Guideline Summary NGC-8400

Guideline Title

Parkinson's disease in the long-term care setting.

Bibliographic Source(s)

American Medical Directors Association (AMDA). Parkinson's disease in the long-term care setting. Columbia (MD): American Medical Directors Association (AMDA); 2010. 37 p. [58 references]

Guideline Status

This is the current release of the guideline.

This guideline updates a previous version: American Medical Directors Association (AMDA). Parkinson's disease in the long-term care setting. Columbia (MD): American Medical Directors Association (AMDA); 2002. 34 p.

Scope

Disease/Condition(s)

- Parkinson's disease
- Parkinsonism

Guideline Category

Diagnosis

Evaluation

Management

Treatment

Clinical Specialty

Family Practice

Geriatrics

Internal Medicine

Neurology

Intended Users

Advanced Practice Nurses

Allied Health Personnel

Dietitians

Health Care Providers

Nurses

Occupational Therapists

Patients

Pharmacists

Physical Therapists

Physician Assistants

Physicians

Social Workers

Speech-Language Pathologists

Guideline Objective(s)

- To improve the quality of care delivered to patients with Parkinson's disease (PD) in long-term care settings
- To guide staff and practitioner practices and performance

Target Population

Residents of long-term care facilities with Parkinson's disease

Interventions and Practices Considered

Diagnosis/Assessment

1. Relevant history, physical examination, assessment of physical function, and mental, emotional, and cognitive status
2. Assessment for signs of dysphagia and altered nutritional and functional status
3. Assessment of medication use
4. Assessment of the risk of developing comorbidities and complications and the need for specialty consultation
5. Summarization of the patient's condition
6. Assessment of need for palliative care or hospice

Management/Treatment

1. Development of an individualized care plan
2. Nonpharmacologic interventions such as physical/occupational therapy, speech therapy, dietary therapy, recreational therapy, complementary/alternative therapy, deep brain stimulation
3. Pharmacologic interventions:
   - Dopaminergic precursor: carbidopa/levodopa
   - Dopamine agonists: bromocriptine, pramipexole, ropinirole
   - Catechol-O-methyl transferase (COMT) inhibitors: entacapone, tolcapone
   - Anticholinergics: benztropine, trihexyphenidyl
   - Glutamate receptor antagonist: amantadine
   - Monoamine oxidase-B (MAO-B) inhibitors: rasagiline, selegiline
   - Tricyclic antidepressants: nortriptyline, desipramine
   - Selective serotonin re-uptake inhibitors: citalopram, escitalopram, venlafaxine, paroxetine, sertraline
   - Other antidepressants: mirtazapine, bupropion
   - Antipsychotics: clozapine, quetiapine
   - Combination product: carbidopa/levodopa/entacapone
4. Nutritional interventions as necessary
5. Management of complications and comorbidities associated with PD
6. Referral to palliative care or hospice as needed
7. Monitoring of patient's response to interventions and subsequent adjustments of interventions as needed
8. Monitoring the status and the need for a change in patient's level of care and review of relevant medications

Major Outcomes Considered

- Symptoms of Parkinson's disease
- Functional status/activities of daily living
- Adverse effects of treatment
- Quality of life

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

Medline, PubMed, and geriatric-specific journals such as the Journal of the American Medical Directors Association

(JAMDA), Annals of Long Term Care, and Journal of the American Geriatrics Society (JAGS) were searched from May 2009 through February 2011. Studies were included if they met the following criteria:

- Studies that are valid, consistent, applicable and clinically relevant
- Studies where the recommendation is supported by fair evidence (based on studies that are valid, but there are some concerns about the volume, consistency, applicability and clinical relevance of the evidence that may cause some uncertainty but are not likely to be overturned by other evidence)

Searches were specific to the guideline topic under consideration.

Number of Source Documents

Not stated

Methods Used to Assess the Quality and Strength of the Evidence

Expert Consensus

Rating Scheme for the Strength of the Evidence

Not applicable

Methods Used to Analyze the Evidence

Review

Description of the Methods Used to Analyze the Evidence

Not stated

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

Original guidelines are developed by interdisciplinary workgroups, using a process that combines evidence and consensus-based approaches. Workgroups include practitioners and others involved in patient care in long-term care facilities. Beginning with a general guideline developed by an agency, association, or organization such as the Agency for Healthcare Research and Quality (AHRQ), pertinent articles and information, and a draft outline, each group works to make a concise, usable guideline that is tailored to the long-term care setting. Because scientific research in the long-term care population is limited, many recommendations are based on the expert opinion of practitioners in the field. A bibliography is provided for individuals who desire more detailed information.

