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Dementia Cal MediConnect Project

Dementia Care Specialist Toolkit *for* DEMENTIA CARE MANAGEMENT

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Toolkit materials have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project.

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HOW TO USE THE DEMENTIA CARE SPECIALIST TOOLKIT FOR DEMENTIA CARE MANAGEMENT

Overview

The Dementia Care Specialist Toolkit for Dementia Care Management has been designed for care managers who have been designated as Dementia Care Specialists (DCS) for dementia care management, to work with members who have dementia, and their families. The toolkit aligns with components of the *Alzheimer's Clinical Care Guideline*, an evidence-based practice guideline developed for primary care providers.

The toolkit offers assessment instruments to help identify people with dementia and their family/friend caregivers, and to assess their needs. Once needs are identified, best practice care plans can be used by the DCS to:

- Further identify/narrow down problem areas
- Educate on triggers and meaning to both the caregiver and the person with Alzheimer's disease or a related dementia (ADRD)
- Brainstorm and problem solve to determine adaptations
- Address clinical support needs
- Proactively provide caregiver support and community resources

Cognitive Assessment

Assessment of cognition may be necessary upon review of the HRA, clinical observation, self-reported and family concerns, and responses to queries. If signs or symptoms of cognitive impairment are present, the DCS should conduct a brief structured assessment. There are several validated screening tools that can be used by the DCS, including the AD8. The AD8 can be administered telephonically and is best answered by an informant. If the AD8 yields a positive result, the DCS should send the screening tool results to the primary care provider to conduct a full diagnostic evaluation.

Identifying a Caregiver

As ADRD progresses, the need to proactively engage a caregiver increases. For some families, multiple people are involved in caregiving, and sometimes, the caregiver will not identify him/herself as a "caregiver." It is important to use culturally and linguistically appropriate language when trying to identify the family or friend caregiver.

The *Tool for Identifying an Informal or Family Caregiver* provides prompting questions to help care managers determine who is involved in care and the extent of involvement. Care managers should be mindful of confidentiality protocols and laws when discussing members' needs with family or friend caregiver

Using Care Needs Assessment Tools

The toolkit provides two assessment tools, which help narrow down problem areas and lead to corresponding best practice care plans.

The *Care Needs Assessment Tool* identifies dementia-specific needs in four domains:

- Challenging behaviors
- Activities of daily living and functional needs
- Safety
- Caregiver needs

If depression/stress is identified under caregiver needs, the *Benjamin Rose Institute Caregiver Strain Instrument* or other validated caregiver assessment tool should be used for additional assessment. The DCS can also utilize other validated screening tools, as needed, such as a depression screen. For example, the PHQ 2 and the PHQ 9 can be used.

Using Standardized Care Plans

The DCS is encouraged to look at the best practice care plans that correspond to the problem areas identified in the *Care Needs Assessment Tool* and the *Benjamin Rose Institute Caregiver Strain Instrument*. The best practice care plans provide cues for the DCS so he/she can collaboratively and empathetically work with caregivers to problem solve. Best practice care plans are not all-inclusive; rather they provide suggestions, prompts, and choices for caregivers.

Because all cases are different, best practice care plans offer *several* suggestions that the DCS can discuss with caregivers to determine which may be most useful, appropriate, and realistic. The DCS should remember that caregivers need choices and the best practice care plans are not meant to be prescriptive. The DCS should consider focusing on two or three suggestions in each category of the best practice care plan, as to not overwhelm caregivers.

Using *IDEA!* for Managing Challenging Behaviors

IDEA! is a simple, three step strategy, incorporated into best practice care plans, to help families determine *why* a challenging behavior is happening and how to help manage it. The tool was developed for the DCS to teach to families so they are better equipped to understand possible causes and triggers of the specific, behavior identified, understand the meaning behind the behavior, for both themselves and the person with ADRD, and to problem-solve ways to reduce the behavior or eliminate the trigger. When families are better able to managing challenging behaviors, their coping skills increase and there are more positive outcomes for both the person with ADRD as well as the caregiver.

Using a Family-Centered Approach

The DCS should use a family-centered approach in all interactions with members and families. A family-centered approach means being respectful of and responsive to the individual member and to family preferences, needs, and values. Member and family values should guide all clinical decisions (adapted from IOM, 2001a definition of "person-centered care"). In using best practice care plans, the DCS should ensure that the dignity of the member is honored, that the well-being of the member and family is promoted, that values, culture, language, and preferences are kept in mind, that the member is engaged as fully as possible, that activities are meaningful, and that social connectedness is emphasized.

The more the DCS can learn about members and families, the more the standardized care plans can be family-centered. The DCS should consider asking the member and family the questions below to get a better overall sense of needs, values, and preferences. The answers to these questions can assist the DCS in customizing the standardized care plans so they are more family-centered.

Questions may include:

- Tell me a bit about what the member was like before he/she started to show trouble with memory.
- How has this affected you (as a family member/caregiver)?
- What are a few things that have always been important to the member?
- Who are some people who are very important to the member?

Other Considerations

The Dementia Care Specialist Toolkit is intended as a guide for dementia care management. The Toolkit is not all-inclusive, nor does it replace standards of care, procedures, and/or guidelines set forth by respective health plans, healthcare agencies, and employers. Assessment tools used in care management practices, such as those used to monitor changes in cognition and functioning, should continue to be utilized. Caregiver assessment tools that are not provided in this toolkit, such as depression screening tools, should also be used if the DCS determines it is clinically appropriate.

The best practice care plans are not mutually exclusive and are meant to complement and enhance existing care management tools and practices. They serve as guides and offer best practices for care management; however, they do not substitute for medical advice and/or emergency procedures.

The DCS is encouraged to use clinical judgment, expertise, and empathy when using the Dementia Care Specialist Toolkit. The DCS is required to follow all standards of practice, codes of ethics, policies, procedures, and reporting mandates for all cases of suspected or known abuse, neglect, and harm to self or others. When necessary, Adult Protective Services (APS), Department of Child and Family Services (DCFS), and/or local law enforcement agencies should be contacted for reporting mandates, assistance, and consultation.

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CRITERIA FOR REFERRING A PERSON WITH ALZHEIMER'S DISEASE OR A RELATED DEMENTIA TO A DEMENTIA CARE SPECIALIST

The following criteria can be used by health plans and healthcare agencies to determine when to refer a person with Alzheimer's disease or a related dementia (ADRD) to a Dementia Care Specialist (DCS) for Dementia Care Management:

- Unable to follow care manager's recommendations
- Behavioral/mood disturbances (such as depression, agitation, refusing to leave the home, wandering, sundowning)
- Lack of a caregiver
- Caregiver has knowledge deficits in ADRD
- Difficulty managing chronic medical conditions that are complicated by ADRD
- Difficulty managing medication regimen
- Healthcare utilization concerns (such as multiple ER visits in the last year or difficulty attending appointments)
- Difficulty completing ADLs (such as dressing, bathing, grooming, eating, and/or toileting)

Adapted from SCAN Memory Program and Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project.

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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
cdph.ca.gov/programs/Alzheimers/Pages/default.aspx
Check for local services in your area.

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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.

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

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 Guideline, first published in 1998 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 45 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.

Cognitive Assessment

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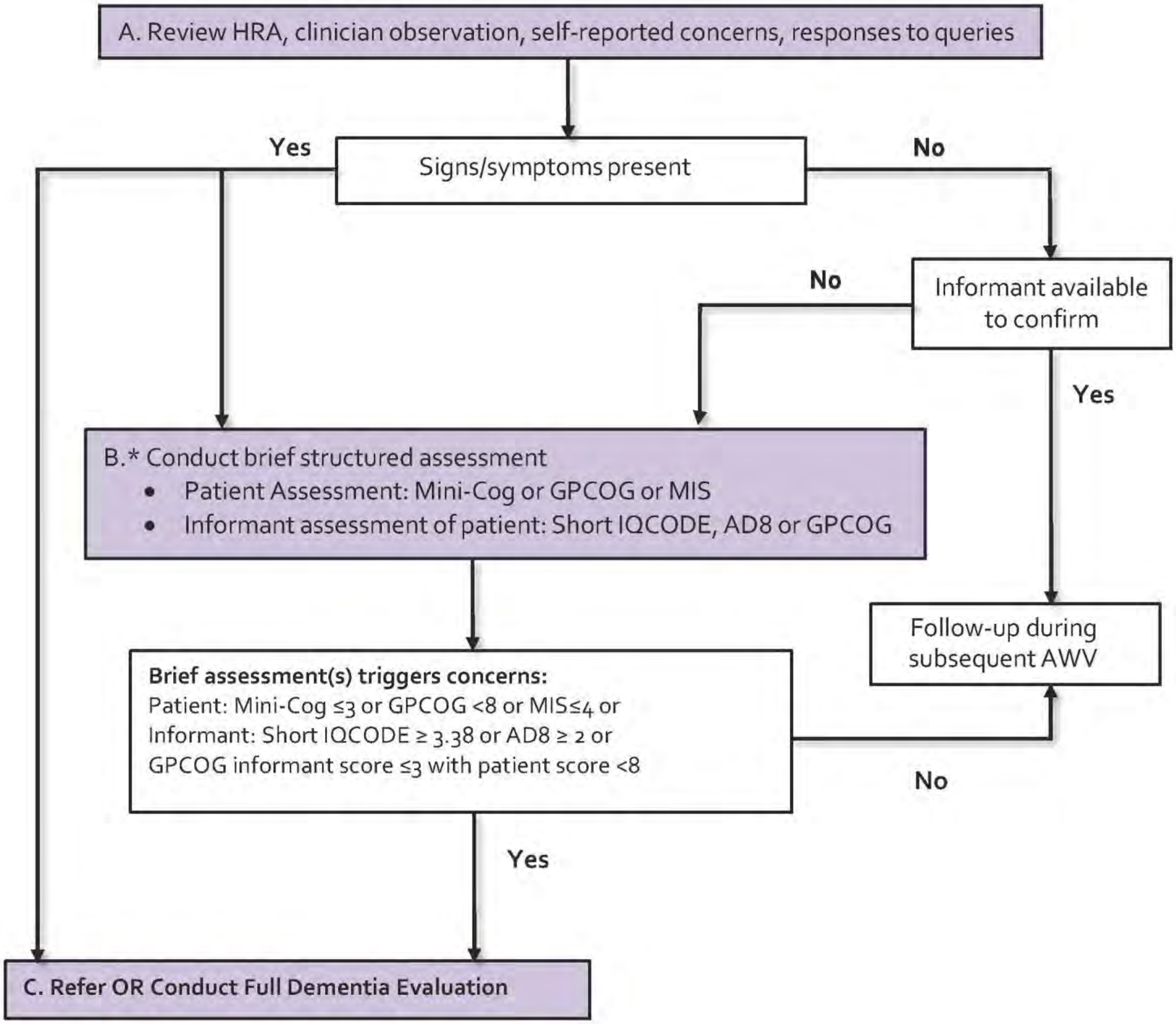
Alzheimer's Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition



A. Review HRA, clinician observation, self-reported concerns, responses to queries

Signs/symptoms present

Informant available to confirm

B.* Conduct brief structured assessment
- Patient Assessment: Mini-Cog or GPCOG or MIS
- Informant assessment of patient: Short IQCODE, AD8 or GPCOG

Follow-up during subsequent AWV

Brief assessment(s) triggers concerns:
Patient: Mini-Cog ≤3 or GPCOG <8 or MIS≤4 or
Informant: Short IQCODE ≥ 3.38 or AD8 ≥ 2 or
GPCOG informant score ≤3 with patient score <8

C. Refer OR Conduct Full Dementia Evaluation

* No one tool is recognized as the best brief assessment to determine if a full dementia evaluation is needed. Some providers repeat patient assessment with an alternate tool (eg, SLUMS, or MoCA) to confirm initial findings before referral or initiation of full dementia evaluation.

AWV = Annual Wellness Visit; GPCOG = General Practitioner Assessment of Cognition; HRA = Health Risk Assessment; MIS = Memory Impairment Screen; MMSE = Mini Mental Status Exam; MoCA = Montreal Cognitive Assessment; SLUMS = St. Louis University Mental Status Exam; Short IQCODE = short Informant Questionnaire on Cognitive Decline in the Elderly

Cordell CB, Borson S, Boustani M, Chodosh J, Reuben D, Verghese J, et al. Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. *Alzheimers Dement*. 2012. In press.

AD8 Dementia Screening Interview

Patient ID#:__________

CS ID#:____________
Date:____________

Remember, "Yes, a change" indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.	**YES, A change**	**NO, No change**	**N/A, Don't know**
1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)			
2. Less interest in hobbies/activities			
3. Repeats the same things over and over (questions, stories, or statements)			
4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)			
5. Forgets correct month or year			
6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)			
7. Trouble remembering appointments			
8. Daily problems with thinking and/or memory			
TOTAL AD8 SCORE			

Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005:65:559-564

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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.

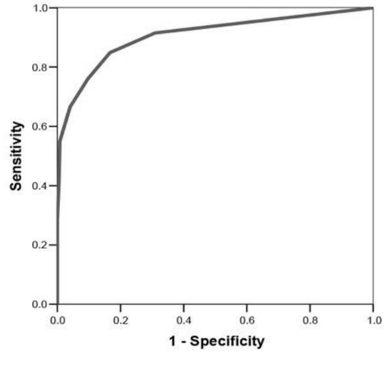
Based on clinical research findings from 995 individuals included in the development and validation samples, the following cut points are provided:

- 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


Reciever Operator Characteristics (ROC) curve for AD8

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Cuestionario al informador AD8 (versión española)

Patient ID#: ________________
Date: ______________________

Con respecto a la persona a la que acompaña, ¿qué opina sobre los siguientes aspectos?:

Recuerde, "Sí, ha cambiado" significa que usted piensa que ha habido un cambio en los siguientes aspectos en los últimos años causado por problemas cognitivos (razonamiento y memoria)	**Sí**, Ha cambiado	**No**, No ha cambiado	**NS/NC** No sabe/ No contesta
1. Problemas para emitir juicios y tomar decisiones adecuadas (ej.: le engañan o timan, toma decisiones financieras erróneas, hace regalos inapropiados, etc.)			
2. Pérdida de interés en sus aficiones y actividades (ej.: ha dejado de hacer actividades que le gustaban)			
3. Repite las preguntas, los comentarios o las cosas que cuenta			
4. Dificultad para aprender a usar herramientas, aparatos o dispositivos (ej.: video o DVD, ordenador, microondas, mandos a distancia, teléfono móvil o inalámbrico)			
5. Olvida el mes o año correcto			
6. Dificultad para manejar asuntos financieros complicados (ej.: ajustar cuentas, talones, impuestos, facturas, recibos, etc.)			
7. Dificultad para recordar las citas y cosas que tiene que hacer			
8. Los problemas de razonamiento y/o memoria son cotidianos y no ocasionales			
TOTAL			

Permission granted by Carnero Pardo C, et al., at the Sociedad Española de Neurología. "Neurología 2012. doi:10.1016/j.nrl.2012.03.012" to reproduce *Cuestionario al informador AD8* in Care Manager Manual.

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Caregiver Identification

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TOOL FOR IDENTIFYING AN INFORMAL OR FAMILY CAREGIVER

> "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?"***

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

[*Adapted from Centers for Medicare and Medicaid Services "Care Tool; Acute Care," 2008*]

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

Name: ____

Relationship to member: ____

Contact information: ____

*Definition of informal of family caregiver adapted from United Hospital Fund "Next Steps in Care; Assessing Family Caregivers,"2013.

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Care Needs Assessments

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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."

***How much does this bother the caregiver?**
0 = not at all
1 = a little
2 = somewhat
3 = very much
4 = extremely
↓

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

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

*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: ______________________________

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Benjamin Rose Institute Caregiver Strain Instrument

Benjamin Rose Institute Caregiver Strain Instrument Bass, Noelker & Reschlin, 1996; Bass et al., 1994b

"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."

	Mark one box ☒ in each row			
The answer options for the next set of questions are "Strongly agree," "Agree," "Disagree," or "Strongly disagree."	Strongly agree ▼	Agree ▼	Disagree ▼	Strongly disagree ▼
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.	☐3	☐2	☐1	☐0
2. uncertain about how to best care for him/her.	☐3	☐2	☐1	☐0
3. that you should be doing more for him/her.	☐3	☐2	☐1	☐0
4. that you could do a better job of caring for him/her.	☐3	☐2	☐1	☐0
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.	☐3	☐2	☐1	☐0
6. that your relationship with him/her was strained.	☐3	☐2	☐1	☐0
7. that he/she made requests over and above what he/she needed.	☐3	☐2	☐1	☐0
8. that you were resentful toward him/her.	☐3	☐2	☐1	☐0
9. that you were angry toward him/her.	☐3	☐2	☐1	☐0
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.	☐3	☐2	☐1	☐0
11. you felt downhearted, blue, or sad more often.	☐3	☐2	☐1	☐0
12. you were more nervous or bothered by nerves than before.	☐3	☐2	☐1	☐0
13. you had less pep or energy.	☐3	☐2	☐1	☐0
14. you were bothered more by aches and pains	☐3	☐2	☐1	☐0
Score ________________ (Sum of items 10–14)				

The answer options for the next 5 questions are "Less often," "The same," or "More often."	Less often ▼	The same ▼	More often ▼
Social Isolation/Activity Restriction: During the past four weeks, because of helping [CR], would you say that you:			
15. participated in church or religious activities.	☐2	☐1	☐0
16. visited with friends or family.	☐2	☐1	☐0
17. participated in group or organized activities.	☐2	☐1	☐0
18. engaged in volunteer activities.	☐2	☐1	☐0
19. went out to dinner, the theater, or a show.	☐2	☐1	☐0
Score _______ (Sum of items 15–19)			

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 Greater 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 FUNCTIONAL/HEALTH LIMITATIONS OF CAREGIVER CARE PLAN.***

Care Plans:
Challenging Behaviors

Alzheimer's
GREATER LOS ANGELES

TABLE OF CONTENTS
Care Plans: Challenging Behaviors

IDEA! Strategy

IDEA! is a simple three-step strategy to help you figure out *why* a challenging behavior is happening and how to deal with it.

*ID*entify the problem/challenging behavior

- What is the behavior that is challenging for you to deal with? Be specific.
- Can you see it?

*E*xplore

Understand the cause of the behavior

- **Health:** Is the person taking a new medication, getting sick, or in pain?
- **Environment:** Is it too noisy? Is it too hot? Is the place unfamiliar?
- **Task:** Is the task too hard? Are there too many steps? Is it something new?
- **Communication:** Is it hard for the person to speak or understand?

Understand the meaning of the behavior to the person

- Does the person feel like he/she is being treated like a child?
- Are there things that remind the person of something unhappy?
- Does the person feel a sense of insecurity, discomfort, or boredom?

*A*djust

Try different things. Pay attention to the person's feelings. Practice being calm, gentle, and reassuring.

- Address the cause or triggers of the behavior
  - Keep tasks and activities simple
  - Keep the home as quiet and calm as possible
  - Speak slowly and gently/try not to say too much at one time
  - Do not argue/try to comfort the person
  - Find meaningful, simple activities so the person is not bored
- Distract or redirect by:
  - Offering the person something he/she likes to eat
  - Watching a TV show or listen to music
  - Asking the person for his/her help with a simple activity
  - Leading the person to a different room

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Sleep Disturbances

Identify the Problem	**PROBLEM:** Sleep Disturbances (waking you or other family members up at night) **GOAL/EXPECTED OUTCOME**: To reduce sleep problems through non-pharmacological approaches
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Is the person napping throughout the day? • Does the person have too little physical activity during the day? • Is the person in pain or discomfort that may lead to awakening? • Is the temperature of the room uncomfortable? • Is there alcohol consumption or a medication that could cause rebound awakening? • Is the person taking diuretics in the afternoon or evening? • Is the person consuming caffeine? • Is the person going to bed too early? • Does the person need to go to the bathroom frequently? • Has the person always been more awake at night time? Did the person always work a night shift? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Does the person feel frightened when he/she wakes up? • Does it bother the person to be up and active at night? **Understand the possible meaning of the problem to the caregiver:** • Does the caregiver feel frustrated? • Does the caregiver feel tired during the daytime? • Does the caregiver feel the person is unsafe to be up and alone at night?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Follow sleep hygiene suggestions: o Limit daytime naps to 15 – 30 minutes and before 3 p.m. o Sleep in bed, not on couches o Create a bedtime routine o Only wear pajamas at night • Create an appropriately active and structured daytime schedule, including exercise • Consider enrollment in CBAS • Check temperature of room • Check to make sure noise is limited (such as from a TV or other appliances) • Avoid stimulants and diuretics after 3 p.m. (unless provider prescribed otherwise) • Leave a night light in the bathroom and in the bedroom if this is comforting • Consider soft music • Consider a comforting object such as a small stuffed animal

	CLINICAL SUPPORT: • Refer to PCP to assess if medical or psychiatric conditions are present and interfering with sleep • Speak to PCP about pain management if needed • Speak to PCP/pharmacist about medications that may be interfering with sleep and to evaluate medication list and schedule (to minimize sleeplessness at night)
	CAREGIVER SUPPORT AND COMMUNITY RESOURCES: • Listen empathically to caregiver and evaluate for level of distress • Refer to CBAS for structured daytime activities • Refer to respite services • Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation o ALZ Direct Connect referral o Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259 o Website: www.alzgla.org • Send literature: o Topic Sheet – "Sleep Issues"
	FOLLOW UP: • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	NOTES: ________________________ ________________________ ________________________ ________________________

Alzheimer’s Caregiving Tips

Sleep Issues

People with Alzheimer’s disease often experience changes in sleep patterns and difficulty sleeping through the night. They may also demonstrate increased behavioral symptoms in the evening hours, frequently known as sundowning. Sleep disturbances can be very challenging for caregivers, as it causes them to lose sleep and experience fatigue throughout the day, increasing stress and decreasing capacity to manage the challenges of caregiving.

