



“Parkinson’s disease affects more than just those who have the disease. As the wife, friend and confidant of someone with PD, I can tell you that our entire family and our close friends have been profoundly impacted as well. What is important to us is to never lose our faith and to never stop living each day to the fullest extent possible.

As I have learned, the fight against Parkinson’s disease is a team effort that can only be effective when everyone is working together. While my husband is and always will be a fighter, everyone affected by Parkinson’s disease needs someone in their corner.”

—Lonnie Ali

## Caregiver Tip Sheet

**Caregivers—family members, friends and other loved ones—play an important role in the health and well being of Parkinson’s disease (PD) patients.** As a caregiver of a PD patient, you carry a lot of responsibility, but it is important to know that you are not alone. Lonnie Ali, wife of Muhammad Ali, is in your corner.

For more than 20 years, Lonnie has served as caregiver for her husband who is in the fight of his life with PD. Lonnie and a PD specialist developed the following caregiver tips, based on Lonnie’s life experiences in caring for her husband. These caregiver tips aim to arm caregivers with guidelines for dealing with both daily issues and lifelong challenges:

- **BE POSITIVE AND FIGHT FOR MORE:** Keep your spirits up. My husband and I focus on what he can do, not what he can’t do. Realize that PD is manageable and don’t let it stop you and your loved one from pursuing your dreams. We push ourselves to stay involved in the community and connected with family and friends. A brighter outlook can help you get through each day. Remember all of the great things you have to live for.
- **EMPOWER YOURSELF WITH KNOWLEDGE:** Educate yourself on all aspects of the disease and caregiving, including disease symptoms, progression, medication side effects, and new treatment options. Behavior such as difficulty in sleeping or fear of narrow spaces is normal for many PD patients. Understanding the needs of your loved one as the disease progresses will help you better anticipate and prepare for the changes. Visit the resources section of [www.FightForMORE.com](http://www.FightForMORE.com) to learn more.
- **EDUCATE YOUR FAMILY:** Once you are armed with information, teach your family members as well. Our sixteen-year-old son understands that, because of PD, his father can’t play baseball with him or talk to him as often as he once did. He knows that his dad is there for him, and that’s what really counts. And, of course my husband has managed to teach our son some of his best boxing moves.

# Caregiver Tip Sheet

- **KEEP PD IN PERSPECTIVE:** As debilitating as PD can be, try to keep a sense of normalcy in your everyday life. Visit with family. Enjoy hobbies. Don't let the disease overtake your life. There is always hope. New and encouraging research and developments are readily available.
- **KEEP YOU AND YOUR LOVED ONE ACTIVE:** Go on walks or engage in a fun physical activity. My husband didn't want to use our home gym, but when he began physical therapy, he loved it. When he bicycles next to others, he starts racing them. He challenges himself. The real competitor in him comes out. Find an activity that you and your loved one can enjoy together and keep to a schedule.
- **TAKE CARE OF YOURSELF:** Eat healthy and get plenty of sleep. I am as guilty as anyone in taking care of my family and forgetting about myself. But remember, if you don't take care of yourself, you won't be able to take care of others. Find time for yourself each day. I am an avid fiction reader and enjoy making time for Pilates. Whether it's reading, running errands, meeting a friend for coffee or going to the gym, take some time for you. You'll clear your head and come back with renewed energy.
- **KEEP A SENSE OF HUMOR:** This can be a very trying time, so it is important to remember to laugh when you can and don't take yourself too seriously. Renting funny movies or laughing with friends can keep your funny bone tickled.
- **DISCUSS YOUR FRUSTRATIONS OR ANXIETIES OPENLY WITH OTHER FAMILY MEMBERS:** Be patient with yourself and your loved one. You are not alone. It's okay to lean on others and ask for moral support. Share information about your challenges in caregiving. Help them to understand that you need not only time to talk about issues, but distractions from caregiving as well. Get other family members involved in the caregiving process and ask for their help so that you can take a break and get out of the house.
- **JOIN ONLINE COMMUNITIES:** Whether it's blogging or in-person caregiver support groups, seek out other PD caregivers to share stories, trade tips or simply lend an ear. I find that speaking with others who are in similar situations makes me realize that I am not alone. You'll find a link to a PD blog in the resource section of [www.FightForMORE.com](http://www.FightForMORE.com).
- **SEE A PD SPECIALIST REGULARLY:** Regular visits with your loved one's PD specialist, a neurologist who specializes in PD, can help alleviate concerns you may have, answer questions and give accurate facts on new PD advancements and medicines. Be open and let your doctor know about issues such as side effects of medications, any trouble with swallowing, and the onset of any new symptoms. Come prepared to each doctor visit with a list of your questions and take notes during the visit. These questions may include: 1) *What are the newest treatment options?* 2) *What foods can or can't be taken with any new medications?* 3) *Is a certain behavior normal?* If you have many questions, make an appointment for a consultation. More questions can be found at [www.FightForMORE.com](http://www.FightForMORE.com).
- **FIND QUALIFIED INTERIM OR SHORT-TERM HELP:** Try to get someone to help as often as possible. Make sure that the attendants are knowledgeable about caring for PD patients and understand the unique needs of your loved one. Because my husband is such a big guy and may need a hand in getting around, the nurses must be physically able to support him and must be educated about PD symptoms. Once you find good interim or respite care, don't feel guilty about leaving your loved one in the hands of caring, trained professionals. Talk to your doctor about resources in your area.
- **ADMINISTER MEDICATIONS PROPERLY:** Use a schedule that requires you to put time and dosage of medications and post it in a place that is easily accessible. Being organized will help not only your loved one, but make life less complicated for you. It is no secret that my husband has always disliked taking his medications. One trick I use to ensure that he adheres to his medication regime is to have our son hand him his medications. While he may have given me a hard time, my husband complies with our son's requests.
- **ASK YOUR HEALTHCARE PROVIDER ABOUT INSURANCE PLANS AND BILL MANAGEMENT:** Some PD patients might eventually need help with this task. It may be a wise idea to seek advice from others that can point you in the right direction. Ask your physician for available resources to help you and your loved one plan for the future and deal with the financial consequences of PD.
- **KNOW YOUR RIGHTS:** Whether it's disability, family leave or elder rights, become aware of your rights. It eventually may become a problem for your loved one to speak for themselves. So, being knowledgeable about your and their rights can empower you both and prepare you for the unknown.
- **TRUST YOUR INSTINCTS:** Remember to rely on your own keen knowledge of yourself and your loved one. If you're not comfortable with a new doctor, medication or even a short-term worker, speak up.