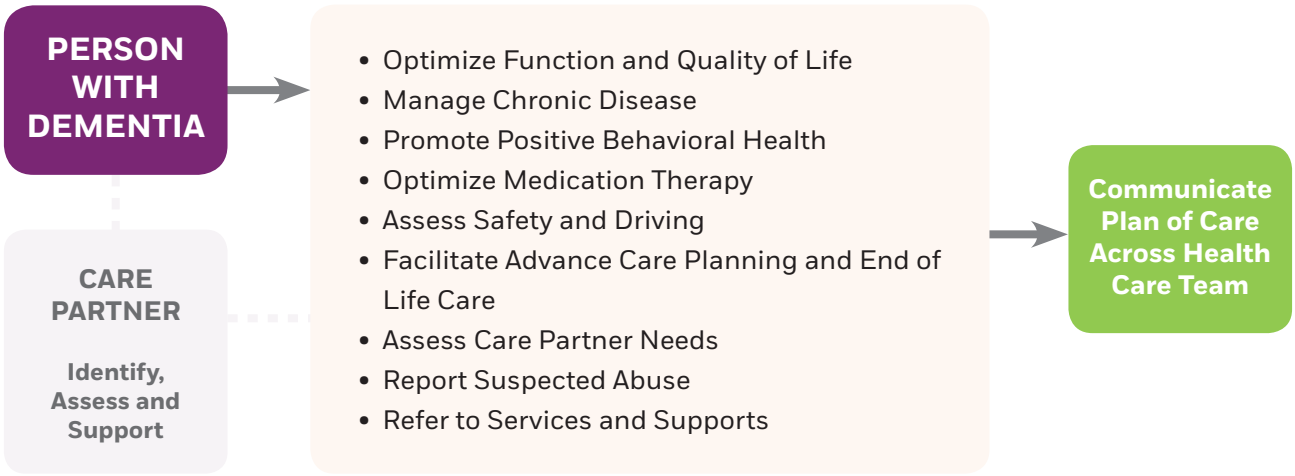
Dementia Friendly America™

Managing Dementia Across the Continuum
(Mid to Late Stage*)



Using Dementia as the Organizing Principle when Caring for Patients with Dementia and Comorbidities: www.mnmed.org/Portals/mma/MMA Events/CME/Schoephoerster.pdf

Optimize Function and Quality of Life

- ☐ Assess cognitive and functional status
- ☐ Identify preserved capabilities and preferred activities; encourage socializing and participating in activities
- ☐ Refer to an occupational therapist and/or physical therapist to maximize independence
- ☐ Encourage lifestyle changes that may reduce disease symptoms or slow their progression (e.g., establish routines for person with disease and care partner)
- ☐ Work with health care team to appropriately treat conditions that can worsen symptoms or lead to poor outcomes, including depression and existing medical issues

Manage Chronic Disease

- ☐ As dementia progresses, modify treatment goals and thresholds
- ☐ Create an action plan for chronic conditions (e.g., CHF) and geriatric syndromes to prevent potentially harmful hospitalization
- ☐ Schedule regular health care provider visits, encourage care partner presence

* The latest DSM-5 manual uses the term "Major Neurocognitive Disorder" for dementia and "Mild Neurocognitive Disorder" for mild cognitive impairment. This ACT on Alzheimer's resource uses the more familiar terminology, as the new terms have yet to be universally adopted.

Promote Positive Behavioral Health

☐ Key steps to promoting positive behavioral health include:

1. Rule out delirium for any acute changes in behavioral expressions and other symptoms
2. Define and categorize the target behavioral expression and other symptom (Examples: hallucinations, delusions, physical aggression, spontaneous disinhibition, mood-related)
    - Identify and address unmet need(s) (**see Figure 1: Screening, Identifying, and Managing Behavioral Symptoms in Patients With Dementia on page 4**)
    - Only treat conditions that are bothersome or negatively affecting the quality of life of the person with the disease
3. Initiate non-pharmacologic therapies aimed at reducing the target symptom
    - **See Table 1: Potential Nonpharmacologic Strategies on page 5**
    - **See Table 2: General Nonpharmacologic Strategies for Managing Behavioral Symptoms on page 6**
    - Give the patient "tasks" that match his/her level of competency
    - Train caregivers to validate, redirect, and re-approach
    - Reinforce that routine is essential
    - Control the level of stimulation in the person's environment
    - Be proactive: Write orders for non-pharmacologic interventions
    - Ask caregivers to re-administer a behavior tool (e.g., Cohen Mansfield) to assess the efficacy of the therapy
4. Consider pharmacologic interventions only when non-pharmacologic interventions consistently fail and the person is in danger of doing harm to self or others, or when intolerable psychiatric suffering is evident
    - Note there is no FDA-approved medication for Behavioral and Psychological Symptoms of Dementia (BPSD), nor strong scientific evidence to support any particular class of medications. If you use any medications, document informed consent in the medical record and counsel caregivers to monitor for degraded functional or cognitive status, sedation, falls or delirium.
    - Regularly attempt to wean or discontinue the medication as soon as possible.
    - Regularly monitor target behaviors to evaluate efficacy of medication, if started.