Guideline revisions are completed under the direction of the Clinical Practice Guideline Steering Committee. The committee incorporates information published in peer-reviewed journals after the original guidelines appeared as well as comments and recommendations not only from experts in the field addressed by the guideline but also from "hands-on" long-term care practitioners and staff.

Rating Scheme for the Strength of the Recommendations

Not applicable

Cost Analysis

A formal cost analysis was not performed and published cost analyses were not reviewed.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

All American Medical Directors Association (AMDA) clinical practice guidelines undergo external review. The draft guideline is sent to approximately 175+ reviewers. These reviewers include American Medical Directors Association physician members and independent physicians, specialists, and organizations that are knowledgeable of the guideline topic and the long-term care setting.

AMDA's guidelines are supported by the following associations/organizations, who are members of its Clinical Practice Guideline Steering Committee. These associations/organizations all have representatives who participate in the external review phase and officially sign off on the guideline before publication: American Association of Homes and Services for the Aging (Now LeadingAge); American College of Health Care Administrators; American Geriatrics Society; American Health Care Association; American Society of Consultant Pharmacists; Gerontological Advanced Practice Nurses Association; Direct Care Alliance; National Association of Directors of Nursing Administration in Long-Term Care; National Association of Health Care Assistants.

Recommendations

Major Recommendations

Major Recommendations

Note from the American Medical Directors Association (AMDA) and the National Guideline Clearinghouse (NGC): The original full-text guideline provides an algorithm on "Parkinson's Disease in the Long-term Care Setting" to be used in conjunction with the written text. Refer to the "Guideline Availability" field for information on obtaining the algorithm, as well as the full text of the guideline, which provides additional details.

Recognition

Practitioners and staff in the long-term care facility should know the signs and symptoms that suggest the presence of Parkinson's disease (PD) or parkinsonism (see table below).

Table: Diagnostic Criteria for Parkinson's Disease

Group A Features (characteristic of PD)

- Resting tremor
- Bradykinesia
- Rigidity
- Asymmetric onset

Group B Features (suggestive of alternative diagnoses)

- Features that do not usually occur early in the clinical course
- Prominent postural instability in the first 3 years after symptom onset
- Freezing phenomenon in the first 3 years
- Hallucinations unrelated to medications in the first 3 years
- Dementia preceding motor symptoms or in the first year
- Supranuclear gaze palsy (other than restriction of upward gaze) or slowing of vertical saccades*
- Severe, symptomatic dysautonomia unrelated to medications
- Documentation of condition known to produce parkinsonism and plausibly connected to the patient's symptoms (such as suitably located focal brain lesions or neuroleptic use within the past 6 months)

Criteria for Definite PD

- All criteria for probable Parkinson's are met, and
- Histopathological confirmation of the diagnosis is obtained at autopsy

Criteria for Probable PD

- At least three of the four features in group A are present and
- None of the features in group B is present (note: symptom duration greater than or equal to 3 years is necessary to meet this requirement) and
- Substantial and sustained response to levodopa or a dopamine agonist has been documented

Criteria for Possible PD

- At least two of the four features in group A are present; at least one of these is tremor or bradykinesia and
- Either (a) none of the features in group B is present or (b) symptoms have been present less than or equal to 3 years and none of the features in group B is present and
- Either (a) substantial and sustained response to levodopa or a dopamine agonist has been documented or (b) the patient has not had an adequate trial of levodopa or a dopamine agonist

*Abrupt, rapid small movements of both eyes

Source: From the National Institute of Neurological Disorders and Stroke. Adapted from Jankovic J. Parkinson's disease: Clinical features and diagnosis. J Neurol Neurosurg Psychiatry 2008;79(4):368-376.

Step 1

Has Parkinson's disease already been diagnosed in this patient?

On admission or during the preadmission assessment, ask the patient and family members if the patient has PD or has shown signs or symptoms that suggest PD. Evaluate the patient for manifestations of PD or parkinsonism (see Tables 2 and 3 in the original guideline document). Determine whether any current or previous medication may have caused drug-induced parkinsonism (DIP) (see Table 4 in the original guideline document for list).

Assessment

Step 2

Conduct a pertinent history, physical examination, and mental status examination to determine whether the patient has Parkinson's disease or parkinsonism.

Because no biological markers for PD exist, a thorough, accurate history and physical examination are essential to the diagnosis. Although the presence of two or more of the cardinal features suggests PD, the clinician must rule out Parkinson-like syndromes (see Table 5 in the original guideline document).

Step 3

Assess the physical function of the patient with Parkinson's disease.

