

CARING FOR AGING PARENTS FROM A DISTANCE

By Michele Hendrix

If you live in a different city or state from your aging parents or family members, you may not be on hand to notice or even address any sudden changes in their health or day-to-day needs. More and more Americans are finding themselves in this situation. Though there are a number of contributing factors, there is an overall increase in our society's mobility that contributes to this surge in long distance caregiving.

Living out of state only compounds the logistics and shortens the time frame in which to deal with caregiving decisions. This presents an extra challenge, from additional time and stress to financial worries. Whether it's simply gathering information about your loved one's care needs, or coordinating senior living and medical services, caregiving at a distance involves a substantial investment of resources.

About one third of long distance caregivers are helping someone with Alzheimer's disease or dementia, reports a 2004 MetLife study. According to a MetLife/National Alliance for Caregiving report, it's estimated that about 34 million Americans are caregivers for an older parent — and of that number, 15% live one or more hours away from the care recipient. A fourth of long-distance caregivers reported that they were the primary or only caregiver; however, in many cases a sibling or other relative provided help.

Even seniors 65 and older are increasingly mobile, reports MetLife: The number of seniors who have switched states over the last decade has increased 65%. And when those seniors experience a change in being able to care for themselves, it's often up to the adult children living some distance away to coordinate senior care. Caregiving is not easy for anyone, not for the caregiver and not for the care recipient. There are sacrifices and adjustments for everyone. When you don't live where the 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. It often is more important than you realize.

Many long-distance caregivers provide emotional support and occasional respite to a primary caregiver. Staying in contact with your parents or family members by phone, email, or Skype might also take some pressure off the relatives who live close to your loved ones. Long-distance caregivers can play a part in arranging for professional caregivers, hiring home health and nursing aides, finding resources, or locating a care facility.

Some long-distance caregivers find they can be helpful by handling things online - locating helpful resources, researching health problems or medicines, paying bills, or keeping family and friends updated. There are some long-distance caregivers who help a parent pay for or towards care, while others step in to manage finances. Keep in mind that some of the continuum of care facilities will also offer a week of care for your loved one so that family caregivers can have a short respite break.

Communication is an important aspect to coordinating a loved one's care. Set up schedules and assign each family member a specific role of responsibility. Think about

your schedules and how you might adapt them to give respite to a primary caregiver or to coordinate holiday and vacation times. I make several trips a year to Alabama to see my mom living in a wonderful care facility located on the church property. While I am there I also provide encouragement, support, relief, and respite to my sister and her family who lives about 45 minutes from our mom.

Being a caregiver, even a long-distance caregiver, can be very rewarding. It also can leave you frequently exposed to stressors like family dynamics, a disruption in the household, financial worry and changes in roles, routines and health conditions. Some families find that it works to have the long-distance caregiver come to town while the primary caregiver is on a family vacation. Many families report that offering appreciation, reassurance, and positive feedback to the primary caregiver is an important, but sometimes forgotten contribution.

Long-distance caregivers can be helpful no matter how far away they live. There is no one right way to be a caregiver; everyone's situation is different. You will find that, among a host of things, family dynamics, financial resources and the ability of your parent(s) to provide guidance for the support that they desire will shape your situation. Coordinating and researching senior care and resources can be a huge challenge even in the best of circumstances. There are many challenges one faces when taking care of aging parents from a distance. When you add in the factor of distance, there are additional issues that may crop up.

- **Get organized.** Compile notes about your loved one's medical condition and any legal or financial issues. Include contact numbers, insurance information, account numbers and other important details. Share this information with other family members. It is important for everyone to be in the loop.
- **Take care of necessary paperwork.** Know where to find all legal, financial, and insurance documents, including birth certificates, social security cards, marriage or divorce decrees, wills, and power of attorney before an emergency happens. Also, know where to find bank accounts, titles, sources of income and obligations, and auto, life, homeowner's, and medical insurance papers. Review these documents for accuracy and update them if necessary.
- **Research your loved one's illness and treatment.** This will help you understand what your loved one is going through, the course of the illness, what you can do to prevent crises and how to assist with disease management. It might also make it easier to talk to your loved one's doctors.
- **Keep in touch with your loved one's providers.** In coordination with your loved one and his or her other caregivers, schedule conference calls with doctors or other health care providers to keep on top of changes in your loved one's health. Be sure to have your loved one sign a release allowing the doctor to discuss medical issues with you - and keep a backup copy in your files.
- **Ask your loved one's friends or church for help.** Understand long-distance caregiving is not a one-person job. Long-distance caregivers should assemble a

team that includes at least one set of local eyes and ears. Whether that is figuring it out with cousins in your hometown, or friends of the family, or hiring people, you are going to need additional support. Stay in touch with your loved one's friends, neighbors, or church family. If possible, ask them to regularly check in on or visit your loved one. They might be able to give you insight and information that can help you understand what's going on with your loved one on a regular basis.

