

DEMENTIA CARE SPECIALIST TOOLKIT

for Dementia Care Management



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Dementia Care Specialist Toolkit for Dementia Care Management

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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) 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 a Health Risk Assessment, 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 cognitive screen. 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 or specialist to conduct a full diagnostic evaluation.

Identifying a Family/Friend Caregiver

As ADRD progresses, the need to proactively engage a family/friend 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 caregivers.

Care Needs and Caregiver 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.

Best Practice 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.

Managing Challenging Behaviors: **IDEA!**

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 manage challenging behaviors, their coping skills increase and there are more positive outcomes for both the person with ADRD as well as the caregiver.

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.

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

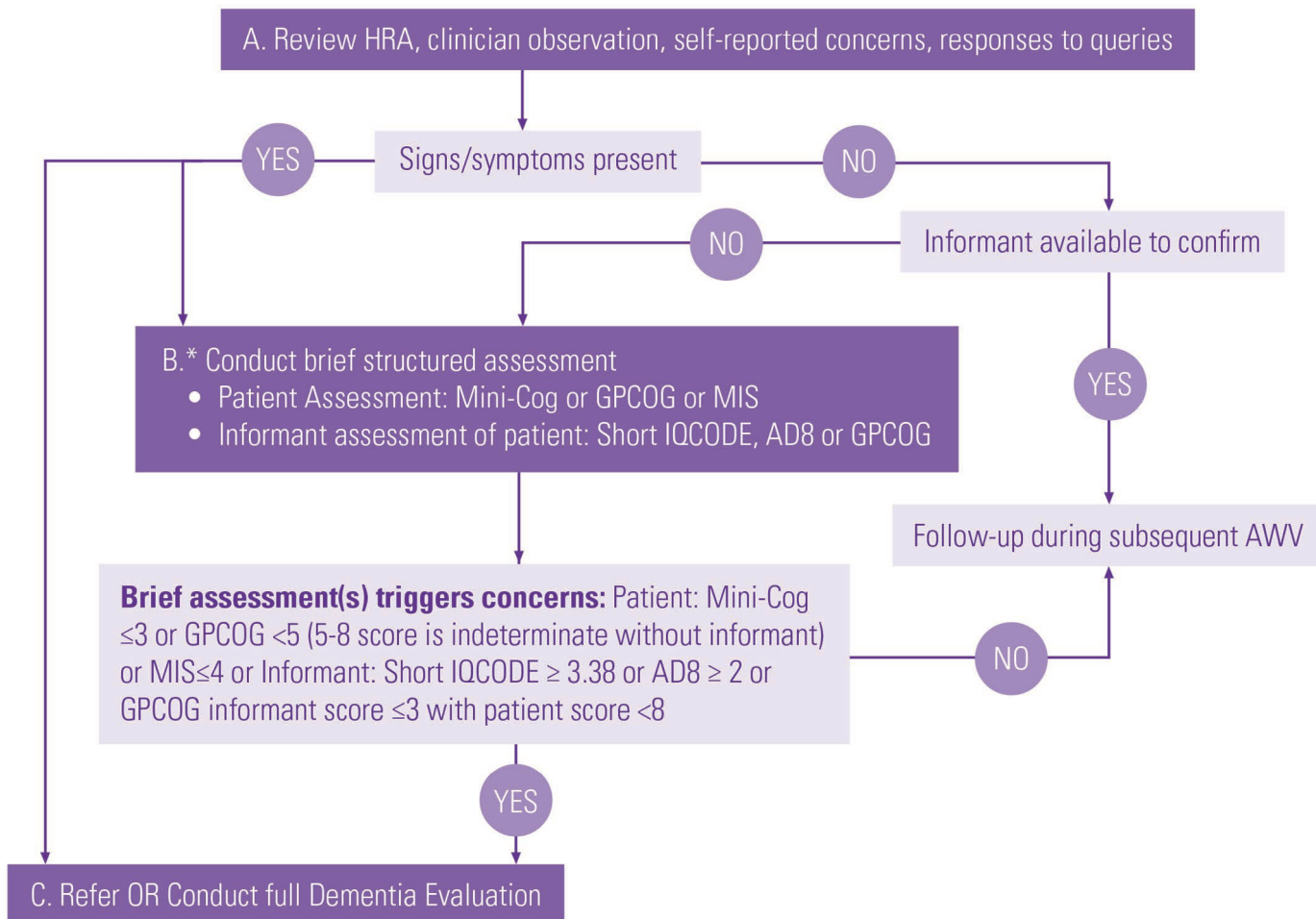
The following criteria can be used by health plans and healthcare agencies to determine when to refer a person with Alzheimer's disease or a related dementia (ADRD) to a Dementia Care Specialist (DCS) for Dementia Care Management:

- 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.

ALZHEIMER'S ASSOCIATION®

Medicare Annual Wellness Visit Algorithm for Assessment of Cognition



* 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 (e.g., SLUMS, or MoCA) to confirm initial findings before referral or initiation of full dementia evaluation.

AD8 = Eight-item Informant Interview to Differentiate Aging and Dementia; **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.* 2013;9(2):141-150. Available at <http://download.journals.elsevierhealth.com/pdfs/journals/1552-5260/PIIS1552526012025010.pdf>.

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
 Copyright 2005. The AD8 is a copyrighted instrument of the Alzheimer's Disease Research Center, Washington University, St. Louis, Missouri. All Rights Reserved.

The AD8 Administration and Scoring Guidelines

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

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

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

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

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

No timeframe for change is required.

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

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

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

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

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

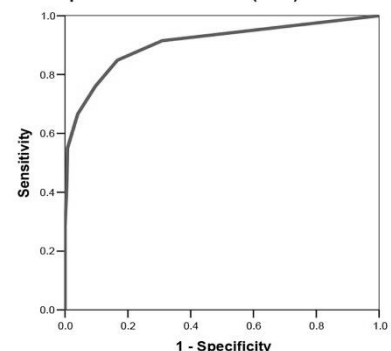
- 0 – 1: Normal cognition
- 2 or greater: Cognitive impairment is likely to be present

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

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

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

Receiver 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			

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.

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 (Ascertain 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.



IMPORTANT CONSIDERATIONS

Time Sensitive Issues

Advance Planning

- Discuss the importance of basic legal and financial planning as part of the care plan and refer to [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.

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 and prepared by Alzheimer’s Los Angeles]

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

Name: _____

Relationship to member: _____

Contact information: _____

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: _____

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.”

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

	Mark one box <input checked="" type="checkbox"/> in each row			
	Strongly agree ▼	Agree ▼	Disagree ▼	Strongly disagree ▼
Caregiver Mastery				
During <u>the past 4 weeks</u> , because of helping [CR] would you say that you were:				
1. unsure whether he or she was getting proper care.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
2. uncertain about how to best care for him/her.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
3. that you should be doing more for him/her.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
4. that you could do a better job of caring for him/her.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Score _____ (Sum of items 1–4)				
Relationship Strain				
During <u>the past 4 weeks</u> , because of helping [CR] would you say:				
5. that he/she tried to manipulate you.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
6. that your relationship with him/her was strained.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
7. that he/she made requests over and above what he/she needed.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
8. that you were resentful toward him/her.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
9. that you were angry toward him/her.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Score _____ (Sum of items 5–9)				
Health Strain				
During <u>the past 4 weeks</u> , because of helping [CR] would you say that:				
10. your physical health was worse than before.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
11. you felt downhearted, blue, or sad more often.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
12. you were more nervous or bothered by nerves than before.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
13. you had less pep or energy.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
14. you were bothered more by aches and pains	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
Score _____ (Sum of items 10–14)				

<i>The answer options for the next 5 questions are “Less often,” “The same,” or “More often.”</i>	Less often ▼	The same ▼	More often ▼
<i>Social Isolation/Activity Restriction:</i> During the past four weeks, because of helping [CR], would you say that you:			
15. participated in church or religious activities.	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
16. visited with friends or family.	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
17. participated in group or organized activities.	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
18. engaged in volunteer activities.	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
19. went out to dinner, the theater, or a show.	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 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 Los Angeles* and refer to **CAREGIVER DEPRESSION/STRESS CARE PLAN.***

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

IDEA! Strategy

An approach to help you figure out **why** a behavior is happening and **what** you can do about it.

Identify the behavior

- What is the behavior that is difficult for you to deal with? Be specific.
- Can you see it? Does it bother others? When does it happen? Who's around when it occurs?

Explore what may be causing the behavior

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 activity too hard for them now? Are there too many steps? Is it something new?
- **COMMUNICATION:** Is it hard for the person to understand what you are saying?

Understand the meaning of the behavior to the person


- Does the person feel confused, scared, nervous, unhappy, or bored?
- Does the person feel like they are being treated like a child?
- Are there things that remind the person of something that they used to do when they were younger like go to work or pick up the children from school?

Adjust what can be done

You are the one who will need to change, the person cannot. Try different things. Pay attention to the person's feelings. Practice being calm, gentle, and reassuring.

- address what is causing the behavior
 - keep tasks and activities simple
 - keep the home as calm as possible
 - speak slowly and gently — try not to say too much at once
 - do not argue — agree and comfort the person whether they are right or wrong
 - find meaningful, simple activities so the person isn't bored
- distract or redirect by:
 - offering something they like to eat
 - watching a TV show or listening to music
 - asking for their help with a simple activity
 - leading them to a different room
- accept the behavior
 - some behaviors you may need to accept rather than change
 - if there are no safety concerns and it doesn't bother the person, you may need to find ways to live with it



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Estrategia ¡IDEA!

Una manera para ayudarle a descubrir **porque** ciertos comportamientos ocurren y **que** puede hacer al respecto.

Identifique el comportamiento

- ¿Cuál es el comportamiento más difícil de lidiar para usted? Sea específico.
- ¿Lo puede ver? ¿Le molesta a otros? ¿Cuándo sucede? ¿Quién está cerca cuando sucede?

Entienda que podría estar causando el comportamiento

Entendiendo la causa del comportamiento

- **SALUD:** ¿Está tomando un nuevo medicamento? ¿Estará enfermándose? ¿Le dolerá algo?
- **AMBIENTE:** ¿Hay mucho ruido? ¿Hace mucho calor? ¿Está en un lugar desconocido?
- **ACTIVIDAD:** ¿Será que la actividad ahora es muy difícil para ellos, aunque antes lo hacían sin problema? ¿Tendrá muchos pasos? ¿Es algo nuevo?
- **COMUNICACIÓN:** ¿Será que la persona está teniendo problemas para entender lo que usted le está diciendo?

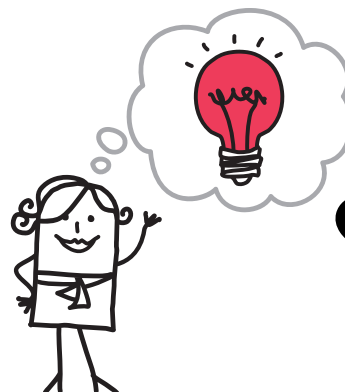
Entendiendo el significado del comportamiento para la persona

- ¿Estará confundido, asustado, nervioso, triste, o aburrido?
- ¿Sentirá que usted lo está tratando como si fuera niño?
- ¿Habrá cosas que le recuerden la persona de algo de cuando era joven, como de cuando iba a trabajar, o recoger a los niños de la escuela?

Adapte lo que se pueda hacer

Usted será el que tiene que cambiar. La persona no puede cambiar. Pruebe cosas diferentes. Ponga atención a los sentimientos de la persona. Practique manteniendo la calma, sea amable, y tranquilice a la persona.

