

## Being a IPF Care Partner

By Dana Olson

When my husband was diagnosed with idiopathic pulmonary fibrosis (IPF) I was in shock. Everything about his health seemed so normal except for a couple of chronic conditions that many people develop as they get older. But he was only 60! And he did not exhibit any of the symptoms I associated with pulmonary fibrosis. But a lung biopsy and a visit with an interstitial lung disease specialist proved me wrong.

For the first couple of years, there wasn't much for me to do as my husband's "care partner." Kevin didn't really care to talk about his IPF, and I knew not to try and push him on it. Once he went on oxygen at two years into his diagnosis things started changing for me somewhat. Though Kevin is very independent as we are being a stickler on his healthcare, there still wasn't much that I did for him except to be present.

As time passed and his oxygen needs grew greater, I started feeling like I was actually "doing" something for him as I helped in carrying his extra portable oxygen concentrator batteries around when we were out and about. In the winter of 2020, his lung function really started to decline. This was when things started to ramp up on the care partnering. Kevin and I had shared cooking meals though in the last few years he had taken on most of that responsibility. That now came back to me. Additionally, he couldn't bend over without being severely short of breath and his ability to lift more than a couple of pounds disappeared. And to be expected, his emotions were raw, and he was easily irritable. Now was the time for me to do my best to let terse or harsh comments roll off my back.

May through August 2020 we made several trips to the regional transplant center in St. Louis. Care partnering turned to preparing for an eventual double lung transplant for Kevin. Much reading was done regarding what to expect and how to prepare for transplant. Lists were made, extra supplies were purchased and on August 13<sup>th</sup>, Kevin became the lucky recipient of a lifesaving call. As we made our way to St. Louis, I knew my care partnering had been minor over the prior 6 years to what it was about to become.