NORMAL AGING vs. WARNING SIGNS OF ALZHEIMER’S DISEASE

**Directions:** Read the “normal aging” statements below and then re-write them to reflect a possible warning sign of Alzheimer’s disease.

<table>
<thead>
<tr>
<th>Normal Aging</th>
<th>Possible Warning Sign of Alzheimer’s Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making a bad decision once in a while</td>
<td></td>
</tr>
<tr>
<td>Missing a monthly payment</td>
<td></td>
</tr>
<tr>
<td>Forgetting which day it is and remembering it later</td>
<td></td>
</tr>
<tr>
<td>Sometimes forgetting which word to use</td>
<td></td>
</tr>
<tr>
<td>Losing things from time to time</td>
<td></td>
</tr>
<tr>
<td>Forgetting someone’s name and then recalling it</td>
<td></td>
</tr>
<tr>
<td>Not feeling like going to dinner with friends because you feel tired</td>
<td></td>
</tr>
</tbody>
</table>
### MYTH vs. FACT

**Directions:** Read each statement below. Mark off if it is a myth or fact. Then, write a concise, accurate, and culturally sensitive explanation that could be shared with a member and his/her family.

<table>
<thead>
<tr>
<th>MEMBER OR FAMILY SAYS...</th>
<th>MYTH</th>
<th>FACT</th>
<th>DEMENTIA CARE SPECIALIST EXPLANATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Everyone with Alzheimer’s has dementia.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My husband makes racist comments; this must be how he always felt about other races.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To meet criteria for major neurocognitive disorder, a person’s cognitive deficits must interfere with everyday activities.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease only affects memory.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My wife has vascular dementia. There is nothing we can do about it.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some dementias can be reversible.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ASSESSING FOR COGNITIVE IMPAIRMENT: USING THE AD8

PART I: Problem-Based Scenario

Your patient, Mr. Frank, a 76-year-old man, was recently discharged from the hospital after a respiratory infection. Mr. Frank is now back at home, where he lives with his partner of 32 years. Mr. Frank has a history of stroke and heart disease. Mr. Frank does not have a diagnosis of Alzheimer’s disease or a related dementia.

While speaking to Mr. Frank on the phone, you notice some possible warning signs of Alzheimer’s disease.

What were the warning signs that you noticed?

What questions might be appropriate for you to ask? To whom would you address your questions?

After speaking to Mr. Frank and/or his partner, what next steps would be appropriate to take?
PART II: Role Play

After completing Part I, get into groups of 3 to role play how to use the AD8.

In the groups, assign roles as:
   (1) Care manager (will administer the screening)

   (2) Mr. Frank or Mr. Frank’s partner (will answer the questions in the AD8)

   (3) Observer (will take notes on the screening process; write down at least one positive observation and at least one area for improvement; observer will report out to the larger group)

PART III: Facilitated Discussion: Lessons Learned

- Observer will report out to larger group

- What worked well?

- Were there any challenges?

- What areas merit further attention/improvement?
AD8 Dementia Screening Interview

Patient ID#: __________
CS ID#: __________
Date: __________

<table>
<thead>
<tr>
<th>Remember, “Yes, a change” indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.</th>
<th>YES, A change</th>
<th>NO, No change</th>
<th>N/A, Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Less interest in hobbies/activities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Repeats the same things over and over (questions, stories, or statements)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Forgets correct month or year</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Trouble remembering appointments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. <strong>Daily</strong> problems with thinking and/or memory</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL AD8 SCORE**

Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005;65:559-564
Copyright 2005. The AD8 is a copyrighted instrument of the Alzheimer’s Disease Research Center, Washington University, St. Louis, Missouri. All Rights Reserved.
The AD8 Administration and Scoring Guidelines

A spontaneous self-correction is allowed for all responses without counting as an error.

The questions are given to the respondent on a clipboard for self-administration or can be read aloud to the respondent either in person or over the phone. It is preferable to administer the AD8 to an informant, if available. If an informant is not available, the AD8 may be administered to the patient.

When administered to an informant, specifically ask the respondent to rate change in the patient.

