

As Time Goes By

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CME BACKGROUND

Original material is selected for credit designation based on an assessment of the educational needs of CME participants, with the purpose of providing readers with a curriculum of CME activities on a variety of topics from volume to volume. This special series of case reports about dementia was deemed valuable for educational purposes by the Publisher, Editor in Chief, and CME Institute Staff. Activities are planned using a process that links identified needs with desired results.

To obtain credit, read the material and go to PRIMARYCARECOMPANION.COM to complete the Posttest and Evaluation online.

CME OBJECTIVE

After studying this case, you should be able to:

- Manage patients with memory impairment and behavioral problems due to dementia, including providing support for patients' caregivers

ACCREDITATION STATEMENT

The CME Institute of Physicians Postgraduate Press, Inc., is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

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DATE OF ORIGINAL RELEASE/REVIEW

This educational activity is eligible for *AMA PRA Category 1 Credit™* through April 30, 2016. The latest review of this material was April 2013.

FINANCIAL DISCLOSURE

All individuals in a position to influence the content of this activity were asked to complete a statement regarding all relevant personal financial relationships between themselves or their spouse/partner and any commercial interest. The CME Institute has resolved any conflicts of interest that were identified. In the past year, Larry Culpepper, MD, MPH, Editor in Chief, has been a consultant for AstraZeneca, Forest, Janssen, Lundbeck, Merck, Pfizer, and Takeda and has been a member of the speakers/advisory board for Merck. No member of the CME Institute staff reported any relevant personal financial relationships.

Faculty financial disclosure appears at the end of the article.

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Ms A presented to the Stead Family Memory Clinic at the Banner Alzheimer's Institute for a new patient evaluation with her husband, who provided the clinical history. Her husband is a reliable informant and presented a clear and detailed history. Ms A is an 80-year-old woman who was first noted to have deficits with short-term memory 3 years ago. At that time, a neurologist diagnosed her with mild cognitive impairment. Since then, her short-term memory has continued to gradually decrease, and she "constantly repeats the same questions."

Currently, Ms A "cannot recall things said 5 minutes ago." She misplaces dishes when emptying the dishwasher, is unable to track appointments even with a calendar, and can no longer follow a plot when watching television. Her husband took over managing the finances 2 years ago when she was struggling to balance their checking account. She drives a car rarely and only if her husband is with her. He reports that her driving is safe. Ms A is no longer able to shop alone, and her husband has gradually been doing more of the cooking. She is able to use a telephone but needs prompting for laundry and cleaning.

Ms A has had mild depressive features for much of her adult life, which is currently unchanged, but has developed occasional mild irritability specifically regarding taking medications. She has no psychotic features and is not socially inappropriate. Donepezil was initiated by Ms A's primary care physician 2 months ago. She had no obvious benefit or side effects with 5 mg daily, but after 4 weeks of an increase to 10 mg, she developed severe nausea and mild headaches, and the dose was reduced back to 5 mg. The nausea resolved with reduction of the dose, but headaches persist.

PAST MEDICAL HISTORY

Ms A has a history of atrial fibrillation and has a pacemaker. She is treated for hypertension and insomnia.

ALLERGIES

Ms A has no known drug allergies.

MEDICATIONS

Ms A's current medications are diltiazem, nebivolol, digoxin, hydrochlorothiazide, warfarin, trazodone 100 mg at bedtime, and donepezil 5 mg daily. Additionally, she takes zinc, fish oil, vitamin D, and vitamin C.

SOCIAL HISTORY

Ms A has 14 years of education and worked as a homemaker. She lives with her husband of 57 years. They have 2 children who live locally. There is no significant history of alcohol or tobacco use.

- To improve the quality of life of those with dementia and of their caregivers, clinicians need to treat the symptoms that can be managed, as well as comorbid depression and agitation, and provide caregivers with management strategies.
- Medication management of behavioral manifestations of dementia is often beneficial.
- Caregiver counseling and support is a vital part of treating behavioral manifestations of dementia.

FAMILY HISTORY

Ms A's father developed Alzheimer's disease in his 80s.

PHYSICAL EXAMINATION

Ms A's vital signs include blood pressure: 132/72 mm Hg, pulse: 80 bpm, height: 67 in, and weight: 151 lb. Her physical examination was unremarkable except for an irregular heart rhythm and bilateral cataracts.

NEUROLOGIC EXAMINATION

Ms A's neurologic examination was unremarkable except for broken smooth pursuits. Frontal release signs were not present.

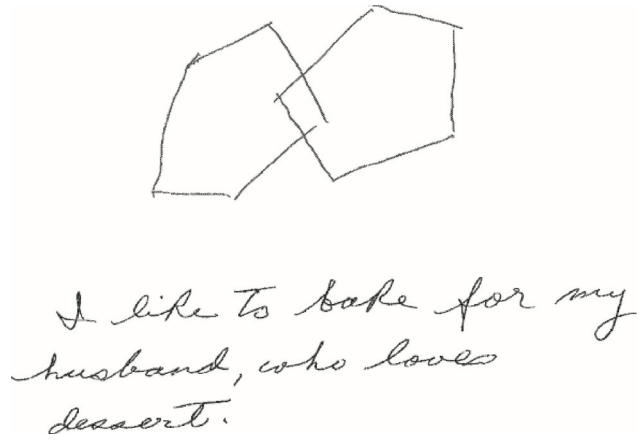
LABORATORIES/RADIOLOGY

Ms A had a recent head computed tomography (CT) that was unremarkable except for moderate atrophy. She also had a relatively recent complete blood count (CBC), comprehensive metabolic profile (CMP), and tests for vitamin B₁₂ and thyroid-stimulating hormone (TSH) levels, all of which were unremarkable.

Smooth pursuit can be tested by asking the patient to track a small moving target at a distance of about 1 m, while keeping his/her head stationary. Both horizontal and vertical smooth pursuit should be assessed. The target should be moved at a slow uniform speed, and the pursuit eye movements are observed to determine whether they are smooth, broken up by catch-up saccades, or a fast movement of the eye. Because smooth pursuit requires the coordination of many brain regions, this is a nonspecific finding, but could be indicative of cerebral degeneration. Sudo et al (2010) reported that impaired smooth pursuit can be indicative of impaired intellectual and frontal lobe function and can be regarded as a primitive reflex (frontal release sign).

Different dementias may be associated with various physical examination findings. However, most often, the physical examination is normal in the early stages. Some subtle general findings can include frontal release signs such as a positive snout, glabellar, or palmomental reflex (Links et al, 2010).

Figure 1. Ms A's Initial Pentagon Drawing and Sentence From the Mini-Mental State Examination



REFERENCES

- Links KA, Merims D, Binns MA, et al. Prevalence of primitive reflexes and Parkinsonian signs in dementia. *Can J Neurol Sci.* 2010;37(5):601–607.
- Sudo K, Mito Y, Tajima Y, et al. Smooth-pursuit eye movement: a convenient bedside indicator for evaluating frontal lobe and intellectual function. *In Vivo.* 2010;24(5):795–797.

Based on the information presented thus far, what would you expect the Mini-Mental State Examination (MMSE) score to be?

- A. 26–30
- B. 21–25
- C. 16–20
- D. 11–15
- E. < 11

A Mini-Mental State Examination score generally correlates with disease severity. Scores ≤ 9 points can indicate severe dementia, scores between 10–20 points can indicate moderate dementia, and scores > 20 points can indicate mild dementia (Mungas, 1991). Although MMSE scores must be interpreted in light of both the patient's age and education, education is the primary demographic factor that affects scores. Therefore, whereas a cutoff of ≤ 23 is widely used in distinguishing between normal and abnormal performance, this cutoff may have less predictive ability in poorly educated individuals (Folstein et al, 1975).

REFERENCES

- Folstein MF, Folstein SE, McHugh PR. "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res.* 1975;12(3):189–198.
- Mungas D. In-office mental status testing: a practical guide. *Geriatrics.* 1991;46(7):54–58, 63, 66.

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

Based on the information presented thus far, what would you expect the MMSE score to be?

A. 26–30	11%
B. 21–25	78%
C. 16–20	11%
D. 11–15	0%
E. < 11	0%

Most conference attendees predicted a mildly impaired MMSE score. Ms A scored 23 points on the MMSE; Figure 1 shows her pentagon drawing and sentence.

Based on the information presented thus far, what would you expect the Montreal Cognitive Assessment (MoCA) score to be?

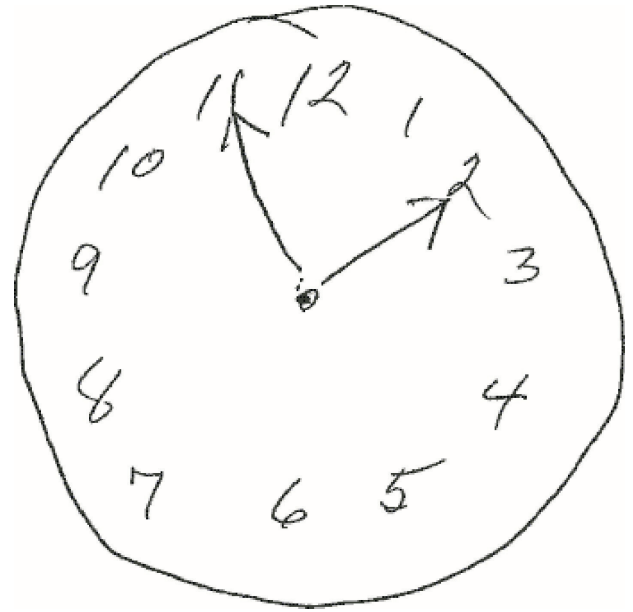
A. 26–30
B. 21–25
C. 16–20
D. 11–15
E. < 11

The Montreal Cognitive Assessment is a 30-point test that assesses several cognitive domains. Because it is more challenging than the Mini-Mental State Examination, it has greater sensitivity for mild cognitive impairment and early stages of dementia. With a cutoff score < 26, the sensitivity for detecting mild cognitive impairment (N = 94) was 90% and the specificity was 87% (Nasreddine et al, 2005). Research has demonstrated that MoCA scores are highly correlated with education. It is recommended that education be taken into account when interpreting MoCA performance, but there are no formal specific cutoff scores for lower education at this time (Johns et al, 2008). This test is available online at <http://mocatest.org/>.

REFERENCES

- Johns EK, Phillips NA, Chertkow H, et al. The Montreal Cognitive Assessment: normative data in the community. *J International Neuropsychological Society*. 2008;41(suppl 1):58.
- Johns EK, Phillips NA, Chertkow H, et al. The effect of education on performance on the Montreal Cognitive Assessment (MoCA): normative data from the community. *Canadian J Geriatrics*. 2008;11(1):62.
- Nasreddine ZS, Phillips NA, Bédirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc*. 2005;53(4):695–699.

Figure 2. Ms A's Initial Clock Drawing



Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

Based on the information presented thus far, what would you expect the MoCA score to be?

