



# 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](http://www.mnmed.org/Portals/mma/MMA%20Events/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

## Facilitate 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

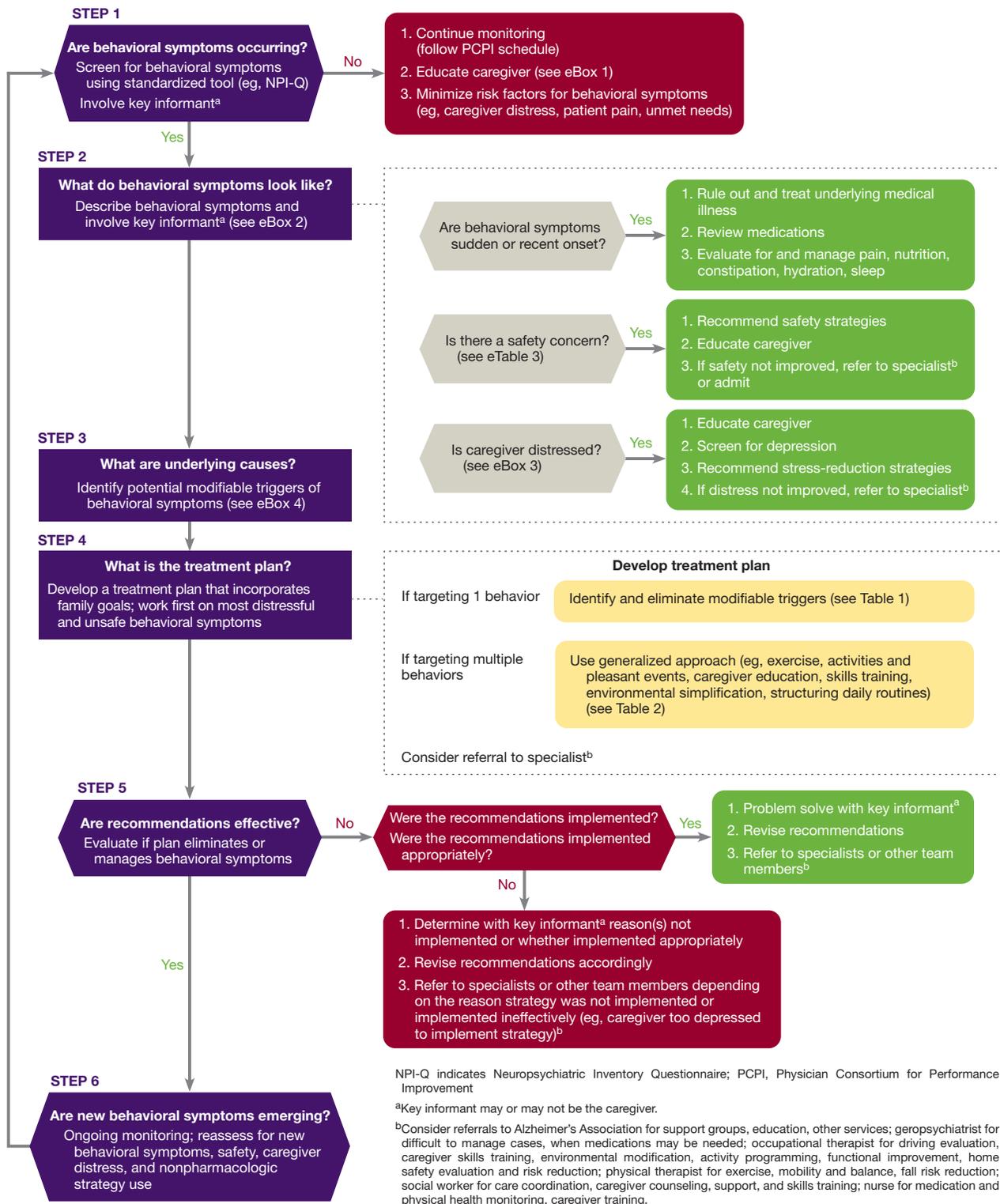
## Report Suspected Abuse

- Report suspected abuse, neglect (including self neglect), or financial exploitation
  - Under Minnesota 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

- Link to an expert by calling Senior LinkAge Line®, A One Stop Shop for Minnesota Seniors at 1-800-333-2433 or visit [www.MinnesotaHelp.info](http://www.MinnesotaHelp.info)® to locate and arrange for support, such as indoor and outdoor chore services, home-delivered meals, transportation and assistance with paying for prescription drugs.
- Contact the Alzheimer's Association Minnesota-North Dakota 24/7 Helpline at 1-800-272-3900 or [www.alz.org](http://www.alz.org).
- Cultural responsive supports and resources: [www.actonalz.org/culturally-responsive-resources](http://www.actonalz.org/culturally-responsive-resources).

