

## ON CATHY'S SIDE

### A CAREGIVER'S PERSPECTIVE

Director and screenwriter Noel B. told his story in our last issue (visit [www.fightipf.com](http://www.fightipf.com) to download a copy). His significant other Cathy S. offers another valuable point of view here.

I admire Noel. After his diagnosis of idiopathic pulmonary fibrosis (IPF), he commuted between three cities and built a country house from the ground up.

IPF did not stop him. After finishing his writing and directing projects, his house became his production. I thought he was doing too much and that it was hurting him, but I think it's kept him going in a lot of ways. I've tried to help in the ways that I can. I've learned from members of our local support group that it's important to keep his immune system strong. So I encourage him to eat a healthy diet and avoid stress, which can be especially harmful to the body. He is clearly very driven, so my main goal now is to help him with stress management.

But that hasn't always been easy. He doesn't like it when I tell him he is doing too much. And I began feeling stress myself, what is

known as "secondary stress syndrome." I am a therapist, so I was able to recognize the triad of anger, grief, and guilt; I was feeling angry because Noel has the disease, grief because I may lose him, and guilt because I'm not doing enough for him.

I think it's important for caregivers to know that it's very normal to experience these feelings. It's been helpful to communicate with support group members online, connecting with others in the same situation. I also have a therapist who helps me with some of these emotions.

My lifelines have been my spiritual fellowship, exercise, and a good diet. I also have a lot of girlfriends with whom I do fun things. I've learned that it's important for caregivers to take care of themselves — otherwise they will not be able to help anyone else.

Noel has been focused on getting his estate situated, but he plans to get back to his writing. He wants to work on a father and son story, that's his next goal. For me personally, it's been important to just stand back and say "Wow, what a brave man you are, Noel." I try to be as supportive as I can and take care of myself.



## ONE BREATH AT A TIME

### Partnering with your healthcare team

Research shows that patients who have good relationships with their doctors, nurses, and other team members tend to be more satisfied with their care and have better results. Once you find a pulmonologist who you are comfortable with, learning to partner with him or her is the next crucial step in a successful doctor-patient relationship. Here are a few tips:

- Bring your up-to-date health records with you when you visit your pulmonologist, such as:
  - A list of your symptoms
  - A list of your medications, including natural supplements or alternative therapies and their ingredients
- Ask questions; otherwise your doctor will assume that you understand. Make a list of questions before your visit and bring it with you.
- Ask for written instructions or brochures to take home with you.
- Bring a pen and paper for taking notes, and ask your doctor to draw pictures if you think it will help you understand.
- Bring a friend or family member to help you take notes and ask questions.
- Tell your doctor personal information, even if you think it's embarrassing. The more your doctor knows, the more he or she can help you.
- Prioritize your list of questions—your doctor may not have time to cover every item during your appointment. Remember, you can always enlist the help of nurses and other staff.



## IPF Diagnosis and Tracking

The **six-minute walk test (6MWT)** measures the maximum distance you can walk on a flat, hard surface in six minutes. The test allows doctors to assess all of the physical systems (including your lungs and cardiovascular system) that contribute to your ability to walk.

Although reviewed by an editorial team of healthcare professionals, this newsletter is for informational purposes only. It is not intended to replace your doctor's advice. Talk to your doctor regarding your condition, appropriate medical treatment, and activities.

To access previous newsletters and additional resources for people who have IPF and their caregivers

VISIT [WWW.FIGHTIPF.COM](http://WWW.FIGHTIPF.COM)

## CAREGIVER'S CORNER

*Suggestions for taking care of yourself while caregiving*

*Eat well, exercise, and get enough sleep.*

*Reward yourself.*

*Accept help from others.*

*Learn as much as you can about IPF.*

*Keep a journal.*

*Remember to laugh.*

*Interact with friends and family.*

*Seek support.*

*For more detailed information, visit [www.fightipf.com](http://www.fightipf.com)*

## NETWORK EXCHANGE

*Joan N. talks about her team*

I was diagnosed with IPF about five years ago and have progressed slowly. I was diagnosed early and I hope that will be to my advantage. I think it helps me that I have a lot of confidence in my pulmonologist and primary care doctor. My pulmonologist's explanations are concise and complete, without being scary. It's very easy to follow his directions.

I get most of my information from him and my medical team. They answer any questions that I have. They are also all good about asking the right kinds of questions to keep up with where I am as a patient. I find them encouraging, but genuinely informative. Nobody is trying to sugar-coat this for me. And that's good, because I like to know what I'm facing, and I like to know what I can do about it.

*Joan lives with her husband in North Carolina. She has six grandchildren and enjoys writing fiction, reading, and traveling.*

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