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# **Fact Sheet**

## **Distant Caregivers**

“More than 15 million adult children nationwide are providing care for their elderly parents, including paying part or all of their housing, medical supplies and incidental expenses, surveys show. According to the *Times*, adult children with the highest expenses are those supervising care long distance”<sup>8</sup>

Regardless of gender or age, caregiving can bring added stresses and unexpected joys. Balancing all the challenging aspects of care with your own life can feel overwhelming, but it can also be a tremendous gift to be able to support your loved one in his or her time of need.

### **Who Are Distant Caregivers?**

A Distant Caregiver is anyone caring for a loved one who lives an hour or more away. It is currently estimated that there are 7 million distant caregivers in the United States alone.<sup>11</sup> On average, a distant caregiver is a 47-year-old female who is working full time and has young children to care for, as well as an aging parent. Statistics show that there are more female than male caregivers, but men are increasingly stepping into the caregiving role. This is in large part due to the increased amount of women in the workforce.<sup>9</sup> However, many professionals in health care and aging services see the same amounts of male caregivers as they do female caregivers and a broad range of ages.<sup>7</sup>

### **The Challenges of being a Distant Caregiver**

On average, a distant caregiver will spend \$329 per month and miss approximately 20 hours of work per week in order to visit their distant loved one.<sup>2</sup> With caregiving experiences lasting an average of 4.3 years, a distant caregiver may find they are spending more than they can afford.<sup>1</sup> Many distant caregivers experience feelings of guilt and frustration of not being physically present with their loved one on a daily basis. Distant Caregivers often find themselves constantly thinking about caring for their loved one and wondering if there is anything additional they can do.

## What Distant Caregivers Can Do

Distant caregiving requires a lot of work, but much of that work is able to be done over the phone. Calling your loved one on a regular basis can help to give you a better picture of what is going on with that person as well as giving them a sense of comfort. Some distant caregivers report that making a few short phone calls in a week helped improve communication and build trust between the distant caregiver and the care receiver.

Some Distant Caregivers are the sole person overseeing their loved one's care, while other Distant Caregivers are supporting family members or friends, who are in turn providing support for the primary caregiver. Other distant caregivers find that sharing caregiving duties with additional family members, so that each person calls on the care receiver on alternating days, helps to ease their stress and get more information from the care receivers. Calling local agencies such as *Meals on Wheels*, adult day care centers, or any other services your loved one may need can help to ease the stress in their lives and support them during this time of need.

One of the benefits of being a Distant Caregiver is being able to see the subtle changes that a person living nearby may not see. It is like seeing an old friend who has lost some weight - she does not see her weight loss but you do because you have not seen her for a while. The same is true for Distant Caregivers; when they are able to visit their loved one they may see a slower walking pace, or that the person is doing less around the house, or they are not driving very well. It may be shocking to suddenly see this decline when a few months ago the person seemed so much better, but your insights can help improve the care of your loved one. Telling the doctor what you saw two months ago and what you are seeing now may help improve treatment and care.<sup>5</sup>

## Get Organized

An important first step in assisting your loved one is deciding what you can do yourself, and what would be too difficult for you to undertake on your own and thus require the help of a “support system” of additional caregivers. Do you have the financial stability and schedule flexibility to visit your loved one every few days? Or is once-per-month a more realistic goal? Certain tasks only need to be done infrequently, such as the changing of light bulbs, paying of bills, doctor's appointments, and shopping for non-essential household items. Other tasks, however, need to be performed on an almost daily basis, such as the taking of medications, shopping for groceries, bathing, and exercise. For these needs, many distant caregivers turn to geriatric care managers or in-home help.

A Geriatric Care Manager is a human service professional - usually a gerontologist, social worker, or nurse - who wants to improve the lives and health of older adults. Currently there are no national standards, regulations or licensing requirements for someone to become a practicing Geriatric Care Manager. Regardless, this privately-funded person can help to oversee your loved one's care, connect you and your loved one to resources in their area and can become a valuable line of communication between you, your loved one and any other service or medical professional involved in the care of your loved one. There is generally an initial assessment of your loved ones needs, followed by a plan of care.