Optimize Medication Therapy

☐ Identify all prescriptions and over-the-counter medications being used, including vitamins and herbal remedies
☐ **Avoid or minimize anticholinergics, hypnotics (benzodiazepines, zolpidem), H2-receptor antagonists, and antipsychotics**
☐ Evaluate the medications for over and underuse and inappropriate prescribing
☐ Periodically reassess the value of any medications, including those being used for cognitive symptoms; consider a slow taper if continued benefit is unclear
☐ Recommend a care partner or health care professional oversees/dispenses medications as needed

Assess Safety and Driving

Continue to discuss home safety and fall risk

☐ Refer to an occupational therapist and/or physical therapist, if indicated, to address fall risk, sensory/mobility aids and home modifications

Continue to discuss safe driving

☐ Refer to driving rehabilitation specialist for clinical and/or in-vehicle evaluation
☐ Report an at-risk driver

Faciliate Advance Care Planning and End of Life Care

- ☐ Continue to discuss care goals, values and preferences with person with the disease and family
- ☐ Discuss the role of palliative care and hospice in addressing pain and suffering
- ☐ Encourage completion of healthcare directive and financial surrogacy documents
- ☐ Complete POLST, when appropriate (and routinely re-evaluate/modify plan of care as appropriate)

Assess Care Partner Needs

Identify care partner/caregiver and assess needs
Encourage self care of care partner

- ☐ Offer suggestions to the care partner for maintaining health and well-being
- ☐ Encourage caregiver support services (e.g., respite) in the care plan for the person with dementia
- ☐ Provide education on behavioral expressions and stages of dementia

Report Suspected Abuse

- ☐ Report suspected abuse, neglect (including self neglect), or financial exploitation
  - Under many state statutes, licensed health care professionals and professionals engaged in the care of a vulnerable adult are mandated to report suspected maltreatment of a vulnerable adult

Refer to Services and Supports

- ☐ Visit the Eldercare Locator at www.eldercare.gov or call 1-800-677-1116 to get connected to aging services such as financial assistance, home delivered meals, transportation, adult day services and long-term care options in every community across the US.
- ☐ Contact the Alzheimer's Association 24/7 Helpline at 1-800-272-3900 or www.alz.org for information, education and support.
- ☐ Culturally responsive supports and resources: www.actonalz.org/culturally-responsive-resources.

Mid To Late Stage Resources

Managing Dementia Across the Continuum

Professional Resource

- Using Dementia as the Organizing Principle when Caring for Patients with Dementia and Comorbidities: www.mnmed.org/Portals/mma/MMA%20Events/CME/Schoephoerster.pdf

Optimize Function and Quality of Life

Professional Resources

- Instrumental Activities of Daily Living (IADL): http://consultgerirn.org/uploads/File/trythis/try_this_23.pdf
- Activities of Daily Living (ADL): http://consultgerirn.org/uploads/File/trythis/try_this_2.pdf
- FAST Scale: http://geriatrics.uthscsa.edu/tools/FAST.pdf
- MN Live Well at Home: www.mnlivewellathome.org
- Patient Health Questionnaire (PHQ-9): www.sfaetc.ucsf.edu/docs/PHQ20-20Questions.pdf

Family Resource

- Stages of Alzheimer's: www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

Promote Positive Behavioral Health

Professional Resources

- ABC of Behavior Management: www.dementiamanagementstrategy.com/Pages/ABC_of_behaviour_management.aspx
- ACT on Alzheimer's Dementia Curriculum and Dementia Trainings for Direct Care Staff: www.actonalz.org/dementia-education
- Confusion Assessment Method (CAM) for identifying delirium: www.healthcare.uiowa.edu/igec/tools/cognitive/CAM.pdf (Adapted from: Inouye SK, et al. Ann Intern Med. 1990; 113: 941-948. Confusion Assessment Method. Copyright 2003, Hospital Elder Life Program, LLC. Not to be reproduced without permission.)
- Delirium Information: www.uptodate.com/contents/delirium-beyond-the-basics
- Cohen Mansfield Agitation Inventory: www.dementia-assessment.com.au/symptoms/CMAI_Scale.pdf
- Pain Assessments: www.geriatricpain.org/Content/Assessment/Impaired/Pages/default.aspx
- Coping with Behavior Change in Dementia: A Family Caregiver's Guide: http://whisppub.com/coping-with-behavior-change-in-dementia/
- Validation Therapy: www.youtube.com/watch?v=CrZXz10FcVM