An assessment of physical function is essential to determining the stage of PD and identifying the interventions likely to be most effective. Interdisciplinary team members should, as clinically indicated, assess the patient's gait, balance, mobility, and ability to perform activities of daily living (ADLs).

Rating scales that can be used to assess the severity and impact of PD are listed in Tables 6 and 7 of the original

guideline document.

Step 4

Assess the patient's emotional and cognitive status.

Depression, anxiety, and psychosis are often part of the prodrome of a dementia syndrome and therefore need to be properly assessed and managed.

Clinical diagnostic criteria for dementia in PD have been published by a task force organized by the Movement Disorder Society. These criteria are summarized in Table 8 of the original guideline document.

Step 5

Assess the patient for signs of dysphagia and altered nutritional status.

Swallowing difficulty may occur as PD progresses. Assess patients' swallowing ability at baseline and as clinically indicated. Train caregivers to observe and report the signs and symptoms of a swallowing problem (see Table 9 in the original guideline document).

Assess the patient on admission and at least monthly thereafter for weight changes, changes in food intake, changes in appetite, and altered nutritional status.

Step 6

Assess the patient's physical functional status.

This should be done at baseline, each time the Minimum Data Set (MDS) is completed, and as clinically indicated, for example, when significant changes occur in the patient's ability to perform activities of daily living (ADLs) or when comorbid disease is present.

Step 7

Assess the patient's medication regimen.

A medication regimen review at baseline and whenever a significant change occurs in the patient's condition will help to identify drugs associated with DIP, drugs that can worsen nonmotor features, and other medication-related problems.

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 fecal impaction. Conduct this assessment at baseline and as clinically indicated. Table 10 in the original guideline document lists common comorbidities and complications with possible interventions.

Step 9

Summarize the patient's condition.

The practitioner's written summary of the patient's medical condition should:

- Describe the patient's medical conditions and stability, including the severity of PD and associated complications as well as other significant medical conditions.
- Describe the impact of PD on the patient's function and quality of life.
- Provide reasons why other suspected diagnoses were not pursued (e.g., patient too frail, terminal, or unwilling to undergo further interventions).

Step 10

Assess the patient's need for palliative care or hospice.

Treatment

A multifaceted approach to treating PD is essential. This involves addressing the patient's spiritual, social, emotional, and cultural needs and concerns as well as his or her physical needs. The implementation of such an approach to care may involve the interaction of clinicians, caregivers, family members, nonclinical facility staff, and patients themselves to the extent that they are able to participate.

Nonpharmacologic and pharmacologic therapies are the mainstays in the primary management of PD. Careful and thoughtful consideration should be given to selection of anti-parkinsonian therapies, and desired outcomes should be individualized. Surgical interventions are reserved for individuals who are levodopa-responsive and are experiencing severe fluctuations and dyskinesia despite medical optimization. Deep brain stimulation has become the most commonly performed surgery for PD in North America.

Step 11

Develop an individualized care plan.

Development of the care plan should be coordinated by the nursing staff, with practitioner oversight and input from all pertinent disciplines as well as from the patient or caregiver as feasible and appropriate. It is important that the patient's individual goals and preferences be incorporated into the care plan and that he or she participates in treatment decisions to the extent possible.

Step 12

Implement appropriate nonpharmacologic interventions.

In many cases, nonpharmacologic interventions can reduce the need for drug therapy. Consider psychological counseling and support groups for selected patients. Environmental adaptations should address potential hazards for falls. Other nonpharmacologic interventions may include:

- Physical and occupational therapy
- Speech therapy

- Speech therapy
- Dietary therapy
- Recreational therapy
- Complementary and alternative medicine

The possible indications and goals of nonpharmacologic therapy are listed in Table 11 of the original guideline document. Some practical techniques for enhancing patient independence, mobility, and safety are listed in Table 12 of the original guideline document.

Step 13

Implement appropriate pharmacologic interventions.

Pharmacotherapy should be combined with nonpharmacologic therapy (e.g., education, exercise, social support, nutrition). Input from a consultant pharmacist is encouraged. Levodopa combined with carbidopa has long been considered the gold standard for treating PD.

Dopamine agonists or monoamine oxidase inhibitors (e.g., rasagiline, selegiline) are considered an appropriate first-line therapy for younger patients. In younger patients, because of the risk of developing levodopa-associated motor complications, initiation of levodopa may be reserved for later in the course of PD.

Refer to Table 13 in the original guideline document for further information on pharmacologic treatment of PD.

Step 14

Implement nutritional interventions as necessary.

