



# The Stress of The Long Distance Caregiver

BY DAVID GOODMAN, *President of Expert Home Care and President/ Founder of Companion Connection Senior Care*

## SENIOR MOMENTS

**Rachel**, an advertising executive in her late 40s, lives in northern New Jersey with her husband and three teenaged children. Her father, Stan, who was widowed several years ago, owns a home near the Jersey shore.

Until recently, the two hour or so distance between father and daughter was not a problem. Ever since her mother had died, Rachel would meet her dad at a restaurant located about an hour away for each of them for dinner once a month, or drive down to the shore with her family for an occasional Sunday or holiday visit. During summers, they would spend a week in his house, living on the first floor that he rented out to vacationers during the remainder of the season. Often her sister, Jackie, who lives in San Francisco, and her family would join them.

This changed abruptly when Stan suffered the first of several minor strokes. He could no longer drive, so the monthly dinners ended. Rachel became more and more concerned about his health and while he always reassured her on the phone that he was fine, she would feel uneasy whenever the call ended. He would sound a little too subdued; a little less responsive. Whenever she visited him, she noticed how her once vibrant and energetic father, a man who was the life of the party, suddenly seemed to be moving much slower and had little energy. He acted forgetful at times, and sometimes seemed depressed. He wasn't as interested in her or her family. Things he once enjoyed, such as working in the garden or putting around in his workshop, he now avoided. She worried about whether he was eating properly, and if he would suffer another, more serious, stroke.

In addition, she found herself regularly on the phone with his doctor. She started taking days off from work to drive Stan to the doctor, or simply to check up on him, even though she could not afford the time off.

She knew there was no way Stan would ever agree to live with them or, God forbid, choose to give up the house and move into an assisted living facility, since her father, after all, still cherished his independence. Rachel often spoke about this with her sister, but she knew that while Jackie shared her concerns she was too far away to help. Decisions needed to be made, and they would need to be made by her.

Rachel's situation is hardly unique: it is the life of the long-distance caregiver. She or he lives an hour to hundreds of miles away, and whether they are the primary caregiver, a child, sibling, relative, or close friend, feels responsible for the health and well-being of an aging or infirmed loved one. Long-distance caregivers face difficult and complex challenges.

According to a study on long-distance caregiving conducted by the National Alliance for Caregiving, in collaboration with AARP, 15%

of the estimated 34 million Americans who provide care to older family members can be considered long-distance caregivers, defined as living an hour or more away from their relative.

Living away from an aging parent can have an impact on one's family life, finances, and career, not to mention emotional well-being. It often requires the caregiver to miss work, manage and supervise paid care providers from a distance, and feel left out of decisions made by health care professionals or other family members who live closer.

The survey also revealed the following about long-distance caregivers:

Despite living an average distance of 450 miles, or nearly seven and-a-half hours of travel time, away from the individual they provide care for, 51% of long-distance caregivers still visit a few times month at least.

Nearly a quarter of the long-distance caregivers are the only or primary caregiver.

About a third of respondents provide help to a loved one with Alzheimer's disease or other forms of dementia.

Nearly 75% help their loved one with the instrumental activities of daily living, such as transportation, grocery shopping, managing finances or medications, or cooking, and spend 22 hours a month doing this.

Almost 40% also provide help with the more intense activities of daily living, such as bathing, dressing, feeding, and toileting for an average of 12 hours per month.

Nearly 80% work either full or part-time, and more than 40% have had to rearrange their work schedules in order to perform their caregiving responsibilities. Furthermore, 36% reported missing days of work and 12% have taken a leave of absence.

### WHAT CAN BE DONE

No hard and fast answers will give these long-distance caregivers peace of mind. Each case is different. Yet, here are several things to consider:

If you are the primary caregiver, identify someone you can trust to be your eyes and ears when you're not available. This may mean counting on a trusted neighbor or friend, or hiring a licensed home health care agency. Professional home care services can range from non-medical care (for companionship, shopping, cleaning, etc.) for several hours a week, to live-in medical services (as provided by a trained home health aide), depending on the situation. Any agency being considered should include 24/7 on-call availability.

Find senior resources located near the loved one to identify available programs. These may range from Meals on Wheels to adult day care programs. The process can begin by contacting the



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## SENIOR CARE

Office of the Aging, a government organization that exists in most counties in New Jersey.

Pull together a list of prescriptions and over-the-counter (OTC) medications used by your loved one, including doses and schedules. With many elderly people simultaneously taking an average of six different prescription drugs and three or four OTC products, they could be at risk for adverse interactions. This list should be provided to both the individual and the caregiver who sees them regularly.

Make your visits count by looking for possible safety hazards in the relative's home. Since visits are at a premium, take advantage of them by looking for accidents that are waiting to happen. This may include such problems as loose rugs, poor lighting, faulty steps, and unsafe clutter. It may also be time to install safety measures, such as grab bars in the shower or a higher toilet seat.

Work with your parent on creating an advance directive stating his or her health care treatment preferences. This written document can help family members avoid conflicts that may occur should there be any disagreement over treatment decisions. It includes naming a surrogate decision maker (with the authority to make decisions should the individual become incapacitated to make them), acceptable treatment options, and steps to consider in the case of an emergency. This document, which can be changed over time, would be placed in the medical record and made available to all family and healthcare caregivers.

Consider the use of a Personal Emergency Response System. This provides the loved one with a pendant, to be worn at all times that will trigger a call to an emergency vehicle and the caregiver should he or she fall or become ill.

For Rachel and others, these recommendations should provide some peace of mind. Yet, nothing will totally assuage those anxious moments that will continue to plague long-distance caregivers whenever they cannot be by the side of an aging loved ones. This, after all, is life as we know it in a world where families must live further apart.

David Goodman is the President of Expert Home Care, a full-service home health agency based in New Brunswick that provides live-



in and hourly medical and non-medical care, as well as the President and founder of Companion Connection Senior Care, which provides non-medical home care through its 160 members around the country.