A. 26–30	0%
B. 21–25	33%
C. 16–20	67%
D. 11–15	0%
E. < 11	0%


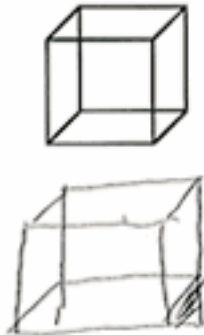
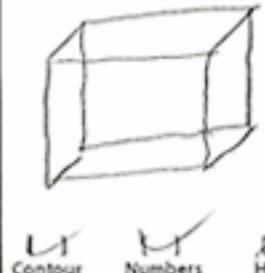
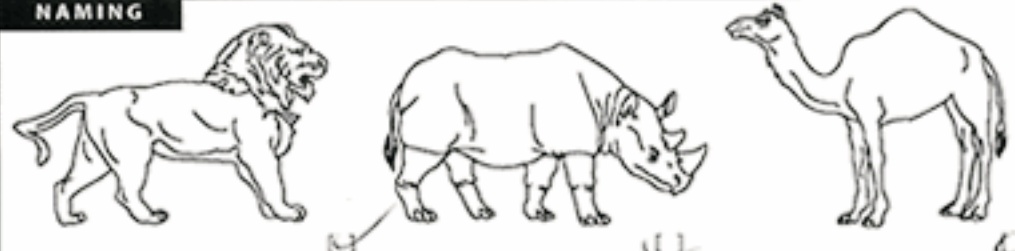
Figure 2 shows Ms A's clock drawing. She scored 18 points on the MoCA (Figure 3).

Based on the information presented thus far, do you believe that Ms A meets criteria for dementia?

- A. Yes
- B. No

The *DSM-IV* defines dementia as multiple cognitive deficits that include memory impairment and at least 1 of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning. The cognitive deficits must be sufficiently severe to cause impairment in social or occupational functioning and must represent a decline from a previously higher level of functioning. A diagnosis of dementia should not be made if the cognitive deficits occur exclusively during the course of a delirium (American Psychiatric Association, 2000).

Figure 3. Ms A's Initial Montreal Cognitive Assessment Results

VISUOSPATIAL / EXECUTIVE		POINTS	
		Copy cube	Draw CLOCK (Ten past eleven) (3 points)
		Contour Numbers Hands	3/5
NAMING			
			
MEMORY			
Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.		FACE	VELVET
1st trial		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
2nd trial		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
ATTENTION			
Read list of digits (1 digit/sec). Subject has to repeat them in the forward order		M 2 1 8 5 4	
Subject has to repeat them in the backward order		J 7 4 2	
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors		[] FBACMNAAJXLBAFAKDEAAAJAMOF AAB	
Serial 7 subtraction starting at 100		[] 93 [] 86 [] 79 [] 72 [] 65	
4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt		2/3	
LANGUAGE			
Repeat: I only know that John is the one to help today. [L]		2/2	
The cat always hid under the couch when dogs were in the room. [L]		1/1	
Fluency / Name maximum number of words in one minute that begin with the letter F		V 1 (N ≥ 11 words)	
ABSTRACTION			
Similarity between e.g. banana - orange = fruit		Y train - bicycle	
watch - ruler		1/2	
DELAYED RECALL			
List to recall words WITH NO CUE		FACE	VELVET
Category cue		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Multiple choice cue		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Optional		CHURCH	DAISY
		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
ORIENTATION			
Date		Month	Year
Day		Place	City
3/16		3/16	
© Z.Nasreddine MD Version 7.1 www.mocatest.org		Normal ≥ 26 / 30	
Administered by:		TOTAL 18/30	
		Add 1 point if ≤ 12/30	

REFERENCE

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 4th ed. Arlington, VA: American Psychiatric Association; 2000.

—

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

Based on the information presented thus far, do you believe that Ms A meets criteria for dementia?

A. Yes 100%

B. No 0%

Ms A has experienced the insidious onset and gradual progression of memory loss and deficits of other cognitive domains that has led to impaired function of instrumental

activities of daily life such as shopping, managing finances, and misplacing items.

Based on the information presented thus far, what is the most likely diagnosis?

- A. Frontotemporal dementia
- B. Alzheimer's disease
- C. Mild cognitive impairment
- D. Pseudodementia
- E. Vascular dementia

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

Based on the information presented thus far, what is the most likely diagnosis?

- | | |
|------------------------------|------|
| A. Frontotemporal dementia | 0% |
| B. Alzheimer's disease | 100% |
| C. Mild cognitive impairment | 0% |
| D. Pseudodementia | 0% |
| E. Vascular dementia | 0% |

All conference attendees agreed that Alzheimer's disease is the most likely diagnosis, although given Ms A's history of atrial fibrillation and hypertension, vascular dementia should be considered in the differential diagnosis.

Up to this point, Ms A has had a head CT, CBC, CMP, and vitamin B₁₂ and TSH tests, all of which were unremarkable. What further testing is indicated at this time?

- A. Neuropsychological testing
- B. Fluorodeoxyglucose-positron emission tomography (FDG-PET)
- C. Lumbar puncture
- D. Florbetapir PET (amyloid imaging)
- E. No further testing is indicated

In April 2012, the US Food and Drug Administration (FDA) approved florbetapir F-18 amyloid positron emission tomography (PET) imaging in patients with cognitive impairment who are being evaluated for Alzheimer's disease and other causes of cognitive decline. Florbetapir F-18 is a radioactive diagnostic agent that binds to amyloid plaques, a hallmark characteristic of Alzheimer's disease, and is detected using PET scan images of the brain.

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

Up to this point, Ms A has had a head CT, CBC, CMP, and vitamin B₁₂ and TSH tests, all of which were unremarkable. What further testing is indicated at this time?

- | | |
|--------------------------------------|-----|
| A. Neuropsychological testing | 67% |
| B. FDG-PET | 0% |
| C. Lumbar puncture | 0% |
| D. Florbetapir PET (amyloid imaging) | 0% |
| E. No further testing is indicated | 33% |

Those conference attendees who chose "neuropsychological testing" argued that the results will clearly illustrate cognitive strengths and weakness that can be used as the basis of a care plan for the caregiver as well as the patient. This testing will also assess Ms A's emotional status and determine if depression could be adversely affecting her cognition. In other words, although neuropsychological testing has both diagnostic and management rationale, for this patient, testing is helpful for management, while it is not necessary for diagnosis.

Those who chose "no further testing is indicated" stated that the clinical history and cognitive screening battery are quite clear, and neuropsychological testing will not provide significant information. Furthermore, in a patient who is displaying irritability, hours of cognitive tests could further increase agitation.

Guidelines for a routine dementia workup include CBC, CMP, vitamin B₁₂, TSH, and structural brain imaging with either magnetic resonance imaging (MRI) or CT (Knopman et al, 2001). Although there was controversy regarding ordering neuropsychological testing, conference attendees did not suggest any other further testing.

REFERENCE

Knopman DS, DeKosky ST, Cummings JL, et al. Report of the Quality Standards Subcommittee of the American Academy of Neurology. Practice parameter: diagnosis of dementia (an evidence-based review). *Neurology*. 2001;56(9):1143-1153.

Ms A could not tolerate donepezil 10 mg due to nausea and headaches. She continues with donepezil 5 mg daily but has persistent headaches that may be due to the donepezil, but it is uncertain. What action should be taken?

- A. Discontinue donepezil. Initiate memantine.
- B. Temporarily stop donepezil to assess whether headaches improve.
- C. Discontinue donepezil. Initiate rivastigmine transdermal patch.
- D. Continue donepezil 5 mg. Add acetaminophen 1,000 mg twice daily.

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

Ms A could not tolerate donepezil 10 mg due to nausea and headaches. She continues with donepezil 5 mg daily but has persistent headaches that may be due to the donepezil, but it is uncertain. What action should be taken?

- | | |
|---------------------------------------------------------------------|-----|
| A. Discontinue donepezil. Initiate memantine. | 0% |
| B. Temporarily stop donepezil to assess whether headaches improve. | 67% |
| C. Discontinue donepezil. Initiate rivastigmine transdermal patch. | 33% |
| D. Continue donepezil 5 mg. Add acetaminophen 1,000 mg twice daily. | 0% |

Most conference attendees recommended a temporary hold of donepezil to assess if headaches resolve. If headaches resolve, then there is evidence that they are a side effect of donepezil. Some attendees wished to switch to rivastigmine transdermal patch to ensure that Ms A did not have a lapse in treatment. Memantine is currently not indicated on the basis of prescribing information, given that the patient is in the early stages of Alzheimer's disease, and headaches are a possible side effect. The most common side effects of cholinesterase inhibitors (donepezil, rivastigmine, and galantamine) include cholinergic side effects of diarrhea, nausea, vomiting, and bradycardia (can be symptomatic with syncope), but headache is also a possible side effect (Farlow et al, 2008).

REFERENCE

Farlow MR, Miller ML, Pejovic V. Treatment options in Alzheimer's disease: maximizing benefit, managing expectations. *Dement Geriatr Cogn Disord*. 2008;25(5):408–422.

Ms A rarely drives and only with her husband. Her husband has no concerns about driving safety. What action, if any, should be recommended regarding driving at this time?

- | | |
|-----------------------------------------------------------------------------------------------------------------------------|-----|
| A. The patient must pass a formal on-road driving assessment in order to continue driving. | 0% |
| B. Driving should stop immediately. | 0% |
| C. Continue driving, as long as her husband continues to closely monitor. | 56% |
| D. Refer patient to a driving education class (American Automobile Association or American Association of Retired Persons). | 44% |

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

Ms A rarely drives and only with her husband. Her husband has no concerns about driving safety. What action, if any, should be recommended regarding driving at this time?

- | | |
|-----------------------------------------------------------------------------------------------------------------------------|-----|
| A. The patient must pass a formal on-road driving assessment in order to continue driving. | 44% |
| B. Driving should stop immediately. | 0% |
| C. Continue driving, as long as her husband continues to closely monitor. | 56% |
| D. Refer patient to a driving education class (American Automobile Association or American Association of Retired Persons). | 0% |

Some conference attendees felt that Ms A can continue to drive, even alone, as long as her husband monitors her driving very closely by being a passenger in the vehicle with her at least once every 2 weeks. Her husband should be asked whether he has to “copilot,” giving directions or prompts while she is driving. If this is the case, she should not drive alone, and her husband must be counseled that, at some point, she will not be able to follow his directions, placing both of them at risk. Others felt that driving can continue as long as she passes a formal on-road driving safety test either through the Department of Transportation or via a private facility. In either case, most attendees felt that she most likely could continue to drive but would need to be continually assessed for safety. At this time, Ms A and her husband should be warned of her safety risk, the public safety risk, and the legal and financial liability of driving with dementia. Also, her husband should be counseled as to warning signs of impaired driving safety such as the following:

- Incorrect signaling
- Trouble navigating turns
- Moving into the wrong lane
- Confusion at exits
- Parking inappropriately
- Hitting curbs/objects
- Driving at inappropriate speeds
- Delayed responses
- Missed stop sign/red light
- Increased agitation
- Scrapes or dents on car
- Becomes lost in familiar places
- Near misses (eg, car accident)
- Moving violation warnings
- Involved in car accident
- Confuses brake and gas
- Stops in traffic for no reason
- Needs prompts or directions to find familiar destinations

Currently, there are no clinical predictive tools of driving safety in dementia. The American Academy of Neurology published guidelines in 2010 (Iverson et al, 2010).

Patients and families can be directed to The Hartford Web site for further information on dementia and driving (<http://www.thehartford.com/mature-market-excellence/dementia>). This material can help family members understand how changes in the brain affect driving, as well as plan for driving cessation. Free guides from The Hartford regarding driving safety and dementia can be downloaded at <http://www.thehartford.com/advance50/publications-on-aging>.

REFERENCE

Iverson DJ, Gronseth GS, Reger MA, et al; Quality Standards Subcommittee of the American Academy of Neurology. Practice parameter update: evaluation and management of driving risk in dementia: report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2010 Apr 20;74(16):1316-1324.

IMPRESSION OF TREATING PHYSICIAN AT FIRST VISIT

Ms A is an 80-year-old woman who presents for a cognitive evaluation. The patient's clinical history and cognitive findings are consistent with dementia. The most likely etiology of Ms A's dementia is Alzheimer's disease. She has mild long-standing depressive features, insomnia, and intermittent irritability. She has not been able to tolerate higher doses of donepezil and suffers from headaches, which may be a side effect.

