AMDA Clinical Practice Guideline: Parkinson's Disease in Assisted Living

Parkinson's disease (PD) can cause assisted living facility residents to lose function and independence. As a result, these individuals are at high risk of experiencing a fall, fall-related injury, or other problems (that necessitate hospitalization or force them to leave their home at the ALF). In fact, a diagnosis of PD or advancement of the disease is a key reason many elderly individuals enter assisted living in the first place.

To enable residents with Parkinson's disease to remain safely in the ALF for as long as possible and to maximize these individuals' functionality and dignity, facility staff need to understand Parkinson's signs and symptoms, the course of the disease, and how it is treated.

This issue of *ALC* features a condensed adaptation of the American Medical Directors Association's (AMDA) clinical practice guideline, *Parkinson's Disease in the Long-Term Care Setting,* for assisted living.

Definition and Introduction

Parkinson's disease is an age-related, chronic, slowly progressive neurodegenerative disease characterized clinically by the presence of at least two of three cardinal features:

- Resting tremor
- Bradykinesia (slowness of movement) with resulting rigidity
- Impaired postural reflexes

The term "parkinsonism" refers to a range of conditions that include Parkinson's disease, Parkinson-like syndromes (including drug-induced parkinsonism), and conditions that mimic Parkinson's disease.

While the exact incidence of PD in assisted living facilities is unknown, it is estimated that the disease affects one in 100 individuals over age 60. In fact, among people age 65 and older, PD is a more common cause of death than motor vehicle-related injury. PD contributes to an average of nearly 250,000 hospital discharges per year; and almost 10% of men and 5% of women over age 65 are admitted annually to a nursing facility with the disease.

PD is characterized biologically by a loss of dopaminergic neurons in a region of the brain known as the substantia nigra. Although it is the loss of these cells that triggers the symptoms of PD, the disease process likely begins years before symptoms appear. While the disease's cause is unknown, possible

links to viruses and chemical-agent exposure have been suggested.

It is important that the practitioner assume a leadership role in the care of the resident with PD. However, within the context of the overall plan of care, other team members may help to address specific patient issues. For example, a dietitian may help to address nutritional issues and a physical therapist may help to address and treat mobility problems.

Recognition

Early detection of PD enables prompt intervention with both nonpharmacologic and pharmacologic treatments that can improve residents' physical and cognitive function, maximize their mobility, and enhance their quality of life. ALF staff, as well as clinicians who care for residents in this setting, should know the signs and symptoms that suggest the presence of PD or parkinsonism and should observe patients for any of these indications.

Signs and symptoms of PD include:

- Family history of PD
- History of falls
- Shuffling or unsteady gait
- Cognitive dysfunction
- Depressive symptoms
- Tremor, involuntary movements (especially at rest)
- Use of multiple medications, including psychotropic agents
- Bradykinesia
- Mask-like facial expression

In addition to knowing signs and symptoms and what to do if they detect any of these, staff should be familiar with the potential benefits of physical, occupational, speech, and recreation therapy; social services; and psychological and psychiatric counseling interventions in improving PD management.

Step 1. Has Parkinson's disease already been diagnosed in this patient? On admission or preadmission, ask the resident or family member(s) if the individual has PD or has shown signs or symptoms that suggest PD. Evaluate the resident for manifestations of PD or parkinsonism. Evaluate current and known previous medications that may cause drug-induced parkinsonism, including:

- Neuroleptic agents
- Atypical antipsychotics
- Adriamycin
- Alpha-methyldopa
- Amphotericin B
- Benzamide (metoclopramide)
- Calcium channel blockers
- Fluoxetine
- Lithium
- Meperidine
- Pyridostigmine
- Reserpine
- Vincristine

Early detection of Parkinson's Disease enables prompt intervention with both nonpharmacologic and pharmacologic treatments that can enhance the resident's quality of life.

Assessment

Step 2. Conduct a relevant history, physical examination, and mental status examination to determine whether the resident has Parkinson's disease or parkinsonism. Because there are no biological markers for PD, a thorough, accurate history and physical examination are key to diagnosis. Although the presence of two or more of the cardinal features suggests PD, the clinician must rule out Parkinson-like syndromes.

