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.
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® 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.
- Cultural responsive supports and resources: www.actonalz.org/culturally-responsive-resources.
**Figure 1: Screening, Identifying and Managing Behavioral Symptoms in Patients with Dementia**

**Step 1:**
Are behavioral symptoms occurring?
- Screen for behavioral symptoms using standardized tool (e.g., NPI-Q)
- Involve key informant\(^a\)

**Step 2:**
What do behavioral symptoms look like?
- Describe behavioral symptoms and involve key informant\(^a\) (see eBox 2)

**Step 3:**
What are underlying causes?
- Identify potential modifiable triggers of behavioral symptoms (see eBox 4)

**Step 4:**
What is the treatment plan?
- Develop a treatment plan that incorporates family goals; work first on most distressful and unsafe behavioral symptoms

**Step 5:**
Are recommendations effective?
- Evaluate if plan eliminates or manages behavioral symptoms

**Step 6:**
Are new behavioral symptoms emerging?
- Ongoing monitoring; reassess for new behavioral symptoms, safety, caregiver distress, and nonpharmacologic strategy use

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**Develop treatment plan**

**If targeting 1 behavior**
- Identify and eliminate modifiable triggers (see Table 1)

**If targeting multiple behaviors**
- Use generalized approach (e.g., exercise, activities and pleasant events, caregiver education, skills training, environmental simplification, structuring daily routines) (see Table 2)

Consider referral to specialist\(^b\)

---

**1. Continue monitoring**
- Follow PCPI schedule

**2. Educate caregiver** (see eBox 1)

**3. Minimize risk factors for behavioral symptoms**
- (e.g., caregiver distress, patient pain, unmet needs)

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**Are behavioral symptoms sudden or recent onset?**
- Yes
  - 1. Rule out and treat underlying medical illness
  - 2. Review medications
  - 3. Evaluate and manage pain, nutrition, constipation, hydration, sleep

**Is there a safety concern?**
- (see eTable 3)
  - Yes
    - 1. Recommend safety strategies
    - 2. Educate caregiver
    - 3. If safety not improved, refer to specialist\(^b\) or admit

**Is caregiver distressed?**
- (see eBox 3)
  - Yes
    - 1. Educate caregiver
    - 2. Screen for depression
    - 3. Recommend stress-reduction strategies
    - 4. If distress not improved, refer to specialist\(^b\)

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**NPI-Q indicates Neuropsychiatric Inventory Questionnaire; PCPI, Physician Consortium for Performance Improvement**

\(^a\)Key informant may or may not be the caregiver.

\(^b\)Consider referrals to Alzheimer’s Association for support groups, education, other services; geropsychiatrist for difficult to manage cases, when medications may be needed; occupational therapist for driving evaluation, caregiver skills training, environmental modification, activity programming, functional improvement, home safety evaluation and risk reduction; physical therapist for exercise, mobility and balance, fall risk reduction; social worker for care coordination, caregiver counseling, support, and skills training; nurse for medication and physical health monitoring, caregiver training.

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*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*

