

## Being a Care Partner

Carolyn A. Zeiger, Ph.D.

When your loved one is diagnosed with Parkinson's Disease, your whole world is suddenly turned upside down. Living with a progressive disease that has an unpredictable course means that you can't go back to life as it was, and you will need to adapt your life accordingly. Yes, you do face many challenges ahead, but take heart: Life does go on, and your life can still be rich and meaningful, perhaps in new and different ways. I am not saying that it is easy or painless, but with perseverance and an open mind and open heart, it is doable and rewarding. I know. I have been and still am in that situation both personally and professionally. Every day I live and work with courageous and inspiring people with Parkinson's (PWPs) and their families who share their challenges and wisdom with me. We link our arms and hearts together and keep on moving!

*Care partner? Caregiver?* Our local support group calls itself Parkinson's Partners, and defines partners as "anyone walking beside someone with PD." This includes spouses, children, siblings, parents, friends and even professional caregivers. There are many kinds of support that partners offer their PWPs, and the form it takes depends on the PWP's particular situation, the stage of the PD and the relationship between the people involved.

We encourage both members of the partnership to maintain the give-and-take of partners as much as possible, for as long as possible. This is the most empowering relationship for both. Realistically, however, there may come a time when the care partner becomes a true caregiver tending to even the most basic physical needs. It's important to stay alert to what the actual needs are as they change, and negotiate with each other—and other family members—about how they will be handled as time goes on.

*Care partner as advocate* The manifestation of PD, and therefore its treatment, varies so much from one person to another that there are no standard guides to living with PD as either patient or care partner. Consequently, it is imperative that you learn as much as possible about PD, available treatments, and how it affects *your* PWP. There is more and more information available in books, websites, conferences and workshops. Using these resources to become a well-informed advocate will improve the quality of life for everyone involved.

One of the key features of the disorder is that the symptoms are generally not as apparent to the PWP as they are to others, especially those closest to them. Even though Paul is a yoga teacher, he was unaware of losing his arm swing and likewise oblivious to the fact that his walk was often more of a shuffle. PWPs often complain that everyone else is becoming deaf when, actually, their friends notice that the PWPs' voices are becoming a whisper. Consequently, to help your PWP get the most effective treatment, you need to become a careful observer who goes to neurology appointments with the PWP to share

your observations and concerns. As advocate, you can also help by asking questions, clarifying treatment recommendations and taking notes. I do this for my brother.

Since medications, exercise, nutrition, and other therapies must be geared to the individual's needs, Paul and I keep a list of symptoms that we go through before every appointment with the neurologist. For each symptom we mark our independent judgments as to whether he is better, worse, or the same. We also add any new symptoms we notice. Then we compare notes and talk about any differences in our perceptions. Our neurologist finds this very helpful—although he does smile at the Excel spreadsheet. But, hey! Paul is a computer scientist.

I do recommend finding a neurologist who specializes in movement disorders. These specialists have the particular expertise and wealth of experience needed to customize treatment for the individual.

*More than a movement disorder* Although PD is still called a “movement disorder,” it also has non-motor and cognitive symptoms that can be as troublesome as the four primary motor symptoms. Remember that PD has many ways it manifests, so don't rely on the physician to ask the “right” questions; bring up everything you are concerned about whether you think it has to do with PD or not. Another important reason to understand these symptoms is that they can create big challenges for the caregiver as well as the PWP. Choking and constipation can become medical emergencies if measures are not taken to keep them in check; neurologically based apathy, anxiety or depression affects both partners; someone whose handwriting has become tiny and illegible can not continue writing checks, so maybe someone else needs to do it. Personally, I hate working with numbers, so Paul now prints checks out on the computer. We all find our own solutions.

*Caring for yourself* Another reason you need to take-on the observer/advocate role is to mitigate the impact on your own health and well-being. The more effective the PWP's treatment, the easier life will be for everyone. And sometimes symptoms that are not particularly troublesome for the PWP are problematic for you. The slowness that is characteristic of PD can be especially frustrating for care partners. This can often be mitigated by the right “cocktail” of medications combined with an exercise program.

Every resource on caregiving you find will tell you to take care of your physical, mental and spiritual health. Fortunately, there are many resources with pointers and sound advice about what to do and how to do it. The trick is *doing* it! And *continuing* to do it...It is easy to get caught up in the day-to-day challenges of re-ordering your life, maintaining your household, and caring for your loved one—pushing yourself to the limit until you collapse. One woman realized she had come to the end of her rope when she had to call 911 for two ambulances: one for her husband who had taken a bad fall, and one for herself because she also fell trying to lift him. (Although she can laugh about it now, they were both hospitalized with serious injuries.) One way to stay on track is to enlist the aid of someone you trust to give you regular feedback about how you are doing: Overtired? Irritable? Depressed? Find ways to make some changes.

*Dealing with others' reactions* There is no telling how others will react to the news that your loved one has PD. For starters, most people know very little about PD. I was stunned by a friend who said angrily, "Why are you so upset? PD is nothing but a little tremor." I was also surprised (and delighted) to discover who reached out and showered us with love and compassion. Those you expect to be the most sensitive or well informed may prove to be the least so and vice versa. Don't take it personally if you get a reaction based on their own fears or lack of knowledge about PD. You can just let it go, or take it as a "teachable moment" and pass on some information about PD, including referring them to your favorite PD website or blog.

