

## Partners: In Sickness and In Health

By Linda O'Connor, LCSW, Sheryl Jedlinski and Julie Sacks, LCSW

Maintaining a marriage or a committed relationship with a significant other can be challenging in the best of times; it takes work as anyone will tell you. But add into the mix a diagnosis of Parkinson's disease, and the "work" of the relationship takes on new meaning.

When one partner is diagnosed with PD, it deeply affects the other as well. When you began your life as a couple, your dreams and expectations for that life did not include a chronic illness. Now you must consider how PD might change your relationship with each other and your already busy lives. You might even be wondering whether your relationship can survive the challenges of living with a chronic illness like PD. The answer to these and other related questions depends, in part, on the strength of your relationship prior to the diagnosis of PD. How well do you and your partner talk to each other about important issues? Are you typically able to resolve differences and support each other when life stresses become overwhelming? If so, this is a good foundation from which to work. If you need help in these areas, don't despair. You can learn how to better communicate and support each other with concerted effort and practice.

You and your partner are likely to experience a range of emotions as you navigate the unfamiliar terrain of PD. It is no surprise that the stress associated with the diagnosis and treatment of PD can take its toll on both of you. What is surprising is that many couples find that by joining forces and managing the situation together they are actually able to strengthen their relationship.

### Supporting Each Other

One of the best ways to create or maintain a healthy relationship while managing PD is to identify *when* and *how* you need support. Keep in mind that the person with PD is not the only one who will need support; you both will. Here are several ways you can nurture the relationship *and* get your needs met:

**Talk openly and honestly.** Talk with your partner about how PD is impacting your life together and how each of you can make life easier for the other. Share your fears and concerns including the potential for disability, unemployment, reduced income, and greater dependence on others.

**Focus on mutual giving.** Although a person with PD may sometimes need extra help from his or her spouse or significant other, remember that you are *both* providers of care for each other, just in different ways. Each of you can try to determine what the other needs and how you might best meet those needs. Keep in mind, doing things for your partner is not the only way to care for him or her. Simple gestures, such as a hug, a kiss, or even a well-placed “thank you,” can convey appreciation. Sometimes the greatest need your partner may have is for you to just listen and offer encouragement, especially when he or she is overwhelmed or stressed.

**Be flexible.** Limitations in functioning due to PD symptoms may cause roles and responsibilities to shift within the relationship. Whether you are assuming a new role or household task or relinquishing an old one, you may find that one or both of you are feeling resistant to the change. Focus on approaching the situation with flexibility and it may make the shift easier. Tell your partner when you need help and when you don't. Although it may take the partner with PD longer to complete certain tasks, that does not mean he or she wants to be “rescued” from doing them. Most people with Parkinson's want to remain independent as long as they can.

**Identify the positive.** This does not mean burying your head in the sand. You and your partner will undoubtedly face certain challenges related to PD, but by being creative and willing to make adaptations to your activities and/or routine, you and your partner may be able to continue to pursue the things you have always enjoyed doing together. Spending some time apart doing things you enjoy, whether alone or with a friend, can often replenish you and bring you back to the relationship feeling rejuvenated.

**Consider counseling.** Sometimes extra help is needed to effectively cope with the changes PD brings. Couples counseling can help facilitate constructive communication between partners, strengthen your relationship, and maintain positive family functioning. Allow yourself to need and ask for help; knowing when to seek counseling is a sign of strength, not weakness.

**Stay informed.** There is much truth in the saying that knowledge is power. The more you both continue to learn about PD, the better prepared you will be to handle the issues that may arise. Consider asking your partner to accompany you on doctor visits so he or she can ask questions, raise concerns, and develop a better understanding of PD and appropriate expectations for the future. The APDA and other PD organizations offer many types of educational programs. Request that each organization place you on its mailing list so you and your family will be aware of all the resources available to you.

Though the diagnosis of PD changes life for both partners in a relationship, it does not have to define who you are as an individual or as a couple. With the perspective that you and your partner are a team, you can better encourage and support one another. Maintaining a generally hopeful attitude, while at the same time strengthening your ability to communicate openly and honestly with each other, will make life with PD easier, and may even deepen your commitment and partnership.

## **Beginning a New Relationship**

What if you have been diagnosed young with PD and, at the time of diagnosis, haven't yet found "the one?" Or what if the person you thought was "the one" turns out not to be, and after years of being with a partner who knew everything about you, you are faced with starting over?

While YOPD has many motor and non-motor symptoms that can make socializing, dating, and sex more complicated, these aspects of life are not off limits to you because of PD. A chronic illness like PD does not eliminate the desire for or the possibility of a romantic relationship. Your doctor may have provided you with many prescriptions, but "no dating" and "no sex" probably weren't among them. In fact, quite the opposite is true. Most doctors are supportive of any activity that keeps you active (as long as it is safe) and diminishes isolation and depression.

If you are dating, you will inevitably be faced with decisions about which potential partners you feel you want to tell about your illness, and when and how you will do so. Similar to disclosing your diagnosis to your employer, these decisions are extremely personal ones and will depend upon many different factors including the severity of your current symptoms, how comfortable you are with the other person, and the personality of your partner. It is not unusual for people to dread this one conversation so much that they avoid any situation that might lead to a romantic involvement. It can be helpful to remind yourself that not everyone needs to know and not everyone needs to know right away. On the other hand, if being upfront with others makes you feel most comfortable, and allows you to become more fully involved, saying something sooner rather than later may be the right decision for you.

Many young people are surprised to discover that their illness is not a "deal-breaker" for a prospective partner. Whether you are single or divorced, if you find yourself wanting the kind of intimacy often reserved for couples, remain open to the possibility and see what happens.