- dirija su atención a lo que puede estar causando el comportamiento
 - mantenga las tareas y actividades sencillas
 - mantenga el hogar lo más calmado posible
 - hable lentamente y con calma — trate de no dar mucha información a la vez
 - no discuta — déle la razón y consuele a la persona sin importar si está equivocada o no
 - encuentre actividades significativas y sencillas para que la persona no se aburra
- distráigalo:
 - ofreciéndole algo que le guste de comer
 - viendo la televisión o escuchando música
 - pidiéndole que le ayude con una actividad simple, como doblar las toallas
 - llévelo a otro cuarto
- acepte el comportamiento
 - hay algunos comportamientos que se tendrán que aceptar en lugar de tratar de cambiarlos
 - si no causan problemas de seguridad y no molestan a la persona, entonces usted debe encontrar formas de vivir con el comportamiento



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Sleep Disturbances

<p>Identify the Problem</p>	<p>PROBLEM: Sleep Disturbances (waking you or other family members up at night)</p> <p>GOAL/EXPECTED OUTCOME: To reduce sleep problems through non-pharmacological approaches</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • Does the person feel frightened when he/she wakes up? • Does it bother the person to be up and active at night? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • 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?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • Follow sleep hygiene suggestions: <ul style="list-style-type: none"> ○ Limit daytime naps to 15 – 30 minutes and before 3 p.m. ○ Sleep in bed, not on couches ○ Create a bedtime routine ○ 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

	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • 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)
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • 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 Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Topic Sheet – "Sleep Issues"
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

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 isn't getting enough physical activity 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

- It's 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 3PM. Speak with a doctor about any medications the person is on that may affect sleep.

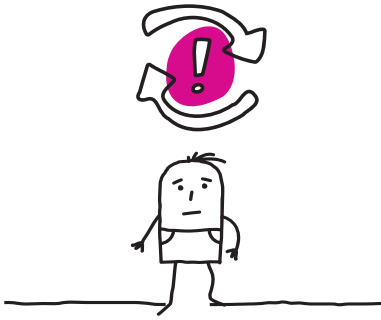
Information adapted from the National Institute on Aging, part of the National Institutes of Health www.nia.nih.gov
Reviewed by Alzheimer's LA January 2016 | NIH July 2012

Repetition

<p>Identify the Problem</p>	<p>PROBLEM: Repetition (doing or saying things over and over)</p> <p>GOAL/EXPECTED OUTCOME: To reduce caregiver level of stress and increase caregiver capacity to cope and manage behaviors</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • Does the person feel anxious? • Is the person confused? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Is the caregiver frustrated? • Is the caregiver angry?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> ○ Redirect with another topic (Avoid questions. Instead, say, "Tell me about...your wedding, your kids, your house, your work...") ○ Offer something the person enjoys, such as a favorite food, an activity or music he/she likes, etc. ○ 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

	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • Because repetition may be due to cognitive decline (i.e., forgetfulness), refer to PCP to discuss if cognitive enhancement drugs would be beneficial <p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • 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 Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – “Repeating” (English and Spanish) <p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Repeating



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



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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.

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

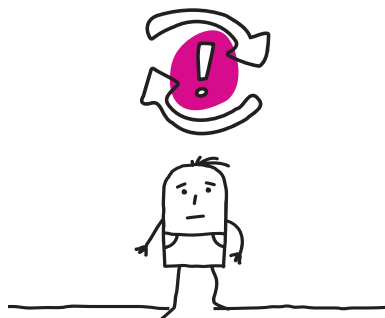
TRY REMINDERS

- 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

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

Repitiendo



¿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
- repetir preguntas o historias porque están nerviosos o tienen miedo
- tener dificultad comunicar lo que necesitan o desean

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? ¿con gente desconocida? ¿tendrán miedo?
- quizás se les olvidó que ya hicieron la pregunta y la respuesta que les dieron
- desean su atención... quieren sentir una conexión con usted
- tal vez están tratando de decirle algo... que tienen hambre, están preocupados por alguien o algo, o que 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 es por 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 o un calendario, o un pizarrón para 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
- espere hasta el último momento para hablar sobre actividades que los pongan nerviosos, tales como: las visitas al médico o bañarse
- si usted está cansada puede reaccionar de manera negativa, y si la persona está segura, váyase a otro cuarto por un momento para calmarse respirando profundamente.



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Sadness and/or Depression

<p>Identify the Problem</p>	<p><u>PROBLEM:</u> Sadness and/or Depression (feeling blue)</p> <p><u>GOAL/EXPECTED OUTCOME:</u> To reduce depression or depressive symptoms</p>
<p>Explore</p>	<p><u>ASSESS FURTHER:</u></p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p><u>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</u></p> <ul style="list-style-type: none"> • 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 <p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • If suicidal ideation is present, follow standards of practice, polices, 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 <p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Discuss opportunities for socialization, stimulation and interaction, such as CBAS • Refer to Alzheimer’s Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org

	<ul style="list-style-type: none"> • Local Community Resources: _____ _____ • Send literature: <ul style="list-style-type: none"> ○ Topic Sheet – “Sadness and Depression”
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>

Alzheimer's Caregiving Tips

SADNESS & 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
Reviewed by Alzheimer's LA January 2016 | NIH July 2012

Combativeness

<p>Identify the Problem</p>	<p>PROBLEM: Combativeness (anger, hitting, pushing, fighting, etc.)</p> <p>GOAL/EXPECTED OUTCOME: To reduce combativeness through non-pharmacological approaches</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • Is something causing the person to feel frustrated? <ul style="list-style-type: none"> ○ Is the person overly tired? ○ Is the person having trouble completing a task that was once simple for him/her? ○ Is there too much going on around the person? ○ Does the person have trouble seeing or hearing that is causing him/her to mistake sights and sounds? ○ 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> ○ I can't ○ I'm scared ○ I don't understand ○ I never liked it and I never will <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Does the caregiver feel unsafe? • Is the caregiver scared?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • You set the tone; try to use a calm, reassuring voice and avoid insults <ul style="list-style-type: none"> ○ Try saying "I know you're feeling angry," to show you understand • Try to avoid triggers if possible <ul style="list-style-type: none"> ○ Make sure the person is comfortable; check for possible sources of pain ○ Offer simple, step-by-step instructions for activities ○ Approach the person slowly from the front and introduce yourself if needed ○ Speak slowly and clearly ○ Keep routines the same each day ○ 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)

	<ul style="list-style-type: none"> • Consider safety <ul style="list-style-type: none"> ○ Stand out of reach of the person ○ 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
	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • 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
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – "Anger, Frustration, & Fighting" (English and Spanish)
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Anger, Frustration, & Fighting



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/scared of:
 - the shower or bath
 - a new place or person

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



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Enojo, Desesperación y Peleas



¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- confundirse con:
 - personas o lugares nuevos
 - algo que ven y no entienden
- frustrarse porque no pueden:
 - ponerse el suéter
 - abrir la puerta
 - encontrar algo que perdió como la bolsa, la cartera o los lentes
- tener miedo de:
 - el baño o la ducha
 - de una persona o un lugar nuevo

Personas con Alzheimer o demencia se confunden, deprimen y se enojan. Tienen dificultad para controlar sus sentimientos y acciones.

Podrían pegar y gritar.

Sus palabras o acciones no se deberán de tomar de manera personal.

Escuchen por el significado, no solo lo que están diciendo.

¿QUÉ PUEDE HACER?

MANTENGA LAS COSAS LO MÁS SENCILLO POSIBLE

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

HAGA UN CAMBIO

- ofrézcale algo para comer como una fruta o un dulce
- llévelo a otro cuarto en la casa
- pregúnteles si quieren ver la televisión u oír música
- háblele de algo que a ellos les gusta

MANTÉNGASE SEGURO

- saquen o guarden bajo llave las armas (pistolas, cuchillos, etc.)
- si usted no se siente seguro, aléjese lentamente y pida ayuda
- llamen al 911 si usted u otra persona está en peligro



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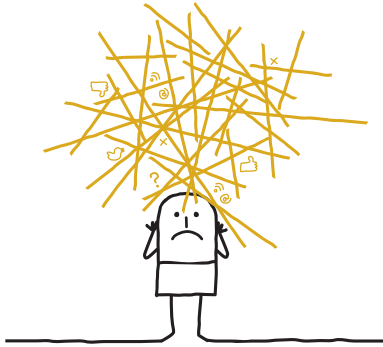
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Hallucinations

<p>Identify the Problem</p>	<p>PROBLEM: Hallucinations (seeing or hearing things that are not there)</p> <p>GOAL/EXPECTED OUTCOME: To increase caregiver's capacity to cope with and manage hallucinations</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • Does the person feel frightened? • Does the person feel unsafe? • Is the person reliving a trauma from the past? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Does the caregiver feel frustrated? • Does the caregiver feel like he/she does not know how to help?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • Change the environment <ul style="list-style-type: none"> ○ Remove or adjust items that may upset the person ○ Cover mirrors and windows if the person does not know who is in the mirror or window ○ Turn on lights to reduce shadows that may look frightening ○ Turn off the TV if it is distracting. The person might also be confused about whether the TV episode is reality ○ Use contrasting colors, such as red plates on white table clothes, to help the person see differences in objects ○ 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

	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • 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
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – "Hallucinations" (English and Spanish)
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Hallucinations



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

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 close ones.

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

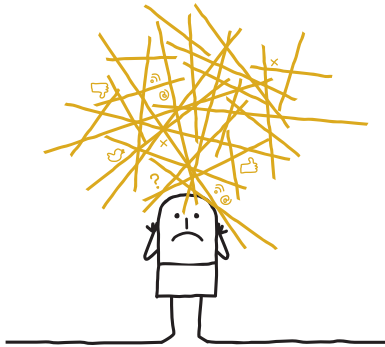
- say things like "don't worry, I'm here and will take care of you"
- agree, don't argue, about whether what's happening is real... it is real to them
- involve him or her in something pleasant to distract them



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Alucinaciones



¿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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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?

VEA A UN DOCTOR

- hable con el doctor para encontrar la causa (lleve TODAS las medicinas con usted a la cita)
- dígame al doctor cuantas veces ha sucedido esto (mantenga un registro: fecha y hora de lo que le sucedió a la persona con Alzheimer o demencia)

PIENSE EN LO QUE PUEDA 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 oscuridad, prenda la luz o use una luz de noche
- si la televisión o la radio lo está confundiendo o asustando, apáguelos

TRANQUILICE A LA PERSONA CON ALZHEIMER

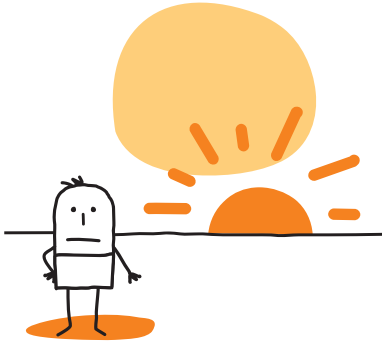
- dígame, "No se preocupe. Yo estoy aquí. Yo le ayudo."
- no discuta sobre lo que la persona con Alzheimer ve o escucha porque es real para él
- trate de distraer a la persona con alguna actividad

Sundowning

<p>Identify the Problem</p>	<p>PROBLEM: Sundowning (more confusion/restlessness in late afternoon/evening)</p> <p>GOAL/EXPECTED OUTCOME: To reduce and better manage sundowning behavior</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • Does the person feel frightened? • Is the person experiencing anxiety from too much stimulation or noise? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Does the caregiver feel frustrated? • Is the caregiver tired?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • 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 <p>CLINICAL SUPPORT:</p> <ul style="list-style-type: none"> • 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 <p>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to CBAS for structured daily activities • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – "Sundowning" (English and Spanish)

	<u>FOLLOW UP:</u> <ul style="list-style-type: none">• Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<u>NOTES:</u> <hr/> <hr/> <hr/> <hr/>

Sundowning



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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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 3PM
- remove access to alcohol and cigarettes

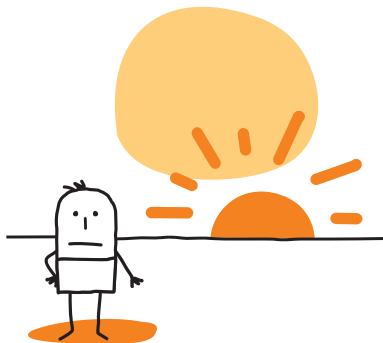
KEEP A SCHEDULE

- 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

Cambios al Atardecer



¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden estar:

- muy cansados por la tarde
- confundidos porque hay menos luz en la casa
- asustados por las sombras
- respondiéndolo a sus sentimientos si usted está cansada



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Personas que tienen Alzheimer o demencia se pueden confundir o ponerse nerviosos por la tarde, especialmente 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.

