

A TIME TO CARE: TWO CAREGIVERS' EXPERIENCES
WITH ALZHEIMER'S DISEASE

Michelle Cerulli

A thesis submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Arts in the School of Journalism and Mass Communication.

Chapel Hill
2011

Approved by
Adviser: Professor Leroy Towns
Reader: Professor Jan Yopp
Reader: Dr. Victor Marshall

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ABSTRACT

Michelle Cerulli: A Time to Care: Two Caregivers' Experiences with Alzheimer's Disease
(Under the direction of Leroy Towns, Jan Yopp and Victor Marshall)

As the oldest baby boomers turn 65 this year, Alzheimer's is becoming a reality for a growing number of people. Between 3 and 5.4 million people in the U.S. have Alzheimer's, and family caregivers provide the vast majority of their care.

These caregivers include husbands, wives and children. They often assume an array of responsibilities, from taking over family finances and driving duties to helping with daily living activities such as walking, dressing and eating. Many Alzheimer's caregivers experience guilt, frustration, anger and grief during caregiving. Further, many caregivers cite support groups and respite care as invaluable resources that help them cope with the changes of the disease.

This project, which follows two caregivers in different stages of caregiving, works to present a detailed, intimate portrait of their experiences with Alzheimer's. It also compiles resources, such as support groups and locally-based programs, that can assist families in the Triangle, N.C.

*To my parents and brother,
who provide an endless supply of love, care and support.*

*And to my friend Joe Clark,
who has taught me that life is an adventure to be lived outside of the box.*

ACKNOWLEDGMENTS

First, thank you to my family for the many words of encouragement, phone calls of support and enthusiastic interest in this project. I am so grateful for the love you provide.

Thank you to Jeannette Barbour and Joan and Bill McCormick for opening up your homes and lives to me, and for letting me tell your important stories. For your honesty, trust and kindness, I am deeply thankful.

To my adviser, Professor Leroy Towns, thank you for your limitless guidance, feedback and enthusiasm. This project would not be half of what it is without your perspective and support. It has been a privilege working with you during my time at UNC. To my committee members, Professor Jan Yopp and Dr. Victor Marshall, thank you for your advice, encouragement and generous time. Your contributions made this project stronger, and for that, I am extremely grateful. Also, thank you to Dr. Barbara Friedman for your instruction in JOMC 754, which opened up a world of narrative nonfiction writers and writing to me that continues to inspire.

Thank you to all of the additional caregivers and Alzheimer's professionals who met with me for coffee, spoke with me over the phone, answered my emails and lent their expertise to this project, especially Lisa Gwyther who has been an invaluable resource. Lisa, I am so grateful for your help. Thank you to Brandi McCullough and Gayle Ginsberg as well.

To my M.A. classmates and friends, thank you for your support and for helping to make my time in this program so memorable. A special thanks to Lynsy Smithson-Stanley for her keen editor's eye and advice on early drafts.

Lastly, a big thank you to Ellen Clegg, whom I feel lucky to call a mentor. Ellen, it was your book on Alzheimer's and your willingness to let me be a part of it that sparked my interest in Alzheimer's caregiving in the first place. I am extremely thankful.

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CHAPTER I

Introduction

I remember driving down a quiet, snow-dusted street one winter evening in 2008, looking for Rosalee's house. I was working as a researcher for a Boston writer's book on Alzheimer's disease. Rosalee was my aunt's coworker, and she had agreed to meet with me for an interview. Her father had Alzheimer's.

Rosalee lived directly north of Boston on the coast. Once I found the right house, I drove a little farther to a bend in the road and pulled my car as close to the curb as the packed snow would allow. I sat for a few minutes, glancing up and down my notepad, reviewing the questions I would ask and wondering how Rosalee would react to them. Sure, she was willing to meet with me and was expecting me to ask personal questions about her dad's disease and how it affected her family. But I felt like an intruder, someone unworthy of going into a stranger's home and asking her to describe what I imagined was one of the most difficult experiences of her life. At some point, I realized I needed to get out of my car.

A few minutes later, I was standing on Rosalee's barely lit front porch. I could hear the lapping of the ocean at the shore nearby. With a hearty greeting, Rosalee welcomed me in and took my coat. The house was still and warm. I slipped off my boots and followed her into her kitchen, taking a seat opposite her at the table.

During the next two hours, Rosalee talked, and I listened. She shared the details of her father's disease and how being a caregiver had changed her. She talked about the guilt

she carried and how hard it was for her and her sisters to put their father into a nursing home when they realized they could no longer provide care for him at home. She confided the strangeness of reversing roles with a parent who becomes the child once a disease debilitates.

Rosalee told me how her father had become a different person, someone unlike the man she had grown up with and admired. “A man’s man,” she had called him. Now he became easily irritated with routine habits like personal hygiene, and he didn’t remember the names of Rosalee’s sisters. There were moments of lucidity but more moments of confusion. His eyes lit up whenever Rosalee recounted stories about the past to him. And he cried whenever he listened to music.

Rosalee and her two sisters had different roles in their father’s care. Her older sister organized his belongings and took over his finances. Her younger sister shaved his face and made sure his teeth were brushed. Rosalee served as his health proxy for all legal affairs. The sisters assumed many more responsibilities, and their acts of caregiving often blended into one another’s. Caring for their father had become a family affair.

This project endeavors to portray the varied experiences and challenges of caregiving for a family member with Alzheimer’s disease. Through two narratives from the perspectives of Alzheimer’s caregivers like Rosalee, this project aims to shed light on the personal side of the disease and how it affects families. As people in the U.S. and other industrialized nations are living longer, the number of families affected by Alzheimer’s has increased. However, many caregivers don’t realize that others are coping with similar struggles. Thinking they are alone, some caregivers aren’t aware of the resources that are available or how to seek help when they need it. In turn, caregivers’ own health often suffers in the course of their caregiving. Most popular media coverage of Alzheimer’s disease neglects to address these

complexities, remaining informational, research-based and largely impersonal. The coverage often neglects to show the feelings of guilt, grief and frustration that caregivers feel while contending with the disease. This project aims to tell some of these relatively unshared stories in hopes of connecting caregivers, spreading awareness of the important work they do and increasing links to the support they need.

Background

*“You lose the person you’re caring for before they actually pass away.
So you’re grieving all the time.”¹*

Caring for a loved one with Alzheimer’s disease presents new challenges for caregivers on a daily basis. Each caregiver’s and patient’s experience with the disease is unique, often encompassing a range of emotional, psychological, social, physical and financial stresses. But as the disease progresses, a commonality forms: caregivers’ responsibilities increase, often in new and unexpected ways.² These changes require not only patience but creativity on the part of the caregiver. One spouse of an Alzheimer’s patient explained the process of teaching her husband how to brush his teeth again: “You take their hand in your hand and get the motion going. Then you slowly move your hand, and the person will continue brushing on their own.”³

¹ Gayle Ginsberg, in-person interview by author, Wilmington, N.C., July 19, 2010.

² Alzheimer’s Association, *2010 Facts and Figures Report* (Chicago: Alzheimer’s Association National Office, 2010), 10.

³ Letty Grissom, in-person interview by author, Wilmington, N.C., July 22, 2010.

Throughout the progression of Alzheimer's disease, increased supervision and personal care are two major tasks caregivers face.⁴ Under the vast umbrella of "personal care" are such routine activities as dressing, bathing, eating and walking. The same caregiver likened her evolving role as her 79-year-old husband's primary caregiver to caring for a child: "He has the mentality of a 5-year-old. But you can teach a child. Alzheimer's patients, they can't learn. They just keep going down."⁵

The caregiver recalled one morning when her husband poured an entire box of cereal into a bowl, not stopping when the contents began to overflow.⁶ Pouring cereal is now one of many small tasks that she has taken on as her husband's disease progresses. And then of course, there are the bigger, more difficult tasks.

What is Alzheimer's?

Alzheimer's disease is a progressive and fatal brain disease that causes cognitive impairment severe enough to interfere with daily life, according to the Alzheimer's Association, the leading U.S. voluntary health organization focusing on Alzheimer's care and support and the largest private, nonprofit funder of Alzheimer's research.⁷ Alzheimer's is the most common form of dementia, a general term for memory loss and cognitive impairment.⁸ While Alzheimer's disease is the cause of the majority of dementia cases, not everyone with

⁴ Alzheimer's Association, *2010 Facts and Figures*, 28.

⁵ Grissom, in-person interview, July 22, 2010.

⁶ Ibid.

⁷ Lisa Roberts, telephone interview by author, Wilmington, N.C., July 15, 2010; Alzheimer's Association, *2010 Facts and Figures*, 5; "About Us," Alzheimer's Association, last modified September 28, 2010, http://alz.org/about_us_about_us_.asp.

⁸ Roberts, telephone interview, July 15, 2010.

dementia has Alzheimer's. Other forms of dementia include vascular dementia, dementia with Lewy bodies and Parkinson's disease.⁹

As of 2007, Alzheimer's was the six-leading cause of death in the U.S.¹⁰ Though an exact cause of the disease is not known, researchers believe that a buildup of abnormal protein-based structures in the brain known as plaques and tangles are the culprits for damaged nerve cells.¹¹ Researchers think these structures disrupt communication in the brain's neural pathways.¹² There is no cure for the disease, only FDA-approved medications that attempt to modify its symptoms.¹³ The Alzheimer's Association is pushing for earlier detection and diagnosis in an education effort called the Alzheimer's Early Detection Alliance. The association believes the effort will help patients and families get help and information as early as possible.¹⁴

⁹ Alzheimer's Association, *2010 Facts and Figures*, 5-6. *Note: Vascular dementia is considered the second most common form of dementia and is caused by decreased blood flow to the brain, which is often a result of a series of small strokes. People with vascular dementia share some of the same symptoms as people with Alzheimer's; however, memory loss does not seem to play as large a role. Dementia with Lewy bodies is characterized by the formation of abnormal protein deposits inside the brain's nerve cells. Symptoms are often similar to Alzheimer's, including impaired cognitive functioning and behavior changes. Tremors and visual hallucinations are also common to this type of dementia. Parkinson's disease is a degenerative central nervous system disorder that damages movement and motor skills. Later-stage Parkinson's patients often develop dementia.*

¹⁰ "Leading Causes of Death," Centers for Disease Control and Prevention, last modified December 31, 2009, <http://www.cdc.gov/nchs/fastats/lcod.htm>; "Deaths and Mortality," Centers for Disease Control and Prevention, last modified June 28, 2010, <http://www.cdc.gov/nchs/fastats/deaths.htm>.

¹¹ "What is Alzheimer's," Alzheimer's Association, last modified September 20, 2010, http://alz.org/alzheimers_disease_what_is_alzheimers.asp; Alice Park, "Alzheimer's Unlocked," *TIME*, October 25, 2010.

¹² "What is Alzheimer's," Alzheimer's Association.

¹³ Roberts, telephone interview, July 15, 2010; Alzheimer's Association, *2010 Facts and Figures*, 21.

¹⁴ "Alzheimer's Early Detection Alliance," Alzheimer's Association, last modified September 8, 2009, <http://www.alz.org/aeda/aeda.asp>.

Stages of the disease

At the earliest stages of change, the symptoms of Alzheimer's disease include memory loss, usually in the form of forgetfulness and confusion.¹⁵ People may have trouble remembering where they put their keys or forget the names or locations of places they frequently visit. Early problems with social and communication skills often appear. People may not be able to find the right words to communicate their thoughts or recall information they recently saw, read or heard.¹⁶ They may begin to compensate for declining memory and cognitive function by making lists or creating other reminders for themselves.¹⁷ Some people may pretend to remember information or events when reminded by family members even if they don't recall the information. This response is often an attempt to hide mental difficulties. Due to patients' techniques to compensate and the commonly mistaken association of symptoms to the natural process of aging, family members are often unaware of the problem in the earliest stages.¹⁸

Cognitive decline may further manifest itself as challenges with time and place, depression, or denial.¹⁹ Decision-making, planning and organizing become increasingly difficult.²⁰ People may also misplace valuable objects. One caregiver recalled doling out his wife's jewelry from a safe every morning as she asked for specific pieces and placing the

¹⁵ Howard Gruetzner, *Alzheimer's: A Caregiver's Guide and Sourcebook* (New York: John Wiley & Sons, Inc., 1992), 24.

¹⁶ Gruetzner, *Alzheimer's*, 24.

¹⁷ Gruetzner, *Alzheimer's*, 25.

¹⁸ Gruetzner, *Alzheimer's*, 24.

¹⁹ Gruetzner, *Alzheimer's*, 26-27.

²⁰ "Stages of Alzheimer's," Alzheimer's Association, last modified September 20, 2010, http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp; Gruetzner, *Alzheimer's*, 26-27.

pieces back in the safe every night.²¹ Prior to this routine, the caregiver's wife had lost her wedding ring and began misplacing other valuables inside and outside of their home.

Early-stage or mild Alzheimer's is usually when family members and friends begin to notice a significant problem. In this phase, complicated tasks that were once routine—planning and cooking dinner, managing finances, performing mental arithmetic—become increasingly difficult. Patients also have trouble remembering their own personal and family histories, and personality changes often begin to appear.²² Planning and organizational skills may suffer, and patients become more dependent on family members and friends for basic needs.²³ Logical and sequential reasoning is negatively impacted, sometimes causing people to complete tasks only partway.²⁴ These difficulties and symptoms often persist throughout disease progression.²⁵

For some patients, withdrawal from social activity becomes necessary. One caregiver explained that at one point in his wife's disease progression, they had to stop going to church.²⁶ The soft chatter of the congregation became too overwhelming and frustrating for his wife's brain to process, he said. She would get upset and not know how to handle the noise. She reacted similarly in restaurants and other locations to what many people consider

²¹ Joe Clark, in-person interview by author, Durham, N.C., September 17, 2010.

²² "Stages of Alzheimer's," Alzheimer's Association.

²³ "Stages of Alzheimer's," Alzheimer's Association; Gruetzner, *Alzheimer's*, 29.

²⁴ Gruetzner, *Alzheimer's*, 29.

²⁵ "Stages of Alzheimer's," Alzheimer's Association.

²⁶ Clark, in-person interview, September 17, 2010.

“background noise.” Noises never fade into the background for Alzheimer’s patients, the caregiver said.

During the middle stage of Alzheimer’s disease, patients need help with day-to-day activities, including bathing, eating and sometimes even walking. Confusion by patients about where they are and time of day may occur²⁷ as well as delusions, repetitive tendencies, paranoia and periodic violent behavior.²⁸ Memory and recognition abilities continue to worsen, and personality and mood keep changing.²⁹ Patients may also wander and become lost. They may have brief periods of lucidity but sometimes do not recognize their caregivers or other loved ones.

