AND THEN WHAT?
WHAT HAPPENS AFTER A DIAGNOSIS OF DEMENTIA?

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What Happens After a Diagnosis of Dementia

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Learning Objectives

By the end of this discussion, participants will be able to...

• Use a tool to stage the severity of dementia in persons living with dementia (PWD)
• Develop a process and a biopsychosocial approach to provide ongoing, stage-appropriate dementia care.
• Use what matters most for each PWD to guide planning for the future
• Create a multi-dimensional, personalized dementia care plan to help PWD live fully and on their terms with this disease
Traditional, Primary Care & Subspecialty Approach to Dementia

How DONEPEZIL works in Alzheimer’s disease?

Consumer Reports in 2012:
Alzheimer’s drugs cost a lot, but help just a little
Here’s why none of them received a Best Buy recommendation
Real Dementia Care: Costs A Lot More...And Affects Everyone

**Toll on Care-Partners (2020)**

- **US**
  - 11,150,000 care partners
  - 15,338,000,000 hours unpaid care provided annually
  - $256,650,000,000 unpaid care annually
- **PA**
  - 500,000 care partners
  - 662,000,000 hours unpaid care (150-300 hours/mo)
  - $9,726,000,000 unpaid care
- **4+ years**

**Toll on Health Care System (2020)**

- **$52,481/PWD**
  Medicare/health care and long-term care (LTC)
- **$11,571/PWD out-of-pocket health care, LTC expenses**
- **$373,527/PWD total cost**

Biomedical Pharmaceutical Approach to Dementia Falls Short

• **No clear benefit of dementia medications**
  – Do not preserve, “enhance” or improve memory, function
  – Do not slow progression of brain cell destruction or brain failure

• **Medications do not help everyday challenges that unfold and intensify as disease progresses**
  – To quality of life
  – To function, safety, independence
  – Demand on care-partners
Purpose of Disease Treatment

Intervention or constellation of interventions designed to...

• To cure or slow process of disease
• To improve comfort, ease suffering caused by the disease
Until There’s a Cure, There’s Care

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Comprehensive Dementia Care Plan

• Core element of effective dementia care management
• Delivery of constellation of services, right time and place in the disease
• Potentially enhance quality of life for PWD and care-partners
• Set client goals
• Identify activities or actions to achieve goals
• Project timeline
• Identify resources needed
• Incorporate interdisciplinary expertise

The Dementia Care Plan: Rationale

• Holistic, biopsychosocial approach
• Based on where the PWD is on the journey
• Anticipates and proactively addresses the challenges, interventions needed at each stage
• Person-centered, specific
  – Ability-based (PWD’s and support system’s)
  – Goal (what matters most)-directed to the extent possible
• Iterative, dynamic
• Educational, informational tool
• Empowering
Cognitive Assessment & Care Plan Services

CPT: 99483

This page is for health care providers.

If you’re a person with Medicare, learn more about your Medicare coverage for Cognitive Assessment & Care Plan Services.

If your patient shows signs of cognitive impairment during a routine visit, Medicare covers a separate visit to more thoroughly assess your patient’s cognitive function and develop a care plan – use CPT code 99483 to bill for this service.

Effective January 1, 2021, Medicare increased payment for these services to $282 (may be geographically adjusted) when provided in an office setting. Added these services to the definition of primary care services in the Medicare Shared Savings Program, and permanently covered these services via telehealth. Use CPT code 99483 to bill for both in-person and telehealth services.

How Do I Get Started?

Detecting cognitive impairment is a required element of Medicare’s Annual Wellness Visit (AWV). You can also detect cognitive

https://www.cms.gov/cognitive
Who is Eligible for CAACPS?

- **Annual Wellness Visit (AWV)**
- **Observation by Provider**
- **Concern Expressed by Family**

**Screen or Diagnose with Cognitive Impairment**

- **Positive (after ruling out reversible cause)**
- **Negative, but not convincing**
- **Negative**

**CAACPS**

Positive

MoCA or neuropsych testing

Negative

Screen at next AWV

PennState Health
Milton S. Hershey Medical Center
How the Dementia Care Plan Works

• Crisis prevention
• CPT 99483: Cognitive Assessment and Care Planning Services Medicare visit
• Update, face-to-face every 6 months
• Identifies and addresses current...
  – Threats to cognition
  – Threats to safety
  – Threats to function
  – Threats to comfort and quality of life
• Plan for the future
How to Create a Dementia Care Plan

