

ALL ON THE FAMILY:
INFORMAL CAREGIVING IN AMERICA

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ABSTRACT

Anne J. Tate All on the family: Informal Caregiving in America
(Under the direction of Barbara Friedman)

The purpose of this thesis is to bring more attention to “family caregivers,” or those who provide unpaid assistance to sick or aging relatives, often to the detriment of their own physical and mental health. More than 30 million family, or “informal,” caregivers are responsible for the care of elderly spouses, siblings and parents – many of whom have Alzheimer’s disease or another dementing illness – and the size of this caregiving population is about to increase as life expectancy increases and baby boomers age.

This thesis assesses the literature and media coverage published heretofore on the subject of informal caregiving in America, and, through a series of five family profiles and an article on a local respite program, adds to the growing body of literature on this significant national issue.

For my mother

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CHAPTER I

Introduction

The inspiration for this series of articles is my mother, a woman who has dedicated the past four years of her life to caring for her aging parents without compensation, recognition or gratitude from most members of her family. In fact, she was treated with outright hostility by her nieces and nephews, all of whom were motivated by a desire to obtain pieces of my grandparents' estate. My uncle, who lives several states away, never offered help. The demands of caring for two adults with dementia, along with the added pressure of avaricious relatives working to undermine her efforts, had devastating results on my mother's health and mental well-being. She developed a debilitating facial tic and suffered from insomnia, depression and exhaustion. Her doctor warned her that her lifestyle put her at high risk for stroke. My younger sister and I helped when we could, but the situation was overwhelming for all of us. We each felt hopeless, angry and resentful.

For a long time I believed my mother's circumstances were unique, but when I set out to report on the topic of eldercare for a journalism class in the fall of 2005, I quickly discovered she was not alone in her role. Our society classifies people like my mother as "family caregivers," or those who give unpaid support to ailing loved ones, ranging from arranging for housing and coordinating professional care to cooking meals and washing clothes. According to a 2004 report by the National Alliance for Caregiving and the AARP,

about 34 million Americans provide informal care to seniors aged 50 or older.¹ And a large majority of those seniors, about 90 to 95 percent, stay at home or move into a relative's place, relying family members to help out as old age diminishes their self-sufficiency.²

While providing care to a loved one can be a rewarding experience, studies show that many family caregivers experience the same health problems and challenges my mother did. According to information culled by a non-profit called The Family Caregivers Alliance, caregivers are more prone to increased blood pressure and insulin levels than non-caregivers, and they may be at greater risk for heart attack. Also, caregivers suffer from clinical depression and insomnia at higher rates than the rest of the population.³ Varying levels of responsibility and gender inequality (women shoulder a disproportionate amount of the caregiving burden) often cause tension and conflict among relatives, as it did in our family.

And caregiving can have devastating financial implications as well. Because of the time-consuming nature of their roles, many caregivers must quit their jobs or take early retirement.⁴ My mother co-owns a television-production business, and her performance and concentration were severely compromised during the period she cared for her parents. Her business partner became frustrated and made threats of dissolving their company, which would have left my mother with almost no income.

¹ "Caregiving in the U.S." (National Alliance for Caregiving and the AARP, April 2004); available from http://assets.aarp.org/rgcenter/il/us_caregiving_1.pdf; Internet; accessed 19 January 2006.

² Tish Sommers and Laurie Shields, *Women Take Care: The Consequences of Caregiving in Today's Society* (Gainesville: Triad, 1987), 21; Nancy L. Mace and Peter V. Rabins, *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life*, updated and rev. ed. (Baltimore: Johns Hopkins University Press, 1999; reprint, New York: Warner, 2001), 264.

³ "Selected Caregiver Statistics" (San Francisco: Family Caregivers Alliance); available from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439; Internet; accessed 18 January 2006.

⁴ Ibid.

Through my research, I have been heartened to discover myriad resources available to family caregivers, including magazines, how-to guides, web sites, respite programs and support groups. I was surprised to find that academics and medical professionals have been studying family caregivers and their demographics for decades. Even popular media outlets like the *New York Times* and NPR have published and produced stories on the subject. Yet somehow my mother—who writes for a newspaper herself and is an avid media consumer—has never seen one article or news segment directly related to her role as a caregiver. In fact, she did not even know the term “family caregiver” existed, or that she was part of a formally recognized group in American society.

While more and more stories on caregiving have begun to appear on television, on the radio and in newspapers, only a few are told from the perspective of the caregiver. Stories about inadequate nursing homes and political controversies over Medicare and Social Security have sparked public dialogue about the state of long-term care in this country, but the day when caregivers are the main foci of the health-care debate has yet to arrive.

When contrasted with the valuable contribution caregivers make to society, the amount of media coverage they receive seems especially scarce. This phantom army of unpaid workers underpins our health care system, and American would be helpless without them. A study commissioned by the United Hospital Fund’s Families and Health Care project estimates the so-called “free” work performed by family caregivers at about \$257 billion a year. That’s more than twice the annual price tag of hired and institutionalized nursing care.⁵ And caregivers’ role in society will become even more vital as life expectancy increases and baby boomers age.

⁵ Carol Levine, ed., *Always on Call: When Illness Turns Families into Caregivers* (Nashville: Vanderbilt University Press, 2004), 5.

The popular media accounts that do focus on the caregiver describe daily routines and provide contextual statistics, but there are aspects of the caregiving experience that simply cannot be captured by straightforward reporting and quantitative data. It's difficult to relay in a single article or broadcast segment just how difficult becoming a caregiver can be, and reporters often miss the unorthodox challenges caregivers confront. For example, Ann Hearn, the subject of one of my articles in this thesis, had to find and hire a veterinarian to capture and euthanize her aunt's 27 pet cats when she moved her aunt into a nursing home. The job was time-consuming, costly, and for an animal-lover like Hearn, it was heartbreaking. Sylvia Hill, a Durham resident who took care of two aunts and her mother, faced a similarly tough obstacle when she had to fly to Arizona to retrieve her mentally incapacitated aunt and bring her back to North Carolina for care. Not only was this an expensive trip, but it was emotionally difficult as well. Hill's aunt refused to leave her home or give up her car, and Hill felt guilty forcing her to do so.⁶ My mother had an analogous experience with her father, who was so upset when she sold his car, he tried to have her arrested.

My project, a series of articles on family caregiving, attempts to contribute a more in-depth look into the lives of family caregivers. I intend to raise public awareness about family caregiving by pursuing publication of these articles in local newspapers in North Carolina and Georgia. By profiling several caregivers and providing relevant statistics, I address the common issues and challenges family caregivers confront. But I also strive to move beyond conventional coverage and to write about the tangential experiences that are usually missed

⁶ Sylvia Hill, interview by author, by phone, Chapel Hill, N.C., December 2005.

in mainstream media profiles. My personal familiarity with the topic helps introduce some of the more nuanced feelings associated with family caregiving.

I also focus on possible solutions to the problems and stresses family caregivers face. Therefore, one of the articles in this series explores Project C.A.R.E., a full-service respite program available in many counties in North Carolina.

My goal is to reach people like my mother and to provide comfort through the awareness of shared experience and hope through the knowledge that resources exist.

Background

Who are family caregivers, and what do they do?

Family caregivers, also called “informal caregivers,” are those who are involved in the long-term care of a loved one, usually without monetary compensation. Responsibilities run the gamut from performing household tasks such as dishwashing and cooking to assisting a loved one with activities of daily living (ADLs). These activities include toileting, bathing, dressing, eating and walking. Even if a patient or elderly person lives in a nursing home, family caregivers still play a vital role in their care by visiting, monitoring quality of care and making decisions on their loved one’s behalf.

The typical caregiver, according to the 2004 NCA/AARP report, is an employed 46-year-old woman with some college education who spends 20 hours a week caring for her mother. Women disproportionately fill the caregiver role at the highest level of burden; 71 percent of caregivers at the highest level are women and 29 percent are men. (In this study, amount of responsibility assisting with ADLs determined burden levels.) At the lowest level

of burden, the distribution evens out somewhat—58 percent are women and 42 percent are men.⁷

The typical care receiver, according to the same report, is a 66-year-old woman who lives alone. Yet the average age of a care receiver is about to increase. U.S. Census Bureau projections show that 5.4 million Americans will be older than 85 by the year 2050, compared with the estimated 700,000 currently in that age bracket.⁸ That means more and more adults will be forced to care for aging relatives with dementia, as age is the single greatest risk for Alzheimer's disease.⁹ In fact, the National Institute on Aging reports that Alzheimer's affects almost half of seniors older than 85.¹⁰

Families caring for an aging adult with Alzheimer's disease or another dementing illness confront some of the toughest challenges. In addition to the time demands of helping a parent or spouse with routine activities, those caring for adults with dementia must cope with loss of dignity associated with the mental deterioration of a loved one. And helping a person with dementia can be complicated and frustrating. Caregivers must learn how to interact with a family member who is forgetful, confused and sometimes combative, as many adults with dementia aggressively refuse baths and meals. This obstinacy requires special negotiating skills from caregivers. As one example, a 2002 *New York Times* article describes how a woman caring for an older husband with Alzheimer's had her two grown sons come to

⁷ "Caregiving in the U.S." (National Alliance for Caregiving and the AARP, April 2004); available from http://assets.aarp.org/rgcenter/il/us_caregiving_1.pdf; Internet; accessed 18 January 2006.

⁸ "Projected Population Change in the United States, by Age and Sex: 2000 to 2050" (U.S. Census Bureau); available from <http://www.census.gov/ipc/www/usinterimproj/natprojtab02b.pdf>; Internet; accessed 14 January 2006.

⁹ "Alzheimer's Disease: Causes and Risk Factors" (National Institute on Aging); available from <http://nihseniorhealth.gov/alzheimersdisease/causes/01.html>; Internet; accessed 18 January 2006.

¹⁰ "Alzheimer's Disease Education & Referral Center" (National Institute on Aging); available from <http://www.alzheimers.org/generalinfo.htm#howmany>; Internet; accessed 18 January 2006.

her Queens home to force their father into the shower.¹¹ The anger and sadness that accompany this type of caregiving are difficult to quantify, though family caregivers often report feeling these emotions. What's more, informal caregivers for those with dementia experience increased stress, family conflict and health problems, resulting in shorter life expectancies, according to the National Alzheimer's Association.

Many caregivers feel isolated, resentful and unprepared. They are often forced to perform quasi-medical duties like dressing wounds, inserting catheters and monitoring medication. Care recipients with chronic conditions require special skills on the part of their caregiver, but many caregivers receive no training whatsoever. A study sponsored by The United Hospital Fund and the Visiting Nurse Service of New York reported that 57 percent of caregivers who had to assist with ADLs had no help or instruction from a medical professional. Thirty one percent of those who change a care recipient's bandages or dressings were not taught specific and necessary techniques. And, alarmingly, about 19 percent of caregivers who administer medication or deal with medical equipment had no direction or oversight.¹² This is yet another indication that a caregiver and his or her needs are virtually ignored by the health care system, contributing to feelings of fear and isolation.

Care receivers usually require attention all through the night, and, unlike babies and children, dependence from an elderly person on the caregiver only increases. Therefore, it is common for an overextended and exhausted caregiver to wish for a loved one to pass on, arousing feelings of guilt and inadequacy. As if these circumstances were not dire enough, the grief associated with watching a loved one die adds to the emotional load.

¹¹ Jane Gross, "Alzheimer's in the Living Room: How One Family Rallies to Cope," *New York Times*, 16 September 2004, sec. 1A, p.1.

¹² *Ibid.*, 12.

While statistics tell the story of the financial and physical losses incurred by caregivers, thousands of frustrations and incidents go undocumented and unmeasured. Like Ann Hearn and Sylvia Hill, caregivers are often forced to make difficult decisions for loved ones, from managing estates to finding a suitable nursing home. These responsibilities can be just as stressful, unpleasant and upsetting as having to help a parent or spouse eat meals, use the restroom or get dressed.

Non-profit organizations to the rescue

In the 1970s and 80s, family caregivers began to recognize their shared problems and common cause and banded together to gather resources and support for their swelling ranks. Many of the organizations dedicated to family caregivers are flourishing, and they now offer web sites with advice, policy information and contacts for local resources and respite care.

One of the pioneers of caregiver support was Clemmie Barry, a social activist who cared for her husband for 17 years after he had a debilitating stroke. Barry, jarred by the unexpected loneliness and frustration of the experience, formed a support group for others like her in Marin County, Calif., in the 1970s; at the time, it was one of only a few in the country. In 1980, Barry attended the White House Mini-Conference on Older Women, where she shared her story with the 400 attendees. As a result, The Older Women's League (OWL) was formed to help bring attention to the issues with which middle-aged and older women grapple.¹³ One of these issues, of course, was family caregiving.

