

Caring in Parkinson's The PD Partnership



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 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 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 insight on what it is to be a caregiver and what it is like to have PD. Before I share 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 progresses at different rates in different people and there is no way to accurately predict its course. So, there is no reason to look at people in the doctor'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 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".
- 4 Find a good doctor.** As soon as possible and if you can, find a neurologist who is a movement disorder specialist and someone with whom you 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.

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- 5 Feel free to seek out a second opinion.** 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. Do not feel that you need to apologize for doing this.
- 6 Educate yourself about PD in stages.** When you are first coping with PD, find your comfort level with learning about it. You don't have to dive in and learn everything all at once — 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 and that is perfectly normal and okay. However, when you are more comfortable, it can be helpful to search the Internet and to call the national Parkinson's organizations. PDF has wonderful information 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 health care professionals.** The public's perception of PD is too often limited to "shaking." 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/his/her face may lack mobility or expression. Describe why sometimes a person with PD 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. 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 care partners.** Many will come to understand the challenges of a chronic disease and of caregiving and will be supportive and present. If people do not offer to help, it is often because they don't know what you need or how to offer.
- 10 Support other people with PD.** When you are both comfortable with PD, you can be a wonderful resource to others. My husband 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 to address estate planning, advance directives and so on. I strongly support having a living will, a health care proxy and a backup, to help make difficult decisions. Discuss these issues to ensure that your wishes are respected.
- 12 Take care of yourself.** Neither of you can do it all. If you are the care partner, you may be very inclined to put the needs of your spouse or partner first. Try consciously to teach yourself to relax, set priorities, accept support and make time for yourself. I found it was one of the most difficult things to do. .

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.

Rhona Johnson is a member of PDF's People with Parkinson's Advisory Council (PPAC) and a long-time spokesperson for caregiving. In 2007, she received PDF's first 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.