



Special Issue

## What I Learned as a Caregiver: Part 5

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### What I learned as a Caregiver: Health happens beyond the doors of the doctor's office

*"Doctors diagnose, nurses heal, and caregivers make sense of it all." – Brett H. Lewis*

When I became a caregiver to my mother in November 2003, I could not have imagined what the following years would bring. Given 2 years to live, the time I had left with her seemed much too short. However, in terms of the caregiving commitment, it also seemed very long. In mom's case, it turned into 6 WONDERFUL years, and while it was a long time as a caregiver, I couldn't be more pleased for the 6 years I had with her.

Mom and I quickly found out that she would have a host of medical problems. PF is called a "rollercoaster disease" for a reason – many ups and downs. We had to quickly adapt to her illnesses and ride the rollercoaster. Many chronic and terminal illnesses are the same. It is important to do what is necessary outside the doctor's office to ensure "health happens".

- Help your loved one stay otherwise healthy. With lung disease, even the common cold can become dangerous quickly. Run interference with family and friends. If someone is sick and wants to visit, politely decline and explain why. Help your loved one avoid other illnesses with good hand washing, wearing a mask when appropriate (pretty much every time they are in a medical facility), help them be proactive with their other care: immunizations, vitamins, a healthy diet, exercise (appropriate to the severity of their illness), regular check-ups with their medical provider, etc. If they are sick or have a change in symptoms, get them medical help and/or contact their medical provider right away. "Waiting the weekend" or "waiting until the next appointment" is often the worst thing one can do in this situation.



- Be a partner to your loved one who is sick. There is so much they have to think about and do. They are living with a terminal illness. Help them prepare for the future. Help with paperwork (last will, Power of Attorney, etc). Make a list of who to notify in the end. Help them plan their final wishes. Don't assume they want to do this on their own. Be part of the process and ask what "they" want.
- Spend "time". As a caregiver, you have the gift of "being present" for and with your loved one. Take advantage of that time together. Talk about what is important. Learn things about them you didn't know. If caring for your elder, learn about their life before you were part of it. Most importantly, make memories together. Spend time wisely. It is the one thing you can never get back when the caregiving is done.

Good physical and emotional health is important. Much of it happens beyond the doctor's office.

... Warmly, Taleena Koch

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