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## There Is No Such Place as Far Away

What is long distance caregiving? Perhaps it is helping your aunt sort through her medical bills or making the most of a weekend visit with a parent to help with chores. It can include trying to relieve the pressure from a sibling who lives locally and regularly helps your parents, or it can be checking references of in-home help that has been hired to support a grandparent.

*If you live an hour or more away from a person who needs care, you can think of yourself as a long-distance caregiver.*

Long distance caregiving describes as many as 7 million people in the United States. There are many common factors families face trying to find a way to be helpful, no matter how far away a loved one lives. While it is difficult, it is by no means impossible. Following are some tips and tools that may be helpful.

### Get organized:

As a long-distance caregiver you need to know what you need to know. The more knowledgeable you are about your loved ones' diagnosis, medication, and his local resources, the better. Keep medical and financial information up to date, and make sure at least one family member has written permission to receive this information from professionals treating him.

### Stay in touch:

Long-distance caregiving is an ever-expanding job. What may start out as an occasional social phone call to share family news might eventually turn into regular phone calls that are focused on managing household bills, getting medical information, and arranging for food delivery. As a long-distance caregiver, you may need to coordinate many moving



parts. Whether with informal caregivers (family and neighbors) or with professional home health aides and services, set aside time to regularly discuss the needs of both the person living with dementia and her hands-on caregivers. If your loved one lives at a residential care facility, set up a regular time with the managing nurse or physician to get updates; maintain ongoing communication with care staff and friends who visit regularly.

### Gather a list of friends and neighbors:

One of the biggest challenges in long-distance caregiving is identifying the indications that your support or help is actually needed. Not realizing there is a problem or not wanting to worry you, your loved one may sound fine on the phone. But ask friends and relatives to check in on him and listen to their reports—they may notice that there is no food in the refrigerator or the trash is never taken out or there are dings and dents on the car. Check in regularly with neighbors, friends, or doctors, to see if they have new concerns or recommendations.

### Plan your visits:

As a long-distance caregiver, plan to spend vacation time with your loved. Make a list of things to accomplish for each visit: doctor appointments, banking, clean out the refrigerator, replenishing supplies, organizing a

*Continued on next page*

## Looking for something new to try?

### Tips & Tools

- Have a neighbor/friend with a calm pet visit
- Cut pictures out of greeting cards
- Wash silverware
- Bake homemade bread
- Sort objects such as beads by shape or color
- Sing Christmas carols
- Say “Tell me more” when they share a memory
- Put silverware away
- Make a Valentine collage
- Play favorite songs and sing together
- Take a ride
- Make a cherry pie
- Read aloud from *Ideals* magazine
- Dye Easter eggs
- Make a basket of socks
- Take a walk
- Reminisce about the first day of school
- String Cheerios to hang outside for the birds
- Make a fresh fruit salad
- Sweep the patio
- Color paper shamrocks green
- Fold towels

messy closet or pantry, or adapting the environment to meet your loved one’s changing needs, or simply give some respite to a primary caregiver. It helps to talk to your loved one ahead of time and find out what he might need, or check in with the primary caregiver to learn what

caregiving responsibilities you can take on while you are in town. There may not be enough time for you to get all the issues resolved, but you can try to tackle the essentials first.

#### Home safety suggestions:

- Are the stairs manageable? Are there handrails? Is a ramp necessary?
- Is the bathroom easily used? Are there grab-bars for the toilet and shower? Does she need a raised toilet seat or a shower chair?
- Are there tripping hazards, such as clutter, exposed electrical cords, or throw rugs?
- Are there house repairs needed? Are there burned out bulbs to be replaced?
- Is there adequate lighting in the house? Are there night lights?
- Is there food in the fridge and staple foods in the cupboard?
- Are bills being paid? Is mail piling up? Is the house clean?
- Is she wandering? Do you need to provide in-home care?

Visit our home safety checklist at [ALZ.ORG/SAFETY](http://ALZ.ORG/SAFETY).

When you don’t see your loved one often, changes in his condition may seem all the more dramatic. It is likely that the primary caregiver may not notice changes as much, which can be a barrier to meeting needs. This is a time to encourage the caregiver or your loved one to get more help.

It is helpful to communicate your concerns to your loved one before

you make arrangements for the changes you recommend. Try not to sound critical but express your particular worry: “It looks like you don’t have much food in the house—are you having trouble getting to the store?” Listen carefully to



the answers and explanations, then discuss what you think could be done: “Would you like me to arrange for groceries to be delivered on a regular basis?”

In some cases, particularly when it comes to safety, you may have to be a little more forceful. You must never leave a frail adult at risk, even if you have to act against his wishes, nonetheless, do discuss your plan with him and explain why you are taking action.

#### Expect to increase the frequency of your trips:

As your loved one’s dementia increases, so will the need for your ongoing involvement in his care. Plan to travel more frequently, and plan to implement changes appropriate to each step of his decline.

With all these overwhelming tasks that need to be tended to it is easy to feel overwhelmed. Pace yourself for each visit, and while you are there remember to time visiting. Participate in his activities with him, take him out for a special activity that you both may enjoy, and use some of the examples in this newsletter under “Looking for something new to try?”

Being far away does not make you immune from feeling overwhelmed and frustrated by what is happening to your loved one. Many caregivers find that worrying about taking time off work, being away from family, or the cost of travel may increase feelings of frustration.

When you don’t live where care is needed, it may be especially hard to feel that what you are doing is enough and that what you are doing is important. Resist the feelings of