

Dutiful Daughters [by Katherine Luck](#)

If you're someone's daughter, there's a good chance that at some point in your life you will end up caring for a parent.

Informal caregivers, who offer support ranging from light housekeeping to intensive physical assistance at no charge, are the largest source of day-to-day care for the elderly in this country. Even with meticulous financial planning for their future care needs, elderly adults must often call upon their daughters or daughters-in-law to coordinate many of the essential activities that ensure quality of life, such as finding appropriate care facilities, accompanying them to medical appointments, and transporting them to visit family and friends.

Only a fraction of seniors rely exclusively on formal care, such as that found in assisted living facilities and nursing homes. An estimated 27 million women in the United States are already serving as informal caregivers.

Angela Blackburn of Mountlake Terrace thought her parents were doing just fine. Her father, James Blackburn, a former general contractor, and her mother, Gloria, were living independently in the house that James had helped build. Gloria, a resident of Mountlake

Terrace since 1952, had been diagnosed with Parkinson's Disease, but together, she and her husband were managing.

Angela and her husband owned and operated a roofing and remodeling company in Missouri, which her father had helped them establish. In early 2005, Angela, who was just 29 at the time, unexpectedly received an urgent call from her parents. Everything was not fine. Angela's father had been diagnosed with cancer and during chemotherapy began to suffer from congestive heart failure. Angela's mother had been attempting to care for him on her own. She soon realized, however, that she could not handle the intense caregiving duties by herself, and she turned to her daughter for help.

Angela arrived in Mountlake Terrace in late January 2005, having left her husband, four children and disabled mother-in-law in Missouri for what she had assumed would be a short visit. She was shocked by the situation she found her parents in.

Limited Resources for Elderly Care

In Seattle, the average monthly cost of a private room in a nursing home exceeds \$6,600. For those who want to stay in their own homes, professional in-home nursing care will typically cost \$21 per hour.

"None of the long-term care options are reimbursed by Medicare or private health insurance. After approximately 120 days in a skilled nursing home, seniors will find that Medicare will end. From there on, they must use private resources to finance their care," explains Anne Biederman, MSW/MA, who has served as a caregiver specialist for several community agencies in the Seattle area.

The average local senior citizen receives just \$993 from Social Security per month. If this is their only source of income, it doesn't take much to put them in financial hardship. As a result, the resource most often utilized by seniors needing care is an adult child: usually, their daughter. Nearly 70 percent of caregivers are women, with an average age of 46.

According to a study conducted by Cornell University, mothers aged 65 to 75 are almost four times more likely to expect a daughter, rather than a son, to be their caregiver if they become sick or disabled. "Mothers weren't especially concerned about practical aspects of whether an adult child could care for them. They expected care from the child they felt closest to and who had more similar values, even if he or she had serious life problems of his or her own, or had other competing responsibilities," said Karl Pillemer, the study's principal investigator. "Gender was definitely the trump card."

Support is available for caregivers through county, federal and state government programs, which are administered by a variety of local nonprofit organizations. Accessing this help, however, can be a full-time job for caregivers already pushed to the limit.

Unfortunately, many caregivers don't know how to access local resources, or even what type of assistance is out there. A recent study of West Coast caregivers found that 75 percent did not know where to access services available to them.

A Delicate Balance

For many elderly people living on fixed incomes, it doesn't take much to tip the balance and put them in financial jeopardy; a medical emergency can quickly rack up a huge debt. When Angela arrived at her parents' house, things were already out of control. First, she learned they had a water bill of over \$400 that they couldn't afford to pay. Then, she found out there were over \$2,500 in unpaid utility bills.

Angela's 17-year-old niece, born with a congenital heart defect and learning disabilities, had dropped out of high school to live with Angela's parents. Also living in the home was Angela's older sister, who was suffering from cancer. A professional dog handler, she had several dogs staying with her in the basement. She was too sick to clean up after the dogs, which weren't house-trained. Approximately \$45,000 of damage had been done to the basement by the time Angela arrived, and the smell throughout the house was intense.

Angela found it wasn't feasible to move her parents to Missouri, given the state of their health, so in early February 2005, she and her husband decided the only thing to do was to move to Mountlake Terrace so she could take care of her parents herself.

"The move back to Washington was a leap of faith; it wasn't about material things," she says. "My parents had never let me down, so I wasn't about to let them down when they needed me."

