



Special Issue

What I Learned as a Caregiver: Part 4

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What I learned as a Caregiver: Be “in the game”.

“It’s not how much you do, but how much love you put in the doing.” - Mother Teresa

When I became a caregiver in November 2003, I didn’t know what all that would entail. I knew I needed to help my mother, but I wasn’t completely sure how. I am a self-starter and I like to research, so naturally, I turned to the internet to “learn”. As luck would have it, there wasn’t much information about PF specifically. I decided then to turn my focus to searching and learning about each symptom or “anomaly” mom was having. This learning helped me help her.

It’s important as a caregiver to be proactive with your loved one. Don’t expect them to know what you should do. Talk with them about how you can help. Ask them what they need and want at the time. Let them know you are there for the long haul and that with time, their needs will change. Ask them to let you know when they need you to change something you are or are not doing.

Other ways you can help them through their journey are:

- Accompany them to their doctor appointments. An extra set of eyes and ears is always best. It is common for us as patients to lose track of what our medical providers tell us when sitting in the exam room. It is also common for us as patients to forget to tell our medical providers details of how we have been feeling. That extra set of eyes and ears can help ensure all details are covered. Take notes at appointments. So much information can be conveyed at one appointment. Write it down to look over later. Go to appointments with a list of issues to discuss: questions, new symptoms, etc. Be a partner to your loved one. Some people are very private and may not want you in the exam room. Ask to be present before and after the exam for giving information and



asking follow-up questions, but step out of the room during the exam if this makes your loved one more comfortable.

- Learn how to read test results. With a lung disease and many other chronic or terminal illnesses, this is very important. Learn how to decipher what is written about your loved ones' last high-resolution lung CT, their last echocardiogram, or how to read all those numbers on a set of PFTs (Pulmonary Function Tests). Ask the medical providers for information. You can also seek answers in support groups (both online and face to face) as well as on the internet.
- Learn about your loved one's disease. With a disease as elusive as PF, it is important to learn as much as you can. Much of the medical community is still learning as well so you may not always be able to get the answers you need from a medical provider. There are resources available from which to learn: medical support entities like *Raremark/Xperiome*, *Pack Health* and *patientMpower*, drug manufacturers like *Genentech/Roche* and *Boehringer Ingelheim*, online support groups like the *Breathe Support Network of Groups* (www.BreatheSupport.org), face to face support groups (usually found at your local hospital or clinic), and foundations like the *Pulmonary Fibrosis Foundation*. You will quickly find that caring for your loved one 24x7 will make you “the expert” about their disease.

When my job description changed from simply “daughter” to “daughter and caregiver”, along with that came the responsibility to be on top of things. Don't let this overwhelm you. Instead, see it as a challenge to grow.

For me, I met the challenge head-on and “learned”. While not a medical professional, I chose to use my experience to help others. I don't want others to have to re-invent the “PF wheel” like mom and I had to do. This isn't the path for everyone, but hopefully, you can take your caregiving experience and apply it positively to your life going forward.

... Warmly, Taleena Koch

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