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Supporting Families Living With Parkinson's Disease

When a family is facing a Parkinson's disease (PD) diagnosis, it can be emotional and confusing. As a professional in the field of aging, you can play a vital role in supporting individuals and their families. Having evidence-based knowledge about the disease and recognizing early signs of PD can help a family begin care to enable their loved one to maintain independence and improve quality of life.

Whether you are a medical professional, a social worker, a legal or financial specialist, an insurance agent, or in another area dedicated to older adults, you can make a difference to families if you have a baseline of helpful information. If you understand how Parkinson's disease progresses and are aware of movement and non-movement symptoms, you can better assist the families you serve. Connecting families with the community resources they need can make the journey smoother and less isolating. This article will offer specific tips for you and family members to help make communication easier with a person living with PD.

About PD

Parkinson's disease is a neurodegenerative disorder that affects dopamine-producing (known as dopaminergic) neurons in a specific area of the brain called the substantia nigra. The loss of dopamine in the brain often leads to the presence of early symptoms, which often noticeably impact movement first.

When you think of PD, movement symptoms such as tremor or slowness may first come to mind. However, there are several non-movement symptoms as well. Symptoms generally develop slowly over years. The combination of symptoms and rate of disease progression is unique to every person living with the disease—no two people experience PD the same way.

One million Americans are living with PD, with another 90,000 diagnosed each year. With the population aging, these numbers are expected to rise. PD is the second-most common neurodegenerative disease after Alzheimer's disease and is 1.5 times more likely to appear in men than women.

Early Symptoms

The Parkinson's Foundation identifies 10 early signs of PD (Parkinson's Foundation, n.d.-d). The presence of a single sign should not cause worry, however, experiencing several signs should warrant making an appointment with a primary physician.

Early signs of PD include:

- a tremor in a finger, thumb, hand or chin,
- small handwriting,
- loss of smell,
- trouble sleeping,
- trouble moving or walking,
- constipation,
- a soft or low voice,
- masked face,
- dizziness or fainting,
- and hunching over.

To consider a Parkinson's disease diagnosis, a physician—ideally a neurologist or a specialized neurologist called a movement disorders specialist—determines if bradykinesia (slowness of movement) is present. In addition to bradykinesia, a person must also have one or more of the following:

- Shaking or tremor in a limb that occurs while it is at rest,
- Stiffness or rigidity of the arms, legs, or trunk,
- Trouble with balance and falls.

In addition to some of the movement-related (motor) symptoms mentioned above, the Parkinson's Foundation has defined a category of symptoms that are unrelated to movement called non-movement (non-motor) symptoms (Parkinson's Foundation, n.d-e). Motor and non-motor symptoms are seen throughout all stages of Parkinson's. According to a Parkinson's Foundation study, people with Parkinson's disease find non-movement symptoms to have more of a negative impact on quality of life than movement symptoms (Martinez-Martin et al., 2011). Non-motor symptoms include depression, anxiety, apathy, hallucinations, constipation, and a variety of cognitive impairments.

Guiding Clients to Act on Behalf of a Loved One

When a loved one's condition is changing quickly, it's easy to miss the signals or associate signs with an injury, age, or another underlying issue. When you meet a family who is worried about a loved one, make note that no single sign of PD means that this is the diagnosis. However, professionals in the industry can guide clients to take the necessary steps to learn more about their loved one's condition in order to best support their needs.

Here are the suggested steps for families:

- Make an appointment with their primary doctor. Suggest that their spouse or adult children attend the appointment with their loved one and ask for a referral to a neurologist, or a movement disorders specialist (a neurologist who has completed extra training in movement disorders).
- Set up an appointment with a neurologist or movement disorders specialist, who will administer several in-office tests, and may order additional tests to confirm their diagnosis. A skilled practitioner can come to a reasoned conclusion that it is Parkinson's disease. Every person with PD has a unique diagnosis story, and some are surprised that a specialist can diagnose them after one in-office visit, while others can be misdiagnosed for years.
- Learn about coping with a diagnosis (Parkinson's Foundation, n.d-f). When a family member is diagnosed with PD, it is typical to experience a range of emotions and several stages of adjustment to the disease. Begin by building a care team to address your loved one's most troublesome symptoms.

