

YOU, YOUR LOVED ONE AND PARKINSON'S DISEASE

Advice from Lonnie Ali and
The Michael J. Fox Foundation



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Lonnie Ali, wife of Muhammad Ali and member of The Michael J. Fox Foundation (MJFF) Founders Council, is widely known and admired for her advocacy on behalf of caregivers. Lonnie offers advice, originally published in Reader's Digest, about the impact of Parkinson's disease on relationships and how best to balance caring for a family member and oneself.

Diagnosis and the First Days with Parkinson's Disease

Lonnie Ali: *Educate yourself and your family about all aspects of Parkinson's disease.* Research causes, symptoms, long-term prognosis, available treatment options and possible new treatments that become available. Arming yourself with knowledge will enable you to anticipate and prepare for changes in behavior as well as physical, mental and emotional needs.

Research and find the best nearby physician/specialist. If at all possible, choose a movement disorders specialist, not a general practitioner or neurologist. Movement disorders specialists have specific knowledge of Parkinson's disease and are aware of the latest treatment protocols available that will affect the long-term well-being of the patient.



Before appointments, prepare a list of questions for your doctor. Particularly in the early days of diagnosis, your list may include long-term prognosis, symptoms you need to be aware of, other existing medical conditions that may affect the health of your loved one, medicine protocol, non-medical treatments and clinical studies that need you or the Parkinson's patient.

MJFF: A Parkinson's diagnosis is a life-changing event for the patient and for his or her loved ones. It can bring with it feelings of denial, fear, anger or even guilt. Communication early on can be key to ensure the person living with PD, as well as loved ones, have an opportunity to voice their thoughts, feelings or concerns. Also be sure to keep lines of communication open with your loved one's doctor. Discuss what the diagnosis means now and in the future.

Parkinson's Disease and Your Marriage

Lonnie: *Focus on quality of life.* Caregiving can be very trying at times, so be sure to keep a positive attitude and sense of humor. Plan some activities for both of you to participate in together. This allows for you to connect with each other outside of the caregiving role.

“WHEN I FIRST HEARD ABOUT MY DIAGNOSIS, I WAS SO ANGRY. AND TRACY JUST LOOKED AT ME, AND SAID SIMPLY, ‘IN SICKNESS AND IN HEALTH.’” —MICHAEL J. FOX

MJFF: Parkinson's disease can place stress on a marriage or relationship. In addition to the emotional stress it can place on a relationship, symptoms of Parkinson's disease can also have practical implications. Parkinson's disease affects movement and mood, possibly impacting your loved one's ability to contribute to previously shared household chores and responsibilities. This can put the caregiver in a position of helping with a loved one's medical needs while managing everyday tasks.



Effective communication remains vital for the long-term health of any marriage. As your loved one's Parkinson's disease progresses it could introduce new situations or obstacles over time. You may consider visiting a counselor or therapist together or individually to help navigate these changes.

Parkinson's Disease And Your Friendships

Lonnie: *Build a supportive group of friends, family, medical personnel and spiritual advisors.* Most communities have organized Parkinson's disease support groups that will enable you to connect with other caregivers. If your time is limited, take advantage of online communities that will allow you to connect with others who share similar caregiving issues and challenges.

MJFF: Others caring for a loved one with Parkinson's disease, who you may meet through support groups and PD-related activities, can provide a shoulder to lean on as you navigate your own experience. It's also important to maintain relationships outside of your loved one's diagnosis. Make time for friends and go on social outings. Caregivers often feel like their priorities have shifted and maintaining a sense of normalcy in other aspects of life — including spending time with friends — can help relieve some of the stress associated with caregiving.





Taking Care Of Your Own Emotional Life

Lonnie: *Caring for yourself is just as important, if not more so, as caring for your loved one.* Eat healthfully, get plenty of rest and make it a point to exercise. But most importantly, don't stop living! Although your life has changed, you still have one. Preserving as much of your life as it was before the diagnosis will enhance the overall quality of life for you and your loved one.

Ask for help. No one is able to take care of a person with a chronic illness 24 hours a day, seven days a week. Put together a list of friends and family members whom you trust and can call upon to relieve you for a few hours or in case of an emergency. If the financial means are available, seek outside professional help for in-home assistance.

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MJFF: As we've mentioned, caring for a person with a chronic illness can be emotionally demanding. Remember to keep your personal needs and interests a part of everyday life. Schedule specific times for relaxation and consider looking into programs or organizations that offer temporary care for people living with PD. Often called "respite care," these programs provide full-time caregivers a few hours on their own.

Learn From Each Other Over Time

MJFF: Every close relationship has an element of caregiving. It's important to remember that Parkinson's disease and its course are different for everyone. How you and your loved one navigate the disease is dependent on your individual relationship and personalities. Over time and as your loved one's Parkinson's disease progresses, you can together establish a system that provides support for both you and your loved one.

Note: This guide has been reviewed by Dr. Rachel Dolhun, one of MJFF's staff movement disorders specialists. The medical information provided in this guide is for general information purposes only. It is crucial that care and treatment decisions related to Parkinson's disease and any other medical condition be made in consultation with a physician or other qualified medical professional.

VISIT [MICHAELJFOX.ORG/CAREGIVING](https://www.michaeljfox.org/caregiving) FOR MORE INFORMATION ABOUT CARING FOR A LOVED ONE WITH PARKINSON'S AND TO HEAR FROM PARKINSON'S CAREGIVERS IN THE MJFF COMMUNITY.