Ten people would be living in the small house, and would have to depend solely on Angela's husband's income and her mother's Social Security. Realizing that they weren't going to make it without assistance, Angela sought help from the Family Support Center of South Snohomish County, a local nonprofit agency that provides information, education and resources to families in need.

Pam Graham, program coordinator of the Family Support Center, enrolled Angela in their Family Caregiver Program, which offers free training, individual and family counseling, and support groups for unpaid family caregivers.

Graham emphasizes, "We're a multi-resource center. We often uncover details about multiple urgent and compelling issues when a family comes in with just one simple request."

Graham helped Angela coordinate with U-Haul's corporate public relations office to receive a donation of boxes, a tow dolly, packing blankets, and a large truck with which Angela would move herself and her family permanently to Washington. Gas cards to fuel the truck were obtained through the Snohomish County Kinship Care Emergent Needs Program.

Angela sold her home in Missouri at a loss, gave up her business, and moved her family into her parents' home. They arrived without jobs and without money. Angela's oldest son offered his college fund to help his grandfather. Angela wouldn't let him use it, however.

Money for building supplies to repair the basement was provided by the Kinship Care Emergent Needs Grant, and the Family Support Center helped link Angela with local businesses for donations of materials. She and her niece cleaned out the basement; removing and replacing the carpet, linoleum, sheetrock, and plasterboard. Another home

was found for Angela's sister and the dogs. The Family Support Center worked with St. Vincent de Paul and Salvation Army to get bedding and furniture for Angela and her children.

Medicare covered hospice care for Angela's father, and also provided for a chaplain and funeral arrangements. Her father died peacefully several weeks after Angela and her family arrived.

Angela found that, "people have to go outside the box and be proactive. When you need help, you need to go seek it yourself. If you run into a roadblock, you just need to look for another way, not give up."

The Loneliest Job

While securing medical care and financial assistance for their loved one is often a high priority for caregivers, it's their own emotional and psychological well-being which seems to be most affected by their caregiving duties, needs which all too often go unmet.

"Caregiving is one of the loneliest jobs in the world. No one who isn't actively providing day-to-day, hour-by-hour care for someone else can understand what's involved," Biederman stresses. "It doesn't happen in isolation, although it may feel very isolating."

Becoming a caregiver is often an unplanned, and seemingly unavoidable, life event for women who may have multiple competing responsibilities, including children, careers, and other family obligations. Over a third of caregivers today are serving as their loved one's only source of care, and nearly one in five spend more than 40 hours each week providing care. The Family Caregiver Alliance reports that as many as half of all caregivers suffer from depression, a rate proportionately higher than among women not serving as caregivers.

Graham believes that it is crucial for caregiver programs to "emphasize the caregiver's inherent competence, and how this can sometimes lead to problems of taking on too much; of self-sacrificing too much without asking for help."

If the assistance provided by informal caregivers had to be replaced with paid services, it would cost this country an estimated \$257 billion each year. This figure greatly exceeds the current annual costs of home health care, at \$32 billion, and nursing home care, at \$92 billion nationwide.

In spite of this, Biederman believes that informal caregiving "is viewed negatively in our culture because caregivers are not financially compensated, and the work they do doesn't require degrees or credentials. I've even heard 'caregiver' used to describe women with 'poor boundaries' who want to nurture others! Such nonsense doesn't exist in many other cultures."

The emotional toll of caregiving can even affect a woman's health, especially when she is a daughter caring for a parent. According to a new study by researchers at Stanford, daughters serving as primary caregivers for ailing parents show more cardiovascular stress than do wives who care for ailing husbands.

“In general, it may be more of an imposition for a younger person who hasn’t planned or bargained for that, as opposed to a wife, who has chosen to marry someone and may be more accepting of that person’s illness,” said the study’s principal investigator, Abby King, an assistant professor of health research and policy with the Stanford Center for Research in Disease Prevention.

The National Alliance for Caregiving has found that only 60 percent of caregivers talk about their problems with family or friends to relieve stress. Biederman emphasizes that it is critical that caregivers open up to their loved ones about problems they are having. “Caregivers look like everybody else because, at any moment across the lifespan, we may become one. We need to find a way to coax caregivers out of the darkness, away from their isolation.”

Tomorrow’s Daughters

For a woman who is caring for an elderly parent 40 or more hours each week, taking an extended leave from work is often the only solution. However, doing so can have highly damaging effects upon her own future Social Security benefits. A recent study found that a woman who serves as a caregiver during her working years has a 2.5 times greater chance of living in poverty as a senior than does one who has never been a caregiver.