Late-stage Alzheimer’s can bring about eating, sleeping and toileting problems. Patients continue experiencing difficulties that first presented themselves in earlier stages. Emotional, behavioral and physical symptoms persist and worsen. In the final stage of the disease, patients can no longer communicate or control movement.³⁰ They need help using the toilet, washing and eating, and may no longer be able to smile or hold their heads up. Patients are susceptible to seizures, pneumonia, coma and other illnesses as brain activity functions at an extremely low level, eventually resulting in death.³¹

It is worth noting that the symptoms, stages and progression of Alzheimer’s disease differ for every patient. Once diagnosed, Alzheimer’s patients may live anywhere from eight

²⁷ “Stages of Alzheimer’s,” Alzheimer’s Association.

²⁸ Gruetzner, *Alzheimer’s*, 31.

²⁹ “Stages of Alzheimer’s,” Alzheimer’s Association.

³⁰ Ibid.

³¹ Gruetzner, *Alzheimer’s*, 35.

to 20 additional years.³² It is also important to mention a rare form of the disease known as younger-onset Alzheimer's. Younger-onset refers to people under the age of 65 who have Alzheimer's.³³ Roughly 200,000 people in the U.S. between the ages of 30 and 50 have younger-onset Alzheimer's disease.³⁴

How many people have Alzheimer's, and how is it diagnosed?

According to the Alzheimer's Association, an estimated 5.4 million people in the U.S. have Alzheimer's disease.³⁵ This translates into roughly one in eight people 65 and older, based on U.S. Census Bureau population data from 2008.³⁶ Scientific studies suggest the prevalence of Alzheimer's disease in the U.S. is anywhere from 2.8 to 5.1 million people.³⁷ Determining the exact number of people with Alzheimer's is an elusive challenge because an

³² Elizabeth Arledge, *The Forgetting: A Portrait of Alzheimer's*, DVD. Directed by Elizabeth Arledge (Alexandria, Virginia: PBS, 2003).

³³ "What We Know Today About Alzheimer's Disease," Alzheimer's Association Research Center, accessed October 12, 2010, http://alz.org/research/science/alzheimers_research.asp.

³⁴ Alzheimer's Association, *2011 Facts and Figures Report* (Chicago: Alzheimer's Association National Office, 2011), 12.

³⁵ Alzheimer's Association, *2011 Facts and Figures*, 12. *Note: In its 2010 and 2011 reports, the Alzheimer's Association provides a citation for a 2003 study published in the Archives of Neurology, which derives its estimates on future U.S. prevalence of Alzheimer's disease from the 2000 U.S. Census. Quoted from the original study: "To indicate the uncertainty in these future estimates, we bracket the estimates derived from the middle-series US Census Bureau estimates of population growth with estimates derived from the high- and low-series estimates of population growth. For 2010, the estimate derived from the middle series is 5.1 million persons with AD and is bracketed by an estimate derived from the low series of 5.1 million persons and an estimate derived from the high series of 5.3 million persons"* (Liesi Hebert, Paul Scherr, Julia Bienias, David Bennett, Denis Evans, "Alzheimer Disease in the US Population: Prevalence Estimates Using the 2000 Census," *Archives of Neurology* 60 (2003) 1119-1122).

³⁶ Alzheimer's Association, *2011 Facts and Figures*, 12.

³⁷ Ron Brookmeyer, Denis Evans, Liesi Hebert, Kenneth Langa, Steven Heeringa, Brenda Plassman, Walter Kukull, "National Estimates of the Prevalence of Alzheimer's Disease in the United States," *Alzheimer's & Dementia* 7 (2011) 61-73.

autopsy of the brain is the only way to confirm that someone had the disease.³⁸ No one examination, test or procedure can detect the presence of Alzheimer's, and doctors must rule out other potential causes of patients' symptoms before making a probable diagnosis.³⁹ In North Carolina, an estimated 170,000 people 65 and older have Alzheimer's or another form of dementia.⁴⁰

The current method of diagnosis typically involves a combination of physical, neurological and psychological exams; screening tests; and medical reviews. The process of diagnosis is far from straightforward, and physicians, neurologists, geriatric specialists and other health care professionals are often involved. As part of the process, physicians may ask patients to spell words backwards and forwards, identify the names of common objects or perform different types of puzzles. An MRI or CT scan may also be used to diagnose a patient with Alzheimer's. As explained by *TIME* senior reporter Alice Park in her October 2010 piece on the disease, "Blood and spinal-fluid tests, along with brain scans, could improve the predictive accuracy" of the standard measures for diagnosis.⁴¹

Doctors and researchers have called Alzheimer's the defining disease of the baby boom generation, the cohort of Americans born between 1946 and 1964. As more Americans live longer, Alzheimer's is likely to affect more and more people since age is the primary risk

³⁸ Roberts, telephone interview, July 15, 2010. Park, "Unlocking Alzheimer's," *TIME*.

³⁹ Gruetzner, *Alzheimer's*, 10; Roberts, interview, July 15, 2010; "Alzheimer's Disease Diagnosis," Mayo Clinic, accessed October 10, 2010, <http://www.mayoclinic.org/alzheimers-disease/diagnosis.html>; "Diagnosis," Fisher Center for Alzheimer's Research Foundation, accessed October 10, 2010, <http://www.alzinfo.org/about-alzheimers/diagnosis>.

⁴⁰ Roberts, telephone interview, July 15, 2010.

⁴¹ Park, "Alzheimer's Unlocked." *TIME*.

factor for developing the disease.⁴² Epidemiological studies conducted in the U.S. have shown that Alzheimer's disease exists in 1 percent of 65- to 69-year-olds and increases to 40 to 50 percent of people 95 years of age and older.⁴³ A study begun in Canada in 1991 showed that roughly 22 percent of Canadians 85 years of age and older had Alzheimer's.⁴⁴

The first baby boomers turn 65 this year.⁴⁵ Increasingly more baby boomers are caring for loved ones with Alzheimer's, and many may experience the disease themselves as their generation is expected to live longer than the ones preceding it.⁴⁶

Who are the caregivers? How do they fit in?

A number of paid caregivers—physicians, geriatricians, neurologists, nurses and other health care professionals; pharmacists; senior daycare, assisted living and nursing home staff members; social workers; and others—provide care for Alzheimer's patients. However, this project focuses on unpaid, or family, caregivers. The vast majority of unpaid caregivers are family members.⁴⁷ These caregivers may live with the patient, or they may visit the patient at his or her home or in an assisted living facility, nursing home or other institution.

⁴² Roberts, telephone interview, July 15, 2010.

⁴³ L.X. Hy, D.M. Keller, "Prevalence of AD Among Whites: A Summary by Levels of Severity," *Neurology* 55 (2000): 198-204; Robert Nussbaum, Christopher Ellis, "Alzheimer's Disease and Parkinson's Disease," *New England Journal of Medicine* 348 (2003): 1356-1364.

⁴⁴ Joan Lindsay, Elizabeth Sykes, Ian McDowell, Rene Verreault, Danielle Laurin, "More Than the Epidemiology of Alzheimer's Disease: Contributions of the Canadian Study of Health and Aging," *Canadian Journal of Psychiatry* 49, no. 2 (2004): 83-91.

⁴⁵ U.S. Census Bureau, "An Older and More Diverse Nation by Midcentury," by Robert Bernstein and Tom Edwards (Washington, D.C.: Public Information Office, 2008), <http://www.census.gov/newsroom/releases/archives/population/cb08-123.html>.

⁴⁶ Roberts, telephone interview, July 15, 2010; Arledge, *The Forgetting*, 2003; Alzheimer's Association, *Facts and Figures*, 12.

⁴⁷ Alzheimer's Association, *2010 Facts and Figures*, 23.

This project will encompass these variations of living arrangements, and unless otherwise noted, all mention of caregiving will refer to unpaid caregivers.

Roughly 15 million people in the U.S. provide unpaid care to people with Alzheimer's or another type of dementia. In 2010, these caregivers provided an estimated 17 billion hours of unpaid care, according to the Alzheimer's Association.⁴⁸ Despite the numbers and figures concerning hours of care and numbers of caregivers, few in-depth, narrative stories have been told through the eyes of caregivers themselves. And fewer stories still illuminate the psychological and emotional tolls of watching a loved one transform into someone unfamiliar to them during disease progression. Alzheimer's caregivers are spouses, daughters, sons, nieces, nephews, cousins, grandchildren and friends. More than 415,000 of them live in North Carolina alone.⁴⁹

Not all Alzheimer's caregivers realize that others are in a caregiving situation similar to their own. Many don't seek help when they need it, further adding to a cycle of stress, isolation and sometimes illness for the caregiver. According to the Family Caregiver Alliance, 30 to 40 percent of caregivers for Alzheimer's and other dementia patients "suffer from depression and emotional stress."⁵⁰ The Shriver Report, a 2009 study by Maria Shriver and the Alzheimer's Association, cites that nearly two-thirds of all working caregivers for Alzheimer's patients "report having to go to work late, leave early or take time off to provide care."⁵¹ Despite this statistic, less support is available for elder care than for child care.⁵²

⁴⁸ Alzheimer's Association, *2011 Facts and Figures*, 25.

⁴⁹ Alzheimer's Association, *2011 Facts and Figures*, 33.

⁵⁰ "Selected Caregiver Statistics," Family Caregiver Alliance, last modified 2005, http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439.

⁵¹ "Overview," The Shriver Report, last modified 2010, <http://www.shriverreport.com/overview.php>.

According to the report, roughly half of all women caregivers, who make up about 60 percent of total Alzheimer's caregivers worldwide, "report high emotional and physical stress."⁵³

Caregivers cannot provide optimal care for their loved ones if they themselves are not physically and emotionally healthy. This is why support, resources and awareness can have a positive impact on caregivers' experiences with the disease. Through written narratives from the perspective of caregivers, this project aims to tell the complex, intimate stories generally missing from popular media coverage of Alzheimer's disease, with a particular emphasis on the psychological and emotional challenges that caregivers face over the course of patients' disease progression. Roy Peter Clark, senior scholar of The Poynter Institute and director of its writing center, points to the powerful voice of eyewitness accounts, which originates from "an authority that can only come from being there."⁵⁴ To construct the narratives, I will rely on caregivers' eyewitness accounts of the disease and its impact on their lives as well as my firsthand observations of their daily challenges.

Literature Review

Much has been written on the topic of Alzheimer's. The literature, which dates back to the late 1970s, traces the history of research on the disease, including the doctors and scientists who have made major contributions to what we know about Alzheimer's. The literature also includes statistics on the estimated number of people in the U.S. and world with the disease, the estimated financial costs of caring for someone with Alzheimer's, and

⁵² "Overview," The Shriver Report.

⁵³ Ibid.

⁵⁴ Roy Peter Clark, "The Journalist as Eyewitness," The Poynter Institute, accessed January 7, 2011, <http://www.poynter.org/uncategorized/29061/the-journalist-as-eyewitness/>.

the percentage risks of developing the disease as people age. Information about the various components of Alzheimer's diagnosis exams and testing can be found in abundance. What we don't yet know about Alzheimer's—if there is a cure, what the exact causes are, if there is an end in sight—is also present in the literature. What the current literature generally lacks are caregivers' in-depth, personal accounts of caregiving for loved ones with the disease.

The 1960s and 1970s brought about some major findings in Alzheimer's research. In 1963, a neuropathologist named Robert Terry was the first scientist to look at the neurobiology of Alzheimer's disease. Terry and his research team at Albert Einstein College of Medicine in New York identified a potential link between Alzheimer's and the brain structures of amyloid plaque and paired helical filament.⁵⁵ In 1976, the late Robert Katzman, a neurologist at University of California San Diego, “identified Alzheimer's disease as the most common cause of dementia and a major public health challenge” in his editorial published in *Archives of Neurology*.⁵⁶ Katzman made the distinction that “senile dementia” was not a natural part of aging, but rather Alzheimer's disease.⁵⁷

Shortly after, in 1984, an advisory group of Alzheimer's and dementia experts was formed and led to the National Institute on Aging's funding of Alzheimer's disease research centers across the country. The mission of these centers, which are located in 30 medical institutions in the U.S., is “to translate research advances into improved diagnosis and care for Alzheimer's disease (AD) patients while, at the same time, focusing on the program's

⁵⁵ Lisa Gwyther, in-person interview with author, Durham, N.C., September 13, 2010; Isabelle Rapin, “History of the Saul R. Korey Department of Neurology,” Albert Einstein College of Medicine of Yeshiva University, accessed October 10, 2010, <http://www.einstein.yu.edu/neurology/history.aspx>.

⁵⁶ Robert Katzman, “The Prevalence and Malignancy of Alzheimer's Disease: A Major Killer,” *Alzheimer's & Dementia*, Vol. 4 (2008): 378–380.

⁵⁷ *Ibid.*

long-term end goal—finding a way to cure and possibly prevent AD.”⁵⁸ Also in 1984, researchers George Glenner and Cai’ne Wong identified beta-amyloid protein as “the chief component of Alzheimer brain plaques and a prime suspect in triggering nerve cell damage.”⁵⁹ Since then, several characteristic Alzheimer’s brain abnormalities have been identified: plaques, which include beta-amyloid proteins; protein tangles; loss of synapses or connections between brain cells; inflammation in regions of the brain; and death of brain cells.⁶⁰

In the late 1980s, the federal government’s now-defunct Office of Technology Assessment (OTA) took an interest in Alzheimer’s. Congress established OTA in 1972 to aid in “the identification and consideration of existing and probable impacts of technological application.”⁶¹ Its function was to produce comprehensive assessment reports on issues and topics requested by Congressional committee chairmen or ranking members of various committees. In 1987, OTA produced its first report on Alzheimer’s and dementia, called *Losing a Million Minds: Confronting the Tragedy of Alzheimer’s Disease and Other Dementias*. The roughly 500-page report discussed characteristics of Alzheimer’s disease; diagnosis, treatment and scientific background; public policy related to Alzheimer’s and

⁵⁸ “AD Research Centers,” National Institute on Aging, last modified August 6, 2010, <http://www.nia.nih.gov/Alzheimers/ResearchInformation/ResearchCenters/>.

⁵⁹ “Major Milestones in Alzheimer’s Research,” Alzheimer’s Association Research Center, accessed October 10, 2010, http://alz.org/research/science/major_milestones_in_alzheimers.asp.

⁶⁰ “What We Know Today About Alzheimer’s Disease,” Alzheimer’s Association Research Center, accessed September 20, 2010, http://alz.org/research/science/alzheimers_research.asp#whatis.