Though OWL still exists as an advocacy group for the large population of females who care for loved ones, informal caregiving is only one of the group's foci. Another non-profit that originated in San Francisco in 1977, the Family Caregivers Alliance (FCA),

¹³ Sommers and Shields, 13-15.

concentrates exclusively on the plight of the informal caregiver. Their multi-tiered web site culls and publishes statistics and relevant research, offers a newsletter and provides advice and resources. Besides supplying helpful information directly to the caregiver through the Internet, the FCA is instrumental in setting up local programs and advancing the cause of caregivers to legislators and policy-makers.¹⁴

In 1992, two women founded an organization similar to the Family Caregivers Alliance. Suzanne Mintz and Cindy Fowler recognized the similarities in their caregiving experiences and decided to reach out to others who might be enduring the same kind of ordeals. They wanted to give this often-ignored segment of the population a voice and make others understand that illness and old age affect more than just the afflicted person. Mintz and Fowler's efforts began with a newsletter distributed through social work offices, and, a year later, they founded the National Family Caregivers Association.¹⁵ The association aims to educate and empower family caregivers by funding research and sponsoring studies on caregivers. Like the FCA, they maintain a web site that is an excellent resource for information and advice.

In the last thirty years, many hospitals, national disease agencies (such as the Alzheimer's Association and the Parkinson's disease Foundation) and even insurance and drug companies (such as State Farm and Pfizer) have sponsored programs and studies on the subject of caregiving. In 1996, a non-profit called the National Alliance for Caregiving

¹⁴ "Who We Are" (Family Caregiver Alliance); available from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=349; Internet; accessed 15 January 2006.

¹⁵ "History of the NFCA" (National Family Caregivers Association); available from <http://www.thefamilycaregiver.org/about/history.cfm>; Internet; accessed 15 January 2006.

synthesized these myriad entities into a coalition, and its web site links to member organizations and corporations, offers caregiving tips and lists upcoming events.¹⁶

The government has joined the support network as well. In tandem with the 2000 Older Americans Act, the federal government formed The National Family Caregiver Support Program (NFSCA) as part of the Administration on Aging. The NFSCA gives grants to states for support and respite services for caregivers and generates original research on the topic.¹⁷ They, too, have an informative web site with links to tips, fact sheets and ongoing studies.

In addition to this growing legion of non-profit groups and government agencies, several celebrities have formed their own organizations to bring attention to this urgent matter. Former First Lady Rosalynn Carter formed The Rosalynn Carter Institute (RCI) for Caregiving in 1987.¹⁸ Though based in Southwest Georgia, the institute has both local and national outreach and enjoys a high profile because of the attention generated by Carter, who, in addition to being a public figure, published a book on the subject of family caregiving in 1994.

The talk-show host Leeza Gibbons recently became another famous advocate for the caregiving community. Spurred by the deeply upsetting process of caring for her mother, who was diagnosed with Alzheimer's disease at a young age, Gibbons also formed an organization called Leeza's Place. Her goal is not only to help caregivers to those with

¹⁶ "Who We Are" (National Alliance for Caregiving); available from <http://www.caregiving.org/about/>; Internet; accessed 15 January 2006.

¹⁷ "About NFCSP" (National Family Caregiver Support Program); available from http://www.aoa.gov/prof/aoaprogram/caregiver/overview/overview_caregiver.asp; Internet; 15 January 2006.

¹⁸ "About Us" (Rosalynn Carter Institute for Caregiving); available from <http://www.rci.gsw.edu/about%20us.htm>; Internet; accessed 15 January 2006.

Alzheimer's, but to find a cure for the disease.¹⁹ Gibbons has made numerous television appearances to promote her organization, bringing increased media attention to the challenges facing those who care for a loved one with Alzheimer's or another dementia-related disorder.

These organizations have the potential to be great resources to family caregivers, and their very existence recognizes the fact that caregivers have tremendous needs and that they provide a vital service to American society. But many people like my mother do not know about or have time to access these resources, indicating that caregivers and their support organizations still do not enjoy the high profile they deserve.

Researchers sit up and take notice

Scholarly literature on informal caregiving grew rapidly in the 1980s. The creation of programs like Medicare and Medicaid brought to light the shared public cost of health care, resulting in the publication of numerous academic and scientific studies about family caregivers.²⁰

Many researchers concentrated on the health of caregivers, setting out to determine if caregiving responsibilities had deleterious physical and mental effects. In 1986, a seminal paper written by Linda K. George and Lisa P. Gwyther concluded that family caregivers experience considerably more stress and mental burden than their non-caregiving peers. The same study showed that caregivers use psychotropic drugs at a higher rate than non-caregivers, though it also revealed little difference in physical health between the two

¹⁹ "A Letter from Leeza" (Leeza's Place); available from <http://www.leezasplace.org/index2.html>; Internet; accessed 15 January 2006.

²⁰ Levine, 6.

groups.²¹ More recent studies, however, report that caregiving has serious physical consequences as well as mental ones and that the chronic stress associated with caregiving can contribute to disease and functional decline.²² A study conducted by The Commonwealth Fund reports that caregivers are more likely than non-caregivers to have health problems, with the former group reporting chronic conditions at the twice the rate of the latter.²³ Many studies examine frequency of depression and related maladies in caregivers, and one study on caregivers of Alzheimer's patients reports that the high levels of grief and feelings of isolation contribute to these conditions.²⁴ Co-residence, longer duration of care and a care recipient with cognitive-behavioral problems (versus only physical impairments) all contribute to higher levels of caregiver strain, family conflict and other negative effects.²⁵ Also, time taken off from work often adds to caregiver stress.²⁶ Few

²¹ Linda K. George and Lisa P. Gwyther, "Caregiver Well-Being: A Multidimensional Examination of Family Caregivers of Demented Adults," *The Gerontologist* 1985 (27), 256.

²² Donna L. Hoyert and Marsha Mailick Seltzer, "Factors Related to the Well-Being and Life Activities of Family Caregivers," *Family Relations* 1992 (41)1, 74-81; Janice K. Kiecolt-Glaser, Kristopher J. Preacher, Robert C. MacCallum, Cathie Atkinson, William B. Malarkey and Ronald Glaser, "Chronic Stress and Age-Related Increases in the Proinflammatory Cytokine IL-6," *Proceedings of the National Academy of Sciences of the United States of America*, 2003 July Vol. 100, 9090-9095.

²³ Alice Ho, Sara R. Collins, Karen Davis, and Michelle M. Doty, "A Look at Working-Age Caregivers' Roles, Health Concerns, and Need for Support" (The Commonwealth Fund); available from http://www.cmf.org/usr_doc/854_Ho_working-age_caregivers.pdf; Internet; accessed 18 January 2006.

²⁴ Sara Sanders and Adams, Kathryn Betts. "Grief Reactions and Depression in Caregivers of Individuals with Alzheimer's Disease," *Health & Social Work*, Vol. 30(4), 287.

²⁵ Hoyert and Seltzer, 77; Nancy W. Sheehan and Paul Nuttall, "Conflict, Emotion and Personal Strain among Family Caregivers," *Family Relations* 1988 (37)1, 92-98; Marjorie E. Starrels, Berit Ingersoll-Dayton, David W. Dowler and Margaret B. Neal, "The Stress of Caring for a Parent: Effects of Elder's Impairment on an Employed Adult Child," *Journal of Marriage and the Family* 1997 (59)4, 860-872.

²⁶ Starrels, Ingersoll-Dayton, Dowler and Neal, 868.

studies concentrate on the positive outcomes of the caregiving experience, though some caregivers report feelings of gratification and satisfaction.²⁷

One consistent finding is that women have traditionally assumed caregiving duties in American society. Many authors emphasize the societal pressures and expectations that seem to relegate women to caregiving roles throughout life.²⁸ Because they are mothers, women are primarily seen as nurturers and thereby are taken for granted as the natural caregiver when it comes time to care for an aging parent or spouse.²⁹ Not only do women disproportionately fill the caregiving role, they often experience more stress and physical strain when caring for a parent or spouse.³⁰

The qualitative and anecdotal research supports the findings of many of the quantitative studies. In a book called *Women Take Care: The Consequences of Caregiving in Today's Society*, a woman named Dorothy writes about leaving her husband and sons in Germany to come home to California to take care of her parents. Her story reveals how men rarely see themselves as responsible for helping out. When Dorothy reaches her emotional and physical limit, she appeals to her brothers for help. One refuses because of his career commitments, and the other simply does not offer to lend a hand—even though he has no steady job.³¹ The author comments on Dorothy's situation: "Daughters and daughters-in-law often face a choice between their paid employment and caregiving or (as Dorothy did)

²⁷ Hoyert and Seltzer, 74.

²⁸ Rick Briggs, *Caregiving Daughters: Accepting the Role of Caregiver for Elderly Parents* (New York: Garland, 1998), 4; Sommers and Shields, 15-16.

²⁹ Ibid.

³⁰ Starrels, Ingersoll-Dayton, Dowler and Neal, 860; Sheehan and Nuttall, 92-98; Ada C. Mui, "Multidimensional Predictors of Caregiver Strain among Older Persons Caring for Frail Spouses," *Journal of Marriage and the Family* 1995 (57)3, 733-740.

³¹ Sommers and Shields, 30-36.

between their husbands/children and caregiving. Men rarely are forced to confront such a choice.”³² Even worse, Dorothy’s brothers complain when they do not approve of decisions she makes regarding their parents’ situation.

For many women, the unexpected and overwhelming responsibility of caregiving comes at an inopportune juncture in their lives: middle-age. During these years a woman’s career might be taking off, or she might still be the primary caregiver for her children—whether or not they are grown. At the same time, middle-age is usually when women are facing health issues of their own, dealing with symptoms of menopause and signs of physical decline.³³ As a result, when the extra burden of caring for an aging parent is added to their load, the stress of balancing different sectors of life becomes overwhelming.

But because society expects women to provide care to a declining loved one—just as they presume women will rear children—it is usually thankless work. Caregivers receive no reward or compensation, even though the American health care system depends heavily on their services. In a book called “Feminist Perspectives on Family Care,” the authors argue that many of our nation’s policies—from health care and employment to Social Security and Medicare—are predicated on the assumption that women will step up to fill the gaps in the long-term care system.³⁴ In this social scheme, caregivers become invisible and their needs and problems ignored. As a result, policy-makers do not address caregivers’ needs. They

³² Ibid., 36.

³³ Jane Norris, ed., *Daughters of the Elderly: Building Partnerships in Caregiving* (Bloomington: Indiana University Press, 1998), 16.

³⁴ Nancy R. Hooyman and Judith Goya, *Feminist Perspectives on Family Care: Policies for Gender Justice* (Thousand Oaks: Sage, 1995) Vol. 6, 244.

see family care as a private responsibility, not a public one, and make no move toward helping this segment of the population.³⁵

This ignorance on behalf of the government, as nurse and researcher Carol Levine argues, creates a vicious and costly health-care cycle. Many caregivers eventually become care recipients themselves because years of exhaustion, stress and isolation put them at risk for disease and depression. Levine, who has had to care for her quadriplegic husband for more than a decade, writes, “Does my managed-care company, realize, for instance, that during the past year it paid more for my stress-related medical problems than for my husband’s medical care?”³⁶ Even with training as a professional nurse, Levine felt alone, unmoored and helpless when she suddenly and unexpectedly became a family caregiver.

Almost every self-reflexive informal caregiving account includes expressions of loneliness, fear and guilt. These anxiety-inducing conditions go untreated and unchecked because caregivers do not have the time or resources to manage them. For example, one case history describes a woman who ignored her personal health problems while taking care of her husband, suffered a stroke and died.³⁷

While the obvious solution for caregivers is to find resources and respite programs that will allow them relief and time to tend to their own needs, too few caregivers know help is available or have time to access it. Many caregivers say doctors often fail to recognize their role, much less offer them help or advice. As one female caregiver testifies, “The outstanding memory I have is of being abandoned by the institutions I formerly had a great

³⁵ Ibid., 13.

³⁶ Levine, 106.

³⁷ Sommers and Shields, 55-57.

deal of respect for...I got no information from his [her husband]'s doctor or the nurse in his office.”³⁸

Some caregivers might be lucky enough to discover the huge body of lay literature on caregiving. There are plenty of manuals, guides and periodicals geared toward caregivers of patients with Alzheimer's and other conditions, all offering anecdotal stories about the hardships endured by caregivers and ways to alleviate associated stresses. In addition to giving helpful advice, this self-help literature serves another extremely important function: letting caregivers know they are not alone in new and unfamiliar territory. Yet just as is true with respite programs and non-profit organizations, the available literature can only help if caregivers become aware of it.

