



Quality of Life with Parkinson's Disease



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James Parkinson first identified the “shaking palsy” symptoms of Parkinson’s disease in 1817, and in April, Parkinson’s Disease Awareness Month, we focus attention on this illness that affects at least half a million Americans today.

Parkinson’s disease is the second-most common neurodegenerative disorder in the U.S., according to the [NIH](#). Because it is largely associated with increasing age, Parkinson’s incidence is expected to double by 2040 with a growing demographic of older adults, they add.

Parkinson’s progression

Parkinson’s begins with motor symptoms such as tremors, slowness of movement, rigidity, stiffness, and balance problems, which can interfere with “walking, talking, swallowing, and completing other simple tasks,” explains the NIH. Among those living with Parkinson’s, the most common reason for admission to a skilled nursing facility is progression to dementia. As explained in the blog, [Understanding Parkinson’s Disease & Dementia](#), estimates are that 4 out of 5 individuals with Parkinson’s disease will eventually develop dementia.

Parkinson’s neurodegenerative changes

Loss of the neurotransmitter dopamine is responsible for the movement symptoms and is treated with medications that increase dopamine levels in parts of the brain—the basal ganglia and substantia nigra. Emerging research suggests that a “number of other brain systems are also damaged,” says the NIH, and disruption of additional neurotransmitter pathways may play a role in dementia symptoms.

There is also an ongoing research focus on accumulation and misfolding of the alpha-synuclein protein, which is present in nerve cells. Abnormal clusters of these protein molecules form the basis of Lewy bodies, causing nervous system dysfunction and nerve cell death, explains the NIH.

Quality of life with Parkinson’s

A cornerstone of person-centered care is honoring the individual’s experience. In a review article published in [Neurology](#), Tosin and colleagues advocate for bringing the “individual’s voice” into the Parkinson’s clinical care model. They examined self-reported indicators of quality of life among both individuals living with Parkinson’s and their care partners, noting that findings in various domains can profoundly influence physical and mental well-being.

Some of the studies Tosin et al. reviewed evaluated quality of life domains according to stage of the disease, while others did not.

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Overall, the researchers found agreement between patients and care partners about what was most impactful on quality of life across all stages of the illness. The top five, ranked areas of concern were:

- Motor functionality, e.g., tremor, rigidity, bradykinesia, postural instability
- Mood, e.g., depression, anxiety, apathy
- Cognition
- Gait, balance, posture, and falls
- Nighttime sleep disorders
- Psychiatric concerns included hallucinations, illusions, delusions, and problems with impulse control. Sleep-related symptoms included behavioral disorder of REM, vivid dreams or nightmares, insomnia, and excessive daytime sleep.

Interestingly, for advanced Parkinson's, perception of quality of life domains between patients and care partners diverged. While care partners ranked "psychiatric symptoms" the most impactful domain, people living with Parkinson's ranked "pain" as the domain most affecting their quality of life.

The researchers flagged this finding as "unexpected," noting that pain may go unrecognized, and that pain may not be reported by patients or care partners in a neurological assessment. They also underscore the need for further investigation of this complex issue.

Pain in advanced Parkinson's

The experience of pain is common among people living with Parkinson's, according to [Tai and Lin](#), and not all mechanisms are fully understood. Musculoskeletal pain, including pain from muscle cramps, may affect as many as three-quarters of individuals living with Parkinson's, they note. Dystonia (involuntary muscle contractions) can also be a major source of pain, they explain. For those who are taking levodopa, dystonic pain can be most acute prior to the first dose of the day, they note. Polyneuropathy is also common, and it is possible that high doses of levodopa may exacerbate (rather than relieve) this type of pain, according to Tai and Lin.

Overall, they conclude, multiple types of pain can occur in Parkinson's, and pain is more common in advanced stages of the illness. It tends to be associated with depression and sleep disorders, but not with cognitive impairment, they note.

As a progressive illness, Parkinson's disease follows a trajectory of change over time. Ongoing neuropsychiatric assessment and finely tuned medication management are essential. Attention to the experience of living with Parkinson's is "crucial to a high-quality Parkinson's disease" care model, conclude Tosin et al.



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The interdisciplinary team at GuideStar Eldercare is keenly focused on reducing suffering and enhancing quality of life for the individuals we serve. Leading with a [neurology-forward approach to clinical care](#), we ensure accurate diagnoses, optimization of medication regimens, reduction of polypharmacy, and holistic support for residents living with Parkinson's disease, families, and nursing home clinicians and caregivers.

Learn more about diagnostic criteria for Parkinson's disease dementia as well as the challenges of medication management in the blog, [Understanding Parkinson's Disease & Dementia](#).

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