⁶¹ “The Technology Assessment Act of 1972,” Office of Technology Assessment, accessed October 10, 2010, <http://www.princeton.edu/~ota/html2/act.html>.

dementia; the impact on families; and financial advice for long-term care.⁶²

A second OTA report centered on Alzheimer's and dementia, called *Confused Minds, Burdened Families*, was published in 1990. This report emphasized public education and awareness of the disease; the need for outreach, support services and resources; and questions caregivers might ask in determining the quality of professional care.⁶³ This report was more focused on providing information for caregivers than the first report, which mainly concerned the disease itself. Around the same time, a U.S. Department of Health and Human Services (DHHS) advisory panel on Alzheimer's disease was formed.⁶⁴ The panel published a handful of reports from 1988 through 1996, and then disbanded.⁶⁵

This timeline of Alzheimer's findings, reports and advisory panels is worth noting because it prompted the publication of media articles, books and scholarly research on the disease. The literature on the whole, dating back from the 1970s through the present, focuses on numerous aspects of Alzheimer's disease, including but not limited to the history of the disease, symptoms, diagnosis, treatment, the state of research, prevalence, available resources, the development and testing of drugs, and national initiatives. In-depth caregiver stories—their experiences, emotions and the day-to-day changes they encounter—are much harder to find among the science and media coverage. These types of intimate accounts take a great amount of time, energy and resources to report, which may explain why they appear more often in books, feature films and documentaries than in newspapers and magazines,

⁶² U.S. Congress, Office of Technology Assessment, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias* (Washington, DC: U.S. Government Printing Office, 1987).

⁶³ U.S. Congress, Office of Technology Assessment, *Confused Minds, Burdened Families: Finding Help for People With Alzheimer's & Other Dementias* (Washington, DC: U.S. Government Printing Office, 1990).

⁶⁴ Gwyther, in-person interview, September 13, 2010.

⁶⁵ Gwyther, email interview, September 19, 2010.

where there are often daily deadlines and budget constraints. Personal caregiver accounts in popular media are mostly found in major publications, which typically have more resources to pursue these types of in-depth stories.

Newspapers and magazines

One of the earliest articles mentioning Alzheimer's published in the mass media is part profile of Dr. Robert Butler, former director of the National Institute on Aging, and part plea for investment in the nation's elderly.⁶⁶ The 1979 article, which appeared in *The Washington Post*, was published around the time of Robert Terry's discovery of amyloid plaque and its potential link to the disease. The article mentions Alzheimer's once, in a quote given by doctor-director Butler: "In the next few years Alzheimer's disease [a form of senility] will be as famous as Down syndrome. It affects half the people now in nursing homes. It is a major cause of death. As many as 1.5 million people over 65 may have it."⁶⁷

A great deal of the media's coverage of Alzheimer's disease focuses on numbers: the number of patients and caregivers, the amount of research dollars devoted to the disease, future estimates of disease prevalence and more. One article details a 1989 federally funded study led by Dr. Denis A. Evans and researchers from Harvard Medical School and Brigham and Women's Hospital in Boston, Massachusetts. The study followed 3,600 elderly people living in East Boston and found that "a startling 47.2 percent" of people over age 85 likely had the disease, doubling the previous estimate for that age cohort.⁶⁸ Prior estimates held that

⁶⁶ Michael Kernan, "The Graying of America," *The Washington Post*, December 13, 1979.

⁶⁷ Ibid.

roughly 2.5 million Americans were living with Alzheimer's. However, the 1989 study found that closer to 4 million people had the disease.⁶⁹ Evans' research remains one of the largest and most in-depth studies on Alzheimer's disease.

In 2000, an *Associated Press* article warned of the dire future predictions of disease prevalence. The article cites experts' claims that by 2025, roughly 22 million people in the world will have Alzheimer's if no cure is found before then. By 2050, prevalence increases to 45 million, according to the article's sources.⁷⁰ The number of people with Alzheimer's in the U.S. alone is expected to reach 16 million by 2050, the *AP* reported.⁷¹

A 1999 article in *The (Columbia, S.C.) State* focused on Alzheimer's numbers for a different purpose: to shed light on the growing number of—and need for—statewide licensed resident care facilities, the rising annual costs of paid care for families affected by Alzheimer's, and the average annual cost per patient for nursing home care.⁷² These articles quote doctors, study authors and other experts. The focus is on the numbers and quantitative data as they relate to Alzheimer's disease. Though some “numbers” stories offer brief anecdotes about caregiving, these anecdotes often only attempt to put a human face on a national and global problem. That face is often used as a lead into the story and is soon

⁶⁸ Warren Leary, “More Afflicted with Alzheimer's than was Thought, Study Finds,” *The New York Times*, November 10, 1989, Accessed September 20, 2010, <http://www.nytimes.com/1989/11/10/us/more-afflicted-with-alzheimer-s-than-was-thought-study-finds.html>.

⁶⁹ Leary, “More Afflicted with Alzheimer's.”

⁷⁰ Luran Neergaard, “Alzheimer's Cases Likely to Climb Fast \ Imminent Worldwide Epidemic Foreseen as Elderly Population Rises,” *Associated Press*, July 10, 2000.

⁷¹ Melissa Block, “The Latest In Treating, Diagnosing Alzheimer's,” *NPR*, August 26, 2010, accessed September 21, 2010, <http://www.npr.org/templates/story/story.php?storyId=129454412>.

⁷² Pat Berman, “Alzheimer's Heavy Burden Disease Expected to Strain S.C. Families,” *The (Columbia, S.C.) State*, October 12, 1999.

forgotten as the reader advances in the piece, which moves into a focus on the numbers and refers little to the personal story.

More recent articles have focused almost solely on the development and testing of potential Alzheimer's drugs and the confounding findings both have produced. Based on field research, for years doctors and other medical professionals have touted the importance of maintaining a healthy, active lifestyle and flexing one's mental skills with puzzles and memory games to help prevent Alzheimer's, or at least, to slow disease progression.⁷³ However, recent articles have challenged this notion, illuminating the possibility that these recommendations might not be effective in warding off or slowing down the disease.⁷⁴ For caregivers, these contradictions further complicate the already arduous process of weeding through vast amounts of existing information on Alzheimer's and deciding what information to trust and use. The contradictions also have the potential to send caregivers on an emotional rollercoaster of highs and lows, hopes and disappointments, possibly putting caregivers' mental and emotional health at stake.

Last spring, the National Institutes of Health assembled a panel of 15 scientists unconnected to Alzheimer's research. During what Gina Kolata, *The New York Times'* veteran health reporter who covered the panel's findings and often writes about Alzheimer's disease, described as a "science court," the panel listened to presentations from Alzheimer's

⁷³ J.C. Smith, et al., "Interactive Effects of Physical Activity and APOE-epsilon4 on BOLD Semantic Memory Activation in Healthy Elders," *Neuroimage* (2010); Alice Park, "Study: Exercise Can Protect People at High Risk of Alzheimer's," *TIME*, September 7, 2010, accessed September 21, 2010, <http://healthland.time.com/2010/09/07/exercise-protects-against-alzheimers>; Susan Swartz, "Building a healthy brain," *Press Democrat*, August 6, 2010, accessed September 21, 2010, <http://www.pressdemocrat.com/article/20100806/LIFESTYLE/100809711/>; "Health Buzz: Vitamin B Could Delay Alzheimer's Onset," *U.S News and World Report*, September 9, 2010, accessed September 21, 2010, <http://health.usnews.com/health-news/diet-fitness/brain-and-behavior/articles/2010/09/09/health-buzz-vitamin-b-could-delay-alzheimers-onset.html>.

⁷⁴ Gina Kolata, "Years Later, No Magic Bullet Against Alzheimer's Disease," *The New York Times*, August 28, 2010, accessed September 21, 2010, <http://www.nytimes.com/2010/08/29/health/research/29prevent.html>.

researchers and Duke University scientists, who had been commissioned to examine hundreds of pages of research papers. Kolata's summary of the examined research says:

“The studies included research on nearly everything proposed to prevent the disease: exercise, mental stimulation, healthy diet, social engagement, nutritional supplements, anti-inflammatory drugs or those that lower cholesterol or blood pressure, even the idea that people who marry or stay trim might be saved from dementia. And they included research on traits that might hasten Alzheimer's onset, like not having much of an education or being a loner.”⁷⁵

After a day and a half of deliberations, the panel concluded that no behaviors or actions, prescription or nonprescription drugs, dietary regimens or supplements, or social, economic or environmental factors decreased one's risk of developing Alzheimer's.⁷⁶ More specifically, “no evidence of even moderate scientific quality exists to support the association of any modifiable factor with reduced risk of Alzheimer's disease,” panel members summarized in their final report.⁷⁷ These findings, along with Kolata's story, generated a great deal of follow-up coverage highlighting the confusing and disappointing news for Alzheimer's patients and caregivers.⁷⁸ Some coverage drew attention to a later study

⁷⁵ Ibid.

⁷⁶ Ibid.

⁷⁷ National Institutes of Health, *NIH State-of-the-Science Conference: Preventing Alzheimer's Disease and Cognitive Decline* (Bethesda, Maryland: April 26–28, 2010), accessed October 10, 2010, <http://consensus.nih.gov/2010/alzstatement.htm>.

⁷⁸ Jean Carper, “What's Going on with Alzheimer's Coverage in the Media,” *The Huffington Post*, September 3, 2010, accessed September 21, 2010, http://www.huffingtonpost.com/jean-carper/does-the-new-york-times-h_1_b_702935.html; Lisa Ahranjian, “Independent Panel Finds Insufficient Evidence to Support Preventive Measures for Alzheimer's Disease,” *NIH News Press Release*, April 28, 2010, accessed September 21, 2010, <http://www.nih.gov/news/health/apr2010/od-28.htm>; Shirley Wang, “NIH Panel: No Evidence that Strategies

published in *Neurology* that found that Alzheimer's patients who reported high levels of mental activity and stimulation were the ones who experienced the steepest cognitive decline.⁷⁹ As the debate continued among the medical community, caregiver voices about what these new conclusions could mean for them were missing from the coverage.

The media's accounts of diagnosis tests and the development of Alzheimer's drugs are similarly faceless and puzzling. A front-page article by Kolata in *The New York Times* warranted a three-paragraph correction roughly one month after it was published.⁸⁰ Kolata's article originally ran with the subhead: "100% Accuracy Found in Study Results."⁸¹ In her lead, she reported that a study found a spinal fluid test to be "100 percent accurate" in predicting mild cognitive impairment (MCI) patients who will go on to develop Alzheimer's disease based on the presence of "a signature level of abnormal (brain) proteins."⁸² However, the study actually produced a much narrower finding: 100 percent of (a limited number of) subjects with MCI who had developed Alzheimer's over a period of five years had shown signature levels of the abnormal proteins in question.⁸³ Not everyone with these abnormal

Prevent Alzheimer's," *The Wall Street Journal*, April 28, 2010, accessed September 21, 2010, <http://blogs.wsj.com/health/2010/04/28/nih-panel-no-evidence-that-strategies-prevent-alzheimers>.

⁷⁹ Melissa Healy, "For the Intellectually Active, Alzheimer's Diagnosis Begins a Steep Slide," *Los Angeles Times*, September 1, 2010, Accessed September 21, 2010, <http://www.latimes.com/health/boostershots/la-heb-alzheimers 20100901,0,2206493.story>.

⁸⁰ Gina Kolata, "In Spinal Fluid Test, an Early Warning on Alzheimer's," *The New York Times*, August 9, 2010, accessed September 21, 2010, <http://www.nytimes.com/2010/08/10/health/research/10spinal.html>; Arthur Brisbane, "The Trouble With Absolutes," *The New York Times*, August 24, 2010, accessed September 21, 2010, <http://publiceditor.blogs.nytimes.com/2010/08/24/the-trouble-with-absolutes>; Robert Langreth, "The New York Times Makes Amazing Correction on Alzheimer's Disease Story," *Forbes*, September 16, 2010, accessed September 21, 2010, <http://blogs.forbes.com/robertlangreth/2010/09/16/the-new-york-times-makes-amazing-correction-on-alzheimers-disease-story/>.

⁸¹ Brisbane, "The Trouble with Absolutes."

⁸² Kolata, "In Spinal Fluid Test."

protein levels at the outset of the study went on to develop Alzheimer's. Despite Kolata's misguided judgment in this story, it is worth noting that *The New York Times* has provided a great deal of sensitive, important stories about Alzheimer's and, in my opinion, has produced the best media coverage of the disease.

Other publications have covered the elusiveness of tests designed to diagnose the disease,⁸⁴ the failure of Alzheimer's drugs in clinical trials,⁸⁵ and the push for an updated list of disease symptoms to promote earlier detection based on recommendations from a 2010 international Alzheimer's research conference.⁸⁶ Not surprisingly, obituaries make up a number of Alzheimer's-related articles in the media as well.

In addition to the plethora of numbers and statistics-based stories on Alzheimer's in popular media, the act of caregiving itself has been the focus of some Alzheimer's stories. A 1989 article in *The Boston Globe* sheds light on why Alzheimer's family caregiving has been called "the ongoing funeral" and "the 36-hour workday" by some caregivers.⁸⁷ Another story

⁸³ Brisbane, "The Trouble with Absolutes."

⁸⁴ Mary Brophy Marcus, "Early Alzheimer's Diagnosis is Crucial, Yet Accurate Test Elusive," *USA Today*, September 16, 2010, accessed September 21, 2010, http://www.usatoday.com/yourlife/health/medical/alzheimers/2010-09-16-alzheimerstesting16_CV_N.htm.

⁸⁵ Gina Kolata, "Doubt on Tactic in Alzheimer's Battle," *The New York Times*, August 18, 2010, accessed September 21, 2010, <http://www.nytimes.com/2010/08/19/health/19alzheimers.html>; Judy Woodruff, "Alzheimer's Treatment Research Dealt Setback," *PBS NewsHour*, August 18, 2010, accessed September 21, 2010, http://www.pbs.org/newshour/bb/health/july-dec10/alzheimers_08-18.html; Laura Blue, "Why Do So Many Alzheimer's Drugs Fail in Clinical Trials," *TIME*, August 26, 2010, accessed September 21, 2010, <http://healthland.time.com/2010/08/26/why-do-so-many-alzheimers-drugs-fail-in-clinical-trials>.

⁸⁶ Gina Kolata, "Rules Seek to Expand Diagnosis of Alzheimer's," *The New York Times*, July 13, 2010, accessed September 21, 2010, <http://www.nytimes.com/2010/07/14/health/policy/14alzheimer.html>; Gina Kolata, "In Push to Detect Early Alzheimer's Markers, Hopes for Prevention," *The New York Times*, August 4, 2010, accessed September 21, 2010, <http://www.nytimes.com/2010/08/05/health/05alzheimers.html>; Jenifer Goodwin, "Biomarkers May Aid in Early Diagnosis of Alzheimer's," *Bloomberg Businessweek*, September 13, 2010, accessed September 21, 2010, <http://www.businessweek.com/lifestyle/content/healthday/643068.html>.