Some Possible Causes of Nighttime Restlessness

- The person naps throughout the day and is not tired in the evening.
- The person is not getting enough physical activity throughout the day to tire the body.
- The person is experiencing pain, discomfort, or fear.
- The person is taking diuretics which cause a frequent need to urinate.
- The person is consuming caffeine too close to bed time.
- The person is going to bed too early.
- The environment is too loud, too light, or at an uncomfortable temperature.

Possible Strategies

- Is important to maintain a regular sleep schedule. Limit day-time naps and create a bed-time routine.
- Make sure the person sleeps in his/her bed at night, and not on the couch.
- Ensure the person gets enough physical exercise throughout the day.
- Check the environment. Be sure there are not loud noises or distractions, and that the temperature is comfortable for the person.
- Avoid any caffeine, stimulants, or diuretics after 3 p.m. Speak with a doctor about any medications the person is on that may affect sleep.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Repetition

Identify the Problem	**PROBLEM:** Repetition (doing or saying things over and over) **GOAL/EXPECTED OUTCOME**: To reduce caregiver level of stress and increase caregiver capacity to cope and manage behaviors
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Is the person having trouble remembering, due to the disease process? • Has the person been separated from a loved one or a personal item? • Is the person's environment new or unfamiliar? • Is the person trying to communicate an unmet need, such as needing to use the bathroom or being hungry? • Is there a sight or sound causing the person anxiety? • Is the environment too loud? • Is the person bored? • Is the person having a medication side effect? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Does the person feel anxious? • Is the person confused? **Understand the possible meaning of the problem to the caregiver:** • Is the caregiver frustrated? • Is the caregiver angry?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Understand that the person is not doing or saying things repeatedly on purpose; it's part of the disease • Be reassuring and comforting to the person, using a gentle tone of voice • Avoid reminding the person that he/she already asked the question • Distract the person: o Redirect with another topic (Avoid questions. Instead, say, "Tell me about….your wedding, your kids, your house, your work…" o Offer something the person enjoys, such as a favorite food, an activity or music he/she likes, etc. o Have personal things for the person to look at, such as photo albums, old catalogues, a memory box of items from the person's life such as travel pictures/postcards, etc. • Turn the repetitious behavior into an activity (i.e., if person is rubbing his/her hands across the table, provide a cloth and ask for help with cleaning. Offer flowers to arrange, offer things to separate or sort into piles, or to sweep the patio, etc.) • Try not to become angry or frustrated in front of the person • Remove things from the environment that might trigger repetitive questions, such as the keys if the person keeps asking if it is time to leave • Try moving the person to a different room/new environment

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

CLINICAL SUPPORT:

- Because repetition may be due to cognitive decline (i.e., forgetfulness), refer to PCP to discuss if cognitive enhancement drugs would be beneficial

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Educate the caregiver about the disease and how it can cause forgetfulness and repetitive behaviors
- Listen empathically to caregiver and evaluate for level of distress
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
  - ALZ Direct Connect referral
  - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
  - Website: www.alzgla.org
- Send literature:
  - Topic Sheet – "Repetition and Alzheimer's"

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

NOTES:

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Repetition and Alzheimer's

Repetitive behaviors and speech can be very challenging for caregivers and family members to cope with when displayed by someone with Alzheimer's disease. But these can be very common symptoms of the disease. A person may forget that he or she already said or did something, or may forget the answer that was given. He or she may also be feeling anxious or fearful, and become fixated on a particular topic or behavior. It is important for the caregiver to understand that the person is not doing the repetitive behavior intentionally, and to provide reassurance and redirection.

Possible Causes of Repetitive Behavior

- Boredom
- The person forgets the answer to a question and continues to ask
- Separation from a loved one or item
- A new or unfamiliar environment
- An attempt to communicate an unmet need, such as needing to use the bathroom or being hungry
- A sight or sound causing the person anxiety
- An environment that is too noisy
- A medication side effect
- The person is feeling anxious or scared

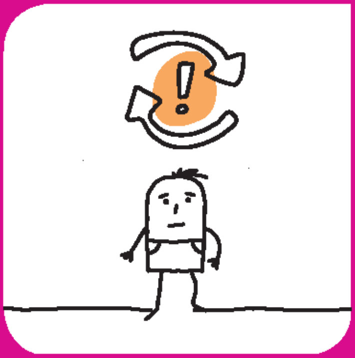
Possible Strategies

- Understand that the person is not doing or saying things repeatedly on purpose; it's part of the disease.
- Be reassuring and comforting to the person, using a gentle tone of voice.
- Avoid reminding the person that he/she already asked the question.
- Distract the person.
- Turn the repetitious behavior into an activity (e.g., if person is rubbing his/her hands across the table, provide a cloth and ask for help with cleaning. Offer flowers to arrange, offer things to separate or sort into piles, or to sweep the patio, etc.)
- Try not to become angry or frustrated in front of the person.
- Remove things from the environment that might trigger repetitive questions, such as the keys if the person keeps asking if it is time to leave.
- Try moving the person to a different room/new environment.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Repeating

People with Alzheimer's or dementia often ask questions or tell stories over and over. While frustrating, it is not harmful. They are not doing this on purpose. This behavior is caused by changes in the brain.



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might be:

- **having problems remembering what they just said or what just happened**
- **repeating questions or stories because they feel nervous or afraid**
- **having trouble saying what they need or want**

WHAT CAN YOU DO?

Think About Why

- new place? new people? somewhere they find scary?
- they forget that the question was asked and/or answered
- they want your attention… to feel a connection with you
- maybe they are trying to tell you about a need… hunger, concern about someone or something, urge to go to the bathroom

Accept the Behavior

- stay calm and be patient, they *can't* change so you will need to
- don't argue or try to correct them
- breathe… and remember the disease is the reason
- calmly answer the question every time it's asked
- smile at the story every time it's told

Try Reminders

- use clocks or photos of items or objects to help with questions that are repeated
- post notes or a daily schedule in a place they often look
- get a big "white board" so you can write and erase information as needed

Ways to Help

- listen to music, watch TV, take a walk, or find something they like to do to get their mind on something else
- think first about how they are feeling and remind yourself it's not their fault
- wait until just beforehand to tell them about things that make them nervous like doctor's visits, bathing, or going out
- if you are tired and might react, and they are safe, go to another room for a bit to breathe

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Repitiendo

Es muy común que las personas con Alzheimer o demencia hagan preguntas o repitan historias una y otra vez. Aunque pueda ser frustrante, no es dañino. No lo están haciendo a propósito. Este comportamiento se debe a cambios en el cerebro.

¿QUÉ PUEDE HACER?

Piense en el por qué

- ¿Están en un lugar desconocido? ¿Están con gente desconocida? ¿Tendrán miedo?
- quizás se les olvidó la respuesta que le dieron
- desean su atención... quieren sentir una conexión con usted
- tal vez están tratando de comunicarle una necesidad... tienen hambre, están preocupados por alguien o algo, o tienen deseos de ir al baño

Acepte el comportamiento

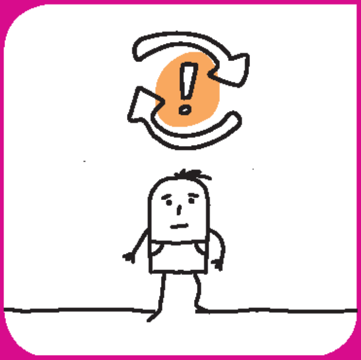
- mantenga la calma y sea paciente, *ellos no pueden cambiar*, entonces usted es la que va a tener que cambiar
- no discuta o contradiga a la persona
- respire profundamente... y recuerde que el problema es a causa de la enfermedad
- conteste la misma pregunta cada vez que se la haga, calmadamente
- sonría cada vez que le cuente la misma historia

Use recordatorios cuando sean necesarios

- objetos tales como relojes y fotos de objetos podrían ayudar a contestar algunas preguntas que se repiten, por ejemplo, una foto de una cama en la puerta para que recuerde donde está el cuarto
- use notitas, un calendario, o un pizarrón para anotar las citas, actividades diarias o eventos importantes. Coloque estos recordatorios en un lugar donde todos lo puedan ver, como la puerta del refrigerador.

Ayude a la persona

- escuche música, vea televisión, vaya de paseo o busque algo que le guste hacer para distraerlo
- recuerde que nadie tiene la culpa, es sólo parte de la enfermedad de Alzheimer
- espere hasta el último momento para hablar sobre actividades que requieran la cooperación de la persona con Alzheimer, tales como: las visitas al médico o bañarse
- si usted está cansada y pueda reaccionar de manera negativa y la persona está segura, váyase a otro cuarto un momento para calmarse respirando profundamente.



¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- **tener problemas al recordar lo que acaban de decir o lo que acaba de ocurrir**
- **estar repitiendo preguntas o historias porque se sienten nerviosos o con miedo**
- **tener problemas tratando de comunicar lo que necesitan o desean**

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Supported by DHHS, ACL (#90AL0002-01-00)

Sadness and/or Depression

Identify the Problem	**PROBLEM:** Sadness and/or Depression (feeling blue) **GOAL/EXPECTED OUTCOME**: To reduce depression or depressive symptoms
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • What is the person's behavior like when he/she is depressed? • What happens before the person's depressive symptoms occur? • How often do the person's depressive symptoms occur? • For early stage individuals, is there evidence that the depression involves reaction to understanding the diagnosis? • Is the depression causing the person to socially withdraw? • Are there any indications of suicidality?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Consider home safety: remove firearms, alcohol, or other substances in the home • Provide dementia education and counseling to people in early stages • Encourage the person to join a support group • Provide the person with predictable routines • Go on regular outings with the person when possible • Stimulate with pleasant smells and sounds (i.e. aromatherapy, baking cookies, music from person's youth) • Help the person engage in favorite activity or hobby • Read books, play games, watch funny shows/movies • Encourage exercise and physical activity
	CLINICAL SUPPORT: • If suicidal ideation is present, follow standards of practice, policies, procedures, and reporting mandates • If self-neglect, follow standards of practice, policies, procedures, and reporting mandates • Follow clinical guidelines and procedures for depression screening, intervention and referral • Refer to behavioral health specialist for depression assessment, diagnosis and treatment, as needed • Consider behavioral health referral for people in early stage

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Discuss opportunities for socialization, stimulation and interaction, such as CBAS
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
    - ALZ Direct Connect referral
    - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
    - Website: www.alzgla.org
- Local Community Resources: ____________________________________
  ____
- Send literature:
    - Topic Sheet – "Sadness and Depression"

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

NOTES:

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Sadness and Depression

Depression can be very common among individuals with Alzheimer's disease, especially in the earlier stages, as the person is experiencing many changes and losses. It is not uncommon for a person with Alzheimer's disease to lose interest in favorite activities, withdraw socially, experience loss of appetite, or sleep throughout the day. It is important for caregivers to be aware of these changes in the person with Alzheimer's disease, and take steps to minimize risk and improve quality of life.

Identifying Depression

What are some common symptoms of depression to look for?

- Lack of interest or enthusiasm in familiar activities.
- Withdrawing from social settings.
- Keeping to oneself.
- Difficulty with attention.
- Excessive sleep.
- Drastic changes in sleep, either insomnia or sleeping throughout the day.
- Drastic changes in appetite, either loss of appetite or over-eating.

It is not uncommon for symptoms of depression to look very similar to changes caused by Alzheimer's disease, so it is important and helpful to consult a healthcare professional when concerned about symptoms experienced by a person with Alzheimer's disease.

Tips

- Consider home safety. Remove any firearms, alcohol, or other substances in the home.
- Provide dementia education and counseling to people in early stages.
- Encourage the person to join a support group.
- Go on regular outings with the person when possible.
- Stimulate with pleasant smells and sounds (e.g., aromatherapy, favorite foods, music the person enjoys).
- Read books, play games, watch funny shows/movies.
- Encourage exercise and physical activity.
- Seek professional help as needed.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Combativeness

Identify the Problem	**PROBLEM:** Combativeness (anger, hitting, pushing, fighting, etc.) **GOAL/EXPECTED OUTCOME**: To reduce combativeness through non-pharmacological approaches
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Is something causing the person to feel frustrated? o Is the person overly tired? o Is the person having trouble completing a task that was once simple for him/her? o Is there too much going on around the person? o Does the person have trouble seeing or hearing that is causing him/her to mistake sights and sounds? o Are there too many unfamiliar people or places? • Is the person experiencing physical discomfort (pain, fever, illness)? • Is the person responding to caregiver stress and irritability? • Is the person experiencing side effects of a medication? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Is the person overwhelmed? • Does the person feel he/she is losing control? • Is the person uncomfortable? • When a person resists, says "no!" or is combative, it can mean: o I can't o I'm scared o I don't understand o I never liked it and I never will **Understand the possible meaning of the problem to the caregiver:** • Does the caregiver feel unsafe? • Is the caregiver scared?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • You set the tone; try to use a calm, reassuring voice and avoid insults o Try saying "I know you're feeling angry," to show you understand • Try to avoid triggers if possible o Make sure the person is comfortable; check for possible sources of pain o Offer simple, step-by-step instructions for activities o Approach the person slowly from the front and introduce yourself if needed o Speak slowly and clearly o Keep routines the same each day o Reduce noise, people, and clutter from the person's area • Try to learn the common causes and avoid them • Use redirection or distraction (i.e., food, activity, music) • Consider safety o Stand out of reach of the person o Leave the room if you can, to let the person calm down for a few minutes, but stay where you can still watch him/her for safety

  - Call for help – neighbors, family, friends, doctor
  - Call the police if needed
- Write down examples of the problem and possible triggers to tell the person's doctor

CLINICAL SUPPORT:

- If abuse or self-harm is suspected, follow standard of practice, policies, procedures, and reporting mandates
- Refer to PCP to assess for possible illness or adverse medication reactions
- If non-pharmacological approaches prove unsuccessful, refer to PCP for medications, targeted to specific behaviors, as clinically indicated

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
  - ALZ Direct Connect referral
  - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
  - Website: www.alzgla.org
- Send literature:
  - Quick Fact Sheet – Anger, Frustration, Fighting (English and Spanish)
  - Topic Sheet --"Coping with Agitation and Aggression"

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

NOTES:

Alzheimer's Caregiving Tips

Coping with Agitation and Aggression

People with Alzheimer's disease may become agitated or aggressive as the disease gets worse. **Agitation** means that a person is restless or worried. He or she doesn't seem to be able to settle down. Agitation may cause pacing, sleeplessness, or **aggression**, which is when a person lashes out verbally or tries to hit or hurt someone.

Causes of Agitation and Aggression

Most of the time, agitation and aggression happen for a reason. When they happen, try to find the cause. If you deal with the causes, the behavior may stop. For example, the person may have:

- Pain, depression, or stress
- Too little rest or sleep
- Constipation
- Soiled underwear or diaper
- Sudden change in a well-known place, routine, or person
- A feeling of loss—for example, the person may miss the freedom to drive
- Too much noise or confusion or too many people in the room
- Being pushed by others to do something—for example, to bathe or to remember
- events or people—when Alzheimer's has made the activity very hard or impossible
- Feeling lonely and not having enough contact with other people
- Interaction of medicines

Look for early signs of agitation or aggression. If you see the signs, you can deal with the cause before problem behaviors start. Try not to ignore the problem. Doing nothing can make things worse.

A doctor may be able to help. He or she can give the person a medical exam to find any problems that may cause agitation and aggression. Also, ask the doctor if medicine is needed to prevent or reduce agitation or aggression.

Tips for Coping

Here are some ways you can cope with agitation or aggression:

- Reassure the person. Speak calmly. Listen to his or her concerns and frustrations. Try to show that you understand if the person is angry or fearful.
- Allow the person to keep as much control in his or her life as possible.
- Coping with changes is hard for someone with Alzheimer's. Try to keep a routine, such as bathing, dressing, and eating at the same time each day.
- Build quiet times into the day, along with activities.
- Keep well-loved objects and photographs around the house to help the person feel more secure.
- Try gentle touching, soothing music, reading, or walks.
- Reduce noise, clutter, or the number of people in the room.
- Try to distract the person with a favorite snack, object, or activity.
- Limit the amount of caffeine, sugar, and "junk food" the person drinks and eats.
- Here are some things you can do:
- Slow down and try to relax if you think your own worries may be affecting the person
- With Alzheimer's.
- Try to find a way to take a break from caregiving.

Safety Concerns

When the person is aggressive, protect yourself and others. If you have to, stay at a safe distance from the person until the behavior stops. Also, try to protect the person from hurting himself or herself.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Anger, Frustration & Fighting

People with Alzheimer's or dementia can get confused, depressed, and angry. Their feelings and actions are sometimes hard for them to control.

They may hit and yell.

Don't take their words or actions personally.

Listen to what they mean, not what they are saying.

WHAT CAN YOU DO?

Keep Things Simple

- try to match tasks and what you expect with what your person can do
- keep your home quiet and calm when you can
- speak slowly and try not to say too much at one time

Make a Change

- offer a treat like a cookie or some ice cream
- lead your person to a different room
- offer to watch a TV show or listen to music
- ask a question about a topic your person enjoys

Be Safe

- remove or lock away all weapons (guns, knives, etc.)
- back away slowly if the behavior is scary
- call 911 if you are afraid for your or someone else's safety

WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- be confused by
  - new places or people
  - something they see and don't know
- become frustrated
  - because they can't pull on a sweater
  - open a door
  - find a lost item like a purse, wallet or glasses
- be frightened or scared of
  - the shower or bath
  - a new place or person

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Enojo, Peleas y Desesperación

Personas con Alzheimer o demencia se confunden fácilmente. También pueden enojarse, gritar y hasta pegar. No se ofenda por lo que digan o hagan. Trate de comprender lo que están tratando de decir.

¿QUÉ PUEDE HACER?

Mantenga las cosas sensillas

- mantenga el hogar tranquilo y calmado
- hable lentamente usando frases cortas y sencillas
- busque actividades que la persona con Alzheimer todavía pueda y quiera hacer

Haga un cambio

- háblele de un tema agradable
- llévelo a otro cuarto
- ofrézcale algo para comer como una fruta o un dulce
- mantenga la calma y trate de distraer a la persona con alguna actividad

Manténgase seguro

- ponga armas y cuchillos bajo llave
- si usted no se siente seguro, aléjese lentamente y pida ayuda
- si usted u otra persona están en peligro, llame al 9-1-1

¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia se frustra porque:

- **no pueden abrir la puerta**
- **no pueden vestirse**
- **no pueden encontrar algo que perdió como el bolso, la cartera o los lentes**
- **no reconocen donde están**
- **desconocen a sus familiares**

Persona con Alzheimer o demencia puede tener miedo

- **del baño o la ducha**
- **de una persona o un lugar nuevo**
- **de su propio reflejo**

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Hallucinations

Identify the Problem	**PROBLEM:** Hallucinations (seeing or hearing things that are not there) **GOAL/EXPECTED OUTCOME**: To increase caregiver's capacity to cope with and manage hallucinations
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Does the person not recognize his/her environment? • Does the person not recognize his/her reflection in windows or mirrors? • Does the person not recognize family members/caregivers? • Is there something in the environment that upsets the person? • Has the person's routines changed? • Does the person have problems with hearing, seeing, or tasting? • Is there a problem with the person's medications? • Does the person have a physical illness, such as an infection? • Has the person recently fallen or hit his/her head? • Has the person not been eating enough or drinking enough fluids? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Does the person feel frightened? • Does the person feel unsafe? • Is the person reliving a trauma from the past? **Understand the possible meaning of the problem to the caregiver:** • Does the caregiver feel frustrated? • Does the caregiver feel like he/she does not know how to help?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Change the environment o Remove or adjust items that may upset the person o Cover mirrors and windows if the person does not know who is in the mirror or window o Turn on lights to reduce shadows that may look frightening o Turn off the TV if it is distracting. The person might also be confused about whether the TV episode is reality o Use contrasting colors, such as red plates on white table clothes, to help the person see differences in objects o Minimize busy patterns that might appear as an obstacle or barrier • Make sure the person's glasses and/or hearing aides are on and working • Offer simple explanations, such as where sounds might be coming from • Do not argue about whether what's happening is real; remember, it's real to the person • Be comforting and reassuring; remind person that he/she is safe • Go for a walk or find another enjoyable activity • Make sure the person is eating and drinking enough fluids • NOTE: You may not be able to stop the experience from happening because it might be part of the disease, but the goal is to help make it less scary and upsetting for the person

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

CLINICAL SUPPORT:

- Refer to PCP to evaluate possible medication reactions/interactions or assistive equipment needs such as glasses or hearing aides
- Test for illness, infection, and/or injury

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
  - ALZ Direct Connect referral
  - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
  - Website: www.alzgla.org
- Send literature:
  - Quick Fact Sheet – Hallucinations (English and Spanish)
  - Topic Sheet – "Hallucinations, Delusions, Paranoia"

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

NOTES:

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Hallucinations, Delusions, Paranoia

As Alzheimer's disease progresses, the person with the disease may have hallucinations, delusions, or paranoia. During a **hallucination**, the person sees, hears, smells, tastes, or feels something that isn't there. He or she also may have **delusions**— false beliefs that the person thinks are real.

Paranoia is a type of delusion in which a person may believe—without a good reason— that others are mean, lying, unfair, or "out to get me." He or she may become suspicious, fearful, or jealous of people.