In-home help—another form of hired support—is anyone whose main duty is working in the house in some capacity. Examples of this are a regular cleaning person or service, someone who provides physical therapy, or a nutritionist who prepares meals at the house. Depending on how much care your loved one needs, this can become a costly affair. Seeking out services and

people, such as volunteers who call or visit seniors, can ease some of that financial strain while maintaining some companionship for your loved one. Also, *Meals on Wheels* can deliver pre-made meals by a person who will often visit with your family member before leaving the food. This is a great way to help ensure adequate nutrition for your loved one.

Make sure you interview anyone whom you choose to hire to help with your loved one's care. Ask about their experience and find out what they know about your loved one's illness. Remember, you are establishing a personal and professional relationship with this person; if you do not like their response, how they interact with your loved one, or if you have any hesitations whatsoever about that person's qualifications, do not hire them. Your trust in the individuals whom you hire is invaluable and should not be compromised for any reason.<sup>4</sup>

## Communication

Communication is the most important tool a distant caregiver has.<sup>3,4,5</sup> Being able to communicate with the doctors, the neighbors, the gardener, and anyone else who is involved in your loved one's life is essential. Knowing these people and having an open line of communication, where you have their contact information and they have yours, provides support for both you and your loved one. These people can be your eyes and ears to let you know when something is not right, or for you to call when you cannot contact your loved one. One caregiver was hesitant to call her father's friends to get their point of view, but when she received a call from them because *they* were concerned and did not know what to do, she stopped hesitating. Often friends and neighbors are concerned but are at a loss as to what they can do to help. Giving them your phone number and permission to contact you can start a valuable line of communication.

Have a family meeting. Get together with your spouse and children and tell them what is going on. Tell them what you are going to have to do to provide care for your loved one. Talk with them about what will happen if there is an emergency with your ill family member and create a plan. If there is an emergency, keep in mind that many airlines offer a reduced rate for a family emergency.

## Education

Inform yourself about your loved one's condition. Understanding what their illness is and how it will affect their daily lives will help you better support them. Many diseases - such as Alzheimer's Disease, Parkinson's Disease, and Huntington's Disease - have specific national associations with regional chapters. This can be a great form of support because you can find a chapter in both your area and your loved one's area to support you.

When looking for services in your loved one's area it can be very beneficial to start with the local *Area Agency on Aging*. Created as a part of the Older Americans Act, every county has an *Area Agency on Aging*, which coordinates and funds programs that contribute to the health and well-being of older adults. If your loved one is 60 years or older, this is a great first step in connecting to resources. Especially in rural areas where services and funds are limited, the *Area Agency on Aging* can become a main source of support, information, and referrals to other services. To find your Area Agency on Aging you can visit <https://www.n4a.org> for a complete listing. This site lists each agency by state and county. Multiple counties are often assigned to one agency, therefore choose the one nearest to your loved one.

Keep all notes, bills, receipts, contracts, letters, brochures, and all other information in an easily accessible place.<sup>10</sup> One caregiver has a notebook for each parent in which she records the date,

time, name and job title of each person she speaks with regarding her parents' care and includes what they said, what she said, and what they recommended. This way she can advocate for her parents' care quickly and accurately from 3,000 miles away.<sup>3</sup>

Having legal paperwork in order now can help ease decisions down the road. Having a trust or will in place as well as a Power of Attorney and documented end-of-life wishes may be emotionally or psychologically difficult. However, if your loved has voiced their wishes for their end-of-life care through advanced care directives and verbal statements, you can use their final days to say goodbye and make peace with their passing, instead of stressing about what decisions need to be made. A valuable guide in starting this process can be using "Five Wishes," a project designed so individuals can write up their own Power of Attorney and Living Will. It can be found online at: <https://fivewishes.org/>. Also, having your loved one give their physician's permission to talk with one or all of the informal caregivers will help improve communication about medical issues. Many distant caregivers reported having to attend a medical appointment with their loved one in order to open the line of communication with the doctor.

Find out exactly what type of insurance your loved one has and what it covers. Many people erroneously think they have long-term care insurance. If you need help understanding Medicare, Health Insurance Counseling and Advocacy Program (**HICAP**) can help answer your questions.