Popular media need to focus more on caregivers

My mother is not alone in feeling neglected by the mainstream media. Research conducted at the Rosalynn Carter Institute in the early 1990s showed that informal caregivers felt they did not receive enough attention from newspapers, television and radio outlets.³⁹ This is not to say the press has completely ignored the issue of family caregiving. As far back as 1985, the cost and strain of caring for aging parents made the cover of *Newsweek*, and PBS's *Frontline* series produced a documentary on the topic.⁴⁰ And it seems that as the baby-boomer generation ages and life expectancy increases, articles and broadcast segments about long-term care have become more frequent. A search of NPR archives reveals at least seven stories in the past five years about family caregiving. To determine whether family

³⁸ Ibid., 29.

³⁹ Rosalynn Carter and Susan K. Golant, *Helping Yourself Help Others* (New York: Random House, 1994), 212.

⁴⁰ Emily K. Abel, “Adult Daughters and Care for the Elderly,” *Feminist Studies* 1986 (12)3, 479.

caregivers receive coverage in newspapers, I conducted a database search of major newspapers in New York and Washington from 2001 to 2006 using the terms “caregiving,” “caregiver,” “elderly” and “Alzheimer’s.” I selected 2001 as a start date because it’s the year the first baby boomers turned 55, the official retirement age, and their parents are likely to be 75 or older. Though I acknowledge my search was not exhaustive because not all editions make it into electronic databases, I believe the sample is representative of the type of coverage informal caregiving receives.

The results were encouraging, but not overwhelmingly so. Many articles focus on the care receiver, not the caregiver. If the story does concentrate on family caregiving, it’s usually to report a recently published study or on an upcoming event or speech.

Both *USA Today* and the *Wall Street Journal* published articles on a 2003 study by the National Academy of Sciences about the negative effects of stress on caregivers. The data showed that older caregivers run a higher risk of getting heart disease and cancer than non-caregivers.⁴¹ Similarly, Cox News Service put a story on the wire about the 2004 AARP and NCA report on family caregiving, highlighting the finding that 44 million Americans are caregivers.⁴²

The *Washington Times* published a short piece about a 2001 event honoring Rosalynn Carter and her caregiving cause.⁴³ And short piece about the need to take care of caregivers appeared in the Health section of the *Washington Post* in 2002.⁴⁴

⁴¹ Kathleen Fackelmann, “Caregivers face getting sick themselves,” *USA Today*, 1 July 2003, sec. Life, pg. 7D; Christopher Windham, “Elderly Caregivers Face Stress Toll; Immune System Suffers, Creating Risk of Disease, According to a New Study,” *Wall Street Journal*, Eastern Edition, 1 July 2003, Pg. D4.

⁴² Larry Lipman, “Study Says 44 Million Americans Are Caregivers,” *Cox News Service*, 5 April 2004 sec. General News, Washington.

⁴³ Gabriella Boston, “Ex-first lady eases caregiver's load,” *The Washington Times*, 14 June 2001, Thursday, Final Edition, Part C; Metropolitan; Life; Brief Encounters, Pg. C8.

Though it's rare, a few papers publish profiles similar to the kind I would like to write. In at least two articles of articles I found on family caregiving, attention to the issue stemmed from the reporters' personal experiences.⁴⁵ This discovery was not surprising considering that my family's situation drew me to the topic.

Jane Gross at the *New York Times* often covers aging, long-term care and problems associated with Alzheimer's disease. She has written two poignant and lengthy pieces on caregivers; one profiles a family caring for a man with Alzheimer's, and the other describes the trend of daughters giving up their successful careers to help declining parents.⁴⁶ Both pieces offer anecdotal information about the challenges caregivers face and statistics that drive home the gravity of the situation.

Sue Shellenbarger at the *Wall Street Journal* has also concentrated on caregiving to the elderly and wrote a representative profile of a couple dealing with impact of a live-in parent on their marriage.⁴⁷ She also has written about the strain of providing long-distance care to an aging relative.⁴⁸

⁴⁴ "Care for Caregivers," *The Washington Post*, 29 January 2002, Final Edition, Health, Pg. F11.

⁴⁵ Andrew Park, "Between a Rocker and a High Chair," *Business Week*, Feb. 21, 2005. Available from http://www.businessweek.com/magazine/content/05_08/b3921133_mz070.htm; Internet; accessed 26 January 2006; Jane Gross, "Striving for a Gentle Farewell," *The New York Times*, August 3, 2003, Sec. 4, pg. 1. Week in Review.

⁴⁶ Jane Gross, "Alzheimer's in the Living Room: How One Family Rallies to Cope," *New York Times*, 16 September 2004, sec. A, p.1.; Jane Gross, "Forget the Career. My Parents Need me at Home," *New York Times*, 24 November 2005, sec. A, p.1.

⁴⁷ Sue Shellenbarger, "A Painful Source of Marital Strife: When an Elderly Parent Moves In," *Wall Street Journal*, Eastern Edition, 1 April 2004, Pg. D1.

⁴⁸ Sue Shellenbarger, "When Elderly Loved Ones Live Far Away: The Challenge of Long-Distance Care," *Wall Street Journal*, Eastern Edition, 29 July 2004, Pg. D1.

I also looked at local coverage in North Carolina and Georgia since these are the states in which I will try to publish articles. A LexisNexis search of both state newspaper databases turned up only five articles in the past six years specifically about family caregivers (though developments with Alzheimer's treatment and prevention were well-covered). The published articles are a mixture of guest columns, reports on programs and short features. For example, an October 2003 article in the *Chapel Hill Herald* ran a piece by an information specialist from the North Carolina Division of Aging and Adult Services; she outlined the family caregiver crisis and detailed some helpful resources.⁴⁹ The (Greensboro) *News & Record* published a few tangentially related articles, including one on a volunteer caregiving organization in their county, but none specifically about informal caregiving.

In March 2004, the *Atlanta Journal & Constitution* reported on the burgeoning population of seniors in Georgia, the difficulties associated with caring for aging loved ones and the local and national resources available to family caregivers. The 800-word article included a few quotes from caregivers about their struggles.⁵⁰ Three years earlier, the paper printed an article that profiled a septuagenarian couple, both of whom were diagnosed with Alzheimer's, and their adult children, who cared for them.⁵¹ Curiously, the reporter never placed this family's story in the context of the national phenomenon of informal caregiving.

Perhaps the most comprehensive and relevant local article on the subject was published by the (Raleigh) *News & Observer* in October 2002. The 1,500-word feature

⁴⁹ Katherine Leith, "Caregivers Need Relief from Stress," *Chapel Hill Herald*, 30 October 2002, sec. Generations, pg. 3.

⁵⁰ Adrienne Murchison, "Parenting Your Parents 101; Growing elderly population imposes unexpected caregiver role," *Atlanta Journal-Constitution*, 11 March 2004, sec. North Fulton, pg. 1JH.

⁵¹ Bill Banks, "Parents in need find children willing and able," *Atlanta Journal-Constitution*, 4 January 2001, sec. Clayton/Henry Extra, pg. 9 JI.

article profiled a middle-aged woman who cares for her small children and her cancer-ridden mother-in-law. The reporter included a sidebar on coping strategies for family caregivers.⁵²

The dearth of coverage on family caregiving in city dailies may explain why my mother and the subjects of Rosalynn Carter's study do not feel they are adequately represented in the media. Though I was encouraged to find some excellent articles and profiles in major newspapers and in the *News & Observer*, I still feel the subject is largely underreported when considering how many lives are affected by family caregiving. With my project, I intend to increase local coverage of the topic, and, as I mentioned before, focus on the obscure challenges and deep emotions associated with the family caregiver role.

Setting the agenda for public concern for caregivers

According to the "agenda-setting" theory proponed by many mass communication researchers, the media can effectively draw the public's attention to certain topics and even assign them special importance. This theory is rooted in a 1972 study of election coverage and voter attention by Maxwell E. McCombs and Donald L. Shaw that strongly suggests the media play a significant role in framing issues for their readership.⁵³ In other words, the stories the media cover tell voters which issues to follow and how significant they are, shaping the public's perception of the political landscape. McCombs and Shaw labeled this type of media influence "agenda-setting."⁵⁴

Following the logic of this theory, the media can pick and choose what issues receive public attention. Yet newspapers rarely tackle topics like family caregiving, in part because

⁵² Kelly Starling-Lyons, "Caregiver squeeze," *News & Observer*, 29 October 2002, sec. Life, pg. E1.; Kelly Starling-Lyons, "How to care for the caregiver," *News & Observer*, 29 October 2002, sec. Life, pg. E3.

⁵³ Maxwell E. McCombs and Donald L. Shaw, "The Agenda-Setting Function of Mass Media," *Public Opinion Quarterly*, Vol. 36(2), Summer 1972, 176-187.

⁵⁴ *Ibid.*, 179-185.

the media do not make a habit of projecting what will likely occur in the future; instead they usually report on what has already happened. Therefore, few newspapers publish stories about emerging trends or ongoing processes, but keep to coverage of isolated instances or dramatic events with a sense of immediacy.⁵⁵ This might explain why there are relatively few stories on family caregiving; even though it impacts millions of lives on an ongoing basis, there are few exceptional events or hard news stories that make the subject immediately relevant. Moreover, ordinary people do not make it into the news unless something extraordinary happens to them, which rules out the publication of human interest stories on family caregivers by most media.⁵⁶ Probably because they have more resources and more seasoned reporters, elite newspapers like *New York Times* do a better job anticipating what will become public issues.⁵⁷ That might explain why most of the in-depth profiles on family caregivers appear in major papers.

Most reporters may find it too difficult or time-consuming to chase down the larger stories that lurk beneath superficial events, but some mass communication researchers argue that the press's agenda-setting power comes with civic responsibility. They say the media should use their influence to affect social change by bringing certain issues to the fore.⁵⁸ Yet while the press can choose which topics they write about, they cannot control the way the public will react. Solutions, they remind us, are hashed out between citizens and their

⁵⁵ Robert Manoff and Michael Schudson, eds., *Reading the News* (New York: Pantheon, 1986), 92-94.

⁵⁶ *Ibid.*, 9-12.

⁵⁷ *Ibid.*, 94-95.

⁵⁸ Donald L. Shaw, Maxwell McCombs and Gerry Keir, *Advanced Reporting*, (Prospect Heights: Waveland, 1997), 325-327.

leaders.⁵⁹ Following this logic, media attention to family caregivers could be crucial in sparking much-needed public debate on the topic, prompting politicians and policy-makers to take action.

While my project alone cannot set the agenda for the public, the articles might provide a fresh perspective on the family caregiving and contribute to a growing body of related mainstream media pieces. And if more and more civic-minded reporters pursue this topic, the more likely it is family caregiving can become the major national story it deserves to be.

Research Questions

1. How are the demands of caregiving experienced by five families?
2. What are the different challenges facing families caring for loved ones in nursing facilities versus home settings?
3. Do the caregivers interviewed in these articles know about and utilize the resources available to them?
4. How does the respite program profiled in this series address the challenges caregivers face? And what kinds of solutions does it offer?

Methods, Limitations and Further Research

The first chapter of this thesis, written following Turabian guidelines, introduces and defines the topic, assesses the available resources available to family caregivers and analyzes media coverage of the topic. The next four chapters, which are written in Associated Press style for the purpose of publication, profile a series of family caregivers, the last of which is a short first-person piece. The final chapter, also written in AP Style, describes a state-run respite program for underserved caregivers in rural North Carolina.

⁵⁹ Ibid.

One of the limitations of this study is that the subjects of my articles do not represent a true cross-section of the family caregiving population. Though I try to make up for lack of diversity with statistical information, all of my subjects are white middle-to-upper-class families who have the financial resources to provide their loved ones with adequate care. Their experiences, while typical in their emotional complexion, do not reveal the added pressures of impending fiscal ruin that characterize many caregiving experiences.

In the same vein, the caregivers in my study did not develop severe physical and mental problems, though their roles put them at higher risk for high blood pressure, cardiovascular disease, diabetes and stroke. Still, the most devastating effects of family caregiving were not illustrated through my project. Most of my interviewees did, however, suffer from forms of exhaustion, stress and depression.

Another limitation is that—with the exception of Chuck Eilber and Sheila Blackley—the family caregivers I interviewed had completed their caregiving duties. While this allowed my subjects time to reflect on their experiences and gain perspective—those advantages might have colored their recollection of daily life as a caregiver. They may have forgotten or shunted aside painful feelings, or they may choose to paint a rosier picture of their experiences to make peace with a difficult past.

My profile of Project C.A.R.E. is not representative of all types of programs and facilities. Project C.A.R.E. is not available in all counties in North Carolina, nor are there analogous programs in all areas of the United States.

