# Successfully Collaborating to Support People Living with Dementia and Their Caregivers

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March 21, 2019

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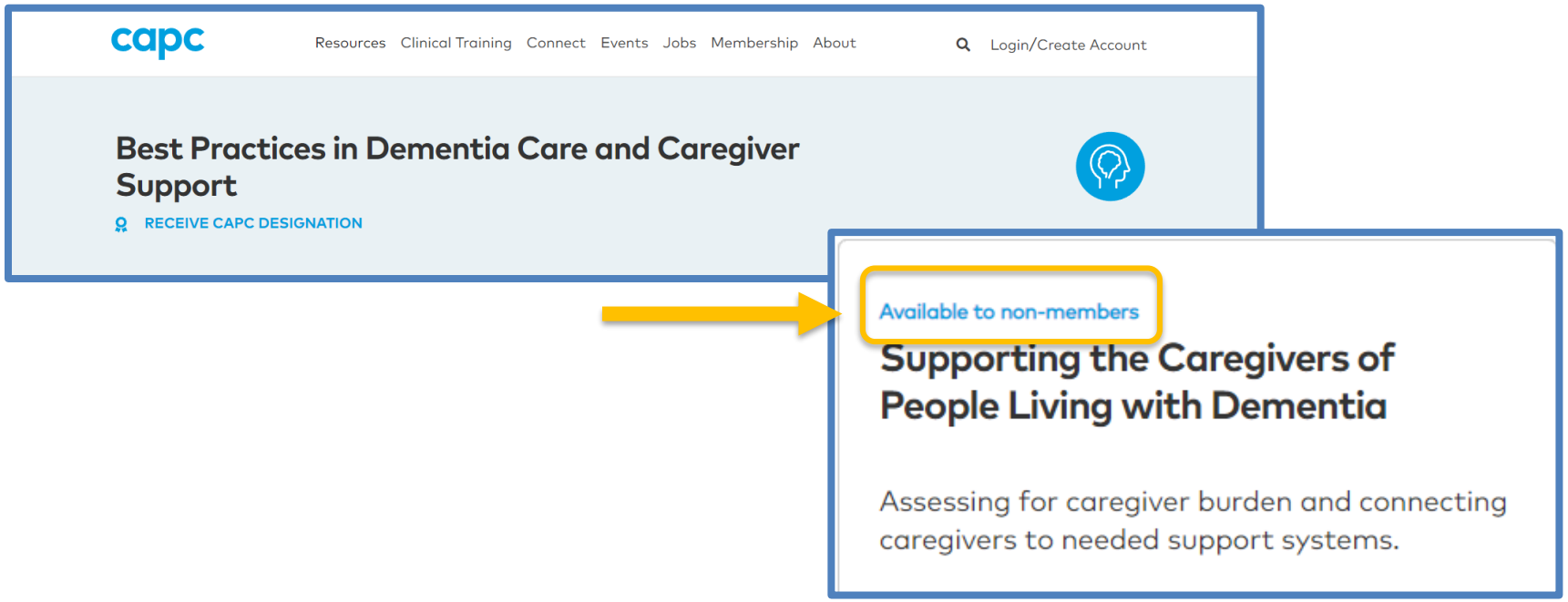
# Available CAPC Resources




**Upcoming Webinars (Members-only):** **capc.org > Events > Events Calendar**

- **Inpatient Palliative Care Billing: Three Case Studies** with Andy Esch, MD, MBA and Sherika Newman, DO

  **Tuesday, April 9 at 12:30pm ET**

- **Caring for Vulnerable Populations with Serious Illness** with Will Kennedy, DO

  **Tuesday, April 30 at 1:30pm ET**

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# Objectives

- Understand potential roles and responsibilities of members of an IDT providing support for people living with dementia.
- Describe effective services/interventions for improving the quality of life of people living with dementia and their caregivers.
- Consider opportunities for partnership between health care institutions and community-based service providers.