## Support Systems

Building a support system is an important challenge for any caregiver. Attending support groups in your area, learning about a specific disease and the options for care will help you to help your loved one. It is important to create a

network of friends and family members who know what you are doing and can help to ease your caregiving stress. Knowing the friends of the care recipient's neighbors and loved ones is also a part of the distant caregiver's support system. Being able to call a neighbor who can check on your loved one and communicate with you offers piece of mind, as well as a better understanding of how your loved one is doing.

If you are not the primary caregiver - if there is another person providing care who lives with or close to your loved one - you can be their support. This is important because the primary caregiver has the daily responsibilities of cooking, cleaning, dressing, bathing, getting up in the middle of the night, taking the care recipient to and from doctor's appointments, and managing medications among numerous other daily tasks.

There are an unlimited number of ways in which responsibilities can be divided. One way in which a distant caregiver can help is to have all of the mail sent to them, and they can pay all the bills, while another caregiver will schedule doctor appointments, transportation and coordinate all other formal help. As long as each person giving care understands what his or her responsibilities are, a support system is an invaluable aid in caring for a loved one.

## Further Resources:

Family Caregiver Alliance

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

Contains various publications, research, and advice for caregivers.

Del Oro Caregiver Resource Center

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

Support for family caregivers of cognitively impaired individuals.

National Family Caregivers Association

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

A website supporting family caregivers who are caring for a loved one who is dealing with chronic illness and frailty.

Family Care America

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

Great source of information for caregivers.

Eldercare Locator

<https://eldercare.acl.gov/Public/Index.aspx>

Offered by the Administration on Aging, this free national service helps people locate resources for older adults in their community.

Health Insurance Counseling and Advocacy Program

<https://cahealthadvocates.org/hicap/>

Free program offering health insurance counseling about Medicare.

Compassionate Care Alliance

<http://www.sachealthdecisions.org/alliance.html>

A non-profit, non-partisan organization providing end-of-life related materials and information.

Five Wishes

[www.agingwithdignity.org/5wishes.html](http://www.agingwithdignity.org/5wishes.html)

*Five Wishes* is a document that helps you express how you want to be treated in the event you become seriously ill and unable to speak for yourself.

Find your legislator

<http://findyourrep.legislature.ca.gov/>

California's site to locate your Assembly person and Senator. If you have issues or concerns about regulations, funding, services or any other, write your legislator and tell them your story and your needs.

## References:

<sup>1</sup> Caregiving Statistics. (2004). Retrieved December 11, 2006, from

[http://www.familycaregiving101.org/not\\_alone/stats.cfm](http://www.familycaregiving101.org/not_alone/stats.cfm)

<sup>2</sup> Pederson Publishing. (2004). Long-Distance Love is a Costly Affair – Caregiving from Afar. Retrieved November 2, 2006 from [www.caregivershome.com/news/article.cfm](http://www.caregivershome.com/news/article.cfm)

<sup>3</sup> Personal Communication, anonymous distance caregiver #1, March 16, 2007.

<sup>4</sup> Personal Communication, anonymous distance caregiver #2, April 13, 2007.

<sup>5</sup> Personal Communication, anonymous distance caregiver #3, April 13, 2007.

<sup>6</sup> Personal Communication, anonymous distance caregiver #4, April 17, 2007.

<sup>7</sup> Personal Communication, Kendra Micka, May 8, 2007.

<sup>8</sup> Kaiser Daily Health Report. (2007). Coverage & Access; Cost of caring for an Elderly Parent Affecting Retirement for Baby Boomers. Retrieved April, 10, 2007 from [http://www.kaisernetwork.org/daily\\_reports/rep\\_index.cfm?DR\\_ID=41862](http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=41862)

<sup>9</sup> Kaiser Daily Health Policy Report. (2006). Health care marketplace; Men increasingly provide home care for family members. Retrieved April 10, 2007 from [http://www.kaisernetwork.org/daily\\_reports/rep\\_index.cfm?DR\\_ID=41259](http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=41259)

<sup>10</sup> Loverde. (2000). *The Complete Elder care Planner*; where to start, which questions to ask, and how to find help, second edition. Random House, New York.

<sup>11</sup> Schwarz & Blixen. (1997). *Journal of community health Nursing*. Does home health care affect strain and depressive symptomatology for caregivers of impaired older adults. 14(1) 39-48.

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