Cardinal features suggestive of PD are:

- Tremor
- Rigidity
- Akinesia/bradykinesia
- Postural instability
- Gait disorder

According to one study, a diagnosis based solely on cardinal features was incorrect in 25% of cases. Further, MRI studies have suggested that about one-quarter of patients with Parkinson-like syndromes do not have PD.

Features that differentiate Parkinson-like syndromes from PD include:

- Lack of a clinical response to levodopa or a dopamine agonist
- Lack of asymmetric motor signs
- Rapid decline over several months to one year
- Presence of clinically significant dementia early in the course or predating motor signs

Other disease processes that may be confused with PD include multiple systems atrophy, progressive supranuclear palsy, normal-pressure hydrocephalus, and diffuse Lewy body disease (LBD). Onset of these variants is usually symmetrical, whereas PD has a unilateral onset and progresses to involve the midline and later the limbs.

Arthritis, essential tremor, depression, and the aging process also can be mistaken for PD. An uncertain diagnosis should prompt the clinician to consider a consultation from a neurologist or psychiatrist with PD expertise.

Step 3. Assess the physical function of the resident with Parkinson's disease. An assessment of physical function is key to determining the stage of PD and identifying the interventions likely to be most effective. Assessments should include the resident's gait, balance, mobility, and ability to perform activities of daily living (ADLs). This is particularly important in assisted

living to determine the level of care and services the resident will need to remain in his or her home.

Step 4. Assess the resident's mental, emotional, and cognitive status. Between 20% and 40% of residents with PD also have dementia or pseudodementia (depression that presents with symptoms of dementia). At the same time, neuropsychiatric symptoms in PD resemble signs and symptoms of dementia; and memory impairment is an early symptom of PD-associated dementia.

It is essential that the mental status and cognition of residents with PD are assessed at baseline and at regular intervals as clinically indicated. The use of the Mini-Mental State Examination (MMSE) is recommended in this population.

Step 5. Assess the resident for signs of dysphagia and altered nutritional status. Staff, caregivers, and family members should be alerted to the fact that swallowing difficulty may occur as PD progresses and educated to watch for signs of such problems, including:

- Coughing, clearing throat when eating or drinking
- "Wet" or "gurgly" vocal quality during meals
- Difficulty with chewing
- Pocketing food in mouth
- Difficulty keeping food or liquid in mouth
- Decreased food consumption
- Slow eating
- Nasal regurgitation
- Difficulty swallowing pills
- Patient complaints of having food "stuck in throat"
- Drooling

The practitioner should consider the possible causes of coughing and swallowing difficulty, including medication side effects, postural drainage, and gastroesophageal reflux disease. When indicated in the presence of such signs and symptoms, the speech-language pathologist should be asked to perform a dysphagia evaluation.

Residents with PD should be assessed on admission and at least monthly thereafter for weight changes, changes in food intake, appetite changes, and altered nutritional status.

Step 6. Assess the resident's functional status. This should be done at baseline and as clinically indicated, for example, when significant changes occur in the resident's ability to perform ADLs or when comorbid disease is present.

Step 7. Have the resident's medication use assessed. This assessment can help identify drug-induced parkinsonisms and other medication-related problems. Falls or changes in functional status may indicate a need for medication adjustment or medications. Caregivers should receive education to enable them to recognize certain effects of the drug levodopa:

- "Wearing-off" effect: The patient's response to levodopa may become progressively shorter over time, resulting in a marked, predictable decline in function before the next dose is administered. A more-frequent dosing regimen can compensate for this effect.
- Dyskinesia: The patient may display abnormal twisting or jerking movements when levodopa is at its peak effectiveness.

A multifaceted approach to treating Parkinson's Disease involves addressing the resident's spiritual, social, emotional, and cultural needs, as well as his or her physical needs.

Caregivers who observe these effects should report their findings to the nursing supervisor, who—in turn—should report them to the practitioner.

