Tips for Caregivers

Dealing with changes in mental status in someone you care about is challenging. As with motor symptoms, and as with life, there are good days and bad days. As the disease progresses, you will have to come to terms with new losses. Changes in cognition can be particularly frustrating, as there are few treatment options, and behavioral strategies and cues you used earlier in the disease are no longer effective. What was once a simple conversation about the weather or a grocery list no longer seems simple. The person with dementia may not be able to participate constructively.

As a caregiver, you play an important role in the quality of life of the person with Parkinson’s. Here are some tips to help you manage day-to-day life with someone with dementia:

• A smile and pleasant manner can invite cooperation.
• Do not leave someone with dementia alone. Lack of judgement and/or impulsive behaviors can create a dangerous situation.
• Use exercise, diet and rest to keep your loved one as healthy as possible.
• Give medication on time as prescribed by the doctor.
• Create and follow a routine.
• Make a list of important phone numbers, and keep a copy with you in case of emergencies.
• Keep written track of appointments, tasks and medication schedules.
• Stay calm and be patient.
• Speak slowly and use simple sentences to communicate.
• Ask one question at a time and wait for an answer. Use either/or questions instead of open-ended questions. Instead of asking, “What would you like for lunch?” try asking, “Would you like soup or a sandwich for lunch?”
• Limit distractions as you try to accomplish the daily routine. Make sure to turn the TV or radio off before asking the person to do something.
• Try not to argue. It is usually not helpful to try to reason or tell the person with Parkinson’s dementia that he or she is wrong.
• Consider what may be causing a disruptive behavior. The person may be hungry, thirsty, tired, in pain, frustrated, lonely or bored.
• If the person seems to be stuck on an idea (e.g., “I have to get dressed for work”), try agreeing with her and then distracting her with something else.
An important part of being a caregiver for someone else is taking care of yourself, both physically and mentally.

- Be kind to yourself, and acknowledge your right to feel emotionally off-balance. Remember you are experiencing normal reactions to abnormal circumstances.
- Build in regular breaks from caregiving, and make them a priority. Take time off to relax, socialize and exercise. Get outside help; this can be a family member or a paid caregiver. Your loved one can survive for a few hours and, periodically, a few days without you, even if he claims he cannot. Getting outside help early on can make the transition easier when dementia becomes more severe.
- Use a journal or other creative outlet to express your feelings.
- Determine your limits, and get help as needed. No one person is ever able to meet all of an individual’s needs, and as Parkinson’s progresses this becomes more and more true.
- Talk to someone. This can be a friend or family member, but a professional counselor is objective and has training and experience working with people in similar situations. The same techniques described on page 25 for people with Parkinson’s can be helpful for you, too.

TIP

As time goes on, you may find that you are spending more time as a caregiver than as a significant other, friend or family member. This can be a difficult adjustment for everyone involved. Remember that there are resources available to help you navigate these changes. Get your free, comprehensive caregivers guide, Caring and Coping, by calling the Parkinson’s Foundation Helpline at 1-800-4PD-INFO (473-4636).