



## Alzheimers Disease Caregiver Tips

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### From the Editor

*If a man has anything in him,  
travel will bring it out –  
especially ocean travel.  
-- Anonymous*



I first wrote about the topic of travel and dementia a dozen years ago; then as now, it is a tricky business. Some of what travel brings out in a person with dementia you might wish you could put back in. National

security restrictions and procedures and more crowded flights can cause delays, anxiety, and frustration. On the other hand, whereas 12 years ago I warned against long-distance travel for people with moderate to advanced dementia, in this issue I have recognized wider possibilities and greater individuality of circumstances.

When I first wrote about travel, I also recognized that most family caregivers tend to live in an ever-shrinking and more isolated world as the dementia of their loved one progresses, and the more the caregivers are likely to need a vacation, the less likely it is that their loved one can go with them. Then as now, I urge caregivers to go anyway. (Details follow.) You need it; you deserve it, and you're worth it. As my mother always said, don't postpone joy.

*Kathy Lawrence*



### Caregiver Respite – On Your Own

One of the reasons caregivers of people with AD become increasingly isolated is that going out becomes increasingly complicated as the disease progresses. People with AD tend to be most comfortable in a small, crowd-free, familiar and predictable environment, but as time passes, their caregivers are likely to crave a break from that narrow world. The other parts of this issue are devoted to how you can travel successfully *with* your loved one, but this section is devoted to urging you to take the vacation you need on your own or with a cheerful, compatible traveling companion – relative or friend.

Many years ago, I learned to juggle scarves from Steve Allen, Jr.. The first step after everyone receives a set of three scarves is “the guilt-free drop.” Nearly all of us in his audience believed we were genetically incapable of learning to juggle, so this was his way of helping us overcome our fear of failure; we watched our scarves fall to the floor, and the world didn't end.



You can leave your loved one for a day, a weekend, a week or a month, if you need it, and the world won't end either, but I advise you to begin with a short, guilt-free trip – a day away while someone else cares for your loved one. Chances are that you have friends or relatives who have been asking what they can do to help. If they are comfortable around your loved one and have some flexibility in their schedule, ask if they would be willing to stay at your house while you leave or, alternatively, take your loved one on a separate outing. If the person is likely to be uncomfortable with that option, tell them you need a break, but you

are overwhelmed by the idea of finding respite care. Would they be willing to do some research for you? If so, ask them to call, for example:

- The local Alzheimer's chapter
- The local Area Agency on Aging
- Adult day centers
- Home health agencies
- Local assisted living communities (which sometimes offer respite care as a means of introducing themselves to people who may one day choose to live there)
- The local Medicaid office (if your loved one is eligible)?

It's likely that at least one of the above groups will know what options are available to fit your budget (including free options for those who may need it). If your loved one is bedridden in the late stages of AD, he may also be eligible for respite care through Hospice.

Plan your day away carefully so that you do something that is truly pleasurable for yourself – on your own or with friends – and don't come back having tried to cram so much into your time away that you are more tired when you return than when you left. Savor the "care-free" moments, and don't let any glitches in your loved one's substitute care spoil your sense of well-being.

When you have gone away once, you can plan your next day away, or a longer more rejuvenating vacation. Our environment influences how we see our challenges. If we feel trapped in our everyday setting, the problems become more daunting, so take a daily vacation in your mind to your favorite haven, but also take a real vacation for both your body and soul's refreshment.

### Traveling together – Should you?

While traveling with his wife in Thailand many years ago, Robert Fulghum rode an elephant. When it was time to descend from the jostling experience, a ladder was raised with a sign that said: "Instructions for dismounting from elephant.



First, compose your mind." Traveling with a person who has dementia is always an elephant dismount situation. Begin by composing your mind.

The first step in composing one's mind is: Should my loved one go with me on this trip? If so, can I manage his care on my own? If not, who can I bring along to help? Factors that would seem to argue against having your loved one travel include:

- Disorientation, tears, anxiety and/or agitation in unfamiliar settings or among crowds
- A tendency to wander off
- Delusional, paranoid, aggressive or disinhibited behavior
- Heavy needs for assistance with dressing, bathing and toileting
- High risk of falling
- Unstable medical conditions

Then ask, in what ways will my loved one or others benefit by taking this trip? If your first grandchild is getting married, for example, and your loved one has long been close to his granddaughter, the extra effort required in making the trip may be worth it for everyone involved. But it helps a lot if your family has more in common with Auntie Mame than Amy Vanderbilt. Does your family delight in the possibility that anything might happen? Can everyone go with the flow?

Many years ago I had an offbeat friend from Michigan of Czechoslovakian heritage whose sister married a Texan. At the wedding reception, all the northern guests were taught country line dancing as a way of introducing them to the southern culture and welcoming them into the family. My friend felt that courtesy called for an equal gesture on her family's part, so she gathered them together, and on the spot made up a Czech folk dance which they dubbed the "Klotzky," whose chief feature was "a jump step" and flailing arms. It was an immediate success,



and I am told is now featured at all family gatherings. If your family is equally spontaneous, consider taking your family member with dementia anywhere you want to go.