⁸⁷ Betsey A. Lehman, "The Families of Alzheimer's Patients Are Also Victims," *The Boston Globe*, June 19, 1989.

details the benefits that home services, adult day care and nursing facilities can have for caregivers.⁸⁸ While these caregiving stories offer tips and resources for caregivers, the advice provided remains somewhat detached from caregivers' personal experiences. Questions asked of caregivers do not delve deeply beyond the daily tasks associated with caregiving. While personal anecdotes that offer insight from caregiver to caregiver are often not the focus of these stories, there are some exceptions.

A first-person account written by a physician who regularly sees Alzheimer's patients tells a story about doctor's visits, exams, and a particular worn-out and sleep-deprived caregiver.⁸⁹ The essence of the poignant and personal story is encapsulated in the following passage:

Later outside the exam room, the son pulled me aside. I noticed the dark circles around his eyes. "You're tired, aren't you?" I asked him.

The man's dark eyes began to fill with tears. I immediately, reflexively almost, started apologizing for not being able to do more for his father. But he stopped me.

"No, no," he said, wiping the tears away with the back of his hand. "It's not that. It's not that at all." He paused and looked toward his father, still lying on the table in the room and smiling at the lights. "It's just that no doctor has ever asked me if I was tired."

In truth, I probably would have never done so either except that a few years ago, I too had spent time caring for a frail loved one.⁹⁰

The doctor uses this personal anecdote to demonstrate that medical professionals, herself included, don't often take the time to check in with caregivers. In the remainder of the article, she pushes for greater awareness of the challenges of caregiving among health professionals

⁸⁸ Jacob Reingold, "How to Cope With Alzheimer's," *The New York Times*, September 12, 1985.

⁸⁹ Pauline Chen, "Offering Care for the Caregiver," *The New York Times*, January 21, 2010, accessed September 21, 2010, <http://www.nytimes.com/2010/01/22/health/21chen.html>.

⁹⁰ Ibid.

and hopes that “the profession’s indifference” to caregivers will end.⁹¹ She writes that attention must also be paid to the mental and physical health of the caregiver. However, aside from the passage mentioned above, no other caregivers are heard from in the article. Doctors and Alzheimer’s committee members comprise the remainder of the author’s sources.

In a long-form narrative piece that ran in *The New York Times Magazine* in January 2010, a daughter relates her experience coping with her father’s disease and his slow decline. The reporter, Katy Butler, recounts a visit to her parents’ home in Connecticut and her mother’s subsequent request for help in turning off her father’s pacemaker, an action to end his life. The writer’s father suffers from Alzheimer’s and “sewn into a hump of skin and muscle below his right clavicle was the pacemaker that helped his heart outlive his brain,” Butler writes. Butler traces her parents’ history together for the reader, characterized by their good health and independence throughout. She then details her father’s illness, which began with a stroke at age 79. Soon after, a cardiothoracic surgeon inserted his pacemaker, bringing the family “two years of limbo, two of purgatory and two of hell.”⁹²

Despite the painstaking detail of the reporter’s experience with Alzheimer’s and the emotions and decisions she struggled with, Butler was a long-distance caregiver; she and her siblings lived in California. Thus, she missed many of the day-to-day, ongoing challenges of living with and caring for someone with Alzheimer’s, experiences that her mother more intimately struggled with. This fact is not meant to diminish Butler’s experience with the disease or authority on the subject, but rather to suggest her limited perspective. The most insightful moments of Butler’s moving narrative come from her mother. “The Jeff I married

⁹¹ Chen, “Offering Care for the Caregiver.”

⁹² Katy Butler, “What Broke My Father’s Heart,” *The New York Times*, June 18, 2010, accessed September 21, 2010, <http://www.nytimes.com/2010/06/20/magazine/20pacemaker-t.html>.

is no longer the same person,” Butler recounts her mother writing in a journal. “My life is in ruins. This is horrible, and I have lasted for five years.”⁹³

Later in the story, Butler writes: “Not long afterward, my mother declined additional medical tests and refused to put my father on a new anti-dementia drug and a blood thinner with troublesome side effects. ‘I take responsibility for whatever,’ she wrote in her journal that summer. ‘Enough of all this overkill! It’s killing me! Talk about quality of life — what about mine?’” These authentic moments of frustration, stress and anger are so rarely seen in accounts of the disease.⁹⁴

In another long-distance caregiver’s account, a reporter describes her mother’s battle with the disease.⁹⁵ Beatriz Terrazas writes that she visits her mother in El Paso, Texas, several times a year and then brings her mother to her home for a few weeks to give her sister an extended break from primary caregiving. Terrazas illuminates the devastation of her mother’s disease progression and the importance of a support network:

My own caregiving days blur with time-gobbling tasks. I prepare Mom’s meals, wash her clothes, dole out medications, remind her to brush her teeth, wash her hands, go to bed, wake up. It is never-ending. But in those minuscule, infrequent pockets of time between tasks—when I put Mom to bed for instance, and she’s lying back on her pillow smiling at me—I search for myself in the cracked mirror of her face. It was easier when she was well, when our roles were that of mother and daughter, and not of mother and caregiver.⁹⁶

⁹³ Ibid.

⁹⁴ Ibid.

⁹⁵ Beatriz Terrazas, “Alzheimer’s Role Reversal,” *D Magazine*, August 18, 2010, accessed September 21, 2010, http://www.dmagazine.com/Home/D_Magazine/2010/September/Alzheimers_Role_Reversal.aspx.

Terrazas later recounts singing her mother's favorite song to wake her from a nap, her mother giggling as she opened her eyes. She writes: "I try to bear in mind the literature about Alzheimer's, the things I hear in my support group. Alzheimer's patients feel a caregiver's mood, whether it's sad, angry, or anxious. My goal is to speak slowly, patiently, and to sound happy, no matter how I'm feeling."⁹⁷ It is this kind of insight, honesty and vulnerability that can reach caregivers in similar situations and make an impact. And it is this kind of insight that is missing from so much of the literature on Alzheimer's disease.

A fascinating 2001 long-form story in *TIME*, written by Michael Lemonick and Alice Park, details the famous "Nun Study," a longitudinal study of 678 members of the School Sisters of Notre Dame, many of whom live in Mankato, Minnesota. The study, funded by the National Institute on Aging, began in 1986 under the direction of scientist David Snowdon of the University of Kentucky and is now led by Dr. Kelvin Lim and Dr. Karen Santa Cruz, both of the University of Minnesota. Since 1986, the study has assessed and followed the sisters' cognitive and physical function, convent and medical records, and general well-being and activity levels. Additionally, more than 600 of the sisters have agreed to donate their brains after death to be studied.⁹⁸ Through these assessments, researchers hope to "determine the causes and prevention of Alzheimer's disease, other brain diseases, and the mental and physical disability associated with old age."⁹⁹ As of 2009, researchers believed 10 to 15

⁹⁶ Ibid.

⁹⁷ Terrazas, "Alzheimer's Role Reversal."

⁹⁸ Lorna Benson, "U of M Resumes Nuns' Alzheimer's study," Minnesota Public Radio, March 25, 2009, last accessed January 27, 2011, http://minnesota.publicradio.org/display/web/2009/03/24/nuns_alzheimers_study/.

⁹⁹ "Frequently Asked Questions," The Nun Study, University of Minnesota, last modified December 15, 2008, <http://www.healthstudies.umn.edu/nunstudy/faq.jsp>.

brains in the donated collection were diseased although “those particular sisters did not show outward signs of memory loss.”¹⁰⁰

One of the most interesting study findings highlighted in Lemonick and Park’s piece is the potential role that language in early life may have in determining later life health. As explained in the article, Snowden and other researchers coined the term “idea density” for the “number of discrete ideas per 10 written words.”¹⁰¹ The researchers studied the written vows the sisters made when they first joined the convent, determining that idea density was a “good marker of educational level, vocabulary and general knowledge.”¹⁰² Lemonick and Park further explain:

Idea density turns out to be an astonishingly powerful predictor of Alzheimer’s disease—at least among the School Sisters of Notre Dame. Snowden found by reading nuns’ early writings, he could predict, with 85% to 90% accuracy, which ones would show the brain damage typical of Alzheimer’s disease about 60 years later.¹⁰³

Of course, as with every study finding, there were exceptions. One example the reporters detail is a sister who exhibited high idea density and remained active and cognitively rich throughout her life but whose brain was found at death to be full of the

¹⁰⁰ Lorna Benson, “U of M Resumes Nuns’ Alzheimer’s study.”

¹⁰¹ Michael Lemonick and Alice Park, “The Nun Study,” *TIME*, May 14, 2001.

¹⁰² *Ibid.*

¹⁰³ *Ibid.*

plaques and tangles characteristic of Alzheimer's disease.¹⁰⁴ The "Nun Study" continues to make scientific progress as it studies the dynamic group of elderly nuns. The *TIME* article is comprehensive in its coverage of the study and its progress over the years; however, it remains largely informational and devoid of firsthand accounts from the sisters and their caregivers at the convent.

Books

Numerous books have been written on the topic of Alzheimer's, with the majority falling under the category of self-help and guidebooks for Alzheimer's patients and caregivers. These books include *Keep Your Brain Young*, *The Anti-Alzheimer's Prescription*, *Learning to Speak Alzheimer's*, *The Alzheimer's Action Plan*, *Alzheimer's: The Complete Guide and Sourcebook*, and various other guides that shed light and map out the stages of the disease. Most of these books offer medical and health advice, tips for coping and seeking outside help and resources, and information about financial issues and outside care. The number of self-help and guidebooks—especially when compared to the number of books focused on in-depth patient and caregiver narratives—may suggest that many caregivers are undergoing the caregiving process on their own and relying on these guides to learn how to cope and what to expect. Many of these books and others provide concrete information about the disease and caregiving, and relay family anecdotes about providing care.

Other books about Alzheimer's include a handful of caregiver and patient-centered stories. One such book details CBS News reporter Barry Petersen's account of coping with

¹⁰⁴ Ibid.

his wife's disease.¹⁰⁵ His short, autobiographical novel, titled *Jan's Story*, recounts his attempt to understand and care for a wife with younger-onset Alzheimer's. As this form of Alzheimer's disease is rare, few accounts of it can be found in Alzheimer's literature.

Learning to Speak Alzheimer's takes a narrative nonfiction approach similar to *Jan's Story*.¹⁰⁶ The author details her Alzheimer's-ridden husband's decline after suffering a massive stroke. The book unfolds with her efforts to take on what she calls a "habilitation" approach to her husband's care, focused on enhancing his quality of life and constantly trying to see the world from his perspective. The author offers tips and advice for caregivers in the context of what she found to be helpful during her experience with the disease. She provides a personal account of the emotions that one Alzheimer's caregiver goes through.

The Alzheimer's Solution: How Today's Care Is Failing Millions and How We Can Do Better is a co-authorship by Dr. Kenneth S. Kosik, a neuroscience research professor at the University of California Santa Barbara, and Ellen Clegg, a former science and technology editor for *The Boston Globe* and current science communications specialist at the Broad Institute of MIT and Harvard.¹⁰⁷ This book takes a unique approach by proposing the formation of community centers devoted to Alzheimer's care across the U.S. The authors believe that patients should remain in close contact with their family members for as long as possible instead of becoming isolated from them, which can happen when patients are moved to professional care or residential facilities. The purpose of the family-oriented centers would

¹⁰⁵ Barry Peterson, *Jan's Story* (Lake Forest, CA: Behler Publications, 2010).

¹⁰⁶ Joanne Koenig Coste, *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease* (New York: First Mariner Books, 2004).

¹⁰⁷ Kenneth Kosik and Ellen Clegg, *The Alzheimer's Solution: How Today's Care Is Failing Millions and How We Can Do Better* (New York: Prometheus Books, 2010). *Disclaimer: I contributed research and reporting to this book, which I mention in the introduction section of this project.*

be to provide expertise and reliable information for patients and caregivers and ease the suffering of the family as a whole. The authors argue that the current U.S. health care system is not serving the people affected by Alzheimer's and other cognitive disorders as well as it should be.

Each of these categories of Alzheimer's books has its own insight to bring to discussions of the disease; however, I believe the personal narratives of caregivers offer the most authentic and helpful picture of caring for someone living with Alzheimer's. These types of stories have the potential to make a meaningful connection with caregivers as well as provide comfort and camaraderie in a way that guides and sourcebooks alone often can't.

Documentaries and motion pictures

A number of films and television shows have featured people struggling with Alzheimer's disease. A handful of documentary films and motion pictures have delved deeply into the nuances and complexities of the disease by exploring it from different angles and through the eyes of the various people affected. These films primarily follow the storyline of one or two families—fictional or real—affected by the disease. Though many issues are discussed and portrayed in these films, two overriding themes about Alzheimer's stand out: the pressures of caregiving and the devastation of loss—loss of memory, control, independence, recognition and patients' former selves. The films rely on the visual storytelling format to appeal to viewers' emotions and establish a sense of urgency and drama. Video puts us in the moment, allowing us to see and hear people's stories directly and relate to them.¹⁰⁸

¹⁰⁸ Mindy McAdams, "Teaching Online Journalism: Cheat Sheet for Multimedia Story Decisions," accessed October 12, 2010, <http://mindymcadams.com/tojou/2008/cheat-sheet-for-multimedia-story-decisions/>.

In *The Forgetting*, a 2003 documentary based on journalist David Shenk's book of the same name, a husband caring for his Alzheimer's-ridden wife says that he feels like he is on a constant treadmill that doesn't stop.¹⁰⁹ Members of another family in the film discuss how long and drawn-out their mother's disease has been since she was diagnosed in 1990 and how helpless they feel in the face of it. One part of *The Alzheimer's Project*, a four-part documentary series by HBO Documentary Films and the National Institute on Aging, tells five families' stories, all of which have their own highs and lows.¹¹⁰ One patient facing the earliest stages of dementia talks to his family around the dinner table about how embarrassing it is to be losing his mind. His wife later talks to the videographer about her struggle to be patient and remind herself of what her husband is facing.

Another documentary film, *Quick Brown Fox*, details a daughter who goes to great lengths to understand her mother's disease and provide care.¹¹¹ She volunteers at an Alzheimer's research center as a test subject and interviews many researchers and doctors in hopes of making sense of the situation that has befallen her family. In *Away from Her*, a feature film based on author Alice Munro's short fiction story "The Bear Came Over the Mountain," Grant copes with wife Fiona's insistence on admitting herself to a nursing home in the early stages of her disease.¹¹² Before making this decision and moving, Fiona compensates for her memory loss by covering their home in yellow sticky notes. She jokes

¹⁰⁹ Arledge, *The Forgetting: A Portrait of Alzheimer's*.

