

The PD Partnership: Tips for People with PD and Their Care Partners

Life with Parkinson's disease (PD) has profound effects not only on the person who is diagnosed, but also on his or her family members and friends. More often than not, there is one person — a spouse, partner, child, parent or other loved one — who takes on the role of primary care partner to the person who has PD.

I prefer to call this relationship a “care partnership” because I believe it is one that is truly reciprocal. As a person with PD adjusts to physical changes and, at times, to changes in personal independence, the care partner must learn to adapt to a different relationship dynamic and perhaps to greater “ownership” of duties that their partner had previously handled (e.g., finances or household management).

As a former caregiver — my late husband, Bob, lived with PD — I have gained some insight on what it is to be a caregiver and on what it is like to have Parkinson's. Before I share some of our experiences, I ask you to keep two things in mind:

First, remember that your experience with PD is unique. Parkinson's is a chronic neurodegenerative disease. It is never acute. It progresses at very different rates in different people and there is no way to accurately predict its course. So, there is no reason to look at the other people in the neurologist's waiting room and think, “that will be us in a few years.”

The second point, which is for caregivers, is that while you did not choose this role — and in most cases were not trained for it — this does not mean that you cannot be good at it. Assess your individual strengths, which will shape your role as a caregiver. With support from others, you will also be able to supplement your abilities in those areas in which you are less confident.

With those thoughts in mind, I would like to share some ideas that helped Bob and me navigate the experiences we faced together. Please remember that these suggestions are drawn from personal experience, so there is no science behind them, but

rather lessons from my own life.

1. Respect your partner's own journey with PD. It will be different from yours. You may feel the need to talk to others in order to better cope and feel less alone. Your partner may want to keep the diagnosis to him or herself; indeed, the person with PD may need to do so if the disclosure of the disease might affect his or her work. One of you may be reluctant to seek out information and help, or more ready to do so than the other. Respect these differences and ask your care partner to respect how you are feeling and reacting.

2. Talk openly to each other about the disease. This is vital if you are to respect each other's feelings. Discuss the impact PD has on each of you and how you want to handle it. Learn to listen.

3. Don't let the disease take over or define your lives. Be sure to maintain your individuality, and put your relationship as a couple first. The aim should always be to avoid becoming “identified by the disease” in the eyes of your family, friends and others.

4. Find a good doctor. As soon as possible and if you can, find a neurologist who is (i) a movement disorder specialist and (ii) someone with whom you both feel confident and comfortable. I think the caregiver should accompany his or her partner to doctor appointments whenever possible. Two pairs of ears will always be better than one, and two people asking questions will cover more ground at each visit.

5. Feel free to seek out a second opinion. If you are the caregiver, encourage your partner to seek an additional opinion if you think it will help, and do not hold him or her back if this is what he or she wishes to do. A second opinion may help to confirm the diagnosis, to open a window on clinical trials, or to suggest a different course of treatment. A confident and understanding doctor will not mind if you seek a further opinion. You should not feel, as many of us are conditioned to, that you need to apologize for doing this.

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6. Educate yourself about PD in stages. When you are coping with the early stages of living with a diagnosis of Parkinson's, you need to find your comfort level with learning about the disease. You don't have to dive in and learn everything all at once and spend hours on the Internet — unless you wish to. Remember, the disease progresses slowly and you and your care partner have time to adjust. Denial may be part of the process for one or both of you and that is perfectly normal and okay. However, when you are more comfortable with PD, it can be helpful to search the Internet and to call some of the national Parkinson's organizations. PDF has a wonderful information service right on its website, www.pdf.org, and a toll-free helpline, (800) 457-6676, which can help answer your questions.

7. Educate others about PD — not only friends and family, but also healthcare professionals. The wider public's perception of Parkinson's too often is limited to "shaking." But you can change this. When you help others to better understand PD, they will be more comfortable around you and other people with the disease. Explain why your voice or your partner's voice is quieter than it used to be, or why your/their face may lack mobility or expression. Describe why sometimes a person with Parkinson's can walk easily, but at other times may shuffle.

8. Find a support group. In a support group, you can ask any question, express any concern, compare your experiences, and discuss medications. Besides providing the opportunity for you to talk with others who are facing the same thing, a support group will also provide you with valuable information about PD and make your doctor visits much more productive.

9. Actively seek out support from friends, family, and other caregivers. Many of them will come to understand the challenges of a chronic disease and of caregiving and will be supportive and present for both of you. If people do not offer to help, it is often because they don't know what you need or how to offer. So you both may need to learn to ask for help.

10. Support other people with PD. When you

are both comfortable with PD, you can be a wonderful resource to others. My husband, Bob, had a scientific and technical background and wanted to understand everything he could about PD. He researched questions raised by people with Parkinson's whom he met via the Internet and through our support group. We attended every regional meeting and conference on PD we could. This empowered us tremendously and it can do the same for you.

11. Tackle life planning decisions. This is something we all put off, but it is important for both of you to address estate planning, advance directives, and so on. I strongly support having a living will, appointing a health care proxy, and a backup. I was my husband's advocate and health care proxy, and, when I needed to assume those roles, I was very fortunate to have a wonderful friend as backup who helped me through the tough medical decisions that arose. Discuss these issues with your families or those involved and circulate copies of your living will, if you have one, to all of them, to ensure that your wishes are respected.

12. Take care of yourself. Neither of you can do it all. If you are the caregiver, you may be very inclined to put the needs of your spouse or partner first. Try consciously to teach yourself to relax, set priorities, and make time for yourself. I found it was one of the most difficult things to do. Accept support from your family, friends, and neighbors.

I hope that both of you will take care of yourselves, because in doing so, you will be helping each other. I also hope that these suggestions will help you to navigate your partnership, so that you can live your lives more fully and so that PD, while a part of your life, is not what defines it.

This piece was adapted from a session, entitled, Caregiver Support Issues, that Rhona Johnson originally presented at PDF's 50th Anniversary Educational Symposium. Ms. Johnson is a member of PDF's People with Parkinson's Advisory Council (PPAC) and a long-time spokesperson for caregiving. In October 2007, she became the first recipient of PDF's Award for Leadership in Caregiving.

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice. This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.

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