

The journey of a typical patient suffering from Parkinson's Disease

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Parkinson's disease is a progressive neurological disorder that affects movement and cognition. The journey for someone diagnosed with Parkinson's can be complex and deeply personal. Here's an overview of the common stages and experiences that individuals may encounter:

1. Pre-Diagnosis:

- **Early Symptoms:** Motor symptoms can start subtly, such as slight tremors, stiffness, or difficulty with balance and coordination. These early signs are often mistaken for normal aging or other conditions.
- **Seeking Medical Advice:** Individuals may visit various healthcare providers before receiving a proper diagnosis. Symptoms may be misattributed to stress, arthritis, or other issues.
- **Non-motor Symptoms:** Non-motor symptom presentation symptoms more likely to be attributed to aging or another condition: smell, sleep (RBD), bowel (IBD) disturbance, psychiatric (depression, anxiety)¹.

2. Diagnosis:

- **Medical Evaluation:** Diagnosis typically involves a neurologist evaluating symptoms, medical history, and performing neurological examinations. Brain imaging or other tests might be used to rule out other conditions. An internal survey found that 35% of patients receive another diagnosis prior to Parkinson's disease. A study found diagnostic accuracy is only 55-78% accurate in the first five years of a PD patient diagnosis².
- **Time to Diagnosis.** Research shows that the average time to diagnosis is 2.75 years for a patient presenting with signs of parkinsonism and/or tremor and some patients took up to 10 years to receive a diagnosis³.
- **Emotional Response:** Receiving a Parkinson's diagnosis can be overwhelming. It's common to experience a range of emotions, including shock, fear, or denial. An internal survey found that patients rank the need for a better, faster, and more accurate diagnosis as 8.5 out of 10.

3. Initial Management:

- **Medication:** Treatment often begins with medications like levodopa or dopamine agonists to help manage symptoms. Adjustments to medication dosages may be necessary.
- **Lifestyle Adjustments:** Patients might start making lifestyle changes, such as incorporating exercise or physical therapy to improve mobility and strength.

4. Ongoing Management:

- **Symptom Management:** As the disease progresses, symptoms can become more pronounced, requiring ongoing medication adjustments and management of side effects.
- **Support Services:** Patients may work with various specialists, including physical therapists, occupational therapists, and speech therapists. Support groups and counseling can also be beneficial.
- **Cognitive and Emotional Impact:** Parkinson's can affect cognitive functions and mood. Cognitive therapies and mental health support can be important components of overall care.
- People with Parkinson's experience greater quality of life when they receive supplemental therapies - physical, occupational and speech-language therapy, and mental health services. Up to 53% of people with PD on Medicare experience depression, only 2% of people with PD with depression see a mental

health professional, 20% see a physical therapist and 33% of people with PD who see an MDS see a physical therapist

5. Advanced Stages:

- **Increased Care Needs:** As the disease advances, daily activities may become more challenging, requiring increased support from caregivers or healthcare providers.
- **Surgical Options:** Some patients might consider surgical interventions like deep brain stimulation if medication alone is insufficient.

6. End-of-Life Care:

- **Palliative Care:** Focus shifts to comfort and quality of life. Palliative care teams can help manage symptoms and support the patient and family emotionally and physically.
- **Family and Caregiver Support:** The role of family and caregivers becomes even more critical, and support systems are essential for everyone involved.

Critical Gaps and Disparities in Access to Parkinson's Care

A 2023 study from the Parkinson's Foundation identified gaps in care for people with Parkinson's disease (PD), utilizing 2019 U.S. Medicare data. This data represents 90% of people living with PD in the U.S., making it the most timely and comprehensive study of those with PD. (<https://www.parkinson.org/blog/awareness/care-access-disparities>).

Overall, only 9% of people with Parkinson's receive PD care from movement disorders specialists (MDS), who are neurologists with additional disease-specific training; 50% of patients consult with a general neurologist, while 29% only consulted a primary care provider, leaving 11% of patients that did not consult with a healthcare specialist of any kind. It is widely recognized that people with PD who see an MDS or neurologist experience a higher quality of life with better symptom management.

People most likely to experience disparities in PD care include people of color (those who identify as Asian, Black, Hispanic and Native American), women and residents of rural areas. Women, people of color, people over 70, and rural residents are less likely to receive PD care from a specialist.

In 2023, there were 660 movement disorders specialists practicing in the U.S.; less than 10 in rural areas. Up to 40% of Medicare beneficiaries with PD did not receive specialized PD care.

References

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Notes

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