Family Resources

- Teaching Families About Delirium: www.viha.ca/NR/rdonlyres/28BFF246-F1F9-4BB8-8145-83FB04C1F545/0/pamphlet_family_09.pdf
- Coping with Behavior Change in Dementia: A Family Caregiver's Guide: http://whisppub.com/coping-with-behavior-change-in-dementia/

Manage Chronic Disease

Professional Resource
- Guiding Principles for the Care of Older Adults with Multimorbidity: www.americangeriatrics.org/health_care_professionals/clinical_practice/multimorbidity

Family Resource
- Geriatric Syndromes and Resources: www.healthinaging.org/resources/resource:guide-to-geriatric-syndromes-part-i/

Optimize Medication Therapy

Professional Resources
- AGS Beers Criteria (2012): www.americangeriatrics.org/files/documents/beers/2012BeersCriteria_JAGS.pdf
- Drugs with Possible Anticholinergic Effects: www.indydiscoverynetwork.org/resources/antichol_burden_scale.pdf
- START (Screening Tool to Alert Doctors to the Right Treatment):
- http://ageing.oxfordjournals.org/content/36/6/632.full.pdf+html
- STOPP (Screening Tool of Older Persons' Potentially inappropriate Prescriptions): http://ageing.oxfordjournals.org/content/37/6/673.full.pdf+html?sid=cabc290d-e3ec-4c69-8dec-a27016271785

Family Resource
- Improve Dementia Care by Reducing Unnecessary Antipsychotic Drugs: www.actonalz.org/pdf/ReduceDrugs.pdf

Assess Safety and Driving

Professional Resources
- American Geriatrics Society Clinic Practice Guideline – Prevention of Falls in Older Persons: www.americangeriatrics.org/health_care_professionals/clinical_practice/clinical_guidelines_recommendations/2010/
- Finding a Driving Assessment Program: http://myaota.aota.org/driver_search/index.aspx
- Practice Parameter Update – Evaluation and Management of Driving Risk in Dementia: www.neurology.org/content/early/2010/04/12/WNL.0b013e3181da3b0f.full.pdf
- AMA Physician's Guide to Assessing and Counseling Older Drivers: www.nhtsa.gov/people/injury/olddrive/olderdriversbook/pages/contents.html
- National Council on Aging Falls Prevention Resource Center: www.ncoa.org/center-for-healthy-aging/falls-resource-center/

Family Resources
- Minnesota Falls Prevention: www.mnfallsprevention.org/consumer/index.html
- Obtain MedicAlert® + Alzheimer's Association Safe Return® www.alz.org/care/dementia-medic-alert-safe-return.asp
- At the Crossroads: www.thehartford.com/sites/thehartford/files/at-the-crossroads-2012.pdf
- Dementia and Driving Resource Center: www.alz.org/care/alzheimers-dementia-and-driving.asp
- STEADI Initiative: Older Adult Fall Prevention: www.cdc.gov/steadi/patient.html

Advance Care Planning and End of Life Care

Professional Resources
- Hospice Criteria Card (2013): http://geriatrics.uthscsa.edu/gerifellowship/documents/updated_08_2013/Hospice%20Card%20%20JSR%20SSR%202013.07.10.pdf
- POLST (Provider Orders for Life Sustaining Treatment): www.polst.org

Resources for Professionals and Family
- National Hospice and Palliative Care Organization - download state specific advance directive forms at www.caringinfo.org
- Advance Care Planning Resources: www.nhdd.org/public-resources/#where-can-i-get-an-advance-directive
- End of Life Decisions: www.alz.org/national/documents/brochure_endoflifedecisions.pdf

Assess Care Partner Needs

Professional Resources
- Caregiver Self Assessment: www.caregiving.org/wp-content/uploads/2010/11/caregiverselfassessment_english.pdf
- Zarit Burden Interview: www.healthcare.uiowa.edu/igec/tools/caregivers/burdenInterview.pdf

Family Resources
- Alzheimer's Association: 1-800-272-3900 or www.alz.org/care/
- Eldercare Locator: www.eldercare.gov or 1-800-677-1116
- Culturally responsive supports and resources: www.actonalz.org/culturally-responsive-resources

Report Suspected Abuse

Professional Resource
- U.S. Preventative Task Force recommendations for screening for elder abuse: www.uspreventiveservicestaskforce.org/3rduspstf/famviolence/famviolrs.htm

Resources for Professionals and Family
- National Adult Protective Services Association: www.napsa-now.org
- National Committee for the Prevention of Elder Abuse: www.preventelderabuse.org/elderabuse/

Adapted from ACT on Alzheimer's® developed tools and resources.