If I were to conduct further research on family caregiving, I would try to find families representing varying financial backgrounds, ethnicities and education levels. While this project was able to capture some of the emotions and unexpected experiences associated with

family caregiving, it covers only a specific segment of the caregiver population. There are so many stories—all of them unique in their pain, fear, joy and love—and I hope reporters will keep telling more and more of them.

CHAPTER II

The Golden Years Revised: When Sudden Illness Transforms Retirement into Rehab

Stroke is a complex enemy. It can be triggered by unhealthy habits like smoking, overeating or lack of exercise. Or it can strike at random, blindsiding a perfectly healthy person without reason or warning.

Most strokes occur when an artery in the brain becomes blocked by a blood clot, cutting off oxygen to other parts of the brain. Within four minutes, the deprived cells begin to die. The extent of the damage depends on which parts of the brain are affected and for how long.

Sometimes, though, a weakened blood vessel in the brain bursts, leaking blood around the covering of the brain. Doctors cannot control or stop the swelling that results. This type of stroke, which is called hemorrhagic, happens a lot less frequently than the kind caused by clots. But it's far more deadly. Hemorrhagic strokes kill almost 40 percent of victims within a month, usually because the swollen brain tissue collapses into the brain stem, which controls vital bodily operations like breathing and heartbeat. Even if the victim of a hemorrhagic stroke survives, brain damage is usually severe. The possibility of resuming a normal life is virtually nil.

The Eilbers envision a long, happy retirement

Chuck and Carol Eilber imagined they would grow old slowly, depending on each other as the process of physical and mental deterioration set in. After all, they'd been

married for almost six decades, working together to raise three daughters, to build careers and even to fight cancer.

“We have always, all of our married life, been equal partners,” said Chuck.

Indeed, the Eilbers seem to have a model marriage. They genuinely adore and respect each other, and after 57 years of wedlock, they still relish each other’s company.

“They’ve always had an incredible relationship,” said Diane, the oldest of Chuck and Carol’s three daughters. “They’ve always been their own best friends.”

The Eilbers looked forward to spending some quality time together after they retired, and they took all the practical steps toward securing a comfortable future. They built a nice savings account, purchased long-term care insurance and designed a one-story home to accommodate their physical needs as they got older. They planned to travel and to spend summers in Martha’s Vineyard.

But the Eilbers’ golden years did not unfurl the way they anticipated. In December 2002, something happened that tested the strength of their marriage and challenged their roles as husband and wife: Carol had a massive stroke.

United in their walk through life

Carol and Chuck met in 1943, in a high school algebra class in Detroit.

“I was in the 12th grade and Carol was in the 11th grade, which was the level of that class,” Chuck said. “And I don’t know why—I honestly have forgotten why I was there a semester or a year late.”

He looks at Carol and asks, “What’s your version?”

“He flunked,” Carol said. They laugh. That story never gets old.

Carol looks a bit like Faye Dunaway, with high, angular cheekbones. She resembles the famous actress in other ways: both have shiny, straight teeth, dark green eyes, and delicate noses. When she was younger, Carol wore her light brown hair in a chignon, highlighting her elegant features.

Carol has always been an independent and innovative person. She has two master's degrees—one in English and the other in communications.

"She's a real powerhouse," said neighbor and friend Emily Weinstein. But, she said, Carol has a light-hearted side as well.

"She's a lot of fun," Weinstein said. "She has a very dry sense of humor, almost caustic at times."

By contrast, Chuck Eilber is a calm, earnest, straightforward Midwesterner. His demeanor suggests he never made a rash decision in his life. Though slight in stature, Chuck's body is well-proportioned and fit. He keeps his thin brown hair combed neatly. Chuck wears khaki pants and polo shirts and has the clean look of a spokesman in a commercial for something serious, like life insurance or a new cholesterol drug.

The Eilbers married after they graduated from Michigan State University in 1948. Chuck, a World War II veteran, made a living teaching math, taking his family with him when he spent a year as a Fulbright exchange teacher in North Wales and another year when he had a scholarship at Harvard. He and Carol had three girls: Diane, Cheryl and Janet.

For 11 years the Eilbers lived in Interlaken, an idyllic little town on the upper peninsula of Michigan that was the site of a 1920s-era summer music camp. It was an old arts community and a great place for their daughters to grow and learn.

Eventually, though, the Eilbers' path led them to North Carolina, where both took jobs with the state government. Chuck spent 10 years as founding director of the North Carolina School for Science and Mathematics. Carol worked for a state agency in microelectronics and later as director of development for the local Planned Parenthood. Things were clicking along.

Then, a hiccup. A big one. In 1989, Carol was diagnosed with breast cancer. She had a mastectomy and reconstructive surgery on her left breast and underwent chemotherapy.

Carol discovered an unconventional way to fight her illness: the macrobiotic diet. This low-fat, high-fiber regimen discourages the consumption of meat and dairy products and promotes the integration of physical and spiritual health. The Eilbers were determined to learn everything they could about the diet. They even attended a seminar with the Macrobiotic Institute's founder in Boston.

So far, Carol's cancer has not returned. And the Eilbers got on with their lives by starting some pet projects together: first a science-education consulting company, then a communal-living neighborhood called Solterra, where they now live.

Solterra took years to build – and there were stressful times when the bank was knocking on the Eilbers' door – but it eventually came together. Once the neighborhood was up and running, the Eilbers could plan for their retirement. They were now in their 70s, both in good health and ready to pursue the hobbies and interests they had placed aside while developing Solterra. Chuck was excited to get into digital photography and to write a family history for his children and grandchildren. Carol enjoyed singing, gardening and swimming. They had built a nice retirement fund and were prepared for their future together.

Then, on a fateful early winter night in 2002, everything changed. The lives that had been in motion for so long ground to a halt when a neighbor found Carol lying half-conscious on the Eilbers' deck.

Everything changes in the blink of an eye

Emily Weinstein remembers something had been "off" that day. Chuck was away on business, so Carol was at home alone. The Eilbers always put their blinds down in the evening, but Weinstein noticed Carol had left them up all night.

Then at 12:30 a.m. on Dec. 9, 2002, Weinstein's dog China began acting strangely. She was pacing and barking and would not let Weinstein go to sleep.

"And so I just simply took her out," Weinstein said. "She was adamant that we get outside then." But China did not follow their normal path. Weinstein said her agitated dog pulled her in the opposite direction and toward the Eilbers' house.

China led Weinstein down their driveway and up the street, and then started barking wildly. The Eilbers motion-detector light was on, and Weinstein saw Carol lying face down on her deck. She was dressed oddly: in formal shoes, a nightgown and an overcoat. Weinstein yelled to her, "Carol, Carol, can you hear me?"

Carol babbled a response. Weinstein ran home and called 911. Then she came back and covered Carol with quilts until the paramedics arrived. She noticed Carol had her car keys in her hand. Weinstein thinks she was planning to drive herself to the hospital before she collapsed.

Every tube imaginable

Chuck called home from a remote town in South Carolina at about 7:30 a.m. on December 9. No one answered.

“I thought, ‘Well, isn’t that strange,’” Chuck said.

He called their daughter Diane, who lives in nearby Chapel Hill, and she rushed over to check on her mom. Another neighbor told Diane she’d seen an ambulance there in the middle of the night. (Weinstein had given the medics Diane’s contact information, but no one had called).

When Diane got to the emergency room, she said her mother was agitated, but seemed unaware of why she was in the hospital. “She was really trying to communicate with me...to express she was still in there.”

But soon the swelling took over her brain, and Carol entered a vegetative state in which she was unresponsive.

Carol had a hemorrhagic stroke, which means a blood vessel in her brain burst. Sometimes high blood pressure causes these types of strokes, but Carol had none of the warning signs. Only a fraction of strokes, or about 9 percent, are hemorrhagic, according to the American Heart Association. But they are the deadliest kind.

“The ER doctor didn’t give her much chance to live,” said Diane. “I said, ‘You don’t know our mother.’”

It took Chuck eight hours to drive home from South Carolina. The doctor prepped him on Carol’s condition when he arrived, but the sight of his wife “just lying there” was still a shock.

“She had every tube imaginable – in her nose, in her throat, in her stomach,” Chuck said.

Carol was in intensive care for two weeks. Then they moved her down to a “step-down” room for another two weeks. During that time, Carol slowly became responsive, and after about a month, it became clear she probably would survive.

But, as Chuck said, the recovery “has been a long struggle as far as the technical side.”

Carol spent a couple of months in Hillcrest Convalescent Center in Durham before moving home.

They took out the breathing tube and did a tracheotomy, after which the nurses would have come in every few hours to clean the tube and her windpipe.

“And that was pretty gruesome to watch,” Chuck said, “they put a long, thin tube down to suction out the mucus. And she was jerking...”

Chuck shudders slightly. Though he recounts the events of his wife’s rehabilitation in his trademark matter-of-fact manner, Chuck cannot help but recoil at the thought of some of the hideous scenes he had to witness.

When the doctors finally removed the trach tube, which was a month-long process involving multiple moves to smaller and smaller tubes, Carol had to complete swallow tests successfully before she could drink thickened liquids on her own.

“And she passed the first one,” Chuck said, “but for some reason the nurses at Hillcrest didn’t suction it right or something, and they had to do a second one. It was very, very stressful for Carol and me.”

The ability to swallow on one’s own is crucial for someone in Carol’s condition who cannot cough up liquids that go down the wrong way. It’s also a necessary to swallow in order to resume eating and speaking.

But there were still other important hurdles to overcome.

“I think the worst thing trying to accomplish was sit you up without falling over,” Chuck said to Carol, who does not remember the day of her stroke or the two months following. “And they put you in a wheelchair and taught you how to go down the hall with it, scooting with your foot. You wobbled back and forth, hit that wall, then that wall.”

Finally, after two months at Hillcrest, Carol was ready to return home. She could not speak more than a few words, and she required round-the-clock nursing care, no doubt difficult circumstances for a woman who had always cherished her independence.

But still, Carol had beaten the odds and survived.

That was the first step.

We are not the typical couple dealing with a stroke

“I’m Carol Brown Eilber. I am 79 years old, and I am a stroke survivor.” It takes Carol a while to get the words out because she suffers from aphasia, which is the medical term for the loss of ability to articulate ideas. Reading is easier, so Carol reads her statement to a class of students studying physical therapy at Duke. It’s November 2005 and Carol sits in a wheelchair, having lost most of the movement in her right leg; her right arm is virtually paralyzed. Her white hair is cut short and swept back from her face. She wears orthopedic shoes with Velcro straps.

Carol explains to the students that she has limited ability to speak, and introduces Chuck to serve as her mouthpiece. He talks candidly about his wife’s condition and recovery.

Actually, Chuck speaks a lot for Carol these days. He’s like a translator. Carol has expressive aphasia, meaning she knows exactly what she wants to say, but she cannot speak

the words the way they are arranged in her mind. For example, many patients with aphasia say “no” when they mean “yes.”

Though she concedes her speech condition is extremely frustrating, Carol finds ways around it. Chuck boasts about the creative words his wife cobbles together to express a thought.

“It’s all up there, and it comes out in wonderful ways that illustrates her marvelous vocabulary and her professional [experience] as a communicator,” said Chuck. “The other night I was setting the table, and for some reason, there were some spoons left from lunch, and I was bringing more spoons, and she said, ‘Chuck, you’ll have a plethora of spoons on the table.’ Now, how many people know the word ‘plethora’ off-hand?”

Chuck is a thorough caregiver. As with everything else they’ve done, the Eilbers take recovery to the highest level. They even attended a conference on aphasia in Tampa, bringing their full-time nurse assistant, Brenda Barnett, along with them. And Chuck helps Carol improve her speech on a daily basis, just by pushing her to say the right words when she wants to give up. He is firm, but patient in their exchanges:

Chuck: Your first master’s degree...where was that?

Carol : Interlaken.

Chuck: We were living in Interlaken, but where’d you go for your master’s...summers...and...?

Carol : Oh.

Chuck: You got a second master’s in English.

Carol : Yeah, uh-huh. Interlaken.

Chuck: We lived in Interlaken, but you did some summer work at one university...

Remember you went back to school in summers to get a second master's?

Carol : Yeah, yeah...in Interlaken.

Chuck: No. You went to summer school in East Lansing.

Carol : Oh, huh.

Chuck: Yeah. [She] left me at home with the kids.

They laugh. Laughter seems to come easily to the Eilbers, making it seem as if they are comfortable with their situation. But even for such a capable, proactive, strong couple, dealing with the aftermath of a stroke has had its challenges.

