PHYSICIAN AND CONSUMER EDUCATION IN EARLY DETECTION, DIAGNOSIS, AND TREATMENT

2021 ALZHEIMER'S DISEASE & RELATED DISORDERS VIRTUAL FORUM

04 NOVEMBER 2021

pennsylvania
DEPARTMENT OF AGING

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

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The 4Ms of Age-and Dementia-Friendly Care ECHO®

And then What?

What Happens After a Diagnosis of Dementia

4 November 2021

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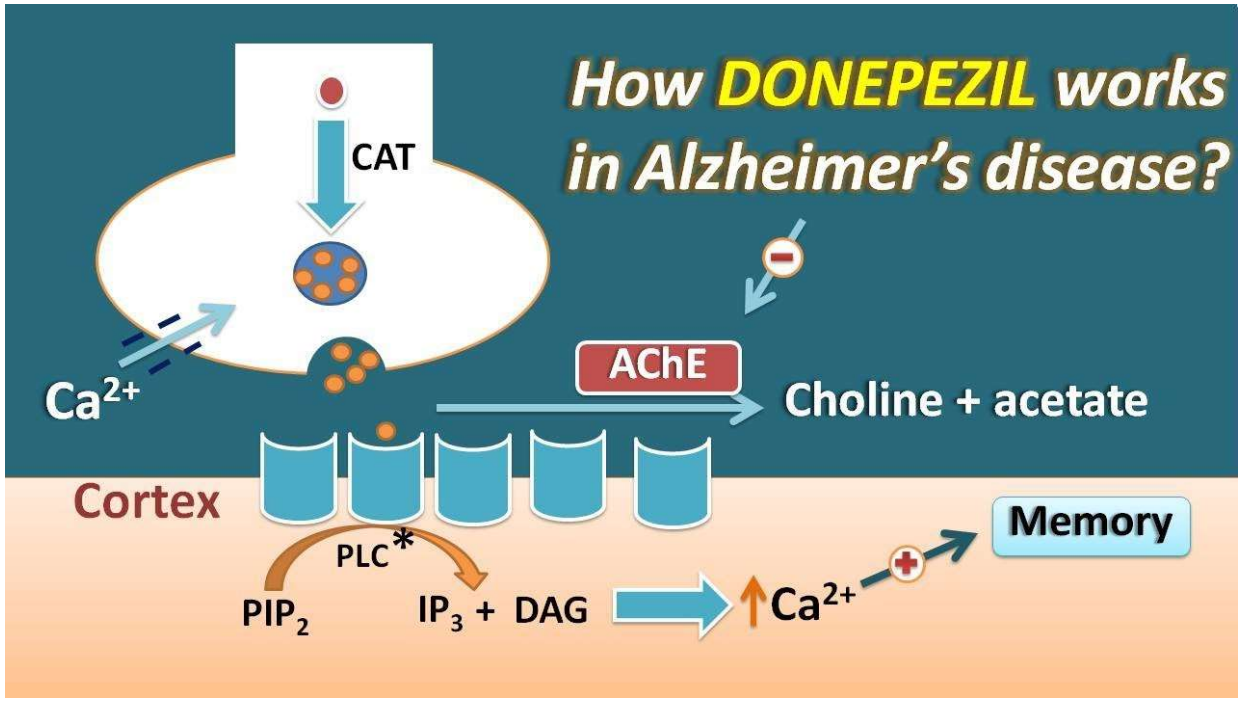
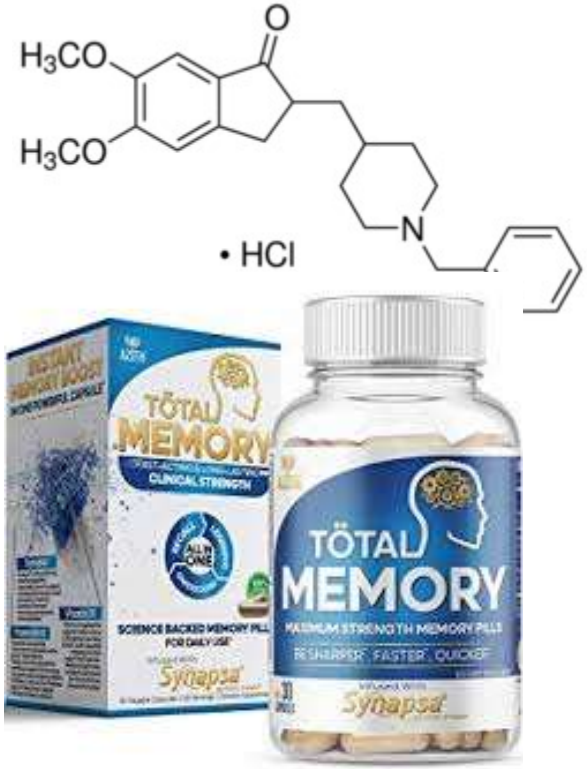
Learning Objectives

