

MY EXPERIENCES WITH LONG DISTANCE CAREGIVING.....

by Cis LeRoy, Long Distance Caregiver

Another problem is that the phone may never ring! My mother and her husband both have dementia and a host of physical problems. When I call them, they tell me they are both fine. When I speak with relatives living in the area, I'm told they're "fine!". Then, I visit, only to discover a filthy house, smelly parents, moldy food in the refrigerator, severe loss of weight, piles of newspapers all over the house, feces rubbed into the carpet, broken dishwashers and laundry machines, mite infestations and dirty dishes in the pantry.

Changes can be very gradual, and therefore not noticed by those who visit frequently. Often, relatives come to visit and chat, and really don't look around the house; they're too busy 'visiting'. Visiting once or twice a year, I see many things that are not noticed or thought to be important.

I've learned several important things: When you visit, LISTEN and WATCH. Take some 'down time' and pretend to read the newspaper. Then observe their routine activities. Is your mother opening the same mail several times a day? Does your father ever get out of his chair in front of the TV? Does your father's incontinence happen at the same time every day? What do they discuss? Are they worried about anything? Are they taking medications as prescribed? Do they understand what medications are for? In a recent visit, I discovered his incontinence only because I watched my mother wash 2 pair of pants each day. I also discovered that she didn't like to use soap because it 'ruined' the water.

Also, LOOK AROUND. Are there any wet towels in or near any bathrooms? Has your mother worn the same clothes all week? What is in her wallet? Where are their medications? What is in the refrigerator? Are any cans about to explode in the pantry? Where are their house keys? Who cleans the house? To whom are they writing checks? How much cash is in the house? What are they eating? Who does the grocery shopping? I took my mother to the grocery store to buy milk and she kept asking "Is \$20 enough?"

Talk with them. Discuss their legal and financial situation. Have the Power of Attorney signed well before you need it. Help them find an attorney to draw up a will or living trust. Find out their internment wishes. Then ask them how you can help. In my case, they have a living trust that they have amended 5 times and even their own lawyer can't figure out what is what.

Then, develop your network. First, visit or write the doctor and follow-up by telephone to ensure you know when doctor's appointments are, what medications are being prescribed, the weight of your parents, and any other potential medical problems. Let the doctor know you are involved and that you need to be kept informed of their condition. Talk with the doctor after each medical appointment. After you leave the first message with the doctor, with each subsequent message, tell the person "this is the 2nd, 3rd, etc., message I have left". Experience has taught me that guilt helps them return phone calls.

Talk to the neighbors and be sure they have your telephone number. Have them call you if your parents suddenly have new 'friends'. Talk to the local police department; sometimes they have 'registration' programs that list phone numbers to call in case of emergency, medications prescribed and health conditions. Let them know if you feel potential abuse of your parents and they may be able to help. I was able to arrange for the local police to drive by a few times per day and take note of any vehicles parked in the driveway.

Talk to the state's division of aging. Sometimes they know of local scam artists and can arrange to visit periodically. In my case, they scared off the relative of a neighbor who had been scamming them of \$3,000 in one month. That, combined with the police cruising by the house, was a simple solution to a potentially dangerous situation.

Visit the bank. On one recent visit, several women approached me to tell me that my mother was cashing several checks a day. They even followed her outside to see who was bringing her to the bank. But, because she hadn't been declared incompetent, they could do nothing. However, they did agree to call me in the future if the situation did not stop.

Visit the pharmacy. My folks have had the same pharmacist for many years, and on a recent visit, I discovered they were having prescriptions filled several times because they kept losing the medications. Give the pharmacist your phone number and ask him to call you when medications are lost.

Hire a geriatric care manager. The *National Association of Professional Geriatric Care Managers* is a registry of agencies with expertise in social work, nursing and a host of other related fields. Their phone number is: (520) 881-8008. They will 'visit' your parents periodically and report back to you. They will let you know if the house needs cleaning, perhaps medications need changing, or perhaps they need ongoing assistance in the home to assist with activities of daily living. They can help interview and screen caregivers and can be your independent set of eyes to ensure all is well. Talk to them at least once weekly.

Don't just rely on everyone telling you they are 'fine'. They may need help but are afraid to ask or are afraid they will be placed in a nursing home. Find out what you can do to ensure they are safe and healthy. If necessary, hire caregivers and speak with them at least once weekly. Discuss nutrition, bathing, medications, house cleaning and shopping. Prepare a checklist for the caregiver to complete each day. Have it readily available for review by care managers. Have them mail it to you each week.

You will be on the telephone a lot. But, hopefully you can be better prepared if the telephone rings with an emergency. As long as you let everyone know that you may be 2,000 miles away but also only a phone call away, they may actually pay attention to what they're doing.

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