“Family caregiving,” or the act of providing informal care to a loved one, often has physical, mental and financial repercussions on the caregiver. The stress and exhaustion associated with the role can have serious health effects, especially for older family caregivers like Chuck. A 2003 study published in the Proceedings of the National Academy of Sciences shows men and women who take care of a spouse with stroke or dementia are more prone to infection, influenza, hypertension, diabetes and heart disease than their non-caregiving counterparts.

Though wives are more often become caregivers than husbands, multiple studies reveal that both genders report emotional strain and role overload when helping a frail spouse. And family caregivers experience depression and insomnia at a higher rate than that of the normal population, according to the Centers for Disease Control and Prevention.

Like many caregivers, Chuck has a lot more on his plate than he ever imagined he would at his age; in addition to running errands and doing household chores, he helps Carol

dress, walk, eat, bathe and go to the bathroom when Brenda isn't around. But Chuck has avoided most of the pitfalls of becoming a family caregiver, not only because he and Carol have a history of working together to overcome challenges, but because they have several advantages other caregivers don't have.

For instance, Chuck is retired, making the demands of his new role a little more manageable. Many family caregivers have to forfeit their jobs or take early retirement, which can cause strain and conflict.

Also, he and Carol are able to afford a full-time nurse's aide, which gives Chuck a break from his caregiving duties. According to one study, a little less than half of spousal caregivers have any secondary help at all.

Chuck admits he and Carol are an exception to the rule:

“Quite simply, we are not a typical couple struggling with recovery. In many cases we hear or read about, a spouse is the caregiver 24-7 and is lucky to get a couple of afternoons free if a kind neighbor or friend is willing to come in to stay with the patient.”

Another huge advantage the Eilbers had was that they had planned so meticulously for their retirement, which helped them afford extra amenities for Carol's recovery. For example, a long-term care insurance policy Chuck and Carol purchased about eight years ago helped them pay for the installation of a \$30,000 therapy pool in their home.

Buying long-term care insurance is a precaution few Americans take. Chuck said that any frustrations they experienced during Carol's rehabilitation would have been magnified without the insurance. But he added that the policy they purchased was not ideal. First, it was expensive because the premiums are higher the older you are when you buy it. Second, the Eilbers thought they would decline gradually, so they chose a plan that paid out

\$100 a day over five years and had a 90-day waiting period. They figured they could take care of expenses for that initial span of time, but that's obviously not how it worked out.

"In retrospect, that 90-day waiting period was a real sock in the pocketbook because Carol needed 24-hour care," Chuck said.

They had to use their retirement funds to fill in the gaps left by Medicare and Carol's state health insurance plan until the long-term care policy kicked in. Otherwise, Chuck said, dealing with insurance and Medicare has been relatively easy. Medicare covered the cost of doctor-prescribed therapies and of equipment like Carol's wheelchair and a special exercise machine.

Chuck said that the only disappointing aspect of the Medicare system was that sometimes physical therapists were lazy and unhelpful because they knew the Eilbers weren't paying out of their own pocket.

"They were just phoning it in," Chuck said of the therapists. "I think some people have the attitude that Medicare's paying for this or insurance is paying for this, so why do you care?"

In fact, the therapy was so ineffective that Carol went back into inpatient care for three weeks because she was not getting the help she needed.

Eventually, though, the Eilbers found Brenda, and they hired her to work for them five days a week for seven and a half hours a day, a luxury few families are able to afford.

Yet while Chuck and Carol are more fortunate than most couples in their situation, they still face the emotional challenges that accompany a catastrophic incident like Carol's stroke.

For example, Chuck said it's hard to see the vibrant, attractive woman he married struggle with things like dressing, eating and speaking. He said he misses being able to do the things they used to do together, such as "travel, just enjoy each other's conversation at the dinner table, touching and cuddling, being a little more intimate than her condition allows."

Plus, Chuck said, they had to give up the leisurely retirement for which they had worked so hard. So far, he has been unable to pursue his hobbies and travel plans.

Being a care recipient is tough as well. Giving up control of your person and your home is not easy, and often results in depression and anxiety. Carol said that at first things "were frustrating beyond measure," and she went through a time where she "was simply getting along." She said it was not easy to suddenly have to depend on Chuck to do the things she used to do. So they both find ways to keep Carol involved in the management of their lives.

For example, Chuck takes Carol out to get the mail every morning, and he consults her when making financial decisions about their house or car.

Brenda said Carol makes an effort to pitch in with activities as much as she can.

"She works very hard," Brenda said. "She came up with the idea of having Chuck build shelves [down low], so she can set the table, mix things [like] salads. Carol does a lot. She picks out her own clothes. Carol comes up with great ideas."

Brenda also takes Carol to lunch and to the movies. "When birthdays come up, I'll take her shopping to get Chuck something," Brenda said.

In these ways, Carol is able to maintain her independence.

And, Chuck said, things that characterized the old Carol are coming back, like her beautiful handwriting.

He also said that she has fallen three times, once breaking her arm. These were frightening moments for Chuck as a caregiver, but he thinks the falls were signs that Carol is regaining control of her body. He points out that Carol has made physical improvements through therapy.

“The leg is coming back,” Chuck said. “The arm we need to work on. That will come with a little more intensive care.”

Of course, Chuck wishes Carol had never had a stroke, but he said, if anything, it’s made their relationship stronger. She depends on him for physical help, and he depends on her for his emotional recovery.

“It can be satisfying,” he said, “especially when I see Carol making progress.”

Brenda has noticed some growth as well. “When I first started working here, they had twin beds. As she improved, they took the twin beds out and brought in a full bed.”

“They have a wonderful relationship,” Brenda said. “They communicate well.”

Diane agrees that her parents’ relationship dynamic is as healthy as ever. “Except for my mother’s speech, not much has changed. Especially with the way my dad still defers to her opinion.” A week or so ago, Diane said that her father was relaying a story and he said, “As usual your mother was right.”

As for Carol, she said her number one priority is to speak. She can walk now with a walker and someone spotting her from behind. She works out on a machine called the “Nu-Step,” which they keep in her home office. And she and Chuck exercise in the pool together about three times a week, singing songs together because the acoustics are so good. Studies show patients with aphasia have the easiest time singing—the words, deeply engrained in

memory, come rolling out without the usual effort and frustration. Carol and Chuck usually sing military songs, but one of their favorites is “I’ve Been Working on the Railroad.”

“We can really belt that out,” said Chuck, who adds that his wife used to sing in a professional women’s choir in Detroit.

Carol may not be able to sing or speak like she used to, but she has no trouble getting across her point. She makes no bones about the frustrations of losing her independence and having to work so hard to recover it.

When asked about her stroke, she thinks a long time and sums it up in her brilliantly pithy style: “First, I was wanting to die. And, second, I was wanting to live. That’s it in a nutshell.”

CHAPTER III

Out to Pasture? Caring for Loved Ones in Nursing Homes is not as Easy as it Sounds

The pivotal decision

In 1998, when Ann Hearn's mother, Elizabeth, realized her health was declining and she soon would need extra help, she made the decision to move from LaGrange, Ga., into an assisted-living facility. Ann found a nice place called Sunbridge in Roswell, Ga., a suburb of Atlanta. The facility was just a short drive from Ann's home.

Though she ended up agreeing to live at Sunbridge, Elizabeth initially was reluctant to move near her daughter. Because she had been a nurse and understood the stress associated with caring for a relative, Elizabeth believed her close proximity would put too much of a strain on Ann's life, especially if she were to become seriously ill.

"Don't bring me to Roswell," she said, "because helping me will kill you. It will take its toll on you, and it will kill you," Ann recalled her mother's words.

"And it almost did," Ann said.

Family caregiving and nursing homes

As an only child, Ann, an accountant from Alpharetta, Ga., had the responsibility of taking care of both her mother and her Aunt Eunice during their final years. Ann's mother had to be moved around a lot to find affordable facilities that could accommodate her increasing needs. When Ann's aunt later joined her, they were able to stay in the same

nursing homes, sometimes even in the same room, thanks to Ann's research and coordination.

Phyllis Immanuel, an administrative assistant from Durham, N.C., also cared for her parents, mostly in nursing-home settings. Her father, Alec Thomas, who had Alzheimer's disease, lived in three different facilities during six years. Her mother, who suffered from emphysema, stayed in one home for the last eight months of her life.

Though she was one of six children, Phyllis took the lead in providing care, in part because she was close to her parents and wanted to do it, but also because she was the only one who volunteered.

Ann and Phyllis were "family caregivers," or people who provide informal care to a loved one, ranging from cooking and cleaning to arranging for professional care and managing estates. About 34 million American adults are classified as family caregivers, and the size of this population is about to grow even larger as baby-boomers age and life expectancy increases.

According to a 2004 study by the AARP and the National Caregiving Alliance, the average caregiver is a 46-year-old employed woman who provides 20 hours a week of assistance to her mother. Ann and Phyllis fit this profile, as they both are middle-aged and worked at full-time jobs while they cared for their relatives.

Though their situations were typical in some respects, Ann and Phyllis belong to the meager five percent of American families who use institutionalized nursing care. Few families can afford it, and others believe the setting is too impersonal.

No matter what the arrangement, however, family caregiving can be a difficult job with serious emotional, physical and logistical challenges.

“You become so intimately involved in every aspect of their lives,” Phyllis said of caring for parents. “Really they become your children.”

Ann’s and Phyllis’ stories both show that even loved ones who reside in nursing homes require a lot of attention, supervision and help from their families.

Finding a ‘home away from home’ for a loved one

Although Elizabeth was a good sport about leaving the home she’d lived in for 50 years, Ann wanted to make the transition as easy as possible, so she spent a lot of time decorating her mother’s apartment at Sunbridge.

Ann’s mother loved living at Sunbridge. “She made a lot of friends there,” Ann said.

Eventually, though, the rates increased so much that Elizabeth had to move to a home she did not like.

As she developed health problems and dementia, Elizabeth floated between different nursing homes and hospitals – some of those facilities were good, and others were absolutely terrible.

For instance, one hospital in Atlanta put Elizabeth in a straitjacket. Another time, Ann found an unmarked plastic bag sitting by the sink in her mother’s hospital room. It turned out to be full of someone else’s blood.

It was a “horrific, deplorable, despicable environment,” Ann said.

But things went wrong too, at some of the nicer facilities that Ann liked and trusted. The nurses at Sunbridge failed to instruct Elizabeth to swallow her timed-release potassium pills, so she chewed them instead. This threw her electrolytes out of balance, and she had numerous painful episodes.

“She’d be screaming with pain, [and] I’d rush her to the hospital,” Ann said. “They couldn’t find anything wrong with her. She had X-rays, cat-scans...had every kind of test you can imagine. They could find nothing wrong with her.”

Finally, the doctors figured out that her medicine was being ingested incorrectly.

Ann said these experiences made her regret her decision to let her mother move into a nursing facility, even though her mother had insisted on doing so.

“I believe my mother would have been happier in her home as long as she could have stayed there,” Ann said. “She would have been better off mentally.”

Unlike Ann’s mother, many older adults do not have the option of staying in their homes.

For example, Phyllis’ father had no choice about moving into a nursing facility.

About fifteen years ago, Alec saw a doctor from nearby Duke University Medical Center speaking about Alzheimer’s disease on TV. He realized he had some of the symptoms being described, and so Phyllis took him to get tested.

It turned out that this hunch was correct. Phyllis’ father was diagnosed with Alzheimer’s disease in 1991. Two years later, a doctor recommended Phyllis’ father move into a nursing home after he had a heart attack.

“Ironically, he was in the room with his nephew, though he didn’t always know it,” Phyllis said.

The biggest problem at first was that he would wander, and one time he was found standing in the middle of Leadmine Road, a major traffic artery running through Raleigh, N.C.

“He was looking for the train,” Phyllis said.

Alec ended up living in three different facilities; two of those provided good care, and one did not.

“He lost 30 pounds,” Phyllis said about his stay in the second home. Her father exhibited other signs of mistreatment, such as skin tears. Other times, he was caked in dried defecation. The nurses there were surly, and Phyllis said one even hit her with his elbow.

So, Phyllis hired a nurse to stay with him until she could find a new place.

Fortunately, Phyllis discovered a great nursing home called Sunnybrook in Raleigh, N.C., where Alec stayed for the last two years of his life.

“He was happy there,” Phyllis wrote in an e-mail. “All in all, it was a very positive experience.”

Duty calls, even in the middle of the night

Though she was pleased with the quality of care at Sunnybrook, Phyllis could not simply sit back and let the professional caregivers take the reins. Her mother still lived at home and her father had numerous health emergencies that required help from family members.

In fact, Phyllis was called to the emergency room 13 times in a six-month span for both her mother and father. Her father was constantly falling down and hurting himself, and her mother often had to be hospitalized for complications from emphysema.

