

**FAST FACTS AND CONCEPTS #361  
PARKINSON'S DISEASE: PART 1 DISEASE TRAJECTORY**

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This *Fast Fact* will address the natural history and illness trajectory of Parkinson's Disease (PD). See *Fast Fact #362* for information on palliation strategies of non-motor symptoms associated with PD.

**Illness Background** PD is a degenerative central nervous system disorder which disproportionately affects the motor system leading to asymmetric muscle rigidity, bradykinesia, and a resting "pill-rolling" tremor (1). It involves a section of the midbrain called the substantia nigra which leads to a depletion of the neurotransmitter dopamine. Dopamine derivatives (levo-dopa) and agonists are pharmacologic mainstays for the motor symptoms. The illness trajectory varies by Parkinsonian syndrome. Typically PD has a longer prognosis and progresses slower with less nonmotor symptoms and cognitive impairment early in the disease course compared with atypical Parkinsonism which includes a variety of disorders such as Multisystems Atrophy, Corticobasal Degeneration, and Lewy Body Dementia (2).

**Impact of Illness** While the progression of functional impairment and disability is quite variable, typically PD progresses over many years, not months. In general, patients begin to have levo-dopa related treatment complications such as dyskinesia (irregular, jerky movements), psychosis, and dystonia, within 5 years of diagnosis (3-5). Within 12 years of disease onset, most PD patients have issues with falls, gait disturbance, and balance; within 15-20 years of disease onset, issues with either hallucinations or dementia are common (6). The symptom burden from the motor and non-motor symptoms of PD has been shown to be comparable to metastatic cancer (3,4). The slow erosion of functional capacity and the increased dependence on caregivers leads many PD patients to suffer from a diminished sense of personhood and identity (1). This can lead to significant caregiver distress, financial hardship, and consequently a high utilization of nursing home placement in the last years of life (7). These factors plus a variable and long prognosis can lead many PD patients to make requests for a hastened death to their clinicians and caregivers. See *Fast Facts* 156 and 159. Involvement of an interdisciplinary team is often necessary to address the unmet spiritual, psychological, and social needs of PD patients (3,4).

**Prognosis** With the improvement in disease-modifying therapies such as deep brain stimulators, life expectancy is only modestly decreased compared to aged-matched controls and is roughly 6 to 22 years at disease onset (8,9). The long illness prodrome should allow for early advance care planning and appropriate palliative care interventions prior to late complications. Late-term PD complications are listed below. When encountered, they should prompt clinicians to help patients and families prepare for a peaceful death and should also prompt clinicians to consider hospice care (10)

- **Dementia:** approximately 40% of PD patients develop dementia (11). It is a significant risk factor for nursing home placement and one-year mortality (7,9).
- **Delirium:** Visual hallucinations and delirium are common in the last years of life. They are also a predictor of nursing home admission (7).
- **Extrapyramidal symptoms:** the presence of muscle rigidity and dyskinesia despite best medical management is associated with an elevated one-year mortality (9).
- **Dysphagia:** this may occur from progression of motor symptoms or dementia. Recurrent hospitalizations and/or aspiration events are common. There is no evidence that feeding tubes improve survival at this stage nor quality of life. Honey-thickened liquids and encouraging a "chin-down" feeding posture are more effective strategies for managing dysphagia in advanced PD (12).

**Hospice Considerations** There are no specific hospice criteria for PD nor are there reliable indicators to help clinicians predict a < 6 month survival. Medicare claims data suggest that only 54% of PD patients utilize hospice prior to death; although, nursing home residents and patients seen by an outpatient neurologist may be more likely to utilize hospice care (13). To better identify hospice-eligible PD patients, clinicians

should look for a pattern of recurring hospitalizations, dysphagia, and/or progressive dementia. See *Fast Facts* #125 and #150 for hospice admission guidelines for general neurologic illnesses.

**End of Life Pharmacologic Considerations** There are no current PD specific guidelines regarding end-of-life care medication management, however, many experts recommend continuing levo-dopa derivatives and agonists as long as the patient is able to swallow pills. Abrupt discontinuation of these medications can be associated with intense and uncomfortable muscle rigidity. Although levo-dopa associated symptoms like dyskinesia may fluctuate dramatically throughout the day and be difficult to observe, patients often prefer these symptoms to the underlying muscle rigidity associated with PD.

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