At the same time, set realistic expectations. If your granddaughter wants her grandfather at her wedding, but hasn't seen him in a year and your gut feeling tells you that he will be more upset than pleased by the event, go

with what will be best for his well-being. Will your loved one with dementia be comfortable in this out-of-the-ordinary setting, or will he be frightened by the crowds, bored by the ceremony, and quickly fatigued by the unaccustomed hullabaloo?

Think of your own ease as well. Are you worried that he might speak his mind at inopportune times, that you will have to constantly look out for him in order to protect him from others who are unaware of his limitations, and that in so doing you won't enjoy the event yourself?

The focus should be on the people getting married, not on your loved one. If either you or he would be more comfortable if he were not there, make arrangements for him to stay behind. If you think he could handle the wedding but not the reception, make arrangements for him to attend only what is most appropriate, and be ready to revise your plans as needed if you guessed wrong.

### Going somewhere familiar

One of the most common travel destinations for older adults is either their children's/grandchildren's homes or their winter or summer home, if they alternate their time between two places. On these trips you know what you can expect at the end of the trail, and



children and grand-children generally try to do their best to be accommodating.

But those factors do not guarantee freedom from problems. The primary rule is to keep routines as normal and unhurried as possible. You can hurry a person with Alzheimer's disease, but it's not likely to get you the results you want, and your loved one isn't likely to understand why you're upset, as this old joke confirms:



*The luggage-laden husband stared miserably out the window of the airline terminal at the departing jet.*

*"If you hadn't taken so long getting ready," he complained to his wife, "we would have caught that plane."*

*"Yes," she replied, "and if you hadn't hurried me along, we wouldn't have so long to wait for the next one!"*

If somebody's routine must change in order to help things run smoothly, make it yours. If you both normally bathe in the morning before leaving the house, try taking your shower the night before instead.

Keep food as close to normal as possible, too. If you can pack some familiar foods, that's terrific, but these days most older adults are used to eating out at chain restaurants that look virtually the same wherever you go, so restaurant eating is not necessarily a problem. If crowds and waiting are upsetting to your loved one, try to revise the routine slightly so that you can eat during "off-hours," such as 11:30 instead of noon. (This may also be helpful in adjusting to any time changes built into your trip.)

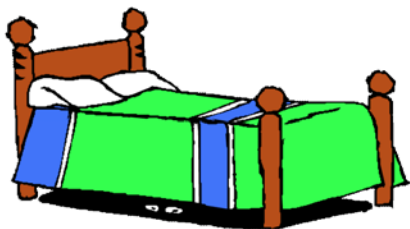
If you are traveling by car, stop often to take a break and stretch your legs. Lower your expectations for the distance you must cover in a day, and build in simple pleasures, if you can -- a walk in a historical garden or along a nature trail. Never leave your loved one alone in the car, and risk having her

wander off or drive off.

If keeping your loved one safely occupied is a problem when you are driving, try to bring along a relative or friend to help out. Plan ahead by bringing along favorite music tapes, recordings of old radio shows, a cozy pillow for sleeping, snacks, magazines and anything that is likely to bring comfort or keep her occupied. Make sure your loved one's clothes are comfortable, non-binding, and easy to manipulate in restrooms. Pack an easily accessible change of clothing and shoes in case of accidents related to eating, drinking or toileting.



Make frequent bathroom stops. If you must provide assistance in toileting and are the opposite sex of your loved one, bring along an "occupied" sign to hang outside the public restroom. Some rest stops have accommodations now for people who need assistance. If the person is still using the restroom on her own, be alert to large facilities that have more than one entrance; watch for the person to exit somewhere other than where she entered.



When you get to the hotel at night, give yourselves a chance to settle in and rest a bit

before going to dinner or meeting others. Bring your loved one's pillow and other favorite comfort items (such as a family picture for the nightstand) into the hotel room. Place a nightlight in the bathroom or anywhere else it is needed to help your loved one find her way to the bathroom. For people with AD prone to seek exits, put a child-proof cover on the doorknob out of the room, if it's round. Place a doorstop alarm in front of the door so that you will know if your loved one tries to leave the room during the night.

Also be aware that many hotels have scalding hot water, and your loved one may need assistance adjusting the shower temperature when faucet

styles are unfamiliar. Consider unplugging and/or putting away hotel hairdryers and coffee pots, if you think they may pose a hazard or unneeded distraction.

Someone once said, "Traveling by plane is wonderful. It allows you to pass motorists at a safe distance."



Traveling by plane can also eliminate some of the above complications simply because a distance that takes several days to drive can be covered in a few hours. Some airlines will also provide additional assistance (for a fee) such as wheelchair delivery of a person to the gate or between gates. On the other hand, airports tend to be loud and bustling places with long security lines and confusing rules (like putting your shoes on a conveyor belt).

Once aboard the plane, the person may feel confined by the small seat space, have ear problems caused by the pressurized cabins and be too hot or too cold during travel. If he has to use the bathroom, it is too small to easily fit an extra person for assistance, and the flush mechanism, the faucet handles and other parts of hygiene may not be understood by him if he goes on his own.