# Alzheimer's Association

- Founded in 1980 – a grassroots effort of family caregivers recognizing the need for an organization that provides support to those facing Alzheimer's disease and related dementias (ADRD)
- 2016 – 80+ independent chapters merge into national org
- The leading voluntary health organization in Alzheimer's care, support and research
- Services include: 24/7 Helpline, Support Groups Alz Direct Connect Health Provider Referrals

# Alzheimer's Association (AA)

Our vision: A world without Alzheimer's

Our mission:

- to eliminate Alzheimer's disease through the advancement of research
- to provide and enhance care and support for all affected
- to reduce the risk of dementia through the promotion of brain health

# UCSF Memory and Aging Center (MAC)

- Formed in 1998 with the A.W. & Mary Margaret Clausen Distinguished Professorship
- 34 faculty (neurology, geriatrics, psychiatry, pathology, neuropsychology, nursing, genetic counseling, statistics)
- 218 employees including faculty, fellows, social workers, pharmacist, administrators, technologists, research assistants
- Evaluate and treat: 10,000 patient visits/year
- 70 research protocols
- 200 medical students, residents, fellows, nurses, pharmacists, students rotate through our clinics

# UCSF MAC

- Our mission
  - to provide the highest quality of care for individuals with cognitive problems
  - to research causes and cures for degenerative brain diseases
  - to educate health professionals, patients and their families
- We want to bring the highest quality care to the widest number of people in a sustainable and replicable manner

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# Collaboration Between AA and the MAC

- PLWD and Caregiver Education
- Early Stage and Caregiver Support Groups
- Care Consultation Referrals
- Research Funding
- Advocacy
- Guidelines