When administered to the patient, specifically ask the patient to rate changes in his/her ability for each of the items, without attributing causality.

If read aloud to the respondent, it is important for the clinician to carefully read the phrase as worded and give emphasis to note changes due to cognitive problems (not physical problems). There should be a one second delay between individual items.

No timeframe for change is required.

The final score is a sum of the number items marked “Yes, A change”.

**Interpretation of the AD8** (Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005;65:559-564)

A screening test in itself is insufficient to diagnose a dementing disorder. The AD8 is, however, quite sensitive to detecting early cognitive changes associated many common dementing illness including Alzheimer disease, vascular dementia, Lewy body dementia and frontotemporal dementia.

Scores in the impaired range (see below) indicate a need for further assessment. Scores in the “normal” range suggest that a dementing disorder is unlikely, but a very early disease process cannot be ruled out. More advanced assessment may be warranted in cases where other objective evidence of impairment exists.

Based on clinical research findings from 995 individuals included in the development and validation samples, the following cut points are provided:

- 0 – 1: Normal cognition
- 2 or greater: Cognitive impairment is likely to be present

Administered to either the informant (preferable) or the patient, the AD8 has the following properties:

- Sensitivity > 84%
- Specificity > 80%
- Positive Predictive Value > 85%
- Negative Predictive Value > 70%

Area under the Curve: 0.908; 95%CI: 0.888-0.925

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What is 1 new thing you learned today?

What is 1 thing discussed today that you will be able to apply to your job?

What is 1 question you have?

What is 1 new thing you learned today?

What is 1 thing discussed today that you will be able to apply to your job?

What is 1 question you have?
Alzheimer’s* Clinical Care 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), ADAS (Aschaeltian 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.
  - Adequacy of home environment including safety, care needs, and abuse 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-asparate 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-pharmacologic approaches prove unsuccessful, THEN use medications targeted to specific emotions, behaviors or moods, if clinically indicated.

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, Physician 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.

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.

For statewide patient and family resources, link to California Department of Public Health, Alzheimer’s Disease Program (916) 552-9900 orph.dph.ca.gov/programs/Alzheimer’s/Pages/default.aspx. Check for local services in your area.

*This guidance may apply to other forms of dementia as well as mild cognitive impairment.

California Department of Public Health
Alzheimer’s Disease and Its Impact

Alzheimer’s Disease is the Most Common Form of Dementia and it Disproportionately Impacts Many Californians. Dementia is a general term for memory loss and other impairments serious enough to interfere with daily life. Alzheimer’s accounts for 60 to 80 percent of dementia cases and currently impacts an estimated 610,000 Californians, a number projected to grow to 840,000 by 2025. Alzheimer’s is the 5th leading cause of death in California and the only condition in the top 10 without a known cause, cure, or prevention.

More women than men have Alzheimer’s disease and other dementias such as vascular dementia and dementia with Lewy bodies, among others. Almost two-thirds of Americans with Alzheimer’s are women, as are the majority of family caregivers. Older African Americans and Hispanics are more likely than older whites to have Alzheimer’s disease and other dementias with African Americans at twice the prevalence rate and Hispanics one and one-half times the rate.

This 2017 Update Reflects New Evidence, Improved Practice and Changes in Law — This is the 4th edition of the California Alzheimer’s Clinical Care Guidelines, first published in 1996 and revised in 2002 and 2008. The 2017 update specified in statute (SB 613, Chapter 577, 2015) addresses changes in scientific evidence, clinical practice, and state and federal law. Changes include:

NEW GOVERNMENT POLICIES

Medicare Reimbursement — The Centers for Medicare & Medicaid Services (CMS) now reimburses physicians for annual wellness visits every 12 months and includes payment for a Health Risk Assessment, including reimbursement for a cognitive screen. Medicare will pay for cognitive and functional assessments and care planning for patients with Alzheimer’s disease and other cognitive impairments.

Adoption of Physician Order for Life Sustaining Treatment (POLST) — The POLST form gives patients more control over their end-of-life care, including medical treatment, extraordinary measures (such as a ventilator or feeding tube) and Cardiopulmonary resuscitation. POLST can prevent unwanted treatments, reduce patient and family suffering, and ensure a patient’s wishes are honored.