¿QUÉ PUEDE HACER?

HAGA 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 o muy altos
- 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 3PM
- manténgalos alejados de alcohol y cigarrillos

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 puedan 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

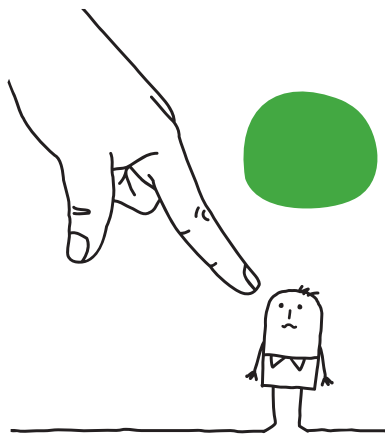
- mantenga su actitud y tono de voz calmada
- sea flexible... si lo que hizo no funcionó, después de un par de minutos trate algo nuevo
- diga o haga algo que tranquilice a la persona
- trate una actividad nueva, como organizar monedas o bailar

Suspiciousness and Paranoia

<p>Identify the Problem</p>	<p>PROBLEM: Suspiciousness and Paranoia (accusing, blaming)</p> <p>GOAL/EXPECTED OUTCOME: To improve caregiver capacity to cope with and manage behaviors of suspiciousness and paranoia</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer’s:</p> <ul style="list-style-type: none"> • Is the person angry? • Does the person feel taken advantage of? • Is the person scared? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • 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?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • 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.) <p>CLINICAL SUPPORT:</p> <ul style="list-style-type: none"> • 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

	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – "Paranoia" (English and Spanish)
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Paranoia



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- lose an item and think it was stolen
- forget something told to them and when re-told, think it's a lie
- feel a spouse is treating them differently and believe it's because of an affair
- be unable to tell what is real and what is not

People with Alzheimer's or dementia may become suspicious and frightened, even of those who love and care for them. Their world can seem strange and confusing, leading them to accuse others of stealing or lying. Don't take this personally; it is a common behavior.

WHAT CAN YOU DO?

BE COMFORTING

- stay calm and use a gentle voice
- don't argue... the situation is very real to them
- let them know they are safe and everything is okay
- hold their hand or give a hug (if they don't mind being touched)

TRY DISTRACTION

- offer a favorite food to eat or activity to do
- help look for missing items and talk with them about items you find along the way such as photos, objects around the house, books, etc.
- take them outside for a walk or to a different room
- talk about something important to them (family, music, hobbies)

MAKE THE ENVIRONMENT CALM AND FAMILIAR

- keep extra items that are often lost like wallets, keys, jewelry
- keep their space quiet and calm
- surround them with things they remember and cherish
- turn off the TV or radio if a show or the news are upsetting
- re-introduce yourself and others as often as needed
- play music from the past that has good memories

OTHER TIPS

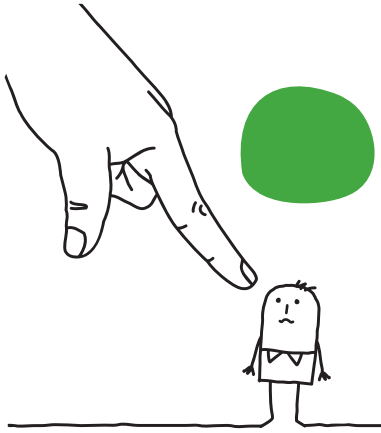
- keep notes to describe the paranoia and share with the doctor
- have legal papers to show police the person's diagnosis, your relationship, power of attorney, etc.
- join a support group or find a friend where you can talk openly about your feelings and frustrations
- remember that sometimes items really do get stolen



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Paranoia



¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- perder o extraviar algo y pensar que alguien se lo robó
- olvidar que se les dijo algo y al repetirlo, podrían pensar que es una mentira
- sentir que su cónyuge los trata de forma distinta y creer que se debe a que les está siendo infiel
- no poder reconocer lo que es y lo que no es real

Las personas con Alzheimer o demencia pueden volverse desconfiados y sentir miedo, hasta de sus seres queridos y también con los que cuidan de ellos. El mundo a su alrededor puede parecer extraño y confuso, llevándolos a culpar a otros de robar o mentir. No se lo tome a pecho; esto es algo común.

¿QUÉ PUEDE HACER?

AYUDE A TRANQUILIZARLOS

- mantenga la calma y el tono de su voz baja
- no discuta... la situación es muy real para ellos
- reafírmenles que están a salvo y que todo está bien
- tomándoles de las manos o dándoles un abrazo (si no los incomoda)

INTENTE DISTRAERLO

- ofrécenles alguna comida favorita o háganlos realizar alguna actividad divertida
- ayúdenles a buscar el objeto perdido y hablen con ellos sobre otras cosas que encuentren en el camino, tales como fotografías, objetos del hogar, libros, etc.
- llévenlos afuera a caminar o a otra habitación
- háblenles sobre algo que les interese (familia, música, pasatiempos)

MANTENGA UN ENTORNO TRANQUILO Y FAMILIAR

- guarde objetos adicionales que se pierden con frecuencia, tales como: billeteras, llaves, joyas
- mantenga su espacio tranquilo y apacible
- rodéelos de cosas que recuerden y que aprecien
- apague el televisor o la radio si el programa es preocupante
- preséntese nuevamente y a los demás con la frecuencia que sea necesaria
- ponga música del pasado que le traiga buenos recuerdos

OTROS CONSEJOS

- tome nota describiendo la paranoia y comuníquese al doctor
- mantenga en un lugar todos los documentos legales para demostrar el diagnóstico de la persona, su parentesco, poder notarial, etc., a la policía u otras personas en caso de una emergencia
- únase a un grupo de apoyo o busque a un amigo para hablar abiertamente sobre sus sentimientos y frustraciones



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Screaming and Making Noises

<p>Identify the Problem</p>	<p>PROBLEM: Screaming and Making Noises</p> <p>GOAL/EXPECTED OUTCOME: To increase caregiver’s understanding of noise as communication to improve caregiver’s capacity to cope with and manage noise</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer’s:</p> <ul style="list-style-type: none"> • Is the person feeling scared or confused? • Does the person feel frustrated he/she cannot tell you what he/she needs? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Is the caregiver frustrated? Annoyed? • Does the caregiver feel confused or “stuck” about what to do? • Is the caregiver embarrassed?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • 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 <ul style="list-style-type: none"> ○ Keep a regular eating schedule for the person with meals and snacks to reduce hunger ○ Keep a regular toileting schedule to reduce accidents ○ Change the person’s position in chairs/bed regularly ○ Clean the person up immediately after an accident • Create a relaxing and calm environment <ul style="list-style-type: none"> ○ Use relaxing techniques, such as massage, gentle touch, talking in a soothing voice, or playing calming music ○ 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 <hr/> <p>CLINICAL SUPPORT:</p> <ul style="list-style-type: none"> • 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

	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Topic Sheet – "Communication" (English and Spanish)
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Communication



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might have changes in their brains that cause them to:

- have a tough time finding the right word
- lose their train of thought
- have problems following a conversation
- not be able to understand what you are saying
- speak only in their native or first language

People with Alzheimer's or dementia can lose their ability to speak clearly and understand what you are saying. This can be frustrating both for the person with Alzheimer's and for you.

WHAT CAN YOU DO?

USE SHORT SENTENCES & SIMPLE WORDS

- give short, one sentence answers
- offer one step directions
- slowly repeat instructions or sentences if not understood the first time
- be patient and positive, even when it takes a long time to answer
- try not to remind them that they forgot or already told you something
- ask a question and offer a simple choice of answers such as "What do you want for dinner? Fish or chicken?"
- ask questions that can be answered with yes or no
- try not to use "baby talk" or a "baby voice"
- avoid negative words. Instead of "Don't go out that door!" try "Let's go this way!" and gently guide the person away

FOCUS THEIR ATTENTION ON YOU

- get on their eye level
- call the person by name
- remove distractions — turn off TV, go to a quiet room
- pay attention to your tone, how loudly you are speaking and your body language — which often "speak" louder than words
- be an active listener — make eye contact, nod your head

OTHER IDEAS TO TRY

- put up signs or pictures to explain what is in the room or cabinet
- have the person's hearing tested to make sure they can hear
- use a chalk or white board to write the schedule for the day or the answers to frequently asked questions
- respond to the person's feelings or emotions, not only to words
- if conversation is hard but you want to do something together, try listening to music or looking at old family photos



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Comunicación



¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia sufren cambios en el cerebro, ocasionando que:

- se les dificulte encontrar la palabra correcta
- se les olvide lo que estaban diciendo
- se les dificulte mantener una conversación
- no puedan entender lo que usted les dice
- hablen sólo en su idioma natal

Las personas con Alzheimer o demencia pueden perder la habilidad de hablar claramente y entender lo que usted dice. Esto podría ser frustrante tanto para la persona con Alzheimer como para usted.

¿QUÉ PUEDE HACER?

USE ORACIONES CORTAS Y PALABRAS SENCILLAS

- evite respuestas largas, use respuestas cortas
- de instrucciones sencillas de un solo paso
- sea paciente y repita lentamente las instrucciones u oraciones lentamente si no entendió la primera vez
- tenga paciencia cuando la persona se tarde mucho en responder
- no le recuerde a la persona que olvidó algo o que usted ya le había dicho algo antes
- cuando usted haga una pregunta, incluya opciones de respuestas sencillas, tales como “¿Qué le gustaría cenar? ¿Pescado o pollo?”
- haga preguntas que se puedan responderse con un sí o un no
- no use “lenguaje infantil” o hable con “voz de bebé”
- sea amable y trate de evitar el uso de palabras negativas; en lugar de decir “¡No salga por esa puerta!”, diga “Salgamos por acá que es mejor” y cuidadosamente aleje a la persona de la puerta

HAGA QUE LA PERSONA ENFOQUE LA ATENCIÓN EN USTED

- colóquese a la vista de sus ojos
- llame a la persona por su nombre
- elimine distracciones — apague la televisión o vaya a un cuarto más tranquilo
- preste atención a su tono de voz, su volumen y su lenguaje corporal — estas maneras de comunicación no verbales a veces “hablan” más fuerte que las palabras
- escuche de manera activa — haga contacto visual y afirme con la cabeza

OTRAS IDEAS QUE PUEDE INTENTAR

- coloque letreros con palabras o dibujos en las puertas para indicar lo que hay dentro de la habitación o el gabinete
- evalúe la audición de la persona para asegurarse de que puede oírlo
- use un pizarrón para anotar el horario de cada día o las respuestas a preguntas frecuentes
- no solo responda a las preguntas de la persona, sino también las emociones o sentimientos de la persona
- si le resulta difícil conversar, pero desea hacer algo juntos con la persona, póngase a escuchar música o a ver el álbum de fotos de la familia



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Disinhibition

<p>Identify the Problem</p>	<p>PROBLEM: Disinhibition (unwanted sexual behaviors or inappropriate behaviors)</p> <p>GOAL/EXPECTED OUTCOME: To increase caregiver capacity to understand, cope and manage disinhibited behaviors</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • Is the person in need of human contact? • Is the person lonely? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Is the caregiver shocked and embarrassed? • Is the caregiver angry?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • 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)

	<ul style="list-style-type: none"> • 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)
	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • 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
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to Alzheimer’s Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send Literature: <ul style="list-style-type: none"> ○ Topic Sheet – “Disinhibition (Intimacy and Sexuality)”
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Alzheimer's Caregiving Tips

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 isn't doing this on purpose.
- Don't try to reason with the person or explain that it's not appropriate behavior.
- Ignore the behavior 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."