Step 8. Assess the patient's risk for developing comorbidities and complications and need for specialty consultation. Major complications that may require additional assessment are altered nutritional status, infections, pressure ulcers, aspiration pneumonia, falls, contractures, altered mental status, depression, dementia, psychosis, and new onset of urinary or fecal incontinence or impaction.

Step 9. Ensure that the practitioner has summarized the PD resident's condition in the medical records. This summary should help identify necessary treatments and services to keep the resident safe and at maximum functioning for as long as possible.

Treatment

A multifaceted approach to treating PD is essential. This involves addressing the resident's spiritual, social, emotional, and cultural needs as well as his or her physical needs. The implementation of a care plan may involve the interaction of clinicians, caregivers, family members, facility staff, and residents themselves.

Step 10. Develop an individualized care plan. Development of the care plan should be coordinated by the nursing staff, with oversight from the practitioner and with input from the patient or family member as feasible and appropriate. Key components of the care plan should be documented clearly in the practitioner's orders. It is also important that information about the patient's condition and the proposed care plan are communicated to caregivers and family members.

Step 11. Implement appropriate nonpharmacologic interventions. Residents with PD may benefit from nonpharmacologic interventions that include physical/occupational therapy, speech therapy, dietary therapy, and recreational therapy. Incorporating such interventions into residents' daily lives can enable these individuals to continue to socialize and participate in leisure interests and other activities. In many cases, nonpharmacologic interventions can reduce the need for drug therapy. Additionally, several studies have documented the potential value of exercise for treating PD.

Step 12. Implement appropriate pharmacologic interventions. Because of the narrow risk/benefit ratio of PD medications, pharmacotherapy for PD residents should be initiated only after nonpharmacologic therapy alone has failed and should be combined with nonpharmacologic treatments.

Levodopa combined with carbidopa has long been the gold standard for treating PD. However, long-term use of levodopa is associated with motor complications. Involuntary movements (dyskinesias) are among the most disabling of these complications. Patients treated with dopamine agonist monotherapy experience a lower incidence of dyskinesia as compared with residents who receive levodopa monotherapy.

Dopamine agonists are considered an appropriate first-line therapy for older residents who have normal physical and cognitive function. On the other hand, levodopa may be preferable for patients over age 70, especially those with dementia. These individuals are at higher risk for side effects from dopamine agonists, including confusion, hallucinations, hypotension, nausea and vomiting, and daytime sedation. Anticholinergic medications should be used with caution in patients with dementia and the very old because they may provoke acute confusional states or cause or contribute to cognitive dysfunction.

Step 13. Implement nutritional interventions as necessary. A daily multivitamin should be considered for all older adults, whether or not they suffer from PD. However, other vitamin therapies and dietary supplements (eg, vitamin C, vitamin E, beta carotene, selenium, coenzyme Q-10) have not been clinically validated. This information should be shared with residents and their families, and intake of a daily multivitamin should be encouraged.

At the same time, caregivers and family members should be alerted to watch for any chewing difficulties or dental caries in residents that may require a dental referral. A dietary consultation also may be useful.

Preventing further decline in an individual's level of functioning with Parkinson's Disease may not always be a realistic therapeutic goal.

Step 14. Work with the resident's practitioner and other clinicians to manage complications and comorbidities associated with Parkinson's disease and obtain specialty consultation if appropriate. The nature of the complication or comorbidity will determine the appropriate interventions and right specialists to call.

It is important to note that specialty consultations may not be appropriate for all ALF residents. It is important to consider the resident's cognitive and functional status, severity of disease, expressed preferences, and life expectancy when determining whether to seek consultation.

Artificial feeding methods may be clinically appropriate for certain individuals with PD when swallowing problems become severe. When a resident is deemed to need artificial feeding interventions, the facility will need to decide whether it is in the individual's best interest to be transferred to a nursing facility or other setting on a temporary or permanent basis. This decision should be discussed in detail with the resident and/or his or her family.