Social Security Grants Compassionate Allowance Benefit for Early-Onset Individuals — Individuals under age 65 diagnosed with Alzheimer’s disease are eligible for the Social Security Administration’s compassionate allowance benefit with minimal objective medical information provided by a physician.

Healthy Brain Initiative — The Centers for Disease Control and Prevention has mapped out a strategy for state and national partnerships through The Healthy Brain Initiative, emphasizing proven public health strategies such as monitoring and evaluation, education and training, policy development, and workforce competencies.

EMERGING PRACTICE TRENDS

Emphasis on Early Detection, Early Diagnosis and Mild Cognitive Impairment — Mild cognitive impairment can cause serious cognitive changes noticed by those individuals who experience changes or by other people, but not severe enough to interfere with daily life or independent function. As with other chronic diseases, public health experts are focusing on possible early interventions to delay the onset and slow the progression of Alzheimer’s disease.

New Evidence About Antipsychotic Medications and FDA Black Box Warning Labels — In April 2005, the U.S. Food and Drug Administration (FDA) notified health care professionals that both conventional and atypical antipsychotics are associated with an increased risk of mortality in elderly patients treated for dementia-related psychosis. The FDA notified health care professionals that patients with dementia-related psychosis treated with atypical antipsychotic drugs are at an increased risk of death. Since issuing that notification, the FDA has reviewed additional information that indicates the risk also is associated with conventional antipsychotics.

Gaps in Disclosure and Documentation — Scientists who studied patient surveys and Medicare claims data discovered only 46 percent of those billed for Alzheimer’s-related care were told by their doctors of their disease. Overlooking or avoiding diagnosis impedes care and denies access to needed services. In an era of electronic health records, documenting the diagnosis is critically important in order to deliver person-centered care.

Lifestyle Modifications — Some risk factors for dementia, such as age and genetics, cannot be changed, but the brain can be protected by some of the same strategies that guard against cardiovascular risk, including smoking cessation; keeping blood pressure, cholesterol and blood sugar within recommended limits; and, maintaining a healthy weight. Regular physical exercise may help lower dementia risk. Diet may impact brain health through its effect on heart health. Evidence suggests heart-healthy eating patterns, such as the Mediterranean diet, which emphasizes eating foods like fish, fruits, vegetables, beans, high-fiber breads and whole grains, nuts, and olive oil may help protect the brain.
ALZHEIMER’S HOME SAFETY

INSTRUCTIONS: Imagine that you are working with a family caregiver to improve home safety for someone living with Alzheimer’s disease. Use the Home Safety Assessment to make recommendations to improve safety. Next to each picture, write your recommendations. *Remember that this home safety assessment is specifically taking into consideration that the person has Alzheimer’s.*

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
The Home Safety Assessment is not all-inclusive, nor do the suggestions in the Assessment substitute for close supervision, at all times, of a person with memory loss.

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UNDERSTAND THE MEANING: REFUSAL TO BATHE VIDEO

In the video, several references are made to why the mother refuses to bathe. The reasons are associated with *meaning*. **What does bathing *mean* to the mother?**

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

How do the adaptations/strategies used by the daughter help address the meaning behind the refusal to bathe?

<table>
<thead>
<tr>
<th>Adaptation used by daughter</th>
<th>How adaptation addresses meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daughter asks mom to help undress</td>
<td></td>
</tr>
<tr>
<td>Daughter asks mom to test the water temperature</td>
<td></td>
</tr>
<tr>
<td>Daughter asks mom to “wash down there” by herself</td>
<td></td>
</tr>
</tbody>
</table>
APPLYING IDEA! TO WANDERING

IDentify the behavior
  • What was the challenging behavior?

E xplore
  • What were the causes/triggers?
    • What did this mean to the father?

