



Advanced Parkinson's Care Considerations

A Guide for Professional Caregivers Supporting Individuals with Later-Stage Parkinson's

As Parkinson's disease progresses, individuals often experience more complex physical, cognitive, and medical needs. Later-stage Parkinson's may affect mobility, swallowing, thinking, sleep, blood pressure regulation, and emotional well-being.

Professional caregivers play an essential role in helping individuals maintain **safety, dignity, comfort, and quality of life**. Understanding how symptoms evolve allows caregivers to anticipate needs, adapt care strategies, and communicate important observations to the healthcare team.

Mobility Support in Advanced Parkinson's

Mobility changes often become more significant as Parkinson's progresses. Individuals may experience increased rigidity, slower movements, balance problems, and difficulty initiating movement.

Common mobility challenges may include:

- Increased stiffness and reduced range of motion
- Difficulty starting or stopping walking
- Frequent freezing of gait
- Shorter, shuffling steps
- Stooped posture
- Difficulty turning or changing direction
- Reduced balance and postural reflexes
- Increased fall risk
- Difficulty standing from a seated position
- Greater reliance on mobility aids or assistance

Mobility may also fluctuate throughout the day depending on **medication timing**.

Supporting Safe Mobility

Professional caregivers can support safer movement by:

- Allowing extra time for the person to initiate movement
- Using simple verbal cues such as “take a big step” or “stand tall”
- Encouraging weight shifting before stepping if freezing occurs
- Avoiding rushing or pulling the individual forward
- Encouraging wide, slow turns rather than pivoting
- Ensuring hallways and walking paths are clear and well lit
- Supporting proper use of walkers or other mobility aids

Regular **physical therapy or exercise programs** can help maintain strength, flexibility, and balance even in later stages of the disease.

Swallowing Changes and Aspiration Risk

Swallowing problems (dysphagia) become more common as Parkinson’s advances. The muscles involved in chewing and swallowing may move more slowly or less effectively.

This can increase the risk of **food, liquid, or saliva entering the airway**, which is called aspiration.

Aspiration can lead to **aspiration pneumonia**, a serious complication in advanced Parkinson’s.

Signs of Swallowing Difficulty

Professional caregivers should monitor for:

- Coughing or choking during meals
- Frequent throat clearing
- Wet or gurgling voice after swallowing
- Food remaining in the mouth after swallowing
- Increased drooling or difficulty managing saliva
- Taking significantly longer to finish meals
- Unexplained weight loss
- Recurrent chest infections

Some individuals experience **silent aspiration**, where food or liquid enters the airway without obvious coughing.

Supporting Safer Eating

Professional caregivers can help reduce swallowing risks by:

- Ensuring the individual sits fully upright during meals
- Allowing extra time for chewing and swallowing
- Encouraging small bites and sips
- Minimizing distractions during meals
- Ensuring recommended food and liquid textures are followed
- Keeping the individual upright for at least 30 minutes after eating

Speech-language pathologists may evaluate swallowing and recommend strategies or diet modifications to improve safety.

Cognitive Changes in Advanced Parkinson's

Some individuals with Parkinson's develop cognitive changes over time. These changes may include difficulties with memory, attention, processing speed, and problem solving.

Parkinson's-related cognitive changes may present as:

- Slower thinking or processing information
- Difficulty following complex instructions
- Short-term memory problems
- Trouble planning or organizing tasks
- Reduced attention or concentration

Some individuals may also experience **Parkinson's disease dementia**, which can include hallucinations, delusions, or fluctuations in alertness.

Supporting Individuals With Cognitive Changes

Professional caregivers can support individuals experiencing cognitive changes by:

- Using clear, simple communication
- Providing step-by-step instructions
- Allowing extra time for responses
- Maintaining consistent routines
- Minimizing environmental distractions
- Offering reassurance during confusion or distress

Approaching the person calmly and respectfully helps maintain trust and emotional comfort.

Emotional and Behavioral Changes

Advanced Parkinson's can also affect mood and emotional regulation. Changes may include:

- Depression
- Anxiety
- Apathy (loss of motivation)
- Irritability or frustration
- Social withdrawal

These changes may occur because of the neurological effects of Parkinson's as well as the emotional challenges of living with a progressive condition.

Professional caregivers can help by:

- Encouraging gentle participation in activities
- Maintaining social interaction and conversation
- Offering reassurance and emotional support
- Avoiding rushing or overwhelming the individual

A compassionate and patient approach helps support emotional well-being.

Medication Considerations

Medication management becomes increasingly important as Parkinson's progresses. Symptoms may fluctuate depending on medication timing and effectiveness.

Professional caregivers should observe for:

- Increased stiffness before the next medication dose
- Sudden worsening of mobility ("OFF periods")
- Excessive or uncontrolled movements (dyskinesia)
- Increased confusion or hallucinations after medication changes

Parkinson's medications should generally be administered **within 15 minutes of the scheduled time** to maintain consistent symptom control.

Observations about medication response should be communicated to the healthcare team.

Care Planning and Coordination

Later-stage Parkinson's often requires **more coordinated care between caregivers, healthcare providers, therapists, and family members.**

Important care planning considerations include:

- Monitoring fall risk and mobility changes
- Adjusting assistance with activities of daily living
- Evaluating swallowing and nutritional needs
- Addressing cognitive and behavioral changes
- Monitoring medication effectiveness and timing
- Supporting emotional well-being and social engagement

Regular communication between caregivers and the healthcare team helps ensure care plans remain appropriate as needs change.

Supporting Comfort, Dignity, and Quality of Life

Even in advanced stages of Parkinson's, individuals benefit greatly from compassionate, respectful care.

Professional caregivers can support quality of life by:

- Encouraging independence whenever possible
- Allowing extra time for daily activities
- Supporting safe mobility and participation in movement
- Maintaining familiar routines and environments
- Providing emotional reassurance and human connection

Small moments of patience, encouragement, and respect can make a meaningful difference in the person's daily experience.

Wisconsin Parkinson Association

The **Wisconsin Parkinson Association (WPA)** provides education, resources, and support for professional caregivers, healthcare professionals, and individuals living with Parkinson's.

To learn more about Parkinson's care resources and educational materials, visit:

wiparkinson.org