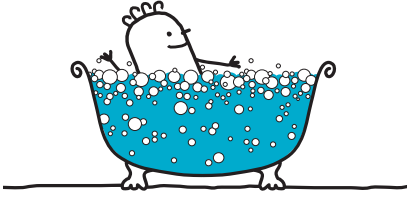
Information adapted from the National Institute on Aging, part of the National Institutes of Health www.nia.nih.gov
Reviewed by Alzheimer's LA January 2016 | NIH July 2012

Resists Bathing or Showering

<p>Identify the Problem</p>	<p>PROBLEM: Resists Bathing or Showering</p> <p>GOAL/EXPECTED OUTCOME: To reduce resistance to bathing or showering</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • Is the person feeling embarrassed about getting undressed in front of you? • Is the person uncomfortable? • Is the person scared or confused? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Is the caregiver frustrated?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • Preparing the bathroom: <ul style="list-style-type: none"> ○ Make sure the room is warm enough for the person ○ Run the water so it is not too hot or too cold ○ Do not use bright lights if possible ○ Have a towel, clean clothing, and non-slip socks ready for use when the person steps out of the tub or shower ○ Try covering the mirror if the person gets agitated around it ○ 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 <ul style="list-style-type: none"> ○ Assure the person you are there to help them ○ Use a calm and reassuring tone of voice ○ Be direct: "Your bath is ready now," instead of "Do you want to take a bath?" ○ Explain what you are doing right before you do it ○ 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

	<ul style="list-style-type: none"> • Other <ul style="list-style-type: none"> ○ Try to be patient and do not rush the person ○ Let the person participate, by giving him/her a washcloth to use ○ Be gentle and look for signs of pain ○ Consider a sponge bath instead of a shower if needed ○ If the person does not want to bathe, try at another time. Also realize that daily bathing may be too much ○ Find the best time of the day when the person is not too tired or anxious ○ Give the person as much privacy as possible, but keep safety in mind
	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • If the person refuses to bathe because of pain, refer to PCP • Discuss with PCP appropriate hygiene
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to IHSS • Refer to Alzheimer’s Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – “Bathing” (English and Spanish)
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Bathing



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

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



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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 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

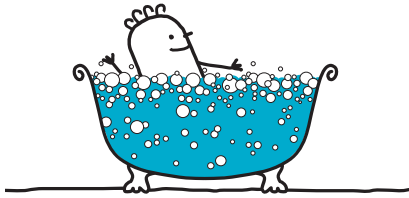
ALLOW TIME & BE POSITIVE

- 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

Bañarse



¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- tener miedo de caerse
- no se sienten cómodos desvistiendo delante de otros
- están asustados o confundidos
- se sienten indefensos



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Personas con Alzheimer o demencia pueden tener miedo a bañarse o les da vergüenza desvestirse enfrente de otra persona. A veces se preocupan de que se van a caer o pueden no recordar cual es la llave fría o caliente.

¿QUÉ PUEDE HACER?

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 alfombra que no se resbale
- use una silla de baño
- ponga sólo 4 pulgadas de agua en la tina
- saque del baño cosas que pueden causarle daño a la persona con Alzheimer, tales como: rastrillos, corta uñas y secadoras de pelo
- nunca deje a la persona con Alzheimer sola en la tina o ducha

TÓMESE SU TIEMPO Y SEA POSITIVO

- si a la persona le gusta bañarse, deje que disfrute su baño
- mantenga la calma
- de instrucciones directas... "El baño está listo"
- en vez de decir "¿Se quiere bañar?" dele indicaciones un paso a la vez
- dígame una cosa a la vez... "Lávese el brazo izquierdo. Bien. Ahora lávese el otro brazo" tenga paciencia... no apresure a la persona

SEA REALISTA

- no discuta con la persona... un baño diario puede ser mucho
- considere un baño de esponja en vez de tina
- muéstrole con ejemplos... haga como que usted se lava el brazo y pídale que copie sus movimientos

Difficulty with Dressing and Grooming

Identify the Problem	<p>PROBLEM: Difficulty with Dressing and Grooming (brushing hair/teeth, shaving, etc.)</p> <p>GOAL/EXPECTED OUTCOME: To reduce difficulty with bathing and grooming</p>
Explore	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • 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	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> ○ Offer the person only two options so there are not too many choices ○ Lay out clothing in the order it needs to be put on ○ Have clothing that is easier for the person to put on, such as slip-on shoes, cardigans, Velcro, elastic waistbands, etc. ○ Buy clothing that is loose-fitting and comfortable, not tight ○ If the person always wants to wear the same things, buy multiples ○ Make sure the room is warm enough ○ Make sure there is enough lighting in the room ○ Close the door and pull down the blinds to create privacy
Problem solve with interventions and actions	

	<ul style="list-style-type: none"> ○ Remove distractions (TV playing, clutter, etc.) ○ Make sure the person has his/her glasses or hearing aids and make sure they are working • Grooming: <ul style="list-style-type: none"> ○ 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
	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • 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
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to IHSS • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Topic Sheet – "Dressing and Grooming"
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Alzheimer's Caregiving Tips

DRESSING & 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. Alzheimer's Greater Los Angeles can you with dentist referrals. 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 as needed. Use an electric razor.
- 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.

(Continued on next page)

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
Reviewed by Alzheimer's LA January 2016 | NIH July 2012

Difficulty with Eating

<p>Identify the Problem</p>	<p>PROBLEM: Difficulty with Eating (including chewing, swallowing, dental concerns)</p> <p>GOAL/EXPECTED OUTCOME: To reduce difficulty with eating</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • Is the person embarrassed to be fed by someone else? • Is the person frustrated or overwhelmed? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Is the caregiver frustrated? • Is the caregiver worried?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • 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 <ul style="list-style-type: none"> ○ Make sure the plate is a different color from the food ○ Try to avoid patterns on placemats, plates and tablecloths. They can be distracting ○ Increase lighting in eating area ○ Reduce the noise and distractions around the person • Make eating simple. Try these options: <ul style="list-style-type: none"> ○ Serve only one food at a time ○ Use bowls instead of plates ○ Try setting the area with only utensils that are needed for the meal ○ Plastic utensils may be too light and might break. Try to avoid them ○ 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

	<ul style="list-style-type: none"> • For over-eating <ul style="list-style-type: none"> ○ 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 <ul style="list-style-type: none"> ○ 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 <p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • Have a good dental check-up of the person’s gums, teeth and dentures • Check with a doctor to see if problems with eating is 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) <p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to IHSS • Refer to Home and Community-Based Services Planning and Management (HCBS CPM) formerly MSSP • Refer to Meals on Wheels • Refer to Alzheimer’s Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Topic Sheet – “Difficulty with Eating” <p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

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 & 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.

FOR UNDER-EATING

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
Reviewed by Alzheimer's LA January 2016 | NIH July 2012

Difficulty Using the Toilet

<u>Identify the Problem</u>	<p><u>PROBLEM:</u> Difficulty Using the Toilet/Incontinence (wetting, accidents)</p> <p><u>GOAL/EXPECTED OUTCOME:</u> To reduce difficulty with toileting/incontinence</p>
<u>Explore</u>	<p><u>ASSESS FURTHER:</u></p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • Is the person embarrassed? Is there not enough privacy? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Is the caregiver frustrated? • Is the caregiver worried? • Is the caregiver embarrassed?
<p><u>Adjust</u></p> <p>Problem solve with interventions and actions</p>	<p><u>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</u></p> <ul style="list-style-type: none"> • 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 • Give the person as much privacy as possible

	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • 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
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to IHSS • Refer to Home and Community-Based Services Planning and Management (HCBS CPM) formerly MSSP • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – “Toileting” (English and Spanish)
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Toileting



WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- have poor control of their body functions
- be taking medications that cause them to urinate a lot
- forget what the bathroom and toilet are used for
- feel embarrassed and ashamed to ask for help
- might not be able to find the bathroom in time
- might not be able to remove their clothes in time



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People with Alzheimer's disease or dementia can have accidents when they want to go to the bathroom.

WHAT CAN YOU DO?

ALLOW TIME & BE POSITIVE

- plan for extra time... be patient... don't rush
- stay calm and use a gentle voice
- give one step directions — "let's walk this way, let's come in here"
- think about if the person is embarrassed to get undressed in front of you or a person of a different sex

KEEP THINGS SIMPLE

- find clothes that are easy to take on and off, such as pants with an elastic waist or Velcro instead of buttons
- try to seat the person closer to the bathroom so they don't need to walk as far
- keep a light on in the bathroom so it can be seen when needed
- use a toilet seat with a bright color so that it can be seen easily
- install a raised toilet seat and grab bars – some individuals feel like they are falling when sitting down on a low toilet
- remove anything that looks like a toilet, such as a trash can

KEEP A SCHEDULE

- create a regular schedule for using the toilet: when they wake up, before and after meals, and just before bed
- limit water and other drinks close to bedtime

ACCIDENTS HAPPEN

- be understanding when accidents happen
- stay calm and comfort the person if they are upset
- be prepared with supplies, such as extra clothes and wipes
- if accidents happen suddenly or more often, talk with their doctor about possible reasons — for example, a new medication or an infection may cause this to happen

Uso del baño



¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- tener poco control de sus funciones corporales
- estar tomando medicamentos que los hacen orinar mucho
- olvidar para qué sirven el baño y el inodoro
- sentirse avergonzados de pedir ayuda
- no encontrar el baño a tiempo
- no poder quitarse la ropa a tiempo



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Personas con la enfermedad de Alzheimer o demencia pueden tener accidentes cuando necesitan ir al baño.

¿QUÉ PUEDE HACER?

DARSE TIEMPO SUFICIENTE Y MANTENERSE POSITIVO

- de tiempo adicional... sea paciente... no apesure
- mantenga la calma y la voz suave
- de instrucciones sencillas de un solo paso — “caminemos por acá, bien, ahora entremos aquí”
- considere que la persona puede sentirse avergonzado al tener que quitarse la ropa delante de usted o de una persona del sexo opuesto

TRATE DE FACILITAR LAS COSAS

- utilice ropa que sea fácil de poner y de quitar: como pantalones con cintura elástica o velcro en lugar de botones
- siente a la persona cerca del baño para que no tenga que caminar muy lejos
- mantenga una luz prendida en el baño para que se pueda ver cuando sea necesario
- use un asiento de inodoro de color brillante para poder distinguirlo con facilidad
- instale un asiento de inodoro elevado con barras de seguridad para sujetarse; algunas personas tienen la sensación de caerse cuando se sientan en un inodoro bajo
- saque o cubra cualquier cosa que se pueda confundir con un inodoro, como el bote de basura, por ejemplo

MANTENGA UN HORARIO

- establezca un horario regular para ir al baño: al despertarse, antes y después de cada comida, y justo antes de acostarse a dormir
- limite el consumo de agua y otras bebidas antes de dormir

LOS ACCIDENTES SUCEDEN

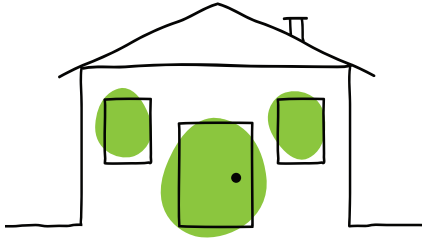
- sea comprensible cuando pasen accidentes
- mantenga la calma y consuele a la persona si se altera
- tenga suministros listos, tales como: ropa y toallas húmedas
- si la persona tiene accidentes súbitos o con mayor frecuencia, hable con el doctor sobre las posibles causas — por ejemplo, un medicamento nuevo o una infección