A djust
  • What adaptations match the causes/triggers and/or meaning?
<table>
<thead>
<tr>
<th><strong>What</strong> is one concept or strategy you will apply to your job in the coming week?</th>
</tr>
</thead>
<tbody>
<tr>
<td>How will you apply this concept or strategy?</td>
</tr>
<tr>
<td><strong>What</strong> is one concept or strategy you will apply to your job in the coming week?</td>
</tr>
<tr>
<td>How will you apply this concept or strategy?</td>
</tr>
<tr>
<td><strong>What</strong> is one concept or strategy you will apply to your job in the coming week?</td>
</tr>
<tr>
<td>How will you apply this concept or strategy?</td>
</tr>
<tr>
<td><strong>What</strong> is one concept or strategy you will apply to your job in the coming week?</td>
</tr>
<tr>
<td>How will you apply this concept or strategy?</td>
</tr>
</tbody>
</table>
“I am going to ask you some questions to help me get a better idea of who assists with [MEMBER]. I would like to know if there is a partner, family member, friend or neighbor* who helps out. In some families there is one person who helps with care, and in other families, there are many people.”

**Note to care manager:** An informal or family caregiver is likely to be the person, or persons, who provide the most help when needed. Keep in mind that not all people identify with the term “caregiver;” ask families what terminology they prefer using. It is also important to identify the person who is recognized to make care decisions on behalf of the member, often referred to as the authorized representative.

The questions/prompts below will help you identify the member’s authorized representative and/or the person(s) assisting with the most hands-on care. Questions/prompts are not all-inclusive, but serve to facilitate conversation.

1. Identify the authorized representative
   
   Name: ___________________________ Relationship: ___________________________
   
   Contact Information: ___________________________

2. Does someone live with the member? ___________________________
   
   If so, name and relationship: ___________________________

3. If the member lives alone, how often does someone visit the home [if at all]? ___________________________
   
   Who is most likely to visit the member? Name and relationship: ___________________________

If questions below are asked directly to the member, consider saying, “If you needed help with any of the following, who would you ask?”

<table>
<thead>
<tr>
<th>Type of assistance provided</th>
<th>Name and relationship of person who provides assistance</th>
<th>No assistance provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>(4a) ADL assistance (e.g., bathing, dressing, toileting, eating/feeding)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4b) IADL assistance (e.g., meals, housekeeping, laundry, telephone, shopping, finances)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4c) Medication administration (e.g., oral, inhaled, or injectable)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4d) Medical procedures/treatments (e.g., changing wound dressing)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4e) Supervision and safety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4f) Coordination of medical care (e.g., scheduling medical appointments, transportation)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Based on your conversation, identify the person who provides the most hands-on care:

Name: ___________________________________________

Relationship to member: ___________________________________________

Contact information: ___________________________________________

* Definition of informal or family caregiver adapted from United Hospital Fund “Next Steps in Care; Assessing Family Caregivers,” 2013.
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Marina and Marco have been married for 53 years. Marco has mid to late stage Alzheimer’s disease and Marina takes care of him. Marco needs assistance with toileting, dressing, and taking medications. Marco often resists bathing and taking his medications; he sometimes gets combative with Marina and this really upsets her.

Marina and Marco have two daughters, a son, and several grandchildren. They all live nearby. One daughter comes over to the house regularly to help with meal preparation while the other is often busy at work. The son helps out here and there.

Marina does a lot for Marco, but never complains or asks for help. She has mentioned frequent headaches and gastritis.

You feel it is important to better assess Marina’s needs as a caregiver so you can provide her with support and engage her as a member of the care team.

**Directions:** With a partner, practice using the *Care Needs Assessment Tool* and the *Benjamin Rose Institute Caregiver Strain Instrument*. One person will act as the Dementia Care Specialist, asking Marina questions and filling out the tools accordingly. The other person will act as Marina and answer assessment questions based on the facts provided above. Remember, the purpose of using these assessment tools is to better understand Marina’s needs and identify areas that need attention.

There’s more…turn over
What are the major needs you identified?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

What needs are priorities? Why?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

What would likely be your next step(s) with this family?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
**CARE NEEDS ASSESSMENT TOOL**

“Caring for someone with Alzheimer’s disease or a related dementia can sometimes be challenging. I am going to ask you some questions to help better plan for care. Some of the questions I ask may be personal, but will help me understand your needs. I’d like to know if you have experienced any of these challenges in the past month, and if so, how much they bothered or upset you when they happened.”