Nutritional status has been shown to worsen in PD with duration of disease, and therefore evaluating nutritional status should be part of the routine evaluation of PD patients.

Consider referring the patient for a dietary consultation as necessary.

Step 15

Manage complications and comorbidities associated with PD and obtain specialty consultation if appropriate.

The nature of the complication or comorbidity will determine the appropriate interventions and the appropriate specialists who should participate (see Tables 10, 14, and 15 in the original guideline document).

Specialty consultation may not be appropriate for all individuals in the long-term care setting who have PD (see Step 8). Consider the patient's cognitive and functional status, severity of disease, expressed preferences, and life expectancy when determining whether to seek consultation.

Step 16

Consider referring the patient with advanced illness for palliative care or hospice.

Because PD is a chronic, progressive disease with limited therapeutic options in its advanced stages, the optimal care of such patients should include applying the principles of palliative medicine. Palliation of PD symptoms should be addressed for all stages of the disease.

Any significant decline in the patient's clinical status should prompt the attending physician and the interdisciplinary team to discuss the patient's preferences with family members and to review his or her advance directives.

Monitoring

At a minimum, reassessment of the patient's overall functioning and medication regimen should occur at each quarterly review and any time a significant change is noted in the patient's condition. The progressive nature of PD also means that preventing further decline in a patient's level of functioning may not always be a realistic therapeutic goal. Periodic reappraisal of the goals of therapy is an essential component of ongoing care.

Additionally, communication mechanisms must be in place in the long-term care facility to ensure that any observations suggesting a significant change in a patient's condition are promptly reported to the unit manager or charge nurse and discussed with members of the interdisciplinary team and the attending physician.

Step 17

Monitor the patient's ability to communicate and carry out ADLs.

Step 18

Monitor the patient's cognitive, mental, and emotional status.

Step 19

Monitor the patient's nutritional status and ability to swallow.

Step 20

Monitor the patient's medications for effectiveness, potential adverse effects, and complications.

Step 21

Monitor the patient for the emergence or progression of comorbidities and complications.

Step 22

Monitor the need for a change in the patient's level of care.

Step 23

Monitor the facility's management of Parkinson's disease.

The appendix of the original guideline document suggests process and outcome indicators for measuring facility performance in the recognition, assessment, treatment, and monitoring of PD. Facilities may wish to select the indicators most relevant to their population and staff for inclusion in their quality improvement process. The medical director should be actively involved in this process.

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Clinical Algorithm(s)

An algorithm is provided in the original guideline document for recognition, assessment, treatment, and monitoring of Parkinson's disease in long-term care settings.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of evidence supporting the recommendations is not specifically stated.

The guideline was developed by an interdisciplinary work group using a process that combined evidence- and consensus-based approaches. Because scientific research in the long-term care population is limited, many recommendations are based on the expert opinion of practitioners in the field.

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Potential benefits associated with the implementation of this guideline include the following:

- Earlier identification of Parkinson's disease (PD) and its complications
- Better management of PD, allowing patients to maintain their highest practicable physical, mental, and psychosocial function
- Greater individualization of care
- Enhanced quality of life
- Better documentation of, and rationale for, patients' personal goals and decision-making processes regarding their disease and its treatment
- More appropriate pharmacologic therapy for PD
- More appropriate physician participation in the care of the patient with PD
- Improved patient and family satisfaction with care
- More appropriate resource utilization
- Improved treatment and monitoring protocols
- Improved staff education and awareness of this complex progressive disease
- More appropriate and timely referral to palliative care and hospice

Potential Harms

- Long-term use of levodopa is associated with motor complications. Involuntary movements (dyskinesias) are among the most disabling of these complications.
- Side effects from dopamine agonists include confusion, hallucinations, hypotension, impulse control disorders, memory impairment, nausea and vomiting, and excessive daytime sedation. Patients over age 70 or those with dementia are at higher risk for side effects from dopamine agonists.

Refer to Table 13 in the original guideline document for adverse effects of specific medications used to treat Parkinson's disease.