As her parents’ power of attorney, she had to help them plan their estate and adjust their insurance policies to accommodate her father’s illness. Phyllis also arranged to have social services cover the costs of the nursing home when her father’s annuities no longer could, and, in addition to visiting her parents, she went to monthly meetings at the nursing home to keep tabs on their care.

In the midst of all these responsibilities, Phyllis was trying to come to terms with her own feelings about her parents' declining health.

"You're also taking care of yourself and dealing with your own grief and sadness about the whole thing," Phyllis said.

Ann, too, had a lot on her plate. Not only was she constantly researching and finding suitable facilities for her mother and aunt, Ann had to sell both their houses. She hired people to help with cleaning, renovating and holding estate sales. She cooked for her mother and aunt, decorated their rooms, cleaned their clothes and rushed to their sides whenever there was an emergency.

"I think my health suffered because of the stress I was under," Ann said. "I was always being called to the hospital in the middle of the night."

Indeed, research shows that caregiving can lead to stress, depression and health problems – and the effects are worse for those dealing with cognitive impairment. In fact, people who care for someone with Alzheimer's or another dementia-related disorder have shorter life expectancies on average, according to the National Alzheimer's Association.

"My health was greatly affected by caregiving of my parents," Phyllis wrote in an e-mail. "However, I was simultaneously taking care of twin step-daughters who were in grief over the loss of their mother, a new house, a full-time job (which my boss allowed me to change to 35 hrs for a while), and my new husband. So, how much the responsibilities of parental caregiving affected my health percentage-wise is questionable."

As Phyllis points out, the stress of caregiving is often compounded by other circumstances. Many family caregivers also have full-time jobs and families, all of which compete for their time.

For Ann, the stress of managing care for her mother and aunt was so overwhelming that at one point, she just walked out of her job. “I don’t see how I kept from having a nervous breakdown,” Ann said, “I really don’t.”

Some studies report that caregiving can also have negative effects on marriages and sibling relationships, especially when the duration of care lasts more than a few months.

This was certainly true for Ann, whose second marriage suffered from the strain of her long caregiving stint. She said her husband, whom she wed four years before she began taking care of her mother full-time, was not emotionally supportive and rarely accompanied her on visits to see her mother and aunt.

Ann also clashed with relatives who were constantly second-guessing her decisions.

“I had cousins telling me what to do,” Ann said. “They would call me up and say, ‘Poor Aunt Betsy, we just feel so sorry for her, living down there in that filth. We wish we could do something for her.’ Yet they would never darken her door or do anything for her.”

Ann’s daughter was in college during most of these years, and though she would help out when she could, she lived three and a half hours away.

Phyllis also had relatives questioning her decisions, but her situation contrasted starkly with Ann’s in terms of support. First, her husband and two stepdaughters, who were 11 at the time she married their father, were extremely supportive.

On Sundays, they would go with Phyllis to pick up her father and take him to get hot dogs “all the way” at Hardee’s and ice cream at Baskin Robbins.

“And they were just so sweet to him – in helping him and doing things for him. It was very positive thing, I think, for them,” Phyllis said.

The presence of siblings also made a huge difference in Phyllis' situation. Though she took the lead in providing care and making crucial decisions, she could rely on her brothers and sisters to help out in minor ways. For instance, one brother would mow the lawn for their mother once a week. When her brother Tim would visit from Virginia, he would take their parents out to "do fun things," Phyllis said. Finally, they took turns going to the nursing home at varying times, ensuring their parents were receiving adequate care around the clock.

Ann confronts some unorthodox challenges

Ann's task was made more difficult because she not only lacked the support she needed, but she also had to deal with some unusual circumstances surrounding her aunt's family and home.

Ann's aunt had two stepsons who were after their stepmother's money and property. They were able to rook her out of \$40,000 by not making good on a loan, and one of them had their father, who was mentally incompetent and in a rest home himself, quit claim property deeds over to him—leaving the other son out of his inheritance.

"They hated each other," Ann said. "They both started trying to steal from my aunt; they worked separately."

Though they did not get along, the stepsons shared a mission to undermine whatever Ann did. They tried to steal her aunt's car and strip her home of anything they could.

"They took all of her plants," Ann said. "They did everything they could think of to drive me crazy. They tried to steal her propane tank from the yard."

Ann had arranged for Meals on Wheels to bring her Aunt Eunice food when she wasn't eating well, and the stepsons cancelled the service. She then had groceries delivered,

but they stole them. The stepsons did this, Ann said, thinking they could report her to social services as an unfit guardian and get her out of the picture.

“What they didn’t understand was I was guardian of property, not the person,” Ann said. “She was still the guardian of herself.” And the only reason Ann had become the caretaker is because her aunt’s lawyer called in 1998 and appealed to her for help, saying Eunice wasn’t paying the bills or taking care of her home.

In addition to watching out for the stepsons, Ann had to deal with another huge problem: Eunice had about 30 cats. As a result, her house was unsanitary and inhospitable to the type of live-in helpers she needed.

“The cats were always having kittens because they weren’t spayed, and a cat had had a litter of kittens in my aunt’s bed,” Ann said. “It was just unbelievable—fleas getting on her legs, biting her legs, her legs bleeding.”

The morning of her uncle’s funeral, Ann opened the door to find her aunt, surrounded by cats, frying eggs in a skillet. “And she just took the pan, and would just throw the greasy food on the kitchen floor,” Ann said, making a flicking motions with her fingers to show how her aunt fed the cats.

One woman, the only caregiver who agreed to live with her aunt would not cook or clean, and she went out on the town at night instead of staying home with Ann’s aunt.

“She was just not the right person to have, but yet she was better than having no one,” Ann said. “To tell you the truth, there are not a lot of people who would live in that filth.”

Her aunt refused to get rid of the cats, and worse, she threatened Ann’s life should she try to remove them.

“If you mentioned getting any of them out of there, she’d say, ‘No, I’ll shoot you,’” Ann said. “And she would because she had a pistol she kept under her bed.”

Eventually, Ann had to make the difficult decision to move her aunt into a nursing home, something she knew Eunice would resist strenuously.

So Ann talked with the administrators at Sunbridge, the place where her mother was living at the time, and they agreed to take Eunice. Ann took her aunt to visit her mother there.

“I took her to nursing home and when it got time to leave, she said, ‘Well, I’m ready to go home.’ And I said, ‘Well, Aunt Eunice, you’re not leaving,’” Ann said. “She said she wouldn’t stay there. I had to get someone to work with her for months to try to keep her from leaving. She didn’t want to see me; she was mad at me.”

Ann’s aunt was so insistent on returning home, she would pack her suitcases every night. Finally, though, Eunice accepted her new circumstances and agreed to stay.

Ann then had to prepare her aunt’s house to be sold. She hired a veterinarian from a nearby town to capture and euthanize her aunt’s cats. This was not an easy decision for Ann, who is a pet owner and animal lover. She gave as many cats away as she could, but many were too wild to be domesticated.

“And I felt terrible, you know, because my aunt loved these cats, and I wanted to find them all homes,” Ann said. “My aunt had one cat with a big head that she loved, and I’m sure he got euthanized, and it breaks your heart.”

Ann then arranged for the house to be fumigated and cleaned before it went on the market. She spent Valentine’s Day cleaning dead roaches out of her aunt’s freezer.

In the midst of all this, Ann was still caring for her mother, whose condition was deteriorating, working a 40-hour-a-week job and attending to her new marriage.

Finding the strength to do what needs to be done

Though Ann and Phyllis share many traits, their reactions to caregiving were diametrically opposed. Phyllis regarded caring for her mother and father as a joyful goodbye, and Ann saw taking care of her mother and aunt as a stressful nightmare.

Part of this difference might be chalked up to personality or to circumstances, but it's hard to say exactly what elements contribute to a caregiver's perspective.

Lisa Gwyther, a leading researcher in the field of family caregiving for 34 years and a clinical social worker at Duke, said that much of the caregiving experience depends on how a person approaches their role.

"Recently, there's been a lot of research on the powerful effect of appraisal, or how you view your situation, how you feel about subjective reality, not objective reality," Lisa said. "Positive appraisals have a powerful effect on outcomes."

Indeed, Phyllis' attitude about caring for her parents helped her deal with the stress and grief associated with her role.

"I wanted to do it," Phyllis said, "and I just wanted it to be a good experience...I wanted to end my relationship with my parents on a good note."

Studies also show that positive emotions, such as affection and caregiver satisfaction, may buffer caregivers from the negative consequences of caregiving.

This seems to have been the case with Phyllis, whose adoration for her father clearly affected how she perceived her job as a caregiver.

“My father was the comfort of my life when I was growing up,” Phyllis said. “He still was even when he had dementia. He was my comfort, and I didn’t want any of that to be tainted by negativity.”

In contrast, even though Ann loved her mother and aunt dearly, she had a rather gloomy view of her situation – and rightly so, as she lacked support and had an overwhelming amount of responsibility.

“You look back, and you just think that you could have done a better job, but when you’re an only child – I’m not trying to make excuses – but the truth is you just get so tired,” Ann said.

Lisa also said the concept of “self-mastery,” or the feeling that “I can do this,” is crucial to performing your job as a caregiver. And it’s hard to feel confident and in control when so much is required of you.

In Ann’s case, the sheer volume of tasks and the amount of resistance seemed to break her down emotionally and physically. And in fact, studies show that multiple and competing demands on caregivers’ time and resources lead to high levels of caregiver stress. And negative outcomes, such as depression, anxiety, and health problems, can be attributed to role overload.

“I feel like the experience definitely took its toll on me,” said Ann, who has high-blood pressure. She said the stress in her life actually hasn’t gotten that much better since her mother died last fall, so she recently started taking anti-anxiety medicine.

“I didn’t want to take it, but I said I’ll try it because I was mad all the time. I was just angry all the time about the tiniest little thing,” Ann said. “And really, anger is a form of depression.”

Phyllis was also helped by a daughters-as-caregivers support group she attended regularly at Duke.

“Support groups, classes, and counseling can reduce what they call negative appraisals in the medical field,” Lisa said.

Phyllis was able to apply some of the lessons she learned from the group to her situation.

“One of the things I learned,” Phyllis said, “is you have to allow people to do the things they can, and not expect them to do more.”

For example, one night Phyllis called one of her sisters from the emergency room to tell her their mother was there, and her sister said, “I can’t possibly come over there. We haven’t even put our Christmas tree up yet.”

Though rushing to the hospital in the middle of the night had been inconvenient for Phyllis, too, she said she was able to accept behavior like her sister’s without resentment because of what she’d learned from her group meetings.

Ann, on the other hand, didn’t have the time or the desire to go to support groups. She said that when she left the nursing home or the hospital, she just wanted to shut it out.

“It’s just so degrading when you’re in the hospital because the nurses and doctors just don’t seem to empathize because they see it every day,” Ann said. “And they’re just like ‘oh well, she’s old and she’s going to die,’ and ‘next.’ It’s just a terrible situation for everyone.”

So, instead of getting help by talking with her peers, Ann found comfort in trying to improve life for everyone at the nursing home. She hung drapes in her mother’s and aunt’s rooms, and she threw them birthday parties and invited all the residents to come. Ann felt sad for those who had no visitors, so she would bring them flowers and take her dog, a

Springer Spaniel named Beau, around to their rooms. She said she felt animals could bring real joy to a lonely person's day.

Looking to God for answers

Personal beliefs also play a role in the coping process. Both Phyllis and Ann have a strong faith in God, which helped them persevere in their caregiving roles.

For Ann, her faith helped her overcome the toughest moments.

When she was having a hard time finding a new place for her mother, Ann met a woman named Judy Davis who ran a small nursing facility with her husband. Although they legally could not admit Ann's mother because she wasn't ambulatory, Judy said she would consider taking care of Ann's mother in her own home.

Ann was certain Judy's husband would not agree to this, but she prayed he would. Ann said she recited the 23rd Psalm over and over again the entire 40 miles back to her house. When she got there, Judy had already called to say she would do it. Ann felt God had answered her prayers.

"I just burst into tears because I had been under so much stress, and I said, 'Thank you, God.'"

For Phyllis, the desire to do God's will inspired her to take on the caregiving role. "I wanted to please Him in the whole process," Phyllis said. "And honor Him and my parents. I think it's really important to honor your parents. I think that pleases God."

Also, Phyllis said she relied on her church for help.

"My church offered incredible prayer support during that time," Phyllis wrote in an e-mail. "There were folks who were always there for us, taking care of the girls when I needed to be in Raleigh or to deal with matters relating to my parents' affairs."

The long goodbye: What it's like to lose someone after years of decline

In the final months of her life, Elizabeth had wasted away to the point that she was almost unrecognizable. She was blind, incontinent and unable to sit up in bed. Her hair was cut short because she kept pulling it out, and she was wisp thin.