<table>
<thead>
<tr>
<th>Challenging Behaviors &amp; ADLs and Functional Needs</th>
<th>Has it happened in the past month?</th>
<th>How much does this bother the caregiver?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CHALLENGING BEHAVIORS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep disturbances (waking you or other family members up at night)</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Repetition (doing or saying things over and over)</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Sadness and/or depression (feeling blue)</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Combativeness (anger, hitting, pushing, fighting, etc.)</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Hallucinations (seeing or hearing things that are not there)</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Sundowning (more confusion/restlessness in late afternoon/evening)</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Suspiciousness/paranoia (accusing/blaming)</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Screaming and making noises</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Disinhibition (unwanted sexual behaviors or inappropriate behaviors)</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td><strong>ACTIVITIES OF DAILY LIVING AND FUNCTIONAL NEEDS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resists bathing or showering</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Difficulty with dressing and grooming (brushing hair/teeth, shaving, etc.)</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Difficulty with eating (including chewing, swallowing, dental concerns)</td>
<td>NO</td>
<td>YES →</td>
</tr>
<tr>
<td>Difficulty using the toilet/incontinence (wetting, accidents)</td>
<td>NO</td>
<td>YES →</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Safety &amp; Caregiver Needs</th>
<th>Has the caregiver experienced this?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SAFETY</strong></td>
<td></td>
</tr>
<tr>
<td>Home safety concerns (falls, guns, knives, stove, leaving the person alone)</td>
<td>NO</td>
</tr>
<tr>
<td>Insists on driving</td>
<td>NO</td>
</tr>
<tr>
<td>Takes medicine the wrong way</td>
<td>NO</td>
</tr>
<tr>
<td>Wanders/gets lost</td>
<td>NO</td>
</tr>
<tr>
<td><strong>CAREGIVER NEEDS</strong></td>
<td></td>
</tr>
<tr>
<td>Depression/stress (feeling blue and/or overwhelmed)</td>
<td>NO</td>
</tr>
<tr>
<td>Difficulty providing care because of your health</td>
<td>NO</td>
</tr>
<tr>
<td>Lacks understanding of dementia</td>
<td>NO</td>
</tr>
<tr>
<td>Legal and financial planning (paying the bills, power of attorney, etc.)</td>
<td>NO</td>
</tr>
<tr>
<td>Long-term care planning</td>
<td>NO</td>
</tr>
<tr>
<td>End-of-life planning</td>
<td>NO</td>
</tr>
</tbody>
</table>

*Care managers should use clinical judgment to gauge caregiver’s capacity to provide care, level of burden to caregiver, and identified unmet needs. This information will determine which standardized care plans are needed.

**Other needs identified:**

*How much does this bother the caregiver?*  
0 = not at all  
1 = a little  
2 = somewhat  
3 = very much  
4 = extremely
Benjamin Rose Institute Caregiver Strain Instrument

The following questions are about you, the caregiver, as they relate to providing care to the care recipient [CR]. The following items refer to how a caregiver feels and behaves as a result of providing care. There are no right or wrong answers.

The answer options for the next set of questions are “Strongly agree,” “Agree,” “Disagree,” or “Strongly disagree.”

<table>
<thead>
<tr>
<th>Mark one box ☐ in each row</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly agree</td>
</tr>
</tbody>
</table>

### Caregiver Mastery
During the past 4 weeks, because of helping [CR] would you say that you were:

1. unsure whether he or she was getting proper care.  
2. uncertain about how to best care for him/her.  
3. that you should be doing more for him/her.  
4. that you could do a better job of caring for him/her.

Score ___________________ (Sum of items 1–4)

### Relationship Strain
During the past 4 weeks, because of helping [CR] would you say:

5. that he/she tried to manipulate you.  
6. that your relationship with him/her was strained.  
7. that he/she made requests over and above what he/she needed.  
8. that you were resentful toward him/her.  
9. that you were angry toward him/her.