PLAN

1. Stop the donepezil for 3 days. If the headaches improve, then discontinue the donepezil and initiate rivastigmine transdermal patch 4.6 mg daily. If headaches persist after stopping donepezil for 3 days, then the donepezil is not causing the headaches and donepezil 5 mg can be resumed and steadily rechallenged at a higher dose by increments of 2.5 mg up to 10 mg daily or 5 mg twice daily.
2. Memantine is not indicated at the current time.
3. Avoid use of acetaminophen PM given the anticholinergic properties of diphenhydramine. Address the issues pertaining to insomnia at the next appointment. Continue trazodone 100 mg at bedtime, which is inconsistently effective. General sleep hygiene strategies were reviewed.
4. Discussed the importance of optimizing physical, social, and mental activities.
5. Referred Ms A's husband to caregiver education classes.
6. Discussed briefly the possibility of participating in clinical research. Ms A and her husband are amenable to this idea and would like to discuss in further detail at future visits.

7. Discussed the issue of driving. At the current time, Ms A's driving is reportedly safe. Her husband will continue to monitor her driving. This issue will be reevaluated at the next visit.
8. Ms A will follow up in approximately 2 to 3 months.

FOLLOW-UP 3 MONTHS AFTER THE INITIAL VISIT

When Ms A stopped donepezil, her headaches resolved. Transdermal rivastigmine 4.6 mg was administered for 4 weeks and was increased to 9.5 mg without incident. Via telephone calls, trazodone was gradually increased to 200 mg at bedtime with excellent control of insomnia. Ms A no longer takes acetaminophen PM.

Ms A's husband observes worsening of short-term memory and worsening of depression. She is increasingly apathetic and needs more encouragement to be involved in hobbies and activities. There have been no changes in her ability to drive. Ms A's husband has attended caregiver classes. He reports that Ms A is having difficulty "accepting the diagnosis," which "lowers her spirits" and further irritates her. He was instructed to avoid focusing on accepting her illness.

IMPRESSION

Ms A is an 80-year-old woman with Alzheimer's disease. She has worsening depressive symptoms. Her headaches resolved with discontinuation of donepezil. Her insomnia resolved with higher doses of trazodone. She continues to have depressive features with irritability.

PLAN

1. Continue rivastigmine 9.5 mg daily.
2. Memantine is not indicated at the current time.
3. Start citalopram 10 mg for treatment of depressive features.
4. Continue trazodone 200 mg at bedtime.
5. Ms A continues to drive but never drives alone. Her husband will continue to monitor the driving.
6. Ms A and her husband are very interested in clinical trial participation. They met with a study coordinator today for further discussion.
7. Ms A will follow up in approximately 3 to 4 months.

FOLLOW-UP 6 MONTHS AFTER THE INITIAL VISIT

Ms A's husband notes significant improvement in her mood since initiating citalopram. The dose was increased to 20 mg via a phone call since the last appointment. Short-term memory, however, continues to significantly decline,

Figure 4. Ms A's Pentagon Drawing and Sentence From the Mini-Mental State Examination 6 Months After the Initial Visit



I like to play cards.

and Ms A is increasingly repetitive. She continues to deny her diagnosis. The mention of Alzheimer's disease angers and agitates her.

Ms A continues to drive, but very rarely. Ms A never drives alone because her husband is very concerned that she might get lost. Otherwise, he reports that her driving skills are intact and that she is a safe driver.

The MMSE was repeated. What would you expect the MMSE score to be?

- A. 26–30
- B. 21–25
- C. 16–20
- D. 11–15
- E. < 11

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

The MMSE was repeated. What would you expect the MMSE score to be?

- | | |
|----------|-----|
| A. 26–30 | 0% |
| B. 21–25 | 11% |
| C. 16–20 | 89% |
| D. 11–15 | 0% |
| E. < 11 | 0% |

Ms A scored 21 points on the MMSE; Figure 4 shows her pentagon drawing and sentence.

At this time, should there be any further medication changes?

- A. Switch rivastigmine to galantamine.
- B. Discontinue rivastigmine.
- C. Add memantine.
- D. No further medical intervention at this time.

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

At this time, should there be any further medication changes?

- | | |
|--------------------------------------------------|-----|
| A. Switch rivastigmine to galantamine. | 0% |
| B. Discontinue rivastigmine. | 0% |
| C. Add memantine. | 33% |
| D. No further medical intervention at this time. | 67% |

What action, if any, should be taken regarding driving at this time?

- A. Suggest to husband to gradually decrease driving frequency and stop over the next few weeks.
- B. Notify the Department of Transportation.
- C. Advise a formal on-road driving safety assessment.
- D. Stop driving.

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

What action, if any, should be taken regarding driving at this time?

- | | |
|-------------------------------------------------------------------------------------------------|-----|
| A. Suggest to husband to gradually decrease driving frequency and stop over the next few weeks. | 22% |
| B. Notify the Department of Transportation. | 11% |
| C. Advise a formal on-road driving safety assessment. | 11% |
| D. Stop driving. | 56% |

Should they be told that driving must stop, it will be important to teach Ms A's husband appropriate strategies. For example, instead of saying, "You can no longer drive," her husband should say, "I'll drive this time. I need the practice."

What action, if any, should be taken regarding Ms A's refusal to accept her diagnosis?

- Logically explain to her how the diagnosis was made; show results of cognitive testing.
- Calmly review Alzheimer's disease using brochures or informative Web sites.
- Do not mention Alzheimer's disease to her; terms such as *memory issues* or other terms may be a better alternative.
- Refer patient and her husband to meet with a case manager.

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

What action, if any, should be taken regarding Ms A's refusal to accept her diagnosis?

- | | |
|------------------------------------------------------------------------------------------------------------------------------|------|
| A. Logically explain to her how the diagnosis was made; show results of cognitive testing. | 0% |
| B. Calmly review Alzheimer's disease using brochures or informative Web sites. | 0% |
| C. Do not mention Alzheimer's disease to her; terms such as <i>memory issues</i> or other terms may be a better alternative. | 100% |
| D. Refer patient and her husband to meet with a case manager. | 0% |

Note: The combination of impaired reasoning and lack of insight creates mood and behavioral issues when family members try to reason with and/or convince a loved one of a diagnosis of Alzheimer's disease.

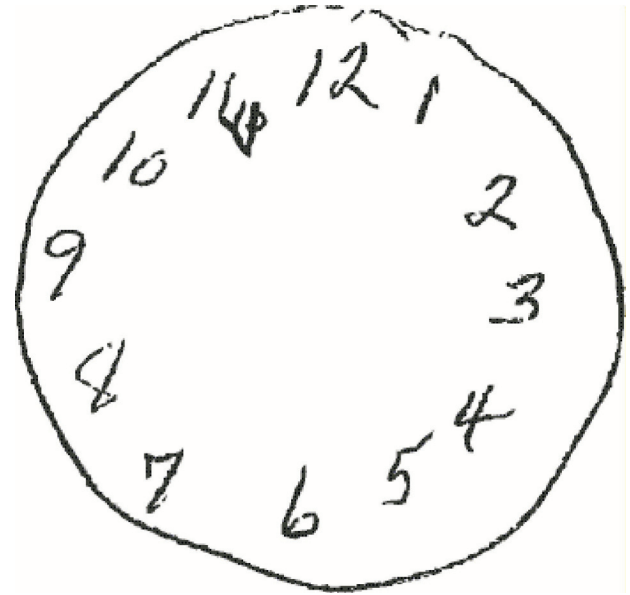
IMPRESSION 6 MONTHS AFTER THE INITIAL VISIT

Ms A is an 80-year-old woman with Alzheimer's disease who has worsened cognitively since her last visit. Her depressive symptoms are controlled with citalopram, and insomnia is controlled with trazodone. Ms A prefers not to use the term *Alzheimer's disease* and prefers other terms such as *memory loss*.

PLAN

- At this time, initiate memantine, as Ms A appears to be encroaching upon the moderate stages of Alzheimer's disease per clinical report and MMSE score. A starter pack was provided as well as a prescription for 10 mg twice daily. Potential side effects were discussed.
- Continue transdermal rivastigmine 9.5 mg daily.
- Continue trazodone 200 mg at bedtime and citalopram 20 mg daily.

Figure 5. Ms A's Clock Drawing 9 Months After the Initial Visit



- Advised at this time to continue to wean Ms A off driving and subsequently stop driving over the next few weeks.
- Discussed caregiver responses to the repetitive questioning such as:
 - Ask "Why are you asking that?" and address concerns the patient expresses.
 - Write the second answer on a card that the patient can carry and refer to.
 - Use distraction such as "Can you help me with (name a task)."
 - Understand that patients often obsess on plans announced in advance; thus, the caregiver should not announce plans in advance.
- Ms A and her husband are interested in clinical trial participation and would like to be contacted should there be a suitable study, but Ms A has a pacemaker, which has excluded her from our current available studies.
- Ms A will follow up in approximately 2 to 3 months.

FOLLOW-UP 9 MONTHS AFTER THE INITIAL VISIT

Ms A was initiated on memantine at the last visit; however, after 1 week, worsening confusion was observed. The patient was unable to recognize her home or a close friend. She was unable to play a simple card game that she has never had problems with previously. After 18 days, memantine was discontinued. Within days, her cognitive status returned to baseline (Note: Confusion is a known rare side effect of memantine [Tariot et al, 2004]).

Figure 6. Ms A's Montreal Cognitive Assessment Results 9 Months After the Initial Visit

VISUOSPATIAL / EXECUTIVE		Copy cube		Draw CLOCK (Ten past eleven) (3 points)		3/5																			
						<input checked="" type="checkbox"/> Contour <input checked="" type="checkbox"/> Numbers <input type="checkbox"/> Hands																			
NAMING				<input checked="" type="checkbox"/> 3/3																					
MEMORY		Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.		<table border="1"> <thead> <tr> <th></th> <th>FACE</th> <th>VELVET</th> <th>CHURCH</th> <th>DAISY</th> <th>RED</th> </tr> </thead> <tbody> <tr> <td>1st trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>2nd trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>			FACE	VELVET	CHURCH	DAISY	RED	1st trial						2nd trial						No points	
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ATTENTION		Read list of digits (1 digit/sec). Subject has to repeat them in the forward order. Subject has to repeat them in the backward order.		<input checked="" type="checkbox"/> 2 1 8 5 4 <input checked="" type="checkbox"/> 7 4 2		2/2																			
		Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors.		<input checked="" type="checkbox"/> F B A C M N A A J K L B A F A K D E A A A J A M O F A A B		1/1																			
		Serial 7 subtraction starting at 100. 93 [] 86 [] 79 [] 72 [] 65 []		4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt		1/3																			
LANGUAGE		Repeat: I only know that John is the one to help today. <input checked="" type="checkbox"/> The cat always hid under the couch when dogs were in the room. <input checked="" type="checkbox"/>		<input checked="" type="checkbox"/> 2/2																					
		Fluency / Name maximum number of words in one minute that begin with the letter F. <input checked="" type="checkbox"/> 8 (N ≥ 11 words)		<input checked="" type="checkbox"/> 0/1																					
ABSTRACTION		Similarity between e.g. banana - orange = fruit. <input checked="" type="checkbox"/> train - bicycle <input checked="" type="checkbox"/> watch - ruler		<input checked="" type="checkbox"/> 2/2																					
DELAYED RECALL		Has to recall words WITH NO CUE.		<table border="1"> <thead> <tr> <th></th> <th>FACE</th> <th>VELVET</th> <th>CHURCH</th> <th>DAISY</th> <th>RED</th> </tr> </thead> <tbody> <tr> <td></td> <td>[]</td> <td>[]</td> <td>[]</td> <td>[]</td> <td>[]</td> </tr> </tbody> </table>			FACE	VELVET	CHURCH	DAISY	RED		[]	[]	[]	[]	[]	Points for UNCUED recall only							
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Optional		Category cue Multiple choice cue																							
ORIENTATION		<input type="checkbox"/> Date <input type="checkbox"/> Month <input checked="" type="checkbox"/> Year <input type="checkbox"/> Day <input type="checkbox"/> Place <input checked="" type="checkbox"/> City		<input checked="" type="checkbox"/> 2/6																					
© Z.Nasreddine MD Version 7.1 www.mocatest.org Normal ≥ 26 / 30		TOTAL		<input checked="" type="checkbox"/> 16/30		Add 1 point if ≤ 12 yr edu																			

In the past 3 months, Ms A has had continued gradual worsening of short-term memory. She is now developing changes in her personality. She gets more frustrated and irritable when people ask her questions that she cannot answer. Ms A is no longer driving. Figure 5 shows Ms A's clock drawing at this visit. A MoCA was repeated; Ms A scored 16 out of 30 (Figure 6).