Hallucinations and Delusions

Here are some tips for coping with hallucinations and delusions:

- Tell the doctor or Alzheimer's disease specialist about the hallucinations or delusions.
- Discuss with the doctor any illnesses the person with Alzheimer's has and medicines he or she is taking. Sometimes an illness or medicine may cause hallucinations or delusions.
- Try not to argue with the person about what he or she sees or hears. Comfort the person if he or she is afraid.
- Distract the person. Sometimes moving to another room or going outside for a walk helps.
- Turn off the TV when violent or upsetting programs are on. Someone with Alzheimer's may think these events are happening in the room.
- Make sure the person is safe and can't reach anything that could be used to hurt anyone or him or herself.

Paranoia

In a person with Alzheimer's disease, paranoia is often linked to memory loss. It can become worse as memory loss gets worse.

For example, the person may become paranoid if he or she forgets:

- Where he or she put something. The person may believe that someone is taking his or her things. That you are the person's caregiver. Someone with Alzheimer's might not trust you if he or she thinks you are a stranger.
- People to whom the person has been introduced. He or she may believe that strangers will be harmful.
- Directions you just gave. The person may think you are trying to trick him or her.

Paranoia may be the person's way of expressing loss. The person may blame or accuse others because no other explanation seems to make sense.

Here are some tips for coping with paranoia:

- Try not to react if the person blames you for something.
- Don't argue with the person.
- Let the person know that he or she is safe.
- Use gentle touching or hugging to show you care.
- Explain to others that the person is acting this way because he or she has Alzheimer's disease.
- Search for things to distract the person, then talk about what you found. For example, talk about a photograph or keepsake.

Also, keep in mind that someone with Alzheimer's disease may have a good reason for acting a certain way. He or she may not be paranoid. There are people who take advantage of weak and elderly people. Find out if someone is trying to abuse or steal from the person with Alzheimer's

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Hallucinations

People with Alzheimer's or dementia can sometimes hear, see, smell, taste, or feel something that is not really there. They may talk to someone from the past who is no longer in the home or even still alive or is a pretend friend. This can alarm family and friends.

WHAT CAN YOU DO?

See a Doctor

- visit the doctor to find out the cause (bring ALL medications with you)
- tell the doctor about every time you think this has happened (keep a log — day, time, and what was going on around the person with Alzheimer's or dementia)

Think About the Cause

- change the possible reason
    - if the person doesn't know who is in the mirror, cover the mirror
    - if things come out in the dark, turn on the lights or use a nightlight
    - if the TV or radio is confusing or scary, turn it off

Be Reassuring

- say things like "don't worry, I'm here and will take care of you"
- agree, don't argue, about whether what's happening is real... it is real to them
- involve him or her in something pleasant to distract them

WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might be:

- **having a reaction to medicine**
- **taking the wrong amount of medicine**
- **going through changes in the brain due to the disease**

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¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- **tener una reacción a algún medicamento**
- **estar tomando su medicina incorrectamente**
- **estar pasando por cambios en el cerebro causados por el Alzheimer**

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Alucinaciones

Las alucinaciones es cuando una persona oye, ve, huele o saborea algo que no existe. Esta persona puede tener conversaciones que para él o ella son reales. El Alzheimer o demencia causa alucinaciones en algunas personas.

¿QUÉ PUEDE HACER?

Hable con el doctor

- lleve todas las medicinas a la visita con el doctor
- reporte los cambios de comportamiento, incluyendo cada cuándo y por cuanto tiempo sucede

Piense en lo que puede estar causando las alucinaciones

- cambie el ambiente
  - si la persona no se reconoce en el espejo, cubra el espejo con una sábana
  - si la persona ve cosas en la obscuridad, prenda la luz o use una luz de noche
  - si la televisión o la radio lo está confundiendo o asustando, apáguelo

Tranquilice a la persona con Alzheimer

- diga, “No se preocupe. Yo estoy aquí. Yo le ayudo.”
- no discuta. Lo que la persona con Alzheimer ve o escucha es real para él
- trate de distraer a la persona con alguna actividad

Sundowning

Identify the Problem	**PROBLEM:** Sundowning (more confusion/restlessness in late afternoon/evening) **GOAL/EXPECTED OUTCOME**: To reduce and better manage sundowning behavior
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Does the person feel fatigued? • Is the person in a room that is very dark and might have shadows? • Is there a lot of noise in the environment? • Is the person hungry? • Is the person asked to do a complex activity late in the day? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Does the person feel frightened? • Is the person experiencing anxiety from too much stimulation or noise? **Understand the possible meaning of the problem to the caregiver:** • Does the caregiver feel frustrated? • Is the caregiver tired?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Increase illumination in the home before the sundowning behavior occurs • Make evening hours less busy (schedule things earlier in the day) • Encourage exercise and activity throughout the day • Distract the person with an enjoyable food or activity • Plan an earlier dinner • Lower the noise level • Reassure the person where he/she is and that he/she is safe • Use a calm, gentle, and reassuring voice
	CLINICAL SUPPORT: • Refer to PCP to evaluate possible medication reactions/interactions or other medical concerns • If non-pharmacological approaches prove unsuccessful, refer to PCP for medications, targeted to specific behaviors, as clinically indicated
	CAREGIVER SUPPORT AND COMMUNITY RESOURCES: • Listen empathically to caregiver and evaluate for level of distress • Refer to CBAS for structured daily activities • Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation o ALZ Direct Connect referral o Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259 o Website: www.alzgla.org • Send literature: o Topic Sheet – "Sundowning"

	FOLLOW UP: - Schedule a phone call with caregiver to discuss outcomes and provide additional support
	NOTES: ____________________ ____________________ ____________________ ____________________

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Sundowning

Late afternoon and early evening can be difficult for some people with Alzheimer's disease. They may experience sundowning—restlessness, agitation, irritability, or confusion that can begin or worsen as daylight begins to fade—often just when tired caregivers need a break.

Sundowning can continue into the night, making it hard for people with Alzheimer's to fall asleep and stay in bed. As a result, they and their caregivers may have trouble getting enough sleep and functioning well during the day.

Possible Causes

The causes of sundowning are not well understood. One possibility is that Alzheimer's-related brain changes can affect a person's "biological clock," leading to confused sleep-wake cycles. This may result in agitation and other possible causes of sundowning including:

- being overly tired.
- unmet needs such as hunger or thirst.
- depression.
- pain.
- boredom.

Coping with Sundowning

Look for signs of sundowning in the late afternoon and early evening. These signs may include increased confusion or anxiety and behaviors such as pacing, wandering, or yelling. If you can, try to find the cause of the person's behavior.

If the person with Alzheimer's becomes agitated, listen calmly to his or her concerns and frustrations. Try to reassure the person that everything is OK and distract him or her from stressful or upsetting events.

You can also try these tips:

- Reduce noise, clutter, or the number of people in the room.
- Try to distract the person with a favorite snack, object, or activity. For example, offer a drink, suggest a simple task like folding towels, or turn on a familiar TV show (but not the news or other shows that might be upsetting).
- Make early evening a quiet time of day. You might play soothing music, read, or go for a walk. You could also have a family member or friend call during this time.

- Close the curtains or blinds at dusk to minimize shadows and the confusion they may cause. Turn on lights to help minimize shadows.

Preventing Sundowning

Being too tired can increase late afternoon and early evening restlessness. Try to avoid this situation by helping the person.

- Go outside or at least sit by the window—exposure to bright light can help reset the person's body clock.
- Get physical activity or exercise each day.
- Get daytime rest if needed, but keep naps short and not too late in the day.
- Get enough rest at night.
- Avoid things that seem to make sundowning worse:
- Do not serve coffee, cola, or other drinks with caffeine late in the day.
- Do not serve alcoholic drinks. They may add to confusion and anxiety.
- Do not plan too many activities during the day. A full schedule can be tiring.

If Problems Persist

If sundowning continues to be a problem, seek medical advice. A medical exam may identify the cause of sundowning, such as pain, a sleep disorder or other illness, or a medication side effect.

If medication is prescribed to help the person relax and sleep better at night, be sure to find out about possible side effects. Some medications can increase the chances of dizziness, falls, and confusion. Doctors recommend using them only for short periods of time.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Sundowning

People with Alzheimer's or dementia may become more confused or nervous later in the day, often as the sun sets. This is called sundowning. They may see or hear things that are not there. They may accuse people of things that are not true, like stealing or lying, and may pace or walk back and forth. This is not done on purpose, and people with dementia cannot control it.

WHAT CAN YOU DO?

Make Changes at Home

- turn lights on early in the afternoon to make the house brighter
- turn down (or turn off) the television or radio
- turn on soothing music
- avoid loud or confusing noises
- clear a path for the person to walk back and forth

Pay Attention to Meals and Snacks

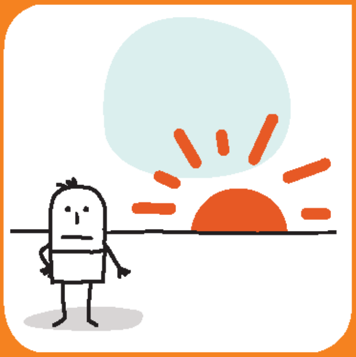
- provide a large meal at lunch and a light meal at dinner
- allow less caffeine, sugar, coffee, tea, and soda after 3:00 pm
- remove access to alcohol and cigarettes

Keep a Schedule

- make going to bed and waking up at the same time every day
- take walks or dance to use up extra energy
- plan doctor visits, outings, baths in the morning

Other Ideas

- be calm and reassuring
- be flexible...if one idea doesn't work, try another
- comfort her and say or do something to calm her fears
- try a new activity, like sorting coins or dancing



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might be:

- more tired in the late afternoon
- confused by changing amounts of light
- scared by shadows
- reacting to your feelings of being tired

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Cambios al Atardecer

Personas que tienen Alzheimer o demencia se confunden o se ponen más nerviosas por la tarde cuando baja el sol. Esto se llama cambios al atardecer. A veces pueden ver o escuchar cosas que no están allí. Pueden acusar a los demás de cosas que no son ciertas, como robar o mentir, y ponerse a caminar de un lado a otro. Recuerde que no lo hacen a propósito o para molestar, si no que no pueden controlar ese comportamiento.

¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden estar:

- **muy cansadas por la tarde**
- **confundidas porque hay menos luz en la casa**
- **asustadas por las sombras**
- **respondiéndoles enojada si usted está agitada**

¿QUÉ PUEDE HACER?

Hacer cambios en el hogar

- Encienda las luces por la tarde para hacer la casa más brillante
- Baje el volumen (o apague) el televisor o la radio
- Ponga música suave
- Evite ruidos confusos
- Mantenga un espacio libre en donde la persona pueda caminar de un lado a otro

Ponga atención a las comidas y bebidas

- Sirva un almuerzo grande y una cena ligera
- Limite el consumo de cafeína, azúcar, café, té y refrescos después de las 3:00 pm
- Manténgalo alejado de alcohol y cigarros

Mantenga una rutina

- Trate de mantener una rutina todos los días, como la hora de dormir y levantarse
- Camine o baile con la persona con Alzheimer para que se cansen y así pueda dormir mejor por la noche
- Cambie las actividades que causan enojo o ansiedad a la persona con Alzheimer por la mañana para cuando la persona esté más tranquila, por ejemplo: visitas al médico, bañarse o ir de compras

Otras ideas

- Mantenga su actitud y tono de voz calmada
- Sea flexible… si lo que hizo no funcionó, después de un par de minutos trate algo nuevo
- Mantenga la calma y tranquilice a la persona.
- Trátela con cariño. Dele un abrazo y dígale “No se preocupe. Yo estoy aquí. Yo le ayudo”
- Hagan actividades relajantes o divertidas juntos para distraerlo, tales como: ver fotos de la familia, cantar, bailar, o jugar con la mascota

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Suspiciousness and Paranoia

Identify the Problem	**PROBLEM:** Suspiciousness and Paranoia (accusing, blaming) **GOAL/EXPECTED OUTCOME:** To improve caregiver capacity to cope with and manage behaviors of suspiciousness and paranoia
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Is the person's environment unfamiliar? • Are the people around the person unfamiliar to him/her? • Was there a change in the person's routine? • Has the person misplaced an item he/she is looking for? • Is there too much going on around the person? • Is the person experiencing hallucinations or delusions due to the disease? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Is the person angry? • Does the person feel taken advantage of? • Is the person scared? **Understand the possible meaning of the problem to the caregiver:** • Does the caregiver feel wrongfully blamed? [It is not uncommon for people with the disease to accuse those who are closest to them of stealing] • Is the caregiver frustrated?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • The source of suspicion might be real! Check it out first • Don't take it personally; this is part of the disease • Try to keep the person's routine the same every day • Use a calm and gentle tone of voice; don't argue with the person • Make sure the lighting is bright • Try to limit noises and distractions around the person • Offer to help the person look for lost things • Learn where the person's common "hiding places" are and let other caregivers know • If the person is often looking for a specific item, have extras available (i.e., multiple wallets, a canceled check, etc.)
	CLINICAL SUPPORT: • Refer to PCP to assess for adverse effects of medications or possible medical or psychiatric conditions, if hallucinations or delusions are present • If non-pharmacological approaches prove unsuccessful, refer to PCP for medications, targeted to specific behaviors, as clinically indicated

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HEALTH RISK ASSESSMENT COGNITIVE IMPAIRMENT TRIGGER QUESTIONS

H ssessments (HRAs) should include questions about cognitive function that can t ed for a validated cognitive screen.

S with cognitive impairment who answer questions on an HRA may not have i eir deficits. As a result, some of their answers to questions will be invalid. Health p erefore, develop a strategy to identify people who are unable to complete the H gnitive impairment.

S nitive Impairment Questions

on #1: During the past year, have you experienced changes in thinking, bering, or decision-making? For example, have you had more difficulty bering people, places, or things? Have you had had more difficulty making ns?

on #2: Does forgetfulness (such a paying your bills or counting change) cause ms in your daily life?

on #3: Has a doctor or other health care professional ever told you that you have ner's disease or other form of dementia?

C ved from: Centers for Disease Control and Prevention. BRFSS Optional C ule (2007 Draft).

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Standardized Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

	CAREGIVER SUPPORT AND COMMUNITY RESOURCES: • Listen empathically to caregiver and evaluate for level of distress • Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation o ALZ Direct Connect referral o Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259 o Website: www.alzgla.org • Send literature: o Topic Sheet – "Suspiciousness and Paranoia"
	FOLLOW UP: • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	NOTES: ____ ____ ____ ____

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Suspiciousness and Paranoia

As Alzheimer’s disease progresses, the person with the disease may have hallucinations, delusions, or paranoia. During a **hallucination**, the person sees, hears, smells, tastes, or feels something that isn’t there. He or she also may have **delusions**— false beliefs that the person thinks are real.

Paranoia is a type of delusion in which a person may believe—without a good reason— that others are mean, lying, unfair, or “out to get me.” He or she may become suspicious, fearful, or jealous of people.

Hallucinations and Delusions

Here are some tips for coping with hallucinations and delusions:

- Tell the doctor or Alzheimer’s disease specialist about the hallucinations or delusions.
- Discuss with the doctor any illnesses the person with Alzheimer’s has and medicines he or she is taking. Sometimes an illness or medicine may cause hallucinations or delusions.
- Try not to argue with the person about what he or she sees or hears. Comfort the person if he or she is afraid.
- Distract the person. Sometimes moving to another room or going outside for a walk helps.
- Turn off the TV when violent or upsetting programs are on. Someone with Alzheimer’s may think these events are happening in the room.
- Make sure the person is safe and can’t reach anything that could be used to hurt anyone or him or herself.

Paranoia

In a person with Alzheimer’s disease, paranoia is often linked to memory loss. It can become worse as memory loss gets worse.

For example, the person may become paranoid if he or she forgets:

- Where he or she put something. The person may believe that someone is taking his or her things. Someone with Alzheimer's might not trust you if he or she thinks you are a stranger.
- People to whom the person has been introduced. He or she may believe that strangers will be harmful.
- Directions you just gave. The person may think you are trying to trick him or her.

Paranoia may be the person's way of expressing loss. The person may blame or accuse others because no other explanation seems to make sense.

Here are some tips for coping with paranoia:

- Try not to react if the person blames you for something.
- Don't argue with the person.
- Let the person know that he or she is safe.
- Use gentle touching or hugging to show you care.
- Explain to others that the person is acting this way because he or she has Alzheimer's disease.
- Search for things to distract the person, then talk about what you found. For example, talk about a photograph or keepsake.

Also, keep in mind that someone with Alzheimer's disease may have a good reason for acting a certain way. He or she may not be paranoid. There are people who take advantage of weak and elderly people. Find out if someone is trying to abuse or steal from the person with Alzheimer's.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Screaming and Making Noises

<u>Id</u>entify the Problem	**<u>PROBLEM</u>:** Screaming and Making Noises **<u>GOAL/EXPECTED OUTCOME</u>**: To increase caregiver's understanding of noise as communication to improve caregiver's capacity to cope with and manage noise
<u>E</u>xplore	**<u>ASSESS FURTHER</u>:** **Understand the possible triggers of the problem:** • Is the person ill, in pain, or uncomfortable? • Is the person unable to speak or be understood because of the disease? • Is the person trying to tell you he/she is hungry? Thirsty? Too cold? • Does the person need to use the bathroom, or need to be cleaned up? • Is the person really tired? • Does the person need help changing position in a chair/bed? • Is the environment too loud or overwhelming for the person? • Is there too much going on around the person? • Is the person bored? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Is the person feeling scared or confused? • Does the person feel frustrated he/she cannot tell you what he/she needs? **Understand the possible meaning of the problem to the caregiver:** • Is the caregiver frustrated? Annoyed? • Does the caregiver feel confused or "stuck" about what to do? • Is the caregiver embarrassed?
<u>A</u>djust Problem solve with interventions and actions	**<u>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER</u>:** • Try finding other ways for the person to communicate, such as using a bell • Try to address the unmet need before it becomes a problem o Keep a regular eating schedule for the person with meals and snacks to reduce hunger o Keep a regular toileting schedule to reduce accidents o Change the person's position in chairs/bed regularly o Clean the person up immediately after an accident • Create a relaxing and calm environment o Use relaxing techniques, such as massage, gentle touch, talking in a soothing voice, or playing calming music o Always approach the person from the front with a calm voice. Use the person's name and introduce yourself, when needed • Break tasks into short, simple steps and explain what you are going to do before you do it
	<u>CLINICAL SUPPORT</u>: • Refer to PCP for good medical examination to assess for illness, infections, pain/discomfort, or impaction • If non-pharmacological approaches prove unsuccessful, then use medications, targeted to specific behaviors, if clinically indicated

	CAREGIVER SUPPORT AND COMMUNITY RESOURCES: • Listen empathically to caregiver and evaluate for level of distress • Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation o ALZ Direct Connect referral o Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259 o Website: www.alzgla.org • Send literature: o Topic Sheet – "Communication and Alzheimer's"
	FOLLOW UP: • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	NOTES: ____________________ ____________________ ____________________ ____________________

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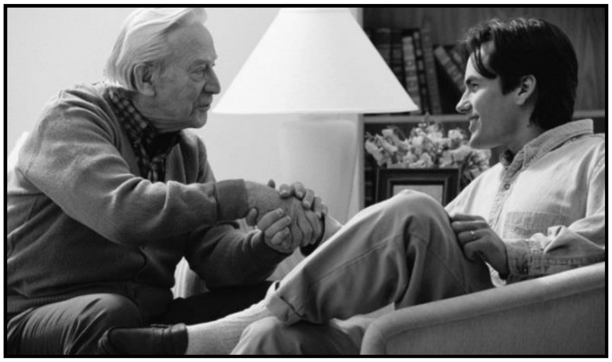
Communication and Alzheimer's



Communication is hard for people with Alzheimer's disease. They may struggle to find words, or forget what they want to say. They may no longer be able to use words at all, or to place them together into full sentences. You may feel impatient and wish they could just say what they want, but they can't.

The person with Alzheimer's may have problems with:

- Finding the right word or losing his or her train of thought when speaking.
- Understanding what words mean or how to use them together in a sentence.
- Paying attention during long conversations.
- Remembering the steps in common activities, such as cooking a meal, paying bills, or getting dressed.
- Blocking out background noises from the radio, TV, or conversations.
- Becoming frustrated if communication isn't working.
- Being very sensitive to touch and to the tone and loudness of voices.

Help Make Communication Easier

The first step is to understand that the disease causes changes in communication skills. The second step is to try some tips that may make communication easier:

- Make eye contact and call the person by name.
- Be aware of your tone, how loud your voice is, how you look at the person, and your body language.
- Encourage a two-way conversation for as long as possible.
- Use other methods of communication besides speaking, such as gentle touch and body language (gestures, eye contact, tone of voice, etc.).
- Try distracting the person if communication creates problems.
- To encourage the person to communicate with you:
- Show a warm, loving, matter-of-fact manner.

- Hold the person’s hand while you talk. Be open to the person’s concerns, even if he or she is hard to understand.
- Let him or her make some decisions and stay involved.
- Be patient with angry outbursts. Remember, it’s the illness “talking.”

To speak effectively with a person who has Alzheimer’s:

- Offer simple, step-by-step instructions.
- Repeat instructions and allow more time for a response. Try not to interrupt.
- Don’t talk about the person as if he or she isn’t there.
- Don’t talk to the person using “baby talk” or a “baby voice.”

Be Direct, Specific, and Positive

Here are some examples of what you can say:

- “Let’s try this way,” instead of pointing out mistakes.
- “Please do this,” instead of “Don’t do this.”
- “Thanks for helping,” even if the results aren’t perfect.