1. Describe the cognitive disorder
2. Ascertain what matters most
3. Identify and address any neuropsychiatric symptoms
4. Optimize functional performance and safety
5. Build and protect the support system
6. Plan for the future

Step 1: Describe, diagnose, stage

A. History of cognitive decline from family
B. Symptoms and risk factors
C. Cognitive function test (MoCA), exam
D. Associated characteristics, behaviors, functional impairments
E. Type or diagnosis
F. Severity and Stage (use a tool)
   - Global Deterioration Scale (GDS)
G. Interventions to preserve, optimize, delay transition to next stage

Diagnosis and Progression

- Pre-Clinical
- Mild Cognitive Impairment
- Dementia

Functionally Independent

No Cognitive Impairment
Clinical and Measurable Cognitive Impairment

Global Deterioration Scale

1 2 3 4 5 6 7

Step 1: Example

A. **Diagnosis:** Major neurocognitive disorder probably due to Parkinson’s Disease

B. **Severity/Stage:** Moderately severe (moderate dementia), GDS Stage 5
GDS Stage 5

- Can no longer survive without **some assistance**.
- **Unable to recall** a major relevant aspect of their current lives (an address or telephone number, names of family).
- Frequently **disoriented to time** (date, day of week, season, etc.) **or to place** and dismisses direct questions about it.
- An educated person may have **difficulty counting** back from 40 by 4s or from 20 by 2s.
- Retains knowledge of many major facts regarding themselves and others.
- Requires no assistance with toileting and eating, but may have some **difficulty choosing the proper clothing** to wear.
Step 1: Example

A. **Dx:** Major neurocognitive disorder probably due to Parkinson’s Disease

B. **Severity:** Moderately severe (moderate dementia), GDS Stage 5

C. **Associated characteristics based on dementia type and stage:**
   - Possibly autonomic dysfunction, motor disturbances
   - Long-term memory preserved, has difficulty remembering recent events and learning new facts, has difficulty with way-finding and task sequencing, needs supervision with all IADLs and supervision or assistance with at least 1 ADL

D. **Cognitive function protection plan:** Acetylcholinesterase inhibitor; daily exercise; sleep; treat pain/constipation and issues that increase confusion; limit or eliminate anticholinergic meds; socialization and activity
Step 2: Ascertain What Matters Most

• In the **context** of the diagnosis
• In the words of the PWD
  – Ideally in earlier stage **while PWD has voice**
• With **collateral informant’s** knowledge of the PWD
• **Elicit specific goals:** staying fit, getting sleep, staying home, minimize suffering, be with family
• **Back up plan** that might be acceptable
Step 3: Identify and address any neuropsychiatric symptoms

A. Identify presence of neuropsychiatric symptoms (use a tool, eg NPI)
B. Rate severity of each symptom
C. Rate severity of care-partner stress caused by symptom
D. Non-pharmacologic and pharmacologic approach to reduce intensity and frequency of behaviors
Step 3: Example

A. Neuropsychiatric Inventory (NPI)

B. 12 Behaviors: delusions, hallucinations, agitation, depression, sleep problem

C. Severity/stress: Severe; very-to-extremely stressful

D. Plan to reduce stress caused by behaviors: Unmet needs; approach; limit tv; occupy; avoid stress; medications (SSRI); SLEEP!

https://n.neurology.org/content/48/5_Suppl_6/10S
Step 4: Optimize functional performance and safety

A. Identify functional needs and safety concerns (use Tools)

B. Identify comorbid medical conditions and treatments that complicate function and safety

C. Recommend modifications and interventions that improve function and safety
Step 4: Example

A. **IADL, ADL, safety assessment tool:**
   1) needs help with setting up meds, paying bills, preparing meals, using remote control, getting dressed
   2) Guns in home, wandering risk, driving risk, frequent falls

B. **Complex medical regimens and high risk meds:**
   diabetes, hypertension, blood thinners, benzodiazepines, diphenhydramine

C. **Interventions:** PT/OT, remove guns, life alert/GPS bracelet, retire from driving, occupational therapy, physical therapy, assist with medication administration, deprescribe high risk meds, 1st floor setup, supervise bathing
Step 5: Build and protect the support system

A. Identify the care-partner(s), support team members and their support roles
B. Assess care-partner(s)’ ability/willingness to supervise and provide direct care
C. Assess knowledge about dementia
D. Assess care-partner stress (stress thermometer) and screen for depression
E. Recommend strategies to reduce stress, strain
Step 5: Example