Home Safety Concerns

<p>Identify the Problem</p>	<p>PROBLEM: Home Safety Concerns (falls, guns, knives, stoves, leaving the person alone)</p> <p>GOAL/EXPECTED OUTCOME: To increase personal and home safety</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <ul style="list-style-type: none"> • 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?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <p>Prevention and safety-proofing the home is important. The goal is to make the environment safe <i>before</i> 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.)</p> <ul style="list-style-type: none"> • Consider home adjustments <ul style="list-style-type: none"> ○ Install grab bars by the toilet and in the shower ○ Use equipment such as hand rails, ramps, adjusted toilets or beds, wheelchair, cane, walker, and lifts, as needed ○ Remove things that can easily break and are not needed ○ Provide enough lighting (stairwells and the doorway to the bathroom should be brightly lit day and night) ○ Unplug the kitchen disposal ○ 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 <ul style="list-style-type: none"> ○ Remove small rugs, rugs that are thick, or rugs that might slide ○ Remove low pieces of furniture that may not be easily seen ○ Don't shine or wax floors ○ Keep items off of the floor that can be tripped over (cords, books, toys, boxes, etc.) ○ Make sure the bathroom and kitchen floors are kept dry and avoid walking on them with wet feet ○ Use tables and chairs that are stable enough to lean on • Remove dangerous items <ul style="list-style-type: none"> ○ Keep knives, scissors, guns, sharp tools, matches and lighters (and cigarettes) in a locked area

	<ul style="list-style-type: none"> ○ 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: <ul style="list-style-type: none"> ○ 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 <p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> ● 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 <p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> ● Listen empathically to caregiver and evaluate for level of distress ● Refer to IHSS ● Refer to Home and Community-Based Services Planning and Management (HCBS CPM) formerly MSSP ● Refer to agencies that provide low-cost home modifications ● Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org ● Local Community Resources: _____ ● Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – "Keeping Home Safe" (English and Spanish) ○ Home Safety Assessment <p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> ● Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Keeping Home Safe



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, or ovens
- forget how to use knives, etc. or where to safely place burning objects



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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

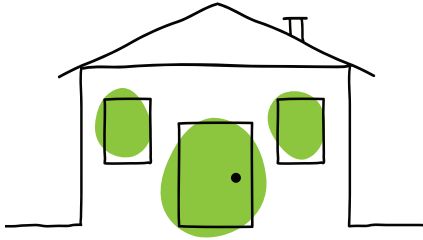
REMOVE DANGEROUS ITEMS

- 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

Seguridad en el Hogar



¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- tropezarse por cambios en el equilibrio o por dificultad al caminar
- tener problemas con la vista
- olvidarse de cerrar la llave de agua o de apagar la estufa o el horno
- olvidarse de cómo usar el cuchillo, etc., o a donde colocar las ollas calientes



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Personas con Alzheimer o demencia pueden tener problemas para entender situaciones peligrosas o tomar decisiones seguras. Ayudándolos a sentirse más relajados y menos confundidos en el hogar, puede ayudar evitar accidentes.

¿QUÉ PUEDE HACER?

MANTENGA LAS COSAS SIMPLES

- mantenga los cuartos limpios
- mantenga "artículos de uso diario" en el mismo lugar
- guarde las cosas frágiles que no necesite, tales como: espejos, vajillas

REVISE EL PISO

- quite alfombras pequeñas, gruesas, o resbalosas que puedan causar tropezos
- no encere los pisos
- no ponga cosas en el piso... cables electrónicos, libros, juguetes, bolsas, cajas, etc.
- asegúrese que el piso del baño y la cocina estén secos y evite caminar con pies mojados
- asegúrese que las mesas y sillas sean lo suficientemente estables como para apoyarse en ellas

GUARDE OBJETOS QUE PUEDAN SER PELIGROSOS

- mantenga todos los medicamentos... vitaminas, aspirina, con prescripción... bajo llave, en un gabinete o en un cajón
- ponga cuchillos, tijeras, pistolas, objetos filosos, cerillos, y encendedores fuera de la vista o bajo llave
- mueva todos los productos de limpieza en un estante alto o bajo llave
- quite los botones de prender y apagar la estufa y horno

NO DEJE A LAS PERSONAS CON ALZHEIMER SOLOS

- en la cocina con la estufa o el horno encendido
- en el baño con el agua corriendo
- en cualquier lugar con cigarrillos o puros prendidos
- cerca de una puerta o portón abierto o sin seguro

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 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 irons.

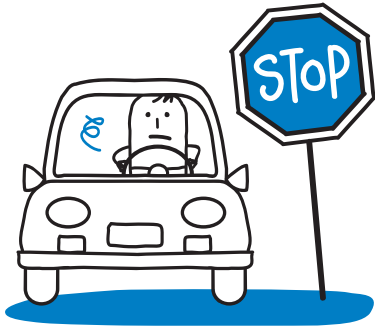
The Home Safety Assessment is not all-inclusive, nor do the suggestions in the Assessment substitute for close supervision, at all times, of a person with memory loss.

Insists on Driving

<p>Identify the Problem</p>	<p>PROBLEM: Insists on Driving</p> <p>GOAL/EXPECTED OUTCOME: To increase driving safety and to be from harm</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • Does the person feel like he/she is losing his/her independence? • Does the person feel angry? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Does the caregiver feel guilty? • Is the caregiver scared for the person's safety?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • 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 <p>CLINICAL SUPPORT:</p> <ul style="list-style-type: none"> • Refer to PCP/social worker for conversations around driving and safety <p>NOTE: Providers must report the diagnosis in accordance with California law</p> <ul style="list-style-type: none"> ○ DMV Form CDPH 110c: Confidential Morbidity Report ○ Available online as a fillable PDF file here: https://www.cdph.ca.gov/CDPH%20Document%20Library/ControlledForms/cdph110c.pdf <ul style="list-style-type: none"> • Ask the person's doctor to talk with the person about driving. Sometimes it's

	<p>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</p>
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to low cost and accessible transportation services • Refer to Alzheimer’s Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Local Community Resources: <hr/> <hr/> • Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – “Driving” (English and Spanish)
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Driving



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

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.

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

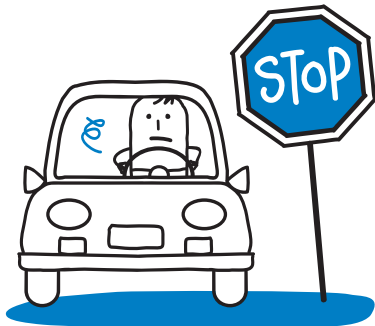
- sell the car... it saves money on gas, insurance, and repairs that can be used for taxis, Uber, LYFT, or paying someone to drive



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Manejando



¿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

Con el tiempo, manejar se convierte en una actividad más difícil para las personas con Alzheimer o demencia. Llegará el momento cuando deban de 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 es 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 a sus citas médicas
- pida ayuda a familiares y amigos... para 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
- 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



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Takes Medicine the Wrong Way

<p>Identify the Problem</p>	<p>PROBLEM: Takes Medicine the Wrong Way</p> <p>GOAL/EXPECTED OUTCOME: To improve medication management, compliance, and safety</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <ul style="list-style-type: none"> • 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?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <p>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</p> <ul style="list-style-type: none"> • Do not leave the person alone to take his/her medication • Watch closely. Make sure the person: <ul style="list-style-type: none"> ○ Takes the right pills and the right amounts ○ Takes medications at the right times ○ Follows the directions on the medication • Lock away medications: <ul style="list-style-type: none"> ○ Do not leave medications in a pill box or cup on the counter ○ Make sure all medications are out of sight and out of reach • Talk to ALL the doctors: <ul style="list-style-type: none"> ○ Talk to the doctor about any medications that may have been prescribed by separate provider ○ Do not stop giving any medication without asking the prescribing doctor first ○ Bring all medications in a bag or box to every doctor visit <ul style="list-style-type: none"> ▪ Include vitamins, herbs, teas, creams, and other pills from the drugstore ○ Ask the doctor if medications can be mixed into food or drinks <ul style="list-style-type: none"> ▪ This may be helpful if you are having trouble getting the person to take his/her pills ○ Ask the person's doctor about switching to medications that last longer so the person does not have to take them as often ○ 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

	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • 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
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to IHSS • Refer to Home and Community-Based Services Planning and Management (HCBS CPM) formerly MSSP • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – "Medications" (English and Spanish)
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

Medications



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

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



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Medicamentos



¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- olvidarse de tomar sus medicamentos
- olvidar que ya se tomaron sus medicinas y volvérselas a tomar
- enfermarse o envenenarse por tomar las pastillas equivocadas o tomar más de lo indicados



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

¿QUÉ PUEDE HACER?

PONGA ATENCIÓN

- asegúrese que la persona este:
 - tomando el numero indicado de las pastillas a las horas señaladas
 - siguiendo las instrucciones al pie de la letra
- no deje las pastillas en un pastillero o una taza sobre el mostrador
- no deje a la persona sola para tomar su medicamento

GUARDE LA MEDICINA FUERA DE LA VISTA

- asegúrese que todos los medicamentos estén fuera de la vista y del alcance de la persona con Alzheimer

HABLE CON TODOS LOS DOCTORES

- no interrumpa ningún medicamento sin hablar con el doctor que los receto primero
- lleve todas las medicinas en una bolsa o caja a cada cita médica
 - incluyendo vitaminas, hierbas, tés, cremas, y otras pastillas sin recetas
- pregunte si puede mezclar la medicina en la comida o con alguna bebida
 - esto le ayudara si la persona a su cargo tiene dificultad para tomar sus pastillas

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

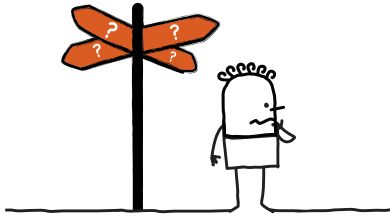
- el cambio puede ser causado por una infección o reacción a los medicamentos

Wanders/Gets Lost

<p>Identify the Problem</p>	<p><u>PROBLEM:</u> Wanders/Gets Lost</p> <p><u>GOAL/EXPECTED OUTCOME:</u> To reduce wandering through non-pharmacological approaches</p>
<p>Explore</p>	<p><u>ASSESS FURTHER:</u></p> <p>Understand the possible triggers of the problem:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the person with Alzheimer's:</p> <ul style="list-style-type: none"> • 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? <p>Understand the possible meaning of the problem to the caregiver:</p> <ul style="list-style-type: none"> • Does the caregiver feel frustrated? • Is the caregiver scared for the person's safety?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p><u>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</u></p> <ul style="list-style-type: none"> • Be prepared: <ul style="list-style-type: none"> ○ Don't leave the person alone near an unlocked door ○ Get a Medic Alert + Safe Return® bracelet for the person ○ Sew or write the person's name and your phone number onto clothing ○ If the person is looking to fulfill a basic need, such as toileting, hunger, or thirst, guide the person ○ 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 ○ Put away items, such as coats, purses, or keys that might make the person think about leaving ○ Cover doors/exits so they are less visible ○ Close curtains so the person does not think about going outside ○ Ask your neighbors to keep an eye out for the person wandering outside alone ○ Encourage physical activity to reduce restlessness • Make the home safe: <ul style="list-style-type: none"> ○ Put child-proof locks on doors, gates, and windows ○ Place locks very high or low so the person can't see or reach the locks ○ Place a bell on doors, gates, or windows so you know if they are opened

	<ul style="list-style-type: none"> • Provide a distraction: <ul style="list-style-type: none"> ○ 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
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Send literature: <ul style="list-style-type: none"> ○ Caregiver Tip Sheet – "Getting Lost" (English and Spanish)
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> ○ Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

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.

