

Partners in Care

By Lisa M. Petsche

Lisa M. Petsche is a social worker and a freelance writer who has personal and professional experience with elder care. She has a close relative who lives with Parkinson's disease.

Flexibility is Key for Parkinson's Caregivers

Parkinson's disease (PD) is a progressive disorder involving damage to nerve cells in the brain that control muscle movement.

According to the American Parkinson Disease Association, 164 Americans are diagnosed with PD every day. Incidence increases with age and the majority of cases develop after age 60.

The main symptoms of PD are shaking (known as tremors), slow movements, rigidity and balance problems. Other symptoms may include fatigue, excessive sweating, loss of coordination, loss of facial expression, difficulty initiating or continuing movement ("freezing"), stooped posture, a shuffling walk, difficulty with handwriting, decreased speech volume, swallowing problems, sleep problems and depression. Dementia may occur in the later stages.

Although symptoms and the rate of progression vary considerably among individuals, PD usually advances slowly and patients can lead active lives for some time. Disease progression tends to be more rapid in older adults.

There is no cure for PD. Medications are available to alleviate certain symptoms, but their effectiveness can vary over time. In cases where medication does not work, surgery may be considered. Lifestyle modifications are an important part of any treatment plan.

Coping strategies

If you have a loved one with PD, read on for a variety of tips for managing caregiver stress, including uncertainty about how the future will unfold.

Mental well-being

- Accept the reality of the illness, and that ongoing adjustments will be required. Let go of any bitterness resulting from unrealized plans and dreams, so you can move forward and channel your energy in constructive ways.
- Learn as much as possible about PD and its management and educate family and friends. The American Parkinson Disease Association at 1-800-223-2732 or www.apdaparkinson.org is a good resource.
- Accept that how your relative feels and what they can do may vary throughout the day, and from one day to the next, and be flexible about plans and expectations.
- Encourage and assist your relative to learn new ways of doing things. Concentrate on what they can rather than can't do.
- Cultivate a focus on living in the moment and enjoying life's many simpler pleasures.



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Flexibility is Key for Parkinson's Caregivers (cont.)

Emotional self-care

- Keep communication lines open with family members and friends in your social network. It's important to stay connected to people who care.
- Recognize that you are only human and allow yourself to experience all emotions that surface, including resentment and guilt, which are normal in care situations. Do get help immediately if you feel an urge to harm your relative or yourself.
- Find an outlet for expressing your thoughts and feelings — talking with a friend, keeping a journal or attending a caregiver support group.
- Seek help from your primary physician or a counselor if you or your relative continually feels anxious, sad or angry. Depression is a legitimate medical condition and is treatable.

Spiritual well-being

- Set aside quiet time each day, to nurture your spirituality and help keep you grounded. Do things that center you and bring inner peace, such as meditating or getting out in nature.
- Do things that provide you with meaning and purpose, such as writing a family history, getting a pet or helping someone less fortunate. Just be careful not to take on too much.
- If applicable, turn to your religious faith for comfort and strength.

Practical tips for daily living

Because PD is incurable, the goal, from a medical perspective, is to achieve the highest possible level of functioning and prevent or minimize complications. The following are some strategies that can help.

- Find a neurologist with PD expertise, whom you and your relative respect and trust.

- Help your relative follow the management plan prescribed by the doctor and allied health professionals, which might include medication, diet changes, exercise, rest, adaptive aids, lifestyle changes, stress management techniques and regular medical checkups. Let medical professionals know right away if a plan is no longer working.
- Encourage your relative to do as much for themselves as possible, to maintain their abilities and independence. Help them find substitutes for enjoyable activities they can no longer engage in.
- If mobility issues prevent your relative from getting around in the community, help them rent or buy a scooter or wheelchair so they can go out independently or with accompaniment.
- Set up a record-keeping system to organize health information. Ready-made products can be found in office supply stores and bookstores.
- Be prepared to advocate for your relative in hospital, rehab and other care settings, to ensure they receive their Parkinson's medications on time. This is crucial for their functioning and quality of life, yet often overlooked in institutional environments.
- Make home as safe as possible — for example, remove scatter mats and install handrails along stairs. Arrange for an occupational therapist to perform a home safety assessment, to identify hazards and make recommendations. If accessibility is an issue, renovate or develop a plan to move before a crisis occurs.
- Accept offers of help and ask for assistance as needed. Also find out about services in your community that can help you and your relative now or in the future.



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