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





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

https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf

Biomedical Pharmaceutical Approach to Dementia Falls Short

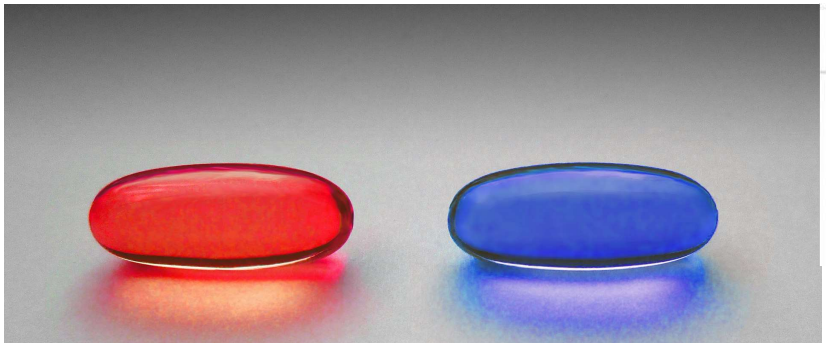
- ***No clear benefit of dementia medications***
  - Do not preserve, “enhance” or improve memory, function
  - Do not slow progression of brain cell destruction or brain failure
- ***Medications do not help everyday challenges that unfold and intensify as disease progresses***
  - To quality of life
  - 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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The Philadelphia Inquirer Subscribe SIGN

The coming crisis in dementia care and why Pa. is woefully unprepared

A lack of beds and staff, soaring costs, and action plans gone unheeded have left Pennsylvania, one of the oldest states in the nation, in a perilous position.

This story was published as part of a collaboration between PublicSource and Spotlight PA as part of the Pittsburgh Media Partnership. Published Sept. 2, 2021

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 interdisclipinary expertise

https://www.cdc.gov/hiv/effective-interventions/treat/steps-to-care/dashboard/care-plans.html

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

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Home › Medicare › Physician Fee Schedule › Cognitive Assessment & Care Plan Services

Physician Fee Schedule

- Physician Fee Schedule Look-Up Tool
- PFS Federal Regulation Notices
- PFS Relative Value Files
- Care Management
- **Cognitive Assessment & Care Plan Services**
- Evaluation & Management Visits
- Office-Based Opioid Use Disorder (OUD) Treatment Billing
- Medicare PFS Locality Configuration and Studies
- Psychological and Neuropsychological Tests

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.