¹¹⁰ John Hoffman, *The Alzheimer's Project*, DVD. Directed by John Hoffman (Los Angeles, CA: HBO Documentary Films, 2009).

¹¹¹ Ann Hedreen, *Quick Brown Fox: An Alzheimer's Story*, DVD. Directed by Ann Hedreen and Rustin Thompson (Seattle, WA: Ronin Films/White Noise Productions, 2004).

¹¹² Daniel Iron, Simone Urdl and Jennifer Weiss, *Away from Her*, DVD. Directed by Sarah Polley (Santa Monica, CA: Lionsgate, 2006).

about not being able to find her way home. Once Fiona has moved, Grant is plagued by loneliness. He struggles to make peace with his increasingly solitary life. None of these caregiving stories, real or imagined, is exactly the same, and yet they are similar in their emphases on grief and difficulty for the caregiver.

Along the theme of loss, another family profile in *The Forgetting* shows a woman in the late stages of younger-onset Alzheimer's lose control of her emotions and alternate between being playful and physically rough with her adult siblings.¹¹³ At times it seems she realizes who they are; at other times, it seems she does not. Another profile in the documentary depicts a woman who doesn't realize that she is related to her 7-year-old grandson. They have the following exchange when he asks her to push him on a swing in the park, and she refuses:

"I don't like him," the woman says to her husband. It's clear in the film that she is not joking or play-acting with the child.

"I don't like her either," the boy replies.¹¹⁴

One part of *The Alzheimer's Project* profiles five children whose grandparents have the disease. Two grandchildren ask their grandfather what it's like to have the disease. To the camera they explain how they feel when they have to introduce themselves to him. Liam, 8, says:

"Once he really forgets us, I think we'll be really, really sad. But for now, we're worried about him, but we're not too sad."¹¹⁵

¹¹³ Arledge, *The Forgetting: A Portrait of Alzheimer's*.

¹¹⁴ Ibid.

¹¹⁵ Ibid.

An Alzheimer's patient in *Quick Brown Fox* laments to her daughter about having lost her independence.¹¹⁶ Another Alzheimer's patient in the documentary speaks into a mirror to her reflection, referring to the image as her best friend. It seems that Fiona doesn't recognize Grant as her husband in *Away from Her*.¹¹⁷ When he visits his wife at her nursing home, Grant watches as her affection is directed toward one of the other resident patients, a man who doesn't confuse her, she tells him during a moment of lucidity. This kind of situation is fairly common to Alzheimer's caregiving. As devastating as it may be for a caregiver to see his or her loved one begin to think of a fellow resident as his or her spouse, the act is not malicious. Rather, it seems to be a common result of the personality, memory and behavior changes that Alzheimer's patients face. However, knowing this does not make facing such a situation any easier for caregivers, who are already experiencing the loss of their loved one in a variety of ways.

In another enlightening moment in *The Forgetting*, the younger-onset Alzheimer's patient talks about the loss of her thoughts, what makes her who she is as a person. She begins by saying that many people come home from work and have thoughts constantly racing through their minds even as they try to unwind. Not her.

“I can go and sit and not have a thought in my head,” she says.¹¹⁸

Though parts of the films provide helpful information about the history of Alzheimer's disease, research and drug development—specifically, *The Forgetting*, *Quick Brown Fox* and *The Alzheimer's Project*—the focus of the films is the patients and

¹¹⁶ Hedreen, *Quick Brown Fox*.

¹¹⁷ Iron, *Away from Her*.

¹¹⁸ Arledge, *The Forgetting: A Portrait of Alzheimer's*.

caregivers themselves. The films paint a diverse portrait of the state of Alzheimer's caregiving in the U.S., a portrait of devastated and devoted caregivers and of the fading loved ones for whom they are struggling to provide care. In *The Forgetting*, younger-onset Alzheimer's patient Fran Powers sheds light on her disease. The documentary shows news footage of Powers giving interviews about the disease shortly after being diagnosed at age 40; she wanted to spread awareness about Alzheimer's while her memory and cognition were still intact.¹¹⁹ In the footage, she talks openly about the mental deterioration she knows she will experience because of the disease. Powers attempted to shatter the taboo of having Alzheimer's by explaining it from within, while she could.

Film is an effective medium through which to tell stories like Powers'. In these types of personal accounts, we see and hear directly from the patients and caregivers affected by the disease. We are transported with them into their homes, onto their sofas and a bit into their thoughts. We are seated at their kitchen tables where we can witness for ourselves a daughter explaining to her Alzheimer's-ridden mother what they will be doing that day, even though she has just told her a few minutes before. We see the urgency of the challenges of Alzheimer's caregiving, and we can relate to the patients and caregivers because they are accessible and similar to us. The films tug at our hearts and emotions, relying on the elements of drama, presence in the scene, motion and experience to make an impact.¹²⁰ Due to the power of these visual story elements, it makes sense that in-depth, intimate narratives of Alzheimer's caregivers and patients are more often seen in this storytelling format than in print.

¹¹⁹ Ibid.

¹²⁰ McAdams, "Teaching Online Journalism."

Scholarly research

More than 15 Alzheimer's drugs are in various phases of testing for treatment trials. Unlike the five current FDA-approved drugs—which modify Alzheimer's symptoms but do not prevent, cure or slow the disease—the drugs in testing aim to change the disease itself by targeting the specific brain changes that scientists now believe Alzheimer's causes. What is known about Alzheimer's from scientific inquiry and research studies is that Alzheimer's disease is not part of the natural process of aging, that it involves the failure of brain cells over time, and that the greatest risk factor is age.¹²¹

Scientists are still trying to determine what causes brain cells to fail in the first place. Some of the research being done to investigate this event involves brain structure itself. A recent article in *Neuropsychiatric Disease Treatment* found that amyloid antibodies that reduce the brain's amyloid B protein (AB) may be able to reverse abnormality in brain synapses.¹²² The authors suggest this technique could at some point rescue or reverse the cognitive dysfunction seen in Alzheimer's patients. Other studies attempt to monitor brain volume change and anatomy.¹²³ While many studies remain out of public sight, scientific research is often where news stories come from, especially if the research relates to an advance or setback of an Alzheimer's drug prospect or a new way of diagnosing the disease.

A current focus of research concerns biomarkers, which are biological molecules found in blood or tissues that are often signs of disease. Since 2009, a major effort by

¹²¹ "Treatment Horizon." Alzheimer's Association, accessed September 21, 2010, http://www.alz.org/research/science/alzheimers_treatment_horizon.asp.

¹²² W. Xia, "Brain Amyloid β Protein and Memory Disruption in Alzheimer's disease," *Neuropsychiatric Disease Treatment* 6 (2010): 605-611.

¹²³ N. Schuff, "Nonlinear Time Course of Brain Volume Loss in Cognitively Normal and Impaired Elders," *Neurobiological Aging* (2010).

scientists to standardize biomarkers to aid in earlier disease detection has been undertaken.¹²⁴ Major media outlets, such as *The New York Times* and *Reuters*, have reported research about biomarkers because of the potential breakthrough of using them to determine if someone is at risk for Alzheimer's before symptoms appear.

Despite the growing amount of literature focused on Alzheimer's disease in mass media, little attention has been paid to caregivers and the psychological and emotional challenges they face while caregiving. The purpose of this professional thesis project is to produce accurate, in-depth narratives of two caregivers' lives that other caregivers going through similar struggles will be able to relate to and learn from. I hope to give caregivers further tools they can use in their own lives and show them what to expect at different stages of Alzheimer's disease. Though I am writing for a general audience of readers, this project is aimed at Alzheimer's and other dementia caregivers, for whom I hope the project will provide help. A secondary audience would be anyone age 60 or older or those who have aging family members. I aim to paint an intimate picture of caregivers and their complex struggles, while highlighting the importance of social support.

Research Questions

This project, composed of two narratives about caregiving for Alzheimer's patients from the perspectives of caregivers, seeks to answer the following research questions:

- 1) How do some caregivers cope with the emotional and psychological challenges of caring for a loved one with Alzheimer's?
- 2) What is it like to grieve for a loved one who is still living?

¹²⁴ "Treatment Horizon." Alzheimer's Association.

- 3) What does loss mean for patients, caregivers and their families? What kinds of losses throughout disease progression are hardest for some caregivers?

Methods

Purpose of the project

The stories examine and explore multiple aspects of Alzheimer's caregiving through two caregivers' perspectives. The complexities and subtleties of caregiving are illustrated through the specific daily challenges these two caregivers face. This project tells the stories of two wives caring for husbands who are in different stages of disease progression. These different stages undoubtedly affect the experiences and challenges the caregivers encounter. A particular focus of this project is the emotional and psychological aspect of caregiving. I sought to learn how these two caregivers find the mental and emotional resolve to care for a person who is changing or no longer resembles their former loved one as well as how they find respite from continuous care duties. I aimed to illustrate what is a constant and often conflicted struggle for caregivers.

Project format

The caregivers' stories are presented as two separate chapters (Chapters II and III) in this thesis project. Both narrative chapters include descriptive scenes and moments of dialogue between caregivers and patients that I have observed while spending time with them. The narrative chapters also include expository sections detailing specifics about Alzheimer's disease, diagnosis, research and other information that is vital to the story and important for caregivers to know. I have loosely structured both stories along the

chronological timeline of the different stages of Alzheimer's, beginning with narrative scenes and exposition about what to expect at the earliest stages, then during diagnosis and the middle stages of the disease, and so on. The stories are meant to be two stand-alone pieces, with the caregivers' intimate narratives and Alzheimer's exposition intertwined. I hope that natural breaks in both stories will be helpful in getting portions of the stories published.

The fourth chapter includes resources in the Triangle to assist caregivers and their families in finding the support groups to help on their respective journeys.

The final chapter of the project, Chapter V, is a first-person reflection about what I have learned during the two years I've been writing and reporting on Alzheimer's, and specifically, Alzheimer's caregiving.

Writing style

The writing style of this project is narrative nonfiction. I believe that narrative nonfiction was the best approach for telling this story because the project sought to present an in-depth and intimate view of caregiving for Alzheimer's patients. Walt Harrington explains the goal of "intimate journalism" as describing and evoking "how people live and what they value."¹²⁵ Using as a model Harrington's "The Reverend Comes Home"—a nonfiction story about an aging, ailing reverend being cared for by his adult daughters—I aimed to show how caregivers live and function with the added responsibilities and challenges of caregiving.¹²⁶ Perhaps more importantly, I hoped to show what caregivers

¹²⁵ Walt Harrington, "A Writer's Essay: Seeking the Extraordinary in the Ordinary," *Nieman Storyboard*, March 28, 1997, accessed September 21, 2010, <http://niemanstoryboard.us/1997/03/28/a-writers-essay-seeking-the-extraordinary-in-the-ordinary-2/>.

¹²⁶ Walt Harrington, *At the Heart of It: Ordinary People, Extraordinary Lives* (Columbia, Missouri: University of Missouri Press, 1996).

value and prioritize and how these values may shift or transform throughout their caregiving experiences. I also sought to shed light on why caregivers make the decisions they do, what motivates them and how they cope. I believed and continue to believe narrative nonfiction is the best way of achieving this goal.

The caregivers

Throughout the course of this project, I followed two Alzheimer's caregivers who were willing to tell their stories. Jeannette Barbour is in her late 70s and is the primary caregiver for her husband, Chuck Barbour, who turned 80 in 2011. He was diagnosed with Alzheimer's 10 years ago and lives in an assisted living facility in Durham, N.C. Joan and Bill McCormick are 65. Bill was diagnosed with younger-onset Alzheimer's roughly 10 years ago. The couple lives together at their home in Hillsborough, N.C.

I first had the opportunity to speak with Jeannette over the phone for an in-depth interview in spring 2010 and met her at her home for the first time during fall 2010. Lisa Gwyther, a longtime social worker and the director of the Duke Family Support Program, put me in touch with Jeannette when I expressed interest in speaking with Alzheimer's caregivers. I first met the McCormicks in December 2010. I was introduced to the couple by Brandi McCullough, a clinical research coordinator at UNC's Memory Disorders Clinic.

Reporting techniques

I have attended many caregiver support group meetings held by the Duke Family Support Program in Durham, N.C., and Alzheimer's North Carolina in Raleigh, N.C. I also attended the 25th Annual Joseph & Kathleen Bryan Alzheimer's Disease Research Center

Conference in February, where I spoke with caregivers, researchers and other Alzheimer's professionals. The bulk of my research and reporting came from extended periods of time spent with Jeannette and Joan and Bill, both in structured, in-depth interviews and in casual activities inside and outside of their homes. I also had the opportunity to visit Jeannette's husband, Chuck, with her at the assisted living facility where he lives.

I have interviewed Alzheimer's doctors and specialists at UNC and Duke medical centers as I aimed to show the medical side of Alzheimer's as it relates to the two caregivers' personal stories and experiences. It was also important for me to be able to incorporate the research side of Alzheimer's into the narratives.

I understood and felt prepared for the challenges of writing about a topic as sensitive as Alzheimer's disease. Prior to this project, I had written two stories about Alzheimer's caregiving, both published in a North Carolina daily newspaper, and spent a great deal of time working on a video story with one Alzheimer's caregiver in spring 2010. I also interviewed several Alzheimer's caregivers as a book researcher during winter 2008. I believe these experiences helped me treat the project with the empathy and compassion needed for such stories. By reminding myself that my primary obligation was to the reader and by being completely open with my sources about what I sought to do, I hope that I was able to portray an accurate and delicate picture of what Alzheimer's caregiving looks like for some caregivers. By showing caregivers in different settings and not getting in the way of letting them tell their stories, I sincerely hope I have presented the caregivers as the tireless and multidimensional people they are.

Limitations

Though I have spent many hours with Jeannette Barbour and the McCormicks, one limitation is time itself. I had roughly 10 weeks to report and write the two stories, which I realize is a luxury and nearly unheard of in the world of professional journalism. However, I understand these 10 weeks represent a relatively small portion of the caregivers' and patients' lives and experiences with Alzheimer's. Thus, I have relied on in-depth interviewing—and reconstruction techniques for the narrative scenes for which I was not present—to provide context for the caregivers' stories and attempt to show caregivers in as many settings as possible to present an accurate picture of their lives.