You also can:

- Ask questions that require a yes or no answer. For example, you could say, “Are you tired?” instead of “How do you feel?”
- Limit the number of choices. For example, you could say, “Would you like a hamburger or chicken for dinner?” instead of “What would you like for dinner?”
- Use different words if he or she doesn’t understand the first time. For example, if you ask the person whether he or she is hungry and you don’t get a response, you could say, “Dinner is ready now. Let’s eat.”
- Try not to say, “Don’t you remember?” or “I told you.” If you become frustrated, take a timeout for yourself.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Disinhibition

Identify the Problem	**PROBLEM:** Disinhibition (unwanted sexual behaviors or inappropriate behaviors) **GOAL/EXPECTED OUTCOME**: To increase caregiver capacity to understand, cope and manage disinhibited behaviors
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Is the person trying to communicate something to you? • Does the person need to use the bathroom? • Is the person feeling too hot or too cold? • Are the person's clothes on too tightly? • Is the person disoriented (i.e. thinking he/she is in the bathroom and trying to urinate)? • Is the person confused by people's identities (thinking that the store clerk is his/her spouse)? • Is the person confused about the time (thinking it's bed time, and taking clothes off for bed)? • Does the person have an infection, such as a UTI, that could lead to itching/handling of the genital area? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Is the person in need of human contact? • Is the person lonely? **Understand the possible meaning of the problem to the caregiver:** • Is the caregiver shocked and embarrassed? • Is the caregiver angry?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Try to find out if the person needs something and direct them to it, such as the bathroom, or different clothing • Try not to react with disapproval or anger. Remember that this is part of the disease and the person is not doing it on purpose • Don't try to reason with the person or explain that it is not appropriate behavior • Ignore the behaviors when possible • Be calm and reassuring when redirecting the person • Try reacting to sexual behaviors by providing extra touch and affection on the person's shoulders, arm, or hand. Smile or give a hug. The person may be expressing a (non-sexual) need for affection and human contact • Substitute a different pleasurable activity that may distract the person • Lead the person to a private place • Use a stalling tactic, such as "We will be alone soon, but let's first go out for a walk" • Take strangers aside and ask that they please excuse the person; tell them that the person has dementia and is not fully aware of his/her actions or what he/she is saying (Some people make up small cards they can quietly pass to wait staff, store clerks, and others that explain this)

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

- If the person frequently undresses, try using hard-to-remove clothing, such as small buttons, pants without zippers, or shirts that zip/button in the back. (Keep in mind, however: changing familiar clothing may cause some people difficulty with toileting needs because they do not recognize how to remove the new clothes)

CLINICAL SUPPORT:

- Refer to PCP to evaluate for physical illness, medication side effects or causes of discomfort/pain
- If non-pharmacological approaches prove unsuccessful, refer to PCP for medications, targeted to specific behaviors, as clinically indicated

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
  - ALZ Direct Connect referral
  - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
  - Website: www.alzgla.org
- Send Literature:
  - Topic Sheet – "Disinhibition (Intimacy and Sexuality)"

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

NOTES:

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

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Disinhibition (Intimacy & Sexuality)

Alzheimer's disease can cause changes in intimacy and sexuality in both a person with the disease and the caregiver. The person with Alzheimer's may be stressed by the changes in his or her memory and behaviors. Fear, worry, depression, anger, and low self-esteem (how much the person likes himself or herself) are common.

The person may become dependent and cling to you. He or she may not remember your life together and feelings toward one another. The person may even fall in love with someone else, or behave inappropriately toward you or others. It can be embarrassing for family members to watch their loved ones demonstrating inappropriate sexual behaviors, but it is important to remember that this is caused by the disease. The person is not behaving this way on purpose.

How to Cope with Changes in Intimacy

Most people with Alzheimer's disease need to feel that someone loves and cares about them. They also need to spend time with other people as well as you. Your efforts to take care of these needs can help the person with Alzheimer's to feel happy and safe. It's important to reassure the person that:

- you love him or her.
- you will keep him or her safe.
- others also care about him or her.

The following tips may help you cope with your own needs:

- Talk with a doctor, social worker, or clergy member about these changes. It may feel awkward to talk about such personal issues, but it can help.
- Talk about your concerns in a support group.
- Think more about the positive parts of the relationship.

Hypersexuality

Sometimes, people with Alzheimer's disease are overly interested in sex. This is called "hypersexuality." The person may masturbate a lot and try to seduce others. The person may remove his or her clothing in a public or inappropriate location. The person may also demonstrate inappropriate sexual behaviors toward others. These behaviors are symptoms of the disease and don’t always mean that the person wants to have sex. To cope with hypersexuality, try giving the person more attention and reassurance. You might try:

- Gentle touch, hugging, or using other kinds of affection to meet his or her emotional needs.
- Not reacting with disapproval or anger. Remember that this is part of the disease and the person is not doing this on purpose.
- Don’t try to reason with the person or explain that it is not appropriate behavior.
- Ignore the behaviors as much as possible, or lead the person to a private area.
- Be calm and reassuring when redirecting the person.
- Use a stalling tactic when needed, such as “We will be alone soon, but let’s first go out for a walk.”

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Care Plans:
Activities of Daily Living & Functional Needs

Alzheimer's
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TABLE OF CONTENTS
Care Plans: Activities of Daily Living and Functional Needs

Resists Bathing or Showering

Identify the Problem	**PROBLEM:** Resists Bathing or Showering **GOAL/EXPECTED OUTCOME**: To reduce resistance to bathing or showering
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Does the person not recognize who you are? • Does the person not recognize his or her self in the bathroom mirror? • Is the person scared? • Is the temperature of the room uncomfortable? • Is the temperature of the water uncomfortable? • Is there poor lighting? • Is the person sensitive to the noise of the running water? • Does the person have difficulty with vision or hearing? • Is there a breakdown in communication? Does the person not understand your directions? • Is the person kept waiting too long while the bath is being prepared? • Is the person fatigued? • Is the person in pain? • Are the tasks involved in bathing too complicated? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Is the person feeling embarrassed about getting undressed in front of you? • Is the person uncomfortable? • Is the person scared or confused? **Understand the possible meaning of the problem to the caregiver:** • Is the caregiver frustrated?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Preparing the bathroom: o Make sure the room is warm enough for the person o Run the water so it is not too hot or too cold o Do not use bright lights if possible o Have a towel, clean clothing, and non-slip socks ready for use when the person steps out of the tub or shower o Try covering the mirror if the person gets agitated around it o Try playing the person's favorite calming music • Make sure the bathroom is safe to reduce fear • Use a non-slip mat in the tub or on the bathroom floor so the person feels more safe • Consider a tub or shower seat. Make it comfortable with a warm towel • Fill the tub with only 4 inches of water to make water seem less scary • Communicating effectively o Assure the person you are there to help them o Use a calm and reassuring tone of voice o Be direct: "Your bath is ready now," instead of "Do you want to take a bath?" o Explain what you are doing right before you do it

  - o Use simple instructions, one at a time, and demonstrate for the person, i.e., pretend to wash your arm so the person can copy you
- Other
  - o Try to be patient and do not rush the person
  - o Let the person participate, by giving him/her a washcloth to use
  - o Be gentle and look for signs of pain
  - o Consider a sponge bath instead of a shower if needed
  - o If the person does not want to bathe, try at another time. Also realize that daily bathing may be too much
  - o Find the best time of the day when the person is not too tired or anxious
  - o Give the person as much privacy as possible, but keep safety in mind

<u>CLINICAL SUPPORT</u>:

- If the person refuses to bathe because of pain, refer to PCP
- Discuss with PCP appropriate hygiene

<u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES</u>:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to IHSS
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
  - o ALZ Direct Connect referral
  - o Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
  - o Website: www.alzgla.org
- Send literature:
  - o Quick Fact Sheet – Bathing (English and Spanish)
  - o Topic Sheet – "Difficulty with Bathing"

<u>FOLLOW UP</u>:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

<u>NOTES</u>:

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Difficulty with Bathing

At some point, people with Alzheimer's disease will need help bathing. Because this is a private activity, people may not want help. They may also feel angry about not being able to take care of themselves.

Helping someone with Alzheimer's disease take a bath or shower can be one of the hardest things you do. Planning can help make bath time better for both of you. If the person is afraid of bathing, follow his or her lifelong bathing habits, such as doing the bath or shower in the morning or before going to bed.

Safety Tips

To keep the person with Alzheimer's safe during bath time:

- Never leave a confused or frail person alone in the tub or shower.
- Always check the water temperature before he or she gets in the tub or shower.
- Use a hand-held showerhead.
- Use a rubber bath mat and safety bars in the tub.
- Use a sturdy shower chair to support a person who is unsteady and to prevent falls. You can buy shower chairs at drug stores and medical supply stores.

Before Bathing

Before starting a bath or shower:

- Get the soap, washcloth, towels, and shampoo ready.
- Make sure the bathroom is warm and well lighted.
- Play soft music if it helps to relax the person.
- Be matter-of-fact about bathing. Say, "It's time for a bath now." Don't argue about the need for a bath or shower.
- Be gentle and respectful. Tell the person what you are going to do, step by step.
- Make sure the water temperature is comfortable.
- Don't use bath oil. It can make the tub slippery and may cause urinary tract infections.

During a Bath or Shower

Allow the person with Alzheimer's to do as much as possible. This protects his or her dignity and helps the person feel more in control. Here are other tips:

- Put a towel over the person's shoulders or lap. This helps him or her feel less exposed. Then use a sponge or washcloth to clean under the towel.
- Distract the person by talking about something else if he or she becomes upset.
- Give the person a washcloth to hold. This makes it less likely that he or she will try to hit you.

After Bathing

Try these suggestions:

- Prevent rashes or infections by patting the person's skin with a towel. Make sure the person is completely dry. Be sure to dry between folds of skin.
- If the person is incontinent, use a protective ointment, such as petroleum jelly, around the rectum, vagina, or penis.
- If the person has trouble getting in and out of the bathtub, do a sponge bath instead.

Other Bathing Tips

For most people, a full bath or shower two or three times a week is enough. Between full baths, a sponge bath to clean the face, hands, feet, underarms, and genitals is all you need to do every day. Also:

- Washing the person's hair in the sink with a hose attachment may be easier than doing it in the shower or bathtub.
- Get professional help with bathing if it becomes too hard for you to do on your own.

Information adapted from the National Institute on Aging, part of the National Institutes of Health*www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Bathing

People with Alzheimer's disease or dementia may be afraid of bathing or uneasy with having someone help them with bathing. Sometimes they worry about falling or can have trouble knowing which is the hot versus the cold water faucets.

WHAT CAN YOU DO?

Prepare the Bathroom in Advance

- make sure the room is calm and warm
- run the water so it is not too hot or too cold
- don't use bright lights if possible

Make the Bathroom Safe

- use a non-slip mat in the tub or shower and as a bath mat
- consider a tub seat
- fill the tub with only 4 inches of water
- remove things that may be dangerous such as razors, nail clippers, hair dryer, etc.
- watch carefully – don't leave him or her alone

Allow Time & Be Positive

- allow your person to enjoy it... if he or she finds bath time relaxing
- stay calm
- be direct... "Your bath is ready now" instead of "Do you want to take a bath?"
- give one step directions... "Let's wash your left arm...good!, now your other one"
- be patient... don't rush

Be Realistic

- don't argue or get frustrated... a daily bath may be too much
- consider a sponge bath instead of a tub bath
- show what you need from them... pretend to wash your arm so that he or she can copy

WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might be:

- **afraid of falling**
- **feeling uneasy getting undressed in front of you**
- **scared or confused**
- **feeling helpless**

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¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- **tener miedo a caerse**
- **no se sienten cómodos desvistiéndose enfrente de otros**
- **están asustados**
- **sentirse sin control**

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Bañarse

Personas con Alzheimer o demencia pueden tener miedo a bañarse. Creen que se van a caer o les da vergüenza desvestirse enfrente de otra persona.

¿QUÉ PUEDE HACER?

Primero prepare el baño

- asegúrese que el ambiente esté calmado y cómodo para la persona
- mantenga el agua a una temperatura agradable
- si es posible, no use luces brillantes

Seguridad en el baño

- use alfombras que no resbalen
- use una silla de baño
- ponga sólo 4 pulgadas de agua en la tina
- saque del baño lo que puede causarle daño a la persona con Alzheimer, tales como: rastrillos, corta úñas y secadoras de pelo
- nunca deje a la persona con Alzheimer sóla en la tina o ducha

Sea positivo, directo y paciente

- si a la persona le gusta bañarse, deje que disfrute su baño
- sea paciente, trate de no forzar ni apresurar a la persona
- de una instrucción a la vez...“Lávese el brazo. Bien. Ahora lávese el otro brazo”
- muéstrele con ejemplos; haga como que usted se lava el brazo y pida que copie sus movimientos

Evite las discusiones y sea realista

- un baño diario puede ser mucho
- considere un baño de esponja
- escoja una hora cuando la persona con Alzheimer esté relajada y no muy agitada

Difficulty with Dressing and Grooming

Identify the Problem	**PROBLEM:** Difficulty with Dressing and Grooming (brushing hair/teeth, shaving, etc.) **GOAL/EXPECTED OUTCOME**: To reduce difficulty with bathing and grooming
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Is the task too hard or confusing (i.e., a lot of buttons)? • Are there too many steps involved? • Are there too many options for what to wear? • Does the person feel tired? • Is the room too cold? • Is there poor lighting? • Are there too many distractions around the person? • Is the person in pain? • Is the person having difficulty seeing or hearing? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Does the person feel a lack of privacy? • Is the person frustrated or overwhelmed? • Is the person upset about needing help? • Has appearance always been important to the person? **Understand the possible meaning of the problem to the caregiver:** • Is the caregiver frustrated? • Is the caregiver worried about ensuring the person's lifelong value of appearance is maintained? • Does the caregiver feel the person is acting this way on purpose?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Keep the routine as familiar to the person as possible • Avoid delays and interruptions in the routine • Encourage the person to do as much as he/she can on his/her own and then help as needed • Give the person and yourself extra time for the task • Demonstrate tasks for the person • Use simple, step-by-step instructions • Dressing: o Offer the person only two options so there are not too many choices o Lay out clothing in the order it needs to be put on o Have clothing that is easier for the person to put on, such as slip-on shoes, cardigans, Velcro, elastic waistbands, etc. o Buy clothing that is loose-fitting and comfortable, not tight o If the person always wants to wear the same things, buy multiples o Make sure the room is warm enough o Make sure there is enough lighting in the room o Close the door and pull down the blinds to create privacy o Remove distractions (TV playing, clutter, etc.)

    - Make sure the person has his/her glasses or hearing aids and make sure they are working
- Grooming:
    - Brush your teeth or your hair at the same time, so the person can copy what you are doing or provide hand-over-hand assistance
    - For men and shaving, use a quiet, electric razor
    - Try to do the person's hair/makeup the way they always kept it

CLINICAL SUPPORT:

- If the person continues refusing to dress, groom and maintain hygiene, have the person evaluated for possible depression
- If indicated, evaluate for possible source(s) of pain

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to IHSS
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
    - ALZ Direct Connect referral
    - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
    - Website: www.alzgla.org
- Send literature:
    - Topic Sheet – "Dressing and Grooming"

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

NOTES:

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Dressing and Grooming

When people feel good about how they look, they often feel better. Helping people with Alzheimer's disease brush their teeth, shave, put on makeup, and get dressed can help them feel more like themselves.

Mouth Care

Here are some tips to help the person with Alzheimer's care for his or her teeth and mouth.

- Show the person how to brush his or her teeth. Go step by step. Remember to let the person do as much as possible.
- Brush your teeth at the same time.
- Help the person clean his or her dentures.
- Ask the person to rinse his or her mouth with water after each meal and use mouthwash once a day.
- Try a long-handled, angled, or electric toothbrush if you need to brush the person's teeth.
- Take the person to see a dentist. Some dentists specialize in treating people with Alzheimer's. Ask the dentist how often the person should be seen.

Other Grooming

Here are some other suggestions for grooming:

- Encourage a woman to wear makeup if she has always used it. If needed, help her put on powder and lipstick. Don't use eye makeup.
- Encourage a man to shave, and help him as needed. Use an electric razor for safety.
- Take the person to the barber or beauty shop. Some barbers or hairstylists may come to your home.
- Keep the person's nails clean and trimmed.

Dressing

People with Alzheimer's disease often need more time to dress. It can be hard for them to choose their clothes. They might wear the wrong clothing for the season. They also might wear colors that don't go together or forget to put on a piece of clothing. Allow the person to dress on his or her own for as long as possible.

Other tips for dressing:

- Lay out clothes in the order the person should put them on, such as underwear first, then pants, then a shirt, and then a sweater.
- Hand the person one thing at a time, or give step-by-step dressing instructions.
- Put away some clothes in another room to reduce the number of choices. Keep only one or two outfits in the closet or dresser.
- Keep the closet locked if needed.
- Buy three or four sets of the same clothes if the person wants to wear the same clothing every day.
- Buy loose-fitting, comfortable clothing, such as sport bras, cotton socks and underwear, and sweat pants and shorts with elastic waistbands.
- Avoid girdles, control-top pantyhose, knee-high nylons, high heels, and tight socks.
- Use Velcro® tape or large zipper pulls for clothing instead of shoelaces, buttons, or buckles.
- Try slip-on shoes that won't slide off or shoes with Velcro® straps

Information adapted from the National Institute on Aging, part of the National Institutes of Health www.nia.nih.gov, NIH July 2012
Reviewed by ALZGLA November 2016

Difficulty with Eating

Identify the Problem	**PROBLEM:** Difficulty with Eating (including chewing, swallowing, dental concerns) **GOAL/EXPECTED OUTCOME**: To reduce difficulty with eating
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** - Is the person having a side effect of a medication that affects hunger? - Is the person experiencing any pain or illness? Is the person constipated? - Does the person have any mouth discomfort, such as painful gums, dentures not fitting right, etc.? - Is the person really tired at meal time? - Is the person's mouth dry? - Are there too many steps associated with eating? - Does the person have difficulty with chewing? - Does the person have trouble seeing his/her food? (The food might be the same color as the plate and blend in - Is the person eating in a place he/she does not recognize? - Are there too many distractions or too much noise around the person? - Does the person not remember to stop and eat? **Understand the possible meaning of the problem to the person with Alzheimer's:** - Is the person embarrassed to be fed by someone else? - Is the person frustrated or overwhelmed? **Understand the possible meaning of the problem to the caregiver:** - Is the caregiver frustrated? - Is the caregiver worried?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** - Make mealtimes simple, relaxed, and calm - Make sure the person is comfortable - Allow ample time for eating - Make sure the person's lips are not dry; use ChapStick as needed - If the person wears dentures, make sure they are properly in place - Preparing the eating area o Make sure the plate is a different color from the food o Try to avoid patterns on placemats, plates and tablecloths. They can be distracting o Increase lighting in eating area o Reduce the noise and distractions around the person - Make eating simple. Try these options: o Serve only one food at a time o Use bowls instead of plates o Try setting the area with only utensils that are needed for the meal o Plastic utensils may be too light and might break. Try to avoid them o Use bendable straws or cups with lids o Serve finger foods that are easier for the person to pick up and eat o Sit in front of the person when helping with eating. Use simple, gentle words - For over-eating o Make sure the person is not sitting around with nothing to do. Try

	redirecting to activities that the person enjoys o Try 5 or 6 small meals a day o Have healthy snacks available, such as apples, carrots, etc. • For under-eating o Talk with the doctor about possible illness, pain, or medication affects o Check with the doctor about supplemental drinks, such as Ensure o Offer the person a glass of juice before the meal to increase appetite o Make sure the person is getting enough exercise o Try to make foods the person likes o Try feeding all of one food before moving to the next. Some people get confused by the change in texture or taste o Be flexible. Let the person eat when he/she is hungry if possible
	CLINICAL SUPPORT: • Have a good dental check-up of the person's gums, teeth and dentures • Check with a doctor to see if problems with eating are a side effect of a medication or health problem • Have vision or glasses checked • Refer to PCP to evaluate for appropriate dietary needs. Request referral for swallowing evaluation (particularly important in later stages)
	CAREGIVER SUPPORT AND COMMUNITY RESOURCES: • Listen empathically to caregiver and evaluate for level of distress • Refer to IHSS • Refer to MSSP • Refer to Meals on Wheels • Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation o ALZ Direct Connect referral o Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259 o Website: www.alzgla.org • Send literature: o Topic Sheet – "Difficulty with Eating"
	FOLLOW UP: • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	NOTES: ______________________________ ______________________________ ______________________________ ______________________________

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Alzheimer's Caregiving Tips

Difficulty with Eating

Eating healthy foods helps everyone stay well, but buying and preparing healthy foods can be challenging with someone who has Alzheimer's disease. A person with Alzheimer's may have difficulty with eating for several reasons. He or she may have a physical challenge with eating, there may be too many food options offered, or the person may forget that he or she already ate, or forget to eat all together. Here are some tips to help with healthy eating routines.

Buying and Preparing Food

When the person with Alzheimer's disease lives with you:

- Buy healthy foods such as vegetables, fruits, and whole-grain products. Be sure to buy foods that the person likes and can eat.
- Give the person choices about what to eat—for example, "Would you like green beans or salad?"
- Buy food that is easy to prepare, such as premade salads and single food portions.

Maintain Familiar Routines

Change can be difficult for a person with Alzheimer's disease. Maintaining familiar routines and serving favorite foods can make mealtimes easier. They can help the person know what to expect and feel more relaxed. If a home health aide or other professional provides care, family members should tell this caregiver about the person's preferences.

Try these tips:

- View mealtimes as opportunities for social interaction. A warm and happy tone of voice, in a calm and relaxing environment, can set the mood.
- Be patient and give the person enough time to finish the meal.
- Prepare the area ahead of time. Make sure the plate is a different color from the food, avoid patterns on placemats, plates and tablecloths. They can be distracting. And increase lighting in the eating area.
- Use bendable straws or cups with lids.
- Serve finger foods that are easier for the person to pick up and eat.
- Sit in front of the person when helping with eating. Use simple, gentle words.