When you have to change planes, it's imperative to allow extra time between flights – the usual hour is not likely to be enough time if the airport is large, particularly if it requires taking a couple of beeping carts, escalators, trains or buses between terminals and/or moving sidewalks.

Nevertheless, if plane travel is at all feasible, prepare your loved one as well as you can, bring along your own food, check your luggage through to your final destination and breathe deeply!

### Going on vacation

When I wrote about travel a dozen years ago, I suggested it was probably foolhardy to take your loved one on a vacation to a place that was unfamiliar or far from home, unless she was in the earliest stages of Alzheimer's disease. Even then,

I suggested taking along sufficient funds or credit cards for unexpected events, including the need to purchase early return tickets. Travel insurance is a must.

More recently I have heard two incidents of people with dementia taking cruises and loving every minute of it. In one case, a woman with early-onset Alzheimer's disease wrote a blog in which she described her cruise adventures. (She got lost aboard the ship a couple of times, but managed to find her way back to where she needed to be, and was proud of doing so.) Read more at <http://www.mindingoureldeersblogs.com/2008/05/dementia-and-tr.html>.

In the second case, an assisted living community took a group of half a dozen people with moderate Alzheimer's disease – and many of them in wheel chairs – on a Caribbean cruise. Each person with dementia was matched to an aide who shared a cabin with them. They, too, had a wonderful time.

More and more, people with Alzheimer's disease are speaking out for themselves and saying, “**Don't underestimate me.**” It's an important message, but it needs to be balanced with everything else advised on these pages.

On a cruise, people sleep in the same room each night and generally have to get used to just a few additional spaces (dining room, sundeck, etc.) Many activities are offered, but they are all optional, including on-shore adventures. In contrast, a bus tour involves nightly changes in hotel rooms, getting off and on the bus many times a day for meals and attractions, and many fewer options for “opting out” of the day's events in favor of a quiet day at poolside, for example. Therefore, if you are thinking of taking a vacation

in which you are not doing the driving, be considerate both of your loved one's needs and the rights of your fellow travelers who could be affected by those needs.



## A basic checklist

It is a basic rule when traveling with someone with dementia that you should be responsible yourself for your travel itinerary, all tickets, keys, passports, money, credit cards and important papers. Beyond that, and depending on the individual needs of the person with dementia you are caring for, here is a checklist of things it is widely advised that you keep in carry-on luggage or a handy travel bag in your car:

- Medicines, first aid kit and hand sanitizer or sanitary wipes, plus your prescription and physician numbers
- Your health/travel/auto insurance cards and papers
- For emergency purposes, copies of legal papers such as healthcare surrogate, living will, advance directives, power of attorney
- A change of clothing
- Extra Kleenex or napkins
- Bottled water and snacks
- A favorite pillow or blanket (something that helps ease sleep)
- Favorite occupiers such as taped music, a newspaper or magazine, simple games or fiddle objects
- If your loved one tends to get up during the night, pack nightlights for the bathroom, bedroom and hallways – as many as you think may be needed where you are staying.
- If you worry that s/he may try to leave while you are sleeping, pack a step-on alarm for the floor beside your bed or at the exit, and childproof door knob covers.
- A camera so that you can take lots of pictures to savor the memories!

Other things to do for safe and smooth travel:

- Make sure you have left your itinerary behind with someone you know well, and send it ahead to the people who are expecting you.
- If possible, schedule your travel for when your loved one is most alert. As much as possible, follow normal routines for rising and retiring, eating and relaxing, etc. Build in plenty of rest time between activities.
  - Yet include points of interest each day, too. The brain craves novelty.



- If you are driving and health problems are a concern, get help from your Alzheimer's chapter or your physician in learning the names of physicians or locations of emergency rooms along your route.
- Be sure your loved one is wearing his Medic-alert or Safe Return bracelet. If you are a participant in the Alzheimer's Association Safe Return program, consider getting your own ID bracelet which identifies you as the caregiver of someone with a memory disorder, should an emergency arise. (For more information, call your local Alzheimer's chapter or the national association at 800-272-3900). Carry a recent photo of your loved one for emergency purposes as well.

### Wiser Now Products

*Alzheimer's Basic Caregiving – an ABC Guide* and *Activities of Daily Living – an ADL Guide for Alzheimer's Care* provide essential information for any family or professional caregiver for just \$7.95 each or \$15/set. (These books are available at reduced prices in quantities of 10 or more.)

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For more information on this topic, type "dementia and travel" in an Internet search.



I have found out that there ain't no surer way to find out whether you like people or hate them than to travel with them."  
-- Mark Twain

"We live in a wonderful world that is full of beauty, charm and adventure. There is no end to the adventures we can have if only we seek them with our eyes open."  
-- Jawaharal Nehru

"A journey is like marriage. The certain way to be wrong is to think you control it."  
-- John Steinbeck

Stop worrying about the potholes in the road and celebrate the journey."  
-- Fitzhugh Mullan