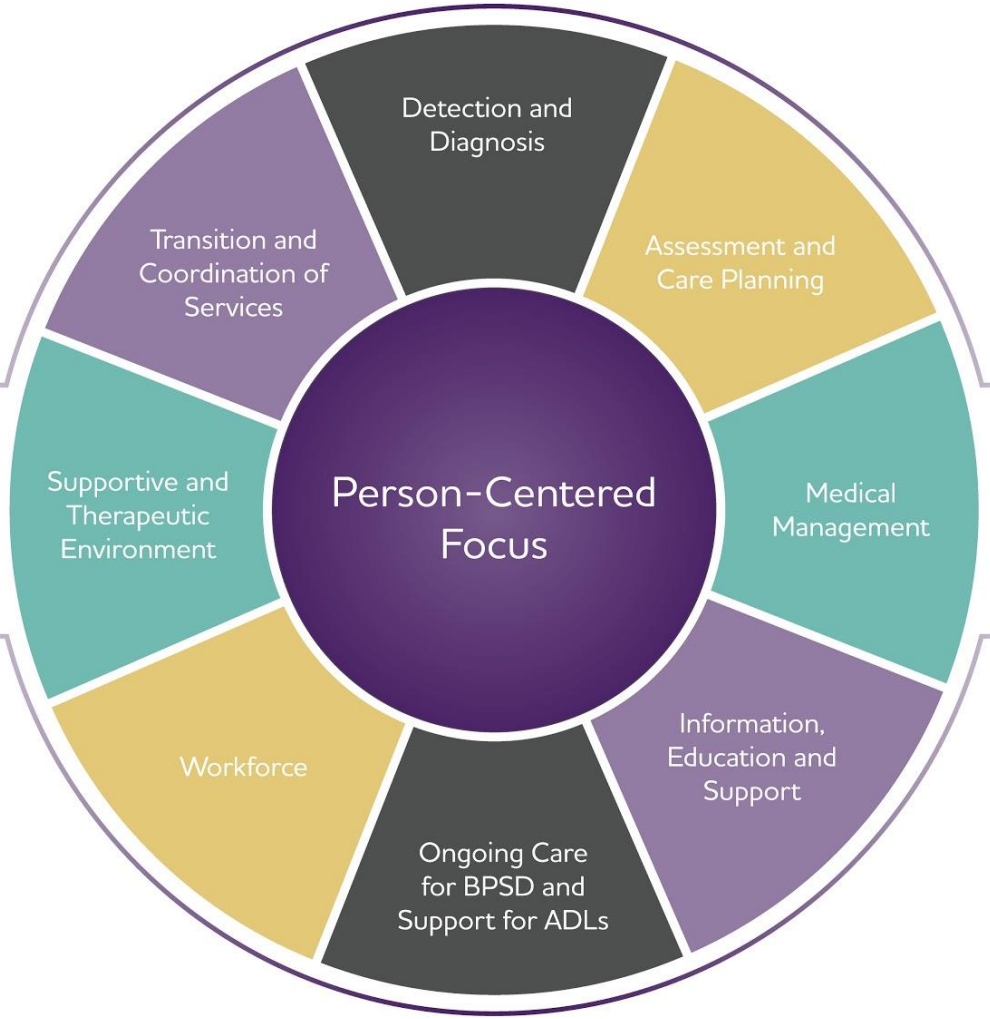
# Background

- Interprofessional collaboration can improve healthcare processes and outcomes but limitations in generalizability. (Zwarenstein M, et all, 2009)
  - Interprofessional rounds, interprofessional meetings, and externally facilitated interprofessional audit
  - Practice-based IPC interventions can improve healthcare processes and outcomes including: positive impact on length of stay and total charges (1/2 studies), appropriate prescribing of psychotropic drugs in nursing homes, and increased audit activity and reported improvements to care (1/1 study).

# Interdisciplinary Teams in Dementia Care

- Clinically meaningful reduction in behavioral episodes over the 6-month period of implementation of interdisciplinary behavior management team (Hughes et al 2000)
  - Information sharing, education, and collaboration => better management of behavioral Sx
- Barrier to diagnosis - limitations to resources, management of behavioral symptoms etc (Hinton, et al 2007; Bradford, et al 2009)
  - Systems limitations: too little time to spend with patient and lack of reimbursement (Bradford, et al 2009)
- CPT code 99483
  - Individuals with cognitive impairment, including Alzheimer's disease, are eligible to receive cognitive assessment and cognitive care planning services under this code. Eligible providers include physicians (MD and DO), nurse practitioners, clinical nurse specialists, certified nurse midwives and physician assistants.

# Dementia Care Practice Recommendations



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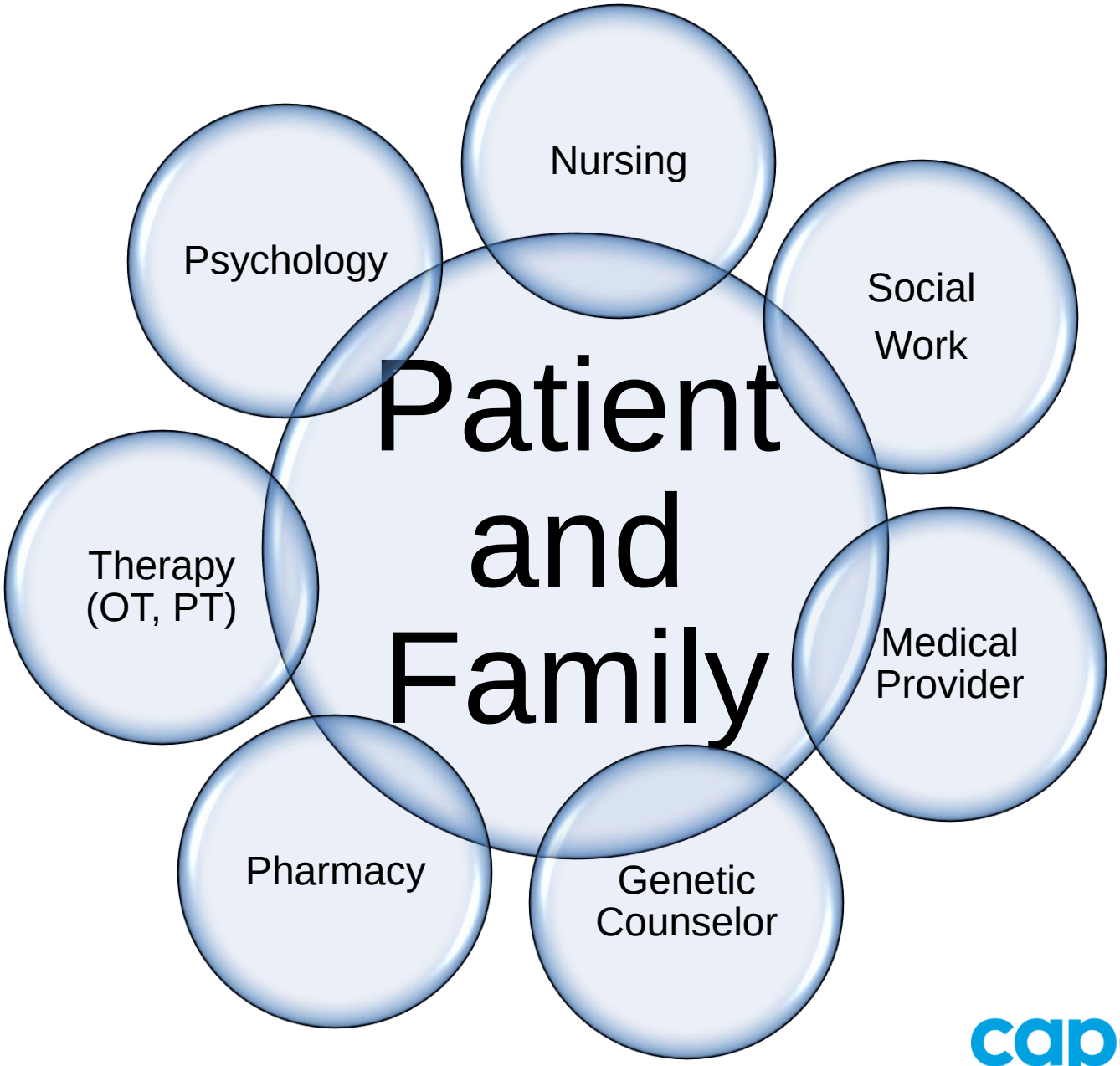


