

TRAVEL GUIDELINES FOR PEOPLE WITH DEMENTING ILLNESS

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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, for example, Alzheimer's disease, multi-infarct dementia, Parkinson's disease, Pick's disease, or 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 moored in reality. A favorite chair, a well-learned TV control, and a familiar floor plan are taken for granted.

Unfamiliar places, however, lack these well-known moorings and result in increased confusion, anxiety, and fear. Even places that once were familiar, such as a winter 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 cause the least 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 your patient'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 patient.
Where will you be staying?	If staying in an acquaintances home, do they understand about dementing illness? If in hotels, attention must be

What will you be doing when you get there?	paid to exits and available amenities. Fatigue, large groups of people, and noise bother many patients. Plan for regular rest, quiet stops, and a relaxed itinerary.
How are you planning to get there?	Use the method that involves the least time and "hassle." As a rule, do not plan for the patient 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 PATIENT'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 intellectual 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 their travel!

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

- Become physically or verbally aggressive
- Miss perceptions, have paranoid thoughts, hallucinations, 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 who require special assistance or equipment with feeding if public dining rooms must be used)
- Have episodes where they do not recognize their caregiver
- Fall
- Yell, scream, or cry spontaneously
- Resist or argue with their caregiver's directions
- Wander or pace
- Demand to leave social settings or restaurants early
- Are easily frightened, confused or agitated
- Are unable to communicate their needs to others
- Have unstable medical conditions

ALSO ASSESS 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 can not manage well during a crisis
- Are embarrassed when their patient "acts out" or does something embarrassing
- Have unstable or complicated health problems
- Are embarrassed to go into an "opposite sex" restroom to supervise the patient
- Are unable to manage in high stress situations or with little sleep
- Insist on maintaining strict honesty and argue with their patient about mistakes and missed perceptions
- Are not able or willing to make significant adaptations during the trip -- often at a moment's notice-- to meet the patient's changing needs, including canceling the travel mid-trip.
- don't think they want to take the trip but will do it for the patient.?
- Think there will be no change in the patient's behavior during the trip
- Are not willing 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. 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.
3. Stick with the familiar. Vacation in ways your loved one was accustomed to before the onset of the disease.
4. Consider a shorter trip. Day or weekend trips may be a better alternative, particularly if you are unsure of your loved one's reaction to travel. If everything goes well, go for a longer visit.
5. If your loved one has not traveled in 6 months, schedule a "trial" overnight stay nearby home to see if the patient can still tolerate travel.
6. 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.
7. 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.
8. Save travel for the patient's best time of day.
9. Use services specifically designated for people with disabilities.

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 patient carry identification!
12. Expect the patient 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 patient.
14. Advise hotels, airlines, tour operators, or people you are visiting that you are traveling with someone with memory impairment. Be specific about your 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 can not 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 can not misplace.
19. Use good judgement when telling your loved one about the trip. Discussing it too far in advance may produce anxiety and agitation.
20. Be flexible. Have a contingency plan that allows you to leave early if your loved one 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 of medical professionals and Alzheimer's Association chapters along your route.
23. NEVER leave your loved one alone 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 travelling at peak travel seasons (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 how 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.

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

TIPS FOR TRAVEL

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.
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7. If your patient 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 patient to pack for the trip. It causes anxiety and 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.

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 limitations of carry-on luggage and food. Few airlines are serving not just meals, but food 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 patient's best time of day. Build a "window" of time with flexible connections so you are not rushing through the airport with your 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 arrange to use them
 - Larger cities and possibly the internet have travel agencies specializing in planning for people with disabilities.
 - Avoid travelling 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. Call the Alzheimer 's Association and register your loved one for the Safe Return Program in case they get lost. Have the patient wear a Safe Return bracelet. If you can't get the person to wear a Safe Return bracelet, try for a Medic-Alert bracelet or pendant.
3. Avoid discussing the trip or travel plans in advance of the day with the patient -- especially if they are 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.
4. The night before
 - Do not give the patient a laxative the night before
 - Make sure the person is well rested
 - Arrange for an emergency number where messages can be left that you can check
 - If the person becomes anxious, use prescriptions for mood.
5. The morning before 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. The metal detectors are often crowded and can be a source of anxiety, confusion, and agitation. Especially during holiday seasons or in large cities, avoid wearing metal buckles or buttons. Explain to the security personnel that your loved one has dementia, even use the "Alzheimer" 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 patient. 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 judgement 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.
 - Bring something such as pictures and a sandwich to use as a distracter
 - If you plan to use a tranquilizer, ask your doctor about when to expect its peak action. Some (e.g. Haldol) should be given five hours before the flight.
 - **Be sure that the patient is carrying identification!**
6. During the trip
 - Pre-board with other passengers requiring extra time
 - Place the patient 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. Never let the patient drink alcohol on the plane!
 - Spend minimal time waiting in crowded gates
 - Use wheelchair or electric carts to travel from gate to gate
 - If there is a long layover, see if there is either a lounge for disabled persons or another quiet area in which the patient can wait in peace.
 - Carry all-important papers yourself. Do not give your loved one boarding passes or passports
 - Bring a snack of the patient 's favorite food, magazines and games to use for diversions, and a sweater
 - Have someone meet your plane whenever possible

