. The patient is my husband. He was diagnosed two years ago and at this time is symptom free. He was diagnosed after a bout with pneumonia. We were very much taken by surprise because we had it figured it to be asthma. But, a pulmonary review group confirmed the diagnosis after our own pulmonary doctor presented a CT scan to them for their expert opinion.

I am in the medical field and have been for 20 years. We had been through the passing of my husband's grandfather 30 years ago from IPF, but things have changed a lot in the medical field since then. I think that the hardest aspect for me to accept is that we are still just combatting the symptoms as they arise. It is very hard to deal with it when everything that is presented to the public is, 'Get your affairs in order because you have three to five years and then you will be gone'. In the medical community we know that each case is different and the main objective is to be honest, but we still need to instill hope. To accept the fact on a day-to-day basis that my husband has a terminal condition is hard because he does not seem sick in any way, shape, or form.

We have changed our lifestyle just a bit, I think. We don't take chances by being around people who are sick. We have removed all of the carpets from our living space and have installed air cleaners and are diligent in their use. My husband has always been scent sensitive, so I watch what I clean with and try to stay on the low chemical end so that he doesn't have breathing and coughing issues.

I guess it has helped that I have a medical background and know the progression and track of the disease that we are up against. The knowledge to me is helpful. It is not easy. It is just being prepared for what may be ahead and knowing that by being prepared, it is not as fearful.

I continue to seek knowledge and I am going to the support group meetings. I find them very helpful.