

# Long Distance Caregiving

by Hanni Epp, MA

## **Dorothy's story:**

**Dorothy had just come home from a long day at work, and checked her voice mail messages. Her mother's neighbor had left a message saying that mother had not picked up her newspaper or her mail for three days. When the neighbor knocked on the door, Dorothy's mother opened it, appearing confused. The neighbor took Dorothy's mother home to spend the night at her house. Dorothy heart sank, but she quickly called the neighbor and said "Thanks. I'll make arrangements to come right away." Dorothy A.**

## **Have you had a call like Dorothy's? If so, you are not alone...**

This sudden shift into a new role may be stressful. You may feel overwhelmed and completely alone. In fact, there are an estimated 7 million Americans – including more than 3 million baby boomers – who provide or manage care for a relative or friend over the age of 55 who lives at least an hour away. Here's the good news: because so many of us are involved in long distance caregiving, there's a lot of information to help.

## **More about Dorothy...**

Dorothy is a 56-year-old woman living alone in a small house with Bitsy, her German Shepard. She works in a mid-sized office as a paralegal clerk and enjoys going to concerts and art galleries with her friends. Dorothy is an only child, and responsibility for her mother's care has fallen to her by default. Her father died 10 years ago, and there are no aunts or uncles close by to help.

“I feel so guilty and ashamed”, said Dorothy. “Mom asked me to come back ‘home’ after my divorce from Don, and again after the children left home for college and work. But, this is where I work, where my friends are and where I go to church. After almost thirty years – this IS home. So, I didn’t move back.

We always celebrate birthdays and holidays together, and once every 3 or 4 months, I make the trip back. It’s about 450 miles, so I can’t just drop by. We talk on the telephone every week, too. Over the last six months, Mom has seemed more forgetful at times, sort of distracted. Other times, Mom seemed to be fine. I just never expected this to happen! I feel like I’ve really let her down.”

### **What’s needed? First steps...**

It’s easy to get swept up in the chaos of the moment. Take a couple of deep breaths before you act, and consider the following:

- In most instances, as a long-distance caregiver you will need to become an information gatherer and a coordinator of services. If your situation is like Dorothy’s, an assessment of your loved one’s situation is a first step in determining what help is needed currently, and what may be needed in the future. You may choose to make a visit immediately, or you may be able to talk with your loved one and others over the telephone, to form an initial plan.
- Your goal is to gather as much information as possible before making care decisions. Has the situation emerged gradually as with Alzheimer’s disease or is there a sudden crisis, such as a stroke? You will want to know who else is

involved in her/his care now, and who may be drawn in later. As you do so, you will be forming the base for your “care team”.

- You probably will want to get a complete medical assessment, both physical and cognitive, to find out what your loved one can do independently, and where help is needed. A geriatrician or trusted physician can provide this service.
- Prepare a checklist of care needs appropriate for your loved one. You may find a sample checklist through the Family Caregiver Alliance ([www.caregiver.org](http://www.caregiver.org)), or by contacting me at [Hanni@wmichcare.com](mailto:Hanni@wmichcare.com). Many of the needs may be met by community service organizations. You will be able to get a resource list from the Eldercare Locator (800) 677-1116) or [www.eldercare.gov](http://www.eldercare.gov), or from your local Area Agency on Aging (888) 456-5664.
- Open a Care Notebook – a three-ring binder works well. As you gather papers, such as healthcare, legal or financial documents, organize them in the Care Notebook. Keep a care journal in your Notebook, and record care and contacts with your loved one. Also, keep notes on all outside contacts, with names and dates, for your reference. Keep lists of individuals including professional, family and friends who might come in regular contact with your loved one. Be sure to include names, telephone numbers and e-mail addresses. These people will all be part of your “care team”.

## **Making the adjustment...**

Team effort: Remember that your loved one’s care is a team effort. You need to be realistic about how much you can do. After assessing the care needs,

it is time to pull out your “care team” list and assess the team strengths to see how you complement one another in the skills needed. This might best be done at a family (or team) meeting – in person, by conference call or in a private web chat room. If at all possible, remember to include your loved one in this meeting. Each person will benefit from having a common understanding of goals and tasks. For a guide on holding a successful family meeting, please contact me at:

[Hanni@wmichcare.com](mailto:Hanni@wmichcare.com).

Paying for services: A central issue is how to pay for services. This will impact some of the decisions you make. There is much confusion about which government programs pay for what. The rules for all insurance programs, government or private, are complicated. The insurances may not focus on the kind of care your loved one needs. You may wish to consult with an elder law attorney or financial planner to help determine how to pay for care. Here are some websites to help you:

[www.medicare.gov](http://www.medicare.gov)

[www.benefitscheckup.org](http://www.benefitscheckup.org)

[www.cms.hhs.gov/medicaid/consumer.asp](http://www.cms.hhs.gov/medicaid/consumer.asp)

[www.naela.org](http://www.naela.org)

If you are employed outside the home: It may also be useful to talk with your supervisor or your Human Resource Department to let them know of your situation. You may be able to negotiate flex-time, or time away from your job to take care of your loved one. The Family and Medical Leave Act of 1993 requires covered employers to provide up to 12 weeks of unpaid leave to eligible

employees for certain family and medical reasons. More details are at this web site: [www.dol.gov/esa/whd/fmla](http://www.dol.gov/esa/whd/fmla).

Preparing and Planning: Much of the research necessary in setting up new services can be done by computer and over the phone. Using your care team list, determine who can do what. Most long-distance caregivers find it not just helpful but necessary to be at their loved one's side when establishing new services and procedures. Make appointments to meet providers during your visit. This will help to develop rapport with providers, as well as serve notice that you are an involved caregiver who will be present to monitor services from time to time.

### **Last thoughts...**

By working as a team and using technology wherever possible, you will soon have an understanding of how to provide good care. Situations change, so remember to stay flexible. Most importantly, you will need to stay fit yourself, so remember to take care of you. Good self-care includes managing stress, setting goals, asking for and accepting help. If you become overwhelmed, seek professional assistance to help you get back on track.

### **References:**

[www.alz.org](http://www.alz.org)

[www.caregiver.org](http://www.caregiver.org)

[www.familycaregiversonline.com](http://www.familycaregiversonline.com)

[www.webmd.com](http://www.webmd.com)

## **More resources**

If you want more information about resources, the Caregiver Resource Network can help. The Network's web page ([www.caregiverresource.net](http://www.caregiverresource.net)) can provide you with information about programs and services, fact sheets, and a questionnaire about caregiver strain. Or call Area Agency on Aging of Western Michigan (616) 456.5664, or (888) 456.5664.

If you have a question you would like to see addressed in a future article, feel free to contact Hanni Epp at: Caregiver's Corner, West Michigan Caregivers Alliance, 233 E. Fulton, Ste. 222, Grand Rapids, MI 49503, or e-mail at [Hanni@wmichcare.com](mailto:Hanni@wmichcare.com).

Column written by Hanni Epp, MA, therapist and consultant in private practice at West Michigan Caregivers Alliance. She is also a member of Caregiver Resource Network, a collaboration of West Michigan organizations dedicated to providing information and support for family and professional caregivers within the community. Be sure to look for the Caregiver's Corner in the next edition of *Mature Lifestyles*.