IMPRESSION

Ms A is an 80-year-old woman with Alzheimer's disease. Cognitive symptoms continue to gradually worsen from visit to visit. Her insomnia is controlled with trazodone. Ms A prefers not to use the term *Alzheimer's disease* and prefers to use other terms such as *memory loss*. Depressive symptoms are worsening.

PLAN

1. Continue rivastigmine transdermal patch 9.5 mg daily. Ms A was not able to tolerate donepezil or memantine.
2. Continue trazodone 200 mg daily.
3. Continue citalopram 20 mg daily. Monitor depressive symptoms.
4. Ms A is no longer driving.
5. Ms A and her husband would like to be notified should there be any studies available that do not require MRIs, as she has a pacemaker.
6. Ms A will follow up in approximately 4 months.

REFERENCE

Tariot PN, Farlow MR, Grossberg GT, et al; Memantine Study Group. Memantine treatment in patients with moderate to severe Alzheimer disease already receiving donepezil: a randomized controlled trial. *JAMA*. 2004;291(3):317–324.

FOLLOW-UP PHONE CALL 12 MONTHS AFTER THE INITIAL VISIT

Ms A's husband called in a panic reporting that Ms A ran out of the house this morning, banging on neighbors' doors and yelling that she could no longer stand living with her husband. They had just returned from visiting family in northern Arizona for 2 days. Over the past 2 weeks, there have been increased episodes of agitated behavior, but "nothing like this." The drive home was uneventful. When they returned home, Ms A suddenly became angry and agitated, fixated on the fact that she is no longer in control of their finances. She became distressed about not having money. Her husband physically pulled her back to the house "by her wrists." Two neighbors helped to calm her down, and she remains calm. Ms A has a follow-up appointment scheduled in less than 2 weeks.

What is the best next step?

- A. Initiate an atypical antipsychotic.
- B. Suggest that she be seen by her primary care physician/urgent care to rule out an occult infection.
- C. Recommend an inpatient geriatric psychiatry evaluation.
- D. Increase citalopram.
- E. No action. Await follow-up appointment in 2 weeks and reassess.

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

What is the best next step?

- | | |
|--------------------------------------------------------------------------------------------------------|------|
| A. Initiate an atypical antipsychotic. | 0% |
| B. Suggest that she be seen by her primary care physician/urgent care to rule out an occult infection. | 100% |
| C. Recommend an inpatient geriatric psychiatry evaluation. | 0% |
| D. Increase citalopram. | 0% |
| E. No action. Await follow-up appointment in 2 weeks and reassess. | 0% |

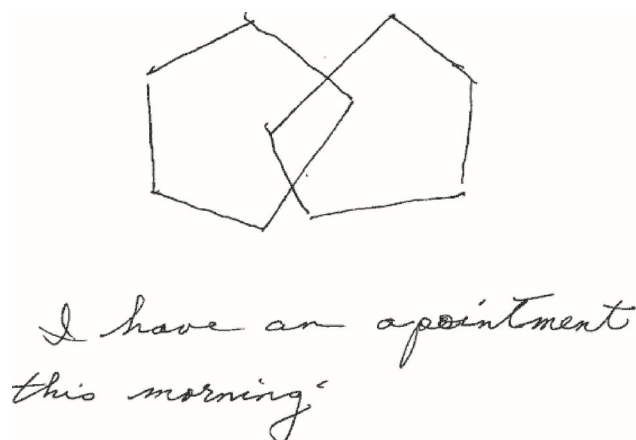
A delirium due to an occult infection such as a urinary tract infection can result in a similar presentation, and, thus, an evaluation is warranted. The most likely etiology of Ms A's agitated episode, however, is her response to the stress of traveling. People with dementia have ever-increasing trouble with changes of pace, changes in location, fatigue, groups of people, changes of time zone, and noise. In a familiar setting, there are many environmental cues that help a person with dementia to remain connected to reality such as a favorite chair or a familiar floor plan. Unfamiliar places can trigger fear, anger, and agitation (see supplementary material for the *Travel Guide for People With Dementia*). In addition to counseling regarding travel, Ms A's husband will need to be counseled in regard to his response to his wife's behaviors.

He should be counseled regarding the possible causes of the agitation and fear and instructed on measures to avoid the development of agitation as follows:

- Avoiding fatigue—having rest periods twice a day in a quiet area;
- Avoiding changes in routine, care provider, and relocation/travel;
- Having appropriate activities throughout the day;
- Avoiding questioning or trying to get the patient to recover lost functions;
- Controlling overwhelming or misleading stimuli (television);
- Preventing illness and treating pain.

Ms A's husband should share these strategies with other family members and friends who may interact with his wife so they too can be aware of common behavioral triggers. Once catastrophic behaviors occur, he should be taught to treat his wife as if these behaviors are a panic attack as follows:

Figure 7. Ms A's Pentagon Drawing and Sentence From the Mini-Mental State Examination 13 Months After the Initial Visit



- Stop any activity;
- Try to get the patient to a secure and quiet place. If it occurs in a public setting such as a restaurant, leave;
- Reassure the patient she is safe in a soft voice. If she allows, rub her back or use gentle touch;
- Explore if the patient is hungry, in pain, or needs to use the bathroom and quietly accommodate these needs;
- Give the patient a 10–15 minute “time out” during which she is encouraged to rest quietly, possibly reading or listening to quiet music. The time out allows the person to rest and regain control and diminishes anxiety.

OUTCOME OF THE FOLLOW-UP PHONE CALL

Ms A's husband was instructed to take her to her primary care physician or urgent care to rule out an occult infection or other acute medical issue. She was seen by her primary care physician after her behavioral episode, and a physical examination, urinalysis, and basic laboratory results were normal.

FOLLOW-UP APPOINTMENT 13 MONTHS AFTER THE INITIAL VISIT

Ms A continues to have intermittent episodes of agitated behavior. For example, she did not want to get out of the car for her appointment. When Ms A finally agreed to be seen, she insisted that she see the physician without her husband present. She insists that all items in their house belong to her, and her husband “can't do anything right.” Her husband states, “I can't disagree with her or she gets very angry.” “Little things” trigger agitation and anger.

Her husband has met with a social worker with the Family and Community Services team for caregiver counseling. They discussed the option of adult day health programs as well how to respond to her agitated behavior. For example,

Mr A was counseled not to reason with his wife and to redirect the conversation. It was recommended that Ms A be on a consistent schedule with regular rest periods. Her response to groups and noise should be monitored and adjusted accordingly. Her daytime activities should include pleasurable activities. These activities need to be easily accessible for the caregiver. Common activities to utilize often include prerecorded old TV comedies and game shows, favorite music, picture books, and favorite foods that are generally soft and sweet (eg, chocolate and ice cream). In responding to Ms A's behaviors, her husband should take a nonconfrontational approach.

COGNITIVE TESTING

Ms A scored 21 points on the MMSE; Figure 7 shows her pentagon drawing and sentence. She scored 15 points on the MoCA (Figure 8).

What medication changes, if any, would you recommend at this time?

- A. Initiate an atypical antipsychotic such as quetiapine.
- B. Switch the citalopram to a different antidepressant.
- C. Initiate a typical antipsychotic such as haloperidol.
- D. No medication changes; continue caregiver education.

Your colleagues who attended the Banner Alzheimer's Institute Case Conference answered as follows:

What medication changes, if any, would you recommend at this time?

- | | |
|-----------------------------------------------------------|-----|
| A. Initiate an atypical antipsychotic such as quetiapine. | 17% |
| B. Switch the citalopram to a different antidepressant. | 0% |
| C. Initiate a typical antipsychotic such as haloperidol. | 0% |
| D. No medication changes; continue caregiver education. | 83% |

IMPRESSION 13 MONTHS AFTER THE INITIAL VISIT

Ms A is an 81-year-old woman with dementia due to Alzheimer's disease. Cognitive symptoms continue to worsen, and she has developed agitated behaviors. Insomnia is well controlled with trazodone. Ms A prefers not to use the term *Alzheimer's disease* and prefers to use other terms such as *memory loss*.

Figure 8. Ms A's Montreal Cognitive Assessment Results 13 Months After the Initial Visit

VISUOSPATIAL / EXECUTIVE		Copy cube		Draw CLOCK (Ten past eleven) (3 points)		Points																			
						<input checked="" type="checkbox"/> Contour <input checked="" type="checkbox"/> Numbers <input checked="" type="checkbox"/> Hands 2/5																			
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MEMORY		Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.		<table border="1"> <thead> <tr> <th></th> <th>FACE</th> <th>VELVET</th> <th>CHURCH</th> <th>DAISY</th> <th>RED</th> </tr> </thead> <tbody> <tr> <td>1st trial</td> <td><input checked="" type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> <tr> <td>2nd trial</td> <td><input checked="" type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> </tbody> </table>			FACE	VELVET	CHURCH	DAISY	RED	1st trial	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	2nd trial	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	No points	
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Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors.		<input checked="" type="checkbox"/> FBACMNAAJ KLBFAKDEAAA JAMOFAB				1/1																			
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LANGUAGE		Repeat: I only know that John is the one to help today. <input checked="" type="checkbox"/>		The cat always hid under the couch when dogs were in the room. <input checked="" type="checkbox"/>		1/2																			
Fluency / Name maximum number of words in one minute that begin with the letter F		<input checked="" type="checkbox"/> 9 (N ≥ 11 words)				0/1																			
ABSTRACTION		Similarity between e.g. banana - orange = fruit		<input checked="" type="checkbox"/> train - bicycle <input checked="" type="checkbox"/> watch - ruler		2/2																			
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© Z.Nasreddine MD Version 7.1 www.mocatest.org Normal ≥ 26 / 30		TOTAL		15/30		Add 1 point if ≤ 12 yr edu																			

PLAN

1. Continue rivastigmine 9.5 mg daily. Ms A is not able to tolerate donepezil or memantine.
2. Given the significant agitated behaviors that have been emerging, initiate quetiapine 25 mg at bedtime with an additional 25 mg as needed every 24 hours for agitation. The side effects of this medication as well as the black box warning, which includes an increased incidence of heart attack, stroke, and all-cause mortality, were discussed at length with Ms A's husband, who has medical power of attorney. Despite the potential risk of this medication, it was agreed that the potential benefit outweighs the potential risk at this time.
3. Continue citalopram 20 mg daily.
4. Once the quetiapine has been initiated, the trazodone could potentially be decreased.
5. Follow up in 6 weeks.