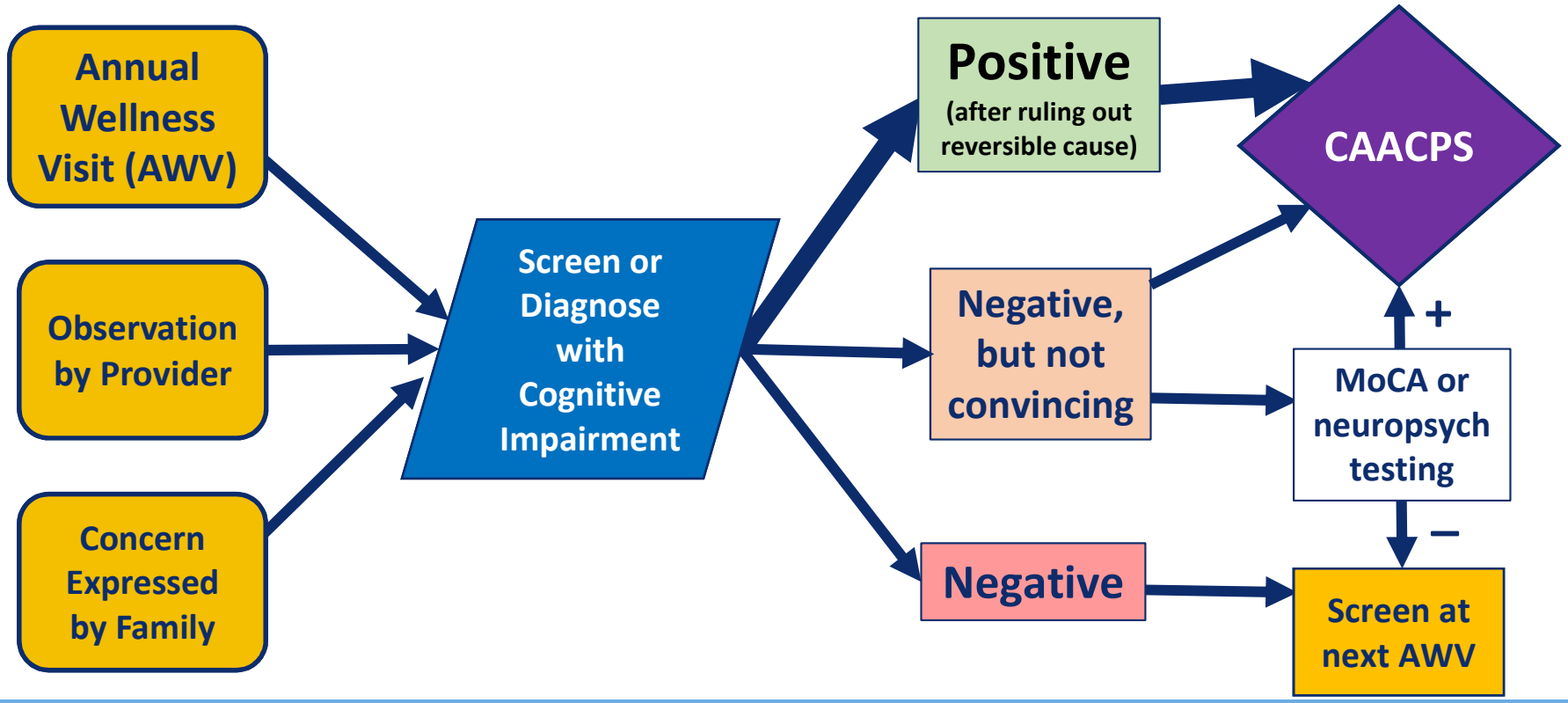
If your patient shows signs of cognitive impairment during a routine visit, Medicare covers a separate visit to more thoroughly assess your patient's cognitive function and develop a care plan – use CPT code 99483 to bill for this service.

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?

https://www.cms.gov/cognitive

Who is Eligible for CAACPS?