Make eating simple. Try these options:

- Serve only one food at a time.
- Use bowls instead of plates.
- Set the area with only the utensils needed for the meal.

For Over-Eating

- Make sure the person is not sitting around with nothing to do. Try redirecting to activities that the person enjoys
- Try 5 or 6 small meals a day
- Have healthy snacks available, such as apples, carrots, etc.

For Under-Eating

- Talk with the doctor about possible illness, pain, or medication affects
- Check with the doctor about supplemental drinks, such as Ensure
- Offer the person a glass of juice before the meal to increase appetite
- Make sure the person is getting enough exercise
- Try to make foods the person likes
- Try feeding all of one food before moving to the next. Some people get confused by the change in texture or taste
- Be flexible. Let the person eat when he/she is hungry, if possible.

Stay Safe

In the early stage of Alzheimer's, people's eating habits usually do not change. When changes do occur, living alone may not be safe anymore. Look for these signs to see if living alone is no longer safe for the person with Alzheimer's:

- The person forgets to eat.
- Food has burned because it was left on the stove.
- The oven isn't turned off.

Information adapted from the National Institute on Aging, part of the National Institutes of Health www.nia.nih.gov, NIH July 2012
Reviewed by ALZGLA November 2016

Difficulty Using the Toilet

Identify the Problem	**PROBLEM:** Difficulty Using the Toilet/Incontinence (wetting, accidents) **GOAL/EXPECTED OUTCOME**: To reduce difficulty with toileting/incontinence
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Does the person have pain or an infection, such as a urinary tract infection (UTI)? • Is the person constipated? • Is the person getting enough to drink or drinking too much? • Has the person had a change in medications? • Does the person have a chronic illness, such as diabetes, Parkinson's, stroke? • Does the person have trouble with vision or moving around that makes it hard to get to the bathroom in time? • Is the person too far from the bathroom or is the bed too high up? • Is it hard for the person to undress in time to use the bathroom? • Does the person not remember what to do once he/she is in the bathroom? • Is the task of going to the bathroom too hard for the person? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Is the person embarrassed? Is there not enough privacy? **Understand the possible meaning of the problem to the caregiver:** • Is the caregiver frustrated? • Is the caregiver worried? • Is the caregiver embarrassed?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Use a bedside commode to make toileting easier • Install grab bars or raised toilet seats to make toileting easier and safer • Maintain proper hygiene: ensure the person has wiped properly, that skin is clean and dry, and that hands are washed • Immediately after an accident, make sure skin is washed and dried and clothes are changed, to avoid rashes and sores • Try to make the bathroom visible from where the person sits or sleeps. Keep the bathroom door open with a light on. • Assist the person to the bathroom regularly, before there is an accident • Try keeping a regular bathroom schedule of after meals and before bed • Be sure the person is drinking enough fluids, but limit fluid intake in the evening • Make steps simple and give one at a time. Explain clearly and in a gentle tone • Make clothing easy for the person to get on and off to use the bathroom, such as elastic waistbands and Velcro • Use protective "undergarments" if needed. Change them regularly to avoid harming the person's skin • Try to avoid getting frustrated or angry with the person when there are accidents

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

- Give the person as much privacy as possible

CLINICAL SUPPORT:

- Refer to PCP to evaluate for any possible infections or medications that may be contributing to the incontinence
- If the person has a fever for more than 24 hours report it to the doctor immediately. UTIs are often accompanied by fevers and can be dangerous when untreated
- If the person is on a diuretic, speak to the PCP about dosage and time of day it is administered
- Refer to PCP to place Durable Medical Equipment (DME) order as needed
- Refer for Occupational Therapy evaluation

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to IHSS
- Refer to MSSP
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
    - ALZ Direct Connect referral
    - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
    - Website: www.alzgla.org
- Send literature:
    - Topic Sheet – "Incontinence"

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

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Incontinence

A person with Alzheimer's disease may have other medical problems over time. These problems can cause more confusion and behavior changes. The person may not be able to tell you what is wrong.

One problem, incontinence, means a person can't control his or her bladder and/or bowels. This may happen at any stage of Alzheimer's disease, but it is more often a problem in the later stages. Signs of this problem are leaking urine, problems emptying the bladder, and soiled underwear and bed sheets. Let the doctor know if you see any of these signs. He or she may be able to treat the cause of the problem.

Causes of Incontinence

Incontinence has several possible causes. Some can be treated:

- Urinary tract infection
- Enlarged prostate gland
- Too little fluid in the body (dehydration)
- Diabetes that isn't being treated
- Taking too many water pills
- Drinking too much caffeine
- Taking medicines that make it hard to hold urine

When you talk to the doctor, be ready to answer the following questions:

- What medicines are the person with Alzheimer's taking?
- Does the person leak urine when he or she laughs, coughs, or lifts something?
- Does the person urinate often?
- Can the person get to the bathroom in time?
- Is the person urinating in places other than the bathroom?
- Is the person soiling his or her clothes or bed sheets each night?
- Do these problems happen each day or once in a while

What To Do About Incontinence

Here are some ways you can deal with incontinence:

- Remind the person to go to the bathroom every 2 to 3 hours. Don't wait for him or her to ask.
- Show the person the way to the bathroom, or take him or her.
- Watch for signs that the person may have to go to the bathroom, such as restlessness or pulling at clothes. Respond quickly.
- Make sure that the person wears loose, comfortable clothing that is easy to remove.
- Limit fluids after 6 p.m. if problems happen at night. Do not give the person fluids with caffeine, such as coffee or tea.
- Give the person fresh fruit before bedtime instead of fluids if he or she is thirsty.

Here are some other tips:

- Mark the bathroom door with a big sign that reads "Toilet" or "Bathroom."
- Use a stable toilet seat that is at a good height. Using a colorful toilet seat may help the person identify the toilet. You can buy raised toilet seats at medical supply stores.
- Plan ahead if you are going out with the person. Know where restrooms are located. Take an extra set of clothing in case of an accident.
- Help the person when he or she needs to use a public bathroom. This may mean going into the stall with the person or using a family or private bathroom.

Accidents Happen

Be understanding when bathroom accidents occur. Stay calm and reassure the person if he or she is upset.

Incontinence supplies, such as adult disposable briefs or underwear, bed protectors, and waterproof mattress covers, may be helpful. You can buy these items at drugstores and medical supply stores.

A drainable pouch may be useful for the person who can't control his or her bowel movements. Talk to a nurse about how to use this product.

Some people find it helpful to keep a record of how much food and fluid the person with Alzheimer's takes in and how often he or she goes to the bathroom. You can use this information to make a schedule for going to the bathroom.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Care Plans:
Safety

Alzheimer's
GREATER LOS ANGELES

TABLE OF CONTENTS
Care Plans: Safety

Home Safety Concerns

Identify the Problem	**PROBLEM:** Home Safety Concerns (falls, guns, knives, stoves, leaving the person alone) **GOAL/EXPECTED OUTCOME**: To increase personal and home safety
Explore	**ASSESS FURTHER:** • Has a home safety assessment been conducted? • Is the person ever left alone in the home? • Does the person cook on his/her own? • Does the person bathe on his/her own? • Does the person take medications by him/herself? • Does the person smoke? • Does the person have access to dangerous or hazardous items, such as medications, cleaning products, knives, guns, sharp tools, matches, etc.? • Is there a lot of stuff on the floors that could be tripped over? • Are there grab bars, hand rails, adjusted toilets or beds in the home? • Does the person use assistive equipment, such as a wheelchair, cane, walker, or lift? • Who would the caregiver call if he/she needed help? • What would the caregiver do in an emergency?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** Prevention and safety-proofing the home is important. The goal is to make the environment safe *before* an accident happens. Remember: people with Alzheimer's can have compromised judgment and ordinarily "safe" and "normal" household items can become hazards (i.e., knives, appliances, cleaning products, etc.) • Consider home adjustments o Install grab bars by the toilet and in the shower o Use equipment such as hand rails, ramps, adjusted toilets or beds, wheelchair, cane, walker, and lifts, as needed o Remove things that can easily break and are not needed o Provide enough lighting (stairwells and the doorway to the bathroom should be brightly lit day and night) o Unplug the kitchen disposal o Inexpensive motion detectors can alert the caregiver when the person enters a room where they should not be or gets out of bed • Look at the floor o Remove small rugs, rugs that are thick, or rugs that might slide o Remove low pieces of furniture that may not be easily seen o Don't shine or wax floors o Keep items off of the floor that can be tripped over (cords, books, toys, boxes, etc.) o Make sure the bathroom and kitchen floors are kept dry and avoid walking on them with wet feet o Use tables and chairs that are stable enough to lean on

- Remove dangerous items
  - Keep knives, scissors, guns, sharp tools, matches and lighters (and cigarettes) in a locked area
  - Keep all medications (prescriptions, vitamins, aspirin, etc.) locked up
  - Razors and nail clippers should be locked up and out of sight
  - Move all cleaning supplies to a high shelf or lock them away
  - Take off stove/oven knobs; use baby locks to secure items in cabinets
  - If total abstinence from smoking is not possible, then watch the person closely when smoking
  - Remove potentially toxic indoor plants
- Don't leave the person alone. Consider safety risks, such as:
  - Stove/oven, running water in the kitchen
  - Running water unattended/scolding hot water in the bathroom
  - Burning cigarettes, cigars, pipes, candles
  - Opened or unlocked doors or gates – risk of wandering/getting lost

CLINICAL SUPPORT:

- If there is any concern about possible safety issues, neglect or harm within the home, follow standard of practice, policies, procedures, and reporting mandates
- Refer to PCP for assistive equipment
- Refer to PT/OT to ensure correct use of assistive equipment

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to IHSS
- Refer to MSSP
- Refer to agencies that provide low-cost home modifications
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
  - ALZ Direct Connect referral
  - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
  - Website: www.alzgla.org
- Local Community Resources:______________________________
- Send literature:
  - Quick Fact Sheet – Keeping Home Safe (English and Spanish)
  - Topic Sheet – "Safety at Home"
  - Home Safety Assessment

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

NOTES:

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Alzheimer's Caregiving Tips

Safety at Home

Over time, people with Alzheimer's disease become less able to manage around the house. As a caregiver, you can do many things to make the person's home a safer place. Think prevention—help avoid accidents by controlling possible problems.

While some Alzheimer's behaviors can be managed medically, many, such as wandering and agitation, cannot. **It is more effective to change the person's surroundings—for example, to remove dangerous items—than to try to change behaviors.** Changing the home environment can give the person more freedom to move around independently and safely.

Basic Safety for Every Room

Add the following items to the person's home if they are not already in place:

- Smoke and carbon monoxide detectors in or near the kitchen and in all bedrooms
- Emergency phone numbers and the person's address near all phones
- Safety knobs and an automatic shut-off switch on the stove
- Childproof plugs for unused electrical outlets and childproof latches on cabinet doors

You can buy home safety products at stores carrying hardware, electronics, medical supplies, and children's items.

Lock up or remove these potentially dangerous items from the home:

- Medicines
- Alcohol
- Cleaning and household products, such as paint thinner and matches
- Poisonous plants — contact the National Poison Control Center at Call 1-800-222-1222 or go to www.poison.org to find out which houseplants are poisonous.
- Guns and other weapons, scissors, knives, power tools, and machinery
- Gasoline cans and other dangerous items in the garage

Moving Around the House

Try these tips to prevent falls and injuries:

- Simplify the home. Too much furniture can make it hard to move around freely.

- Get rid of clutter, such as piles of newspapers and magazines.
- Have a sturdy handrail on stairways.
- Put carpet on stairs, or mark the edges of steps with brightly colored tape so the person can see them more easily.
- Put a gate across the stairs if the person has balance problems.
- Remove small throw rugs. Use rugs with nonskid backing instead.
- Make sure cords to electrical outlets are out of the way or tacked to baseboards.
- Clean up spills right away.

Make sure the person with Alzheimer's has good floor traction for walking. To make floors less slippery, leave floors unpolished or install nonskid strips. Shoes and slippers with good traction also help the person move around safely.

Minimize Danger

People with Alzheimer's disease may not see, smell, touch, hear, and/or taste things as they used to. You can do things around the house to make life safer and easier for the person. For example:

- Check all rooms for adequate lighting. Use nightlights in bathrooms, bedrooms, and hallways.
- Be careful about small pets. The person may not see the pet and trip over it.
- Reset the water heater to 120 degrees Fahrenheit to prevent burns.
- Label hot-water faucets red and cold-water faucets blue, or write the words "hot" and "cold" near them.
- Install grab bars in the tub/shower and beside the toilet.
- Put signs near the oven, toaster, and other things that get hot. The sign could say, "Stop!" or "Don't Touch—Very Hot!"

You can also try these tips:

- Check foods in the refrigerator often. Throw out any that have gone bad.
- Put away or lock up things like toothpaste, lotions, shampoos, rubbing alcohol, soap, or perfume. They may look and smell like food to a person with Alzheimer's.
- If the person wears a hearing aid, check the batteries and settings often.

You may want to re-evaluate the safety of the person's home as behavior and abilities change.

For more home safety tips, see "Home Safety for People with Alzheimer's Disease," *www.nia. nih.gov/alzheimers/ publication/home-safety-people-alzheimers-disease*.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Keeping Home Safe

People with Alzheimer's or dementia may have trouble knowing what is dangerous or making safe decisions. By helping him or her feel more relaxed and less confused at home, you can help stop accidents.

WHAT CAN YOU DO?

Keep Things Simple

- make sure rooms are neat
- place "often used" items in the same place
- remove things that might break and aren't needed

Look at the Floor

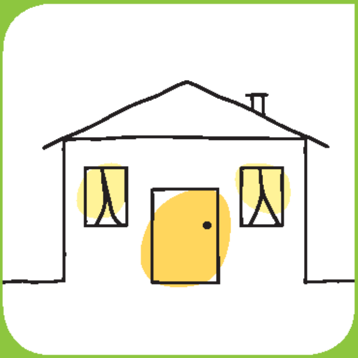
- remove small rugs, rugs that are thick, or rugs that might slide on floors
- don't shine or wax floors
- keep items off floors... cords, books, toys, bags, boxes, etc.
- make sure bathroom and kitchen floors are kept dry and avoid walking with wet feet
- use tables and chairs that are stable enough to lean on

Remove Dangerous Items

- keep all medicines... vitamins, aspirin, prescriptions... in a locked box, cabinet, or drawer
- place knives, scissors, guns, sharp tools, matches, and lighters out of sight or in a locked area
- move all cleaning supplies to a high shelf or lock them away
- take off knobs from the stove and oven

Don't Leave Him or Her Alone

- in the kitchen with the stove or oven on
- in the bathroom with water running
- anywhere with burning cigarettes, cigars, or pipes
- near an open or unlocked door or gate



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- **trip because of changes in balance or trouble walking**
- **have problems seeing clearly due to poor eyesight**
- **forget to turn off water, burners, ovens**
- **forget how to use knives, etc. or where to safely place burning objects**

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Seguridad en el Hogar

Personas con Alzheimer o demencia a veces no pueden entender lo que ven. Por ejemplo, los escalones pueden verse planos o las alfombras negras pueden parecer hoyos. También pueden tener problemas para entender situaciones peligrosas o tomar decisiones seguras. Para evitar estas situaciones, le ayudaría si usted hace algunos cambios al hogar.

¿QUÉ PUEDE HACER?

Evite el desorden

- mantenga los cuartos cómodos
- mantenga los artículos de uso diario en el mismo lugar
- guarde las cosas frágiles que estén al alcance, tales como: vidrios, espejos y vajillas

Revise el piso

- quite alfombras pequeñas que puedan causar tropiezos
- no deje cables electrónicos, libros, juguetes o basura en el piso
- asegúrese que el piso del baño y la cocina no estén resbalosos
- asegúrese que las sillas y mesas sean lo suficientemente estables como para apoyarse en ellas

Guarde objetos que puedan ser peligrosos

- mantenga TODOS los medicamentos (incluyendo vitaminas) bajo llave o fuera del alcance
- mantenga herramientas filosas fuera de la vista o bajo llave, tales como: cerillos, cuchillos y pistolas
- guarde bajo llave todos los productos de limpieza, tales como: amonia, windex, jabón y detergentes
- quite los apagadores de la estufa y horno, y desenchufe aparatos electrónicos

No deje a la persona con Alzheimer sola

- en la cocina con el horno o estufa encendida
- en el baño con el agua corriendo
- con cigarrillos o un puro prendido
- con la puerta abierta o sin seguro

¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- **tropezarse por cambios de balance y el equilibrio**
- **tener cambios de la vista**
- **olvidan de apagar el agua, la estufa, hornos**
- **olivdan cómo usar objetos que pueden ser peligrosos (armas, cuchillos, etc.) de forma segura**

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Home Safety Assessment

General Home Safety

☐ Do not leave care recipient home alone.
☐ Make sure car keys are well hidden.
☐ Weapons, such as firearms, should always be unloaded and put in a locked cabinet.
☐ Post emergency numbers on or near telephones.

Securing Exits & Entrances

☐ Doors leading to exits should be locked.
☐ Lock sliding glass doors (use a wooden dowel in the runner at the bottom of the door).
☐ Doors leading to unsafe areas (i.e. pool, garage, closets where dangerous items are stored) should be locked.
☐ Windows and balcony doors should be secured.
☐ For doors that lock from the inside, remove the lock or keep an emergency key in a nearby, secure location.
☐ Give a spare key to a trusted neighbor, family member, or friend for emergencies or store an extra key in a secure, hidden location.

Wandering

☐ Get identification bracelet for care recipient (Alzheimer's Greater Los Angeles MedicAlert® Found California program provides an identification bracelet and registry).

Fall/Trip Hazards

☐ Clear walkways and staircases from trip hazards like electrical cords, books, toys, and trash.
☐ Remove throw rugs to reduce the risk of falls or trips.
☐ Remove or secure furniture that rolls, falls over easily, or cannot support a person's weight.
☐ Use nightlights in the bathroom, hallway, and bedroom.
☐ Increase brightness of lamps and fixtures.

Fire/Burn Hazards

☐ Have a working fire extinguisher.
☐ Install smoke detectors and carbon monoxide detectors.
☐ The thermostat on the hot water heater should be lowered to its lowest setting or no higher than 120 degrees Fahrenheit.
☐ Replace extension cords with surge protections.

Kitchen Safety

☐ Remove the knobs from the stove and oven or use knob covers to hide the knobs.
☐ Remove knives and scissors from counters and keep out of reach.
☐ Secure all cleaning supplies.
☐ Disable the garbage disposal and instant hot water.
☐ Unplug all electrical appliances when they are not being used.
☐ Products that can be eaten in excess and cause illness (i.e. sweeteners) should be placed out of reach.

Bathroom Safety

☐ Store medications, including vitamins and over-the-counter medications, in a locked cabinet or out of reach.
☐ Toxic products and products that can be eaten in excess and cause illness (i.e. toothpaste) should be placed out of reach.
☐ Remove razors and other sharp objects from counters and drawers; keep them out of reach.
☐ Use non-skid mats in the shower and tub.
☐ Install grab bars or safety rails in shower/tub.
☐ Install a toilet safety rail.
☐ Use a shower bench (for stability) in the shower/tub.
☐ Remove and hide personal electrical equipment such as hair dryers and curling iron.

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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Insists on Driving

Identify the Problem	**PROBLEM:** Insists on Driving **GOAL/EXPECTED OUTCOME**: To increase driving safety and to be from harm
Explore	**ASSESS FURTHER*:* **Understand the possible triggers of the problem:** • Does the person see his/her car keys and think of driving? • Does the person see his/her car and think of driving? • Does the person feel he/she needs the car to get something done? • Does the person feel powerful by getting certain tasks done for the family? • Has the person always had a routine that involves driving, such as going to work or running certain errands? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Does the person feel like he/she is losing his/her independence? • Does the person feel angry? **Understand the possible meaning of the problem to the caregiver:** • Does the caregiver feel guilty? • Is the caregiver scared for the person's safety?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • If the person tries to drive most in the morning, be prepared with other activities during that time of day • Offer the person other forms of safe, reliable transportation • Reassure the person that he/she will still be able to get to where he/she needs to go • Park the car on another block or in a neighbor's driveway so it is not visible • Do not leave car keys where the person can see them • Replace the car keys with a set that won't actually start the car • Find creative reasons the person cannot drive, such as the car needs to be repaired. If the person accepts this reasoning, continue to use it • Try to get to the car first, so the person does not have time to get into the driver's seat before you • Find another way for the person to feel empowered, such as asking him/her to take control of a different activity • If the person insists on getting a certain task done, assure him/her that it is already taken care of and then redirect to an enjoyable activity

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

CLINICAL SUPPORT:

- Refer to PCP/social worker for conversations around driving and safety
- Ask the person's doctor to talk with the person about driving. Sometimes it's helpful for doctors to write a "prescription" for the person to stop driving. If they see it written from the doctor, they might be more likely to follow the instructions. If this is helpful, it may need to be repeated often because the person may forget it happened

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to low cost and accessible transportation services
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
  - ALZ Direct Connect referral
  - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
  - Website: www.alzgla.org
- Local Community Resources:
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- Send literature:
  - Topic Sheet – "Driving"

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

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Driving

Good drivers are alert, think clearly, and make good decisions. When a person with Alzheimer's disease is not able to do these things, he or she should stop driving. But, he or she may not want to stop driving or even think there is a problem.

As the caregiver, you will need to talk with the person about the need to stop driving. Do this in a caring way. Understand how unhappy the person may be to admit that he or she has reached this new stage.

Safety First

A person with some memory loss may be able to drive safely sometimes. But, he or she may not be able to react quickly when faced with a surprise on the road. Someone could get hurt or killed. If the person's reaction time slows, you need to stop the person from driving.