Additionally, the caregivers and patients who are part of this project come from fairly similar financial and cultural backgrounds as they are white, middle-class families, living in Durham and Hillsborough, N.C. Though one of the caregivers expressed concern about the financial aspect of Alzheimer's caregiving, I imagine financial difficulties are even more pervasive for families with fewer means, as the costs of caring for a loved one with Alzheimer's can be staggering. Though these caregivers may not have the added, urgent stresses of trying to figure out how to subsidize their loved ones' care, their concerns are undeniably present. It is my hope that this project will connect Alzheimer's caregivers and provide them with some form of support. I hope that journalists will increasingly shed light on the unique stories of love, loss and hope that Alzheimer's caregivers have to share.

CHAPTER II: THE McCORMICKS: LIFE'S NEW REALITY

October 2001. Highway 86, Hillsborough, N.C.

Joan McCormick remembers the day when Bill, 55, first told her something was wrong with his memory.

Bill is driving his '95 Buick station wagon on Old N.C. 86 to his home in Hillsborough. It's a clear, mild autumn afternoon. He is paying close attention to the road. He knows exactly where he is and where he is going.

And then he doesn't. In a matter of seconds, Bill can't figure out if he is driving north or south, toward home or away from it.

An elementary school principal at the time, Bill reorients himself after a few minutes. But he doesn't mention the incident to his wife until two or three days later.

"Honey, do you ever get confused about which way is north and south on Highway 86?" he asks.

"Well, no, I don't suppose that I do," Joan says.

"Oh."

The incident worries Joan. She monitors Bill, on the lookout for signs of stroke, which she thinks may have caused his disorientation. Bill has high cholesterol, which can lead to blocked arteries and decreased blood flow, two precursors to stroke.

Or maybe he's feeling overstressed and preoccupied with work, Joan thinks. She makes a mental note that Bill needs to go for a physical exam.

The idea that Bill may have Alzheimer's disease never crosses her mind.

Alzheimer's disease explained

Alzheimer's is a progressive and fatal neurological disease, for which there is no cure. It is the most common form of dementia, a general term for memory loss and cognitive impairment. Different epidemiological studies have found that Alzheimer's affects anywhere from 3 million to 5.4 million people in the U.S.

Alzheimer's destroys brain cells, causing memory loss and problems with thinking and behavior that are severe enough to affect daily life. It gets worse over time until it eventually kills you. It is often called "the long goodbye" because it involves an accumulation of losses over time.

Gayle Ginsberg, a social worker and support group leader in Wilmington, N.C., said she believes the hardest thing for caregivers is the realization that their loved one is a different person from who he or she once was.

"You lose the person you're caring for before they actually pass away," Ginsberg said. "So you're grieving all the time."

About 15 million people in the U.S. provide unpaid care for someone with Alzheimer's or another type of dementia, according to the Alzheimer's Association's 2011 *Facts and Figures* report. Roughly 415,500 of these caregivers live in North Carolina. The Alzheimer's Association – the leading U.S. voluntary health organization in Alzheimer's

care, support and research – says these calculations are based on 2009 data from the Centers for Disease Control and National Alliance for Caregiving.

Alzheimer’s caregivers are spouses, children, siblings, friends and sometimes parents. Throughout disease progression, which is often slow, these people lose the pieces of the loved one they once knew.

“That’s part of grief reaction,” said Lisa Gwyther, director of the Duke Aging Center’s Family Support Program. “Those losses are prolonged in a degenerative process, and people grieve each one of them separately.”

An accumulation of mental notes

The McCormicks are soft-spoken, gentle people, who are nearly inseparable. Joan’s gray-white hair, worn in a short bob, sweeps across her forehead to one side. Both wear oval-shaped glasses.

A mutual friend introduced them when Joan was in nursing school at UNC-Chapel Hill. Bill was an undergraduate.

“I was telling people that I met the girl that I was going to marry,” said Bill, his heavy lidded eyes directed at Joan.

Joan said she didn’t know that at the time. It took some convincing.

She smiled. “I guess he kept impressing me.”

They married in 1969. Joan went on to work in public health nursing, and Bill became a middle and high school science teacher before going to graduate school at UNC and becoming a school principal in Hillsborough. The couple had two children who now live in Southport, N.C., and Savannah, Ga., and are raising families of their own.

“It’s been fun ever since,” Bill said. A smile signals he’s teasing, but he means it.

It’s hard to tell Bill, 65, has Alzheimer’s. He and Joan exercise every day at the Duke Center for Living or on their home treadmill. They attend support group meetings several times each month. They go out to eat and visit with family and friends in and around North Carolina.

Unlike people in later stages of the disease, Bill always knows who Joan is. He has never forgotten his kids’ names. When he is frustrated, he doesn’t refuse to eat or revert to childlike behavior, two behaviors characteristic of more advanced Alzheimer’s.

Their home in Hillsborough is set back from two main roads in a wooded area. Bill enjoys watching the birds flit around his yard and near a feeder, which Joan outfitted with a special cover to keep squirrels and deer from getting at the seeds.

They maintain as normal a routine as they can.

Beginning in 2000, little signs, like Bill’s disorientation with direction, would occur every three to four months.

“His last month or two at work, he told me about a time of going into his co-worker’s office by mistake,” Joan said. “He thought it was his office. I think he was puzzled about what was happening. And so we just took little mental notes.”

An accumulation of those mental notes eventually brought Bill and Joan to their family doctor in 2003, at Joan’s insistence.

Initially, their doctor dismissed Bill’s cognitive problems as depression. He referred Bill to a psychiatrist, but Bill didn’t make the appointment. Neither Bill nor Joan thought he was depressed. Plus, the psychiatrist was the parent of one of the students at the school where Bill worked, so he didn’t feel comfortable going.

Soon after, Bill went back to the doctor for a follow-up appointment for high cholesterol and blood pressure. Joan encouraged him to bring up his directional problems again.

Bill did, and this time his doctor referred him to a general neurologist. At the time, Bill and Joan didn't know about specialty clinics like the UNC Memory Disorders Program. They ended up seeing Dr. Michael Soo, a neurologist in Durham, who saw Bill's problem for what it was, Joan said.

Dr. Soo said he thought Bill had a neurodegenerative disease in the family of Alzheimer's. What Bill had was mild cognitive impairment (MCI), but Soo didn't call it that at the time, Joan said.

“What he didn't have for us was what to do about it,” said Joan, with a soft, short laugh. “You know, when you tell someone you may have Alzheimer's, that's a real bombshell, and then you don't know if it's real or if it's really going to progress. We didn't get an immediate, definitive diagnosis or definitive steps about what to do.”

After cognitive testing, lab work and an MRI, Dr. Soo offered Bill a medication called Aricept, one of five FDA-approved drugs that attempt to modify Alzheimer's symptoms. Bill began taking it, unsure if it would help him. For many people, these medications are not effective.

When called Bill's caregiver, Joan is quick to correct that they are care partners, equal agents in Bill's care.

Diagnosing Alzheimer's

Alzheimer's diagnosis typically involves a succession of doctors and a combination

of screening tests, exams, brain scans, questionnaires and reviews of medical history. Physicians specialize in the disease, but a certain Alzheimer's diagnosis is only possible after death through brain autopsy.

Further, some patients are seen by physicians, neurologists, psychologists and other medical professionals before receiving a probable diagnosis. The process can take one or two doctor's visits or several years, depending on the patient and his or her stage of the disease.

"It's certainly not a rapidly progressive disorder," said Dr. James Burke, a neurologist at Duke. He is also the associate director of the Bryan Alzheimer's Disease Research Center, which is one of 30 national Alzheimer's research centers funded by the National Institute on Aging.

Burke looks for two things when it comes to Alzheimer's diagnosis: that a patient's daily functioning has become impaired and that his or her cognitive testing also shows impairment. Patients who exhibit mild impairment in cognitive tests but have no changes in daily functioning likely have MCI – a degree of cognitive impairment that is greater than would be expected from aging alone.

"MCI is a very heterogeneous category," Burke said. "At the end of three years, 50 percent will convert to dementia and 50 percent won't. It has nothing to do with what people are doing. We watch for changes in their clinical situation."

No single examination, test or procedure can detect Alzheimer's. Doctors must rule out other potential causes of patients' symptoms, such as stroke, vitamin B12 deficiency or thyroid disease.

"Alzheimer's historically has been a diagnosis of exclusion," said Dr. Daniel Kaufer,

a neurologist and director of UNC's Memory Disorders Program. "We want to make sure there isn't an alternate explanation that could account for the cognitive symptoms."

As part of the process, physicians often ask patients to spell words backwards and forwards, identify the names of common objects and complete puzzles. They also use brain imaging, such as MRI or CT scans.

The exact cause of Alzheimer's is not known. Researchers are designing tests to measure the two hallmarks of Alzheimer's disease, plaques and tangles in the brain. Many people develop these protein-based structures as they age, but Alzheimer's patients develop many more. While the number of plaques a person has does not correlate with his or her degree of dementia, there is a correlation between the amount of tangles and the degree of the disease.

Some researchers believe plaques and tangles damage nerve cells and disrupt communication in the pathways of Alzheimer's patients' brains. But no one knows how and why these structures form. Researchers don't know if they cause the disease or are merely symptoms of it.

What they do know is that Alzheimer's is not a part of the natural aging process, but age is its greatest risk factor.

Blood and spinal-fluid tests for biomarkers – molecules found in blood or tissues that can be used to measure disease progress – might someday improve the accuracy of an Alzheimer's diagnosis. However, these tests are research tools, and not yet standard clinical practice.

The hope is that biomarkers will eventually help determine if someone is at risk for Alzheimer's before symptoms appear.

October 2007. Bill's home office, Hillsborough, N.C.

Joan and Bill sit down together in front of their home computer after dinner. They are in Bill's office, a small square room with paintings of dogs hanging on the walls and keepsakes displayed atop a desk and dresser.

They are going to write a letter.

About a year ago, Bill became involved with the Alzheimer's Disease Neuroimaging Initiative. The initiative, developed by the National Institutes for Health, included a five-year national study that aimed to identify biomarkers of Alzheimer's disease.

Along with 800 other adults age 55 and older, Bill became part of the study. The participants were divided into three groups: people with Alzheimer's, people with mild cognitive impairment (MCI) and people without memory problems.

The people in the Alzheimer's group tested for cognitive problems and reported impaired daily functioning, while those in the MCI group showed cognitive problems but no impairment to function.

Bill initially placed in the MCI group.

Every six months for two years he went to Duke for cognitive testing and brain scans as part of the study. He also had two spinal taps.

Close friends and family knew about Bill's health. Joan and Bill told them about his neurodegenerative disease diagnosis back in 2003, after visiting with Dr. Soo.

But as time went on, the McCormicks realized Bill's condition was likely headed toward full-blown Alzheimer's. Brain scans showed hypometabolism, the brain's decreased use of glucose for fuel, in Bill's brain that was consistent with Alzheimer's.

So sitting in front of their computer, Joan and Bill begin to write a letter to tell neighbors and friends they don't see regularly about Bill's condition.

Bill types the first line.

Dear friends, I want to share information with you concerning my health.

Because Bill's visual problems have worsened in the last few years, using a computer is hard for him today. Joan decides to take over the typing. Bill sits next to her, explaining what he wants the letter to say.

Perhaps you have noticed I am a little different from my old self. I have a cognitive disability categorized as "Mild Cognitive Impairment" or "MCI." This is a condition that statistically often progresses to Alzheimer's disease.

It took time for Joan to convince Bill that writing the letter was a good idea. She had to work on him. Bill eventually realized that he would need neighbors' assistance if Joan ever needed help that he couldn't provide. They needed to know about his disease.

Bill talks, and Joan types.

My greatest difficulties are with visual-spatial tasks. My navigational compass is disabled. I have some difficulties with memory and processing multiple tasks or sequences. I experience these difficulties on a fluctuating continuum and therefore have better and worse times.

Bill asks Joan to mention the medical care he receives at Duke and his gratitude for the abilities he still has. He wants the letter to be helpful and honest. He wants friends and neighbors to know they can ask questions.

I share this information about me to increase your understanding of me and perhaps make our interaction more comfortable. I would be grateful for your assistance if Joan is

ever incapacitated. Your greatest gift would be to interact with me normally now that you understand my “new normal.”

Sincerely,

Bill

Over the next few weeks, Joan and Bill will hand-deliver the letter to neighbors. Bill will visit the school where he was principal and give the letter to the colleagues he feels closest to. Joan will slip the letter into Christmas cards to extended family, old college friends and others.

Joan will find the act of sending the letter to be freeing. She will feel relief that more people know about Bill’s condition.

Months later, Bill will switch from the study’s MCI group to the Alzheimer’s group. Life with Alzheimer’s will become his and Joan’s new normal.

Baby boomers’ disease

Researchers and medical professionals call Alzheimer’s the defining disease of the baby boom generation, the oldest of whom turn 65 this year.

Increasingly, more baby boomers are caring for parents, siblings or spouses with the disease, providing a glimpse of what could be their own future.

Most of the 3 million to 5.4 million people in the U.S. with Alzheimer’s are 65 or older; however, the disease affects about 200,000 younger people as well. Early- or younger-onset Alzheimer’s refers to people like Bill who are younger than 65 when diagnosed.

Bill still has what doctors call “insight” about his disease. He belongs to a support group of the same name, an effort between the Orange County Department on Aging and

UNC's Memory Disorders Program. The group is for people with different types of dementia who are still aware of their disease and want to talk about it.

Though Bill and Joan belong to a couples' support group, the insight group is for patients only. Its leaders evaluate patients once a year to make sure they remain a good fit. This year's group includes nine patients.

"The idea is that since we all know these diseases progress over time, and individuals eventually lose insight, we want to ensure that members are still appropriate for the group as time goes by," said Brandi McCullough, a clinical research coordinator for the Memory Disorders Program and a co-leader of the group.

Bill's yearly evaluation took place late one Friday morning at the end of January 2011. Two weeks later, he found out that he was still eligible to be part of the group.

This was good news for Joan and Bill, who together belong to a total of four support groups.

February 2011. Alzheimer's North Carolina office, Raleigh, N.C.

Joan and Bill and six other couples sit around tables arranged in a large square at the Alzheimer's North Carolina office in Raleigh.

It's a few minutes after 1 p.m. Most of those in attendance have already gone over to a table in the corner of the room and come back with a piece of pound cake, a box of raisins, water or coffee.

The meeting starts off as it usually does. Dee Dee Harris, one of two group leaders, welcomes everyone. Dee Dee is the Family Services Director for Alzheimer's N.C., a non-

profit that provides support and education about Alzheimer's to families in the Raleigh community.

Dee Dee turns to the couple to her left. She asks the husband, who has Alzheimer's, how he's been. Are there any recent problems he'd like to share?

Dressed in a crisp button-down shirt, the gentleman talks about his wife's recent acquisition of two more cats. The couple banters back and forth. Dee Dee asks questions, and some of the other couples share their own pet stories.