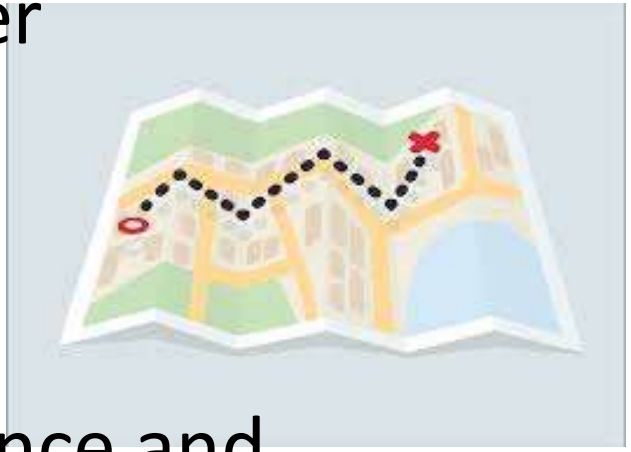


How the Dementia Care Plan Works

- 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



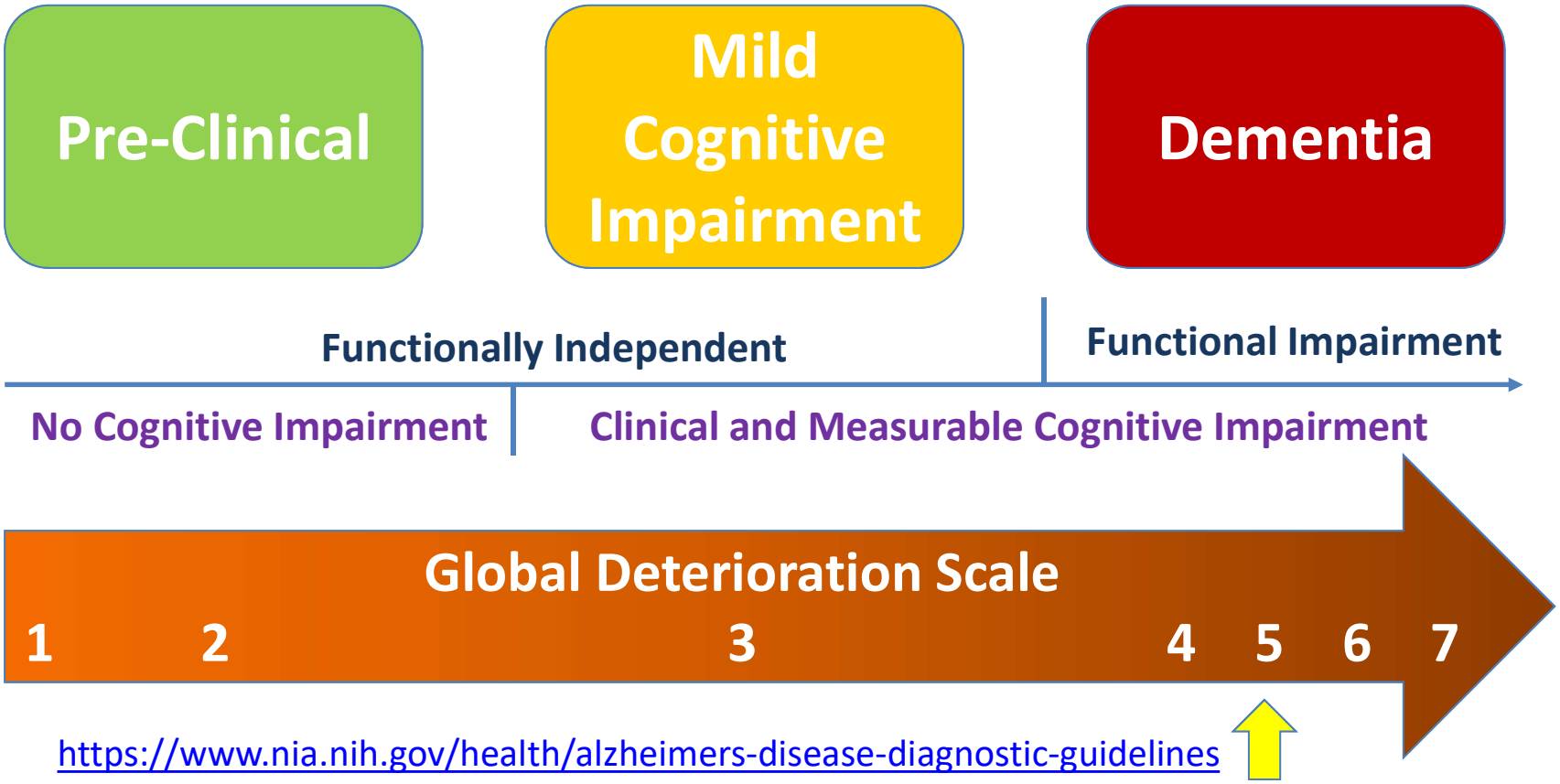
https://www.alz.org/careplanning/downloads/cms-consensus.pdf

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

https://www.fhca.org/members/qi/clinadmin/global.pdf

Diagnosis and Progression



https://www.nia.nih.gov/health/alzheimers-disease-diagnostic-guidelines
https://www.fhca.org/members/qi/clinadmin/global.pdf

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!

