

What I learned as a caregiver: part 1 of 6

by Taleena Koch, Caregiver and PF Advocate for Patients and Families
Breathe Support Network of Groups

What I learned as a Caregiver: You are not alone

“There are only four kinds of people in the world. Those who have been caregivers; those who are currently caregivers. Those who will be caregivers; and those who will need caregivers.” – First Lady Rosalynn Carter

Statistics show that 65 million people in the U.S. are caring for a chronically ill, terminally ill, disabled, or aged family member. That is over 1/4th of the population.

A caregiver frequently feels alone, like no one around them understands what they're going through. On top of that, caregivers often feel guilty because they live with the mindset that their biggest responsibility is to take care of their loved one who is sick – and they believe there is nothing they are going through that can be as bad as what is happening to the person they love. They live with “caregiver guilt”.

1/4th of our nation's population is living with “caregiver guilt”.

You are not alone and all that you are feeling is completely normal.

In November 2003, I became caregiver to my mom. She was very sick and it took the next 6 months to get the “correct” diagnosis – Idiopathic Pulmonary Fibrosis (IPF). Neither of us knew what IPF was or had ever heard of it. Her diagnosis set us on a path unbeknownst to both of us.

What is a caregiver's job? I had never cared for a terminally ill person before, so I had no idea what I should do. At the time, I didn't know of any caregiver support groups to turn to, so I had to figure this out on my own. I hope I can pull from what I learned to help you on your caregiver journey.

Over the next few weeks, I will be sharing ways I found over the years to balance my life and the job I had taken on as a caregiver. It's the toughest job I've ever had. There are good days and then there are “not good” days. It's all a part of the journey.

However, before sharing my experiences, I encourage you to start with a good hard look in the mirror. Tell yourself that caring for yourself is just as important as caring for your loved one; For, if you are not a priority in your life, you will not be fully equipped to care for another.

Here, on this blog, I want you to find hope in shared community. I hope you know you are not alone. I discovered that there are many resources to help us caregivers stay in tune with ourselves.

... Warmly, Taleena Koch

What I learned as a caregiver: part 2 of 6

by Taleena Koch, Caregiver and PF Advocate for Patients and Families
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What I Learned as a Caregiver: Caregiver, care for thyself

“When you’re a caregiver, you need to realize that you’ve got to take care of yourself, because, not only are you going to have to rise to the occasion and help someone else, but you have to model for the next generation.” - Naomi Judd

The first thing a caregiver should do is “care for thyself”. I know this seems counterproductive to caring for your loved one, but if you are not healthy, you cannot care for someone else.

As I mentioned in my last blog, in November 2003, I became a caregiver for my mother who was diagnosed with Idiopathic Pulmonary Fibrosis. Not only did I not know “how” to care for someone with a terminal illness, let alone IPF, I had no idea the toll it would take on me.

Within a year, I was exhausted, having my own host of medical problems, and taking 12 different medications daily. I had also gained a substantial amount of weight. I was emotionally and physically spent.

This singularity in focus, while seemingly noble, is not sustainable for any of us with the job description of caregiver. After reaching this point of exhaustion, you would think I would realize that taking care of myself was just as important as taking care of Mom. If I was not at my best, I was not capable of bettering her everyday life. I did not see it then. Now, looking back, that realization should have led me to rethink the way I approached each day. I encourage you to do this.

It is important that you take time daily to tend to your needs, even if it’s just 15 or 30 minutes here and there. Do something for “you”.

- Go for a walk and enjoy nature.
- Meditate – and truly focus on your breathing.
- Exercise.
- Be with others; meet a friend for coffee, go out to lunch with a friend, etc.
- Nurture a hobby; maybe you knit or sew or you like to read.

Your mental health, as well as your physical health, should still be your priority. If you are having medical problems, see your doctor. Do NOT put off your own health in lieu of caring for your loved one. The worst thing imaginable would be to pre-decease your loved one. I have seen it happen.

You may be saying to yourself “I don’t have time” or “I need help”. In the next post in this series, I will share some ideas to get you started. ... *Warmly, Taleena Koch*

What I learned as a caregiver: part 3 of 6

by Taleena Koch, Caregiver and PF Advocate for Patients and Families
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What I Learned as a Caregiver: Enlist help.

“The only mistake you can make is not asking for help.” - Sandeep Jauhar

In November 2003, my mother was diagnosed with Idiopathic Pulmonary Fibrosis. Within a few days, my job title changed from daughter/wife/mother - to daughter/wife/mother and caregiver. It has been a journey with ups and downs, but I fall asleep each night having learned that love can go much further than I ever imagined.

Last time I wrote to you all about the importance of taking care of yourself. I hope that you have found ways to implement small changes that help to improve the balance of caring for yourself and caring for your loved one. I encourage you to continue to seek out ways to better your personal mental and physical health along the caregiving journey.

Beyond making time for yourself, it is just as important to resist the temptation to try and do it all on your own; to be the “strong” one. You do not have to be alone in this journey.

Look to those around you for help: other family members, friends, neighbors, friends of your loved one, etc. You might be surprised how many people are there if you simply ask. Don’t expect others to just step up... most will not. Not because they don’t want to help, but because they don’t know what to do or they don’t want to “intrude”.

Be specific with your request. *“Can you sit with mom for an hour on Thursday so I can go grocery shopping?” or “I have a doctor’s appointment on Friday. Can you stay with mom while I’m gone?”*

When my mother was still alive, she was having serious back problems, on top of the IPF. She could not be left alone. I had an appointment to attend to. I finally broke down and asked a friend of mine to come sit with mom while I was at my appointment. As it turned out, my friend very much enjoyed getting to know my mom better. She even brought it up at mom’s memorial service, as one of her fondest memories of my mom.

By showing other people in your life that there are ways they can care for your loved one *and* you, you might be surprised at how you feel less alone and can better take care of yourself. ... *Warmly, Taleena Koch*

What I learned as a caregiver: part 4 of 6

by Taleena Koch, Caregiver and PF Advocate for Patients and Families
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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 IPF 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 IPF, 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 *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), news services like *Responsum* 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*

What I learned as a caregiver: part 5 of 6

by Taleena Koch, Caregiver and PF Advocate for Patients and Families
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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 a 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 and Testament, 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 important, make memories together. Spend time wisely. It is the one thing you can never get back when the care giving is done.

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

... *Warmly, Taleena Koch*

What I learned as a caregiver: part 6 of 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 own 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 actually 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 for them. 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 ones 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 care giving 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 care giving 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 “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, heartbreaking, 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*

Dedications:

To my mother, Beverly Ann Williams-Hart, diagnosed with Idiopathic Pulmonary Fibrosis (IPF) 11/26/2003, breathing freely again 9/27/2009. You continue to teach me every day to be thankful, positive, and humble. You continue to give me strength to honor your life and your fight.
To the many medical professionals I have come to know in the Pulmonary Fibrosis community. You supported me while I was caring for my mom and have continued that support and education so I may in turn help support the worldwide PF community.
To all those I have grown to know and love in the Pulmonary Fibrosis community. You have taught me more than I could ever know, not only about this disease, but also about humanity. You have become “family” to me. I will fight for a cure until my last breath.