The seven couples vary in age and disease stage. Five of the seven caregivers are women. Joan and Bill are one of the younger couples; the oldest is in their 80s. One couple is African-American, and the rest are white.

Sometimes they laugh at the silly things that Alzheimer's makes them do. And sometimes they laugh at things that have nothing to do with Alzheimer's.

When it's Bill's turn to talk – about how he's been and what's on his mind – he starts slowly.

“I guess I've been pretty good,” says Bill, with Joan beside him. He tells the group that he's been listening to books on tape.

Visual and spatial problems have been Bill's worst symptoms throughout his experience with MCI and then Alzheimer's. He often trips while walking. At home, he sometimes enters his bedroom when he means to go into his office and vice versa.

More recently, these visual problems have jeopardized Bill's ability to read. He wears glasses, like most of the people in the room, but his glasses no longer help him read. This has been the most devastating aspect of Alzheimer's for him so far.

As recently as six months ago, Bill would steal away into his office for hours to read everything he could about U.S. history and English literature. One wall of the McCormick's living room is filled floor-to-ceiling with hardcovers and paperbacks, books he can no longer enjoy.

In the last six months, trying to read has become increasingly tiring for Bill. The visual and spatial problems from his disease make it difficult for him to "hold the words together in the right order," Joan says.

Joan made sure Bill could have a replacement for his favorite hobby. She contacted the North Carolina Library for the Blind and Physically Handicapped and found out about its books on tape loan program.

"We had to have our neurologist sign an application," Joan tells the group. "But it's very easy."

A few of the other spouses jot down notes. Then Dee Dee thanks Bill and Joan and says it's good to see them here.

The meeting keeps on this way. Several minutes later, it's Dot's turn to talk about how she's been. Her snow-white hair matches the color of her sweater. She looks at least 80 years old. Her husband, who is her primary caregiver, is sitting beside her.

"And how are you today, Dot?" Dee Dee asks.

"Oh, I'm just fine," she says.

Dot begins elaborately detailing the family reunion she and her husband went to since the last support group meeting. She tells everyone how wonderful it was to see her whole family and how much fun they had. Her eyes are bright, and her husband gazes at her as she

speaks. She periodically looks to him for confirmation. She says she feels like she is doing pretty well.

When Dot is done speaking, Dee Dee asks Dot's husband if there have been any changes.

"Well," he starts slowly, looking at his wife, "She hasn't been doing very well."

He pauses again. Then, as gently as possible, he says: "I'm not sure what she means about the family reunion because we didn't go to anything like that. We saw our son though."

The room is very quiet. If hearing about what's potentially to come upsets Joan or Bill, they do not let on.

Seeking support

Many caregivers and Alzheimer's professionals emphasize the importance of support groups throughout disease progression.

Social worker Gayle Ginsberg described the purpose of her Wilmington support groups as twofold: "To provide caregivers with the information and tools they need to carry out caregiving while allowing them to have sharing time with others going through a similar journey."

Many support groups are based on a similar mission.

Meetings often include time for open discussion, during which caregivers and patients can talk about their difficulties, frustrations and successes. Caregivers might share ideas for coping with the challenges of the disease or discuss informational resources, such as elder care lawyers, respite care options and helpful websites. Some group leaders invite guest speakers to talk about specific aspects of the disease or caregiving.

The Orange County Department on Aging hosts three caregiver support groups, which meet for an hour and a half each month, at the Seymour Center, Central Orange Senior Center and The Cedars of Chapel Hill at Meadowmont, a continuing care retirement community.

UNC's Memory Disorders Program, Duke's Family Support Program and Alzheimer's North Carolina offer support groups for patients, caregivers and couples as well, most of which are open to new members.

"You get ideas about how others have handled an issue," Joan said. "A lot of the members that I've met in the support groups are caring for someone who has more advanced dementia than Bill. They have a whole set of different problems and issues than we have, but I still find benefit in getting to know them. I can't help but think that this may help us down the line, help us see the things that are coming, so we can think about how to work with this.

"I guess it's an example of adapting to the new reality," Joan said. "It's a continual sort of rebalancing. You know, you adjust your life and do things that accommodate the disability at this level, and maybe there's another change, and so you figure out how to work this out and still participate and engage in life the best we can. And that sort of keeps us going."

January 2011. Joan and Bill's home, Hillsborough, N.C.

Sitting on his couch, Bill squints his eyes and pauses when asked about the challenges of living with Alzheimer's. He looks over to Joan in the armchair beside him.

"I don't know," Bill says. "I probably get more perturbed with Joan. But I have a

sense that I understand that because of my brain. I'm still aware that my brain is not like it used to be. So I can be more irritable with her than she is with me." He pauses.

"But when I say I'm more irritable, I'm not, I'm not really—," he adds.

"No, I think you are frustrated by what you can't do," Joan finishes. In many ways, Joan is not a typical caregiver, or care partner. She doesn't show anger or frustration. She is always soft-spoken, calm and composed.

"But it's not like—" Bill's voice switches to a clearly exaggerated, over-the-top, woe-is-me tone—"*I'm frustrated, and I don't know what to do!*"

His playful response reflects Bill's attitude toward the disease. This is not a pity party. You have to laugh despite the frustrations.

Joan explains that one of Bill's biggest frustrations was giving up the keys to his car. She says it was something she had to talk him into.

The issue first came up during a support group meeting. Members of the group were discussing the dangers that drivers with Alzheimer's could pose to others and the increased risk of lawsuits if an accident occurs.

"I asked Bill, 'Would you drive with our grandson in the car?' And Bill said, no, he didn't think that was a good idea," Joan says. "And I told him that I would take him wherever he wanted to go."

"With a smile," says Bill, his eyes squinting again, this time to accommodate a full grin.

Joan and Bill know that a sense of humor will not cure Alzheimer's. They cannot laugh Bill's disease away. But in the business of Alzheimer's care, comfort comes in different forms, and on some days, laughter can mean everything.

CHAPTER III: THE BARBOURS: THE TOLL ON CAREGIVERS

October 2009. Jeannette's home, Durham, N.C.

Jeannette Barbour stands at her bathroom mirror. She sweeps bright pink lipstick across her bottom lip and pats powder on her face.

She switches off the light and leaves her bathroom. She grabs her keys and purse and is on her way to visit her husband Chuck, 78, in the Alzheimer's unit of the assisted living facility where he lives. He moved there one week ago.

It's a clear day. Jeannette drives her red Honda down Roxboro Street. The drive from her house to Chuck's new home is about 10 minutes.

Once there, she parks in the open lot and lifts her purse off of the passenger seat. She gets out of her car and walks up the path to the red brick building with stately white columns.

Jeannette enters the building and says hello to the attendant sitting behind the front desk. She signs in and moves across the linoleum-floored foyer toward the door to the Alzheimer's unit.

She opens it, and the smell of slightly stale air envelops her. She makes her way down the hall, past residents' bedroom doors, to the living room, where she expects Chuck to be.

Eager to see him, Jeannette quickens her step, bag in hand.

She reaches the living room and sees the residents sitting around in plush armchairs. As soon as she spots her husband, Jeannette's heart drops deep down into the pit of her stomach.

She sees Chuck sitting, holding hands with the female resident beside him.

Jeannette forces a smile. Then she looks at a nearby aide, who is attending to things behind a desk.

"Well, I guess our 58-year-old honeymoon is over," she says.

Becoming a caregiver

Jeannette, 78, has been her husband's primary caregiver since he was diagnosed with Alzheimer's in 2001. She is an animated, petite woman whose voice sounds as if it's been dipped in sweet tea.

She describes Chuck as a self-made man and her childhood sweetheart. Both from Durham, they met at a church Halloween party, while bobbing for apples. Jeannette was 9 years old. Chuck, her elder by two years, was dressed as a pilot, and she was a gypsy.

"I was trying to get an apple," Jeannette said. "And he walked up and said, 'You want me to show you how to get one of those apples?'" and I said, 'Sure.' I guess I just assumed he was going to show me some trick. Well, he reached his hand down and picked up the apple and gave it to me.

"And that's kind of the way Chuck Barbour was," she said. "He loved to tease."

Chuck joined the Army at 17 and fought in the Korean War. When he came back, days before Jeannette's high school graduation, they got married, without telling anyone until after they did it. Jeannette was afraid her family would try to talk her out of it.

Chuck became a reporter and later managing editor for the *Durham Morning Herald*. Jeannette worked as a switchboard operator for a business and loan association. They went out dancing. Chuck took up golf. The Barbours started a family together in Durham, and in five years, they had four children, three daughters and a son.

This year marks Jeannette and Chuck's 60th wedding anniversary. Their life is not what Jeannette hoped it would be.

She lives alone in the tidy house she and Chuck shared. Two of her daughters and her sister and brother-in-law live nearby. Nowadays Jeannette flits from task to task, getting distracted easily, sometimes losing her train of thought or forgetting what she entered a room for.

One January 2011 morning, standing in her hallway, she pointed to a handsome man in a large family portrait hanging on the wall.

"Yep, that was my hubby," she said. Then corrected herself. "Well, that *is* my hubby."

For the past two years, Chuck has lived in the Alzheimer's unit of an assisted living facility in Durham. Jeannette visits him almost every day. He always recognizes her, but sometimes calls her by his mother or sister's names.

She said Chuck adjusted quickly to living in a new place, much more quickly than she did. As much as she wanted to be able to continue to care for Chuck at home, Jeannette could no longer manage his problems with incontinence or lift him if he fell. When Chuck first moved into the facility, Jeannette called his bedroom "our room," an effort to maintain some semblance of their normal life. She still calls it that.

At the beginning, Chuck walked around the facility, patting the other residents on the shoulder and asking them how they were. More recently, he has begun to have trouble walking. He plays with his food and needs help going to the bathroom.

The man Jeannette married was a conversationalist who loved to charm and joke. But when Chuck talks, he doesn't make much sense anymore.

She refers to Chuck's disease as his "memory problem." She doesn't use the word Alzheimer's when speaking to him because he doesn't know what it means.

Caring for loved ones

Alzheimer's is the most common form of dementia, a general term for cognitive impairment. Other forms of dementia include vascular dementia, dementia with Lewy bodies, frontotemporal dementia and Parkinson's disease.

Memory loss is typically the earliest and most pervasive symptom of Alzheimer's. As the disease progresses, patients often begin to have trouble communicating. Confusion with time and place can occur as well as personality and behavior changes.

Once diagnosed, Alzheimer's patients may live anywhere from eight to 20 additional years. There is no cure.

Between roughly 3 million and 5.4 million people in the U.S. are living with the disease. Differences in the criteria of prevalence studies account for the substantial range.

"The federal government is extremely interested in this difference," said Dr. James Burke, a neurologist and associate director of Duke's Bryan Alzheimer's Disease Research Center.

National disease prevalence plays a role in the amount of federal funding devoted to the disease as well as future Medicare costs.

Fifteen million people in the U.S. – like Jeannette Barbour – provide primary or secondary unpaid care for a loved one with Alzheimer’s or another type of dementia. Many of these caregivers want to keep their loved one at home for as long as possible. They often feel like they are the only ones who can care for the patient, or that they should be able to.

Take Joe Clark. Like many others, Joe had been an Alzheimer’s caregiver to his wife for several years before realizing his limits. His days were long and often difficult, but Joe wanted his wife to be able to stay in their home. After his visit to the emergency room for full-blown pneumonia and an extensive recovery period, Joe recognized that he needed more help.

“I felt like a failure there for a while because I knew people who had taken care of their spouses longer,” Joe said. “But the doctor said, ‘Everybody has their own limits, and you were having to look after her 24 hours a day. Even with help, you were still worried about her.’”

In working with Alzheimer’s families, veteran social worker Lisa Gwyther has found that guilt and grief are endemic among the most responsible and committed caregivers.

“People feel guilty about not recognizing the problem early enough, about what they feel is going back on promises that they couldn’t have predicted, about losing their patience and getting angry,” Gwyther said.

Additionally, some caregivers feel alone in their struggles with the disease. They may not realize there are resources, such as support groups and outside help, that can make an Alzheimer’s diagnosis more bearable and less lonesome.

January 2011. Grey Stone Baptist Church, Durham, N.C.

About 15 minutes into a support group meeting for Alzheimer's patients and caregivers, Jeannette quietly slips into the room to join the others.

She mouths "I'm sorry" to Lisa Gwyther, a co-leader of the group, as she settles into an open seat by the door. Gwyther, the director of Duke University's Family Support Program, holds the monthly meetings in a basement room of the Grey Stone Baptist Church in Durham.

Thinly cushioned chairs form a loose circle, around which eight caregivers, three patients, the co-leaders and a neurology intern sit. Colorful children's paintings with phrases like *I love Jesus* and *Jesus is my Savior* decorate the walls.

Before Jeannette arrived, Gwyther handed out the regular attendees' nametags and gave first-timers tags to write their names on. Though the meetings consist of a loyal core group of long-time members, there are often a few new faces each month.

"Are we the youngest ones here?" a new caregiver asked the group. His wife sat beside him, expressionless and silent.

"You might be," said Gwyther, cheerily.

Introductions were made; upcoming birthdays and special dates revealed. Then Gwyther explained the meeting agenda. Caregivers stay in this room with her and her intern. Their loved ones—the three Alzheimer's patients, though she didn't explain it this way—form their own small group with co-leader Edna Ballard in a room across the hall.

This structure gives patients time to meet and converse on their own with Ballard's gentle guidance. It also provides caregivers with an hour to speak freely about their frustrations with the disease and get support from others who have been there.

When Jeannette enters the room, the group is offering advice to the new caregiver. Smiling, Gwyther walks over to give Jeannette her nametag, one that has been part of Gwyther's collection for several years.

Jeannette listens as the caregiver, who seems overwhelmed and anxious, details his wife's new and strange behaviors. He says that during the day, while he is at work and his wife is in the care of his mother, she stands by the door for hours. The caregiver asks the group what he should do.

"If she's not trying to leave your mother's house, let her stand by the door," one caregiver says.

"She might find some comfort in that," says another.

A few minutes later, one group member asks if there are any activities the new caregiver's wife still enjoys.

"She loves to watch cooking shows," he says.

"You can get DVDs of those to play for her," someone offers.

"You had videos for Chuck, didn't you, Jeannette?" says Joe Clark, former caregiver and long-time group member, from across the room. Some caregivers, like Joe, continue attending the monthly meetings, even after their loved one has died.

"Yes, I would put on a video tape for Chuck," Jeannette says. "He really enjoyed that."

She used to play the video while she was getting ready in the morning, to keep Chuck occupied. The video was produced by the Namenda Company, which makes one of five FDA-approved, symptom-modifying drugs for Alzheimer's.