A. **Care-partners:** Spouse, son who lives nearby

B. Spouse willing and physically able to provide most supervision and care; son works at night and helps with showers and on weekends

C. Counsel and provide education/materials about what to expect, how to assist with supervision, safety, and direct care ([www.alz.org](http://www.alz.org))

D. Care-partner stress thermometer: very stressed

E. **Interventions:** Treat depression, problem-solve the 3 biggest stressors, support group, respite, home health aide, adult day care
Step 6: Plan for the future

A. Discuss prognosis, signs of, and needs at end-stage disease
B. Revisit what matters most
C. Plan for loss of capacity
D. Name/activate power of attorney
E. Discuss advance care planning, complete advance directive
F. Financial planning: need assets to meet needs for next several years
G. Backup plan: personal care needs in later stage dementia may exceed care-partner ability and $
Step 6: Example

- Identify POA + backup
- Complete advance directive
- Advise to complete and file last will and testament
- Explore future care settings, future need for helpers
- Financial plan
<table>
<thead>
<tr>
<th>Domain</th>
<th>Measures/Tests</th>
<th>Comments, Care Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognition</td>
<td>St Louis Univ Mental Status Exam (SLUMS)</td>
<td>History from informant</td>
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<tr>
<td></td>
<td>Montreal Cognitive Assessment (MoCA)</td>
<td>Cognition-Focused Exam, Studies</td>
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<tr>
<td></td>
<td>*prefer widely used, familiar instrument to trend</td>
<td>Cognitive function test</td>
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<td></td>
<td></td>
<td><em>Identify, reduce threats to cognition</em></td>
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<tr>
<td>Function</td>
<td>Basic Activities of Daily Living (Katz)</td>
<td>Complete with informant/care-partner</td>
</tr>
<tr>
<td></td>
<td>Instrumental Activities of Daily Living (Lawton-Brody)</td>
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<tr>
<td>Stage of Impairment</td>
<td>Global Deterioration Scale</td>
<td>Provider-determined</td>
</tr>
<tr>
<td></td>
<td>Dementia Severity Rating</td>
<td>Care-partner rated</td>
</tr>
<tr>
<td>Decision-making Ability</td>
<td>Capacity testing</td>
<td>Global clinical judgment</td>
</tr>
<tr>
<td></td>
<td>Able to make decisions, Not Able to make certain decisions, Uncertain</td>
<td><em>Statement about ability</em> <em>(independent, needs assistance, not able)</em></td>
</tr>
<tr>
<td>Neuropsychiatric Symptoms</td>
<td>Neuropsychiatric Inventory</td>
<td>10 min with informant</td>
</tr>
<tr>
<td>(Behaviors)</td>
<td>BEHAVE 5+, Cohen-Mansfield, PHQ2, GAD7</td>
<td><em>6 high-impact items</em></td>
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<td><em>Behavior prevention/mitigation</em></td>
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<td></td>
<td></td>
<td><em>Counsel, treat depression or anxiety</em></td>
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<tr>
<td>Medication review</td>
<td>Medication list reconciliation</td>
<td>High risk medications</td>
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<td></td>
<td>Who helps with medication administration technique</td>
<td>High risk administration</td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Deprescribing, administration safety recommendations</em></td>
</tr>
<tr>
<td>Safety</td>
<td>Safety Assessment Checklist (7 questions)</td>
<td>Safety risk reduction plan</td>
</tr>
<tr>
<td>Care-Partners and Needs</td>
<td>List/describe support system</td>
<td>Confirm ability to care</td>
</tr>
<tr>
<td>Assessment</td>
<td>Identify knowledge base</td>
<td><em>Counsel, provide education</em></td>
</tr>
<tr>
<td></td>
<td>Stress thermometer &amp; 3 things</td>
<td><em>Stress reduction plan</em></td>
</tr>
<tr>
<td>Advance Care &amp; Future Planning</td>
<td>Power of attorney</td>
<td>Document, Determine what matters</td>
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<td>End-of-life checklist, POLST</td>
<td><em>Complete Advance Directive</em></td>
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<tr>
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<td>Future-planning checklist</td>
<td><em>Outline To-Do list</em></td>
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Summary

• Dementia progresses over many years with many challenges that arise at every step and every stage.

• Fortunately, these challenges are predictable and, to some extent, avoidable.

• PWD need PCPs to develop a comprehensive dementia care plan they will share and update every 180 days.

• The best treatment and primary care for PWD is a good dementia care plan.
Thank You!

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