

Long-distance Care-Giving: Five Steps to Providing Effective Care

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For years, Jan kept in contact with her parents by a weekly telephone call, and managed to make the 12-hour drive with her young family to see them twice a year. Jan knew her father's health was failing and assumed that her mom was able to care for him because she had not complained or asked for any help. During a recent visit, Jan noticed that her father's health was much worse than she was led to believe and he rarely left the house. Her mother looked tired and quietly complained about her own health problems. The once well-maintained home needed long overdue maintenance and the rooms had not been cleaned thoroughly for some time. Jan realized that her parents needed more than her weekly phone call. She could not relocate to be closer to her parents, but realized she needed to become more involved in their lives. Like many other adults providing long-distance care, she was happy to help but felt uncertain about what she should do next and how the future would unfold.

Jan and people like her face many new challenges when caring for a loved one who is no longer able to manage life independently. While the support provided may allow older adults to remain living in the community, it may also lead to increased levels of stress and strain for those providing care. This publication is designed to acquaint you with five basic steps to providing efficient and effective care from a distance.

Profile of Long-distance Caregivers

Fifteen percent of family caregivers are considered long-distance carers. That is, they live more than one hour's travel time from the person receiving their help (National Alliance for Caregiving and AARP, 2004). Long-distance carers tend to be college-educated,

between the ages of 35 and 64, and in excellent health. Most consider themselves secondary care providers who support a primary caregiver.

Long-distance care may begin slowly with simple tasks such as listening to a problem over the telephone or helping with household chores during a visit. It can also start suddenly in response to a medical crisis. Regardless of how care begins, the role of the long-distance carer is likely to evolve over time as the needs of their loved one change.

Competing Demands

Balancing family, work, and care-giving can be stressful and time consuming, even from a distance. Because the ability to provide direct care is limited, long-distance care-giving generally includes two primary activities: gathering information to inform decision making and coordinating care to ensure adequate help is provided (Rosenblatt and Van Steenberg, 2003). However, the average carer still travels over 700 miles a trip each month to provide direct assistance in the home (National Alliance for Caregiving and AARP, 2004). As a result, long-distance carers face competing demands on their time, resources, and family life including:

- Increased periods of time spent away from the family (planned and unplanned)
- Demands on personal time for resolving care-related issues
- Additional travel costs to spend time with loved one
- Lost wages from missing work
- Need for initiating back-up plans for child care

- Increased interactions with health providers to seek information
- Coordination of care services with informal and formal carers
- Increased contact with siblings and other family members

What competing demands do you think Jan might face in the future?

Five Steps for Providing Effective Care

To ensure long-distance care activities are an efficient and effective use of your time, energy, and resources, implement the following five steps for providing effective care: ask what needs to be done, assess the situation, develop an action plan, maintain a care-giving notebook, and communicate with other family members (Mature Market Institute, 2004; MetLife and National Alliance for Caregiving, 2005; National Alliance for Caregiving and AARP, 2004; Rosenblatt and Van Steenberg, 2003).

Ask What Needs to Be Done

The first step to providing appropriate and timely care starts with a frank discussion with the person needing help and assistance. Making assumptions about what a person needs only hampers the care-giving process and can create bad feelings that may ultimately impede care. Allow your loved ones to maintain as much independence as possible in their life and direct their own care for as long as possible. Ask about care and living preferences and listen to explanations about needs and wants. Be sure to understand what is expected of you and others offering support.

Assess the Situation

The second step in providing effective care is to assess, preferably in person, the person's ability to complete his or her daily routine and maintain the home environment. Use the Long-distance Care Checklist at the end of this publication as a guide for identifying potential areas of needed support. During your visit, be sure to set aside enough time to discuss sensitive issues such as financial and legal matters. Ask questions about how the estate is being managed and by whom.