There are no US Food and Drug Administration (FDA)-approved medications to treat agitation or psychosis for Alzheimer's disease, so use of atypical antipsychotics, which is common practice, is considered "off-label" use. Atypical antipsychotics carry an FDA boxed warning for use in dementia that states that these medications increase the risk of mortality by 1.6 to 1.7 fold. This warning is based on a meta-analysis of 17 trials, and although the causes of death were varied, most of the deaths were cardiovascular or infectious in nature (FDA, 2005).

REFERENCE

US Food and Drug Administration. Deaths With Antipsychotics in Elderly Patients With Behavioral Disturbances. April 11, 2005. [http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/DrugSafetyInformationforHealthcareProfessionals/PublicHealthAdvisories/ucm053171.htm?utm_campaign=Google2&utm_source=fdaSearch&utm_medium=website&utm_term=Deaths With Antipsychotics in Elderly Patients With Behavioral Disturbances 2008&utm_content=1](http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/DrugSafetyInformationforHealthcareProfessionals/PublicHealthAdvisories/ucm053171.htm?utm_campaign=Google2&utm_source=fdaSearch&utm_medium=website&utm_term=Deaths%20With%20Antipsychotics%20in%20Elderly%20Patients%20With%20Behavioral%20Disturbances%202008&utm_content=1). Accessed May 23, 2012.

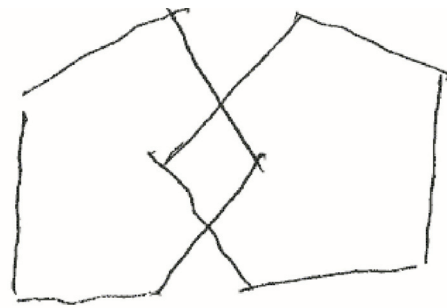
FOLLOW-UP 14.5 MONTHS AFTER THE INITIAL APPOINTMENT

Ms A's husband reported that quetiapine is "a miracle drug." Her agitated behaviors have resolved, and she has returned to her baseline personality and behavior. She is "friendly again." No further medication changes were made. She continues to take transdermal rivastigmine 9.5 mg daily, quetiapine 25 mg at bedtime, citalopram 20 mg daily, and trazodone 100 mg at bedtime.

FOLLOW-UP 17 MONTHS AFTER THE INITIAL APPOINTMENT

Ms A continues to live at home with her husband with support from their daughters. Due to an increase in morning agitation, Ms A has been taking an extra 25 mg of quetiapine every morning in addition to her evening dose. When she intermittently does not remember being married and does

Figure 9. Ms A's Pentagon Drawing and Sentence From the Mini-Mental State Examination 14.5 Months After the Initial Visit



*I have done this
questioning before.*

not recognize her husband, her agitation increases. She will lock herself in the bedroom. She is also insistent that she control her own medications and does not allow for assistance. Upon arriving to our institute, the sign at the entrance stating "Banner Alzheimer's Institute" angered her, and she did not want to enter the building. She has no insight into her illness and does not believe she has a problem. The MMSE score was 21 of 30 and the MoCA score was 10 of 22. The MoCA was not fully completed, as Ms A grew angry and refused to finish the testing. Figure 9 shows Ms A's pentagon drawing and sentence from the MMSE. Figure 10 shows Ms A's MoCA results.

IMPRESSION

Ms A is an 81-year-old woman with moderate stage Alzheimer's disease with significant behavioral issues. She refuses to take medications and demands control of them, focuses on wanting to drive, and intermittently does not recognize her husband. Behaviors seem to be worse in the early morning and then again in the late afternoon/early evening hours.

PLAN

1. Increase quetiapine to 50 mg at bedtime and 25 mg in the morning, with an additional 25 mg as needed. Monitor and adjust as needed.
2. General communication strategies were discussed to minimize frustration and to address delusions. The discussion was also focused on identifying triggers for the behaviors and eliminating them either from the environment or from communication interactions.
3. Medications can be crushed, placed in food, or dissolved in liquid in order to facilitate taking them. Medication bottles should be placed out

Figure 10. Ms A's Montreal Cognitive Assessment Results 14.5 Months After the Initial Visit

VISUOSPATIAL / EXECUTIVE		POINTS																			
			1/5																		
NAMING		3/3																			
		3/3																			
MEMORY		No points																			
Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.		<table border="1"> <thead> <tr> <th></th> <th>FACE</th> <th>VELVET</th> <th>CHURCH</th> <th>DAISY</th> <th>RED</th> </tr> </thead> <tbody> <tr> <td>1st trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>2nd trial</td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>			FACE	VELVET	CHURCH	DAISY	RED	1st trial						2nd trial					
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Serial 7 subtraction starting at 100.		[] 93 [] 86 [] 79 [] 72 [] 65																			
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© Z. Nasreddine MD Version 7.1 www.mocatest.org Normal ≥ 26 / 30		TOTAL 30/30																			
Administered by:		Add 1 point if ≤ 12 yr edu																			

of sight so that they do not serve as a trigger for behaviors.

4. A men's support group was recommended to Ms A's husband, and the issue of caregiver stress and the need for respite was reviewed.
5. It was stressed that Ms A cannot be left alone and requires 24/7 supervision.
6. Ms A will follow up in 4 months.

FOLLOW-UP 21 MONTHS AFTER THE INITIAL APPOINTMENT

Ms A did not speak with her husband for 2 days after the last appointment. She refuses to come to the Banner Alzheimer's Institute, and the term *Alzheimer's* continues to cause great anger. She refused to attend today's appointment, and her husband presented alone. She continues to cognitively worsen, but with the current medication regimen, her behavioral issues are generally very well controlled. Given her continued refusal to present to the "Alzheimer's Institute," we agreed that we will manage any new issues via the telephone, so long as Ms A is seen in the clinic at least once a year.

FOLLOW-UP 31 MONTHS AFTER THE INITIAL APPOINTMENT

Ms A has continued progressive cognitive decline. She cannot recognize objects. She confuses the remote control and the telephone. She is unable to get items out of the refrigerator. The morning dose of quetiapine was discontinued. With quetiapine 50 mg at bedtime, behaviors are controlled with limited aggression, although she was quite irate about coming in to the "Alzheimer's Institute" today. She scored 12 points on the MMSE and 8 points on the MoCA. Figure 11 shows Ms A's pentagon drawing and sentence from the MMSE. Figure 12 shows Ms A's MoCA results. Figure 13 shows Ms A's clock drawings from the first visit to 31 months later.

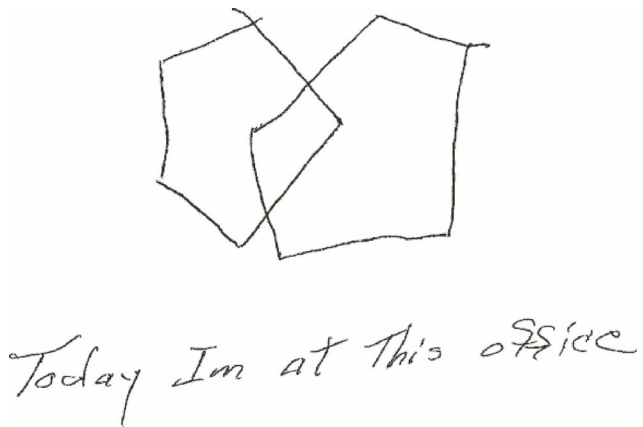
IMPRESSION

Ms A is an 82-year-old woman in the moderate-to-severe stages of Alzheimer's disease dementia. She has been having a relatively rapid progression of symptoms. She has had significant behavioral issues and agitation, which are currently well controlled on her current medication regimen. Ms A becomes very irate when coming to our Institute, and the term *Alzheimer's disease* is not to be used with her.

PLAN

1. Continue transdermal rivastigmine 9.5 mg daily.
2. Continue quetiapine 50 mg at bedtime, with an additional 25–50 mg as needed daily.
3. Continue citalopram 20 mg daily.
4. Ms A will follow up in approximately 1 year. The cognitive testing will not be repeated at that time, given that it creates significant anger in this patient.

Figure 11. Ms A's Pentagon Drawing and Sentence From the Mini-Mental State Examination 31 Months After the Initial Visit



DISCLOSURE OF OFF-LABEL USAGE

The authors have determined that, to the best of their knowledge, quetiapine is not approved by the US Food and Drug Administration for behavioral management in dementia.

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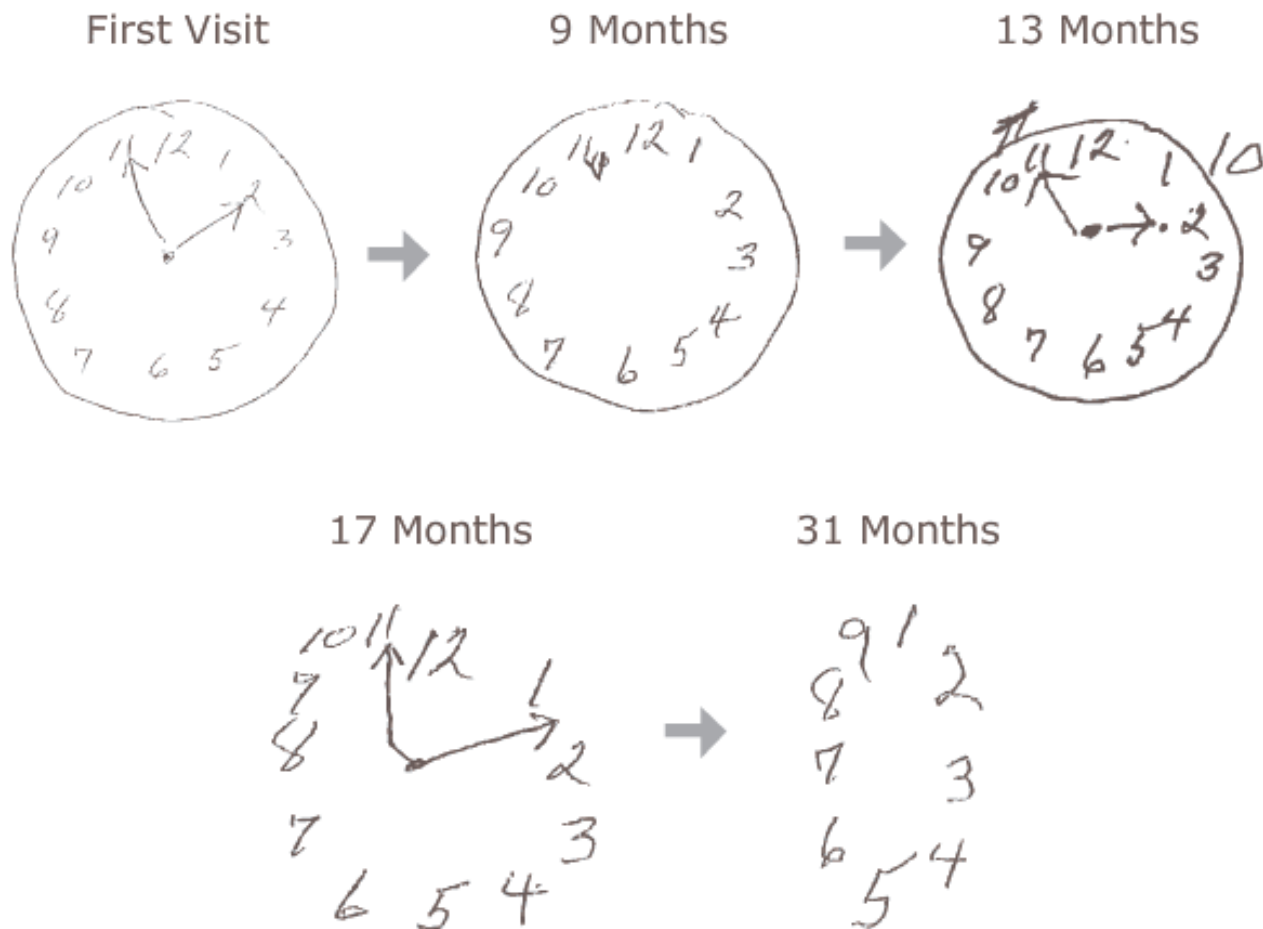
FINANCIAL DISCLOSURE