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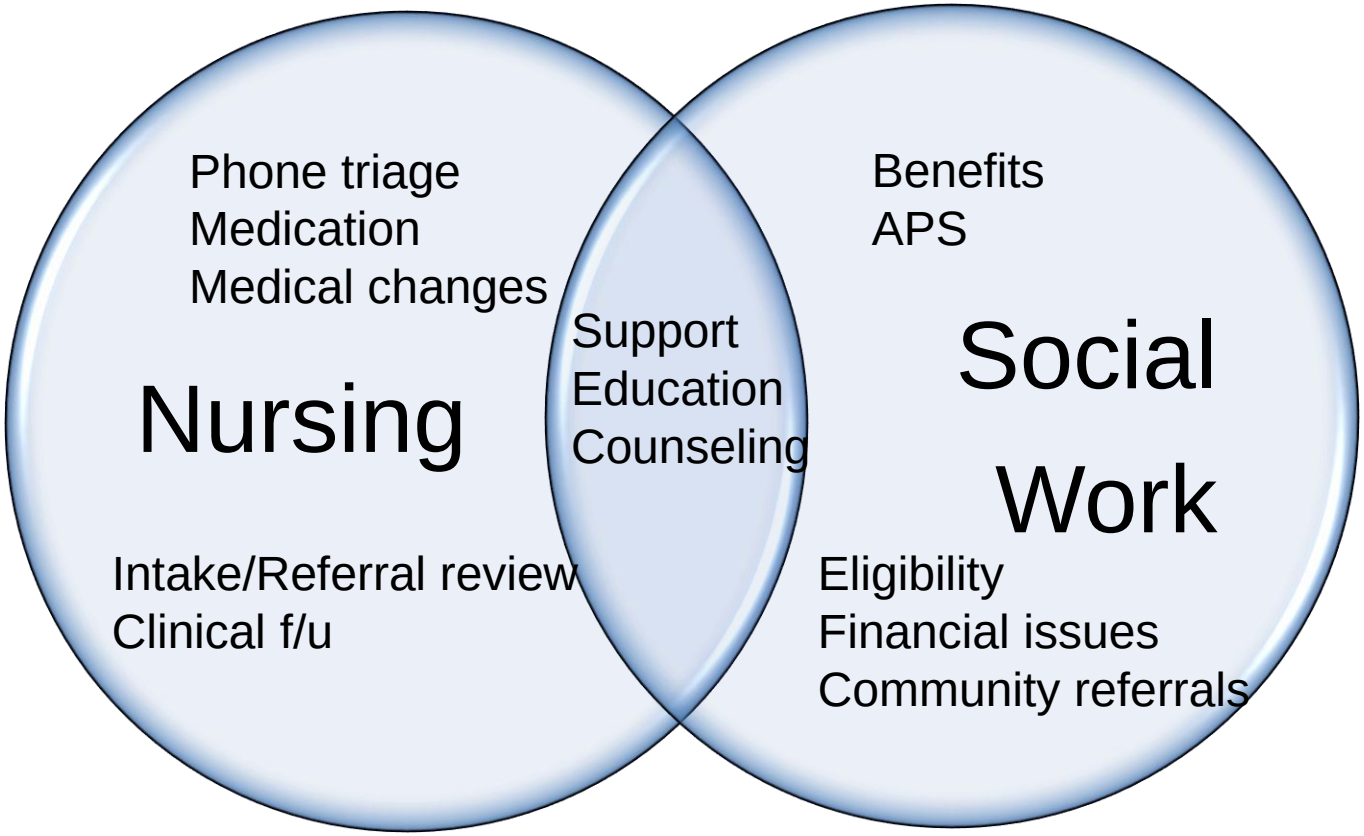
# Team Members