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

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 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 out

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

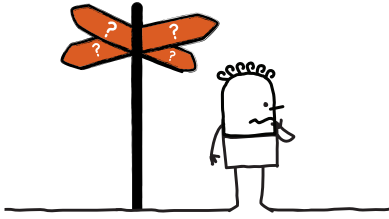
- offer food or do something that will take his or her mind off wanting to leave
- ask for help... folding clothes, making dinner, etc.
- sit quietly with him or her... listen to music or watch a TV show



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Perderse



¿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 – sentirse inseguros al no reconocer donde están
- tratar de ir a trabajar o hacer algo que hacían antes
- estar tratando de escapar del ruido o de la actividad adonde están
- estar aburridos
- tener hambre, frío o necesidad de usar el baño

Algunas personas con Alzheimer o demencia se pueden perder al salir de casa. A veces se pueden perder, en un lugar público, o también puede que salgan a caminar o ir a la tienda y olvidar el camino de regreso a casa. Puede que tampoco recuerden su domicilio o número de teléfono.

El perderse es aterrador y puede ser muy peligroso.

¿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 sola 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

- ofrézcale algo de comer o hagan alguna actividad que le guste para distraerlo
- pídale que le ayude a doblar la ropa o a preparar la cena
- Síntese tranquilamente con la persona con Alzheimer a escuchar música suave o a ver la televisión



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Caregiver Depression/Stress

<p>Identify the Problem</p>	<p>PROBLEM: Caregiver Depression/Stress (feeling blue and/or overwhelmed)</p> <p>GOAL/EXPECTED OUTCOME: To reduce caregiver depression and stress</p>
<p>Explore</p>	<p>ASSESS FURTHER:</p> <ul style="list-style-type: none"> • Depression <ul style="list-style-type: none"> ○ What happens right before the caregiver feels depressed? ○ How does the caregiver know when he/she is depressed? What does it feel like physically and emotionally that lets him/her know? ○ How often does the caregiver feel depressed? How many times per day/week? ○ How does the caregiver act when he/she is feeling depressed? ○ Is there anything the caregiver does that helps to reduce feelings of depression? ○ Is there anyone the caregiver can talk to when he/she is feeling this way? • Stress <ul style="list-style-type: none"> ○ What happens right before the caregiver feels stressed? ○ How does the caregiver know when he/she is stressed? What does it feel like physically and emotionally that lets him/her know? ○ How often does the caregiver feel stressed? How many times per day/week? ○ How does the caregiver act when he/she is feeling stressed? ○ Is there anything the caregiver does that helps to reduce feelings of stress? ○ 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?
<p>Adjust</p> <p>Problem solve with interventions and actions</p>	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • 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 <i>able</i> 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 <i>you</i> enjoy. Consider physical activities when possible, such as taking a walk • Plan ahead for emergencies to reduce anxiety and stress

	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • 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
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to respite services • Refer to IHSS • Refer to Home and Community-Based Services Planning and Management (HCBS CPM) formerly MSSP • Refer to CBAS • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Local Community Resources: _____ _____ • Send literature: <ul style="list-style-type: none"> ○ Topic Sheet - "Caregiver Depression"
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>

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. Caregivers often place all 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?
- 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 group, or identify a trusted friend, family, or community member to talk to when you are feeling this way. You don't 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
Reviewed by Alzheimer's LA January 2016 | NIH July 2012

Difficulty Providing Care Because of Your Health

Identify the Problem	<p><u>PROBLEM:</u> Difficulty Providing Care Because of Your Health</p> <p><u>GOAL/EXPECTED OUTCOME:</u> To reduce problems related to functional limitations</p>
Explore	<p><u>ASSESS FURTHER:</u></p> <ul style="list-style-type: none"> • 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 <i>the caregiver</i> use assistive devices to help with getting around, such as a wheelchair, cane, or walker? • Does the <i>person with dementia</i> 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	<p><u>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</u></p> <ul style="list-style-type: none"> • 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 <p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • 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 <p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to IHSS • Refer to Home and Community-Based Services Planning and Management (HCBS CPM) formerly MSSP • Refer to CBAS • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation

	<ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org ● Local Community Resources: _____ _____ ● Send literature: <ul style="list-style-type: none"> ○ Topic Sheet – “Safe Body Mechanics” ○ Topic Sheet – “Caregiver Health”
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> ● Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>

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 eye level.
- 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.

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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.

FURTHER INFORMATION

Always consult your healthcare provider to ensure the information displayed on this page applies to your personal circumstances.

Alzheimer's Caregiving Tips

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 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.

(Continued on next page)

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 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
Reviewed by Alzheimer's LA January 2016 | NIH July 2012

Lacks Understanding of Dementia

Identify the Problem	<p><u>PROBLEM:</u> Lacks Understanding of Dementia</p> <p><u>GOAL/EXPECTED OUTCOME:</u> To increase understanding of the nature, symptoms, and course of dementia</p>
Explore	<p><u>ASSESS FURTHER:</u></p> <ul style="list-style-type: none"> • 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	<p><u>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</u></p> <ul style="list-style-type: none"> • Learn effective communication strategies • Learn how to use the <i>IDEA!</i> strategy to manage challenging behaviors • Learn about potential safety concerns <p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • Refer to PCP, nurse and/or social worker for disease education: <ul style="list-style-type: none"> ○ Nature of disease ○ Symptoms, course of disease, and changes that may occur ○ What to expect in terms of treatment and recommendations ○ Care recommendations <p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to Alzheimer’s Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Local Community Resources: _____ • Send literature: <ul style="list-style-type: none"> ○ Topic Sheet – “What is Alzheimer’s Disease?” <p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <p>_____</p> <p>_____</p> <p>_____</p>

Alzheimer's Caregiving Tips

WHAT IS ALZHEIMER'S?

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 & SYMPTOMS

MILD ALZHEIMER'S

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

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, paranoia, and may behave impulsively.

SEVERE ALZHEIMER'S

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.

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Alzheimer's
LOS ANGELES

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AlzheimersLA.org

DIAGNOSIS OF ALZHEIMER'S

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.
- Carry out standard medical tests, such as blood and urine tests, to identify other possible causes of the problem.
- Help Conduct tests of memory, problem solving, attention, counting, and language.
- 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

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
Reviewed by Alzheimer's LA January 2016 | NIH July 2012

Legal and Financial Planning

Identify the Problem	<p>PROBLEM: Legal and Financial Planning (paying the bills, power of attorney, etc.)</p> <p>GOAL/EXPECTED OUTCOME: To facilitate legal and financial planning</p>
Explore	<p>ASSESS FURTHER:</p> <ul style="list-style-type: none"> • 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	<p>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</p> <ul style="list-style-type: none"> • Discuss with family importance of getting legal/financials affairs in order • Have all necessary documents completed, notarized, and filed in an appropriate place
	<p>CLINICAL SUPPORT:</p> <ul style="list-style-type: none"> • 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
	<p>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</p> <ul style="list-style-type: none"> • Listen empathically to caregiver and evaluate for level of distress • Refer to low/no cost legal services • Refer to Alzheimer's Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Local Community Resources: _____ • Send literature: <ul style="list-style-type: none"> ○ Topic Sheet – "Legal and Financial Planning"
	<p>FOLLOW UP:</p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p>NOTES:</p> <hr/> <hr/> <hr/> <hr/>

Legal and Financial Planning

Many people are unprepared to deal with the legal and financial consequences of a serious illness such as Alzheimer's disease. Legal and medical experts encourage people recently diagnosed with a serious illness—particularly one that is expected to cause declining mental and physical health—to examine and update their financial and health care arrangements as soon as possible. Basic legal and financial instruments, such as a will, a living trust, and advance directives, are available to ensure that the person's late-stage or end-of-life health care and financial decisions are carried out.

A complication of diseases such as Alzheimer's is that the person may lack or gradually lose the ability to think clearly. This change affects his or her ability to participate meaningfully in decision making and makes early legal and financial planning even more important. Although difficult questions often arise, advance planning can help people with Alzheimer's and their families clarify their wishes and make well-informed decisions about health care and financial arrangements.

When possible, advance planning should take place soon after a diagnosis of early-stage Alzheimer's while the person can participate in discussions. People with early-stage

disease are often capable of understanding many aspects and consequences of legal decision making. However, legal and medical experts say that many forms of planning can help the person and his or her family even if the person is diagnosed with later-stage Alzheimer's.

There are good reasons to retain the services of a lawyer when preparing advance planning documents. For example, a lawyer can help interpret different State laws and suggest ways to ensure that the person's and family's wishes are carried out. It's important to understand that laws vary by state, and changes in situation—for instance, a divorce, relocation, or death in the family—can influence how documents are prepared and maintained.

LEGAL, FINANCIAL, AND HEALTH CARE PLANNING DOCUMENTS

When families begin the legal planning process, there are a number of strategies and legal documents they need to discuss.

Depending on the family situation and the applicable State laws,



some or all of the following terms and documents may be introduced by the lawyer hired to assist in this process. Broadly speaking, these documents can be divided into two groups:

- documents that communicate the health care wishes of someone who may no longer be able to make health care decisions
- documents that communicate the financial management and estate plan wishes of someone who may no longer be able to make financial decisions

ADVANCE DIRECTIVES OF HEALTH CARE

Advance directives for health care are documents that communicate the health care wishes of a person with Alzheimer's disease. These decisions are then carried out after the person no longer can make decisions. In most cases, these documents must be prepared while the person is legally able to execute them.

A **Living Will** records a person's wishes for medical treatment near the end of life. It may do the following:

- specify the extent of life-sustaining treatment and major health care the person wants
- help a terminal patient die with dignity

- protect the physician or hospital from liability for carrying out the patient's instructions
- specify how much discretion the person gives to his or her proxy (discussed below) about end-of-life decisions

A **Durable Power of Attorney for Health Care** designates a person, sometimes called an agent or proxy, to make health care decisions when the person with

Alzheimer's disease no longer can do so. Depending on State laws and the person's preferences, the proxy might be authorized to:

- refuse or agree to treatments
- change health care providers
- remove the person from an institution
- decide about making organ donations
- trusts to manage the estate
- funeral and/or burial arrangements
- decide about starting or continuing life support (if not specified in a living will)
- decide whether the person with Alzheimer's will end life at home or in a facility
- have access to medical records

A **Do Not Resuscitate (DNR) Order** instructs health care professionals not to perform cardiopulmonary resuscitation if a person's heart stops or if he or she stops breathing. A DNR order is signed by a doctor and put in

a person's medical chart.

Access to private medical information is closely regulated. The person with Alzheimer's disease must state in writing who can see or use personal medical records.

ADVANCE DIRECTIVES FOR FINANCIAL AND ESTATE MANAGEMENT

Advance directives for financial and estate management must be created while the person with Alzheimer's still can make these decisions (sometimes referred to as "having legal capacity" to make decisions).

These directives may include some or all of the following:

A **Will** indicates how a person's assets and estate will be distributed upon death. It also can specify:

- Arrangements for care of minors
- Gifts
- Trusts to manage the estate
- Funeral and/or burial arrangements

Medical and legal experts say that the newly diagnosed person with Alzheimer's and his or her family should move quickly to make or

update a will and secure the estate.

A **Durable Power of Attorney for Finances** names someone to make financial decisions when the person with Alzheimer's disease can no longer do so. It can help people with the disease and their families avoid court actions that may take away control of financial affairs.

A **Living Trust** provides instructions about the person's estate and appoints someone, called the trustee, to hold title to property and funds for the beneficiaries. The trustee follows these instructions after the person no longer can manage his or her affairs.

The person with Alzheimer's disease also can name the trustee as the health care proxy through the durable power of attorney for health care.

A living trust can:

Include a wide range of property

- Provide a detailed plan for property disposition
- Avoid the expense and delay of probate (in which the courts establish the validity of a will)
- State how property should be distributed when the last beneficiary dies and whether the trust should continue to benefit others



WHO CAN HELP?

Health Care Providers—Health care providers cannot act as legal or financial advisors, but they can encourage planning discussions between patients and their families. Qualified clinicians can also guide patients, families, the care team, attorneys, and judges regarding the patient's ability to make decisions.