Importance of Early Detection and Care

Receiving a diagnosis early in the disease progression is associated with better quality of life in the long term. It is advisable that people with PD build their care team over time as new symptoms arise and work to find the combination of treatments and lifestyle adjustments that work for them.

People living with PD who seek expert care have better outcomes. Their complication risks are lower, and they enjoy better quality lives. Better access to this care could help tens of thousands of people with the disease.

Getting the right care at the right time can make a difference for people living with PD. The goal is to provide "individualized, person-centered care and to sustain and improve function, optimize ability to perform activities of daily living, increase quality of life and live as well as possible with PD" (González-Ramos et al., 2019). Everyone's PD symptoms and rate of progression are unique to them. People with PD should communicate their most intrusive and any new symptoms to their PD doctor, who can provide referrals to other specialists well-versed in PD care.

A Parkinson's care team often includes a:

- Movement Disorders Specialist or Neurologist
- Speech Language, Physical or Occupational Therapist
- Social Worker
- Nutritionist
- Other specialists, including a Mental Health Professional

How to Support Families

PD is a progressive disease. Learn about PD, the myriad symptoms associated with the loss of dopamine in the brain, and how to build a care team to address them. After a diagnosis, people can socially isolate, as they may feel symptoms can be embarrassing or slow them down. Help families find nearby social activities—including PD support groups and wellness events.

There is no one-size-fits all treatment for PD. Treatment should be tailored to an individual's symptoms via a shared decision-making process with a doctor. Treatment often includes medications aimed at improving symptoms, physical, occupational therapy, speech therapy, complementary therapies and exercise. Help families keep an open mind so they can explore new treatments that may work for them.

A longitudinal analysis showed that people with PD who start exercising earlier in their disease course for a minimum of 2.5 hours per week experience a slowed decline in quality of life compared to those who start later (Rafferty et al., 2016). Parkinson's-specific exercise classes offer the added benefits of addressing PD symptoms and building a support community.

Parkinson's Disease & Dementia

As PD progresses into its later stages, people can develop permanent cognitive changes that impact daily living. The combination of movement and cognitive impairments can be particularly challenging, even limiting a person with PD's ability to participate in social settings and perform basic activities.

Parkinson's disease dementia is diagnosed when a person living with PD experiences significant cognitive decline after a year or more of motor symptoms (most typically after many years of experiencing motor symptoms). Parkinson's disease dementia is most common in people 75 and older, who've had PD for more than 15 years, affecting 50% to 60% of this age group (Cleveland Clinic, 2024). There are treatments the person with PD can explore with their care team to address the symptoms, however, like PD, there is no way to stop the disease's progression.

Tips for Communication

People with PD can have trouble communicating due to speaking issues or cognitive symptoms. Social engagement and maintaining social ties are important for emotional and cognitive health. Professionals can benefit personally from understanding these tips and can also guide families in understanding how to adapt to their loved one's needs.

When communicating with someone with Parkinson's disease:

- Choose the right time and setting to have conversations. For many, medications work in the mid-morning, after their first dose of PD medication.
- Avoid times of stress or distraction.
- Let them speak freely and validate their feelings.
- Be patient. Allow ample time for the person with PD to communicate.
- Offer gentle help, repeating or rephrasing without raising your voice or exaggerating speech.

About the Parkinson's Foundation

The Parkinson's Foundation is a nonprofit organization with the mission to make life better for people with Parkinson's disease by improving care and advancing research toward a cure. •CSA

RESOURCES

Learn more about Parkinson's disease and explore resources at Parkinson.org or call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636).

John L. Lehr is the President & Chief Executive Officer of the Parkinson's Foundation. John guides the overall Parkinson's Foundation strategy of mission programs and resources that make life better for people with Parkinson's. He works to expand the Foundation's reach, research initiatives and presence, while working to improve health equity among the Parkinson's community and medically underserved. He ensures that all Foundation programs and resources aim to improve care and advance research toward a cure.

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