Dr Yaari is a consultant for Amedisys Home Health. **Dr Tariot** has served as a consultant for Abbott, AC Immune, Adamas, Avanir, Boehringer-Ingelheim, Chase, Chiesi, Eisai, Elan, MedAvante, Merz, Neuroptix, Otsuka, and Sanofi-Aventis; has received consulting fees and research

Figure 12. Ms A's Montreal Cognitive Assessment Results 31 Months After the Initial Assessment

VISUOSPATIAL / EXECUTIVE		POINTS																				
		Draw CLOCK (Ten past nine) (3 points) 	1/5																			
[0]	[1]	[0] Contour [0] Numbers [0] Hands																				
NAMING																						
 horse [0]	 pig [1]	 kangaroo [1]	2/3																			
MEMORY		<table border="1"> <thead> <tr> <th></th> <th>TRAIN</th> <th>EGG</th> <th>HAT</th> <th>CHAIR</th> <th>BLUE</th> </tr> </thead> <tbody> <tr> <td>1st trial</td> <td>X</td> <td>✓</td> <td>X</td> <td>X</td> <td>X</td> </tr> <tr> <td>2nd trial</td> <td>✓</td> <td>✓</td> <td>✓</td> <td>✓</td> <td>✓</td> </tr> </tbody> </table>			TRAIN	EGG	HAT	CHAIR	BLUE	1st trial	X	✓	X	X	X	2nd trial	✓	✓	✓	✓	✓	No points
	TRAIN	EGG	HAT	CHAIR	BLUE																	
1st trial	X	✓	X	X	X																	
2nd trial	✓	✓	✓	✓	✓																	
ATTENTION		Read list of digits (1 digit/sec). Subject has to repeat them in the forward order [1] 5 4 1 8 7 Subject has to repeat them in the backward order [1] 7 4 8 1 5		2/2																		
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors		[1] FBACMNAAJKLBAFAKDEAAAJAMOFAB		1/1																		
Serial 7 subtraction starting at 80		[0] 73 DK [0] 66 [0] 59 [0] 52 [0] 45 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt		0/3																		
LANGUAGE		Repeat: She heard his lawyer was the one to sue after the accident. [0] The little girls who were given too much candy got stomach aches. [0]		0/2																		
Fluency / Name maximum number of words in one minute that begin with the letter B		[0] 10 (N ≥ 11 words)		0/1																		
ABSTRACTION		Similarity between e.g. banana - orange = fruit [1] eye - ear [1] trumpet - piano		2/2																		
DELAYED RECALL		<table border="1"> <thead> <tr> <th>Has to recall words WITH NO CUE</th> <th>TRAIN</th> <th>EGG</th> <th>HAT</th> <th>CHAIR</th> <th>BLUE</th> </tr> </thead> <tbody> <tr> <td>Category cue</td> <td>X</td> <td>X</td> <td>X</td> <td>X</td> <td>X</td> </tr> <tr> <td>Multiple choice cue</td> <td>hicycle</td> <td>egg</td> <td>hat</td> <td>lamp</td> <td>red</td> </tr> </tbody> </table>		Has to recall words WITH NO CUE	TRAIN	EGG	HAT	CHAIR	BLUE	Category cue	X	X	X	X	X	Multiple choice cue	hicycle	egg	hat	lamp	red	Points for UNCUED recall only
Has to recall words WITH NO CUE	TRAIN	EGG	HAT	CHAIR	BLUE																	
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© Z.Nasreddine MD Version 7.1 www.mocatest.org		Normal ≥ 26 / 30		TOTAL 8/30																		
Administered by: _____				Add 1 point if ≤ 12 yr edu																		

Figure 13. Ms A's Clock Drawings From the Initial Visit to 31 Months Later



support from AstraZeneca, Avid, Bristol-Myers Squibb, Eli Lilly, Genentech, GlaxoSmithKline, Janssen, Medivation, Merck, Pfizer, Roche, and Toyama; has received research support only from Baxter, Functional Neuromodulation, GE, and Targacept; has received other research support from Alzheimer's Association, Arizona Department of Health Services, National Institute of Mental Health, and National Institute on Aging; is a stock shareholder in Adamas; and is listed as a contributor to a patent owned by the University of Rochester (Rochester, New York) for "Biomarkers of Alzheimer's Disease." **Drs Hall, Fleisher, and Seward** and **Mss Brand and Dougherty** have no personal affiliations or financial relationships with any commercial interest to disclose relative to the activity.

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None reported.

CASE CONFERENCE

The Banner Alzheimer's Institute Case Conference is a weekly event in which physicians and staff discuss challenging and/or teaching cases of patients seen at the Institute's Stead

Family Memory Clinic. These conferences are attended by a multidisciplinary group that includes Banner Alzheimer's Institute dementia specialists, community physicians (internal medicine, family medicine, and radiology), physician assistants, social workers, nurses, medical students, residents, and fellows.

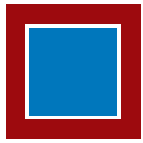
BANNER ALZHEIMER'S INSTITUTE

The Banner Alzheimer's Institute located in Phoenix, Arizona, has an unusually ambitious mission: to end Alzheimer's disease without losing a generation, set a new standard of care for patients and families, and forge a model of collaboration in biomedical research. The Institute provides high-level care and treatment for patients affected by Alzheimer's disease, dementia, and related disorders. In addition, the Institute offers extensive support services for families and many unique and rewarding research opportunities.

DISCLAIMER

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THE PRIMARY CARE COMPANION FOR CNS DISORDERS

Supplementary Material

Article Title: As Time Goes By

Author(s): Roy Yaari, MD, MAS; Geri Hall, PhD, ARNP, GCNS, FAAN; Helle Brand, PA; Jan Dougherty, RN, MS; Adam S. Fleisher, MD, MAS; James D. Seward, PhD, ABPP; and Pierre N. Tariot, MD

DOI Number: doi:10.4088/PCC.13alz01518

List of Supplementary Material for the article

1. Travel Guide for People With Dementia

Disclaimer

This Supplementary Material has been provided by the author(s) as an enhancement to the published article. It has been approved by peer review; however, it has undergone neither editing nor formatting by in-house editorial staff. The material is presented in the manner supplied by the author.

Travel Guide

for People with Dementia

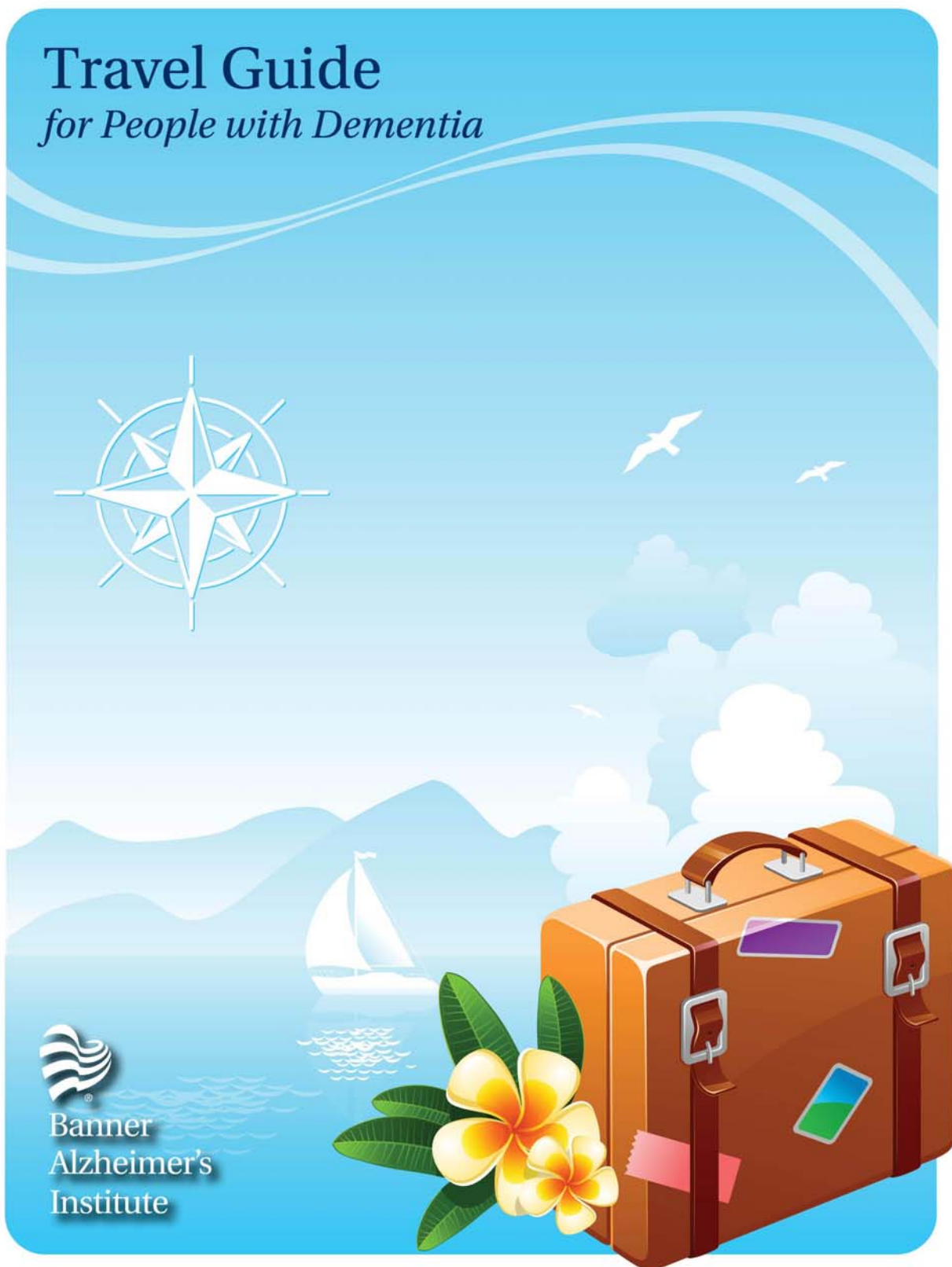


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Created and compiled by: Geri Hall, PhD, ARNP, CNS, FAAN; 4/2007

Introduction

Many people enjoy travel as a form of recreation, relaxation, and an opportunity to learn. While travel may be a positive experience for most people, it poses special problems for people with dementing illnesses, such as, Alzheimer's disease, vascular dementia, Lewy Body Dementia, or any injury that results in disabling intellectual impairment.

People with dementia have ever-increasing trouble with changes of pace, changes in location, fatigue, groups of people, changes of time zone, and noise. In a familiar environment there are many environmental cues that help a person with dementia to remain connected in reality. A favorite chair, a well-learned TV control, and a familiar floor plan are taken for granted. Unfamiliar places, however, lack these familiarities and can result in increased confusion, anxiety, and fear. Places that once were familiar, such as a second home, can seem new or alien, triggering fear or anger. Caregivers who are planning to travel need to plan trips carefully in advance, using both travel and health care professionals to determine the best possible methods to minimize distress to the patient.

The following guidelines have been developed to assist you with travel planning. After reading the guidelines you might want to discuss them with either your physician or your local chapter of the Alzheimer's Association.