Develop an Action Plan

Developing a plan for family care giving is the third step. Call a family meeting to discuss the care needed and identify the type of help and resources each person is willing to provide. Sharing burdens and joys reduces caregiver fatigue and alleviates the pressure of feeling you are alone and have to do it all. Divide care responsibilities taking into account each person's:

- Ability to provide help
- Desire to help
- Distance from care receiver
- Time available
- Access to resources

Knowledge and experience

Although a particular family member or friend may appear best suited to provide a specific type of support, ask about his or her willingness and ability to help and participate in the care-giving plan. Everyone has competing demands on his or her time and no one should be forced to take on responsibilities he or she cannot handle. Quality of care ultimately suffers and family tensions increase. Refrain from blaming those who decline to offer assistance. As time goes on, encourage everyone to acknowledge when their circumstances change so responsibilities can be shifted and shared.

Maintain a Care-giving Notebook

The fourth step to effective care-giving is to create and maintain a caregiver notebook. It is easier to provide assistance from afar if current medical information and care resources are stored in one place and updated regularly. The notebook should include a medical profile (with diagnoses), a list of physicians' names and contact information, a list of current medications and dosages, contact information for other carers and neighbors, insurance information, and information about community support programs in the area. By keeping information organized in one place, it is easier to find needed information when coordinating care, speaking to medical personnel, and responding to emergency situations.

Communicate with Family

Finally, identify your own needs, wants, and expectations in the caring relationship and communicate your thoughts,

feelings, and observations with other family members. Talking through your frustrations with other family members will relieve stress and tension and provide an opportunity to share information about the current care situation. As life situations change and the care receiver's health improves or declines, the five steps should be revisited, ensuring continuity and quality of care.

If you have questions or are interested in other human development information on older adults and their families, contact your local Virginia Cooperative Extension office. Family and Consumer Sciences agents offer a variety of educational programs related to family life, personal fitness, nutrition, and food safety.

If you would like further information on topics concerning older adults please see:

Elder Abuse Alert – Considerations About a Hidden Problem, Virginia Cooperative Extension publication 350-251, <http://pubs.ext.vt.edu/350-251/>

Substitute Decisions By and For Older Adults and Their Families, Virginia Cooperative Extension publication 350-253, <http://pubs.ext.vt.edu/350-253/>

Living Options For Adults Needing Assistance, Virginia Cooperative Extension publication 350-254, <http://pubs.ext.vt.edu/350-254/>

References

Mature Market Institute (2004). *Miles away: The MetLife study of long-distance caregiving*. Retrieved on July 25, 2007, from www.caregiving.org/data/mile-saway.pdf

MetLife and National Alliance for Caregiving (2005). *Since you care: Long distance caregiving*. Retrieved on July 25, 2007, from www.metlife.com/WPSAssets/20778401118179212VIFLong%20Dist%20Caregiving.pdf

National Alliance for Caregiving and AARP (2004). *Caregiving in the U.S.* Retrieved on July 25, 2007, from www.caregiving.org/data/04finalreport.pdf

Rosenblatt, B., and Van Steenberg, C. (2003). *Handbook for long-distance caregivers*. Family Caregiver Alliance: San Francisco.

Long-distance Care Checklist

Personal Care

Is additional help needed with...?

- Bathing Dressing Grooming Toileting

Health

- Scheduling medical visits Understanding medical diagnoses Asking medical questions
 Seeking a second opinion Managing medications Getting exercise

Household Activities

- Daily household chores Grocery shopping Preparing nutritious meals Laundry
 Caring for pets

Home Maintenance

- Home modifications (grab bars, wider doorways, handrails, ramps, etc.)
 Brush and debris removal Lawn maintenance
 Snow removal Routine maintenance

Finances

- Paying routine bills Paying for medications Paying winter heating costs
 Paying credit-card bills Restructuring debt

Transportation

Are transportation arrangements needed for ...?

- Church events Medical appointments Shopping
 Social and community activities Socialization

Are opportunities available to...?

- Socialize with friends outside the home Visit with family members outside the home
 Participate in community programs or activities

Emotional Support

Is there a need for ...?

- A daily reassurance phone call to make sure everything is going well
 Participating in a care-related support group
 Spiritual guidance or support

Future Health and End-of-Life Planning

Which of the following remain unplanned?

- Advance care directives Living will or Five Wishes Organ donation
 Medical power of attorney Do Not Resuscitate (DNR) orders Funeral arrangements
 Burial arrangements Executor of the estate Last Will and Testament
 Who will assist spouse/partner with decisions after death?