Here are some other things to know about driving and memory loss:

- The person may be able to drive short distances on local streets during the day but may not be able to drive safely at night or on a freeway. If this is the case, then limit the times and places the person can drive.
- Some people with memory problems decide on their own not to drive, while others may deny they have a problem.

Signs that the person should stop driving include new dents and scratches on the car. You may also notice that the person takes a long time to do a simple errand and cannot explain why, which may indicate that he or she got lost.

When Driving Becomes Unsafe

Here are some ways to stop people with Alzheimer's disease from driving:

- Try talking about your concerns with the person.
- Take him or her to get a driving test.
- Ask your doctor to tell him or her to stop driving. The doctor can write, "Do not drive" on a prescription pad, and you can show this to the person.
- Hide the car keys, move the car, take out the distributor cap, or disconnect the battery.

There are other ways to get around:

- Ask family or friends to drive the person.
- Find out about services that help people with disabilities get around their community. These services may include free or low-cost buses, taxi service, and carpools. Contact your local Area Agency on Aging or call the Community Transportation Association at 1-800-527-8279.

If the person with Alzheimer's disease won't stop driving, ask your state Department of Motor Vehicles about a medical review. The person may be asked to retake a driving test. In some cases, the person's license could be taken away. (California DMV office: 800-777-0133)

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Driving

Over time, driving gets harder for people with Alzheimer's or dementia. At some point they will need to stop driving and this can be very hard for them. It feels like a loss of freedom for both drivers and family members, yet SAFETY is most important for everyone.

WHAT CAN YOU DO?

Keep an Eye Out

- watch for parking or traffic tickets
- look for new scratches, marks, or dents on the car
- listen for complaints about other drivers or how the car operates

Help Them Stop Driving

- ask the doctor to tell them they can no longer drive
- make sure the doctor files a report to alert the Department of Motor Vehicles (DMV) of the dementia diagnosis
- have a close friend or a minister, priest, or rabbi ask your person to stop driving
- tell them someone else will drive them to the store or appointments
- ask others for help… deliver meals, pick up prescriptions, or just to visit

Be Creative

- hide the keys
- park the car out of sight
- remove the battery or starter wire
- say the car is in the shop
- get in the car first so you can be the driver
- give a set of keys that look like the old keys but won't start the car
- make having someone else drive sound like fun

Finally

- sell the car… it saves money on gas, insurance, and repairs that can be used for taxis, Uber, LYFT, or paying someone else to drive

WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia may be unsafe when they:

- **don't follow traffic signs**
- **go too fast or too slow**
- **become angry at others in the car or other drivers**
- **hit curbs**
- **cross over lanes**
- **confuse the brake and gas pedals**
- **forget where they are going**
- **get lost going places they know**

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Manejando

Con el tiempo, manejar se convierte en una actividad más difícil para las personas con Alzheimer o demencia. Llegará el momento cuando tengan que dejar de manejar y esto puede ser muy difícil. Se siente como una pérdida de independencia para los conductores y la familia, sin embargo, la SEGURIDAD ante todo debería ser lo más importante.

¿QUÉ PUEDE HACER?

Manténgase atento a

- multas de tráfico o infracciones de estacionamiento, "tickets"
- nuevos daños, marcas o golpes al carro
- quejas acerca de otros conductores o del carro

Ayudándoles a dejar de conducir

- pídale al médico que le diga a la persona con Alzheimer que ya no puede conducir
- asegúrese de que el doctor notifique al Departamento de Vehículos Motorizados (DMV) del diagnóstico... esto significará que la persona con problemas de la memoria tendrá que tomar de nuevo el examen de manejo
- pídale a una persona de confianza, como un Padre, Pastor, Ministro, etc., que le pida a su familiar que deje de conducir
- díganle que alguien va a llevarlo a la tienda o sus citas médicas
- pida ayuda a familiares y amigos... traer comida, recoger los medicamentos, o simplemente que lo visiten de vez en cuando

Sea creativo

- esconda las llaves
- estacione el carro fuera de la vista
- retire la batería o cable de arranque
- diga que el carro está en el taller
- entre al carro primero para que usted sea el conductor, y dígale que usted va ser el chofer
- dele un juego de llaves que se parezcan a las del carro, pero que no sean del carro
- mantenga la experiencia divertida... ponga música que le guste o converse sobre algo alegre

Finalmente

- venda el carro... se ahorrará dinero en gasolina, aseguranza y reparaciones que podrá usar para pagar a un taxi, Uber, LYFT, u otro conductor

¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden estar en peligro cuando:

- **no siguen las señales de las carreteras**
- **van demasiado rápido o demasiado lento**
- **se enojan con los pasajeros u otros conductores**
- **pegan la banqueta**
- **se pasan de un carril a otro sin precaución**
- **confunden los pedales de freno y acelerador**
- **olvidan a dónde van**
- **se pierden manejando a lugares conocidos, como a la casa**

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Takes Medicine the Wrong Way

Identify the Problem	**PROBLEM:** Takes Medicine the Wrong Way **GOAL/EXPECTED OUTCOME**: To improve medication management, compliance, and safety
Explore	**ASSESS FURTHER:** • What medication is the person taking? Can the caregiver make a list? • Is there anything that is causing the person to have trouble taking medications the way they were prescribed? • Is the person taking medications on his/her own? • Is the person refusing to take medications? • How often does the person have trouble with medications? • Where are the medications being kept? • Are all of the medications stored in the same place? • Has the person been showing any sudden and unusual changes in cognition and/or behavior?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** As Alzheimer's disease progresses, the caregiver will need to take over medication management. Caregivers will not be able to rely on the person with Alzheimer's to take medications on his/her own • Do not leave the person alone to take his/her medication • Watch closely. Make sure the person: o Takes the right pills and the right amounts o Takes medications at the right times o Follows the directions on the medication • Lock away medications: o Do not leave medications in a pill box or cup on the counter o Make sure all medications are out of sight and out of reach • Talk to ALL the doctors: o Talk to the doctor about any medications that may have been prescribed by separate provider o Do not stop giving any medication without asking the prescribing doctor first o Bring all medications in a bag or box to every doctor visit ▪ Include vitamins, herbs, teas, creams, and other pills from the drugstore o Ask the doctor if medications can be mixed into food or drinks ▪ This may be helpful if you are having trouble getting the person to take his/her pills o Ask the person's doctor about switching to medications that last longer so the person does not have to take them as often o Ask the person's doctor about the possible side effects of each medication • Try setting alarms for when medications need to be taken • Help the person get to the pharmacy or have the medications delivered to the home

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

CLINICAL SUPPORT:

- Refer to PCP if there is ANY sudden and unusual change in person's cognition and/or behavior. It could be caused by a medication reaction, medication interaction, or a new illness
- Refer to pharmacist to review all medications
- Refer to PCP or pharmacist to discuss any difficulties with medication administration and compliance
- Refer to PCP or pharmacist to discuss alternative methods of medication administration, such as crushing pills or longer-lasting dosages

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to IHSS
- Refer to MSSP
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
  - ALZ Direct Connect referral
  - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
  - Website: www.alzgla.org
- Send literature:
  - Quick Fact Sheet – Medications (English and Spanish)
  - Topic Sheet – "Managing Medications"

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

NOTES:

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Alzheimer's Caregiving Tips

Managing Medications

People with Alzheimer's disease may take medicines to treat the disease itself, mood or behavior changes, and other medical conditions. Caregivers can ensure that medicines are taken safely and correctly.

Learn the Basics

Know **each** medicine (prescription and over-the-counter) the person with Alzheimer's disease takes. Ask the doctor or pharmacist:

- Why is this medicine being used?
- What positive effects should I look for, and when?
- What are the possible side effects, and what can I do about them?
- Can this medicine cause a problem if it is taken with other medicines?
- How long will the person need to take it?
- How much should he or she take each day?
- When does the person need to take the medicine?
- What if the person misses a dose?

Managing medications is easier if you have a complete list of them. The list should show the name of the medicine, the doctor who prescribed it, how much the person with Alzheimer's takes, and how often. Keep the list in a safe place at home, and make a copy to keep in your purse or wallet. Bring it with you when you visit the person's doctor or pharmacist.

People with Alzheimer's should be monitored when a new drug is started. Follow the doctor's instructions and report any unusual symptoms right away. Also, let the doctor know before adding or changing any medications.

Use Medicines Safely

People with Alzheimer's disease often need help taking their medicine. If the person lives alone, you may need to call and remind him or her or leave notes around the home. A pillbox allows you to put pills for each day in one place. Some pillboxes come with alarms that remind a person to take medicine.

As Alzheimer’s gets worse, you will need to keep track of the person’s medicines. You also will need to make sure the person takes the medicines or give the medicines to him or her.

Some people with Alzheimer’s take medicines to treat behavior problems such as restlessness, anxiety, depression, trouble sleeping, and aggression. Experts agree that medicines to treat behavior problems should be used only after other strategies that don’t use medicine have been tried. Talk with the person’s doctor about which medicines are safest and most effective. With these types of medicines, it is important to:

- Use the lowest dose possible.
- Watch for side effects such as confusion and falls.
- Allow the medicine a few weeks to take effect.

People with Alzheimer’s should NOT take anticholinergic drugs. These drugs are used to treat many medical problems, such as sleeping problems, stomach cramps, incontinence, asthma, motion sickness, and muscle spasms. Side effects can be serious for a person with Alzheimer’s. Talk with the person’s doctor about other, safer drugs.

Other Safety Tips

Some people, especially those with late-stage Alzheimer’s, may have trouble swallowing pills. In this case, ask the pharmacist if the medicine can be crushed or taken in liquid form. Other ways to make sure medicines are taken safely:

- Keep all medications locked up.
- Check that the label on each prescription bottle has the drug name and dose, patient’s name, dosage frequency, and expiration date.
- Call the doctor or pharmacist if you have questions about any medicine.

For information about medicines to treat Alzheimer’s disease, see the “Alzheimer’s Disease Medications Fact Sheet,” *www.nia.nih.gov/alzheimers/publication/alzheimers-disease-medications-fact-sheet.*

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Medications

People with Alzheimer's or dementia may need help with taking their medicine. Taking too much... or too little... or not following the directions... can be dangerous.

WHAT CAN YOU DO?

Watch Closely

- make sure he or she
  - takes the right number of pills at the right times
  - follows the directions on the medication
- do not leave medications in a pill box or cup on the counter
- do not leave him or her alone to take their medicine

Lock Away Medicine

- make sure all medications are out of sight and out of reach

Talk to ALL the Doctors

- do not stop giving any medicine without asking the prescribing doctor first
- bring all medicines in a bag or box to every doctor
  - include vitamins, herbs, teas, creams, and other pills from the drugstore
- ask the doctor if medicines can be mixed into foods or drinks
  - this is helpful if you are having trouble getting your person to take their pills

NOTE: If you notice sudden changes like violent behaviors or trouble with bathroom accidents, call the doctor.

- these changes could be caused by a reaction to a medication or a new illness

WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- forget to take their medications
- forget that they took their medication, so they take them again and again and again
- get sick or be poisoned because the wrong pills or too many pills were taken

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Medicamentos

Personas con Alzheimer o demencia necesitan ayuda para tomar sus medicinas de una manera segura. Puede ser peligroso si toman demasiada o poca medicina, o no siguen las instrucciones correctamente.

¿QUÉ PUEDE HACER?

Vigile que la persona con Alzheimer esté:

- tomando la medicina correctamente
  - a la hora que debe
  - el número exacto de pastillas
- siguiendo las instrucciones del doctor
- tomando sus pastillas con agua antes o después de la comida (algunas medicinas no se deben tomar con jugos cítricos, tales como: naranja, limón, toronja y mandarina)
- no piense que la persona con Alzheimer se tomará la medicina correctamente sin ayuda

Siempre guarde la medicina fuera de la vista y del alcance de la persona con Alzheimer

- guarde todos los medicamentos bajo llave o fuera de la vista

Hable con TODOS los doctores que atienden a la persona con Alzheimer

- no le de pastillas de otras personas
- hable con su doctor antes de dar vitaminas, remedios caseros u otras pastillas a la persona con Alzheimer
- no pare de dar la medicina sin primero hablar con el doctor
- lleve las vitaminas, tés, cremas o pastillas que usted ha comprado sin receta a las citas con el doctor

NOTA: Si usted ve cambios fuera de lo normal como agresividad o la persona se hace del baño accidentalmente, llame a su doctor

- el cambio puede ser causado por una infección o reacción a los medicamentos

¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- olvidarse de tomar sus medicamentos
- olvidar de que ya se tomaron sus medicinas y se las vuelven a tomar
- tomarse los medicamentos incorrectamente y enfermarse o hasta envenenarse

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Wanders/Gets Lost

Identify the Problem	**PROBLEM:** Wanders/Gets Lost **GOAL/EXPECTED OUTCOME**: To reduce wandering through non-pharmacological approaches
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Has the person recently moved to an unfamiliar place? • Is the person trying to go somewhere like work, church, or home? • Does the wandering happen around the same time every day? • Is the person trying to meet a basic need, such as hunger or thirst? • Is the person searching for the bathroom? • Is the person bored? • Is the person trying to get away from too much noise or an unpleasant activity? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Does the person feel lost and scared? Is he/she looking for home? • Is the person confused by his/her surroundings? • Is the person experiencing anxiety from too much stimulation/noise? **Understand the possible meaning of the problem to the caregiver:** • Does the caregiver feel frustrated? • Is the caregiver scared for the person's safety?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Be prepared: o Don't leave the person alone near an unlocked door o Get a Medic Alert + Safe Return® bracelet for the person o Sew or write the person's name and your phone number onto clothing o If the person is looking to fulfill a basic need, such as toileting, hunger, or thirst, guide the person o In the early stages, cues such as signs or pictures can be placed on things such as the bathroom door so the person can more easily find things o Put away items, such as coats, purses, or keys that might make the person think about leaving o Cover doors/exits so they are less visible o Close curtains so the person does not think about going outside o Ask your neighbors to keep an eye out for the person wandering outside alone o Encourage physical activity to reduce restlessness • Make the home safe: o Put child-proof locks on doors, gates, and windows o Place locks very high or low so the person can't see or reach the locks o Place a bell on doors, gates, or windows so you know if they are opened

- Provide a distraction:
  - Use positive words when you are redirecting the person. Try not to say "No, Don't, Can't, Should Not…" Try saying, "Let's do this first," "Wouldn't it be fun to…" "What if we…"
  - Plan activities during the time of day that the person wanders most
  - Offer the person something he/she likes to eat
  - Ask the person for his/her help with an activity, such as folding laundry or setting the table
  - Sit quietly with the person and listen to music or watch TV

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to Alzheimer's Association for Medic Alert® + Safe Return® bracelet
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
  - ALZ Direct Connect referral
  - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
  - Website: www.alzgla.org
- Send literature:
  - Quick Fact Sheet – Getting Lost (English and Spanish)
  - Topic Sheet – "Wandering"
  - Topic Sheet – "MedicAlert®" Found California

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

NOTES:

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Alzheimer's Caregiving Tips

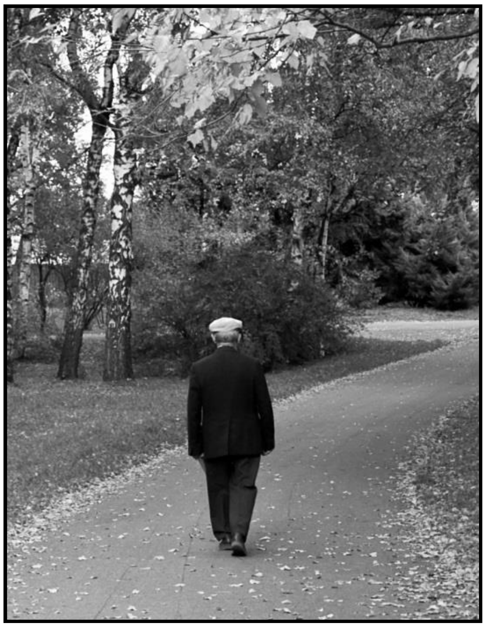
Wandering

Many people with Alzheimer's disease wander away from their home or caregiver. As the caregiver, you need to know how to limit wandering and prevent the person from becoming lost. This will help keep the person safe and give you greater peace of mind.

First Steps

Try to follow these steps before the person with Alzheimer's disease wanders:

- Make sure the person carries some kind of ID or wears a medical bracelet. If the person gets lost and can't communicate clearly, an ID will let others know about his or her illness. It also shows where the person lives.
- Consider enrolling the person in MedicAlert® Found California (call 1.844.435.7259 to find out more information).
- Let neighbors and the local police know that the person with Alzheimer's tends to wander. Ask them to alert you immediately if the person is seen alone and on the move.
- Place labels in garments to aid in identification.
- Keep an article of the person's worn, unwashed clothing in a plastic bag to aid in finding him or her with the use of dogs.
- Keep a recent photograph or video recording of the person to help police if he or she becomes lost.



Tips to Prevent Wandering

Here are some tips to help prevent the person with Alzheimer's from wandering away from home:

- Keep doors locked. Consider a keyed deadbolt, or add another lock placed up high or down low on the door. If the person can open a lock, you may need to get a new latch or lock.
- Use loosely fitting doorknob covers so that the cover turns instead of the actual knob
- Place STOP, DO NOT ENTER, or CLOSED signs on doors.

- Divert the attention of the person with Alzheimer's disease away from using the door by placing small scenic posters on the door; placing removable gates, curtains, or brightly colored streamers across the door; or wallpapering the door to match any adjoining walls.
- Install safety devices found in hardware stores to limit how much windows can be opened.
- Install an "announcing system" that chimes when the door opens.
- Secure the yard with fencing and a locked gate.
- Keep shoes, keys, suitcases, coats, hats, and other signs of departure out of sight.
- Do not leave a person with Alzheimer's who has a history of wandering unattended.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Getting Lost

People with Alzheimer's disease or dementia can get lost outside of their home. Sometimes they wander away in a public place. They may go for a walk or to the store and not be able to find their way home. They may not remember their address or phone number.

Getting lost is scary and can be dangerous.

WHAT CAN YOU DO?

Be Prepared

- get a MedicAlert® bracelet for your person with dementia
- sew or write his or her name and your phone number onto clothes
- don't leave him or her alone near an unlocked door
- ask your neighbors to keep an eye out and to tell you if they see your person with dementia outside alone or walking away from home
- help him or her exercise during the day... take a walk or dance to music
- put away purses, coats, keys, sunglasses... things that might make your person think about leaving
- close the curtains so he or she doesn't think about going outside

Make Home a Safe Place

- put child-proof locks on doors, gates, and windows
- place locks very high or low so your person with dementia can't see or reach the locks
- place a bell on doors, gates, or windows so you know if they are opened

Be Comforting

- offer food or do something that will take his or her mind off wanting to leave
- ask for help... folding clothes, making dinner, etc.
- sit quietly with him or her... listen to music or watch a TV show

WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- **be confused... mainly in the afternoon or evening**
- **feel fearful ... home may not seem the same**
- **try to go somewhere they used to go often... work, church, etc.**
- **attempt to get away from noise or too much activity**
- **be bored – not having anything to do**
- **have a reaction to a new medicine**

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Perderse

Algunas personas con Alzheimer o demencia se pueden perder al salir de casa. Estas personas se pierden fácilmente y olvidan el camino de regreso a casa, su dirección o número de teléfono. Perderse puede ser peligroso para la persona con Alzheimer.

¿QUÉ PUEDE HACER?

Esté preparado

- obtenga un brazalete/pulsera de MedicAlert®
- cosa o escriba el nombre de la persona con Alzheimer y un número de emergencia en la ropa
- no deje a la persona con Alzheimer sóla o cerca de una puerta que no tenga seguro
- pídale a sus vecinos que le avisen si la persona con Alzheimer se sale a la calle
- si es posible, saque a la persona con Alzheimer a caminar o hagan algún tipo de ejercicio en casa
- guarde monederos, llaves y abrigos que puedan causar que la persona con Alzheimer quiera salir de casa

Mantenga el hogar seguro

- instale seguros en puertas y ventanas
- coloque los seguros en puertas y ventanas fuera del alcance de la persona con Alzheimer
- instale una campanita en la puerta para que suene cuándo se abra

Si la persona con Alzheimer se encuentra nerviosa

- trátela con cariño, y dígale “No se preocupe. Yo estoy aquí. Yo le ayudo.”
- ofrézcale algo de comer o hagan alguna actividad que le guste para distraerlo
- pídale que le ayude a doblar la ropa o preparar la cena
- siéntese en silencio con la persona con Alzheimer o escuche música agradable

¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- **confundirse especialmente por la tarde y por la noche**
- **tener una reacción a un medicamento nuevo**
- **tener miedo–se sienten inseguros al no reconocer donde están**
- **pueden tratar de ir a trabajar o hacer algo que hacían antes**
- **estar tratando de escapar del ruido o de la actividad en el cuarto**
- **estár aburridos**
- **sentir algún malestar**
- **tener hambre, frío o necesidad de usar el baño**

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MedicAlert® Found California

MedicAlert® is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a medical emergency. We provide 24-hour assistance, no matter when or where the person is reported missing.

How it works:

Report a wandering incident:

- Call 911
- Then call 800.625.3780,
  MedicAlert® emergency response line

If an individual with Alzheimer's or a related dementia wanders and becomes lost, caregivers can call the 24-hour emergency response line (1.800.625.3780) to report it.

A community support network will be activated, including local Alzheimer's organizations and law enforcement agencies, to help reunite the person who wandered with the caregiver or a family member. With this service, critical medical information will be provided to emergency responders when needed.

If a citizen or emergency personnel finds the person with dementia, they can call the toll-free number listed on the person's MedicAlert® ID jewelry.