Elder Law Attorneys (ELAs)—An ELA helps older people and families:

- Interpret state laws
- Plan out how their wishes will be carried out
- Understand their financial options
- Learn how to preserve financial assets while caring for a loved one

Geriatric Care Managers (GCMs)—GCMs are trained social workers or nurses who can help people with Alzheimer's disease and their families:

Learn how to preserve financial assets while caring for a loved one

- discuss difficult topics and complex issues
- address emotional concerns
- make short- and long-term plans
- evaluate in-home care needs
- select care personnel
- coordinate medical services
- evaluate other living arrangements
- provide caregivers stress relief

OTHER ADVANCE PLANNING ADVICE

Start discussions early. The rate of decline differs for each person with Alzheimer's disease, and his or her ability to be involved in planning will decline over time. People in the early stages of the disease may be able to understand the issues, but they may also be defensive or emotionally unable to deal with difficult questions.

Review plans over time. Changes in personal situations—such as a divorce, relocation, or death in the family—and in state laws can affect how legal documents are prepared and maintained. Review plans regularly, and update documents as needed.

Reduce anxiety about funeral and burial arrangements. Advance planning for the funeral and burial can provide a sense of peace and reduce anxiety for both the person with Alzheimer's and the family.

Steps for Getting Your Affairs in Order

- **Gather everything you can about your income, property, investments, insurance, and savings.**
- **Put copies of legal documents and other important papers in one place.** You could set up a file, put everything in a desk or dresser drawer, or just list the information and location of papers in a notebook. If your papers are in a bank safe deposit box, keep copies in a file at home. Check regularly to see if there's anything new to add.
- **Tell a trusted family member or friend where you put your important papers.** You don't need to tell this friend or family member your personal business, but someone should know where you keep your papers in case of emergency. If you don't have a relative or friend you trust, ask a lawyer to help.

bar association, local non-profit agencies, foundations, and social service agencies.

SUMMARY

Facing Alzheimer's disease can be emotionally wrenching for all concerned. A legal expert and members of the health care team can help the person and family address end-of-life issues. Advance health care and financial planning can help people diagnosed with Alzheimer's and their families confront tough questions about future treatments, caregiving, and legal arrangements.

RESOURCES FOR LOW-INCOME FAMILIES

Families who cannot afford a lawyer still can do advance planning. Samples of basic health planning documents can be downloaded from state government websites. Area Agency on Aging officials may provide legal advice or help. Other possible sources of legal assistance and referral include state legal aid offices, the state



Overview of Medical, Legal, and Financial Planning Documents	
Medical Document	How It Is Used
Living Will	Describes and instructs how the person wants end-of-life health care managed
Durable Power of Attorney for Health Care	Gives a designated person the authority to make health care decisions on behalf of the person with Alzheimer's
Do Not Resuscitate Form	Instructs health care professionals not to perform CPR in case of stopped heart or stopped breathing
Legal/Financial Document	How It Is Used
Will	Indicates how a person's assets and estate will be distributed among beneficiaries after his/her death
Durable Power of Attorney for Finances	Gives a designated person the authority to make legal/financial decisions on behalf of the person with
Living Trust	Gives a designated person (trustee) the authority to hold and distribute property and funds for the person with

Information adapted from the National Institute on Aging, part of the National Institutes of Health www.nia.nih.gov
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For More Information

Alzheimer's Disease Education and Referral (ADEAR) Center

P.O. Box 8250
Silver Spring, MD 20907-8250

1-800-438-4380 (toll-free)
www.nia.nih.gov/alzheimers

The National Institute on Aging's ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to Alzheimer's disease. Staff members answer telephone, email, and written requests and make referrals to local and national resources. Visit the ADEAR website to learn more about Alzheimer's and other dementias, find clinical trials, and sign up for email updates.

Eldercare Locator

1-800-677-1116 (toll-free)
www.eldercare.gov

Families often need information about community resources, such as home care, adult day care, and nursing homes. Contact the Eldercare Locator to find these resources in your area. The Eldercare Locator is a service of the Administration on Aging.

National Institute on Aging Information Center

P.O. Box 8057
Gaithersburg, MD 20898-8057
1-800-222-2225 (toll-free)
1-800-222-4225 (TTY/toll-free)
www.nia.nih.gov/health
www.nia.nih.gov/espanol

This service of the NIA offers many helpful publications, including:

- *AgePage: Getting Your Affairs in Order*
- *Advance Care Planning: Tips from the National Institute on Aging*
- *End of Life: Helping with Comfort and Care*
- *So Far Away: Twenty Questions and Answers About Long-Distance Caregiving*

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844.HELP.ALZ
AlzheimersLA.org

**National Library of Medicine
MedlinePlus**

www.medlineplus.gov

Search for:
"Advance Directives" "End-of-Life Issues"

NIHSeniorHealth

www.nihseniorhealth.gov

This senior-friendly website from the National Institute on Aging and the National Library of Medicine has health and wellness information for older adults. Special features make it simple to use. For example, you can click on a button to make the type larger.

Other Organizations

AARP

601 E St., NW Washington, DC 20049
1-888-OUR-AARP (1-888-687-2277; toll-free)
www.aarp.org

Aging with Dignity

P.O. Box 1661
Tallahassee, FL 32302-1661
1-888-5WISHES (1-888-594-7437; toll-free)
www.agingwithdignity.org

American Bar Association

Commission on Law and Aging
1050 Connecticut Avenue, NW
Suite 400
Washington, DC 20036
1-202-662-8690
www.americanbar.org/aging

Family Caregiver Alliance

785 Market Street
Suite 750
San Francisco, CA 94103
1-800-445-8106 (toll-free)
www.caregiver.org

National Academy of Elder Law Attorneys

1577 Spring Hill Road Suite 220
Vienna, VA 22182
1-703-942-5711
www.naela.org

Aging Life Care Association

3275 West Ina Road Suite 130
Tucson, AZ 85741
1-520-881-8008
www.aginglifecare.org

National Hospice and Palliative Care Organization

1731 King Street
Alexandria, VA 22314
1-800-658-8898 (toll-free)
1-877-658-8896 (Spanish/toll-free)
www.caringinfo.org

Long-Term Care Planning

<p><u>I</u>dentify the Problem</p>	<p><u>PROBLEM:</u> Long-Term Care Planning</p> <p><u>GOAL/EXPECTED OUTCOME:</u> To facilitate long-term care planning</p>
<p><u>E</u>xplore</p>	<p><u>ASSESS FURTHER:</u></p> <ul style="list-style-type: none"> • 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? <ul style="list-style-type: none"> ○ Financial needs? ○ Legal needs? ○ Durable Power of Attorney for Finances? ○ Durable Power of Attorney for Healthcare? ○ Residential options (possible changes in residence?) ○ Finding other available caregivers? ○ End of life decisions? • Staying at home <ul style="list-style-type: none"> ○ Will the person be safe to remain at home with 24/7 in-home assistance? ○ Are there resources available to maintain living at home? (i.e., financial resources, caregiving resources, family support) ○ Does the person have adequate hours of in-home supportive services to assist with: <ul style="list-style-type: none"> ▪ Medication management? ▪ Overnight/daytime supervision? ▪ Medical care? ▪ ADL assistance? ▪ IADL assistance? ○ Is there someone available to live with the person long-term and provide needed care for the needed hours? ○ Does that caregiver understand symptoms and safety concerns of caring for a person with dementia? • Long-term care out of the home <ul style="list-style-type: none"> ○ Is there any opposition to long-term care facility placement as needed? ○ Does the caregiver know about residential care facility options? (Suggest visiting a variety of facilities before a crisis arises). Consider: <ul style="list-style-type: none"> ▪ 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?

<p><u>Adjust</u></p> <p>Problem solve with interventions and actions</p>	<p><u>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</u></p> <ul style="list-style-type: none"> • 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
	<p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • Refer to PCP to discuss and assess medications, medical care needs, and required levels of care (ongoing assessment)
	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • 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 Home and Community-Based Services Planning and Management (HCBS CPM) formerly MSSP • Refer to Alzheimer’s Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Local Community Resources: _____ _____ • Send literature: <ul style="list-style-type: none"> ○ Topic Sheet – “A Guide to Different Levels of Care”
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>

Alzheimer's Caregiving Tips

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 and offer a wide range of options, all the way from independent living to special care. Residents are usually admitted when they live independently. As 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, 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 & 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 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.

Information adapted from the National Institute on Aging, part of the National Institutes of Health www.nia.nih.gov
Reviewed by Alzheimer's LA January 2016 | NIH July 2012

End-of-Life Planning

<p><u>Identify the Problem</u></p>	<p><u>PROBLEM:</u> End-of-Life Planning</p> <p><u>GOAL/EXPECTED OUTCOME:</u> To increase understanding of preserving dignity at the end-of-life</p>
<p><u>Explore</u></p>	<p><u>ASSESS FURTHER:</u></p> <ul style="list-style-type: none"> • 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 <i>person's</i> understanding of hospice care? How does the person feel about hospice? • What is the caregiver's understanding about the <i>person's</i> wants and needs for end-of-life care? Did the person ever discuss this with the caregiver? • What are the <i>caregiver's</i> 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?
<p><u>Adjust</u></p> <p>Problem solve with interventions and actions</p>	<p><u>TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:</u></p> <ul style="list-style-type: none"> • 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 <hr/> <p><u>CLINICAL SUPPORT:</u></p> <ul style="list-style-type: none"> • 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

	<p><u>CAREGIVER SUPPORT AND COMMUNITY RESOURCES:</u></p> <ul style="list-style-type: none"> • 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 Los Angeles for support groups, disease education, and care consultation <ul style="list-style-type: none"> ○ ALZ Direct Connect® referral ○ Provide Helpline #: 844.HELP.ALZ 844.435.7259 ○ Website: www.alzheimersla.org • Local Community Resources: _____ <hr/> <ul style="list-style-type: none"> • Send literature/refer to website: <ul style="list-style-type: none"> ○ 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)
	<p><u>FOLLOW UP:</u></p> <ul style="list-style-type: none"> • Schedule a phone call with caregiver to discuss outcomes and provide additional support
	<p><u>NOTES:</u></p> <hr/> <hr/> <hr/> <hr/>



EMSA #111 B
(Effective 4/1/2017)*

Physician Orders for Life-Sustaining Treatment (POLST)

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): <i>If patient has no pulse and is not breathing.</i> <i>If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.</i>
	<input type="checkbox"/> Attempt Resuscitation/CPR (Selecting CPR in Section A requires selecting Full Treatment in Section B) <input type="checkbox"/> Do Not Attempt Resuscitation/DNR (Allow <u>N</u> atural <u>D</u> eath)

B Check One	MEDICAL INTERVENTIONS: <i>If patient is found with a pulse and/or is breathing.</i>
	<input type="checkbox"/> Full Treatment – 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. <input type="checkbox"/> <i>Trial Period of Full Treatment.</i> <input type="checkbox"/> Selective Treatment – 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. <input type="checkbox"/> <i>Request transfer to hospital <u>only</u> if comfort needs cannot be met in current location.</i> <input type="checkbox"/> Comfort-Focused Treatment – 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: <i>Offer food by mouth if feasible and desired.</i>
	<input type="checkbox"/> Long-term artificial nutrition, including feeding tubes. Additional Orders: _____ <input type="checkbox"/> Trial period of artificial nutrition, including feeding tubes. _____ <input type="checkbox"/> No artificial means of nutrition, including feeding tubes. _____

D	INFORMATION AND SIGNATURES:
	Discussed with: <input type="checkbox"/> Patient (Patient Has Capacity) <input type="checkbox"/> Legally Recognized Decisionmaker
	<input type="checkbox"/> Advance Directive dated _____, available and reviewed → Health Care Agent if named in Advance Directive: <input type="checkbox"/> Advance Directive not available Name: _____ <input type="checkbox"/> No Advance Directive 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: _____
	Mailing Address (street/city/state/zip): _____ Phone Number: _____

Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011, 10/1/2014 or 01/01/2016 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
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NP/PA's Supervising Physician

Name:	Preparer Name (if other than signing Physician/NP/PA) Name/Title:	Phone #:
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Additional Contact

 None

Name:	Relationship to Patient:	Phone #:
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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



EMSA #111 B
 (En vigor a partir del 1/1/2016)*

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

Primero siga estas órdenes. Luego comuníquese con el médico/NP/PA. Una copia firmada de las POLST es una orden médica legalmente válida. Cualquier sección que no esté llenada implica tratamiento completo para esa sección. **Las POLST son un complemento a una directiva anticipada y no tienen el objetivo de reemplazar ese documento.**

Apellido del paciente:	Fecha de preparación del formulario:
Nombre del paciente:	Fecha de nacimiento del paciente:
Segundo nombre del paciente:	Nº de registro médico: <i>(opcional)</i>

A Resucitación cardiopulmonar (RCP): *Si el paciente no tiene pulso y no está respirando. Si el paciente NO está sufriendo un paro cardiopulmonar, seguir las órdenes en las secciones B y C.*

Marque uno

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 Intervenciones médicas: *Si el paciente se encuentra con pulso y/o está respirando.*

Marque uno

Tratamiento completo – el objetivo primario es prolongar la vida por cualquier medida que sea eficaz desde el punto de vista médico.
 Además del tratamiento descrito en Tratamiento selectivo y Tratamiento enfocado en la comodidad, usar entubación, intervenciones avanzadas en las vías respiratorias, ventilación mecánica y cardioversión según sea indicado.