# Community Resources as Care Team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# Case Study

62yo man
Married, lives with wife and 2 children
Fit, active
Does a lot of home repair

Stellar employee who begins to have trouble at work – can't learn new computer system and isn't completing tasks

Getting counseled by his employer
Reaches out to HR
Takes a medical leave

# Case Study

Consults his PCP
Diagnosed with anxiety and depression and started on meds

Continues to worsen- wife now noticing changes at home with repairs, managing finances
Is unable to return to work
Requests referral for specialty evaluation

Seen at specialty center and diagnosed with Early Onset AD and started on medications, follow-up scheduled in 6 months

# Early Stage – Issues

- Disclosure
  - Who and how to tell?
- Autonomy vs Risk
  - Home repair
  - Driving
- Lack of insight
  - Awareness vs Acceptance
- Behavioral symptoms
  - Depression
  - Anxiety

# Interventions – Early Stage

- Medical
  - Further workup
  - Medications
  - Goals of care
  - Referrals (PT, Speech)
  - Clinical trials
  - Driving issues
  - Capacity declaration
- Nursing
  - Clarification about diagnosis/prognosis
  - Follow-up on side effects
  - Provide coaching about behavior management
  - Home safety (guns, supervision, home repair)

# Interventions – Early Stage

- Social Work
  - Care Planning
  - Disability
  - Legal/financial referrals for planning
  - Community resources
  - Education/Support Groups
  - Caregiver self-care
  - Meaningful activity
  - Psychosocial coaching
- Pharmacy
  - Counseling about polypharmacy
  - Guidance about supplements
- Therapy
  - Devices, adaptations

# Case Study

Patient can no longer drive
Wife returns to work for financial reasons
Patient having problems during the day making meals

Patient is increasingly irritable and frustrated
Spends much of the day watching TV and less attention to hygiene; sleep affected
Family is considering edible cannabinoids

Wife is concerned about her husband being home alone – making bad decisions and getting lost when walking in the neighborhood

# Interventions – Moderate Stage

- Medical
  - Review goals of care
  - Counseling about health maintenance
  - Capacity declaration – invoke DPOA
  - Medications for mood
- Nursing
  - Review environment
  - Sleep hygiene
  - Provide coaching about behavior management
  - Training about providing physical care
- Social Work
  - Safe Return/ID bracelet
  - Resources for day program or companion/in-home care
  - Counseling for children
  - Respite resources
  - Long-term care options
- Pharmacy
  - Counseling about new rx
  - Recommendations for sleep
  - Guidance about cannabinoids

# Case Study

Patient becomes incontinent and frequently can't identify his children
His balance is changing and he has had several falls and is losing weight
Requires assistance now with all ADL's

Children are beginning to resist being around their Dad and express fear for their safety

Wife finds work a respite and needs financial income
Considering placement and hospice

# Interventions – Severe Stage

- Medical
  - Review goals of care/consider stopping interventions
  - Palliative/Hospice referral
  - Comfort measures
- Nursing
  - Training about aspiration, falls, incontinence care
- Social Work
  - Respite
  - Palliative care or Hospice referral
  - End of life planning
  - Grief planning
- Therapy
  - Counseling about falls, ROM
  - Recommendations about DME