The meeting keeps on. The new caregiver asks questions and the other members provide answers the best they can. Answers they have learned themselves, from earlier stages of their loved one's disease.

At the end of the hour, the new caregiver's wife walks back into the room with Ballard and the two others. She is smiling and visibly excited and leans over to tell her husband something as soon as she sits down next to him.

Respite care

Gwyther sees support groups as a way for families affected by Alzheimer's and particularly caregivers to learn from one another, exchange resources and realize they're not alone.

"So many of these families have lost their friends because when a person's behavior is different, friends often don't know how to respond," Gwyther said. "So for many people, it's a way to develop a replacement social network for friends that have dropped off."

Caregivers' need for support typically increases throughout patients' disease progression. Though it's not always the case, many Alzheimer's patients eventually lose the ability to recognize caregivers and other family members and friends.

"One of the issues there for caregivers is the sense of losing the person and the relationship bit by bit," said Dr. Laura Clark, chief psychologist of the geriatric unit at Central Regional Hospital. "The person is still there. They still need love and attention, but they're not who they were before. There can be a lot of anticipatory grieving of little losses adding up slowly."

Roughly half of all women caregivers, who make up about 60 percent of total

Alzheimer's caregivers worldwide, described having high physical and emotional stress, according to the Shriver Report, a 2009 study by Maria Shriver and the Alzheimer's Association. Maria Shriver's father, Sargent Shriver, suffered from Alzheimer's before his death.

Thus, it's no surprise that many social workers and caregivers emphasize the importance of respite care, or breaks from caregiving.

At the New Hanover County Senior Center in Wilmington, N.C., social worker Gayle Ginsberg helps caregivers find respite through licensed adult day care centers and home health care providers.

"A trained caregiver can come in and relieve the caregiver for a few hours," Ginsberg said. "Some caregivers say they just want to go into their bedroom and close the door for a while and know that someone is watching their loved one."

Staff at the Orange County Department on Aging help caregivers find similar local services. The county has established the Caregiver Respite Choice Program through funding from the National Family Caregiver Support Program. The respite program provides up to \$1,000 for Orange County families to use toward respite care, depending on the program's available funds and the family's priority of need, which is assessed by a clinician from the Department on Aging.

Respite options include adult day care, certified nursing assistants and help from staffers at *A Helping Hand*, a Durham-based agency that provides in-home care. Financial assistance from the program can also go toward living facility and nursing home costs, which are increasingly expensive. Families receiving Medicaid-funded personal care services or

Community Alternatives Programs services in their homes are not eligible for respite choice program support.

Medicare doesn't cover the long-term care most needed by Alzheimer's patients, such as support with eating, bathing, walking and toileting. So programs that provide financial support for these activities of daily living can be a huge help to caregivers.

Changing roles for caregivers

Since Chuck's diagnosis, Jeannette has faced many changes.

There are the obvious and painful changes to Chuck that Alzheimer's continues to cause. There are also the decisions about Chuck's care she now makes.

"It felt like everything was on me, almost overnight," Jeannette said.

She went from managing one checking account to handling all of her and Chuck's finances and filing their taxes, things she had never done before.

Jeannette has also learned how to comfort Chuck through his disease. As Alzheimer's patients often do, Chuck sometimes asks for his parents, who died years ago.

"At first, if he would ask me, 'Do you know where my mama is?' I'd say, you know, honey, she's in the same cemetery as my mama is," Jeannette said. "But when I would tell him that, it got so like I was telling him his mama died for the first time. And he would cry sometimes and ask if I was telling him the truth."

Now, if Chuck asks, Jeannette tells him his mother is visiting family out-of-state or running errands.

"It comforts them," she said. "You tell big fat lies about this and that. When you tell them the truth, they're just so upset about it."

You can't keep getting them upset like that, she said.

Jeannette has also learned how to deal with anger, especially her own, which is not easy. She said the best thing she can do is walk away for a little while.

"I have to remind myself what it would be like to have a brain that's not able to figure out anything that's going on," she said. "You have to deal with it in a calm manner rather than fussing or being bossy."

Jeannette's twin sister died of Alzheimer's years ago. She suspects that her mother, who died at age 95 and had many of the symptoms she now sees in Chuck, also had Alzheimer's or another form of dementia.

Jeannette loses her train of thought or can't find the word she's looking for, and she laughs and calls it a senior moment. But it's more than that. It's also a nagging worry about her own future.

A number of factors, the greatest of which is age, contribute to a person's likelihood of getting Alzheimer's. Jeannette knows that family history is also a factor.

March 2011. Chuck's assisted living facility, Durham, N.C.

Jeannette follows as an aide helps Chuck down the hall to his bedroom. Chuck walks slowly with his knees bent out to the sides. He checks the numbers and name plates of some of the rooms he passes.

"Your pants are looking a little short, honey," says Jeannette, a few steps behind. "Guess that's because we've been washing them so much."

When Jeannette arrived earlier, Chuck was napping in a chair in the living room. Other residents were scattered about the room as well. The TV in the corner was set to an oldies music channel.

The aide guides Chuck into his room once they reach it.

Jeannette has decorated the room to look like home. A deep red valence hangs above a window that looks onto the patio outside. A brightly colored, patterned bedspread is taut across Chuck's twin bed, which is pushed against one wall. A special rail keeps him from falling out at night.

The aide helps Chuck find his way into one of two chairs. Both are positioned under several signed photos and service medals hanging on the wall. At the center is a giant framed collage of family photos positioned around a timeline of nearly 50 important family dates and descriptions, like the birth of grandchildren and wedding anniversaries.

The wall is a tribute to a living man's full life.

Chuck settles into his chair. Jeannette sits by his side. He appears small and wears a steady smile. His clothes are neat and clean. He babbles, and Jeannette can make out a few words. She repeats the words and adds phrases like, "Is that right?" or "I suppose so."

A former journalist, lobbyist and PR man, Chuck loved to talk to people and to be at the center of things. These days, Jeannette can't make out most of what Chuck says.

He drifts between sleep and consciousness. He scratches his arm, utters strings of words that don't make sense, and reaches out for his wife.

Jeannette visits Chuck at least five days per week. She often goes around 4 p.m. and stays through dinnertime. After dinner, she helps Chuck to bed and says goodnight before

leaving. Sometimes she shuts off the lights and turns on music he likes and sits by Chuck until he drifts asleep.

Today her visit is earlier than usual, which is likely why Chuck is dozing. This may be his usual naptime.

Jeannette is often frustrated with the quality of care provided at Chuck's assisted living facility, which costs about \$7,000 per month. It's not an easy job, and staff turnover is high. Only two or three staffers are consistently available to look after the 19 residents in the Alzheimer's unit.

Jeannette's paid caregiver, who has been helping her with Chuck for years, recently began taking Chuck's dirty clothes and bed linens home to wash and dry. The facility staff hadn't been keeping up with the task, and it became too much for Jeannette.

She cries when she's upset. Sometimes she raises her voice to the staffers. She spends time with her daughters to take her mind off of her disappointment with the facility, which she says has been the biggest recent challenge.

Chuck mumbles something and wakes himself up. He looks over to Jeannette and tries to talk to her. He seems to find comfort in her being there, in being able to reach out and hold her hand.

Alzheimer's has taken much away from Chuck and Jeannette. This is not the life Jeannette had hoped they would have. But for now, Chuck is comfortable and content. He still knows who she is, and Jeannette can ask for nothing more.

CHAPTER IV: RESOURCES TO AID FAMILIES WITH ALZHEIMER'S PATIENTS

Local support group leaders

- Durham County: Edna Ballard, 919-660-7510; Cordelia Davis, 919-806-3294; Lisa Gwyther, 919-660-7510.
- Orange County: Allison O'Shea, 919-929-5850; Vibeke Talley, 919-968-2087.
- Raleigh: Dee Dee Harris, 919-832-3732; Melanie Bunn, 919-832-3732; Nancy Broadwell, 919-832-3732.

For support group meeting times and locations, please call the contacts listed above.

For additional support groups, please visit <http://www.alznc.org> (click "Support Groups" on left).

Local Alzheimer's associations

Alzheimers North Carolina, Inc. | 919-832-3732 | <http://www.alznc.org>

- Dee Dee Harris, family services director, dharris@alznc.org.

Alzheimer's Association, Eastern North Carolina | 919-573-1851 | <http://www.alz.org/nc>

- Lisa Roberts, executive officer, Lisa.Roberts@alz.org.

Locally-based statewide programs

Duke Family Support Program | 919-660-7510 | <http://www.geri.duke.edu/service/dfsp>

- Lisa Gwyther, director, lpg@geri.duke.edu.
- Edna Ballard, social worker, elb@geri.duke.edu.
- Cheryl Copeland, program coordinator, cheryl.j.copeland@duke.edu.

Joseph & Kathleen Bryan Alzheimer's Disease Research Center | 919-668-0820 |
adrc.mc.duke.edu

- Lisa Gwyther, core director, lpg@geri.duke.edu.
- Rev. Henry Edmonds, African-American outreach director.
- Edna Ballard, support group coordinator, elb@geri.duke.edu.
- Cheryl Copeland, outreach coordinator, cheryl.j.copeland@duke.edu.

UNC Department of Neurology | 919-966-4401 | <http://www.med.unc.edu/neurology>

To request an appointment, please call the UNC Memory Disorders Clinic at the number listed above. Appointments are on a referral-only basis.

Other local resources

- UNC Institute on Aging | 919-966-9444 | <http://www.aging.unc.edu>
- Orange County Department on Aging | 919-968-2070 |
<http://www.co.orange.nc.us/aging>
- North Carolina Division of Aging and Adult Services | 919-733-3983 |
<http://www.ncdhhs.gov/aging>

- Attorney Dori Wiggen, partner and elder care attorney, Wiggen Law Group PLLC
| 919-680-0000 | <http://www.wlgnc.com>
- Ellison Jones, family caregiver support specialist, Area Agency on Aging (AAA)
Family Caregiver Support Program, Orange County | 919-558-9391 |
www.ncdhhs.gov/aging/fchome.htm

CHAPTER V: REPORTING AND WRITING ON ALZHEIMER'S

I had no idea that a short-term assignment in fall 2008 would shape my reporting and writing interests in graduate school and inspire the subject of my master's thesis project. I received the assignment in October of that year from someone I consider a great mentor, for whom I had done prior book research. At the time, a neurologist in Santa Barbara, Calif., was writing a manuscript about Alzheimer's care in the U.S., and he asked my mentor to be his co-author. Her job was to add a human narrative to the manuscript's exposition on Alzheimer's. That's where I came in, she told me.

My job was to interview as many people affected by Alzheimer's as I could. I was in Boston at the time, and I scoured every local resource I could find to get in touch with people who really knew Alzheimer's. I wanted to talk with daughters, sons and spouses of people with Alzheimer's, social workers and home health aides, doctors, researchers, anyone who was willing to speak with me.

Through the help of family, friends and many people on the receiving end of my cold calls, I was able to find sources to talk with me. Most were relatives and primary caregivers of Alzheimer's patients. Some were paid caregivers who worked in assisted living facilities and nursing homes. I remember feeling the knots in my stomach twist and tighten every time I got ready to dial a phone number or ring a source's doorbell. In these moments, this synopsis sometimes played through my head: *Hi, my name is Michelle. I know we just met,*

but can you please detail for me what has probably been the most difficult experience of your life? I knew that asking deeply personal questions comprised the job of a journalist, and so I got over my fears each time. But I still wondered if my sources would be willing to tell me, a complete stranger, about such an intimate part of their lives.

Their openness and generosity surprised me every time.

More than two and a half years later, I am still frequently surprised by the kindness and honesty of sources. When I walked into former Alzheimer's caregiver Joe Clark's life one March morning in 2010, lugging a tripod and camera bag as big as I was, he welcomed me into his home and shared his story. When I called him a week later because the lighting and sound were bad in the video I recorded, he was patient and understanding and invited this amateur videographer over again.

In March 2010, I also called Jeannette Barbour for the first time and asked her if I could record our conversation. She gave me a sweet, Southern-drawled "Sure" and went on to speak about the impact of her husband's disease for nearly an hour. I didn't realize it then, but I would become a much more frequent observer of Jeannette's life and would eventually get the opportunity to meet that lovely husband of hers. I would also come to call Joe Clark a friend.

One of many things this project has taught me is the importance of sensitivity and care when interacting with sources, many of whom have never been followed or interviewed before. It also gave me a deep respect for what caregivers do. As a journalist, I consistently stepped back from the reporting and writing to make sure I was getting the bigger-picture view and not losing myself or the story in the details of the caregivers' lives. As a journalist, it was vital for me to step back, not only for my integrity as an independent reporter but also

for an emotional escape from such a difficult topic. Some of the stories Jeannette told me, such as the time she visited Chuck to find a female resident holding his hand, filled me with sadness. A few scenes I witnessed, such as Dot's detailed account of an imaginary family reunion, were devastating. But I realized that these families don't have the luxury of stepping back like I did. Alzheimer's is their reality all of the time.

In speaking with Jeannette, Joe, the McCormicks and others, two recurring themes emerged: the importance of support groups and, for those dealing with the later stages of Alzheimer's, respite care. Hearing and learning from others who are going through similar experiences helps caregivers realize "they're not standing alone in their shoes," as one social worker explained it. Similarly, I learned that breaks from caregiving are essential for caregivers and that local resources are available to help them find respite care.

As more baby boomers enter their mid-60s and Alzheimer's affects even more people, an increasing number of caregiving stories will need to be told. In future articles, or multimedia stories, I would explore Alzheimer's caregiving from a son or daughter's perspective. I would examine life after a caregiver's loved one has died, the challenges of long-distance caregiving and the feelings of service surrounding some caregivers' journeys. As this project has taught me, many caregivers don't view their responsibilities as a burden, but as the least they can do for their loved one. More exploration into this notion would undoubtedly be worthwhile as well as hearing from those who don't share this sentiment.

A few weeks ago, I was sitting outside a market in Carrboro, working on Joan and Jeannette's stories. At some point, the couple sharing the table to my left struck up a conversation with me and asked what I was working on. I explained my project to them. The wife, who looked to be in her late 40s or early 50s, asked what made me decide to tell this

story. She was a creative nonfiction writer and teacher, and she told me about a writing exercise she gives to her students. She instructed me to summarize my thesis project in one page, then half a page, then one paragraph, and to keep going until I finally came to a single word. That word would be the essence of my story. She made me promise to email her with what I find.

I admit I haven't emailed her yet. I haven't completed the writing exercise. But when I reflect on my experiences reporting and writing on Alzheimer's caregiving, one word consistently comes to mind. That word is *hope*.

I realize this might be cheating, but I won't be surprised if I discover the same word once I complete the exercise.

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