



Special Issue

What I Learned as a Caregiver: Part 6

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What I learned as a Caregiver: This stuff is personal

*“Caregiving often calls us to lean into **love** we didn’t know possible.” – Tia Walker*

Over the last several weeks, I have shared some of the lessons I learned through the years: 6 years caring for my mother and many more years in the PF support community. I can only hope these insights have given you food for thought in your approach to the caregiving process. As I’ve taken the time to sit down and reflect on my own experiences, I’ve been reminded that caregiving is incredibly personal. It is intimate and often pushes the boundaries of love. Yet, it is a privilege to bring light into the lives of the ones we care for deeply.

With those thoughts in mind, here are some of my final tips for improving your life as a caregiver.

- Be empathetic. Remember that you are not the one living with PF (or whatever chronic or terminal illness your loved one has). You don’t know what they are feeling – emotionally or physically. They are going through a lot and they need your support. For someone with PF, just walking across the room might be difficult. When their body isn’t getting enough oxygen, they feel awful: fatigued, listless, and generally unwell. This is both an emotional and a physical struggle, as their brains want to be more active, but their body won’t let them. Understand that your loved one is going through something, you don’t fully comprehend. Respect what they are going through.

Disclaimer: There are caregivers out there who are also living with or have had the same disease or illness as their loved one whom they are caring for. In this instance, you do know much of what they are feeling and have the added benefit of being able to be “sympathetic”.



- Honor your loved one's wishes. This is often the most difficult part of the caregiver process. As humans, we are naturally selfish and we do not want to say goodbye. We may not agree with our loved ones' wishes, but it is important to remember that this is their life and it is up to them how they leave it. Put their wishes before your own.
- Don't go through this alone. Through this entire process, both the caregiving and "after", seek help from another. Find a caregiver support group (either the *Breathe Support Network* online or a face-to-face support group at your local hospital or clinic), talk to a friend who has been through this, talk to a mental health expert, etc. You, as the caregiver, are not in this alone.
- No regrets. When the caregiving is done, have no regrets. Know that you did the best job possible given your circumstances. Everyone has their own unique experience in this journey. There is no "right way" to be a caregiver.

The journey of a "caregiver" is one without a defined path. We don't always know the best things to do or for how long we will be doing this. It can be for a short time or it can be for years. It can be frustrating, heart-breaking, and even make us feel angry and selfish. Many are stuck in the "sandwich" generation, where they are raising a family on one side and caring for their ill parent/s on the other. Many caregivers may also be working a job outside the home. Caregiving is one of the hardest jobs you will ever do – It can also be one of the most rewarding.

... Warmly, Taleena Koch

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