# Strategies for Success

- Establish leader of team
- Who's your client/patient?
- Roles & boundaries
- Communication!
- Take the time
- Build your team: think outside your clinic

# Develop Referral Network

- Alzheimer's Disease Research Centers
  - http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers
- State Alzheimer's Centers
  - http://cadc.ucsf.edu/cadc
  - http://www.wai.wisc.edu
  - https://gamemorynet.org/
  - www.health.ny.gov – COE for Alzheimer's Disease
- Neuropsychologist
  - American Academy of Clinical Neuropsychology https://theaacn.org/adult-neuropsychology/
- Psychiatrist
- Neurologist, Geriatrician

# Develop Referral Network

- Genetic Counselor
  - https://www.nsgc.org/findageneticcounselor
- Care managers (SW or Nurse)
  - www. aginglifecare.org
- Occupational therapy
  - https://www.aota.org/Practice/Productive-Aging/Driving/driving-specialists-directory-search.aspx

# Community Services as Team Members

- Alzheimer's Association
  - alz.org or 24/7 Helpline: 1-800-272-3900
  - Alz Direct Connect Program
- Other disease specific organizations (AFTD, CurePSP, LBDA)
- Caregiver Resource Centers
  - https://www.caregiver.org/family-care-navigator
- Alzheimer's Disease Education and Research (ADEAR)
  - https://www.nia.nih.gov/health/alzheimers
- Area Agency on Aging
  -
- State Department of Public Health

# Other Team Members

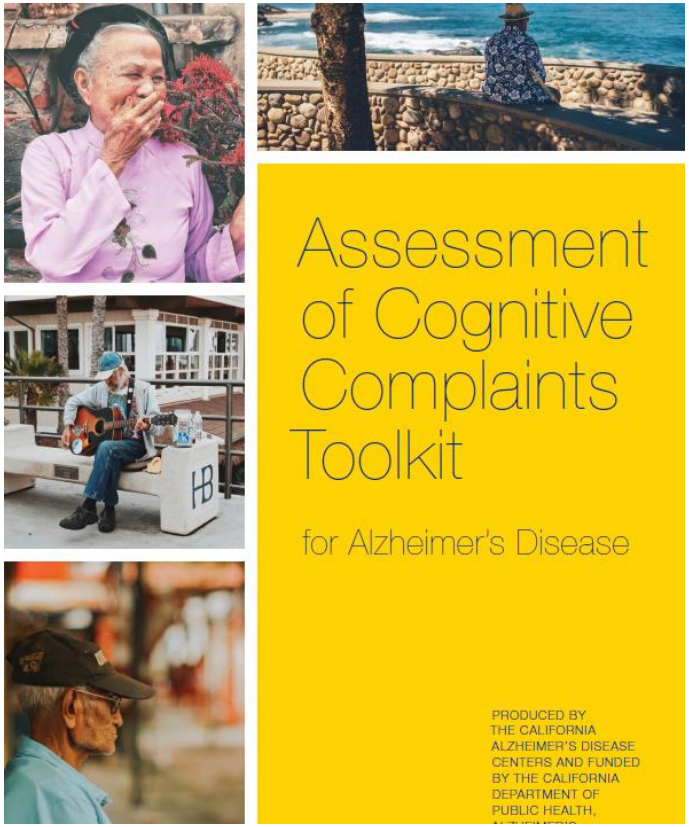
- Employee Assistance Programs
  - Employer based
  - Consultative, referral
- Medicare/Medicaid
  - https://www.medicare.gov/
- Social Security/Disability
  - https://www.disabilityapplicationhelp.org

# Other Team Members - CAPC

- CAPC Best Practices in Dementia Care and Caregiver Support

- Coming Soon: dementia care toolkit, Implementing Best Practices in Dementia Care, which focuses on operationalizing dementia care practices

# Guidelines: ACCT-AD Toolkit




- Questions and Interpretation
  - History
  - Exam
  - Diagnostic Tests
- Scripts
  - Disclosure
  - Driving
  - Behaviors
  - Treatment
- Billing Guidance

https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDCB/Pages/AlzheimersDiseaseResources.aspx