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

Automobile Travel:

Think about the following things when traveling more than one hundred 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.
2. Have activities such as simple car games or sing-alongs to help pass the time. Include cassette tapes of your loved one's favorite music.
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 your loved one's 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 patient 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 patient 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 "bothering" 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 a 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.

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

Bus Tours:

1. Consider another means of transportation, if possible.
2. Only go on short bus 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 patient each day
7. Have plans for returning home at several points during the trip should the patient 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 patient wears a Safe Return bracelet and has identification in their wallet.
11. Carry a recent photograph of the patient.
12. In restaurants, eat familiar favorite foods at non-peak hours, sticking to the patients 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 a person with dementia during their vacation.

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 fly to a city where the tours/cruise starts, allow for extra overnight time in that city to assure the patient 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.

Celebrations:

1. Travel one or two days in advance to allow the patient time to rest before the celebration
2. Try to attend events scheduled early in the day
3. Provide the patient 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 patient to remember names of family or friends
6. Do not feel disappointed if your patient does not remember the event
7. Pack suitcases for the patient

Weddings:

1. Know what to expect. Discuss the event with your family, the bride, and the groom.
2. Don't let "shoulds" make the decision such as "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 patient attend the wedding, rest for an hour, attend the reception for a brief period, and call it a day. You may decide to attend the 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 patient whether he/she attends the wedding or not.

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

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 patient 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 demented patients travel, it is safe to assume their confusion will worsen for the duration of the trip. This may produce, discomfort, fear, or worse. Some patients demand to go home immediately. Some become agitated, even violent. It is important for the caregiver to realize that the patient 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 patients 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 patient from the uncomfortable situation, the easier the problem will be to manage.

1. Recognize rising anxiety take steps to get the patient to a quiet area to rest if at all possible. Keep the patient 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 patient has identification on at all times. (Medic-Alert bracelets can be used)
4. If traveling to a single destination, know where emergency medical care can be obtained. Seek it early before the patient 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 throughout the trip
8. Avoid traveling 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 pamphlet, you decide traveling with your demented loved one involves too many risks, seek respite for the patient 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.

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 Person: _____

Title _____

Phone _____

Questions and Notes:

TRAVEL INFORMATION PLANNING

Patient's name:

Nickname:

Caregiver's name:

Home Address:

Phone:

In case of emergency contact:

Family/Next of Kin
Address
Phone

Family/Next of Kin
Address
Phone

Primary Physician
Address
Phone

Specialist Physician (Type) _____
Address
Phone

Physician (Type) _____
Address
Phone

Medicines:	Dosage	Prescription Number	Doctor
1.	_____	_____	_____
2.	_____	_____	_____
4.	_____	_____	_____
5.	_____	_____	_____
6.	_____	_____	_____
7.	_____	_____	_____

8. _____
9. _____
10. _____
11. _____

Pharmacy: _____ Phone _____

Over the counter medications (herbs, laxatives, cold pills, pain relievers, vitamins)

Medical history: (Conditions person has/is treated for)

- 1.
- 2.
- 3.
- 4.
- 5.

Allergies:

Special foods needed:

Health Insurance numbers:

Company:

Policy:

Agent:

Phone Number:

Authorizations needed:

Company:

Policy:

Agent:

Phone Number:

Authorizations needed:

HMO

Name:

Address:

Phone:

Policy Number:

Pre-approval/member services 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

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Travel agent:

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
- _ Loved 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 Towelettes
- _ 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
- _ Loved one's favorite things

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References

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

Comments regarding travel from members of the ALZHEIMER Web site,
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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.

Neurologists from the Department of Neurology, Mayo Clinic Scottsdale