Score ___________________ (Sum of items 5–9)

### Health Strain
During the past 4 weeks, because of helping [CR] would you say that:

10. your physical health was worse than before.  
11. you felt downhearted, blue, or sad more often.  
12. you were more nervous or bothered by nerves than before.  
13. you had less pep or energy.  
14. you were bothered more by aches and pains.

Score ___________________ (Sum of items 10–14)
Exact cutting points for heightened caregiver risk have been determined for this tool. Answers can help caregivers describe difficulties they are experiencing, and with repeated administrations, it can be used to assess change in the care situation over time. However, scores greater than 8 for Mastery, greater than 10 for Relationship Strain or Health Strain, or greater than 5 for Social Isolation/Activity Restriction may indicate heightened risk and may warrant further clinical investigation.

If score is > 8 for Mastery, > 10 for Relationship Strain or Health Strain, or > 5 for Social Isolation/Activity Restriction, then refer to Alzheimer’s Los Angeles and refer to **CAREGIVER DEPRESSION/STRESS CARE PLAN**.

If score is > 10 for Health Strain, then refer to **CAREGIVER DEPRESSION/STRESS CARE PLAN AND DIFFICULTY PROVIDING CARE BECAUSE OF YOUR HEALTH CARE PLAN**.

---

<table>
<thead>
<tr>
<th>The answer options for the next 5 questions are</th>
<th>Less often</th>
<th>The same</th>
<th>More often</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Less often,” “The same,” or “More often.”</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

**Social Isolation/Activity Restriction:**

During the past four weeks, because of helping [CR], would you say that you:

<table>
<thead>
<tr>
<th>Question</th>
<th>Less often</th>
<th>The same</th>
<th>More often</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. participated in church or religious activities.</td>
<td>□2</td>
<td>□1</td>
<td>□0</td>
</tr>
<tr>
<td>16. visited with friends or family.</td>
<td>□2</td>
<td>□1</td>
<td>□0</td>
</tr>
<tr>
<td>17. participated in group or organized activities.</td>
<td>□2</td>
<td>□1</td>
<td>□0</td>
</tr>
<tr>
<td>18. engaged in volunteer activities.</td>
<td>□2</td>
<td>□1</td>
<td>□0</td>
</tr>
<tr>
<td>19. went out to dinner, the theater, or a show.</td>
<td>□2</td>
<td>□1</td>
<td>□0</td>
</tr>
</tbody>
</table>

Score _______ (Sum of items 15–19)
Mr. Lin is an 86-year-old man with mid-stage Alzheimer’s disease and type 2 diabetes. Mr. Lin lives with his 83-year-old wife who is his primary caregiver. Mr. Lin and Mrs. Lin have been married for 50 years and used to enjoy dancing, singing, and going to church. They have two children who live nearby. Mrs. Lin’s has her own health issues, including arthritis and osteoporosis.

Mr. and Mrs. Lin are on a fixed income and have Medi-Cal. The Lins struggle with paying rent and sometimes do not have enough food to eat.

Mrs. Lin often gets impatient with her husband and yells at him when he is too slow in eating or puts on his clothes incorrectly. She also gets angry when he refuses to take his medications. She doesn’t understand that this due to the Alzheimer’s disease. Mrs. Lin also gets frustrated when her husband follows her around the house. Mr. Lin frequently misplaces things, like his bible, and accuses his wife of stealing various items.

Mrs. Lin is exhausted and feels like she has no time to herself. She has not shared with her friends or extended family about Mr. Lin’s Alzheimer’s because it is shameful to her. The Lin’s children regularly call to check in. Mrs. Lin tells them that everything is fine. She does not want to burden them.

**Directions:** Develop a care plan for Mr. Lin that includes:

- Guidance for managing Mr. Lin’s diabetes (remember to use an Alzheimer’s-informed lens)
- **IDEA!** to help Mrs. Lin better manage Mr. Lin’s behavioral symptoms
- Support for Mrs. Lin
- Referrals to home and community-based services