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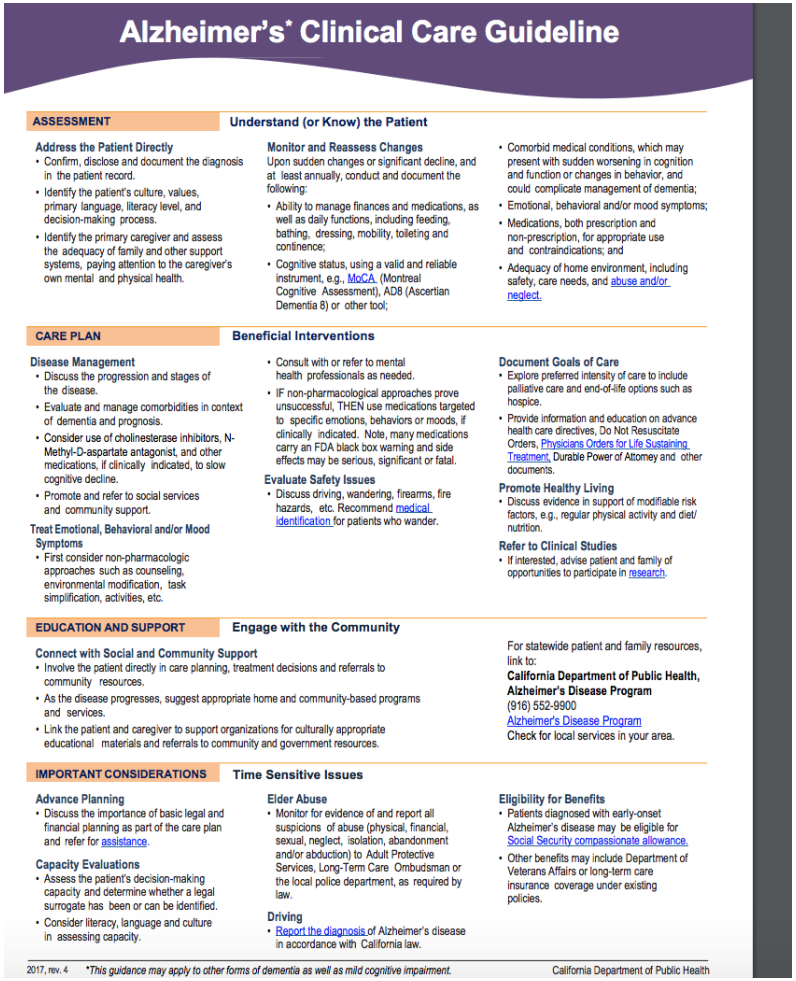
# Guidelines: 2017



## Alzheimer's* Clinical Care Guideline

### ASSESSMENT — Understand (or Know) the Patient

**Address the Patient Directly**
- Confirm, disclose and document the diagnosis in the patient record.
- Identify the patient's culture, values, primary language, literacy level, and decision-making process.
- Identify the primary caregiver and assess the adequacy of family and other support systems, paying attention to the caregiver's own mental and physical health.

**Monitor and Reassess Changes**
Upon sudden changes or significant decline, and at least annually, conduct and document the following:
- Ability to manage finances and medications, as well as daily functions, including feeding, bathing, dressing, mobility, toileting and continence;
- Cognitive status, using a valid and reliable instrument, e.g., MoCA (Montreal Cognitive Assessment), AD8 (Ascertian Dementia 8) or other tool;
- Comorbid medical conditions, which may present with sudden worsening in cognition and function or changes in behavior, and could complicate management of dementia;
- Emotional, behavioral and/or mood symptoms;
- Medications, both prescription and non-prescription, for appropriate use and contraindications; and
- Adequacy of home environment, including safety, care needs, and abuse and/or neglect.

### CARE PLAN — Beneficial Interventions

**Disease Management**
- Discuss the progression and stages of the disease.
- Evaluate and manage comorbidities in context of dementia and prognosis.
- Consider use of cholinesterase inhibitors, N-Methyl-D-aspartate antagonist, and other medications, if clinically indicated, to slow cognitive decline.
- Promote and refer to social services and community support.

