



Lonnie Ali's Young-Onset Care Partner Tips

My husband, Muhammad Ali, was diagnosed with Parkinson's disease (PD) when he was 42 years old. I became his wife and care partner just a few years later. I recognize the unique needs, challenges and rewards of being a young-onset care partner and how this devastating disease takes its toll on one's family, romantic relationship, friendships and work. At the same time, I believe that facing each day with a positive attitude makes a huge difference in the lives of the care partner, PD patient and his or her family. From my more than twenty years of care partnering experience, I have developed the following tips to share with you. And always, remember to keep up the important Fight for MORE!

— *Lonnie Ali*

- **Plan ahead for the long-term:** Don't let PD get in the way of pursuing your dreams. While this disease will require many adjustments to your partner's and your lifestyle, don't let PD limit you in getting what you want out of life. Know what to expect and think through the variables to plan for the long-term. PD care partnering can affect careers, home buying, and family life.
 - **Career:** Don't give up your career passions, just modify them. Perhaps that means taking classes to adjust your career choice or making changes to your work schedule, but take steps today to set yourself on the right path for the future. Consider the economic implications of care partnering and amend your financial planning as well.
 - **Home Buying:** When Muhammad and I recently purchased a home, we had many unique considerations – limited steps, wide hallways and no slippery floors. Find a patient real estate agent who will accommodate your needs. Or, if you're already a homeowner, work with a contractor who can help you to adapt your house or condominium over time.
 - **Family Life:** My husband and I knew that having our son would be a great joy, but also more challenging for us than for typical parents. If family is what's most important to you, tailor your life to make it work. Educate your children early on about PD and how it affects their parents' lives. As they get older, engage them in various aspects of caregiving. Our son helped to give Muhammad his medicines when he resisted taking them from me.
- **Establish a strong relationship with a PD specialist:** Find a neurologist who specializes in movement disorders and with whom both your loved one and you feel comfortable. Attend doctor visits together and come prepared with detailed notes of your partner's side effects, dyskinesia time or behavioral changes. Fortunately, new developments in PD occur frequently and new medications, exercises, physical therapy or dietary changes may help to better manage the disease. Research information online at a trusted source and ask your PD specialist about any advances. www.fightformore.com has links to leading PD sites.
- **Get counseling or attend group support sessions:** The tumultuous feelings that go along with care partnering should not be suppressed. Learning that your loved one has PD can be a tremendous blow. Seek out the support of others to ensure that you can be a stalwart care partner. The young-onset community is close knit. Once you feel empowered by your convictions and knowledge as a care partner, get active in sharing this experience with others and become a mentor to those in need.

Additional caregiver tips can be found on the Fight for MORE Web site at www.fightformore.com.