Because of their time away from work, informal caregivers are believed to miss out on an average of \$25,494 in Social Security benefits, \$67,202 in pension benefits, and \$566,433 in wages, for a lifetime total of \$659,139.

“Over the average of six or more years of taking care, the loss of income is significant. It’s even more difficult, however, to put a price on the losses of self and self-esteem for the family member who retires early or passes up promotions or challenging career opportunities to be a caregiver. Little wonder that depression is common among family caregivers,” Biederman cautions.

Graham believes that the Family Support Center’s programs have been successful at reaching out to local caregivers because, “we don’t try to make people fit into available programs; we help make programs flexible to meet each person’s needs.”

Recent programs have included a weekly caregiver support group; “Coping with Holidays and Illness” classes; and an afternoon of free respite care for families caring for a loved one to allow them to prepare for the holidays.

It is this sort of creative assistance that many of today’s caregivers desperately need. By the time today’s daughters are senior citizens, it is estimated that 20 percent of the population of the United States will be over the age of 65. With the future of Social Security uncertain, pension plans increasingly being eliminated by employers, and the cost of medical care on the rise, unpaid family caregivers will likely continue to be the largest source of long-term care in the United States. It is estimated that there will be an 85 percent increase in the number of informal caregivers in the United States by the year 2050.

Biederman sees the solution to the unmet needs of today’s caregivers as both a local and a national issue. “I dream of a system in which generous federal and state funding make two

things possible: The first is an easily accessed respite service where middle-income seniors and families can schedule regular breaks in their weekly caregiving work. Secondly, I imagine our community hospitals partnering with local agencies to conduct screening, counseling, and referrals to the many caregivers who either support patients or — just as likely — are themselves patients.”

Although caregiving can be very a difficult role for many women, studies have shown that there are many beneficial effects. Caregivers often find it very rewarding to be able to help a loved one. The feeling of being appreciated, and a sense that their relationship with their loved one has been strengthened by their care, can be very fulfilling.

Biederman feels that, above all else, it is important to remember why it is that so many daughters are taking care of their elderly parents. “Caregiving is born of our most basic instinct to compassionately respond to the needs of another. It may just be our highest calling as human beings.”

Katherine Luck is a freelance writer. Her first novel, In Retrospect, was the recipient of the 2006 Celebration Foundation Grant, and will be available in 2007.

Long-Term Care Insurance

By the time you reach retirement age, you will have a 40 percent chance of spending part of your life in a nursing home. In preparation for this possibility, more than six million people in the United States have purchased long-term care insurance; a number which has nearly doubled since the year 2000.

How is long-term care insurance different from health insurance?

A person who needs long-term care has difficulty with their day-to-day activities, such as walking, feeding themselves and bathing. Long-term care insurance provides reimbursement for both in-home assistance and nursing home care. Many plans also offer care coordination services to assist the client in making choices between care options as their needs change.

What about Medicare?

Many individuals are unpleasantly surprised to learn that long-term care is not covered by Medicare. Many veterans, as well, expect to have their long-term care needs covered by the Department of Veterans Affairs. However, in general, only care needs directly related to a disability incurred in the line of duty are covered.

When is the best time to buy a policy?

By the time you need long-term care insurance, you may no longer be eligible to purchase a policy. Since approximately 40% of adults who need long-term care are under the age of 65, it's a good idea to obtain a policy before you retire. Once an individual policy is in

place, it's generally renewable for the rest of your life and can't be cancelled by the insurance company.

How much will it cost me?

Premiums for long-term care insurance rates vary depending upon your age and health at the time you purchase your policy, as well as the monthly benefit amount you want and how long you want the benefits to last. An older person who is not in optimal health when they sign up will pay significantly more per month than a younger adult.

To help defray costs, you can often deduct a percentage of your long-term care insurance premiums from your income taxes.

Where can I find a policy?

Many employers today are offering group long-term care policies as part of their employee benefits packages. However, these plans may not be tax-deductible or renewable for your lifetime, and rates may be increased or changes made to your policy.

If you wish to purchase long-term care insurance for yourself or a loved one, plans are available from several major insurance providers. Check out www.healthdecisions.org to find a list of insurers offering plans in Washington.

— *Katherine Luck*

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