MedicAlert® will notify the listed contacts, making sure the person is returned home.

Cost and ID jewelry

MedicAlert® provides an ID bracelet or pendant to be worn by the individual with dementia.

For more information on this program, please contact Alzheimer's Greater Los Angeles at 888.HELP.ALZ | 888.435.7259.

For information about medicines to treat Alzheimer's disease, see the "Alzheimer's Disease Medications Fact Sheet," *www.nia.nih.gov/alzheimers/publication/alzheimers-disease-medications-fact-sheet.*

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
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Care Plans:
Caregiver Needs

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TABLE OF CONTENTS
Care Plans: Caregiver Needs

Caregiver Depression/Stress

Identify the Problem	**PROBLEM:** Caregiver Depression/Stress (feeling blue and/or overwhelmed) **GOAL/EXPECTED OUTCOME**: To reduce caregiver depression and stress
Explore	**ASSESS FURTHER:** • Depression o What happens right before the caregiver feels depressed? o How does the caregiver know when he/she is depressed? What does it feel like physically and emotionally that lets him/her know? o How often does the caregiver feel depressed? How many times per day/week? o How does the caregiver act when he/she is feeling depressed? o Is there anything the caregiver does that helps to reduce feelings of depression? o Is there anyone the caregiver can talk to when he/she is feeling this way? • Stress o What happens right before the caregiver feels stressed? o How does the caregiver know when he/she is stressed? What does it feel like physically and emotionally that lets him/her know? o How often does the caregiver feel stressed? How many times per day/week? o How does the caregiver act when he/she is feeling stressed? o Is there anything the caregiver does that helps to reduce feelings of stress? o Is there anyone the caregiver can talk to when he/she is feeling this way? • Is the caregiver feeling socially isolated? • Is the caregiver having increasing family disagreements? • Is the caregiver having uncomfortable feelings about his/her relationship with the person he/she cares for? • Does the relationship feel strained? • Does the caregiver have feelings of guilt?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Join a support or education group or identify a trusted friend/family/clergy member you can talk to when you are feeling this way • Try to stay connected with family and friends • Focus on what you are *able* to do as a caregiver; remember that caregiving can be very challenging • Set realistic goals • Ask for help with caregiving from others in the family or community • Try to take a break and do something *you* enjoy. Consider physical activities when possible, such as taking a walk • Plan ahead for emergencies to reduce anxiety and stress

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

CLINICAL SUPPORT:

- Follow clinical guidelines and procedures for depression screening, intervention and referral
- If abuse and/or neglect is suspected, follow standards of practice, policies, procedures, and reporting mandates
- Encourage caregiver to discuss his/her depression and stress with a social worker/therapist. Direct to PCP for referral as needed
- Review specific questions to help prepare the caregiver for the discussion with PCP
- Coach caregiver on how to talk with PCP
- Consider further screening and assessment as needed

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Refer to respite services
- Refer to IHSS
- Refer to MSSP
- Refer to CBAS
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
  - ALZ Direct Connect referral
  - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
  - Website: www.alzgla.org
- Local Community Resources: ______________________________________
  ____
- Send literature:
  - Topic Sheet – "Caregiver Depression"

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

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Alzheimer's Caregiving Tips

Caregiver Depression

Caring for someone with Alzheimer's disease can be a 24/7 task, and can be very challenging for a caregiver. There are many losses and changes experienced by the caregiver, and it is not uncommon for the caregiver to feel stress, anger, sadness, depression, isolation, and guilt. Often times, caregivers place all of their focus and energy on the person with Alzheimer's disease, and end up neglecting their own needs and health. It is important that caregivers of people with Alzheimer's focus on their own needs and get the support that they require.

Identifying Depression

- Are you feeling isolated? As though you are alone?
- Are you having uncomfortable feelings about your relationship with the person you are caring for?
- Are you having feelings of worthlessness or guilt?
- Are you feeling hopeless?
- Do you have thoughts of death or suicide?
- Are you feeling extra fatigued? Is it more difficult than usual to get out of bed?
- Are you neglecting your own health? Not eating? Over-eating? Missing medical appointments?
- Are you having trouble with your own thinking or memory?
- Are you experiencing headaches, stomach issues, or pain?
- Do you find yourself crying more than usual?

Tips

- Speak with a healthcare professional
- Join a support or education group, or identify a trusted friend, family, or community member to talk to when you are feeling this way. You do not have to go through this alone.
- Try to stay connected with family and friends.
- Focus on what you are able to do as a caregiver; remember that caregiving can be very challenging.
- Set realistic goals.
- Ask for help with caregiving from others.
- Try to take a break and do something you enjoy. Consider physical activities when possible, such as taking a walk.

Information adapted from the National Institute on Aging, part of the National Institutes of Health www.nia.nih.gov, NIH July 2012
Reviewed by ALZGLA November 2016

Difficulty Providing Care Because of Your Health

Identify the Problem	**PROBLEM:** Difficulty Providing Care Because of Your Health **GOAL/EXPECTED OUTCOME**: To reduce problems related to functional limitations
Explore	**ASSESS FURTHER:** • Is there someone else helping with caregiving needs that are harder for the caregiver to do alone? • Who would the caregiver call if he/she needed help? • What would the caregiver do in an emergency? Who would the caregiver call? • Is there equipment in the house that helps the caregiver with caregiving needs, such as grab bars, hand rails, adjusted toilets or beds, lifts? • Does *the caregiver* use assistive devices to help with getting around, such as a wheelchair, cane, or walker? • Does the *person with dementia* use assistive equipment to help with getting around? (This may help make caregiving easier on the caregiver) • Is the caregiver fatigued? Remember: fatigue may become a health problem when caregiving. Tiredness, poor sleep and low energy may be signals that more help is needed from others than is currently being provided
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Remove anything on the floor that may create a risk for falling/slipping, such as rugs, shoes, or other objects • Install grab bars by the toilet and in the shower • Use equipment such as hand rails, adjusted toilets or beds, wheelchair, cane, walker, lift if they are needed • Try to let the person do as much as he/she can on his/her own, but always put safety first • Ask for help from family or friends
	CLINICAL SUPPORT: • If abuse or self-harm is suspected, follow standard of practice, policies, procedures, and reporting mandates • Schedule a visit or phone call with PCP • Encourage caregiver to discuss functional limitations and health concerns with his/her PCP • Review specific questions to help prepare caregiver for the discussion with PCP: encourage caregiver to write questions down • Refer to Physical Therapy/Occupational Therapy for correct use of assistive equipment and safe body mechanics. Discuss how to safely lift and carry
	CAREGIVER SUPPORT AND COMMUNITY RESOURCES: • Listen empathically to caregiver and evaluate for level of distress • Refer to IHSS • Refer to MSSP • Refer to CBAS • Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation o ALZ Direct Connect referral

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

	o Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259 o Website: www.alzgla.org • Local Community Resources: ______________________________________ ____ • Send literature: o Topic Sheet – Safe Body Mechanics o Topic Sheet – "Caregiver Health"
	FOLLOW UP: • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	NOTES: ____ ____ ____ ____

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Caregiver Health

Taking care of yourself is one of the most important things you can do as a caregiver. This could mean asking family members or friends to help out, doing things you enjoy, using adult day care services, or getting help from a local home health care agency. Taking these actions can bring you some relief. It also may help keep you from getting ill or depressed.

Here are some ways you can take care of yourself:

- Ask for help when you need it.
- Join a caregivers' support group.
- Take breaks each day.
- Spend time with friends.
- Keep up with your hobbies and interests.
- Eat healthy foods.
- Get exercise as often as you can.
- See your doctor on a regular basis.
- Keep your health, legal, and financial information up-to-date.

It's Okay to Ask for Help

Many caregivers find it hard to ask for help. They feel like they should do everything themselves, or that no one will help them even if they ask. They may think it's not right to leave the person with Alzheimer's disease with someone else. Maybe they cannot afford to pay someone to watch the person for an hour or two.

It's okay to ask for help from family and friends. You don't have to do everything yourself. If you have trouble asking for help, try these tips:

- Ask people to help out in specific ways like making a meal, visiting the person with Alzheimer's, or taking the person out for a short time.
- Join a support group to share advice and understanding with other caregivers.

Your Emotional Health

You may be busy caring for the person with Alzheimer's disease and don't take time to think about your emotional health. But, you need to. Caring for a person with Alzheimer's takes a lot of time and effort. Sometimes, you may feel discouraged, sad, lonely, frustrated, confused, or angry. *These feelings are normal.*

Here are some things you can say to yourself that might help you feel better:

- I'm doing the best I can.
- What I'm doing would be hard for anyone.
- I'm not perfect, but that's okay.
- I can't control some things that happen.
- Sometimes, I just need to do what works for right now.
- Even when I do everything I can think of, the person with Alzheimer's disease will still have problem behaviors because of the illness, not because of what I do.
- I will enjoy the moments when we can be together in peace.
- I will try to get help from a counselor if caregiving becomes too much for me.

Meeting Your Spiritual Needs

As the caregiver of a person with Alzheimer's, you may need more spiritual resources than others do. Meeting your spiritual needs can help you cope better as a caregiver and find a sense of balance and peace. Some people like to be involved with others as part of a faith community, such as a church, temple, or mosque. For others, simply having a sense that larger forces are at work in the world helps meet their spiritual needs.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Alzheimer’s Caregiving Tips

Safe Body Mechanics

What are proper body mechanics?

Body mechanics refers to the way we move during daily activities. Proper body mechanics can help you avoid injury and muscle fatigue. Follow these 3 guidelines of proper body mechanics:

- Bend at your hips and knees instead of your waist. This helps you maintain your balance by dividing your weight evenly between your upper and lower body.
- Spread your feet apart to create a foundation of support. This helps you maintain your balance from side to side.
- Keep your back, neck, pelvis, and feet aligned when you turn or move. Do not twist or bend at your waist.

How do I practice proper body mechanics?

When you stand:

- Keep your feet flat on the floor about 12 inches (30 cm) apart.
- Do not lock your knees.
- Keep your shoulders down, chest out, and back straight.

When you lift an object:

- Your feet should be apart, with one foot slightly in front of the other.
- Keep your back straight.
- Bend from your hips and knees.
- Do not bend at your waist.
- Lift the object using your arm and leg muscles.
- Hold the object close to your body at your waist level.
- Use the same process if you need to push or pull something heavy.

When you sit:

- Sit with your back straight and place extra support behind your lower back.
- Get up and change positions often if you sit for long periods of time.
- Ask about exercises to stretch your neck and shoulders.

- Adjust your computer so the top of the monitor is at the same level as your eyes.
- Use a paper holder so that the document is at the same level as the computer screen.
- Use a headset if you use the telephone often.

What else do I need to know about proper body mechanics?

- ***Wear shoes with low heels, closed backs, and nonslip soles.*** This will help prevent falling and improve your body alignment.
- ***Pull rather than push an object to avoid strain on your back muscles.*** The muscles you use to pull are stronger than those you use to push.
- ***Ask for help or use an available device for assistance.*** Assistive or mechanical devices help decrease your risk for injury.

Proper Body Mechanics - Care Guide. (n.d.). Retrieved February 17, 2015, from http://www.drugs.com/cg/proper-body-mechanics.html

Lacks Understanding of Dementia

Identify the Problem	**PROBLEM:** Lacks Understanding of Dementia **GOAL/EXPECTED OUTCOME**: To increase understanding of the nature, symptoms, and course of dementia
Explore	**ASSESS FURTHER:** • What is the caregiver's understanding of Alzheimer's disease and dementia? • What would the caregiver like to know more about? • Is the caregiver frustrated because he/she does not understand the disease or the symptoms of the disease? • Does the caregiver feel confused or "stuck" about what to do in challenging situations? • If refusal of care is occurring, does the caregiver understand it is a part of the disease process? • Is the caregiver worried? • Is the caregiver in denial? • Are there cultural barriers to the caregiver's understanding of the disease?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Learn effective communication strategies • Learn how to use the *IDEA!* strategy to manage challenging behaviors • Learn about potential safety concerns
	CLINICAL SUPPORT: • Refer to PCP, nurse and/or social worker for disease education: o Nature of disease o Symptoms, course of disease, and changes that may occur o What to expect in terms of treatment and recommendations o Care recommendations
	CAREGIVER SUPPORT AND COMMUNITY RESOURCES: • Listen empathically to caregiver and evaluate for level of distress • Refer to Alzheimer's Association for education programs • Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation o ALZ Direct Connect referral o Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259 o Website: www.alzgla.org • Local Community Resources: ____________________________________ • Send literature: o Topic Sheet – "What is Alzheimer's Disease?"
	FOLLOW UP: • Schedule a phone call with caregiver to discuss outcomes and provide additional support

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

	NOTES: ____________________________________ ____________________________________ ____________________________________ ____________________________________

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What is Alzheimer’s Disease?

Alzheimer’s disease is an irreversible brain disorder that gets worse over time. It slowly destroys memory and thinking skills and, eventually, the ability to carry out simple tasks. Alzheimer’s affects people’s ability to communicate, think, problem-solve, behave, and function physically.

Signs and Symptoms

Memory problems are usually one of the first signs of cognitive impairment related to Alzheimer’s disease. Symptoms can vary from person to person and will change throughout the progression of the disease.

Mild Alzheimer’s Disease

As Alzheimer’s disease progresses, people experience greater memory loss and other cognitive difficulties. Problems can include wandering and getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, and personality and behavior changes.

Moderate Alzheimer’s Disease

In this stage, damage occurs in areas of the brain that control language, reasoning, sensory processing, and conscious thought. Memory loss and confusion grow worse, and people begin to have problems recognizing family and friends. They may be unable to learn new things, carry out multi-step tasks such as getting dressed, or cope with new situations. In addition, people at this stage may have hallucinations, delusions, and paranoia and may behave impulsively.

Severe Alzheimer’s Disease

People with severe Alzheimer’s cannot communicate and are completely dependent on others for their care. Near the end, the person may be in bed most or all of the time as the body shuts down.

What Causes Alzheimer’s

Scientists don’t yet fully understand what causes Alzheimer’s disease in most people. In people with early-onset Alzheimer’s, a genetic mutation is usually the cause. Late-onset Alzheimer’s arises from a complex series of brain changes that occur over decades. The causes probably include a combination of genetic, environmental, and lifestyle factors. The importance of any one of these factors in increasing or decreasing the risk of developing Alzheimer’s may differ from person to person.

Diagnosis of Alzheimer’s Disease

Doctors use several methods and tools to help determine whether a person who is having memory problems has “possible Alzheimer’s dementia” (dementia may be due to another cause) or “probable Alzheimer’s dementia” (no other cause for dementia can be found).

To diagnose Alzheimer’s doctors may:

- Ask the person and a family member or friend questions about overall health, past medical problems, ability to carry out daily activities, and changes in behavior and personality.
- Conduct tests of memory, problem solving, attention, counting, and language.
- Carry out standard medical tests, such as blood and urine tests, to identify other possible causes of the problem.
- Perform brain scans, such as computed tomography (CT), magnetic resonance imaging (MRI), or positron emission tomography (PET), to rule out other possible causes for symptoms.

Treatment of Alzheimer’s Disease

Alzheimer’s disease is complex, and it is unlikely that any one drug or other intervention will successfully treat it. Current approaches focus on helping people maintain mental function, manage behavioral symptoms, and slow or delay the symptoms of disease. Researchers hope to develop therapies targeting specific genetic, molecular, and cellular mechanisms so that the actual underlying cause of the disease can be stopped or prevented.

Managing Behavior

Common behavioral symptoms of Alzheimer’s include sleeplessness, wandering, agitation, anxiety, and aggression. Scientists are learning why these symptoms occur and are studying new treatments—drug and nondrug— to manage them. Research has shown that treating behavioral symptoms can make people with Alzheimer’s more comfortable and makes things easier for caregivers.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Legal and Financial Planning

Identify the Problem	**PROBLEM:** Legal and Financial Planning (paying the bills, power of attorney, etc.) **GOAL/EXPECTED OUTCOME**: To facilitate legal and financial planning
Explore	**ASSESS FURTHER:** • Does the person have capacity to make legal and financial decisions? If so, engage the person as much as possible to plan ahead • Does the person have a Durable Power of Attorney for Finances? • Does the person have a Durable Power of Attorney for Healthcare? • Does the person have a conservator? If so, what type? • Does the person have an authorized representative? • Who pays the bills? • Who manages any bank account(s)? • Where are the person's important documents kept?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Discuss with family importance of getting legal/financials affairs in order • Have all necessary documents completed, notarized, and filed in an appropriate place
	CLINICAL SUPPORT: • If financial abuse is suspected, follow standards of practice, policies, procedures and reporting mandates • Guide family to speak with a doctor and social worker about healthcare documents and legal and financial considerations • Refer family to legal services, if needed
	CAREGIVER SUPPORT AND COMMUNITY RESOURCES: • Listen empathically to caregiver and evaluate for level of distress • Refer to low/no cost legal services • Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation o ALZ Direct Connect referral o Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259 o Website: www.alzgla.org • Local Community Resources: ____ ____ • Send literature: o Topic Sheet – "Legal and Financial Issues"
	FOLLOW UP: • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	NOTES: ____ ____ ____ ____

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Legal and Financial Issues

People with Alzheimer's disease often have problems managing their money. In fact, money problems may be one of the first noticeable signs of the disease.

Early on, a person with Alzheimer's may be able to perform basic tasks, such as paying bills, but he or she is likely to have problems with more complicated tasks, such as balancing a checkbook. As the disease gets worse, the person may try to hide financial problems to protect his or her independence. Or, the person may not realize that he or she is losing the ability to handle money matters.

Signs of Money Problems

Look for signs of money problems such as trouble counting change, paying for a purchase, calculating a tip, balancing a checkbook, or understanding a bank statement. The person may be afraid or worried when he or she talks about money. You may also find:

- Unpaid and unopened bills
- Lots of new purchases on a credit card bill
- Strange new merchandise
- Money missing from the person's bank account

A family member or trustee (someone who holds title to property and/or funds for the person) should check bank statements and other financial records each month to see how the person with Alzheimer's disease is doing and step in if there are serious concerns. This can protect the person from becoming a victim of financial abuse or fraud.

Take Steps Early

Many older adults will be suspicious of attempts to take over their financial affairs. You can help the person with Alzheimer's feel independent by:

- Giving him or her small amounts of cash or voided checks to have on hand
- Minimizing the spending limit on credit cards or having the cards cancelled
- Telling the person that it is important to learn about finances, with his or her help

To prevent serious problems, you may have to take charge of the person's financial affairs through legal arrangements. It's important to handle the transfer of financial authority with respect and understanding.

You can get consent to manage the person's finances via a durable power of attorney for finances, preferably while the person can still understand and approve the arrangement. You can also ensure that the person finalizes trusts and estate arrangements.

Guard Against Financial Abuse and Fraud

People with Alzheimer's may be victims of financial abuse or scams by dishonest people. Sometimes, the person behind the scam is a "friend" or family member. Telephone, e-mail, or in-person scams can take many forms, such as:

- Identity theft
- Get-rich-quick offers
- Phony offers of prizes or home or auto repairs
- Insurance scams
- Health scams such as ads for unproven memory aids
- Threats

Look for signs that the person with Alzheimer's may be a victim of financial abuse or fraud:

- Signatures on checks or other papers don't look like the person's signature.
- The person's will has been changed without permission.
- The person's home is sold, and he or she did not agree to sell it.
- The person has signed legal papers (such as a will, power of attorney, or joint deed to a house) without knowing what the papers mean.
- Things that belong to you or the person with Alzheimer's, such as clothes or jewelry, are missing from the home.

If you think a person with Alzheimer's may be the victim of a scam, contact your local police department. You can also contact the State consumer protection office or Area Agency on Aging office.

Information adapted from the National Institute on Aging, part of the National Institutes of Health *www.nia.nih.gov*, NIH July 2012
Reviewed by ALZGLA November 2016

Long-Term Care Planning

Identify the Problem	**PROBLEM:** Long-Term Care Planning **GOAL/EXPECTED OUTCOME**: To facilitate long-term care planning
Explore	**ASSESS FURTHER:** • Does the person have capacity to make long-term care planning decisions? If so, engage the person as much as possible • What are the long-term planning issues? o Financial needs? o Legal needs? o Durable Power of Attorney for Finances? o Durable Power of Attorney for Healthcare? o Residential options (possible changes in residence?) o Finding other available caregivers? o End of life decisions? • Staying at home o Will the person be safe to remain at home with 24/7 in-home assistance? o Are there resources available to maintain living at home? (i.e., financial resources, caregiving resources, family support) o Does the person have adequate hours of in-home supportive services to assist with: ▪ Medication management? ▪ Overnight/daytime supervision? ▪ Medical care? ▪ ADL assistance? ▪ IADL assistance? o Is there someone available to live with the person long-term and provide needed care for the needed hours? o Does that caregiver understand symptoms and safety concerns of caring for a person with dementia? • Long-term care out of the home o Is there any opposition to long-term care facility placement as needed? o Does the caregiver know about residential care facility options? (Suggest visiting a variety of facilities before a crisis arises). Consider: ▪ Monetary cost ▪ Travel time to the facility ▪ Physical environment of the facility ▪ Background/interests of the person you care for • Does the caregiver and/or the family know about Medicaid waiver programs?