# FIGURE 1: SCREENING, IDENTIFYING AND MANAGING BEHAVIORAL SYMPTOMS IN PATIENTS WITH DEMENTIA\*



\*Figure from Gitlin LN, Kales, HC, Lyketsos CG. Nonpharmacologic management of behavioral symptoms in dementia. *JAMA*. 2012; 308(19):2020-2029. Used by permission. © 2012 American Medical Association. All rights reserved.

## TABLE 1: POTENTIAL NONPHARMACOLOGIC STRATEGIES\*

Targeted Behavior by Presenting Dementia Stage	Select Nonpharmacologic Strategies <sup>a</sup>
Mild cognitive impairment Forgetfulness about taking medication	Evaluate capacity for taking medications independently Use assistive aids (calendar to remind of time for medication, checklists, pill dispenser <sup>b</sup> ) Supervise medication taking and secure medications
General forgetfulness; disorientation to time	Use memory aids (calendar or white board showing current date) Simplify daily routines
Moderate dementia Falling and poor balance	Use a fall alert system if patient can remember to activate <sup>b</sup> Consider referral to occupational therapy for home safety evaluation and removal of tripping hazards Minimize alcohol intake Consider referral to physical therapy for simple balance exercise
Hearing voices or noises (especially at night)	Evaluate hearing and adjust amplification of hearing aids <sup>b</sup> Evaluate quality and severity of auditory disturbances <sup>b</sup> If hallucinations are judged to be present, evaluate whether they present an actual threat to safety or function in deciding whether or not to use antipsychotic treatment <sup>b</sup>
Inability to respond to emergency (difficulty calling for help)	Educate caregiver about need to supervise patient <sup>b</sup> Inform neighbors, fire department, and police of situation Develop emergency plan involving others if possible
Leaving the home; wandering outdoors	Outfit with an ID bracelet (eg, Alzheimer Safe Return Program) or badge with patient's name and address <sup>b</sup> Notify police and neighbors of patient's condition <sup>b</sup> Identify potential triggers for elopement and modify them
Memory-related behavior (eg, disorientation or confusion with object recognition)	Label needed objects Remove unnecessary objects to reduce confusion with tasks Present a single object at a time as needed Keep all objects for a task in a labeled container (eg, grooming)
Nighttime wakefulness, turning on lights, awaking caregiver, feeling insecure at night	Evaluate sleep routines <sup>b</sup> Evaluate environment for temperature, noise, light, shadows, level of comfort, or other possible disturbances Eliminate caffeinated beverages (starting during the afternoon) <sup>b</sup> Create a structured schedule that includes exercise and activity engagement throughout the day <sup>b</sup> Limit daytime napping <sup>b</sup> Address daytime loneliness and boredom that may contribute to nighttime insecurities <sup>b</sup> Implement good sleep hygiene <sup>b</sup> Use nightlight <sup>b</sup> Hire nighttime assistance to enable caregiver to sleep <sup>b</sup> Create a quiet routine for bedtime that includes calming activity, calming music
Repetitive questioning	Respond using a calm, reassuring voice <sup>b</sup> Use calm touch for reassurance Inform patient of events as they occur (vs indicating what will happen in near or far future) Structure daily routines Provide meaningful activities during the day to engage patient Use distraction

<sup>a</sup>Strategies are potential approaches used in randomized clinical trials but are not exhaustive. A suggested strategy may be effective for one patient but not another. Any single strategy may not have been evaluated for effectiveness for use with all dementia patients with the same presenting behavior. These strategies should only be considered once a thorough assessment has been completed (Figure, steps 2 and 3).

<sup>b</sup>Strategies discussed, considered, or implemented by Mr P's physician and caregiver.