Tratamiento completo durante un período de prueba.

Tratamiento selectivo – el objetivo es tratar los problemas médicos y evitar las medidas onerosas.
 Además del tratamiento descrito en Tratamiento enfocado en la comodidad, usar tratamiento médico, antibióticos intravenosos y fluidos intravenosos según sea indicado. No entubar. Se puede usar presión positiva no invasora en las vías respiratorias. Evitar en general los cuidados intensivos.

Solicitar el traslado al hospital solo si no se pueden suplir las necesidades de comodidad en la ubicación actual.

Tratamiento enfocado en la comodidad – el objetivo primario es maximizar la comodidad.
 Aliviar el dolor y el sufrimiento con medicación por cualquier medio necesario; usar oxígeno, succión y tratamiento manual de la obstrucción de las vías respiratorias. No usar los tratamientos indicados en Tratamiento completo y Tratamiento selectivo a menos que sean consecuentes con el objetivo de comodidad. **Solicitar el traslado al hospital solo si no se pueden suplir las necesidades de comodidad en la ubicación actual.**

Órdenes adicionales: _____

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

Marque uno

Administrar nutrición artificial a largo plazo, incluyendo la alimentación por tubo. Órdenes adicionales: _____

Período de prueba de nutrición artificial, incluyendo la alimentación por tubo. _____

No administrar nutrición por medios artificiales, incluyendo la alimentación por tubo. _____

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 → Agente para la atención de la salud, si fue nombrado en la directiva anticipada:

Directiva anticipada no está disponible Nombre: _____

No hay una directiva anticipada Teléfono: _____

Firma del médico / Enfermera con práctica médica (NP) / Asistente médico profesional (PA) (Médico/NP/PA)

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

Nombre del médico/NP/PA en letra de molde:	N.º de teléfono del médico/NP/PA:	N.º de licencia del médico/PA, N.º de Certificado de la NP:
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Firma del médico/NP/PA: <i>(requerida)</i> XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX	Fecha:
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Firma del paciente o encargado de tomar decisiones reconocido legalmente

Sé que este formulario es voluntario. 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 del individuo que es objeto del formulario.

Nombre en letra de molde: Firma: <i>(requerida)</i> XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX	Relación: <i>(escribir Si mismo si es el paciente)</i>
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Firma: <i>(requerida)</i> XXXXXXXXXXXXXXXXXXXXXXXX	Fecha:	FOR REGISTRY USE ONLY/ PARA USO EXCLUSIVO DEL REGISTRO
Dirección postal (calle/ciudad/estado/código postal):	Número de teléfono:	

Enviar el formulario con el paciente cuando sea trasladado o dado de alta

*Las versiones de los formularios con fechas de vigencia el 1/1/2009, 4/1/2011 o 10/1/2014 también son válidas.

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**

Médico supervisor del NP/PA

Nombre de la persona que preparó el formulario (si no es el médico/NP/PA que firma)

Nombre: _____ Nombre/Cargo: _____ Número de teléfono: _____

Contacto adicional

Ninguno

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 el entorno hospitalario, un paciente será evaluado por un médico, o una enfermera con práctica médica (NP) o un asistente médico profesional (PA) actuando bajo la supervisión del médico, quien emitirá órdenes adecuadas congruentes con las preferencias del paciente.
- **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 de la persona 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.
- Un encargado de tomar decisiones reconocido legalmente puede ejecutar el formulario de las POLST solo si el paciente no tiene la capacidad o ha designado que la autoridad del encargado de tomar decisiones cobre vigencia inmediatamente.
- Para ser un formulario de POLST válido, tiene que ser firmado por (1) un médico, o enfermera con práctica médica o asistente médico profesional actuando bajo la supervisión de un médico, y ejerciendo funciones según lo autorizado por ley y (2) el paciente o la persona que toma decisiones en nombre del paciente. Las órdenes verbales son aceptables con una firma posterior del médico/NP/PA de conformidad con las normas de la instalación/comunidad.
- 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 un paciente que seleccionó "No intentar resucitación".

Sección B:

- Cuando no se puede lograr la comodidad del paciente en el lugar actual, se debe trasladar al paciente, incluso si desea "tratamiento enfocado en la comodidad", a un lugar que se le puedan proporcionar comodidad (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 "Tratamiento enfocado en la comodidad".
- El tratamiento de la deshidratación prolonga la vida. Si un paciente desea fluidos intravenosos, indique "Tratamiento selectivo" 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 al paciente de un lugar de atención o nivel de atención a otro o
- hay un cambio sustancial en el estado de salud del paciente o
- cambian las preferencias de tratamiento del paciente.

Cómo modificar y anular las POLST

- Un paciente con la capacidad para hacerlo puede solicitar que se anulen las POLST en cualquier momento, por cualquier medio que indique su intención de anularlas. Se recomienda que la anulación se registre tachando las secciones A a D con una línea, escribiendo "VOID" (nulo) en letra grande, firmando y escribiendo la fecha en esta línea.
- Una persona designada legalmente para tomar decisiones en nombre del paciente puede solicitar una modificación de las órdenes, en colaboración con el médico/NP/PA, según los deseos conocidos del paciente, o si no se conocen, el mejor interés del paciente.

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 el paciente cuando sea trasladado o dado de alta



Alzheimer's Los Angeles is the leading community-based health organization providing programs that address the needs of people living with Alzheimer's and other dementias and their family caregivers, in the three-county region of Los Angeles, Riverside, and San Bernardino.

Serving as the local voice for people with cognitive impairment and their families, Alzheimer's Los Angeles's core programs are:

HELPLINE

Our Helpline 844.HELP.ALZ (844.435.7259) offers information, emotional support, and referrals for people with memory loss, caregivers, professionals, and general community members. Available in 190 languages.

CARE COUNSELING

Confidential Care Counseling and support helps families and caregivers of those with Alzheimer's disease with care planning, education, coping techniques, respite and emergency assistance for low income caregivers. Individual and ongoing sessions are available in person or by telephone, in English and Spanish.

SUPPORT GROUPS

Support groups are open gatherings for people to come together and share their experiences to better cope with and manage the challenges of dementia in a safe environment. They are held at various times and locations, and in multiple languages.

EARLY STAGE PROGRAMS

Information, education, family consultation, and support groups are available for those with memory concerns or who have been diagnosed in the early stages of the disease and their care partners¹.

MEMORIES IN THE MAKING

A unique fine arts program that offers a creative and non-verbal way of communicating and capturing precious moments through art. Small group classes are held throughout the community at various sites and in different settings.

MEMORY MORNINGS ACTIVITY PROGRAM

Every Friday morning, people living in the mid-stages of Alzheimer's disease or other dementias and their family caregivers enjoy two hours of fun; cognitively stimulating activities that include, music, art, gardening, entertainers, field trips and more!

MedicAlert® FOUND CALIFORNIA

MedicAlert® Found California is a 24-hour, nationwide emergency response service for individuals with Alzheimer's disease or other dementias who may wander and get lost or have a medical emergency. An identification bracelet provides emergency medical information and assists in the event of a wandering incident.

COMMUNITY EDUCATION & OUTREACH

Education is offered throughout the Southland region on a variety of topics and are available in multiple languages. Educational classes for caregivers include *Savvy Caregiver*, a free six-week course that provides family caregivers with basic knowledge, skills, and attitudes to provide care to a family member who has memory loss, and *Savvy Express*, a three-session version of *Savvy Caregiver*. Outreach allows us to raise awareness through participation in health fairs and other community events.

PROFESSIONAL TRAINING

On-site and web-based trainings are offered to social workers, case managers, physicians, nurses and other professionals. Trainings can be customized to meet the specific needs of the training participants.

¹ Our Memory Club® families have requested that the term 'care partner' be substituted for caregiver



ALZ DIRECT CONNECT[®]

REFERRAL PROGRAM

Partnering with healthcare and aging service providers to improve care and support for people with Alzheimer's or dementias & their families

ALZ DIRECT CONNECT[®] allows healthcare and aging services providers to directly link patients/clients and families to Alzheimer's Los Angeles for:

- access to care coordination & psychosocial support
- referrals to supportive services
- help with understanding the disease & navigating its progression
- a 360° approach to care through feedback to the referring provider



844.HELP.ALZ • AlzheimersLA.org

ALZ DIRECT CONNECT[®] does not fulfill mandatory legal reporting requirements for healthcare professionals. Alzheimer's Los Angeles maintains high professional & ethical standards for care & safety and therefore reports any and all allegations or suspicions of elder abuse and/or child abuse.

See reverse side for ALZ Direct Connect[®] Referral Form 

ALZ DIRECT CONNECT® REFERRAL FORM



Fax or email this form to Alzheimer's Los Angeles

Fax # 323.686.5106

Email alzdirectconnect@alzla.org

Date _____

Check if primary contact

PATIENT/CLIENT NAME

Address _____

City _____ Zip _____

Phone# _____

Email _____

Primary Language: English Spanish Other (specify)

Is the patient/client on Medi-Cal AND Medicare?

Yes No

Check if primary contact

FAMILY CAREGIVER NAME (if available)

Address _____

City _____ Zip _____

Phone# _____

Email _____

Relationship to Patient/Client:

Spouse/Partner Child Professional Caregiver

Other (specify) _____

Primary Language: English Spanish

Other (specify) _____

I give permission to the referring provider to forward my contact and patient information to Alzheimer's Los Angeles. I understand that a representative will contact me and/or my caregiver about support, programs, and other services and will follow up with the referring provider. **Referrals will be entered into our secure database, unless indicated otherwise by checking this box** .

Signature _____

Date _____

(Patient/Client or Personal Representative/Family Caregiver)

The person being referred provided verbal consent instead of signature Yes

REASON FOR REFERRAL (check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Social Work Consultation & Support | <input type="checkbox"/> Research & Clinical Trials Information |
| <input type="checkbox"/> Early Stage Services | <input type="checkbox"/> Legal & Financial Considerations |
| <input type="checkbox"/> Support Groups | <input type="checkbox"/> Healthcare Directives |
| <input type="checkbox"/> Activity Programs | <input type="checkbox"/> Respite Services |
| <input type="checkbox"/> Safety Issues | <input type="checkbox"/> Caregiver Education |
| <input type="checkbox"/> Home Safety | <input type="checkbox"/> Other (specify) _____ |
| <input type="checkbox"/> Driving | |
| <input type="checkbox"/> Wandering (MedicAlert®) | |

Additional Information: _____

REQUIRED INFORMATION

Referring Provider Name _____ Title _____

Provider Organization _____

Phone # _____ Fax # _____ Email _____

How would you prefer to receive follow-up? Fax Email Follow-up unnecessary