“Nothing looked like her other than her nose and her hands,” Ann said, her voice shaking. “She was nothing, just breathing. My mother had no quality of life whatsoever.”

Though her faith was strong, Ann said she could never make sense of her mother's agonizing physical and mental decline.

“What I can't understand,” Ann told a counselor a few years ago, “is why my mother is suffering like she is. I just don't get it. She's never done anything wrong in her life. For her to just be lying there and not be able to see and wearing diapers, and she can't walk – Why? Why? Why?”

Ann described her mother as “intelligent” and “saintly,” a wonderful mother and a great community leader who deserved to die “with dignity, under a magnolia tree, raking leaves.”

Instead, Elizabeth died in her bed in Ashley Oaks Personal Care Home in Marietta, Ga., in October 2005. She was 94 years old.

Phyllis' father, on the other hand, remained physically able and never reached the so-called “fetal” stage of Alzheimer's. Phyllis even remarked how good he looked when she visited him just days before his death.

“He was completely clean, shaven, in a freshly ironed shirt and pants,” Phyllis said. “He looked wonderful. I walked in that room and I looked at him, and he didn't look a day over 65. It was amazing.”

While Phyllis was there, the nurse had trouble finding his blood pressure, and her father was having visions of angels.

Still, Phyllis went with her family to Myrtle Beach, S.C., that weekend. Phyllis said she was shopping with her stepdaughter when all of a sudden she had a sensation. She gasped. And her stepdaughter asked, “What is it?”

“I don’t know,” Phyllis said. “Something happened.”

Phyllis’ cell phone rang 30 seconds later, and she took it outside the store to hear. It was her favorite nurse from the home, and she said, “I’m sorry to have to tell you this, but your dad died. He died just a few minutes ago.”

Phyllis said she realized what she felt her father’s spirit leaving the earth, “I was so connected to him,” she explained.

“It was a shock, but I was very calm. You know what –you’re not going to believe this—but I had the deepest, strongest joy I’ve ever had in my whole life,” Phyllis said. “The thing I kept thinking was, ‘Daddy is with the Lord.’ For 55 years, he preached, he witnessed, he loved the Lord. And I knew he would never suffer again.”

And despite her sour feelings about the caregiving experience, Ann, too, was glad to know her mother would no longer have to endure the pain of her weakening body and found solace in the belief her mother was finally in heaven.

“She lived such a saintly life,” Ann said. “And she was so intelligent. And she was always concerned about other people. She was extremely unselfish, always doing something for others, and she was a fabulous mother, just a fabulous mother. I’m sure she’s with her heavenly father today.”

Caregiving is not the same experience for everyone

Needless to say, Ann and Phyllis came away from their jobs as caregivers with different views.

Though Ann loved her mother and aunt dearly and worked hard to give them the best care she could, she hated the stress, suffering and sadness involved with end-of-life care.

“It was a horrendous, horrendous experience for my mother, for my aunt, for me,” Ann said. “I hope I don’t ever have to go through that again. And I hope nobody has to do it for me.”

Phyllis, on the other hand, said she would do it all over again. Though she concedes that it was difficult to watch her parents suffer, Phyllis said she was happy to take care of them.

“I loved it,” she said, “My parents invested so much in life, it was a joy to be able to give back to them...It is hard work, but it is so worth it. I don’t have a single regret, because I did what I could do. I gave it everything I had.”

CHAPTER IV

A Family Affair: Siblings Take Turns Caring for Their Housebound Parents

Taking care of aging parents in a home setting

“My motto is: Do what you have to do,” Sheila Blackley said about taking care of her 78-year-old father, Jim, who has Parkinson’s disease, and her 81-year-old stepmother, Viv, who suffers from bipolar disorder.

“Some people just buck and scream,” Sheila said, “but I think you just gotta get in there and get the job done.”

Sheila, who is almost 60, but looks younger, is cheerful and resilient. She has short, wavy gray-blond hair, and her lips are covered in a bright, tropical red lipstick.

Although four other siblings live nearby, Sheila and her stepsister, LuAnne Latta, 53, have taken the lead in coordinating care for their parents. Jim and Viv still live in their home, but neither can drive, and they need help with cooking, cleaning and running errands.

Because of his Parkinson’s, Jim has trouble speaking and walking.

“Sometimes he can’t tell his legs to move when he wants them to move,” Sheila said. “He’s fallen several times.”

The tremors in Jim’s hands make it hard for him to do things around the house, and he has mild dementia and incontinence.

While Viv is physically healthy, her mental illness prevents her from helping out. Her condition has even kept her from driving for the past 25 or 30 years.

“She won’t take care of anything,” Sheila said matter-of-factly about her stepmother. “She would like to be in a nursing home, being taken care of.”

LuAnne confirmed Sheila’s characterization of Viv. She said that her mother has always required a lot of extra help because of her mental illness.

“She loves people to care for her,” LuAnne said in a friendly, calm voice. “I’ve taken care of her since I was probably in the fourth or fifth grade.”

LuAnne said that when she was a child, Viv would sometimes retreat to her bedroom and stay there for days, leaving her young daughter to take over the house chores like cooking and ironing.

Sheila points out that her father is not easy to handle, either. “He has a difficult personality to start with,” she said, adding that he is stubborn and cantankerous.

But despite being dependent on others for help with daily activities, Jim is reluctant to give up life as he knows it.

For example, Jim cannot drive and does not have the money to pay taxes on his car, but he holds onto it as one of the last vestiges of his independence. “It just sits there in front of the house,” Sheila said. “It’s a symbol.”

Jim also refuses to move out into a nursing home.

“He doesn’t want to talk about it,” Sheila said. “He doesn’t want to give up control.”

Jim’s attitude is common among older Americans. In fact, only about five percent of seniors live in a full-time nursing facility, either because they do not want to move or because they cannot afford the cost of institutionalized care. The remaining 95 percent live at home or with relatives, depending on family members to provide the help they need. And

because Jim is physically handicapped and Viv's depression keeps her from doing household chores, they require more assistance than most wards.

"They won't even scoop out the cat litter," Sheila said.

Shifts for siblings, hired help: A system that works (for the most part)

A few years ago, when Jim stopped driving, he and Viv began to rely on Sheila and LuAnne almost exclusively.

"We were getting called all the time, any time" Sheila said. "Because you tend to call the daughters first I guess."

In fact, many "family caregivers," or those who provide informal, unpaid care to loved ones, are adult daughters. The typical caregiver is a 46-year-old, employed woman who spends 20 hours a week caring for her mother, according to a 2004 study by the AARP and the National Family Caregivers Alliance.

Because Sheila and LuAnne both have full-time jobs and families of their own, caring for their parents often cuts into their work and family schedules.

"You always feel a sense of intrusion on your time," LuAnne said. "Anything can happen and at any time, and they're going to depend on you to fix it."

Unlike some daughters in their position, however, Sheila and LuAnne are fortunate enough to have each other and to have siblings who are willing to pitch in and help when asked. Family caregivers spend an average of 20 hours a week caring for their loved one, but Sheila said her responsibilities take only about five to six hours a week.

"It's a little bit easier when you have a network of children," LuAnne said.

To avoid the frustration of being "on call" around the clock, Sheila and LuAnne devised a system where each of the four siblings who lives nearby participates in a weekly

rotation of duties. If it's one person's week, he or she is responsible for the groceries and the chores, and Viv and Jim are directed to call that person only if they need something.

The two siblings who live in other states take over the responsibilities when they visit.

In addition, a professional caregiver named Alease Venable supplements the family caregiving. She comes to the house three times a week for five hours a day. Her salary paid by Jim's VA benefits. Alease does some light housework, helps Jim get bathed and dressed, and runs errands with them. Most importantly, Alease takes Viv to her many doctors' appointments, which is something that used to eat up valuable work hours for Sheila and LuAnne.

The system isn't perfect, though.

First, Viv does not always follow the rules. She insists on instant gratification, so when the assigned caregiver for the week is not available, she immediately calls another sibling rather than waiting until the designated one is free to help.

A couple of Sundays ago, for example, Viv and Jim wanted lunch from Burger King. Even though it was LuAnne's week, Viv called Sheila's brother to go get the food because she knew LuAnne was in church and would not be reachable for a few hours. Viv also realized that LuAnne likely would not approve of a fast food lunch because she'd just taken them to the grocery store the night before.

"She just decided that she didn't want to go through the normal channels," Sheila said. "She wanted what she wanted right away. Viv is very manipulative like that."

Second, the rotating-week system breaks down when Jim and Viv have a problem they do not feel comfortable sharing with Sheila's brothers or with Alease.

For example, during one of the brothers' weeks, Jim called Sheila because he'd had an accident. He'd been sick to his stomach and had diarrhea, and the carpet needed cleaning. He was embarrassed for Alease to come in the next day and have to clean it up, so Sheila went over and did it.

Also, Sheila's brothers and sisters do not always see eye-to-eye on what the caregiving responsibilities include, which can cause tension.

"It's hard to define what the duties are, when one person has their opinion about what the duties are and another person has the opinion about what the duties are," she said, adding that she often finds herself at the center of these conflicts.

"Well, the stress that I have is mostly dealing with keeping the peace among the siblings," Sheila said. "It's hard being a peacemaker."

Finally, the caregiving duties are never evenly divided because Sheila and LuAnne simply rise to the occasion more than their siblings. Because LuAnne is organized and detail-oriented, she takes care of their finances and records and doles out medication.

Sheila works at Duke University Hospital, so she often goes across the street to the VA hospital to pick up her father's prescriptions, which has at times required an hour-long wait. Now and then, Sheila and her daughter Deborah spend a day intensively cleaning Jim's and Viv's house.

"My daughter and I like to go over there and clean their house good," Sheila said. "The caregiver that comes just does the light stuff like dishes and stuff. But we like to get the down-deep stuff because they make a lot of mess with their bowels, and they're not neat."

The siblings offer to pay to have a cleaning lady come, but Sheila said she does not want to add \$60 more a week to their financial load.

“So Deborah and I just do that,” Sheila said, “that’s our gift.”

The cost of caregiving

In addition to using up time and energy, providing care to ailing parents can be an expensive. Many family caregivers give up wages, Social Security and pension benefits due to interrupted employment. According to statistics culled by a non-profit agency called the Family Caregivers Alliance, the average loss for an individual caregiver is about \$650,000 for the duration of their duties.

Unlike most caregivers, however, Sheila and LuAnne are fortunate enough to be able to divide the cost evenly among six siblings, making the financial brunt of Jim and Viv’s care a little easier to shoulder. Jim and Viv do not yet require round-the-clock care, but they still do not have enough income to cover their monthly expenses and medication.

“If the hot water heater breaks, as it did a couple of years ago, we divide the cost,” Sheila said. They also purchased new carpet for Jim and Viv a couple of years ago. And, they used to spend hundreds of dollars fixing her father’s car when he was still driving.

These repairs accumulate, Sheila said, and it would be impossible for just one person to absorb the cost of maintaining Jim’s and Viv’s house.

Medicine can be a huge expense as well. Jim’s prescriptions are free through the VA, but Viv’s medications are expensive despite her disability insurance, so the siblings rotate paying for them in \$150 increments.

LuAnne charges Viv’s insurance co-payments to her credit card, and the person whose turn it is writes her a check. “It used to be \$350,” Sheila said. “But that got to be too much.”

Estate-planning, which can often be a point of contention among siblings, is not an issue for Jim and Viv and their children.

“They’ve already sold their house to Fannie Mae,” Sheila said. “It’s a reverse mortgage, so when they die, that house goes to the bank. They don’t have anything.”

Jim and Viv have already made their funeral arrangements and bought their graveyard plots, but that’s where their self-sufficiency ends.

“Right now they don’t have the money to pay taxes,” Sheila said. “They’re not financially secure at all. If they were to go into nursing home, it would have to be Medicare.”

Sheila and LuAnne stay positive

Family caregiving can be a stressful and costly job that causes health problems and depression, but Sheila and LuAnne are lucky to have strong support systems that mitigate the possible negative effects of taking care of their parents.

Both women say that, in addition to their siblings’ help, their husbands and children have been understanding and cooperative.

LuAnne’s husband, who is a handyman, will fix things around the house for Jim and Viv. “He’s been a wonderful support,” she said.

Sheila describes her situation more bluntly. “My family has been very good,” she said. “You marry your family. My husband married my family. I married his. That’s the way I feel about it.”

But even with the extra help, Sheila and LuAnne often are pushed to their limits.

“You’re taught as a little child to have respect for your parents,” LuAnne said, “but it’s OK to feel like you’re going to beat your head against the wall.”