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## TABLE 2: GENERAL NONPHARMACOLOGIC STRATEGIES FOR MANAGING BEHAVIORAL SYMPTOMS\*

Domain	Key Strategies <sup>a</sup>
Activities	<ul style="list-style-type: none"> <li>Introduce activities that tap into preserved capabilities and previous interests</li> <li>Introduce activities involving repetitive motion (washing windows, folding towels, putting coins in container)</li> <li>Set up the activity and help patient initiate participation if necessary</li> </ul>
Caregiver education and support	<ul style="list-style-type: none"> <li>Understand that behaviors are not intentional</li> <li>Relax the rules (eg, no right or wrong in performing activities/tasks as long as patient and caregiver are safe)</li> <li>Consider that with disease progression, patient may have difficulty initiating, sequencing, organizing, and completing tasks without guidance and cueing</li> <li>Concur with patient's view of what is true and avoid arguing or trying to reason or convince</li> <li>Take care of self; find opportunities for respite; practice healthy behaviors and attend preventive physician visits</li> <li>Identify and draw upon a support network</li> </ul>
Communication	<ul style="list-style-type: none"> <li>Allow patient sufficient time to respond to a question</li> <li>Provide 1- to 2-step simple verbal commands</li> <li>Use a calm, reassuring tone</li> <li>Offer simple choices (no more than 2 at a time)</li> <li>Avoid negative words and tone</li> <li>Lightly touch to reassure, calm, or redirect</li> <li>Identify self and others if patient does not remember names</li> <li>Help patient find words for self-expression</li> </ul>
Simplify environment	<ul style="list-style-type: none"> <li>Remove clutter or unnecessary objects</li> <li>Use labeling or other visual cues</li> <li>Eliminate noise and distractions when communicating or when patient is engaging in an activity</li> <li>Use simple visual reminders (arrows pointing to bathroom)</li> </ul>
Simplify tasks	<ul style="list-style-type: none"> <li>Break each task into very simple steps</li> <li>Use verbal or tactile prompt for each step</li> <li>Provide structured daily routines that are predictable</li> </ul>

<sup>a</sup>Strategies are potential approaches used in randomized clinical trials but are not exhaustive. A suggested strategy may be effective for one patient but not another. Any single strategy may not have been evaluated for effectiveness for use with all dementia patients with the same presenting behavior. These strategies should only be considered once a thorough assessment has been completed (Figure, steps 2 and 3).

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# 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](http://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://consultgeri.org/try-this/dementia/issue-d13.pdf>
- Activities of Daily Living (ADL): <http://consultgeri.org/try-this/general-assessment/issue-2.pdf>
- FAST Scale: <http://geriatrics.uthscsa.edu/tools/FAST.pdf>
- MN Live Well at Home: [www.mnlivewellathome.org](http://www.mnlivewellathome.org)
- Patient Health Questionnaire (PHQ-9): [www.sfaetc.ucsf.edu/docs/PHQ20-20Questions.pdf](http://www.sfaetc.ucsf.edu/docs/PHQ20-20Questions.pdf)

### Family Resource

- Stages of Alzheimer's: [www.alz.org/alzheimers\\_disease\\_stages\\_of\\_alzheimers.asp](http://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](http://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](http://www.actonalz.org/dementia-education)
- Confusion Assessment Method (CAM) for identifying delirium: [www.healthcare.uiowa.edu/igec/tools/cognitive/CAM.pdf](http://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](http://www.uptodate.com/contents/delirium-beyond-the-basics)
- Cohen Mansfield Agitation Inventory: [www.dementia-assessment.com.au/symptoms/CMAI\\_Scale.pdf](http://www.dementia-assessment.com.au/symptoms/CMAI_Scale.pdf)
- Pain Assessments: [www.geriatricpain.org/Content/Assessment/Impaired/Pages/default.aspx](http://www.geriatricpain.org/Content/Assessment/Impaired/Pages/default.aspx)
- MN Partnership to Improve Dementia Care – CMS Letter to Medical Professionals: [www.health.state.mn.us/divs/fpc/cwww/letter072513.pdf](http://www.health.state.mn.us/divs/fpc/cwww/letter072513.pdf)
- Validation Therapy: [www.youtube.com/watch?v=CrZXz10FcVM](http://www.youtube.com/watch?v=CrZXz10FcVM)

### Family Resource

- Teaching Families About Delirium: [www.viha.ca/NR/rdonlyres/28BFF246-F1F9-4BB8-8145-83FB04C1F545/0/pamphlet\\_family\\_09.pdf](http://www.viha.ca/NR/rdonlyres/28BFF246-F1F9-4BB8-8145-83FB04C1F545/0/pamphlet_family_09.pdf)