Plan Early

Careful well-informed planning is the best way to guarantee a successful trip. These plans involve considering the following:

Considerations	Reason
What are the person's limitations and strengths?	To determine whether the person should be able to manage the trip you are planning.
Where are you going?	The distance traveled and location will determine the most efficient method of travel.
How long is the trip?	Prolonged travel involving many destinations or touring can be very disruptive to the person.
Where will you be staying?	If staying in an acquaintances home, do they understand dementia? If in hotels, attention must be paid to exits and available amenities.

Considerations	Reason
What will you be doing when you get there?	Use the method that involves the least time and “hassle.” As a rule, do not plan for the person to help with driving.
What resources or special things will you need during the trip?	Many hotels and airlines offer special services for the disabled. Using them can enhance the success of the trip.
What can be done in case of emergency?	Do you know of medical services in the areas you travel to? Do you need to take special medications with you in case of agitation? Having a plan can save hours of stress and panic.

What are the person’s limitations and strengths?

As a general rule, the more advanced the disease, the more difficult travel will be. For example, someone who is still relatively independent and cares for themselves will have fewer problems with travel than someone who requires direction to bathe and change their clothing. Also, people with behavioral problems such as paranoia or delusions (missed perceptions, fears, or fixed false beliefs or thoughts) have a more difficult time even when intellect skills are relatively good.

As a rule, someone who requires assistance with bathing, changing clothing, dressing, and toileting will have significant difficulty even with short simple overnight trips. At a time when it may be easier for retired people to visit adult children who work, it may be better to have the children visit you – even if it means paying for travel!

Persons who exhibit any of the following behaviors should **avoid** overnight travel (unless in an emergency):

- Become physically or verbally aggressive.
- Misperceptions, have paranoid thoughts, hallucinations (see things that are not present), or delusions (for example, think people steal from them).
- Become confused during or after social outings.
- Waken at night confused.
- Have poorly managed incontinence (or require special assistance or equipment)
- Need help with feeding if public dining rooms must be used.
- Have episodes where they do not recognize their caregiver.

- Prone to falling.
- Yell, scream, or cry spontaneously.
- Resist or argue with their caregiver's directions.
- Wander or pace.
- Demand to leave social settings or restaurant early.
- Easily frightened, confused or agitated.
- Unable to communicate their needs to others.
- Have unstable medical conditions.

What are the caregiver's limitations?

There are also caregiver-related issues to be considered. Caregivers should avoid traveling with their impaired person if they (the caregiver) have any of the following characteristics:

- Become upset or cannot manage well during a crisis.
- Are embarrassed when their person "acts out" or does something embarrassing.
- Have unstable or complicated health problems.
- Are embarrassed to go into an "opposite sex" restroom to supervise the person.
- Are unable to manage high stress situations or with little sleep.
- Insist on maintaining strict honesty and argue with the person about mistakes and misperceptions.
- Are not able or willing to make significant adaptations during the trip – often a moment's notice – to meet the person's changing needs, including canceling the travel mid-trip.
- Don't think they want to take the trip but, "will do it for the person."
- Think there will be no change in the person's behavior during the trip.
- Are not will to plan well in advance.
- Resist seeking help as needed, thinking they can manage on their own.
- Think that trips to familiar places (such as an adult child's home or cabin) will be "just like it used to be", because it's "familiar and fun."

The trip

While travel may be enjoyable, getting to your destination is generally not relaxing. The following are principles to consider when planning the trip:

1. The process of "getting there" should be as short and simple as possible. Plan a trip that involves as few changes as possible.

2. Plan to travel during the “best time of the day” for the person.
3. Trips should be to a single destination, rather than a series of visits. For example, you would want to travel to a wedding and home, but not take three months stopping at friends homes along the way.
4. Stick with the familiar. Vacation in ways your loved one was accustomed to before the onset of the disease.
5. Consider a shorter trip. Day or weekend trips may be a better alternative, particularly if you are unsure of the loved one’s reaction to travel. If everything goes well, go for a longer visit.
6. If you loved one has not traveled in 6 months, schedule a “trial” overnight stay nearby home to see if the patient can still tolerate travel.
7. Gather necessary papers and documents: insurance cards, passports, physician’s phone number, medication refills, and the patient’s medical record. Do not expect your loved one to carry these documents or tickets.
8. Rest periods should be built into the travel schedule. Planning too many activities, such as meals in a restaurant, can lead to late night confusion or agitation. Do not plan activities for the night you arrive.
9. Use services specifically designed for people with disabilities – this includes bypassing long security lines in airports. Ask for a wheelchair escort to bypass these lines
10. Spend as little time as possible in areas with large groups of people (more than 20), loud noises, or lots of activity (for example airport gate areas). Avoid busy places and situations that will cause anxiety for your loved one.
11. NEVER expect the person with dementia to travel alone. Do not expect travel employees (flight attendants, gate personnel) to care for or supervise your loved one. Always have the person carry identification!
12. Expect the person to become more confused, agitated, or behaviorally difficult during the trip. Assist with menus and choices.
13. Do not expect other members of a tour to volunteer or be agreeable if you need help with the person.
14. Advise hotels, airlines, tour operators, or people you are visiting that you are traveling someone with memory impairment. Be specific about safety concerns and special needs. If you are staying in a private home, guest home, or bed and breakfast, do not “surprise” your overnight host with your loved one’s condition. Explain it fully, well in advance. Do not think they won’t notice. Don’t be upset if they feel they cannot handle the visit – especially if there are children in the home.
15. NEVER travel without a full set of reservations!
16. Always provide family members with an itinerary and call home regularly.
17. Make a list of the daily routine and special items you need to take with you.

18. ALWAYS have the person with memory loss identified, preferably with a bracelet the patient cannot misplace. (MedicAlert Safe Return Program is advised with the Alzheimer's Association, www.alz.org/safetycenter)
19. Use good judgment when telling your loved one about the trip. Discussing it too far in advance may produce anxiety and agitation.
20. Be flexible. Have contingency plan that allows you to leave early if your person becomes ill, agitated, or wants to go home.
21. Keep your sense of humor and laugh at all the things that happen. They will be part of a wonderful memory of your travels together.
22. If the trip is prolonged, develop a list a medical professionals and Alzheimer's Association chapters along your route.
23. NEVER leave your person or ask strangers to watch him/her. A person who does not know your loved one or the disease will not know how to react in a difficult situation.
24. Avoid traveling at peak travel seasons (e.g. holidays such as Thanksgiving, Christmas).
25. Take medications with you to manage stomach upset, diarrhea, or other temporary problems caused by changes in food and water.
26. Know who to get help and who can help in countries where you do not speak the language.
27. Check the "Yellow Pages" to see if there is a travel agent in your area specializing in planning trips for people with disabilities. If so, use the specialized service.
28. Ask Banner Alzheimer's Institute for business cards that can be passed out discretely to explain the person's memory loss/behavior (card says: My companion has a medical condition that affects memory and thinking. Your patience is appreciated.)

Tips for Travel

For Hotel Stays:

1. Ask for a large quiet room in advance of your arrival.
2. Take familiar pajamas, robe, slippers, and if possible, pillows.
3. Use room service the night you arrive.
4. Take several night lights with you for the bathroom and bedroom.
5. Evaluate the room for safety and remove potential hazards. Unplug the coffee maker, hair dryer, etc.
6. Be on guard against wandering.
 - If there are two beds in the room, sleep in the one closest to the door.
 - If you are a sound sleeper and your loved one is not, obtain a door alarm from a catalogue specializing in travel needs.

- Travel with a childproof doorknob cover so if the room doorknob is round you can use it.
 - Avoid rooms with sliding glass doors leading to the outside.
7. If your person has a prescription for a medication for mood control, take it with you and use it when he/she begins to become anxious.
 8. Never ask the person to pack for the trip. It will likely cause anxiety and/or confusion.
 9. Allow for extra time for everything. Bathe and dress the person without rushing. Lay toiletries and clothing out in plain view for the patient. Carry only comfortable clothing that allows for ease in using the toilet.
 10. Provide time for naps. Rest is important for both the person with dementia and for you.

For Airplane Travel:

Since September 11, 2001, the world of travel has changed. Passengers are now being exposed to prolonged waits, rigorous security checks long lines, and limitation of carry-on luggage and food. Few airlines are serving meals or snacks of any kind. These new regulations make it more difficult to fly with someone with a dementing illness.

1. When making the reservations:
 - Fly during the person's best time of day. Build a "window" of time with flexible connections so you are not rushing through the airport with you loved one.
 - Reserve bulkhead (first row) seats and place the person next to the window – away from other passengers.
 - Try for as few connecting flights (plane changes) as possible.
 - Ask about services and lounges for disabled persons – have the travel agent or airline ticket agent arrange to use them.
 - Larger cities and possibly the internet have travel agencies specializing in planning for people with disabilities.
 - Avoid traveling at peak travel times (Thanksgiving, Christmas, spring break) and when there will be a high risk of weather delays (snow storms, ice storms, thunderstorms, fog).
2. Connect with the Alzheimer's Association (www.alz.org or 1-800-272-3900) and register your loved one for the MedicAlert Safe Return Program in case they get lost. Have the person wear a Safe Return bracelet/pendant.
3. Avoid discussing the trip or travel plans too far in advance – especially if he/she is easily upset or will worry about it.
4. If the person is easily upset, have the doctor/practitioner prescribe a light dose of a mood controller and start it a few days before the trip.

5. **The night before:**
 - Do not give the person a laxative.
 - Make sure the person gets to bed earlier.
 - Arrange for an emergency number where messages can be left that you can check.
 - If the person becomes anxious, use prescriptions for mood.
6. **The morning of the trip:**
 - Make sure the person is wearing very little metal, slip-on shoes, and garments with few pockets to minimize the need for additional security checks. Avoid wearing metal buckles or buttons. The metal detectors are often crowded and can be a source of anxiety, confusion, and agitation.
 - Arrange for a wheelchair escort to the gate to minimize waits in security lines, especially during holiday seasons or in large cities. Explain to the security personnel that your loved one has dementia, even use the “Alzheimer’s” word, and that you need to be with him/her if they want to “wand” the patient.
 - Minimize carry-on luggage and purses, but carry on medicines. Pack the suitcases for the person. Check every bag you can to minimize security problems. If your loved one is carrying a purse or suitcase, there is a good chance it may be searched. This could cause agitation.
 - Use judgment when thinking about the security. If there are soldiers with automatic rifles, will your loved one misinterpret that?
 - Avoid caffeine and limit fluid intake for three or four hours before the trip.
 - Be sure to pack something to keep your person occupied or distracted during the trip. Things like a magazine, pictures, a deck of cards and a favorite sandwich/snack will be helpful.
 - If you plan to use a tranquilizer, ask your doctor about when to expect its peak action. Some mood controlling medication should be given five hours before the flight.
 - Be sure that the person is carrying identification!
7. **During the trip.**
 - Spend minimal time waiting in crowded gates.
 - Pre-board with other passengers requiring extra time.
 - Place the person in a seat next to the window so they interact only with you.
 - No fluids unless it is a long flight – then stick with juices or water. Avoid the person drinking alcohol on the plane!
 - Use wheelchair or electric carts to travel from gate to gate.

- If there is a long layover, talk with the ticket agent about a lounge for disabled persons or another quiet area in which the person can wait in peace.
- Carry all-important papers yourself. Do not give your loved one boarding passes or passports.
- Anticipate when to use the distracters you have packed e.g. a snack/ favorite food, magazines and games, and a sweater.
- Have someone meet your plane whenever possible.