Best Practice Care Plans have been adapted from the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Project

<u>A</u>djust Problem solve with interventions and actions	**<u>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER</u>:** • Learn about different long-term care options • Utilize respite resources, including other family members, friends, community members, neighbors, volunteer organizations, etc., to maintain living at home • Professional caregiver, short and long-term in-home help • Discuss facilities that provide over-night respite • Discuss long term care plans with all involved caregiver and the person being cared for, before a crisis happens • Learn about and discuss the challenges of physical care in the late stages of the disease • Seek assistance from family and friends when touring facilities and making decisions
	<u>CLINICAL SUPPORT</u>: • Refer to PCP to discuss and assess medications, medical care needs, and required levels of care (ongoing assessment)
	<u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES</u>: • Listen empathically to caregiver and evaluate for level of distress • Refer to Legal and Financial Planning and End-of-Life care plans, as they may overlap • Refer to MSSP • Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation o ALZ Direct Connect referral o Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259 o Website: www.alzgla.org • Local Community Resources: ____ ____ • Send literature: o Topic Sheet – A Guide to Different Levels of Care
	<u>FOLLOW UP</u>: • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<u>NOTES</u>: ____ ____ ____ ____

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A Guide to Different Levels of Care

Before you can even begin the process of evaluating assisted living, it's important to familiarize yourself with all the terms. There are many types of care ranging from skilled nursing to senior living. They all vary based on the level of assistance required by the resident. What is the difference? Let's find out.

Senior Communities

Senior housing is designed for high-functioning elders, defined as those not requiring assistance with ADLs. Senior communities are usually neighborhoods or towns (consider Sun City, the nation's "first and finest" senior community) that are limited to people of a minimum age. They are designed for active seniors and have a variety of social clubs such as golf, arts and crafts and cards. While some senior communities offer additional levels of care, many are not equipped for individuals who require assistance with ADLs. Some senior communities require the resident move on, should they require this level of care.

Continuing Care

Continuing care communities are sometimes called "step care" or "progressive" care facilities. They offer a wide range of options, all the way from independent living to special care. Residents are usually admitted when they live independently. As their needs increase, they are guaranteed vacancies in the lower level of care. An entry fee is often required, making this option quite expensive.

Assisted Living

Assisted living offers the elderly a place to live outside of their own home, where they can receive basic assistance in one or more of the following areas: housekeeping, meal preparation, 24-7 monitoring, shower assistance, toileting, medication assistance or reminders, transportation, eating, dressing, activities or socialization.

In assisted living, your loved one will likely have his/her own apartment, unless you or your loved one consents to sharing a room with someone. A private bathroom is most often in the apartment to allow for privacy and dignity. Most facilities will have a kitchenette in the apartment with a sink, microwave, refrigerator, and cupboard space. Each apartment will likely be climate controlled individually. There will be access to common areas such as a TV room, an activity room, dining room, library, and communal sitting areas.

Assisted living facilities are designed for people who need help with complex ADLs on a daily basis. If you remember from the previous chapters, basic ADLs include eating, bathing, dressing and hygiene. More complex ADLs include cooking, shopping and money management. Assisted living aims to be the mid-point between independent living and long-term care. Most assisted living facilities have a dining room decorated like a restaurant as well as a variety of activities. Most assisted living facilities are not licensed to administer IVs, requiring patients who need IVs to temporarily relocate to a skilled nursing facility.

Board and Care

Board and care is similar to assisted living in terms of care, although some group homes work with lower functionality seniors than those found in assisted living. A woman I spoke with recently had placed her mother, suffering from Alzheimer's disease, in a board and care facility, sometimes known as a 'group home.' This is usually a single-family dwelling which has been converted into a residence for elderly and disabled residents. The monthly rent paid commonly includes room, three meals a day, laundry services, and some transportation – in addition to a 24-hour staff person. While basic medical care can be attended to, residents who have serious medical conditions will be expected to move into a more suitable facility.

Skilled Nursing

Skilled nursing (also called SNF or "sniff") is the first level of care that is licensed to administer medical treatment with nurses. In fact, there are strict regulations that require nurses to be on duty and to regulate the nurse-patient ratio.

As the name denotes, such a facility offers extensive nursing services for the residents. Admission must be initiated by a person's physician, who recommends that a patient enter either 'rehab care' or a 'special care' facility.

- Rehab care. Located in hospitals or nursing homes, rehab care programs are sometimes called "Level 1" or transitional care. They provide intensive medical care for patients who are expected to regain functional capacity and return home in a relatively short time.
- Special care. There are two types of special care facilities: those involved with unique medical issues (sometimes called "Level 2" care), and those which manage behavioral problems that may arise from dementia.

Many patients are admitted to skilled nursing to address an acute condition such as rehabilitating a broken hip, or treating an infection with IV antibiotics.

Many skilled nursing facilities have a portion of their residents who are long-term care patients. These are patients who require the treatment capabilities of a SNF, yet their condition requires that level of care permanently. Long-term care includes nursing supervision, but it is custodial in nature – focused on maintenance as opposed to curative care. Here the condition is not expected to improve, and the nursing activities are focused on keeping the person healthy and safe.

Adapted from A Guide to Different Levels of Elder Care. (2011, January 1). Retrieved February 13, 2015 from http://www.insideeldercare.com/assisted-living/a-guide-to-different-levels-of-elder-care/

End-of-Life Planning

Identify the Problem	**PROBLEM:** End-of-Life Planning **GOAL/EXPECTED OUTCOME**: To increase understanding of preserving dignity at the end-of-life
Explore	**ASSESS FURTHER:** • Does the person have capacity to make end-of-life plans? If so, engage the person in this process as much as possible to plan ahead • What is the *person's* understanding of hospice care? How does the person feel about hospice? • What is the caregiver's understanding about the *person's* wants and needs for end-of-life care? Did the person ever discuss this with the caregiver? • What are the *caregiver's* wants and needs for the person he/she is caring for? • Does the person have a POLST (Physician Order for Life Sustaining Treatment) on file with the medical team? • Does the person have an Advanced Healthcare Directive? • Does the person have a Durable Power of Attorney for Healthcare to make end-of-life medical decisions? If so, who is making these decisions? • Is there someone the caregiver trusts and feels comfortable discussing these questions with? • Is the caregiver overwhelmed? • Is the caregiver confused about end-of-life care options? • What are the caregiver's cultural/religious beliefs about end-of-life?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Complete necessary paperwork (POLST, Advanced Directives, etc.) • Discuss medical care decisions with family and doctors • Learn about hospice care (hospice is provided to people with a life expectancy of 6 months or less and offers many supportive services to the person and family that focus on comfort and enhancing quality of life) • Speak to trusted family, friends or clergy about your concerns
	CLINICAL SUPPORT: • Refer to PCP to discuss POLST, Advanced Healthcare Directive, Durable Power of Attorney for Healthcare, etc. • Refer to doctor for discussion about end-of-life care needs for the person • Refer to social worker for social/emotional support, counseling and assistance with end-of-life planning • Refer family to PCP for hospice referral • Suggest caregiver speak to hospice about pain/discomfort management • Encourage self-care for caregiver

CAREGIVER SUPPORT AND COMMUNITY RESOURCES:

- Listen empathically to caregiver and evaluate for level of distress
- Identify possible informal community support systems (church/clergy, neighbors, friends, family, etc.)
- Refer to local hospice services
- Refer to Alzheimer's Greater Los Angeles for support groups, disease education, and care consultation
    - ALZ Direct Connect referral
    - Provide 24/7 Helpline #: 844.HELP.ALZ | 844.435.7259
    - Website: www.alzgla.org
- Local Community Resources: ____
  ____
- Send literature/refer to website:
    - http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3277 (Advanced Directives)
    - http://www.nhpco.org/about/hospice-care (Discussing hospice care)
    - http://capolst.org/ (POLST form in English and Spanish)

FOLLOW UP:

- Schedule a phone call with caregiver to discuss outcomes and provide additional support

NOTES:

____

____

____

____

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HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 1/1/2016)*

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: *(optional)*

A

Check One

CARDIOPULMONARY RESUSCITATION (CPR): *If patient has no pulse and is not breathing.*

If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.

☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A <u>requires</u> selecting Full Treatment in Section B)

☐ **Do Not Attempt Resuscitation/DNR** (<u>A</u>llow <u>N</u>atural <u>D</u>eath)

B

Check One

MEDICAL INTERVENTIONS: *If patient is found with a pulse and/or is breathing.*

☐ **<u>Full Treatment</u> – primary goal of prolonging life by all medically effective means.**

In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.

☐ ***Trial Period of Full Treatment.***

☐ **<u>Selective Treatment</u> – goal of treating medical conditions while avoiding burdensome measures.**

In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

☐ ***Request transfer to hospital <u>only</u>*** *if comfort needs cannot be met in current location.*

☐ **<u>Comfort-Focused Treatment</u> – primary goal of maximizing comfort.**

Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital <u>only</u> if comfort needs cannot be met in current location.***

Additional Orders: ______________________________

____

C

Check One

ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible and desired.*

☐ Long-term artificial nutrition, including feeding tubes.
☐ Trial period of artificial nutrition, including feeding tubes.
☐ No artificial means of nutrition, including feeding tubes.

Additional Orders: ______________________________

D

INFORMATION AND SIGNATURES:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _______, available and reviewed →
☐ Advance Directive not available
☐ No Advance Directive

Health Care Agent if named in Advance Directive:
Name: ______________________________
Phone: ______________________________

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)

My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert. #:
Physician/NP/PA Signature: *(required)*		Date:

Signature of Patient or Legally Recognized Decisionmaker

I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name:		Relationship: *(write self if patient)*
Signature: *(required)*	Date:	**FOR REGISTRY USE ONLY**
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011 or 10/1/2014 are also valid

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Patient Information

Name (last, first, middle):	Date of Birth:	Gender: M F

NP/PA's Supervising Physician	**Preparer Name** (if other than signing Physician/NP/PA)	
Name:	Name/Title:	Phone #:

Additional Contact ☐ None

Name:	Relationship to Patient:	Phone #:

Directions for Health Care Provider

Completing POLST

- **Completing a POLST form is voluntary**. California law requires that a POLST form be followed by healthcare providers, and provides immunity to those who comply in good faith. In the hospital setting, a patient will be assessed by a physician, or a nurse practitioner (NP) or a physician assistant (PA) acting under the supervision of the physician, who will issue appropriate orders that are consistent with the patient's preferences.
- **POLST does not replace the Advance Directive**. When available, review the Advance Directive and POLST form to ensure consistency, and update forms appropriately to resolve any conflicts.
- POLST must be completed by a health care provider based on patient preferences and medical indications.
- A legally recognized decisionmaker may include a court-appointed conservator or guardian, agent designated in an Advance Directive, orally designated surrogate, spouse, registered domestic partner, parent of a minor, closest available relative, or person whom the patient's physician/NP/PA believes best knows what is in the patient's best interest and will make decisions in accordance with the patient's expressed wishes and values to the extent known.
- A legally recognized decisionmaker may execute the POLST form only if the patient lacks capacity or has designated that the decisionmaker's authority is effective immediately.
- To be valid a POLST form must be signed by (1) a physician, or by a nurse practitioner or a physician assistant acting under the supervision of a physician and within the scope of practice authorized by law and (2) the patient or decisionmaker. Verbal orders are acceptable with follow-up signature by physician/NP/PA in accordance with facility/community policy.
- If a translated form is used with patient or decisionmaker, attach it to the signed English POLST form.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid. A copy should be retained in patient's medical record, on Ultra Pink paper when possible.

Using POLST

- Any incomplete section of POLST implies full treatment for that section.

Section A:

- If found pulseless and not breathing, no defibrillator (including automated external defibrillators) or chest compressions should be used on a patient who has chosen "Do Not Attempt Resuscitation."

Section B:

- When comfort cannot be achieved in the current setting, the patient, including someone with "Comfort-Focused Treatment," should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).
- Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), bi-level positive airway pressure (BiPAP), and bag valve mask (BVM) assisted respirations.
- IV antibiotics and hydration generally are not "Comfort-Focused Treatment."
- Treatment of dehydration prolongs life. If a patient desires IV fluids, indicate "Selective Treatment" or "Full Treatment."
- Depending on local EMS protocol, "Additional Orders" written in Section B may not be implemented by EMS personnel.

Reviewing POLST

It is recommended that POLST be reviewed periodically. Review is recommended when:

- The patient is transferred from one care setting or care level to another, or
- There is a substantial change in the patient's health status, or
- The patient's treatment preferences change.

Modifying and Voiding POLST

- A patient with capacity can, at any time, request alternative treatment or revoke a POLST by any means that indicates intent to revoke. It is recommended that revocation be documented by drawing a line through Sections A through D, writing "VOID" in large letters, and signing and dating this line.
- A legally recognized decisionmaker may request to modify the orders, in collaboration with the physician/NP/PA, based on the known desires of the patient or, if unknown, the patient's best interests.

This form is approved by the California Emergency Medical Services Authority in cooperation with the statewide POLST Task Force.
For more information or a copy of the form, visit **www.caPOLST.org**.

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

La versión en español solo se debe usar con fines educativos (Spanish version is for educational purposes only).
La ley HIPAA permite la revelación de las POLST a otros profesionales de atención de la salud en la medida que sea necesario

Órdenes del médico de tratamiento para el mantenimiento de la vida
(Physician Orders for Life-Sustaining Treatment, POLST)

EMSA #111 B
(En vigor 4/1/2011)

Primero siga estas órdenes y después póngase en contacto con el médico. Esta es una Hoja de órdenes del médico basada en el estado médico y deseos actuales de la persona. Toda sección que no esté completada implica tratamiento completo para esa sección. Una copia del formulario POLST firmado es legal y válido. Las POLST son un complemento a una directiva anticipada y no tienen el objetivo de reemplazar ese documento. Se debe tratar a todos con dignidad y respeto.

Apellido del paciente:	Fecha de preparación del formulario:
Nombre del paciente:	Fecha de nacimiento del paciente:
Segundo nombre del paciente:	Nº de registro médico: *(opcional)*

A

Marque uno

Resucitación cardiopulmonar (RCP): ***Si la persona no tiene pulso y no está respirando.***
Cuando NO se halla en paro cardiopulmonar, seguir las órdenes en las secciones B y C.

☐ **Intentar resucitación/RCP** (Si selecciona RCP en la sección A **tiene que** seleccionar Tratamiento completo en la sección B)
☐ **No intentar resucitación/DNR** (permitir la muerte natural)

B

Marque uno

Intervenciones médicas: ***Si la persona tiene pulso y/o está respirando.***

☐ **Solo medidas paliativas** Aliviar el dolor y el sufrimiento por medio del uso de medicación por cualquier vía, posicionamiento, cuidado de las heridas y otras medidas. Usar oxígeno, succión y tratamiento manual de la obstrucción de las vías respiratorias según sea necesario para el confort del paciente. *Trasladar al hospital solamente si las necesidades paliativas no se pueden cumplir en la ubicación actual.*

☐ **Intervenciones adicionales limitadas** Además de la atención descrita en Solo medidas paliativas, usar tratamiento médico, antibióticos y fluidos intravenosos según esté indicado. No entubar. Se puede usar presión positiva no invasora en las vías respiratorias. Evitar en general cuidados intensivos.
  ☐ *Trasladar al hospital solamente si las necesidades paliativas no se pueden cumplir en la ubicación actual.*

☐ **Tratamiento completo** Además de la atención descrita en Solo medidas paliativas e Intervenciones adicionales limitadas, usar entubación, intervenciones avanzadas en las vías respiratorias, ventilación mecánica y desfibrilación y cardioversión según esté indicado. *Trasladar al hospital si está indicado. Incluye cuidados intensivos.*

Órdenes adicionales: ______________________________
____

C

Marque uno

Nutrición administrada artificialmente: ***Ofrecer alimentos por boca, si es posible y deseado.***

☐ No administrar nutrición por medios artificiales, incluyendo la alimentación por tubo.
☐ Período de prueba de nutrición artificial, incluyendo la alimentación por tubo.
☐ Administrar nutrición artificial a largo plazo, incluyendo la alimentación por tubo.

Órdenes adicionales: ______________
____
____

D

Información y firmas:

Hablado con: ☐ Paciente (paciente tiene capacidad de hacerlo) ☐ Encargado de tomar decisiones reconocido legalmente

☐ Directiva anticipada con fecha ________, disponible y revisada →
☐ Directiva anticipada no está disponible
☐ No hay una directiva anticipada

Agente para la atención de la salud, si fue nombrado en la directiva anticipada:
Nombre: ______________________
Teléfono: ______________________

Firma del Médico

Mi firma a continuación indica que a mi mejor saber y entender estas órdenes son consecuentes con el estado médico y las preferencias de la persona.

Nombre del médico en letra de molde:	Nº de teléfono del médico:	Nº de licencia profesional del médico:
Firma del médico: XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX		Fecha:

Firma del paciente o encargado de tomar decisiones reconocido legalmente

Al firmar este formulario, el encargado de tomar decisiones reconocido legalmente reconoce que este pedido relativo a medidas de resucitación es consecuente con los deseos conocidos y el mejor interés de la persona que es objeto del formulario.

Nombre en letra de molde:		Relación: *(escribir Sí mismo si es el paciente)*
Firma: XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX		Fecha:
Dirección:	Nº de teléfono de día:	Nº de teléfono de noche:

Enviar el formulario con la persona si se le trasladada o da de alta

La ley HIPAA permite la revelación de las POLST a otros profesionales de atención de la salud en la medida que sea necesario

Información del paciente

Nombre (apellido, nombre, segundo nombre):	Fecha de nacimiento:	Sexo: M F

Profesional de atención de la salud que ayuda a preparar el formulario

Nombre:	Título:	Número de teléfono:

Contacto adicional

Nombre:	Relación con el paciente:	Número de teléfono:

Instrucciones para el profesional de atención de la salud

Cómo llenar las POLST

- Llenar un formulario POLST es voluntario. La ley de California requiere que los profesionales de atención de la salud cumplan con lo indicado en las POLST y otorga inmunidad a aquellos que las cumplan de buena fe. En un entorno hospitalario, el paciente será evaluado por un médico quien emitirá las órdenes apropiadas.
- Las POLST no reemplazan una directiva anticipada. Cuando esté disponible, revise la directiva anticipada y el formulario POLST para verificar que sean consecuentes y actualizar los formularios de manera apropiada para resolver cualquier conflicto.
- Las POLST tienen que ser llenadas por un profesional de atención de la salud basándose en las preferencias del paciente y las indicaciones médicas.
- Un encargado de tomar decisiones reconocido legalmente podría incluir a un tutor administrativo o tutor nombrado por la corte, agente nombrado en una directiva anticipada, sustituto nombrado oralmente, cónyuge, pareja de hecho registrada, uno de los padres de un menor, pariente más cercano disponible o persona que el médico del paciente considere que conoce mejor lo que está en el mejor interés del paciente y que tomará decisiones de acuerdo a los deseos y valores expresados por el paciente en la medida que se conozcan.
- Para que sean válidas, las POLST tienen que ser firmadas por un médico y por el paciente o encargado de tomar decisiones. Las órdenes verbales son aceptables con la firma de seguimiento del médico de conformidad con las normas de la instalación/comunidad.
- Ciertos problemas médicos o tratamientos podrían impedir que una persona viva en una instalación de cuidados residenciales para personas mayores.
- Si se usa un formulario traducido para un paciente o encargado de tomar decisiones, adjúntelo al formulario POLST en inglés firmado.
- Se recomienda enfáticamente el uso del formulario original. Las fotocopias y los facsímiles de los formularios POLST firmados son legales y válidos. Se debe archivar una copia en el registro médico del paciente, en papel Ultra Pink de ser posible.

Cómo usar las POLST

- Toda sección incompleta de las POLST implica tratamiento completo para esa sección.

Sección A:

- Si se encuentra sin pulso y no está respirando, no se deben usar desfibriladores (incluyendo los desfibriladores automatizados externos) ni compresiones de pecho en una persona que seleccionó “No intentar resucitación”.

Sección B:

- Cuando no se puede lograr la comodidad del paciente en el lugar actual, la persona, incluyendo a alguien con “Solo medidas paliativas” debe ser trasladada a un lugar en el que se le puedan proporcionar las medidas paliativas (como por ejemplo, el tratamiento de una fractura de cadera).
- La presión positiva no invasora de las vías respiratorias incluye la presión positiva continua de las vías respiratorias (CPAP), presión positiva en dos niveles de las vías respiratorias (BiPAP) y respiraciones asistidas por bolsa válvula máscara (BVM).
- Los antibióticos por vía intravenosa y la hidratación en general no se consideran “medidas paliativas”.
- El tratamiento de la deshidratación prolonga la vida. Si una persona desea fluidos intravenosos, indique “Intervenciones limitadas” o “Tratamiento completo”.
- Dependiendo de las normas de los servicios médicos de emergencia (EMS) locales, es posible que el personal de EMS no implemente las “Órdenes adicionales” escritas en la sección B.

Revisión de las POLST

Se recomienda una revisión periódica de las POLST. Una revisión se recomienda cuando:

- se traslada a la persona de un lugar de atención o nivel de atención a otro o
- hay un cambio sustancial en el estado de salud de la persona o
- cambian las preferencias de tratamiento de la persona.

Cómo modificar y anular las POLST

- Un paciente con capacidad puede, en cualquier momento, solicitar un tratamiento alternativo.
- Un paciente con capacidad puede, en cualquier momento, revocar las POLST por cualquier medio que indique la intención de revocarlas. Se recomienda que se documente la revocación: trace una línea a través de las secciones A a D, escriba “VOID” (anulado) en letra grande, y firme y escriba la fecha en esta línea.
- Un encargado de tomar decisiones reconocido legalmente podría solicitar modificar las órdenes en colaboración con el médico, basándose en los deseos conocidos de la persona o, si no se conocen, en el mejor interés de la persona.

Este formulario está aprobado por la Dirección de Servicios Médicos de Emergencia de California en colaboración con el grupo de trabajo POLST de todo el estado. Para obtener más información o una copia del formulario, visite **www.caPOLST.org**.

Enviar el formulario con la persona si se le trasladada o da de alta