Sheila expressed similar sentiments. “It can be happy, it can be sad, it can be frustrating, it can be ... it’s just a lot.” She added that it’s important to keep in mind the way Jim and Viv might feel, as well.

“You have to look at it from their perspective,” she said. “They’re dealing with six children of totally different personalities.”

But Sheila points out that although caregiving is hard, it can be rewarding, too.

“If they’re happy when you leave, and they like what they’re eating, or if you clean up, and you keep them from falling on the cockleberries... You know, there’s satisfaction.”

LuAnne agrees. “It is a blessing that doesn’t always feel like a blessing,” she said. “You feel you got your kids raised and you feel like you should get some time for yourself, but you don’t.”

As for the future, none of the siblings knows how their parents will fare, but everyone agrees Jim and Viv need to move into an assisted-living facility or nursing home soon. They agree too, that the occasion will not be an easy one, because Jim is resolute in his desire to stay at home.

“He will not even consider the idea,” Sheila said. “If you mention it to him, he says, ‘I’m just going to pretend like you didn’t say that to me.’”

CHAPTER V

Family Caregiving: Personal Experience Reveals an Underground American Phenomenon

In the spring of 2002, my mother called to tell me that her parents were dying. My grandmother had come down with pneumonia, and my grandfather had caught it from her. Both were weak, and the doctors did not think they had long to live.

I called them to say goodbye. My grandmother answered the phone, and we had an oddly perfunctory conversation. I told her I loved her. She said that she and granddad had “enjoyed having me as a granddaughter” and that they loved me, too. I hung up the phone, almost too stunned to cry.

But my grandparents did not die then. In fact, my grandfather lived three years longer, and my grandmother is still alive today, living in a nursing home in South Georgia.

Since that fateful day in 2002, my mother has become a “family caregiver,” a term used mostly by the medical community to describe people who provide unpaid, informal assistance to loved ones. Caregiving responsibilities can range from doing laundry and cooking meals to helping a person bathe, eat and walk. Many family caregivers also take over financial decisions for their wards, such as paying bills, filing taxes and managing estates.

There are approximately 34 million family caregivers who provide care to someone 50 or older in the United States, according to a 2004 study done by the AARP and the

National Family Caregivers Alliance, and it's a population that will only grow as baby boomers age and average life expectancy increases.

For my mother and for many other family caregivers, their new role and its myriad responsibilities came crashing down without warning. My grandparents declined rapidly after their respective bouts with pneumonia. Almost overnight, they required round-the-clock nursing care that had to be coordinated by my mother, who lived 45 minutes away. She found herself taking trips to her parents' house two and three times a week to buy groceries, take them to doctors' appointments and fill in when professional caregivers cancelled – which happened at least once every month. And, she said, the calls always came at the last minute.

“One night Nivea (the overnight caregiver) called at about 11:30 on a week night and said she couldn't be there,” my mother said. “She didn't give any excuse or anything. So I put on a coat over my robe, and drove down there and spent the night.”

She could not put her parents in a nursing home, however, because her father and mother, who had been married for more than 60 years, would have had to be separated into different units. My grandfather had dementia and he needed to live on a floor with higher security.

“People would say, ‘You need to put them in a home,’ but it's not that simple,” my mother said. “They couldn't have been in the same place.”

And because they stayed at home, my mother often had to tend to emergencies at her parents' house, such as a broken hot-water heater and frozen pipes in the winter.

“You had your household breaking down and their household breaking down,” she said. “When you're trying to keep somebody in their home, it's a lot of work.”

The extra responsibilities might have been manageable if my mother did not have two jobs. She had also recently become a single parent to my sister, 17, and me, 24, when my father died of a heart attack three years earlier.

To make matters worse, my cousins descended upon our ailing grandparents like jackals, going after my grandfather's business, his farm and other pieces of his estate. They worked hard to undermine my mother's efforts and to turn my grandparents against her, hoping it would help them get their hands on my grandparents' money and property.

"That was one of the most hideous things," my mother said. "I should have caught on earlier, but I didn't. I just didn't dream that people would do something like that."

But sadly, this kind of conflict is common in many family caregiving situations.

My mother's brother, who lives a few states away, did not make the situation any easier. Instead of helping out, he would add more chores to her already heavy load. For example, when he visited my grandparents, he expected my mother to bring them groceries. He also pointed out things that needed to be done, but would not take care of them himself.

"He would call me up and say things like, 'Did you know that the oven and a burner on the stove is out?'" my mother said. "It didn't even occur to him to call the repair people."

Another time, when my mother was in Arizona taking my sister to college, a caregiver called her at 6 a.m. to cancel for the next couple of days. My mother called her brother to see if he could fill in. He said he could not and suggested she contact some of the other off-duty caregivers to see if they might be available.

"Other siblings don't realize," my mother said. "They know you're doing it, but they don't have a clue as to the extent of what you're doing."

Though she relished the extra time she got to spend with her parents, the mounting stress and grief began to wear on my mother, and she developed a debilitating facial tic. She suffered from anxiety, insomnia and depression, and her doctor told her she was at risk for stroke. Her business partner, who felt that my mother had become distracted and unproductive, threatened to stop working with her. My sister and I helped out when we could, but the situation was overwhelming for all of us. We each felt angry, sad and scared.

Perhaps the most frightening thing is that my mother's story is hardly unique. Many family caregivers develop serious mental health problems due to an overload of responsibilities, and studies show that anywhere from 20 to 60 percent of caregivers report feeling depressed. Family caregivers also take psychotropic drugs at a higher rate than the rest of the population. And a study conducted by The Commonwealth Fund shows that working-age family caregivers are twice as likely as non-caregivers to have chronic health conditions.

Also, the financial strain of caregiving can be devastating, as family caregivers often have to miss valuable work time, take early retirement, or quit their jobs.

But for all their troubles, family caregivers largely go unnoticed by the American public. And even though there are non-profit agencies, support groups and how-to guides that cater to this population, many family caregivers do not know about them. My mother, for example, was not even aware the term "family caregiver" had entered the vernacular, much less that help was available to her.

The good news is there are resources out there. Most states have a Division of Aging with employees dedicated specifically to family caregiving issues. Many hospitals, senior centers and churches offer support groups and respite services for family caregivers. At the

national level, a non-profit called the Family Caregivers Alliance, available online at www.caregiver.org, gives valuable support information, reports and policy advice.

The bad news is that even though there are resources for family caregivers, the very people who need help often do not have the time or energy to take advantage of them.

“When you’re caught in the middle of it, you don’t have any time,” my mother said. “I say I would have gone to support groups, and I think I would have gone if I had known about them, I just didn’t know.”

Yet getting help can often be the difference between successfully managing a loved one’s care and descending into physical, mental and financial ruin. My mother said that a support group would have been helpful because friends and family members did not understand what she was going through.

“People kept saying you’ve got to take care of yourself, and you just wonder how you could,” she said, “You just never know until you’re there. You can’t even imagine what it’s like.”

But, she added, for all the grief she endured and sacrifices she made, she feels happy about having been able to give back to her parents.

“I loved my parents, and they took great care of me,” my mother said, “I have no resentment whatsoever, even though my life was put on hold. I don’t regret the loss of my life at all.”

CHAPTER VI

Project C.A.R.E., a Lifeline to Those Isolated by Alzheimer's Disease is in Danger of Being Cut

Taking care of a parent or spouse with dementia can be a 24-hour, seven-day-a-week job, and it's one more and more adults will have to take on in the coming decades.

As baby boomers age and average life expectancy increases, the population of Americans aged 85 and older will grow to 5.4 million by the year 2050. That's more than five times its current size. As a result of this increase, millions of families will be providing care to aging relatives with dementia, as Alzheimer's disease affects almost half of seniors 85 and older.

Dealing with dementia requires extra patience and skills on the part of "family caregivers," or those who provide informal care to a loved one. And nearly three quarters of those who develop Alzheimer's disease are cared for at home. Right now, the U.S. Administration on Aging provides grants to states to help them set up programs that support people with Alzheimer's and their families. But proposed budget cuts for the 2007 fiscal year are threatening this funding.

Since 2001, North Carolina has used its annual federal grant awards to create and run a program called Project C.A.R.E., which stands for "Caregiver Alternative to Running on Empty." The program's mission is to provide free and temporary respite, or relief, to family caregivers in rural and underserved areas who have a loved one with Alzheimer's or dementia living with them in their home.

The respite services, which range from enrolling a family member in adult day care to having a professional caregiver visit the home, might seem secondary or inconsequential to some, but, in fact they are essential to the well-being of family caregivers, many of whom suffer from depression and other health problems themselves. Studies show that between 20 and 60 percent of family caregivers experience depression as a result of their responsibilities, and the levels are higher among those who care for someone with dementia.

Project C.A.R.E. has won several regional and national awards for its personalized approach to respite care and has helped North Carolina become a leader in providing help to family caregivers. Karisa Derence, who directs the program and works at the state Division of Aging and Adult Services, said she is pleased with their success and would like to expand the program into all 100 counties in North Carolina. Project C.A.R.E. currently serves 10 counties.

Derence is discouraged by news of the possible budget cuts. If approved, Alzheimer's Disease Demonstration Grants to States, which are the primary source of funding for Project C.A.R.E., will be eliminated.

Though Derence said she will try to keep the program alive by seeking money elsewhere, she said the dissolution of Project C.A.R.E. would be a huge blow to the hundreds of families who depend on the program for survival.

Jeff Bradley, an insurance salesman from Raleigh, said his parents are one such family. Bradley's mother has Alzheimer's disease and his father takes care of her. They live on a fixed income in a rural area near Asheville and use Project C.A.R.E. funds to hire a professional caregiver a couple of days a week.

Bradley said his father could not survive without the help.

“It’s definitely crucial to his mental well-being, because my mom is at the point, quite frankly, where she calls his name every few minutes,” Bradley said. “He’s under a lot of stress. He has panic disorder and has had a couple of full-blown panic attacks.”

Len Erker, who runs Project C.A.R.E. for six counties in the western part of the state, said the kind of respite the program provides can save a caregiver from having to go to the hospital for his or her own problems.

“They might simply push themselves until maybe there’s a health crisis,” he said, adding, “because caregiving is 24-7 kind of a commitment, it will not only wear the person down emotionally, and wear the person down physically and exhaust financial resources, it’s also isolating.”

Derence points out that many of these families come from cultures and communities that are traditionally resistant to outside help. She said that even though the caregivers are overextended, they will not ask for help because they regard it as failure or inadequacy.

“For most families, this is their first experience receiving this type of support,” Derence said. “Part of our job is teaching them how to accept help...If they want to survive themselves, they’ve got to learn how to reach out for help.”

Though almost all the participants in Project C.A.R.E. are low-income, the only requirement is having a loved one with dementia in a home setting. Many participants hear about the program by word of mouth, and once they call for help and are accepted, a consultant visits to assess the family’s specific needs. The consultant will then educate families and direct them toward other forms of support, but the initial step is giving caregivers a much-needed break from their responsibilities.

“In order for people to tap into the other support services, they often need immediate respite relief,” Derence said, “They’re not going to be able to accept anything else until they have that relief.”

Project C.A.R.E. provides in-home personal care, adult day care or overnight respite.

“By far the first choice is adult day care,” Erker said. “If that’s not an option because the person cannot travel outside the home, then we provide in-home care.”

That way, Erker said, the person can get out and reconnect with the community. They can go to church, get some rest and have some fun.

“So by giving them a respite break, we essentially are helping them do what they want to do most: keep their loved one in a home setting,” Erker said.

Both Derence and Erker said they’ve had nothing but positive feedback from people who have used the program. “It’s a relief just to be able to go to the grocery store,” wrote one of the many pleased participants who filled out comment forms on Project C.A.R.E.

Erker said his branch alone has helped about 500 families in the past five years, and there’s always a waiting list.

And the need for Project C.A.R.E. will only continue to grow stronger. The number of individuals with Alzheimer's disease and other dementia-related disorders in North Carolina is growing rapidly, mirroring the national trend. By 2025, the total number of seniors with the disease is expected to balloon to more than 250,000, almost twice the current amount.

In light of population projections and the already serious impact of Alzheimer’s disease in this country, President Bush’s proposed cuts seem ill-timed. And Project C.A.R.E. would not be the only program affected. In addition to doing away with Alzheimer’s

demonstrations grants, budgets for other family-caregiver-support services and long-term care-advising programs will be slashed, as would a “maintain your brain” campaign directed by the Centers for Disease Control and Prevention. Congress will vote on the budget on April 15.

In the meantime, Derence said, she will apply for state funding to try to keep Project C.A.R.E. going. For now, dreams of reaching out to other parts of the state might have to be set aside.

“We had wanted to expand,” she said, “but the priority is to sustain what we have.”

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