## Manage Chronic Disease

### **Professional Resource**

- Guiding Principles for the Care of Older Adults with Multimorbidity:  
[www.americangeriatrics.org/health\\_care\\_professionals/clinical\\_practice/multimorbidity](http://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/](http://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](http://www.americangeriatrics.org/files/documents/beers/2012BeersCriteria_JAGS.pdf)
- Drugs with Possible Anticholinergic Effects:  
[www.indydiscoverynetwork.org/resources/antichol\\_burden\\_scale.pdf](http://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](http://www.actonalz.org/pdf/ReduceDrugs.pdf)

## Assess Safety and Driving

### **Professional Resources**

- Minnesota Falls Prevention: [www.mnfallsprevention.org/consumer/index.html](http://www.mnfallsprevention.org/consumer/index.html)
- AMA Physician's Guide to Assessing and Counseling Older Drivers:  
[www.nhtsa.gov/people/injury/olddrive/olderdriversbook/pages/contents.html](http://www.nhtsa.gov/people/injury/olddrive/olderdriversbook/pages/contents.html)
- American Geriatrics Society Clinic Practice Guideline – Prevention of Falls in Older Persons:  
[www.americangeriatrics.org/health\\_care\\_professionals/clinical\\_practice/clinical\\_guidelines\\_recommendations/2010/](http://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](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](http://www.neurology.org/content/early/2010/04/12/WNL.0b013e3181da3b0f.full.pdf)

### **Family Resources**

- Actions to take if concerned about a family member's driving:  
<https://dps.mn.gov/divisions/ots/older-drivers/Pages/default.aspx>
- Minnesota Falls Prevention: [www.mnfallsprevention.org/consumer/index.html](http://www.mnfallsprevention.org/consumer/index.html)
- Obtain MedicAlert® + Alzheimer's Association Safe Return®  
[www.alz.org/care/dementia-medic-alert-safe-return.asp](http://www.alz.org/care/dementia-medic-alert-safe-return.asp)
- At the Crossroads: [www.thehartford.com/sites/thehartford/files/at-the-crossroads-2012.pdf](http://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](http://www.alz.org/care/alzheimers-dementia-and-driving.asp)

## 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](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.mnmed.org/Portals/mma/PDFs/POLSTform.pdf](http://www.mnmed.org/Portals/mma/PDFs/POLSTform.pdf)

### **Resources for Professionals and Family**

- Health Care Directive: [www.extension.umn.edu/family/live-healthy-live-well/healthy-futures/health-care-directive/](http://www.extension.umn.edu/family/live-healthy-live-well/healthy-futures/health-care-directive/)
- Honoring Choices: [www.honoringchoices.org](http://www.honoringchoices.org)
- Mid-Minnesota Legal Aid: <http://mylegalaid.org>
- Office of the Attorney General of the State of Minnesota: [www.ag.state.mn.us](http://www.ag.state.mn.us)

## Assess Care Partner Needs

### **Professional Resources**

- Caregiver Self Assessment: [www.caregiving.org/wp-content/uploads/2010/11/caregiverselfassessment\\_english.pdf](http://www.caregiving.org/wp-content/uploads/2010/11/caregiverselfassessment_english.pdf)
- Zarit Burden Interview: [www.healthcare.uiowa.edu/igec/tools/caregivers/burdenInterview.pdf](http://www.healthcare.uiowa.edu/igec/tools/caregivers/burdenInterview.pdf)

### **Family Resources**

- Alzheimer's Association Minnesota-North Dakota, 800-272-3900 or [www.alz.org/care/](http://www.alz.org/care/)
- Senior LinkAge Line®, 800-333-2433 or [www.MinnesotaHelp.info](http://www.MinnesotaHelp.info)
- Cultural responsive supports and resources: [www.actonalz.org/culturally-responsive-resources](http://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](http://www.uspreventiveservicestaskforce.org/3rduspstf/famviolence/famviolrs.htm)

### **Resources for Professionals and Family**

- Minnesota Department of Human Services Adult Protective Services Unit: [www.dhs.state.mn.us/main/id\\_005710](http://www.dhs.state.mn.us/main/id_005710)
- S.A.F.E. (Stop Abuse & Financial Exploitation) Elders Initiative: <http://safemn.org>