- **Contact the aging network.** Contact the local Department on Aging in your relative's community. This agency can help you identify helpful services, including obtaining a caseworker. Use the National Eldercare Locator Service at (800) 677-1116 to find local aging agencies.
- **Seek professional help.** If necessary, hire someone to help with meals, personal care and other needs. A geriatric care manager or social worker also might be helpful in organizing your loved one's care.
- **Communicate and schedule regular family meetings.** As a long-distance caregiver, you may coordinate many moving parts. Set regular check-in times to discuss your loved one's care at an online family meeting. Involve family and friends in the check in and discussion. Phone, Skype, or Web Chat can easily arrange this. Discuss your goals, air feelings and divide up duties. Appoint someone to summarize the decisions made and distribute notes after the meeting. Be sure to include the loved one in need of care in the decision-making process.
- **Encourage your family caregiver to network with others by joining a support group – and you join one too.** This can be an important outlet and means of encouragement for both of you to consider. It is helpful to share information, and receive support from others who are experiencing many of the same conditions and challenges. Joining an online community support group can also help you connect to others experiencing many of the same issues and concerns.
- **Plan for emergencies.** Set aside time and money in case you need to make unexpected visits to help your loved one. Consider inquiring about taking unpaid leave under the Family and Medical Leave Act.
- **Regularly check to see if they need specific help.** When asked, most caregivers tell church members they are "doing okay" and don't need help. However, if a specific action plan is in place, most caregivers will accept the offer. Be sure to set a specific date. If you don't, they will not likely take you up on your offer. Try taking some of the pressure off your family member who lives in the same town with your loved one who needs care.
- **Stay in touch.** Send photos to your loved one and to your family. Arrange to have photos sent to you as well so you can see how they are doing. Try sending your loved ones short digital movies of yourself. Send cards or e-cards. Set a

time each week for phone calls with both of your loved ones – the care recipient and the family caregiver. Acknowledge their efforts and celebrate even the small successes with them.

- **Caregivers need your prayers.** Maintain constant contact with caregivers asking how you may pray more specifically for their needs as well as for the family member for whom they are caring. Follow up on those prayer needs and become an advocate for helping meet some of those needs.

If you are a long-distance caregiver, you are definitely not alone. There may be as many as 7 million people in your same situation in the United States including more than three million Baby Boomers, that provide or manage care for a relative or friend over the age of 55 who lives at least an hour away. That is according to the “Handbook for Long-Distance Caregivers” according to the National Institute on Aging. And you don't have to live across the country to be a “long-distance” caregiver. Anyone who lives an hour or more from the person they are caring for is considered a long-distance caregiver.

Be kind to yourself. Living out of town does not mean you aren't involved or that you don't care. Get support by connecting with others who are long-distance caregivers through a support group or an online community. There are no simple answers or solutions. Each person's situation is different. Each child has a different relationship with his or her parent, and this may also determine the level of your involvement. You need to think about your parent's needs and your own needs as well.

Once you've had enough time to really assess what the true needs of a loved one are, you'll probably be able to create a really solid plan of action and care for them, even though there may be thousands of miles between you. Planning for the future, continually gathering information, and taking care of what's needed right now are the three main areas of focus for a long-distance caregiver, and while it may be stressful, it's not impossible, especially if you remember that you don't have to take this walk alone.

The good news is that with so many of us involved in care from a distance, there's lots of information to help. Here are a few additional sites I used as a reference for this article offering resources, checklists, and specific tips to help you in your long-distance caregiving journey.

Administration on Aging's Eldercare Locator. Helps to find local resources for the elderly. Phone: 800-677-1116. Website: www.eldercare.gov

AARP - Tips for the Long-Distance Caregiver. Helpful tips to keep in mind while contemplating caring for your parent from a distance. Website: http://www.aarp.org/relationships/caregiving-resource-center/info-09-2010/pc_tips_for_long_distance_caregiver.html

be Smart. be Well. Provides practical information about long-distance caregiving. Website: besmartbewell.com/caregiving/long-distance-caregiving

CareZone. A simple online tool to take care of yourself and your family. Keep everything organized and easily coordinate with the people that matter to you. Website: www.carezone.com

Children of Aging Parents. Provides information, referral service and educational outreach. Phone: 800-227-7294. Website: www.caps4caregivers.org

ElderLawAnswers. Provides news and explanations of Medicaid coverage of long-term care, Medicare benefits, estate planning, guardianship, and other legal issues affecting seniors. Website: www.elderlawanswers.com

Family Caregiver Alliance. Provides information, education, services, research and advocacy for caregivers. Phone: 800-445-8106. Website: www.caregiver.org

The MetLife Caregiving Cost Study: Productivity. Conversation that focuses on issues of family caregiving. Website: www.metlife.com/.../mmi-caregiver-cost-study-productivity.pdf

Morningside Ministry – mmLearn.org. Online training and information for caregivers. Improving the quality of care received by older adults. Website: www.mmlearn.org

National Council on Aging Benefits Check-Up. Checks eligibility to receive benefits. Website: www.benefitscheckup.org

National Association of Professional Geriatric Care Managers. Locates geriatric care managers in your area. Phone: 520-881-8008. Website: www.caremanager.org

National Eldercare Locator Service. The Eldercare Locator, a public service of the US Administration on Aging and the National Association of Area Agencies on Aging, can help find resources for older adults in any community in the United States. Phone: 1-800-677-1116. Website: www.eldercare.gov/Eldercare.NET/Public/Index.aspx

National Family Caregivers Association. A support organization for caregivers. Phone: 800-896-3650. Website: www.caregiveraction.org

National Institute on Aging. Handbook for Long Distance Caregivers. Website: www.nia.nih.gov

PBS NEWSHOUR. How to care for your aging parents from a distance. Website: www.pbs.org/newshour/updates/long-distance-caregiving-parents

***Ms. Michele Hendrix** has served two terms as the President of POAMN. She has worked for over 25 years to advocate, educate, involve, and motivate people in the process of aging and self-care; and to recognize the connections among church, health care, non-profit, community, state, federal, and local agencies while encouraging adults of all ages in managing their self-care, chronic conditions, respite, and caregiving roles. Michele has focused her work on intergenerational and interfaith programs for adults, evidence-based health promotion, ministry programming and development, respite for caregivers, and fall-prevention programs. She is a Deacon, Stephen Leader, Caregiver Specialist, Speaker and Trainer with expertise in Older Adult Ministry, Intergenerational Ministry, and Caregiving for all ages.*