**Treat Emotional, Behavioral and/or Mood Symptoms**
- First consider non-pharmacologic approaches such as counseling, environmental modification, task simplification, activities, etc.
- Consult with or refer to mental health professionals as needed.
- IF non-pharmacological approaches prove unsuccessful, THEN use medications targeted to specific emotions, behaviors or moods, if clinically indicated. Note, many medications carry an FDA black box warning and side effects may be serious, significant or fatal.

**Evaluate Safety Issues**
- Discuss driving, wandering, firearms, fire hazards, etc. Recommend medical identification for patients who wander.

**Document Goals of Care**
- Explore preferred intensity of care to include palliative care and end-of-life options such as hospice.
- Provide information and education on advance health care directives, Do Not Resuscitate Orders, Physicians Orders for Life Sustaining Treatment, Durable Power of Attorney and other documents.

**Promote Healthy Living**
- Discuss evidence in support of modifiable risk factors, e.g., regular physical activity and diet/nutrition.

**Refer to Clinical Studies**
- If interested, advise patient and family of opportunities to participate in research.

### EDUCATION AND SUPPORT — Engage with the Community

**Connect with Social and Community Support**
- Involve the patient directly in care planning, treatment decisions and referrals to community resources.
- As the disease progresses, suggest appropriate home and community-based programs and services.
- Link the patient and caregiver to support organizations for culturally appropriate educational materials and referrals to community and government resources.

For statewide patient and family resources, link to:
**California Department of Public Health, Alzheimer's Disease Program**
(916) 552-9900
Alzheimer's Disease Program
Check for local services in your area.

### IMPORTANT CONSIDERATIONS — Time Sensitive Issues

**Advance Planning**
- Discuss the importance of basic legal and financial planning as part of the care plan and refer for assistance.

**Capacity Evaluations**
- Assess the patient's decision-making capacity and determine whether a legal surrogate has been or can be identified.
- Consider literacy, language and culture in assessing capacity.

**Elder Abuse**
- Monitor for evidence of and report all suspicions of abuse (physical, financial, sexual, neglect, isolation, abandonment and/or abduction) to Adult Protective Services, Long-Term Care Ombudsman or the local police department, as required by law.

**Driving**
- Report the diagnosis of Alzheimer's disease in accordance with California law.

**Eligibility for Benefits**
- Patients diagnosed with early-onset Alzheimer's disease may be eligible for Social Security compassionate allowance.
- Other benefits may include Department of Veterans Affairs or long-term care insurance coverage under existing policies.

2017, rev. 4 *This guidance may apply to other forms of dementia as well as mild cognitive impairment. California Department of Public Health

# Alzheimer's Clinical Care

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# Summary

- Care of patients and families with dementia is complex and requires a comprehensive team approach
- For success, teams require clear leadership and communication
- Expanding our definition of team to include virtual and community members can enhance care and better provide support to providers, patients and families.

Memory and Aging Center

Alzheimer’s Association



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# Questions?

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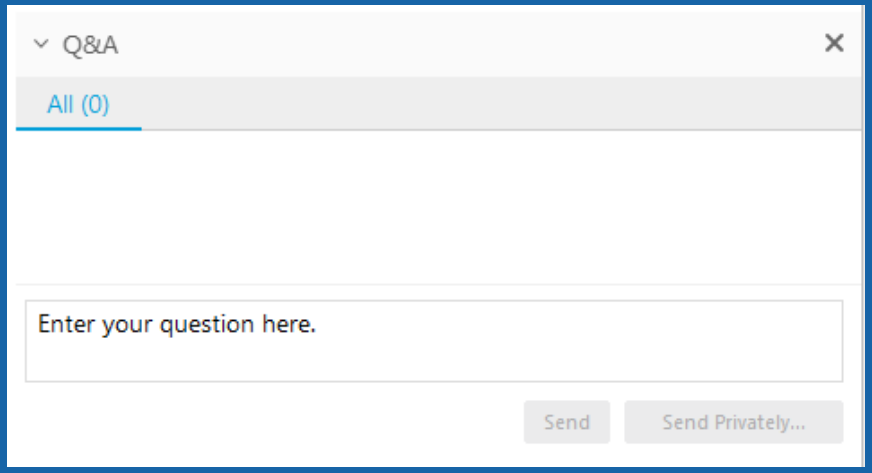


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Tipping Point
CHALLENGE

# LEAD THE CHARGE FOR CHANGE

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