*Getting support* A woman recently told me she was reluctant to ask for support because "things are not *bad*." At every stage of PD, caregivers need support! Things do not need to be "bad." Being heard and understood by others who know what we are dealing with is a great comfort in itself. And when we are stretched to the max, it is really critical. There was a time when my husband went through repeated hospitalizations and trips to the ER due to medical problems associated with PD. I finally broke down and wept with exhaustion and frustration in a doctor's office. I will always be grateful to the physician who put his arm around me and said, "Call me any time you need help. Even if it is outside my medical specialty, I will help you get what you need." I wish I had *asked for help* sooner and more directly.

- *Support groups* It has been helpful to me to go to PD support groups to understand PD better, and how people go about living well. I think it is also valuable for Paul and me to go by ourselves sometimes, so we can speak freely without fear of upsetting or hurting the other person. Look for a caregivers support group also. In our group, we really let it "all hang out." To live well with PD, you need to be honest with yourself about how you are doing, and be open to others' ideas and suggestions. In addition, sometimes our group has speakers address topics that we think we need to understand better.

The first time you go to a support group, it can be a little daunting. Know that you are likely to see PWP's who are in later stages of PD, but don't let this scare you off. For one thing, it doesn't mean that the progression of the disorder for your PWP will be the same as that of the people you meet there. Also, the broad range of experiences that people share with you is invaluable.

It is important to find the right group for *you*. If your PWP has early-onset PD, for example, you will have more in common with others in this category who are likely to be working or raising children, as opposed to older retired people facing challenges more common to senior citizens. Go to different groups in your area to see where you feel most comfortable—or create your own group! Maybe it is just two families; do what works for *you*.

- *Internet blogs and websites* can also be tremendous resources for both information and heart-to-heart sharing with others in your situation.

- *Counseling and psychotherapy* One session with a skilled grief counselor got me through the worst of my distress when Paul was diagnosed. I came to terms with the fact that although previously I was the one who had serious health problems, my exceptionally healthy and fit husband and I had now switched roles. I had to face the loss of our imagined future life together and revise my scenarios. You too might discover that you are sad, depressed, or angry and resentful. You might also feel guilty about these reactions.

Psychotherapy can be expensive, so check your health insurance to see if it is covered. If not, look for reduced-fee services through your local PD association or mental health center. Some university graduate programs for psychologists or social workers have training clinics. I look forward to the day when these services are offered to both the PWP and caregiver as part of the standard treatment for PD.

- *Your PWP can be one of your most valuable sources of support.* Doing everything they can for themselves, and expressing their appreciation for all you do can really keep you going. In addition to managing his own meds, Paul looks for opportunities to help me out. He hunts for TV programs he knows I would enjoy, encourages me to take time to myself, and hangs in there doing all the household chores he can still manage.

*Embracing change* Although PD is a progressive disorder, don't get in the mind-set that it is all downhill. Changes in medication, life circumstances, reduced stress, the addition of exercise and nutrition can maintain your PWP on a plateau for a long time, or even make things better! Yes! Sometimes the change is for the *better*. So much is unpredictable in this PD-Life that the more flexible you stay, the more you go with the flow, the easier it will be for everyone. "Going with the flow" has *ease* in it. Many new doors open; so keep your eyes open for new opportunities. Paul and I could never have guessed that his and my professional work would come together for a new career late in life.

*Continuing your own life* Your PWP is not just someone with PD and you are not just a PD care partner. Continue with activities you enjoy; move on from activities and relationships that no longer nurture you. Find new interests and activities that give you energy. Avoid isolation; human beings are social creatures. Stay engaged with existing communities or find new ones, bearing in mind that you might need to change to less demanding roles. If you say you are too tired or too busy to lead any kind of independent life, then you need to reach out to others to help you change that.

*Becoming a skilled care partner* With the progression of the disease, you may find yourself more in the role of a true caregiver, as opposed to care partner. Be reassured that should you need them, there are valuable resources on how to do this including books, websites, and local workshops and resource centers. PD support groups and PD caregiver support groups can be invaluable resources here. In our groups, we constantly share our

solutions with each other, and laugh uproariously over our failures (Ah, the healing balm of laughter!) In addition, at this point, you really need to reach out to all those people who have offered help, telling them exactly what you need and when. Without this guidance, well meaning people hold back because they don't know what to do and don't want to be intrusive.

*Looking at both the short term and the long term* To get off on the right foot, it is good to know about some moves you need to make now, *and* also be aware of some that will need to be made in the future—perhaps the near future. I have noticed that when people keep “waiting until later” to even *think* about, let alone *plan* for, later stages of the disease, they almost always wait too long. At which point they are usually in crisis and unable to make good decisions, or they find that the help or services they need right away are not available or not affordable. It will serve you well to do some thinking ahead about such matters as wills and trusts, financial planning, medical powers of attorney, long term care insurance for the caregiver, possible nursing care for the PWP, moving into a simpler, easier living space, paying for additional helpers, etc. If you start planning early, a crisis won't catch you unprepared.

*Nurturing your being* I believe that everyone has a place inside him or her that is pure and whole, and that we can access it when we get totally absorbed in some activity that focuses and calms the mind. Such “centering” activities can include meditation, walking, Tai Chi, singing, prayer, yoga, watching swallows circle in the sky, painting a picture...or a porch...whatever activity absorbs and uplifts you. As the mind quiets down worries fall away, and love, strength, peace and joy arise spontaneously. When we gently hold onto this state and carry it into our everyday lives, it radiates out to others and brings out the best and highest in them also. Please take the time to discover and practice the centering activity that nurtures your being, and spread the goodness on to others. We *can* live well with Parkinson's Disease.

**An abbreviated version of this piece appears in the PD manual produced by the Davis Phinney Foundation, *Every Victory Counts*, 2010.**