<table>
<thead>
<tr>
<th>Targeted Behavior by Presenting Dementia Stage</th>
<th>Select Nonpharmacologic Strategiesa</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mild cognitive impairment</strong></td>
<td></td>
</tr>
<tr>
<td>Forgetting about taking medication</td>
<td>Evaluate capacity for taking medications independently</td>
</tr>
<tr>
<td>Use assistive aids (calendar to remind of time for medication, checklists, pill dispenser(^b))</td>
<td></td>
</tr>
<tr>
<td>Supervise medication taking and secure medications</td>
<td></td>
</tr>
<tr>
<td><strong>General forgetfulness; disorientation to time</strong></td>
<td>Use memory aids (calendar or white board showing current date)</td>
</tr>
<tr>
<td></td>
<td>Simplify daily routines</td>
</tr>
<tr>
<td><strong>Moderate dementia</strong></td>
<td></td>
</tr>
<tr>
<td>Falling and poor balance</td>
<td>Use a fall alert system if patient can remember to activate(^b)</td>
</tr>
<tr>
<td>Consider referral to occupational therapy for home safety evaluation and removal of tripping hazards</td>
<td></td>
</tr>
<tr>
<td>Minimize alcohol intake</td>
<td>Consider referral to physical therapy for simple balance exercise</td>
</tr>
<tr>
<td><strong>Hearing voices or noises (especially at night)</strong></td>
<td>Evaluate hearing and adjust amplification of hearing aids(^b)</td>
</tr>
<tr>
<td>Evaluate quality and severity of auditory disturbances(^b)</td>
<td></td>
</tr>
<tr>
<td>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(^b)</td>
<td></td>
</tr>
<tr>
<td><strong>Inability to respond to emergency (difficulty calling for help)</strong></td>
<td>Educate caregiver about need to supervise patient(^b)</td>
</tr>
<tr>
<td>Inform neighbors, fire department, and police of situation</td>
<td></td>
</tr>
<tr>
<td>Develop emergency plan involving others if possible</td>
<td></td>
</tr>
<tr>
<td><strong>Leaving the home; wandering outdoors</strong></td>
<td>Outfit with an ID bracelet (eg, Alzheimer Safe Return Program) or badge with patient’s name and address(^b)</td>
</tr>
<tr>
<td>Notify police and neighbors of patient’s condition(^b)</td>
<td></td>
</tr>
<tr>
<td><strong>Memory-related behavior (eg, disorientation or confusion with object recognition)</strong></td>
<td>Label needed objects</td>
</tr>
<tr>
<td>Remove unnecessary objects to reduce confusion with tasks</td>
<td></td>
</tr>
<tr>
<td>Identify potential triggers for elopement and modify them</td>
<td></td>
</tr>
<tr>
<td><strong>Nighttime wakefulness, turning on lights, awaking caregiver, feeling insecure at night</strong></td>
<td>Evaluate sleep routines(^b)</td>
</tr>
<tr>
<td>Evaluate environment for temperature, noise, light, shadows, level of comfort, or other possible disturbances</td>
<td></td>
</tr>
<tr>
<td>Eliminate caffeinated beverages (starting during the afternoon)(^b)</td>
<td></td>
</tr>
<tr>
<td>Create a structured schedule that includes exercise and activity engagement throughout the day(^b)</td>
<td></td>
</tr>
<tr>
<td>Limit daytime napping(^b)</td>
<td></td>
</tr>
<tr>
<td>Address daytime loneliness and boredom that may contribute to nighttime insecurities(^b)</td>
<td></td>
</tr>
<tr>
<td>Implement good sleep hygiene(^b)</td>
<td></td>
</tr>
<tr>
<td>Use nightlight(^b)</td>
<td></td>
</tr>
<tr>
<td>Hire nighttime assistance to enable caregiver to sleep(^b)</td>
<td></td>
</tr>
<tr>
<td>Create a quiet routine for bedtime that includes calming activity, calming music</td>
<td></td>
</tr>
<tr>
<td><strong>Repetitive questioning</strong></td>
<td>Respond using a calm, reassuring voice(^b)</td>
</tr>
<tr>
<td>Use calm touch for reassurance</td>
<td></td>
</tr>
<tr>
<td>Inform patient of events as they occur (vs indicating what will happen in near or far future)</td>
<td></td>
</tr>
<tr>
<td>Structure daily routines</td>
<td>Provide meaningful activities during the day to engage patient</td>
</tr>
<tr>
<td>Use distraction</td>
<td></td>
</tr>
</tbody>
</table>

\(^a\) 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).

\(^b\) Strategies discussed, considered, or implemented by Mr P’s physician and caregiver.