Step 15. Consider referring the resident to community resources or for palliative care. Consider referring the resident or his or her family to PD support groups and to hospice care where appropriate. A consultation with social services, a review of community resources, and assessment of the resident's spiritual needs may be useful as the PD progresses. A list of agencies and organizations that offer support for PD patients and family members is offered in Table 1.

Any significant decline in the resident's clinical status should prompt his or her practitioner and facility staff to discuss the resident's preferences with family members and to review the individual's advance directives.

Monitoring

Because PD is a progressive disorder, residents with the disease must be reassessed regularly and when there is a significant change in a resident's condition.

It is important to note that because of the progressive nature of PD, preventing further decline in an individual's level of functioning may not always be a realistic therapeutic goal. Periodic reappraisal of

therapy goals is essential to ongoing care. Regular reassessments also should address whether it is safe and appropriate for the resident to stay in the ALF and, if not, what care, services, or interventions may enable the individual to stay in his or her home.

Step 16. Monitor the resident's ability to communicate and carry out ADLs. As PD progresses, secondary manifestations—such as dementia, sleep disturbances, and pain—become more disabling. It is important that residents be watched for changes in physical function, perhaps suggesting a need for physical or occupational therapy, restorative nursing, assistive devices, and/or other interventions to maximize independence. It also is important to check the resident's ability to communicate basic needs, wants, and ideas. Work with practitioners, physical therapists, and other consultants to determine the possible benefit of appropriate assistive devices.

Step 17. Monitor other elements. To keep residents with PD as functional, independent, and safe as possible, there are several other elements of life and care that clinicians, ALF staff, and family members should monitor. These include the resident's:

- Cognitive, mental, and emotional status
- Nutritional status and ability to swallow
- Medications (for effectiveness, adverse effects, and complications)
- Appearance or progression of comorbidities and complications

Step 18. Monitor the need for a change in the resident's level of care. As the resident with PD becomes increasingly ill and disabled, he or she may need to be transferred to a facility that can provide higher level of care, palliative care, or hospice care. It will be important for staff to discuss these options with the resident's practitioner as well as with the resident and his or her family (or other designated decision maker). It will be important at this time to review the resident's advance directives to ensure that his or her wishes regarding end-of-life care are known and respected.

If it is determined at this time that the resident needs to move to another setting, this should be done in a way that minimizes the individual's stress and protects his or her dignity and well-being.

Table 1.
Organizations Offering Support for Residents with PD and their Families

American Parkinson's Disease Association, Inc.
1250 Hylan Blvd., Suite 4B
Staten Island, NY 10305
800/223-2732
www.info@adaparkinson.org

The Bachmann-Straus Dystonia and Parkinson Foundation
Mount Sinai Medical Center
1 Gustave L. Levy Place, Box 1490
New York, NY 10029
212/241-5614
www.dystonia-parkinsons.org

European Parkinson Foundation Inc.
1504 NW Ninth Ave., Bob Hope Rd.
Miami, FL 33136-1494
800/433-7022
www.parkinson.org

The Parkinson's Disease Foundation
710 West 158th Street
New York, NY 10032
800/457-6676
www.parkinsons-foundation.org

The Michael J. Fox Foundation for Parkinson's Research
840 3rd St.
Santa Rosa, CA 95404
707/544-1994
www.michaeljfox.org

The Parkinson Foundation of Canada
4211 Yonge Street, Suite 316
Toronto, Canada, M2P 2A9
416/227-9700
www.parkinson.ca

We Move
204 West 84th St., 3rd Floor
New York, NY 10024
www.wemove.org

Summary

PD is a progressive degenerative brain disorder that commonly presents in late life. Many clinical manifestations of the disease can be treated with a combination of nonpharmacologic and drug therapies. ALFs must be prepared to identify and monitor residents who are at high risk of the disease, those who enter the facility with PD, and those who develop the illness during their residence. Facility staff and clinicians caring for residents with PD must do everything possible to keep PD residents safe and maximize their quality of life. They also must be prepared to deal with situations where it is unsafe or otherwise unfeasible for the resident with PD to remain in this setting. ALC