For Automobile Travel:

Think about the following when traveling more than one hundred (100) miles by car.

1. Never leave a confused person alone in a car. He/she can “play” with the gearshift or release the parking brake or decide to get out of the car and take a walk.
2. Have activities such as simple car games or sing-alongs to help pass the time. Include recorded favorite music or even a book on tape.
3. Dress the person in comfortable casual washable clothing that allows for ease when using restrooms.
4. Prepare for spills and soiled clothing by keeping an extra set of clothes and shoes in the car.
5. Make sure you have emergency equipment in the car including a gallon of water, cat litter or sand (for ice), blankets, de-icer spray, jumper cables, ice scrapers, spare tire, and if at all possible, a cellular telephone.
6. Carry a covered cup and straw for drinking.
7. Pack a container of wet wipes in the car for accidental spills.
8. Never drive more than two hours without taking a break.
9. Stop early in the day – Covering too much distance in one day may cause confusion at night – even if the person slept all day in the car.
10. On overnight trips, bring familiar pajamas, robe, slippers, and the person’s pillow. Pack the suitcases for the patient.
11. Do not plan activities for the night you arrive at your destination.
12. People with dementia should not drive, therefore, do not rely on the person to assist with driving, reading the map, locating exits, or finding addresses.
13. If the person becomes confused or belligerent, stop for the day at the next available place. DO NOT attempt to calm the person and keep going as he/she may try to leave the moving car or wrestle the driver for the steering wheel.
14. Take an additional driver/caregiver on trips involving more than 6 hours of driving time.

15. Do not take risks rather than “bother” family or friends for help. If your children who live in another state tell you “things will be fine” or “you are making too much of a fuss,” tell them they don’t understand the problem!
16. Make sure the car has good tires and is serviced regularly.
17. Plan the itinerary well in advance and leave copies with family or friends. Check in with family nightly.
18. Plan to use the restroom at regular intervals. Make sure you pack an “occupied” sign to hang on a public restroom door.
19. Make sure the person is wearing a Safe Return bracelet, carrying wallet identification, and you have recent picture with you.
20. ALWAYS, ALWAYS keep the seat belt buckled and the doors locked.
21. Remember that an automobile has high potential for danger. Proceed accordingly.

For Bus Tours:

1. Consider another route, if possible.
2. Only go on short trips.
3. Go with familiar people.
4. Make sure the person gets adequate rest. This may mean using room service at night or skipping some of the planned activities.
5. Try to set up the room in the same way each night.
6. Try to avoid packing in front of the person each day.
7. Make back up plans for returning home at several points during the trip should the person be unable to manage. This may involve renting a car.
8. Carry an “occupied” sign for restrooms.
9. Have the person wear comfortable clothing that provides easy access for using the toilet.
10. Make sure the person wears a MedicAlert Safe Return bracelet/pendant and has identification in their wallet.
11. Carry a recent photograph of the person.
12. In restaurants, eat familiar favorite foods at non-peak hours. Sticking to the person’s usual schedule whenever possible.
13. Other tourists are not caregivers, therefore, do not expect them to help you. Many times other tour members become angry or offended if they must tend to person with dementia during their vacation.

For Tours and Cruises

1. Make your own airline transportation reservations to allow for increased flexibility at the beginning and end of the trip. For example, if the tour/cruise requires you to fly to a city where the tours/cruise starts, allow for extra overnight time in that city to assure the person is well-rested prior to joining the tour.

2. Take extra medications with you and a medical history in case of medical emergencies or changes in trip plans. Always take medications with you rather than checking them with other luggage.
3. Keep the schedule simple and make sure extra rest is planned at the end of each day.
4. Check in regularly with family members.
5. Make sure family members have the trip itinerary and telephone numbers of hotels where you will be staying.
6. NEVER travel without hotel reservations. While spontaneity may be fine for people who are well, trying to find a place to sleep when a person with cognitive loss is present can be a nightmare.
7. Make sure your health insurance will cover emergencies while not at home.

For Celebrations:

1. Travel one or two days in advance to allow the person time to rest before the celebration.
2. Try to attend events scheduled early in the day.
3. Provide the person with short periods of attendance at parties and activities alternating with quiet rest periods.
4. Minimize times spent in large groups, noisy places, and with “spontaneous” or energetic children.
5. Do not expect your person to remember names of family or friends.
6. Do not feel *disappointed* if your person does not remember the event.

For Weddings:

1. Know what to expect. Discuss the event with your family, the bride, and the groom.
2. Don't let “should” make the decision, e.g. “Grandpa should attend because the groom is his only grandson”.
3. Set realistic expectations about travel plans, rest before and during the event, and length of stay during the wedding. For example, you may have the person attend the wedding, rest for an hour, attend the reception for a brief period, and call it a day. You may decide to attend only the wedding.
4. If the usual caregiver has responsibilities during the wedding, it is best to find two good substitute caregivers who are comfortable and compatible with your loved one. Have the caregivers stay with the person whether he/she attends the wedding or not.

For RV Travel and the Travel Lifestyle:

1. Understand that traveling will be more difficult than in previous years.

2. If you live in an area seasonally, make sure you have a physician in both areas and the physicians communicate and pharmacies with each other, sharing the same plan of care.
3. When arriving in a new area, give the person time to adjust and rest before participating in activities.
4. Understand what was a familiar residence last year, may not be familiar this year.
5. Make sure you have a support system in each location where you plan to stay:
 - A church.
 - Community services including day care, visiting nurses, Alzheimer's Association, respite care, homemaker services, meal services, and support groups.
 - Supportive friends and/or family.
 - Transportation services.
6. If you are "roaming" and the person becomes confused, stop and have the person rest – perhaps as long as a few days. If the confusion does not resolve, seek medical attention at a nearby hospital.
7. Know your medical coverage and where you are entitled to seek care. Know what types of permission are required for medical care to be reimbursed.
8. Carry a copy of your durable power of attorney and advanced directives in case of emergency.
9. Have an emergency plan in place in case the caregiver becomes ill, including family who know your itinerary and will come if needed.
10. Have vital information about you and your patient in a prominent place in the motor home.
11. Have the motor home serviced regularly and the tires checked.

Should the Worst Occur...

When planning care for people with dementia, a good rule to follow is "Plan for the worst and hope for the best."

This rule certainly applies to travel. Whenever people with dementia travel, it is safe to assume their confusion will worsen for the duration of the trip. This may produce, discomfort, fear, or worse. Some people demand to go home immediately. Some become agitated, even violent. It is important for the caregiver to realize that the person will not be able to control his/her behavior when this happens. They cannot be reasoned with. Therefore, the caregiver must have a plan developed in case of behavioral emergencies.

Most individuals will have increasing anxiety before losing control of their emotions. Learn to recognize the early warning signs of increased anxiety in your

loved one: increased movement; statements about the crowds, the menu, or things going on in the environment; attempts to leave a situation; anxious statements about needing to go home or to the toilet; loss of eye contact; crying; becoming physically ill; becoming incontinent of urine or stool; or wanting to lie down. The earlier you can recognize increasing anxiety and remove the person from the uncomfortable situation, the easier the problem will be to manage.

1. Recognize rising anxiety and take steps to get the person to a quiet area to rest if at all possible. Keep the person in the quiet area until the anxiety disappears. Then get the person to the hotel room to rest. DO NOT continue the activity!
2. Keep any mood controlling medications with you and use them when you notice anxiety building, rather than waiting until the situation is out of control.
3. Make sure the person has identification on at all times. (MedicAlert bracelets can be used)
4. If traveling to a single destination, know where emergency medical care can be obtained. Seek it early before the person loses control.
5. Take a brief written medical history with you, a list of the patient's medications, allergies and a copy of your power of attorney.
6. Have an emergency telephone number you can call to check for messages.
7. Check in with family members through the trip.
8. Avoid driving to places where health care and support will not be available.
9. During the trip, be flexible enough to take the most expedient route home if things are going poorly.
10. Do not plan to rely on the kindness of strangers to help you in a crisis.
11. Do not put off crisis planning because "We'll cross that bridge when we come to it," or "that would never happen to my loved one!"
12. If, after reading this booklet, you decide traveling with your loved one involves too many risks, seek respite for the person and go on the trip with a friend or relative. The trip may provide you with much-needed respite, thereby allowing you to care for your loved one far longer.

Advance Travel Planning

The purpose of these guidelines has been to assist you with planning travel with your loved one with dementia. It is suggested you contact both your physician and your local chapter of the Alzheimer's Association when planning travel. Discuss these guidelines and your concerns with them and other dementia professionals. Advanced planning can only enhance the success of your trip and help to assure pleasant memories.

Resource Numbers

Resource Person	
Title	
Phone	

Travel Information

Patient's Name	
Nickname	
Home Address	
Phone	

In case of Emergency Contact	
Family/Next of Kin	
Address	
Phone	

Family/Next of Kin	
Home Address	
Phone	

Primary Physician	
Address	
Phone	

Specialist Physician (Type)	
Address	
Phone	

Physician (Type)	
Address	
Phone	

Medicines	Prescription Number	Doctor
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		
11		
12		
13		

Pharmacy	
Phone	

Medical History (Conditions person has/is treated for)
1
2
3
4
5

Allergies

Special foods needed

Health Insurance Numbers	
Company	
Policy	
Agent	
Phone	
Authorizations needed	

Company	
Policy	
Agent	
Phone	
Authorizations needed	

HMO	
Name	
Address	
Phone	
Policy number	
Pre-approval/member service number	
Do they cover emergency room visits for non-covered hospitals	
Do they cover medical care outside the country?	
What authorizations are required before care can be reimbursed?	
How much of the care will you have to pay out of pocket?	

Travel Destination

Itinerary

Day 1	Location	
	Lodging	
	Phone	

Day 2	Location	
	Lodging	
	Phone	

Day 3	Location	
	Lodging	
	Phone	

Day 4	Location	
	Lodging	
	Phone	

Day 5	Location	
	Lodging	
	Phone	

Day 6	Location	
	Lodging	
	Phone	

Day 7	Location	
	Lodging	
	Phone	

Travel Checklist

Identification (bracelet, clothing, wallet; baggage and item tags	_____
List of medications, prescription numbers, and pharmacy phone number	_____
Adequate supply of medications (prescriptions and occasional over the counter medications) for the trip and an extra week	_____
List of physicians: primary, specialists, and MDs along the way	_____
Insurance and HMO policy numbers, who to call for prior approval, and phone numbers	_____
Itinerary for family members	_____
Alzheimer's Association chapters at your destinations	_____
Night lights	_____
Accessible changes of clothing	_____
Love one's own pillow, favorite "jammies," robe, slippers	_____
Doorstop alarm	_____
Puzzles, games, distracters, snacks	_____
Decal or Suncatcher for sliding glass doors	_____
Safe return instruction card	_____
Recent photograph and written description of loved one	_____
Container of moist novellettes	_____
Passports, etc.	_____
First aid kit	_____
"Occupied" sign for restroom	_____
Spare tire	_____
Blankets, sand, drinking water, emergency food; and bad weather equipment for car	_____
Spare set of car keys	_____
Pre-marked road map of itinerary	_____
Love one's favorite things	_____

References

This booklet was a team effort, developed to assist families with demented loved ones plan travel. The following sources of information and editorial support are gratefully acknowledged for their help in the preparation of this booklet.

Alzheimer's Association, Greater Phoenix Chapter, Phoenix, Arizona

Comments regarding travel from members of the Alzheimer's Website,
ALZHEIMER@wubios.wustl.edu

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Moxley, J. (1996). Totebag and Toothbrush: Travel Tips for the Alzheimer's Caregiver. Winston-Salem, North Carolina: Piedmont Triad Alzheimer's Association

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