*Table 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 2: GENERAL NONPHARMACOLOGIC STRATEGIES FOR MANAGING BEHAVIORAL SYMPTOMS*

<table>
<thead>
<tr>
<th>Domain</th>
<th>Key Strategiesa</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities</td>
<td>Introduce activities that tap into preserved capabilities and previous interests</td>
</tr>
<tr>
<td></td>
<td>Introduce activities involving repetitive motion (washing windows, folding towels, putting coins in container)</td>
</tr>
<tr>
<td></td>
<td>Set up the activity and help patient initiate participation if necessary</td>
</tr>
<tr>
<td>Caregiver education and support</td>
<td>Understand that behaviors are not intentional</td>
</tr>
<tr>
<td></td>
<td>Relax the rules (eg, no right or wrong in performing activities/tasks as long as patient and caregiver are safe)</td>
</tr>
<tr>
<td></td>
<td>Consider that with disease progression, patient may have difficulty initiating, sequencing, organizing, and completing tasks without guidance and cueing</td>
</tr>
<tr>
<td></td>
<td>Concur with patient’s view of what is true and avoid arguing or trying to reason or convince</td>
</tr>
<tr>
<td></td>
<td>Take care of self; find opportunities for respite; practice healthy behaviors and attend preventive physician visits</td>
</tr>
<tr>
<td></td>
<td>Identify and draw upon a support network</td>
</tr>
<tr>
<td>Communication</td>
<td>Allow patient sufficient time to respond to a question</td>
</tr>
<tr>
<td></td>
<td>Provide 1- to 2-step simple verbal commands</td>
</tr>
<tr>
<td></td>
<td>Use a calm, reassuring tone</td>
</tr>
<tr>
<td></td>
<td>Offer simple choices (no more than 2 at a time)</td>
</tr>
<tr>
<td></td>
<td>Avoid negative words and tone</td>
</tr>
<tr>
<td></td>
<td>Lightly touch to reassure, calm, or redirect</td>
</tr>
<tr>
<td></td>
<td>Identify self and others if patient does not remember names</td>
</tr>
<tr>
<td></td>
<td>Help patient find words for self-expression</td>
</tr>
<tr>
<td>Simplify environment</td>
<td>Remove clutter or unnecessary objects</td>
</tr>
<tr>
<td></td>
<td>Use labeling or other visual cues</td>
</tr>
<tr>
<td></td>
<td>Eliminate noise and distractions when communicating or when patient is engaging in an activity</td>
</tr>
<tr>
<td></td>
<td>Use simple visual reminders (arrows pointing to bathroom)</td>
</tr>
<tr>
<td>Simplify tasks</td>
<td>Break each task into very simple steps</td>
</tr>
<tr>
<td></td>
<td>Use verbal or tactile prompt for each step</td>
</tr>
<tr>
<td></td>
<td>Provide structured daily routines that are predictable</td>
</tr>
</tbody>
</table>

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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
• 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
• Delirium Information: www.uptodate.com/contents/delirium-beyond-the-basics
• Pain Assessments: 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/cww/letter072513.pdf
• Validation Therapy: www.youtube.com/watch?v=CrZx10FcVM

Family Resource
• Teaching Families About Delirium: 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

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

Optimize Medication Therapy

**Professional Resources**
- 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**
- Minnesota Falls Prevention: www.mnfallsprevention.org/consumer/index.html
- 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

**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
- Dementia and Driving Resource Center: www.alz.org/care/alzheimers-dementia-and-driving.asp
Advance Care Planning and End of Life Care

*Professional Resources*

- POLST (Provider Orders for Life Sustaining Treatment): www.mnmed.org/Portals/mma/PDFs/POLSTform.pdf

*Resources for Professionals and Family*

- Honoring Choices: 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

Assess Care Partner Needs

*Professional Resources*

- Zarit Burden Interview: 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/
- Senior LinkAge Line®, 800-333-2433 or www.MinnesotaHelp.info
- Cultural 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/3rduspsft/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