Delusions	Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?		
Yes No	**SEVERITY:** 1 2 **3**	**DISTRESS:** 0 1 2 3 **4** 5	
Hallucinations	Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?		
Yes No	**SEVERITY:** 1 2 **3**	**DISTRESS:** 0 1 2 3 4 **5**	
Agitation/Aggression	Is the patient resistive to help from others at times, or hard to handle?		
Yes No	**SEVERITY:** 1 2 **3**	**DISTRESS:** 0 1 2 3 **4** 5	

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

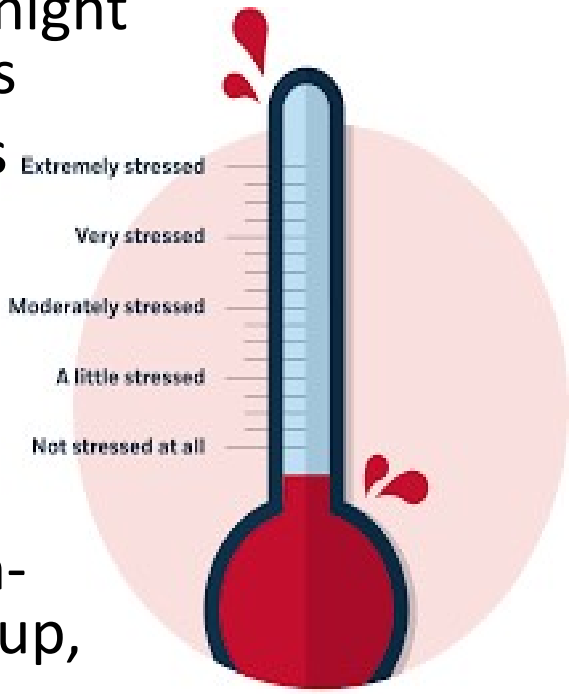
C. **Interventions:** PT/OT, remove guns, life alert/GPS bracelet, retire from driving, occupational therapy, physical therapy, assist with medication administration, deprescribe high risk meds, 1st floor setup, supervise bathing

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)
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

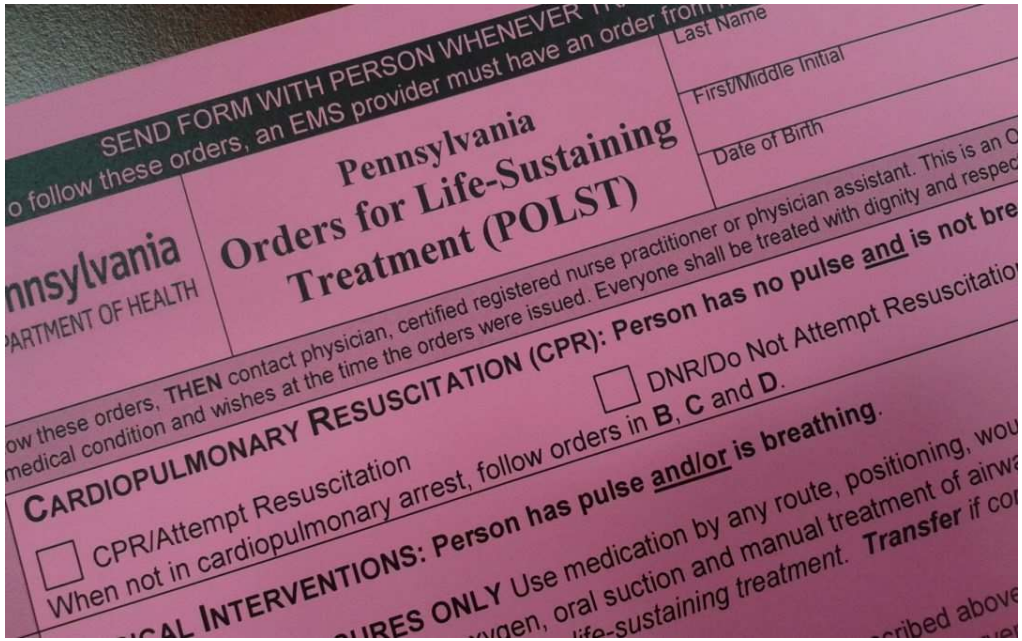


Step 6: Plan for the future

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



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

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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Questions? rwright4@pennstatehealth.psu.edu