

APPLYING *IDEA!* TO WANDERING



Identify the behavior

- What was the challenging behavior?

Educate yourself

- What were the causes/triggers?

- What did this mean to the father?

Adapt

- What adaptations match the causes/triggers and/or meaning?

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 the past 4 weeks, 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 the past 4 weeks, 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 the past 4 weeks, 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 Greater Los Angeles and refer to **CAREGIVER DEPRESSION/STRESS CARE PLAN.***

*If score is > 10 for Health Strain, then refer to **CAREGIVER DEPRESSION/STRESS CARE PLAN AND FUNCTIONAL/HEALTH LIMITATIONS OF CAREGIVER CARE PLAN.***

MYTH vs. FACT

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

MEMBER OR FAMILY SAYS... 	MYTH	FACT	DEMENTIA CARE SPECIALIST EXPLANATION 
Everyone with Alzheimer's has dementia.			
My husband makes racist comments; this must be how he always felt about other races.			
To meet criteria for major neurocognitive disorder, a person's cognitive deficits must interfere with everyday activities.			
Alzheimer's disease only affects memory.			
My wife has vascular dementia. There is nothing we can do about it.			
Some dementias can be reversible.			

TOOL FOR IDENTIFYING AN INFORMAL OR FAMILY CAREGIVER

"I am going to ask you some questions to help me get a better idea of who assists with [MEMBER]. I would like to know if there is a partner, family member, friend or neighbor* who helps out. In some families, there is one person who helps with care, and in other families, there are many people."

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

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

(1) Identify the authorized representative:

Name: _____ Relationship: _____

Contact Information: _____

(2) Does someone live with the member? _____

If so, name and relationship: _____

(3) If the member lives alone, how often does someone visit the home [if at all]? _____

Who is most likely to visit the member? Name and relationship: _____

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

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

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

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

Name: _____

Relationship to member: _____

Contact information: _____

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

UNDERSTAND THE MEANING: REFUSAL TO BATHE VIDEO



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

What does bathing *mean* to the mother?

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

Adaptation used by daughter	How adaptation addresses meaning
Daughter asks mom to help undress	
Daughter asks mom to test the water temperature	
Daughter asks mom to “wash down there” by herself	

USING A CAREGIVER ASSESSMENT: MARINA AND MARCO



Marina and Marco have been married for 53 years. Marco has mid to late stage Alzheimer's disease and Marina takes care of him. Marco needs assistance with toileting, dressing, and taking medications. Marco often resists bathing and taking his medications; he sometimes

gets combative with Marina and this really upsets her.

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

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

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

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

There's more...turn over 

What are the major needs you identified?

What needs are priorities? Why?

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

USING A COGNITIVE SCREENING TOOL



María Teresa is a high risk member. She is 78 years old and has diabetes and high blood pressure. You work with María Teresa telephonically. She has alluded to cognitive decline, problems with disease self-management, and remembering things. When speaking to María Teresa you have noticed forgetfulness.

What screening tool might you consider using? Why?

You ask María Teresa if she lives with anyone. She tells you that she lives with her daughter and gives you permission to speak to her.

You conduct the AD8 with María Teresa's daughter.

Here are the AD8 results:

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	5		

Adapted from Galvin JE et al. The AD6, a brief informant interview to detect dementia. *Neurology* 2005;65:559-564
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Based on María Teresa's results, what are the next steps?