Qualifying Statements

Qualifying Statements

- This clinical practice guideline is provided for discussion and educational purposes only and should not be used or in any way relied upon without consultation with and supervision of a qualified physician based on the case history and medical condition of a particular patient. The American Medical Directors Association (AMDA), its heirs, executors, administrators, successors, and assigns hereby disclaim any and all liability for damages of whatever kind resulting from the use, negligent or otherwise, of this clinical practice guideline.
- The utilization of AMDA's Clinical Practice Guideline does not preclude compliance with State and Federal regulation as well as facility policies and procedures. They are not substitutes for the experience and judgment of clinicians and caregivers. The Clinical Practice Guidelines are not to be considered as standards of care but are developed to enhance the clinicians' ability to practice.
- The corporate supporters of this guideline provided funding without condition of product use, formulary status or purchasing commitment.
- Long-term care facilities care for a variety of individuals, including younger patients with chronic diseases and disabilities, short-stay patients needing postacute care, and very old and frail individuals suffering from multiple comorbidities. When a workup or treatment is suggested, it is crucial to consider if such a step is appropriate for a specific individual. A workup may not be indicated if the patient has a terminal or end-stage condition, if it would not change the management course, if the burden of the workup is greater than the potential benefit, or if the patient or his or her proxy would refuse treatment. It is important to carefully document in the patient's medical record the reasons for decisions not to treat or perform a workup or for choosing one treatment approach over another.

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Implementation of the Guideline

Description of Implementation Strategy

The implementation of this clinical practice guideline (CPG) is outlined in four phases. Each phase presents a series of steps, which should be carried out in the process of implementing the practices presented in this guideline. Each phase is summarized below.

I. **Recognition**

- Define the area of improvement and determine if there is a CPG available for the defined area. Then evaluate the pertinence and feasibility of implementing the CPG.

II. **Assessment**

- Define the functions necessary for implementation and then educate and train staff. Assess and document performance and outcome indicators and then develop a system to measure outcomes.

III. **Implementation**

- Identify and document how each step of the CPG will be carried out and develop an implementation timetable.
- Identify individual responsible for each step of the CPG.
- Identify support systems that impact the direct care.
- Educate and train appropriate individuals in specific CPG implementation and then implement the CPG.

IV. **Monitoring**

- Evaluate performance based on relevant indicators and identify areas for improvement.
- Evaluate the predefined performance measures and obtain and provide feedback.

Implementation Tools

Audit Criteria/Indicators

Clinical Algorithm

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

End of Life Care

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

American Medical Directors Association (AMDA). Parkinson's disease in the long-term care setting. Columbia (MD): American Medical Directors Association (AMDA); 2010. 37 p. [58 references]

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2002 (revised 2010)

Guideline Developer(s)

American Medical Directors Association - Professional Association

Guideline Developer Comment

Organizational participants included:

- American Association of Homes and Services for the Aging
- American College of Health Care Administrators
- American Geriatrics Society
- American Health Care Association
- American Society of Consultant Pharmacists

- American Society of Consultant Pharmacists
- Gerontological Advanced Practice Nurses Association
- National Association of Directors of Nursing Administration in Long-Term Care
- National Association of Health Care Assistant

Source(s) of Funding

American Medical Directors Association

Medtronic, Inc. and UCB Pharma were corporate sponsors of this guideline.

Guideline Committee

Clinical Practice Guideline Steering Committee

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Financial Disclosures/Conflicts of Interest

All contributors must submit an Accreditation Council for Continuing Medical Education (ACCME) approved disclosure form prior to being accepted as a volunteer member of the guideline workgroup. This disclosure form is reviewed by the chair of the American Medical Directors Association (AMDA) Clinical Practice Committee. If any conflicts are perceived, that person is not accepted to be part of the workgroup.

Guideline Status

This is the current release of the guideline.

This guideline updates a previous version: American Medical Directors Association (AMDA). Parkinson's disease in the long-term care setting. Columbia (MD): American Medical Directors Association (AMDA); 2002. 34 p.

Guideline Availability

Electronic copies: Not available at this time.

Print copies: Available from the American Medical Directors Association, 10480 Little Patuxent Pkwy., Suite 760, Columbia, MD 21044. Telephone: (800) 876-2632 or (410) 740-9743; Fax (410) 740-4572. Web site: www.amda.com.

Availability of Companion Documents

The Appendix of the original guideline document offers suggestions for general process indicators as well as clinical process and outcome indicators specific to measuring facility performance in the management of Parkinson's disease.

Patient Resources

None available

NGC Status

This NGC summary was completed by ECRI on September 3, 2003. The information was verified by the guideline developer on April 8, 2004. This summary was updated by ECRI on January 18, 2006, following the U.S. Food and Drug Administration advisory on Clozaril (clozapine). This summary was updated by ECRI on May 31, 2006 following the U.S. Food and Drug Administration advisory on Paxil (paroxetine hydrochloride). This summary was updated by ECRI on November 22, 2006, following the FDA advisory on Effexor (venlafaxine HCl). This summary was updated by ECRI Institute on April 17, 2007 following the withdrawal from the market of Permax (pergolide). This summary was updated by ECRI

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